

# Evaluating the Side by Side peer support programme

# 2017

Julie Billsborough, Richard Currie, Sarah Gibson, Steve Gillard, Sarah Golightley, Rajvi Kotecha-Hazzard, Andreja Mesaric, Sajid Mohammed, Vanessa Pinfold, Daryl Sweet, Rose Thompson & Sarah White





## **Executive summary**

#### Evaluating the Side by Side peer support programme

This report describes an evaluation of the Side by Side programme, which was funded by the Big Lottery, aimed at increasing the availability of community based peer support across the UK. The Side by Side programme was led by the mental health charity Mind, in collaboration with Depression Alliance (which merged with Mind during the programme) and Bipolar UK. The peer support was delivered in 46 new projects across the programme.

The Side by Side programme took place between July 2015 and December 2016. It aimed to improve the lives of people experiencing mental health problems across England by increasing the availability of peer support and learning how to improve the quality of peer support delivered in the community. The programme also sought to add to the existing evidence base for the effectiveness of peer support.

Our evaluation team was a partnership that included a mental health research team from St George's, University of London (SGUL), a research charity, The McPin Foundation and other key collaborators. We took a 'coproduction' approach to the evaluation. This means that:

- Many of the researchers on the evaluation team bought lived experience of mental health difficulties and peer support to their work, and drew on this experience alongside a range of research skills
- We used a combination of experiential and academic knowledge in shaping the evaluation
- o All members of the team were included in key decision making as far as possible
- We reflect on the impact of using lived experience in this way on the knowledge that we have produced about peer support

The evaluation was composed of four parallel work streams:

- 1. Develop and test a set of 'values and principles', asking where these values and principles might be common across all approaches to peer support, and where specific issues might apply that reflected the great diversity of peer support that we encountered
- 'Does peer support work?' was addressed using an innovative approach the 'peer support log' – that tested how change in the amount of peer support people decided to access was related to change in a range of individual outcomes, including measures of wellbeing
- 3. How can peer support capacity be built in different regions involving large and small organisations or informal groups?
- 4. The views and attitudes of health and social care commissioners towards peer support with the aim of gaining a better understanding of how peer support could fit within the commissioning process

#### An overview of the literature on peer support in mental health services

We conducted an overview of the current literature on peer support in mental health to inform the development of this evaluation and to help us consider our findings in a wider context. The research team at SGUL had previously undertaken an extensive review of one to one peer support for another

project. This review, in combination with a number of other published reviews of peer support and a considerable amount of 'grey literature' (reports and commentaries) formed the basis of our review for the Side by Side evaluation. We provided an overview of:

- The wide variety of approaches to peer support: group, one to one and online; within, alongside and outside of formal mental health services; mutual peer support, peer-led and professionally facilitated
- Understandings, experiences and impacts of peer support with different groups and communities, including peer support in gender, sexuality and Black and Minority Ethnic specific contexts, and peer support for groups of people with particular diagnoses
- The values and principles underpinning peer support as they were described in the literature, focusing on core values of shared experience and identity, reciprocity and mutuality, safety and trust, and empowerment and agency

#### Developing core peer support principles and values

We conducted consultation work early on into the Side by Side Evaluation to identify and produce our early draft of the peer support values and principles. We used three different ways to gather information:

- **Consultation events**: 2 were held, one in London and the other in Leeds, with a range of people involved in some way in peer support (26 people in total). Peers were asked to identify the key principles and values of peer support and to rank which features they considered to be most important.
- *Hub group interviews* with people who were going to be involved in delivering the Side by Side programme (9 hubs, 38 people), staff from Depression Alliance (3) and those working on the Elefriends platform (3). We asked interviewees to describe what they thought was important about peer support, including any peer support they were currently involved in, and to give some practical examples of peer support, and how peer support may work across diverse communities.
- An online survey of people involved in peer support about their views on what was important about peer support, and also what they would consider not to be peer support (responses from 163 people).

Our findings suggested that while there was consensus on some core features of peer support, there was also great diversity the way in which people considered other features of peer support to be important. Peers also had clear ideas about what peer support was not, and that peer support was different from statutory or clinically based services as it did not have the following features:

- Based on the medical model and involving supportive relationships that are one directional
- Support from people who have no direct experience of mental health difficulties or are unwilling to disclose their difficulties
- Support that is outcome or advice-focused and does not inspire or help people to develop solutions to their own problems
- Support that peers consider to be judgemental and where there is a lack of empathy

We looked at how the data from the three different strands of the consultation corresponded with each other. Where a feature arose in at least two strands of the consultation we used this to produce our first draft of the peer support principles and values. Peers told us the following were essential components of peer support:

Universal Characteristics of Peer support			
Shared Lived Experience		1utuality	Purpose
	_		
Values		Principles	
Inclusive		Peer ownership	

literasive	
Empathy	Feeling Safe
Equality	Flexibility
Being Human	Active Sharing
Valuing experience	Support

#### Understanding the values and principles of peer support

We then went on to test the principles and values that we developed through the consultation work by conducting interviews with peers across the Side by Side programme. Our findings from initial findings from 69 interviews indicated two important things:

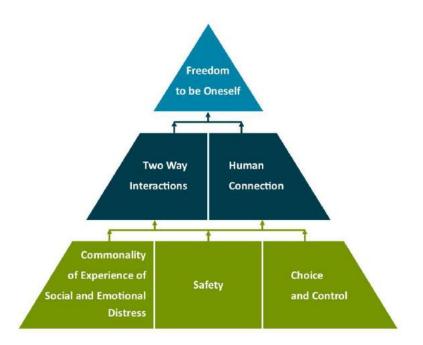
- There was great diversity in the ways in which peer support was being delivered, which made it difficult to talk about specific models of peer support. We instead identified three broad approaches to peer support; group, one to one, and online.
- Our draft principles and values framework was too complicated and we found that many of the concepts were spoken about in interchangeable or overlapping ways in the data.

We conducted a thematic analysis of the interview data and used this analysis to simplify and refine our approach. Our final core values framework was comprised of six core values:

- Experience in common
- Safety
- Choice and control
- Two way interactions
- Human connection
- Freedom to be oneself

From the evidence collected through this evaluation, we believe that for a form of support to be called peer support all six of these values must be present and endorsed within a peer support setting. We believe that this is relevant across all three approaches to peer support. However it is also important to recognise that none of these values work in isolation and all are interconnected. The first three core values on the list, 'Experience in common', 'Safety', and 'Choice and control', form a foundation on which the final three values, 'Two way interactions', 'Human connection' and 'Freedom to be oneself' rest. If peers do not feel they are with other people who have similar experiences, are safe to express themselves, and have choice and control over whether, when and how they express themselves, they are unlikely to engage in two way interactions and develop

human connections with other peers. Without the five preceding core values being in place it is unlikely that peers will come to feel like they can freely be themselves in peer support. **Figure 1: The core Values Pyramid** 



We also found from our interviews that peer support can be highly responsive to the context that it occurs in. People involved in organising peer support made a number of practical decisions about how a particular project should work to best suit the needs of a particular group of people. We identified five broad categories of decisions that shaped what a peer support project looked like in a particular context:

- Level of facilitation
- Types of leadership
- Focus of peer support 'sessions'
- Types of membership
- Organisational support

How people chose to organise peer support through these different categories shaped how the resulting peer support worked on the ground with the people that were involved with it. This meant that making different choices on a number of these categories resulted in a range of projects that looked quite different from each other and that were tailored carefully to the local context. How the core values were present in these diverse projects also therefore looked quite different to account for this diversity. However, the core values were present in some form. If they were not present in a project we would argue that that project cannot be called peer support.

#### Black and Minority Ethnic specific peer support

We also explored how peer support took place within Side by Side projects specifically aimed at peers from a Black and Minority Ethnic (BaME) background. This was based on qualitative data collected through interviews and focus groups with 39 peers taking part in BaME specific peer support. Based on this, we developed a typology of BaME projects in Side by Side that included:

- General BaME peer support
- Community specific peer support
- Refugee and migrant peer support

We found the reasons why BaME peers engaged with BaME specific rather than mainstream peer support were related to their understanding of what constituted relevant experience in common. This shaped who was considered a peer within the context of a particular project. In addition to experience of social and emotional distress, which was relevant across all Side by Side projects, we identified the following aspects of common experience as important in establishing peer relationships in BaME specific peer support:

- Shared cultural background
- Experience of migration
- Racism and discrimination
- Intersectional experiences (minorities within minority communities, e.g. LGBT)

We found that the core values and decision mechanisms underpinning peer support were shared between BaME and mainstream projects. However, the experience of social and emotional distress of peers in BaME specific projects was so significantly shaped by other aspects of their lived experience that they needed to be addressed in an identity specific peer context.

#### Does peer support work?

Within this work stream we collected a range of data about the way in which people accessed peer support through a 'peer support log'. We first asked people who they were (in terms of age, gender, ethnicity and so on) and then each month invited people to completed the log either online or on paper. We asked people to complete the same questions every month about the different types of peer support they had accessed in the previous month and how they were feeling at that time (measures of hope, self-efficacy, social connection and wellbeing). The log was coproduced by the SGUL evaluation team and the PEER group (a mental health service user research advisory group). This co-production involved developing and testing the log in a series of stages to produce a data collection process that was not too burdensome for peers in Side by Side to use. A short version of the log with translations of key questionnaires was developed for people completing the log in community languages.

People who completed the log for us were supported in several ways:

- By the people coordinating Side by Side projects on the ground
- By researchers based in three of the hub areas

• By a researcher recruited to provide support in Black and Minority Ethnic specific peer support projects

The log was designed so that we could test whether changes in the amount of peer support people decided to access was related to change in a range of outcomes (wellbeing, hope, self-efficacy, contact with friends, family and neighbours, and their general health status)

Over 700 people completed the log, and many people completed the log a number of times. This represented about a quarter of people who were involved in peer support across the Side by Side programme.

Nearly two thirds of the people who completed the log were female. The profile of people completing the log was highly diverse in terms of ethnicity and sexuality, and included people from a broad range of ages, reflecting the profile of people who involved with Side by Side.

#### Key findings:

Analysis of peer support log data indicated that change in engagement with peer support was associated with change in outcomes in lots of different ways and for different groups of people. The evaluation team used the qualitative interview data described above to help make sense of what these findings mean. It is this combined analysis that is presented below.

The team found that people chose to engage with different approaches to peer support for different reasons and at different times. In other words, engaging with peer support was purposeful, in response to a range of needs and aspirations including a desire for meaningful activity, a need for social contact, sometimes referred by mental health services but sometimes to address a gap in services, as a space to share experiences of mental health difficulties and strategies for coping, and sometimes in response to crisis.

As participants' wellbeing and general health improved, and as they experienced more supportive contact with friends and family, they chose to access less peer support. However, people did not seem to stop accessing peer support altogether but rather maintained a 'core' level of peer support. Maintaining the same amount of group peer support received was associated with a reduction in contact with friends, reflecting qualitative data that suggest that people maintain a certain amount of peer support as a source of social contact.

Well, yeah, I've got very isolated so some social contact was, kind of, that was one thing I thought that I might get. [PV24, group]

#### Mutual sharing or 'doing peer support'

In the log people were asked about how much of a number of different approaches to peer support (one to one, group, online) they were involved in giving and receiving over the previous month. This was so that the two-way interactions of peer support could be understood.

People who increased the overall number of *types* of peer support they were giving reported increases in their levels of wellbeing and hope in the future. People who increased the *amount* of group-based peer support they gave reported improvements in wellbeing, hope, self-efficacy and increased contact with friends. People who increased the amount of one-to-one peer support they gave reported improvements in wellbeing and hope.

The team explored the qualitative interview data to try and make sense of what 'giving' peer support meant in this way. People described an active, mutual giving or sharing of peer support – of 'doing peer support' – as a two-way interaction that embodied a sense of agency in the peer support process. It is this mutual sharing and doing peer support together that seems to be associated most widely with change in participants' outcomes, especially in the context of group peer support but also in one-to-one peer support. This was described as distinct from the way in which people might more passively make use of other mental health services.

... this is what sets peer support apart from any other kind of mental health service I've experienced. It's what makes it different from group therapy. It's what makes it different from counselling or speaking to your doctor or speaking to a parent or a partner maybe, I don't know, in that it is mutual and everyone there is giving and receiving and sharing experiences ... [PV23, group]

These benefits were experienced by people giving more peer support in group, one-to-one, and online environments. However, the way in which peer support was described could differ for different peer support approaches. It is possible that 'giving' and 'receiving' roles are more clearly demarcated in some (but not all) one-to-one and online peer support, with some people acknowledging they did more of one than another:

I like the fact that we're all, kind of, helping each other ... I think if you're signing up to do peer support, I think you do need to recognise that it is giving, and receiving, support. [PV15, group]

When I will see the results of my help I will be excited ... I will be more proud. That is for me a good thing for me to feel well. [PV39, one to one]

... there are some people that will be on Elefriends that will never post and will never like something .... but they are there and they obviously take, there is a reason why they are on it ...[PV44, Elefriends]

#### **Choice and Control**

While people engaged with slightly more of some kinds of peer support when they first accessed the Side by Side programme, over time people accessed less peer support over all. At the same time, outcomes as a whole were maintained over the course of the evaluation.

These findings provide evidence for commissioners that people access less peer support over time while continuing to live well in the community (maintaining good outcomes). Importantly, we did not find evidence that the more peer support that was offered, the more peer support people 'used'. This is unlike the usual pattern observed with many conventional mental health services.

It's just as important that [participants] choose not to attend a group, as it is to attend a group ... I mean, if people don't want to turn up, they don't have to turn up. Yes, I've had people who have turned up, in the past, and halfway through a meeting, have decided to leave, the reason being because, actually, they have got what they wanted from the meeting [PV52, group]

The research findings suggest that people try out different approaches to peer support in response to a range of needs and aspirations. When offered a range of different types of peer support, over time people identified the approaches that worked well for them, making increasingly efficient and effective use of peer support as a result. The results appear to suggest that, when people are offered a range of locally developed approaches to peer support, it is the sense of agency – choice and control – in deciding what peer support to access, when and why, that is associated with positive outcomes.

I just kept it as a trial and error kind of thing, so I tried it and if I didn't like it then I wouldn't continue with it, but I do like it, so I carried on with it [PV21, group]

This highlights the importance of supporting the diversity of peer support on offer so that people can make meaningful choices about the approaches that work best for them.

#### Capacity building for peer support

In this work stream we explored how the Side by Side programme supported the development and growth of the peer support community across the country through a structured programme of activities and events. This part of the programme was called 'capacity building'.

We interviewed leads of all the various organisations involved in the process; national Mind, the nine hubs, strategic partners, Elefriends and local peer support groups. 21 people in total. We also attended and observed events.

We used our findings to map out the resources and processes that helped to build capacity through the hubs. We used this to build a framework diagram – a draft 'Theory of Change' for capacity building in peer support (see figure 2 below) – that showed how these fit together across the whole programme.

From this work we found that there were some challenges to capacity building work. These included:

- Leadership there was a central tensions within the way Side by Side was structured. National Mind wanted to create an environment in which peer support could grow organically in response to local context, and yet also took on the role of close project management, including collecting monitoring data.
- Relationship building in some areas organisations who had not worked together before, and who had previously been in the position of competing for money, were now working together. These relationships took time to build.
- Time the Side by Side programme was time limited in some areas hubs and projects felt they were only really getting going at the point at which Side by Side was winding down
- Engaging commissioners there was varying success in the extent to which hubs were able to engage commissioners in areas where there were pre-existing relationships this worked very well, in areas where these relationships did not exist this was very difficult.

From this work we gained the following insight on the 'active ingredients' of capacity building:

**Peer leadership**: Even if activities are not exclusively peer-led, there does need to be a substantial amount of peer leadership.

**Sharing knowledge:** Exchanging skills, knowledge, and experience is essential to nurture diverse approaches to co-creating peer support locally. This includes sharing resources in the community (such as venues and links to other organisations or stakeholders) as well as joining together to supervise volunteer facilitators or planning promotional activities.

Active learning: An active sense of learning both among those people already giving and receiving peer support, but also in understanding how the full diversity of cultures and communities needs to evolve in peer support locally.

**Creating safety:** Creating positive, safe, trusting spaces for peer support - good experiences of peer support foster capacity building - within and across communities and cultures.

**Changing ways of working:** Being prepared to think differently about how peer support is provided, challenging and adapting ways of working that can be constrained by conventional thinking about services, models and care giver/user roles

**Time:** Capacity building will require sustained efforts over a long period to build a credible reputation. Time is also required for communities, organisations and individual peers to share and learn from each other.

**Strategic factors:** some will help, others will hinder. Being aware of strategic changes, influencing local and national agendas, and working alongside others in the health and social care space will be important. This requires a mutual sharing of local knowledge and national policy expertise.

#### **Commissioning for peer support**

We took a mixed methods approach to working with commissioners of mental health services (both NHS and Local Authority), incorporating both qualitative and quantitative data collection. Our initial plans involved conducting a survey of commissioners' views and attitudes towards peer support at two time points. We encountered significant problems in recruiting commissioners for this part of the work, and altered our approach following the initial baseline survey. We conducted semi-structured interviews by telephone with commissioners (11) to ascertain their views on the value of peer support in relation to mental health. Interview questions probed commissioning priorities, their understanding of peer support, and their views of working with the voluntary and community sector.

All commissioners spoke about the difficulty in commissioning new or 'innovative' services against a landscape of cuts and financial austerity. Commissioners were looking for evidence of the following when making commissioning decisions about peer support:

- Meet a clear set of outcomes from a wellbeing perspective.
- Work across a range of outcomes, both in the form of quantitative monitoring data and qualitative reports from people who used the 'service'.
- Work with peers to produce their own recovery outcomes.
- Understand how peer support fits within national guidelines (e.g. NICE guidelines) and what kind of outcome data will demonstrate this.
- Providers need evidence of governance, for example, training, support and supervision arrangements, financial stability.
- Providers need evidence of risk management and assurance that both the peer supporter and the person receiving the support will be protected.

#### Figure 2: Draft Theory of change for Side by Side capacity building

Approach	Resources	Activities	Enablers	Intermediate outcomes	Final goals
Range of approaches and diversification of model. Social models	Funding	Project management – awarding grants, monitoring, national meetings.	Peer Leadership – passion, commitment, local knowledge, expertise	Increased number of people involved in peer support	Sustainability of peer support
Collaborative, co- production, non- prescriptive	Juction, non- rriptive       Planned activities – networking events, training, mentoring, experts on call.       knowledge, role model passion         tured (including ts)       Staff, volunteers, external consultants       Promotional work - newsletters, case studies, outreach,       Changing –adapting current approaches, expanding scope of existing practice	Increased confidence in giving and receiving peer support	Growth in peer support		
Structured (including targets)		Staff,experts on call.Volunteers,Promotional work -externalnewsletters, caseconsultantsstudies, outreach,	approaches, expanding scope of	Increased understanding of the	locally
Inclusive			retain volunteers, cultural	value of peer support for different people	
		peer support,	eer support, opportunities for trust and	Increased number of relationship with local commissioners	
			Increased levels of partnership working		
			Time – peer support needs time to develop and establish a reputation	Increased stability of peer support community	
			External factors – changes to		x

#### Conclusions

The scope of the Side by Side evaluation provided us with both opportunities and challenges as a research team. We were successfully able to draw on the experiences of people engaged in a diverse range of peer support projects, and who were from a diverse range of personal and community backgrounds. This resulted in our being able to collect a large quantity of data, however the logistical effort involved in doing so was considerable and it was not always possible to provide people in the projects with the support they needed to engage fully with some parts of the evaluation.

As a team we took a co-production approach to the evaluation to ensure that the voices of people with lived experience of mental health difficulties were fully included at all stages of the evaluation. However, given the scale of the evaluation, and the speed at which we were working, this was not without challenges. In later stages of the evaluation much decision making, write up and analysis was occurring at a speed where it became difficult to fully include all members of the team.

Our key conclusions were that peer support was valued and helpful to people involved. There were 6 core values that appeared to underpin all forms of peer support, and how these values may look in a given project is shaped by practical decisions that are taken about how a project will operate. Those values applied across communities, although the experiences of social and emotional distress of peers in BaME specific projects could be so significantly shaped by other aspects of their lived experience that these were sometimes best addressed in an identity specific peer context.

Increasing the amount of peer support that people were actively engaged in giving or sharing together was associated with improvement in wellbeing and hope in all forms of peer support, for all groups of people. Over the course of the evaluation, peers accessed less peer support overall, possibly as they found the approaches that worked for them, while outcomes were maintained or slightly improved over the same period.

Our findings relating to choice and control suggest that peer support enabled people to recover a sense of personal agency and usefulness within a peer support community, which was in turn beneficial to their wellbeing. People did not 'use' peer support like other mental health services, where access can be prescribed and time limited. There are important lessons for commissioners and organisations supporting peer support initiatives here. Our evaluation suggests that peer support works best where commissioners, provider organisations and communities work together to develop a range of approaches to peer support, reflecting the needs and aspirations of the full diversity of communities locally, and where people are enabled to take control of how and when they engage with the peer support that works best for them.

Going forward the evaluation team will use the wealth of data we have collected to further develop these findings. We will produce a 'toolkit' that will help organisations, groups, projects and communities, large and small, to develop and tailor peer support initiatives that best address their needs and aspirations. We will use the peer support log and interview data to explore and try to understand in detail how people from different BaME communities understand and engage with peer support. And we will do a similar piece of work making sense of the complex relationships between how and why people engage with the sorts of community-based peer support projects we observed in the Side by Side programme, informal peer support (including support from friends and family members) and support from mental health services.

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### Acknowledgements

We would like to express our thanks and gratitude to our collaborators – David Crepaz-Keay, Virginia Minogue, Mary Nettle, Clare Ockwell and Jan Wallcraft – for the wisdom and insight they brought to both developing this evaluation and interpreting our findings.

Many thanks to members of the team at McPin who worked with us in the early days of the project; Sarah Hamilton, Karen James, Sarah Matthews and Ben Perry.

Thanks to the team at Mind – especially Jacob Diggle, Elizabeth Ladimeji and Brigid Morris – for being such patient and resourceful partners throughout the evaluation.

A huge thank you to the hundreds of people involved with the Side by Side programme who gave their time as participants in the evaluation, evaluation ambassadors and project coordinators, and leaders of peer support projects large and small across the country. We could not have undertaken this evaluation at all without your commitment and energy.

And finally, a special thank you to Alison Faulkner who has been an inspiration to so many of us in this work.

## Notes on this report

#### Our approach

This evaluation has been coproduced, designed and delivered by a team of researchers and collaborators combining multiple areas of research expertise. Many of us explicitly use our lived experience of mental health difficulties, and of offering and receiving peer support in our work as researchers. We describe our approach to coproduction in the introduction. We have also reflected as a team on the way we coproduced the evaluation and the impact this might have had on the outcomes of our work. We present these reflections alongside our conclusions at the end of the study.

As part of this work of evaluating peer support, we have given considerable attention to our own experiences, values and understandings of peer support. We have thought about what we have learned from the people who took part in the evaluation. We have heard and understood the concerns of many about how important it is that peer support continues to be underpinned by shared values and principles. We have also heard that this is especially important that peer support is not 'professionalised' where it is commissioned to form part of mental health services. We hope that this report offers a useful addition to the evidence base for peer support, contributing to a firmer foundation for people developing, leading and sharing peer support in the future.

#### **On language**

In the world of mental health service evaluation in general, and peer support in particular, language can carry meaning that relates to people's identities (socially, culturally, and politically) in relation to mental health services and to wider society. For example, for different people and at different times, labels such as patient, peer, survivor or service user can be either useful or an unhelpful simplification our complex sense of identity. In undertaking this evaluation we have tried to be mindful of this. We have considered this carefully as a team and have tried to choose our language thoughtfully, while at the same time recognising that the language that we use will not sit well with everyone.

As a general principle we have tried to avoid using over simplified labels. Instead we try to describe people's roles and identity in relation to the Side by Side programme and evaluation, even where our text might be a bit more cumbersome as a result. For example, we began by referring to researchers working on the evaluation, who explicitly brought lived experience of their own mental health difficulties to their role, as *peer researchers*. At neither SGUL nor McPin had we done this in the past, having preferred to use other terms and expressions. We had done this because it seemed to be consistent with an evaluation of peer support.

However, as the evaluation progressed, members of the evaluation team stated that they did not feel comfortable with the peer researcher label as it seemed to claim a sense of shared identity with such a diverse range of people involved in Side by Side. Following further discussion we decided, collectively, to refer to *Researchers who explicitly draw on their lived experience of mental health difficulties*. We use this expression, and variations on it, throughout the report where we wish to specify which members of the team were involved in which parts of the evaluation.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> For further details please see McPin's organisational policy: <u>http://mcpin.org/mcpin-foundations-patient-and-public-involvement-methods-week/</u>. In the mental health research team at St George's, University of London people are free to self-identify in various ways, including as Service User

Similarly when we refer to people taking part in the research we will either refer to 'people taking part in Side by Side projects' or to the specific communities in which those projects were based (e.g. people taking part in Black and Minority Ethnic specific peer support). We will also use the term *participants* or *interviewees* when we are specifically referring to people who took part in elements of the evaluation (e.g. peer support log participants).

Researcher or Survivor Researcher. Our values and aspirations statement as a group states that 'knowledge based on the full diversity of lived experience of mental distress and of using mental health services shapes the way we do our research'.

# Chapter 1: Background to the Side by Side evaluation

#### What is the Side by Side peer support programme?

Side by Side is a Big Lottery funded programme that 'aims to improve the lives of people experiencing mental health problems across England through access to peer support' (<u>http://www.mind.org.uk/get-involved/peer-support/peer-support-programme/</u>). The programme was developed by the mental health charities Mind, Depression Alliance and Bipolar UK and project managed by Mind.

The evaluation was established to build the evidence base for the effectiveness of different approaches to peer support – and promote the value of peer support to service providers and commissioners, as well as to the people who might access peer support.

#### Scope and structure of the Side by Side peer support programme

The peer support programme was ambitious in scope. This section aims to describe the various structures and the role of various groups involved in the work.

The peer support programme operated in nine areas of England: Suffolk, Coventry, Northamptonshire, Leeds, Blackpool, Southampton, Plymouth, Middlesbrough, and Kensington & Chelsea.

#### Hubs

In each of the areas a peer support 'hub' was established. Hubs were both a physical and virtual spaces that operated through local Mind associations. They were tasked with building and strengthening the local peer support community in various ways:

- Raising awareness of peer support to new audiences
- Facilitating spaces and conversations where peers could transfer knowledge and resources
- Using their own expertise to skill up people in the existing peer support community through training and support

#### **Strategic Partners**

In addition to the hubs, in each of the nine areas, a 'strategic partner' was present to expand the peer support community by offering and engaging peer support to new audiences. Strategic partners were organisations that had existing expertise in setting up, delivering and sustaining peer support groups. Three of the nine strategic partner projects were run by the local Mind associations (local Mind associations acted as both strategic partner projects and hubs in those areas), three by Depression Alliance and three by Bipolar UK. Table 1.1 illustrates the associations between the hubs and strategic partners across the 9 areas of delivery

#### Table 1.1: Hubs and strategic partners by area

Hub Area	Hub Organisation	Strategic Partner Organisation	Strategic partner delivery area
Suffolk	Suffolk Mind	Suffolk Mind	Ipswich and Suffolk Coastal
Coventry	Coventry & Warwickshire Mind	Bipolar UK	Coventry and Rugby
Northamptonshire	Kettering Mind (on behalf of Northampton Minds Collaboration Corby, Kettering, Northampton, Oundle, Rushden and Wellingborough)	Depression Alliance	Northamptonshire rural areas and Kettering
Leeds	Leeds mind	Leeds Mind	Leeds South and East
Blackpool	Lancashire Mind	Bipolar UK	Blackpool, Blackburn and Darwen
Southampton	Solent Mind	Solent Mind	Southampton and New Forest
Plymouth	Plymouth Mind	Depression Alliance	Plymouth and surrounding rural areas
Middlesbrough	Middlesbrough and Stockton Mind	Bipolar UK	Middlesbrough & Stockton on Tees
Kensington & Chelsea	Kensington & Chelsea Mind	Depression Alliance	Borough of Kensington & Chelsea, including Queens Park & Paddington

#### Grant funded projects

In addition, grants to develop and provide new peer support projects in smaller, grassroots organisations were made available competitively in the nine areas. A total of 37 projects were funded, with areas awarded between one and nine projects each.

A key feature of the programme was the freedom for projects to develop a wide variety of peer support approaches. Peer support could take place in group settings, involve one-to-one peer support, be provided online or involve a combination of approaches. Applications for grant funded projects were particularly welcomed from projects supporting Black and Minority Ethnic (BaME) specific peer support and peer support in rural areas.

As well as BaME specific projects, there were peer support initiatives aimed at younger adults, LGBT groups, gender specific projects for men and women, and migrant and refugee work. Most funded projects were group focused, with some based around activities such as gardening, cooking, crafts and physical activity. In some projects peer support targeted specific issues, such as experience of homelessness, self-confidence and self-esteem or experience of emotional crisis. This work was often open access over an extended period of time and had a focus on mutual support and sharing of experiences and strategies. Some of the group projects focused on developing skills as a peer facilitator, and many of the one to one projects were focused on training in peer mentoring or in providing peer support for others. These projects tended to be time limited over a number of sessions. In other projects volunteers or trained peer mentors provided one to one support around general, or in some cases, specific mental health related experiences.

There were no online specific projects although all people accessing the Side by Side would have an opportunity to access the final component of the programme. This involved expanding and promoting, across the nine areas, Mind's existing 'supportive online community' called Elefriends (https://www.Elefriends.org.uk/), a well-established, moderated online peer support forum.

Throughout this report we have referred to 'the peer support community' to describe the collective of people bought together by the hubs, strategic partners, grassroots organisations and local groups as described above in this effort to create, expand and sustain peer support opportunities for anyone in these 9 areas who may want to try peer support. Figure 1.1 below shows how the hubs, strategic partners and grant funded projects worked together in a given Side by Side area.

Peer support projects, including both strategic partner and grant funded projects, were to be developed through the spring and summer of 2015. Strategic partner projects were to begin providing new peer support from July of 2015 with grant funded projects coming online by October 2015 and operating until the end of September 2016. All in all, there were 46 peer support projects across the programme.

It was the responsibility of the lead organisations delivering the programme – Mind, Depression Alliance and Bipolar UK – to monitor and collect data on project activity (including numbers of people accessing the projects and their socio-demographic characteristics) against targets agreed with the Big Lottery.

#### Figure 1.1: Partners in developing peer support opportunities in the Side by Side areas



#### WHAT ARE MIND'S AIMS?

Raise awareness of peer support to 40,000 people

Deliver online peer support to 6,000 people

Face-to-face peer support to 2,400 people

#### HOW WILL THIS BE ACHIEVED?

National mind to expand Elefriends, Run National Communications Campaign, develop policy with commissioners

Establish 9 hubs and strategic partnerships across the country

Commission an evaluation of the impact of peer support

#### ROLE OF EACH HUB

Facilitate learning and capacity building to local organisations and groups involved/interested in peer support

Coach and mentor 24 grass roots organisations of which, 5 will be awarded grants to help run peer support projects. Grants focus on rural and BAME

#### ROLE OF EACH STRATEGIC PARTNER

Engage 156 new people into peer support

#### The evaluation brief

The contract for this evaluation was awarded by competitive, open tender, and reviewed by a Research Advisory Group engaged by the Side by Side programme. The brief for the evaluation specified, first and foremost, that the evaluation should be methodologically robust and add to the current evidence base for the effectiveness of peer support in mental health. The brief also specified that the evaluation method should enable comparison of the effectiveness of different approaches to peer support; group, one-to-one and online (including Elefriends). As such we needed an evaluation design that could be used across all peer support approaches that make up the Side by Side programme. In addition, the brief required us to compare peer support among different communities (in particular, but not limited to BaME communities) and in different settings (especially rural areas).

The evaluation was to explore the outcomes of peer support, the values and principles that underpin peer support, capacity building for peer support, and the attitudes and engagement of health and social care commissioners with peer support. We have described our approach to the evaluation in a number of parallel, linked work streams below.

A key priority of the funders was that the evaluation would provide a robust, evidence-based understanding of what approaches to peer support work well in which contexts, enabling informed decisions to be made by provider and commissioner organisations about future funding priorities for peer support. A separate economic evaluation of peer support was commissioned from the London School of Economics (LSE). Where there is interface between our evaluation and the work of LSE this is specified below.

#### The evaluation

The evaluation was organised around a number of work streams. We have presented the aims of each work stream below.

#### Work stream 1 – The effectiveness of the Side by Side programme

This work stream was focused on the question of whether or not peer support 'works'. Effectiveness in evaluation is about measuring change in impacts or outcomes for people, and then determining the extent to which that change is as a result of a new treatment or service people have received. In this case, we wanted to know if the Side by Side peer support programme brings about change for people. In work stream 1 we were particularly interested in exploring the association between change in wellbeing and change in peer support use.

We also wanted to know if there were any differences when we compare peer support in different communities and settings, or different approaches to peer support.

The main questions addressed were as follows:

To what extent does the Side by Side peer support programme bring about change in the amount of peer support people in the programme access?

How is change in the overall amount of peer support people access related to change in a range of individual outcomes?

How does change in outcomes relate to the amount of peer support people are giving or receiving?

How is change in giving and receiving different approaches to peer support – group, one-to-one and online – related to change in outcomes?

How is change accessing peer support by different groups of people – e.g. people from different BaME communities, or in rural or urban communities - related to change in outcomes?

#### Chapters of report that relate to work stream 1:

- Chapter 3: Evaluating the impact of peer support
- Chapter 4: Findings from the peer support log
- Chapter 8: Developing a better understanding of peer support: synthesising peer support log and interview data

#### Work stream 2 - Principles and values of peer support in Side by Side

This work stream focused on identifying the principles and values of peer support in order to understand what peer support was and what it was not. This started by working with people across England who were involved in various forms of peer support, and later narrowed in scope to working with the peer support community within the Side by Side programme. This work stream involved an iterative approach: we first drafted principle and values through early consultation and later refined these to develop a core values framework through engagement with the peer support community in Side by Side.

The main questions addressed were as follows:

What do people involved in peer support identify as its core characteristics?

What do people giving and receiving peer support within the Side by Side programme identify as peer support core features?

How does peer support as delivered in the Side by Side programme vary by setting or population group?

#### Chapters of report that relate to work stream 2

- Chapter 5: Peer Support Core Principles and Values Consultation and Early Development
- Chapter 6: Principles and Values Underpinning Peer Support
- Chapter 8: Peer Support in a BaME Context

#### Work stream 3 - Capacity building in the Side by Side programme

This work stream was focused on explaining how to develop, grow and sustain peer support capacity within a region. In this work stream we explored what kind of resources were needed, how the different partners had worked together, and what practical activities had happened for the Side by Side programme to work towards their aim of creating peer support opportunities for all who want them. We refer to this as 'building a theory of change' for developing peer support capacity. We took a co-production approach to this part of the evaluation, working with hubs and strategic partners to observe how they were approaching the task of sustaining activities beyond the life of the Side by Side programme. Our evaluation created a draft visual 'Theory of Change' diagram, or map of this process, looking at who was active and in what role they were doing that activity. This theory of change will provide a spring board from which further knowledge can be developed around capacity building activities such as those occurring in Side by Side. The main question addressed was as follows:

What kinds of support, resource and capacity are required to deliver different models of peer support effectively, in line with peer support principles and values?

#### Chapters of report that relate to work stream 3

• Chapter 9: Capacity building work

#### Work stream 4 – Commissioning and peer support

This final work stream sought to investigate the attitudes of health and social care commissioners towards peer support and commissioning peer support in their local area. This involved identifying who was commissioning mental health services locally and encouraging them to talk to the research team about their attitudes and current commissioning plans. This work stream was very challenging and did not follow the original study design. The main questions addressed were:

How can commissioners be supported and encouraged to commission different types of peer support?

#### Chapters of report that relate to work stream 4

• Chapter 10: Commissioning of peer support – challenges and advantages

#### The evaluation team

This evaluation was undertaken by a partnership between an established mental health research team in the Population Health Research Institute at St George's, University of London (SGUL), the mental health research charity the McPin Foundation (McPin) and a number of individual collaborators that brought specific expertise to the partnership. As described in the next section of the report, the partnership used a 'coproduction' approach to undertake the evaluation.

#### St George's University

The team at SGUL, and the evaluation as a whole, was led by a health services researcher (Steve Gillard) with experience of leading a number of large scale, multisite evaluations of innovative approaches to mental health services. The SGUL team included an experienced researcher (Sarah Gibson) who explicitly draws on her lived experience of mental health difficulties. Sarah's role in the evaluation was to ensure that lived experience perspectives ran through the whole project, and to support other members of the evaluation team in drawing on their lived experience of mental health difficulties in their work. The SGUL team also included a statistician (Sarah White) with extensive experience of designing and undertaking research that tests the complex change processes underlying mental health services and treatments. Two researchers (for the first 18 months of the project, Sarah Golightly, and latterly Sajid Mohammed), each drawing on their own lived experiences of mental health difficulties, were employed for four days a week to coordinate the bulk of the work stream 1 evaluation work. Daryl Sweet from McPin helped the SGUL team in the latter stages of the evaluation, contributing significantly to chapters 2 and 4 of this report. The SGUL team has an established track record in evaluating new approaches to mental health services, with a strong, recent focus on peer support. Alongside the Side by Side evaluation, the team are funded by the National Institute for Health Research to undertake a five year programme of research to develop, pilot, and trial nationally a new peer worker role to support people during the process of discharge from inpatient to community mental health care. We drew on this expertise, as well as a number of smaller evaluations of peer support initiatives, to inform this evaluation. All of the research and evaluation undertaken by the SGUL team integrates team members' lived experience of mental health difficulties into the design, conduct and leadership of our work.

#### **The McPin Foundation**

The McPin Foundation is a specialist mental health research charity that champions collaborative research approaches placing expertise by experience at the heart of research (www.mcpin.org). McPin was co-founded, and is led by Vanessa Pinfold, an experienced health services researcher, who oversaw work streams 2, 3 and 4 in this evaluation. The McPin team included Rose Thompson as senior researcher (working 2 days per week) who managed a team of researchers who together with Rose delivered the qualitative research components of this evaluation, drawing on their lived experience of mental health difficulties using peer research methods: Rajvi Kotecha-Hazzard, Andreja Mesaric, Julie Billsborough and Richard Currie. The team are experienced qualitative researchers and McPin drew on previous experiences of delivering other Peer Research studies to ensure each stage of the research process followed co-production principles and integrated academic and experiential expertise and experience. Rose worked closely with the whole team to design and collect data for work stream 2, with Rajvi taking a lead role in early consultation work before Rose was in post. Rajvi also took a lead role in designing and collecting data for work streams 3 and 4. The evaluation as a whole was a huge team effort and there were other individuals involved, particularly at earlier stages,

including Alison Faulkner, Karen James, Ben Perry and Sarah Matthews. In addition, the McPin researchers (Rajvi Kotecha-Hazzard, Andreja Mesaric, Julie Billsborough and Richard Currie) supported work stream 1 data collection, visiting groups and maintaining relationships with Side by Side projects to complete the logs. All researchers contributed to the write-up of the evaluation report, and worked across work streams in this effort.

#### Collaborators

As well as the core SGUL and McPin teams, a number of expert collaborators worked on the development of the evaluation, helped shape its early stages and then re-engaged with the evaluation as we developed our findings and conclusions. Most of our collaborators – Jan Wallcraft and Mary Nettle as private consultants, David Crepaz-Keay from the Mental Health Foundation and Clare Ockwell from The CAPITAL Project – bring lived experiences of mental health difficulties to their work as mental health researchers, service providers and campaigners. All have been extensively involved in developing, evaluating and leading peer support initiatives. Virginia Minogue brought a strategic perspective on commissioning and the wider mental health policy context from within NHS England, grounded in her own track record in supporting and developing service user and carer research capacity within the NHS.

#### Coproducing the Side by Side evaluation

Patient and Public Involvement (PPI) in health and social care research is increasingly established in the UK since pioneering work undertaken in mental health research in the 1990s (Faulkner & Layzell, 2000; Rose, 2001). PPI ranges in scope from consultation with patient or public groups on how aspects of a research project might be done, to research and evaluation that is wholly controlled, led and produced by people who bring lived experience of a health condition of using health and social care services. In mental health research this has often been called service user-, or survivor-led research and is supported by powerful ethical (Faulkner, 2004) and rights-based arguments (Beresford, 2005).

Most 'involvement work' in mental health research sits in a very broad and varied collaborative space in between these consultative and 'user-controlled' positions. Work undertaken by the SGUL team over the last decade has developed the idea of a 'coproduction' approach to mental health research. Moving beyond making space for service users and carers in the research process, this approach involves actively reflecting on how we all – whatever our background – produce knowledge about mental health, and so challenging the way that clinical-academic research is conventionally done. We identified some of the key characteristics of the coproduction approach to mental health research as follows:

- 1. High value research decision-making is spread across the team
- 2. Different interpretations of data are owned and understood in terms of 'who we are'
- 3. Consideration is given to who is involved in which parts of the process and how that impacts on the research (the 'evenness' of coproduction)
- 4. There is flexibility in the way we do our research where scientific conventions constrain the input of team members
- 5. There is critical reflection on how we did the research and why
- 6. Outputs of the research report on how the knowledge was produced (Gillard et al 2012).

This evaluation is guided and shaped by this coproduction approach. As a partnership and evaluation team, we understand coproduction in this project to be about foregrounding the full range of voices on the team that draw explicitly on lived experiences of social and emotional distress, mental health difficulties and of using mental health services. This includes the voices of those who are core members of our research teams, our collaborators and the part time researchers employed to undertake the research in the field. We also undertook to engage, early in the process, with the people coordinating and accessing peer support as part of the Side by Side programme to ensure that evaluation was as accessible as possible and reflected their priorities. We integrate this experiential knowledge with technical knowledge about research and mental health service delivery also held by members of the team, noting that many team members bring more than one source of knowledge or expertise to their role.

We believe that this coproduction enables us to critique and empower the way we work, with experiential knowledge at the heart of shaping and undertaking the evaluation. In turn, we hope this approach ensures that our findings reflect the experiences and priorities of people directly involved in peer support, and that our recommendations can contribute meaningfully to making effective peer support as widely accessible as possible. We reflect on the extent to which we managed to coproduce the evaluation at the end of this report, and on the impact of our efforts on the evaluation process and findings.

#### The context of the Side by Side evaluation

No research or evaluation takes place in a vacuum. There are always issues of resources and relationships that shape the way the evaluation is done. As an evaluation team we were faced by a number of challenges and opportunities when we designed the project. We briefly discuss this context below and again reflect on these issues and their impact on the evaluation at the end of the report.

#### A complex programme

The first challenge, and opportunity in equal measure, was the sheer scope and scale of the Side by Side programme. It was a real privilege to have the opportunity to evaluate a peer support programme that reached across England and was inclusive of such a range of communities. In turn this provided us with the possibility of trying to understand what peer support means for different people in different contexts.

Relating to the scale of the Side by Side programme was the issue of resource for the evaluation. Side by Side encompasses nine areas of England as well as Elefriends, we only had resource to focus closely on three of those areas. At the same time people involved in delivering the programme, quite rightly, wanted the evaluation to be as inclusive and as far reaching as possible. Research and evaluation increasingly makes use of technological solutions to make evaluation both accessible to large numbers of people and cost –effective to undertake. The resource available for the evaluation meant that those hi-tech solutions were not an option and that old fashioned 'boots on the ground' would be our principle approach. The requirement that we collect data for the externally delivered economic evaluation was a further capacity challenge for us.

The sheer number and diversity of partners to the programme was also both opportunity and challenge. It was a challenge for us to understand the structure of the programme at strategic partner, regional and local level, and how those multiple organisations were differently involved in programme management, capacity building and project delivery. We needed to build different sorts of relationships with different sorts of partners who all had different expectations of both the Side by Side programme and the evaluation. But this diversity of

expertise and constituency was also a great asset to the evaluation in terms of providing infrastructure, enabling access and supporting our researchers on the ground.

#### The diversity of peer support

We had to devise an approach to evaluation – both in terms of measuring impacts and understanding experience – that worked equally well for all people in all contexts. Evaluation is easiest to do, and the results easiest to understand, when the thing that you are evaluating is as uniform as it can be. Peer support is complex so it was not our intention to find the most straightforward approach to undertake the evaluation. We wanted to understand that complexity. As a result it was always going to be a challenge to find an evaluation approach that would fit everywhere and for everyone. In particular, finding an approach that could be used equally to evaluate and compare the online peer support provided by Elefriends and the face to face peer support provided by projects on the ground, for example, was always going to be hard to achieve. We were tasked, in effect, with both defining approaches to peer support while at the same time foregrounding the full diversity of identity, experience and understanding of peer support that we would inevitably encounter.

#### **Evidence versus Experience**

It should also be noted from the outset that there are acknowledged tensions in any evaluation of peer support in mental health. For many, peer support, either within or outside of mental health services, has a political or 'emancipatory' purpose. For some, peer support embodies looking beyond a medical understanding of mental health, embracing a more socially informed approach that recognises the importance of people's own experienced-based knowledge about their mental health (Mead & MacNeil, 2006). Any evaluation that a) reduces that experiential knowledge to measurable outcomes, and b) presents peer support – grounded as it is in interpersonal connections and relationships – as a commissionable service, is arguably at risk of missing out on understanding the fundamentally human processes underpinning peer support. The challenge of not falling into this trap, while still delivering on the evaluation brief, was one that marked the entire evaluation process. In fact, the coproduction approach we describe above – and in particular the integration of lived experience of mental health difficulties throughout the evaluation – was in large part our response to this challenge.

# Chapter 2 – an overview of the current literature on peer support in mental health services

There are a number of existing reviews of at least parts of the literature about peer support in mental health services (e.g. Davidson et al, 1999; Lloyd-Evans et al, 2014), and so this chapter does not attempt to systematically review research about peer support. Instead we set out to present an overview of writing about peer support in a way that usefully informed the design of this evaluation and then helped us to place our findings in that wider context.

#### **Review method**

The development and undertaking of this evaluation has been guided and shaped by the team's reading of the ever expanding literature on peer support and mental health. This is a very broad literature that includes formal research studies of all types – from research that focuses on people's lived experience of peer support to highly structured, randomised controlled trials of peer support in mental health services - as well as reports about peer support projects written by peers, individual narrative accounts of sharing peer support, and writing about the values and principles underpinning peer support.

#### The peer support literature

We used three main sources of literature in this chapter. First, members of the evaluation team based at St George's, University of London have been involved in another research programme in parallel to Side by Side, developing, piloting and evaluating a new one to one peer worker role designed to support people with their experience of discharge from inpatient to community mental health care (http://www.hra.nhs.uk/news/research-summaries/enrich-peer-worker-programme-to-enhance-psychiatric-discharge/). As part of that programme we conducted a formal, systematic review of research about one to one peer support in mental health services. This review encompassed academic research papers and so-called 'grey literature'; evaluations of projects that are written up as reports or are published online but do not appear in academic journals. This review included 95 publications about one to one peer support, including 12 publications from the grey literature.

Second, because the ENRICH review focuses on one to one peer support we needed to expand our reading to include other approaches to peer support, including group and online peer support. To do this we used the existing set of reviews of the peer support literature referred to above. This included eight reviews, two of which provided general overviews of the literature (Repper & Carter 2011; Mahlke et al 2014), two reviewed randomised controlled trials of peer support only (Pitt et al 2013; Lloyd-Evans et al 2014), one reviewed randomised controlled trials and other studies that measured outcomes (Chinman et al, 2014), one reviewed qualitative research about peer support (Walker & Bryant, 2013), one reviewed research abut peer workers experiences of providing peer support (Vandewalle et al, 2016) and one reviewed the effectiveness of consumer-led mental health services when compared to traditional services (Doughty & Tse, 2011).

Third, most of the literature referred to above is from the formal academic literature. To redress this balance we felt that we needed to include more of the grey literature, and in particular reports and evaluations that were peer-led. We also wanted to include writing about peer support, and especially about the values and principles underpinning peer support, that was not necessarily written up in the form of an evaluation report or research paper. This sort of writing is not usually included in literature reviews because it is not based on data collected in a research or evaluation project. However as a team we were aware that there was

influential writing about peer support, grounded in people's lived experience of peer support, which would usefully be included in this overview. In conducting the ENRICH review referred to above we collated a great deal of this wider literature (that we did not include in our review). We refer to this resource here.

#### Structuring the overview

In reading this literature we noticed patterns emerging that would usefully inform this evaluation. The literature referred to a number of different approaches to peer support that were much more finely grained than a simple breakdown of one to one, group and online peer support. For example, there was peer support that was provided as part of formal mental health services (e.g. Salzer et al, 2009) and grassroots peer support that was community based (e.g. Adame & Leitner, 2008); peer support where peers were employed and trained in peer worker roles (e.g. Sledge et al, 2011) and peer support that was more instinctively shared (Faulkner et al, 2013); and peer support that was wholly led by peers (e.g. Doughty & Tse, 2011) and peer support that was co-delivered with mental health professionals (e.g. Salzer et al, 2009). And these categories were not mutually exclusive; peer support could be provided in a myriad of complex ways. The first section of our overview will describe this complex variation in the ways in which peer support is shared and provided. This work informed the way we collected data about the different sorts of peer support they accessed, as reported in chapter 4 below.

We were aware from the literature that peer support is provided and shared in a wide range of different contexts. Within general adult mental health services peer support is provide in inpatient and in community settings, for military veterans (e.g. Chinman et al, 2010) and in rehabilitations services, and increasingly in specialist settings, for example, for younger people (e.g. Webb et al, 2008) and in eating disorders services (e.g. McKey et al, 2003). A small but growing number of reports and papers also indicated that peer support could mean very different things to people in different community settings, for example within different cultural communities (e.g. Economic Change CIC, 2013). Culturally grounded understandings of mental health, and different language around 'who is a peer', suggest very strongly that assumptions about peer support that might make sense in the context of formal mental health services do not necessarily apply across community contexts. The second section of our overview will explore understandings and language of peer support in different settings and community or cultural contexts. This work very importantly informed data collection strategies described in chapter 3, and especially the work we did to explore Black and Minority Ethnic (BaME) specific peer support, as report in chapter 7.

Finally, as noted in the introduction to this report, part of the remit for this evaluation is to understand the values base underpinning peer support, and to identify how that understanding might inform evaluation and capacity building in peer support. We looked for writing about values and principles in all the literature we explored above, in the academic literature as well as writing that specifically set out to discuss and communicate those values. The final section of this overview summarises this developing thinking about values and peer support, and fed directly into the work developing our values and principles framework discussed in chapter 5 below.

#### Approaches and models of peer support

The literature has identified a large variety of ways in which peer support is shared and provided. Although there is much overlap between the approaches below, a number of main themes emerge:

#### One to one peer support

One to one peer support can involve formal contexts in which peer support is scheduled, organised and agreed upon, and more naturally occurring one to one interactions that might happen between friends or on a hospital ward. A variety of peer support services offer support from a 'peer support worker', often as part of formal mental health services but also within the third sector or community services. Most of the empirical research about peer support focuses on these formal one to one models. For example, Sledge et al (2011) evaluated an approach in the USA where peer support workers were recruited and trained using a recovery focus to provide personalised support to people with a range of different mental health diagnoses and who had experienced multiple psychiatric hospitalisations. Support involved telephone or face to face meetings at least once a week with a peer, alongside usual clinical care. The study found that people who joined this programme had significantly reduced readmissions to hospital, compared to those assigned to a control group receiving the same clinical care options but not receiving peer support.

A similar approach was tested in the UK by Simpson et al (2014) but focused on the role of peer support workers in increasing hope and quality of life for people discharged from hospital. This model of peer support involved six weeks of contact time, two or three of which were before discharge and the remaining post. It also involved face to face and telephone contact and the study found that peer support reduced admissions compared to the control group, but did not find any significant difference in quality of life or hope. Faulkner et al (2013) reviewed a wide range of peer support models across England, highlighting that in formally provided, one to one models there was a clear distinction between peer support worker and the person being supported, with the former usually at a later stage of their own recovery supporting someone in a mental health crisis to plan recovery, wellbeing and practical strategies.

In comparing peer support workers to professionals who had similar roles, such as case management, a review by Pitt et al (2013) noted that peer support workers provided services differently, spending more face to face time with clients and less time office based. However, they did not find any evidence that these types of roles improved quality of life, satisfaction with services, hospital use or other outcomes. The authors concluded that employing people who currently or previously have used mental health services to provide services themselves leads to outcomes that are no better or worse than those achieved by professional staff. Another review has found that one to one peer support in mental health services has a strong positive effect on social support and social functioning, reduced hospitalisation and improved empowerment, compared to traditional mental health services (Repper & Carter, 2011)

While most of these one to one models within services involve a peer support worker providing emotional, practical and social support to other, with reciprocity more of an implied value as in the examples above, other one to one models involve the explicit reciprocal exchange of support between two peers. Some of the models reviewed by Faulkner et al (2013), particularly those which were peer-led, emphasised this mutual support approach, in which both individuals were explicitly learning about recovery and self-management from each other. Armstrong et al (1995) interviewed peer volunteers in Canada who provided support to clients, but who emphasised that the focus of their relationships were reciprocal connections

as human beings and who reported their own quality of life improving to a similar degree as clients. The 'helper-therapy' principle (Riessman, 1965) has been applied to this mutually supportive exchange, in which even where one individual is explicitly the helper and the other the receiver of help, it is recognised that the help giving itself is very beneficial for a person's own recovery and wellbeing, increasing a sense of one's own sense of competence through having a positive impact on someone else's life (Salzer & Shear, 2002). Indeed, Bracke et al (2008) found that providing peer support was more beneficial to empowerment and self-esteem than receiving it, creating new identities for the 'giver' and often providing paid employment.

Moreover, not all one to one peer support models take place within such formal contexts, and can occur more naturally or do not make such a distinction between the giver and receiver of support. In some voluntary settings, this idea of mutual support in one to one relationships is at the heart of the service's philosophy (Faulkner et al, 2013), while naturally occurring relationships of this sort are often difficult to distinguish from friendship and might be labelled that way by those involved (Davidson et al, 2006). A 'peer' has been described as an 'informed friend' whose experiences resonate with the person they are providing support to or receiving it from (Faulkner & Kalathil, 2012). These more naturally occurring forms of one to one peer support are less represented in the literature.

#### Peer support in groups

Group-based peer support involves people getting together to use their own experiences to support each other and can include groups in the community which are 'naturally occurring' and user-led, self-help or support groups linked to hospitals, mental health services or voluntary organisations, or online communities either supported by organisations or those set up and run by peers themselves. In group based approaches, compared to one to one models, mutuality and reciprocity is often an explicitly central aspect of the interaction (Repper & Carter, 2011). Narratives on peer support within groups written by mental health survivors also emphasises the importance of a safe space to share experiences freely, as well as the acceptance and normality provided by such spaces (Bell et al, 2010)

Peer support groups include those which are entirely user-led with no facilitation by practitioners or professionals, for example the Prosper peer support network (Barrett et al 2015) which combined group training for peer leadership with mutual support. Other peer support groups involve varying degrees of professional facilitation. The SUN Project offered open access peer support groups to people who identify with experiences described as personality disorders, and is co-facilitated by a peer and mental health professional using a coping strategy appraisal approach (Gillard et al 2014). Another model was studied by Castelein et al (2008), where 56 individuals took part in 16 peer support group sessions in which participants decided the topic and daily life experiences were discussed together both in pairs and in groups. Nurses facilitated these groups but had minimal involvement. A randomised control trial of this approach found it had a positive effect on social support and social networks in comparison with the control group.

Some group approaches are self-help and/or psycho-education based, for example the 'In-Sight Training' intervention developed by an expert by experience involving 12 weekly threehour sessions of group work for people with bipolar which focuses upon managing the condition. An evaluation of this intervention found it to be effective in improving mood stability, coping, quality of life and empowerment, and it identified the user-led element of the intervention as a primary mechanism in its effectiveness (Straughan & Buckenham, 2006). The review by Lloyd-Evans et al (2014) included four programmes of mutual peer support which comprised three peer support groups and one un-moderated internet support group. The review found a large improvement of empowerment and quality of life in these mutual support approaches, but the quality of evidence was low and other outcome measures such as hospitalisation and psychiatric symptoms were not impacted. Another review has found that mutual support groups improve the social networks and quality of life, as well as the symptoms, of individuals who take part (Davidson et al, 1999). Pistrang et al (2008) reviewed the effectiveness of mutual help groups and included 12 studies in their review, which included groups for chronic mental illness, depression/anxiety, and bereavement, of which seven reported positive changes for those attending the groups, including two RCTs which found that outcomes were similar to those of much more expensive professional interventions. While most of these peer support groups involved face to face sessions, there is an increasing use of online platforms to provide and deliver peer support, which will be reviewed in the next section.

#### Peer support online

Online peer support is a burgeoning area of both naturally occurring peer support exchanges, and increasingly, those maintained and facilitated by organisations or services. A variety of online peer support settings and approaches have been described in the literature, from those which provide a space for peers to support each other (e.g. Freeman et al, 2008), to those which provide formal one to one support online from trained peer workers (e.g. Simon et al, 2011).

Webb et al (2008) describe the Australian Reach Out! Online Community Forum aimed at young people aged 16-25, developed in consultation with people in this age group and facilitated with their help but also involving trained moderators. This platform is a safe space where individuals can share strategies and resources for managing their mental health difficulties. The authors describe some unique potential benefits of such trusted peer communities, including providing an anonymous space to share experiences that might otherwise be felt to be stigmatising, but also point out the potential dangers in unsupervised forums for young people, particularly around contagion of self-harm and suicide. An evaluation of an online mutual support group for college students with various psychological problems found that people in the mutual support group showed an improvement in well-being and life satisfaction, but not to a greater degree than the control group who used online information only (Freeman et al, 2008).

Online peer support can take very different formats to the forum models described above. Proudfoot et al (2012) describe a psycho-education programme where support was entirely email based, with 'Informed Supporters' recruited to answer questions and give selfmanagement advice to clients, with a restriction of two 300-word emails a week from the Informed Supporter. They found that this approach increased participants' perception of control and reducing perceived stigma, while improving symptoms of both anxiety and depression, compared to a control group.

The role of health professionals within these groups varies. A systematic review (Ali et al, 2015) of online peer-to-peer support for young people with a variety of mental health problems in Australia, covered six interventions and forums which were moderated by health professionals, other peers or researchers. They found that two of the randomized controlled trials were associated with significant positive outcomes when compared to control groups, in reducing anxiety and smoking behaviour.

In terms of the mechanisms that make peer support in online settings unique from face-toface settings, there is limited discussion of this in the literature. Ali et al (2015) point to the fact that an increasing majority of young people use online resources to learn about their condition and to connect with others, while Horgan & Sweeney (2010) reported that 68% of 18 to 24 year olds would use the internet for mental health support if they required it, and 30.8% of respondents already did so. Horgan et al (2013) evaluated an online peer support forum for university students with symptoms of depression and found that a large number of male students participated, suggesting that perhaps online peer support may be particularly appealing to men, who traditionally show lower help-seeking behaviour than women. The same study found that various participants registered and browsed the forum without engaging directly by posting on it. This perhaps suggests that the ability to be an observer, at least at first, is a beneficial mechanism of online settings for peer support, compared to faceto-face settings where people might feel under more pressure to engage earlier. Further, research has highlighted a particular benefit for people living in rural areas who would otherwise find it very difficult to access social and/or professional support for their mental health (O'Dea & Campbell, 2010).

As hinted at above, there has also been a debate around whether such online support forums help alleviate behaviours such as self-harm, or exacerbate them through social influence or contagion. Some researchers have raised concerns about the normalisation of such behaviours through online groups, or indeed the danger that such forums actively encourage self-harming behaviour, providing how-to guides or details about methods to which individuals would not otherwise have access (Whitlock, Powers & Eckenrode, 2006). A study on this specific question which surveyed 102 members of one self-harm group, found that most participants felt the forum helped to alleviate both the frequency and the severity of their self-harm behaviour (Murray & Fox, 2006).

Online peer support is likely to also take place in many more naturally occurring ways that don't fall easily into simplistic categories and which are likely to be missed by the literature – for example friends connecting or in groups one to one via social media or email to share tips and advice, or peer support that happens spontaneously in forums or other online settings not specifically set up for peer support purposes.

#### User-led and grassroots models

Much of the history of peer support is based in grassroots, user-led and 'bottom-up' movements that have developed over the last few decades; user-led organisations have been vital in pushing the peer support agenda forward (Basset et al, 2010; Faulkner & Kalathil, 2012). Although not always called 'peer support', service users have long supported each other informally and through self-help groups, as well as through activism and the survivor movement (Basset et al, 2010).

In contrast to formal approaches in which peer support is integrated into or works alongside the mental health system, other models – particularly those which have their roots in the survivor movement – sit completely independent of services and are a part of approaches which seek alternatives to traditional mental health care. They tend to value their user-driven model and their independence from the mental health system (Faulkner & Kalathil, 2012). These models recognise that much of the movement towards peer support has been organic, and often in conflict with traditional psychiatry and its top-down, disempowering philosophy, thus they often have a socio-political focus (Adame & Leitner, 2008). An example of such approaches which are distinct from the ethos of formal mental health models is the Leeds Survivor Led Crisis Service which has a unique attitude to dealing with crisis; the centre is nonmedical and non-diagnostic, while self-harm is to some extent allowed as a way of managing psychological distress (Williams May, 2011)

As peer support increasingly moves into formal mental health services, there have been fears that the user-led, informal and friendly approach that grassroots peer support emphasises, and which has traditionally located itself in community settings and maintain edits independence is under threat (Faulkner & Kalathil, 2012). This same report also raises concerns around peer support within mental health services being viewed as 'cheap labour' rather than something that has its own value, the latter being another emphasis of grassroots and user-led models. However, it has also been argued that integrated and complementary models of peer support may have the opportunity to change the mental health system from within, whereas models outside of the system cannot do so (Adame & Leitner, 2008).

### Peer support in formal mental health services

Formal mental health roles for peer support are those which are often integrated into or complementary to the clinical services provided by mental health teams and tend to involve recruited, trained and paid roles. These models arguably manifest a professionalisation of the grassroots approaches described above (Faulkner & Kalathil, 2012). They can be extremely outcome-driven, involving the provision of structured one to one support such as helping people prepare documents for housing, benefits or employment, or providing advocacy at meetings for such purposes. In other models, a trained peer support worker may take on a navigating role, helping someone to develop connections both to services and to the community (Jacobson et al, 2012).

Primary care navigators are a more recent model of formal peer support, in which community based peer support is provided to people in transition between services or back to the community following a stay in hospital. Griswold and colleagues (2010) examined the effectiveness of this navigator role in helping people connect to primary care after mental health crises, finding that those who were provided general peer support or a specific peer navigator were more likely to connect with primary care, while those who were provided with both were even more connected to primary care. This access is important given the increased mortality for people with severe mental health diagnoses and the accompanying physical health problems that can result from medication.

In these approaches to peer support, there is often a formal training process for the peer worker (e.g. Salzer et al, 2009), sometimes with a clinical mental health element (e.g. Brekke et al, 2013) and thus an inevitable element of professionalisation of the peer support role. In addition, in formal peer support models the peer worker is often required to be further along in their recovery than the persona they are supporting (Repper & Carter, 2011; Hunkeler et al, 2000). However, there are also examples of peer support in this setting where the role is much less outcome driven, aimed at providing companionship and emotional support (e.g. Klein et al, 1998). In addition, peer support in formal mental health services can be naturally occurring. Jones et al (2009), for example, describe a culture of peer support that naturally occurs within psychiatric wards in England as a positive and therapeutically beneficial exchange between inpatients. This can be as informal as people being friendly to each other in what can be a frightening environment for some people.

These roles can be of therapeutic value to the provider of peer support as well as the receiver. A qualitative systematic review of peer support within mental health services found a number of benefits for people employed in a peer worker role, including increases in confidence, selfesteem and social networks, as well as progression towards employment, but reports of negative attitudes from non-peer staff members who often treated peer workers as patients and not colleagues (Walker & Bryant, 2013). The same review also found that non-peer staff were impacted by the presence of peer support workers within the service, reporting increased empathy towards the concept of recovery, as well as people in recovery. Some of the research on these roles has argued that good practice should ensure that those involved in peer support have the right and opportunity to influence and act upon decisions around the delivery of peer support (Faulkner et al, 2013).

### Integrated versus complementary

Within formal mental health service roles, there is a distinction between peer support which is integrated into mental health teams and care approaches, and peer support which is separate but complementary to mental health service provision – moreover, various levels exist between these two 'extremes' (Pitt et al, 2013). The approach described by Salzer et al (2009), for example, is a model in which the peer worker functioned as a full member of the assertive community treatment team, attending and participating in treatment planning meetings and performing some case management activities. By contrast, some approaches, such as the one based in the USA, described above and evaluated by Sledge et al (2011), involve a role which complements the services that an individual already receives, sitting alongside rather than forming part of services. In this study, peers were paid by mental health services but their role was independent of the clinical system and they did not report to staff within the services. Potentially, this latter model may help alleviate the concern sometimes voiced in the literature that maintaining a distinct role for peer support workers becomes difficult as they are increasingly integrated within the mental health system and adopt the traditional ways of working found in these services (Oades et al, 2012).

### Professionally-led versus user-led

A related distinction that can be made in peer support models is that of professionally-led, versus user-led, peer support. An example of the former is the nurse-led approach that has been described above (Castelein et al, 2008a). The authors have described this approach as initially setting out to move on from nurse-led guidance to a user-led format, but they report (Castelein et al 2008b) that the groups lost momentum during this transition - due to the cognitive and social disabilities associated with schizophrenia - and therefore they used a minimal guidance group structure supported by a manual for practitioners. They reported that having a nurse in the group maintained structure, continuity and security to sessions but does not interfere with the focus on peer to peer interaction.

In contrast, various examples of peer support which is user-led exist and have already been described above. Another example of this model is within user-led mental health communities online. A review (Giles & Newbold, 2011) of these forms of peer support has highlighted that these formats of interaction offer advice and information that can deviate from standard medical opinions. This review makes no judgement of whether this is a positive or negative aspect of user-led approaches, except to point out that some professionals view these forums as dangerous due to potentially inaccurate advice and a risk self-diagnosis that can result from this lack of moderation could be dangerous, while others view them as a useful complement to traditional services.

### Peer support in different community and identity contexts

Peer support is given and received in a wide variety of contexts from community-based to those that occur in hospital, residential and forensic settings. In addition, a wide variety of community and identity contexts can be differentiated, including veterans, diagnosis-based provision, and in different BaME or cultural groups. It is likely that across these settings there are important variations in the way in which peer support works and is understood, and perhaps in how effective it is. Moreover, some have argued that such identities may be more central to peer relationships than mental health diagnoses (e.g. Faulkner et al, 2013).

The issue of cultural sensitivity has been raised in a variety of approaches to peer support and forms an aspect of some of the training that is provided to peer support workers. For example, part of the curriculum for the 'Peer Support Technician' for Veterans reported by Chinman and colleagues (2010) is cultural competence; developing an understanding of how ethnicity, religious, sexual orientation and other cultural factors might influence recovery. Yet despite some recognition of the importance of these factors, there has been a lack of research that explicitly explores such community, cultural and identity issues in relation to peer support. However, there is some literature that explores similar issues in relation to social and community approaches to mental health support. This section will review some of the research that does exist and which can guide our understanding of how these factors might impact peer support.

#### **Diagnosis-specific contexts**

Although peer support often has a more general mental health and/or wellbeing theme, there are numerous examples of diagnosis specific contexts, of which we will cover just a few here as illustrations. Hearing Voices peer support groups are an example of a worldwide form of support that helps people to understand what can be extremely frightening experiences through connections with other people who have had, or are having, the same experience; in these groups voice-hearing is not simply dismissed as a 'positive symptom' to be controlled with medication but is seen as an important part of a person's life and connected deeply to their life story including experiences of trauma and abuse (Dillon & Hornstein, 2013). Voice hearing can be particularly stigmatizing and the safe space provided to explore these experiences with peers is thus extremely valuable; some evidence is available that suggests participation in these groups helps voice hearers reduce the distress they experience (Ruddle et al, 2011).

Another example of peer support focusing on a particularly diagnosis is the email exchange format of peer support offered to people recently diagnosed with bipolar disorder, reviewed by Proudfoot et al (2012). The authors suggest that for bipolar disorder there is the potential for peer support to be less effective due to the interpersonal difficulties associated with the condition and the emotionally-taxing nature of engaging in peer support which might exacerbate mood instability for some people. However their analysis found that those who took part benefited from peer support in similar ways to people with other conditions.

Peer support for eating disorders has also received attention in the literature. An evaluation of such groups within schools by McKey et al (2006) found that they can help improve bodybased self-esteem and reduce potentially unhealthy dieting habits. The authors point to the social pressure related to body image and the particular vulnerability of teenager to such pressure as a basis for the benefits that peer based interventions can provide for such diagnoses, although in their study the majority of participants did not report body image or eating problems at the outset of the intervention and the impact of the peer support group work was primarily preventative. In supporting each other to become more accepting of themselves, this form of group peer support has the potential to make a very significant impact on future strategies to manage eating, dieting and self-esteem together, rather than facing such issues alone.

#### Peer support in Black and Minority Ethnic communities

There has been some (limited) literature that addresses peer support specifically within BaME communities which provides an insight into how concepts like peer and mental health may be understood differently and the implications for peer support approaches in these contexts.

A Canadian report by O'Hagan and colleagues (2010) identifies peer support as something that often happens informally and naturally within various ethnic minority communities, where individuals might use the support of their family or community, but that the idea of peer support was less well recognised in these communities. In addition, peer support was not supported or funded formally for these groups, and most of those who engaged in peer support in Canada were middle-aged Caucasians. The report also points out that identity issues can be complicated for people who have two or more marginalised identities – in this case, that of having a mental illness as well as a minority ethnic identity – and that such individuals might experience stigma in relation to both their ethnicity and their experiences of mental health difficulties.

A related point was made in a report by Faulkner and colleagues (2013) which identified a potential gap in peer support services in the UK for ethnic minority communities, suggesting that such groups existed but took on different forms that do not use a mental health label (while providing similar benefits and using similar peer support values and approaches). As such, the report argues that firm definitions of peer support that exclude the funding of projects in such communities should be avoided.

A social impact report on a Hayaan Somali Mental Health project run by Mind in Harrow (Economic Change CIC, 2013), which involved the recruitment of Somalian peer educators, highlighted that mental illness is not recognised in Somalian culture as a medical issue that can be treated but as a spiritual issue, and that stigma and lack of help seeking are therefore major barriers to supporting wellbeing in this community. The use of peers to support and educate in this context was vital in ensuring that the language used around mental health was acceptable and the report found that this approach helped the Somalian community to increase their own understanding of mental health, but also helped service providers increase their understanding of this community. A similar study of Mental Wellbeing Champions in Black communities in South London indicated that shared community organisations such as churches.

Edge (2011) has explored black Caribbean women's perceptions of perinatal mental health care and found that peer support is given and received informally by family and friends. The women interviewed talked about an ideal service model that was community based and not necessarily delivered by professionals; they also pointed out that interventions need not be culturally specific as this is often interpreted as delivering them in ethnic groups. The women interviewed felt that multi-ethnic groups were preferable as people might not want to disclose distress in Black-only groups. This example highlights a potential pitfall of thinking that peer support should necessarily be provided separately for each different ethnic and identity group. Rather, integrated approaches which are culturally sensitive may be a more effective solution. In studies such as this work with Black Caribbean women, peer support was not always how people describe these exchanges, talking instead about friendship, social support, community support or help from friends and family (who have similar experiences).

Other work on BaME communities has similarly used alternative terms in describing similar processes. For example a report by NHS Bradford and Airedale with the University of Central Lancashire (2009) highlighted that people wanted to give and receive support from peers who share identities such as ethnicity, age, gender or mental health experiences. They outline a wide range of communities who identify the importance of mutual support; many but not all identified shared ethnicity as an important aspect of this, including the importance of people of their ethnicity helping to develop, lead and deliver community support services more generally. The importance of support through religious institutions and faith leaders was also highlighted, in which churches and mosques provided a strong structural network around which support could be provided and received, while one of the most common threads was that shared experience was vital, not necessarily shared ethnic identity.

Ethnicity-specific peer support provision may, on the other hand, help to address common issues of exclusion by involving people with shared cultural and ethnic identities as well as knowledge of local communities (JCP-MH, 2014). The co-produced nature of peer support relationships has been seen as a potential strategy to mitigate the disproportionate representation of Black people in coercive mental health services, increasing trust and providing advocacy to help individuals be aware of and use their rights (JCP-MH, 2014).

#### Peer support for veterans

In the US, researchers have developed a large body of evidence around the implementation and effectiveness of peer support for veterans who are experiencing various psychiatric difficulties. Greden et al (2010) report on a 'Buddy-to-Buddy' programme for citizen soldiers who have developed mental health difficulties such as Post Traumatic Stress Disorder and depression on returning from service. Although various aspects of peer support processes and principles in this context overlap with peer support in other contexts, some unique features are identified by the authors. A major barrier to help seeking for this population was not wanting their issues to be recorded in military records, while the programme itself uses aspects of military culture to help people overcome barriers to seeking help. In particular, it addresses an issue for veterans who feel that people who have not also served as citizen soldiers would not understand their experience and how it has impacted their mental health; buddying with other veterans can counteract this issue. Resnick & Rosenheck (2008) examined people who took part in the Vet-to-Vet mental health peer support programme, finding that participants had significant improvements in empowerment, confidence and reduced alcohol use compared to a quasi-control group.

### Peer support for ex-offenders

An evaluation of a peer support project in the UK (TSIP, 2015) which employs ex-offenders as caseworkers providing both psychological and practical for other ex-offenders, found that this approach was viewed very positively by those receiving support. In particular, the shared experience acted as an inspiration for many, indicating that they could turn their own lives around and changing attitudes to reoffending.

#### Peer support in LGBT communities

LGBT communities are another context in which peer support involving shared experience seems likely to be of importance in combating stigma, self-stigma and rejection by families or friends. Mutanksi et al (2011), for example, found that for lesbian, gay and bisexual youths, victimisation as a result of sexual orientation was very common and led to psychological stress, but that peer and family support significantly reduced this distress. However, younger LGBT people often face increased difficulties establishing supportive peer relationships due to social

rejection (Williams et al, 2005), indicating that more formally organised peer support resources may be beneficial for this group. Faulkner & Kalathil (2012) interviewed the MindOut service for LGBT people and found that some LGBT people have had poor experiences with other mental health services including homophobia or heterosexism, which reduces engagement with these services and means a safe space for this shared identity is important.

Research has found that use of online forms of support in particular are beneficial for young LGBT people in identity development; using social network sites to develop sexual identity was associated with lower amounts of paranoia in one study (Ceglarek & Ward, 2016). Other studies have suggested that young LGBT people might use online peer support more than non-LGBT young people, but the same study found that offline peer support helped reduce the odds of victimisation, while online forms did not (Ybarra et al, 2015).

### Gender differences in peer support

It has long been recognised that men tend to talk about mental and emotional distress much less than women (Vaux, 1985; Yousaf et al, 2015). Men are also less likely to seek help for mental health issues and have less favourable attitudes to using mental health services than do women (Oliver et al, 2005), while both genders sometimes have their own emotional communication styles (Kring & Gordon, 1998). This might imply that gender specific peer support groups or gender matching in one to one provision will be of benefit to at least some men and women, however the research on peer support in mental health has not particularly focused on gender differences. Some studies (e.g. Sledge et al 2011) have reported that part of the peer support process being evaluated was to offer peer matching on the basis of gender if requested, but such studies have not tended to examine whether or not this has a significant impact on the effectiveness of peer support.

There are examples of gender specific peer support groups. Men in Sheds is an expanding community based programme that provides a space for peer support and has a focus on practical skills and meaningful activities such as woodwork. Some of these programmes are focused on men's health and wellbeing, with the benefits of peer contact described (Wilson & Cordier, 2013). This focus is perhaps behind the rapid expansion of the programme, given the evidence around men's lack of engagement with more traditional models of health service delivery and lack of friendship networks. Men in Sheds may provide a safe space for men to share health experiences and build important social connections (Misan & Sargeant, 2009).

There are a variety of examples of peer support interventions specifically for women, including telephone based peer support aimed at preventing postnatal depression which research has shown to be effective (Dennis et al, 2009) and female peer support groups such as those for women bereaved by still birth, both online and face-to-face (Gold et al, 2016). There are also groups more generally on mental health and wellbeing for women but these are not well represented in the literature. One such group was described in the Women Speak Out report (Resisters, 2002) and – reflecting the fact that people have a variety of different identities that impact their experience of mental health – is a general mental health support group for South Asian Women, in Leeds. Women who attended this group found it very beneficial for reducing isolation, increasing belonging, accessing practical and emotional support, and connecting with people who had similar backgrounds and experiences in their own language.

Another question we might ask about gender specific provision is do the same values and principles apply or are there unique aspects to male and female groups? As with the other community specific groups above, this has not been explored in any detail within the literature.

### Principles and values of peer support

The articulation of principles and values that underpin peer support has been heavily contributed to by the grey literature, as well as peer-reviewed research. There is a growing consensus that principled and value-driven approaches are vital within peer support and that it is important to retain these across settings. We note that this writing has been in reference to a wide variety of approaches peer support; the question remains whether a single set of principles and values applies to all models of peer support in all contexts, or whether we need specific sets of principles and values that reflect the diversity of peer support referred to above? The following is not a comprehensive breakdown of the values and principles that have been described in the literature, but rather an overview of those found most consistently.

### **Identity and authenticity**

Identity is a central principle within peer support given that peer workers and members of peer support groups will share identities based upon common experiences as well as, in many cases, shared cultural and ethnic identities. Indeed, these aspects of identity are a requirement for the role of peer support worker, participation in peer support groups and one to one matching, while naturally occurring peer support will also be predicated on these shared identities. As a result, some of the peer support literature has emphasised the importance of enabling and supporting peer workers in professional roles to use their peer identity in their work and to have control of how they disclose this (e.g. Gillard et al, 2014). This has the potential to create identity challenges for some peer support workers in moving from the identity as someone who has made use of services to that of a provider (Moll et al, 2009). Others have pointed out that this identity transition can be positive, as people move from feeling powerless and labelled as patient to being valued and being labelled as an expert (MacNeil & Mead, 2005). A counter-point here is that for some peer support workers, taking on this role may mean that they feel they never move on from a patient identity because they see their occupation as defined by 'sickness' (Bailie & Tickle, 2015) and that they are pigeonholed by this identity (Moran et al, 2013).

Beyond these transition issues, other identity pressures have been discussed in the literature, such as the extent to which lived experience defines the role of peer support worker as compared to other skills required and how the peer worker identity is distinct from non-peer roles (Berry et al, 2011). Some peer support workers have reported not feeling accepted within the teams they work with as equal partners (Gillard et al, 2013) or have experienced negative attitudes from other staff who have placed non-preferred identities on them (Dyble et al, 2014). Despite these challenges, a range of benefits a result of taking on a peer worker role have also been described in the literature, such as personal growth and improvements to self-esteem and confidence (Bailie & Tickle, 2015). As we noted above, many people involved in peer support prioritise different identities over mental health, such as having connections to people who share cultural, ethnic, LGBT or gender identities (Faulkner et al, 2013).

Closely linked to these identity principles is authenticity; a expectations of peer support is often that individuals are honest, intimate and authentic about themselves – their identity and their experiences - in contrast to roles where professional barriers are prioritised over personal connection (Scott, 2011). Without authenticity, much of the benefits of peer support roles will be reduced as the insights and expertise gained from personal lived experiences are what allows people involved in peer support to connect with each other on a deeper level (Mancini & Lawson, 2009). This has been described in terms of concepts such as 'honest direct communication' and 'respect that comes from your heart' in conceptual writing about peer support (Mead et al, 2001).

### Safety, trust and confidentiality

The sharing of identity in an authentic way is not possible without the principle of safety being adhered to; people need to feel safe in order to disclose their personal experiences in spaces where they know they will not be judged (Repper & Carter, 2011). An example of this are Hearing Voices groups, which provide this safe haven to talk openly about a highly stigmatized issue For people who would like to do so (Tanis, 2008). A study of online peer support for post-partum depression found that online, people felt safe to reveal negative thoughts about motherhood that they otherwise might feel unable to because of idealised stereotypes about motherhood and being a good mother (Evans et al, 2012). In these ways, peer support groups both online and offline, can be enabling places that provide a space in which recovery-oriented progress and activities can be undertaken (Duff, 2012) and new identities can safely be practiced (Mead et al, 2001).

### **Reciprocity and mutuality**

The transactional nature of peer support is highlighted in the literature, with reciprocal sharing of common experience and provision of support, rather than a one-sided relationship, consistently identified as a central value (e.g. Dyble et al, 2014). This mutual sharing of experience is seen as a unique dimension of peer support which establishes trust, understanding and helps individuals feel that they are not alone (Gidugu et al, 2015). The relationship created as a result is often seen as closer to friendship than a practitioner-client relationship (Reidy et al, 2013) and removes the sense that one person is the expert and the other lacks expertise (Walsh et al, 2015).

Giving and receiving of support, and working together to find solutions are central components of peer support relationships (Repper et al, 2013). Within the context of online, group or grassroots peer support this reciprocity is likely to be common in practice, but in the context of more professionalised peer support worker roles, there may be a tendency for relationships to be comparatively more one-sided (Faulkner & Kalathil, 2012), albeit not to the extent of traditional practitioner-client relationships. This might be particularly true where – as described above – peer workers are provided training and are further along their recovery than the person they are supporting. However, as we also noted above, in these cases providing support can in itself be therapeutic and rewarding, contributing to the 'helper's' recovery, redefining the peer worker's own distressing experiences into something that has value (Salzer & Shear, 2002). Thus mutual benefit is another aspect of mutuality which is identified as central to peer support, and a central feature of peer support and self-help groups (Solomon, 2004)

In addition, while the experience of any two peers is never going to be identical, commonalities will often be found in terms of understandings of the challenges of accessing support, taking medication, or living with the label of mental patient (Repper et al, 2013). Thus mutuality of experience is seen as a fundamental principle across all variations of peer support.

### Empowerment, agency and self determination

Supporting individuals to be in control of their own recovery and increase their own selfefficacy is seen as a central role of one to one peer support (Grant et al, 2012), with individuals increasing their confidence in their own abilities to manage recovery and make decisions (Legere, 2014). This empowering role for the peer worker is a major shift from the traditional marginalisation of people with mental health problems towards an expertise that is valued and given authority (Adame & Leitner, 2008). This arguably differentiates the peer support role from other members of staff; the latter role is more explicitly caregiving while peers support each other to do things for themselves (Paulson et al, 1999). Peer-support is viewed as being non-directive with suggestions, rather than instructions, provided and received (Repper et al, 2013) and has been described as underpinned by a strengths-based, recovery philosophy (Scott & Doughty, 2012). Choice and freedom to decide to participate in peer support are fundamental, as is a person's agency to decide what is best for them (Legere, 2014).

In any peer support context, whether group-based, one to one or online, mutual empowerment can be achieved through the opportunity to move beyond a focus on disability and diagnosis (Miller & Stiver, 1997). Encouraging self-determination to explore options and supporting people to take steps that the individual feels are best for them is a related principle which has been highlighted as fundamental, particularly within formal peer support worker roles (Sunderland & Mishkin, 2014). Indeed, empowerment is not only a guiding principle, but has been found to be an outcome of engaging in peer support (Repper & Carter, 2011)

Agency, empowerment and self-determination are also reflected in the fact that many community peer support groups, as well as some of those which are delivered in partnership with formal services, are led by peers themselves. Indeed some have argued that such services must be peer-driven and led in order to ensure their effectiveness and their adherence to other key values and principles (Solomon, 2004).

### Equality

Related to the above principles of agency and self-determination, peer support is often said to involve a collaborative partnership rather than an imbalance of power. In formal one to one models, the peer worker and person they are supporting aspire to learn together, make decisions together and, in that sense, are on an equal footing. A report by O'Hagan and colleagues (2010) in Canada emphasises the importance of equality as a value identified by people engaged in peer support, as a contrast to what are often felt to be unequal power relationships within mental health services. These power structures have regularly been emphasised by grassroots and socio-political models of peer support as defining distinctions between traditional mental health care and the unique value that is provided by peer support. Power-relations should be openly discussed and open to renegotiation, according to Legere (2014).

### **Recovery and hope**

Another consistent theme in the literature (e.g. Byrne, 2013) is that peer support is underpinned by a recovery-oriented approach and rejection of medical models which encourage the power imbalances alluded to above and have a focus on illness, symptoms, deficits and risks. Recovery approaches, by contrast, emphasise assets, collaboration and self-determination. These avoid clinical language and rather use language based on common experiences (Davidson et al, 1999). This recovery approach increases hope for a better future for the individual (Sunderland & Mishkin, 2014) with peer support workers acting as role models of hope and recovery to the people they support (Lawn et al, 2008) and as living embodiments of recovery (Austin et al, 2014). Through supportive peer interactions, people can learn to grow from challenges and setbacks that they experience; many of the training guidelines that currently exist for peer support workers emphasise this recovery-orientation to the relationship (Sunderland & Mishkin, 2014).

### Empathy

An emphasis in many peer support approaches is on the quality of relationship between individuals, whether the peer support is mutual or being offered by a peer support worker. People who receive support from a peer worker often say that relating to peer support workers is much easier due to their shared experiences (e.g. Politt et al, 2012). This includes the need to have empathy in relating to the other individual, understanding their experience from their point of view and showing compassion even where it might conflict with the person's own experience (e.g. Reynolds et al, 2010). Similarly, some researchers have suggested that shared experience may lead to a heightened awareness for peer support workers of the importance of their job and the impact of mental ill health on individuals (Basto et al, 2000).

### **Professionalisation and boundaries**

There has been some tension around the principle of professionalisation in peer support, with some concerns raised in qualitative studies of peer support workers that it could erode the core peer quality of the role (Gillard et al, 2014), in particular undermining the principle of equality by establishing power imbalances. Other interviews of peer support workers have suggested that having a professional identity can be beneficial, particularly in managing multiple identities such as patient, service user, friend and peer (Dyble et al, 2014). There is often a tension in the role of a peer resulting from a blurred boundary between the personal and professional; personal experience is shared while training and integration into services might emphasise objectivity and the maintaining of boundaries (Colson & Francis, 2009). The boundaries that a peer support worker will have cannot be the same as those used by other staff who specifically withhold personal information, and in peer support scenarios boundaries are often blurred (Reidy et al, 2013). The guiding principles here remain unclear and problematic.

### Positive risk taking

Traditional mental health services have tended to take a risk-averse approach and one of the principles that is unique to peer support is that this is not emphasised, rather that there is a 'dignity in risk' (Scott et al, 2011) that supports self-determination and views risk and crisis as potential opportunity. In peer support relationships, because of the safety and trust that have been described above, it has been argued that people are more able to take these sorts of risks and share the risk together, feeling more comfortable in disclosing things that would be withheld from services because they might be considered risky in a negative sense by mental health professionals (Mead & MacNeil, 2004).

### Conclusions

This overview of the literature on peer support has highlighted a number of key points which will inform the rest of the report. First of all, peer support is a diverse set of activities which takes place in a wide variety of settings. Aside from the basic distinctions between group, one to one and online peer support, peer support can take place outside, alongside or as part of formal mental health services. Peer support can have varying degrees of facilitation (or none, being wholly mutual in nature), with or without some kind of professional involvement. In our evaluation we have needed to be mindful of the subtleties in this variation while at the same time attempting to draw broad conclusions about both the effectiveness of peer support and the way in which peer support works.

The overview of different populations, cultural and identity contexts has highlighted that there are large gaps in our knowledge of how peer support is understood, shared and impacts on people's lives in these different contexts. While there seem to be some common elements to peer support across contexts – in particular, a safe space to share experiences – we need to be cautious in our evaluation about assuming that peer support means the same thing to all people in all places. We have seen how people identify with each other in different and multiple ways, not just in terms of their experiences of mental health difficulties. While the issues of gender, ethnicity and sexuality described above seem particularly pertinent to this evaluation, we also note that the language of peer support and of mental health is not the same in all contexts. This evaluation has aimed to remain aware of, and build on emerging understanding of this rich diversity of peer support.

As has been shown above, there is wide acceptance that peer support is and should be principled and underpinned by a strong values base. While different language is used by different people, there is broad consensus on core sets of values around shared identity, safety and trust, reciprocity and mutuality, empowerment and agency, and so on. There are also concerns about maintaining and protecting these values where peer support is provided as part of formal mental health services; where the role of peer supporter and supported peer becomes demarcated and where institutional practice can be pervasive. Interestingly, while these core values are clearly grounded in a social, grassroots movement, much of the empirical research that reflects on the experience of peer support (research where data is systematically collected about people's experiences) has been sited at the more formal end of the peer support spectrum. While we might argue that there is a relative wealth of writing about the values and principles of peer support, it is important that this evaluation properly explores people's experience of those values and principles as they are enacted across the very wide range of community based peer support projects that we have encountered in the Side by Side programme.

We have used our reading of the growing literature on peer support in mental health services, as reviewed above, in helping us design this evaluation, informing the questions we have asked, how we have asked them and who we have asked them of. We have used this insight – alongside the personal, experiential insight of many members of the evaluation team – to help us interpret what people have told us about their peer support. And we have returned to this literature as we have tried to make sense of our findings in the wider context of the peer support movement.

# Chapter 3 – evaluating the impact of peer support

# The evaluation approach - why a peer support log?

Central to the remit for this evaluation was to build on and improve the evidence for the effectiveness of peer support in England; to make a major contribution towards understanding the impact of peer support in mental health. We needed an approach to evaluation that enables comparison of the effectiveness of different approaches to peer support (including online as well as face-to-face peer support), among different communities (especially BaME communities) and in different settings (including rural settings).

### Randomised controlled trials and peer support

The literature presented in chapter 2 described research that used of a number of different approaches to evaluating peer support. The conventional approach to establishing effectiveness – asking the question 'does this work?' – is the randomised controlled trial (RCT). While this method is considered to be the 'gold standard' in most health research, it is important to consider the context and the way in which a treatment or service is being provided to ensure that such an approach is both ethical and feasible.

For peer support, where personal motivation and choice to take part, and the fluid way in which many people may engage, are crucial elements of the support, an RCT may not be the best fit. Randomisation might be unethical if it is introduced where peer support is already available because half of the people currently involved in peer support might be randomised to the 'no peer support' arm of the trial (so that a comparison can be made). In addition, the process of allocation to receive or not receive peer support arguably undermines the choice and control at the heart of peer support (can you really randomly select people to build a relationship?).

### Comparison group studies

As an alternative to the RCT some studies compare a group of people receiving the new treatment or service with a similar group who are not. However identifying large numbers of individuals who are sufficiently similar to make a fair comparison is very hard to do. It is also not really possible or ethical to prevent people in the 'control' group from accessing peer support, so if people in both groups are involved in peer support this would dilute any potential evidence of effectiveness. In the Side by Side programme it is likely that many people will already be accessing at least some other peer support outside the programme and so the evaluation must be able to account for this.

In addition, much of the peer support offered through Side by Side is likely to take the form of projects that people are free to drop in and out of as they choose. Again, the evaluation method must be able to explore the relationship between accessing more or less peer support, and the impact of that for people. As a further complication, it is anticipated that roll-out of new peer support within Side by Side will begin at different times in different projects. As such it will be impossible to collect 'clean', pre-peer support baseline data at all sites in order to conduct a 'before and after' study. An innovative, but scientifically robust approach is needed that addresses these methodological and ethical challenges.

### The peer support log – an alternative approach

We returned to the question posed in the evaluation brief above: 'what changes in participant outcomes are related to both giving and receiving peer support?' To answer that question, while taking into account the challenges described above, an evaluation method is needed

that enables us to understand how outcomes change for people as they choose to give and receive more or less peer support. To do this the evaluation will use a *time series* approach to data collection and representation of data (Biglan, 2000), while a *self-controlled case series* design (Whitaker, 2008) will inform the statistical analysis.

These approaches are described technically in the Analysis Plan section below. What this means for people who choose to become involved in the evaluation is that they will be asked to complete a number of measures of outcome (questionnaires about possible impacts on their lives) at regular intervals for the duration of the time that Side by Side peer support is available to them. During this time people will also 'log' the amount of peer support they were involved in giving and receiving. We call this regular collection of information, or data, the 'peer support log'.

What this approach enables us to do is to track the amount of peer support people give and receive over time, and also how outcomes change over time (e.g. people's sense of wellbeing). We will be able to combine this data for everyone involved in the evaluation, or for particular groups of people we are interested in (e.g. for people from different ethnic communities; people living in cities and people in rural areas; people who access one-to-one peer support and those who access group peer support). We will be able to present this data on graphs so that change over time can be easily compared (this is the 'time series' approach described above).

In order to address the question of whether there is a relationship between how much peer support people choose to give and receive, and any change in outcomes, we have to do a different analysis. For each individual we will compare how outcomes change between points in time – entries in the log – where the amount of peer support they give and receive drops, with points in time where the amount of peer support increases or stays the same. When we combine this information from all people involved in the evaluation we will be able to 'model' the relationship between choosing to give and receive more or less peer support, and change in each of the outcomes we measure in the log. This is the 'self-controlled case series' approach referred to above. Again, we can do this for everyone involved in the evaluation or, where groups are large enough, for specific groups of people we are interested in. Technical information about how we analysed peer support log data is included later in this chapter.

# Scope of the peer support log

We noted in chapter 1 that there were resource constraints on this evaluation. We took a decision at an early stage of developing our evaluation approach that we would not be able to cover all nine regions of the Side by Side programme at the same level of detail. This applied in particular to supporting the collection of data through the peer support log. We decided that we would focus in depth on three of the nine regions while still providing as much support as possible to the log in the other six regions. Our different strategies for providing this support are detailed in the sections that follow.

In deciding which three regions to select for our 'close focus' we considered the following criteria (guided by the funding brief):

- The three regions should include one region led by each of the three strategic partners to the Side by Side programme (Mind, Bipolar UK and Depression Alliance;
- The regions selected should maximise BaME participation and participation from other minority groups as far as possible;
- The regions should include at least one rural location

The table 3.1 below provides an overview of the nine sites with information on each of the three criteria:

Region	Strategic partner	Etnicity	Rural/urban
Suffolk	Suffolk Mind	95.2% White; 1.8% Asian; 1.6% Mixed; 0.9% Black; 0.3% Other	Rural 80%+
Coventry	Bipolar UK	73.8% White; 16.3% Asian; 2.7% Mixed; 5.5% Black; 1.6% Other	Large Urban
Northamptonshire	Depression Alliance	91.5% White; 3.6% Asian; 2.1% Mixed; 2.5% Black; 0.4% Other	Corby - Other urban; N'hants - Other urban; Wellingborough - Significant rural
Leeds	Leeds Mind	85% White; 7.7% Asian; 2.7% Mixed; 3.5% Black; 1.1% Other	Major urban
Blackpool	Bipolar UK	69.1% White; 28.1% Asian; 1.2% Mixed; 0.6% Black; 0.8% Other	Blackpool - Large urban population; Blackburn with Darwen - Other urban population
Southampton	Solent Mind	85.9% White; 8.4% Asian; 2.4% Mixed; 2.2% Black; 1.2% Other	Large Urban
Devon	Depression Alliance	96.1% White; 1.5% Asian; 1.3% Mixed; 0.6% Black; 0.4% Other	Other urban
Teeside	Bipolar UK	88.3% White; 7.9% Asian; 1.7% Mixed; 1.3% Black; 1.1% Other	Large Urban
Kensington and Chelsea	Depression Alliance	70.6% White; 10% Asian; 5.7% Mixed; 6.6% Black; 7.2% Other	Major urban

Table 3.1: selection criteria for the nine Side by Side regions

BME population figures are taken from 2011 Census data. Rural/urban status are taken from DEFRA's classifications

(http://webarchive.nationalarchives.gov.uk/20130402151656/http://archive.defra.gov.uk/evid ence/statistics/rural/rural-definition.htm).

Based on this information, we selected Suffolk, Blackpool and Kensington & Chelsea as our three regions for close focus:

- Suffolk is the only rural site and would cover Mind as a strategic partner
- Of the sites where Depression Alliance is the strategic partner, only Kensington and Chelsea has a significant non-White population (including the largest Black and Other populations)
- Of the sites where Bipolar UK is the strategic partner, Blackpool has the biggest non-White population (including the largest Asian population)

We were also aware that Blackpool has a large LGBT population.

# Data collection method

### What sorts of questions did we ask?

As described above, data collection for this strand of the Side by Side evaluation took the form of a 'log' completed on a regular basis by people who had the opportunity to access new peer support provided through the Side by Side programme. The log was a series of questionnaires that asked:

a) how much of a number of different types of peer support people had given and received in the previous month;

b) how people self-rated a number of measures of outcome (see below).

When people first signed up, or registered to take part in the evaluation, they were also asked questions relating to age, gender, ethnicity, where they live and so on, so that we could make the group comparisons referred to above (and so that we can describe the people who took part in the evaluation).

As noted in chapter 1 above, an economic evaluation of Side by Side took place in parallel to the evaluation conducted by SGUL and McPin. The LSE team that undertook the economic evaluation required data on potential economic impacts for people accessing Side by Side peer support, including mental health service use, access to other community based services, employment and a measure of Quality of Life regularly used in economic evaluations. This data was, by agreement, collected through the peer support log, to be transferred securely to LSE following data collection.

### How often do people complete the log?

The evaluation method described above is more robust, the more time points we have for each person involved (because more comparisons can be made between time points). However it would be demanding to ask people to complete the log on a very regular basis over an extended period of time. In the evaluation we asked people to complete the log once a month – the 'monthly log' – for the duration of the time they accessed Side by Side projects. Depending on when people first engaged with Side by Side, this was generally a period of between 6 and 12 months.

The economic questionnaires added considerable length and completion burden to the log. However the economic evaluation team at LSE confirmed that they did not need this information on a monthly basis. A longer 'quarterly log' was developed that included the economic questionnaires in addition to the monthly log questionnaires. Participants would complete the quarterly log as the first and last log they completed, and quarterly in between. Copies of the registration, monthly and quarterly logs can be found in appendices 3.1-3.3.

The Peer Support Log was available to people to complete online or by paper version. The online version was designed to be completed either on a personal computer or by mobile device, and was hosted at SGUL using Limesurvey<sup>©</sup> software. A paper version was produced so that people without easy or regular access to the internet would not be excluded from the evaluation.

### Asking people for their consent to participate in the peer support log

The online version of the log included a link to video material - produced by the evaluation team - introducing people to the evaluation and explaining the Peer Support Log approach [insert hyperlink here]. Paper and online versions of the log contained written information about the purpose of the evaluation, what people would be required to do if they chose to participate and what would happen to the information they provided. On registering people were asked to tick a box indicating their consent to participate in the evaluation on the basis of the information provided.

### Staying in touch with the evaluation team

The questionnaire survey used for the evaluation did not have the facility to provide people with personal identification numbers. Sets of ID numbers were issued to projects to be assigned to people as they registered. Alternatively people who wished to participate were able to contact a researcher based at SGUL who would then issue them a personal ID number. This researcher was working from lived experience of mental health difficulties and would be the key contact for people taking part in work stream 1 of the evaluation. The registration log also asked people to provide their preferred contact details, and indicate whether or not they would be prepared to be contacted about participating in an in-depth interview (as part of the qualitative part of the evaluation described below).

### The peer support log monthly prize draw

Finally the registration log asked people if they would like to be entered into two prize draws each time they completed a monthly or quarterly log. A prize of £20 worth of vouchers was given to an individual randomly selected from all people completing a log each month, and a prize of £50 worth of vouchers given to the Side by Side project attended by one other individual randomly selected from all people completing a log each month.

### Monthly reminders

Once people completed registration online they were directed to a link to the quarterly log. If people completed registration on paper they could access, at their Side by Side project, a paper copy of the quarterly log to complete. Having registered and completed a first log, participants were sent a single monthly reminder each month to complete the next log by their preferred method of contact (in practice this was mostly by email and SMS message). The reminder contained a link to either a monthly or quarterly online log, depending on which they were due to complete, as well as contact details for the SGUL-based researcher whose role included providing remote support to people completing the log. This researcher was able to

respond by telephone or email to any queries and regularly provided advice and support to people completing the log. Where people were completing logs on paper, a paper copy of either the monthly or quarterly log was made available to people at their Side by Side project (see below).

## **Regional researchers & evaluation ambassadors**

A strategy was developed to introduce the evaluation to people who had access to Side by Side peer support projects, and to support their ongoing participation in the evaluation. As described above, Side by Side took place in nine regions in England plus the Elefriends online peer support network hosted by Mind. As resourced, the evaluation had capacity to provide close support to this strand of the evaluation in three of those regions only. The process of selecting regions has been described above.

### Regional researchers

A part time researcher, working from the perspective of lived experience of mental health difficulties, was employed by McPin to work in each of the three regions. Researchers introduced the evaluation to people attending both strategic partner and grant funded Side by Side projects, provided information sheets on the evaluation, answered questions and supported people to register with the evaluation and complete logs, either on paper or online (on their own mobile devices, or on personal computers or tablets available where projects met).

Researchers visited Side by Side projects in their region on a regular basis to either recruit new participants or to support existing participants to complete the log on a monthly basis (and to support local project staff with facilitating the evaluation in their absence), providing online links or paper copies of monthly and quarterly logs as appropriate. The McPin researchers received log-specific support in their role from the researcher working centrally at SGUL, and more general support and guidance from a senior researcher within McPin (who was also their line manager).

### Evaluation ambassadors

In the six other regions a strategy was developed to enlist and support volunteer 'evaluation ambassadors', attached to Side by Side projects, who would, where there was capacity, provide a degree of the support offered by our researchers in the other three regions. It was envisaged that evaluation ambassadors would be people with lived experience of mental health difficulties who had a personal association with the projects being evaluated.

The researcher based at SGUL was tasked with providing support to evaluation ambassadors by providing them with a telephone induction to the evaluation, role description and briefing materials to support the ambassador role, and ongoing telephone support as necessary.

In practice it proved challenging to identify and recruit evaluation ambassadors, as envisaged above, in many of the Side by Side projects. More often than not, the ambassador role was taken on by someone involved in coordinating the peer support project, typically a peer group facilitator or someone involved in managing or coordinating the organisation that was hosting the Side by Side peer support project. Often this person brought their own lived experience of mental health difficulties to the role, but not in all cases.

The researcher based at SGUL provided the level of support as described above, in many cases having regular telephone contact with evaluation ambassadors and project coordinators, plus making visits to projects in many parts of the country. Project coordinators and evaluation

ambassadors then provided support to people to register and complete the log in much the same way as did our researchers, focusing on the single project with which they were involved.

### Additional support for the peer support log

A number of additional measures were introduced as the evaluation progressed in order to support registration and log completion. Once the log was up and running, rates of new registrations and log completion were monitored by the SGUL team, broken down by region, on a monthly basis. This information was discussed with the Side by Side team within Mind and passed to the strategic partner organisations leading Side by Side within each region so that appropriate support could be targeted at projects. As a result of these discussions, project visits were arranged by the SGUL-based researcher and a webinar held for project coordinators and evaluation ambassadors to support them in supporting the evaluation.

Feedback from projects – to the SGUL team via the Mind Side by Side team – indicated that a number of people had a preference for completing the paper log. However, some projects – smaller grant funded project in particular – did not necessarily have the resources to send completed logs back to SGUL. Postage-paid return envelopes were made available to local projects to facilitate this, greatly increasing the number of paper version of the log sent to SGUL to be entered into the database by the SGUL team (see chapter 4 below for details of log returns).

Further feedback indicated that, while supporting the log in group-based peer support projects that met regularly was relatively uncomplicated, where peer support projects were one-to-one in nature, were time limited or did not have a regular meeting space, supporting people to complete the log on an ongoing basis was challenging. The Mind Side by Side team provided some additional resource to these projects to enable them to bring people together on a small number of occasions to support log completion.

A strategy was developed with the Elefriends team to introduce the evaluation to people accessing Elefriends. Elefriends makes use of a particular style of messaging and, as part of the arrangement with people accessing Elefriends, does not facilitate direct access for third parties. As such all messaging about the evaluation went through the Elefriends team who provided personal IDs for people who chose to participate. Invitations to participate in the evaluation were made via periodic news briefings sent by the Elefriends team. Once people had consented to participate, monthly reminders were sent by email in the usual way.

Finally, the SGUL based researcher invited all regional researchers, evaluation ambassadors and project coordinators supporting the log to participate in an online discussion forum. Regular updates on the evaluation, advice and guidance on supporting people to register and complete the log, and additional information materials were shared through the forum. Researchers, ambassadors and coordinators also posed questions about supporting the log through the forum, receiving responses from each other and form the SGUL researcher.

### **Recruitment from Black & Minority Ethnic specific peer support projects**

Part of the brief for the evaluation was that we would seek to identify if there were particular impacts of peer support for people from different Black and Minority Ethnic (BaME) populations, as measured through the log (paralleling equivalent questions asked in the qualitative work streams of the evaluation). In order to do this we had to ensure that we were successful in recruiting to the peer support log people from a range of BaME populations. This included people accessing BaME specific Side by Side peer support projects, as well as all other Side by Side projects.

Feedback from the Side by Side Research Advisory Group and from our own collaborators suggested that there might be barriers to completing the log both where English was not people's first written or spoken language, and where concepts of mental health implicit in the questionnaires that comprised the log were not culturally appropriate.

Early discussions with project coordinators who were supporting the evaluation in BaME specific peer support projects indicated that the biggest obstacle they had in surmounting those barriers was time. Some people needed extensive one-to-one support to translate the logs and to explain some of the concepts. This could be prohibitive in the limited time available to run a peer support group. On the basis of these discussions a number of measures were put in place.

### The 'short version' of the peer support log

First the SGUL evaluation team produced a 'short version' of both monthly and quarterly logs. The short version of the monthly log contain just two questionnaires that were readily available in validated translation into most community languages (a wellbeing and a quality of life questionnaire; see below for details of questionnaires used), as well as the questions about the amount of peer support people had given and received in the previous four weeks. The short version of the quarterly log also included a reduced number of the additional questions about service use, focusing on those services that might have the largest impact on cost. The registration log was the same for people completing short versions of monthly and quarterly logs as it was for all other participants as it was necessary to ask the same questions relating to consent and to socio-demographics.

Where a need was identified to use the short version of the log – i.e. where most of the work in a project took place in a language other than English – the SGUL team sourced translated versions of the appropriate measures, provided paper copies or online links to short versions of the logs, and provided support to project coordinators as necessary. In addition to BaME specific projects, one Side by Side project, where the majority of people accessing the project also experienced Learning Difficulties, used the short version of the logs. The proportion of participants who completed short versions of logs is given in the following chapter.

### Dedicated BaME researcher time

In addition the Mind Side by Side team made some additional resource available to support the evaluation in BaME specific projects in the form of a researcher with expertise in undertaking research in BaME communities as well as lived experience of mental health difficulties. This researcher was based in one of the regional strategic partner projects where there was a concentration of BaME specific work. The researcher was able to spend time directly in BaME specific Side by Side projects – in that region and in other regions nationally where there were similar projects – supporting project coordinators and providing direct support to people registering and completing logs.

### Peer involvement in log design and selection of questionnaires

The SGUL team sought the advice of the Peer Expertise in Education and Research (PEER) group to design the peer support log. The PEER group is a research advisory group of people who use mental health services jointly supported by SGUL and the local Mental Health NHS Trust. The PEER group provided general advice on the wording and layout of the log, including the wording of the invitation to participate and description of the evaluation on the front page of the log. This was done at meetings where we developed initial paper versions of the log, and then where members of the PEER group tested prototype online versions of the log. The PEER group also made the suggestion that the monthly prize draw should include a prize for projects as well as individuals. Members of PEER felt that it was in the spirit of peer support that completing the logs individually might potentially benefit the peer group.

### Asking questions about 'giving' and 'receiving' peer support

The PEER group provided specific advice on the categorisation and description of different types of peer support as described in the questions in the monthly and quarterly logs that asked people how much peer support they had given and received in the previous week (see appendix 3.1). In developing these questions we were aware that the distinction between giving and receiving peer support is somewhat artificial; many people speak of sharing, or of just supporting each other as peers. However we were also very aware, from our reading of the literature on the values and principles underpinning peer support in chapter 2, that a reciprocal relationship is considered by many to be fundamental to peer support. We felt it was important that the log somehow explored the two way nature of the peer support relationship. As a result we decided, in discussion with the PEER group, that asking about both giving and receiving peer support, while perhaps clumsy, was an important approach to take in the log.

### Selecting questionnaires

The PEER group was particularly involved in the choice of validated questionnaires included in the log. A measure of wellbeing (Warwick Edinburgh Mental Being Scale; Stewart-Brown et al, 2009) was included as the funding brief had expressed an interest in the relationship between peer support and wellbeing. In addition a measure of Quality of Life (EQ5D; Brooks et al, 2003) routinely used in economic evaluations was included to provide data for the economic evaluation team at LSE. The choice of additional questionnaires was a product of two workshops held by the SGUL team and the PEER group.

That discussion was informed by the wider literature on the impact of peer support (as described in chapter 2 above), as well as in-depth qualitative research that the SGUL team had previously undertaken modelling how peer support is associated with change (Gillard et al, 2014). We were constrained in our choice of questionnaires by our desire to keep the log as short as possible, and the need for questionnaires to be structured in such a way that they could be completed easily online. Given the number of questionnaires, as indicated above, that we had already decided to include – and with the additional service use questions for the economic evaluation included in the quarterly logs – we decided that we had space to include two additional questionnaires.

Because of the social nature of peer support, and especially because Side by Side funded projects were to take place in community rather than service delivery settings, we decided that one of the questionnaires should measure the extent to which peer support impacted on people's connection to community, or their strength of social network. There are limited validated measures in this area, and many of them, such as the Social Network Schedule (Dunne et al, 1990) or Social Contacts Assessment (Giacco et al, 2016) take a long time to complete and also require people to identify different individual contacts. This would be overly time consuming and also would not work well given the survey software that we were using.

In discussion with the PEER group we decided to use a version of the Lubben Social Network Scale (Lubben & Gironda 2004) which asks people to indicate the number of family, friends and neighbours they have had contact within the previous month, and how many of those contacts involved discussing private matters and/ or asking for support.

### Coproducing questionnaire selection

For our remaining questionnaire we decided that we would identify a measure of empowerment or related concept (the evaluation brief had indicated an interest in selfefficacy as a possible outcome). Because there is a range of overlapping concepts broadly related to the idea of empowerment we shared a number of short, self-complete questionnaires with the PEER group. These were the Mental Health Confidence Scale (Carpinello et al, 2000), the Work and Social Adjustment Scale (Mundt et al, 2002), the Generalised Efficacy Scale (Schwazer & Jerusalem, 1995), the Locus of Control scale (Craig et al, 1984) and the Patient Activation Measure (Hibbard et al, 2005). The PEER group suggested that any questionnaire we use should cover important constructs underpinning ideas of personal recovery; hope, control and opportunity (Repper & Perkins, 2003).

We held a first workshop with the PEER group in which members of the group took it in turns to present one of the questionnaires listed above to the rest of the group. The questions asked by each questionnaire were considered in relation to those core constructs of hope, control and opportunity (this is known as an assessment of the 'content validity' of a questionnaire). A grid was drawn on a white board on which we indicated whether or not each questionnaire sufficiently covered those core constructs and recorded any particular strengths or limitations of the questionnaire. That grid can be seen in table 3.2 below:

Criteria Questionnaire	Норе	Control	Opportunity	Comments
Work & Social Adjustment Scale	Negative (deficit) representation of person	х	Х	Focus on problems/ gendered language
Mental Health Confidence Scale	v	V	±	Easy to answer but some questions 'triggering'
Generalised Self-Efficacy Scale	Prioritises self- reliance over connection to community	V	Х	Feels judgemental (about 'trying harder')
Locus of Control Scale	±	V	x	Language not 'user friendly'
Patient Activation Measure	x	√ (but with focus on condition)	Х	Feels medical

Table 3.2 Selecting an 'empowerment' questionnaire	Table 3.2	Selecting an	'empowerment'	questionnaire
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v = criteria covered by questionnaire; ± = criteria partly covered by questionnaire; x = criteria not covered by questionnaire

As can be seen from the grid, none of the questionnaires addressed the issue of 'opportunity'. The PEER group acknowledged that we might not find a suitable questionnaire that addressed this issue, and that questions about opportunity in relation to peer support might best be addressed through the qualitative work streams of the evaluation. As indicated in the grid above, all questionnaires addressed issues of hope and control to a greater or lesser degree. PEER group members decided that the Mental Health Confidence Scale (Carpinello et al 2000) was the best of those considered but had concerns that some of the questions in that scale were potentially triggering where they might invoke difficult issues for people completing the log.

While an experienced researcher might be able to support someone with that in a face to face interview, the group felt this would not be appropriate where people were potentially answering these questions remotely without access to support. The PEER group asked the SGUL team to identify another option that better met their priorities. We identified the Mental Health Self-Efficacy scale (Clarke et al, 2014) as being both short and better reflecting the PEER group's priorities with respect to the crucial concept of control. At a second workshop with the PEER group we agreed to use this questionnaire in the log.

In selecting the Mental Health Self-Efficacy scale, the PEER group noted that the questions making up the scale did not reflect the concept of hope as well as some of the other questionnaires. An improved sense of hope in the future had been identified in our peer support change model (Gillard et al 2015) and has been used as an outcome measure in previous trials of peer support (e.g. Simpson et al 2015). The PEER group suggested that an additional questionnaire measuring hope be included in the log, even though this would add to the length of time taken to complete the log.

There are two main questionnaires used to measure hope in mental health studies. The Beck Hopelessness Scale (Beck et al, 1974) was rejected by the PEER group because of the negative nature of the language. We decided to use the Herth Hope Index (Herth, 1992), developed to use with a general population of people with long term conditions, as a more appropriate measure.

The PEER group tested the online version of the full log, including the additional measure of hope, and felt that the questionnaires did not take too long to complete. They noted that it was the health economic questions about service use that took the most time to complete and agreed that it would be helpful if these only had to be completed on a quarterly basis. The final version of both monthly and quarterly logs as agreed with the PEER group can be found in appendices 3.1 and 3.2

### Analysis plan

The section that follows (until the end of the chapter) is technical in nature. We include this because it is necessary to demonstrate the scientific robustness of the analysis process if we are to claim that we are making an addition to the evidence base for peer support. It is not necessary to read this section to understand how the evaluation worked as we have described the principles behind the peer support log approach at the beginning of this chapter.

A modified self-controlled case series design (Whitaker 2008) was adopted for our quasianalysis of effectiveness. The self-controlled case-series design approach is particularly suited to evaluating the effect of forms of support that participants can choose to dip in and out of over time, as is likely to be the case with peer support. The design is modified in this context as the methods are conventionally applied to binary outcomes/events (e.g. occurrence of cardiac event or not) whereas the outcomes in this study will be assumed to be normally distributed continuous outcomes.

The self-controlled case series design is appropriate to examine the association between transient episodes of exposure and events, and is commonly used in vaccine safety studies. It has been used in a mental health setting to examine the association between exposure to antipsychotics and the risk of stroke (Douglas 2008). It relates the risk of an event occurring during an episode of exposure to the risk of it occurring during an episode without the exposure. It has the advantages of a within subject design, with participants acting as their own control therefore minimizing the influence of time-invariant confounders like gender or ethnicity.

In this modification of the design we used multi-level regression modelling to examine the association between participants' change in outcome and change in their use of peer support, given and received, over concurrent one month periods. Having multiple one month periods per participant allows the model to compare change in outcome during periods when a participant may have increased the number of different types of peer support they give with

periods when they had unchanged or decreased the number of types of peer support they give (i.e. a within person analysis). A very similar analysis was conducted by members of the evaluation team in a study of supported employment in mental health where the association between being in work at any given time point and change in measures of clinical and social functioning over the subsequent six months was examined (Burns 2009).

Using this approach we cannot make claims about effectiveness in its conventional sense (as we might in an RCT) but the analysis will allow us to examine objectively how change in the amount of both giving and receiving of peer support is associated with change in outcomes.

### Our analyses

The multi-level regression models are specified as follows;

- The dependent variable in each model is the change in the respective outcomes between consecutive log completions. On all outcomes a high score is a positive outcome therefore change in outcomes were calculated so that a positive change was an increase in that outcome, improvement, and a negative change indicating a decrease or worsening of that outcome.
- The value of the outcome at the beginning of each period over which change has been calculated is entered into all models as an independent variable to minimise the impact of regression to the mean and reduce random variation in the dependent variable.
- The respective change in peer support use variable being explored will be entered as a fixed factor with three levels, decreased, unchanged and increased.
- The three sets of variables above are all reported at the period level; that is periods between two consecutive log completions. There are therefore multiple observations per participant at the period level, one less than the number of logs they completed. In order to account for this non-independence of observations a random subject effect was fitted to adjust for the correlation between observations from the same participant.
- In conducting the subgroup analyses the relevant sociodemographic variable (observed at the participant level, i.e. unchanging over the course of the study) was entered as a fixed factor both as a main effect and interaction term with the peer support use variable. Interpretation of the interaction term enabled inferences to be made with respect to the extent to which the association between change in peer support use and change in outcomes differed across the various levels of the sociodemographic variable being studied.

In interpreting the results of the numerous regression models the following process was followed;

• Hypothesis tests of whether the peer support use variables were significantly associated with the dependent variable and explained a significant amount of the variation in that variable were first examined. When the p-value related to the calculated F-statistic was less than 0.05 it indicated in these models that the mean

change in outcome in at least one of the levels of the peer support use variable was significantly different from at least one other level of the same variable.

- For those variables where the above condition was met estimates of mean change in outcome for each level of the peer support variable was outputted with 95% confidence intervals. These were then examined and, where the 95% confidence intervals do not encompass 0, statements can then be made about, for example, the predicted mean change in outcome for those who have decreased the number of projects they attend. When the confidence intervals overlap 0 we were unable to say that there is significant change in outcome in relation to that level of the peer support variable.
- When the confidence intervals did not encompass 0 the predicted mean change in outcome has been expressed as an effect size (ES). The ES was calculated as a standardised response mean (SRM), i.e., mean change in outcome divided by the standard deviation of the change in outcomes for the whole sample. SRM is an appropriate variant of ES to use when analysing responsiveness or within person change. Cohens thresholds (Cohen 1992) were applied to the interpretation of the SRM's. There has been criticism that these thresholds may over or under estimate the relative size of effect when applied to SRM's due to correlation between repeated measurements. To mitigate against this the estimates of mean change in outcome are taken from regression models that include the outcome variable at the start of the respective interval as covariates, therefore accounting for the correlation.
- All analysis was undertaken using IBM SPSS Statistics v24.

### Sample size considerations

In this study the primary analysis explored the association between change in wellbeing score and change in peer support use. We defined change in peer support use as having decreased, stayed the same or increased. The analysis results were therefore presented as mean change in outcome (wellbeing) for those participants who have decreased, maintained or increased their peer support use. As we were looking at within person change it was therefore a within subject design.

In considering the required sample size for this study the first step was to explore the number required to be able to detect likely change in wellbeing, the primary outcome. Maheswaran (2012) is a study of the responsiveness of the Warwick Edinburgh Mental Well-being Scale and presents estimates of the mean change and standard deviation (SD) for 12 studies that have used the scale in a pre-post intervention design. Two studies were conducted with participants with long term mental health illnesses such as schizophrenia examining the impact of 1) a recovery programme and 2) a one-to-one healthy living information session, both self-care focused interventions. Follow-up was for 12 weeks in both studies. Their estimates of mean change and SD were similar and resulted in within subject effect sizes of 0.72 and 0.75 respectively. If we assume that the within subject effect size for change in wellbeing scores when not receiving a self-care type intervention is small, approximately 0.2, it seems appropriate to identify the sample size required to be able to detect a within subject effect size of 0.5 with 80% power at a 5% significance level.

Thirty four participants are required to be able to detect this clinically meaningful, within subject effect size for any pre-specified group of participants. Therefore we aimed to recruit at least 34 participants from each of the partner projects (six in each of our three focused regions) plus Elefriends to be able to estimate whether there has been significant change in outcomes in each partner project, a minimum total sample size of 646 (19 projects multiplied by 34) participants.

We also wanted to explore how change in wellbeing and other outcomes attributable to peer support varied between groups of participants (including both BaME specific peer support projects, and BaME participants from across the evaluation), different regions (e.g. rural and urban), different forms of peer support and other independent variables. These analyses were conducted within a multi-level regression model framework and the choice of independent variables guided by the different strands of the evaluation and consultation with involved partners.

In summary a minimum of 34 participants in each partner project were required to be recruited and needed to provide data at multiple data points. To be included in the main analysis a participant had to complete at least two peer support logs.

# Chapter 4 – Findings from the peer support log

# Summary

We collected data about the way in which people accessed peer support, impact, and who they were (in terms of age, gender, ethnicity and so on) using a 'peer support log'. Each month people accessing Side by Side peer support projects were invited to completed the log either online or on paper. The development of the log was coproduced by the St George's evaluation team and the PEER group (a mental health service user research advisory group).

Completing the log was supported by the people coordinating Side by Side projects on the ground, with additional resources provided to enable completion of the log in Black and Minority Ethnic specific peer support projects. The log was designed so that we could test whether changes in the amount of peer support people decided to access was related to change in a range of outcomes (wellbeing, hope, self-efficacy, contact with friends, family and neighbours, and their general health status).

Over 700 people completed the log, many of them several times, about a quarter of people who participated in the Side by Side programme as a whole. About two thirds of the people who completed the log were female and of a range of ages; the profile of people completing the log was highly diverse in terms of ethnicity and sexuality, reflecting the profile of people who accessed Side by Side.

We found that:

- The amount of peer support of all different types that people accessed reduced slightly over the course of the evaluation, while the outcomes we measured remained stable or increased slightly over the same period of time
- People reduced the number of peer support projects they accessed as their sense of wellbeing increased and they had more contact with friends and family
- When people were involved in giving an increasing amount of peer support they also experienced improvement across a range of outcomes, especially (but not only) with respect to giving group-based peer support
- There were some but less –associations between improvement in outcome and receiving more peer support that varied with types of peer support (group, one to one and online)
- There were some differences, in relation to age and gender, in associations between change in the amount of peer support people accessed and change in outcomes
- There were more extensive differences when we compared people from different broadly defined ethnic groups
- Our analyses suggested that people who also use secondary mental health services, have physical disabilities, identify as having a learning disability and who live in rural area all have slightly different patterns of peer support use in relation to outcome

All of those findings identified above need to be considered in more detail in relation to our qualitative interview data about people's experiences of peer support in different settings and communities.

### Aims

In this chapter we report the findings from work stream 1 of the evaluation - the peer support log – where we set out to measure the extent to which peer support in the Side by Side programme was working. We aimed to address the following set of questions:

To what extent does the Side by Side peer support programme bring about change in the amount of peer support people in the programme access?

How is change in the overall amount of peer support people access related to change in a range of individual outcomes?

*How does change in outcomes relate to the amount of peer support people are giving or receiving?* 

How is change in giving and receiving different approaches to peer support – group, one-toone and online – related to change in outcomes?

How is change accessing peer support by different groups of people – e.g. people from different BaME communities, or in rural or urban communities - related to change in outcomes?

We begin by describing who completed which versions of the log, when and how often. We break that information down by region and then by socio-demographics such as age, gender and ethnicity. We then describe how much of different approaches to peer support people were involved in giving and receiving, and how that engagement with peer support changed over time. We follow this by describing how the various outcomes we measured with the log – hope, wellbeing and so on – changed over the course of the evaluation.

To answer our main set of questions above we then asked how change on access to peer support – both overall and for different approaches to peer support – were related to change in outcomes. The methods we used to do this are described in the previous chapter. We did those analyses for everyone who completed the log and then separately for different groups of people.

The log asked a lot of questions of a lot of different people. We collected more data that we could feasibly analyse in the time we had available to complete the evaluation and write up the report. We focus on answering our key questions above. There are many other questions we could explore in the data, especially for our different groups of participants. For example, we do not explore change in giving and receiving specific approaches to peer support (group, one to one and online) and the impact on outcomes for people from different ethnic communities, concentrating on overall access to peer support instead. We also did not have time to explore relationships between the informal and organised peer support people engaged in. This is work we would hope to do at a later date and we identify some of those additional questions we might ask at the end of the chapter.

We report our findings below, illustrating the data with charts where helpful. At the end of the chapter we try and make sense of these findings in terms of the implications for the Side by Side programme and for peer support more generally. It is not always clear what findings mean from the log data alone. Where this is the case we explore some of these issues in more depth using our qualitative interview data in chapter 8.

## Registration and response to the log

### Overall response to the log

The first participant was recruited and registered into the study on 25/09/15 and recruitment continued until 30/09/16. Participants were asked to complete logs on a regular basis until 21/12/16. As presented in Figure 4.1 below, 703 participants were registered throughout this period and of these 566 (81%) completed at least one log. These 566 registered participants completed 1969 logs in total of which 1080 were quarterly logs (including additional questions on employment and health and social care service use), and 889 monthly logs. Eighty three participants completed a total of 125 logs without having registered for the study. For these 83 participants who were not registered their entered logs have been used in analysis wherever possible. However in any analysis that used demographic data they would not be included as demographic data was collected through the registration process. Therefore a total of 2094 logs were completed.

### Duplicates

Closer examination of these logs through the data cleaning process revealed 30 duplicate logs. These occurred through two different avenues. It was evident that some people completed the wrong version of the log, realised this and then completed the correct version on the same day. Alternatively it was possible that when paper copies of the logs were being entered at SGUL that some logs were entered twice in error. After deletion of these thirty logs the final sample size for any analysis using individual logs was 2064. These were completed by 649 participants.

### 'Paired' logs

The main analysis examined the association between change in access to peer support and change in outcomes. We refer to the different sorts of peer support people accessed and the different outcomes that we measured 'change variables'. To estimate change in these variables between completions of logs, pairs of logs completed by individual participants are required. Two hundred and forty six participants only completed one log and so the main analysis is based on 403 participants who completed two or more logs over the course of the evaluation. In total there are 1414 estimates of change in the peer support use and outcome variables from the sample, 1364 from 376 registered participants.

### Short versions of the logs

As described in chapter 3, in order to maximise recruitment and completion of logs in communities where English was not the first language a short version of both the quarterly and monthly logs was developed. Of the 2063 logs completed 514 (25%) were the short version.

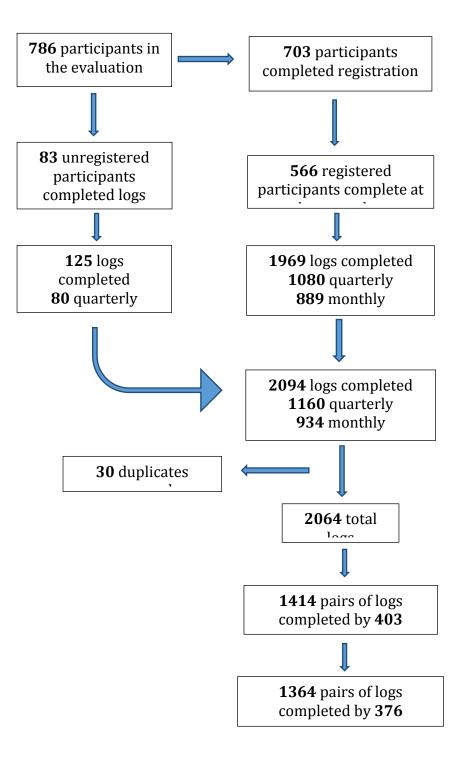
### Paper logs

Although the registration and logs were developed to be completed by the participant themselves online (by PC, laptop, tablet or smartphone) it became evident that was not going to be possible for many people and so participants were able to complete paper copies. These were then entered by regional researchers or project coordinators, or sent to SGUL for entering into the database. In total 1037 logs (50%) were entered online by the participants themselves, with the other 50% completed on paper.

In about half of the logs completed on paper, the information about peer support access was incorrectly recorded. Instead of responding with the number of times someone had accessed that type of peer support in the last month a number of participants had ticked the box. Of the total of 2063 logs completed, 373 of the logs (18%) had been entered in this manner. In these logs it can be assumed that, where ticked, these types of peer support were accessed. We created new peer

support variables indicating the number of different types of peer support which had been 1) given and 2) received so that we could combine the logs with ticks with those logs that used numbers.

Figure 4.1: Flow chart of recruitment, completion of logs



### Progress in recruitment to the log

Figure 4.2 displays the progress in recruitment over the course of the evaluation. As can be seen recruitment started slowly but steadily increased (except for a slow December) and reached its peak in March 2016, remaining high until June before tailing off again.

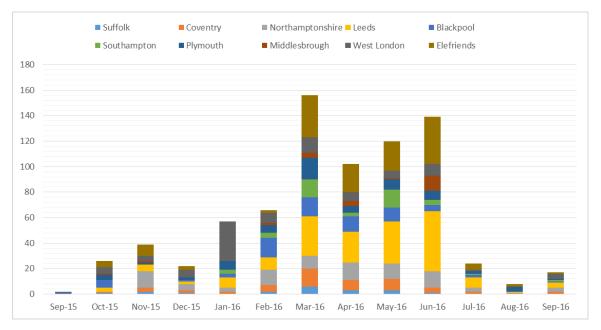
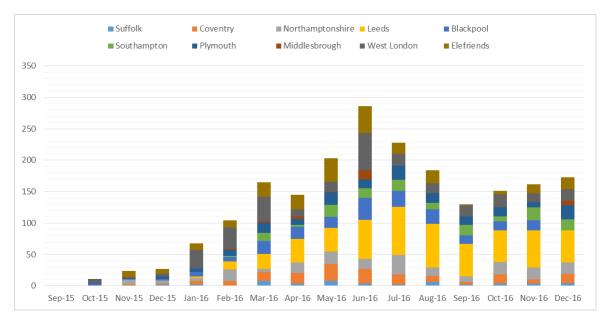


Figure 4.2: Bar chart representing registrations per month over course of the evaluation by region

There was a similar steady increase in the completion of logs which reached its peak in June '16 (Figure 4.3). From February '16 onwards more than 100 logs were completed each month and over 260 were completed in June.

Figure 4.3: Bar chart representing logs completed per month by region



The primary analysis of this quantitative evaluation requires repeated completions of the log by participants in order to analyse the association between change variables. It was therefore important that participants completed the log multiple times. 403 participants completed two or more logs, 213 of these completed four or more logs, 121 participants completed six or more logs,

and seven completed 12 or more logs. If we referred to the first time each participant completed a log as 'month 1' (regardless of which calendar month this took place in), the completion of logs over the course of the evaluation is indicated as follows (see figure 4.4):

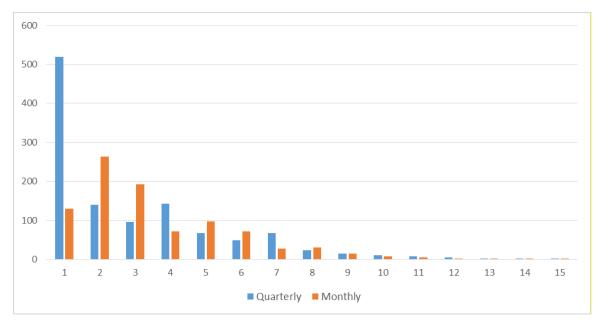


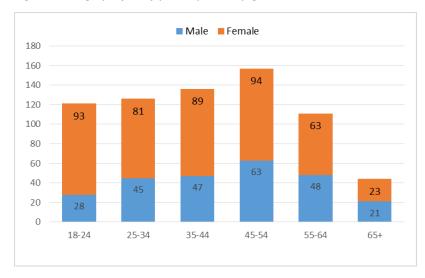
Figure 4.4: Number of logs completed for each month of the evaluation

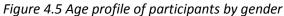
These data are broken down by region in Table A4.1 in the appendices.

### **Socio-demographics of respondents**

Of those people who participated in the log, there are valid demographic data on 703 participants for most variables.

One hundred and thirty eight particpants (20%) were from Elefriends, 17 (2%) from Suffolk, 42 (6%) from Coventry, 77 (11%) from Northamptonshire, 156 (22%) from Leeds, 69 (10%) from Blackpool, 43 (6%) from Southampton, 56 (8%) from Plymouth, 18 (3%) from Middlesborough and 87 (12%) from Kensington & Chelsea. As can be seen in Figure 4.5 we recruited from across the age distribution.





Two hundred and fifty three (36%) of the sample were male, 63% female, 2 preferred not to say, 2 specifying 'other'. As can be seen in Figure 4.5 there is more of a gender discrepancy in the lower age groups. Six participants had a transgender history, 4 were not sure, and 15 preferred not to say. Five hundred and fifty nine (80%) of the sample were heterosexual, 42 were lesbian/gay, 46 were bisexual, 35 preferred not to say, and 15 specified 'other'.

Four hundred and fifty six (65%) of the sample were White British, 9 were White Eastern European, 18 were White other, 8 White Irish, 13 were Asian/Asian British Indian, 39 were Asian/Asian British Pakistani, 7 were Asian/Asian British other, 5 were Mixed White & Asian, 11 were Mixed White & Black Caribbean, 3 were Mixed other Mixed background, 23 were Black/Black British African, 23 were Black/Black British Caribbean, 10 were Black/Black British other Black background, 20 were Somali and 5 were Arab. Fifty three people described their ethnicity in other terms than the prescribed categories. After closer examination of the ethnicity data for the purposes of the main analysis, ethnicity was collapsed into four groups, 70% White, 14% Black, 11% Asian and 5% 'other'.

Three hundred and eighty nine (55%) participants lived in cities/large town, 245 (35%) in small to medium sized towns, 61 (9%) in rural/village areas. Two hundred and eighty (40%) of the sample used formal community mental health services. Two hundred and forty one (34%) said they had a long term physical illness or disability. One hundred and three (15%) participants considered themselves to have a learning disability.

These socio-demographic characteristics are broken down by region in Table A4.2 in the appendices.

Descriptive statistics broken down by region for the following variables and the outcome measures used in the primary analysis are reported in Table A4.3 in the appendices. Using the first log completed by each participant (649 participants), it was possible to present further characteristics describing the recruited sample. At entry to the study 79 (12%) participants were employed full-time, and 55 (9%) employed part-time. One hundred and sixteen participants (18%) were doing voluntary work, 96 (14%) were unemployed and 117 participants (18%) were not working due to illness. Thirty seven participants were retired (6%) and 55 (9%) were students. People were able to select more than one category.

Thirteen participants (2%) had been admitted to hospital in the previous three months for mental health reasons. Two hundred and forty seven participants (38%) had taken medication for mental health reasons in the previous three months.

### Giving and receiving peer support

As described in the previous chapter, we asked people completing the log how many times they had 'given' and 'received' a number of different approaches to peer support in the previous month. To help make sense of the data below the categories we used for different approaches to peer support are as follows:

**Informal peer support** - this is when peers actively seek or provide support to each other separately from any organised project

**One-to-one peer support** - this might include mentoring, befriending, recovery coaching or peer support worker roles where one person supports another

**Peer support pairs** - this is 'mutual' one-to-one peer support where both people are supporting each other, e.g. co-counselling

Peer support groups - these are groups where all group members are supporting each other

**Peer-led or facilitated groups -** these are activity, support or self-management groups that are led or facilitated by a peer

**Peer support networks** - networks are where peers share contact information so that they can support each other or arrange to meet to provide support or take part in activities

#### Elefriends online peer support network

Other online peer support

At entry to the evaluation (first completion of the log), it can be seen in Figure 4.6 that informal peer support was engaged in most (compared to other, organised forms of peer support). For all types of peer support participants reported more receipt of support rather than giving but the differences are not large. With respect to the formal types of peer support the most commonly used are groups, including peer-led or facilitated groups. More detailed information on engagement with peer support at entry to the evaluation, broken down by region, is presented in Table A4.4 in the appendices.

At entry to the evaluation 175 participants (27%) reported that they had not attended any peer support projects in the previous month. One hundred and sixteen participants (18%) had attended three or more projects in the previous month. A third of participants, 216, had not given peer support of any type, 139 (21%) had not received any in the previous month. Fifty two percent, 337 participants, had given peer support in two or more different forms in the previous month. Sixty percent, 390 participants, had received peer support in two or more different forms in the same time period.

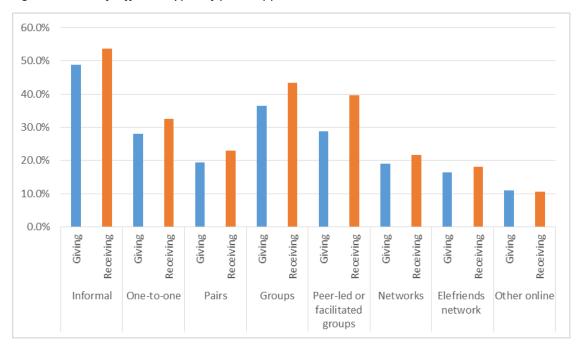


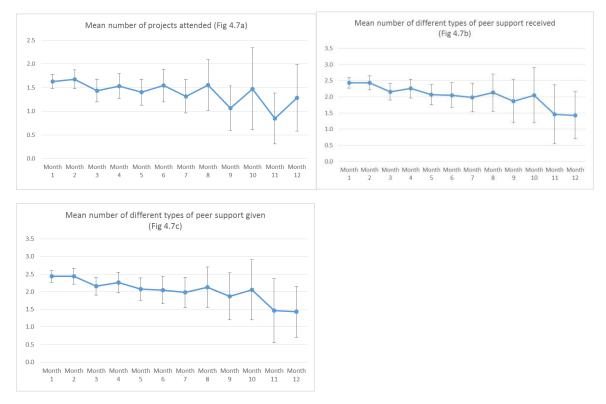
Figure 4.6 Use of different types of peer support at recruitment to the evaluation

### Change in engagement with peer support

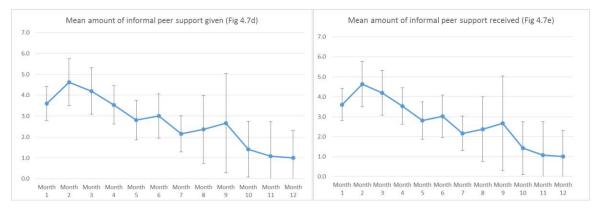
Engagement with peer support over the course of the evaluation is presented in Figures 4.7a-4.7q below. These figures are all 'error bar plots'. For each month the mean (average) number of the variable being presented is indicated by a round blue marker. The vertical lines either side of the blue markers are error bars which indicate the '95% confidence interval' around the estimate of the mean. In our case, the confidence interval is the range of values within which we are 95% confident that the true mean lies.

The wider the confidence interval around the mean value – the longer the error bars – the less accurate the estimate of the mean may be. The width of the confidence interval (or length of the error bar) is influenced by the spread of the values being described and the number of values being averaged to calculate that mean value. For example, where error bars are long in the first few months of the evaluation this would indicate a lot of spread in the values (as people gave lots of different answers to questions). And as the sample size gets smaller, as the months increase the error bars get longer because there are less data to base our estimates on. These figures are restricted to 12 months as there is very little data after that point.

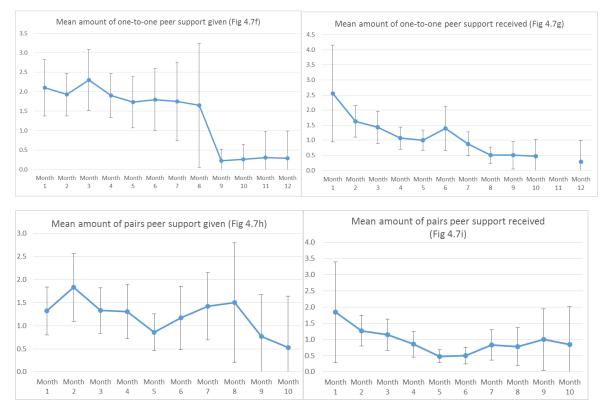
It can be seen that the number of projects attended by participants (in the previous month) over the course of the study decreases very slightly (Figure 4.7a) from an average of just over 1.5 to just under 1.5 projects. However examining figures 4.7b and 4.7c it appears that participants were on average receiving and giving peer support in 2.5 different forms, this dropping to 2 forms by month 5 and continuing to drop to 1.5 different forms by month 11.



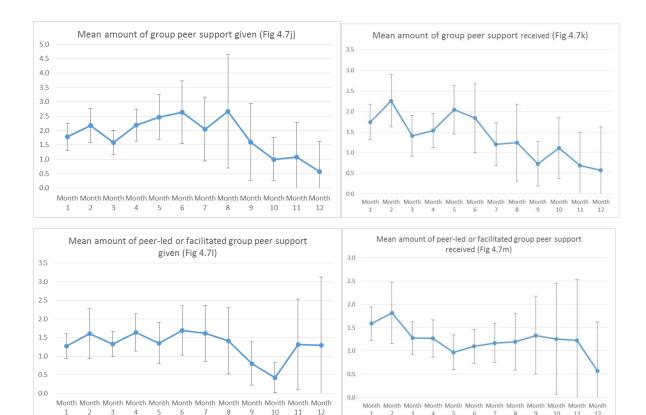
Figures 4.7d and 4.7e indicate that informal peer support being given and received increases over the first month and then steadily decreases.



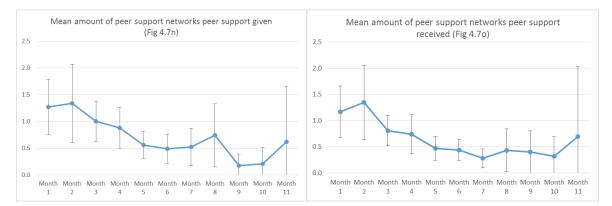
The given and received profiles for one-to-one peer support appear different in figures 4.7f and 4.7g. The amount of one-to-one peer support given remains fairly constant over the first 8 months before dropping, in contrast to the received one-to-one peer support which starts relatively high at the start and drops quite sharply to low levels by month 4. The changes in one-to-one peer support is echoed to a slightly lesser extent by figures 4.7h and 4.7i, peer support pairs, the difference between giving and receiving being evident. The wide errors bars around the mean estimates at month 1 for the receiving of both one-to-one and pairs peer support are due to some participants having a lot of involvement in these forms at the start of the study (and therefore a wide spread in data).



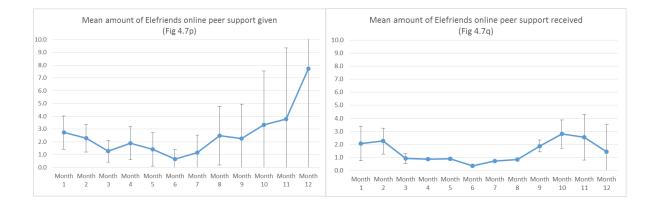
Examining figures 4.7j to 4.7m it can be seen that for both mutual peer support groups, and peer led or facilitated groups, the amount of peer support given increases slightly up to month 7 and 8 before decreasing. In contrast peer support received in this form decreases slowly over the course of the study.



Engagement with peer support networks, both given and received, figures 4.7n and 4.7o, is less overall and drops over the course of the study.

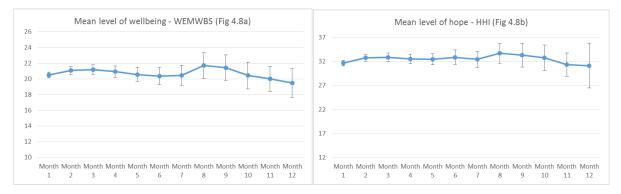


Access to Elefriends peer support given and received show different variation of use over the course of the study, figures 4.7p and 4.7q. The figures have been drawn so that the vertical axes are on the same scale. It can be seen that there is a lot more variation between participants in the amount of peer support given through Elefriends than received. In terms of the mean amount of Elefreiends peer support given and received it appears that levels drop from the start and then increase back to earlier levels, if not exceeding them, from about month 8.

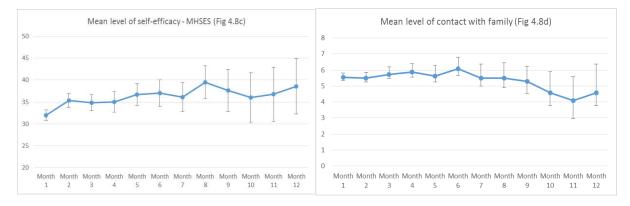


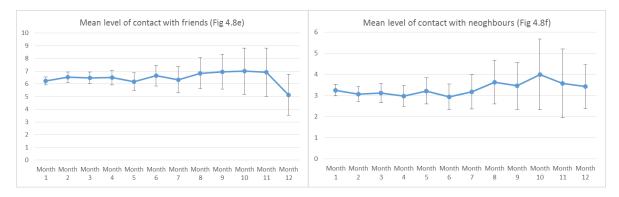
## **Change in outcomes**

The following figures 4.8a to 4.8g are error bar plots and should be interpreted as above. Figures 4.8a to 4.8g present the mean levels of the different outcomes collected over the course of the study. It can be seen that wellbeing and hope (figures 4.8a and 4.8b) change very little on average in the whole sample over the study period.

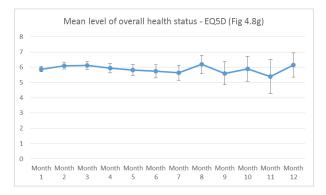


However mean levels of self-efficacy do appear to increase markedly throughout the study by approximately eight points on the MHSES (figure 4.8c). With respect to social networks it appears that participants have most contact with friends (figure 4.8e) and this slightly increases over the study with a drop towards the end. There are slightly lower mean levels of contact with family (figure 4.8d) which increase over the first six months but then drop. Mean levels of contact with neighbours (figure 4.8f) are a few points lower than friends and family, stay stable over the first seven months and then appear to increase.





Overall health status as measured by EQ5D in the whole sample remains fairly constant over the study (figure 4.8g).



## The association between change in peer support and change in outcomes

Change in the number of projects attended was not associated with any of the other change in peer support variables, both giving and receiving, and so has been retained in all regression models as an independent variable. This means that when exploring the other peer support variables their relationship with the outcome can be better estimated (that is, simply attending peer support projects, and the idea of giving and receiving peer support are not measurements of the same thing, they are meaningfully different activities).

The following three variables are being considered overall measures of change in peer support use; 1) change in number of projects attended, 2) change in number of types of peer support where support is given and 3) change in number of types of peer support where support is received. Other more specific peer support variables to be examined later (giving and receiving specific approaches to peer support) contained more missing data and therefore less observations in the statistical analysis. For ease of analysis and interpretation, all of these change in peer support variables have been categorised. Change has been simply defined as decreased, unchanged and increased between each pair of consecutive log completions.

## **Overall engagement with peer support variables**

When examining the error bar figures in this section, of interest is the position of the error bar in relation to 0 on the vertical axis. If the error bar is completely above or below the level of 0 on the axis then it can be inferred that there has been a statistically significant increase or decrease in that outcome for participants who had had the respective category of change in peer support. That is to say, on the basis of the number of measurements of change we have, we are 95% confident that this change is 'actual' and not just a chance observation.

The associations described below are those that satisfy the following conditions; 1) there was evidence that change in outcome differed significantly between the three categories of change in peer support use, decrease, unchanged, increase, at a 5% level of significance and 2) for any

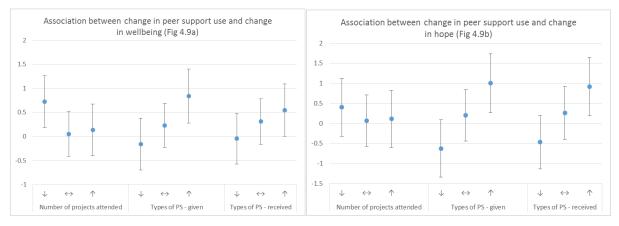
category of change in peer support use, the 95% confidence interval around the estimated mean change in outcome did not include 0. This is illustrated below with reference to figure 4.9a. Detailed tables of magnitude of change, 95% CIs and p-values for all analysis models can be found in tables A4.5 – A4.11 in the appendices.

Where the second condition is met the magnitude of the change in outcome is interpreted using effect sizes (ES). Effect sizes are a means of standardising estimates of change/differences whether within or between groups across a range of outcomes which may have varying ranges of values. The widely accepted interpretation of effect sizes given by Cohen (1992) provides a means by which effect sizes can be categorised into 'small' (ES=0.2-0.5), 'medium' (ES=0.5-0.8) and large (ES>0.8). Effect sizes less than 0.2 are generally considered 'trivial'. Where the second condition above has been met the ES has been reported in tables A4.5 – A4.11 in the appendices. In this chapter we shall use the Cohens thresholds to provide a qualitative assessment of the size of the ES when ES>0.2, i.e., 'small', 'medium', and 'large'.

Looking at the left hand third of figure 4.9a it can be seen that participants who had decreased ( $\downarrow$ ) the number of projects they attended between logs had significantly improved with respect to wellbeing, the lower end of the error bar lying above 0. On average there had been no change in wellbeing for those who had increased ( $\uparrow$ ) or maintained ( $\leftrightarrow$ ) the number of projects they attended, the mean change (indicated by the blue markers) close to 0 and error bars crossing 0.

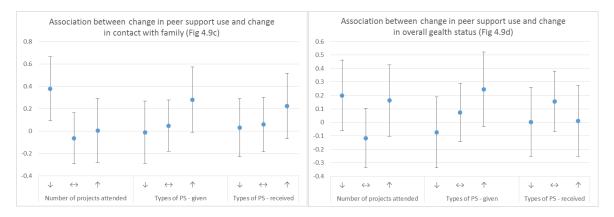
Participants who had increased the number of different types of peer support, both given and received can be seen to have had a significant increase in wellbeing, the effect being larger for those who had increased the number of types of peer support they were giving, a significant 'small' ES. However as the three error bars in the right hand third of figure 4.9a overlap considerably it cannot be inferred that the change in number of types of peer support received is associated with change in wellbeing. See Table A4.5 in the appendices.

While change in the number of projects attended was not associated with change in hope (figure 4.9b), both change in number of different types of peer support giving and receiving variables were. For both giving, a significant 'small' ES, and receiving of different types of peer support an increase was associated with a significant increase in hope.

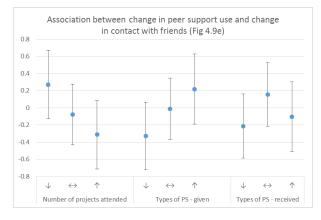


In contrast, change in the number of projects attended was found to be associated with change in contact with family (figure 4.9c) and change in overall health status (4.9d). A decrease in the number of projects attended was associated with an increase in contact with family and overall health status. The picture for overall health status is not as clear cut however.

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Change in contacts with friends was shown to be associated with change in peer support in the following manner. An increase in the number of projects attended was associated with a decrease in contact with friends. A decrease in contact with friends was also seen when participants decreased the number of different types of peer support in which they gave support (figure 4.9e).



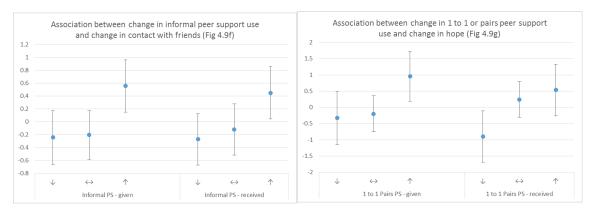
In the whole sample there was no significant association between any of the three overall measures of change in peer support and change in self-efficacy. This is also true for change in contact with neighbours.

## Engaging with specific forms of peer support

In this analysis we grouped together some of the different approaches to peer support that we asked questions about in the log so that we would have more data on which to basis our analysis of peer support change variables. We grouped together one to one and peer support pairs data to create a new one to one peer support variable, mutual peer support groups and peer-led or facilitated groups to create a group peer support variable, and Elefriends and other online peer support to create an online peer support variable.

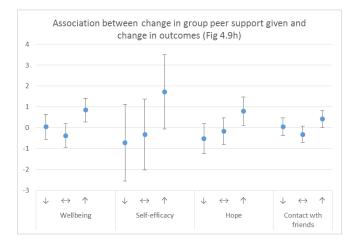
An increase in the amount of peer support given informally was associated with an increase with family contact. This was true also for an increase in contact with friends but not neighbours. Participants who decreased the informal peer support received had an increase in contact with friends (figure 4.9f). See Table A4.6 in the appendices.

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An increase in the amount of peer support given one-to-one or as part of pair was associated with a significant improvement in wellbeing ('small' ES) and greater hope. In addition a decrease in the amount of peer support received in this form is associated with a decrease in hope (figure 4.9g). While maintaining the amount of peer support received one-to-one or as part of a pair is associated with an improvement in overall health status, reducing receiving this support is associated with a decrease in overall health status. See Table A4.7 in the appendices.

Increasing the amount of group peer support being given is associated with a significant improvement in wellbeing ('small' ES), self-efficacy, hope, an increase in contact with friends (figure 4.9h). Note, these outcomes are measured on different scales, in particular self-efficacy which has a larger range of scores. Maintaining the same amount of group peer support being received is associated with a reduction in contact with friends. See Table A4.8 in the appendices.



An increase in the amount of peer support received online is associated with a significant decrease in self-efficacy ('small' ES) and overall health status. See Table A4.9 in the appendices.

## Subgroup analyses – peer support in different communities

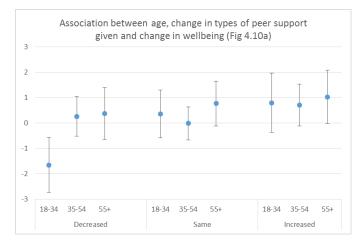
In exploring how the association between change in peer support and change in outcomes may be influenced by various socio-demographic and other factors we have used only the three overall measures of peer support defined above; change in number of projects attended, change in number of types of peer support given and change in number of types of peer support received. This is because this analysis was based on data from only those participants who had also completed registration and because these are the peer support variables we have maximum data on. See Table A4.10 in the appendices for results of the analysis models.

#### Gender

There was no significant difference between male and female gender with respect to the association between change in the number of projects attended and any of the outcomes being studied. While women who increase the number of types of peer support they give have an unchanged overall health status, men see an increase in their health status ('small' ES).

### Age

A participant's age had an influence on the association between the number of types of peer support given and change in wellbeing. The younger age group, <35, who decreased the number of types of peer support given had a significant decrease in wellbeing ('small' ES). All age groups who increased the number of types of peer support given had an increase in wellbeing, with the older age group, 55+, experiencing a significant increase ('small' ES) (figure 4.10a). The middle age group, 35-54, who had increased the number of projects attended had a significant decrease in contacts with friends ('small' ES). The younger age group, <35, who decreased the number of project attended had a significant increase in contact with friends ('small' ES).



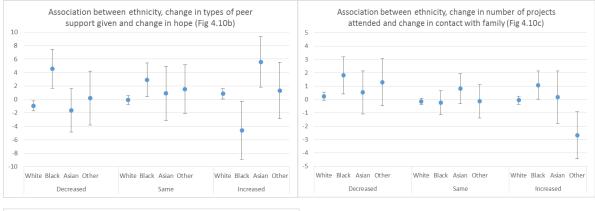
#### Ethnicity

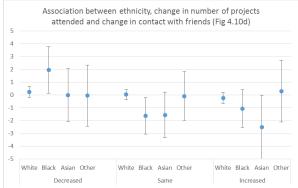
A complex relationship between our broad ethnicity categories, change in number of types of peer support given, and change in hope is evident. While people of Black ethnicity who have increased the number of types of peer support given have had a large decrease in hope ('large' ES), those maintaining their level of support ('medium' ES) or decreasing it ('large' ES) have increased hope. In contrast people of Asian ethnicity who increased the number of types of peer support given have an increase in hope ('large' ES). This is also true of people with White ethnicity but with a lesser increase in hope. White people who decreased the number of types of peer support being given had a decrease in hope ('small' ES) (figure 4.10b).

While all ethnic groups show an increase in self-efficacy when they decreased the number of projects attended, those in the Other ethnic group category had a significant and large increase in self-efficacy ('large' ES). People of Other ethnicity who maintained the number of projects attended had a near significant decrease in self-efficacy. Asian participants who decreased the number of projects they were involved had a significant increase in hope ('large' ES). When they increased the number of projects attended they had a non-significant decrease in hope of similar size. Black participants who maintained their number of projects attended had an increase in hope of a similar magnitude ('large' ES).

Black people who increased the number of types of peer support they gave had a large increase in contact with family ('large' ES) (they also had a significant increase in contact with family over the course of the evaluation that was independent of that association). Black participants who either

increased ('small' ES) or decreased ('medium' ES) the number of projects attended had an increase in contact with their family. Those participants of the Other ethnic group who had increased the number of projects attended had a decrease in contact with family ('large' ES) (figure 4.10c). Black participants who decreased the number of projects attended had an increase in contact with friends ('medium' ES). Black participants who maintained the number of projects they attended had a significant decrease in contact with friends ('medium' ES). Asian participants who had an increase in number of projects attended had a large decrease in contact with friends ('large' ES) (figure 4.10d).





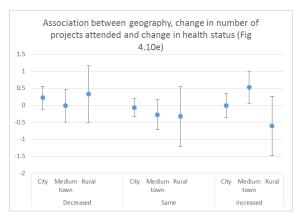
Participants of all ethnicities who increased the number of types of peer support from which they receive support had very little change in wellbeing. However Asian participants who decrease the number of types of support they receive have a significant decrease in wellbeing ('medium' ES). Black participants who maintain the number of types of support they receive have a significant increase in wellbeing ('small' ES). Black participants who decrease the number of types of support they receive have a significant increase in hope ('medium' ES). In contrast Asian participants who increase the number of types of support they receive have a large and significant increase in hope ('large' ES).

## Sexuality

There was no evidence that the association between change in peer support and change in outcomes differed between those participants who are heterosexual and those who are LGBT.

#### Geography

Participants living in medium sized towns who have increased the number of projects attended had an improvement in overall health status ('small' ES), as opposed to those living in rural locations who have a near significant decrease in health status (figure 4.10e). Participants living in medium sized towns who have increased the number of types of support they receive had a decrease in self-efficacy ('small' ES).



#### Use of formal mental health services

People who were not using formal mental health services at registration to the study had an increase in self-efficacy independent of their engagement with peer support. Those people using formal mental health services who had decreased the number of types of peer support where they gave peer support had a significant decrease in self-efficacy ('small' ES). This is in contrast to those who did not use services who showed a non-significant increase in self-efficacy. Those people using formal mental health services who decreased the number of types of peer support they gave had a significant decrease in contact with friends ('small' ES) and neighbours ('small' ES).

#### Learning disability, physical disability and long term health condition

Participants who reported having a learning disability who increased the number of projects they attended had a decrease in self-efficacy that was approaching significance, with an increase in self-efficacy when they decreased the number of projects they attended.

People with a physical disability or long term health condition who decreased ('small' ES) or increased the number of types of support they gave had a significant decrease in health status. However participants with no physical disability had an improvement in general health status when they increased the number of types of support they gave ('small' ES).

## Discussion

As we noted in chapter 1 of this report, we decided to take an alternative, somewhat unconventional approach to the challenge of evaluating a highly diverse range of open access, peer support projects. We did this because we felt strongly that any evaluation needed to take into account when and why people chose to access more or less peer support over time. The success of the evaluation depended on sufficient numbers of people completing our peer support log on a repeated basis. As demonstrated above, through the commitment of our evaluation team, the evaluation ambassadors and project coordinators they worked with and, primarily, the generosity of the people accessing Side by Side peer support, we collected a substantial amount of data and were able to generate an extensive range of findings that stood up to rigourous statistical testing. We have considered the main implications of our findings below.

### Who completed the log?

We saw a reasonable spread of log completion across the nine regions of Side by Side, plus Elefriends. It had not been our intention to make comparisons between regions but we were able to report, above, comparison in our analyses between people accessing Side by Side peer support through Elefriends (online peer support) with group and one to one Side by Side projects. The only region where we had sufficient log data to consider that region separately was Leeds. We report this analysis in the data synthesis chapter (chapter 8) below.

We noted that the number of logs completed for each month of the evaluation (if we consider each participant's first log as 'month 1') tailed off as the evaluation progressed. While more than 400 participants completed multiple logs, and over 120 completed six or more logs, the number completing logs on a monthly basis for a year was, understandably small. This means the reliability of our charts (above) plotting change in use of peer support and change in outcomes over a one year period drops off towards the end of the year (as illustrated by the length of the error bars). However these charts were largely illustrative, and our main analyses benefited from over 1400 paired data points (evidence of change).

We were particularly pleased with the demographic reach – the diversity – of the people who completed the log. It would be fair to say that the peer support log 'population' was more diverse – in many respects – than the population of England as a whole, and this again is testament to the hard work of the evaluation team and Side by Side partners on the ground, and especially to the additional work funded and delivered to enhance recruitment to the log in BaME specific peer support projects.

Side by Side activity figures provided by the programme team indicated that 3255 new people accessed Side by Side peer support projects during the course of the programme. With a total of 786 people taking part in the peer support log we reached nearly a quarter of that total. The age and gender profile of people participating in the log was virtually identical to the profile of all people accessing Side by Side. We had a greater diversity in terms of sexuality with 20% of people not reporting themselves as heterosexual (compared to 12% in the programme as a whole), although perhaps this was because we allowed people to indicate 'Other' sexuality or to indicate where they 'preferred not to say', giving people more scope to identify with non-heterosexual identity.

Again, the distribution of ethnicity in the log population was extremely similar to the Side by Side population as whole (within 1% in most categories), once we had made sensible allocations of people who had self identified with an Other ethnicity where it was possible to do so. As such both the Side by Side and log populations were more ethnically diverse than the English population as a whole. This reflects the regional distribution of the Side by Side programme and the allocation of grant funding to a number of BaME specific projects, and the success of the evaluation in reaching those communities.

Programme data recorded disability generally across people accessing Side by Side peer support (at 45%). The evaluation took a slightly more nuanced approach, finding that 40% of people completing the log were using formal mental health services, 34% said they had a long term physical illness or disability, 15% considered themselves to have a learning disability, with 18% saying that they were not working because of illness. Participants were able to tick more than one of these categories.

#### Sample size

As described in Chapter 3 we had intended to report within project effect sizes. However apart from Elefriends we did not achieve sufficient number of participants completing multiple logs within projects to do this. The focus of the evaluation changed somewhat (see our reflections in chapter 11) to recruiting from more projects, rather than concentrating on more participants in less projects. Despite this we did achieve a large sample size of people who used a range of different types of peer support (group, one to one and online). Many participants completed multiple logs allowing us to explore how change in peer support was associated with change in a range of outcomes, and how various socio-demographic factors impacted these associations. The statistical method used, multi-level regression models, enabled all data collected to be used to its maximum, and we constructed change in peer support use variables (increased, decreased, stayed the same) so as to make maximum use of data. However in some subgroup analyses some significant differences or significant change in outcome for a specific group may have been missed due to small sample sizes.

#### Accessing peer support

It is important to bear in mind in reading the results of the chapter above that we were not only considering the peer support that people accessed as part of the Side by Side programme. We felt at the outset that it would not be meaningful or methodologically possible to evaluate Side by Side peer support in isolation as we would not be able, ethically, to control the amount of other sorts of peer support people accessed, including informal peer support. We also found as we undertook the evaluation that many people did not clearly identify the peer support they were engaged with as 'Side by Side', in part because of the range of project names used. In addition, trying to understand how engaging with different types of peer support might be related is of interest.

We noted above that over a quarter of participants said they had not attended any peer support projects in the month prior to joining the evaluation, with a third not giving peer support of any types and a fifth not receiving peer support of any type. We saw small initial increases in the amount of some types of peer support that people gave and received (which might be expected as people were introduced to new projects). However the overall trend in accessing peer support, as well as trends in use of most types of peer support, was gradually down over the course of the evaluation.

These findings raised important questions about why people choose to access peer support and, just as crucially, why people might choose to access *less* peer support over time. We returned to these questions in detail in our synthesis chapter (chapter 8) where we brought together our log data with qualitative interview data where people told us about when and why they decided to access peer support (or not).

#### Change in outcomes

As was explained in the previous chapter, we chose our outcomes carefully, hoping to measure impacts that we might expect to change in association with people's decisions to access more or less peer support. When we considered overall trends in outcomes over the course of the evaluation what is most striking is that most outcomes – wellbeing, hope in the future and general health status – are largely unchanged. There was slightly more fluctuation in levels of contact with friends, family and neighbours, and one outcome, self-efficacy, improved quite substantially over the course of the evaluation.

On balance what we observed, taking our data as a whole, was outcomes remaining largely stable for people, or even improving over time, while the amount of peer support people accessed gradually decreased. We could begin to read implications into that but we should treat these observations with caution pending further analysis in the following chapters. Our plots of overall change in peer support and outcomes are illustrative, while our main analyses explored change at an individual level.

#### Association between change in engagement with peer support and change in outcomes

There were a wealth of findings that demonstrated a significant association between change in the amount of peer support individuals accessed overall, and of different types of peer support, and change in a range of outcomes. When trying to make sense of these findings we should remember the approach we took to analysis. We did not simply compare outcomes when people were accessing less peer support over a period of time when they accessed more (a simple before and after approach to evaluation). We compared change in outcomes over periods when someone accessed more peer support with periods when they accessed an unchanged amount of peer support and periods when they accessed less peer support. And we did this, for many of the analyses, with over 1400 measurements of change, using analytical models (as described in the technical section at the end of chapter 3) that were designed to be as statistically robust as possible.

One of the first things we discovered was that as people decreased the overall number of peer support projects they accessed their sense of wellbeing increased significantly. While we would like to assume that this means people decide to access less peer support as they feel increasingly well, in theory this might mean that people feel increasingly well as a result of accessing less peer support. It is important to note that these analyses do not tell us the direction of the observed effect. With this particular finding, and many others, we returned to our qualitative interview data in chapter 8 to make better sense of what we had discovered.

As noted in chapter 3, we decided with the PEER group that we would ask people about the amount of different types of peer support they gave and received, in order to try and further understand the reciprocal nature of the peer support relationship. Giving more peer support, especially (but not only) in a group context, was associated with improvements in a number of outcomes. We found some, but less association, between change in outcomes and change in the amount of peer support that people received. There was variation between, broadly speaking, group, one to one and online peer support.

We could jump to conclusions here about the benefits of peer support. However we note that our log questions about giving and receiving peer support were necessarily simplistic. We returned to these findings in depth in chapter 8 where we explored what people understood by giving and receiving peer support, and what they experienced as the impacts of peer support in group, one to one and online contexts.

Our log data generated findings in relation to informal peer support. What we have not had time or resources to explore here is how engagement with informal peer support relates to engagement with organised forms of peer support. We have data on how both change over time across all people completing the log but we did not explore changing patterns of engaging with peer support at an individual level, in our log data or in our qualitative interview data. We also need to make sense of the associations between change in engagement with informal peer support and changing contact with friends and families. We will return to this data in the future.

#### Peer support in different communities

Understanding the impacts of peer support in different communities – including, but not exclusively BaME and rural communities – has been a key aim of this evaluation. The size and diversity of the sample of people involved in the peer support log has enabled us to do much of this work but there are some caveats to what we have been able to do. First, out of necessity we have combined our ethnicity categories into broad Black, Asian, White and Other categories. We understand that these are not homogenous groups of people but we need to have sufficient data in each group so that comparative analyses can take place. Our group analyses should be read with this in mind but hopefully are still of value, at least where they suggest that more in depth enquiry is warranted.

Second, we have undertaken these group analyses looking at change in overall access to peer support only, rather than in terms of giving and receiving different types of peer support. We focused on overall access to peer support in part because we had most data on these variables. In addition, a huge number of tests would result if we repeated the whole set of analyses reported above for each possible group. These are analyses that should be done in more depth in the future.

Men's general health status improved as they access more peer support (in comparison to women). In chapter 2 we saw how men's help seeking behaviours can be different to women. Men might be accessing peer support in relation to their health in general rather than more specifically in terms of their mental health, but analysis of our qualitative data by gender would be needed to explore this in more details.

We also see people of different ages responding differently to the change in the amount of peer support they accessed. Younger people felt less well as they decreased the number of peer support projects they attended, but did so as they had more contact from friends. Older people felt increasingly well as they access more peer support. It might be that younger people seek out peer support when they have less contact with friends, but that contact with friends is not necessarily as supportive of their wellbeing. Again, we would need to explore our qualitative data in depth to understand that better.

We noted a larger number of differences in our analysis of ethnicity. Black people in our evaluation had increased contact with family as they increased the amount of peer support they gave, but at the same time experienced decreased levels of hope in the future. Black people had decreased contact with friends but an increase in levels of hope as they maintained the amount of peer support, and as contact with friends increased the amount of peer support they accessed fell away.

There is a possible story here about people from Black communities turning to family and actively giving and sharing peer support at times when they feel less hopeful about the future, and perhaps continuing to access peer support when they have less contact with friends. And then as a sense of hope and contact with friends return, the need to access peer support projects seems to recede. In contrast we saw people from Asian communities in our evaluation accessing less peer support as they felt more hopeful about the future, but feeling less well the less peer support they received from others. Like Black participants, Asian people in our evaluation maintained their access to peer support as they had less access to friends.

It is possible that the relationship with peer support is different between people from different BaME communities, but it is also possible that something might have been different about our groups as they first accessed peer support (that might have been related to the sorts of peer support that were on offer). For example, the Black people in our evaluation might have turned to peer support when they were feeling more isolated from friends and family and least hopeful about the future – compared to other people in the evaluation – and therefore experienced large increases in social contact and hope in the future as they actively engaged in peer support. In chapters 7 and 8 we had some opportunity to explore these findings in relation to our data about BaME specific peer support but there is potentially much more work we can do to understand these stories with the wealth of both log and interview data we have about experience of peer support from people from BaME communities.

People in the evaluation who were using formal mental health services experienced a decrease in self-efficacy and decreased contact with family and friends as they gave less peer support. This group of people is possibly the 'least well' of our population as a whole, with these findings suggesting either that as they become isolated socially they find it more difficult to access peer support, or alternatively where they are less actively involved in giving peer support their sense of feeling able to make connections drops away. It would be interesting to try and understand, from our qualitative data, how this large group of participants' experiences engaging with open access peer support, outside of formal mental health services.

In contrast people who identified as having a learning disability accessed more support when they were feeling less self-efficacious, and less peer support when their self-efficacy increased, implying that access to peer support for them was motivated by specific need. Differently again, some people with a physical disability or long term condition turned to peer support when their general health status decreased while others attended less, perhaps because they were too unwell to do so.

People in rural areas – one of our target populations – attended more peer support projects when their general health status was lower. This might be because peer support was easier to access closer to home than other health services that might be more geographically dispersed, but this is an issue that again warrants further investigation.

Taken together, this last set of findings suggested that there was a complex relationship between peer support and people's wider mental and physical health and wellbeing. People accessed peer support for different reasons at different times and benefited in different ways. Not all mental health peer support takes an explicitly holistic approach to wellbeing – although many do, especially with respect to BaME (as we saw in chapter 2) – but this complexity of need and benefit should be carefully considered.

As final reflection, and as we have reiterated above, these group analyses have been informed by preliminary analyses of our log data only. In producing this report, constrained as we have been by resource, we have had minimal opportunity to explore our statistical findings from the log in relation to our qualitative interview data (with the exception of the work we have done with respect to BaME specific peer support in chapter 7). Future work would enable us to develop a more in-depth understanding of these important issues of community, identity and peer support.

# Chapter 5: Peer Support Core Principles and Values: Consultation and Early Development

## Summary

This chapter describes the consultation work we conducted to identify and produce our early draft of the peer support values and principles. We used three different ways to gather information:

- **Consultation events**: 2 were held, one in London and the other in Leeds, with a range of people involved in giving or receiving peer support (26 people in total). Peers were asked to identify the key principles and values of peer support and to rank which features they considered to be most important.
- *Hub group interviews* with people who were going to be involved in delivering the Side by Side programme (9 hubs, 38 people), staff from Depression Alliance (3) and those working on the Elefriends platform (3). We asked them to describe peer support, including any peer support they were currently involved in, to give some practical examples of peer support, and how peer support may work across diverse communities.
- **Online survey** of people involved in peer support about their views on peer support and to describe other forms of support for their mental health (responses from 163 people).

Our findings suggested that while there was consensus on some core features of peer support, there was also great diversity the way in which people considered other features of peer support to be important. Peers also had clear ideas about what peer support was not, and that peer support was different from statutory or clinically based services as it did not have the following features:

- Based on the medical model and involving supportive relationships that are one directional
- Support from people who have no direct experience of mental health difficulties or are unwilling to disclose their difficulties
- Support that is outcome or advice-focused and does not inspire or help people to develop solutions to their own problems

• Support that peers consider to be judgemental and where there is a lack of empathy We looked at how the data from the three different strands of the consultation corresponded with each other. Where a feature arose in at least two strands of the consultation we used this to produce our first principles and values draft. Peers told us the following were essential components of peer support:

Universal Characteristics of Peer support					
Shared Lived Experience	Experience Mutuality				
Principles Values					
Peer ownership	Inclusive				
Feeling Safe	Empathy				
Flexibility	Equality				
Active Sharing	tive Sharing Being Human				
Support	Valuing experience				

## Background

Working to understand the core principles and values of peer support was a central focus of the evaluation brief. This part of the evaluation was informed of our reading of the wider peer support and mental health literature as reported in chapter 2. In addition, a number of organisations have developed values frameworks that serve as guidance for peer working (please see Table 5.1). In the UK, ImROC have developed a list of 8 core principles to guide peer workers in their work (Repper, 2013), and the Scottish Recovery Network have developed 6 key principles for peer support (The Scottish Recovery Network, 2012). In 2013 the authors of the Piecing Together the Jigsaw Report reported 5 core principles as being endorsed by all peer support groups they spoke to during their research (Faulkner, with Sadd, Hughes, Thompson, Nettle, Wallcraft, Collar, de la Haye and McKinley, 2013).

ImROC	Scottish Recovery Network	Piecing Together the Jigsaw
<ol> <li>Mutual</li> <li>Reciprocity</li> <li>Non-directive</li> <li>Recovery focused</li> <li>Strengths based</li> <li>Inclusive</li> <li>Progressive</li> <li>Safe</li> </ol>	Hope Experience Authenticity Responsibility Mutuality Empowerment	Mutuality Respect A non-judgmental approach Inclusivity Equality

Table 5.1: previous principles or values frameworks

The Side by Side programme created the opportunity to develop a principles and values framework through while working with a large number of people involved in peer support across, mostly in the community, across the UK. Within the Side by Side programme there was great diversity in the types of peer support happening in different areas. This ranged from structured peer-facilitated peer support offered in a group setting through to casual social network style peer support that could be accessed online. The challenge was to identify a set of core principles and values that were essential to all forms of peer support, and that made peer support different from other forms of mental health support. We conducted this work in two stages as outlined in Figure 5.1 below.

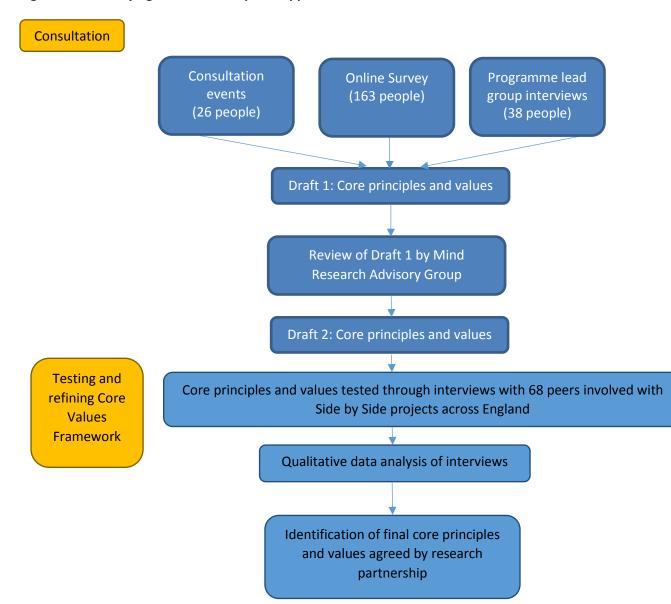


Figure 5.1: Identifying core values of peer support

In this chapter we describe the first phase of our principles and value work – the consultation phase.

## Our aim

The aim of the consultation phase was to identify peer support principles and values, and understand how they might vary by context. Through our consultation work with peers, from across the county prior to Side by Side establishing the programme, we sought to answer the question: What do people involved in peer support identify as its core characteristics?

## Methodology

We started this work exploring what people involved in peer support identified as its core characteristics. This included people involved in the set-up of peer support 10 years ago, as well as people more recent to this way of working. We used three different ways for people to engage with us at our consultation stage:

- Consultation events we held 2 consultation events (one in London and one in Leeds) with a
  range of people who had been involved in giving or receiving peer support. During these
  events we asked these people to identify what they believed to be the key principles and
  values of peer support. (2 events, 26 people)
- 2. Hub group interviews we conducted interviews with people who were going to be involved in delivering the Side by Side programme based in the regional hubs across the UK. They were interviewed during the set up phase of the programme. (9 hubs, 38 people)
- 3. Online survey we invited people involved in peer support across the UK to participate in an online survey about their views on peer support. (Responses from 163 people)

# **Consultation findings**

## **Online Survey Findings**

We asked participants who completed our online survey to sum up what they believed peer support was in three words or simple phrases. There was a wide range of responses to this question, provided by 157 people, indicating how varied experiences can be reflected in different descriptions of peer support. We conducted a content analysis on this data during which we grouped similar words or phrases that described similar characteristics. We then looked at which groups were the most popular amongst survey participants. Table 5.2 shows the number of people who suggested words from the top 15 most popular groupings.

## Table 5.2. Words used to describe peer support

Word grouping	Number of people
Empathy (words in this group: empathy, empathetic, empathetic friendship,	(n=157) 36 (23%)
common empathy, genuine empathy)	50 (23%)
Shared Experience (words in this group: experience, common experience,	35 (22%)
experiential, experts by experience, lived experience, shared, shared experience,	55 (2270)
shared lived experience, sharing, sharing our vulnerability, sharing your	
vulnerability and worries)	
Non-Judgement(words in this group:less judgemental, non- judgemental, without	34 (22%)
judgement, no assumptions made, not being judged, unconditional, acceptance,	54 (2270)
accepting, genuine acceptance, mutual acceptance, respect, respect of others and	
their own values, mutual respect)	22 (210/)
Support (words in this group: peer to peer support, peer support, mutual support,	33 (21%)
support, supportive, support group, support from someone who truly	
understands, support without telling me what [], support through experience,	
unstinted loving support, A supportive relationship based on sharing [], a	
journey of support, emotional support, giving, giving to others, giving and	
accepting support)	
Understanding (words in this group: understanding, understands, mutual	31 (20%)
understanding, mutual understanding of struggles, working with someone on	
your level, support from someone who truly understands)	
Safety (words in this group: safe, safe environment, safety, safe to be out and	28 (18%)
proud, feeling safe in space, trust, trusted, confidential, private)	
Human connection (words in this group: connection, connecting, connecting with	21 (13%)
others, ability to connect, human connection, network, fellowship, togetherness,	
together we can recover, collective, community, I'm not alone, no longer alone,	
reduces isolation and loneliness, standing by someone in their recovery, you're	
not alone, being there for me, being there for each other)	
Help (words in this group: Help, helpful, helping people help themselves, helping	15 (10%)
people make positive change, empowerment, empowering, empowers self, self-	
help group, self-directed)	
Equality (words in this group: equal, equality, equal relationship, equal platform,	15 (10%)
inclusive, relationships of equality, relationship based on equality, we are all	
equal, no one is an expert or knows better)	
Mutuality (words in this group: Mutual, mutuality, the mutuality of shared	13 (8%)
experience, Reciprocal, reciprocity)	
Listening (words in this group: listening, listening and being listened to, creative	13 (8%)
listening)	
Friendship (words in this group: Friends, friendship, making friends, peers are	11 (7%)
potential friends)	
Hope (words in this group: Hope, hope-filled, inspire hope, Instilling hope that	11 (7%)
recovery is possible, offering hope, there is hope)	
<i>Encouragement</i> (words in this group: encouraging, encouragement, nurturing,	11 (7%)
reassurance, reassuring)	

We also asked participants to tell us how they would describe mental health support that was not peer support, to help assess the differences between peer support and other mental health support available. We also conducted a content analysis on these answers to identify key themes in the data (see Table 5.3).

Table 5.3. What is not peer support
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Theme	Number of people
meme	(n=156)
Medical model treatments, medications, talking therapies, clinical services	44 (28%)
(including inpatient services)	· · ·
Support that is prescriptive, directive, target, outcome or advice focused	37 (24%)
Support delivered by professionals including health care or clinical	36 (23%)
professionals and project staff	
Supportive relationships that are one-way, hierarchical, unequal, embody a	30 (19%)
power imbalance or resulted in respondents feeling disempowered or	
controlled	
Support delivered by people who do not have lived experience of mental	29 (19%)
health problems	
Support that respondents perceived to be judgemental, judgemental,	19 (12%)
stigmatising, dismissive, patronising, condescending, or implied that the	
recipient could not be trusted	
Support in which respondents felt there was a lack of empathy, true	19 (12%)
understanding or that they were not listened to	
Support that was useful and helpful but different from peer support	15 (10%)
Support that is problem focussed, not individualised, does not inspire or help	13 (8%)
people to develop solutions to their own problems	
Support that was perceived to be impersonal, lacked personal connection,	12 (8%)
distant, remote, 'just a job' or a purely clinical relationship	
Support which was time limited or in which respondents felt staff did not	12 (8%)
have enough time to pay attention to individuals	
Support that was characterised by formal structures, procedures and	9 (6%)
professional boundaries, including those that prevent staff from disclosing	
personal experiences of mental health	
Informal support from friends, family, neighbours who do not have lived	8 (5%)
experience of mental health problems	
Support that involved a waiting list, is not available at the time that it is	8 (5%)
needed, is only available at times that are convenient to the services involved	
Support that is forced, involved compulsory treatment or admission to	6 (4%)
hospital	

#### **Events**

We held two consultation events, one in Leeds and one in London in June 2015. Within these events we asked people who were involved in various ways in peer support to tell us what they thought the most important characteristics of peer support were, and to tell us which of those characteristics were the most important to them.



Within these events participants of our consultation were asked to identify the key principles and values of peer support and to rank which features they considered to be most important. In Table 5.4 below the key top features from the event at Leeds and the event in London are listed. In the London event an overall top list was produced for the whole group within the event. In the Leeds event different groups developed different top lists.

#### Hub group interviews

Between April and July 2015 we conducted focus groups with people involved in the early stages of the set-up of the Side by Side programme. We interviewed key staff members at all 9 of the Side by Side Hubs (36 in total) and also interviewed the staff who worked for Depression Alliance (3) and who works on the Elefriends platform (3). We asked people in these consultations to tell us about the following things:

- Peer support they were already involved in
- Distinguishing features of peer support
- What they would identify as being the core principles and values of peer support
- What was not peer support
- Practical examples of peer support
- How peer support may work across diverse communities
- How they would describe peer support in three words

These focus group style consultations were audio recorded with the verbal consent of the individuals in the room, and we made notes from these recordings to inform our development of the principles and values detailed at the end of this chapter.

London	Leeds
1. Shared experience	Group 1
2. Mutuality and reciprocity	Trust
3. Recovery focus	Boundaries
4. Structure	Safety
5. Hope	Positive focus
6. Safety	(recovery/empowerment)/hope
7. Trust	
<ol> <li>Boundaries</li> <li>Goal oriented</li> </ol>	Stability, reliability, continuous
10. Fundng	Group 2
11. Empowerment	Shared experience
12. Equality	Mutuality/ reciprocity
13. Facilitation skills	<ul> <li>Recovery focus/ goal oriented</li> </ul>
14. Honesty and openness	Trust, openness and honesty
	Challenges traditional power structure
	Group 3
	<ul> <li>Safety and trust (esp. in marginalised communities)</li> </ul>
	<ul> <li>Mutuality and reciprocity (equality)</li> </ul>
	<ul> <li>Hope for recovery (setting goals, role models)</li> </ul>
	• Person directed choice and control,
	personal responsibility
	<ul> <li>Boundaries and ground rules (inc.</li> </ul>
	structure)
	Group 4
	Empowerment
	Listening skills (active)
	<ul> <li>Purpose – not 'end goal'</li> </ul>
	Safety and boundaries
	<ul> <li>Mutuality and reciprocity (equality, equal footing)</li> </ul>

## Table 5.4: key principles and values of peer support identifies in consultation events

Principle/value	Coventry	Kensington & Chelsea	Blackpool	Leeds	Middlesbrough
Shared Lived Experience (UC)	We develop relationships with our peers because we <b>are</b> <b>like minded, we have a</b> <b>similar experience</b> and that will happen in friendship development as well.	Peers make the most credible messengers to people who are going through similar experiences. When it comes to challenging life experiences, to know that someone really understands what you are going through creates an <b>equal relationship</b> . A worker can never really truly identify with the experiences that people are going through.	The difference is anyone can go to a group that is socially orientated – you attend with the expectation that there are people. For peer support, you go with the expectation that you will meet people who have 'worn the t shirt'.	Core in our use of the term peer support is that it is <b>people supporting each</b> <b>other in groups with their</b> <b>mental health</b> . Have to be able and willing to have open discussion about your mental health.	Shared life experience – you know where people are coming from. You can identify with people.
Mutuality (UC)	Mutual support through a journey together –a two way process. Peer support is not about rescuing, or aiding, it is about sharing, and to feel confident in that. It's not about one person having all the		It is not just about going to a group to off load – it is <b>a</b> <b>two way street</b> – it's about offering support to other too. Some people come along just to offload which changes the dynamic of the group.	Mutual – it is giving and receiving support; not 'them and us', equal sharing and giving.	Mutual, reciprocal.

## Table 5.5 part 1: Evidence from group hub interviews for draft 1 principles and values

	information and other don't.				
Purpose (UC)	If one has a mission, or a purpose – hanging on to that is important – it is the skeleton of the structure– it is important to hold on to that and revisit it – it doesn't have to prevent the natural growth of relationships but by reiterating the mission, you remember why you are there, which could be rather more than just a cup of tea.	People are there to provide inspiration and structure that helps people achieve their goals and outcomes so anything that is working against that is not peer support. Bad peer support happens when organizational structures prevent people from working in this way or when people are un-boundaried, or colluding, or over identify with the person they are working with. Peer support is not just about being a friend, it is about providing a service to people- that negates the professional role that peer support can play in helping people achieve their goals.	Groups have to meet a need. There should be a purpose to the group. Groups which define themselves as a 'mental health' support group + combine an activity, may not talk about mental health but they still peer support.	Core in our use of the term peer support is that it is <b>people supporting each</b> <b>other in groups with their</b> <b>mental health</b> . Have to be able and willing to have open discussion about your mental health.	People have their own resources they can draw on, not just about 'professionals' giving the answers. People have the answers within themselves. They know what their skills and interests are – people are not seen as problems/difficulties that need solutions – peer support is fundamentally a different approach to mental health and wellbeing.
Inclusive (V)	Peer support provides the "I'm not a lone, it's not just me" element	Understanding language is really important, and where individuals put themselves in terms of their own experience, because a lot of people may talk about	Yes, definitely. The cultural issues are totally different – certain women for example will have certain restrictions regarding honour and	For me it's a <b>real belief in</b> <b>people</b> – that people can lead things themselves. Important to ensure that the work is culturally	To be involved with Mind in Middleborough and Stockton, one doesn't need a particular

		wellness, but not call it mental illness. To take their	<b>religion</b> – you can't apply same model to these	relevant, not just translating it. Plus have to have people	diagnosis/level of service use.
		real experience of their	women. Zee suggests	from those communities	
		experience and not fit it into	referrals to Mind but	delivering it. Facilitators are	
		a medical model. E.g.	women respond with 'they	bilingual, and make it	
		hearing voices is not always	might not understand my	culturally significant. Can	
		seen as negative- prophets	issues'. It is about working	talk about mental health in	
		in the bible heard voices.	together and building	their own culture.	
		Having a credible diversity	bridges.		
		profile is really important			
		with any project. You need			
		people to be working with			
		people who they can			
		identify with in terms of			
		age, gender, culture.			
Empathy (V)	But to do that in Peer	There is <b>empathy</b> we can	Within the BAME groups	Empathy – being	Safety to be open and
	support, with a group	have to people in all	there is a <b>real empathy</b> ,	understood, without having	talk about things.
	of people with similar,	different kinds of situations,	which fosters a safe	to explain everything,	They've been through
	shared experiences	but there is an <b>authenticity</b>	environment to talk in	feeling understood	the same kind of thing –
	allows for a greater	to the empathy from	confidence about issues		empathy – know how
	sense of empathy, less	someone who has been	that mainstream services		you are feeling.
	of a need to fulfill	there themselves.	consider 'criminal'		
	expectations – this is a				
	very positive thing.				
	Feel that you are not				
	going to be judged.				
Equality (V)	Positive aspect of peer	In statutory services it is	It is not about 'expertise'	Then we work in rounds so	People with MH
	support – people are	about the traditional	being given to you, being	you know when it is your	problems often see
	supporting each other	hierarchy, peer support cuts	told what you need to get	turn. It is not a 'free for all',	themselves as lower
	on an equal level,	through the hierarchy by	better. People want to get	very structured. This can be	than everyone else but
	without their being a	creating and <b>equal</b>	away from the experts –	relaxed after a while when a	

	member of staff involved. Someone can move from tea maker, to facilitator and vice versa. Fluidity of responsibilities, non- hierarchical.	<b>relationship</b> , but also works as a bridge between the individual and their psychiatrist/CPN etc.	disconnect from anything "professional". This helps to remove the barriers people experience from professional services.	group is used to working together. It does mean that you don't have to fight for space to speak, and you will be given the chance to speak. You can 'pass' and say nothing but it can be very empowering for people who wouldn't normally	as a peer supporter you are equal.
Valuing experience (V)	One can have problems with doctors, psychiatrists and feel alone in their struggle. Chatting about such struggles with someone who understands what you mean, has had a similar experience and then can proffer a	From and organizational point of view peer support <b>legitimizes lived</b> <b>experience</b> . When you have a peer support structure embedded in an organization it <b>normalizes</b> <b>it, reduces the stigma</b> it allows the mood to relax in the room.	Its' the empathy certain cultures share within their own communities. It is difficult to work cross culturally. <b>"I want my</b> <b>practitioner to</b> <b>acknowledge that I have</b> <b>suffered from</b> <b>discrimination – but</b> <b>service providers,</b> <b>sometimes, cannot</b>	speak. A lot of people who come here have struggled with statutory services – the labels you are given, etc. [Peer support here] is giving people a chance to be heard. You show you value people – e.g. by providing sandwiches.	What it comes down to is – do people feel valued for their services. Are their own aims and aspirations being taken into account? It's our moral responsibility to support volunteers with those aspirations – if they give up their time to volunteer and help
	solution/bit of information/support is very <b>enabling</b> . This connection of similar experiences can help foster the confidence to challenge the situation (in this case, have doctor changed)		acknowledge this. How can a White, British person empathise with what I have been through? It is not their fault. No equal opportunity training is going to give them that experience. I want someone to understand		us.

	and bolster self-		what I have been		
	esteem in the process.		through."		
Being Human	Peer support provides		It is quite <b>nice to see</b>	Peer support is what we do	Something about
(V)	the "I'm not a lone, it's		people becoming friends	as humans; interconnecting	language and way one
	not just me" element		– our main impetus is	relationships if you don't	connects with people
			social inclusion so we	have that in your life, you	that possibly those
			want to see people	need somewhere to go to	without lived experience
			become less isolated. You	get it for your mental	can't. An intensity of
			are grown adults, but	health.	feeling that motivates
			there are triggers and it		and inspires people to
			comes back to looking		do stuff.
			after yourself. We focus		
			on wellbeing.		
Peer Ownership (P)	Peer support is self- initiated. It is done, because people want to help - It is not a tick box, a KPI, it is not a job. It is authentic.	One value is <b>no</b> <b>assumptions</b> . Moving away from boxes- and putting people in boxes. Allowing people to self-define.	It is peers themselves who determine what the group is going to be – from the start – the first decision. For it to be truly user led, it needs to be. It is about it being 'your' group and not 'ours' – <b>ownership</b> . It's about the <b>balance of</b> <b>power</b> .	Plus there are leadership roles for people with lived experience. The steering group is all people with lived experience, and they support what they want to see happen. All the activities are designed by peer supporters and they are constantly evolving.	Lead does not determine the dynamic of the group. This can make the difference between staying on the course/leaving after a week. Members themselves, police the sessions. It is an empowering way for group to take ownership
Feeling safe (P)	However, these	XX has been a peer	People still want to	The groups are structured.	of their dynamic – also enables increased participation. A lot of time in PS
	friendships can also be	supporter in voluntary	discuss their mental	There are 10 rules for	groups is dedicated to

	invaluable because one can sit in silence with a peer — can just 'be' with a peer, don't have to be anything other than what you are, at that particular time. Other friends might approach my mental health with a different level of judgment.	sector and works as a peer support worker in the NHS. Feels that it is very important to have training around <b>boundaries- the art</b> <b>of sharing lived experience</b> , the therapeutic use of self, for peer support workers, and also staff who work with peer support workers (so they understand disclosure too)	health but, maybe, not with people who form an opinion of them. People don't judge. It is not as prescribed or structured – too much structure kills the dynamic.	behaviour in groups, which underpin everything we do, helps keep the structure. [examples include 'talking from the I', be kind to yourself and others, respect]. It is a framework for keeping safe.	setting ground rules – feedback from peer members: this is one of the things they've enjoyed about the groups. The collaborative setting of ground rules helps members feel safe and supported.
Flexibility (P)	Sometimes, parameters need to flexible because everyone's needs are different. This increases the chances of people getting involved. SU's often have strong desire to be involved, but if services are too formal, they don't engage. Adaptations are necessary.	Peer support is <b>not about</b> <b>telling people what to do,</b> <b>or guiding people</b> . It is not people having a platform to speak about their experience- it needs to be tailored to the person you are supporting.	To address the inequalities BAME Lancashire are <b>innovative</b> in the ways they communicate. For example: use whattssap for peer support. They have one <b>whattsap group</b> at the moment – it is free, easy to download and provides a voice for those who are marginalised/introverted – not everybody can express himself or herself vocally– especially if culturally supressed. Women may not vocalise in a face-to- face group if men from	How we support volunteers – constantly changing and adapting. The pathways people come through changes – e.g. connecting earlier, before they are leaving the wards. Thinking of having a group outside the recovery centre to straddle the ward/community. How to support people over difficult transitions like that, setting up and changing how we're offering that.	Mentors have lived experience of MH problems then matched to people to help them achieve their goals. From this scheme, peers have developed other interests – have developed their own groups.

			their own community are		
			in attendance. Group		
			dynamics need to be		
			,		
			culturally sensitive.		
Active sharing	The whole thing about	Sharing lived experience-	When a group gels, trust	Then we work in rounds so	Peer supporters bring
(P)	peer support is sharing	sharing one's own personal	build up, disclosure and	you know when it is your	genuineness and depth
	experience.	experience, explicitly, but	common factors begin to	turn. It is not a 'free for all',	to training programme
		knowing where the	be shared	very structured. This can be	through speaking about
		boundaries are to keep it		relaxed after a while when a	their experiences – give
		person centered. Shared		group is used to working	examples of what it is
		experience is used in order		together. It does mean that	like to be on a ward, for
		to build the relationship,		you don't have to fight for	example. This sharing
		communicate <b>empathy</b> , and		space to speak, and you will	encourages others to do
		an <b>authentic</b>		be given the chance to	the same. Learners on
		understanding.		speak. You can 'pass' and	course think 'hang on,
				say nothing but it can be	this is like me' and this
				very empowering for people	support them to share.
				who wouldn't normally	Lends peers confidence
				speak.	to offer opinions and
					views.
Support (P)	It is about giving	It is not to turn the	Facilitators get the	'We will not write off a	there is a high level of
	people tools and	relationship to be about me,	conversation going,	person under any	enthusiasm for PS in
	options so they can	or my whole life story- it is	signpost with local	circumstances'	local community but
	pick for themselves	about the parts of my life	knowledge. We say 'come		people sometimes don't
	what works – not	story which could be helpful	along to get some peer		show up on the day.
	providing a crutch.	to you. That's why <b>training</b>	support, and in time you		Why? Anxiety, high and
	Giving tips and tools	is important, otherwise the	may be able to give it		confidence, low. Mind
	so they can hopefully,	balance could be completely	too'the <b>two way</b>		to introduce a PS buddy
	be empowered to take	out. There are a lot of skills	dynamic is a process of		to physically support

things forward	to that- communication,	becoming. There can be	peers at that final stage
themselves. To use	relationship building,	times, where support is	of getting through the
what fits the individ	ual. diplomacy.	one way, especially when	front door.
		an individual is unwell.	

Principle/value	Northamptonshire	Plymouth	Southampton	Suffolk
Shared Lived Experience (UC)	Commonality of mental health experience – being in hospital, for example - swapping of similar stories.	The bit that makes it the peer is your own experience. Shared knowledge of other feelings such as a lack of motivation, generalized feelings of what it's like to have a mental health issue. Feelings of helplessness, no one understands – shared emotions and feelings are the next layer up from shared, specific lived experiences.	About shared lived experience and a very supportive relationship. Therapist may/may not have lived experience but not likely to share	about a group of people who come together through a common interest/experience. Groups are about a connection to something, such as coming out of hospital/secondary MH care.
Mutuality (UC)	It is the mutuality. It is about building trust – like peeling layers off an onion. As people begin to trust one another, they reveal more about themselves – enables disclosure. As trust develops, mutuality develops along with it.	An understanding that volunteering is mutually beneficial —you also get a lot out of it. A good peer supporter has the ability to see potential in other people.	When someone understands, you walk away feeling less isolated, lonely and silly. Peer support empowers both people in the relationship. Reciprocity.	Art group, for example, have a mutual interest in doing something. Doing is as important as the shared experience of MH. Talking happens at same time as doing something.
Purpose (UC)	What it is: "I've had depression. This helped me. Maybe, if you tried it" This phrase is enabling.	Give people opportunity to talk about recovery, gain control back over their lives – <b>about raising</b> <b>confidence</b> , helping people to get out of the house.	Peer support is strengths based. Peer support does not say "What's wrong with you?". It is about interests, thinking about the future, life before getting ill. Peer support is about a fundamental belief in people's assets even if the	The mechanisms of the intervention that underpin the peer-ness about self- responsibility. It's me that decides what happens, me who decides how to deal with my depression, anxiety. Only I can change it. I can ask for support,

 Table 5.5 part 2: Evidence from group hub interviews for draft 1 principles and values

	The current commonalities of	If a group thought they were being	individuals don't feel in touch with them. Language is important. One can't	but when the chips are down, it is about relying on self. A lot of people in MH have lost touch with their own internal world. People may have experienced
Inclusive (V)	The current commonanties of our peers are as follows: the psychiatric system, older generation , restricted income, unlikely to be in work, have been institutionalized. That is why our we maintain a little bit of old fashioned-ness in our service delivery - the whole concept of recovery and MH learning/training is not a reality for some of our SU's – people who have been in the system for so long, their expectations are limited. They want to feel included and we do a lot of advocacy on their behalf.	advertised as a separate entity, then you are marginalizing them even more. Groups for people from other ethnicities have to be tailored because of the vast cultural differences – especially of how mental health is perceived. You could run a course on assertiveness and self-esteem but if it's not appropriate for their culture, it is of no benefit to them.	Language is important. One can't assume other communities will know what peer support, or even what mental health means. If this language is used, engagement may not happen. Other communities may define peer support as reducing isolation, or a support group. That is one consideration.	<ul> <li>People may have experienced</li> <li>judgment. PSN provides a place</li> <li>where people can talk about</li> <li>how they feel, as an individual,</li> <li>and there isn't an expectation</li> <li>of others – this is a powerful</li> <li>thing.</li> <li>I believe it is about having</li> <li>access to good quality peer</li> <li>support wherever they live,</li> <li>connection might not be just</li> <li>about a commonality around</li> <li>having MH issues.</li> <li>In Suffolk mind, we have a</li> <li>sense that all people are on a</li> <li>continuum of MH from well to</li> <li>not so well.</li> <li>Public transport –people want</li> <li>services within their own</li> <li>locality then you have to make</li> <li>sure that enough people</li> <li>attend that locality. People</li> <li>with varying emotional health</li> <li>may not want to get on a bus</li> </ul>

				in the evening/travel on their own. People who come to the groups are not working – mainly on ESA/JSA – groups run during the working day. Lack of money could be a challenge; group members don't have a lot of money.
Empathy (V)	That is where understanding comes in. If, for example, someone comes in with poor hygiene and a dishevelled appearance, concern will be voiced. Instead of saying things like "Look at the state of him' there is genuine concern noted with comments such as 'Are you OK'.	in our support groups there is lots of sharing of what people have gone through. There are situations where people say 'Yes, I have been through this" - there is a real power to someone who has been through that recovery journey – they can empathise – that is one of the main things. "I know what you are going through".	I have bipolar and anxiety and my mentee's say because I have empathy, and understand what they are going through it helps them. No such thing as a silly question when people share experiences.	
Equality (V)	Counselling is not an equal relationship; they are there to help solve a problem.	try to enable all group members to be a peer supporter so that there is not a dependency on one individual for facilitation ( <b>related to equality</b> <b>of roles in peer relations</b> ). Take it in turns. It is about equality and empowerment – people may not want to lead a group but 'step up' to ensure continuity.	In inpatient setting – boundaries are challenging. By the very virtue of employing peer workers you are blurring the boundaries of the 'them' and 'us' culture of the ward.	Network is about setting up a psychological space between peers. No one in charge of the space, network, session. For example – if I was in crisis, and you weren't each member still has equal amount of time during a set (session – can be 20 minutes long - example given by interviewee's). Not about giving advice.

Valuing experience (V)	It is more natural. You know you are accepted.	The key ingredient is the lived experience, and valuing that lived experience and being able to use that to benefit others.	The mentoring role helps attribute a positive meaning to the mentor's mental illness Mentors feels that their experiences and recovery methods can help others and the mentee's feel similar – they feel their experiences can help other to – but maybe in the future. See mentor as a role model.	PSN gives the basic human given of being listened to. I've been a room with people who have never had that direct attention, of being listened to, attended to.
Being Human (V)	The informal groupings are not as regulated. They are friendships. They are the naturally, evolving things.	We want people to connect – we don't want to people to identify with each other solely because they have a MH problem. They have to find a common ground based on other things – like a football team – I like relationships that are not totally defined by having a MH problem. The person who leads our reading group is a volunteer. She has lived experience, but a volunteer like everyone else.	Relationships are powerful. Feedback is that mentee's feel they can really connect with their mentors in a one to one setting.	The 'organic-ness' is the social pub meetings that have grown off the back of the network. There is a variety of ways people use the network. Crosses over into more of what Sarah is doing (informal peer groups), but people approach the socialising with a different awareness of their own needs and responsibilities. Bit like the human givens that underpins all of Mind's work – people all have a set of emotional needs and we all have a set of innate resources to meet them.
Peer Ownership (P)	Service users run their own service – have weekly meeting with an agenda – discuss visits from outside speakers etc. Peer	It is about understanding and listening and often not about advising – allowing people to come to their own conclusions – example of role modelling here " this is	Empowerment to help others achieve what they want. "They" being the operative word – it is about self-determination. The peer supporter is not prescriptive or	Driver is the one with the initial for a group –found this was developing naturally – people presenting with ideas,

	workers role is to support this process.	what I did in similar situation, it may help you too"	directive – they are enablers of 'space' to develop self-belief.	passionate about them – the idea generator. True form of peer support – members have equal responsibility for group. If driver falls out, the group can continue and not fall apart. They all decide together. Someone will collect tea/coffee – could be a different person each week. All members know where to go, what to do.
Feeling safe (P)	<ul> <li>We have a boundary policy for members: specific rules for the protection and safe guarding of the group. Service users write these. Get reviewed every couple of years.</li> <li>Peer support is their first step into a service. It's the knowing they are in a safe environment.</li> <li>There isn't an expectation from them, they can come in to the drop in and be themselves.</li> </ul>	It's knowing someone has been through the same as you – this brings with it an element of hope, trust and safety that you may not find in other relationships.	Boundaries and expectations are set regarding relationship. E.G. Sessions last an hour – this is a strict boundary – related to helping maintain a routine. Mentee's are made aware of this in advance – being clear with messages – be honest with them – have due diligence to mentor and mentee and safety measures are needed.	Confidentiality – what happens in the group stays in the group. We evaluate the boundaries every six months. Each new member gets a copy at the beginning. Training sessions often start with establishing basic principles of trust and confidentiality. People will consider it and then accept it.
Flexibility (P)	Peer support worker supports people as, and when, needed.	Being <b>patient</b> – you can see potential in others but letting the other person move at own pace. It's about being <b>personable and</b> <b>approachable</b> – helping people with	In our training we have structure but it is flexibly used in individual mentoring relationship– work	With the PSN training, the people who take it on have to commit to listen and then to speaking –have to dedicate a certain amount of attention. It

		practical things such as getting out of the house for a coffee.	through a WRAP and a goals setting tool for the ten sessions.	is a two way process. People also have to be at a level of mental wellness to participate in the PSN training process. Sometimes people cannot commit and that is when trainer talks to them and asks them if it would do something else in preparation.
Active sharing (P)	Within the group, they do talk about their MH. It is very mild level of MH. Talk about medication etc. Mutuality is very present here. It is a trusting group, which means they can ask those questions.	Have training - Lots of role-play involving the sharing of experiences (also around boundaries) – which is quite powerful. Organization reflected on the need for different types of training for those with lived experience but thought it was better to train everyone together.	This is where language can shift the balance from advice giving to role modelling: "I tried this, maybe it would work for you" is different to saying "You should do this, because it can change your life". If you have lived experience and don't talk about it or use it positively, then it is not peer support.	If trainer is skilled enough, during the course of the session, everyone will have declared something personal/sensitive about self - so the <b>trust is a mutual thing</b> . Moreover, if you are talking to someone about inner most feelings you can use own discretion whilst divulging information about details/back story.
Support (P)	Peer relationships are sometimes about giving support and sometimes receiving support.	It's about being personable and approachable – helping people with practical things such as getting out of the house for a coffee.	The peer supporter is not prescriptive or directive – they are enablers of 'space' to develop self- belief. They are the cheerleader – encouraging and affirming.	<b>Supportive</b> , I value other people who have committed the time to training and come to meetings.

# **Draft Principles and Values**

The aim of this component was to produce a set of principles and values to help define peer support and provide a framework that could support both delivery and commissioning of peer support. We reviewed our three data sources and used this as a basis on which to produce our first principles and values draft (See Appendix 5.1). Our draft was divided into three sections.

- A set of *Universal Characteristics (UC)* that we understood to be core to all peer support. Without these characteristics a form of mental health support could not be considered as peer support.
- A set of *Values (V)*, which were qualities that should be present in all forms of peer support, but that may be difficult to measure objectively.
- A set of *Principles (P),* which were guiding rules that needed to be in place for peer support to be effective. How people involved in offering different forms of peer support chose to implement these principles would be different depending on delivery context.

In Table 5.6 we provide information against each data source to identify how the draft framework was constructed. This draft was then reviewed by the Mind Research Advisory Group, who provided feedback, before a final draft was produced and used by us with people within the Side by Side programme (see Chapter 6).

Component included in first	Evidence present in consultation components		
draft	Online survey	Consultation events	Group interviews with hub leads
Shared Lived Experience	$\checkmark$	$\checkmark$	✓
(UC)			
Mutuality (UC)	$\checkmark$	$\checkmark$	✓
Purpose (UC)	x	$\checkmark$	✓
Inclusive (V)	$\checkmark$	х	✓
Empathy (V)	$\checkmark$	х	✓
Equality (V)	$\checkmark$	✓	✓
Valuing experience (V)	$\checkmark$	✓	✓
Being Human (V)	$\checkmark$	$\checkmark$	✓
Peer Ownership (P)	$\checkmark$	$\checkmark$	✓
Feeling safe (P)	$\checkmark$	$\checkmark$	✓
Flexibility (P)	$\checkmark$	х	✓
Active sharing (P)	✓	✓	✓
Support (P)	$\checkmark$	$\checkmark$	$\checkmark$

### Table 5.6. Evidence used to support inclusion of draft principles and values at Stage 1

# Conclusions

Through our initial consultation we identified a set of Universal Characteristics, Principles and Values that underpin peer support (see appendix 5.1 for a full draft). In this early consultation work it was clear to us that while there was consensus on some aspects of peer support, there was also a wide diversity in the kinds of things that peers considered to be important to peer support. In the next chapter we describe how we went on to test this initial set of principles and values through a large number of one to one interviews with peers.

# Chapter 6: Principles and values underpinning peer support

# Summary

Our findings from initial findings from 69 interviews conducted with peers in the Side by Side programme indicated two important things:

- There was great diversity in the ways in which peer support was being delivered, which made it difficult to talk about specific models of peer support. We instead identified three broad approaches to peer support; group, one to one, and online.
- Our draft principles and values framework was too complicated and we found that many of the concepts were spoken about in interchangeable ways in the data.

Our final core values framework was comprised of six core values:

- Experience in common
- Safety
- Choice and control
- Two way interactions
- Human connection
- Freedom to be oneself

We believe for a form of support to be called peer support all six of these values must be present and endorsed within a peer support setting. We believe that this is relevant across all three approaches to peer support. However it is also important to recognise that none of these values work in isolation and all are interconnected. The first three core values on the list, 'Experience in common', 'Safety', and 'Choice and control', form a foundation on which the final three values, 'Two way interactions', 'Human connection' and 'Freedom to be oneself' rest. If peers do not feel they are with other people who have similar experiences, are safe to express themselves, and have choice and control over whether, when and how they express themselves, they are unlikely to engage in two way interactions and develop human connections with other peers. Without the five preceding core values being in place it is unlikely that peers will come to feel like they can freely be themselves in peer support.

We also found from our interviews that peer support can be highly responsive to the context that it occurs in. People involved in organising peer support made a number of practical decisions about how a particular project should work to best suit the needs of a particular group of people. We

identified five broad categories of decisions that shaped what a peer support project looked like in a particular context:

- Level of facilitation
- Types of leadership
- Focus of peer support 'sessions'
- Types of membership
- Organisational support

How people chose to organise peer support through these different categories shaped how the resulting peer support worked on the ground with the people that were involved with it. This meant that making different choices on a number of these categories resulted in a range of projects that looked quite different from each other and were responsive to the local context. How the core values were present in these diverse projects also therefore looked quite different to account for this diversity. However the core values were present in some form. If they were not present in a project we would argue that that project cannot be called peer support.

Study Limitations: A large proportion of our data was derived from people involved in group forms of support

# Background

Working to understand the core principles and values of peer support was a central focus of the evaluation brief (as described in Chapter 5). In this chapter, we move from understanding what the wider sector understood as principles and values of peer support to what those taking part in the Side by Side programme experienced.

# Our aim

To identify peer support principles and values, and understand how they might vary by context. Thus we sought to answer two key questions:

- 1. What do people giving and receiving peer support within the Side by Side programme identify as peer support core values?
- 2. How does peer support as delivered in the Side by Side programme vary by setting or population group?

### Methods

We conducted one to one interviews with people involved in peer support projects across the 9 Side by Side hubs and people who used Elefriends. We were interested in their experiences of peer support within the Side by Side programme, and explored how the principles and values emerging out of our development work (see Chapter 5) matched experiences within the programme. An iterative approach to data collection was adopted. This is in line with a grounded theory approach to data collection, where interview transcripts are reviewed and analysed while data collection is still occurring, and interview schedules are changed in order to explore emerging themes further or seek clarification on questions that the analysis identified (Lawrence and Tar, 2013).

This process occurred in a number of stages:

- We met to discuss the questions that should go into our interview schedule. As part of this process, researchers with lived experience of mental health difficulties and of using peer support drew on their personal experiences. The product of this meeting was a draft interview schedule.
- 2. Pilot interviews (n=8) were conducted in spring 2016.
- Interview transcripts were reviewed and the interview schedule was amended by the evaluation team in July 2016. This involved meeting to review data transcripts and reflect on researcher interview experiences. Changes were agreed collectively.
- 4. Interviews were conducted in July and August 2016. Interview prompt cards were produced to facilitate data collection around principles and values (n=40). A small number of interviews were also conducted during this time that focused on the experiences of people attending groups that were for people from an LGBT or BaME background (n = 6).
- 5. Interview transcripts were reviewed at a third meeting of the evaluation team in September 2016. The interview schedule was revised again to elicit more information about the role facilitators (n=14). This was an identified gap in the existing data set and was emerging as an important influence on peer support experiences.

All interviews were carried out by researchers who alongside their research background also had experience of mental health difficulties. Researchers disclosed their experiences of managing mental health difficulties and/or using peer support, either before or during the interview, in as much detail as they felt relevant or comfortable. The process was supervised by the project coordinator at McPin.

#### Recruitment

Interviews (69) took place between March 2016 and early November 2016. We invited people to take part in interviews who had participated in work stream 1. We also invited other people who were involved in the Side by Side peer support programme, particularly those who had expressed an interest to staff in providing feedback through an interview not the outcomes log questionnaire. We tried to ensure that we had spoken to people who:

- Used peer support in different amounts
- Used different types of peer support, including Elefriends
- Were of different ethnicities, ages, and genders to provide a diverse sample

The process of identifying and asking people to take part in interviews involved different approaches:

- Researchers approaching hub leads and project coordinators to promote the interviews and hub leads
- Researchers talking directly with peers, whom knew them through previous work on the logs
- Emails to people registered through Elefriends with the research team
- Letters sent to people registered with the research team via the log or telephone calls where details were held.

Interested participants were provided with an information sheet prior to making a decision over whether to take part or not. Written consent was taken at the time of the interview for face to face interviews, or by the phone or email for telephone interviews. Interviews were audio recorded and transcribed where permission was granted (n= 65). Where the interviewee did not want to be recorded detailed notes were taken by the researcher (n= 4).

#### **Co-production**

A central part of the methodology was the use of peer research methods. The evaluation team adopted a co-production approach with all team members contributing expertise to deliver the research (Gillard et al 2012). There were a number of specific ways in which co-production principles impacted on how we undertook the evaluation, including the way the data was collected and analysed. In summary:

 We specifically recruited a team of researchers to use both their research and experiential knowledge in the evaluation. Experiential knowledge was based upon both use of formal and informal forms of peer support and living with a mental health difficulties. Four researchers were active in drawing on their lived experience as a source of expertise throughout the research process. They worked alongside other "non-peer" researchers who had different skills to help deliver the evaluation.

- We had project meetings with the whole team regularly, both McPin and St George's staff.
   Mentoring was available for the research staff being asked to draw on experiential knowledge as part of the research process from within the study team.
- We frequently spoke, on an informal basis, with people active in delivering the Side by Side programme, about what they believed to be important in peer support.
- We involved the project consultants at various stages, particularly when drafts were available for comments.
- We sent early drafts of our principles and values and other outputs from this research to the hubs and Mind Research Advisory Group.

### Analysis

Analysis of the data was conducted over a series of meetings between September 2016 and February 2017. The analysis was conducted through a number of stages:

- 1. Review of a selection of interview transcripts.
- 2. Comparison of what interviewees told us about their experiences of peer support with our Phase 1 draft principles and values.
- 3. Construction of a new 'Core Values' Framework
- 4. Review of remaining interview transcripts
- 5. Comparison of what remaining interviewees told us with the new Core Values Framework
- 6. Refining of Core Values Framework
- 7. Qualitative coding of all interview transcripts using new Core Values Framework
- 8. Further analysis and write up of findings

### The role of lived experience in the analysis process

Some of the researchers who worked on the analysis of the data from this part of the evaluation had personal experience of managing mental health difficulties and of using formal or informal forms of peer support. During the analysis meetings these researchers drew on their lived experience when discussing different aspects of the data. In order to capture how personal experience might impact the analysis process, the McPin research team reflected on their perceptions of peer support at three different time points;

 After we created the Core Vales Framework we asked the research team to reflect on what their experience of peer support had been before Side by Side and how that had changed during data collection

- After we had completed the data coding the research team reflected on how they now perceived peer support in relation to the particular part of the evaluation researchers were working on at that time
- 3. After we had completed a first draft of the write up we completed a final set of reflections.

# **Findings: participants**

We recruited 69 people to interview as part of our evaluation. Table 6.1 below shows the demographic breakdown of these participants.

Characteristic	Number of people (percent of sample)
Age	
18-24	4 (5.8)
25-34	11 (15.9)
35-44	12 (17.4)
45-54	17 (24.6)
55-64	14 (20.3)
65+	4 (5.8)
Missing	7 (10.1)
Gender	
Male	27 (39.1)
Female	41 (59.4)
Other	1 (1.4)
Ethnicity	
African	3 (4.3)
Asian British Bangladeshi	1 (1.4)
Asian British other	1 (1.4)
Asian British Pakistani	2 (2.9)
Black British African	2 (2.9)
Black British Caribbean	2 (2.9)
Mauritian	1 (1.4)
Mixed White and Black Caribbean	1 (1.4)
Other – Eritrean	2 (2.9)
Other – Greek-Cypriot	1 (1.4)
Other – Iranian	2 (2.9)
Other - Somali	
Other mixed background White British	2 (2.9) 39 (56.5)
White Irish	1 (1.4)
White other	
	3 (4.3) 3 (4.3)
Missing data Peer support approach recruited from	5 (4.5)
	FO (72 F)
Group	50 (72.5)
One to one	7 (10.1)
Elefriends	9 (13.0)
Co-counselling - Peer Support Network (PSN)	3 (4.3)
Type of locality	(0.0)
Large town/city	42 (60.9)
Small town	15 (21.7)
Rural	7 (10.1)
Missing data	5 (7.2)
Sexual orientation	
Heterosexual	44 (63.8)
Bisexual	5 (7.2)
Lesbian/gay	9 (13.0)
Other	1 (1.4)
Prefer not to say	2 (2.9)
Missing data	8 (11.6)
Peers in facilitation/leadership roles	
Group facilitators	23 (33.3)
Mentors	6 (8.7)
Online moderators	1 (1.4)

Table 6.1: Demographic characteristics of participants in qualitative interviews

## **Findings: Revised Core Values Framework**

Through the process of analysing the Side by Side interview data we identified two important things that were challenges to our original approach to exploring 'the principles and values of peer support across different models':

- 1. Diverse ways of doing peer support There was great diversity in the way in which peer support was happening across the Side by Side programme. This meant that there were multiple possible 'models' of peer support that were difficult to clearly distinguish from each other. When looking at the data we found that these multiple variations appeared to cluster more around the type of peer support as defined by the delivery mechanism. These three types were group, one to one and online forms of peer support.
- 2. Original draft was too complicated and long The draft principles and values framework was too complex to describe the essence of peer support if was to be valuable to people on the ground. In response to this we developed a new Core Values Framework, which was simpler and describes six essential 'Core Values' to peer support. We also identified a set of 'Key decisions' that people involved in offering peer support need to think about in order for peer support to function effectively.

As can be seen from table 6.1 above a large proportion (72.5%) of the sample were members of group forms of peer support. This means when doing our analysis, data from groups had a bigger influence on our understanding of peer support than data from other approaches as we had less data to work with. This is likely to be reflected in the findings described in this report, and also reflect the dominance of the group peer support within Side by Side.

Our analysis is structured around three types of peer support approaches. We briefly introduce these 3 approaches before presenting data supporting the generation of our six core values. The below structure will also inform our development of a toolkit which will contain useful information for anyone looking for peer support or to organise their own peer support.

**Group peer support**: The majority of people interviewed for the work stream 2 had been involved in some form of group peer support. Peers told us that their peer support consisted of:

- Groups of three or more people
- Meeting on a regular basis
- Face to face contact

- Groups were frequently (but not always) facilitated by someone in an official 'facilitator role'
- Meetings held in public venues

**One to one peer support**: A smaller number of peers we interviewed were involved in forms of one to one peer support. Peers told us that this consisted:

- Meeting on a regular basis
- Face to face contact
- Peers may take specified roles within the relationship (e.g. mentor and mentee)
- Training and regular (typically monthly) group supervision of mentors that involved exchange of peer support among mentors
- Regular (typically weekly or fortnightly) face to face meetings of mentor-mentee pairs
- Occasional group events bringing all mentors and mentees together (this was the case in one projects, not sure if the others got off the ground enough to do anything like that)

**Online peer support**: Also a few of the peers we interviewed were regular users of the Elefriends online peer support platform. Peers who used this form of peer support told us that it consisted of:

- Support available at any time, day or night
- An online platform that was similar in form to Facebook
- Peers may post about their own thoughts or feelings, and respond to postings by other Elefriends
- It was possible to be anonymous on this platform

Within each approach there was lots of diversity in the way in which different projects organised peer support. People involved in organising peer support in a given context adapted the approach to suit the people their peer support was aimed at, the local setting, and the resources they had available to them.

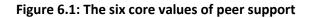
There was also a cross over between approaches. For example facilitators involved in group peer support may also have experienced one to one approaches in any support or supervision they received. A second example was the co-counselling approach, where members of the network met in groups on a regular basis, but where the majority of their support was provided through highly structured one-to-one interactions. A clear message from the evaluation was that peer support isn't

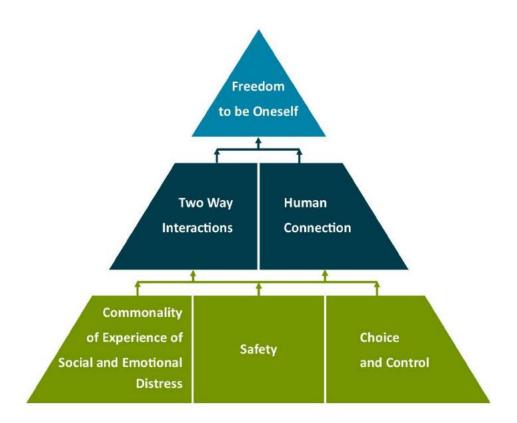
a model to be captured but a dynamic approach with core characteristics that adapts to context and the people involved.

Through our analysis of 69 interviews, we identified the following six Core Values, that we believe are essential to all forms of peer support. We present these, drawing on the data collected, and present definitions for each within this chapter. The six core values are:

- 1. Experience in common
- 2. Safety
- 3. Choice and Control
- 4. Two way interactions
- 5. Human connection
- 6. Freedom to be oneself

Our findings suggest that these core values are heavily interconnected, so that the existence of certain values are dependent on others being present, and endorsed, within peer support (see figure 6.1 below). We believe that three of these core values can be thought of as forming the foundation of peer support values (commonality, safety, choice and control). Without these three core values in place, the remaining core characteristics are unlikely to flourish.





The next section of this chapter introduced each core value in turn. The structure is to introduce the concept through the data collected, and conclude with a definition of each value that has been produced by the research team.

# 1. Experience in common of social and emotional distress

The majority of people who were participating in peer support through the Side by Side programme told us that having a common experience of social and emotional distress (although not necessarily actively sharing that experience) was very important to peer support. Peers described knowing that they had an experience in common with others, that they were 'not the only one' with difficulties, as comforting and reassuring.

I don't know, I just think that it's comforting to know that all those people are kind of going through the same thing, just like a little group community, socialise, but also like having that comfort of knowing that these people are feeling the same way you are. (PV1, group)

I think it is really nice because it means that you are speaking to people who know how you feel and have probably experienced that themselves and obviously it's difficult when you have people around you, you know, saying, "Oh, it's okay. You'll be okay" and you are kind of like, "You don't know what I mean" and, like, "You don't know how I feel" and to be able to take comfort from someone who maybe does know exactly how that feels and be able to get advice maybe from someone who knows how it feels, it is completely different. (PV44, online)

Peers across Side by Side used a range of ways to describe the feeling that knowing they were with peers who had experienced similar issues including being "in the same boat", "on the same page", "comrades", "not alone" and "normal".

It sort of relaxes me in a way that I'm not the only person in the world that feels like this because that's how you do feel when you've got it; I'm the only person in the world that's got this. (PV22, group)

#### Experience in common as providing a basis for empathy

This sense of being together with other peers who understood what it was like to experience social or emotional distress was described by peers as a route into understanding each other and relating to each other.

You get to hear about other experiences. Then you can identify that yes, you're not the only one that has these thoughts or experiences. You've experienced some of their experiences and you can relate to them, what they're thinking and what they're going through and all the feelings that... yes, it rings a bell with you, what's happening to you. (PV22, group) Peers described this ability to relate to each other and to understand each other as enabling peers to have great empathy with each other.

I guess because it's all about mental health, and you feel this solidarity with everyone else on there [...] because you can read through so many comments and think, 'that's how I felt, that's how I feel, that's how I'm feeling today, that happened to me or the person that I'm caring for'. And there's so much empathy as well with how you're feeling because they get it, and sometimes I don't even have to put a lot on there. And someone will reply, and what they say it's like they just get it and I don't have that anywhere else. (PV45, online)

Some peers went as far as to say that they felt that people who had not experienced social or emotional distress would not be able to truly understand what those experiences were like, and so would have difficulty in feeling empathy for people who had been through those experiences. Common experiences provide a strong foundation for empathy, but as the second quote below illustrates, people involved in peer support also feel those without shared experiences can 'still empathise or sympathise'.

Empathy is such an important word in a situation because otherwise your parents especially don't often know what it's like for example or your friends don't know what it's like because they haven't been through it. If they haven't been through a mental health issue, especially bipolar, which is even one step further than just depression because you're dealing with two things, you're dealing with the hypomania as well as the lows. (PV16, group)

I'm curious if somebody who hasn't necessarily been through something. Is there anybody who has not been through something? Surely everyone's been through something, right? But I wonder if somebody who doesn't feel that they've been through something could still support somebody. I'm sure there are people out there who have a level of empathy without being able to necessarily say, "Yeah, I've been there." But they could still empathise or sympathise. (PV25, one to one)

Some peers explicitly contrasted their experiences of peer support with experiences of using mental health services and described finding it difficult to communicate what they were feeling to professionals who they felt could not understand, and were classifying rather than hearing peoples' stories.

So it's not easy to do those kind of... I think there's a bit of a reliance in mental health on ticking these boxes and it's very easy to do that when actually, some people would really like to explore in a greater depth. I'm not saying psychiatry but just as human beings we like to

tell a story. I know for myself, I can't really operate without having my narrative straight. [PV2, group]

The findings from our interviews relating to experiences in common and empathy correspond with what peers told us in the early consultation phases of this work. Peers spoke frequently about not needing to repeatedly explain themselves, and about being able to communicate their difficulties easily to other peers. Throughout Side by Side peers spoke about a mutual sense of empathy and shared understanding as being an important component in what was effective about peer support. This extended beyond emotional and social distress to common experiences based upon migration and culture.

I'm less isolated. I have options. I can just be somewhere and not have to explain myself. I know that I'm understood tacitly because everyone's in the same boat. So, that's what I'm getting out of it. I can be with people without having to explain myself, or justify why I'm there... (PV8, group)

If somebody is not a migrant and hasn't experienced issues of being a migrant and came and started to work as a mentor, then I think maybe they can't help them because to not have any experience of living in his country, where everything has been fine and they don't understand his life, Middle Eastern life, Mediterranean life. I know about Middle East culture, Middle East life type and I think it is much better when the mentor and the mentee are from the same situation and the same migrant circumstances. (PV11, one to one)

#### Experience in common as a resource

The common experiences of social and emotional distress were also described by peers as a resource. Peers spoke in ways that suggested that experiences in common formed the basis of a collective source of knowledge. Through talking about and sharing their experiences peers could draw from this knowledge base and identify new coping strategies that may be helpful to them.

I am sure there was a girl sitting next to me when I was there and I was telling her about my clutter and you see that when you are open with people and you are not ashamed of anything that is negative about oneself, you know, and then when I share with other people like with her I can feel...she said, "Oh God, yes...". I can't remember exactly what she said but she started to share and said her mother has to come and help her, you know? [...] So, I don't know what kind of clutter she has, but when you look at yourself, you know...I mean, I am getting better each time. When you are not ashamed about talking about yourself and it helps them think as well and the more you talk about something that is not right which is

related to your depression, the more you talk, the more you get rid of it, it slowly goes away, you know? (PV4, group)

Peers described learning together as being helpful, and that they could understand their own mental health in the context of a range of similar experiences.

Talking. Talking about your own problems and listening to other people's. You are not the only one in the world with it. [...]There are others out there who have got the same as you and it's learning how to deal with it altogether. (PV18, group)

So it was very useful personally for me, because I know that person, where he comes from, it's not his nationality, it's more his issues. So helping people with their problems, similar problems that he was going through, it helped us to understand ours better and reduced our stress. (PV11, one to one)

For some peers, knowing that techniques or coping strategies came from someone with lived experience of social and emotional distress gave those strategies more credibility.

I think when you talk to somebody with lived experience, when they describe stuff it's like, "Oh yes, that's the same as me," or, "That's very similar." Whereas from a professional you think, "You don't know what's truthful, you've learnt out of a textbook, not out of real life." So I think that's why it's so, so important. (PV34, group)

On occasions peers also spoke about the knowledge they had gained through their experiences as a form of expertise, and recognised that this expertise could collectively be useful.

At peer-support, you know other people, and you know, you absolutely know, other people have been through similar experiences, they will have their own strategies of how they coped, and it might be a strategy that you don't know about, that you could utilise for your own support too, so we're all professionals at getting better. (PV62, Online)

### Specific shared life experiences of importance

Across Side by Side there were a range of projects that had been designed to support people from a variety of specific personal circumstances. Examples included:

- Peer support that catered for people who were migrants or refugees, some of whom had experiences of trauma
- Peer support that was only for women (some of whom had experiences of domestic violence) or only for men
- Peer support for people from the LGTB community

• Peer support for people with learning disabilities

Some peers described certain specific life experiences as being important in feeling a sense of commonality with other peers. It was important that their peers shared a number of common experiences, of which mental health was just one, before they were able to feel more understood.

Yes, for instance our group here [LGTB specific group] is an asylum seeker refugee, whatever, so, yes, of course, like, when I'm with people like that – I think the reason why I'm more connected is because I generally believe and assume that they've all gone through stuff that I've gone through. Everyone has stories but similar, you know, family, rejection, friends, church, religion, institutions, whatever. So that brings us even more close. So it's not like – when we share stuff, there's no room for disbelief or shock, like, "Really?" Because it's all understood. (PV65, group)

Sometimes you feel annoyed about certain things and how you are treated in a certain place, like all of us have gone to the Home Office so you find it so distressful, you've got someone, as if you are a criminal. So we shared that and we found that everyone was treated the same, I thought I was being treated like that. I said maybe it's because I looked xxxx or maybe it's because I look or, I started judging myself. Then afterwards, when we discussed and said, oh, so that is the Home Office, that's how they treat people. [...] But I hated that place, whenever I entered it I could feel somebody, because I know those people hate me. But after sharing then I said, 'oh, so it's not me alone. (PV26, one to one)

#### Challenges to commonality of experience

One peer suggested that they did not agree with experience in common being the primary reason for which peers may come together because they felt that thinking about a group in this way was stigmatising.

For me, I think it cannot be the primary reason why we get together because that will bring stigma; we are a bunch of depressed people that get together to talk about our misery and blah, blah, blah. Although that happens as a consequence of getting together but it's not the primary reason because otherwise I would feel stigmatised, yes. (PV6, group)

Peers also had a nuanced understanding of how far they could have experience in common with each other. While it was true that peers of Side by Side may have similar experiences, many peers were careful to highlight that there were limits to this. There was a strong understanding that *similar* experiences did not mean that all peers had had the *same* experiences, and that there was diversity of experience within single groups. We understand that bit of it, that everybody is in the same... we've all had it, but it's a bit like going to group and saying, "We all have physical illness." Somebody's got a broken leg, somebody's had cancer, somebody's got something else wrong with them. So we don't necessarily, I don't think, understand exactly because we have people who have psychosis, we have people who have been sectioned before, which is obviously a lot more severe than what I've got. (PV34, group)

Some peers also suggested that even when there was a shared understanding based in common experiences, this did not automatically lead to peers being able to express empathy. Peers acknowledged complications and limits to this. For some individuals who experienced a high degree of empathy, hearing the difficult experiences of others could be too upsetting. Some peers may not feel or express empathy as strongly as others and that had to be acceptable.

Empathy is really important but, like, I think it's also important to realise that not everyone has the same levels of empathy so like I've always kind of known myself as a really empathetic person. But... I am kind of too empathetic in a way. I get really into people's...I get really upset about other people but whatever, but like, you know, I've had friends who are not empathetic at all. They have literally no ability to express empathy. They can sympathise, they just cannot express empathy and also I think there are a lot of people like that, who suffer from mental health problems, who might go on [online forum] and it is really difficult because, you know, there is only so much you can...you can't force someone to be empathetic and also some mental health issues involve having a lack of empathy sometimes so it's a really difficult situation because you can't force someone to be empathetic. (PV44, online)

A minority of peers did not feel a shared experience of social or emotional distress was important, and instead felt that for them the important quality of peer support was that people were able to come together to form a community and tackle isolation in this way.

I don't think it's massively important that everyone has necessarily had that. [...] We do have that. Everyone has shared that sort of thing, but I don't know if it's necessarily important. Because, I think, even if there were people coming and helping to run it who hadn't struggled with their mental health, I think that they'd still be helping to provide a community. They'd certainly help to support people. I don't think they'd necessarily have to have had their own mental health problems. (PV53, group)

#### Experience in common of social and emotional distress as a foundation for other values

We have identified experiences in common as a foundation value for peer support on which other core values appear to rest. Peers told us that it was because they knew that other people around them had been through similar experiences as them, they were more likely to approach each other with understanding. Peers also felt that people who had similar experiences in social and emotional distress were less likely to judge them, or to try to push them to talk about things that made them feel uncomfortable or exposed.

You come in here, everybody's cheerful, "Would you like a brew? Would you like to take a seat? Pleased to meet you," or whatever, they're always really friendly, very understanding. There's no discrimination or anything. No matter who it is, they welcome them, they support them, they help them and really, I think it's brilliant what they do here at the [name] centre, I really do. (PV21, group)

Knowing that the people around them had been through similar experiences was suggested as the reason that peers felt safe, accepted, understood and that they had a bond with each other.

People have experienced things themselves. They know what it's like to be dragged through the rack with whatever it might be, depression or anxiety. It's just that sort of common ground, you just meet them and start talking and you suddenly feel, "Yes, they understand. They know what it's like." With family, well I mean it's just my particular family, what I get is a great deal of concern but that concern is rather undermining actually. (PV36, group)

There's certain weaknesses that we've found are pretty common to a lot of us. So things like being flakey because of your meds or being too anxious to carry out plans that you've made, things like that.[...] Because everybody understands that's what's happened, nobody has recriminations for situations where that happens. That makes it a lot easier to come next time. (PV63, online)

### **Final reflections**

The majority of peers we spoke to told us that having experiences in common of social and emotional distress was of central importance to peer support. For some peers this experience could be limited to similar experiences of mental health, while for others there were multiple layers of experiences relating to culture and identity that were also important. For some peers actively sharing these experiences was important, while for others just knowing that people around them had that experience was enough. We found that this experience in common could be seen as a foundation value for peer support, and that it was this experience that enabled peers to feel safe and to have a human connection with the peers around them. From our analysis we have created the following definition for Experience in Common of Social and Emotional Distress:

Peers have experiences in common of social and emotional distress. This can form the basis of their connection to each other, regardless of the extent to which this experience is openly discussed. Peers can share experiences of broadly defined social and emotional distress or experiences linked more narrowly to a particular mental health diagnosis. In some peer support, specific additional aspects of personal experience or identity shaped by gender, ethnicity, age, sexuality, disability, and migration are critical to people recognising each other as peers.

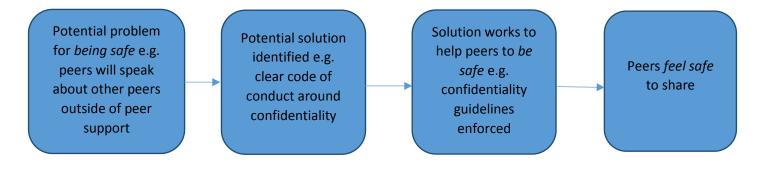
# 2. Safety

Safety was a dominant theme within the interview data, and most participants spoke about it. There were two interrelated components to this theme:

- *Being safe*: the structures or features of a project that were designed to practically ensure the safety of everyone involved with peer support.
- *Feeling safe:* how those structures enabled peers to feel safe within a project and what this meant.

For people to feel safe projects first needed to identify factors that may make people feel unsafe, and to find some form of practical solution to tackle that particular problem to enable people to be safe. Safety was an essential element of all peer support because without safety, peer to peer support cannot be offered; people will not use, run or commission it. We provide some diagrams below to illustrate some of the issues connected to safety as a core value (see figures 6.2, and 6.3).

### Figure 6.2: creating safety in peer support



Peers spoke at length about why feeling safe within peer support was so paramount; that without that feeling of safety peers would be unable to share their experiences and engage with the support others were offering.

Sometimes you can't talk to family. A lot of the girls have said that, they can't say to their partners, "This has happened." Sometimes their partners and family are sick of them telling them so it's a fresh ear. People can feel safe enough to say this is happening. Sometimes they don't share it with anybody else and that's why we always say in the groups, "What goes on tour stays on tour. This is safe. This is our safe haven," and to provide people with that safe place to work into, isn't it? It's good. (PV16, group) I've used lots of other social media, I've shared my thoughts online and it hasn't gone so well. It hasn't been received well. I've got the typical like, "Pull up your socks" kind of answers. "Pull your socks up" kind of things, which were completely unhelpful because it just made me feel worse about myself. Whereas [online forum], even if there aren't specifically lots of replies to what you've posted, it's just some understanding. There might just be people saying that they've been through it or they understand or they're here for me, or anything like that. It's quite a safe space, [online forum], in particular. (PV43, Online)

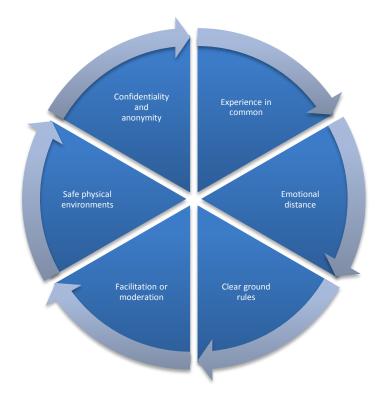
Without structures or mechanisms in place to support peers, it is likely that people may feel that the environment in which they are giving or receiving peer support is unsafe. We have found that the integrity of peer support requires safety.

Everyone was just getting so irate and I thought, if someone comes on and they're feeling so emotionally distraught and they see people just yelling at each other and using what I call shouty capitals, they're not going to want to come back. [...] In the end the [site moderator] was just like, I'm just going to take this post off. Then they posted a nice one of a cup of hot chocolate and it was like, everyone relax. Take five minutes. I was like, okay. (PV61, Online)

There were a number of key features of peer support that were designed to help peers feel safe. These factors may be more or less obvious in particular projects, but when implemented together they created a safe environment for peers.

### Figure 6.3: Important components in creating safety in peer support

Evaluating the Side by Side Peer Support Programme - © St George's, University of London and McPin Foundation 2017



### Experience in common of social and emotional distress

Peers spoke about knowing that the people in their peer support also had lived experiences of social and emotional distress as an important factor enabling them to feel safe (also see above). Some peers spoke about finding relief in knowing that they did not have to explain themselves or pretend to feel better than they actually did, because fellow peers had 'been there' and understood what it was like. Distress did not always need to be 'named', indeed some peers identified not having to actively talk about distress as important to safety. However, there was an underlying understanding that peer support was addressing emotional wellbeing.

Oh yes. I feel safe and I feel at home there. [...] Among people who just get it and you don't have to explain a lot, but they get it. Whereas with my peers, I would have to go into great detail I think and it would just get messy and complicated, and I'd rather not go there. (PV45, Online)

You feel comfortable, like I mentioned (peer) with the social group, you think, "That's amazing, we've got something in common." So when sharing something, sharing experiences people find in common, although you won't be able to speak out at that particular point of hearing somebody's experience, then at least you can nod your head and say, "I've got the tshirt"... (PV19, group)

#### **Emotional distance**

One of the qualities of peer support that allowed some peers to feel safe was how they would be sharing distressing experiences with people who were not too close to them. Some peers found that sharing distressing personal experiences within families could cause problems, and that were less worried about hurting or upsetting peers in their peer support.

I mean I think that probably peer support groups I'm part of know more about my past and mental health problems than say my parents do because they'd get quite distressed listening to that kind of stuff, whereas when you're in a group where you know that all of you have had that same experience, it feels safe, you're more able to say it because that's the purpose of you being there. [PV23, group]

A degree of emotional distance was also a feature of online forms of peers support. One peer spoke about how, after a traumatic event had happened to her, she found that when people were kind to her, this could lead to her being visibly distressed in front of them, and that she found this very difficult. By using online peer support she was able to connect to other peers without worrying about this being a problem.

I'm probably not very good at having that physical face to face support because I feel that if I start opening up the floodgates that they might never shut. [...] So I kind of closed down a little bit, and I hold a lot in face to face that I found that getting that from an online forum, I was able to control it better. (PV32, online)

Another peer spoke about finding it too difficult to be physically with people who were in distress to be able to support them. However they found that they were able to offer support online as it allowed for a certain amount of emotional detachment.

No, not really; I find it very difficult. I'm getting better at it, but I find it very difficult to go into spaces and platforms, where I actually talk about my experience of my illness, and it's hard for me, also, to actually be in a room and listen, personally, to other peoples' pain, but it's much easier to do online, because, if you're in a room with someone, you feel you're having to be accepting of their emotional state, whereas, online, you're more detached from it. (PV62, online)

#### Confidentiality

Many peers spoke about how rules enforcing confidentiality were seen as essential to face to face forms of peer support. Confidentiality was strongly linked to a sense of having choice and control over what was shared, when it was shared, who it was shared in front of and in how much detail. Many peers spoke about how important confidentiality and privacy were in enabling them to feel safe enough to share in a group setting, but this also applied in one to one peer support. Some people expressed the value of keeping true to the principle 'what is said in peer support, stays in peer support'.

I just need that space to be safe and confidential and for me to share whatever I want to and then share whatever it is to somebody else. It might be a year later because that's where I am with that person. But having that safe space. Sometimes I might not need a reminder of the conversation that I had like, a week ago, about saying that I want to hurt myself and then they see me in the shopping mall, "Are you still hurting yourself?" I don't want to know. I might not want to have that conversation, you know? I think it's important because I think the thing that people really struggle with is, "I don't want people knowing" and that's that self-stigma I guess we all have. (PV37, group)

There were also a number of ways in which peers found the rules around confidentiality reassuring in face to face peer support. One issue of importance was how peers may react if they saw fellow peers out in public. One facilitator explained how important this boundary was to preventing unintended consequences:

...that's like me saying how I work. So it is keeping the boundaries there really and keeping yourself safe and saying to them, "If I see you out, I don't want you to discuss your story with me. I will make eye contact and if you want to speak to me, that's fine," because she might be with somebody who doesn't know anything about her coming here. (PV16, group)

Peers also felt secure when there were clear guidelines against speaking about what other peers had shared within peer support. Confidentiality was described by one person as enabling peers to feel in control within peer support as well as outside of it. Knowing the fellow peers would not bring up another peer's personal issues shared within peer support allowed them to be in control of how and when that issue was spoken about.

[...] they have a set of golden rules, and that is one of them; that is the confidentiality golden rule, and it's important because otherwise you end up giving advice or more, and you are continuing and the problems that can arise if you do refer to what someone has said – partly,

there's a safety issue because I might not want to be talking about an issue that I have come across; I may wish to air it in the safe space, but I don't then want to be talking about it in a conversational way. So, if that is referred to, I may feel there is an invasion of my privacy despite the fact I have been talking about it before. (PV57, one to one)

I think it's important that everyone is able to trust one another and confidentiality is not broken. Sometimes you can say things that you wouldn't want the wider community to know about. It just comes out sometimes. [...] Yeah. And if you feel that that confidentiality is going to be broken, then that's not a good thing. [...] In this group, I think people can say what they want to say without the fear of that coming out. (PV10, group)

Peers using online forms of peer support spoke about how they felt safer as they were able to be anonymous. In online peer support anonymity seemed to occupy the role that confidentiality played in creating safety for peers in face to face peer support. Peers spoke about how their privacy was very important to them, or how it was easier to talk freely online when people did not know who they were.

Obviously you can upload a profile picture and I have always been the type of person that I don't like putting up pictures just of anything, I do want it to be a picture of me but I don't want people to recognise me so I'll use like a photo I've never used or something and the photo I have on there my face is actually scribbled out because, I don't know, my belief is that I am on there for me and I am very suspicious of the internet and I take my privacy very seriously. (PV44, online)

*Challenges to confidentiality:* Some peers spoke about no longer feeling safe to share personal details within their peer support after confidentiality had been broken, and personal issues they shared within peer support had been discussed by fellow peers outside of it. This was compounded when peers spoke to the facilitators of their groups about their confidentiality and found them unwilling to confront any problems.

So basically, because I'd met them, and really it came down to trust for me, I shared part of my problem with a particular person and this particular person went and told one of our other friends, [...] one of the reasons why I have trust issues. It's not that I have trust issues; it's just that I guard myself. So basically now I'm quite reluctant to tell people in [name of group] anything about me and my personal stuff, that basically I don't want them to know. If it's a [name of group] matter, I'll talk to them but if it's not a [name of group] matter I won't. [...] I've spoken to staff about it and staff said, "Well, yes, basically, we know where you're coming from and I'd love to help you, but it's not a [name of group] issue, it's a matter that's happened because they've done it outside." So it's just made me realise. The thing is, with me, I am my own worst enemy because basically I'm too trusting with people. (PV12, group)

While many peers spoke of anonymity as important in allowing them to feel safe online, it could also create feelings of unease where peers had posted content that was uncomfortable or was ambiguous in meaning.

Yes, I think so. Usually, yes, because a lot of members are anonymous. You don't see their photo. They may not even have a profile. So, you'll click on their profile and there's nothing there. I think that... and I'm sure it's not just me that reacts in that way. I think it can be quite a common thing. You don't really... it's harder to see the person behind the text, the message. Whereas, when they're right in front of you you're almost like, "Okay, yes, I accept that that's a person and they're quite reasonable and yes, they have different opinions and that's fine." Whereas, when you see a message, you're like, you're already making almost judgements about that person and you think, "What kind of person would say that?" (PV43,online)

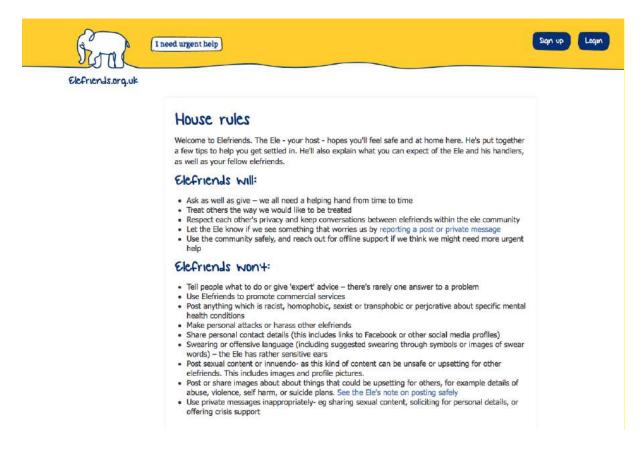
Many of the peers we spoke to felt that being able to share problems and experiences was one of the key ways in which peer support was helpful. Situations in which peers did not feel safe to share because of concerns about confidentiality represent a serious challenge.

#### **Ground rules**

While confidentiality was important in Side by Side, there were a number of other ground rules or boundaries that peers also spoke about as important contributors to safety. Peers frequently reported that their peer support had a set of guidelines or ground rules that outlined limits on aggressive behaviour and abusive language. This cut across all approaches to peer support.

We've obviously got the ground rules set up for the group. We went through those right at the beginning when we started, but when we come back after a half-term break, I'll re-issue them again and just remind everyone of them. When we get to the stage where we've got four new attendees who haven't been there for a session where we've been through it, I'll just revisit them again. We put them in with the housekeeping stuff, like the health and safety, fire escapes, so group that all together, which you just have to do every now and again anyway. But they're all aware of what the ground rules are. They're, generally, always on the wall, but they've just been amended so we need to stick them back up, and they're all pretty good. (PV15, group) Also listening, not talking when someone else is talking. You have to listen. If you are to give a comment, wait until the other person has stopped, then you can give your comment, [...]. Even if they are given the example they are not going to mention names so they are mature in that way, yes. (PV26, one to one)

The Elefriends platform was also careful to ensure that all peers knew the 'house rules'. They have these rules available clearly on the website, and available in an online video.



The scope of the kind of guidelines that groups suggested to ensure safety varied across Side by Side. While most guidelines related only to banning aggressive language and behaviour, confidentiality and allowing people to speak freely without interruption, some guidelines went further.

The thing that has amazed me the most is that the stuff that happens in the groups, the guidelines that we have—so we have guidelines around things like it's okay to make mistakes or being kind to ourselves and others, stuff like that. There's a list of about twelve guidelines that are used with the groups. (PV59, group)

In some groups where the guidelines were well understood, interviewees (particularly facilitators) spoke of how groups may take collective responsibility for ensuring those guidelines are followed and for dealing with potentially difficult situations.

We are all, collectively, in charge of what goes on in the room and keeping it safe. [...] And, anybody can intervene. Anybody can say, 'this isn't working for me', or 'I think we're getting away from our principles here', and pull us back if we're straying into advice giving or any of the other principles, like not being kind to ourselves, and things like that. We have a set of guidelines which I have nailed on the wall, about how we will behave in the room, which is designed to keep what happens safe. The whole group facilitates what is going on, in a way. (PV35, group)

Some interviewees who used online peer support also reported this kind of collective work to make the space safe.

So if someone says, "No, I'm right. This is the way it is. This is how you should tackle this issue" I just leave them there. Usually the other members do the work for me. [...]So the thing is, if there is a particular person who is quite rigid in their thoughts and not accepting of others' opinions then, usually, someone comes in to remind them that, you know, we all have opinions and we all have our differences, and that's fine. (PV43,online)

In some forms of peer support, peers received training on ground rules including boundaries to enable them to interact safely within groups or a one to one situation.

It's a, sort of, group for people to... it's based on co-counselling, I suppose. We get a bit of training.[...] I mean, it's pretty... you know, just a little bit, just to make sure we understand about keeping people safe, I suppose, and respecting people. (PV50, one to one)

As we found for confidentiality, where boundaries and ground rules were clear, peers were able to feel that they knew what to expect. Some peers spoke about being able to go into peer support knowing that they would not be judged. Peers also knew that there were rules in place to prevent other people in that peer support forum from being aggressive or abusive be that online, or in group or one to one settings. Knowing that these rules were in place allowed peers to feel safe.

And, I feel like that's really helpful so even if it's, you know, completely different mental health issues, the fact that you have a safe space is really important I think, where people can't judge you there, kind of thing, like they can in the outside world. (PV44, online)

#### Official facilitator roles in groups

Facilitators described having a number of responsibilities within their role (for more detail please see pages 168-177). They identified their role in ensuring people felt safe as particularly important. This

involved managing group dynamics and being the person who was responsible for ensuring ground rules were followed. Where they did not, peers could feel unsafe.

One of our guidelines is that we don't interrupt during rounds and that's so that everybody gets a chance to speak and be listened to. Another thing about rounds is that you can pass if you want to. But if you just say pass then there's no judgement or nobody asks any questions about why you've passed. You just say pass and then we move on. But rounds gives everybody the chance to share and then listen to what everyone else is saying. (PV59, group)

Facilitators also saw it as their responsibility to create a space in which all members, including those who may feel less confident, or like they have less to say, may feel comfortable to speak.

We would make sure, in the group, that everybody has had their turn to talk, because some people are quick to leap in, and tell their bit, so the first bit we do, we try and go around the room, and take turns, and I always make sure I prompt people, sometimes, and just say, 'do you feel like that?', or, 'how have you been that month?', and just give them that opportunity to say, because some people are a bit shyer than other people, and, especially if it's a new group, or they're not feeling very well, so yes, that's very ... it would be awful if somebody came to the group, and then came away thinking, 'I didn't get chance to say anything'; that would be terrible, so that's very important. (PV51, group)

Facilitators spoke about role modelling sharing as important to facilitation. However they were careful in how they approached this. Some facilitators felt it would be dangerous for peers in their groups to see them in distress as this may dishearten peers at an early stage of their journey. Facilitators were also conscious of the difficulty they may have in supporting other peers if they themselves were very distressed. Decisions around what facilitators decided to share was balanced against their need to stay safe, and to keep the group space safe.

I think being a facilitator, I was aware of the boundaries of my sharing and so I did try and always make sure that what I shared was appropriate and wasn't going to cause too much distress or things like that in the group. So I think generally it didn't have a negative reaction. I think that it was, on the whole, positive. I mean I was conscious not to share times when things have gone really badly and everything just went wrong and there was no solution because that could be a bit disparaging. So I think generally when I shared my weaknesses, I shared ones that are things within myself that I have learnt to accept or I'm trying to accept like, I don't know, I'm not going to be the best at everything all the time and that's okay. Can I still have self-esteem with that, and stuff like that. But I wouldn't necessarily share a weakness about very unhealthy coping mechanisms that I might still use or whatever because both, that would be quite upsetting for me to talk about and I don't want to put myself in that position in the group. (PV23, group)

Other peers discussed how knowing there would be a facilitator there as reassuring. This gave peers the security that there would be someone there who would take responsibility for ensuring that ground rules were followed, and who would know what to do in an emergency.

You've got people you're going to meet and chat with, which is not like a pub environment, it's a clean, safe, controlled environment with somebody with authority to control if anything got out of hand or was upsetting you or if you felt intimidated. It's that sort of environment and it's good. (PV19, group)

We describe these issues in more detail in our section on Facilitation (see pages 168-177). So the safety role of facilitators in groups emerged as having several elements:

- Creating safe spaces for people to share modelling sharing, discussing ground rules with group members, ensuring those ground rules are followed
- Dealing with practical matters such as booking rooms, arranging refreshments
- Manging difficult group dynamics
- Taking responsibility for managing a breach of official group rules, which may mean asking a peer to leave a situation or project

### Official moderator roles in online spaces

In online spaces the moderator role was essential to maintaining safety by monitoring the content of online contributions. For example, Elefriends displays clear guidance on what moderators will and will not do or be responsible for on its website (see below). This enabled peers using online forums to have clear expectations that moderators were responsible for removing content that may be disturbing or triggering to other peers, and for giving direct support to people who needed it. This monitoring of the site was important for peers in protecting them against the kind of bullying or abuse that occurs on other social networking sites (we have further explored the role of online moderators in maintaining safety in our section on facilitation (page 174).

I think it's, again, very important that everyone feels that they won't be... for me, the main thing was that I won't be subject to some of the abuse or bullying that does occur on other social networks. [...] So that was very important for me. That it is controlled to a certain extent where people just can't post un-empathetic or unhelpful things.[...] That was very

important for me. (PV43, online)

## The Elephant and his handlers will:

- Respect your confidentiality. What you share here is between you and Mind. We would only tell
  someone else (for example, by calling 999) if you ask us to, or if we know your name and where
  you are and you've told us that you're at risk of serious harm, or if we are worried that someone
  else might be hurt.
- · Review all reports and private messages sent to the Ele's inbox, and do what we can to help
- Take your concerns seriously Elefriends is yours, and we want you to feel safe and supported here
- Where possible, read all posts and comments, and remove anything which breaks the house rules
- or leaves the community feeling unsafe. We may give you feedback to help you post safelyDo our best to resolve any technical problems as quickly as possible

## The Elephant and his handlers won't:

- Trample on your conversations the Ele and his handlers may need to pop in from time to time, but
  this is your space to talk about what's on your mind. Private messages stay private, unless an
  elefriend tells us that they're worried
- Pass on your details or use your information for anything else unless we have your permission. We
  may contact the emergency services if you tell us that you're unsafe, and give us enough details to
  locate you
- Be able to respond to reports or messages from 2am-6am, when we're not moderating.

# Tips on posting safely

The Ele encourages his friends to write openly and honestly about their experiences. With some topics, like thoughts of self harm or suicide, the Ele and his handlers ask his friends to be mindful of the following:

- It's ok to share thoughts and feelings around self harm and suicide. But please avoid graphic descriptions or images, or detail about methods.
- If you're feeling very unsafe, please consider contacting your mental health team, the Samaritans (116 123 / jo@samaritans.org), or the emergency services first. Elefriends may worry that you need more urgent help than they can give.
- It's ok to share thoughts and feelings about food, eating and drinking. But please avoid numbers of
  calories, measurements, amounts of food eaten, images of weight loss or detail about methods of
  gaining or losing weight. The Ele finds this guidance from Time to Change useful.
- We know a lot of elefriends might struggle with issues such as addiction or alcohol abuse. It's fine
- to seek support, but please do avoid specifics about quantities or details about illegal drug use
  If you feel worried or uncertain, Mind has some information about staying safe online that you might find helpful.
- · Learn more about removing posts or private messages you don't want to see.

#### Safe Environments

The careful choice of venues in face to face peer support was one example of the careful planning process to ensure practical and emotional safety. This was a consideration for both face to face and group forms of peer support.

We interviewed a number of facilitators who spoke about how carefully they chose venues for peer support groups.

So we'd always go somewhere that has a good non-smoking section and the smokers will be outside so she wouldn't feel that that was an issue for her. We've got another person who's got a problem with dogs so we'd never go somewhere where dogs are accepted. There would be a list of these are things that we need. We've got one guy who's got mobility problems so we always look for somewhere that's got disabled access. (PV63, online) Facilitators felt the following features were important when choosing venues for peer support:

- o Comfortable
- o Non clinical
- o Public
- o Well lit
- Accessible by public transport
- Had access to a kitchen or refreshments
- Were staffed by people who could assist in an emergency

[...] we're in a building where we've got the caretaker on hand; he's always in the building, so I never feel like we're totally alone, or, you know, would get stuck in a situation that we couldn't get out of. (PV51, group)

[...] safety is crucial, so what I mean by that one is, you've got to make sure that every member of that group feels safe, so you want a nice big car park, that's well-lit, so if they're meeting in the evening, people don't feel vulnerable; you want a room that is well-lit, you want a place which has good exit strategy, in the event of fire, or whatever it might be, so that when you go in there, you feel safe and secure, and that is crucial. Not everywhere will be able to provide that, so I looked at a leisure centre, originally, and they showed me the room which they would provide to us, and the room was, literally, in their basement; it was very low-ceilinged, it was all artificial light, it wasn't right. The rooms which I have used, high ceilings, natural lighting, with nice, very, very discreet lighting tucked into the walls, and that makes the big difference, I think; it's almost high-class, so you're almost treating yourself, by going along to group. (PV52, group)

One of the key concerns about the physical environment for peer support was that it was quiet and private. Peers had concerns about being able to hear each other when talking about sensitive issues, and that they were only heard by other peers. In this way having an appropriate physical environment is another way in which peers were able to feel a sense of control over who they shared with, and thus were able to feel safe.

Well we've met in one, two, three, four different places. The place doesn't really matter. The place is irrelevant as long as you can sit down and it's not too loud and there's seating. It really doesn't matter. [...] Well I was about to add, as long as there's not too many people around. Obviously laying out deep, heartfelt issues when there's people at the next table having a birthday party becomes a little farcical. But that's the only... I mean there's always going to be quiet places around so the where it's held, I'm not sure how important that is. (PV48, group)

The physical environment was also a factor for peers using online forms of peer support. The ability to access support instantly, and to be able to do so from your own home was seen as a major advantage. Peers described being able to access support at different times of day, or even in the middle of the night, and that it was possible to access very discretely.

Yes. Oh yes, definitely because as far as they're concerned I'm just on my iPad. I could be looking at anything, couldn't I? [...] Yes, because it's very private. There's an app now. (PV32, online)

#### Safety challenges

A key theme to emerge from our data was peer support size. The size of a group or project could be seen as a challenge to safety where groups became too big. Peers involved in face to face and in online peer support expressed discomfort at larger group size, and this was exacerbated where group dynamics were poorly managed. This could result in some peers feeling they were unable to express themselves in those environments.

It's just got big, yes. I think it wasn't very well known at the beginning and now I think a lot more are finding out about it and like you say, I think that's great, but it kind of makes me hold back a little bit more when I talk about my personal situation just in case I am recognised on there at all.. (PV45, online)

If the groups got much bigger, I think we'd feel a bit squashed up, in that room. We could set it out differently, so we sit at tables, but that doesn't really ... I think, for peer-support, it does work better if you all feel you're on a level setting, rather than us officially putting in groups, before you start talking, so that might become an issue, but there's nothing we can do about that; I think we'll just have to lump it, because we can't really afford a bigger room. (PV51, group)

We also found lack of face to face interaction online could also cause problems for peers which could be disruptive and upsetting. Online peer support mostly took the form of posts and private messages through a social media like forum. In the absence of helpful cues like eye contact, tone of voice and body language inherent in face to face contact some peers found it difficult to express themselves online in a way that was not open to misinterpretation. On occasions this had led to arguments or resulted in other peers becoming upset, which had a negative effect on the person writing the posts.

I've only had one bad experience and I did come off it for a little while because it upset me so much, where I made a comment and another person took offence, and I tried to apologise and it wasn't meant the way it was taken. What it made me think was that you've got to be very careful because not everyone is going to get you or what you say. There's some very sensitive people on there who are going through some really awful things and they're not always going to see the funny side of something maybe that you've seen, you know? And my intention was to make people laugh and not to upset them. It was only a small comment, I can't remember what it was now and the guy took offence and was quite... not threatening, but the comments he put underneath just made me scared. But it wasn't like that. I think that's the thing, he took it the wrong way and then I took what he said the wrong way and I think you can get that. (PV44, online)

Another challenge was time limited support. The Side by Side project was able to provide short term funding to a variety of projects. This meant that some projects were due to end not long after they had begun their activity. This caused anxiety for peers within those projects.

It would be helpful if there wasn't a time limit. "What's the point if you know it will end in 6 months." "When you put structures, you feel less comfortable." "It's more like a project we're doing, it's not like a friend, like someone supporting. [...]That is the worst part" – the mentoring is time limited, she knows it will end. She is feeling alone but at least "for 6 months I won't be alone. (PV42, one to one)

Interpersonal dynamics could pose a challenge in group peer support. One of the core purposes of peer support is to bring people together. Peers with different interpersonal styles may make each other feel uncomfortable. While good facilitation may go some way to ameliorating this issue, it is unlikely to completely remove the problem. This is an example of how in any peer support context, peers may do everything in their power ensure their fellow peers can *be* safe, but they cannot guarantee that fellow peers will *feel* safe to speak as they need to.

You know, there is one lady and I do talk a lot and she doesn't and she likes people to say one sentence each and I think when people are waffling and this is just, you know, her preference that we all say it and shut up, say it and shut up and then some people are a bit more like me and a bit more waffly so it's just a little bit of tension in the group. It's not necessarily that person because I don't like saying "It's her. It's him" but it's a tension in the group and you feel like you don't want to share because you think you are getting the look of 'shut up'. [...]The facilitators do manage it very well but sometimes it's that thing where you want to be able to have free speech because that's what I go for and if I am not going to be able to speak freely and have a little bit extra maybe then you come out feeling a bit frustrated. (PV49, group)

#### **Final reflections**

In our initial scoping work we found that respondents liked peer support as it went against the risk adverse culture that dominates many statutory services. Respondents to our early consultation described peer support as organic and flexible to the needs of peers. However, collectively the mechanisms put in place to ensure safety across Side by Side suggest that this does not mean that peer support is a 'free for all'. An alternative culture of safety building was present throughout the Side by Side project, and where parts of this culture broke down, there were harmful consequences, illustrating the importance of safety mechanisms.

As a result of these findings we developed the following definition of safety:

Peer support has structures in place to create physically and emotionally safe spaces. Safety building is essential and can include creating guidelines or 'ground rules' to address confidentiality, and how peers behave with respect towards each other. It also includes reviewing meeting locations for privacy and accessibility, role modelling the way peers can share (or not share), and clarity over how peers may discuss particular topics (e.g. the level of detail peers give about self-harm may be limited). The knowledge that 'what is shared in peer support, remains in peer support' helps to create trust that allows peers to be able to express themselves without fear of judgement. In some forms of peer support the responsibility for creating safety in peer support may rest with online moderators, group facilitators or supervisors. In other forms of peer support peers collectively take responsibility for creating safety. Evaluating the Side by Side Peer Support Programme - © St George's, University of London and McPin Foundation 2017

# 3. Choice and control

The third core value identified by interviews with Side by Side peers was choice and control. Peers spoke about exercising choice and control over their participation in peer support in a number of ways, including:

- When to participate
- When to share
- What to share
- Who to share with
- In what detail to share
- What advice to follow
- What coping strategies to use
- What to ignore

The importance of Choice and Control

The level of choice and control peers felt they were able to exercise was important in enabling peers to feel safe. Peers who felt they were able to choose when to attend, when to share, when to participate and when to take up advice linked this to feeling safe within their peer support.

Yeah. It's okay not to say something. It's okay to say, I'm not going to talk about this because I don't feel comfortable talking about this so I'm not going to. That's okay as well. That's sort of more important to me than the kind of emergency, or aggression or unsafe conduct things. They're not frequent. They're exceptional and it's good to have those safeguards, but it's not the, kind of, bread and butter of feeling safe. (PV24, group)

Some peers also suggested to us that choice and control were important in peer support because people who have had experiences of social and emotional distress often feel that they have lost control, or there was a sense that they may feel they have failed in other aspects of life. Where the value of choice and control could be upheld in peer support, peers were able to feel they could begin to regain a sense of that control.

I think a lot of people with mental health problems, it's their sense of self-worth that's been very damaged so it's important for people not to feel inferior within the group experience because the world out there is judging people on standards that I personally wouldn't necessarily say were relevant. It's not about success in that way and I think lots of people are very damaged by feeling that they haven't been successful and they've failed. (PV2, group)

'It's up to people to disclose what they want to disclose but yes, I do feel it's quite inclusive. I haven't disclosed anything that is very intimate but there isn't there is this atmosphere of... that you can take part'. (PV6, group) Peers spoke about being able to choose when and how to take responsibility for themselves and for their own mental health. Some peers explicitly contrasted this with other forms of mental health support they had been a recipient of, where they felt that they had not been in control, for example clinical services.

I don't go to the psychiatrist and say, "Can you lower this?" because he'll say, "No, you don't want to do that," because they like to be in control all the time. It's too controlling by the psychiatrist because they think they know it all when they don't. In fact, they don't know half of the things. They can get half of them wrong really, in my opinion. (PV19, group)

I am not putting myself in the hands of an expert, and saying to my GP 'I'm feeling terrible', and he's saying 'take these pills and you'll be well in five months', or 'five out of six people will be well in five months', which they tended not to do, in my case. I'm taking responsibility, entirely, for me and what I do about it, and what I take from the room, and what I say in the room, and so on, and how I behave in the room. So, that's a really important thing, and, in terms of people's mental health, I find that really helpful; it was helpful to me, and I think other people find it really helpful, to be taking back control of their own lives and their own emotions and their own actions. (PV35, group)

Peers spoke about being able to retain control of the process, rather than feeling obliged to talk about things that may be uncomfortable as had been the experience working with clinicians.

Yeah. Exactly. If you don't want to be here, then don't be here. Don't make me talk to you. I don't know who you are and you're making me talk to you about stuff that I don't want to talk to people about. Whereas, with peer support it's just, let's go and have a coffee, do you want to have a chat? You don't want to have a chat? Fine, we'll just sit here and have a coffee. (PV25, one to one)

We found that a key influence on how choice and control in peer support was experienced related to the role of facilitation. We have covered the role of facilitators in 'Safety' (page 113) above and 'Levels of Facilitation' (page 168) below. Here we briefly explore the issues directly linked to choice and control.

### Control over what to disclose, or not?

Facilitators in particular spoke about the importance of their role in ensuring that peers were able to feel a sense of ownership over what happened in the group and how group members were able to choose to take up more or less active roles in their peer support.

I think that's from day one. We've heavily promoted the fact that, "It's your group" Obviously it's a [name of place] group but it's not mine, the facilitator's, group, it's us as a group of people around the table, because they wanted facilitators who have experienced mental health issues themselves. I am absolutely no different to anyone in the room except if the fire alarm goes off, I'm going to make sure everyone's [left] the room, but I also know that half my girls would do that, as well, anyway. The ones who like to be mum, and it means it's my responsibility just to make sure all discussions don't get out of hand. But, again, we're at the state with this group that they do that themselves. They really do. If things start getting out of hand, I've got two ladies who will step in and I know I wouldn't even have to. But, obviously, it's not their responsibility to, so I always do. But yes, in regards to the involvement, yes, they can pick and choose, they really can. (PV15, group)

Some peer facilitators saw an important part of their role as helping peers to develop an ability to exercise choice and control over disclosure of difficult experiences. For example one facilitator spoke about how she encouraged new members not to share too quickly to enable them to have time to make decisions about what they would and would not want to share.

But, other people do come into the room and feel able to share, and listen to what people say about some quite difficult things, quite quickly. It's down to them; they are managing the pace of that, and if anything, when I'm facilitating, it's trying to keep people safe by not having them just jump in over their heads too quickly, and then perhaps wish they had never done it. (PV35, group)

Peers spoke to us about having control in how they engaged with their peer support. It was up to the individual to decide whether they were comfortable in:

- Actively seeking support
- Actively sharing their experiences
- Actively offering support to others
- Being present to listen to other sharing their experiences

I had a lady, she didn't say anything for four weeks, at all, and I was quite worried about her and sat her down and said, "Is everything okay? I know it's strange with a new group. It's new ladies, but you've got to know them a bit now. It's the same girls coming." It was brilliant, she went, "Oh, no, I love coming here. It's ace!" She said, "I just don't talk much" and she thoroughly enjoyed the mornings. She got loads out of the sessions and she loved it. She just, literally, didn't want to say anything, and that's fine. As I say, I've got talkers in my group who like to be really involved with everything. When I'm doing the sessions where I'm open to suggestions on what they want to do, how they want sessions to be, I get some people who don't really mind. I think they prefer to be led. Then I've got ones who really do want to have their say of how they want this to go. (PV15, group)

Yes, that's pretty fundamental. Well this is good, yes but I know some people don't always want to share their experiences. Maybe sometimes it's good not to talk about it. I mean, it's there if it's needed but I don't think it's that important because I know some people don't want to talk. (PV3, group)

Within Side by Side, some peers felt they were not confident to actively engage with other peers either giving or receiving peer support. We heard it can take time to nurture trust to fully participate in a peer support space. But within that journey, the person in control is the individual – they are responsible for controlling when they are ready to take more active part, and choose how to take those steps.

One thing I learnt from peer support here at [name of organisation], is that one of our guidelines is, "I take full responsibility to get my own support needs met" because basically, no-one's a mind reader. So, actually, if I need help, it's so hard, but I will say, "I need help" and there may be times when I might not be able to say that but with such a great group of people here, if I don't say it, people know. Like, "I think you need a bit of time out. Shall we just go for a walk?" "Yeah, come on then." It is that. It's because it's so safe and it's nurturing and that's really, really important. For me, it's really important, I guess. On a personal level, I need to have that trust and that safety there and the trust that people trust me to make my own decisions. I think now, if I do feel suicidal, I think I would say because I know what happens when I don't. I've come so far, I wouldn't want to go back. (PV36, group)

Some peers told us that while there was a general feeling that everyone 'gives and takes' some peers did not actively participate in sharing their own experiences or comment on other people's experiences. Some peers gained support from simply reading or hearing what others had shared.

I think there's quite a lot of [online peers] that just read others' posts. When I went to one of the [name of organisation] groups, there was a girl there that she's on [online forum] but all she ever does is look at others, and she gets comfort from that. She never posts anything herself. So again, it's not the most important to me that all people post because there's so many people, but that does happen on [online forum]. (PV32, online)

Other peers chose to only engage in one side of the interaction such as seeking or giving support. A number of peers spoke about choosing to use online forms of peer support because they actively

wanted to offer support to others in a similar situation to themselves, rather than simply seeking support for their own issues.

I tend to use it more when I'm having like a bad time but I try to go on it at least twice a week just to, kind of...not necessarily actively post anything but just to, kind of, like remember I should be supporting other people as well... but when I am not feeling very good I do tend to go on it quite a lot and I do go on it every day at least and then if I post then obviously will go on it more and stuff, so it really varies depending on how I feel. (PV44, online)

If you want to just give support rather than talk about yourself, there's ample opportunity to do that as well. I often fall into that category myself really. I'm in a good space so I don't really feel the need to give anybody my life story. (PV46, online)

### Shaping peer support: choosing how it runs

Creating safety requires input from group members. Giving members opportunities to have collective control over how the group operates is an important feature in some projects. This can help people 'feel safe' (as covered above). The example below is of a highly structured, facilitated peer support environment that has mechanisms in place to encourage peers to participate in making decisions about how the project is run.

We do, yes. We have feedback forms after every suggestion so sometimes people say, "We'd like there to be more tight control of the rounds so that people are not interrupting," and that kind of thing. So in terms of the structures that we offer, we do get feedback from them and that's often very candid, which is very good. [...] We go through it after every single session and we discuss it. We discuss anything that could be done better or with the structure of the actual programme itself so anything about the content and how that could be organised better. (PV36, group)

In contrast other peers actively did not want to have heavily structured forms of peer support and preferred to meet informally in casual settings.

I like to chat about important things, you know? Sometimes it's nice to gossip and chat for a little bit like, "Oh yes, I did this and I did that" but not for long because I am a doer, I have to be doing something, or I get bored so I go to Monday because I pass by on my way to the gym and so on my way I just pop in to say hello. (PV4, group) We heard that there were challenges over how peers could be encouraged to take control in groups. Over time group membership may change and the responsibilities that have previously been shared may pass, intentionally or unintentionally, to people in leadership roles. This is an indication of the diversity in which people using peer support may exercise their need to be in control. Some peers wanted to take responsibility for different activities in the projects while others wanted to know that someone else would take on those responsibilities.

Well, it has changed; what I used to like was that everybody would be involved in the decisions, and it wouldn't just be them and us. That is how we, originally, wanted to go, but, over the last few weeks, we have found that the group, as a whole, they actually don't want it like that; [...]they want my colleague and myself, who set up the group, the founders, to basically be like their leaders, and telling them what to do. (PV55, group)

### Control over personal use of peer support

Peers were able to decide how frequently they would physically attend meetings, or in choosing when and how frequently to access online forms of peer support. For many peers knowing that they would be able to come and go as they pleased, and that they would not feel under pressure to attend when they did not want to was an important feature of their peer support.

Yes, because you will get some people where one week they can be bothered and then some other weeks...they have good days and bad days, well, I do. If it was one of my bad days and it was here I would come in my pyjamas because I only live up the road so I am alright. [Laughter]. (PV18, group)

For me personally, but overall I would say yes, at the end of the day you can put in as much or as little as you want. There's no rules to say if you only post three things in a month then you're banned. You can put in as much or as little as you want. Yes, you've got total ownership and you can click off, can't you? (PV32, online)

*Yes, yes. If you don't feel up to coming one week and you feel like coming the next week, that's fine. You don't have to come all the time. (PV16, group)* 

The way in which peer support was delivered was also an important element of choice and control. There was a diverse array of projects in Side by Side, ranging from groups that happen on a fixed regular basis through to peer support accessible any time online. For some peers, especially those who were uncomfortable in groups of people, being able to choose how and when they accessed their peer support was important. I've looked into other [groups]... you know, on the website. I've looked at things and I've been to a couple of groups, face to face groups but for me I think [online forum] is better for me because you don't have to go anywhere. You know, it's not face to face support. I think that I get very anxious if I go into group settings. (PV32, online)

Others highlighted liking online forms of peer support as they had the freedom to discuss anything they wanted to, and were not limited to discussing a particular topic.

I think it depends on the support group. Because [online forum] doesn't have a particular defined purpose in the sense of, "We're going to talk about this, or that," There isn't a topic, as such. It's just in general, share what you're feeling, without judgment, or support others. Whereas the offline groups, yes, they have more specific kind of purposes. [...] Whereas, where I've been disappointed with peer support in some groups, is that they stick rigidly to the particular topic, or the particular purpose of the group and there is no room for anything else. [...] Which can be really limiting, because we experience all kinds of things and we don't fit in perfect boxes. (PV43, online)

Peers within Elefriends were able to choose to present themselves as anonymous, and had control over how much information they gave away about themselves. Having this level of control over what other Elefriends would know about them contributed to peers feeling safe online.

Yes, definitely. Obviously you can upload a profile picture and I have always been the type of person that I don't like putting up pictures just of anything, I do want it to be a picture of me but I don't want people to recognise me so I'll use like a photo I've never used or something and the photo I have on there my face is actually scribbled out because, I don't know, my belief is that I am on there for me and I am very suspicious of the internet and I take my privacy very seriously. (PV44, online)

Peers also spoke about being able to access online peer support at any time, and being able to post their thoughts or feelings almost immediately. This contrasted with the accessibility of some forms of face to face peer support. They could also withdraw quickly without the emotional impact of physically leaving a room on themselves or other peers; they could simply click a button.

Yes, no, that's good. I think that applies as well, and again goes back to it being there whenever you need it. It's always available. You can pick and choose and get as much from it as you need or as little from it as you need. Whatever your circumstances are. (PV45, online)

It depends how much time I've got because my time is very constricted with my caring role, so I try maybe about ten minutes at a time. I will try and scroll through the whole of the recent what everyone has put as much as I can. I might even go back on there later and make a comment if I don't have time then. It depends, yes. It just depends on what's happening in the day really and how things are going at home. (PV45, online)

Without anybody touching me or hugging me or making me upset, and if I did I could just click it off. [...] Do you understand what I mean? [...]Yes, it gave me a little bit of what I needed and I could control the emotion behind it. I could just switch it off if I found it was too hard. (PV32, online)

Elefriends had some very specific features that helped peers to control their use. For example, peers spoke about being able to use the technology to 'hide' posts that they did not wish to view or use the private messaging feature.

As [online forum] has evolved, they've started changing the way things are. And so now, you could hide that post. You don't have to report it, but if it triggers something off in you that you're not happy with, you could just hide that post and then move on. So you're not seeing it there all the time. (PV32, online)

I never give out personal details but I think a lot of the support people get on that is via the direct messaging, so it's not actually on the site. I think a lot of people talk behind the scenes. Whenever I've done it, people don't actually want to put it on the main board. You'll suddenly then get a private message asking about, "Thank you for the support. I didn't want to put this on there but this is what I'm going through," kind of thing. (PV46, online)

### Limits to choice and control

For all forms of peer support, there are limits to how much perceived and actual control individual peers can have in that space. The most highly controlled space is an online forum, where peers can leave easily by logging off. In face to face peer support there are compromises for choice and control. Some projects were limited in the time that they could access a particular venue, for example in the following project that takes place in an allotment.

I think, to an extent, you can't suit everyone. [....] because there are certain things we can't change. We can't change the time or the location for people who are unable to make it, so, I guess, that's a no on both of them. (PV53, group)

Where group members chose to have a facilitator, there were limits on the types of choices that individual group members or peer facilitators were able to make. For example where facilitators

applied a set of ground rules to group activities, peers were limited in the ways in which they as individuals were able to behave for the benefit of the group as a whole.

I think that's a bit of a two-way street actually. I think we all need to fit in so obviously it can't be perfect for everybody because we're all different. I think we all need to be flexible in both ways. I think we need to be able to fit into the group. Also, the group has to accommodate us so there has to be some sort of flexibility both ways there. (PV22, group)

Yes. So we be flexible and make the group accessible for people but we also need to maintain the safety of the group so if someone wants us to, I don't know, let them shout and rant in a very aggressive way in the group, that isn't necessarily a thing that we're going to be able to be flexible to meet because that would have an impact on other people in the group. That might be what they feel they need, and I'm not going to disagree with that, there could be a lot of value in shouting and screaming, that can let out a lot of emotion but that's not necessarily going to be appropriate for the group. (PV23, online)

There were also limits on Elefriends, with moderators reviewing posts and making decisions to remove content. People may post online with the intention of being supportive, however if the way in which they expressed themselves contradicts one of the house rules they would find their posts removed. Most people using online peer support identified moderation as enabling them to feel safe, and accepted this as a reasonable limitation.

[...] they allow people to express how they are feeling and if they are not feeling great obviously they don't want to enable anyone else or anything and they are really good at moderating that sort of thing so I feel like I can go on there, express how I feel and I won't be shut down by anyone and I understand that if I say something really...you know, if I said something that might, kind of, trigger someone then that might get removed or I might get a message and I understand that and I really like that aspect of it that you have freedoms to express how you feel. (PV44, online)

We spoke to a number of peers who were participating in one to one style peer support projects in which they were participating in a mentoring role. Many of the peers we spoke to had not yet been matched with a peer to support. It was unclear from our interviews how this matching may occur or what level of control peers in these projects may have over who they were matched with. This is another area in which there may be limits on the extent to which peers may have control over who they share with etc.

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### **Final reflections**

Within our consultation work, described in Chapter 5, one of the key themes that emerged was that of power. The main finding here was that the people we spoke to in our consultation identified the power dynamics they had previously experienced in clinical services as being disempowering. They explicitly contrasted the more equal power dynamics characteristic to peer support with these experiences, and highlighted them as more beneficial. In our interviews with peers in the Side by Side Programme, 'power' was not explicitly spoken about in the way it was described through our consultation work. However where peers discussed explicitly compared peer support with clinical services in the way described above, the difference in power dynamics are implicit. Where peers feel able to exercise choice and control over the strategies they may try in managing their mental health, this may be a different experience to experiences of being relatively powerless with clinical services.

Peers themselves described aspects of taking control, and having choices over a range of activities, as things that enabled them to feel safe, and that they were treated with empathy, dignity and understanding. For some peers the choice not to actively participate was equally important as the choice to take on an active role with responsibility. Choice and control was an essential element of peer support, but what that looked like varied.

Through our analysis we developed the following definition of Choice and Control:

It is up to the individual peer to decide how they will participate in the peer support environment. This includes control over when they attend or take part in peer support, what they choose to share, what support they want to try, what role they take in a group or interaction, and how long they stay in peer support. Peers can withdraw from peer support for a period of time and return to it later on without being penalised.

# 4. Two-way interactions

Our next core value was the 'two-way interactions' which captures how peer support is based upon the principle of reciprocity. Many peers we spoke to during our evaluation of Side by Side described the supportive relationships they had developed. These relationships grew out of a number of important activities:

- Sharing experiences and listening to other people's experiences
- Sharing coping strategies and learning coping strategies from other peers

At the heart of peer support is a two way commitment to share time together in the same space. These activities then grow out of that shared space. What happens in that space is not uniform, people take on different roles at different times. However, a sense of equality is present, and is in part created through the two-way commitment of peer to peer support.

I've said it [peer support] means being supported by equals, people like you. And, by support I mean, sort of, having somebody with you who can make you feel better, feel like a proper human being, because there is somebody like you. I think that kind of thing, really. And, it's equal, so I might be supporting them and they might be supporting me. It's a mutual, equitable relationship of... and helping, yes. (PV50, one to one)

Unlike the one directional relationships that peers may have had with clinicians, the peer support relationship operates in both directions. At any time there is the potential for peers to be receiving peer support, and to also be supporting other peers. This involved peers sharing their own life experiences, and listening to others sharing theirs. We explore this in more detail below.

## Sharing and listening to other people's experiences

Sharing was identified by many peers as a core activity in peer support. It helped generate a mutual understanding, building trust and helping people feel safe, whilst acknowledging the peers don't always want to share.

If you find the right person to talk to or people can just get advice from me or I can, you know, and vice versa so, yes, I think because they understand, they are living the sickness, they're living it, so they're that's why we're more able to be open with each other, but that doesn't mean with everyone. (PV4, group)

For some peers, this common bond took away the stigma of talking about distressing experiences. This feeling of being able to share also helped peers feel less isolated. Feel able to share - Not ashamed of anything negative about yourself. (PV4,group)

I'm less isolated. I have options. I can just be somewhere and not have to explain myself. I know that I'm understood tacitly because everyone's in the same boat. (PV8, group)

For peers, sharing experiences was not just about a chance to talk about their mental health difficulties, it was also an opportunity to talk about other difficulties in their lives, and to feel understood and even feel better ('*I*'ve noticed positive improvement').

I know when I talked about my renting crisis with the one guy [...] it was kind of like advice so I looked to valid life experience from them, which is nice. Like a lot of my friends still live with their parents, so I can't really talk to them about my renting crisis (laughter), they'd be like 'okay' (PV5, group)

Sometimes I've been when I've been pretty bad, and upset about things, and I've gone along to the meetings, shared it with other people, and it really has helped. I've noticed positive improvement. I'm thinking of one Saturday meeting that I attended about five months ago, and I had a particular problem with the NHS, and doing referral paperwork, and I just brought it up, but everyone wanted to talk about it afterwards, so it spent disproportionately lots and lots of time on my issue, the more the people were really supportive. (PV1, group)

Listening was also emphasised as the second core element of peer support – sharing requires others to listen. Some peers spoke about listening, rather than sharing, both in the context of being the listener and being listened to as a powerful component in peer support.

I find it very supportive. [...] just having somebody listen to you [...] And, you listening back to them, it's very powerful somehow. I don't know how, but it is. (PV50, one to one)

*My self-esteem is improved. I also like listening to what people have got out of it. I feel useful, for want of a better word. I feel it's very enjoyable to help other people, it's not at all altruistic. I enjoy feeling worthwhile. I think most people do. (PV2, group)* 

Some forms of peer support, such as the co-counselling approach, had very strict structures in place to ensure sharing was equal. In this approach to peer support peers had training on how to respond to each other, covering treating each other with respect and behaving without judgement. They also used timers within peer support sessions to ensure people had exactly equal amounts of time to speak and to listen before giving other specific support such as tips or feedback. [...] we arrange to split up into pairs or threes; you look after it as a three, in terms of having equal time as well, with two people listening and one person talking, at the same time. Yes, I use it on a fairly regular basis; at least once a month at those meetings, but you can also arrange to chat to anyone on the phone, using the same rules, or meet up and use the same rules. (PV57, one to one)

In one to one forms of peer support such as mentoring, a number of structures were put in place to develop the skills of mentors in sharing with and supporting mentees. These structures included formal mentoring training and group supervisions. Mentors described these structured opportunities for active sharing as important. They used these times to be open about any problems they were having with the person they were supporting. Mentors discussed their mentees' difficulties with other mentors, and then the groups used their own experiences to discuss new ways they could help the mentees.

[...] active sharing I think is important because you can know your colleagues experience, you can listen to your advisor and you can share your experience. (PV39, one to one)

[...] in those groups I could learn from each other what one has gone through, the experiences they have, we could discuss other people's problems that we'd come across and then the solution, how can we help them. (PV26, one to one)

The Elefriends site also has technological structures in place to facilitate two-way relationships. For example, there is a section on the site which identifies new members as they join, allowing existing members to get in touch to welcome them to the forum.

In terms of giving support, I usually say, "Hello" to the new members, because [online forum] has got a section where it identifies new members and then you can just click on their profile and say, "Hi" to them and welcome them. So it encourages you to welcome new members, so I do that. (PV43, online).

Peers using Elefriends perceived this form of support to provide high levels of equality. Some peers we interviewed from Elefriends received support from both online forums and face-to-face peer support groups, and explained the differences. One peer talked about online forums and how "everyone's voice is heard equally" (PV43, online). This same peer had attended a face to face peer support group but had found the group unhelpful due to some people dominating the conversations.

It wasn't a fair platform where everybody had an equal chance to talk about what they were going through. It started to become a bit one-sided. So that was a bad experience, and I decided to stop using that support group because it was making me feel worse. (PV43, online).

Some peers in group forms of peer support spoke about clear structures that had been implemented by facilitators to ensure that all peers had the opportunity to share if they wanted or needed to, and that others could actively listen. One of these structures was described as a 'round'. Sometimes facilitators were aware of particular difficulties within the group and used 'rounds' to encourage support for the peer on this topic.

Sometimes I've literally gone around the table and said, "One at a time, tell me something you did to make yourself feel better when you had social anxiety." As I say, a lot of the girls have social anxiety'. (PV15, group)

Facilitators also spoke about using rounds to share good news. This was often suggested as a way in which facilitators may act to lift everyone's mood.

When I do the rounds, every time I try to make it different; something that's made you smile this week, something that's made you laugh out loud, something you've seen that's funny, anything. (PV16, group)

Facilitators were aware that not all peers came to a group with the confidence to be able to share their experiences, and used 'rounds' to help peers feel more confident.

As facilitators, we like to lead by example and share as much as we feel safe to as it encourages people, as we speak in rounds where everyone takes a turn to talk and it makes them more confident in sharing their own experiences and it's when there is freedom of expression and an openness of communication that peer support is at its best. (PV58, group)

## Sharing and learning coping strategies

Descriptions of structured two way interactions went beyond the mechanics of simply sharing and listening, and also involved the nuances of how peers responded to each other. For example, drawing on the 'rounds' strategy, we heard how facilitators might ask everyone in turn to share a little about how they had been since the last meeting. This gave members a chance to speak, if they wanted, sharing any particular difficulties they were having and for other peers to respond by sharing coping strategies.

So you still work in a round but what would happen is somebody would bring up an issue they're having, so say if I said, "I've been feeling really anxious this week," then the group

might help that person by suggesting ways that they have found of balancing their anxiety (PV34, group)

This was also described as a helpful strategy when enabling newcomers to get used to speaking in the group.

Then, we break for tea, and then we have an informal, unstructured discussion on anything that anyone wants to talk about; it might be several of the points raised, about people going round, and it's often done to help the new people – people who've come for the first time – they might have lots of questions. (PV1, group)

Rounds were also used at the end of sessions to provide peers with a space in which they were able to reflect on what they had learnt from the session.

But rounds gives everybody the chance to share and then listen to what everyone else is saying. Then at the end of a session we'll always have, or at the end of a round or something, we'll have an opportunity for people to say something they're taking away from that. So something that they heard from some of the other people that is important to them or something they might use or something that's struck home. (PV59, group)

Peers described discussing and sharing coping strategies as one of the key activities that was helpful in peer support.

The different coping mechanisms, talking about that, the tapping, the elastic band, somebody shared that, wear a bracelet and ping it if you're starting to feel tense. I shared about the five things when you have an anxiety attack, the grounding, the smell, the feel, so all sharing that. I've handed out handouts for them to read later because sometimes you can listen to it and then think, "What did [name of facilitator] say about that?" so I'll say, "Right, I'm going to give you the handout. This is my handout, look at it," and teaching them how to do hand massage when you're feeling absolutely... definitely, yes. (PV16, group)

However many peers were careful to distinguish sharing coping strategies from actually giving advice. Giving advice was often described as being one of the things that does not happen in peer support, as peers may feel obliged to take that advice, which would impinge on their ability to exercise choice and control.

Yes, we do share our relevant experience and the strategy of coping but not really. We don't really give advice to each other, like I did this and you can do that, you can try that, not really. We just talk. (PV11, one to one)

In one to one forms of peer support, mentors described discussing any difficulties they had with mentees with other mentors during supervisions. These opportunities allowed them to think and talk through new ways of supporting their mentees.

Exactly, because the thing with the supervision and being a wellbeing coach, you need to be able to say—well, look, I'm stuck in this area, has anyone got any ideas? That's great because we all get along really well and we're all very open with each other about, you know, this might work. This has worked for me but it might not work for you. If you have that open relationship, it just makes things so much more easy—much easier to be able to get to the next step or just kind of say, oh okay, maybe I need to think about this a bit more; which is great (PV25, one to one)

Peers who used Elefriends spoke about how reading about how other peers had got through some difficult times was useful to them.

That's the bit I like is the active sharing. It's people telling you how they got through it or what they've done. Some of it you might find totally irrelevant and think, "How on earth did you do that?" but some of it, every now and again there's a gem. It's like going prospecting for gold, isn't it? Every now and again you find an absolute diamond (PV63, online)

For some peers being able to share their own experiences in a way that may be helpful to other peers was a source of satisfactions.

Yes, and sometimes people will write two or three pages, and not everyone will read it, but some people will read it and respond, and they're needing to write all that out, and you think, 'wow, you've written all that out; it's now out of your head, how gorgeous'. You don't have to read it, and you don't have to respond. [...] I encourage people to write; someone will say, 'my head is going truly crazy', and I'll say, 'try writing it all out for us; this is a safe place', and they do, and they will sometimes. [...] I guess, you see, I had it for so long, I learnt such a toolbox; I ended up with such a toolbox of strategies, that I've been able to pass those on to other people, and that is such a gift, wow, it's such a gift (PV62, online)

Indeed some peers were able to describe specific instances where they had been able to directly help someone and had had direct feedback from the individual about how helpful that help had been.

So she sent me a private message and said, you've really helped me because you've given me something that I can do and we're getting help for him now. and if it wasn't for you...(PV32, online)

Peers not only give and receive emotional support but also offered practical support. Sometimes, this practical support helped them emotionally too.

I think support is definitely important and people do provide practical support... Well, sometimes people have offered to drive me to places if I've been stuck. Or they're arranged to meet up somewhere if they know I'm going somewhere on my own, they're arranged to meet up to go with someone else. So I guess in a way that is emotional support. (PV10, group)

One of the practical things was one of the girls had said that her benefits had been stopped. I didn't hear, I heard the benefits... I sent her to [name] who is our fantastic, and [name] who know everything about it. The other girls had had a whip round for her. They went and bought her tea, coffee, sugar, bread, a chicken. I said, "You don't need to do this you know," and they said, "No, it's fine." She was absolutely hysterical but when she got on her feet she bought everybody a present. Every single person got this little notebook. So it was her way of saying thank you. I love that. I love that they look after each other. (PV16, group)

In some mentoring projects, mentors shared telephone details so they always had someone to turn to for advice. This gave them peace of mind.

But the fact that we all have each other's numbers and we all know that we can be there, we can pick up the phone if we need to speak to somebody. Again, I don't need to call them. I just need to know that I can. Yeah? Again, it makes a massive difference. (PV25, one to one)

Peers within a co-counselling approach to peer support also shared contact details with other peers in the network. This enabled them to meet when they felt they needed extra support. Some peers described knowing the support was readily accessible as being helpful.

And the fact that I have contact details of other people that I could be arranging to meet on a weekly basis, if I'm not feeling so great. The chances are I might be able to find someone who would, equally, say 'yes, now is the time when it would be useful to be meeting on a more regular basis, just you and I'. So, yes, the equality and the accessibility are the huge ones. Knowing it's there, which other forms of healthcare, at the moment – in our culture of massive cuts, you just don't know what is going to be available'. (PV57, one to one)

Peers using Elefriends told us how support was also given in the form of general encouragement. They were encouraged to report back to the forum – to let others know how they had got on. This made peers feel supported. So there's a bit of back and forth support there, where they'll say, "How did you get on yesterday? I know you said you were going to struggle to get on the bus. Did you manage it?" You know, that kind of thing goes on in [online forum], and I think that's important for feeling supported in peer support (PV32, online)

Sometimes peers reported how they had achieved something as a result to the support and encouragement they had received on Elefriends.

Somebody else will say, "I really wanted to sort my washing out and I really couldn't face it, but thanks to you I've managed to put two loads of washing on and I've put them out on the line." So you do feel like it's really happening, an active support there. (PV32, online)

### Challenges for two way interactions

Unsurprisingly, we found a number of challenges within two-way relationships, and themes that interlinked with other sections in the report such as breaches of confidentiality, people feeling unsafe or unable to stay safe in a peer support environment, the peer support space being too large for two-way interactions to be achievable, and unequal opportunities to give and receive support

The use of rounds did not always feel helpful. Some peers described finding it difficult to talk about negative or distressing things, and preferred instead put on a "positive front".

But I think sometimes you go round the table and they're all like, "What did you do this week?" And it doesn't work that way because like at the end of the day it's the fact that some people are like, "Oh, I've had a really fantastic week, blah, blah, blah, this that and..." Because they don't want to talk, they don't want to say to people how they're feeling. (PV12, group)

A number of peers spoke about having chosen not to share after having experiences in peer support where sharing had resulted in negative consequences. For example one peer support group facilitator told us how she had shared too much about herself and had been hurt as a result of this. It sounded as if peer support was not happening well in this group.

So basically, I let my guard down for [name of group] to get to know people but once I did I got really hurt quite badly so now I've sort of built that resilient back up. And like I'm very careful of what I say to who and what and when. (PV12, group)

A number of peers also described experiences in which their confidentiality had been betrayed and other peers had shared personal information told to them in confidence. The consequence of this failure in confidentiality was that these peers now avoided sharing anything about their mental health within their peer support. This again is an important illustration of the importance of boundaries or ground rules around safety, and how they must be maintained or peer support cannot occur. Breaches in confidentiality threaten the culture of peer support.

I did share things once over with [group member 2] and stuff like that but not now, not so much now, because I'm not sure that when I talk to him if he'll go and talk to our other mutual friend [group member 3] and then this person that's really gossipy, that they'll go and talk to them. So I don't share stuff like that really with him, no. I don't do that. (PV12, group)

As the examples above illustrate, two way relationships are built on a foundation of other values, and actively maintaining the values of 'safety' and 'choice and control' is vital for peer support to thrive.

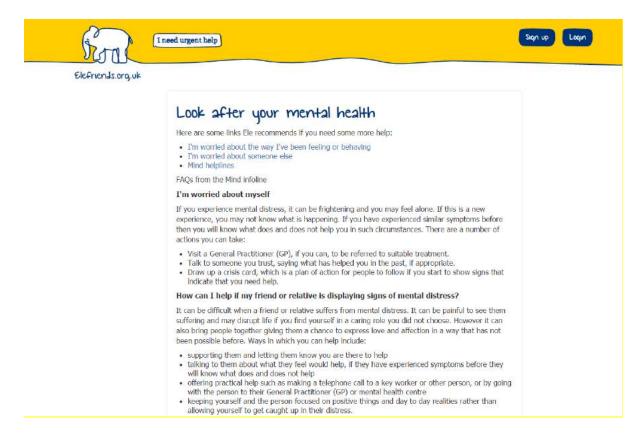
Some peers using Elefriends talked about having worries about what was safe to post online. While it is possible to remain anonymous on Elefriends, and peers are encouraged not to share personal contact details, some peers still had concerns that they might be recognised. This made some peers more wary about sharing too much information about themselves.

And I'm also worried that I might get recognised on there. [Laughter]. So I tend to hold back a little bit on there about myself. So I tend to give more support on that one than I do get something back, does that make sense? (PV45, online)

One theme that came out of the interviews with members of Elefriends, but not in the other types of peer support project was the need for self-care. The sheer number of people using Elefriends has a potential danger for some peers who may want to support multiple people at once. This may eventually take an emotional toll on those peers, leading some to describe recognising that it is possible to give too much and that, as recommended by Elefriends, they needed to look after themselves too.

So you do have to respect the fact that it's a virtual website and you can't support everybody, and in order to support somebody you have to also help yourself. So I think self-care is very important. (PV32, online)

This is something that Elefriends themselves are aware of, and they feature online advice on the Elefriends site.



Another challenge we observed related to time. Some of the peers we interviewed commented that it had taken time to build good relationships in peer support. Mentors in one to one forms of peer support noted this in particular. Many of the mentors we interviewed were involved in projects where activities had only become established late in the in the Side by Side Programme, and some had still not been matched with a mentee at the time of interview. Some described feeling anxious about early meetings with their mentees, and feeling that they wanted these to go well.

If you are helping someone you are just guide, but to you, you are carrying the whole burden on yourself so that was really effective. So I was always carrying and wanting to solve the problem, wanting to...but just to guide those people. Also, another thing that I've learnt is to cut the first small, small bits. At first I was so anxious I wanted this one to go right, I wanted this one to go right. I have learnt to go step by step, take this first step, she does this thing then another until achieve what you want so this one I'm learning from the discussion, how to, as a group. (PV26, one to one)

The first time or the first meetings with mentee, it will be like, I will try to do it perfectly but it will be maybe not perfectly. After then when I will contact with my supervisor or with my colleagues, it become more closer to me and I easily can give advice or do something for them, and job will become more learning, more easy for me. (PV39, one to one) Not everyone we interviewed felt there was an equal opportunity to both give and receive support, or to have an active role within their peer support project. Peers identified the pressure of trying to please multiple people in groups as contributing to this problem, and that some peers may not feel listened to as a consequence.

I'm not too sure there are equal opportunities to give and receive support. There are sometimes, but not all the time. I'm just trying to think of an example. [...] I just feel perhaps sometimes some of the people kind of, if you don't speak up for yourself, you won't get listened to, I guess. I guess that's a good thing, in a way, because it encourages you to speak up. If you didn't, I guess it could make people feel more isolated if they were there, but overall I think it's a positive thing because it's a skill you need to learn anyway...to speak up for yourself. But overall, I think it does happen, just not all the time. I can't really think of an example. There's an example in the park walk actually, where people wanted to go in one direction and some of the group wanted to go in another direction and perhaps they felt that the people—I think some of them felt that they weren't listened to when they went in the one direction. The ones that were left in that direction felt, perhaps, a bit like their views weren't listened to. (PV10, group)

Some peers also felt that the way online platforms were structured did not always lead to as much giving and receiving as in face-to-face peer support.

I think on a place like [online], you maybe don't get that giving and receiving at the same time although it's healthy to be able to do that. It gives you balance to be able to do that. I think it sometimes doesn't happen and you get people who are very sick and very needy and like that for a long time. (PV63, online)

#### **Final reflections**

For many peers the key activities that lead to the development of mutually supportive relationships involved sharing. Peers may share their own feelings, experiences or coping strategies, or may listen to other peers sharing in the same way. Many peers drew a link between sharing with each other and peer support being effective. While peers may share more or listen more depending on how they were feeling in a given moment, there was always a potential for the relationship to function in both directions. For this two way sharing to occur, the values of 'experience in common', 'safety' and 'choice and control' need to be in place. For peers to be able to share they needed to feel safe in their peer support environment, and to have control over how that sharing happened. Where peers had experienced a breach in their feelings of safety and of having control through their confidentiality broken, peers told us that they were no longer willing to share, and so would not be

actively participating in these two way relationships as they may have done if they had been feeling safe and in control.

From our analysis we developed the following definition of Two Way Interactions:

The interactions between peers are two way, and involve both giving and receiving support. In other contexts this type of two way interaction may be called 'reciprocity' or 'mutual support'. At different points in time peers may give more or less support or receive more or less support depending on their circumstances. What is given and received may vary, but there is always the potential in peer relationships to both give and receive support.

# 5. Human connection

One of the core features of peer support that peers talked about as being important was the human connections and human relationships that were possible in peer support. Peers spoke to us about how being with people who were going through similar experiences to them was helpful. Peers felt they could understand each other as a consequence of having, and often sharing, these experiences in common. The two-way nature of peer support allowed peers to develop strong, caring connections with each other over time. We found that in addition to having experiences in common and creating an environment for two-way relationships to flourish, human connections in peer support were also important. The formation of human connections meant that the simple act of being with each other, physically or virtually, was helpful to many peers.

Just having mental health problems gives you an alliance with these people and it's that thing of like, "We are all going through something tough and we are going through something that people who aren't experiencing this won't understand, and I might not understand how you are feeling but I can understand it sucks that other people don't get it. (PV44, online)

We analysed the data from Side by Side peers in relation to human connection to understand dimensions of 'being human' that were particularly important for peer support. We identified the following core components in our data:

- The co-construction of warm friendly environments
- Reducing isolation and creating a sense of community
- Establishing genuine relationships and friendships

### Warm friendly environments

Peers spoke about peer support environments that were warm, friendly and supportive. This warm and friendly environment was described as being actively produced by the people involved. Peers spoke about actively choosing to try to create a friendly, human peer support environment.

For some reason, and I just don't understand people sometimes, but in today's society I would have expected that that humanity is more prevalent and it's just not. A lot of people don't have that touch. They don't understand that smiling is okay. It's okay to say hello to a stranger. It's okay to smile. I know I keep using smiling as an example because it's what I do. But, you know, it just makes such a difference to just be a bit human. (PV25, one to one) Facilitators in particular spoke both about their own efforts to make the environment welcoming, and about how peers may do the same.

It gives me structure because I'm going to turn up ten minutes before, or half-an-hour before the session and stay back to tidy up and stuff." But that doesn't always happen because everybody just chips in. Everybody just says, "Right, we're done now. I'll sort the teas out and you can do the chairs," or whatever. We all just do it. (PV37, group)

*Yes, there is a definite meeting group that we all come together, we all feel encouraged. They're friendly and they do make you feel welcome. (PV22, group)* 

Peers also described acting with intentional kindness and patience in order to help individuals who were less confident in speaking to develop some confidence.

Like now we have some people who, we call it stammering. [...] Stammer when they are talking. Here they say, there is another term they use but oh, we are so patient. We are so patient, they come up with their point, so we always motivate them to talk more, motivate them to express more because they know that you are going to listen. Even though they have that problem of speech but we are there listening and they are encouraged. So they don't sit back and listen because of their speech. (PV26, one to one)

Some facilitators spoke about the importance of friendliness in encouraging people to continue attending. This is an important factor in ensuring the sustainability of peer support.

It's not caring and warm then people aren't going to come or if they do, you're going to lose them straightaway. It's hard sometimes to keep people coming anyway because their lives are quite rocky at the time. So we want it to be somewhere they can come and actually feel, "Well I go there, I get support. I feel better once I've been and that enables me to carry on living my life the best I can. (PV34, groups)

The feeling of being welcomed had a strong impact on some peers and was a factor in enabling them to feel safe.

It's even more, because I used to compare with [African Country]. LGBT group in [African Country] is in the night. First, it's in the night and we talk very less because we don't have much time. The more we stay the more we are at risk. So, when I came here, I thought we would be sitting and staring at each other for one hour and then we would be leaving. But when I came, over my tea I got – the first day I came I got a pack of milk. A pack of milk, sugar. Oh, my God. Like, welcoming. Fruits. It was amazing. It was amazing. (PV64, group)

[...] I usually say, "Hello" to the new members, because [online forum] has got a section where it identifies new members and then you can just click on their profile and say, "Hi" to them and welcome them. So it encourages you to welcome new members, so I do that. (PV43, online)

### Creating a sense of community

Peers spoke to us about the role peer support had for them in reducing isolation and creating a sense of community. Peers spoke about how human 'connection', was something they was often missing from their lives. Peers spoke about either not having people around them to support them in the form of friends and family, or about finding friends and family could not understand what they were going through. Peer support was therefore appreciated by people who felt lonely and isolated.

I don't have anybody in my life apart from my mother who lives down south.......There's only her in my life. I don't have anybody else in my life apart from the peer support network that I'm a member of now. (PV38, group)

I don't really have in the real world, anyone who can empathise with me....... I've got no-one in the same position as me that is close to me who understands. For me, that's a big part of [online forum] I think. (PV45, online)

It's just life, which is sometimes difficult circumstances when you have no support whatsoever from anyone. Mental health can affect you easily but if you find support, someone to say, "You need to see your GP. You haven't slept well last night, today try to go to bed early," just someone to show that he or she cares about you. But we have been left alone. (PV11, one to one)

Elefriends had a particular advantage for those whom felt alone, as it was accessible 'on tap', 24 hours a day, seven days a week.

[online forum] is always there so when I wake up with nightmares at 2 o'clock in the morning, there's somebody writing on [online forum]...... I suppose it's a bit of comfort. It's knowing there's other people that are up with insomnia while I'm up with nightmares. (PV63, online)

People who were feeling isolated described peer support environments as providing them with a sense of positive purpose. For some people it was a place to socialise and find a source of

companionship. This enabled peers to engage in activities that distract from social and/or mental distress and encourage wellbeing.

At least coming here, you actually feel like you are a person, you are worth something. It takes your mind off all your problems and stuff like that. It gives you something to focus on, something to build your confidence up, a new interest. (PV21, group)

Peers often talked about peer support being like a family or community. There was a sense that what is different or desirable about these communities was that they were defined and owned by peer members. It was peers who shaped and moulded what happened within the community.

I've been with twenty-five years, probably; that's become a significant part of my life, and the main benefits I get there are an on-going community, and that's national, and even international. I've got people from all over the world, and a whole structure, there, of events and workshops and residential, and things, that we can go to, and some people that I know and trust very much, and can do some brilliant work with. (PV47, one to one)

So the support that I've had on a personal level has gone beyond just doing activities in a group. It's become like a proper family, a proper support for me which has been really important because I do often doubt whether people like me. I can really have a lot of self-doubt and be very self-critical and think that I'm not a very likeable person. So to have people reaching out and saying, actually you're doing okay and you are a nice person. It makes a huge difference. (PV59, group)

Some peer support groups were part of a larger organisational structure. Peers described having a sense of being part of something that was 'bigger than the sum of its parts', and which provided access to an ongoing network of support. In this way, peers were able to find a way of integrating peer support into other parts of their social life.

We go for coffee afternoons...... And then through them we'll get to know more groups. You know, more events, more gatherings. And for me, personally, that means a lot to me because I get to meet people. I get to share my experiences. I get their experiences as well and then, you know, and the chain gets bigger and bigger[...].([PV65, group)

### **Genuine relationships**

Peers described the relationships they developed in peer support (particularly face to face forms) as genuine and full of everyday moments of care and regard. For example noticing that peers seemed to be genuinely pleased to see each other, or getting in touch with someone to check they were ok after not being contact for a few weeks. I think so. I do think so. People seem very genuinely pleased to see each other every week. People showed a lot of care and compassion when people would be sharing about things that's very difficult; that sounds really hard. (PV23, group)

Even on [online forum] there are some members who, if I haven't heard from them for a long time I will check whether they are alright and they will check whether I'm alright, as well. (PV43, online)

Facilitators also noted how peers would come to know each other, and knew how to be sensitive to a fellow peers mood at any given time.

Some days the very extroverted characters are very introverted and just sit there quietly and drink tea all day and you know they need a bit more of a mental hug that day, so you're flexible. I think, because they all know each other, they can recognise it in each other, as well. (PV15, group)

Peers spoke about the importance of recognising each other as whole human beings, rather than being defined by their experiences of social and emotional distress.

You've got to have that respect for people being individuals, and human beings with emotions, fears, dreams, desires, otherwise you're not going to get anywhere, I don't think. I, genuinely, don't think you will benefit from peer support unless you respect the fact that everything you think and want, everyone else probably is, as well. You know, that insight into, "It's not just me." (PV15, group)

Yes, the first thing that is, being human because we are human and we work with humans, you know? So, human beings, they're the most important thing so we can't go out from that human being frame, you know? Everything we will do in a human beings, inside that frame. (PV39, one to one)

Our data suggests that because these connections develop through the sharing of difficult and emotional experiences, peers develop a strong sense of empathy for each other. Peers spoke about these empathic connections in ways that suggested that they were powerful and that they considered these to be part of what makes peer support effective.

I had a lady say today, "I've had severe depression, as bad as you can get it." We all knew exactly what that meant. We knew where she's been, what thoughts she's had, what she's possibly tried to do and she didn't need to say any more. We all knew it and she would have seen, I think, on our faces that we just got it. It is a big part of the group. It's part of the reason they are pulled together in this group. A big part of it. (PV14, group)

Some peers explicitly contrasted this with their experiences of talking about social and emotional distress with clinicians, other professionals and sometimes friends and family. Peers spoke about this as being difficult and embarrassing.

Personally, when I was going through the worse time with my story, I found it very difficult to work with professionals who hadn't experienced what I was going through, because it is impossible to verbalise your thoughts with some things. Severe depression, how do you explain to another grown adult that you couldn't get out of bed even though, physically, there wasn't anything wrong with you, if they've not been through it? I can understand why some people just say, "Get over it" because there is nothing physically stopping you. It's impossible to understand it. (PV15, group)

Peers described empathy within peer support as potentially being enabling. For some it was the catalyst for opening up and sharing. These 'human connections' were strongly related to the two way interactions seen in peer support. These were described as empowering, and as enabling peers to feel confidence and validate one's own sense of self-worth. Some peers described this as leading to positive outcomes such as feeling able to ask for help, turning to appropriate sources of support, and learning from others. This was particularly true for groups of people who faced multiple barriers. For example immigrants who do not have English as a first language or refuges who may have experienced discrimination.

Before I met them, I wasn't confident enough. I wasn't strong. I was scared. I used to be scared, but when I joined this group it's more friendly. I've managed to be able to express myself, talk to people..... It's not easy doing this back in my country. I'm from [African country]. It's not easy. ..... You know, it is not easy to meet – like me, coming from a country that doesn't accept LGBT people, it's not easy to meet people that are telling you they're LGBT.... But when I got through the door, it was lovely. They welcomed me. They were happy to see me. I felt at home and I don't want to leave this group because it has made me stronger, happier (PV66, group)

### Friendship in peer support

Some peers told us that relationships initially established through peer support had moved towards a more concrete type of friendship. This was especially evident when peers begin to socialise outside the boundaries of the peer support space, or to swap personal details so they could be in contact outside of peer support.

I have their private number. I can call them any time if I feel alone, lonely, I call [name] and he says, "[name], take the bus. Come, we'll have [lunch]." We'll have tea, ten, eleven pm and then take the bus back and then it is really good. (PV64, group)

Some peers described these friendships have a deep, emotional connection, which was rooted in the sharing of experiences of social and emotional distress, at their core. Friendships built on these connections may be quite different to the evolution of every day friendships determined by things such as location, work or common interests.

It's like the completely opposite, I think, way of getting to know someone. Normally you get to know what they like and little things, less significant things, not really deep, emotional things about the other person straightaway, at least. Whereas, this is the other way around. You know what they're experiencing, things they wouldn't normally share with other people first...... (PV43, online)

### Challenges to human connection

**Challenges to 2 way interactions** - many of the genuine, human connections seen in peer support appear to grow out of peers feeling safe and able to interact with each other in an equal, bidirectional way. For this reason anything that poses a challenge to peers being able to establish a pattern of two way relationships will also pose a challenge to the full development of these human connections.

**Nature of online communication** - Peers using Elefriends described a wide variation in the extent to which they posted on Elefriends, or replied to other posts comments. While this was generally identified as a positive characteristic of online peers support in the level of choice it enabled, it could have a drawback in respect to human connection. Where people come together in face to face forms of peer support, particularly in groups, peers may support each other through being physically present together without saying anything. However some peers suggested that they had found it difficult to develop the same kinds of connections through Elefriends.

The relationship, I think it's very difficult to have any sort of meaningful relationship on [online forum]. (PV46, online)

As a large number of people use the Elefriends site, posts from individual peers could quickly disappear from the main Elefriends feed and remain uncommented on. In these situations peers may be left feeling abandoned and unsupported. This could hamper the development of

relationships or even leave some peers feeling like no one had noticed or responded to their distress. This could make peers feel ignored and further isolated.

Yes, because people pick and choose if they want to respond to you so, you know, someone could just not respond to you at all and like, not put anything and I guess you kind of have to take that kind of thing. It can be quite upsetting, like if you are in a really bad place, say, like you have fallen out with someone or something and you are thinking, "Ahh, I have no friends. I'll go on [online forum]," and there are no replies and you are like, "Oh no, I feel even worse." Do you know what I mean, like hypothetically? (PV44, online)

### **Final reflections**

There was lots of evidence from our data that suggests that the human connections people form through peer support, based on having experiences in common of social and emotional distress, have an important impact on peers. This value was strongly linked with two way interactions, and is likely to work in a non-linear way, so the more people feel connected to each other, the more likely they are to interact. The more they interact the more likely they are to feel connected.

Through our analysis we developed the following definition of human connection:

Peers actively acknowledge that they have a connection with each other based on having experiences in common. These common experiences provide a basis on which peers feel they may have a better understanding of each other than other people in their lives. Previous negative experiences can be put to a positive use through this connection. Peers work together to create a warm, friendly, welcoming environment for all peers, and act with intentional kindness towards each other online or face to face. Peers understand, emotionally support and care for each other, which generates a culture of companionship and belonging. Through the connection with each other, peers may come to feel less isolated and feel that that are part of a supportive community.

# 6. Freedom to be oneself

The final core value for peer support is freedom to be oneself. Peers told us how they needed to feel listened to and heard by other peers. They needed to sometimes describe difficult, distressing and painful experiences, for example feeling very down, overwhelmed or not coping, without fearing that those around them would criticise or ignore them. Some participants in Side by Side told us that they did not have other people in their lives that they could turn to, to talk about their mental health difficulties.

Well, it would be to meet other people who suffer with depression, because you don't normally meet them. So often, you don't meet them, or it's difficult to talk about it, to people who don't have it. (PV3, group)

This friend that I met through [online forum], when you go into a meeting or you go to have dinner with them or whatever, there are no barriers there as you already... you know they understand mental health, you know that they've gone through things and they know the same about you. So you don't have any barriers up, you just feel completely free to talk about whatever you want. Whereas, with traditional friends, it may take a long time before you would actually open up about anything that you're experiencing. (PV43, online)

This value relies heavily on 'Experiences in Common', 'Safety', and 'Choice and Control' being present and endorsed as part of peer support. In part, peers described feeling able to be oneself as a consequence of being in an environment where there was respect for different views and experiences, and these differences of opinion were acknowledged and discussed using language that was considerate to the views and feelings of all.

You've got to have that respect for people being individuals, and human beings with emotions, fears, dreams, desires, otherwise you're not going to get anywhere, I don't think. I, genuinely, don't think you will benefit from peer support unless you respect the fact that everything you think and want, everyone else probably is, as well. You know, that insight into, "It's not just me. (PV15, group)

After analysing our data we identified three key components to this value:

- Feeling heard and listened to by other peers
- Non-judgemental attitude/respect for differences
- Validation of self/normalisation of mental health experiences

#### Feeling heard and listened to by other peers

Participants spoke about the importance of feeling listened to and heard by other peers. One group facilitator told us how peers needed that space to talk and offload.

I've only really had one who has not shared. Some people when they get here, they're so proud of themselves for actually, (a) getting out the house; (b) using public transport; (c) having the courage to walk through the front door and then actually get into the room, and they're so chuffed with themselves by then, quite rightly so, that they're really happy to share. Because I think some of them are just desperate to offload, desperate to talk, desperate to get some advice. [...] I can't, off the top of my head, think of anyone that I've dealt with who hasn't wanted to share with the group, and they're all really keen to, I think. Certainly the ladies who have heard about it through word-of-mouth. I think we've got a good rep. Everyone keeps coming back. (PV15, group)

At times the subject of these conversations involved relatively 'everyday' irritations and successes, for example domestic arrangements that were irritating them.

It can be a range of things. Sometimes the support is as simple as there is a room full of people to listen to what you have to say, and even if that's just a gripe about, your husband's not cooking the dinner and you want him to, you know? It's just that supportive... just an ear, a shoulder to cry on (PV15, group)

At other times, participants needed to talk about more difficult issues, and found that they did not have opportunities to talk about to friends and family outside of peer support and feel heard.

I think that knowing that you are going somewhere where you will be heard and the time will be given for you to be heard is one of the reasons why people come back. I don't think you would come back if you think that there's not going to be time for you to talk. (PV23, group)

Okay. Well, it means that I've always got a place to go if I feel like I've got no one to talk to. I think that would be the first thing that sprung to my mind.... If I'm ever feeling—if I feel like I need to speak to someone that is going through similar issues to me regards my mental health, then I have an alliance of people that I know that I can always talk to either via the internet or in person (PV54, group)

Participants described needing someone to listen to them. It was this feeling of being listened to and feeling heard that gave participants a reason to keep attending their peer support project.

The difference with peer-support is that the expectations are somewhat lower; the expectation is that I will go to a peer-support meeting, I will be listened to and I will feel listened to, and that is actually very relieving in itself. (PV57, one to one)

Participants who were part of online projects felt heard too. There were mechanisms built into the Elefriends platform to ensure that peers could indicate they were listening to each other, even if they did not want to make comments on posts. Peers could simply click a button to say, "I hear you".

I have posted on it a few times. I like to think of it, like, a non-judgemental Facebook in a way and, you know? I don't tend to put a lot of stuff on my social media anyway but it's really nice to just post something and I have had it before where I have had issues [...] it was really helpful because even if people didn't want to reply they can press, like, a button saying, like, they hear you and they are sending support, kind of, thing so even if they don't want to actively reply, it's more than just a 'Like', it's literally them saying, you know, "I hear you" (PV44, online)

### Non-judgemental attitude / respect for differences

Another key component of 'freedom to be oneself' was feeling able to talk about all aspects of mental health, including difficult experiences – without feeling judged. Some participants explained how they had previously disclosed their mental health difficulties to friends or family and had felt misunderstood and judged. This experience had made them feel worse.

Peer support is good like that because you feel once you get to know people you can let your guard down a bit, which is lovely to have that. It's probably the one place where you feel you can and just totally let that guard down. So that's why I went to it and then thought it was good (PV34, group)

Participants wanted to be with people who understood and weren't judging them. For some people interviewed as part of Side by Side, this meant being with other people who had similar mental health difficulties.

[...] being with people with the same problems as you and not being judged for a change. (PV18, group)

[...] it gives me free reign to say whatever I need to or want to about bipolar. They all seem to understand and can relate to it. (PV22, group)

Peers talked about how there was a respect for different views and experiences and how these differences of opinion were acknowledged and discussed using language that was considerate to the

views and feelings of all.

I don't know, I'd say the minimum there is acceptance, a kind of 'I don't really understand what's going on with you, but I can see it is really difficult', and my experience is that it varies a lot, from fantastic support from people who really seem to get you, to people who don't. (PV47, one to one)

There was a respect and understanding that everyone's experiences were of equal value. Feeling equal to one another, while also acknowledging these differences, was an important factor in feeling able to be oneself.

I think if you take valued as in taken as having equal value then yes, because within the group, someone's really difficult day might be that they had a panic attack and they had to go to A&E and they felt really suicidal or something. Another person's really difficult day might be that they got really anxious going on a bus. Those two experiences are very, very different. They're of equal value because people's distress is of equal value and it's not a competition or something like that (PV23, group)

So, 'my stuff is not important', well, yes, it is; it is equally important, and we treat it all with the same degree of respect (PV35, group)

Feeling understood and being in a non-judgmental space allowed participants the freedom to express some very difficult emotions, including suicidal feelings and harmful coping strategies.

I think that's really important, otherwise I don't think peer support would have been helpful because I needed to talk about stuff that, actually, I really needed some help with and that is those ruminating thoughts, and thoughts about hurting myself and thoughts that I'm just the worse person on this planet and why do I even exist? It's all those. They are not nice thoughts. (PV37, group)

Sometimes, their strategies for coping are not very great, but we don't say 'well, going home every night and having half a bottle of wine is a really bad thing' – that is their strategy for coping, and if they share that well, that is their strategy for coping, but we're not saying, necessarily, that's the right answer for me, if I am listening to that, but we're not there to criticise, we're just letting people say what they feel, and what worked for them, and what doesn't work for them. We don't say, 'well, have you thought that might be leading you to alcoholism'. (PV35, group)

Peers felt they could talk about whatever they wanted without feeling stigmatised. Peers found this experience helpful.

We can talk about any subject whatsoever. Nobody thinks you're odd, you're just you. (PV20, group)

Many facilitators saw the ability to share experiences in a safe and non-judgmental environment as essential to making peer support work.

I have been in groups where I've said, "I do feel suicidal right now, but I know I'm not going to do it because I can't do it. I can't do this to myself, but I feel it. But I'm also feeling guilty for sharing this because I don't want anyone else to feel triggered." I will talk about stuff like that and that encourages others to kind of say, "I've been there and that's exactly how I would feel. I've never said to people because I didn't want them to panic. But you've said it in such a way." Equally other people do it. I'm not just saying that I'm the one that does it. Everyone does it. It just takes that one person to break the ice in some way and talk about the elephant in the room, kind of thing. (PV37, group)

### Validation of self/normalisation of mental health experiences

As we found in 'Experiences in Common' many peers spoke about feeling like they were 'normal' or 'in the same boat' as everyone else in their peer support. This normalisation of mental health difficulties made participants feel comfortable, and allowed them to feel like they could just be themselves.

Really, it's because of all the other people who are there have lived experience of mental health issues. Nobody is there as a, kind of, expert at one step removed from it all. So, you don't feel that you're being judged. You feel that you're being understood and accepted. People can see past mental health issues and see you as a person (PV24, group)

This allowed peers to share experiences without feeling like they would shock others in their peer support, or that they were odd or strange in comparison to those around them.

So it's not like – when we share stuff, there's no room for disbelief or shock, like, "Really?" Because it's all understood (PV65, group) Peers non-judgemental attitudes towards one another normalised and validated their experiences of social and emotional distress. This meant that they felt comfortable explaining these experiences and felt accepted and understood. This was sometimes in stark contrast to peers past experiences in other contexts.

It's like opening a door and entering a different world, shutting the door and then being able to breathe and think, oh I can take a sigh of relief and think 'I'm here, I'm with people that get it, have got it and aren't going to say, that's [Name]. You wouldn't believe she had anything like that'. They're not going to say that. [Laughter]. Because I have mentioned in the past and then regretted mentioning to friends because then they look at you like you've told them you've got leprosy or something and you think, 'why did I?' I think that's another reason I don't because of the reactions I've had in the past. ([PV45, online)

The freedom to be oneself was an essential component of all the peer support projects because, if people did not feel able to be themselves, they did not feel comfortable sharing their difficult experiences and thus did not fully engage with peer support.

#### Challenges to freedom to be oneself:

**Group dynamics** - Some participants who spoke to us had felt that they were not able to get their voice heard at times, due to other peers interrupting them. For some participants, this was a real problem and could put them off speaking up or even attending the group.

I just don't get a say. When I try to say something, I get interrupted. I have been brought up, when I was fostered and when I had a mentor just to "Let people have their say and when they have finished then you can have your say," so that should be the same for everyone really and that's why I don't feel comfortable in the group (PV13, group)

While many facilitators told us that it was part of their role to manage these kinds of group dynamics, this job can be challenging. Some facilitators told us how they had tried to address the problem but were not always successful.

I have some who have a lot to say, but because they're quite quiet, they very easily get interrupted and it's difficult to keep on top of that every single time it happens (PV15, group)

No and plus it's even when you have cards on the table or put your hand up and that should be looked into because I know that some of the people aren't getting a say as well.... What we have in [name] meetings is we have traffic light cards so red is to ask a question, orange is if you don't understand something and green is if you want to stop or to suggest something (PV13, group)

**Feeling judged** - While peers across Side by Side reported not feeling judged within their peer support, at times peers did experience negative comments, or made comments about other peers which were perceived as being judgmental.

Now and again you just get the odd comment about something. Like, "You were young when you got pregnant" kind of thing, which isn't inappropriate, but it's not entirely appropriate, because you're not here to judge (PV15, group)

In addition some aspects of mental wellbeing, for example, addictions, were not understood by all peers, and this could lead to tensions within projects.

# So do you think some things are stigmatised more than others within a group? What kind of things?

- R: Well when I was talking about the argument, one of them involved alcohol. Who it was with, she said, "But I don't drink anymore," and that's what it was about really.
   Some people can't understand some things.
- I: Couldn't understand her problem with alcohol, is that what you're saying?
- *R:* Yes. To me there was a reason she drank but people don't seem to look at that. It's just, "She was an alcoholic."
- I: So do you feel she was dismissed because of that?
- *R:* Yes. Maybe drugs would be the same. I mean we haven't had that this year.

# (PV20, group)

**Volume of online posts** – The online forum Elefriends is used by a large number of people, who produce a big volume of posts. Some peers may contribute online and find that their post gets missed by other peers. As a consequence of this, some using online projects did not always feel heard.

Sometimes it's a bit too huge, and people don't feel that they can be heard... Because, say for instance, you might post something. The next person might post something, the next person might post something and the wall is constantly moving. (PV32, online)

#### **Final reflections**

Freedom to be oneself was spoken about by peers across Side by Side as being an important component of peer support. For some, feeling free to express themselves without the fear of judgement was valuable. This value is closely linked to the other core values, which need to be visibly endorsed in peer support for peers to feel able to be themselves. Peers are unlikely to feel like they can be themselves in peer support if they do not feel surround by others with similar experiences, do not feel safe, or do not feel like they have control over how and when they may express themselves within those situations.

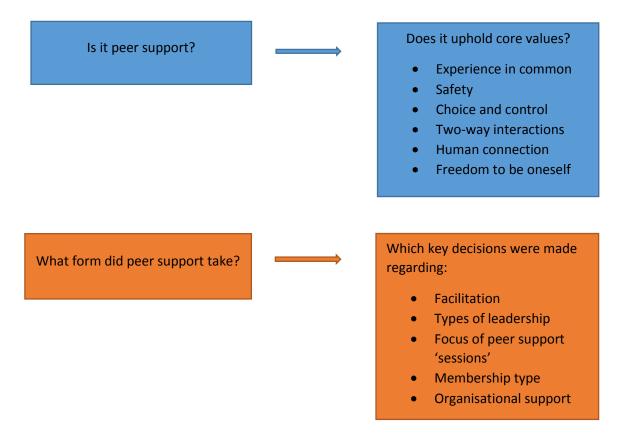
Through our analysis we developed the following definition of 'Freedom to be Oneself':

The ability to express themselves freely – without fear of judgement – is necessary for peers to be able to share difficult issues, not all directly about social and emotional distress, and to feel comfortable in doing so. The experience of feeling heard and understood in peer support is powerful. For this to happen peers need a space in which they can be vulnerable and talk about difficult experiences. Structures need to be in place to create this safe space, which means having ground rules to address the way peers behave towards each other. For many peers, peer support allowed them to feel like they were normal, and were just like any other person in their peer support. This was in contrast to having felt different, stigmatised or excluded in other aspects of life.

# Findings: Key decisions in planning peer support

In the sections above we have explored the six core values of peer support in Side by Side. Our research suggested that for a form of support to be called 'peer' support, these core values needed to be present, and endorsed by a project. Alongside this finding, our data also revealed that there were other key characteristics that helped define the nature of peer support. We understood these characteristics as a series of important decisions that people organising a form of peer support had made about the structure and practical logistics of their project. While some of these decisions might have been made spontaneously, without much obvious 'planning', they nevertheless shaped the nature taken by the particular peer support. For example getting a group of peers together in an informal social environment was not necessarily a deliberate decision to run peer support with a social focus rather than, say, an educational focus; however it did determine what that peer support will look like in practice.

# Figure 6.4: Core values and key decisions



In contrast to core values, where the absence of these values may raise questions about whether what happens within a particular project can be considered peer support, key decisions do not involve absolute right or wrong answers. They involve choices and what is 'best' will vary depending on content and objectives of the peer support project in question. In the remainder of this chapter we take a look at how each of these five decisions impacted on the shape of peer support within Side by Side and the range of peer support projects this resulted in.

# 1. Facilitation

We found variability in the extent to which different peer support projects in Side by Side appointed someone within the role of facilitator and how that role was carried out. This was an official and named role, and it was something the person did regularly within the peer support setting. In different projects this was a paid staff position or a volunteer role. Facilitation roles were taken up by peers as well as non-peers. The impact of the decision of who has taken up the facilitation role is explored in more detail under 'Key decisions: types of leadership'. This section focuses on the process of facilitation and how the decision to have a facilitator or not influences peer support.

Peers involved in Side by Side had different opinions on the importance and role of facilitation. These ranged from those that felt facilitation goes against the ethos of peer support as a space where equals come together, to those who felt having a facilitator was essential in making peer support feel safe. The decision regarding the need for a facilitator partly depended on the type of peer support being delivered. More structured forms of peer support, such as mentoring schemes or projects that included educational courses had a bigger need for a facilitator to maintain that structure.

We found that some peer support projects in Side by Side chose not to allocate a facilitator role. Instead, the tasks involved in making peer support happen were divided amongst different peers so that there was a collective responsibility for sustaining activities. While the facilitator role was described by many peers as being important for creating a safe environment, as described below, this did not mean that core peer support values could not flourish in their absence. Some peers suggested that not having a facilitator present had an empowering effect on group members.

That's, really, what support groups should be about, that it shouldn't be down to a facilitator; the group itself should find a way to, actually, support each other, outside of set group sessions, and that's the strength. (PV52, group)

I think if there was no moderator there it would allow people to be more expressive, perhaps. [...] I think perhaps it would encourage independence and for people to move on from whatever problems they are having, perhaps, if the groups allowed more independence, it would encourage that. (PV10, group)

Thus, some projects in Side by Side deliberately chose not to have a facilitator.

*Like everybody is supposed to go there on an equal footing. There aren't any leaders. We all have to organise stuff and sort things out ourselves. (PV57, PSN)* 

In other projects facilitation was an identified role and it was allocated to a named individual or individuals if the responsibilities were shared.

Usually if there's two of us we can sort it, we're like a tag team. You think, "Right, I can sort that one." Some people you know with their history, they're going to come in and cause chaos so then it's stealing their thunder before they start. Get them involved in activities straightaway. When you're coming to do a positive round, you know that person is going to say something negative so either get her to say it first, you contain it and say, "Don't forget it's only five minutes. You've got five minutes." Pull her back in and get her to either make the drinks. Give her some kind of responsibility. I find that usually works. (PV16, group)

In projects that did use facilitation, the facilitator role included the practical running of the project and maintaining an environment that enabled the values of peer support to thrive. It consisted of some or all of the following aspects:

## Practical running of the project

Having a facilitator was reported to ensure the smooth running of a peer support project. Facilitators were responsible for the logistics of organising group sessions such as booking venues and sending meeting date reminders to members. This took place in peer support group projects as well as in one to one projects, which all had a group aspect in the form of training, and in some cases supervision. It was also required of peer supporters in arranging one to one meetings but was less important in an online setting.

I think it's good, get the facilitator to organise a date and put the dates in a diary and send the emails out and have a contact number that other members are aware of just so they have, they can ring or text that person to say when is the next meeting or where is the next meeting? From that point of view, I think it's just the logistics of the organisation. (PV7, group)

We go out to different meetings, to get funding; it's not just two hours, twice a week, for us. Sometimes, it works out two days a week, because of all the bits and pieces that we have to do, within it. (PV55, group)

### Facilitating activities and discussions

Facilitators were responsible for facilitating the exchange of peer support as it was happening. The level of their input regarding this reflected the focus and structure of the project. Some projects had a social focus and informal structure, where peers would meet primarily to socialise. There, the facilitators' involvement in facilitating their interaction was limited to encouraging conversation and ensuring newer members were included. Other projects were more structured. This included

projects with a therapeutic focus where peers would meet to actively discuss their mental health in a structured way that allowed every member to share their experience. Here, the role of the facilitator was essential in ensuring everyone had an equal say and bringing the discussion back to focus if needed. Projects that included training also took a structured approach where the facilitator was responsible for delivering course content. The role of facilitation was also important in some projects with an activity focus, for example art groups, where the facilitator was responsible for guiding the activity.

It's okay jogging along but I do believe that you do need to guide the activities to help otherwise you're not being a good facilitator. (PV16, group)

Facilitators ensured everyone felt included and that none of the peers dominated the conversation. They made sure peers did not feel pressured to share more than they were comfortable with, which supported the peers' in controlling their involvement in peer support.

I think the peer support project, the person who is actually running it needs to make sure that everybody feels comfortable in how much they want to share. They might not want to say anything but I think you've got to allow that person if they want to do it, if they want to become involved. (PV16, group)

These aspects of facilitation were particularly prominent in groups but were also relevant in an online setting. Website moderators also took a similar role in encouraging discussion. They posted content that encouraged discussion around topics related to mental health, and responded to user posts that were inappropriate or not in line with the supportive purpose of the website.

#### Safeguarding and resolving disagreements

We found a key part of the facilitator role involved creating an environment that enabled the values of peer support to be embodied in practice. This related particularly strongly to the value of safety with facilitators supporting the creation of an environment where peers could feel emotionally safe.

So that's when the mum [moderator] comes in, I think, to the situation, because it's so hard for us to monitor that ourselves because we're not able to. I can honestly say that I've not really had a problem on there or seen anything that has worried me. [...] You're not going to open up in a situation where you don't feel safe or comfortable. I think that's very important. (PV45, online).

I think a huge role of a facilitator is to keep the group safe and deal with any difficulties that might arise. (PV59, group)

Facilitators were responsible for guiding peers in agreeing on ground rules or providing them with ground rules in cases where they had been pre-agreed (for example, in an online setting). They were responsible for responding to breaches of those ground rules, ranging from making sure peers did not dominate discussion to addressing disagreements among peers and managing aggressive behaviour.

It's better if there's two of you because then one can take the... if something happens you've always got somebody there to say, "Do you want to pop outside? Come and talk to me outside." If somebody's aggressive, I tend to say to them, "Come on, let's go outside a minute. Let's talk about this outside, don't let's shout. Nobody's listening to you." (PV14, group)

I should say, and not only the ones here, but I've never had a bad experience with any of the facilitators, ever. They just seem to understand it all, absolutely perfectly, and I think (facilitator) should be in the diplomatic corps. (PV8, group)

Some of the peers we interviewed said that they would not feel safe going to a group that did not have a facilitator. For them, the very presence of a named facilitator in a position of authority implied there would be ground rules and someone was responsible for resolving situations where they were not followed.

You've got people you're going to meet and chat with, which is not like a pub environment, it's a clean, safe, controlled environment with somebody with authority to control if anything got out of hand or was upsetting you or if you felt intimidated. It's that sort of environment and it's good. (PV19, group)

# Information sharing and signposting

Information sharing and signposting via facilitators happened both within a group context and privately. Both of these types of information sharing happened in all three peer support settings. In group projects, facilitators shared information in group sessions and speaking privately to members alongside or after a session. One to one projects all had a group element to them, which had a particularly strong emphasis on training and hence information sharing. Online, Elefriends moderators posted informative content on the website as well as messaged users privately. In some projects, information sharing involved delivering educational content in the form of a structured course or training session. This was the case in group and one to one settings (as one to one projects all involved preparatory training) but not online.

Yeah because they have all this information at their hands when it comes to delivering a course or a session. They're the ones with the information and so they're the "go to". They're the person that, in a sense, they're being looked up to because it's expected of them. (PV35, group)

It also included informal sharing of information such as signposting and connecting people with other support available in the local area.

Well she [facilitator] interacts with everybody and she's also there if people want a little bit of advice or guidance. It might be, "We've got a problem with this. How best can the centre help me?" and she might guide them to talking to someone from finance that works here or someone for the homeless or if they're stuck for food it might be helping with the food bank or whatever. So she tries her best to try and guide people in the right direction as well as supporting each other within the actual group. (PV21, group)

In the next section we consider how the decision to use facilitation or not was described across the three types of peer support we evaluated.

# Facilitation in groups

The role of facilitation was most visible in peer support projects taking place in a group setting. Running a peer support group involved arranging a venue and any other resources required for group activities.

Well, she [facilitator] looks after them and makes sure they are safe if there is a fire or anything like that. Regarding facilities, she will check to make sure we have got a drink which is important. If there is food about she will check if everyone has got a biscuit, or if there is a party, then she will sort it out ready for people. (PV13, group)

Ensuring safety was paramount in group settings. Facilitators were expected to enforce ground rules and deal with challenging behaviour.

Yes, I had a couple of cases of people stepping on boundaries with me and something that I find really crucial is for the facilitators to be able to... I'm not asking for them to get involved but at least to make sure that everybody is aware that boundaries have to be respected. (PV6, group)

I think it's good to have a facilitator because people, they could behave...because there are people with all types of depression and there are people who behave properly and there are people who don't. Probably, I don't know; maybe they could misbehave or take over, I don't know. (PV4, group)

Managing breaches of ground rules generally did not result in peers being asked to leave a project, but rather in facilitators offering them additional support outside of the group. This type of additional one to one support was also available to peers who raised concerning issues or become upset during group meetings. Peers felt this supported the creation of a safe space.

I think sometimes some people find it helpful if there is at least one person in case when they're sharing something comes up and it's just like somebody needs to then take that responsibility. Other people are not well in the group and don't know what to do, so I guess it's a bit around safeguarding. (PV37, group)

She's the one, if anybody gets upset or anybody ends up kicking off or whatever, she's the one that will ask them to come out of the room and seek another member of staff or whatever. (PV21, group)

# Challenges to group facilitation

There were challenges with both approaches. Peers spoke about groups that had become over reliant on a facilitator for organising group meetings. This meant the existence of groups was vulnerable if the facilitator moved on or was unavailable. There were also issues around safety, managing group tensions and upholding ground rules in the absence of facilitators, particularly in groups that had previously been run by one.

I had some time off and they had to shut the group because some of the girls were taking advantage of me not being there. [...] One came in smashed out of her head, absolutely drunk. The other one decided to pick a fight with somebody else. One other girl had come in who knew this girl's history, I knew nothing about it, and came in and shouted something horrible through the door so it got shut down. (PV16, group)

Well, with no staff doing it, it felt like we were doing it but it didn't feel good because there were loads of arguments. I have just noticed today there were probably only about seven people in today whereas normally there are about fifteen so there is a big difference in today. (PV13, group)

Some peers had concerns about peer support groups not being run by a facilitator.

So, there would also have to be a third party there holding the room, would there not? I would think, because not the nicest of people could get quite involved in it, and then maybe personalities would come to the fore. So, yes, I like the idea of a structured peer-to-peer group, but not all of us in a room just on our own. I think there would have to be somebody like yourself, for example, holding the room. (PV8, group)

# Facilitation in one to one projects

We found while some facilitation was involved in the one to one peer relationships themselves, the biggest role for facilitation in one to one projects was within training and supervision of peer supporters. This was particularly relevant in structured one to one support schemes, such as mentoring, that included initial training for the role of peer supporter and group supervision meetings for peers offering support. The role of the facilitator in this setting was similar to the role in other group settings, particularly in groups that took a structured approach to the sessions such as courses. In the preparatory training, course tutors acted as facilitators and were responsible for involving everyone in group discussions and managing disagreements.

Yes, and I was also, sometimes when you talk, okay, she has to see that everyone makes a point, even if you don't have, okay, she will ask, 'do you have anything that you feel we've left out'. So that is involving everyone. (PV26, group)

In group supervision meetings, the facilitator had a similar role, although some peers thought they could have done more to ensure everybody got an equal say.

Basically, I would love actually the supervisor to monitor other people's behaviour who we are sharing the same supervision, the same. So more monitoring... (PV11, group)

Facilitators also served as a resource for peer supporters, supporting them outside of supervision sessions, and signposting to other organisations and projects.

This communication between me and [facilitator] and the mentee from mentee to mentor to [facilitator] is very close together and I never talk to or give advice to my mentee before talking with

# [facilitator] because I know [facilitator] has good experience and it should help me with my mentee. (PV41, group)Challenges to facilitation in one to one projects

Challenges regarding facilitation in a one to one context were similar to those in group settings. In addition to this, some Side by Side projects found transitioning from staff facilitated group supervision to peer facilitated group supervision after the end of the initial project funding challenging, as described in the 'Types of leadership' chapter. This could pose further challenges to the sustainability of the peer support.

## **Online facilitation**

We found within the online peer support setting, Elefriends, the role of the facilitator or using the project's language 'moderator' was to monitor what members posted on the site. The online moderator role served many of the same functions as facilitation in face to face groups. The main function was to maintain the emotional safety of the peer support environment. A team of moderators trained to work on Elefriends responded to any inappropriate posts, for example those that were too detailed and graphic in their description of self-harming practices, and therefore could be upsetting for others to read or could be triggering for people. Members were also able to privately report anything they perceived as a breach of the rules to the online moderators. Peers felt this supported the creation of an online safe space that was different to other, non-moderated, online platforms. Occasionally online moderators would also remove peers from an online forum who were behaving aggressively towards others.

I think someone was excluded for a while, and they then can private message the [online forum] people, and they, then, consider whether they can let them back in or not. I mean, some of them might have a rage for a few days, and they get excluded, and their language gets bad; you're not allowed to use bad language, or anything, and they have been back, eventually, once they have calmed down, and it's flexible, in that way. (PV62, online)

Peers spoke about being able to get the help of moderators to deal with problems in a number of ways. For example, within online forms of peer support there were technological functions built into the site to manage safety concerns.

There was one time, where someone got very angry with me, but there is a report button, you see, so you can report people and, actually, if posts aren't appropriate then [name of organisation] quickly take them down; there is someone that oversees everything that goes on, on [online forum], all the time, not twenty-four hours a day, I don't think, but a lot of the time, and you can report anything that's horrible. (PV62, online)

Peers reported that moderators deleted posts that were not seen as relevant to the purpose of the site in supporting people with their mental health. In doing so they served a similar function to facilitators of face to face groups in guiding discussions back to the focus of the group. Moderators also sent private messages to individual members, either explaining why they had removed their posts and reminding them of the website's rules, or to offer additional one to one support. However, as discussed below these actions by moderators did impact on peer relationships.

So I kind of chatted to the elephant a little bit and got some support from them privately. Rather than making it public. [...] I just needed to get something off my chest and they just listened really and just put back something really nice and it just made me feel better. (PV45, online)

#### Challenges to online facilitation

We found peers felt that because all moderators on the Elefriends website appear as anonymously as 'Sam', the Ele Handler, it was unlikely a lasting two-way relationship would be built between moderators and peers using the website. Peers were unable to get to know the Ele handlers, who did not share personal details in the same ways as peers using the site.

I mean, the [moderator] is great. I love the pictures of the [moderator] and occasionally I'll have a giggle with it. But it sometimes feels like these people...obviously, you can leave [online forum] at any time. There's no "you have to stay". But you just think, well, they know you because they monitor what you put so if they know you and they're monitoring you, so you're technically giving some of yourself away, why should they be able to hide behind 'Sam the [moderator]'? (PV61, online)

There was some suggestion that moderation of online forms of peer support could be heavy handed, and sometimes peers felt that posts were removed that were did not break the 'house rules'. Peers thought that discussions using inappropriate language and tone were simply shut down by the moderators rather than constructively resolved. Some peers also disagreed with moderators regarding which posts are inappropriate for the Elefriends website and considered moderators to be too quick in taking down posts.

I think I'm kind of on the fence. I think they do in the sense that obviously, they have to make it safe and make sure that we're all being good little [peers] and not swearing and things like that. But in the sense of, sometimes they can go overboard, like with [name of peer] and her picture. (PV61, online) I suppose [online forum] is very much a peer support place and it is very much about the people who are talking at that time. Then you've got [moderator] who comes in. There's quite a lot of disputes about when [moderator] comes in because he can seem a bit interferey at times. I think people would like to be able to express a lot more about suicidal thoughts and things on [online forum] but it's not really the forum for it because there's no professional input so there's nobody to kerb the discussion. I can see where the conflict comes from with that. (PV63, online)

The nature of the type of online communication also caused problems, which meant that managing tensions and disputes among users of an online platform was more challenging for website moderators than in a group setting. Written posts can be interpreted in numerous ways and content that seems inappropriate to some people may not seem inappropriate to others. Moderators have limited options in dealing with ambiguous content. In a face to face context, issues that arise can be discussed and explored, while in an online environment the same content may instead be quickly removed leading to peers feeling they have been shut down or chastised.

It can be a bit difficult because some people might, you know, express themselves in a way that other people might find triggering, and I think that's where difficulties can lie and where, like, kind of, ground rules might have to be established. I know it's difficult when you get to those grey areas, kind of thing, but I think it's an important aspect of it, like respecting and respectfully disagreeing as well, so if you don't like this, yes, so like when I was saying about that user who was saying you should add an option where you could hide people from a newsfeed if you find them quite triggering, like, it should be allowing stuff like that because you are basically politely saying, "I don't really want to see what you have to say. It doesn't mean that I don't respect you, it's just that it might trigger me kind of thing. (PV44, online)

#### Facilitation summary

Peer support projects range from those with an official facilitator to those who purposively do not. In facilitated projects, a named person takes on leadership of activities and is responsible for undertaking a series of tasks relating to the practical running of the project and maintaining the safety of peers. In projects without facilitation, tasks are divided amongst different people within the project so the group takes collective responsibility for their peer support.

The facilitator role varies but may include the following tasks:

- Ensuring that peer support happens on a regular basis
- Ensuring that procedures are put in place to support peers to feel safe

# • Sending out messages to peers

Facilitation is relevant in all types of peer support, but it is especially important in group settings. This can include:

- Arranging practicalities such as booking venues
- Developing an agenda for a meeting
- Moderating group discussions (online or face to face)
- Supporting new members to integrate into a group
- Dealing with problems between group members

# 2. Type of leadership

We found peer support in Side by Side relied on different types of leadership. This included peer-led and non-peer led initiatives that differed based on whether people in leadership positions had been trained for their specific role, and whether they were paid or acted as volunteers. These three aspects of leadership types intersected in a variety of ways. A project being peer-led or not did not determine whether the person in a leadership position had been trained or was receiving payment. There were peer-led projects in Side by Side that had informal systems of leadership and facilitation, where the majority of activities were performed on a collective basis by people who have not been trained specifically for that role. There were other peer-led projects that were highly structured and peers facilitating them received specific training to carry out their role (e.g. a designated number of sessions taught by a peer facilitator trained to run the course). We found volunteers as well as paid members of staff among peers taking on leadership roles and responsibility within Side by Side. This section looks at the implications of each of these three aspects of leadership.

## Peer led or non-peer led

Most common peer leader roles included facilitators in group settings and mentors in a one to one setting; moderators on the Elefriends website also included people with lived experience of mental health difficulties.

We found examples of peer support projects in Side by Side that were entirely led by people who identified as peers. The experiences of social and emotional distress that peer leaders and peers had in common were key in establishing trust and supporting emotional safety. When group members experienced those in leadership positions as peers, this diminished barriers and made them seem more approachable.

I think the shared lived experience is one of the key things with peer support. I think people will, genuinely, take more advice off someone who they know has been through it than someone in a suit on the other side of a table with letters after their name, telling them what to do, because that person doesn't necessarily know. Whereas, I always say to the girls, "Unless you've had depression, it is impossible to describe what it is like to, physically, not be able to get out of bed." But when you've had it, you know it and you can empathise and you can sympathise and you can respect someone for the fact that they've pulled themselves from being in that situation all the way to back at full time work. So, yes, I think the shared lived experience is really, really important. (PV15, group)

It's important that it is peers, that are in that role, and I think it's good that there are a few of us helping, and, really, the more the merrier, I think, because if you have a month when

you're very busy, or you're overwhelmed, or you're not very well, it's good to know that there are other people that can step in, and do that, but to have them all as peers is very important as well, yes; I think that's quite crucial. (PV51, group)

Because they've got more understanding of the condition or not, somebody who hasn't got that condition or hasn't had it, it's difficult for them to understand. I mean I'm not saying it's impossible and everybody has empathy but it is difficult for people to understand how somebody is feeling if they've never ever been there themselves. (PV21, group)

In one case, peer leadership extended to the management structure of the lead organisation the peer support project was attached to.

I think it was just recently when I was talking to a manager and she was just saying that she's finding it difficult and I was like, "We say that we're a peer support group, yes you are the manager of this service, however, I would say that we are still all peers and that we should be able to seek support from whoever you think that you can talk to." So, that encouraged a conversation which facilitated that process where we could offer support to each other. Because I go to support her, it's not one-way. (PV37, group)

In some peer support projects, we identified a tiered leadership structure where some positions were occupied by peers and others by non-peers. In those cases, senior leadership positions were more likely to be occupied by non-peers, although this was not a rule. For example, in several mentoring projects peers took on leadership positions as mentors but they were in turn supervised by a leader who was not a peer.

A minority of projects in Side by Side were run by leaders who had no personal experience of mental health problems (although they may have had professional or clinical experience). We found some peers preferred projects that were not peer-led. They perceived non-peer paid members of staff as being more accountable and reliable leaders. They felt safer when there was a leader that they saw as a "professional" present. This was a reflection of the members' concerns about peers not being trained and experienced enough as well as concerns about peer leaders' own mental health. Some were cautious because of their previous experience with facilitators who were peers.

It was a peer facilitator, yes and there was a big argument and I felt so embarrassed because I introduced them to the place. We went there once and it was okay and then the second time we went there was a big problem and there was somebody that I know, you know, she was a grown-up woman and I was surprised that she didn't handle the situation properly. [...] We cannot rely 100% on the peer. I mean the person didn't know how to deal with the matter. (PV4, group)

To be quite honest, the people there mostly are too sick to be able to take on the responsibilities. They'd maybe like to but we suffer badly from being flakey, so, "I can do it this week, I can do it next week but the week after that I'm going to be too sick. I'm not going to be able to tell you I'm too sick because I'm too sick". (PV63, online)

Some peers thought that leadership should not have to be the peers' responsibility. In the case of a diagnosis specific project with a social focus where groups often met in public spaces, the leadership provided crucial safety structures that were more challenging to maintain in public spaces compared to the environment of a space associated with a lead organisation.

I think with the peer thing it probably wouldn't work and it wouldn't be fair on the person who just happened to be organising the trip to suddenly be dealing with forty years of pent up emotion, all crystallised in that one instant. No. Unless they had the intellect and judgement of Solomon it wouldn't be fair on them and it shouldn't be expected of them either. (PV8, group)

The preferences we observed for facilitators who identified as peers, or as non-peers illustrated the importance of the choice and control as a core value of peer support. This is indicates that a diverse peer support market in a given local area is important in enabling people to access the type of peer support that best suits their social and emotional distress needs and preferences for support.

There were also examples of projects that were run by leaders with experience of social and emotional distress, who were not recognised as peers by project members. This was either because leaders had not disclosed their experience clearly or because other aspects of their lived experience were considered too different to qualify them as peers, for example when a refugee peer support project was led by a white British person. Some peers also understood affiliation of a project with a national organisation as indication that it was not peer-led.

So peer ownership would be a group that's been set up by peers for peers and I know of groups in the area that run like that but the groups that I'm part of don't run like that. [online forum] is set up by [name of organisation]. It's run by [name of organisation]. [name of organisation] take charge over it. (PV63, online)

#### Leadership training or not

We found people in leadership positions, whether peers on non-peers, had been trained to differing extents. It appears that non-peers who were employed to work on Side by Side projects as professionals were generally trained in leadership roles, however we did not collect data on this systematically and so this finding should be considered with caution. In some projects, peers spoke about suggesting new activities when they first joined as members, that they proposed to run themselves. We found lead organisations provided necessary resources to run such activities, but did not necessarily offer these volunteers training in preparation for their new role. This was especially the case if their suggestion was of an informal, and non-structured nature. In some cases there were logistical challenges in organising new activities which could compound this difficulty.

The group that I go to meets every fortnight, but there's a big demand for it, and, if it was possible, it'd be better to run the group every week, and there'd definitely be demand for it, so I tried to do that, I tried to set up a group in the same setting on the alternative Thursday night, but there were no spaces available so, instead of doing that, it seemed like this was the next best alternative, if you like, to help and assist, and do this group and, as I say, it's only once a month. If it was every fortnight, it'd be better, but that's what the motivation was; it was thinking, meeting once a fortnight for people, whilst it's very good, there could be a higher level of support, and it was to increase that support level slightly. (PV1, group)

This lack of training could have an impact on the ability of peer leaders to support a safe environment, although our researchers did not record any serious incidents as a result of this. It did have an impact on some peers being reluctant to attend groups that were run by peer leaders. Other projects that involved existing members as peer leaders provided them with comprehensive training for the specific peer leader role they were taking on. In some cases, training was open also to peers who did not necessarily go on to take up leadership positions, increasing the equality in the two way relationship between peer leaders and peers.

Well it started about two and half years ago I guess when I got involved with [name of organisation] for the first time. I got involved as a service user taking part in groups. Quite soon after that I left my job to try and pursue a self-employed career and at that point I had quite a lot of free time. So I trained to be a facilitator as well, which was something that I wanted to do to help me give something back really. I've been doing facilitating and also helping out at [name of organisation], working on the reception, working with the admin team to prepare packs for peer support groups and also taking part myself as well on an ongoing basis. (PV36, group) While the extent of training offered and required of peer leaders in group settings varied greatly across projects, all peer leaders in projects taking place in a one to one setting received compulsory training, as described in the one to one setting section. Some of the interviewed peer leaders expressly stated their desire to become professional peer supporters and saw their leadership role within peer support as part of their career path. This suggests a trend towards professionalisation within peer support.

I think you should teach more and still teach and meet more than mentor to peer mentor. I am very big on mentoring but over the next two years I will maybe become a professional peer mentor. (PV41, one to one)

So, that is formal support, if you like; that is formal support, which is part of career, professional development, CPD, so that is a very formalised way of engaging, and supporting, to ensure that I am fully compos-mentis, and that I am ... my mental state of health is good. (PV52, group)

#### Paid or voluntary positions

People in leadership position on Side by Side projects were a mix of paid staff and volunteers. Peers were taking on both volunteer and paid roles, and in many projects training was available to both staff and volunteers. Sometimes having defined paid or unpaid roles of responsibility, for example 'official' group facilitators, created hierarchical relationships within a project. This could be especially pronounced if those in voluntary positions within the project were peers, while those in more responsible paid roles were not peers. In some projects, more experienced paid members of staff served as mentors to peer leaders who were just starting out as volunteers. In other projects, the division between paid staff and volunteers had an unwelcome, disempowering effect of volunteer peers leaders.

So every new facilitator is allocated a mentor. The mentor is a staff member who's experienced in facilitating and then the mentor will meet the trainee facilitator every three months, something like that, or at the beginning and end of a course that they're facilitating to set goals and catch up and find out how things are going and support people to develop their skills. (PV59, group)

I think it's always interesting in any group where there's the staff and the rest of us. I do remember being at some event I think it was, I think it was a health commission thing or something and I remember somebody, a member of (Side by Side project), making the comment that it's like, "The staff, they're listening to the staff more than they're listening to us." I hadn't really noticed that. I mean it might have been true but I think that kind of divide between paid employees, and us as a rank and file, although I haven't personally experienced it like that but I think that's always going to be the case. It's very difficult, a feeling that... I mean it suits me very well, for lots of reasons, to be a volunteer rather than... I've worked like that for a very long time. I'm very conscious of the class divisions and all that kind of thing. (PV2, group)

Some of the peers we spoke to were very clear that they did not perceive someone who was paid as better at their job.

Like I was saying before, I think it's really important that wherever possible, people who have been members of the group are coming through to lead the group because they'll have all the lived experience that you might look for in a facilitator but also that experience of being part of the group and not just someone coming in and saying, "Well I'm going to lead it now because I'm paid to do it," or whatever. That doesn't make you more qualified. (PV23, group)

However, we also found some evidence that suggests some peers perceived paid staff as more accountable especially if they were not peers, as described in the section on peer leadership.

#### Leadership in groups

Leadership roles within group peer support were tied to the function of being a group facilitator. People in leadership roles were the facilitators of peer support (see chapter on facilitation). Groups were often facilitated by peers who considered themselves to be equal members of the group. This supported a two-way relationship, where peer leaders did not only offer but also received support from the group they led.

Yes, I also, as I mentioned before, think the really, really incredible thing about peer support and the thing that people comment on the most when they first start is that there isn't a person who is separate and above and, in some ways, superior to the rest of the group, that the people who are leading it are leading it in so far as they are making sure that those boundaries are held and they're keeping track of time and those kind of things but they're sharing openly and equally and they have exactly the same boundaries for behaviour as everyone else. (PV23, group)

The peer leaders in group settings role modelled recovery. Some spoke about the importance of taking on a leadership role in supporting their own 'recovery' and considered it a part of their 'recovery journey'.

Taking part in peer support, being able to have that opportunity to be paid for that work as well in time and the structure and the skills that peer support has given me has meant that my recovery has gone forwards leaps and bounds so far in the last year and a half. (PV23, group)

They also role modelled active sharing of their mental health experiences for the wider group; this was viewed as supportive and gave confidence to others to share. Several of the interviewed peer facilitators highlighted the importance of limiting how much they shared, maintaining boundaries and not "burdening" other group members.

I'm conscious that, as a facilitator here, I have to keep a level of capacity, I suppose, for want of a better word. I can't come in here crying my eyes out. To be honest, I know I could and they'd be great, but it's not professional and I've got to remember that I am in here first and foremost because I am a facilitator. I need the girls to have faith in me that things get better and if I'm having a wobbly few weeks, that could set them back thinking 'God, it never gets better. I always looked at [facilitator] thinking she's got it together now, but she hasn't'. (PV15, group)

They've got enough rubbish in their world. I want to be their lightness. They don't need to be my lightness. I can be their lightness so there's got to be boundaries with my peer support group. (PV16, group)

There was great variety within the Side by Side projects regarding the types of groups led by peers and the level of their involvement in running the overall project. We found peers led a wide range of groups. Many ran courses or training and not only informal support groups based around social activities.

So I volunteer with (Side by Side project) and basically I started with them facilitating about, well it was January of this year was when I started. So I help facilitate groups who tend to do courses or workshops. So I either do one day individual workshops or, like at the moment, I'm doing a six week course with them. (PV34, group)

We also found there was multi-layered leadership in some of the Side by Side projects we visited. For example, peers would only come in to run sessions, while the practicalities of running the group such as booking venues, sending reminders to group members and securing any necessary resources were taken care of by staff of the lead organisation. In other projects, peers were in charge of running all aspects of the group. I didn't have to do anything. I just swan along whereas in my professional life I had to find venues, make sure there was enough money coming in to cover the venues and all of that kind of thing, which was much harder work. This is simple, isn't it? It's like royalty, you just swan in and go, "Hello group". (PV2, group)

Well, it's mainly with (Side by Side project) and, most of the time, I'm running it as an organiser, and I've been doing that for fifteen years, and that involves two of them now, one in [location 2]. So, that means I actually facilitate it, and take the enquiries and manage the emails. (PV3, group)

# Challenges to leadership in groups

Although group members and peer leaders were connected by experience they had in common, some peers felt that not all peers in facilitator roles behaved like one of the group. At times facilitators instead acted from a position of authority. This did not support a meeting of equals that group members felt to be essential for peer support. There were also examples of tokenistic peer leadership where a peer was given the title of facilitator but was not given any real responsibility within the group. Some peers in the leadership role of a facilitator felt that other group members did not take ownership of the peer group. They felt they were expected to 'provide a service' to the group members. They found this challenging because it mean undertaking responsibility for all aspects of running the group and felt this was not 'true' peer support.

It's not really running like a peer group. (Facilitator), the other facilitator, and myself, are doing everything; we're doing the rent, paying the rent, we apply for funding, have the cheque-books for the funding, in that way, and collecting the brochures, and doing this. (PV53, group)

Occasionally peers spoke about instances where a facilitator had not managed a difficult situation well, or had failed to ensure that ground rules around respect were followed, resulting in peers feeling vulnerable or exposed.

I went to that support group. I went there for quite a while. It was helping me a lot to understand and to talk with other people who have the same diagnosis, but after a while I found it too disruptive. There were too many people and it was a bit out of control, almost. [...] It wasn't a fair platform where everybody had an equal chance to talk about what they were going through. It started to become a bit one-sided. So that was a bad experience, and I decided to stop using that support group because it was making me feel worse. (PV43, online) There were challenges around how peer leaders used their lived experience of social and emotional distress in their role. We came across groups where members were not aware that the facilitators were peers because this had not been made explicit. Additionally, for some peer facilitators the responsibility of the role could have a negative impact on their mental health, especially where their efforts in trying to create a nurturing or empowering environment were not fully embraced.

I think, if you're dealing in mental health, especially, not just like a bowling group that's peersupport, but in mental health, because people are up and down, and you yourself are up and down, at times, and if you have problems, like I took it really badly when I was rejected; I had to phone up the crisis team, because I had a real, real down. (PV55, group)

#### Leadership in one to one projects

One to one projects included co-counselling and mentoring projects. Mentoring projects had a two tier leadership structure. The leadership role of mentor was taken up by peers who received training for the role and carried out this role in a voluntary capacity. They acted as leaders in their one to one relationships with mentees. Experience in common was highlighted as important in the one to one peer relationship, with mentees being supported by peer supporters, who were further along in their recovery. Similar to peer leaders in a group setting, peer mentors role modelled recovery and active sharing.

Okay, I got through everything, hard things and easy things. Somebody helped me sometimes, sometimes I would give up that and sometimes I would get upset about everything but I am here now. I can pass on my big experience to somebody exactly like me because in this way we are the same. [...] Yes, I think it's very helpful that I had a mental problem and now I am improving. I can pass on my experience from my very bad time, my very difficult time and I can work as a mentor for somebody. I think it's a very good idea. (PV41, one to one)

Peer supporters received training for carrying out their specific role at the initial stage of the project. While this supported mentors in carrying out their role, it also shaped the relationship between the mentor and mentee as not completely reciprocal. Although mentors reported gaining benefits from this type of engagement in peer support, the roles of mentor and mentee were not interchangeable. Some mentors reported they had already been offering informal peer support to people before joining the Side by Side project, and found the training they received as part of the project enabled them to become better peer supporters.

Before I was doing it [outside of Side by Side], as someone who is destined, feeling for other people that didn't have the right skills so this course has helped me get the right skills to use.

Because I remember one time when I came in, I spoke to this girl. I spoke to her and she got annoyed. Then I didn't know that the approach was wrong but now I know and I can look at her and say, 'Okay, what I'm saying is not crazy. How can I frame it another time?' so now I've got that skill and the method. (PV26, one to one)

Mentors were supported in regular supervision meetings by project leads who were paid members of staff and generally, as far as we were aware, not peers. Some of these projects had planned to hand over leadership and facilitating of group supervision to peers, which would also ensure its sustainability beyond the initial Side by Side funding. This was scheduled to happen after the evaluation data collection phase so we are unable to report on the long term success of this transition.

Co-counselling took a different approach to one to one peer support by choosing an explicitly flat leadership structure where roles were interchangeable. Members of the project would meet as a group and then split up into pairs that offered counselling to each other. Co-counselling pairs followed prescribed rules of interaction, with each member having an equal amount of time to speak and both members of the pair getting the chance to both speak and listen. This process was not facilitated by a leader but was rather decided by all members of the project mutually. This reinforced the reciprocal nature of the peer support and equality in the two way relationship between peers. This approach extended to training. All peers joining the project were trained in how to use cocounselling as an integral part of the project. Non-one could be part of the project without the training. This was also true for the research team; access to the group was limited to people in the evaluation team who had co-counselling training.

It's also, I find, quite useful in terms of the fact that everyone is equal, so that if I'm talking to someone else, I am aware that they have been trained so that they must not show any judgment or give any advice or anything along those lines, which means there is a bit more of a freedom to express what I'm thinking or worrying about, because I know I'm not going to get advice back. The arrangement is to talk it out and then work out what the issues are, myself. The listener is trained in making a number of prompts or interventions, but they're only designed to try and help me along, rather than to solve any issue that I flag up. (PV57, one to one)

# Challenges to leadership in one to one projects

Interviews with some of the one to one peer supporters in the mentoring projects suggested that it took some of them a while to fully understand and 'learn' their role. This could have been a result of

them not being involved in the design of the project at the initial stage which raises questions about its peer-led nature.

At first I did not really take to the project very easily but I think it takes time to understand the project, to easily understand every point, every page and for everything to become clearer. Now I can say everything is clear for me about the project but it takes time for it to be clear for someone. (PV39, one to one)

Some of the peer supporters relied heavily on the project lead for additional support outside of the group supervision meetings, which could create capacity issues. Some Side by Side projects found transitioning from staff facilitated group supervision to peer facilitated group supervision after the project funding ended challenging. This could pose further challenges to the sustainability of the peer support projects. In one case, moving from non-peer leadership to peer leadership led to disagreements among peers about who was most suitable to take up the leadership role.

Last time we were on the last supervision and we decided not to stop meeting but we can't supervise each other as a peer, as a client. We decided one of us can be the supervisor and none of them announced their name or said, "Yes, I can be the supervisor." After two minutes quiet, I said if everybody doesn't want to do it for the first time, I will be more than happy to be the supervision, if it's okay with everyone. [...] They said, "Why do you want to do it? Why are you being selfish? We can do it." (PV11, one to one)

## Leadership online

The Elefriends website is led by moderators, who have received training to carry out their role. Many of the moderators are peers, however, this is not made explicit and they appear on the website anonymously. All of the moderators use the same two identities: the Elephant, who posts website content and guides people in using it; and Sam the Ele-handler, who sends direct messages to users offering support or reminding them of the website rules. Peers using the website can respond to content posted by the elephant as well as start their own discussion threads, however, those can be taken down by the moderation team if considered inappropriate.

I think it's a leadership role because the Ele-handlers – and I'm an Ele-handler but I'm the Elephant too because I write the content – but yeah, I think it's a bit of both because there's an element of leadership in the sense that the house rules are enforced by us, even though they're decided by the community and so forth. Then I think the Ele-handler is more of a guide than a leader, if that makes sense. (PV69, online)

## Challenges to leadership online

We found that the anonymous leadership was problematic for peers using Elefriends who often found it depersonalised. Additionally, although many of the website moderators were peers, this was not disclosed to the website users. As we found in the facilitation section of the report, this caused difficulties in establishing more prolonged two-way relationship did not develop.

So all the moderators have one login, which is the Elephant. So none of us ever share our story. And we all use one name as a moderator. So it's really hard to explain this. The Elephant is the public on the wall [online forum] guide to the message forum. In private messages we're Sam, which is the ele-handlers. So we all use one name, Sam. We don't use our real names. (PV69, online)

#### Leadership summary

Leadership in peer support was found to be important in its absence or presence in a project. It shaped the culture of peer support provided and impacted on members' experience of peer support.

We found types of leadership fall under three key characteristics:

**Peer-led or non-peer led** - Peer support may be entirely led by people who identify as peers at one end of the spectrum, or by people who have no personal experience of mental health problems at other end (although they may have professional or clinical experience).

**Leadership training or not** - The extent to which facilitators, one to one peer supporters, and project leads have been trained to carry out their specific role within peer support.

**Paid or voluntary positions** - Whether the facilitators and others taking on roles of responsibility are paid members of staff or volunteers.

These intersect to form different types of leadership roles in a project, e.g. peers who are trained and paid, peers who are trained and volunteer, non-peers who are trained and paid, etc. Different types of leadership may be appropriate in different contexts, however, decisions regarding the type of leadership will have an impact on peers' experience of peer support.

# 3. Focus of peer support

We found that peer support projects in Side by Side had a range of foci. There were projects that focussed explicitly on peers discussing their mental health, however they represented a minority of the projects within Side by Side. In most projects the focus was social or based around an activity such as gardening or cooking. Some projects had an educational focus, where designated (peer or non-peer) leaders shared information related to mental health and other topics with peers. The focus of a project often determined its structure. For example, projects based around peers actively sharing their mental health experiences and educational projects lent themselves to a more structured approach compared to projects with a social focus. This range of projects with different foci allowed peers greater choice and offered them the chance to try out which approach worked best for them. Some peers favoured certain approaches to others based on their current needs or general preferences. Other peers considered different projects as serving different purposes and some attended several types of projects at the same time. There were also projects where different foci overlapped and projects that encompassed several strands dedicated to separate foci.

I mean, there are different types of peer support; you have got like your activity groups, the ongoing support groups and the social groups. These are more chances to check in every week with the same group of people to see how you are getting on whereas the courses and workshops are more about, you know, something looked at by one group for an amount of time. (PV58, group)

Again, it depends; some groups that I'm part of have a specific purpose, and they're there to look at something, or learn a technique, or something, or practice something. Other groups are there deliberately for mental health purposes, and, in that instance, it's partly about the shared vulnerability, I think, of everybody saying 'well, we're here because we struggle with our mental health, or our wellbeing', and it's much easier to talk to people who understand that; that's, probably, the biggest thing. (PV47, one to one)

#### Social focus

Projects with a social focus enabled peers to come together with others who have similar experiences with the primary purpose of socialising. Peers reported that the main benefits of projects of this type were having something to get them out of the house, and making friends. Emphasis on reducing isolation was particularly important in group and one to one peer support, both being face to face settings. In such projects experiences of social and emotional distress are discussed infrequently and rarely in depth. Some projects with a social focus avoided using mental health language completely, although they did provide an opportunity for peers to refer to their experiences of social and emotional distress using other language, for example that of 'stress'.

There isn't actually that much discussed about depression, it's covered lightly. You might talk about film, or what's on television, or a discussion that you'd have anywhere else, with any other people, you know, about football, could be about anything, not necessarily about depression. (PV1, group)

Well, we meet in the pub afterwards, so that's where we talk about other things. Generally, conversations can be about anything in the pub afterwards, and that's an informal group, so people just go along if they feel like it. (PV3, group)

Just that it gives you an opportunity to get out of the house, I guess, to stop being isolated. That can be a problem for me. I don't have a network of people to support me, as such. So it's good I can go and interact with people, I guess. (PV10, group)

Peers reported that what attracted them to projects with a social focus was their informal and nonstructured nature. Peers found it helpful that they were not expected to discuss their experiences of social and emotional distress. They appreciated that projects with a social focus reduced isolation and provided an opportunity for meeting other peers without the pressure of having to share.

It is not structured and I think that now I can't really imagine that group being anything else because that is just the way that it is. I mean, and if I am trying to think if it was to be structured – what are you going to do? Structure conversations? You can't do that so, maybe, I don't know, because it is just weird. (PV5, group)

Just meeting other people, I think. It wasn't the fact that it was, like, people were wanting to ask you questions; it was just very relaxed and very informal. That's what I like about it. (PV7, group)

Probably because places I don't feel like talking about issues in that but nevertheless I'm not a person to really open up completely and totally. So for me, just talking about everyday life without having to mention depression is quite helpful, I don't have to address the issue all the time. (PV6, group)

For some peers, projects with a social focus restored their sense of personal identity outside of being a service user or someone with experience of mental health problems.

So we'll organise things like going to the cinema. It's getting out into normal life, doing more normal things. Or we'll arrange... food always goes down well with everybody. We went out

for a meal on Friday night. You're going out as a big group of friends which is nothing to do with mental health, there's usually very little conversation about mental health goes on when we go out socially but it's reclaiming your role in society, reclaiming your place in society outside of services, outside of anything that's been organised by the NHS. (PV63, online)

Even though peer support projects with a social focus were not explicitly focussed on addressing peers' experiences of social and emotional distress, they had a positive effect on the peers' wellbeing through providing opportunities to socialise and normalise their experience.

#### **Activity focus**

Projects with an activity focus brought peers together by involving them in a joint activity. Side by Side included peer support projects based around a wide range of activities including art, gardening, walking, cooking, and outings such as going to the cinema.

Well, before, we used to make cards, Christmas cards and Mother's Day cards and we used to sell them to the Church. That was a chance for people to gain practical skills and the money made was put back into the project. So it was a social run thing. (PV10, group)

Everyone that went all had different ways of learning stuff and they had different likes, like in the gardening thing and it, sort of, catered for everybody, so if something didn't need doing, like cleaning the greenhouse or something, you could pretty much just do something that you liked. (PV33, group)

Like, sometimes, because women, because you've been so down, sometimes doing hand massages, doing henna, stuff like this boosts our confidence a little bit. [...] Yes, craft activities, and henna stuff for the beauty, you know, things like that. [...]Yeah. So that's quite good, because that really lifts you up. [...] Yes. And I think we're hoping to do a little bit of cooking together as well. (PV67, group)

These projects often had a strong social element to them, creating some overlap between social and activity-based projects. Similar to projects with a social focus, peers reported reduced isolation as an important outcome of this type of project.

The activity groups are more social groups. So they are things like gardening, textiles, relaxation. I think the helping mechanisms there are the socialising. It's a place where people can go to be in the company of others. It gives people a routine to their week. It gives them a fun activity that might be a bit of a relief from stress of everyday stuff. For an hour you can come and do the garden, or a couple of hours you can come and do the garden and get away from feeling horrible or being on your own, or stressing over money and stuff like that. I think having that space really helps. (PV59, group)

In contrast to projects that focussed only on socialising, activity-based projects allowed peers to focus on doing an activity, alleviating anxiety about having conversations with people they did not know well, which was especially helpful for members just joining a project. Activities also provided an incentive for peers who were anxious about getting involved in peer support but were attracted to projects based around their hobbies and interests. Activity-based projects provided a similar non-pressurised environment in terms of sharing personal experience of social and emotional distress to projects with an explicitly social focus.

So I started going to the arts groups because that was the one that interested me most. (PV2, group)

I think with a support group, people, I would imagine... I've never been to a support group [i.e. group focused on sharing mental health experiences], but one would imagine it would be just that. That people would, maybe, have a chance to air what was going on in their life and then someone, or the group, could come forth with positive ideas of support. That isn't what happens here. It's simply people who get together, sometimes for the cinema, for the theatre, for a walk. It's not structured in that sense. I suppose, in a way, that's actually quite beneficial because if you're not looking for a support group, you can just be there without having to explain yourself or talk or discuss. You can be anonymous in the group. You can enter, and leave. It's all very informal. So, it works very well like that, I think. (PV8, group)

The nature of the activity shaped the structure of project sessions. Most activity-based projects were fairly non-structured, however, those that involved instruction on how to do the activity or discussion about the results of the activity took on a more structured form. While many activity-based projects did not involve much explicit discussion of social and emotional distress, there were some projects were activities served as a lead into discussing difficult experiences more openly. In some cases, this resulted from the nature of the activity, for example in poetry and creative writing groups where peers discussed emotions and experiences reflected in the work.

There's a poetry group that I attend. That was started off by a writer named [name] who, sort of like, invited us to a poetry, kind of, workshop in which we read different poems and discussed what those poems meant to us emotionally and so forth. And after a while she said, "Look, it'd be nice if you wanted to carry this on." So we carried on a, kind of, poetry model in which a bunch of people would come and bring different poems that they knew and they would explain them, maybe give them out to everybody and read them out. And we would, like, sift through the meanings and what those poems meant to us and so forth. Sometimes we might even bring in poems that we'd written ourselves. (PV9, group) I mean I set exercises so each week they'll probably write two different stories which they'll read out to the whole group in the feedback session and then everybody will talk about how they've experienced that. So that means that the people in the group get feedback on their stories. It also means that you get a glimpse into situations they've created within the stories, the 'what happened'. [...] But that enables some back and forth of feeling and obviously, if people then say, "Well I noticed that when my mother was very ill," then we all stop and ask how that went and how the situation was and how the person was feeling. It's organic rather than coming in to talk about how you're feeling. It arises through the work. (PV2, group)

In other cases, peers were encouraged to talk as a result of the informal and relaxed environment created by an outdoor setting. This was particularly useful for peers who struggled to share in a peer support setting that in their eyes resembled a clinical environment, for example if a peer support group used the structure of speaking rounds reminding peers of a therapy group or if they felt uncomfortable in a formal indoor space.

These are small things. A barbecue, a barbecue on the allotment on Sunday. No-one misses that. No-one misses that. It means that activities free people. Yes, yes, they are free. And they tell you what they won't tell you in normal circumstances. [...] Then you will see one who will come to me, follow me, and grab my hand and then talk. Talk. Can you imagine, talk. I'm listening and she's talking. I'm listening. It's lovely. It's wonderful. While we are walking. If the event wasn't there, she won't tell me the story. (PV64, group)

Activity-based projects provided a non-pressurised environment where peers could be with others who shared similar experience of social and emotional distress without having to focus on those experiences. However, a project having an activity focus did not always mean that it avoided conversations about mental health. Activities also served as a way of approaching sensitive issues in more indirect ways.

### Focus on sharing experiences of social and emotional distress

These projects had an explicit focus on peers coming together (face to face or online) to share their experiences of social and emotional distress. Projects falling within this type relied on explicit use of mental health language rather than wellbeing or stress. Although peers highlighted the ways in which this type of peer support was different from mental health services such as being based on common experience and a reciprocal two way relationship between peers, some peers also drew parallels between the two.

*I suppose it's kind of like a counselling session but not with a counsellor, with other peers.* (*PV17, group*)

Well, the first part of the meeting, people go around and say something about themselves, like an AA group, and after that it's open for anything people want to say, so then you get general conversation; people talking about themselves, or they might talk about topics related to depression. I suppose some people use it like a therapy group, sometimes, as well. (PV3, group)

In projects of this type, peers shared their experiences of social and emotional distress including tips and coping mechanisms. This often included discussion of specific diagnoses, effects of medication, and their experiences of using services.

We spoke a lot about anxiety and all it's different forms. So anxiety with a big A like the diagnosis and also anxiety with a little a in the ways in which it permeates all through life. [...] We spoke a lot about different ways of coping. So some people shared a lot about exercise, some people shared about, I don't know, talking to friends and things like that. We shared about creative ways to deal with problems. (PV23, group)

At each meeting we share how we've got there, how we started with bipolar and how we've been... we've had bipolar and how we've been on the tablets that we're on and what affect the tablets have on us and whatever. I suppose in a way, medication is brought into a lot of it and the way we're treated by the professionals, the doctors and so on. (PV22, group)

Projects that focussed on sharing mental health experiences generally ran in a very structured way, for example by speaking in rounds in the case of groups or allowing members of peer support pairs equal amounts of time to speak. This served as a way of maintaining a balance between more vocal and less vocal members, and helped to ensure peers had equal opportunities to give and receive peer support.

The first part is, everyone in the room, no matter how many people are there, so it might be as little as five, sometimes, it might be as many as fifteen, sometimes; everyone's got a few minutes to talk about what's troubling them at the moment, or what's happening in their lives, or some background about themselves, whatever their issue is, we all go round in a circle. So, it's a chance to ventilate whatever frustrations you might have. (PV1, group) The way that we do it at (Side by Side project) is by speaking in rounds. So we all take it in turns to go round and there's pros and cons to that but the main reason that we do it is to make sure everyone has an opportunity to talk and everyone has an opportunity to be heard. (PV23, group)

So you still work in a round but what would happen is somebody would bring up an issue they're having, so say if I said, "I've been feeling really anxious this week," then the group might help that person by suggesting ways that they have found of balancing their anxiety. They work like that. So they are different ways of doing it but the ones that I've particularly been involved with are definitely the more structured. (PV34, group)

Some projects of this type encouraged or required peers to undertake preparatory training in order to make the best use of this structured approach bringing them closer to peer support with an educational focus, which we explore in the next section.

#### **Educational focus**

Projects with an educational focus had an emphasis on giving peers knowledge and information about mental health and a range of other issues that impact on their wellbeing. Side by Side included projects where this was the primary aim as well as other projects that delivered occasional sessions with an educational focus. Some projects included structured courses with a designated number of sessions that focused on particular mental health issues or particular skills related to managing social and emotional distress.

It's not a peer support group, no. What I've done is take part in various different short term groups like workshops and courses. So I might do say a workshop on anxiety management. I've done that. I've done one of depression. I did facilitate a course but you also are a participant really when you do that. I did one very recently on stigma of mental health. (PV36, group)

There are other support groups that are just week to week support groups but all the stuff that I'm involved with have been course related. So I've done anxiety workshops. (PV34, group)

So for six weeks we'd look at one skills course, like assertiveness, building self-esteem, anxiety and then at the end of those six weeks have a little evaluation session and get feedback from people. (PV23, group)

Some projects included one off educational sessions that focused either on mental health more directly or spoke about other issues of concern to peers in the project. Although not framed in terms of mental health, these generally addressed issues that had an impact on peers' experience of social

and emotional distress. This included a range of topics such as physical health, benefits advice and hate crime.

One specific thing we've dealt with is social anxiety, tips for overcoming that. Another one that was very useful one week was learning how to say, "No." I think a lot of the ladies benefitted from that, but one lady in particular really benefitted from having... I think we had a good six or seven people in that day, of everyone giving her advice and she's taken it on board and she has made changes and she feels great about it. (PV15, group)

Well, the lady was quite good, she was talking about like different sorts of mental health issues and different conditions and stuff like that. [...] And things like vulnerability training as well, you know, like hate crime and stuff like that. Stuff that basically, for me, this is for me personally, I did not know that even existed. (PV12, group)

For talk about advice, about eat, some eat together, healthy eat, because they have diabetic, they have some advice for diabetic, healthy food advice. We have group, talk with each other, it's good. (PV31, group)

Projects with an educational focus were typically very structured. They involved a (peer or non-peer) leader running a course or one-off advice sessions that often included handouts with additional information. However, there was flexibility within that structure to address any concerns that arose among peers.

There was one volunteer and one paid member of staff who led the group in a sense and would bring the paperwork because it was an actual structured course. Then basically, everybody was involved. So we would discuss something, like it might be why do I find it hard to be assertive, it could be something like that. Then the whole group, including the facilitators, would answer that question. So we'd go round in a very strict round so that everybody can get a chance to speak. You can pass, you don't have to say anything but usually nearly everybody will say something. (PV34, group)

One, we would roughly call coursework, but it's facilitated group work, where we follow – I don't want to say a course, it's almost a script, but we work through a series of activities and so on. Like, perhaps we're learning about self-esteem over five or six weeks, and so that's quite heavily structured, and we're working through some work. (PV35, group)

I mean the courses have titles, they're structured around particular topics so they are quite purposed. They're directed in some respects, in that knowledge is imparted I suppose but the focus is always on peer support involvement and the peers getting involved in coming up with their own ideas and resources. (PV36, group) While most projects with an educational focus used a group format, projects taking place in a one to one setting also involved an important educational dimension. All of the one to one projects required at least half (and in one case all) peers to undertake training prior to engaging in one to one peer support. Therefore the initial phase of taking part in the project for those peers had a primarily educational focus. This is explored in more detail in the section on peer support within a one to one setting. Peer support projects in Side by Side had a range of foci not all of which addressed mental health explicitly. However, regardless of whether a project involved a direct focus on discussing peers' experience of social and emotional distress, peers reported them to have a therapeutic effect.

Sometimes just being here in a friendly environment and supporting each other, it's worth it. A lot of people might say that that two hours, it's just an art group but it's not. It's more than that. Without the art group, I don't think a lot of them would manage. I think the art group is something that everybody enjoys coming to. We all give each other ideas. We try and support (facilitator). She runs the art group as well. I know she's staff and she's running it and that but sometimes it's nice just to have a little bit of help and feedback. (PV21, group)

It's not really a weakness, but it's the idea that it's not a health professional running it, and, therefore, the direction is no different to just chatting with your friends, but, I guess, that's all it has to be; it would be therapeutic if you were to talk with your friends about depression. That could be therapeutic for a person, but that's not always easy to do in open society, whereas, when there's a peer support structure, then they can talk about that. (PV1, group)

But, as I said before, what someone can tell you in a meeting – it's not the same in a cinema having a popcorn, for instance. The allotment has proven to be a therapy because, as I said before, there were people here who could not say a word, but now the allotment is like their sanctuary. They live there, because it's outdoor. It's outdoor. They prefer the grass than the sofa. (PV64)

#### Focus in peer support in groups

Peer support projects within a group setting included the full range of foci described above. There was overlap of different foci in many of the group projects, for example most activity groups also had an important social element, and many of the social groups included one occasional educational or activity sessions. There was a significant number of Side by Side projects that ran several groups, each of them with a different focus.

The other thing is that we do – we've got several different types of groups. One size doesn't fit all. We try to have a range of things that meet different people's needs. There's courses

which can last up to about six weeks and skills based courses look at particular tools and techniques. [...] We also do activity groups. (PV59, group)

There are general support groups. They're the broadest based ones. But, yeah, the courses and workshops that they do have a specific focus and then there's activity groups that aren't directly involving your mental health. (PV24, group)

## Challenges to focus in peer support groups

We found several challenges relating to choosing and maintaining a focus within peer support taking place in a group setting. Some of the peers that attended projects with a social and activity focus reported that they felt discussion of social and emotional distress was discouraged within the project. There were also peers that struggled with the informality and loose structure of projects with a predominantly social focus.

I mean I don't want to sound as if I'm criticising this group in a bad way or the facilitation but I felt it was almost too much in the direction of look, we're all just here doing art group. It was quite evasive about... I mean nobody's condition... I can remember occasions on which there was one person in particular who would mention something, usually about their physical health but, to me, it was clearly psychosomatic at some level. But it was a general dampening down of any expression of difficulty. I was quite surprised by that when I was first there because I thought is there a deliberate- I mean I was new to it- is there a deliberate policy not to discuss what we're all here for? While I think it's important not to push people, if they don't want to say something, fine. But I think it's also important to take note of the reality of the situation. (PV2, group)

Because once you realise that it is unstructured and everybody kind of has to like start their own conversation then it is easier. But when you are new and you are sitting there and you are like, "What are we supposed to be doing? Like, are we supposed to be saying things or not saying things, like what are we supposed to be talking about?" And that was a little bit intimidating because when it's your first time, you're not gonna wanna just start up all these conversations with different people. (PV5, group)

In projects with an educational focus, some peers found the intensity of taking in new knowledge draining. In projects that included occasional educational sessions, the time taken up by those sessions had to be balanced off against time dedicated to peers sharing their own experiences. There was also a danger of unsettling the equality and two way nature of the relationship between peers if educational sessions were not being led in line with the core values of peer support.

I think [name of group] can be quite draining at times, especially some of the stuff that comes up. So, yes, I think that can be quite draining at times with [name of group]. Some of it's really good; the training you access through [name of group]'s really good. But some of the stuff that you hit on can be quite close to people's hearts, you know, and I think that's...That's why they should have like... I don't know, they should have something like at the side of it as well where you can just come in if you just wanted to read a magazine or do a bit of knitting or whatever. (PV12, group)

I think, sometimes, there's always the option of having a speaker, but I always feel people have so many questions for speakers, that I know, when we do have a speaker, and we probably will have one soon, nobody will get to say anything that month. (PV51, group)

I like to think that the informality helps people want to open up as well rather than feel like they are being lectured. I don't ever want to appear like a teacher having to stand in front of a class and say, "You should do this and you should do that." That's the absolute opposite of what I am after. (PV58, group)

In groups that focused on the sharing of mental health experiences, having to speak about their own experiences of social and emotional distress could be challenging for some peers. There were also challenges regarding structure in those groups, with some peers finding very structured forms of conversation too constraining.

Yes, the kind of general issues that we dealt with might be... so we had, as I've mentioned before, this guideline about speaking from your own experience and that I think was quite difficult for some people to do because it does feel so vulnerable to share from your own experience and not make a generalisation like when you do this, it's like this or whatever. (PV23, group)

There's not enough time to discuss that and like I said, it seems like a job, like a chore at times to get through everyone. There's not enough to be a little bit less formal in order to chit chat to your neighbour, who you're sat next to, to say, "Well yes, that happened to me. I know what you mean." (PV19, group)

Yes, I mean, it's a very difficult one because, whilst it would be lovely for everybody to have equal amounts of time to talk, the reality of the situation is that it's never going to happen and, actually, you want an organic-styled way of conversation, you don't want it to be mechanistic; you don't want to be saying to people, 'you've actually had five minutes, just there, time to hand over to somebody else', because the person who might have just spoken for five minutes, might actually be the first time that they have spoken, to date. (PV52, group)

#### Focus in one to one peer support

One to one projects included those that had a social and activity focus as well as those that focussed on sharing mental health experiences. All one to one projects also included a strong educational element, although in some projects this only applied to peer supporters.

Co-counselling had an explicit focus on sharing experiences of social and emotional distress in a very structured way. Peers were trained how to interact with other peers in a particular, prescribed way that involved a structured exchange of mental health experiences and non-judgmental listening.

And, then we normally have sometimes, what they call... because it's a co-counselling thing, we have some time to do – well, what they call – a session, which would mean getting into pairs or sometimes small groups. Then the groups or the pairs take an equal time to talk to the other person or people. You can say whether you want just to be listened to, or you want the people to ask questions or make interventions, comments, and what sort you want. And, it's part of the agreement in that we're supportive. We don't say, "What did you do that for, you lunatic?" or anything like that. (PV50, one to one)

One to one projects using a mentoring approach had a primarily social and activity focus. Mentormentee pairs generally met in social settings such as cafes and other public spaces. They discussed a wide range of topics, many of which were not explicitly related to mental health. However, compared to other projects with a social and activity focus, mentoring had a bigger emphasis on supporting mentees to achieve agreed goals.

Yes, so most of the time we're talking about football, we're talking about jobs, politics a bit, English politics. We challenge about Brexit and stuff like that. So yes, we have fun. (PV40, one to one)

At the beginning of the meetings I talk very normally and we just talk about normal life with each other like, "Would you like coffee, would you like tea? Which coffee? This coffee is very nice. This tea is very good. Oh my God, this muffin is wonderful," and things just like that. [...] After that, after two meetings I talk about the job situation, college, everything, registering for an insurance number, anything and how to get through everything, just talking about college, just talking about the health situation and that's it." (PV41, one to one) "The current guy, we are working towards a goal. It's going to take longer than that so they set a target. They like to move people on within six months so every six months I would change but it's a maximum of two years. If, at the end of two years, it's still not going anywhere or it's too slow, they step in and they would stop it." (PV46, online)

All one to one projects included an educational component. Mentors in the case of mentoring projects and all peers in the case of co-counselling, had to be trained before taking up their role as peer supporters. These training sessions took place in a group setting but were essential in preparing peers for their role in one to one peer support.

Okay, in the class we had really a good facilitator. She was so good. She was using good methods. [...] So I found that it was a little bit of help, that method was good. It gave us time to be in small groups, then after which we could discuss other things so we were learning from each other. What I found out, that group was really good because we had that attachment from that time. So it was a really nice group. (PV26, one to one)

They teach any mentor about access to any charity community, about health centres, mental health centres, which one is useful for everybody. They teach things like that and I remember somebody coming here and talking to us about psychology... (PV41, one to one)

Everybody has this, sort of, about three days' training, and you can do some more if you want to. Well, I guess that's funded by the Lottery. I don't know. To be honest, I don't know. I'm sure I was told at the time. And, then it's all of us; we're just as equals, yes. (PV50, one to one)

#### Focus in online peer support

We found that the Elefriends website had a diffused focus. While it provided peers with an opportunity to share personal experiences and ask questions related to mental health it was also open to peers posting about topics unrelated to mental health. Although it did not take place face to face it still provided peers with social contact. Sometimes it even resembled activity-based projects, with the website moderators encouraging peers using the website to get involved with various activities in order to promote good mental health.

I think sometimes, like when the Olympics was on – the [moderator] challenged all his [online peers] a different set of tasks in line with the Olympics. You could add these little badges things onto your profile which, I know [peer] started gardening. Now she's got a thing for it. I had to hear all about these plants which sometimes you're like, oh my god not more plants. So it kind of works. (PV61, online)

If we've been out running, then we can put a picture about being active, or say, 'I've just run for three miles', or if you've done something creative, you can post a picture of what you've done, and that's being creative, and there are lots of things... (PV62, online)

The flexible focus of the Elefriends website was seen by peers as positive because it enabled them to post about any issue that was important to them. Some peers contrasted this with their experience of peer support groups that could become focussed too rigidly on a particular topic.

Because [online forum] doesn't have a particular defined purpose in the sense of, "We're going to talk about this, or that," There isn't a topic, as such. It's just in general, share what you're feeling, without judgment, or support others. Whereas the offline groups, yes, they have more specific kind of purposes. However, I feel that the good offline groups are quite open to discussing other topics that are not the main purpose of the group. So I feel that where they work, are where they are a bit more like the [online forum] model in the sense that –yes, "We're here for a particular thing, but if you bring up other things, we can still discuss them." (PV43, online)

Yes, so I think it's an aspect of it but I feel like [online forum]'s purpose is just to let people be and let people just kind of express how they feel and just talk about anything. So, that's still a purpose but it's not as direct as some other peer support groups for example. (PV44, online)

## Challenges to focus in online peer support

We found there were also challenges related to this openness of Elefriends to peers engaging with the website in a variety of ways. Peers reported that some peers use Elefriends in a way similar to mainstream social media platforms such as Facebook and Twitter. They believed this was inappropriate for a website dedicated to mental health. Peers also reported that the website moderators deleted posts they considered to be irrelevant.

I think the main thing is I think if you've seen these posts on other social media, such as Twitter or Facebook, people would think it's attention seeking. But I think quite often you get a lot of comments on there saying that people are trying to use it like Facebook. This isn't the platform it's supposed to be for. People are posting videos and photos. Then you start getting fighting, silly little comments and then before you know it all the posts are deleted by the moderation team. (PV46, online)

## Focus of peer support summary

Based on our findings we developed the following definition of focus within peer support.

'Focus' describes the primary emphasis of a peer support project. Peer support project foci can be grouped in the following categories:

- Social projects based around informal socialising of peers that may or may not include discussing experiences of social and emotional distress
- Activity projects based around peers engaging in a particular activity such as arts and crafts or sports that may or may not include discussing experiences of social and emotional distress
- 3. Sharing experiences of social and emotional distress projects with an explicit focus on peers exchanging their personal experiences of social and emotional distress in a structured way and typically by using mental health language
- Educational projects that inform and educate peers on topics related to mental health or other issues of concern

Peer support projects can prioritise one focus throughout their existence or switch between different foci from session to session as appropriate to the needs of peers.

# 4. Membership type

We found that Side by Side projects differed regarding how broadly or narrowly they defined boundaries around who could attend the peer support project – something we describe as membership decisions. Some projects were open to people from a wide range of backgrounds experiencing any type of social or emotional distress joining peer support. Others had specific criteria regarding who was able to join. Decisions on how to define membership of a peer support project were closely linked to who was considered a peer within the context of a particular project.

I think that's the main point. The rest of it, I think, is incidental. Part of it, but on the periphery. [...] I'm interested in what you're saying and I want to hear, and I'm comfortable with you for that one thing, because that's the thing we have in common. I don't care if you're married, or you're a pauper or whatever, or what your social status is. I think the thing that brings us together is that one thing. It could be depression. I suppose, if you're an alcoholic... for example, someone who's an alcoholic wouldn't join Gamblers Anonymous, and that's the point. (PV8, group)

These membership decisions influenced the form taken by peer support projects and in some cases also shaped the content of sessions and the type of support provided. For example, one project based around a particular mental health diagnosis was focused on openly discussing peers' mental health experiences relating to that diagnosis. Several projects working with refugees and migrants were focused on navigating UK government systems and experiences of discrimination. A disabilities project included training sessions on hate crime relating to that particular disability. In genderspecific projects, peers felt free to talk about issues they would not feel comfortable discussing in a mixed group.

Membership decisions tended to be made in the following way:

## Type of mental health issues

These criteria were linked to who was considered a peer within the context of a particular project. They were related to common experience of social and emotional distress as one of the core values of peer support. They reflected which aspects of common experience were prioritised within a particular project when it was being set up by the lead organisation. Some peer support projects within Side by Side were open to anyone who self-identified as needing support for broadly defined social or emotional distress. This included Elefriends.

But the poetry group, I think, is a social group as well because it's open to anybody, anybody that wants to come in, maybe dip in and dip out. And that's really helpful especially if there are some people who are feeling a bit down and they might bring poems that inspire them or help them get through the day even, you know? Because poems might hold words and language of support in a very positive way. (PV9, group)

Very diverse, extremely diverse. I mean, there's one lady who has just had a new baby, and we're all supporting her, and she's not in the best of positions to be able to care for and look after this baby, so we're all supporting her. Then there are some university students, and there are some people that live in New Zealand, and it's very diverse, very diverse. (PV63, online)

Other peer support projects were based around a specific mental health diagnosis, such as depression or bi-polar. In this case, members needed to have experience of living with (or sometimes caring for someone living with) a particular widely recognised mental health diagnosis in order to be able to join.

*They've maybe not got a crossover of groups or whatever, it's not an open group or anything. It's one particular group for one particular thing. (PV22, group)* 

> Open membership (anyone can join)

Closed membership (*restricted joining criteria*)

#### Inclusion of carers as members

Another membership category was having carers as members. This related to people who were joining specifically as carers rather than because they had their own experience of social and emotional distress, although many had that as well. In projects that had clear criteria on whether carers could join or not, this decision was made by the lead organisation. Including carers was not very common but it did happen in some peer support settings. Some peers found being able to bring along their close ones very helpful.

My mum came to that group with me and that was really helpful because then she could be there and she could learn about mental health as well. It helped that there was a group where both of us could be there. That's a different kind of - to peer support that we do at [Side by Side project] because if carers come along to peer support at [Side by Side project], they're asked to share their own experiences of mental health difficulties. So if a carer doesn't have experience of mental health difficulties then they can't attend the groups. Whereas the recovery group that I went to, the carers didn't have to have experience of mental health difficulties to be able to attend. (PV59, group)

We found that the presence of carers also created tensions in the peer support projects. Some peers felt that carers did not have enough common experience with others in the room. They experienced this as a barrier between peers and carers. Some peers thought that this could be overcome. Even though carers did not have first-hand experience of the mental health issue in question, they still had experience of supporting someone who had. Other peers felt strongly that the presence of carers changed the nature of peer support. In some cases it inadvertently stigmatised peers and ran counter to creating a safe environment.

The other thing as well, our group also carers can come to our group. Which was something actually going back to what you said about anything I would change. I would change that in as much as one bloke came in and he was like, 'Well I've not got an illness. I'm perfect. I'm normal.' [...] In actual fact I just turned round and said, 'You're normal?' and he said, 'Yes.' I said, "We're all normal." (PV22, group)

#### Identity as a criteria for membership

Another set of criteria for peer support projects that was linked to who was considered a peer within a particular context were identity categories not linked specifically to mental health. They referred to additional layers of common experience shaped by different aspects of a person's identity such as gender, sexuality, disability, ethnicity, and migration status. Many of the Side by Side projects were aimed at people experiencing social and emotional distress who also identified with one or more of those identity aspects.

Asian background. There's lots of women like me. Because I've suffered a lot, and I know that there are still people suffering. So it's, like, opened my eyes, and it's broadened me, and I want to do something about it. (PV67, group)

Because we, as LGBT asylum seekers, from repressive countries, homophobic countries, we are alone. We're alone. Even our family can't help. Our family can't help. The Government is the worst. So, here, knowing that (peer), an asylum seeker like them, LGBT, can help, is a

therapy. It's like half relief, then the other half, if you tell your problem, I can help you. It's very important, just to be there. "I am here with you, what's the problem?" (PV64, group)

There were projects that strongly identified with another common experience, and distanced themselves from mental health. Although addressing social and emotional distress was a feature of those projects, they generally did not use mental health language. Interestingly, some of the peers from those projects interviewed by our researchers did refer to mental health, talking about depression in particular. In establishing who was considered a peer, other aspects of people's identity and lived experience were considered important. Some projects had highly defined membership criteria that sought to achieve greater connection and support for peers through the sharing of common experiences. For example, in one group this was defined very specifically as being an LGBT person from Africa, who is seeing asylum because of persecution in their home country.

It's about supporting people who come from Africa, come from every other part of the world and have problems with, back there, about LGBT and they cannot – they need people to talk to. They need to talk to somebody. They need a friend. They need somebody to tell them it's going to be okay. (PV66, group)

Yes, for instance our group here [Side by Side project] is an asylum seeker refugee, whatever, so, yes, of course, like, when I'm with people like that – I think the reason why I'm more connected is because I generally believe and assume that they've all gone through stuff that I've gone through. Everyone has stories but similar, you know, family, rejection, friends, church, religion, institutions, whatever. So that brings us even more close. So it's not like – when we share stuff, there's no room for disbelief or shock, like, "Really?" Because it's all understood. (PV65, group)

In another peer support project for women from north-east Africa, the most relevant common experience was that of being a refugee or migrant from a particular region of Africa and how that shaped their current life in the UK. This included common experience of social isolation, raising large families on a budget, navigating statutory services and language barriers.

Sometimes you don't have housing benefit, and the housing association, the problems, schools, children, and the GP, I always have problems. Especially for me, I have, you know, I have, all the time I'm sick, you know, sometimes I have period and I lose lots of blood sometimes. I book appointment, they don't hear me properly, you can't find the road. I always have problems. [...] Even though I speak English, but there will be things that I

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misinterpret and don't understand, so I feel more freely to come here. And there's no support elsewhere that provides that." (PV28, group)

Several mentoring projects matched refugees and migrants, who had lived in the UK for longer periods of time, and who may have also travelled further in their mental health recovery, with refugees who had more recently arrived in the country. In addition to having common experiences of the challenges they faced as a result of their migration to the UK, this also provided a structure where someone who was more settled provided support to someone still struggling with those challenges.

For a start, it's very hard because I remember when I first came to the UK I was very sad because I start my second life. Your second life is a very, very hard life. [...] Everything is new like the culture, the smell, food, weather, people, language, everything. It's very hard. It's very hard and at that time I was very sad and was anxious about everything. After pass that experience, I believe I can help somebody who is in exactly the same situation now as I was eight or nine years ago. (PV41, one to one)

We found safety was a large consideration in deciding on project membership parameters. Shared identity and common experience was one way of ensuring a greater level of trust between peers that allowed them to feel safe. This encouraged the giving and receiving of peer support in both group and one to one settings. We did not find identity based membership criteria in an online setting; Elefriends was open to anyone who wanted to join.

## Stage of recovery

Some Side by Side projects were explicit about only being able to accept members that had reached a certain stage of recovery. This decision was made in order to ensure the safety of peers. In some projects this decision was also related to peers taking on specific leadership roles, for example as facilitators or mentors. In other cases, only peers currently experiencing a crisis were excluded as peer support because projects felt that they were not able to support them appropriately.

We put the limit at eighteen, for obvious reasons, but yes, nobody is unwelcome in the group, and the only people that we can't support, in the group, are people who are really in crisis and are being supported elsewhere, or aren't willing to work with the guidelines, as the rest of the group don't feel safe... (PV35, group)

In some cases, peer support projects wanted to ensure that peers were "ready" to engage productively with peer support. This was a judgement call that required that assessments were made. In mentoring projects, peers were interviewed and only a certain number of applicants was accepted into the project. Peer supporters also needed to be well enough to complete training in preparation for their role. Additionally, they had to have reached a stage of recovery that enabled them to support a designated mentee by role modelling recovery and offering practical and emotional support. In co-counselling, peers needed to be well enough to be able to complete the requisite training. They also needed to be able to engage in a project with a leadership structure, where all members were equally responsible for running the project.

#### Training

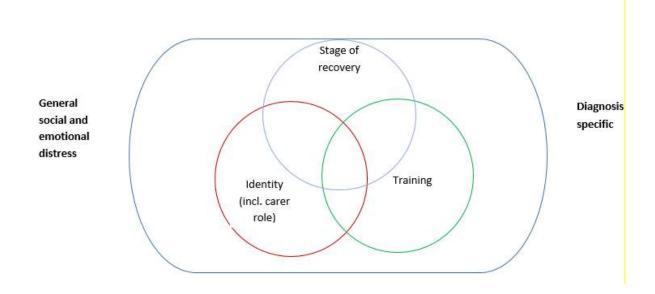
There were peer support approaches that required peers to undergo training prior to joining a project. This ranged from projects where all peers had to undergo training to projects where this only applied to peers taking on particular roles. In co-counselling, where there was no designated facilitator or coordinator and all peers had equal responsibility for running the project, all peers underwent training that prepared them for using the co-counselling approach. Mentoring projects had a structure of peer pairs where one peer supported the other. In these projects, half of the peers, i.e. the peer supporters, completed training.

We had lots of mentoring meetings with training with a lot of different people, learning about which organisation is good for access and which organisation is good for mental health, which ones are good for the body, anything. They were very good in supporting me in my mentoring. (PV41, one to one)

Although peer supporters highlighted the usefulness of this training in preparing them for their role, it raised issues regarding equality and reciprocity in the mentor-mentee relationship related to the two way relationship between peers as a core value of peer support. These issues were worked through within individual projects.

Many of the peer support projects taking place in a group setting were run by peers, who had received training in preparation for their role, however, training was not a requirement for peers to join the group as such.

Okay, so I think a crucial part to this, and I think this is where peer support does need to be looked at, is the facilitator themselves, I believe, should have a degree of training. So, (Side by Side project), for instance, does mental health first-aid at work courses, it's a two-day course; they also do (name of training), which is the suicide prevention training, and I think that any facilitator, as a bare minimum, should have that in place, so that, at least, when they go into a situation, which would be uncomfortable for some people, at least the facilitator knows how, potentially, to handle that situation. (PV52, group) The emphasis on training in many of the Side by Side projects suggests a trend towards the professionalization of peer support, which we discuss in the chapter on types of leadership.



#### Figure 6.1 Factors impacting on peer support membership

# Membership in peer support groups

Side by Side projects taking place in a group setting included those open to people experiencing any kind of social or emotional distress and those based around a specific mental health diagnosis such as bi-polar or depression. In some cases, groups were not open to people experiencing any type of mental health issue because facilitators felt they were only equipped to support people with a particular diagnosis.

Something I am familiar with, are things like depression, anxiety, but I'm not familiar or comfortable with psychosis. If someone comes to the group who might have schizophrenia, we wouldn't be able to deal with it, and wouldn't particularly want to either, because it's a very different condition, which involves different ways of interacting, which aren't really suitable for depression. (PV3, group)

This highlights the different purposes peer support projects had in Side by Side. An openness to anyone or highly defined criteria for membership. These decisions shaped the ethos of the group – and shaped its character. For example, Side by Side projects included mixed gender groups as well as specific men's and women's groups. This variety increased the number of possible peer support options that peers could choose from allowing them greater control over what type of peer support to engage in. We found that different peers preferred different options.

I don't think it would be appropriate to have groups just for men or women. I think it definitely should be mixed, from my experience. Perhaps some men might feel that they could relate better with just men, but for me, personally, I think it would be a bad idea. (PV10, group)

It's just a group specifically for men that have had mental health issues in the past. It just gives them an opportunity to socialise and voice any concerns that they've got and just have a bit of a laugh together really. (PV54, group)

Certain groups catered specifically to the needs of minority groups based on ethnicity, migration status and sexuality. These were often set up to cater for people who identified as peers in very specific ways, addressing several aspects of identity at the same time, for example a project for LGBT asylum seekers.

We are LGBT. We are asylum seekers. So the support they give us is for LGBT and for asylum seekers. Everything in a bundle. It's good. (PV64, group)

We observed the impact of these membership decisions on peer support culture. Criteria defining the numbers of people who could attend, level of training required for a role or shared identity characteristics of members gave sessions a focus and structure. Criteria regarding common experience in terms of specifically defined mental health issues or shared identity were fundamentally linked with the value of safety and supported human connection.

#### Challenges to membership in groups

We found some challenges regarding membership that were specific to peer support taking place in a group setting. If a group grew too much in size it could become difficult to facilitate. It could become difficult to comfortably accommodate all members in the group space. This could also lead to rising costs that impact on sustainability of peer support.

We have twelve people in one sitting, and really, there's only enough room for eight; we did explain that we were trying to set up a new day, and a new group, but we can't magic it up, so it's the next week. It takes weeks, because we also meet each person before they come to group, to see whether they are suitable, and to see whether they think they would enjoy the group, as well, so we have to meet them first, then we have to arrange to get the room, and get the rent, for what we want. (PV55, group) If a group has narrowly defined membership criteria it can be challenging to maintain its boundaries. This can lead to disagreements if established group members believe new members do not meet the criteria.

When it first started I think there were about six of us and it grew and grew, because somebody else got them to come into the group. (Peer) comes in here, he asks these people in town who we don't really know to go into the group. But that's how the trouble starts really. [...] I can understand if they've got learning disabilities or if they're disabled, but not just the public on the street. (PV14, group)

#### Membership in one to one peer support

In contrast to groups, none of the one to one projects in Side by Side were focused on a specific mental health diagnosis. They did, however, have a similarly wide range of membership types based on identity as did group projects. For example, one mentoring scheme was aimed at people with a specific experience of migration where being a refugee was an important aspect of the group's identity.

I think with this situation, this refugee situation we need more mentoring to help to us as refugees. (PV41, one to one)

Compared to groups, one to one projects had a greater emphasis on peers being "ready" to join the projects' particular type of peer support. This included being at a certain stage of recovery, and having a willingness and ability to undertake training in preparation for joining peer support. In the co-counselling project, all peers wanting to join had to be trained in using the co-counselling approach beforehand. This limited accessibility of peer support, as entry criteria required significant investment of time.

Everybody has this, sort of, about three days' training, and you can do some more if you want to. (PV50, one to one)

The arrangement is that, then, you can pair up with other people who are similarly trained, and then give each other equal time to listen to what they have got to say; their frustrations, worries, or whatever. (PV57, one to one)

While co-counselling was the only Side by Side project using a one to one approach that required all members to be trained, training was also an important part of mentoring projects. Peer supporters in those projects were trained in how to carry out their role before they were matched with the peers that they supported.

Also training as well, I had training how to be a mentor. [...] So many things. How to share information, how to distance yourself from the mentee. (PV40, one to one)

Being further along in their recovery was an important aspect of being able to join a one to one peer support project as a peer supporter. In mentoring projects, for example, this allowed the mentors to better support their mentees. In the co-counselling project, where all members effectively held leadership roles, members were expected to be at a particular stage of recovery to be able to undergo training and engage in peer support productively.

If people are in crisis, I mean, obviously we'll listen. We won't say, "Go away, we're not going to talk to you". We might, you know, make a... if people are in crisis, we think of places where they could go; to their GP or the mental health services or something. But mainly, the group is for people who experience mental health problems. It might be experiencing depression; or an anxiety; they might find it difficult to go out and things like that; but if they are really ill then we signpost them somewhere else. (PV50, one to one)

#### Challenges to membership in one to one peer support

Challenges of peer support in a one to one setting related primarily to the accessibility of peer support. Training in preparation for joining the project required a significant amount of time to be spent before peers started to engage in peer support. When it came to co-counselling and peer mentors, having to undertake training and being at an advanced stage of recovery limited the number of people that could get involved in peer support. It also limited the number of mentees that could benefit as projects could only involve as many mentees as their limited number of trained mentors could support. This represented a limiting factor to the choice and control some peers were able to exercise over the kind of peer support they may have engaged with.

#### Membership in online peer support

Elefriends was open to people experiencing any type of social and emotional distress and of any identity background. It was open to people with a wide range of mental health experiences, although moderators did signpost people in urgent need of support to other services. Training was not required as part of the project criteria, however, Elefriends was only accessible to peers who were computer literate.

It's an absolute mass of ranges, from physical health which affects their mental health. People who are just low, people who things have happened to them which have made them the people they are today, that haves been affected because of an incident like me. (PV32, online)

It's important. [Online forum] has been flexible in that way. It's gone from mostly people with depression and looking for ideas to people who need more support. It's been flexible like that. It's worked flexibly because the format is not so restrained that it didn't have space for people to use it that way. (PV63, online)

The setup of Elefriends, where peers could access the website 24 hours a day supported flexibility and the control peers had over dipping in an out of online peer support. It also increased accessibility of peer support to people who lived in places where they did not have access to face to face peer support, especially in rural areas.

Like I say, I'm very isolated, so to get that is very important for me. (PV45, online)

# Challenges of membership in online peer support

Peers also reported some challenges of the open membership model. Due to the nature of Elefriends being an online platform, it was difficult to monitor its membership. Although it was designed to be used by people experiencing social and emotional distress, any member of the public could have set up a user account. This had an impact on how safe some peers felt on Elefriends and influenced how they used the website.

I mean you have to join obviously to see what people are saying on [online forum], you can't just look at it without joining but then anyone could join, couldn't they? I guess that's the same with the Facebook groups really. Anyone could join. (PV45, online)

The setup of the website, which was open to anyone experiencing social and emotional distress, had one main page where users posted messages. This meant that individual messages were quickly pushed down the page and could lead to peers feeling that their messages were not read by anyone. This impacted on how people felt about themselves, and the effectiveness of the peer support community if non-one responded. One peer suggested introducing discussion forums on specific topics to reduce this problem.

I think if it was split into...if they had a depressions one, an anxiety one, a post-traumatic stress disorder. Like you go to a forum, an area almost so it's a bit more narrower, everybody is posting in. It's that quick, your post can be off the main page within 10 minutes. It can disappear quite quickly so you can feel as though nobody has seen it. If they had areas, if you go to the site and go to an area where people all had your experience, I think that would be better than it currently is, which is just a free for all. (PV46, online)

Setting up peer support as open to anyone or limiting membership to a particular group of people had an impact on the form and content of peer support projects in Side by Side. In many cases limiting membership increased emotional safety and the connections peers felt to each other. On the other hand, keeping membership open enabled anyone needing support to have access to it and encouraged equality within peer support.

# Membership summary

Different types of peer support vary in the extent to which potential members need to fulfil some form of criteria. At one end of this spectrum is peer support that is open to anyone who self identifies very generally as needing support for social or emotional distress. At the other end of this spectrum is peer support that requires potential members to:

- 1. Have a particular mental health diagnosis
- 2. Have a particular identity characteristic (gender, sexuality, disability, ethnicity, migration status)
- 3. Be at a certain stage of recovery
- 4. Undertake particular types of training

A peer support project can be defined along several sets of criteria at the same time, for example a peer mentoring scheme aimed at refugees that requires mentors to be at a certain stage of recovery and undertake training.

# 5. Organisational support

Peer support projects in Side by Side received different levels of support from organisations they were affiliated with. This was a reflection of the organisational structure of the peer support projects. Some projects worked under the name of an umbrella organisation to which they were only loosely linked. Others were fully incorporated into an organisation and formed part of its 'service delivery'. Thus, the level of organisational involvement and support that they received differed between Side by Side projects. Some were organised directly by large, nationally recognised charities (Mind, Bipolar UK Depression Alliance). Others were part of local or regional organisations funded through the grants programme. Examples included refugee and migrant organisations, women's and men's organisations, disability organisations, user-led community mental health organisations and social enterprises, among others. Due to the nature of how peer support within Side by Side funding peer support needed to be structured as a time limited 'project', managed by a constituted organisation. This shaped the form that peer support within Side by Side could take and led to varying degrees of formalisation, and professionalization, of peer support. This created a tension with the idea of peer support as non-hierarchical, informal, and ongoing.

Support that Side by Side projects received from their lead organisations included the following:

## Infrastructural support

This related to practical support that helped establish peer support and encouraged it to thrive in practice. We found that in many Side by Side projects the form taken by a project was determined by the organisation it was associated with. This was especially noticeable with peer support projects linked to a brand of a national organisation. For example, projects that worked under the umbrella of Bipolar UK, and many Mind projects ran sessions that were structured in a way that allowed all peers to speak, sometimes in rounds, within an allocated time.

I am pretty sure peer support happens out there, away from [Side by Side organisation], away from staff, and that people aren't aware sometimes about peer support. If there's a good circle of friends, say, for example, or a choir group or whatever, I'm sure there are elements of that happening. I guess, because this is specific for mental health, and it's set up as somewhere to go, it needs to have that structure. I don't know, I'm not sure what the success would be without it. (PV37, group)

Lead organisations provided practical support required for running a project that included material resources and staff time. This involved providing access to free venues, providing activity resources (art materials, gardening tools, etc.), and coordinating communication (sending reminders about

meetings, advertising events in newsletters, posting content on Elefriends). In doing so, lead organisational input began to provide 'structure' to the Side by Side projects.

Because I don't think the meetings would be as structured, either they wouldn't have the formal communication that goes out in the monthly newsletters, having that contact phone number to ring or text someone to find out if we are meeting or if the meeting's been cancelled, or if it's been moved. So yes, I think it's quite important to have that structure. (PV7, group)

That's quite an issue, because there are quite a wide range of us peer-groups, under the [Side by Side] umbrella, and they all meet in different places. I mean, some of them, for example, are gardening groups, and they meet on an allotment; some do struggle to find anywhere suitable, but we get a lot of help from [lead organisation], and quite often use their premises. (PV47, one to one)

This type of practical support allowed peers to develop their own initiatives, when they might not otherwise be in a position to do so.

I mean I always say to anybody who asks, I just suggested it to [lead organisation] and they took me up on it and made all the arrangements and provided the notebooks and the pens and so on so it didn't cost me anything. It was wonderful really, just to go, 'I've got this idea,' and then have it taken up and then be facilitated and a room booked. I didn't have to do anything. (PV2, group)

Well, because I'm not from this area, I'm out of borough, there isn't a huge amount of scope for me to be able to do placements in the same way, however, I have had support from organisers and the coach herself who was actually teaching us, in terms of being able to set up something in my borough—one of the places that I volunteer in. (PV25, one to one)

An important feature of some of the Side by Side projects was that they were linked to organisations that provided other services unrelated to peer support. These could be addressing mental health, for example counselling, or other matters such as housing or legal issues. The contact that peers had with the peer support project increased the accessibility of those other services, for example if they took place in the same building, or if they were coordinated by the same member of staff.

It would be too different because she [coordinator] is always running lots of projects like painting projects, music projects, travel projects and English class projects. I come to English class as well and it's every Wednesday from 1 o'clock to 3 o'clock and there is a wonderful teacher. Yes, this is not just [peer support] supervision. She can do lots of things for any meeting and every week. (PV41, one to one)

This project is just there for them, it's just there for them, and people think they've got support. Other people just travel in from their country, they've got mental issues and everything, so they don't know how to get involved in the organisation to get counselling. But in [lead organisation], they've got everything there, even a lawyer every week. Counselling, they do counselling there. They've even got some courses, education for, you know, illiterates, maths, stuff like that, even cultural event, music. It's good. (PV40, one to one)

These interconnections between projects were reported as beneficial because they allowed peers to access additional social and specialist support. The latter was particularly relevant with projects that were aimed at a narrowly defined membership group, such as for example refugees, where many peers needed additional support with legal issues, housing and language.

#### Safety structures

We found that an important aspect of organisational support was related to safety, one of the core values of peer support. Some projects were provided with a list of safety guidelines developed by the lead organisation.

So we have [lead organisation] peer support guidelines for behaviour in groups and that covers things like it's okay to make mistakes, it's okay to say sorry and make amendments, it's okay to leave and come back. We agree to not interrupt. We agree to listen and not pass judgement. (PV23, group)

Being part of a wider organisational structure provided peer support projects with clear lines of accountability and procedures when peer leaders or other peers had concerns regarding safety or wanted to signpost someone to additional support. The presence of safety structures was reported as reassuring.

I think in the time I've done it, there's been two times where I've needed to seek extra support for somebody who was really worried. So, I guess, that's that element. I guess in terms of working for a charity like [lead organisation], we have to be accountable, as well. (PV37, group)

And if I saw something I didn't like, I could report it. So I felt that was good for me as well, to be able to have somebody that was kind of overseeing it. We were under a bit of an umbrella of care then. (PV32, online)

#### Training and supervision for peer leaders

We found an important part of organisational support was providing training to peers who were taking on leadership roles. This included training peer leaders in facilitation techniques that support core values such as safety, two way relationship, and choice and control.

It's quite a short training course. It's quite intensive. On the one hand, I kind of feel like maybe if it had all been done in a slightly closer block, but then it was once, twice a week, which isn't actually really that bad at all. It gives you time to mull over things and think it through and write answers to questions that you've had time to think about. So in that sense, yes, it is good. (PV25, one to one)

Where provided, peer leaders found ongoing supervision to be an important aspect of organisational support. Supervision took the form of one to one meetings with a manager in the lead organisation or facilitated group supervision meetings. In some cases, peer leaders that acted as co-facilitators provided supervision support to each other, however, this was primarily the result of a lack of regular supervision from the lead organisation.

Apart from my colleague, if we have a problem, we talk about it between each other, and supervise each other; we feel that, if you are a peer leader in a group, you need supervision. (PV55, group)

Supervision enabled peer leaders to discuss issues or concerns that arose during their work as peer supporters. We also heard how some peer leaders felt that appropriate supervision was supportive of their own mental health recovery.

Yeah, I think that's also to do with the supervision and management support I received because that's been so valuable to me. That's enabled me to keep doing my job, you know, when I felt so low, like in previous jobs I would have rung in sick because I felt so low, so bad, I would have thought I can't face this. (PV59, group)

For some peer leaders, organisational support extended beyond supervision meetings. Peer leaders felt they could get in touch with the project coordinator and other organisational staff to support them in their role at any time.

Yes, they support and give me advice about everything because I don't know everything, yes? I should tell [coordinator] what I am thinking of doing like, "I want to refer him to mental services" and she told me, "Okay, that one is better because it is near his house and it's like that and like this." They are very helpful about it not just in...sometimes I talk to her over the phone, not just in the meetings and she is always ready to help me. (PV41, one to one)

Having lead organisational support provided ensured those leading peer support in Side by Side felt confident to do so, through supervision and training. They felt safe and knew they could provide safety structures for the peers receiving and giving peer support online, in groups and within one to one peer support projects.

#### Organisational support in groups

In this section, we consider how having lead organisation assistance has supported Side by Side groups. We found examples of projects where organisational affiliation determined the structure of the group in great detail and practical arrangements for when it was held, where, group size, safeguarding procedures and even what food was served.

The other group at [organisation 1] they are really good. We have a meeting to about twelve o'clock or half twelve something like that and then lunch is out ready and then people just have lunch, have a natter and go out. At [organisation 2], like I say, they do the food for us. At [organisation 3], they do the teas and biscuits for us and things like that. (PV13, group)

The thing is that the groups are always on a night and I am not sure if they might be better run through the day because the one I run at [location] is through the day and we get people coming in then but it's structured really by [lead organisation] because basically I can see that they have all their groups from 7 o'clock to 9 o'clock at night and maybe that works better, you know that in the daytime people might drop off. (PV56, group)

We also found that groups that were strongly linked to lead organisations, ensured that peers could benefit from their resources and contacts including inviting speakers to give talks or sign posting to other services such as an advice desk or employment projects. These benefits were mostly well received.

They also offer a housing service in terms of practical support and there's a key worker who is also involved in that area who has clients and helps them with any problems that they have. So that is more practical orientation with the housing. (PV36, group) He's a great guy. He brought a lawyer last week – the last meeting we had – and I think it's going to be more of a continuous thing because that's one thing that we refugee seekers need because, you know, we don't have money to access lawyers. You know, lawyers are charging a lot, considering the fact that we haven't got access to support, you know. (PV64, group)

Some peer leaders reported that undergoing initial training increased their confidence and had an empowering effect on them.

Even when I was doing the training, I kept thinking, "I can't do it," because I had to do a presentation and that, to me, was something that, you can imagine, awful. For somebody that has panic attacks, it's like... but I did it. I passed the course so I then started to facilitate. (PV34, group)

Peers who were involved in group peer support found safety guidance provided by a lead organisation were very valuable.

Then if it's something that needs even more, say we're still not sure, then obviously there's people at [lead organisation] that are higher than us that we can go to and we have stuff like I go to group supervision meetings where I meet up with other facilitators and we can discuss things there. (PV34, group)

But if they go into a room by themselves, they're going to have to know that if the room doesn't work for any reason, they're going to have the support and the back-up they need from the people who have made that peer-to-peer group possible, if that makes sense. (PV8, group)

This back-up was experienced as reassuring. In some cases the association between safety and facilitator as organisational presence was so strong that peers avoided attending groups that were purely peer-led and did not have a staff member present, as discussed in the chapter on types of leadership.

We did find, however, that some peers were concerned that too much organisational input into the structure and content of peer support compromised peer ownership.

Because, when you come here, it's a bit of food, it's playing cards, there's a bit of music, blah, blah, blah. But it's going to be genuine people. This isn't peer-to-peer because we haven't organised this venue. We haven't paid for the food. So, that's not peer-to-peer. (PV8, group) Yeah, I mean, I wouldn't say that it's not, I think I probably wouldn't say that it is peer led, it's not peer led at all. So yeah that is different but I think that, that's just the environment of it, you go in and you talk. (PV5, group) Peers in some groups felt that they were not able to change the structure that was imposed by the lead organisation. This limited the extent to which they could adapt peer support to meet their needs.

You could do something different. I mean I could suggest it to them rather than hear people's situations but I don't know. [...] No, there's no opportunity there I must admit which is one downside to things I think maybe. No, there's no opportunity to add feedback. (PV19, group)

On the other hand, peers highlighted several issues that arose when a peer support project was not given enough organisational support. In some cases, peer leaders running new projects without much previous experience felt that the support they received was not sufficient for them to run the project confidently.

I guess, with the project in general, I think I could have done with a bit more support from higher up sort of people. Sometimes I feel I've been left to be autonomous, so I could have done with a bit more support. (PV53, group)

I mean, we had no help, to be honest, setting up our group; we didn't know what to do. [Lead organisation] gave us £150, and, basically, that was it, get on with it. I mean, I already had a DBS anyway; my colleague didn't, so she has had to get one. We didn't know about bank accounts, we didn't know that it had to be a constituted group, we didn't know about this, we didn't know about that; we found out, on the journey, but it would have been nice to have somebody, from the beginning, perhaps somebody from (lead organisation), as they gave us the money, to actually support us. (PV55, group)

Support from a lead organisation enabled peer support in a group setting to develop effective safety structures and provided material support that helped groups with meeting spaces and activity resources. Groups that received limited input from lead organisations found that lack of support challenging, however, other groups found that too much control from the lead organisation limited peer initiative.

## Organisational support in one to one peer support

In this section, we consider how having lead organisation assistance has supported Side by Side projects delivering one to one support. In particular, we found these projects adopted well established project structures for peer mentoring or co-counselling already developed by a lead organisation. This prescribed the form of supervision and training, session frequency, and safeguarding. There was some flexibility around locations and times of group sessions that were negotiated with peers. Locations and times of one to one meetings were arranged independently by peers.

In peer mentoring, peers applied for peer supporter roles. They were trained and matched by the lead organisation with other peers based on being at different stages of recovery. While peers reported that they felt equally included in meetings, they could not influence the structure of the project as such as this was pre-determined. This raises questions related to values of two way relationship, and choice and control.

To be honest with you, I don't know the name of the project. I self-referred myself to [lead organisation] after I had read all sorts of information on their website. [...] We were introduced to the company called [organisation] or something. They did training and coaching. [Coordinator] was very helpful actually. She brought the person from that company to [lead organisation] and we've been interviewed and we've been accepted on this course. (PV11, one to one)

In one to one projects, training provided by the lead organisation was particularly important. In mentoring projects, all mentors were trained before being matched with a mentee. Co-counselling used a model that did not involve fixed mentor and mentee roles. In co-counselling all members took turns in supporting each other in structured, timed interactions. Therefore all members were required to undergo training that was provided by the lead organisation. This also applied to members of our research team that visited the project.

How it works is you have a short training course of three days, spread out as a day a week for three weeks, which is where you're kind of coached in listening skills. The arrangement is that, then, you can pair up with other people who are similarly trained, and then give each other equal time to listen to what they have got to say; their frustrations, worries, or whatever. The arrangement is that it's confidential around the same confidentiality agreement that you outlined to me earlier, and that everything is always equal; the division of time is always equal. (PV57, one to one)

This standardisation provided co-counselling with a highly structured approach that was managed by the lead organisation. However, once peers were trained and became members of the network, the emphasis within the model was on peer-led decision making.

#### Challenges to organisational support in one to one peer support

The pre-determined structure of mentoring projects limited the control peers, including peer leaders, had over the shape taken by peer support. Peers reported that they had been trained and were ready to start mentoring but because matching with mentees was under the control of the lead organisation they could not do anything about any delays that occurred in this process. She (coordinator) was trying to organise but it hasn't been put in place yet. [...] The thing that could be improved, like I said, they should offer training, get people that you are going to deal with, which they haven't done yet. Some of us are wasted when we should be in the field helping other people. They said they are working on it. (PV26, one to one)

In one to one peer support projects, the biggest organisational influence was the highly structured nature of the projects over which peers had very little influence. This included compulsory training for some or all peers joining the project.

#### Organisational support in online peer support

In this section, we consider how Elefriends has developed within Side by Side having been created by Mind over several years. Mind provided the infrastructure for the Elefriends website, and was responsible for maintaining it. This included the layout of the website and content posted by the Elephant. The controls within Elefriends pre-date the Side by Side programme. For example, Mind provided peers using Elefriends with safety guidelines as well as safety tips that were posted on the website by the moderators under the persona of the Elephant.

And also, the [moderator] – he can post things to say what's going on in the community of [online forum] to keep it safe. So every now and again, he'll post/she'll post what's on their wall and give you some tips and ways to keep yourself safe. So I think safety is utmost in [online forum's] mind. (PV32, online)

Safety measures included monitoring of posts and discussion that the website moderators took off the website when they considered them to inappropriate or triggering. Peers using the website also had the possibility of reporting anything abusive or inappropriate and escalating it to the moderators through a report button.

There was one time, where someone got very angry with me, but there is a report button, you see, so you can report people and, actually, if posts aren't appropriate then [lead organisation] quickly take them down; there is someone that oversees everything that goes on, on [online forum], all the time, not twenty-four hours a day, I don't think, but a lot of the time, and you can report anything that's horrible. (PV62, online)

The success of Elefriends has led to decisions needing to be made about its sustainability, including whether to create regional Elefriend sites and decisions over more active signposting.

They've just done two surveys for [online forum], and they were trying to change it, and I don't think that it ... it gets very busy at times, I will say, and I guess more and more people are linking into it, and it's difficult for [lead organisation] to know how to move forward with it, and they're talking about making it regional, which I think would be very sad; I still think it should remain a national thing. (PV46, online)

They've extended the time that they're available [the moderators], but I think the main thing is that they've improved the way that they forward people on to different services. (PV43, online)

The medium of an online setting required the lead organisation to develop and maintain a website. This meant the structure of the online peer support project was determined by the lead organisation. Although the support peers offer each other takes an informal tone, the lead organisations moderators have editing powers to delete any post they deem inappropriate, reinforcing the level of organisational control.

## Organisational support summary

Organisational support describes the extent to which peer support receives assistance from a lead organisation or runs independently of a lead organisation. Organisational input can vary from light assistance to significant control. Lead organisations can be national organisations, such as Mind or Bipolar UK, or smaller local or regional organisations. Support provided by lead organisations includes infrastructural support such as venues and other material resources, implementing and maintaining safety structures, and providing training and supervision to peer leaders.

# Discussion

#### Approaches to peer support

Through the interviews we conducted while developing our Core Values Framework we found that there was great diversity in the peer support that people were a part of in the Side by Side programme. We found that because of this great diversity, it was difficult to clearly define a number of separate 'models' of peer support, and we instead began to think about our data in terms of three underlying approaches to peer support. These approaches were peer support happening within groups of people, peer support happening on a one to one basis, for example in mentoring projects, and peer support happening online, through social networking sites such as Elefriends.

While these distinctions are helpful to us in organising our findings and describing what they mean for peer support, they are necessarily simplistic. Within our data we have evidence that some forms of peer support may feature elements of two different approaches, such as in mentoring or in cocounselling. In these examples much of the peer support occurs in one to one, or one to two situations, however in both models there was also a strong group component. In mentoring projects mentors come together in groups to discuss their how their mentoring is going, to receive group supervision and to support each other. In co-counselling people come together as a group in the first instance and then break off into pairs or groups of three to provide peer support to each other. The group in this context also acted as a spring board for some members to socialise outside of the peer support context. Elefriends is another example of a blended form of peer support. While many people support each other through a series of posts, comments and other responses on the main messaging page of Elefriends, which was visible to many people, peers also reported supporting each other, or receiving support from the site moderators, on a one to one basis through the private messaging functions on the site.

To tease apart the many potential varieties of peer support would be the subject of another large research project in itself. Our key learning from this was that people doing peer support were always doing so in a way that was adapted to their local context. This meant that people who developed projects may be responsive to a wide variety of factors including the local geographical context, the language and culture of the people who used that particular project and the resources that may be available to a particular project.

#### **Core Values**

When trying to develop a core values framework we found that the things that people described as being important to peer support were heavily intertwined and difficult to tease apart. As a result we see our core values as being constituent parts of a picture, rather than standing alone in isolation. Some of the values appear to be dependent on other values being in place. People told us that the felt safer because they knew that they were around people who had experienced similar things to them, and because they were able to exercise a level of choice and control over their participation in peer support that they had been unable to exercise in other forms of mental health support. In keeping with this theme we believe that the fourth, fifth and sixth core values, Two Way Interactions, Human Connection, and Freedom to Be Oneself are dependent on the previous three. If Experience in Common, Safety and Choice and control are not present and actively endorsed within a peer support context it is unlikely that these later values, that underpin the nurturing relationships in peer support, will be able to develop.

#### **Key decisions**

While developing our Core Values we became aware of a number of key decisions the people who develop projects need to make in order to practically organise a particular peer support context. The key decisions could not be said to be unique to peer support, and yet were very important in shaping the kind of peer support that occurs in a particular peer support context. When drafting these key decisions we became aware of the true diversity in opinion around what could constitute peer support. For example some peers may feel very strongly that peer support can only be peer support if it is led by peers and has a peer facilitator. Further many felt that it is the active use of lived experience of mental health difficulties within a peer support context that makes a support group 'peer' support. However we also spoke to people who were involved in peer support that was led by a paid member of staff or by a facilitator who did not actively disclose any experiences of poor mental health, who none the less considered themselves to be doing peer support. Given this wide variety of opinions we have tried to use these sections describing the range of options that may be relevant to these key decisions to give some indication of the rich variety of ways in which peer support was delivered across the Side by Side programme.

#### Limitations

The Side by Side programme gave us an opportunity to talk to people doing peer support across the UK in a wide variety of ways and contexts. However the sheer number of people and projects involved in Side by Side, and the limited time scale posed challenges to the research team.

We conducted a significantly higher number of interviews with peers taking part in peer support groups (72.5%) compared to one to one and online peer support. While this reflected the composition of Side by Side projects, it nevertheless means that our findings were based largely on data relating to peer support taking place in a group setting. In addition to this, the data relating to peer support taking place in a one to one setting came from only three projects, all of which were operating in a very specific context. Two of these three projects were mentoring schemes that were aimed specifically at refugees and migrants. The third project used a co-counselling approach, and as described above, was not solely a one to one peer support context.

Another challenge was that the mentoring projects were not very far along into their work at the time of interviews (summer-autumn 2016). In one project, most mentors had not yet been matched with mentees, and in a second project mentors had only been mentoring for a few months. This also meant that mentors (n=6) were over represented in our sample compared to mentees (n=1). Possibly as a consequence of this, we found that a lot of data from one to one projects actually referred to group dimensions of the project. This included training and mentor supervision meetings where mentors supported each other, and group elements of the co-counselling project sessions, before peers broke off into pairs and when they came together as a group again at the end of the session.

The peer interviews were focussed on those two regions where our regional researcher were based (West London, and Lancashire). We did not have high recruitment rates in our third regional site, and so did some additional interviews out of region by telephone, primarily in Leeds (n=12). This means that we know more about peer support occurring in Lancashire, Leeds and London, than we do about other regions where Side by Side was Active.

Despite locating a regional researcher in Suffolk, which has a large rural population, we struggled to recruit rural participants (n=7). This reflected how difficult it is for those living in remote areas to take part in peer support, especially if they have to travel long distances to reach the nearest peer support projects.

Because of the emphasis on teasing out the principles and values in the qualitative interviews, we collected limited data regarding certain other issues that only became evident as important in the analysis stage of the research, especially issues related to the processes of running peer support projects. For example, we initially worked on the assumption that facilitators within all projects were peers. However exploration of our data suggested that some facilitators did not have, or did not disclose lived experience of social or emotional distress. We would need to do further research to assess whether this impacted on how peer support happened in those settings. On a related issue, the question of who can be considered a peer leader within the context of a particular project was more complicated to answer than we initially expected. Based on our findings, having lived experience of mental health difficulties was not enough to establish peerness in contexts where other aspects of identity were considered crucial in shaping peers' lived experience. In light of these findings it would have been helpful to ask more targeted questions about the facilitation process in non-peer led groups as this would have given us a better understanding of the processes of

facilitation from the facilitators' perspective. We also had limited data on facilitation and leadership in Elefriends, where much of this happens "backstage" and out of view of peers using the website.

## Conclusions

There was a wide variety of types of peer support being delivered through Side by Side and as a consequence we have encountered diverse views across the project. As a consequence we have developed a set of Core Values that we believe should be present in all forms of peer support (although they may look different in those different forms of peer support). We have also tried to understand the different decisions that people developing peer support may make when shaping their particular projects. People doing peer support adapted their projects to work in their particular local contexts.

# Chapter 7: Peer support in a BaME context

# Summary

This chapter looks at how peer support took place within Side by Side projects specifically aimed at peers from a Black and Minority Ethnic background. It is based on qualitative data collected through interviews and focus groups with 39 peers taking part in BaME specific peer support. Based on this, we developed a typology of BaME projects in Side by Side that included:

- General BaME peer support
- Community specific peer support
- Refugee and migrant peer support

We found the reasons why BaME peers engaged with BaME specific rather than mainstream peer support were related to their understanding of what constituted relevant experience in common. This shaped who was considered a peer within the context of a particular project. In addition to experience of social and emotional distress, which was relevant across all Side by Side projects, we identified the following aspects of common experience as important in establishing peer relationships in BaME specific peer support:

- Shared cultural background
- Experience of migration
- Racism and discrimination
- Intersectional experiences (minorities within minority communities, e.g. LGBT)

We found that the core values and decisions mechanisms underpinning peer support were shared between BaME and mainstream projects. However, the experience of social and emotional distress of peers in BaME specific projects was so significantly shaped by other aspects of their lived experience that they needed to be addressed in an identity specific peer context.

# Background

Side by Side included a variety of peer support projects aimed specifically at peers from Black and Minority Ethnic (BaME) backgrounds that were funded through the small grants programme. Alongside a focus on addressing needs of people living in rural areas, this was one of the priority areas of Side by Side. The McPin Foundation were commissioned to carry out additional qualitative work alongside the main study to further explore the experiences of BaME communities with regard to peer support. It is important to acknowledge this was a small and limited piece of work that did not engage with the full diversity of minority populations living in England. It is a limited piece of research that explored only briefly how emerging findings from the Side by Side evaluation rested with feedback from people attending peer support specifically designed for people from minority ethnic communities.

# **Our** aims

This part of the research aimed to establish whether there were differences between how BaME and White British peers in Side by Side engaged with peer support and if so, identify what those differences were.

# Methods

In order to answer this question we spoke to peers who were taking part in those Side by Side projects that were aimed specifically at peers from a BaME background. As part of the overall evaluation we had spoken to other BaME peers, who were taking part in mainstream peer support within Side by Side. We use mainstream peer support to refer to peer support that was open to both White British and BaME peers. Mainstream peer support projects in some of the Side by Side regions had a high proportion of BaME members. This reflected the area's demographics, for example in West London. Although we interviewed a number of BaME peers taking part in those projects, data from those interviews are not included here as this chapter is focussed on peer support designed specifically for BAME peers. Therefore, this chapter is based on data we collected by speaking to peers that were taking part in peer support catering specifically for peers from a BaME background. This included three focus groups, totalling 22 participants, and 18 interviews (see table 7.1 below). One peer had taken part in both an interview and a focus group bringing the total of peers we had spoken to for this part of the research to 39. The ethnic and gender breakdown of the peers we spoke to largely reflected the demographic composition of BaME peers in Side by Side but was also influenced by which projects offered our researchers access to their members. We spoke to peers from seven different projects spread out across five of the nine Side by Side regions.

Characteristics	Participants
Ethnicity	Black African: 14
	Black Caribbean: 2 Black - unknown: 1
	South Asian: 12 (South Asian-Pakistani 7, South Asian-Bangladeshi 1, South Asian-Other 1, South Asian-unknown 3)
	Arab: 1
	White - other: 1
	Other mixed background: 1
	Other: 7 (Somali 3, Eritrean 2, Iranian 2)
Gender	Female: 26
	Male: 13
Region	West London: 12
	Northampton: 9
	Leeds: 8
	Teesside: 7
	Coventry: 3

#### Table 7.1: Demographic characteristics of participants

# **Findings**

# Types of BaME peer support

Our first task was to consider how peer support approaches were tailored to different BaME communities. We found there was no distinct approach or approaches but there was a wide variety of BaME-specific projects regarding setting (group or one to one), focus (social, educational, activity, sharing of experiences of social and emotional distress), gender (gender specific or mixed), language of communication (community languages, English, or both), and audience. Projects in Side by Side differed regarding how they defined their target group within a broad BaME context. This provides a typography of groups:

## **General BaME peer support**

This peer support was open to anyone identifying as belonging to a minority ethnic community. They included peers from a variety of ethnic backgrounds (for example Black Caribbean and South Asian) in the same project, and a mix of first generation migrants and British-born BaME peers. Although they were open to anyone identifying as BaME, demographics of the local areas sometimes led to a large proportion of peers from a particular background. In general BaME peer support, the main language of communication was English. In projects with large numbers of peers from a particular language community, some activities (especially informal conversations) happened bilingually.

*Well, it is fine if a person cannot speak English in this group, but those who can, speak English. So we can talk in English or Urdu both. (PV60, group)* 

#### Community-specific BaME peer support

This peer support was aimed specifically at peers from a particular BaME community. These ranged from wider definitions of an ethnic community such as Black African to narrowly defined ethnic communities such as Bangladeshi. Several of the latter projects ran activities using community languages. This was particularly important for peers with low levels of spoken English, who would struggle to take part in other peer support, including BaME peer support that used English as the main language of communication. There were also examples of multilingual peer support, for example a group working with women from northeast Africa, which ran its activities in Somali, Arabic and English.

The ownership things, I will add, the Thursday group, the knitting group, they're all Arabic speakers, so that make them very, they share the same language, so they speak the same language. (PV31, group)

# Refugee and migrant peer support

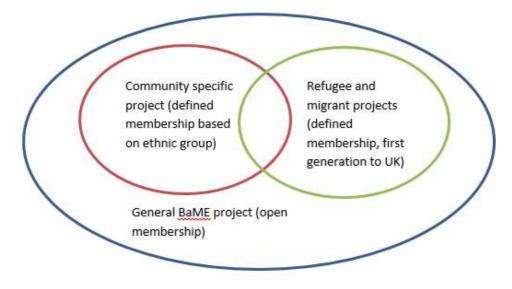
This peer support was aimed at people who were first generation migrants. Some of these peer support projects worked specifically with refugees and asylum seekers. Others were open to all migrants to the UK. Refugee and migrant projects were often focused on experiences of social and emotional distress that were shaped by peers' experience of migration, and, in the case of refugees, by peers' experiences of persecution in their home country. This type of peer support often provided access to wider social and legal support either through the project itself or through the lead organisation. The majority of peers in these refugee and migrant peer support projects had been

settled in the UK for less than a decade. They had the widest variety of ethnic backgrounds among peers, including white other.

If somebody is not a migrant and hasn't experienced issues of being a migrant and came and started to work as a mentor, then I think maybe they can't help them because to not have any experience of living in his country, where everything has been fine and they don't understand his life, Middle Eastern life, Mediterranean life. I know about Middle East culture, Middle East life type and I think it is much better when the mentor and the mentee are from the same situation and the same migrant circumstances. (PV41, one to one)

There was some overlap between these types of peer support. For example, many community specific projects included a high number of recent refugees and migrants and offered advice and support in accessing services.

In summary, our typography was interlinked.



# Reasons for engaging in peer support

Some of the reasons peers listed for engaging in BaME peer support were similar to those we heard from peers taking part in mainstream peer support. In contrast to mental health services, where support is often limited to a small number of sessions, peer support provided ongoing support. Peers also preferred the informal nature of peer support compared to mental health services. Some peers spoke about the greater immediacy of peer support – there was no need for waiting lists; social networks they established through peer support afforded them an opportunity to talk to someone when they needed to, without a structured appointment system.

Some BaME projects in Side by Side avoided using mental health language in order to attract peers that might not want to engage with a project that was explicitly focused on mental health, either out of stigma or because they did not perceive the difficulties they were experiencing as related to mental health. However, many of the peers we spoke to joined peer support because they were dissatisfied with their experiences with mental health services. This challenged the assumption that people of BaME backgrounds turn to peer support primarily because of stigma attached to formal mental health services.

I got referred to assessment and then I had to wait six months for... it was due to bereavement, my situation was due to bereavement. But then what happened was that I had to wait for six months. Mental health doesn't wait for an appointment, it just basically hits you. I started basically getting counselling privately, even though if you do that privately you still have to go through a structured format where you sit down on a date that's given by someone. It's not like you are able to ring up somebody and say, "Well I'm having a crisis this particular minute." (FG1, group)

I hate it when it has to be structured like what (peer) has been... here's a bit from my doctors, my GP and all that, when you have to sit in front of the counsellor and they will tell you she's got only 30 minutes with you and I'm thinking, "Okay, where will I start," because the list is just so endless. When I come to (Side by Side project) I know that this is the time to empty myself and feel better and I've seen this working just for me as a person and not as a presenter (i.e. facilitator). (FG2, group)

I had a terrible temper when I was doing therapy and for about eight months, seven to eight months, when they kept talking about the same thing over and over, from the beginning we talked about anger management and stuff, after several months I used to go back to those things and wake up all those memories again. You go back, you transfer all that aggression on people. To me, it's not working. It doesn't work. (FG3, group)

Peers were dissatisfied with what they experienced as an over-reliance on the medical model in the NHS. Many spoke about being prescribed medication without being offered access to other treatment. They preferred peer support to this because it afforded them an opportunity to talk about their social and emotional distress.

Yeah, before I came to this group I was more depressed. I used to go and see my GP and they would give me these tablets all the time and it would not go. I was always depressed. I wouldn't find sleep. I could remember things that used to happen to me in Uganda. And now, as I started coming to this group, I found out that loads of people are going through the same thing, it's not only me and it's just that you have to be better. You have to talk to – actually, this group helps you to be more relaxed, more to forget the past and focus on the future and focus on where you are going right now. (PV66, group)

Then I remember there was a time she (GP) gave me some tablets to take. Trust me, I didn't take them. I just threw them in the bin because I didn't need that because obviously I knew I was going to sleep. When I sleep, what's going to happen? The dreams will come. So what's the point of taking them? So I had to put them in the bin. All I wanted was people, I wanted someone to talk to who would understand me and not to judge me. So I felt so judged every time I'm sitting there and she's got 10 minutes to attend to me and then my story is too long for 10 minutes. (FG2, group)

We just need to talk, we don't need no tablets, no, they don't do good to us. Since we were girls, we're still taking tablets until now, I'm 60 and I'm still taking tablets. I just want to talk to someone, it's my nature to listen. It's therapeutic for us to be listened to, isn't it? Yes, we just want someone to sit there and listen to me, it's natural./.../ just listen, give me your ear and I will understand and then I will pour out. By the time I leave there I'm a free spirit so it's just natural. This abracadabra with medicine, tablet, take this injection and take that, we don't need that, talk to us. You are listening to me, I feel good, it's natural. (FG4, group)

This could be interpreted as a result of the Western medical model not being culturally appropriate to the needs of certain BaME communities. However, this argument should not be overemphasized since there were many white British peers who valued the social nature and human two-way relationships created by peer support over the medical approach to addressing mental health problems. Some BaME peers highlighted how the medical model neglects the impact of socioeconomic factors on social and emotional distress, which they saw as particularly relevant in the case of people of BaME backgrounds.

I am aware about black issue when it's not a solution only if every black person goes to the hospital just to prescribe drug and also labelled they have mental, brain problems. The problem is situational, the situation, social issues, job issues, relationship issues so we need to address that so that it's not just when the people go there they just get a prescription for the drug and that drug, you can't get cured, it's just controlling, you don't have any cure without drugs. So it is how to address that issue with the right people and also in the right place and how also people, BaME group or the minority can have access to the talking therapies, in social, sometimes not with the professionals. Lay people sometimes are better than the professionals with wisdom and also equality and honesty. (FG5, group)

While peers taking part in BaME-specific Side by Side projects were critical of a purely medical approach to mental health this was not necessarily the result of their ethnic background. From this perspective, they had a shared view of the benefits of peer support with peers in mainstream Side by Side projects. Peers in BaME-specific projects stressed the importance of human connection, in contrast to impersonal professional mental health services, two-way relationships that develop between peers, and the importance of similar lived experience that peers share in common. The structure of the BaME-specific peer support projects also enabled peers to have choice and control over which elements of peer support they get involved with and to what extent.

Yes, because one to one (i.e. counselling) I feel like I'm talking to myself. The person in front of me is listening to me all the time, not saying anything, so I feel I'm the only one who has that problem. But in the group, no, I can feel normal. Many people they have the same problems as me, not only me. (FG6)

The majority of people have more or less gone through the same thing like you've gone through in your life or going through in your life. It's just nice to get with a group of women that have gone through that same situation and you've got that support there because they understand it. If you've got somebody who doesn't understand... yes okay, he's done the therapy side of everything but not actually gone through what you've gone through. I don't think anybody can really understand that. (FG7)

Different nationality, depending who comes and depending who trusts you. I offered myself, I said, 'If you don't have family, do you want me to do this for you? Do you want me to pray for you? Do you want me to meet up with you?' It's an open question and if you feel comfortable to talk to me or comfortable to go out together, there is no force because it's open and flexible as well. (FG8 )

We found that the core values of peer support in BaME-specific projects did not differ from those in mainstream peer support projects. However, the way those values translated into practice was shaped by the nature of the peer support. This was particularly important in relation to which aspects of experience in common were considered relevant in establishing who was seen as a peer.

That is why BaME peers we spoke to had chosen to take part in BaME rather than mainstream peer support projects.

### Reasons for engaging in BaME-specific peer support

We found that the understanding of what constituted 'experience in common' as a core value of peer support was key in defining the scope of peer support and who was considered a peer in any particular context. In BaME-specific projects experience of social and emotional distress was not enough to constitute commonality unless it was supplemented by additional layers of common experience such as shared cultural background, migration, and racism and discrimination. While this overlaps with the typology of BaME projects outlined at the start of the chapter - as those are also based on who was considered a peer - these facets of experience appeared to be relevant to some degree in all BaME specific Side by Side projects.

We found several reasons why peers took part in BaME specific peer support:

#### Shared cultural background

For some peers, a shared cultural background constituted an important part of experience in common. One aspect of this was staying in touch with one's cultural heritage, ease of communication and culturally familiar foods. This was particularly prominent in community-specific peer support projects but was also raised by peers in general BaME projects that had a high proportion of peers from a similar background.

When I go to the GP, sometimes I need interpreter but when I come here, I speak my own language. (PV30, group)

You can go, you can have your food, you can speak your language, you can sing, dance. (PV67, group)

Well I was happy with the other group which I did and I was separated from my culture, separated from my family. I was isolated, I was outcast, but you know, I did cope. I had friends who loved me, who cared for me but deep down, deep, deep, deep down you know who you are. You miss your roots and I like to be involved with my roots and now I feel like I can give them so much as well because I know there is a massive need in our community... (FG9, group)

Shared cultural background was raised as important by peers involved in one to one peer support projects. Some reported that matching peer pairs based on cultural background led to a faster process of establishing trust, which supported establishing safety within peer support.

I think when choosing the mentor and mentee it's very, very important that you choose something that matches between them. /.../ For example, culture, religion, maybe a little bit of language, yes? This is important because the mentee is very quickly getting to trust the mentor about improving and about anything. /.../ Yes, it would be more difficult, someone from Latin America with someone from Syria or someone from Afghanistan; it's a completely different culture. (PV41, one to one) Peer support where peers had a shared or similar cultural background facilitated a better understanding of how social and emotional distress is conceptualised within particular cultural contexts and how cultural expectations of appropriate behaviour impact on one's mental health.

There's no word for depression in Somali, you say 'lack of faith'. (PV27, group)

Well I was getting a lot of help from, well I had help from (organisation 1) and from (organisation 2) but when I came to (Side by Side project), I found it different because their understanding was more like mine. They understood a lot more what I was going through, with it being the same background. /.../ Pakistani. They obviously understood about arranged marriages and all the different things. I found it a lot easier in that sense and then I've been obviously getting a lot of support from (Side by Side project), going to court and everything, they've really helped. (FG10, group)

But I think most importantly I have empathy because I understand the culture, I know about the sensitivities. I think you feel comfortable. You know you don't have to... it's like in counselling as well, I think that when you... we link in with (name of service) where it's bilingual counselling service, but what's quite good, I always refer a lot of ladies who can't speak English there because I find it so difficult when they go into counselling and then there's certain words you can't say and you can't explain, there's certain words you can't explain that feeling and I think a lot of people talk about what it means to them and a lot of agencies and services don't understand and I think we do. We know what the consequences are if you do challenge those behaviours. (FG11, group)

In some cases, peer support substituted culturally embedded social support systems that were disrupted by the peers' migration to the UK. It stepped in to provide an opportunity to socialise in ways that otherwise were not available to peers in the UK.

Women back home socialise in different ways so they might never have stress. (PV27, group)

Back home, you'd fall into some bereavement of some kind but that same moment when you hear about the news, the whole house is filled with people. People are singing, people are praying, people are just chatting over a meal, which is exactly what we miss when we are here. But now with (Side by Side project) there we are, we are talking, she tells this and you know, time goes. By the time we go home I feel better, especially networking, meeting new people. I mean it's just the best that you could have. (FG2, group)

While many peers highlighted the benefits of being supported by peers with a similar cultural background, there were other peers who preferred a multicultural mix or who deliberately avoided those of their own cultural background.

It is not important I think from which country is mentee or mentor. It's not important, important to do something to help the mentee. That way mentor is responsible to do his job properly to help others and that's it. The country is not really important. (PV39, one to one)

Yes, there is a mixed vibe and then obviously if somebody was racist or whatever, they wouldn't come. They'll know it's a mix. We all know we're gonna, it's going to be better because there will be no judging. (FG12, group)

Well, it's not that important, and we have people from different countries in this group /.../ No, it is not a problem for me; a person can be comfortable by meeting people from different countries. (PV60, group)

Those who avoided peer support specific to their own cultural background often did so for fear of being judged. Fear of judgement, however, was not related primarily to mental health stigma but rather to disrupting rules of expected behaviour mostly in relation to gender and sexuality.

They judge you, they will make an image of you in their own mind. (PV42, one to one)

To be honest, I keep myself away if I know it's Arab culture or something, I prefer to be away from them because all the time they judge other people, they don't know what is their problem or what happened in their life, just judging from outside. (FG6, group)

But there are loads of people here in the UK who are still scared, you know, cultures and stuff. And, for me, as an African, when I find myself in an African environment, which I tend not to, not to go into because, you know, but then I'm still consciously aware of the way they look at me. But fortunately and fortunately for them we're in the UK so they can't do anything. They can't even speak. You can only whisper. (PV65)

This underlines the importance of choice and control as a value of peer support, whereby peers have the freedom to choose the type of peer support project in which they feel comfortable and safe. A shared cultural background can serve as a positive point of connection between peers, however this connection cannot be assumed and peers should be given a range of support to choose from rather than being routinely signposted to a project that matches their cultural background.

#### **Experience of migration**

Many peers we spoke to preferred BaME-specific to mainstream peer support but did not opt for peer support catering to a single community. The underlying common experience in many BaME-specific Side by Side projects was that of migration or, in some cases, specifically of being a refugee. Although cultural similarity was sometimes still a factor in these peer support projects, a crucial dimension of experience in common was living as a migrant in the UK. This type of peer support often focussed on how the concomitant socio-economic and legal barriers, including racism and discrimination, shaped the peers' experience of social and emotional distress. One of the issues raised by peers that had a disproportionate effect on refugees and migrants was social isolation.

She lives by herself at home, so she feels isolated if she stays at home by herself, so she says it's good to come here and meet other people. She says she wants to learn new skills because they do knitting group on Thursdays, and she said she'd like to meet new people and make friendships. (PV31, group – via interpreter)

I meant to say in the beginning of the interview that it is good to get people out of the house to remove isolation. So that's a big contribution to the group. (PV28, group)

When I was made redundant by the NHS, they didn't even think about my responsibility. I was new in this country, I got my refugee asylum and I was happy, I didn't claim any benefits. I worked so hard. I saved money. /.../ So I lost my job, I lost my house. I lost my friends as well because my friends who had been made redundant, the ones who I met in the hospital

where I was working, they went to Australia, they went to New Zealand, they found jobs there. They went to Canada. So I've been left alone. (PV11, one to one)

An important element of common experience for refugees and migrants was navigating British government systems and overcoming barriers in accessing services. Encounters with these were a source of great social and emotional distress for many.

... she was okay, she had even got off the medication and now she went to the office in the council and then the person there, the way she treated her. /.../ So the doctor is also wondering why, because they knew that she was getting better. See, those are the people, even you, yourselves, I have told you that you end up crying when you're sat in offices. Someone looks at you as if you are just rubbish, the way they answer, the way they treat you, you come out, I'm just trying how to stop crying when I go through this course, when there's crying, when someone looks at you and gives you a certain response, so the society's not helping but putting them really in the worst situation. (PV26, one to one)

As it is, the guy was suspended, the manager suspended him but that kind of support is where sometimes people suffer because they don't know how to navigate the system around them. It can be local authorities, it can, in this case, the NHS or the education system and so on. (FG13, group)

After the joy of the refugee status, then it's back down. Yes. The lid go down because the person is, it's like you free a child outside, he will be going all over the place. He doesn't know he's a child. But we need support in that where to apply for benefit, where to apply for accommodation, where to apply for English course, if English is not your first language, where to apply for college. (PV64, group)

For asylum seekers, as well as others with insecure immigration status, this insecurity was a source of great anxiety. Living under threat of potential detention and deportation, asylum seekers could also be dispersed to other parts of the UK increasing their social isolation and disrupting the continuity of any medical care they were receiving.

And also, we are LGBT asylum seekers and we live in uncertainty. Right now, if the Home Office won't give me leave with my boyfriend, I don't lie you, I will be in a mess. (PV64, group)

Before I came to (city 1) I was in London. No – yes, I was in London. The Home Office moved me from London. They brought me to (city 1). And I stayed in the hostel for about, oh, about four weeks. That's a month. And then I was moved to (city 2). I kept going to the LGBT building in (city 1) and I had met friends. I was getting used to them and then the Home Office moved me to (city 2) and it was a bit hard. I needed somebody – it was, it was like I was going back to zero. (PV66, group)

Some recounted how their experiences with the Home Office had a direct negative effect on their mental health. In some peer support projects, these experiences formed an important element of common experience. Peer support offered peers an opportunity to discuss these distressing experiences and reassured them that they were not alone in this.

So we have shared those experiences like, we have anxiety, depression, and sometimes we say how it came about. Sometimes you feel annoyed about certain things and how you are treated in a certain place, like all of us have gone through the Home Office so you find it so distressful, you've got someone (treating you) as if you are a criminal. So we shared that and we found that everyone was treated the same, I thought I was being treated like that. I said maybe it's because I looked ugly to that person or maybe it's because I look or, I started judging myself. Then afterwards, when we discussed and said, oh, so that is the Home Office, that's how they treat people. So I felt afterward. But I hated that place, whenever I entered it I could feel somebody on me, because I know those people hate me. But after sharing then I said, "oh, so it's not me alone". (PV26, one to one)

And each of them I can know, I can see on their face that there's something wrong here and then I ask, "What's the point?" "Oh, [name], the Home Office!" "What Home Office? Tell me." If she can't, it's okay. We'll meet after, in town, a milkshake then we'll discuss and then she tells me. She tells me. I say, "That's nothing. That's nothing. We'll do it." If it's a letter, I'll help write a letter. If it's any – I say, "Don't worry. I know about this case. You'll be fine. Call the solicitor and then give this evidence. It is fine." And, you see, a few words; it really moves mountains. It does. (PV64, group)

Without a legal right to work and minimal financial support from the government, asylum seekers also could not take part in other projects that required them to spend money, even if this was a small amount.

I would say yes, because I believe that people who are in the same situation I am, belong to this group. Sometimes you go to groups and people expect you to do things and you have no money, you don't know your way around the place, but if you come to this group it helps you a lot because they know you have no money. They know you don't know England. You don't know this place and it makes it easy. It makes it easy. (PV66, group)

... to be fair, it's transport because some of the women have got financial, obviously, a strain on their finances because they're seeking asylum, they only get so much a week which is nothing. So then we're asking them to come to a group and they have to pay the bus fare, that's the problem. It makes it really difficult to be honest. (FG11, group)

#### **Racism and discrimination**

Some of the experiences highlighted by peers talking about the effects of migration on social and emotional distress already hinted at the importance of considering the influence of racism and discrimination on mental health. Several peers taking part in BaME-specific Side by Side peer support also spoke more explicitly about their experience of racism as a cause of their social and emotional distress. This was particularly common among black men.

I can't really answer that. I don't really think about being black. /.../ Because I always thought I was British. That's why I couldn't understand what was happening to me when I was younger and that. "Why is it happening?" And I still thought I was British. Then I thought, "Oh, you have to be strong." /.../ Maybe that's what's sent my head a bit funny, because I couldn't work out why I was being treated like that. (PV68, group) It's a very bigger picture and mental health is in the bigger picture. When I got here, very briefly, I was the only black in my class and I was the only foreign student in my class, in (name of university), and of course the different culture and all this and so on, part of it was probably because of me not understanding the culture. So it was very difficult to cope with it and sometimes I heard them making jokes about me and one day I just said, "Enough." I picked up the phone I rang the scholarship office and I said, it was early on Tuesday. I said, "On Friday I want a single ticket back to Johannesburg." They said "What?" I said "this Friday, a single ticket back to Johannesburg." "Why?" and I told them, I said, "I cannot cope with this racism and so on." I said, "I got away from racism in South Africa and then I come and get it here." I was aware that it was impacting on my studies, I couldn't sleep. (FG14, group)

Statistically, it's proportionately equal but if you ask the police what they're doing at this particular moment in order to improve confidence in the work that they do amongst black people, most of them are obviously suffering from mental health because of them, they're looking at reducing disproportionality. That is not the issue. People are concerned about the quality of the police. That is exactly the same thing within the NHS. It's not about proportionality, it is about the quality of the service that we get when we come into contact with the services. (FG1, group)

Several peers complained about experiencing racism when accessing NHS services from staff as well as other patients. Some perceived this to be an institutional problem rather than a case of discrimination by individual staff members.

Well sometimes I feel like there's racism. /.../ Yes, because in the (mental health centre) it's really hostile. Last time I was there it was really hostile and I couldn't get out of it. I just wanted to get out. I behaved myself, took the medication that they gave me, because they give you like a higher dosage or whatever. I couldn't take it. I just wanted to get out because it was really hostile. There was a lot of racism. You could see it but you couldn't do anything about it so I just had to stay away from it. I think they did a survey but I just wrote everything that I could on the survey afterwards. You have to do that because they can get away with literally murder. It's not the staff, it's the patients. (FG15, group)

Don't get me wrong, the background is not just the colour (of the medical practitioner) /.../ because sometimes you get people who are institutionally racist themselves but it is the institution that's making them behave in a certain kind of frame. (FG1, group)

Peers reported that racism within the NHS and wider society was one of the reasons they were engaging in peer support that caters specifically to people of BaME backgrounds. Although some peers had experience of mainstream peer support, and some were taking part in both BaME and mainstream peer support at the time of research, many had not attempted to access mainstream peer support. This was partly because they expected to experience racism within that context based on their experiences with mental health services and wider society, and partly because a mainstream peer support environment would not provide enough of a common ground with other peers. If an important cause of social and emotional distress was racial discrimination then this could only be addressed, from a peer support perspective, in an environment where others have experienced the same type of racial discrimination. Peers highlighted the effect this had on creating trust among peers, which was crucial for creating a safe environment. Yes, that was, if it was mixed with white people then I wouldn't have gone. /.../Yeah, I wouldn't have gone. I don't trust them. /.../ Everything bad that's happened to me, there's always been a white face behind it. I'm not racist though but it's just everything bad that's happened, it's always been a white man behind it. /.../I can't talk to them. It sounds racist but it's not. Trust me. I just can't talk to white people like I can talk to black people, you know what I mean? (PV68, group)

When you've got racism as the base of your issue, you are more than likely going to find solutions that are race specific or that have got a racial dimension so that's how we end up being of a particular racial group because the roots of our problem, we believe that it's racialisation. /.../ So consequently the racialisation of our groups is the default position for us to think, "Well if we are being discriminated, which has put us in this position, can we try and use the same kind of racialisation of our group to try and attack it?" /.../So we've been helping each other writing letters to address the grievances, including the grievances that myself, I didn't realise actually as part of the group we've been able to write letters to address the specific concerns that we have which are racialised problems, hence I wouldn't go to say Mind with my issues, not because I think that they're ineffective but because it loses the potency of my original argument. (FG1, group)

For many peers who experienced racism as at least a partial source of their social and emotional distress mainstream peer support did not provide the kind of safe environment essential for peer support. Peer support projects catering specifically for BaME peers or particular groups of BaME peers offered an environment where peers had enough experience in common to allow peer support and its core values to flourish.

#### **Intersectional experiences**

Some projects narrowed down what was considered relevant 'experience in common' even further to include not only social and emotional distress and identifying with a particular BaME group but also other facets of identity. Using an intersectional approach, they focused on how the experience of social and emotional distress by BaME peers was further shaped by their gender and sexuality. Gender specific projects enabled a greater degree of commonality among peers and also allowed them a space where they felt more comfortable to share and discuss their problems.

Well it's a lot different (from a mixed group) because obviously, you can't really talk as much as you can talk about personal things, like if you've got any problems, in front of everybody where if they come to the women's group, we know there's just us and we can say whatever we like, like if we've got any problems or whatever... (FG10, group)

While this could in some cases be interpreted as a cultural issue this should not be overstated. Side by Side included several mainstream men's and women's projects and single gender peer support projects cannot be seen as an exclusively BaME domain.

An LGBT asylum seeker project that was funded through Side by Side is a good example of why in some cases the experience in common that impacts on peers' social and emotional distress needs to be defined even more narrowly than being BaME or having experienced forced migration. The

experience in common in this project included persecution in the peers' home countries on the basis of sexuality, enduring the UK asylum system, and continued discrimination by members of their ethnic community in the UK. Peers that were forced to flee their countries because of persecution not only by government but also by the majority population cannot feel safe in a peer support project aimed at their particular ethnic community, unless it catered specifically to LGTB people from that community. This example underlines the importance of choice and 'freedom to be oneself' as core values of peer support.

Yeah, obviously I'm LGBT. I'm African ... I came out recently, last year, but I've always known that I'm a lesbian, but obviously culture, tradition and family and friends and church and stuff couldn't let me. Because, you know, I was just surrounded by negativity, you know, criticism and torture and... You know, mind-blowing things that even got me confused as a person. /.../ None of them stood by me, which helped me because I had to make fresh friends, new friends of the same identification, same gender, you know, same group in question. My relatives, I just didn't care because I had lived for people for years and years and years so I said to myself, "You know what? Suddenly I'm standing up for myself." So I identify as a gay woman so strongly, like, I don't think I have to explain, it's just me. (PV65, group)

Yes, I've tried to go to church but I failed to try to tell anybody in church that I'm LGBT and in (city) I don't find any churches that are LGBT. And before, when I was growing up, I used to like going to church but they started preaching stuff about gay, LGBT people being evil, being inhuman, being – they said – they used to say LGBT is a sin. So I stopped going to church. But when I got here I thought it would be different, I would go to church, but I still find it difficult, in church, to tell people I'm gay or I'm LGBT. It's not easy. But I've tried to go to church. I've tried to go to (name of LGBT bar) and tried to meet people who are like me, but sometimes they are a bit different. (PV66)

### Range of support offered by BAME-specific projects

BAME peer support projects within Side by Side did not have a uniform shape and included peer support groups as well as one to one peer support. There was a similar range in terms of facilitation, types of leadership and focus in both BaME and mainstream Side by Side peer support projects. BaME projects included peer support with a social, activity and educational focus as well as those focussed on sharing experiences of social and emotional distress, often including several foci within the same project. Projects were facilitated to varying degrees, depending on their structure – a led discussion, for example, required more facilitation than a walking group. Most BaME projects were led by peers in terms of not only experience of social and emotional distress but also ethnic background and other relevant lived experience. However, there were some BaME projects that were not overall peer-led in that sense, although they had peers in other leadership positions, for example, as peer mentors.

In terms of organisational support, lead organisations served as an important link to other support. BaME lead organisations often offered their own advice services on issues such as housing and benefits and served as a source of information on how to access other services. This included legal advice on immigration and family court cases. Other people just travel in from their country, they've got mental issues and everything, so they don't know how to get involved in the organisation to get counselling. But in (lead organisation), they've got everything there, even a lawyer every week. Counselling, they do counselling there. They've even got some courses, education for, you know, illiterates, maths, stuff like that, even cultural event, music. It's good. (PV40, one to one)

*Like those who have domestic problems or external ones, like any problems with the Council or income tax departments, then they help and offer support. (PV60, group)* 

While there were examples of mainstream peer support projects in Side by Side that served as a link to other services, this type of support seems to have been particularly common in BaME projects and especially in refugee and migrant projects. Some of the peers we spoke to, entered the peer support projects through first being in touch with an advice service run by the lead organisation. In some BaME peer support projects that did not have an overt mental health focus, addressing social and emotional distress was one in a range of its aims. Some projects created a space for peers to support each other alongside staff-led workshops aiming to educate and inform.

This type of holistic support was not only offered by the lead organisation but also by the peers themselves. While sharing of information about other services was not unusual in mainstream peer support projects, it was particularly relevant in projects with a high number of peers who were new to the UK.

I am the one who brought all here to college. People have been here for three years. They didn't know that college exist. They can go to college free, after six months of applying for asylum. Now, I go to college. Because, (name), my boyfriend, I search on-line, I find the information. He's now doing English at college and I brought the information and he said, "(Name), are you serious?" I said, "Yes, after six months asylum you go to college free of charge and you get bus pass." A girl is doing cosmetics. The other is doing something, maths. GCSE maths. (PV64, group)

After that, after two meetings I talk about the job situation, college, everything, registering for an insurance number, anything and how to get through everything, just talking about college, just talking about the health situation and that's it. (PV41, one to one)

Yes, it helps you get access to the GP, counselling. It helps you get access to education, because they advised me to get to college. Malcolm advised me the best way I can get to college and I'm waiting to start college in September. (PV66, group)

#### Discussion

There were several limitations to the research. This chapter is based on speaking to peers taking part in seven different Side by Side projects. While we spoke to a significant number of peers, their experiences may not reflect the experiences of peers taking part in other BaME-specific projects in Side by Side. While we tried to ensure peers from a number of ethnic communities were included in the research, this was restricted by the demographic composition of the BaME peer support projects and influenced by which Side by Side projects chose to engage in the research. As a result of these factors, there were significant numbers of black African and south Asian peers that participated in the research with smaller numbers of black Caribbean peers and peers from a Middle Eastern background. There were significant minority communities that were not represented in the research sample at all, for example Latin American and East Asian. There were also twice as many women as men included in the research. While this reflects the fact that Side by Side projects tended to have a higher number of female peers as well as the inclusion of two women's projects in our research sample, it also means some of our findings might be more reflective of women's experiences of BaME peer support.

Our research sample had a bias toward peers with a good level of English. We conducted four interviews via Somali and Arabic interpreters (two each) and one interview was conducted by an Urdu speaking member of our research team. The remaining interviews and focus groups were conducted in English. This limited our access to the experiences of peers who spoke little to no English. Peers who had a good enough level of English to take part in the research but were not completely fluent also might have struggled to get their views across as clearly as they wished.

It is important to keep in mind that our findings are based on BaME peer support taking place within the context of Side by Side. Being funded through Side by Side required peer support to be developed in the form of 'projects' and managed by constituted lead organisations. BaME peer support taking place outside of a major nationwide project or informal BaME peer support taking place outside of the project paradigm completely may look very different from what we found through our research.

We did not explore BaME engagement with mainstream Side by Side projects in this chapter. That was primarily because we considered that BaME specific projects will give us a better insight into potential differences in how BaME individuals engage with peer support, which was our central research question. In chapter 8 below will be able to relate some of the findings from this chapter to our peer support log data. However, there is much further work that could be done comparing the experiences of those BaME individuals taking part in mainstream peer support and those taking part in BaME specific peer support.

More research is needed to further illuminate some of our preliminary findings, for example the impact of culture on peers engagement in peer support. Our findings suggest that BaME peers preferred peer support because it allowed them to discuss their difficulties in contrast to medication-based treatment they were offered through the NHS. This could be interpreted as either a rejection of a Western medical model resulting from cultural differences or a part of a general trend among those turning to peer support. We also found a preference for women-only projects within some communities that emphasised the freedom allowed by gender-specific spaces. However, this is also a characteristic of many mainstream women's project, especially those working with survivors of domestic abuse and sexual violence. This highlights the importance of considering cultural factors in understanding BaME peers engagement with peer support without being too quick to explain all of their behaviour through the prism of an essentialised notion of culture. Our findings also show that while shared cultural background can serve as a point of connection furthering trust between peers, this is not the case with peers who represent minorities within their own communities or who have other negative experiences with people of their own background.

#### **Conclusions**

This chapter aimed to establish whether there were differences between how BaME and White British peers in Side by Side engaged with peer support. We found BaME and mainstream peer support were based on the same set of core values and peers were drawn to peer support for fundamentally the same reasons – seeking support from peers with whom they had experience in common in a safe environment where they had the freedom to be themselves. However, BaME peer support projects had a distinct identity because of their definition of who was considered a peer within that particular context - someone from a particular ethnic community, someone with personal experience of migration or someone with the general experience of belonging to a minority community within what is a largely white British context. There was just as much variation in approaches to peer support within BaME specific projects as there was between BaME and mainstream projects. Therefore we cannot speak of a BaME voice or BaME experience as such, as different BaME peers, both within and across communities, preferred different approaches to peer support. If there was any unifying experience among BaME peers it was that of racial discrimination, which many peers identified as an important source of their social and emotional distress. Therefore, although the principles and values of BaME peer support did not diverge from those of mainstream peer support, BaME specific projects provided an important space for BaME peers to offer support to each other in a way that they could not within mainstream peer support.

# Chapter 8–Developing a better understanding of peer support: synthesising peer support log and interview data

## Summary

We revisited some of the findings from both our peer support log and our in-depth interviews to see if we could better understand and make sense of what we had discovered. We did this in two ways. First, where there were statistically significant findings in our chapter 4 log data we looked again at our qualitative interview data to see if people's accounts of their experiences helped explain our findings about how and why people do peer support. Second, where people told us in interviews about things that were important for peer support we looked for log data that backed up what people had told us. This process of 'data synthesis' suggested that:

- People chose to access peer support of all sorts in response to particular needs and aspirations (meaningful activity, social contact, gaps in existing services, crisis and so on)
- There were some similar issues and also some very distinctive issues that related to people choosing to access BaME specific peer support that should be carefully considered going forward
- As people's sense of wellbeing and general health increased, and as they experienced more supportive contact with friends and family, they chose to access less peer support
- Over time people involved in Side by Side accessed less peer support overall while maintaining or increasing the level of benefit (especially their self-efficacy)
- People did not seem to stop accessing peer support altogether, maintaining a core level of support (for example attending a peer support group as a source of ongoing social contact with friends)
- When offered a range of different types of peer support, over time people identified the approaches that worked well for them, making increasingly efficient and effective use of peer support as a result
- Giving peer support should be understood as an active, reciprocal sharing with others, especially (but not only) in the context of group peer support
- Increasing the amount of peer support people give in this way brings about significant change for people in a number of areas
  - People giving more peer support in this reciprocal, active way in groups saw improvements in their sense of wellbeing, hope for the future, self-efficacy and increased supportive contact with friends (new friendships were made both in and outside of peer support groups)
  - People giving more peer support one to one saw improvements in their sense of wellbeing and hope for the future, also benefitting as they came together as groups (for example, for training as mentors)
- Giving and receiving roles could be more demarcated in one to one peer support, and especially in online peer support
- People derived some benefit to their general health status from receiving one to one peer support in response to specific problems, and asked for support from others online when they were feeling less well
- People like giving support to peers in the form of advice and guidance (especially one to one and online)
- On balance it would seem to be the *agency* in peer support that brings about most change, both in terms of choice and control over what sorts of peer support to access and why, and with respect to an active, reciprocal sharing of peer support

# Aims of the synthesis

When trying to answer complex evaluation questions – such as 'how does peer support work?' – looking at data from different sources (e.g. statistics and what people have told us about their lives) can often be useful in answering the question. This approach is sometimes referred to as *data synthesis*. Different sources of data are compared to see if:

- one set of findings confirms another
- different sorts of data help explain what is going on in more detail
- some of our data challenges our other findings suggesting that the questions we were considering might be even more complex than we first thought.

In this evaluation we synthesised quantitative data from the work stream 1 peer support log and qualitative data from the values and principles interviews in work stream 2. We did this in two ways:

- 1. Where our statistical data from the peer support log data told us there was a link between change in access to peer support and change in outcomes (see chapter 4 above), we used qualitative interviews to try and understand how and why people accessed peer support and whether if made a difference to their lives;
- 2. Where people told us in the qualitative interviews (see chapter 6) about how principles and values made a difference to their experiences of peer support, we went back to the statistical peer support log data to see if it supported what people told us.

In other words the synthesis process works both ways, asking if our qualitative interview data can help explain our quantitative log data, and vice versa.

## Synthesis methods

We developed two approaches to synthesis to reflect the two-way process of combining data described above. The first involved consideration of the statistically significant findings observed in the log data in chapter 4 and identifying qualitative interview data that would enable us to unpick those results from an experiential perspective. The second approach involved considering where it might be feasible to ask additional questions of the log data in order to test, statistically, observations made of the values and principles work.

In both cases we decided that we would identify a limited set of focused questions that it might be possible to address through data synthesis. We did this in part because it was not possible to address every single finding in this way, both in terms of time and also because the relevant data might not be available to do so. We also did this because there has to be a clear rationale, grounded in the data, for synthesising data. That is to say, the data needs to be telling us a coherent story or to be offering an explanation that can be meaningfully explored in more detail. Simply looking for data that seemed to 'fit together' would not really tell us anything meaningful about how peer support works.

To identify these data synthesis questions we held a workshop that brought together members of the evaluation team involved in one or both of the work stream 1 peer support log component of the evaluation and work stream 2 values and principles interviews. This included researchers working from the perspective of mental health difficulties. Each work streamlead presented to the others their main, preliminary findings. As a group we explored possible interpretations of our findings and specifically considered if and how data from one work stream might build on the findings of the other. On the basis of what it was possible to do, and whether the data seemed to be telling us a coherent story, we developed a focused set of synthesis questions.

#### Using interview data to explore findings from the peer support log

In chapter 4 our analysis told us that overall changes in the amount of peer support people accessed were associated in different ways with people's sense of wellbeing and hope in the future, and with their contact with friends and family:

i) a decrease in the total number of peer support projects people attended was associated with an increase in wellbeing, general health status and in contacts with family;

ii) an increase in the number of peer support projects people attended was associated with a decrease in contacts with friends;

ii) an increase in the number of different types of peer support (group, one to one and online) that people had both given and received was associated with an increase in both wellbeing and hope in the future.

As noted in chapter 4, it is possible to interpret these findings in a number of different ways. For example we cannot be sure from the log data alone if people give more peer support because they are feeling increasingly well, or if they feel well as a result of giving more peer support? Also it is not clear why decreasing total number of projects attended and increasing the number of different types of peer support given and received might both be associated with increased wellbeing? In this section of the report we used our qualitative interview data to try and understand these associations. We did so through addressing the following question:

#### Why do people decide to access more or less peer support overall?

The log data also told us that changes in the amount of different types of peer support (group, one to one and online) that people gave and received were associated with changes in outcomes in various ways:

i) Increasing the amount of group peer support being *given* is associated with a significant improvement in wellbeing, self-efficacy, hope in the future, and increase in contact with friends;

ii) Maintaining the same amount of group peer support being *received* is associated with a reduction in contact with friends;

iii) Increasing the amount of peer support *given* one-to-one is associated with a significant improvement in wellbeing and hope;

iv) A decrease in the amount of peer support *received* one-to-one is associated with a decrease in hope;

v) An increase in the amount of peer support *received* online is associated with a significant decrease in self-efficacy and overall health status.

Many of these significant associations were between changes in outcome and 'giving' peer support, with less emphasis overall on the idea of 'receiving' peer support and how that might be associated with change. As we highlighted in chapter 3, we felt that this distinction between giving and receiving peer support was somewhat artificial. We had asked these questions in the log because we wanted to explore the reciprocal, or two way nature of the peer support relationship. 'Two-way interaction' (based upon the idea of reciprocity) was identified as a core value underpinning peer support in chapters 5 and 6, justifying our decision to attempt to collect data about giving and receiving this through the log. This also meant that we had a wealth of qualitative data to use in exploring the association between change in giving and receiving peer support, and change in outcomes. We decided to explore the following questions in our synthesis:

# What do 'giving' and 'receiving' peer support mean to people in group, one to one and online peer support contexts?

# How is change in the amount of peer support given and received associated with change in outcomes for people in those different contexts?

In order to address these questions in relation to the qualitative interview data collected in work stream 2 a targeted analysis of interview data was carried out in a number of stages:

- The full set of themes that were developed in the work stream 2 analysis of the values and principles interviews (see chapter 6 above) were considered in order to identify which themes included data that would offer insight into our synthesis questions, as indicated above;
- 2. The themes 'choice and control' and 'entry into peer support' were identified as informing our question on decisions to access peer support;
- 3. The themes 'two way interactions' and 'impacts\_benefits' identified as informing our questions around giving and receiving peer support and relationship to change in outcomes;
- 4. Those data were analysed in depth and organised under headings that helped us understand our synthesis questions;
- 5. In addressing our question about giving, receiving and change in outcomes we also organised that analysis in terms of group, one to one and online approaches to peer support;
- 6. These analyses are presented below with headings used to clearly indicate how qualitative interview data helps explained our quantitative peer support log findings.

#### Using log data to explore findings from the values and principles interviews

Chapter 6 reported a number of themes relating to values and principles of peer support, and to decisions made about the way that peer support is structured and facilitated. In discussing the findings relating to values and principles it was clear that we would not be able to explore these issues in the log data set (we did not collect data relating to values in the log). We therefore decided that there were two sets of qualitative findings relating to the structure of peer support where it would be both meaningful and feasible to explore those findings in the log data.

First, it was identified in the qualitative data that some peer support projects were targeted at particular groups of people who shared something in common. We did not have sufficient log data from individual projects to explore change in outcomes in relation to change in access to peer support in relation to, for example, an LGBT project or a refugee project. In chapter 4 we reported comparative analyses for groups of log participants of different ethnicity, age, gender, sexuality and so on. Where we did have sufficient log data was in relation to diagnosis specific projects as all Bipolar UK and Depression Alliance strategic partner projects were, by definition, diagnosis specific. This enabled us to address the following question:

#### How does change in use of peer support relate to change in outcomes for people who attended a diagnosis specific Side by Side peer support project compared to people attending other Side by Side projects?

Second, it was identified in the qualitative data that there was a spectrum of organisational support to peer support, with some having a well-established, funded and staffed lead organisation, infrastructure that included access to venues and materials, supervision and training opportunities for peers and so on, while other peer support projects were informal and operated with a minimum of budget, infrastructure and resource. It was not an objective of the evaluation to classify projects in terms of their organisational or resource structure. However, strategic partner projects were run by well-established and relatively well resourced organisations (local Minds or branches of Bipolar UK and Depression Alliance), whereas grant funded projects were more likely to be run by smaller, grassroots organisations. Where we could clearly identify whether log participants attended grant funded or strategic partner projects, we would be able to make comparisons between these two groups.

In addition, our qualitative interview data (chapter 6), as well as our capacity building (chapter 9) and our commissioner work (chapter 10) to be reported below, have indicated that the peer support projects in the Leeds region were, on the whole, well supported by the infrastructure, resources and networks maintained by the local Mind (one of the programme's strategic partners and the hub organisation for the region). Leeds was also the region with the highest number of log participants and the most consistent monthly log completion (it was the only region with sufficient completed logs to enable a region specific analysis). On this basis we were able to ask the following question of the log data with respect to level of organisational structure and support:

# How does change in use of peer support relate to change in outcomes for people who attended peer support projects with greater or lesser levels of organisational and infrastructure support?

We note that there were other questions we might have explored in this synthesis chapter. In chapter 4 we compared change in access to peer support to change of outcomes for a number of groups of people. In particular we identified a number of differences between broad groups of people from different ethnic communities. We might have explored these issues here using our qualitative interview data. However we were specifically commissioned to report on experiences and understandings of peer support among people from different BaME communities (see chapter 7) and so some of these issues are considered there. Where we can, we will integrate the findings from chapter 7 into the Discussion section at the end of this chapter.

As noted at the beginning of the chapter, this synthesis work is necessarily constrained by resource. Each of the synthesis questions we have identified above is considered in turn below using data from the peer support log or qualitative interviews as relevant. We have used the same approach to identifying interview data that was used in chapter 6. These IDs do not identify interviewees by region, gender, age or ethnicity because we tried to ensure anonymity of evaluation participants. With the exception of contrasting findings in relation to group, one to one and online peer support, this chapter explores associations between accessing peer support and outcomes generally rather than in relation to specific groups or communities.

# Why do people decide to access more or less peer support overall?

Analysis of log data told us that there was a decrease in the number of peer support projects people attended when people's sense of wellbeing and their general health status increased, and when the supportive contact they had with family increased. This data also told us that increasing the number of types of peer support given and received was associated with an increase in wellbeing and hope in the future. We wanted to explore why people decided to access more or less peer support overall in order to better understand these findings. It was clear from our qualitative interview data that people were aware that they had choice over whether or not attend groups:

You get encouragement to come but on the other side of it, if you don't feel like coming one day, it's entirely up to you. [PV19, group]

We analysed interview data that specifically explored why people choose to access peer support – or not – and identified a number of main reasons, illustrated below with examples from the interview data.

#### **Meaningful activity**

A number of people identified a need to have something meaningful to do with their time. Interestingly we know from our socio-demographic data that many of our participants were retired or not working for other reasons:

I have to go out and do something, you know, whether it's with the [peer support group] or out with friends or going out for a coffee in the evening. I think it's to do with retirement as well. You know when you work, you are always with colleagues and there are always things happening and you are busy, your mind is busy. I think the retirement really gave me that state of mind. [PV4, group]

I was looking for something to fill an empty space in my life as I wasn't working. So, I got in touch with [mental health organsiation] because I knew they existed because I had, about twenty years previously, I had worked for them—just to find out what was on offer. That's how I discovered about the peer support programme. [PV24, group]

Some people referred to a specific activity that they enjoyed or were interested in trying:

I started going to the arts groups because that was the one that interested me most. [PV2, group]

I was quite ill at the time and I wanted something to fill time other than appointments and stuff like that, so I was looking for something outdoors and we came across that so I thought I would just try that. [PV33, group]

Sometimes there was a vocational or training opportunity that motivated people to access the peer support, especially those projects that offered training in peer support role (whether one to one or as a peer facilitator of a group):

I was looking for volunteering opportunities, obviously and I have always kind of volunteered with mental health so that's how I came across [name] so, no I wasn't looking for anything, I was just looking for volunteering. [PV5, group]

One of them said, 'oh well, there's this project for training, to take up training for wellbeing coaching if anybody's interested'. So I thought, 'well, that sounds great! I'll give that a shot. Why not?' There we are. That's how I managed to find that. [PV25, one to one]

I was referred to this course when it came up so they called me and said that course is suitable for you so that's how it was. Then I went to attend it, there were many of us. Then they said, "Okay, they are going to choose only 10," so I was among the 10 that were selected and attended. [PV26, one to one]

After I had finished my treatment with my psychologist, she told me, "You are eligible for that. You can go into, start working as a mentor. There will be some studying and training for a short time and after that you can start mentoring." This is my first, story of coming here. [PV41, one to one]

For some people the peer aspect of the contact was important because it reduced the stress or anxiety they might otherwise feel about attending something new for the first time:

I'd been unwell with anxiety for years and years and I was fed up just going round in circles really. I wanted to try and make some progress so that's how I landed up. I was trying to look for something that I thought I could go to where hopefully, with having anxiety, it wouldn't be too stressful compared to going to something maybe where I'd have to sit there and nobody would know about my anxiety. So that's how I came into it. [PV34, group] I was introduced to the concept of group work, peer support and, the first time I spoke about mental health, was in the peer setting. Although daunting at first, it's been wonderful and it's really helped me to try and talk about my stuff in an environment where others are comfortable talking about it, as well. There is no stigma and no judgment and we all are respected for our own way of managing our own wellbeing, or not managing it, whichever way you want to look at that. [PV37, group]

#### Social contact

For many people peer support was a source of social contact:

*I suppose it was more of a networking, just to meet other people really and find out what the group was about. That was my only expectation. [PV7, group]* 

... that would have been whenever the Bond movie, Spectre, was out, because that was the very first thing I did with [peer support group]. We all went to see that. So, maybe, last autumn? I thought, "This is interesting." I sort of thought, "It's not a support group," because it isn't a support group, but I had lots of different opportunities with it. [PV8, group]

*I haven't got a very big support network, I haven't got much family, or friends, or anything, so I quite like the idea of something structured.* [PV51, group]

Initially, it was quite by accident really. I just needed somebody to talk to really. There was a lot going on and ... I think somebody just kind of said, 'oh well, why don't you go and have a chat with', this is where the group had come in initially, you know, there were a few of us. We'd just hang out in the café and chat about whatever. So it was sort of by accident. [PV25, one to one]

Some people described a sense of loneliness or isolation that they sought to address through peer support:

I think that started it, I got very depressed. I was depressed but it became worse when I was living by myself, that loneliness, I just couldn't get used to it, you know? [PV4, group]

Well, yeah, I've got very isolated so some social contact was, kind of, that was one thing because I thought that I might get. I didn't know that it would be possible to get anything else. [PV24, group]

#### Referral by mental health services

Some people acknowledged that their initial reason for attending was because they had been referred or signposted by other services, such as a counsellor and community mental health worker:

It kind of started at the beginning of this year when I was going through a pretty bad period myself, where my GP had diagnosed me as having depression and anxiety problems. From there on in, he referred me to the local mental health authority known as [mental health service] ... from there on in, I found out about the other local charity called [mental health organsiation], who ran further courses and sessions regarding mental health issues such as managing depression, anger, resilience, assertiveness etc. I got in touch with them in order to continue my own personal form of therapy through experiencing the peer support groups, you know, like I just mentioned, anger, resilience etc. [PV38, group]

Sometimes this referral was in relation to specific symptoms or a diagnosis:

I've had some anxiety issues and depressive illnesses. I went to see my doctor and they referred me to the psychiatric liaison nurse and during discussions with her, she

recommended going to [name] groups. So that's how I got involved. It was about three years ago now. [PV10, group]

... when I was first diagnosed I was still at university, and I struggled for while with my diagnosis but after a while I got over the fear of the label of schizophrenia and I did some research into the role to help with my recovery, at which point my [Community Psychiatric Nurse] suggested I could take a peer support course through the NHS. [PV58, group]

#### Addressing a gap in mental health services

For others they had sought out peer support because they found that mental health services were not providing the support that they needed:

*I began as just a service user; there was nothing available on the National Health Service, and I found this online, and went along to the group. [PV35, group]* 

This was sometimes because they had tried medication and not found it to be helpful:

... but when I was weaned off the pills, the anxiety and depression returned. So, we were back to square one, and there didn't seem to be much else on offer except for more pills, back then, so I just went online to see what else I could find, and found this group. So, that is how I came to it in the first place. What did I hope to get out of it? I hoped to find a way to get better. [PB35, group]

Medication didn't help me at all. I stopped medication without asking my GP and when I stopped my medication I referred myself to [mental health organsiation]. [PV11, one to one]

Other people found the waiting times to access services an issue and wanted something more immediate:

... although it was entirely self-referral but most people heard about it from a teacher or a [Child & Adolescent Mental Health Services] worker or through trying to access counselling but the waiting list was too long and that kind of thing. [PV23, group]

Mostly I use Elefriends ... I was taking part in group therapy but because I became physically poorly, they had to take me off the group that was currently running and put me on the waiting list for the next one. [PV61, Elefriends]

#### Space to share

Some people sought out peer support as a space to share experiences of mental health difficulties and also strategies for coping:

I first discovered them on the website and I found that there were lots of people that had similar issues, not directly the same as mine but very similar, and the website was kind of twofold. It was an outlet for people to discuss their problems and post their problems and people would often sort of post quite positive replies to help you with your problems. [PV7, group]

My link worker put me in touch with [mental health organisation] peer support groups. I have had a lot of individual therapy and I reached the point where I started to think I was the only one struggling with things and I think it's a really good idea to link in with Mind because there are people in a group who are sharing some or similar experiences to you and it's much nicer than feeling isolated and thinking you are the only one. It was getting in the way of my therapy being as good an experience as it could be so I am really pleased that she did. [PV49, group]

I think just some way of helping me feel like I was coping with it, really ... I mean, I know they can't physically do anything, but knowing that people are there, and half the battle is just finding your own way through it, anyway; it's not really about asking people to give you a definitive answer, or a piece of information, it's just finding your own way through it, and I like that. [PV51, group]

I've learned loads from people sharing ways that they cope. I've been able to think, oh I might try that. Some of it has worked and some of it hasn't. [PV59, group]

So, I think I feel I would be up for somewhere for me to, you know, get a bit of emotional support about the stuff I have to do at work. That was one thing. And just, you know, I was feeling quite low, and feeling like I wasn't really coping very well. [PV50, PSN]

One person spoke about choosing to access peer support as a way of taking control of their own mental health:

I really like to actively try and, like, how I would with my physical health, I would keep, you know, try and keep my mental health stable as well. So, like, I think it was just through [mental health orgnasiation] and the Mind website and I am pretty sure I just found it through that website and I just thought, "This could be really nice" and that I wouldn't actively join the forum but I decided to because I thought, you know, I have got nothing to lose, kind of, thing. [PV44, Elefriends]

#### Crisis

For a few people, especially (but not only) those accessing online peer support through Elefriends, turning to peer support was a response to experience of crisis in their mental health:

I was kind of in a crisis situation at that time; looking back, being in reflection about it, so I wasn't frightened of anything, as such, I was just trying to get myself better, and was grabbing at straws in the dark. [PV1, group]

Well, I was at crisis point after having an attempt and my local crisis team suggested that I should use this online forum called, Elefriends. So I called Mind and then they told me more about it and I logged on. [PV43, Elefriends]

I had been suffering with mental health issues for a number of years but I have never really actively pursued help and I have always, kind of, kept under the cover and it's only recently in my third year at university that ... everything kind of just all started rolling and, you know, my mental health really went downhill and so, then I joined Elefriends because I was having such bad episodes ... [PV44, Elefriends]

#### Choosing to access less peer support

Both face to face and online, some people talked about choosing not to access peer support when not feeling well or when they felt they could not cope at the time:

There was a course that I did recently on self-compassion and I left half way through one because I just couldn't cope with it. Then the next week I turned up but then said, I'm not coming in, I'm going home. [PV24, group]

... sometimes I have real problems with what people have posted. It can be very emotive for me ... sometimes it is better to avoid it. [PV32, Elefriends]

In contrast, a larger number of people - accessing group, one to one and online peer support - all suggested that they would choose not to access peer support where they did not feel they had a specific need to do so (or were occupied in other activities):

... if somebody wanted to go along, then there was somebody there for them ... so it's just as important that they choose not to attend a group, as it is to attend a group ... I mean, if people don't want to turn up, they don't have to turn up. Yes, I've had people who have turned up, in the past, and halfway through a meeting, have decided to leave, the reason being because, actually, they have got what they wanted from the meeting, and they're tired, so, therefore, they just get up and go.[PV52, group]

I can just click on it and for a few days I might not go on it at all, but it's there when I need it. Yes, which you don't have with your counsellor or you can't just ring them at weekends or get hold of somebody. Whereas Elefriends is there 24/7 ... It's always available. You can pick and choose and get as much from it as you need or as little from it as you need. Whatever your circumstances are ... because life is not inflexible, is it? It changes so much all the time that you can't keep it rigid. [PV45, Elefriends]

I guess if I think I'm feeling a bit low, I'll go ... while, if I don't, I can, other things take priority, because I'm quite busy ... I'll be doing something else, even if it's just cooking supper. But, sometimes I think, "Look, I have to look after myself as well," and that's a way of doing it. [PV50, PSN]

... so sometimes I don't need so much as others, and other times I'll be going through a really bad patch with myself or the others that I'm caring for and then I feel like I need to reach out more. [PV45, Elefriends]

One person accessing Elefriends explained how, with more contact with family, they would be less likely to access online peer support:

It's like this morning, I went on there for half an hour, and just made a comment to a few people, and then I came away, and I haven't been there for a couple of weeks, because I've been with my daughter who is home from [place], and my grandsons, and the nice thing about Elefriends, too, is you can hook in and out whenever you want; you choose. [PV62, Elefriends]

#### **Ongoing peer support**

While the analysis above has explored change in amount of peer support people accessed, some people did tell us about when and why they decided to continue to make more consistent use of peer support over time. This was generally related to attending with, or at the suggestion of friends and seemed to provide an opportunity for continuity of social contact

I just kept it as a trial and error kind of thing, so I tried it and if I didn't like it then I wouldn't continue with it, but I do like it, so I carried on with it ... at the time I just saw my friends joining so I thought, 'yes'. [PV21, group]

One of my friends had said to me about the [project] and they said, "Have you ever been in it?" and I said, "no" ... and they said, "Well why don't you come up and come and apply for coming here?" So I've been coming here quite a while now. I've done quite a lot of different things since I've been coming here. [PV21, group]

We summarised these findings exploring why people decide to access more or less peer support:

- People chose to access peer support of all sorts in response to particular needs and aspirations (meaningful activity, social contact, gaps in existing services, crisis and so on)
- As people's sense of wellbeing and general health increased, and as they experienced more supportive contact with friends and family, they chose to access less peer support
- Some people described maintaining a core level of support (for example attending a peer support groups as a source of social contact with friends)

# What do 'giving' and 'receiving' peer support mean, and how does this relate to change in outcomes for people accessing different approaches to peer support?

Analysis of log data indicated that a change in the amount of peer support people gave and received was variously associated with change in outcomes for different approaches (group, one to one and online). Our literature work in chapter 2 was indicative of key variations in those broad types of peer support, and our qualitative interviews – especially where they reflected on the different ways in which approaches to peer support were structured, led and organised (see chapter 6) – also cautioned against assuming that peer support fulfilled the same role for people in different contexts.

As noted above, we organised our qualitative interview data to reflect whether our interviewees were recruited into the evaluation through a group or one to one Side by Side project, or through the Elefriends online peer support forum. This enabled us to consider what giving and receiving peer support means, on how that is associated with change in outcomes, in each of those group, one to one and online contexts in turn.

#### Giving and receiving group peer support

The impacts of giving more peer support in a group context were wide ranging, being associated with improved self-efficacy, wellbeing and hope and increased supportive contacts with friends. Where people received a stable amount of group peer support over time this was associated with a reduction in contact with friends. We explored the data from participants who had attended group-based Side by Side peer support to try and understand what giving and receiving peer support meant to them, and how they described the impacts or outcomes of doing so.

We noted in chapter 3 when we developed the log questions how the distinction between giving and receiving peer support felt somewhat artificial. We picked this up again in our principle and value work in chapter 6, particularly in our findings around human connection and two-way interaction. Interviewees found it hard to separate giving and receiving peer support in a group context:

... it's not like people are just taking support and not giving it, I think everyone does value the support given and tries to give back. [PV3, group]

I like the fact that we're all, kind of, helping each other ... I think if you're signing up to do peer support, I think you do need to recognise that it is giving, and receiving, support. [PV15, group]

It means people helping me and me helping others and listening to other people and them listening to me. Sharing each other's problems. [PV18, group]

People explained that it was the act of sharing that was synonymous with being involved in peer support:

... that's what peer support is. The essence of it is shared experiences, swapping ideas of what's worked for you ... [PV16, group]

... this is what sets peer support apart from any other kind of mental health service I've experienced. It's what makes it different from group therapy. It's what makes it different from counselling or speaking to your doctor or speaking to a parent or a partner maybe, I don't know, in that it is mutual and everyone there is giving and receiving and sharing experiences ... [PV23, group]

It's something important about peer support that all peers are involved in giving and receiving support and sharing experience and encouraging others. [PV34, group]

A number of people described the importance of 'giving something back' through the act of sharing with peers:

Well, I feel it's giving something back, you know, like over the years where I have been ill or not ill or, well, stable, I feel like I am giving something back because a lot of the time I have been taking out, if you know what I mean? [PV56, group]

However it was acknowledged that there were some people who seemed, at particular times, to need the group more explicitly as a source of support – to receive peer support - rather than more actively sharing or giving support to others:

.. we haven't got that with everyone. I think there are some people who are a little bit quieter and keep themselves to themselves but it's still nice that they can come and get whatever they want help with. [PV53, group]

... you get some people where it's all about them and not about others. It's all about them ... I think you get one or two people who only want support. [PV18, group]

#### Benefits of giving and sharing in peer support groups

There were a number of reported benefits from this active giving and sharing through group-based peer support that reflect the findings from the log. As a whole these findings – presented below – suggest that it is the agency expressed through this active giving and sharing of peer support that brings about change for people. For example, people referred in various ways, often quite emotive, to a sense of wellbeing – of feeling good – gained from this act of giving through peer support (our bold added for emphasis):

It's got me through some really tough times recently. It's really helped me so much just being able to share what I'm going through and know that there's other people who are going through that too ... **it's just fantastic. I love it**. I love peer support. [PV59, group]

I was looking to give something back or give something back as in help other people that are struggling, but at the same time, I get something out of being able to do that. I think that's what I think I would get out of it. **I would get a nice feeling of helping other people.** [PV54, group]

... so you're all learning together and sharing together and **it feels really nice** when you can see that something that you have shared has helped someone else or when someone shares something and it's really powerful to you, it really, really touches you, that feeling I think is fantastic ... **that feeling is, to me, what is so special and so transformative about peer support.** [PV23,group]

The group was sharing in the room all of the issues, which were quite negative, and for me to come back to the group and say I've done this and I've done this and talk about something that's quite positive actually lightened the mood in the group, which I thought was quite nice. So I came away from that meeting actually feeling quite good about myself ... [PV7, group]

Well I seem to get some very pleasant feedback and I like that. My self-esteem is improved. I also like listening to what people have got out of it. I feel useful, for want of a better word. I feel it's very enjoyable to help other people, it's not at all altruistic. **I enjoy feeling worthwhile.** I think most people do. [PV2, group]

Other people referred to a sense of hope in the future derived from group peer support:

So that shared lived experience, as I said before, that's, I think, what gives a lot of people hope. [PV15, group]

... it gives me hope and it gives me something to get up for ... I can be feeling rubbish. [PV18, group]

It's made me see that I could live a normal life because quite a few of them work, which is something I haven't done for [number] years ... yes, it changed my life. It changed the way I was thinking. [PV22, group]

A sense of social connection derived from taking part in peer support groups was identified by a number of people:

The feeling that I'm not alone, the feeling that I don't need to be isolated because there are others who share that experience. The feeling of almost comradeship, that we're in this together and that we have resources. [PV36, group]

There's all these kind of elements which when I look at that as a whole, it's hard to pin down any particular one. It's the fact that I'm able to share and also to listen and be a part of something where I feel as though I'm doing some good. I'm also still very much a part of that community. I think that community is another major factor as well. [PV38, group]

Those connections made within the group were often sustained outside of group meetings, with friendships made that extended out into the community:

I now socially see some of the people that go along, and some of the people that no longer go along, but I meet them socially; one guy is having a birthday party, that I'm going to go to this weekend ... so that would be an unexpected thing. That's probably the main one, on the social side of things. [PV1, group]

I've made a few friends there, and we also meet up socially; occasionally do various things, usually like meet up in the pub, although it's not a formal group, it's just if other people in the group want to meet up after the meeting. [PV3, group]

Some people described how new connections and relationships grew through people they had originally met through their peer support group (this corresponds strongly with the findings from our log data that suggest people's supportive contact with friends increases as they give and share more peer support in groups):

I met up with one or two people and then that has got me into more groups. Once you meet up with one person, things change. You get introduced to one or two other people and then when you are with that group you then know a few other people and you get involved in more things then. [PV13, group]

And that that the social contact that people made through group peer support impacted on the quality of relationships they had in their wider lives:

... peer support I think has really helped me ... to change my relationships for the better. So I think I have a much more open and honest and better relationship with my parents and with friends and I'm able to be assertive in romantic relationships, about what I need and don't need and stuff. I feel like it's permeated all aspects of my life. [PV23, group]

People referred to enhanced sense of self-efficacy in a number of ways. First people felt they got better at making use of peer support:

I know that when I was a group member, if I saw someone else or heard someone else sharing something openly, then I'd think, 'oh actually that's okay for me to share too. Maybe this is a place where I can do that'. So I learned from what they did. [PV59, group] ... we speak in rounds where everyone takes a turn to talk and it makes them more confident in sharing their own experiences and it's when there is freedom of expression and an openness of communication that peer support is at its best. [PV58, group]

Then what people learnt through engaging actively in peer support resulted in them feeling more efficacious in talking about and understanding their own mental health:

... it is just learning how to talk about it, in a way that is informative rather than sounding like I'm trying to use people as a sounding board. I suppose it's probably helped do that; if I do talk about it more, I can talk about it in a more informative way, rather than coming across as being needy. [PV3, group]

I used to bottle everything and not speak about anything but I am slowly coming out of it now, talking about it more, talking about my own problems where I wasn't before. [PV18, group]

I've also been a lot more confident, a lot more able to talk about my own mental health without being distressed by it. I used to not be able to talk about my mental health problems without having a panic attack but that's going back quite a few years now. I'm now really able to talk about things quite openly and I'm also aware of what things are difficult for me to talk about and what things aren't. [PV23, group]

This often led to people describing greater self-confidence in general:

*I think it would help a lot with my confidence because I do tend not to interact with many people. [PV33, group]* 

For me, I would say the big, big ones are more confidence. Because I could go to somewhere that was quite safe, suddenly, even if I would have a panic attack there, it wasn't the end of the world. [PV34, group]

And finally people identified that self-efficacy extending into other areas of their lives:

It gives me skills and training to be able to face situations that normally, because I never learnt that skill ... otherwise I would just stay in my house, stay away from it and not do it. [PV12, group]

I have learned more as well in this last year because of having to organise the flyers for [name of group]. If you had asked me to do that five years ago, I would have said, "No, I can't do it" and I was not comfortable with it but somehow, I have been doing more work than the staff have been doing. They have done all the printing and that but besides that I have been putting the word about. I have just been to speak to college students ... so I have been doing more things than I ever thought I would be doing, to be honest. [PV13, group]

In summary, the data on giving and receiving group peer support indicated to us that:

- For many people accessing group-based peer support, the idea of an active, reciprocal, giving and sharing of peer support was important
- This sense of agency and mutuality in peer support seemed to be a powerful force for change for people in a number of ways
- For some people groups were somewhere they could receive support from their peers at times when they felt they needed to, for example as a way of maintaining social contact

#### Giving and receiving one to one peer support

Giving more one to one peer support is associated in an improvement in wellbeing and sense of hope for people, while conversely, a decrease in the amount of peer support received was associated with a decrease in hope. Maintaining the level of one to one support received over time was associated with an improvement in general health status, with a reduction in the amount of one to one peer support received associated with decreased general health status.

Note in the section below we include data with the PSN (Peer Support Network) identifier – the project that was focused on co-counselling – as well as other one to one peer support projects.

As was the case with group peer support, the close link between giving and receiving peer support was evident in some interviews with people accessing one to one Side by Side projects:

Because if you value somebody as a human, then I can receive and I can give as well. So don't expect just to receive, you have to give as well ... you cannot expect somebody to give so much information while you withhold your information yourself. You have to kind of share information, share conversation. [PV40, one to one]

However in other cases, in this one to one context, interviewees were more qualified about the idea of both people in the peer support relationship sharing in the same way:

...we do share our relevant experience and the strategy of coping but not really. We don't really give advice to each other, like I did this and you can do that, you can try that, not really. We just talk. [PV11, one to one]

... we're sharing, well, whilst maintaining confidentiality, we're sharing thoughts and ideas about how to work through certain things whether that's a direct example of a client who will obviously remain nameless, or whether it's linking our experiences of whatever it might be. [PV35, one to one]

... it doesn't always happen, in my experience ... I guess, in principal, the theory would be, yes, everything is equal and open to everybody. It feels to me like, sometimes, that doesn't really work, and that people need to take some initiative, some leadership. [PV47, PSN]

Many of the one to one peer support projects in the Side by Side programme were set up to provide training for people in taking on mentoring or befriending roles. Perhaps reflecting this apparent demarcation of mentor and mentee roles, for some people one to one support was about one person *giving*- in the sense of providing support - to another person (as we have seen above, sometimes differentiated as a 'client'):

...you find that people are attentively listening to what you are saying and they are learning something. [PV26, one to one]

The first time or the first meetings with mentee, it will be like, I will try to do it perfectly but it will be maybe not perfectly. After then when I will contact with my supervisor or with my colleagues, it become more closer to me and I easily can give advice or do something for them, and [the] job will become more learning, more easy for me. [PV39, one to one]

I think it's very helpful having somebody like me having experienced mental experience ... It helps mentors and helps mentees as well, because mentors have a lot of experience and they are very excited to give it to the mentee and the mentee just has to be heard, just to be listened to and follow any correct way about his new life. [PV41, one to one]

#### Benefits of giving and sharing one to one peer support

As noted above, many of the people involved in Side by Side one to one peer support were undertaking training as part of their project. As a result several people talked about the benefits of training in terms of undertaking, for example, mentoring roles in the future. In addition, there was evidence that some people experienced a sense of wellbeing resulting from supporting others through one to one peer support that mirrored that observed in the group-based projects:

This is my first mentee, he was such a nice guy. He was willing to share information with me, so we became friends and stuff like that. He was so nice, I really enjoyed it. [PV40, one to one]

... it's a nice experience. I mean, sometimes it can be distressing too, because you hear somebody's story and you think, "God! Things are grim for some people." But nevertheless, on the whole, I come away feeling like maybe I've done something useful for them as well ... it's friendly and it is supportive, and that's a good thing. [PV50, PSN]

Sometimes this sense of wellbeing was explicitly derived from the act of successfully giving or providing support to another person:

When I will see the results of my help I will be excited ... I will be more proud. That is for me a good thing for me to feel well. [PV39, one to one]

As much of the mentoring training was delivered in a group context, people seemed to describe some of the benefits of sharing peer support in a group that we noted above, including increased sense of hope in the future, enhanced social connection through the group and an increased self-efficacy:

Peer support helped me to meet people who are overqualified and they've been hit by their mental illness, so it's not only me. That makes me value myself, not to underestimate myself, so mental health can hit anyone. One of my group, she's a psychologist and when she finished her training she became mentally unwell because of the pressure from her course. Now she's doing very well actually. [PV11, one to one]

... some sense of belonging, and I like being part of things, yes, companionship, I suppose, company ... it has, certainly, increased my confidence, and resilience, I suppose, is the word, a feeling of an ability to cope, hugely increased self-knowledge of understanding my patterns and history, and why I do what I do, that sort of thing. So, I think that's, sort of, the personal part of it, and the other bit is the interaction, I've made some deep connections, and some good friendships that have become a very important part of my life. [PV47, PSN]

The one to one peer support was helpful, a lot more helpful than I thought it would be, for a start. I think that, in itself, has helped me to be able to say, do you know what? Yes, I'm going to do this interview with you today. A few years ago I wouldn't have been able to do this ... I was actually opening up a lot more than I realised I would be able to. So it's helped in ways that I didn't expect it to. I have been able to speak in front of other people. I have been able to tell people things about myself that I didn't think I would. [PV25, one to one]

Perhaps because most of the one to one peer support projects we considered were structured around training for mentoring we had less data that reflected on a more passive receipt of peer support. Reflecting log findings, there was some indication of improvement in general health status as a result of being involved in one to one peer support:

I changed my diet. I changed my sleeping times. I changed the way I think, everything. I lost 17 kilos. I've been exercising every day, watching what I eat. So I can say that I am living a comfortable life ... [PV11, one to one]

To summarise the data on giving and receiving one to one peer support:

- Key understandings of a reciprocal giving and sharing of peer support also applied in the one to one context and were experienced as beneficial by people
- People involved in one to one peer support also benefitted when they came together in groups
- But roles in the one to one peer support relationship could be more demarcated (as 'giver' and 'receiver')

#### Giving and receiving online peer support

Our findings on online peer support were more limited, with log data indicating that an increase in the amount of peer support received online is associated with a significant decrease in self-efficacy and overall health status. While there were no significant findings in our log data relating to the idea of giving peer support online, our interview data nonetheless reflected on this. The understanding of 'giving peer support' as 'giving something back' found particularly in group approaches was also found in the context of online peer support:

It was mainly down to having had my own issues previously ... It made me think maybe I could help ... it was something I always wanted to do before. It was a friend of mine years ago. She was older and retired but she was meeting with people who just had no family, no friends and I thought it would have been a really nice thing to do ... as I'm sure you know, if you feel as though you're helping somebody else, it gives you a boost as well ... [PV46, Elefriends]

For some people, the relationship between giving and receiving peer support described above in face to face contexts also applied online:

*I would say it's giving and receiving support all the time and sharing experience, that happens a lot. [PV46, Elefriends]* 

However, as we saw to a certain extent with group peer support, it was noted that not everyone in online peer support was engaged in that two way interaction of both giving and receiving. Some people might be more 'active' in giving support than others, with giving peer support online often taking the form of giving advice:

I think it's more important for some than others. I think that it depends what your circumstances are, but for instance, if you're struggling to go outside that day, somebody would say, "Well, just walk to the end of your road," and they'll give active support and say 'let us know how you got on'. [PV32, Elefriends]

Whereas we were told, in the third person, that other people were perhaps accessing peer support online in order to receive the support of peers at a time of need (we noted in chapter 4 that people accessing online peer support had lower baseline scores in our outcome measure, on average, compared to people accessing group and one to on peer support):

... there are some people that will be on Elefriends that will never post and will never like something .... but they are there and they obviously take, there is a reason why they are on it ...[PV44, Elefriends]

The first guy, he used to ask me all about my experiences. It was all he wanted to know about. He wasn't going to share any of his, he just wanted to talk to me about that. But it's mainly supporting them, not mutual ... there are people on there that are just on there only to receive the support. They don't talk to others about, they empathise with others but they might not be in the correct mental space to do that. They might just need that support. [PV46, Elefriends]

Interview data suggested that some people 'shared' in the online context as a way of seeking support or advice from others – sharing their problems – in contrast to the active, reciprocal sharing that was in evidence with group peer support projects:

I shared my fears about my employer referring me to occupational health, I was saying, "I don't know what I should do in terms of should I accept or should I not, should I go to the assessment, what do you think?" There was lots of good advice about that ... [PV43, Elefriends]

... it's this shared, somebody will say, "I'm going through this. How can I get help or where can I go for help?" And someone else will say, "This happened to me and this is where I went, or this is what I did or tried". I've picked up a lot of that on there, ways of coping. [PV45, Elefriends]

#### Benefits of giving and receiving peer support online

While the log data did not indicate increased benefits of giving more support peer support online, our interviewees did tell us about experiencing a sense of 'doing something good' resulting from supporting others:

... if I see any particular post that I feel I can help that person, or I can give them advice, then I do that because it's been given out to me and it's been very helpful to me. It is quite good to give that support back and it does help you, as well, from a point of view where you feel that you're helping others, so that does have a good effect both ways. [PV43, Elefriends]

I think it's helped a lot. It gives you a sense of, I don't know how to put it ... it helps your selfesteem in a way. You feel as though you're doing something good. [PV46, Elefriends]

Our interview data did not provide a great deal of specific insight into the impacts of a more passive seeking of peer support online, perhaps because those people who might access online peer support at times when they had particular difficulties they needed support for might feel less inclined to volunteer, online, to engage in the evaluation. However a number of people did describe a general sense of increased of self-efficacy, through accessing peer support online, that they were then able to transfer to their wider lives:

... it was also, kind of, a stepping stone because I started initially going on that and then I realised the next step would be trying to get support from like my actual friends and my family so I have actively pursued that more now and I am kind of on the next level ... just seeing these people who probably went through the exact same sort of anxious feelings about going to the doctor's that I did, it kind of pushed me ... I think that being on that forum really helped me kind of think, "Look, if you want help you need to go pursue help, it's not always going to come to you." So, I don't know, I think it normalised it, kind of, for me. [PV44, Elefriends]

It means that you're not going through stuff alone. It means that you can see where you've come from so you've got a sense of achievement. You can see where you're going to so you've got a sense of, you're able to step small steps into becoming a normal functioning member of society again. This is my aim, I wish to be a normal functioning member of society again, whatever normal is.[PV63, Elefriends] To summarise the data on giving and receiving online peer support:

- Giving and receiving online peer support seemed more demarcated with our interview data suggesting we were perhaps talking to different groups of people accessing online peer support for different reasons
- Some people accessed online peer support when they were feeling less well as a source of advice and support for particular problems
- Other people did experience benefits of offering advice and support to others but the effects were not significant compared to the active giving and sharing of group peer support

# How does change in use of peer support relate to change in outcomes for people attending diagnosis-specific peer support projects compared to other peer support?

When we compared the relationship between change in overall access to peer support (number of projects attended and number of types of peer support given and received) and change in outcomes between people attending diagnosis specific projects (Depression Alliance and Bipolar UK) and people attending other Side by Side peer support projects we found no differences. In other words the benefits or impacts for people attending diagnosis-specific peer support projects are no different for people attending peer support projects that might be aimed at other groups or communities, or no specific group or community.

# How does change in use of peer support relate to change in outcomes for people attending peer support projects where there is a greater or lesser level of organisational and infrastructure support?

We needed to find a way of organising our data to explore level of organisational structure. We did this in two ways. First we compared the relationship between change in overall access to peer support and change in outcomes between people attending strategic partner projects and people attending grant funded projects (as broadly representative of greater and lesser levels of organisational and infrastructure support respectively). We found that, where participants who were recruited through a grant funded project decreased the number of projects they attended, this was associated with an increase in self-efficacy. For these people an increase in self-efficacy was also associated with an increase the number of types of support they gave (with the opposite also being true).

Interestingly when we then repeated these analyses for people accessing peer support in the Leeds region – where there are high levels of infrastructure support across all projects provided by a strong organisational network – we found that participants who maintained the number of types of support they were giving experienced a significant decrease in self-efficacy.

The implications of these two sets of findings are that people attending smaller, grassroots projects, and/ or projects which benefit from less infrastructure support, might be demonstrating a higher degree of independence in the choices they make about accessing peer support. These findings describe a virtuous circle whereby people feel more self-efficacious as they give more peer support, and as a result feel less need to attend peer support (for their own support needs). As they identify what they find to be helpful, people accessing less formal, smaller peer support projects seem to focus on the peer support that works for them.

However, while interesting, these findings should be treated with some caution. We note that some of the strategic partner projects – including local Minds and Bipolar UK projects – were in themselves quite small organisation, s not all enjoying well-resourced infrastructure, and as such our

comparison was not precise. It might be sufficient to conclude that small, grassroots peer support projects, with a minimum of resource and organisational support, have as much potential to bring about significant change for people as their better resourced and organised counterparts.

## Discussion

Qualitative interview data were illuminating of our peer support log findings, and helped us to address questions about why people decided to access more or less people support at different times in response to different needs and aspirations. The interviews shed light on why people chose to access less peer support when they were feeling increasingly well and had increased supportive contact with friends and family. However neither our interview nor log data suggested that people stop accessing peer support altogether (see the 'use of peer support' figures in chapter 4), maintaining a core level of peer support, probably as a source of ongoing social contact.

Our exploration of people's experiences of accessing BaME specific peer support in chapter 7 suggested that people decided to access BaME specific projects for many of the same reasons that people decided to access peer support in general (e.g. social contact, dissatisfaction with formal mental health services). However the interviews and focus group with people accessing BaME specific peer support were also indicative of a range of very specific reasons for doing so, relating to:

- a wider, cultural sense of shared identity that was not only focused on shared experiences of mental health difficulties;
- experiences of racism and discrimination, both in society generally and, for some people, specifically from mental health services;
- experiences of stigma relating to mental health form within participants' own culture.

Some very specific shared experiences, such as recent and traumatic migration (especially among refuges and asylum seekers), and the intersectionality of race and sexuality were particularly key to both a sense of 'peer' and of the need for a safe space to voice those experiences and share peer support. Given that issues of choice and control were shown (in chapter 7) to be particularly important for people accessing BaME specific peer support, it seems likely that associations between deciding to access more or less group peer support and outcomes (wellbeing, hope, self-efficacy etc.) described in this chapter apply just as strongly here. However we would need to explore both our qualitative and quantitative data in more detail to state that with certainty.

In addition, in chapter 7 it was noted that the issue of racism was referred to particularly (although not exclusively) by Black men. Peer support log data in chapter 4 indicated a number of clear differences in the association between change in use of peer support and change in outcomes for Black people compared to other ethnic communities. We have not had the resources to explore these in this report but our interview and focus group data clearly provide the opportunity to do so in the future.

Interview data also told us what people understood by giving and receiving different types of peer support and how that was associated with change in outcomes for them. More of our interviewees had accessed group peer support projects than had accessed one to one and online peer support as part of the Side by Side programme (reflecting the fact that the majority of projects funded through the Side by Side programme offered group peer support). As a result we had a wealth of data to help us understand how peer support worked in the group context. This data described an understanding of 'giving' peer support that related to an active, reciprocal sense of sharing in the group context. People's sense of self-efficacy, wellbeing and hope, and their supportive contact with friends, all increased as they gave the group more peer support in this way.

We had less interview data exploring one to one and online peer support. While peer support in one to one and online contexts was described as reciprocal there was demarcation of giving and receiving roles. Some people accessed online peer support in order to receive support from others when they were not feeling well, while other people enjoyed giving peer support, in the form of advice and guidance, both one to one and online. We had more data on 'giving' rather than 'receiving' peer support in one to one and online contexts perhaps as a result of who we interviewed (this is called a *selection bias* in research). That is to say, a) we interviewed a number of people who were being trained, as mentors, to offer one to one peer support, and b) perhaps those people who accessed peer support online in order to receive support for a specific problem were less inclined to volunteer themselves for an online evaluation that people who proactively went online in order to give support to others.

Considering this synthesis as whole, we can reflect on the relationship between deciding to access more or less peer support in response to need, and the impact of change in use of peer support and change in outcomes. In chapter 4 we saw that, while overall access to peer support fell during the course of the evaluation (as did amount of peer support given and received for most types of peer support), outcomes on the whole stayed the same and in the case of self-efficacy increased quite markedly. The implication of this is that, presented with a range of different types of peer support, over time people become better at accessing the approaches to peer support that work for them.

When we asked questions of our peer support log data, informed by analysis of our qualitative interview data, we made two interesting observations:

- 1. That while diagnosis-specific peer support might be described differently in some ways to peer support aimed at other groups, diagnosis-specific peer support groups do not seem to have different sorts of impacts for people;
- 2. Less formal, smaller grassroots peer support projects seem to have as much potential to bring about change for people as their more highly organised counterparts (people who increasingly accessed these smaller projects experienced significant increases in their sense of self-efficacy).

# Conclusions

Taken together, this synthesis of our peer support log and qualitative interview findings was suggestive of the following findings:

- People chose to access peer support of all sorts in response to particular needs and aspirations (meaningful activity, social contact, gaps in existing services, crisis and so on)
- There were some similar issues and also some very distinctive issues that related to people choosing to access BaME specific peer support that should be carefully considered going forward
- As people's sense of wellbeing and general health increased, and as they experienced more supportive contact with friends and family, they chose to access less peer support
- Over time people involved in Side by Side accessed less peer support overall while maintaining or increasing the level of benefit (especially their self-efficacy)
- People did not seem to stop accessing peer support altogether, maintaining a core level of support (for example attending a peer support group as a source of ongoing social contact with friends)
- Our findings suggested that, offered a range of different types of peer support, over time people identified the approaches that worked well for them, making increasingly efficient and effective use of peer support as a result
- Giving peer support can be understood as an active, reciprocal sharing with others, especially (but not only) in the context of group peer support
- Increasing the amount of peer support people gave in this way brought about significant change for people in a number of areas
  - People giving more peer support in this reciprocal, active way in groups saw improvements in their sense of wellbeing, hope for the future, self-efficacy and increased supportive contact with friends (new friendships were made both in and outside of peer support groups)
  - People giving more peer support one to one saw improvements in their sense of wellbeing and hope for the future, also benefitting as they came together as groups (for example, for training as mentors)
- Giving and receiving roles could be more demarcated in some one to one peer support, and especially in online peer support
- People derived some benefit to their general health status from receiving one to one peer support in response to specific problems, and asked for support from others online when they were feeling less well
- People like giving support to peers in the form of advice and guidance (especially one to one and online)
- On balance it would seem to be the agency in peer support that brings about most change, both in terms of choice and control over what sorts of peer support to access and why, and with respect to an active, reciprocal sharing of peer support

We will reflect further on the findings from this chapter in our final discussion (chapter 11) when we bring together the results from across the evaluation.

# Chapter 9: Capacity building work

# Summary

In this work stream we explored how the Side by Side programme supported the development and growth of the peer support community across the country through a structured programme of activities and events. This part of the programme was called 'capacity building'.

We interviewed leads of all the various organisations involved in the process; national Mind, the nine hubs, strategic partners, Elefriends and local peer support groups. 21 people in total. We also attended and observed events.

We used our findings to map out the resources and processes that helped to build capacity through the hubs. We used this to build a framework diagram that showed how capacity building and sustainability may be achieved going forwards.

From this work we found that there were some challenges to capacity building work. These included:

- Peer leadership there was a central tensions within the way Side by Side was structured. National Mind wanted to create an environment in which peer support could grow organically in response to local context, and yet also took on the role of close project management, including collecting monitoring data.
- Relationship building in some areas organisations who had not worked together before, and who had previously been in the position of competing for money, were now working together. These relationships took time to build.
- Time the Side by Side programme was time limited in some areas hubs and projects felt they were only really getting going at the point at which Side by Side was winding down
- Engaging commissioners there was varying success in the extent to which hubs were able to engage commissioners in areas where there were pre-existing relationships this worked very well, in areas where these relationships did not exist this was very difficult.

This work provided insight into the 'active ingredients' of capacity building:

**Peer leadership**: Even if activities are not exclusively peer-led, there does need to be a substantial amount of peer leadership.

**Sharing knowledge:** Exchanging skills, knowledge, and experience is essential to nurture diverse approaches to co-creating peer support locally. This includes sharing resources in the community (such as venues and links to other organisations or stakeholders) as well as joining together to supervise volunteer facilitators or planning promotional activities.

Active learning: An active sense of learning both among those people already giving and receiving peer support, but also in understanding how the full diversity of cultures and communities needs to evolve in peer support locally.

**Creating safety:** Creating positive, safe, trusting spaces for peer support - good experiences of peer support foster capacity building - within and across communities and cultures.

**Changing ways of working:** Being prepared to think differently about how peer support is provided, challenging and adapting ways of working that can be constrained by conventional thinking about services, models and care giver/user roles

**Time:** Capacity building will require sustained efforts over a long period to build a credible reputation. Time is also required for communities, organisations and individual peers to share and learn from each other.

**Strategic factors:** some will help, others will hinder. Being aware of strategic changes, influencing local and national agendas, and working alongside others in the health and social care space will be important. This requires a mutual sharing of local knowledge and national policy expertise.

### Introduction

A key aim of Side by Side was to develop more peer support capacity across the country.

#### What is capacity building?

Capacity Building can be defined as a process by which a community can achieve sustainable growth over a given period of time. As people working to build capacity operate in a complex, 'real world' environment, the process may be complicated, involving the mobilisation of multiple components. This process requires 'resources' such as people, their skills and practical items such as rooms or photocopying, and 'activities' that encourage growth and well defined concrete 'outcomes' to work together achieve the overarching vision of sustainable growth.

When doing capacity building work, those involved may need to consider some of the following questions: What skills and assets already exist within our organisation? How do we leverage them so more people know what we have to offer? What are the gaps in our knowledge that need to be developed to grow the peer support market? Who else can we learn from, and work with, in the community to ensure people who want peer support can get it in a timely manner? The answers to these questions may shape the form a particular capacity building effort may take. In the following chapter we describe the results of our evaluation of the capacity building work of the Side by Side programme.

We had the following research question:

What kinds of support, resource and capacity are required to deliver different models of peer support effectively, in line with peer support principles and values?

Peer support within the Side by Side programme, as described in other chapters, was a diverse group of people who worked within the peer support movement. This collective grew from a grass roots movement of people living with, and working out how to manage, their own mental health difficulties, rather than originating in medical models of mental health support systems. It is decades old. Its appeal has always been its non-prescriptive nature, where peers are able to choose which approach worked for them, rejecting a 'one size fits all' view of mental health support. Crucially it shifted 'power' away from systems towards individuals to define what worked best for them in terms of recovery. When trying to build and strengthen an approach that was so broadly defined, and where assets were widely spread out amongst those involved, and the principles were owned by a grass roots movement not organisations, there were always going to be challenges.

To tackle this challenge, Side by Side worked within a well-defined, yet adaptable system. Figure 9.1, at the end of this section, illustrates the design and structure of the capacity building system that underpinned the Side by Side programme. Although this idea of achieving specific outcomes seems to be at odds with the organic development of peer support culture, flexibility was encouraged. This created an overall system that that had external coherence, but that was flexible enough to allow people working within it to use their own initiative and creativity.

Early data collection asked people involved in parts of the capacity building work to define what the term meant to them. There was coherence across all groups. In Box 9.1 a distilled summary of their responses is provided.

### Box 9.1: Capacity Building in Side by Side can be defined as a process of:

- **Growth**: Increase in the number of people doing peer support
- Improved understanding: Ensure people interested in peer support had a clear understanding of what peer support is and what it is not, and were equipped to engage in peer support safely and meaningfully
- Awareness raising: of peer support's value among communities not previously familiar with this approach, including those in rural areas, commissioners who could fund peer support, and those from ethnically diverse backgrounds.

# People involved in Capacity Building

The Side by Side capacity building system involved 4 distinct groups of people who had defined roles and targets within the programme:

#### 1. National Mind

National Mind were the architects of the overall capacity building structure, determining where and how activity happened. Many of the capacity building activities were a response to recommendations of previous research. The 'Piecing together the Jigsaw' report (2013) recommended that the following would be useful to building and strengthening the peer support community:

- Creating opportunities for local peer support groups and organisations to network
- Access to mentoring
- Access to information around good practice, governance and evaluation

National Mind were also responsible for overall management of activity. Their staff provided direction and guidance to the other organisations and projects involved in the capacity building process; helping them to stick to targets, time frames and monitoring of delivery in line with Big Lottery Funding (BLF) guidelines.

National Mind steered away from being too prescriptive. They encouraged those involved on the ground to develop a range of delivery approaches that appealed to the local community and worked with people with lived experience of mental health difficulties. There was also a recommendation for groups and organisations to work in partnership to deliver peer support. They created nine leadership 'hubs' across various parts of England, to act as the focus for the development of the peer support in the area.

# 2. Hubs

The hubs were coordinated by a Local Mind and worked alongside a strategic partner, chosen by Mind for their expertise in delivering of a certain type of peer support led by people with lived experience of mental health difficulties. Hubs were a central resource, representing a catalyst for peer support to flourish in the local area. They had a dedicated local mind staff member to oversee and coordinate the various activities set out by National Mind to build capacity. Hubs were expected to achieve the following targets:

- Engage with 29 groups and organisations across two years through the following activities and means:
- Deliver 3 networking events
- Facilitate 4 more focussed activities to build the skills, expertise and confidence of peer support projects and individuals
- Develop tools to engage with commissioners

During our evaluation we spoke to people coordinating hub activities at each of the nine Side by Side areas and asked them about the role of the hub. A summary of their responses is provided in Box 9.2

# Box 9.2: Role of the hub

- Raising awareness of peer support to new audiences
- **Facilitating** spaces and conversations where peers could transfer knowledge about peer support and also share community resources such as rooms
- Using **organisational expertise** to skill up people in the existing peer support community with the tools to engage in peer support.

National Mind also offered a number of peer support groups in each of the nine 'hub' areas, a grant for their specific development. These grantees were expected to engage with the hub activity and their progress was monitored.

# 3. The Strategic Partners

Strategic partners were organisations that had existing expertise in setting up, delivering and sustaining peer support. Each worked to a different model of peer support and Bipolar UK and Depression Alliance were part of the overall funding application to Big Lottery Fund. The chosen partners were:

- Depression Alliance
- Bipolar UK
- 3 local Mind peer support projects

These organisations and groups had the most direct impact on building capacity. They were involved with delivering 'new' peer support 'on the ground', with a target of engaging 167 new people into peer support, per area. Each hub was affiliated to one strategic partner (see Table 9.1 below).

	Targets for engagement	Strategic Partner	Target for engagement
Hub 1: Kensington & Chelsea	29 groups	Depression Alliance	167 new contacts
Hub 2: Coventry & Warwickshire	29 groups	Bipolar U.K	167 new contacts
Hub 3: Suffolk	29 groups	Local Mind Suffolk	167 new contacts
Hub 4: Northants	29 groups	Depression Alliance	167 new contacts
Hub 5: Blackpool	29 groups	Bipolar U.K	167 new contacts
Hub 6: Leeds	29 groups	Local Mind Leeds	167 new contacts
Hub 7: Plymouth	29 groups	Depression Alliance	167 new contacts
Hub 8: Stockton and Middlesbrough	29 groups	Bipolar U.K	167 new contacts
Hub 9: Solent	29 groups	Local Mind Solent	167 new contacts

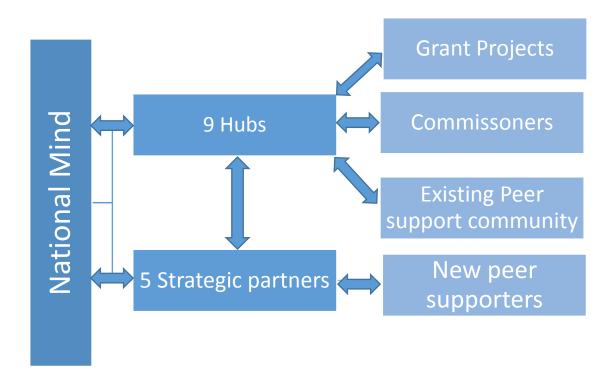
#### Table 9.1: Capacity building targets and relationships for hubs and strategic partners

#### 4. The Peer Support Community

If National Mind were the architects of the capacity building work and the hubs and strategic partners determined the structure and led activities, the local peer support community were the ones that made the whole process come to life. There was a natural drive to engage anyone interested in peer support, but there were also certain community groups Mind had a particular interest in building capacity with: Commissioners, BaME communities and rural populations. The peer support community typically consisted of the following groups of people:

- Groups already engaged in, or interested in setting up peer support
- Side by Side grant funded projects
- Individuals interested in peer support
- Commissioners of peer support
- Rural/BME population groups





# **Our** aims

The evaluation team were tasked with answering the following research question.

What kinds of support, resource and capacity are required to deliver the different models effectively, in line with the peer support principles and values?

As described in the introduction, the process of capacity building is a complex one that involves a number of different components that interact with each other. To understand this complex process and how it operated in Side by Side, we used a specific approach called 'Theory of Change'. A Theory of Change (TOC) (Harris et al., 2014) is a structured way of looking at how a programme may achieve its 'goals'. It has been used by different organisations to help them plan programmes of work, including the Lankelly Chase Foundation and New Philanthropy Capital.

In this instance, we have used the TOC approach to map the various components involved in Side by Side and link them to the desired goal of sustained growth of peer support. We structured the components into a framework as follows:

1. **Approach** – The overarching vision and underlying principles that were brought into Side by Side

In the introduction, we have already described some of the approaches that lay at the heart of the capacity building process. One was the structured way in which

Mind set out targets, goals and types of activity. This helped provide order to a complex process. Another was the peer support movement.

2. Resources - Inputs available to the Side by Side team for capacity building

The introduction has already highlighted a number of key resources, most notably the groups of organisations involved in the capacity building process; National Mind, Hubs, Strategic Partners, and the Local Peer Support Community. The role of these groups as a resource is so central to the whole process that we have structured the findings section of this chapter around them. In each section, we unpick what specifically about these four groups made them important and useful resources in the capacity building programme.

3. Activities – What Side by Side actually did to build capacity

Our introduction has outlined some of these activities. For example, the networking events coordinated by the hubs.

4. **Enablers and Challenges**– Factors that were helpful to the running of the capacity building process and achieving outcomes and factors that were unhelpful.

Enablers and challenges can be described as two sides of a coin. The identification of challenges was a useful way of understanding what can be improved or learnt from a process, in other words, what the 'enablers' of the future could be.

It is also important to note that some enablers within the Side by Side capacity building process were components that already existed in the environment before the programme began. We could say they were 'preconditions' such as potential grantee projects already being led by people with lived experience of mental health difficulties. Other enablers, described later in our findings, were 'emergent'. In other words, they appeared as a result of the capacity building process.

5. Intermediate outcomes – Things that the programme sought to change

As described in the introduction to this chapter, the capacity building process sought to increase the offer of peer support in the nine areas it was active. Some of these outcomes were very concrete, determined via targets. E.g. strategic partners tasked with engaging 167 new people into peer support. Others were less concrete. For example, it is difficult to assess how 'awareness peer support' may have increased for new audiences.

6. Final Goals – Increase in availability of sustainable peer support

# Figure 9.2: Components of our theory of change framework



Figure 9.2 shows a simplified diagram of the Theory of Change model we were using, which suggests a linear progression from 'Approach' through to 'Final goal'. In reality the process of capacity building is more complex, mirroring the environment in which it operates, but this structure helped us organise the data collection and analysis stages of this work.

The TOC we present through our analysis is a preliminary outline of the necessary components needed for building capacity and not a full theory. We have not examined all the underpinning mechanisms for change and assessed how they interconnect. We have produced lists of factors emerging as important and thus our TOC provides a detailed map of various components, which could be developed further by the sector if that was judged as useful.

# **Methods**

#### **Data Collection**

Our approach was to use qualitative methods including participant observation and semi structured interviews. A key aspect of this work was the involvement of peers as researchers within the team. This enabled us to build relationships with data collection sites, facilitating access to potential interview participants, including senior managers. Our findings are based on four sources of data:

- Observations and early scoping work, networking and workshops in the hubs (n = 6)
- Interviews with all the hub coordinators and strategic partners (n=11)
- Interviews with programme managers and coordinators from National Mind (n=4)
- Interviews with the lead of a local peer support group that had varying degrees of involvement with the hub (n=6)

#### Analysis

The analysis process can be broken down into three stages.

- Our analysis initially used Nvivo to organise the qualitative data. Data relating to components of the framework; approaches, resources, activities, enablers, intermediate outcomes and goals, were coded and identified by the four groupings. We placed elefriends together with strategic partners as they had a similar function with regard to capacity building.
  - National Mind
  - Hubs
  - Strategic partners and Elefriends
  - Local Groups engaged in peer support

- 2. The second stage of the analysis was a collaborative process between two members of the research team, one of whom actively used their lived experience of mental health difficulties in the process. The researchers interrogated the NVIVO coded data further producing themes that are used to organise the findings section of the report. There were three themes identified per grouping.
- 3. The third stage of the analysis was to start building a Theory of Change. Each theme produced in stage 2 was further dissected for factors that could populate the ToC framework figure as outlined in figure 9.2. Questions such as 'what resources does this grouping bring to the capacity building process? What outcomes do they evidence?' were asked. The results of this process allowed us to take the original Nvivo coding and produce a more structured visual representation of ToC components for each grouping.
- 4. The final stage was to review the four ToC component figures and further refine them, removing duplication, to create an overarching summary which represents our draft ToC model. We also reflected on data gaps.

# **Findings**

The findings are presented by each of the four groupings, with components for the TOC summarised at the end of each of these sections. In each section we are searching for elements of capacity building as described in our data set. This should be viewed acknowledging limitations of the evaluation process. We carried out interviews before capacity building was fully complete. We had to collect some data by email interview, though most was telephone or face to face which may impact on data quality. We could not interview everyone involved in capacity building and thus important perspectives may well be missing.

# National Mind

National Mind project managed the capacity building work and allocated resources. Their staff provided structure to the programme, monitoring targets and time frames for the delivery of peer support activity in each local hub areas.

And I'm just driving for them to realise that they are a resource to each other. They must learn from each other. They are equal. They are on the same page. (CB1)

Mind is project managing it very tightly. So there have not been too many deviations that I have picked up. (CB1)

The three themes explored in this section were time, achieving collaboration, and experts and expertise.

#### A time limited programme

The Side by Side Programme received funding for two years of activities from the Big Lottery. We found that the funding timetable of Side by Side was challenging, and it impacted on the overall goal of sustainability, because of the pace of delivery.

Unfortunately it's only a short programme so it's at this halfway point that people are probably saying, "Actually we are just getting going" so, you know, it feels a bit strange that it's only another year at the halfway point. (CB4)

This was a new model, that we were trying out, but actually......I'm thinking particularly of the grantees here, were under a lot of pressure to get up to speed and start delivering really quickly, their priorities in the first six/nine months of the programme was about getting their project set up, getting participants recruited, making sure those participants had a good experience, not about the future sustainability of the programme. (CB4)

It takes longer to build that infrastructure, as well as the trust that goes with that. (CB4)

The National Mind team were fully aware that building expertise was a process that required longer than the time that was available.

That expertise isn't there yet as well. I think hub stuff are generating that expertise development, but it's too short, and I think at least another two years probably...... And for people to get their heads round what peer support is within their organisation and how that organisation can develop and grow because of it, I suppose. And then what their core business is and how that can change and how that can be led. At the end of the day, it's about services that are being led by people with mental health problems, that's what it is, isn't it? I think there isn't a market out there. It's emerging but it's too soon. It's very, very early on. It feels like we're making great strides in some ways but when you're talking about embedding services and peer leadership and all that; organisations being peer led and it's quite a way away from that, I think. (CB2)

Side by Side was a large programme to establish and the National Mind team experienced complications in the early stages of set up which caused delays, particularly impacting on capacity building objectives. This included staff changes at senior levels in National Mind, resulting in some 'vagueness' in the understanding of how specific activities should be implemented, and a delay in programme branding. The project was only named in July 2016, several months after the start which delayed the production of promotional materials.

The people who wrote the bid, they kind of... we won the funding and then they moved on so we kind of had a bit of a disconnection to some of the thinking behind it and then trying to make sense of, "What does that mean and how does that...", so trying to make sense of it, I think some of the stuff got a bit miscommunicated or a bit lost perhaps but I suppose the plus side of all of that was that we then were able to be quite honest about that and say, "Well, we don't really know ...in a general way, it's over to you to explore that in your local area" which is probably better than actually being more prescriptive. (CB2)

Mind were contractually obliged to take a structured approach to capacity building. Targets helped keep the programme on track. In spite this, Mind were self-aware that they did not want to be prescriptive in their approach and that bulk of activity would be determined by the hubs. The activities they did implement were procedural and did not directly link to any outcomes. As we described in the methods section, enablers and challenges can be considered as representing two sides of the same coin. Time was a constraint but also a necessary enabler for capacity building. The comments by programme leads allude to the 'need for time' being a pre requisite for building trust between partners in the programme. The ambition of Side by Side, to spread peer leadership, was also considered to be potentially ahead of its 'time' in some regions. We summarise these insights within a TOC framework in Figure 9.3

Approach	Resources	Activities	Enablers	Intermediate
Structured	Funding for hub	Developing	Time	Outcomes
Targets Not prescriptive	Grantee funding Staff	promotional materials Recruitment of grantees	Trust (between partners) Market (demand) Peer leadership	

Figure 9.3: Emerging	elements from a time limi	ited programme -	the TOC framework
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# Achieving collaboration

The role of National Mind was on one hand to tightly project manage and ensure compliance with targets, and on the other, to build and open up the peer support community so that was available to anyone who needs support. To nurture, empower and encourage it to flourish. We found staff members within National Mind talked about taking a 'collaborative' approach to the programme.

I guess some organisations can be in that contractual arrangement and just being really paternal about it all but we don't have that approach. It's very much a kind of a "Let's work together and let's understand this together". (CB2)

Some like [local minds] to a degree have all been working in quite a big way in peer support in different projects and sometimes they come perhaps with their own take on it, so it's like, "We have been doing it like this. This is our model so this is what we are going to continue to push" and it's like, well, it's not what this programme is about. This programme is about a range of models, it's not about your way. Yes, that's all very well and good, you can carry on doing it but this programme is about talking about all sorts of different approaches' (CB2) It's a community development approach, which I really subscribe to, where the answers are emerging from the work that we are doing.....And I think people get excited by that, because there is an inbuilt element of producing together – co-production..... where people with lived experience are leading the peer support. We know that... like for the grants, it needed to be peer led peer support, for example. So we know that people with lived experience of mental health problems are leading some of these core parts of the projects. (CB1).

I think Mind's ambition – I have to give credit where it's due – has been to try to engage. I'm not saying that they have got it right, but they have been ambitious to try to get BAME groups engaged. And for me I adapted. I took to it like a duck to water, you know. (CB1)

The ambition for capacity building was a recognised focus for Side by Side but not everyone took to it "like a duck to water". Local Minds were chosen to be regional leaders, due to their perceived experience in peer support and links to local commissioners. However, in reality, not all hubs started from the same place; where some had established, long standing relationships with commissioners and community groups, others did not. They were also required to work with organisations that in a different context were competitors, which required a cultural shift, relationship building and dedicated resources.

The reason that we commissioned these hubs in the first place was so that they would be able to demonstrate good links to commissioners, links to the local monetary community sector, in their area, and, therefore, they were coming in from an expert perspective. (CB4)

We are another charity who may potentially be taking their business so to speak. I am not saying they look at it like that but in the cold light of day they may have bipolar groups themselves and feel they don't want to promote ours. (CB5)

So, in some areas, Bipolar UK and Depression Alliance could be seen as competitors for the local Mind so, yes, you know...and it had been expressed at the very first meeting, "Why should I work with this organisation because I am applying for money from the commissioner for something.....and some, you know, we were asking them to work with organisations that they hadn't worked with before and it was, kind of, like, "Well, why should we?" so it was exploring all that with people at the very early stages. (CB2)

It was a bit of a problem for a while, but yes, so that collaboration seems to have come together now but that's only because they invested in a coordinator that had the time to concentrate and work on that relationship working. (CB2)

Through collaboration and discussion with National Mind, local Minds were able to change capacity building activities to better fit local needs. Primarily, new peer support groups identified needing tools to get started including safeguarding, boundaries and telling your story.

We also found that strategic partners and grantees struggled to meet the data monitoring demands of Side by Side; a target culture that was at odds with their approach to peer support; collaborative and social. The evaluation component was 'difficult' and viewed as a distraction, and, a burden, taking time away from other activities.

We aren't driven by having to get target figures of attendances. We don't measure the success of our groups on whether they get five people or 30 people. That's not what we do. (CB5)

That's the only barrier that we've kind of had. I think what we found difficult is doing the evaluation part of it.....We've struggled with that because some of the women don't speak English. The only once a month they meet, they're there for a couple of hours and then you've got to complete the form, it's quite time consuming. (CB6)

Side by Side also benefitted National Mind as the programme progressed. The reciprocal sharing of expertise and learning ran across all levels of organisations in the programme, and was particularly on show at networking events.

The key thing that is often missed out, from these kinds of conversations around capacity building, is the capacity of the national organisation, of Mind, in this space, as well. It's often seen as a top down thing, where the big national organisation knows everything......and, actually, no, it's a reciprocal process.... (CB4)

Mind were mindful to be inclusive in their approach, working with local organisations and groups to achieve success. The resources National Mind provided at this stage were linked to setting up of activities and not directly linked to capacity building outcomes. The activities they engaged with were supportive of the other actors in the programme to enable them to obtain targets and build to camaraderie between hubs. We summarise these insights within a TOC framework in Figure 9.4

# Figure 9.4: Emerging elements from the theme of achieving collaboration – the TOC framework

Approach	Resources	Activities	Enablers	Intermediate
Collaboration	Grantee funding	National	Relationship	Outcomes
Targets	Staff	meetings	building with new partners	
Co-production	Get started tools	Awarding and managing	Relationships with	
Range of approaches		contracts	commissioners	
Inclusive of		Evaluation tasks	Shared learning	
minority groups		Monitoring of targets	Peer leadership	
		, in the second s	Knowledge and experience (of	
			peer support)	
				282

#### Experts and expertise

Peer support was not well understood by everyone in the programme. Before capacity building could start, there needed to be a firm understanding of what peer support was and what it was not.

When I talk about capacity building within the context of the peer support programme, I still think... there is a step back before capacity building. How do I give them the same starting line as my counterparts? And there is some preparative work, for me to understand what, for example, concepts like peer support are, which I may not understand. I may have it in my community, but I don't call it that. (CB1)

Several of those interviewed from National Mind spoke about how the "small projects" could be helped to flourish through the 'expertise and experience' of the larger hub:

If I was a small, black project who was not in [the consortium], how do I get a look in? (CB1)

So, what we really need is openness, as opposed to specific, technical skills in commissioner influencing; what we need from larger organisations, in local areas, like local Minds, for example, but also people like local Citizen's Advice Bureau, or local Age UK, and these federated charities with that local reach, is to hold the space for small organisations in those areas, to not be driven solely by their own fundraising priorities, and obviously snap up all funding opportunities in their areas, but actually to hold the space for small, local organisations, and to continue to network and to share information and opportunities. (CB4)

Despite this national level enthusiasm for collaboration and cooperation between all holders of 'expertise' from the national to the local, we noticed local organisations take a cautious approach to working together with others. There were a number of reasons for this.

National Mind had originally termed one activity an 'expert on call' session. The idea being to connect peers with 'experts' who could help with sustainability, for example, in governance, fundraising, or volunteer management. The notion of bringing in 'external expert consultation' was not well received by some hubs, whom deemed it incompatible with core characteristics of peer support, namely equality amongst peers.

We felt that experts on call as a term didn't really reflect the peer model and values and feelings, I guess. So we've called them Experts by Experience sessions with the idea that they are smaller workshops, people all come together and we are all experts. We all bring our own experiences and skillsets and various bits of knowledge, whether we've been doing it five minutes or fifty years, you know? (CB8)

The hubs, as part of capacity building, were required to deliver case studies and other communications tasks, as well as carry our evaluation work that was often unfamiliar. They found this hard, and considered it a distraction from frontline mental health work. National Mind understood this, but their staff overall felt local Minds would have benefited from the

experience becoming more 'expert' in the process writing quarterly reports, using press releases, and working with commissioners.

I think people are thinking they have to become reporters. I don't know, it was a real... it's quite a barrier I think, because I think it has taken people away from what these two maybe, I don't know, mental health work, or whatever it was they were doing, to then suddenly become a media person or to generate case studies and become a researcher or whatever it is. It's that thing and it becomes intimidating. (CB2)

I think they would actually eat their words now and would probably say it was a great thing that we forced upon them and told them that they should work with other organisations, you know, so I think it's learning, it's certainly for the smaller, local Minds (CB2)

A key influence on the programme structure was the expert guidance provided from National Mind, both through one to one support and networking events. We identified that engagement managers were operating as informal mentors to people attending hub events.

I try to keep them focused on the goal, motivate them to not feel so isolated, and support them to network within the regional hubs in order to achieve what they collectively aim to do. (CB1)

The quarterly meetings are really useful, because I don't think we've been to one where we haven't come back with a different idea of something to try, and they're really good from a reassurance perspective, because I think, in many ways, Side by Side is quite broad.' (CB9)

Meetings were held in London every quarter, bringing together all hubs and strategic partners. It is not clear why they were always London based. The national team also attended local networking events, facilitating workshops and delivering presentations on concepts and progress. The communications team developed documents and toolkits on how to write case studies and press releases. The National Mind team described these meetings over time as symbolising 'togetherness' within Side by Side. We also heard that on occasion, the national meetings events were demotivating for peer leaders. We heard an example of how they imparted a sense of competition between hubs and left people feeling isolated and disempowered.

To be told, "Why don't you go and visit them and see what they're doing?" Every time I see them. I think, 'what, are they doing something better than me then?' That has a negative impact on me as well......That's the point I'm making about these London things.... I come away feeling a bit downhearted about the whole thing. And that's why I missed the last one, because I couldn't face going again. (CB10) Mind were keen to embrace a collaborative approach to capacity building, designing activities that bring together multiple stakeholders from the wider peer support community to share expertise. There was some initial resistance for this amongst local organisations, who thought external 'expert' support negated the value of equality inherent to peer support. Hubs were also reticent to work with partners who are traditionally viewed as competitors. Key enablers that emerged through the Side by Side programme, linked to the national approach for collaboration, were the opportunity for the various actors to work through differences and adapt current practices to be more inclusive. Activities such as networking events and national meetings provided fertile ground for such learning to occur. These processes allowed the various people involved in the programme to increase their collective understanding of peer support. We summarise these insights within a TOC framework in Figure 9.5

Approach	Resources	Activities	Enablers	Intermediate
Range of approaches Collaboration Cooperation Targets Equality	Toolkits – fundraising, coms, PR Staff	Networking Share information Expert on call / EbE sessions Workshops National meetings Mentoring from National Mind	Openness Opportunities for small organisations Acquiring new skills Learning new ways of doing peer support (shared learning) Peer leadership and expertise Adapting current approach	Outcomes Increased understanding of peer support

#### Figure 9.5: Emerging elements from experts and expertise - the TOC framework

The final TOC in this section (see figure 9.6) combines the insights from the themes of time, collaboration and expertise. We learnt from the interviews with the national Mind team, and the other interviewees who spoke about national Mind's role in Side by Side how the structure was developed and their vision for how capacity building might be "enabled".

# Figure 9.6: Emerging TOC framework - considering the role of National Mind

Approach	Resources	Activities	Enablers	Intermediate
ApproachCollaborationCooperationCo-productionStructuredTargetsNot prescriptiveRange of approachesInclusive of minority groupsEquality	Resources Toolkits – fundraising, coms, PR Funding for hub Grantee funding Get started tools Staff	ActivitiesNetworkingShare informationShare informationExpert on call / EbE sessionsWorkshopsNational meetingsMentoring from national MindDeveloping promotional materialsRecruitment of granteesAwarding and managing contractsMonitoring of targets	EnablersOpennessOpportunities for small organisationsAcquiring new skillsLearning new ways of doing peer support (shared learning)Peer leadershipAdapting current 	Intermediate Outcomes Increased understanding of peer support
		Awarding and managing contracts Monitoring of	partners) Market (demand) Relationships with	

#### Nine regional Hubs

Hubs were the central resource and driving force for the capacity building work in Side by Side, chosen by National Mind to facilitate hub space and activity because they were considered the local experts in peer support.

....because they are leaders after all. I mean, we have selected [them] from a few that had a pop at the opportunity to be a hub..... (CB1)

The three themes explored in this section to explain the hub role in capacity building were expertise and leadership, building local connections, and expanding the peer support offer.

### Hub expertise and leadership of peer support

We found the hubs had different levels of experiences of peer support. Variations existed in areas such as peer leadership, the range peer support offered, and existing community links and partnerships. This could be described as a continuum of experience. Our findings showed a universal commitment to peer support values underpinned all peer support approaches, but this was punctuated by varying levels of experience of peer support practice. On one hand there was well-established organisation with over a decade of experience building the local peer support community to, on the other hand, a consortium of Local Minds who had never worked together before as a network. In between these ends of the continuum existed varying levels of peer support experience. Some examples include; a local Mind that managed peer support workers placed in an NHS trust; another that ran accredited training programmes for peer volunteers and another that offered co-counselling as a form of peer support.

Our research seems to show local Minds holding a dual identity when thinking about their role in the Hub. Hub leads saw their role as a 'facilitator' of a space where local organisations and groups could share knowledge and expertise amongst themselves.

From the start I've had to fairly continually explain that I am not running a peer support group. It's a central point of contact for people already doing it, people interested in developing it, sharing expertise and knowledge and skill as a point through and beyond that (CB11)

So it's not just Solent Mind saying as part of our core work we are doing X courses and we are the expert but it's actually all the expertise of everybody in the room and we can share (CB12)

They also recognised that they were, to some extent, chosen to be the 'leaders' or beacons of good practice and guidance in the community.

The centre-point for contact, I suppose, for peer-support, so people can contact us and request training, what would be helpful; they can ask us what is peer-support, they can be signposted to peer-support, and trying to create a directory, as well, so that local people can find out how they can access peer-support from all the different types of organisations, and the referral routes for that, so just bringing everybody together (CB16)

A key resource in the hubs were the people coordinating activity – the 'capacity building treasures'. People in these roles were either paid staff or volunteers and many brought their own mental health experiences, as well as personal experience of peer support to the team. We observed energy, commitment and a drive to ensure Side by Side was a success.

Yes, they're very passionate about peer support. They have good connections with the local mental health networks, because that's definitely an enabler, the local contacts for commissioning and for all sorts of things, as well. (CB3)

I think right at the top of our strategic level, at our board level, the value of peer support is huge......we have peer support available four days a week.....I think it's now twelve different peer support activity groups. So everything from drama, music, arts, talking groups, walking groups. (CB13)

She is absolutely...she won't mind me saying this but when she was in her teens and twenties she suffered from depression and psychosis and so she essentially has that experience to draw upon which she brings to the work.... (CB12)

And the majority of our volunteers have lived experience...... I'm not sure, but most of them, I'd say 99 percent, they've had experience of anxiety, depression, or lots of other issues. So we're really excited about that, and how the volunteers are capacity building treasures, if you like. (CB15)

Local Mind leadership was also important for articulating the value and nature of peer support, including its principles and values. This was central to the Side by Side programme which aimed to establish a standard of good practice.

It's just making people think peer-support is more important, rather than it being something that just happens, or is an add-on to a service, because there's almost a bit of an idea that it's a by-product; it just happens, like people will say, 'we do peersupport, because there's people in a room together doing a course on healthy eating. (CB9)

However, introducing the idea of 'standards' did present some challenges, as people were wary of professionalising the peer support offer.

I do have a bit trepidation about very professionalised courses around becoming peer supporters..... Bottom line it is not sustainable.....its saying you have to be somebody different to facilitate a group.....it just...I don't feel particularly comfortable...' (CB24).

Having commissioned the hubs to deliver capacity building, National Mind did not take a back seat from the project. Hubs experienced being actively monitored, and occasionally challenged by National Mind about decisions they took locally. This resulted in a tension in

the project around the autonomy of hubs. For example, one hub questioned how sustainability could be achieved while relying on external experts.

....if they do that, where is the sustainability? Where is the learning? Because it doesn't come back into the organisation if you keep having somebody external..... the investment doesn't come back into the community and, for me, that's important in terms of the sustainability. I'm not saying it shouldn't use external partners or external colleagues, but you have to find a way of getting that learning and that training back in, so you can keep delivering it. This money is not, well, it's not going to last forever, so you need to be thinking about that in the long term. (CB3)

However we observed the use of external consultants as having a clear value in some circumstances. In some instances workshops were co- delivered, strengthening partnership working. One workshop session was attended by our researcher, who observed the value of bringing in external expertise. The facilitators, from BAME communities and with experience of peer support, were able to explore cultural differences and answer questions from peer support providers with authority, providing useful suggestions for improved engagement with people from ethnically diverse backgrounds.

Another hub partnered with a local trust to co-facilitate regular meetings for peer support workers in the region. The hub was able to form a collective of local peers who could then share learning, practice and feel part of a network. The hope was to improve the local labour market for peer support workers in the trust.

Once a month, anybody who's working, voluntary or paid, as a peer-worker.....can come along to that, to meet other peer-workers and discuss; not supervision, but like an informal supervision, where they can meet each other and share ideas, problem solve, talk about challenges, and that kind of thing. .....that's facilitated by me and by [name] from [name of organisation]. (CB16)

Hubs were encouraged to do capacity building around reciprocal learning including drawing on national and local expertise. We did not collect data at the end of the capacity building programme so cannot comment on how well the tension of expertise was overcome.

The tension around the idea of 'expertise' kept surfacing in interviews. However, we can see that as the hubs progressed through the Side by Side programme, they found working together with other local organisations that held a different type of expertise around peer support to be a firm enabler. New levels of understanding of peer support from alternative cultural perspectives were produced through working together and sharing knowledge and skills. Hubs held a dual identity; at once a 'facilitator' of activity for the peer support community and a 'leader' of good practice through activities such as signposting and training. People who coordinated the activity of the hubs were clearly passionate and knowledgeable about mental health. This commitment, combined with the structured approach to activities, ensured targets for engagement could be reached. We summarise these insights within a TOC framework in Figure 9.7

# Figure 9.7: Emerging elements from hub expertise and leadership - the TOC framework

Approach	Resources	Activities	Enablers	Intermediate
Structured	Local staff and volunteers External consultants Venues – meeting space Directory of peer support locally Training tools	Training National meetings Workshops Supervision Signposting	Peer leadership (and expertise) Passion, commitment, energy of staff and volunteers Local networks and connections Defining standard of good practice Cultural adaptation Local partnerships Knowledge & experience (PS)	Outcomes Increased understanding of how peer support is valued by different people Increased number of people engaged in peer support

#### Building local connections

Hubs that had established local networks at the start of the programme were better able to promote their activities, assisting a speedy set up of activity. This includes distributing newsletters. They were also able to reach out to encourage peers to join the hub, drawing on personal connections and reputations.

I guess this service has had about sixteen years doing peer support.....it's had plenty of time to build up not only a really strong good reputation for doing peer support in this region but also a significant bank of resources and courses ........So I guess that equips us with all the experience in all of those areas and a really good platform to support others to do the same. (CB8)

We offer City & Guilds training to people with mental health difficulties, and anyone that has gone through that, and got their qualification, can come back as a volunteer.....they'll now be accessing the training that I'm delivering, as part of Side by Side. (CB16)

The hub acted as a community connection builder. In order to do this, the facilitators of the hub had to acknowledge the variety of ways in which peer support was valued and experienced in the region. This was particularly true for parts of the population that did not readily identity with the language of western notions of mental (ill) health.

At the BaME meeting, there was one organisation .....starting a health and wellbeing things up..... when they were talking about what they did, then listening to me explain a bit about peer-support and what one of the other organisations were doing, they were thinking, 'maybe what we're doing is peer-support', but they hadn't really heard the term before, what peer-support means, and so it was all very new to them, but they got a bit of a revelation, really.... The community would never use the word peer-support; they don't use the words mental health, because of the cultural stigma around it.... (CB16)

Muslim men are sometimes...they know there's an issue, a mental health issue there but they might blame it on something else. So it might be, "You at Mind cannot help me.....because it's the jinn that's got me, not mental health," that kind of thing...I've run peer support where people have come and they've talked about jinn and things like that and black magic and stuff but it's still helped them. They've come and got it off their chest..... (CB17)

Rural communities were particularly difficult to engage due to issues of distance, transport costs and a lack of understanding of peer support. Side by Side resources enabled hubs to extend their reach and collaborations.

I learnt that people in rural areas still expect the old way of being provided a facilitator to run groups. People still expect that we do all this for free. People in rural areas do not understand that this is not a statutory service 'like it used to be'.....I

have learnt that people in rural areas are probably the most difficult to engage with for many different reasons – including public transport.... (CB10)

We're also linking with an organisation .....who work over a broader geographical area than us but they do try and engage with rural communities. We're seeking help from them to get the message out there about peer support. (CB18)

We also found one impact of the programme was network building with new partners.

So it's sort of combined the knowledge. They had the expertise of working with people in the BAME community linked with the support from the hub to get the training off the ground. It worked really well because I don't think it's something that we could necessarily have done on our own and they could have necessarily done on their own. (CB18)

And the third sector needs to learn that – to say, "Do you know what? The sum of the parts is more important than just us as individuals. (CB1)

Leadership and expertise (as discussed above), was linked to hub approaches to establishing local networks to build per support. Hubs that held a strong standing in the local voluntary and community sector were at a natural advantage when promoting the work. This was a strong pre-existing enabler to achieving the goal of engagement and partnership working for some areas. The programme also provided the opportunity for hubs and strategic partnerships to forge connections with new peers, such as with rural and ethnic populations. This promoted greater learning and understanding of alternative perspectives of mental health, and peer support. This can be considered an emergent enabler of the programme. We summarise these insights within a TOC framework in Figure 9.8

Approach	Resources	Activities	Enablers	Intermediate
Collaboration	Training tools Toolkits Staff Local community	Promotion work Newsletters Workshops	Existing relationships with individuals and organisations in the community (local networks) Local Mind's peer support reputation Adaption of ways of working - such as language Opportunities for relationship building - meeting new orgs.	Outcomes Increased in number of people engaging in peer support Increased partnership working Increased understanding of peer support

# Figure 9.8: Emerging elements from building local connections – the TOC framework

#### Expanding the peer support offer

We heard how capacity building relied on skilling up staff and volunteers locally in large numbers, with confidence to deliver peer support 'projects'. It was felt that the set up phase was particularly important for delivery of quality peer support.

I think training and supporting the volunteers – all the staff involved – is really fundamental in that. Because actually if you have a really high turnover of volunteers, then that adds a huge knock-on effect to your service users, and once that happens and people start to fall away, I think that it's really hard to claw back. So I think getting it right at the beginning, and ensuring people are well trained and well informed, and that people's expectations are right, and it's really fundamental to making it sustainable, really. (CB19)

However, there was reticence within National Mind around 'standardising' peer support through training, with them voicing concerns that this could diminish the organic essence of community led activity. This tension runs throughout the capacity building programme: the ideal of creating a sufficiently customised and bespoke solution for people experiencing mental health difficulties was pitched against a replicable framework that commissioners can use to assess quality of provision against pre-existing criteria.

Everybody approaches peer support totally differently, in different regions and in different communities, and for different stakeholders actually. But peer support isn't going anywhere. So I feel that if we... if I start to pin it around training, the dangers are you will start creating models of peer support, and it starts to, I think, lose the spirit and essence of what peer support was supposed to be. (CB1)

A number of people who attended training and workshops spoke of how the sessions enabled a baseline understanding of peer support good practice, especially around issues of safeguarding. One group mentioned that volunteers also gained a sense of achievement through participating.

The most recent course I did was applied suicide intervention skills training.... put it this way, it was quite useful to know and pick signs up off people. (CB20)

Training as well about adult training, adult safeguarding. I think it's given them a bit of achievement and they feel as if they've achieved something if they are getting certificates through Side by Side. (CB6)

A few people appreciated that regular contact with the hub enabled a greater sense of community cohesion, especially for smaller groups whom may be self-funded and managed. This in turn, supported the signposting of individuals to local and National Mind for additional support services.

I know that I could go to them with anything and say, "Look, we need help from you". (CB21)

We do send people to Mind. A lot of the people that come to us don't know where it is, have never contacted them and I think you must go and see them because they will be able to help you. Of course, they have a wonderful craft section down there. (CB21)

Knowing about what other sorts of counselling or different services are out there because it may be that yes we can support them through peer support but it may be that they need additional support which it could be we can't offer. (CB6)

Events also enabled internal learning for the hubs. First events were scoping and mapping exercises. The hubs used these to identify local needs, gaps in provision. Second and third events focussed on more of a theme such as evaluation, approaches to peer support, how to engage with BAME populations, the commissioning landscape. The final events offered a reflection on project achievements and successes

Certainly our first hub event was around mapping and discussing gaps and things like that, to kind of have a look at where we would sit in that and how things are at the moment, and get a good picture, regionally, of how things are. (CB19)

One local Mind shared how important geography was in their activities. They realised they could not set up new peer support groups in places it already located other local Mind activities and expect people to come to them; they learnt they needed to reach out to new venues local to new communities.

I probably would, if we went back again a year ago, I would have thought, right, this is completely the arse over face way to do it, with BAME groups in particular, is around bringing the service, bringing the resources to them, rather than expecting people to come to us and to find out from us in a physical place. I mean, there's a lot of learning around this that will feed into the other work we do (CB15)

The capacity building programme had a specific aim to make peer support sustainable across diverse local communities. For one local Mind that meant creating an 'ethos' that others would sign up to, and imbuing it with an 'identity' that could outlive Side by Side funding.

So what we discussed - with the members who were there - was the idea of the hub agreeing some core fundamental areas where they share 'approach' if you like, so that if we promote the hub as something that can help people with mental health, when people go to some of those organisations, they're going to get almost a basic commitment and be treated in a certain way that gives them some reassurance. I think by doing that the hub could almost create its own identity and people might sign up to an ethos. (CB18)

One of the targets for hubs was to build relationships with local commissioners. The rationale was that once Side by Side ended, local commissioners may be willing to continue funding local peer support. However, this aspect of the hub brief was extremely challenging.

Where a lack of a positive response was received from commissioners, this impacted on staff confidence. Commissioners were very busy and often difficult to reach for meetings or conversations.

I don't know how you'd engage somebody who doesn't want to be engaged (CB15)

Some of the Hubs are very good in dialogue with their commissioners, and others there is hardly anything. (CB3)

Some hubs were trying to establish relationships in a climate of budget cuts and financial pressure, which made promoting peer support as a standalone package difficult. However but it did enable hubs to better understand the commissioning landscape. It helped hub staff assess where peer support might fit into future funding streams and pathways of care:

Because of the cuts, we've had some of the worst cuts in the country, more services are being stripped back, eligibility for things is being stripped back, so they don't really have any other option, on some degree, than to focus on empowering communities, so a lot of it is on resilience, wellbeing, the five-ways, so it all does support peer-support, but they'll look at it on quite a general level, which I don't think is a bad thing, because that then helps reduce stigma, or this idea it has to be segregated out. (CB9)

Some hubs found that commissioners did have a clear understanding of the values of peer support but this was narrowly applied to NHS delivery models. Hubs were trying to promote and inform commissioners about how peer support is not a one size fits all model, and that there are variations that work well in the community. They were also keen to promote the voluntary sector in peer support leadership.

We're offering it up to commissioners and saying, this is how collectively as peer support groups and networks we are describing what peer support is, and that helps inform their work, it helps inform how things will look locally and I guess regionally as well, and in the future. (CB8)

Do they know all the different forms that peer-support can take, or do they just have one model that they think of, when they think of peer-support? So, that's the sort of conversation I'd want to have; how it can take all sorts of different forms, how it can be specifically useful for particular groups of people. (CB16)

Part of the hubs work was to raise awareness of peer support. The activities were an opportunity for hubs to utilise their peer leadership and expertise. Local groups we spoke to appreciate this offer for multiple reasons. Training set a base line of standards around good practice and offered peers a sense of achievement. More generally, activities enabled greater community networking and signposting to other mental health services in the area. In short, it supported the awareness of choice for the local community, a value that aligns with the peer support values described in Chapter 6. Hub activity also allowed the local minds to learn internally. They realised that to promote expansion of peer support, their

work needed to move into the community. The Side by Side programme focus on commissioner engagement, enabled local minds to understand more about the local funding landscape and how to effect change. We summarise these insights within a TOC framework in Figure 9.9

Approach Targets Diversification of peer support	Resources Staff Volunteers Local community	Activities Training Workshops Networking events Supervision	Enablers Retaining volunteers Quality standards Understanding commissioner priorities Peer support	Intermediate Outcomes Increased number of relationships with local commissioners Increased awareness of peer support and outcomes/ impact
		National meetings Promotional work Signposting	community cohesion	Increased confidence giving and receiving peer support Increased stability of peer support community

# Figure 9.9: Emerging elements from expanding the peer support offer - the TOC framework

The final TOC in this section (see figure 9.10) combines the insights from the themes of expertise and leadership, local connections and expanding the peer support offer. These are similar to those emerging under our analysis for the national Mind grouping but the insights gained from hubs were more detailed. Again it is the enabling factors that are most spoken about in interviews. Hubs were focused on final goals and collapsed the general sustainability objective into several parts involving work with peers, partner organisations and commissioners.

# Figure 9.10: Emerging TOC framework - considering the role of the hubs

Approach	Resources	Activities	Enablers	Intermediate
ApproachStructuredCollaborationTargetsDiversification of peer support	Resources Local staff and volunteers External consultants Venues – meeting space Directory of peer support locally Training tools Toolkits Local community	ActivitiesTrainingNational meetingsNetworking eventsWorkshopsSupervisionSignposting workNewsletters	EnablersPeer leadership (and expertise)Passion, commitment, energy of staff and volunteersLocal networks and connectionsDefining standard of good practiceCultural adaptationLocal partnershipsKnowledge & experience (PS)Existing relationships with individuals and organisations in the community (local networks)Local Mind's peer support reputationAdaption of ways of working - such as languageOpportunities for relationship building - meeting new orgs.Retaining volunteersQuality standardsUnderstanding commissioner prioritiesPeer support community	Intermediate OutcomesOutcomesIncreased understanding of how peersupport is valued by different peopleIncreased number of people engaged in peer supportIncreased awareness of peer support and outcomes / impactIncreased partnership workingIncreased partnership workingIncreased partnership workingIncreased partnership workingIncreased number of relationships with local confidence giving and receiving peer supportIncreased confidence giving and receiving peer supportIncreased stability of peer support

#### **Strategic Partners**

Each hub was affiliated to a strategic partner whose job it was to directly expand peer support offers in the area by engaging 167 'new' people into peer support. Most of these targets were reached and exceeded based on Side by Side monitoring data. Three locations fell short. However, these targets do not help us to understand sustainability because this was the creation of new demand and tells us nothing about whether people came more than once to a group or whether after Side by Side these new members stayed engaged. However, before sustainability starts, there needs to be a firm foundation of peer support to build on and strategic partners were tasked with delivering peer support in greater volume than previously offered in nine regions.

		Actual new members (target = 167)
Area A	External partner 1	191
Area B	External partner 1	152
Area C	External partner 1	186
Area D	External partner 2	149
Area E	External partner 2	177
Area F	External partner 2	176
Area G	Local Mind 1	223
Area H	Local Mind 2	176
Area I	Local Mind 3	130

#### Table 9.2 Strategic partner new member targets

Each strategic partner brought different approaches to the role. An important observation was how the two external partners and one local Mind had their own model of peer support. All three models (A Friend in Need from Depression Alliance; Bipolar UK groups; Leeds Mind) had a 'self-help' ethos, emphasising that the sustainability of practice is determined, to a large extent, by peers who use them. Two strategic partner approaches rely heavily on volunteer facilitators, one had over 140 volunteers across the country.

Although not an official strategic partner, Elefriends was also set targets by Side by Side to develop and sustain current membership. For Elefriends capacity building was not just about drawing in new peers, it was also enabling people with the 'skills and knowledge' to use the platform effectively and ensuring that the current user base stay engaged; ensuring the interface is easy to engage with, comfortable and safe.

From our findings, we identified several elements of strategic partner and Elefriends' work that demonstrated how they built capacity in Side by Side. We understood these as:

- Spreading the word
- Use of volunteer & organisational support

#### Spreading the word

Promotional activities were essential when working in new areas. Some of the strategic partners were located in places where they had few connections prior to Side by Side. Elefriends also wanted to attract a more diverse profile of users. Elefriends had a sign up target of 6 thousand new users. To support this, Elefriends ran a two month Google add words campaign, particularly targeting potential audiences in rural locations. This was moderately successful and found that the search phrase that drove the most traffic from rural areas was 'I am lonely'. Elefriends also ran some workshops with communities that may not use Elefriends to learn more about what their needs may be and the challenges they face using online peer support. One with young afro Caribbean men spoke of how the tone of the interface was considered 'soft fluffy and potentially childish'.

Strategic partners worked within hubs and joined forces to help each other promote events and new peer support groups. This reciprocal relationship was an asset for capacity building, helping build stronger bonds between local mind and their designated partner.

I think what has developed is that they have got that real clear understanding that actually signposting to another organisation is best for the clients because we obviously have that knowledge and understanding about bipolar specifically whereas they are perhaps more generic (CB5)

A two-way thing, we give her knowledge of the local area like venues and volunteers, where you can recruit volunteers, promotion roots that are available and circulars and stuff like that. So we give [name] that and they give us back a lot of experience.... to learn about having a specific diagnose group as opposed to just a peer support group (CB17)

In spite of the gains made through hub collaboration, external partners still found it difficult to recruit peers from specific groups in the community due to a lack of local knowledge and links. The promotional activities they led helped them gain an understanding of how different cultures approach peer support.

It's getting in with the right leaders within these organisations and communities but it's hard enough developing relationships in the communities with anybody let alone going into a completely different culture. (CB5)

Elefriends found working with the hubs and strategic partners to spread the word of on line peer support frustrating due to scattered and disjointed lines of communication. It was also suggested that hubs may not have fully grasp the concept of online peer support. Stretched resource in Side by Side and limited time were a cause of this, but Elefriends were hopeful for continued local collaboration between on line and offline peer support.

To an extent Side by Side has been really useful, but it has also been a slight....it's almost made it harder in some ways, because everyone is so busy....building capacity in their own areas. (CB23)

We found that in terms of promotion the large brand of Mind was viewed as both helpful and unhelpful. From the point of view of the new external partner, the hub and Mind brand imparted credibility. This helped the external strategic partner reach a wider audience.

Even with the big lottery tag and the tag of Mind and all working together it definitely gives it that credibility (CB5)

One of our monthly meetings we held at [name of] Mind so that was great. She [name of Mind lead] was very helpful and sent out a whole mail shot to everybody, to their members about what we were doing so that was really helpful (CB7)

I have now got people and organisations in those communities that I can ring and say, "Do you know of any events?" They actually get back to you because they know you and so that makes a difference. (CB5)

However, it was also acknowledged large brands were at odds with 'grassroots' leadership and peer ownership.

People can be protective of, especially, peer to peer support.....it being the kind of grassroots, user led thing and Elefriends being, probably one of the more, we're not corporate, but we are run by Mind......The impression might be given that it is led by Mind, rather than we are just there to facilitate things. And once you explain that, people are quite positive that we're not there to tell people how to do peer support. We are there, literally to keep the place safe and provide guidance..... (CB23)

It would be much easier for us to 'drive the show' and dictate how it's done, but if it is to really work as a peer support group then we have to take a back seat and wait until asked. (CB7)

In areas where strategic partners already had a presence, there was an acknowledgement that promotion work to generate new interest in peer support was harder. The message was not a new one.

We had already made the links so there wasn't any particular work for me to do extra there.....we tried to do something different .....and get a few more different people, slightly different selection of people involved...... Obviously it was more difficult to make an impact because we already had things going on (CB7)

Partners generally found promoting their brand of peer support a challenge in new locations and to new audiences. One strategic partner found the credibility of the Mind brand was an enabler. The collaborative approach enabled one strategic partner to feel part of stronger network. The programme encouraged some organisations to explore promotion to new community interest groups. Even if these explorations didn't always lead to meeting goals, they did enable learning of what their platform does and could offer for them in the future. We summarise these insights within a TOC framework in Figure 9.11

## Figure 9.11: Emerging elements from spreading the word - the TOC framework

Approach	Resources	Activities	Enablers	Intermediate
Collaborative	Venues Volunteers Staff Local community	Promotional work (online campaign) Workshops Networking Events Signposting	Credibility of Mind brand and BLF. Local Knowledge and connections Adaptation of approach Learning new approaches	Outcomes Increasing numbers of new people accessing peer support Increased understanding of the value of peer support for different people

#### Volunteering and organisational support

Depression Alliance and Bipolar UK use a model that relies on volunteers to deliver and sustain peer support.

These things take so long to get going, don't they, but people are making friends and building up their own support networks, which is the idea of it. So when we walk away, there will definitely be, in all areas, people that will still have made friends with each other and will still keep in contact. (CB7)

Bipolar UK had a structured planning phase for all new volunteers and groups, where those who take on a more active role are DSB checked. Depression Alliance did not have any formal training for volunteers, beyond a mental health first aid course. One of the local Mind strategic partners was part of an international model that had a manualised, mandatory training programme. In terms of sustainability, these approaches and their use of volunteers was an important area to consider for the evaluation team.

For Side by Side, the usual tactics for setting up groups had to be amended. One partner was accustomed to growing interest around existing demand, where volunteers step forward to set up groups. In Side by Side they had to actually find those volunteers.

Normally we have already got some people who are interested because otherwise we haven't got the capacity to...because there are quite a lot of costs attached to those things, especially with travel, time, room bookings and all of those kinds of things it can be quite expensive (CB5)

Side by Side funding enabled new tactics to be trialled over some time, yielding surprising, and positive results, with new groups showing a steady increase in participation across the programme.

We had two people at the planning meeting but over only a couple of months and I went to both of those, we quickly started to get people to come to that one and they have had 36 new people through that group over that period now and things are going well with that group......(CB5)

That's one of the main successful outcomes of the whole thing. And [name of strategic partner lead] is an expert peer support group manager, so they linked with her. We also put her in contact with our training manager here, who went and did some mental health awareness. And she's got a little group up and running. She's involved in the peer support work, and she's also going to attend all the additional events that have come up. So she said that, without this, she would never have set the group up (CB15)

All peer support approaches need a stable set of core people to sustain support. These maybe volunteers, paid staff or peers. However, to reach the stage of core stability in peer support membership, substantial time and some organisational input, especially at the beginning are required. One participant mentioned staff input at the initial set up of a group can require six months to a year commitment. This is particularly the case when following district practices, such as all Bipolar UK groups signing a code of conduct agreement at every meeting. Our researchers observed that in one area, the organisational lead was running two of the new groups set up as part of Side by Side. Another strategic partner lead, coordinated planning meetings and training where volunteers learnt how to keep peer support environments safe. To some extent, organisational input at the planning phase helped ensure the foundations of community ownership and inclusivity, which are important for sustainability, were established.

We very much try and make it a team approach. The person who brings the tea and coffee is equally as important as the facilitator, who is equally as important as the one welcoming.....' (CB14)

The merits of formalised training and prolonged organisational support was debated by many people we interviewed. Some believed it had the potential for destabilising the sustainability of a group, by creating power dynamics.

Because it's that peer support, it's not a "them and us" type thing. I think that makes quite a key difference because if we were to say we're a trained person, it's like we're coming because we're trained. But you don't need to be trained, it's an experience thing, isn't it? It's equality of... do you know what I mean? It's that sort of peer support... (CB7)

It was also important that the volunteers had certain attributes to support sustainability. These included; local connections to aid promotion and recruitment after the removal of organisational support and lived experience of mental health difficulties to sustain peer leadership.

She was already volunteering at [name of local] Mind so she was on the patch. So they helped me do that and it was perfect because obviously she was already a volunteer with Mind so she was already part of that whole Mind (CB7)

We are reliant then on the people who are volunteering to run the group to perhaps make those links but they may not be that type of person. They may run the group really well but they may not be the type of person who wants to go out and spread the word or forge relationships with community mental health teams, Mind and all of those kinds of things. (CB5).

Our analysis showed that in order to achieve sustainability, some organisational support is required or needs to be borrowed with regards to providing a safe space, planning of meetings, roles and training as required in the set up phase and a steady core of knowledgeable volunteers are needed to maintain a group. Strategic partners had to adapt their usual practice to achieve the targets for Side by Side. We summarise these insights within a TOC framework in Figure 9.12

# Figure 9.12: Emerging elements from volunteering and organisational input - the TOC framework

Approach	Resources	Activities	Enabler	Intermediate
Inclusive Social model of disability	Volunteers Training tools Venues Funding Staff	Set up – booking rooms, travel, refreshments Planning meetings Facilitation Training Guidance	Mental health awareness trainingLocal knowledge and connectionsLived experience of mental health difficultiesTimeAdapting recruitment methodsCreating safe spaces	Outcomes Increasing number of people attending Increasing stability of the group

The final TOC in this section (see figure 9.13) combines the insights from the themes of spreading the word and volunteering and organisational support from strategic partners and elefriends. Achieving sustainability of new peer support was approached with energy and commitment by the strategic partners and elefriends.

Approach	Resources	Activities	Enabler	Intermediate
Collaborative Inclusive Social model of disability	Volunteers Staff Funding Venues Training tools	Set up – booking rooms, travel, refreshments Planning meetings Training Promotional work Workshops Events	Credibility Mind brand & BLF Local Knowledge and connections Adaptation of approach and learning new approaches Mental health awareness training Local knowledge and connections Lived experience of mental health difficulties Time Creating safe spaces	Outcomes Increasing number of people attending Increasing stability of the group Increased understanding of the value of peer support for different people

## Figure 9.13: Emerging TOC framework considering the strategic partners and Elefriends

#### Local groups and wider peer support community

Finally, we look at the perspective of peers within peer support. We spoke to people whom either initiated, ran or facilitated (in some cases all three) community peer support groups in the areas Side by Side were active. Some of these individuals had contact with the hub, others had none. The local peer support landscape looked different across each region with a mix of organisations and individuals involved. The types of peer support groups we spoke too range from women's only social groups to very structured groups for people with a specific diagnosis.

#### Benefits of capacity building programme

Local groups found the activities of the hub and support from strategic partners was broadly positive and helpful. The only activity that they did not enjoy was the evaluation. We found that networking events and workshops were generally considered useful. People were able to gain a better understanding of different types of peer support in the community and the way they may work differently. This was considered inspiring and thought provoking.

That was really great to get ideas of what other people were doing and good practice..... although the element of peer support is there, they're all really diverse (CB22).

Some of the workshops that we did with these Asian guys, it was quite an eye opener. I think some of them wished they could come to a group like ours but because of their religion and things, I think it would stop them. (CB20)

Meeting other providers of local mental health support, increased everyone's knowledge of what was 'out there'. We found that group facilitator's signposted members of their group to other support. Networking also encouraged collaborations beyond Side by Side peer support.

I think people go away from events and training and things, with much more of an idea; are more open-minded that peer-support isn't just, necessarily, one-to-one or not necessarily just a group, there are lots of different ways of doing it. They go away with ideas, and more confidence to do something different. (CB16)

We also found that capacity building was particularly beneficial for small organisations – helping them "into the tent". That was the goal and we did find evidence this was beginning to be achieved.

The definition of that peer-support community has also been expanded, horizons have been expanded; it now includes small organisations within [name of region], for example, who were never part of the broader picture, and I think they're now being helped into the tent, with everyone else, and I think those conversations will continue. I think. (CB4) So they're starting to really get together now so instead of groups out on their own, doing things on their own, they're starting to get more confident in working with each other. They have a supporters group, facilitators group every other month where they can offload or share good practice or talk about upcoming events and things like that, where they can work together. (CB18)

It is important to note that we only spoke to six groups in total, of which only half had contact with the hub and the Side by Side programme. Networking events enabled local projects to connect and be signposted to other groups in the area, in in doing so expanded their knowledge of what else was available. We summarise these insights within a TOC framework in Figure 9.14

# Figure 9.14: Emerging elements from benefits and challenges: TOC framework

Approach	Resources	Activities	Enablers	Intermediate Outcomes
Inclusive (involving lived experience expertise)	Staff Local community	Training Workshops Networking events Signposting Supervision	Knowledge & experience (PS)	Increased knowledge of available support locally Increased understanding of different types of peer support Increased number of local providers of peer support Improved confidence to give and receive peer support

#### Key ingredients for successful peer support

The following section is an analysis of what the six local groups interviewed said was important for making peer support work in their experience. Some of these things were evident in their practice, others were absent, but deemed desirable by peers. Although none of these examples directly talk to what the local groups gained from Side by Side, we have included them to help the programme learn what components related to ToC are necessary for building capacity. It is evident that some of the factors peers talk about clearly overlap with factors evidenced in other sections of this chapter.

We found that having one's own experience of mental health difficulties, or an identity that the group all shared, was almost universally considered vital for successful peer support.

The user drivers the project so because of word of mouth people start coming, more people start joining, the word spreads out so as a result (CB32)

Sharing a common experience can be a mobilising resource in and of itself. One group, set up in memory of a young man who took his own life, was able to garner a lot of community support, in particular pulling together a strong volunteer base, by connecting the man's name with their project publically.

Once they read about [name], they so understood what I was going through. They just became volunteers and suddenly we had a room full of volunteers who we could talk to and express our desires for what we wanted to do (CB21)

Having lived experience of mental health difficulties was viewed as an enabler. This relates to the values pyramid in Chapter 6, where sharing common experiences was at the heart of all peer support approaches we analysed. This in turn enabled a steady core of volunteers to access to community resources and the opportunity to network with other local organisations.

Having a history of being a service user enabled one facilitator to leverage pre-existing connections to gain access to a venue, which in turn enabled them to access material resources to support their role:

I mean some of the people I knew from having been part of the recovery community anyway ......helping to make the funding for my role go a bit further in that I haven't had to worry about dealing with fees for rooms and stuff, they've let us have the room so that's been really helpful. (CB34)

We heard other examples of how important existing connections were for growing peer support, including access to free resources such as venues.

I do volunteering in the local community and it's a tenants and residents association so I'm able to use the base......It's a property. It's a flat. It's got facilities in there like for cooking and making brews and stuff. So it's a safe place for people to come..... we get that for free (CB20). As all we do at the moment is hold free meetings in the Central Library once a month, it is quite easy to run now. The numbers attending do not need to fund it at the moment as the venue is provided free. (CB35)

Two organisers spoke of the benefits lived experience brought to the delivery of professional services.

So no one was better placed to know what was great, what wasn't, what could be better, than them. So we had a meeting with our group work coordinator and our service manager and they completely reshaped what we're doing about groups (CB22)

Their own coping strategies rather than a professional doing it was a lot more powerful, fellow participants that worked so I think that was really powerful. (CB36)

One of the more established groups we spoke to identified both time and flexibility as being really important to developing a strong peer support community.

Really just being flexible with it, so it's not too prescriptive in terms of if somebody would like to become involved, it's not prescriptive in terms of what that means, what their roles and responsibilities are. (CB22)

It was more time and space to be able to give people an opportunity to really talk through their concerns, highlight any issues or barriers and try and overcome them as best we can (CB22)

A few groups clearly identified the importance of training for sustainability. Training can guide peers to understand the values that enable good peer support, such as safety.

Training is paramount because they need to have training, they need to know their barriers as peer supporters, that they're there to listen (CB6)

We would like to run a workshop for our members - there has never been one in the [name of] region as far as we know, on any aspect of living with Aspergers /high functioning autism - it really is disgraceful as there is precious little counselling or anything else for us. (CB35)

And the provision of a facilitator, or supervision for facilitators, can help those with lived experience from having to take on the responsibility for group management or coordination. One interviewee spoke of how carrying such responsibility risked 'burn out':

It is a worry that the group may fold as fewer of us have the time and energy to keep it going yes we'd like a facilitator to take our meetings, and we have approached various organisations in the past, to no avail.....there just isn't the funding. (CB35) Another interviewee talked about how training may blur the boundary of ownership in peer support. There is evidence from our evaluation that people desire it to be 'non prescriptive' and peer led. However, there was also evidence to suggest that for peer support to be safe and effective, a certain level of expertise is required to keep it going. Some training might be required to acquire this expertise.

There needs to be some ownership over it and some sort of guidance and supervision but then who provides that, that's the big question. Who provides it and whose name is it under and where does the responsibility lie (CB34)

One facilitator talked of the future desire for collaborative supervision between the various funders of services in the city.

I think if there's different providers and the providers are working in partnership and they're having those discussions, there could be some sort of group supervision where people come along and share their experiences. (CB34)

Regions with a well-developed, voluntary and community sector (VCS) found these established collaborations were supportive to building capacity. Peer support had found a voice within the sector, and was gaining momentum as a viable and respected alternative to statutory support. One hub lead had the following reflections on this:

I think there has been a change because when we started, if you go back four or five years, when we used to run peer-support groups, often the perception was...... it was like the poor man's choice, because services were cutting back, and support wasn't what it used to be. Whereas, quite a lot of people who had a previous amount of access to day centres, almost like this is just because services are cut, whereas now, what we're finding is, is that more people are asking for services to be like peersupport, rather than professional.... (CB9)

Side by Side training activities would have benefited some of the local groups we spoke to that had little to no contact with their areas hub. For small, self-funded organisations, the opportunity for formal facilitation training and good practice guidelines was seen as highly desirable for sustainability. We summarise these insights within a TOC framework in Figure 9.15

Approach	Resources	Activities	Enablers	Intermediate
Approach Inclusive Flexibility (not too prescriptive) Collaborative	Resources Volunteers Venues – non charging! Funding	Activities Workshops Training Supervision Facilitation Peer support sessions	EnablersSharing common experiencesEstablished connections / partnershipsPassion and commitment of volunteersSafe spacesTrust and openness	outcomes Increased number of people engaged in peer support Increased stability within the
			Adaptation of ways of work - less professional Time External factors – strength of voluntary and community sector Changes in commissioning needs (cost sensitive)	peer support community

### Figure 9.15: Emerging elements from key ingredients for success: TOC framework

#### Challenges to sustainability of peer support

Peer support groups identified a number of challenges to sustaining activity. The most widely stated, and in many ways, most obvious, problem was that of funding. However efficiently run, most peer support projects incur some costs.

What we tend to do is either pay for their crèche or we've had to pay for their transport because a lot of these women have those barriers where they can't afford to pay for their bus ticket each week because of their circumstances because some of them are seeking asylum so they have a strain on finances. (CB6)

Two groups spoke of how the short term nature of funding they were given by the statutory sector for pilot schemes didn't enable the time necessary for groups to get beyond just 'getting to know each other'. As evidenced elsewhere in the report, peer support is takes time to develop, especially in marginalised communities, which means a longer length of time is needed to build trust and openness between peers.

The project ended and then we didn't get any more funding. The idea was the peer supporters, by then we only had a couple, they were meant to sustain it themselves. It can work really well but it takes a long time to get that trusting relationship. So

yes, definitely, it takes longer than even a year to be fair, it does take quite a while. (CB36)

Another identified the process of applying for funding as a barrier where it was confusing and cumbersome. This can lead smaller organisations to lose confidence and feel disillusioned, becoming less likely to seek support in the future.

We tried to apply for funding to take a group of blokes out for a day but the criteria was just too confusing. Too many questions basically so we gave up on the idea. To get the funding, the criteria was ridiculous..... (CB20)

There were also some challenges specific to the local context including capacity and skill sharing.

[name of] Mind wanted me to go and set up.....courses using [their] peer support model, whereas...the description says to embed peer support city wide and I can't do that on my own in 18.5 hours a week so it made sense to me that other people be equipped with the skills to go and do that (CB34)

I know some people don't attend meetings that they want to attend, because they're part-time, or they're voluntary, or people don't want to put their volunteers on the training, because their volunteers only do two days a week, and that two days is facilitating the peer-support group... (CB16)

Funding was critical barrier, exasperated by short time frames for projects. This echoes the earlier sections, where time was evidenced as a vital enabler for building networks and relationships. We summarise these insights within a TOC framework in Figure 9.16

Figure 9.16: Emerging elements from challenges to sustainability: TOC framework
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Approach	Resources	Activities	Enablers	Intermediate
	Funding Staff Volunteers	Peer support sessions Facilitation	Trust and openness Time Self-sustaining model (not reliant on one person)	outcomes Increased confidence to give and receive peer support

The final TOC in this section (see figure 9.17) combines the insights from the themes of benefits of capacity building, key ingredients for good peer support and challenges to sustainability. These overlap with data in other groupings, but in the local context a key focus was on enablers including core values found in chapter 6: safety and sharing common experiences.

# Figure 9.17: The TOC framework – considering feedback from local peer support groups

pproach	Resources	Activities	Enablers	Intermediate
aclusive nvolving ved (perience (pertise) exibility not too rescriptive) ollaborative	Staff Volunteers Venues – non charging! Funding Local community	Workshops Networking events Signposting Training Supervision Facilitation Peer support sessions	Sharing common experiencesEstablished connections / partnershipsPassion and commitment of volunteersSafe spacesTrust and opennessAdaptation of ways of work - less professionalTimeExternal factors – strength of VCSChanges in commissioning	outcomesIncreased number of people engaged in peer supportIncreased knowledge of available support locallyIncreased knowledge of available support ocallyIncreased number of of different types of peer supportIncreased number of local providers of peer supportIncreased number of local providers of peer supportImproved confidence to give and receive peer
not too rescriptive)	Local	Supervision Facilitation Peer support	Safe spaces Trust and openness Adaptation of ways of work - less professional Time External factors – strength of VCS	locally Increased understanding different types support Increased num local providers support Improved con

Self-sustaining model (not

reliant on one person)

Increased stability within the peer support community

# Conclusions

#### Capacity building in Side by Side: A draft theory of change

This chapter has sought to draw on interviews and observations from across the Side by Side programme to understand what components were necessary to grow and sustain the peer support offer. This has led to the construction of a draft theory of change. Figure 9.18 below represents the merging of all the proceeding ToC figures presented in this chapter. The framework should, however, be considered as "work in progress" because it does not seek to link components, it is only a list of components.

The components presented in figure 9.18 are things that are necessary for capacity building. This includes intermediate outcomes such as:

- An increase in the number of people engaging in peer support; confidence in giving and receiving peer support;
- Increased understanding of the value of peer support;
- Increase in the number of relationships with other peer support providers and commissioners.

The evaluation did not measure all of these outcomes and we cannot assess whether Side by Side did achieve sustainability. The limit of the evaluation is identifying factors that look helpful for capacity building and sustainability.

Through the process of our analysis we identified a number of key enablers for capacity building. We define these as 'key ingredients' (see box 9.3). Some of these enablers were evident from the start of the programme, such as the importance of peer leadership in all groupings. Others became more apparent as the programme evolved. Also the absence of these enabling factors was frequently identified as a challenge to capacity building activity.

# Limitations

We began to list limitations of the capacity building evaluation at the start of this chapter. The data must be considered in the light of several substantial limits.

- There are some key people we could not interview, namely people involved in local peer support projects. The research team were, to some extent, reliant on hubs for introductions to local groups for interview. This channel of communication was not always successful. We had limited capacity to carry out capacity building interviews, thus the sample size is small.
- We attempted to interview towards the end of the programme to gain a fuller picture of
  process that influenced the growth and sustainability of peer support outcomes but it was
  not feasible to leave all interviews to the end, so we may have gaps in the data set. Capacity
  building was time sensitive and activities took a while to establish. We may have interviewed
  some key leaders too early to capture their full learning journey.

The ToC approach works best as an iterative, collaborative process, feeding back information to participants and working together to build the TOC through drafting and re-drafting. We have not done this feedback loop.

#### Box 9.3 The active ingredients for capacity building:

- **Peer leadership**: Passion, commitment and personal knowledge of mental health problems. If not exclusively, this has to be present as a substantial component
- Sharing knowlede: Exchanging expertise, knowledge, and experience. This is of peer support but also resources in the community from local resources such as venues, links to other organisations to national resources such as policy expertise.

Active learning: An active sense of learning both among those people already doing peer support, but also in understanding how other cultures and communities understand mental health and peer support

- **Creating safety**: positive, safe, trusting spaces for peer support good experiences of peer support foster capacity building. Creating new connections to other people and organisations in the community.
- Changing ways of workin: Being prepared to think differently about how peer support is provided, challenging and adapting ways of working that can be constrained by conventional thinking about services, models and care giver/user roles.
- **Time**: Capacity building will require sustained efforts over a long period to build a credible reputation. Time is also required for communities, organisations and individual peers to share and learn from each other.
- **Strategic factors**: some will help, others will hinder. Being aware of strategic changes, influencing local and national agendas and working alongside others in the health and social care space will be important.

## Figure 9.18 Components of a Theory of change for Side by Side capacity building

Approach	Resources	Activities	Enablers	Intermediate outcomes	Final goals
Range of approaches and diversification of model. Social models	Funding	Project management – awarding grants, monitoring, national meetings.	Peer Leadership – passion, commitment, local knowledge, expertise	Increased number of people involved in peer support	Sustainability of peer support
Collaborative, co- production, non- prescriptive	Ing Staff, volunteers, external consultants Venues – meeting spaces The local community	Planned activities – networking events, training, mentoring,	knowledge, role model passiongivin peerChanging –adapting current approaches, expanding scope of existing practiceIncreasionLearning – new skills, how to retain volunteers, cultural adaptationIncreasionCreating – safe spaces, opportunities for trust and openness, good peer experiences, new relationshipsIncreasion	Increased confidence in giving and receiving peer support	Growth in peer support locally
Structured (including targets)		volunteers, external consultantsPromotional work - newsletters, case studies, outreach, flyers, signpostingVenues – meeting spacesGiving and receiving peer support, supervision, and facilitation.		Increased understanding of the value of peer support for different people	
Inclusive				Increased number of relationship with local commissioners	
				Increased levels of partnership working	
	Data collection	Time – peer support needs time to develop and establish a reputation	Increased stability of peer support community		
			External factors – changes to commissioning (market for PS)		315

# Chapter 10: Commissioning of peer support – challenges and advantages

# Summary

We took a mixed methods approach to working with commissioners of mental health services (both NHS and Local Authority), incorporating both qualitative and quantitative data collection. Our initial plans involved conducting a survey of commissioners' views and attitudes towards peer support at two time points. We encountered significant problems in recruiting commissioners for this part of the work, and altered our approach following the initial baseline survey. We conducted semi-structured interviews by telephone with commissioners (11) to ascertain their views on the value of peer support in relation to mental health. Interview questions probed commissioning priorities, their understanding of peer support, and their views of working with the voluntary and community sector.

All commissioners spoke about the difficulty in commissioning new or 'innovative' services against a landscape of cuts and financial austerity. Commissioners were looking for evidence of the following when making commissioning decisions about peer support:

- Meet a clear set of outcomes from a wellbeing perspective.
- Work across a range of outcomes, both in the form of quantitative monitoring data and qualitative reports from people who used the 'service'.
- Work with peers to produce their own recovery outcomes.

• Understand how peer support fits within national guidelines (e.g. NICE guidelines) and what kind of outcome data will demonstrate this.

- Providers need evidence of governance, for example, training, support and supervision arrangements, financial stability.
- Providers need evidence of risk management and assurance that both the peer supporter and the person receiving the support will be protected.

# Introduction

A key part of the Side by Side project activity was for the regional hubs to build capacity and create a sustainable platform for peer support. As part of this work the regional hubs were required to engage with local commissioners, in order to;

- Understand their views on the needs of people with mental health problems in their locality
- Communicate the potential role that peer support may have in supporting mental health and wellbeing to commissioners

In this work stream we sought to engage with commissioners to evaluate the impact of the Side by Side programme and develop an understanding of commissioner attitudes towards peer support.

# **Our** aims

To understand how can commissioners could be supported and encouraged to commission different types of peer support in line with the peer support principles and values.

The research questions addressed in this work stream are:

- 1. What are commissioner views about peer support?
- 2. How do services that run peer support get their project commissioned?
- 3. What are the challenges to commissioning peer support?
- 4. What is your experience of commissioning the third sector, and views of their role in mental health provision locally?

# Methodology

We used a mixed methods approach, incorporating both qualitative and quantitative data collection. However, there were significant challenges which led to changes in the methodological approach adopted during the study.

- We initially planned to conduct two surveys of mental health commissioners at two different time points, one early in the programme and one towards the end. We also planned, supplementary data collection during capacity building interviews of local stakeholders and Side by Side programme leads (see chapter 9).
- We struggled to complete the baseline survey with commissioners, and therefore changed to a telephone interview method for follow-up. This was to ensure we got in-depth data from those willing to engage with the research team rather than placing efforts chasing responses to a second survey that may not yield useful information. We were aware of major changes in the commissioning landscape that may have impacted on responses during the duration of this piece of work, so sought to use a flexible and pragmatic approach.

#### Data collection

There were two methods of data collection, an initial survey followed up by individual interviews. Both were co-produced. The survey went through several stages of development:

- 1. Researchers drafted a survey and consulted other members of the research team
- 2. Review of the first draft with the evaluation consultant group, which included an NHS England commissioning expert.
- 3. Piloting of survey with 4 commissioners at two hub events (Leeds and Solent). The survey design was amended based on their feedback.

The final survey contained both open-ended and closed questions. It was designed to collect information about commissioner views on the value of peer support in relation to mental health. The survey was delivered using SurveyMonkey software, and distributed via emails to potential participants.

The interview study also involved several stages of development:

1. Firstly the schedule was co-produced with hub leads. Each lead was asked: "What are your top 3 questions for commissioners?"

2. The research team developed an interview schedule based on the questions suggested by hubs and on the research aims listed above. At this stage National Mind reviewed the interview schedule and suggested further questions

3. The research team reviewed the interview schedule in light of suggestions from National Mind. Minor amendments were made.

4. The interview schedule was piloted with one commissioner. This interview was not audio recorded.

Questions probed commissioning priorities, the use of lived experience in decision making, their understanding of peer support, evidence based service provision and working with the voluntary and community sector. The interviews enabled the research to broaden the scope of learning. More fundamental questions about how commissioners and the voluntary / community sector may work together and what the later can do to leverage influence and support for mental health service funding, taking the current economic climate into account, were explored. Interviews were conducted via phone by a researcher with lived experience of mental health difficulties. Interviews were audio-recorded and consent was taken at the beginning. Our researcher was able to bring her own experience of giving and receiving peer support in a community and NHS setting to the interview process.

#### Survey participants

We recruited health (NHS) and social care (local authority) commissioners. They were identified from three sources:

- An existing database of commissioner contacts held by Side by Side, or direct referrals from Side by Side hub leads
- Research team's internet search of commissioners located within the nine regions of Side by Side
- Contacts from national Mind

The survey was open between late November 2015 and early February 2016. Potential respondents were contacted via email and follow up phone calls.

The aim was to survey 90 commissioners, 10 from each Side by Side region. In the end, 64 were identified from which we received 19 responses (CCG commissioners, 4; Local Councils, 12; NHS Foundation Trusts, 3). We excluded 3 responses that provided no data and one where the commissioner explained they did not commission mental health services (CCG commissioners, 1; Local Councils, 2; NHS Foundation Trusts, 1). This provided a data set of 15 responses (5 of which were from one locality, and overall we only covered 7 localities).

#### Interview participants

Commissioners were identified through existing contacts and personal introductions made to improve engagement with the study team, learning from the problems experienced in survey recruitment.

The aim was to recruit commissioners from the 9 Side by Side regions. This was achieved in only 3 regions (n=9), and a further 2 interviews were conducted with commissioners outside of the Side by Side study who were familiar with peer support. As with the survey data, one region dominated the interview data with 5 commissioner interviews from one locality.

The spread of interviews between health and social care was evenly spread. 6 commissioners associated with clinical commissioning work ranging from adult mental health care to performance and management and six local authority commissioners, working with the councils were interviewed.

#### Data analysis

The analysis is descriptive, drawing upon both survey data and interviews to answer the four specific research questions looking across the data sets for common themes and contrasting information. The limited data set did not warrant another analysis approach. It is important to emphasise the data in this section comes from only 7 Side by Side regions, with one region providing 37% of

participants in the data set. This means that our interpretation may be skewed by having more information about one regional context than the others.

#### **Findings**

While the results from the small number of survey responses (n=15) should be interpreted with caution, we found on the whole commissioners who took part were positive about the value of peer support as part of the provision of local mental health care.

I think we could probably ensure that peer support is built into commissioning plans more systematically in terms of people having access to it and using it to achieve the outcomes enabling them to become independent and confident more quickly. We need to have a better understanding of the potential for peer support and what the mechanisms are for putting it in place. (CS3)

Initially peer support was commissioned as a standalone pilot service. Whilst this proved useful and did get good outcomes for individuals, other services which integrate peer workers/peer support into wider models also I feel that peer support has the ability to be included as an element within most services and delivery models, however at present it has not been rolled out in this way. I would like to see a requirement or requirement to consider peer support within all future services. (CS12)

Equally the interview participants (n=11) showed interest in the role of peer support locally, but some acknowledged it wasn't necessarily a commissioning priority.

So, it's not a commissioning priority. So, the commissioning priorities at the moment...the major issues are obviously to make sure that we have got enough care managers to deliver care assessments to ensure that people have access to personal budgets but from a transformational point of view obviously what we are wanting is just much more independence so that people can move away from traditional services and I guess peer support would be a very good way forward. (CI20)

For the remainder of this chapter we will present our findings by combining survey and interview data to answer our specific research questions and to illustrate key points.

#### What peer support is being commissioned and why is it being commissioned?

In the survey, 10 commissioners confirmed that they currently commissioned mental health services with elements of peer support, 3 reported that they did not and 2 were unsure. This peer support was varied and was described within a system of commissioning.

Peer support workers based within community mental health teams with a focus on access to sustainable community support post CMHT intervention, recovery and raising profile of recovery and collaborative working within a statutory service. (CS1)

People using services find the opportunity to discuss issues with 'Non Professionals' supportive and reduces stigma" (CI19)

Where responses were no or unsure, we found commissioners were aware that they might or wanted to provide elements of peer support within services but queried if their plans were formally peer support. Where an element of peer support is provided within a commission, it was not always viewed as a specific commission.

Our 'Mental Health Support Service' does run groups but I'm not sure if they count as peer support - they are organised by a paid worker but the people in the group do give support to each other - there is a women's group and a social group. (CS3, Plymouth)

Awaiting clarity on financial allocation for coming financial year. Possibly include some peer support within mental health awareness training. (CS9, Plymouth)

The commissioners we interviewed also viewed peer support as helpful, improving outcomes.

So, yes, so peer support is very much in relation to the individual, as I say, working with the defined client group really and the lived experience is key and obviously we know that we get better outcomes where people who have got lived experience are able to support people at work. (Cl21)

We asked what peer support, as defined by the respondent, was being commissioned. We found a variety of groups being supported in this way:

- 4 peer support within statutory services, CMHT, advocacy service, housing projects, crisis support
- 2 Organised groups, may involve paid staff
- 1 Dementia peer support
- 1 carer peer support
- 1 Wellbeing hubs with peer support
- 1 Peer support within acute units, delivered by voluntary sector
- 1 Voluntary sector peer support

We also found that commissioners were interested in commissioning peer support for its potential to address a variety of outcomes:

- 5 Building networks to reduce isolation / reduced loneliness
- 4 Increased self confidence
- 4 Recovery outcomes (hope, empowerment)
- 3 Reducing depression and anxiety / mental ill health
- 3 Building resilience
- 3 Improved wellbeing

Others highlighted carers and people with autism as particular groups who may benefit.

Well, I suppose the other area we haven't talked about is autism. In mental health autism is a massive gap. We don't have sufficient services from the...I know, I think the CCG are looking at some provision at the moment in our area but we have a huge waiting for assessments for autism but again the voluntary sector could play a large part, certainly peer support could work as well in supporting people with autism. (CI22)

Some commissioners viewed peer support as fitting in particularly well as services designed as preventative measures, to help people manage in the community rather than being reliant on secondary services. Some also considered peer support as being helpful in easing reliance on acute services:

If you're going to address the health issues of the city and to have much less demand on the acute services which is what we need because they're massively overstretched, is that those are the things which will deliver is better social support, less isolation and all those kinds of... and in terms of safeguarding and things like that, that's also... if people are less isolated then they're less vulnerable to that exploitation or other issues. (Cl23)

We found that peer support is being seen by commissioners as a potential strategy for helping a great range of people with support needs that are spread across a spectrum from low level general 'wellbeing' in the community to people with significant mental health needs in an inpatient setting.

Asked if the commissioners were happy with the amount of peer support commissioned locally, only 7 said yes. As we will explore more later in this chapter, commissioning decisions were being made against a landscape of financial pressure and budget cuts. This was a common theme in survey and interview data, and was reported as a direct limit on the commissioning of peer support.

Against a backdrop of significant budget pressures and reductions in services, a corporate goal is to build resilience in the local community and peer support is a crucial element of this. Within children's, we also commission a specific peer support service from the third sector which has been successful. (CS17)

#### Understanding of the principles of peer support

Our interviews also explored with commissioners their understanding of what peer support was and what values may underpin it. They understood peer support through a 'service delivery' framework, and as a consequence spoke about peer support in ways that used much more 'service orientated' language than many of the other people we interviewed for the evaluation. However, they did grasp a number of the same core values of peer support that we had identified and it was on the basis of these core values that some commissioners chose to commission peer support.

Many recognised that the core mechanism of support was for people with mental health difficulties to support each other through using their own experiences of mental health difficulties. Many understood that the rationale for this was that 'peers' were better able to understand some of the challenges other peers were going through, and would be able to share useful and practically relevant knowledge and coping strategies.

# Being able to share your experiences with someone who's been in a similar situation is really powerful. (CI24)

Some commissioners had strong views about how peer support would be 'delivered' and believed true peer support needed to be peer-led, not run by a paid member of staff who was not also deriving some form of personal benefit from the peer support. The two-way nature of peer support was important to these commissioners.

Yes. There's been cases in Leeds where Peer Support has been discussed as an example of Third Sector Service, delivering a whole different range of groups and it's been run and it's been facilitated by a member of staff. And that member of staff may have mental health experience, but they're being paid to deliver Peer Support. I think sometimes it gets mixed up with service user involvement so they kind of view it... because the service users are involved in the design and delivery, but I think, ultimately, if it's a paid member of staff that's delivering it and they're not getting some sort of gain out of it themselves, I personally wouldn't view that as Peer Support. (CI25)

However, there was not consensus on this issue across our data. Some commissioners spoke about peer support in a way that appeared to be influenced by their understanding of NHS style peer working where people with lived experience of mental health difficulties are employed in paid roles to work with people in a support role, often in a one to one basis.

*Peer support is around, is being able, to support somebody through their recovery, utilising your own experiences. (Cl24)* 

There were further differences of opinion over whether peer support should be 'offered' by paid workers, or whether it should be 'offered' by volunteers.

But I don't think it's always necessary to pay volunteers. I think it becomes difficult if it's a paid job, then does it change the nature of the peer support? I don't know about that. We often discuss this in terms of people involved in our consultations, and you get professional consulters almost. Do they get a sense that it's now a person's paid job and does that change the nature of the relationship in terms of peer support? (CI23)

The commissioners we interviewed spoke of how peer support may be helpful in supporting people with mental health difficulties in the community, where there was often a lack of other forms of support.

So I think there's some of that where the natural peer support within the community is less forthcoming for people with mental health conditions, and people are still less inclined to talk about them and to say they've had them to help people out, aren't they? [...] So it's almost like we're having to formalise what might happen naturally in the community. [...] Because the community isn't readily prepared or able to do it itself at the moment. (CI23)

In keeping with the 'service delivery' framework through which commissioners work, describing peer support as an intervention was a feature of the data from commissioners, which we did not see in data from other strands of the evaluation.

Supporting recovery - offering people a choice of interventions /support adding depth and breadth to support services (CS6)

Information about how these services are delivering the outcomes from the previous questions. Organisations need to be able to identify how demand for statutory services will be reduced by their intervention and how people will be benefitting from the services. (CS14)

#### How can services get their projects commissioned?

It is a challenging commissioning environment, thus understanding what information commissioners value in order to make decisions over commissioning peer support was viewed as important. These concerned both choosing to commission peer support in the first place, and to continue commissioning existing projects. We asked survey respondents what information they needed to receive and the key themes (see Table 10.1)

Theme	Example:			
Process and monitoring information – how many people, where, cost.	"Information about the number of potential peer supporters and the numbers who could be supported; the infrastructure, including support to peers, training, and the framework for the peer support; cost; times available and where available; evidence of progress against personal goals set by the person supported" (CS4, Northamptonshire).			
Evidence and outcome data for peer support	"Outcomes - in particular that it prevents the need for use of primary and secondary mental health services, reducing packages of care, is more cost effective than other interventions" (CS3, Plymouth)			
Explanation of system integration	<i>"Some information about what they can offer not to duplicate services".</i> (CS7, Southtees)			
Management and staffing information	"It is also important that providers can demonstrate effective management and staffing structures to manage services effectively" (CS12, Southampton).			
Evidence of partnership working	"Knowledge and enthusiasm and a partnership approach to working with statutory services" (CS14, Leeds).			

#### **Table 10.1: Commissioner Information requirements**

The majority of commissioners interviewed spoke about the importance of different kinds of evidence in their decision making process. They spoke about using this evidence to assess whether commissioning a particular project would be good value and deliver effective care, and how that project may potentially relieve pressures on other services.

Evidence relating to the effectiveness, outcomes and value for money need to be strong in order to be successful when bidding for work. Measuring pure mental health indicators can be tricky, but looking to wider indicators can help - has peer support reduced the amount of CMHT or GP visits a person makes, kept someone in work etc. These wider outcomes not only help quantify cost savings for example through reduce CMHT time, they do also indicate an increase in wellbeing and independence which should tally with the measurement of pure mental health outcomes. It is also important that providers can demonstrate effective management and staffing structures to manage services effectively. (CS12)

Different kinds of evidence may fall into a number of categories:

1. Monitoring data

At the most basic level commissioners expected to be provided with data that would allow them to understand what service does and for how many people.

What's been provided, what the groups are, where, how, who, number of people accessing it, the numbers of people moving on; also qualitative – case studies and services, feedback and evaluations. (Cl25)

#### 2. Outcomes data

Commissioners also cited a number of other outcomes that projects could monitor to demonstrate their impact including, although many of these may be difficult to measure in practice:

- Pre-arranged key performance indicators (KPIs)
- A reduction in mental distress
- Reduced services

- Maintaining employment
- Length of time people spend in inpatient services
- Re-admission rates
- Specific outcome measures such as the Recovery Star or the Questionnaire about the Process of Recovery

So if it's to help keep people out of hospital or to prevent admission or, in our case, to help get people out of hospital quicker, then the data you'd be looking at are referrals in, how long were they for and whether they end up back in hospital. (CI26)

They spoke about wanting to see people's mental health improving, and to see people moving on.

Outcomes for improvement for people but also looking at recovery and how people have moved on because the ultimate aim is that we don't want people in traditional mental health services. We want people to, you know, be independent but feel supported. (Cl20)

Some commissioners suggested, in line with the peer led values of peer support, that peers should be supported to set their own goals, and that these goals could then be used to monitor the success of a peer support service

We use Recovery Star and there is also something called a QPR as well so there are some research bases but they are more along the lines of psychosis but I guess it's about general peer support and where people are at. [...] I guess what we are looking at is a reduction in mental distress and a reduction in symptoms that people can, as I say, set their own goals for recovery and not, as I say, have things done to them. (CI20)

3. Service user experience

It was acknowledged that some forms of evidence were more difficult to collect than others, and that many useful insights could be learned through more qualitative approaches to gathering evidence. This could be particularly useful where people using services may have different journeys over time, and may consider different outcomes as important to them personally.

What we always struggle with in terms of the complex needs we've been discussing the outcomes and how do we much better measure them, and we do tend to fall back on nice easy numbers and that's not always... because it's easy to count things, isn't it? But there's a lot of other things which would be probably much better in terms of peoples social and personal development. (Cl23)

Commissioners were concerned about the quality of services and how people using those services experienced them. Commissioners responding to our survey suggested that they relied on 'word of mouth' and case studies to understand this less quantifiable aspect of services.

But then again, as a commissioner, the sort of things I look at when I get the outcome data is it's feedback from service users or what service users' experience has been of Peer Support through [name of organisation]. I'm really keen to hear about things that have worked but things that haven't worked as well, because it's really important for the service to be able to learn from that. So I think a combination of those things are really important. (CI25)

One commissioner spoke about relying very much more on what 'service users' told him about a service. This commissioner wanted to know that a 'service' was producing an impact on 'natural

outcomes' and that he was less concerned with measurable outcomes than with the real life impact on people.

I don't need a report – people will tell us that is a good service – that people are happy in their involvements – it is not about a spreadsheet. It is about going into a service and getting a feel of what is going on. (Cl27)

#### Local and National frameworks

Some commissioners talked about the importance of peer support being able to align itself with local and national mental health service frameworks, for example NICE guidelines. They suggested that it was good practice for people 'delivering' peer support to understand how their 'service' may fit in with local and national priorities.

Yes. Well basically I think sort of stepping right back, it's about how it links into local and national guidance. So the national guidance obviously, it's things like the Mental Health Five Year Forward View, because, like I was saying before, there's a clear statement about Peer Support. I think there's about two or three different places actually. So basically it talks about Peer Support and how important it is and how it needs to be developed and enhanced across the country. So there's a real clear steer there. But then locally as well, just like I was saying, it's part of our Mental Health framework too. So that's really important. (Cl25)

Yes, natural outcomes. If I do something and it suits me, I'm happy and I get a benefit from it, the outcomes will come naturally. It is like an outcomes framework. Sometimes we are too focussed on the inputs. How many people are you catching, are they dependent on you? I hear this a lot. I am looking for high level outcomes – value in lives, independence, and part of their community. (CI27)

#### Evidence of governance structures and risk management

All the commissioners we interviewed talked about the need for organisations who may provide peer support to have governance and risk management procedures in place. For some commissioners working in the NHS there were specific procedures in place and that 'provider organisations' would need to comply with to be commissioned.

We have a framework that we go through to look at contracts but essentially for us, there are three really well known established organisations in the community that have a really good track record of working with people. So we had to have a governance process to check out are they sound organisations, are they ethically appropriate for us as an NHS provider to work with. (Cl26)

Before the provider, or any subcontractor, engages or employs any person, for provision of services, or any activity in relation to, or connected to provision of services, the provider must ensure [they] comply with NHS employment check standards, and any other checks, as required by the DBS'. [...] So, I'm sure they're doing some part, or all, and it's how you front up to the provider of, 'we're just an amateur ...', or you go in saying, 'we understand your landscape; we've aligned ourselves to your landscape, and now we're ready to deliver your outcomes'. That is the space that they need to be in, I think. (CI28)

Peer support projects wishing to be commissioned would need to have a strategy in place for 'risk management'. However some commissioners did have a nuanced approach to risk, and understood

that the way people providing peer support think about risk may be different from the approach taken in NHS services.

I think the diversity of the team as a whole has had an impact on that. I think the third sector staff have had an impact on that because they'll often say things like, "Well we manage somebody who's a lot riskier than this in the community all the time." I think there's a false belief on the ward sometimes because staff have always worked on the ward for 20 years, they understand risk within their own parameters and they think, "Oh my God, this person is really risky," but actually there's loads of people who are much riskier in the community having not made it into services or have been held by another service. (CI26)

I don't think there are any risks specific to peer support from a commissioning point of view any more than other services. The key thing for commissioners would be the measurement of outcomes and evidence the service is effective in order to justify investment. On a service level there are risks around relationship boundaries, the wellbeing of mentors etc. I would expect any organisation offering/providing peer support would be able to demonstrate knowledge of this and ways of managing the risks" (CI23)

Commissioners also spoke about needing evidence of suitable support structures for those in peer supporter roles, and that a 'provider' of peer support has considered issues like training and regular support or supervision.

Yes, definitely that training is really important, isn't it? And then I guess supervision for peer support is as they're going along and you would expect some kind of monthly check-ins or monthly catch ups with the peer supporter just to say, "How is it going? Are you comfortable? Are you still feeling confident with it?" [...] And maybe an open door advice if the peer supporter feels like they want to ask some questions about how it's going. (CI29)

I totally get that it's not as straightforward as just finding a group of volunteers because, actually, you need to set up infrastructures, as you say, around support and, potentially, mentoring supervision. Peer support workers need training and if it's paid peer support, then there needs to be processes around payment in place. You also need to organise the availability of peer support workers, as well. It's not just a case of someone turning up and saying, "Right, I'm available today." Then, as you say, there are all the policies and safeguards around lone worker policies, safeguarding, things like, do peer support workers need any kind of CRB? (CI30)

One commissioner identified that without appropriate support in place, peer supporters working within NHS organisations would find it difficult to maintain peer support values because established practices are so different to peer support principles and values.

So there's a lot of cross organisational supervision and peer supervision so a bit of a mixture to try and keep it fresh and alive really. But yes, that's the biggest risk really, that the staff lose their unique identity and just become another worker in an NHS team. (CI26)

#### Challenges to commissioning peer support?

#### **Evidencing peer support**

Commissioners are under pressure to commission services where there is firm evidence of efficacy, and this can pose a challenge for peer support.

We would need to ensure that it is more effective, including cost effective, than other interventions being used. (CS3)

This was a particular issue where commissioners viewed peers support as being part of a preventative strategy.

I think it would help in terms of when we're reviewing service pathways and if we can put the evidence in there, then that would help us commission peer support. I have some small unofficial... well they're not really structured as peer support but what they effectively do is peer support, and they are challenging to maintain the funding for those kind of services because it's quite difficult. Because it's often under the prevention agenda. [...] So it's preventing something happening for the peer support, and that's quite difficult to evidence. (CI23)

They acknowledged that peer support is not a 'quick-fix', and that it could take people extended periods of time to recover. Commissioners noted that it can be difficult to evidence the efficacy of peer support where results are expected only in the longer term, where they commissioned projects only for short periods.

So, yes, that's quite challenging and it's a longer term thing as well. I think that's the problem as well is it's going to be the results and the impact are over a longer term. [...] And I think that's the other challenge, in that it's not a quick fix and we were talking in another... we've been looking at how we design services across the city generally, in [name of city]. And we're talking about, often, services are time limited to a year or four years. Well not four years, but actually it can take a very long time for some people to move through from being quite seriously ill or in a difficult place to being much more independent, and that's one of the issues as well around the time. (Cl23)

If peer support is unable to align with local and national frameworks it becomes difficult for commissioners to commission it.

I think it would be the evidence on the outcomes rather than actually... but that again, as I say, that's got to be balanced again. We have to meet NICE guidance and [...] yes. I mean if it's not in [...] If it's not in NICE guidance then that's when it becomes a struggle to evidence and to commission. (CI23)

#### Suitability of peer support

Some expressed doubts over who would find this 'intervention' most appropriate, and suggested that some people may be too 'unwell' to sustain meaningful involvement in peer support.

Also, the very nature of people with enduring mental illness is that it is enduring, and sometimes combined with a chaotic lifestyle; the whole idea of coming to a group, at a set time, at a set place, would be an anathema for some people. There are those with anxiety, low-mood, who might benefit from a short intervention, and knowing that they're not the only people in the world who are in the grip of an early depression". (Cl28)

Others had concerns that peer support could be seen as a panacea, and that it could be unthinkingly considered to be the answer to all mental health concerns. This may result in a lack of appropriate 'professional input' and in not investing in staff and training.

Seeing it as panacea and therefore cutting necessary professional input. Not offering enough training or support to volunteers. (CS6)

#### Budget pressures, lack of resources

Commissioners spoke about peer support being relatively cheap in comparison to other services. However this did not mean that they considered peer support to be a cheap option. Commissioners took into account costs including recruitment, training and mentoring of peer support workers when they spoke about the financial implications of peer support.

When you compare that to some of our much more expensive building-based services, in terms of unit costs and value for money, it compares really, really well. But for me again, what's really important there is it should never, ever be viewed as a cheap option because it isn't a cheap option. [...] It's supposed to be delivered properly. It needs to be resourced, it needs to have solid governance around it. So for example, the Peer Supporters need to have training and supervision and stuff like that. (CI25)

Some commissioners were concerned, however, that staff working within pressured NHS services may consider peer support, especially peer workers, as a form of 'cheap labour'.

I think my other concern about peer support is that, by some people, it can be seen as cheap labour. [...] So, I think you've got to be clear about what peer support is and what it isn't. It's not just about handing off tasks that no-one else wants to, or can't be bothered to do. I think it does have to have a clear focus and remit. (CI30)

Commissioners viewed peer support as more financially sustainable as it could be run relatively cheaply in comparison to other, clinically based services. One commissioner suggested that people could provide peer support to each other with very little financial resource.

Interventions, services etc. are driven around the amount of money you have in the pot. Whereas PS is more sustainable. Group can meet up with no money in the pot and support each other (CI31)

However commissioners who responded to both the survey and the interviews spoke about the financial pressures commissioners were currently working under and explicitly identified these as a challenge to commissioning peer support.

Against a backdrop of significant budget pressures and reductions in services, a corporate goal is to build resilience in the local community and peer support is a crucial element of this. Within children's, we also commission a specific peer support service from the third sector which has been successful. (CS17)

All the commissioners we interviewed talked about the difficulties of commissioning services against a landscape of funding cuts and austerity. Some commissioners suggested that the funding

landscape they are working in has changed quite dramatically, and previous sources of funds they used to commission 'innovative services' no longer existed.

The whole commissioning landscape is a bit of a nightmare [...] it's about cherries, on icing, on cakes; we're being told we don't have enough money for the cake, let alone the icing, let alone the cherries, so it's a very difficult place to roll out new ideas . A few years ago, we used to have transformation monies; we used to be given x/y/z-many million pounds, just to transform things, to try things, so that a few years ago, you'd just come to me and say ... well not me, the organisation, and say, 'we've got this great idea; we think this is going to work. We think, if we can link people together, and build in resilience, and make them more emotionally resilient, because of this support network, that they won't rely on the GP so much, they won't rely on mental health support workers, and they will begin to grow their own recovery', and we'd go, 'yes please and have some pump prime money to fund it (Cl28)

They were explicit about the financial pressure within their organisations. To commission new peer support they would need to see an existing evidence based that indicated peer support would result in financial savings.

The main barrier with commissioning peer support, as with everything at present, is funding. There will always be a requirement to meet high end and crisis needs which can make it difficult to free up and move resources towards Peer Support. Outcomes/cost effectiveness and cost avoidance/prevention need to be well documented and evidence based in order to secure funding. There are no specific issues in working with the voluntary sector. (CS12)

I think the problem for us at the moment would be we would have to be seeing how it would make savings, because I don't have extra money for peer support. So most of the extra money that is coming down is being directed at very specific services and actually in quite specific ways. So for instance, the First Episode Psychosis service is very detailed about how many CBT/psychosis practitioners I should have and how many family therapists I should have, and things like that. So when I invest my money, obviously I've got to invest it in that way. So I think that's a challenge for us to find the funds to release into the peer support. I think for us then that's going to have to come out of other areas. The service have got to see the efficiencies or the improved outcomes for people, you know, reduced admissions to mental health services or improved recovery. (Cl23)

Some commissioners also spoke about the pressures on mental health funding in general, and note that making an argument for mental health services in the face of high demand on physical health services was difficult in the current climate.

We do not have the money to offer complete parity we should be spending more money on mental health and, definitely, less on physical health but, unfortunately it is difficult to restrict physical health demands of patient who presents with a health need. The mental health patient typically moves in and out of the service so is less visible. (Cl28)

Commissioners also acknowledged that the funding structures they used may disadvantage smaller projects.

I think that a challenge for them is finding enough funding to support their core costs against the project work that we're usually after. We're usually after specific projects rather than supporting them to just exist. (Cl29) [...] I guess the sustainability of the finance. I mean, often, we're looked to to give the core funding and then that supports them bringing in extra money, but the challenge is for us, always, is can we justify continuing being that central core funding. And so often we're running on very year on year contracts. (Cl23)

Some commissioners were explicit that funding voluntary organisations to deliver services may require a culture change in those organisations, as they would not be funding core costs in the future.

Lot of organisations are core funded – support the staff rather than an activity. Need to change this to we are going to give you money if you 'do things' (Cl27)

Commissioners were also aware that smaller projects may not have the resource, expertise or capacity to take part in consultations or apply for larger amounts of funding. Commissioners also recognised that they found it easier to engage with larger organisations, and that these organisations could come to dominate the market.

Yes, I think so. I think certainly there's a whole range of challenges. I think in [name of city] we've been, for many years, really lucky, we've got a really strong Third Sector across the city. We've got masses of Third Sector Services, a whole range, a real diversity which really benefits the city. That brings massive benefits but it also brings some problems as well because quite a lot of those services are very small. They don't have the time or the resource to be involved in some of our city-wide discussions. And also, they've often got lots of short-term non-recurrent funding, so there's multiple funders, multiple reporting requirements and so on. So I think that creates a real challenge. (CI25)

#### **Practical concerns**

Commissioners also raised a number of concerns they had around the ability of some peer support projects to deliver services as needed; scaling up to benefit larger populations. Commissioner noted that one of the practical problems with this was that the voluntary sector is diverse and does not have a strong history of working together.

I think the challenge is that people say work with the community and voluntary sector, or the community and voluntary sector need to do this. And it's like, actually, do you know what, it's not a homogenous group; the community and voluntary sector. It's massively diverse and massively different and you can't just lump them all in together. [...] And expect some kind of coherent response. So I think that's possibly a bit of a challenge, is they're not all the same and recognising and valuing that diversity is really important. (Cl29)

There were also concerns over the practical capacity of small projects to manage large volumes of referrals if they were commissioned as part of statutory service provision.

The risk of the third sector is do they have enough staff to fulfil the demands that we'll put upon them really. When we first set up, we got some really good staff because those organisations saw that as this was an opportunity to work more closely with us (Cl26)

One suggestion to counter this problem would be for voluntary sector organisations to work in partnership with other organisations to produce projects that would be able to meet demand. This was known to work well.

One of our delivers, [name], support runs floating support and supported housing in [name of city] have got together with a library and with the local trust to run a community resource a bit differently. This runs every week and allows people to drop in. People have a theme every week – have a self-starting trips. It is a platform for people to come together and devise ideas they want. They do this themselves. (Cl27)

Where peer support projects were reliant on volunteers to make parts of their project function, commissioners highlighted that while using volunteers had many benefits, the recruitment, training, long term commitment and support needs of volunteers can pose challenges.

How long. And for peer mentors, how long can they be involved or commit? That's another area for them, I guess. It's part of the challenge around that.[...]I think it's a difficult one. I think there's room for both. If there's people who want to do it on a voluntary basis, but they do need. There's a lot of commitment and a lot of time to training and stuff like that; safeguarding and appreciative listening and all those kinds of things that they'll need and skills. And also the supervision. (Cl23)

#### Risk adverse commissioning culture

Commissioners told us that they have historically worked within risk adverse cultures, and that this may pose a challenge to commissioning community services like peer support.

Yes. I think there's some staff that worry and I think we're starting to overcome that...oh gosh. Are they more vulnerable? Is a peer support worker more vulnerable and are they going to say, "Advise the service user to do something which is against what traditional approaches might have suggested"? Again, I imagine that varies loads between services but I know we're going to have some nurses that are a bit old fashioned and will have conflict with the peer support model because they'll be like, "You shouldn't say that, that's too dangerous," but I'm only trying to promote a risk free service here so we're really positive in how we take risks with people. If somebody really wants to try something, let's try that. If they fail, that's okay. We'll just try again and try something different. In the same way, historically, when one medication doesn't work, we try a different medication. What's wrong with failure? (CI26)

While commissioners spoke about trying to move towards a culture with a more positive view of risk, many also spoke of having responsibilities towards the people they commissioned services for relating to their safety and wellbeing.

That's a really important part of the picture and that's one of the things that we were talking about when we were doing the review. And again, that's one of the real benefits I think of this project, because what we're being really clear about, particularly from a commissioning perspective, if we're funding Peer Support, there needs to be a real robust governance surrounding it, so safeguarding's a really key issue. And it's about the quality of what's being provided and how providers can assure us of that quality. (Cl25)

Finally commissioners spoke about how services working in the community like peer support may be viewed as risky by clinical services, and that this can make partnership working between community and clinical services difficult.

*Clearly, there are challenges because I think there are quite often different perceptions and sometimes it feels as if we're just battling against hierarchies. I think there is always a risk in* 

a service that combines clinical and wellbeing services, in that the clinical services see them as at the top of the hierarchy, rather than equal partners. One of things we've been doing is bringing the partners together to develop the new care pathways for the service, so looking at how someone gets into a service, what happens once a referral is received and how other services might be accessed. I think there has been quite a lot of nervousness from clinical services about who has responsibility for a particular person, because they're in the Community Living Well, does that end up meaning that we take responsibility for everyone? [...] what happens if someone comes in, in crisis? What happens if we give advice to a member of staff from one of the wellbeing services? I think the message we've been giving back is that wellbeing services already deal with sometimes quite high levels of risk and they manage that and so this service should be no different to that but, certainly, I think on the negative side those are some of the challenges. However, there have been some real positives, as well. (CI30)

#### Views on third sector delivery of peer support?

The survey explicitly asked for commissioner views of the third sector and 10 respondents provided a viewpoint. We also asked commissioners for their views on working with the voluntary sector during interviews.

#### Advantages of working with the voluntary sector

Commissioners who completed the survey and who spoke to us in interviews recognised a number of advantages in working with the voluntary sector as opposed to traditional statutory style services. One key characteristic that commissioners noted was the ability of voluntary sector organisations to be flexible and to adapt to the local context and to the needs of individuals who may use a service.

*They have greater flexibility compared to statutory services and have less stigma attached to them. They also proactively recruit those with a lived experience. (CS15)* 

*Voluntary sector organisations have more freedom to tailor their service offer, and can offer a service user genuine choices. (CS14)* 

That voluntary sector organisations were more likely to be person centred was seen as a particular benefit when thinking about commissioning services.

It appears that voluntary sector organisations are more likely to be client led and have the trust of clients that their needs will be put first rather than the needs of the service. Although I think statutory services have the potential to use peer support as well. (CS3)

Commissioners suggested that voluntary organisations may be more able to work productively within the community and to react to specific challenges to participation in a local context. As a consequence of this they may have an advantage in reaching 'seldom-heard' groups.

And one of the things they were talking about in the BaME project was getting to the service is quite difficult. [...] And for some of the... they're quite often women, is that they don't have an opportunity to go out without their spouse or significant other because of the nature of their community. So in order to get there, what they're giving them is a rover ticket which also means that then for the rest of the day they can get out in the city. (Cl23)

Some commissioners also recognised that people can feel stigmatised while visiting or working in statutory services, and that working in the community with the voluntary sector can be a less stigmatising experience.

A few recover workers moved on because they struggled with where we're at as a service. So I think they came in thinking it would be really easy and accepting to work as a peer support worker but actually it's quite challenging because sometimes staff aren't sensitive and are still staying quite stigmatising things. So I think they struggled with that and actually preferred to work actually in [name of organisation] providing peer support to people in the community. We still have really good relationships with those people but I can see why they moved on. (Cl26)

One of the challenges that commissioners raised that may impact upon commissioning projects with voluntary sector organisations was that commissioners worked in an existing risk adverse or rigid culture. Some commissioners had experienced working with the voluntary sector as helping them to think about challenging these cultures and to think more innovatively about services.

Yes. I think you definitely need senior staff in each service to want to work in a certain way and have a certain culture because if you don't...I know you only need one manager to come in, don't you, who has a completely different view and it's all changed. [...] Yes. It stifles people and people then don't feel like they'd be able to speak openly. We really try to promote a culture here where we can challenge each other and people can come in and challenge me if I say something that isn't quite right. The culture is very much about innovation and trying new things and stuff and I think that's really important. (CI26)

When you get the statutory sector involved – it is very difficult because they have a paternalistic instinct. They are concerned with risk. Look at risk and would involve themselves. (Cl27)

The voluntary sector was also seen as being able to offer services is an economical way, and so could potentially produce greater value for money services.

The voluntary sector are very flexible and offer value for money. (CS18)

#### Solutions for working together

All the commissioners we interviewed talked about ways they were working on to attempt to making it easier for the voluntary sector organisations to get their peer support projects commissioned. Many had intentions for creating commissioning pathways that may be easier for voluntary sector organisations to negotiate.

I think you just need a few people to say, "Well why do we do it like that? Why can't we just do it together and then all see it happening?" Now we're developing a framework that enables us to work with partnership organisations much more easily. It just happened really intrinsically. It's quite weird really. I think it's just been a few of us that have started to challenge the status quo and tried to be a bit different. (CI26)

Some commissioners were actively working on developing new systems that could involve service users and carers in their service development processes.

Yes, the partnership board was set up for services and carers to participate and to be able to be part of service development. It came from the health and wellbeing board as a sub group of that. So, when I refer to the mapping event that has come out of that partnership board to move things forward. (CI20)

I think it's about... I mean, what we're trying to explore more is around how we commission services that are much more on an outcomes based system saying you will do this, this and this, and then working in co-production in terms of developing what the model as a service might be. (Cl23)

One commissioner acknowledged that some people may not feel comfortable to attend meetings and suggested that other methods of participation should be considered.

lots of people might want to contribute but may be fearful of attending the meeting so we need to have a range of options for people to be able to have their say like blogs and different things as well, you know, I don't think we use social media very well. We could be looking at that as well for engagement. (CI20)

In one city commissioners recognised that it was difficult for small voluntary sector organisations to meaningful have a voice in discussions around setting commissioning priorities in mental health. Their solution was to set up an organisation to represent voluntary sector organisations within those discussions to enable them to have a stronger voice.

I think in [name of city] we've been, for many years, really lucky, we've got a really strong Third Sector across the city. We've got masses of Third Sector Services, a whole range, a real diversity which really benefits the city. That brings massive benefits but it also brings some problems as well because quite a lot of those services are very small. They don't have the time or the resource to be involved in some of our city-wide discussions. And also, they've often got lots of short-term non-recurrent funding, so there's multiple funders, multiple reporting requirements and so on. So I think that creates a real challenge. What we've done a number of years ago to try to respond to that is we funded an organisation, it's an organisation, no doubt you've heard of it. It's called Volition. [...] And Volition is a Mental Health infrastructure organisation so they've got over 100 members in the city and the aim is to represent the Third Sector Mental Health services in strategic planning in the city in commissioning discussions and commissioning decisions. So where a provider can't necessarily attend the forum, Volition may well do on behalf of its members and feed back and feed in and challenge and so on. (Cl25)

Some commissioners were aware that voluntary organisations may feel disempowered in their dealings with commissioners. One commissioner spoke about being willing to work directly with voluntary sector organisations to best meet the needs of the local population.

Third sector organisations need to be bolder about their needs – this hierarchical system people feel like they need to please commissioners that sit in ivory towers – thumbs or thumbs down services. I get booed and hissed at for being a commissioner [but] you can influence what I do, you have the knowledge you explain what you need, you tell me what we need to do. And then we shall explain how it fits in with our strategy which needs to be bottom up point of view. (Cl27)

#### Solutions for funding

Some commissioners suggested that people in receipt of services could self-fund some of those services, possibly through using personal budgets and personal health budgets to fund peer support. The rational here was that groups of people could talk to their local councils about jointly funding voluntary sector peer support projects.

Actually a lot of people in our services that are not poor and would pay for services. [Gives the example of a group badminton – interlinking services to places where people can support themselves]. People to support themselves where possible and when they can't that is when we have to ensure there is a fair access for things through assessment and then a personal budget – stage we want to get to.(Cl27)

Some commissioners also acknowledged that issuing longer contracts to the voluntary sector would be helpful.

Okay, there is strong investment available for mental health or we reinvest to transform services but we need voluntary sector to be part of that and I guess the other issue is that with the voluntary sector, if they again contract rather than it just being year on year, we have moved to like a three year or five year contract for people. (CI20)

Other options for supporting voluntary organisations financially included providing use of venues or computing to voluntary sector organisations.

It is staring people in the face. But if I go in-front of 300 people and say 'go forth and do PS' they would think 'what are you talking about'– I need to foster a culture where peers feel able to set things up and that I can support them around peripheral things such as a room, or a PC, a bit of funding etc. (CI27)

### Conclusions

One of the key features of the data from this work stream was that commissioners spoke about peer support in a different way to many of the other people we spoke to across Side by Side. Commissioners spoke about commissioning 'services', and working with 'provider' organisations, and at times referred to peer support as an 'intervention'. They were also more likely to use terms like 'outcomes' and 'frameworks'. In contrast people within Side by Side may refer to 'groups', 'peer support' and make statements about knowing that 'peer support' works or seeing people 'doing well'. This difference in language may mean that people who commission peer support and people who do peer support may not always be speaking the same language.

The findings from this work stream suggest that the commissioners that participated in our research are familiar with peer support have a good understanding of the risks and benefits. However our findings are based on a small sample of commissioners who will not be representative of the commissioning landscape in the UK as a whole. We know from our evaluation in work stream xxx of capacity building in Side by Side that engaging commissioners was particularly difficult in some areas. A significant proportion of the data we collected in this work stream was derived from one area. This may mean that our findings are skewed somewhat to reflect their working practices. The fact we struggled so much in reaching commissioners was itself a finding; identifying them and engaging with them was incredibly hard. We believe this was in part because commissioners did not want to talk to researchers about their views of peer support; the commissioning landscape was in flux with changes in staff; commissioners are extremely difficult to get hold of and secure a time with for an interview.

Notwithstanding the very obvious limitations of our data set, even within our small sample there was great diversity in the groups of people commissioners viewed as being appropriate for peer support. This is an opportunity for both the voluntary and statutory sector building stand-alone peer support offers as well as embedded projects within other larger service models.

There was more agreement over the kinds of evidence that commissioners want to see to have the confidence to commission peer support. Commissioners suggested a combination of routine monitoring data that would describe what a project does and for how many people, and more complicated outcome measures that may be specific to mental health. Commissioners also indicated that the experiences of people using a particular project would be important in their commissioning decisions, and indicated that case studies and speaking with people who used peer support would be appropriate in this context.

There was consensus from commissioners we engaged with that they are working in a financially challenging context, and were making commissioning decisions against a landscape of austerity and budget cuts. All commissioners spoke about needing to see evidence that peer support was effective, or that it may lead to tangible savings elsewhere in the portfolio. This is because to commission peer support many commissioners would need to make cuts to other services.

Commissioners were willing to work directly with voluntary sector organisations in developing projects and proposals. One suggestion was that several voluntary organisations work together or with clinical services to produce joint projects that would better meet local needs at scale. This might include sharing supervision arrangements. We believe that it is important to consider how the refiguration of commissioning through Sustainability and Transformation Plans (STPs) might provide an opportunity for the commissioning of peer support.

# Chapter 11: Discussion and conclusions

In this final chapter we begin by exploring the challenges and opportunities presented to us, as an evaluation team, in undertaking the evaluation of the Side by Side peer support programme, and the possible benefits and limitations of that wider context on what we managed to achieve in the evaluation. We then reflect, as a team, on our coproduction approach to the evaluation, noting the extent to which we achieved coproduction in the evaluation as originally envisaged, how we responded to the unexpected and, again, the impact of that on the evaluation process and findings. Finally we bring together and summarise the findings from the evaluation as a whole, drawing out the main learning and locating those findings in the context of the existing literature on peer support and mental health, indicating where new insight has been generated by the evaluation and where further investigation is necessary.

# **Reflecting on the challenges and opportunities of the evaluation** Scope and scale

In chapter 1 we noted that the scale and scope of the Side by Side programme was both an opportunity and a challenge for the evaluation. The scale of the programme provided us with an opportunity to generate a substantial data set, both quantitative and qualitative, while the scope of the programme, especially in terms of the ethnic diversity of people engaged with the programme, enabled us to reflect that diversity in our sample and our analyses. The range and variation of peer support projects funded through the programme also ensured that our findings have a validity grounded in a diversity of approaches to peer support.

In an evaluation that sought, more conventionally, to test the effectiveness of a particular approach to peer support, that variation would be a weakness. However we set out to explore the impact of the programme on access to and experience of peer support more generally, and in particular to understand why people engaged in peer support and the impact that had on outcomes for them. As such this variation was an asset to the evaluation. Given that we noted in chapter 2 that the majority of evaluation of peer support is focused on peer support 'services' or peer worker roles within formal, clinical mental health services, this evaluation represents a substantial contribution to the literature on less formal, open access peer support as it develops in the community, away from formal mental health services.

There were some limitations inherent in the scope of the programme. The majority of peer support projects supported through the programme were group based, limiting what we were able to find, quantitatively and qualitatively, about one to one and online peer support. In particular, many of the one to one projects that comprised the programme were focused on training and skills building for people to take on a peer mentoring role. As such many of our observations there seem to relate to the role of giving or providing peer support, from one individual to another, rather than exploring our important findings around making connections and two way interaction in a one to one peer support relationship. This idea of a peer supporter role is closer to the research on peer workers in formal mental health services. We cannot be sure if this means that one to one peer support in community organisations is similar to that found within mental health services, or if it was the scope of one to one peer support projects funded through the Side by Side programme that constrained our findings.

Similarly, our data suggested that the people completing the log via Elefriends were more likely to be people who found it rewarding to 'give something back' through Elefriends, in terms of advice for others for example, rather than people who were accessing Elefriends at a time of urgent need for support, again impacting on the completeness of our data. It could be that the sorts of questions the log asked or the way the log was presented was less approachable for some people accessing

Elefriends. Because of concerns about confidentiality for people access Elefriends communication about the log was moderated through the 'Elehandlers'. This meant that were not able to support the evaluation in the same way that we were with other projects. This is potentially a disadvantage of having to design an evaluation to work equally across such diversity of approaches to peer support project.

#### Resources

The scale of the programme also represented a huge challenge to the evaluation in terms of spread and focus of evaluation resources. As noted earlier in the report, we were unable to resource bespoke software that would have significantly improved the user interface with the log, the management of data and then the statistical analyses. Much of the time of the SGUL researcher employed to coordinate work stream one was taken up with managing the log and database on a day to day basis, impacting on the time they had to engage with our regional researchers and the peer support projects on the ground.

Our proposal in response to the resource constraints of the programme was to focus on three regions, with a regional researcher employed by McPin in each who would be responsible for supporting registration and data collection through the log as well as qualitative interviewing. The SGUL-based researcher would then support the regional researchers around working with the log. The evaluation ambassador approach was developed so that projects elsewhere in the other six regions over the programme could participate in the log, with arms length support from the SGUL researcher, where they had the capacity to do so. We had hoped that the strategic partner projects in those six regions would have this capacity but that the involvement of grant funded projects outside of the three regions where we had a researcher would be a bonus.

### Inclusivity

As the programme progressed it became very clear that the organisations managing Side by Side felt strongly that access to the log should be supported programme wide. Some additional measures were introduced to facilitate this, in particular resourcing a researcher to work with BaME specific projects and to fund return envelopes for logs. It is in part as a result of these measures that so many people were involved in the log and that the sample is so diverse. However an impact of this was that the already stretched researcher resource at SGUL was spread ever more thinly across the 46 projects involved in the programme. Both of the researchers who took on this role at SGUL were extremely dedicated and committed to providing as much individual support to project coordinators as possible but it is clear that data quality was compromised with respect to data quantity. We have noted in chapter 4 that of the 786 people who participated in the log, 83 did not register and so their log data could not be used in any of our group analyses. We also know that of the 703 participants who registered only 566 went on to complete any logs, so there was an apparent lack of clarity communicated at a project level about what was required to enroll in the log.

For example, in one project people were carefully completing the registration form – providing the same socio-demographic data – on a monthly basis for a number of months, without completing any log data at all. This was eventually spotted by the SGUL researcher and participants then went on to successfully complete a number of quarterly and monthly logs, but this is just one example of where time and commitment was given by a number of people to the evaluation that would have been more wholly put to use if the researcher had been able to work more closely with a smaller number of projects. Over 1400 logs were used in our main analyses, but out of more than 2000 that were completed in total. Arguably we might have generated as much quality data from a smaller number of projects had we been more focused, without having asked a large number of people, in effect, to give of their time and energy to data that were not used.

In addition, resourcing postage for paper logs similarly increased the quantity of our data while decreasing the quality of the data. We had always intended to make paper log completion available so as not to exclude people from the study who did not have online access. We also know from our regional researchers and project coordinators that many people switched from online completion to paper logs once the support for postage became available (i.e. people who had not previously been excluded from the evaluation by online completion). The disadvantage of paper completion is that a paper form cannot validate the data people enter, and so the amount of missing or invalid data increased as a result. As noted in chapter 4, nearly half of data on access to peer support was incorrectly entered (as ticks rather than numerical values) on paper forms, substantially impacting on the analyses were we able to undertake about the amount of different approaches to peer support that people gave and received.

A successful modification of the approach was the introduction of short versions of the logs, including translated versions of key wellbeing and quality of life questionnaires. When we did this we had been concerned that projects across the programme, where there was not a language challenge, might begin using the short version of the log out of preference, but we did not find this to be the case. We did find at least one project where a number of people reported also having learning disabilities using the short version of the log (with the questionnaires in English). While the short version of the log did not include all of our outcome questionnaires or health economic questions – resulting in a slightly smaller data set for some of those analyses – we felt that one balance, along with the other measures introduced to support data collection in BaME specific projects, this development had a beneficial impact on the diversity of our participants.

#### Time

The sheer scale of the programme also had an impact on the analysis of both qualitative and quantitative data. Due to the late start up of many peer support projects, both strategic partner and grant funded, data collection was extended by three months. Because of the time constraints of the Side by Side programme as a whole, it was only possible to extend the end date of the programme by two months, severely compressing work on the analysis. This had a particular impact on the analysis of the very large qualitative dataset. All analyses were completed as planned but it was not possible to undertake synthesis of log and interview data across all areas of the evaluation as a result.

# Complexity

We also noted in chapter 1 that the complexity of Side by Side, in terms of the range of different partners at different levels of the programme, was both challenge and opportunity. As an evaluation team, we certainly learnt from the many organisations, large and small, delivering peer support. This is especially the case with the BaME specific projects where we learnt from them in adapting the evaluation, as far as we could, to improve its accessibility. The programme team at Mind and in the various hub and strategic partners in the regions were an invaluable resource to us in negotiating organisational complexities and access to projects, as well as in delivering the capacity building and commissioning work streams of the evaluation.

We found it extremely helpful to work with the programme team on a monthly basis around recruitment to the peer support log as this enabled us to identify and problem solve gaps in recruitment regionally and with respect to particular socio-demographic communities. We did become concerned that success in recruiting participants to the log might have come to be seen as something of a performance issue by some delivery partners in the programme. We were concerned both ethically – participation in any research or evaluation should be on the basis of informed consent, rather than a sense of obligation – and that this did not support the relationship building work our team were doing with peer support projects (we were aware that the evaluation was

placing demands on the time and resources of project teams). As we shifted the emphasis away from recruiting new participants to the log and on to encouraging people who were already registered to remain engaged these issues dissipated.

Finally, we noted in chapter 1 that we were concerned that the demands on the evaluation – to measure outcomes and define values – might reduce the diversity of experience of peer support to a simplistic set of 'models' of peer support that can be commissioned in the same way as a conventional mental health services. Our coproduction approach, and in particular the integration of lived experience into the design and conduct of the evaluation, was intended in large part to protect against this. We explore these issues in the section below, reflecting on our coproduction approach.

# Coproducing the Side by Side Evaluation: Reflecting on what we have done together

We set out our intended approach to coproducing this evaluation in Chapter 1 making particular reference to a number of key characteristics of coproduction. We placed particular emphasis on the value of experiential knowledge as a form of expertise, on reflecting on the quality of our decision making, on equality and power sharing, and on conducting this evaluation in a way that considered and valued the experiences of the people taking part both as members of the evaluation team and as participants and the people supporting them.

Coproduction is also about the practical ways that members of the team who were explicitly using their lived experience in the evaluation process were supported. Examples include creating opportunities for dialogue, hearing and supporting each other to be heard, discussion, debriefing and honest open communication as key to how well coproduction worked. Reflection, dialogue and flexibility in the evaluation methodology enabling dynamic coproduction were also important.

This section of the report is based on the individual reflections of fourteen of members of our research team and collaborators on what we had done together.

# Who coproduced this evaluation? People, organisations, roles and expertise

Our evaluation team's partnership between a mental health research team in the Population Health Research Institute, St George's, University of London (SGUL), the mental health charity McPin Foundation (McPin) and our collaborators is described in Chapter 1. We also set out there the way that experiential knowledge of mental health difficulties was valued in both the quantitative and qualitative research teams. In addition, members of our evaluation drew on experiential knowledge as members of different BaME, LGBT, disability and activist communities in England. Many of our team also drew on personal lived experience of peer support, survivor research and of coproducing prior research in this area.

Due to the funding resources available, researchers were recruited in stages across the evaluation. Changes of research staffing meant that that differing skills, experiential knowledge and expertise were lost and gained at SGUL part way through work stream 1, as well as in the regional researcher team at McPin. This was particularly significant since first a LGBT and then a BaME researcher moved on from the team as they were successful in gaining new roles to further their careers. Successive research managers and two regional researchers from McPin also left the project part way through. Funds were invested at the end of the study to enable the remaining regional researchers to stay on with McPin as part of the evaluation team until the end of the project to ensure their knowledge and expertise remained part of the analysis and writing up stages.

The role of the PEER (Peer Expertise in Education and Research) Group based at St George's, University of London in advising on the design and development of work stream 1 is described in Chapter 3. This group have also been kept regularly updated as stakeholders in the progress of this evaluation.

The role of Mind, the national mental health charity who was the lead partner in delivering the Side by Side programme emerged, in some ways, as an unexpected partner in delivering this evaluation. Despite commissioning and this study as an independent piece of academic research, they remained involved and influential in decisions about the evaluation delivery, use of resources and priorities throughout the evaluation process. It is unusual for an academic research team and a research commissioner to have this working relationship and added layers of complexity to our coproduction.

The evaluation team also coproduced parts of the evaluation with members of Side by Side hubs, project teams and peer support coordinators. These working relationships and were highly valued and extremely important to the delivery of the evaluation in a way that benefitted both people participating in the evaluation and the findings of the evaluation itself. The evaluation team designed and hoped for a more collaborative relationship with some of the evaluation participants becoming evaluation ambassadors. The expertise and experience of evaluation ambassadors and project coordinators was highly valued by the research team and led to tailoring of the approach to delivering the peer support log in many projects.

This was especially the case in a number of BaME projects where the researcher allocated this role devoted considerable time and energy in developing relationships, through face to face visits and/ or by telephone, with project coordinators and group members, negotiating an approach to registering participants and support log completion – often using the short version of log – that worked best in each individual project.

### Who had the power? Coproducing decisions about the Side by Side evaluation

Decisions were coproduced in this evaluation right from the design phase through to writing up this report. Researchers using lived experience of peer support and mental health difficulties brought their experiential expertise alongside academic expertise from a number of disciplines.

The organisations and teams we worked in did still have built in hierarchies. These impacted less on decision-making as the project went on as decisions were made more by consensus with differing perspectives being sought and heard. Earlier in the programme however, input from the lead researchers and research managers in particular seemed to hold more weight than the regional researchers' experiential and academic expertise. As time went on team members generally found that their ideas and perspectives were being valued and listened to. Where there was a particular area of expertise - for example, our statistician - they had greater say in decisions in that area.

Considerable investment was made in supporting researchers to further develop skills, which enabled them to contribute. However the resources for this were limited and not everyone got all the support that they needed to feel that they could contribute fully. This was especially true in the final stages of the project where many decisions were made in large meetings. This setting is far easier for some people to contribute to than others, so this left some team members less well heard. The pace of work also meant that the project moved ahead quickly as decisions were taken sometimes without everyone understanding what those decisions had been.

Lastly evaluation team members' power and confidence grew as we got to know each other's roles, skills and the expertise that each team member had to offer. We also got better to an extent at noticing when each other needed support in getting their voice heard and in understanding what was and wasn't helpful to individual team members. We were better able to input individually and then make decisions as a team for example about how we would structure of interpret the findings

as we recognised the different perspectives that we had examined together and gained more confidence in our coproduced decisions.

# What difference did it make? The impact of coproducing this evaluation

As a result of the good links built up with Side by Side projects, consultation events and the involvement of many people with lived experience of peer support in the design of the questionnaires, interview schedules and peer support log materials we were able to collect more data of better quality. Peer support log data was unusually complete. We had a much broader range of people and projects involved than we originally expected and designed for.

We were keen to invest in supporting participants who wanted to take part to complete the log. Mind's intervention and monitoring of where participants were being recruited from may have led to increased participants over a wider geographical area and with a wider demographic range. This led to challenges in supporting them all and meant a herculean effort on the part of both regional researchers using their own lived experience and the SGUL based researcher in liaising personally with an army of peer support project coordinators.

Ensuring that experiential knowledge of peer support and mental health difficulties in general was retained in the project team right through the analysis, data interpretation and writing up stages ensured that alternative explanations for the relationships between findings could be tested against our experience as well as checking back into the qualitative and quantitative data sets. Our collaborators expertise was also invaluable at this stage in enabling us to focus our thinking on the key findings and messages that the report needed to highlight.

Investing in creating space for dialogue across perspectives in the analysis meetings meant that differing experiences, understandings and data interpretations could be heard and challenged. This was challenging both in terms of getting everyone there and in supporting each other to be heard. However we think we were broadly successful at the end of the project

# Barriers and challenges to coproducing this evaluation: What would we do differently in the future?

Time: coproduction requires dialogue. It requires investment in making sure people are heard, supported to understand and contribute to decision-making, and have time to develop and express their skills and expertise. Toward the end of this project the team was under such pressure to meet deadlines that our coproducing conversations and processes were extremely challenged. The time we had scheduled for analysis and write up of the report was shortened by a month due to the data collection period being extended. Mind asked for outputs at stages in the research process where the findings and analysis required to produce these were not yet due to be completed. This led to time being taken up producing drafts of project outputs, which had been allocated to other parts of the research programme. Squeezed timelines meant that coproduction meetings were shorter than they should have ideally have been. More time would also have enabled researchers who were developing skills and ways of working together to grow in these skills and gain more confidence in their working relationships.

Resources: making sure that people had information and support they needed whilst working at a distance across multiple regions was challenging. The scope of the regional peer researcher role was underestimated at the design stage. Regional peer researchers were employed only two days a week; this meant they had to juggle Side by Side work with other work and there were too many tasks to fit into their role at the same time. Their roles involved travelling, collecting log data, supporting participants and undertaking interviews all at the same time.

Not enough resources were written into the project budget either to bring these regional peer researchers together for face-to-face support and reflection meetings or to work with the collaborators and draw on their expertise during the course of the project. This meant that the collaborators were only included at the start and end of the evaluation and much of the support and learning from the regional researchers was offered on a one-to-one basis via email and telephone conversations. People were more isolated than they should have been at times and left trying to manage practical issues in the field, which might have been solved better by bringing the team together.

Hierarchy and structures: Mind's priorities for data collection – as noted above, maximum coverage of projects – shifted the regional researchers' role from the evaluation's original design spreading them more thinly and changing the shape of the data we collected so that they were less able to support people to fully complete peer support logs whilst being encouraged to recruit from a wider pool of peer support groups. As a result the regional researchers – who's role had been designed to foreground local and community experiential knowledge in the data collection and research process – were left with much less power to shape their roles and the way that they worked with their regions than intended.

Messaging around the Side by Side evaluation has also been a challenge. Involvement in the research was in part communicated as being about 'proving that peer support works' rather than to find out about peer support and its outcomes for people. This messaging from programme delivery partners could mean that we have less negative descriptive findings about the challenges of peer support in our data than we might have otherwise had. This is a potential loss to knowledge about peer support.

Our own team (SGUL/ McPin) and organisational hierarchies and our perceptions of these were also a barrier to distributed decision-making. Researchers found more confidence in using their voices in discussions and decision-making as the project went on. Although the leads of both research teams were invested in this coproduction approach there was still expectation by other members of the evaluation team that leads would have the final say on decisions and their ideas had more power because they had more authority.

# What we have learned and suggestions for future coproduction

Finding resources to include research assistants and regional researchers working from their lived experience of mental health difficulties earlier on in the design and funding to enable them to continue right to the end of the study and on into the dissemination phase would also enhance coproduction, especially their specific voices being heard and particular skills and knowledge being even better used.

More resources should also be asked for to support the inclusion of specific groups - e.g. people with multiple disabilities, cultural and minority identities - and to create time to conduct the extra analyses this specific data warranted.

Clear early conversations about the evaluation and programme teams' expectations of their working relationships and about how the programme team would be involved in relationships with potential evaluation participants are vital. These should include agreements about how the research would be described and how people could and should not be encouraged to participate for us to be sure that the evaluation was independent.

Greater clarity across the team about our coproduction principles from the start – distributed decision making, being flexible and reflective; thinking about what we have done and why – might

have given team members who were newer to this approach greater confidence and expectation that they should be heard and supported to express their ideas.

Clearer communication between the team and our collaborators during the project would have enabled the collaborators to offer their expertise earlier in the process. Each of them had skills and knowledge to offer that the research team did not make full use of because paid time for their input was not budgeted in frequently enough.

#### In summary

We should trust ourselves and ask others to trust us. A large proportion of the team have lived experience of mental health and physical disability and are members of minority groups and communities. We were also geographically distributed and built good relational networks within the contexts in which we were undertaking the research.

We could have been more confident in the plans we had coproduced and priorities we set to deliver the project, and been less responsive to the programme team's calls for more and sooner. This would have put less pressure on our coproduction and enabled us to take care of ourselves and each other better and taken the time we needed to all the cross the finish line feeling we had been heard and empowered to contribute equally.

As a team we intend to spend some time following completion of the evaluation to reflect further and write up our experiences and the shared learning of attempting to coproduce a project on this scale.

# Discussing and concluding the findings of the Side by Side evaluation

There were four distinct work streams to our evaluation of the Side by Side programme and the findings of these have been presented above. However it was not always possible to interpret fully these findings in isolation from one another. This was especially the case with the peer support log data, and observations from all work streams contributed to a fuller understanding of mental health peer support in the community. As we discuss the main learning from our findings as a whole here, we will not follow the sequence of the chapters of the report. Instead, where appropriate, we will bring findings together from across the chapters in order to combine learning and to best present a coherent narrative. In doing so we will refer back to the literature we reviewed in chapter 2 in order to place our findings in a wider context of peer support internationally and across settings and communities.

## Values and peer support

We observed a great variety of peer support across the Side by Side programme. However our findings suggest that there was a core set of values underpinning ALL peer support, as we observed it in the programme, whether that peer support took place online or face to face, in groups or one-to-one.

These six values were interconnected and did not work in isolation from one another. In particular we noted that the first three values – 'Experience in common', 'Safety', and 'Choice and control') – seemed to form a foundation on which the final three values rest; 'Two way interactions', 'Human connection', and 'Freedom to be oneself'. We felt that the evidence was telling us that all six values need to be present for organised approaches to community-based mental health support to be experienced as peer support. When looking at how our findings compare with existing literature on the principles and values of peer support, we see that they converge with previous work:

#### Experience in common of social and emotional distress

Experiences in common of social and emotional distress form the basis of peers' connection to each other, regardless of the extent to which this experience is openly discussed. As identified elsewhere (Faulkner & Kalathil 2014), in some peer support, specific additional aspects of personal experience or identity shaped by gender, ethnicity, age, sexuality, disability, and migration are critical to people recognising each other as peers.

#### Safety

The process of creating peer support involves developing structures to provide physically and emotionally safe spaces, and this is a theme that recurs across much of the wider mental health peer support literature (Repper and Carter 2011). Safety building can include creating guidelines or 'ground rules' to address confidentiality and how peers can behave respectfully towards each other. The responsibility for creating safety in peer support may rest with online moderators, group facilitators or supervisors, while in other forms of peer support peers collectively take responsibility for creating safety.

#### Choice and control

It is up to the individual peer to decide how they will participate in peer support, including control over when they attend or take part in peer support, what they choose to share, what support they want to try, what role they take in a group or interaction, and how long they access peer support. Peers can withdraw from peer support for a period of time and return to it later on without being penalised. The idea of choice, or a sense of agency over when to engage in peer support is widely present in the literature (Legere, 2014), it being argued that

that shift of power demarcates peer support from other mental health services (O'Hagan et al 2010).

#### Two way interactions

As a consistent theme across a broad range of peer support literature (Dyble et al 2014; Gidugu et al 2015; Walsh et al 2015), we found that the interactions between peers are two way, and involve both giving and receiving support. This two way interaction may be called 'reciprocity' or 'mutual support'. At different points in time peers may give more or receive more or less support depending on their circumstances. What is given and received may vary, but there is always the potential in peer relationships to both give and receive support.

#### Human connection

Peers actively acknowledge that they have a connection with each other based on experiences they have in common of social and emotional distress. Peers act with intentional kindness towards each other online or face-to-face, and understand, emotionally support and care for each other. This generates a culture of companionship and belonging. Through the connection with each other, peers may come to feel less isolated and feel that that are part of a supportive community. This sense of connection and communication grounded in compassion and mutual respect underpins the well-established Intentional Peer Support approach developed in the US (Mead et al, 2001).

#### Freedom to be oneself

The ability to express oneself freely – without fear of judgement – is necessary for peers to be able to share difficult issues. The experience of feeling heard and understood in peer support is powerful. Peer support allows peers to feel like they are normal, and are just like any other person in their peer support. This is in contrast to having felt different, stigmatized, or excluded in other aspects of life. This sense of peer support as a space where peers are free to identify and interact unconstrained by the expectations of clinical services is epitomised in Faulkner and Kalathil's (2012) report, *The freedom to be, the chance to dream: Preserving user-led peer support in mental health*.

Some of the wider literature on peer support refers to a 'recovery-oriented approach' underpinning peer support (Davidson et al 1999; Byrne et al 2013), but this was not something that our participants particularly focussed on.

#### Approaches to peer support

We found that there was so much diversity in the peer support that we encountered that it was too simplistic to try and define 'models' of peer support over and above a straightforward distinction between group, one to one and online peer support. Instead we found that peer support was shaped by a number of key decisions about how peer support – as an organised, community-based activity or project (as opposed to naturally occurring peer support between individuals) - might be structured. These also converged with some aspects of the literature we reviewed:

#### Facilitation

In most Side by Side projects facilitation was an identified role and it was allocated to a named individual (or individuals if the responsibilities were shared). However, there were some projects that chose not to allocate a facilitator role. Instead, the tasks involved in organising peer support were divided amongst different peers to ensure that there was a collective responsibility for sustaining activities. In our overview of the literature we did find examples of peer-facilitated

self-help groups (Straughan & Buckenham 2006) and mutual peer support group that did not identify a formal facilitator (see Lloyd-Evans et al 2014). Groups that were either co-facilitated by professionals and peers (Gillard et al 2014) or professionally facilitated (Castelein et al 2008) were absent from this evaluation.

#### Types of leadership

Projects within Side by Side employed different types of leadership and could be either: peer-led or non-peer-led; provide leadership raining or not; have paid of voluntary leadership positions. None of these decisions were mutually dependent. The centrality of peer-leadership to peer support has been emphasised (Solomon 2004; Faulkner & Kalathil, 2012), but wider questions of training and terms of employment for leadership in peer support are comparatively neglected in the existing literature.

#### Focus of peer support (e.g. social, educational)

Within the Side by Side programme, there were projects that focussed explicitly on peers discussing their mental health but they represented a minority of projects, with other projects taking a more social focus, being activity based, structured around information sharing or training (an educative focus) or a combination of the above. The peer support literature often notes the range of different approaches to peer support more generally (e.g. Repper & Carter 2011), and that in many contexts the focus of peer support for mental health is not inevitably, explicitly on mental health (Faulkner & Kalathil, 2012). However, there is a lack of work that describes the range of activity that can constitute peer support for people.

#### Membership

Side by Side projects differed in how broadly or narrowly they defined who could join their activities; who was a peer. Some projects were open to people from a wide range of backgrounds experiencing any type of social or emotional distress. Others had specific criteria regarding who was able to join, including: diagnosis-specific type groups; groups that included carers; projects that defined membership in terms of gender, ethnicity, sexuality, and disability; stage of recovery; requirement to undergo prior training. There is precedent for diagnosis, or mental health–specific peer support in relation to voice-hearing (Dillon & Hornstein 2013), bipolar disorder (Proudfoot et al 2012), eating disorders (McKey et al 2006) and so on. We note the that potential for gender-specific peer support to respond differences in help seeking behaviours between man and women remains under-explored (Wislon & Cordier 2013). This evaluation also adds to growing knowledge about the potential for peer support to address a range of mental health-related issues - including stigma, rejection by families and victimisation - in LGBT communities (e.g. Mutanski et al 2011). We consider issues of ethnicity and peer support below.

#### Organisational support

Peer support projects in Side by Side ranged from independent or 'stand alone to those that received different levels of support from other affiliated organisations including practical, infrastructure support, safety structures and procedures, and training and support for peer leaders. The wider peer support literature tends to focus on organisation support in the context of formal mental health services (Gillard et al, 2014). There is a relative lack of literature on how peer support is supported at an organisational level in the community and grassroots sector.

In summary, we found that people engage with peer support in a range of ways, in a number of different contexts, and that the way that peer support is offered – the decisions made about how peer support should be made available by projects and organisations – should reflect those different

circumstances. As a legacy of the evaluation of the Side by Side programme the evaluation team will be producing a 'toolkit' to enable groups and organisations, large and small, to make those crucial decisions about how best to structure and support peer support in a way that is relevant to the needs and aspirations of individuals and communities.

# Diversity and peer support

Issues of identity, community and culture were vitally important to people's understandings, experiences and expectations of peer support. However, we found that the core values underpinning peer support – as described above - seemed to apply broadly across peer support in all communities and cultural contexts (people did not tell us that any of those values did not apply to them).

However, we did find that the reasons why people choose to access peer support could be different in different community contexts. This included a wider cultural sense of shared identity that was not defined or focused on experiences of mental health difficulties, experiences of racism and discrimination (both within society and from mental health services), and because of experiences of stigma relating to mental health from within people's own cultural community. An emerging literature on BaME-specific peer support in the UK notes the importance of peer support that does not explicitly use the language of mental health while still, in practice, having a mental health focus (Faulkner et al 2013), especially where this might be a barrier within a specific cultural community (Economic Change CIC 2013).

Given the potential for community-driven peer support to address health inequalities (JCPMH 2014) the findings of this evaluation are timely, although other research notes that it should not be assumed that people prefer culturally-specific peer support groups where it might be difficult to disclose experiences of distress in the community context (Edge 2011).

Data collected in our evaluation about the particular opportunities and challenges around peer support, mental health and complex intersections of disadvantage (e.g. ethnicity, sexuality and migration) offer potential new insight into understanding issues of diversity and peer support.

## Peer support and outcomes

We had a range of findings from the peer support log that provided evidence of statistically significant associations between change in the amount of peer support people engaged in (either over all or specific approaches), and change in the outcomes we measured. To help understand what those findings might mean we revisited qualitative interview data where people told us why they engaged with peer support and what they felt the impact was for them. The findings as we discuss them below are interpretations of our data based on that synthesis process. Where relevant we relate these findings to a wider literature on mental health outcomes.

- We found that people choose to engage with different approaches to peer support for different reasons and at different times. In other words, engaging with peer support was purposeful, in response to a range of needs and aspirations including a desire for meaningful activity, a need for social contact, sometimes referred by mental health services but sometimes to address a gap in services, as a space to share experiences of mental health difficulties and strategies for coping, and sometimes in response to crisis.
- People accessed less peer support as their sense of wellbeing and general health status increased, and as they had more contact with family and friends. Bringing together our log data and qualitative interview data, we think that might mean that people:

- Choose to access less peer support as they feel increasingly well (mentally and physically) and have more social contact with friends and family
  - o Do not seem to access peer support just because it is there
  - o Access less peer support as a positive choice associated with improved outcomes
- There were a number of associations in our log data between giving more peer support and improvements in outcomes
  - People who increased the overall number of types of peer support they were giving reported increases in their levels of wellbeing and hope in the future
  - People who increased the amount of group-based peer support they gave reported improvements in wellbeing, hope, self-efficacy and increased contact with friends
  - People who increased the amount of one to one peer support they gave reported improvements in wellbeing and hope
- When we looked at our interview data, people described an active, mutual giving or sharing
  of peer support of 'doing peer support' as a two way interaction that embodies a sense
  of agency in the peer support process (as we described above) that is distinct from the way
  in which people might more passively make use of other mental health services
- This was especially the case for group approaches to peer support where giving more peer support in this way was associated with change in most outcomes
- People also spoke of feeling rewarded through giving peer support in a more uni-directional, helper sense, especially in one to one and online peer support

Improvements in hope as an outcome have been reported in a number of studies of one to one peer support (Davidson et al 2006; Simpson et al 2014) but similar data has been lacking for communitybased peer support. Qualitative studies have reported increased social contacts for people accessing a range of approaches to peer support (Ochoka et al 2006; Rogers et al 2007) and this evaluation provides quantitative evidence of the effect in relation to group peer support. While a number of studies have measured empowerment in relation to peer support (e.g. Resnick & Rosenheck 2008) it is only recently that a trial of community based one to one peer support has identified a positive effect in relation to self-efficacy (Mahlke et al 2017), once again our evaluation finding an effect on self-efficacy in relation to peer support. To date, change in wellbeing has not been widely explored in relation to peer support. As was noted in chapter 4, the effect sizes observed in the evaluation are small and of the order generally seen for psychosocial outcomes in mental health studies.

- People derived benefit from receiving the advice and support of others in a more passive sense, especially online and also in one to one peer support
  - People who increased the overall number of types of peer support they were receiving reported increases in their levels of hope in the future
  - People's sense of hope in the future and general health status decreased as they received less one to one peer support (general health status increased as they maintained one to one peer support)

• The amount of peer support people received online increased as their sense of selfefficacy and overall health status decreased, suggesting that people sought peer support online when they were feeling less well

These findings suggest that giving and receiving roles could be more demarcated in some one to one and online peer support in the Side by Side programme (compared with much of the group peer support we observed). We note that a number of the one to one projects within Side by Side focused on training people in peer mentoring type roles, and that this could have shaped our data. Nonetheless, this reflects findings from other research that suggest – particularly in the case of one to one peer support – that providing peer support to others, and for some, adopting a more explicit 'giver' identity, can have positive impacts (Salzer & Shear, 2002, Bracke et al 2008).

Taken as a whole, our findings suggest that people try out different approaches to peer support in response to a range of needs and aspirations, finding out which approach works best for them, perhaps maintaining a core approach to peer support while accessing other peer support as and when they feel a need to do so. Maintaining the same amount of group peer support received was associated in the peer support log data with a reduction in contact with friends, reflecting qualitative data that suggested that people maintain a certain amount of peer support as a source of social contact. Again, the association between peer support and social contact has been noted elsewhere (Ochoka et al 2006; Rogers et al 2007).

## Peer support, diversity and outcomes

We noted a number of significant differences – between communities and groups of people – in associations between change in outcomes and change in engagement with peer support. As we note in chapter 4, while overall effect sizes in change in outcomes were small, we observed medium and large effect sizes in relation to changes in outcome for people from specific BaME communities, suggesting that there are important potential differences here that need further careful consideration. We also note, as reservations, that we collapsed reported ethnicity into broad ethnic categories here in order to undertake these analyses, and that we had little or no scope to explore the differences we observed in our qualitative interview data, so all of the findings flagged below are tentative and need further work, based on the data we have collected, to understand fully.

- A complex set of findings suggested that Black people in our evaluation turned to family and became more actively involved in giving peer support at times when they felt less hopeful about the future, but as they had increased contact with friends and felt more hopeful they accessed less peer support generally
- In contrast, people from Asian communities reported giving more peer support as they felt more hopeful about the future but their sense of wellbeing decreased as they received less peer support from others. Cultural values associated with giving and receiving support within Asian communities might help explain these findings, but further detailed work with both the qualitative and quantitative data is needed to understand this in more detail

The limited literature that explicitly explores issues of ethnicity, culture and peer support notes the importance of family and friend networks – and how these might interact with peer support for mental health - in different cultural contexts (O'Hagan et al 2010, Edge 2011). Our initial analyses of our data indicate an opportunity here to add to this important literature.

• As men became involved in giving more peer support their general health status improved (it stayed the same for women) suggesting that men might engage in peer support for broader health related reasons

That men have different health seeking behaviours to women is well recognised (Oliver et al 2005), as have been the potential benefits of a wider health and wellbeing focus to peer support for men (Wilson & Cordier 2013).

- All people who gave more peer support experienced an increase in wellbeing, with older people benefiting most. However younger people also felt less well as they gave less peer support, and attended fewer peer support projects as they had more contact from friends, suggesting that peer support might play an important protective role for younger people when they are more isolated
- People in the evaluation who were using formal mental health services experienced a decrease in self-efficacy and decreased contact with family and friends as they gave less peer support. This group of people is possibly the 'least well' of our population as a whole, with findings suggesting a complex association between peer support, social isolation and feeling able to connect with others
- People in rural areas attended more peer support projects when their general health status was lower. This might be because peer support was easier to access closer to home than other health services that might be more geographically dispersed
- People who identified as having a learning disability accessed more support when their sense of self-efficacy decreased, and less peer support when their self-efficacy increased, implying that access to peer support for them was motivated by specific need
- Some people with a physical disability or long term condition turned to peer support when their general health status decreased while others attended less, perhaps because they were too unwell to do so, suggesting that peer support is relevant to a wider set of health needs for this group

We note that these findings all warrant further investigation, and as such potential to add to knowledge on peer support in different community contexts. Some of this we will be able to do on the basis of the extensive qualitative data set we collected while other findings raise important questions for future research.

We also note that we did not find differences in outcomes for people accessing diagnosis specific peer support (compared to peer support aimed at other groups or communities, or no particular group), or for people identifying as LGBT. This is not to downplay the importance of providing peer support spaces where people feel safe to discuss their mental health in relation to the sexuality (Williams et al 2005, Faulkner & Kalathil 2012); rather that, where that space is provided – there were a number of LGBT specific projects within the Side by Side programme – equitable outcomes can be expected. Our findings also indicated that similar outcomes could be expected from smaller, grassroots peer support projects as in those supported by larger organisations with more extensive infrastructure.

# Capacity building for peer support

Our work on capacity building gives clear indications of what the active enablers might be in developing a range of community-based peer support options, noting the importance of:

- Peer leadership in the capacity building process
- Sharing of expertise and resources among the organisations and individuals committed to peer support

- An active sense of learning both among those people already doing and supporting peer support, but also in understanding how the full diversity of cultures and communities understand mental health and peer support
- Creating positive, safe, trusting spaces for peer support good experiences of peer support foster capacity building within and across communities and cultures
- Being prepared to think differently about how peer support is provided, challenging and adapting ways of working that can be constrained by conventional thinking about services, models and care giver/user roles
- Time for communities, organisations and individual peers to share and learn from each others' expertise in order to build peer support capacity in this way

There is literature that points to barriers and facilitators, at an organisational level, to introducing new peer support initiatives but, as has been noted above, much of this literature is focused on one to one peer support in formal, clinical settings. For example, studies point to the need for role clarity and distinctiveness compared to clinical support roles (Creamer et al 2012), clear of job description for peer workers (Kemp & Henderson, 2012), access to appropriate training and support (Tse et al., 2013), preparation and training for the team that will be working alongside peers (Stewart et al., 2008), and well-signalled strategic support for peer support from the top of the organisation (Gates & Akabus, 2007). This evaluation adds considerably to what we know about building capacity for peer support in community-based settings away from formal mental health services.

# Commissioning for peer support

The *Piecing Together the Jigsaw* report (Faulkner et al 2013) made recommendations for commissioning of peer support. A small number of studies, including those by members of the team (Gillard et al 2015), have made efforts to include the views of commissioners when exploring organisation issues around peer support and mental health services. However, there is an absence of literature that explicitly explores the role of commissioning in building capacity for peer support in mental health services.

The findings from the peer support log told us that, while people accessed slightly more of some approaches to peer support when they first accessed the Side by Side programme, over time people accessed less peer support overall. At the same time, outcomes as a whole were maintained over the course of the evaluation with some (especially self-efficacy) improving. We combined our outcomes analysis with our qualitative interviews about when and why people engaged with more or less peer support. Taken as a whole, the evaluation suggest that, when people are offered a range of locally developed approaches to peer support, it is a sense of agency – choice and control – in deciding what peer support to access, when and why, that might be enabling people to maintain outcomes while accessing less peer support over time. We did NOT find evidence that, the more peer support that was offered, the more peer support people 'used', as is found with many conventional mental health services

Our work on commissioning suggested that some commissioners have a good understanding of the benefits of peer support and of the importance of working with the voluntary sector and with peers on developing new peer support options. As a limitation of the evaluation we were unable to speak to those commissioners who might have in incomplete understanding of peer support or who were less positively disposed towards peer support.

However even those commissioners well disposed towards peer support by and large thought in terms of discrete services, models or interventions that could be purchased and provided to improve

defined outcomes for specific populations. Commissioners wanted to see a combination of routine monitoring of access to peer support, standardised measures of outcome and individual accounts of experience of specific peer support initiatives in order to be able to make decisions about funding peer support. This evaluation provides commissioners with this type of evidence.

This evaluation has demonstrated that peer support works as a network of approaches that are produced by communities of peers, for those communities. Rather than acting as separate interventions or services, different approaches to organised, community based peer support interface in complex ways with informal peer support, contact with friends and family, and access to other services and sources of support. Commissioners wanted to know that peer support can be integrated into existing care pathways. They were also concerned about governance; while different from clinical risk management practice, this evaluation has noted that creating safe spaces was prioritized in peer support projects across the Side by Side programme.

The 'jigsaw' metaphor seems apt (Faulkner et al 2013) at both a community and individual level; while it can be something of a puzzle to work out what works well and for whom, as long as time and space is provided for individuals and communities to do that piecing together, different approaches to peer support can interlink and constitute a more complete picture of support for people.

These are new findings for the peer support literature and have important implications for the commissioning of peer support. The evaluation is strongly suggestive of the need for a new approach to commissioning for peer support (compared to conventional purchase of fixed units of service in response to specified assessments of clinical need), specifically:

- That it is the role of commissioners to work with partners in the community sector locally to piece together the jigsaw of approaches to peer support – alongside other forms of support and care – that reflect the needs and aspirations of the full diversity of communities locally
- That people are enabled to take control of how, when and what peer support they engage with (peer support is not prescribed or gate-kept by referral criteria)
- And that as a result, commissioners can expect people to maintain levels of wellbeing, hope, self-efficacy and general health – to continue to live well in the community – while accessing less peer support over time

#### Looking forward

Going forward the evaluation team will use the wealth of data we have collected to further develop these findings. We will produce a 'toolkit' that will help organisations, groups, projects and communities, large and small, to develop and tailor peer support initiatives that best address their needs and aspirations. We will use the peer support log and interview data to explore and try to understand in detail how people from different BaME communities understand and engage with peer support. And we will do a similar piece of work making sense of the complex relationships between how and why people engage with the sorts of community-based peer support projects we observed in the Side by Side programme, informal peer support (including support from friends and family members) and support from mental health services. Finally, as noted above, we will reflect further and write up our experiences and the shared learning of attempting to coproduce an evaluation of this scale and scope.

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# Appendices

Appendix 3.1: Peer Support Log Registration

## **Evaluating the Peer Support Programme**

#### 1 Welcome to the Peer Support Programme Evaluation!

Lots of people have described how peer support has made a real difference to their lives. Mind, Bipolar UK and Depression Alliance recently set up a new Peer Support Programme that aims to make peer support for mental health available to all people who need it nationally.

This programme is an opportunity to put peer support on the map and make sure that peer support is available to all people who would benefit. It is really important that peer support is properly evaluated, but we can only do this with the help of people giving and receiving peer support. With your help!

Many of the team bring their own experiences of mental health difficulties to the evaluation process. We would be extremely grateful if you could help us to evaluate the Peer Support Programme by completing our *Peer Support Log*.

#### 2 The Peer Support Log

The *Peer Support Log* is designed to record the benefits of both giving and receiving peer support. We would like people to complete the *Peer Support Log* once a month so that we can compare times when people choose to use more or less peer support.

The *Log* can be completed on a computer, phone or tablet, or by pen and paper. Please ask a member of your project or the evaluation team if you would like some help filling in the *Log*.

Each time you complete the *Log* both you and the peer support project you are part of will be entered into a prize draw. There are monthly prizes with a value of £25 for individuals and £50 for projects.

It should take about 10 minutes to register for the *Peer Support Log* the first time you use it, and about 15 minutes to complete the *Log*. Every three months the *Log* will include a few extra questions and take a bit longer to complete.

# Agreeing to take part in the evaluation

3 For a detailed information sheet about the *Peer Support Log* please ask a member of the research team for a copy.

# If you have read the information sheet and are interested in taking part please indicate your agreement with the statements below:

4 I have read and understood the information provided about the Peer Support Log

Please choose **only one** of the following:

Yes No

5 I agree to receive monthly reminders about the Peer Support Log

Please choose **only one** of the following:

TYes No

6 I agree to the information I provide in the *Peer Support Log* being used for the research as described in the Information Sheet

Please choose only one of the following:

TYes No

7 In order to proceed with registration it is necessary to answer 'Yes' to all of the

three questions.

## ID details

8 You have been given a Personal ID by the Peer Researcher or Evaluation Ambassador that has talked to you about this study.

The Personal ID is 4 numbers. Enter one in each box below.

## **Please enter your Personal ID:**



Please make a record of your Personal ID. Your ID cannot be used by anyone else to access information about you. We will use your ID only so that we can track changes in your answers over time.

Each time we send you a reminder to complete the *Peer Support Log* it will include your Personal ID.

If you forget your Personal ID at any time or have any questions about the *Peer Support Log* please contact Sarah at <u>peersupport@sgul.ac.uk</u>

#### Please enter today's date: (dd/mm/yy)



#### 9 Contact details

Please indicate below how you would like to be contacted about the *Peer Support Log.* This is so that we can send you monthly reminders, let you know if you win a prize in the monthly prize draw each time you complete the *Log* and to keep you informed about the research.

We will not use these details for any other purposes. You may indicate all methods of contact if you prefer.

Please select at least one answer.

🗄 By text

By email

10 If you would like to be contacted by text, please write your mobile number

11 If you would like to be contacted by e-mail, please write your email address

12 If you would prefer to complete the *Peer Support Log* with pen and paper and then post the data back to us please enter your name and address here. We will send you the form to be completed on a monthly basis.

Please write your name and address here:

If you would like to update your contact details at any time please contact Sarah at peersupport@sgul.ac.uk

# About you

13 The following questions are designed so that we can compare the different regions and projects in the Peer Support Programme, and so that we can compare the impacts of peer support for different groups of people. You will only be asked these questions once while registering for the *Peer Support Log.* 

# Which region is your project in?

If you found out about the project through *Elefriends* please select *Elefriends* instead of a

region:

Please choose **only one** of the following:

<b>Suffolk</b>	Coventry	Northamptonshire
<b>Leeds</b>	Blackpool	Southampton
Plymouth	Middlesbrough	EKensington & Chelsea
<b>□</b> Elefriends		

14 What is the name of the peer support project you are involved in?

Please write your answer here:

If you are not sure about the name of your project please ask a member of your project.

## More about you ...

15 Age?

Please choose <b>only one</b> of the following:									
⊡18-24	E 25-34	<b>35-44</b>	<sup>™</sup> 45-54	₿55-64	№65+				
16 Gender?									
Please choose	e <b>only one</b> of th	ne following:							
Male	Female	Prefer not to	o say 🖾 🗈 Otł	ner					
17 Do you have a transgender history?									
Please choose <b>only one</b> of the following:									

Image: Not sureImage: Prefer not to say

18 Sexual orientation?										
Please choose <b>only one</b> of the following:										
Heterosexual/straight	الله العامة العامة العامة المانين الم	an/gay	Bisexual	Prefer not to say						
BOther										
19 Ethnicity?										
Please choose <b>only one</b> of the following:										
White British		🗄 White Irish								
White Eastern European		SWhite other								
Black/Black British Caribbea	an	Black/Black British African								
Black/Black British other Black	ack bacl	kground								
Asian/Asian British Banglad	leshi	EAsian/Asian	British Chinese	2						
EAsian/Asian British Indian		EAsian/Asian	British Pakista	ni						
Asian/Asian British other										
Mixed White & Black Africa	in	Mixed White	e & Asian							
Mixed White & Black Carible	bean	Mixed other	Mixed backgro	ound						
■Arab		Gypsy or Tra	veller							

🗄 Other .....

20 Which of the following best describes the area you live in?

Please choose **only one** of the following:

City/large town Small-medium sized town Village/rural

21 Do you use formal mental health services (i.e. a Community Mental Health

Team)?

Please choose **only one** of the following:

EYes ENo

# 22 If yes, for approximately how many years?

Please write your answer here:

23 Would you say you have a long-term physical health condition or disability

(including sensory impairment)?

Please choose only one of the following:

Teres No

24 Do you consider yourself to have a learning disability (including developmental

disorders)?

Please choose only one of the following:

🗄Yes 🖾No

25 Do you have a free public transport pass because of a mental or physical health

problem?

Please choose **only one** of the following:

Teres In No

# 26 Interviews about peer support

We would also like to interview some people, to find out about their experiences of peer support. The interviewer will be a peer researcher who has personal experience of mental health difficulties.

Interviews would be held at a time and place mutually agreed by you and the researcher. This could be at the peer support project you are involved in, by telephone, Skype or another online face-to-face networking platform.

We would use the information you provided about you on the two previous pages to decide who to interview. This is because we want to interview people living in different areas and from a range of different ages and communities.

You do not need to decide now if you would like to take part in an interview, but please indicate by ticking Yes or No if you might be interested in taking part in an in-depth interview in the future:

Please choose **only one** of the following:

Tes No

If you are selected for an interview we will contact you using the contact information you provided above.

# 27 The peer support log prize draw

Each time you complete the *Log* both you and the peer support project you are part of will be entered into a prize draw. **There are monthly prizes worth £25 for individuals and £50 for projects.** There are also £50 prizes at the end of the evaluation for individuals who complete the *Log* most often.

Please tick the appropriate box below to indicate if you do or do not want to be entered into the prize draws:

Please choose **only one** of the following:

🗄 Do enter me 👘 Do not enter me

If you win an individual prize will we contact you using the contact information you provided above to inform you that you have won and to work out the best way to get your prize to you. We will also contact you to let you know if you have won your project a prize.

# Thank you for completing this survey.

### Appendix 3.2: Quarterly Peer Support Log

#### **Quarterly Peer Support Log**

The *Peer Support Log* is designed to record the benefits of both giving and receiving peer support. We would like people to complete the *Peer Support Log* once a month so that we compare times when people choose to use more or less peer support.

The *Log* can be completed on a computer, phone or tablet, or by pen and paper. Please ask a member of your project or the evaluation team to help you fill in the *Log*.

#### Information and Log On

For a detailed information sheet about the *Peer Support Log* please ask a member of the research team for a copy of the Peer Support Information Sheet.

#### 1. To complete the *Log* please enter your 4 number Personal ID below:



If you have forgotten your Personal ID or have any questions about the *Peer Support Log* please contact the research team at <u>peersupport@sgul.ac.uk</u> or 020 8725 2785

Today's date: (dd/mm/yy)								
		/			/			

#### Giving and receiving peer support

We would like to find out how much peer support people are involved in, either giving or receiving peer support or both. We are interested in all different sorts of peer support, including face-to-face, telephone and online peer support.

Please answer the questions below about each sort of peer support that you have been involved in. As far as you can remember, please indicate the **number of times in the last month** that you have been involved in giving or receiving **each** sort of peer support.

	Giving support	Receiving support
Informal peer support		
(this is when peers actively seek or provide support to each		
other separately from any organised project)		

Peer support as part of an organised project	Giving support	Receiving support
a) One-to-one peer support		
(this might include mentoring, befriending, recovery coaching or		
peer support worker roles where one person supports another)		
b) Peer support pairs		
(this is 'mutual' one-to-one peer support where both people are		
supporting each other, e.g. co-counselling)		
c) Peer support groups		
(these are groups where all group members are supporting each		
other)		
d) Peer-led or facilitated groups		
(these are activity, support or self-management groups that are led		
or facilitated by a peer)		
e) Peer support networks		
(networks are where peers share contact information so that they		
can support each other or arrange to meet to provide support or take		
part in activities)		
f) Elefriends online peer support network		
g) Other online peer support		

# 4. What is the total number of different peer support projects you were involved with in

# the last month?



# 5. What were these projects called?

## Well-being

6. The next few pages include a number of short questionnaires about things that might change while taking part in more or less peer support.

### The Short Warwick-Edinburgh Mental Well-being Scale

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful:					
I've been feeling relaxed:					
I've been dealing with problems well:					
I've been thinking clearly:					
I've been feeling close to other people:					
I've been able to make up my own mind about things:					

# Herth Hope Index

**7.** The following questions ask about how hopeful you might feel about various aspects of life. Listed below are a number of statements. Read each statement and tick the box that describes **how much you agree with that statement right now.** 

	Strongly Disagree	Disagree	Agree	Strongly Agree
I have a positive outlook on life				
I have short and/or long range goals				
I feel all alone				
I can see possibilities in: the midst of difficulties				
I have a faith that gives me comfort				
I feel scared about my future				
I can recall happy/joyful times				
I have deep inner strength				
I am able to give and receive caring/love				
I have a sense of direction				
I believe that each day has potential				
I feel like my life has value and worth				

# Lubben Social Network Scale

Think back about the different people you might have been in touch with. This includes face-to-face, telephone and online communication.

# 8. FAMILY Considering the people related to you

Please choose the appropriate response for each item:

	0	1	2	3-4	5-8	9+
How many family members do you see or hear from <b>at least once a month</b> ?						
How many family members do you feel at ease with that you can talk about private matters?						
How many family members do you feel close to such that you could call on them for help?						

## 9. FRIENDS Considering all your friends...

	0	1	2	3-4	5-8	9+
How many friends do you see or hear from <b>at least once a</b> <b>month?</b>						
How many friends do you feel at ease with that you can talk about private matters?						
How many friends do you feel close to such that you could call on them for help?						

10. **NEIGHBOURS & ACQUAINTANCES** Considering all your neighbours and acquaintances

(people who you see or hear from that you might not consider to be friends)...

	0	1	2	3-4	5-8	9+
How many neighbours and acquaintances do you see or hear from <b>at least once a month?</b>						
How many neighbours and acquaintances do you feel at ease with that you can talk about private matters?						
How many neighbours and acquaintances do you feel close to such that you could call on them for help?						

# Mental Health Self Efficacy Scale

The next set of questions asks about how any mental health difficulties you might have experienced affect how confident you feel about everyday life. The questions refer to stress, anxiety or depression but please consider these questions in terms of *any* mental health difficulties that you might experience, however you describe them.

Please read each question and rate how confident you are that, **on an average day in the next month**, you will be able to do the following things.

# Rate from 1 to 10 where 1 = not at all confident, 10 = totally confident

On an average day in the next month, how confident are you that...

You can keep your stress, anxiety or depression from interfering with the things that you want to do?										
1	2	3	4	5	6	7	8	9	10	
You can do the different tasks and activities needed to manage your stress, anxiety or depression so as to reduce your need to see a doctor?										
1	2	3	4	5	6	7	8	9	10	
	You can do things other than just taking medicine to reduce how much your stress, anxiety or depression affects your everyday life?									
1	2	3	4	5	6	7	8	9	10	
You ca	an make	your day	ys at leas	st modei	rately en	joyable	?			
1	2	3	4	5	6	7	8	9	10	
You w	You will have moderate amounts of time where you do not experience stress, anxiety or depression?									
1	2	3	4	5	6	7	8	9	10	
You will be able to effectively manage any stress, anxiety or depression that you do experience?										
1	2	3	4	5	6	7	8	9	10	

## EuroQoL EQ5D

**12**. The following questions are about your general quality of life. We have included these questions both because we are interested to know how use of peer support might relate to quality of life, and also because measurement of quality of life is used in working out the cost benefits of different forms of support.

By placing a tick in **one box in each group** below, please indicate which statements best

# describe your own health state today.

#### 13. Mobility

Tick one	
	I have no problems in walking about
	I have some problems in walking about
	I am confined to bed

#### 14. Self-care

Tick one	
	I have no problems with self-care
	I have some problems washing or dressing myself
	I am unable to wash or dress myself

## 15. Usual Activities (e.g. work, study, housework, family or leisure activities)

Tick one	
	I have no problems with performing my usual activities
	I have some problems with performing my usual activities
	I am unable to perform my usual activities

# 16. Pain / Discomfort

Tick one	
	I have no pain or discomfort
	I have moderate pain or discomfort
	I have extreme pain or discomfort

# 17. Anxiety / Depression

Tick one	
	I am not anxious or depressed
	I am moderately anxious or depressed
	I am extremely anxious or depressed

18. To help people say how good or bad a health state is, we have drawn a scale on which the best state you can imagine is marked 10 and the worst state you can imagine is marked 1.

Please choose the appropriate response for each item:

How good or bad is your own health today?

(Worst) 1 2 3 4 5 6 7 8 9 10 (Bes	(Worst) 1	2	3	4	5	6	7	8	9	10 (Bes
-----------------------------------	-----------	---	---	---	---	---	---	---	---	---------

The above question is about your overall mental and physical health.

**19.** The final few pages include the extra questions we will ask every three months. These questions cover a wider range of issues such as employment, volunteering and training, health and social care services you might use, and other community activities.

It is really important that we collect this extra information so that we can work out how accessing peer support relates to your everyday life and if peer support has any impact on the wider costs of services people use.

# Participation in employment, volunteering, education and training

b) Paid or self-employed (part-time)

d) EIn work-related training

f) Not working due to illness

### How do you currently spend your time?

Please choose **all** that apply and complete the additional questions where relevant:

- a) Paid or self-employed (full-time)
- c) 🗉 Voluntary work (unpaid)\*
- e) 🗉 Unemployed
- g) 🗄 Retired

i) THomemaker/ housewife/ househusband j) TFamily caregiver

k) 🖾 Other: \_\_\_

\* Please do not include participation in the peer support programme when considering voluntary work

h) 🗄 Student

# Only answer questions 20 to 22 if you ticked a) or b) above:

20. Briefly describe your occupation

21. How many hours per week do you normally work?

22. Over the last 3 months how many days have you taken off work because of poor health?

# Only answer questions 23 to 25 if you ticked c) above:

23. Briefly describe your volunteering role

24. How many hours per week do you normally volunteer?

25. In the last 3 months how many hours of volunteering have you missed/not been able to attend because of poor health?

# Only answer questions 26 to 28 if you ticked d) or h) above:

26. Briefly say more about what you are studying and any qualifications you are working towards?

27. How many hours per week do you normally spend in formal education/training programmes?

28. In the last 3 months how many hours of education have you missed because of poor health?

# Only answer question 29 if you ticked e) or f) above:

29. How many weeks have you been unemployed in the last 3 months (Assume 13 weeks = 3 months)?

# This question can be answered by everyone

30. Please feel free to say anything else that you would like about your current employment situation

# Family and friends

We are interested in knowing how much help support with your mental health you normally receive from your family and friends.

**Over the last three months** in a typical week how many hours of help and support have you received from your family?

32. **Over the last three months** has anyone in your family chosen to take time off work to provide you with help and support?

Please choose **only one** of the following:

Yes No

33. **Over the last three months** in a typical week how many **hours** of help and support have you received from your friends?

34. **Over the last three months** have anyone of your friends chosen to take time off work to provide you with help and support?

Please choose **only one** of the following:

EYes ENo

35. Please feel free to say anything else that you would like to add about impacts on your

family and friends

#### Medication

It would also be very helpful to know about changes in your use of medication for your mental health over the last month.

Have you taken any prescription medications in the **previous month** related to your mental health? Please circle **only one** of the following: Yes INO

37. If yes, has your use of medication for mental health reasons changed over the last

# three months?

Please circle **only one** of the following:

Decreased Stayed the same Increased

#### Health and social care

#### **Hospital Inpatient Services**

We would like to know more about any overnight stays you have had in hospital and other medical facilities, for both mental health and non-mental health reasons. Please complete

the table on overnight stays over the last three months.

Please state 0 if you had no overnight stays.

	Total number of admissions <b>in last 3</b> <b>months</b>	Total number of nights spent in hospital <b>in last 3</b> <b>months</b>
Overnight stay for mental health problems		
Overnight stay for physical health problems		

Overnight stay related to pregnancy and childbirth	
Overnight stay including short-term residential care	

#### Other Visits to Hospital /Specialist Medical Unit Services

We would also like to know more about any other visits to hospital or other specialist medical unit that did not involve an overnight stay for both mental and non-mental health reasons **over the last three months**.

#### Please state 0 if you had no hospital visits during this time.

	Total number of visits / appointments in the last 3 months
Accident & Emergency visit (A&E) for mental health reasons	
Accident & Emergency visit (A&E) for physical health reasons	
Other hospital outpatient visits for mental health reasons	
Other hospital visit for a non-mental health service	

#### Use of community health and social care services

Please complete the table to show your use of community health and social care services **over the last three months.** (Please do not include any services provided in hospital). **Please leave blank if service not used during this time.** 

	Total number of contacts / appointments <b>in the</b>	Average duration of contacts
	last 3 months	(minutes)
Community Mental Health Team		

Crisis Resolution / Home Treatment Team	
Other Mental Health team	
Group-based counselling or talking therapy	
Individual counselling or talking therapy	
GP (incl telephone consultations & home visits)	
GP Practice Nurse (incl telephone consultations & home visits)	
Health Visitor	
Midwife	
Alternative / Complementary Medicine Therapist	
Home help / home care worker	
Day centre / social club	
Specialist supported employment services	
Recovery College	

Other community and faith-based groups	
Other (Please state):	

Please feel free to add any additional information you would like to add about these health and social care services

# Thank you for completing this survey.

### Appendix 3.3: Monthly Peer Support Log

### **Monthly Peer Support Log**

The *Peer Support Log* is designed to record the benefits of both giving and receiving peer support. We would like people to complete the *Peer Support Log* once a month so that we compare times when people choose to use more or less peer support.

The *Log* can be completed on a computer, phone or tablet, or by pen and paper. Please ask a member of your project or the evaluation team to help you fill in the *Log*.

#### Information and Log On

For a detailed information sheet about the *Peer Support Log* please ask a member of the research team for a copy of the Peer Support Information Sheet.

#### 1. To complete the *Log* please enter your 4 number Personal ID below:



If you have forgotten your Personal ID or have any questions about the *Peer Support Log* please contact the research team at <u>peersupport@sgul.ac.uk</u> or 020 8725 2785



### Giving and receiving peer support

We would like to find out how much peer support people are involved in, either giving or receiving peer support or both. We are interested in all different sorts of peer support, including face-to-face, telephone and online peer support.

Please answer the questions below about each sort of peer support that you have been involved in. As far as you can remember, please indicate the **number of times in the last month** that you have been involved in giving or receiving **each** sort of peer support.

	Giving support	Receiving support
Informal peer support		
(this is when peers actively seek or provide support to each		
other separately from any organised project)		

Peer support as part of an organised project	Giving support	Receiving support
a) One-to-one peer support	support	support
(this might include mentoring, befriending, recovery coaching or peer support worker roles where one person supports another)		
b) Peer support pairs		
(this is 'mutual' one-to-one peer support where both people are		
supporting each other, e.g. co-counselling)		
c) Peer support groups		
(these are groups where all group members are supporting each		
other)		
d) Peer-led or facilitated groups		
(these are activity, support or self-management groups that are led		
or facilitated by a peer)		
e) Peer support networks		
(networks are where peers share contact information so that they		
can support each other or arrange to meet to provide support or take		
part in activities)		
f) Elefriends online peer support network		
g) Other online peer support		

# 4. What is the total number of different peer support projects you were involved with in

the last month?


# 5. What were these projects called?

## Well-being

**6.** The next few pages include a number of short questionnaires about things that might change while taking part in more or less peer support.

## The Short Warwick-Edinburgh Mental Well-being Scale

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful:					
I've been feeling relaxed:					
I've been dealing with problems well:					
I've been thinking clearly:					
I've been feeling close to other people:					
I've been able to make up my own mind about things:					

# Herth Hope Index

**7.** The following questions ask about how hopeful you might feel about various aspects of life. Listed below are a number of statements. Read each statement and tick the box that describes **how much you agree with that statement right now.** 

	Strongly Disagree	Disagree	Agree	Strongly Agree
I have a positive outlook on life				
I have short and/or long range goals				
I feel all alone				
I can see possibilities in the midst of difficulties				
I have a faith that gives me comfort				
I feel scared about my future				
I can recall happy/joyful times				
I have deep inner strength				
I am able to give and receive caring/love				
I have a sense of direction				
I believe that each day has potential				
I feel like my life has value and worth				

## Lubben Social Network Scale

Think back about the different people you might have been in touch with. This includes face-to-face, telephone and online communication.

# 8. FAMILY Considering the people related to you

Please choose the appropriate response for each item:

	0	1	2	3-4	5-8	9+
How many family members do you see or hear from <b>at least once a month</b> ?						
How many family members do you feel at ease with that you can talk about private matters?						
How many family members do you feel close to such that you could call on them for help?						

# 9. FRIENDS Considering all your friends...

	0	1	2	3-4	5-8	9+
How many friends do you see or hear from <b>at least once a</b> <b>month?</b>						
How many friends do you feel at ease with that you can talk about private matters?						
How many friends do you feel close to such that you could call on them for help?						

10. **NEIGHBOURS & ACQUAINTANCES** Considering all your neighbours and acquaintances

(people who you see or hear from that you might not consider to be friends)...

	0	1	2	3-4	5-8	9+
How many neighbours and acquaintances do you see or hear from <b>at least once a month?</b>						
How many neighbours and acquaintances do you feel at ease with that you can talk about private matters?						
How many neighbours and acquaintances do you feel close to such that you could call on them for help?						

# Mental Health Self Efficacy Scale

The next set of questions asks about how any mental health difficulties you might have experienced affect how confident you feel about everyday life. The questions refer to stress, anxiety or depression but please consider these questions in terms of *any* mental health difficulties that you might experience, however you describe them.

Please read each question and rate how confident you are that, **on an average day in the next month**, you will be able to do the following things.

# Rate from 1 to 10 where 1 = not at all confident, 10 = totally confident

On an average day in the next month, how confident are you that...

You ca do?	an keep y	our stre	ess, anxie	ety or de	pressior	n from ir	nterferin	g with tl	ne things that you want to
1	2	3	4	5	6	7	8	9	10
	an do the educe ye					eded to	manage	your sti	ress, anxiety or depression so
1	2	3	4	5	6	7	8	9	10
	an do thi ssion aff	-	-		g medici	ne to re	duce ho	w much	your stress, anxiety or
1	2	3	4	5	6	7	8	9	10
You ca	an make	your day	ys at leas	st modei	rately en	joyable	?		
1	2	3	4	5	6	7	8	9	10
You w	ill have r	noderat	e amour	nts of tin	ne where	e you do	not exp	erience	stress, anxiety or depression?
1	2	3	4	5	6	7	8	9	10
You w	ill be abl	e to effe	ectively r	nanage a	any stres	ss, anxie	ty or de	pression	that you do experience?
1	2	3	4	5	6	7	8	9	10

# EuroQoL EQ5D

12. The following questions are about your general quality of life. We have included these questions both because we are interested to know how use of peer support might relate to quality of life, and also because measurement of quality of life is used in working out the cost benefits of different forms of support.

By placing a tick in **one box in each group** below, please indicate which statements best

# describe your own health state today.

## 13. Mobility

Tick one	
	I have no problems in walking about
	I have some problems in walking about
	I am confined to bed

#### 14. Self-care

Tick one	
	I have no problems with self-care
	I have some problems washing or dressing myself
	I am unable to wash or dress myself

# 15. Usual Activities (e.g. work, study, housework, family or leisure activities)

Tick one	
	I have no problems with performing my usual activities
	I have some problems with performing my usual activities
	I am unable to perform my usual activities

# 16. Pain / Discomfort

Tick one	
	I have no pain or discomfort
	I have moderate pain or discomfort
	I have extreme pain or discomfort

# 17. Anxiety / Depression

Tick one	
	I am not anxious or depressed
	I am moderately anxious or depressed
	I am extremely anxious or depressed

18. To help people say how good or bad a health state is, we have drawn a scale on which the best state you can imagine is marked 10 and the worst state you can imagine is marked 1.

Please choose the appropriate response for each item:

How good or bad is your own health today?

(Worst) 1	2	3	4	5	6	7	8	9	10 (Best)
-----------	---	---	---	---	---	---	---	---	-----------

The above question is about your overall mental and physical health.

Thank you for completing this survey.

# Table A4.1: Completion of logs split by region

							Logs com	pleted							
Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Q/M															
Suffolk	14/2	2/6	2/4	2/3	1/3	1/3	3/1	3/0	3/0	1/0	0/0	0/0	0/0	0/0	0/0
Coventry	42/8	9/12	5/12	8/7	4/7	4/6	2/8	3/6	3/4	4/2	4/0	0/1	0/0	0/0	0/0
Northamptonshire	54/15	23/30	23/12	14/6	5/4	3/2	1/3	2/1	3/0	1/0	1/0	0/0	0/0	0/0	0/0
Leeds	119/23	37/59	22/52	50/12	10/41	14/34	36/4	5/12	1/1	2/0	1/0	0/0	0/0	0/0	0/0
Blackpool	56/11	20/24	12/16	8/11	5/10	3/8	5/3	1/4	3/1	0/2	0/1	0/0	0/0	0/0	0/0
Southampton	39/3	3/23	9/14	13/5	8/7	8/1	8/0	2/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0
Plymouth	39/22	18/20	8/16	5/9	6/7	4/5	4/3	2/1	0/2	0/2	0/2	1/1	1/1	1/0	0/0
Middlesbrough	3/17	6/2	1/2	0/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0	0/0
Kensington & Chelsea	58/25	12/49	8/40	26/14	20/12	7/9	4/4	1/5	0/5	0/2	0/2	2/0	1/1	0/1	1/1
Elefriends	95/4	10/38	6/25	16/4	9/6	5/4	4/2	4/2	2/2	3/0	2/0	2/0	0/0	0/0	0/0
Total	519/130	140/263	96/193	142/71	68/97	49/72	67/28	23/31	15/15	11/8	8/5	5/2	2/2	1/1	1/1

Row		Suffolk	Coventry	Northamp	Leeds	Blackpool	Southamp	Plymouth	Middlesbr	Kensington	Elefriends	Total
		n=17	n=42	tonshire n=77	N=156	n=69	ton n=43	n=56	ough n=18	& Chelsea n=87	n=138	n=703
Age at registration	18-24	1 (5.9)	1 (2.4)	0 (0.0)	32 (20.8)	25 (36.2)	18 (41.9)	5 (8.9)	1 (5.6))	4 (4.7)	36 (26.1)	123 (17.6)
U U	25-34	3 (17.6)	8 (19.0)	13 (16.9)	22 (14.3)	7 (10.1)	7 (16.3)	15 (26.8)	5 (27.8)	11 (12.8)	36 26.1)	127 (18.1)
N (%)	35-44	3 (17.6)	11 (26.2)	16 (20.8)	31 (20.1)	4 (5.8)	6 (14.0)	9 (16.1)	6 (33.3)	20 (23.3)	30 (21.8)	136 (19.4)
	45-54	4 (23.5)	12 (28.6)	18 (23.4)	37 (24.0)	16 (23.2)	10 (23.3)	13 (23.2)	3 (16.7)	26 (30.2)	19 (13.6)	158 (22.5)
	55-64	6 (35.3)	9 (21.4)	20 (26.0)	22 (14.3	13 (18.8)	2 (4.7)	9 (16.1)	2 (11.1)	16 (18.6)	13 (8.7)	111 (15.9)
	65+	0 (0.0)	1 (2.4)	10 (13.0)	10 (6.5)	4 (5.8)	0 (0.0)	5 (8.9)	1 (5.6)	9 (10.5)	5 (3.6)	45 (6.4)
	MISSING				2					1		3
Gender	Male	7 (41.2)	22 (52.4)	36 (46.8)	71 (46.1)	15 (21.7)	23 (53.5)	30 (53.6)	1 (5.6)	34 (39.5)	14 (10.1)	253 (36.0)
N (%)	Female	10 (58.8)	20 (47.6)	40 (51.9)	82 (53.2)	53 (76.8)	20 (46.5)	26 (46.4)	17 (94.4)	52 (60.5)	123 (89.1)	443 (63.0)
	Prefer not to say	0 (0.0)	0 (0.0)	1 (1.3)	1 (0.6)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (0.3)
	Other	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.4)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.7)	2 (0.3)
	MISSING				2					1		3
Transgende	Yes	0 (0.0)	0 (0.0)	0 (0.0)	3 (1.9)	1 (1.4)	1 (2.34)	1 (1.8)	0 (0.0)	0 (0.0)	0 (0.0)	6 (0.9)
r history	No	17 (100.0)	41. (97.6)	72 (96.0)	150 (97.4)	64 (92.8)	40 (95.2)	52 (92.9)	12 (66.7)	86 (100.0)	17 (99.3)	671 (95.4)
N (%)	Not sure	0 (0.0)	0 (0.0)	2 (2.7)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (5.6)	0 (0.0)	1 (0.7)	4 (0.6)
	Prefer not to say	0 (0.0)	1 (2.4)	1 (1.3)	1 (0.6)	4 (5.8)	1 (2.4)	2 (3.6)	5 (27.8)	0 (0.0)	0 (0.0)	15 (2.1)

Table A4.2: Descriptive statistics of participants registered to Side-by-Side evaluation

	MISSING			2	2		1	1		1		7
Sexual	Heterosexual	17 (100.0)	22 (52.4)	65 (89.0)	134 (88.2)	60 (87.0)	32 (74.4)	38 (67.9)	13 (72.2)	79 (91.9)	98 (71.0)	559 (80.2)
orientation	Lesbian/gay	0 (0.0)	13 (31.0)	1 (1.4)	3 (2.0)	3 (4.3)	3 (7.0)	6 (10.7)	0 (0.0)	4 (4.7)	9 (6.5)	42 (6.0)
N (%)	Bisexual	0 (0.0)	4 (9.5)	4 (5.5)	7 (4.6)	2 (2.9)	4 (9.3)	4 (7.1)	0 (0.0)	2 (2.3)	17 (12.3)	46 (6.6)
	Prefer not to say	0 (0.0)	2 (4.8)	3 (4.1)	5 (3.3)	3 (4.3)	3 (7.0)	7 (12.5)	4 (22.2)	1 (1.2)	7 (5.1)	35 (5.0)
	Other	0 (0.0)	1 (2.4)	0 (0.0)	3 (2.0)	1 (1.4)	1 (2.3)	1 (1.8)	1 (5.6)	0 (0.0)	7 (5.1)	15 (2.2)
	MISSING			4	4					1		9
Location	City/large town	5 (29.4)	20 (47.6)	16 (20.8)	125 (83.9)	17 (24.6)	22 (51.2)	37 (66.1)	0 (0.0)	84 (97.7)	65 (45.7)	389 (55.3)
N (%)	Small-medium sized town	8 (47.1)	19 (45.2)	48 (62.3)	20 (13.4)	47 (68.1)	17 (39.5)	12 (21.4)	17 (94.4)	1 (1.2)	56 (40.6)	245 (34.9)
	Village/rural	4 (23.5)	3 (7.1)	13 (16.9)	4 (2.7)	5 (7.2)	4 (9.3)	7 (12.5)	1 (5.6)	1 (1.2)	19 (13.8)	61 (8.7)
	MISSING				7					1		8
	nental health ໌)	4 (23.5)	19 (45.2)	25 (32.5)	62 (39.7)	25 (36.2)	27 (62.8)	18 (32.1)	8 (44.4)	30 (34.5)	62 (44.9)	280 (39.8)
services N (%		4 (23.5)	19 (45.2) 6.6 (0-30,	25 (32.5)	62 (39.7) 5.2 (-1 -	25 (36.2)	27 (62.8)	18 (32.1) 8.2 (0-25,	8 (44.4)	30 (34.5)	62 (44.9)	280 (39.8)
services N (% Mean years	6)											
services N (% Mean years service use (l	6) mental health Min-max, S.D.)	13.3 (4-	6.6 (0-30,	12.1 (1-	5.2 (-1 -	10.7 (0-	6.2 (1-24,	8.2 (0-25,	3.3 (1-10,	13.6 (1-71,	4.8 (0-30,	7.5 (-1 – 71, 8.8)
services N (% Mean years service use (I Learning disa Long-term pl	6) mental health Min-max, S.D.) ability N (%) hysical health	13.3 (4- 30, 12.3)	6.6 (0-30, 7.5)	12.1 (1- 30, 8.2)	5.2 (-1 - 21, 5.2)	10.7 (0- 45, 10.7)	6.2 (1-24, 6.2)	8.2 (0-25, 8.5)	3.3 (1-10, 2.9)	13.6 (1-71, 15.2)	4.8 (0-30, 6.3)	7.5 (-1 – 71, 8.8) 103 (14.7
Services N (% Mean years Service use (I Learning disa	6) mental health Min-max, S.D.) ability N (%) hysical health	13.3 (4- 30, 12.3) 0 (0.0)	6.6 (0-30, 7.5) 4 (9.5)	12.1 (1- 30, 8.2) 10 (13.0)	5.2 (-1 - 21, 5.2) 17 (10.9)	10.7 (0- 45, 10.7) 21 (30.4)	6.2 (1-24, 6.2) 13 (30.2)	8.2 (0-25, 8.5) 17 (30.4)	3.3 (1-10, 2.9) 0 (0.0)	13.6 (1-71, 15.2) 5 (5.7)	4.8 (0-30, 6.3) 16 (11.6)	7.5 (-1 –

White Eastern European	0 (0.0)	2 (4.8)	3 (4.0)	1 (0.6)	1 (1.4)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.2)	1 (0.7)	9 (1.3)
White Other	0 (0.0)	0 (0.0)	2 (2.67	1 (0.6)	0 (0.0)	2 (4.7)	0 (0.0)	0 (0.0)	9 (10.8)	4 (2.9)	18 (2.6)
Arab	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (4.8)	1 (0.7)	5 (0.7)
Black/Black British Caribbean	0 (0.0)	2 (4.8)	1 (1.3)	16 (10.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (4.8)	0 (0.0)	23 (3.3)
Black/Black British African	0 (0.0)	5 (11.9)	6 (8.0)	6 (3.8)	0 (0.0)	0 (0.0)	0 (0.0)	2 (11.1)	4 (4.8)	0 (0.0)	23 (3.3)
Black/Black British other	0 (0.0)	1 (2.4)	0 (0.0)	8 (5.1)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.7)	10 (1.4)
Asian/Asian British Bangladeshi	0 (0.0)	0 (0.0)	0 (0.0)	6 (3.8)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	6 (0.9)
Asian/Asian British Indian	0 (0.0)	3 (7.1)	0 (0.0)	5 (3.2)	2 (2.9)	0 (0.0)	0 (0.0)	0 (0.0)	3 (3.6)	0 (0.0)	13 (1.9)
Asian/Asian British Pakistani	0 (0.0)	1 (2.4)	1 (1.3)	23 (14.7)	3 (4.3)	0 (0.0)	0 (0.0)	11 (61.1)	0 (0.0)	0 (0.0)	39 (5.6)
Asian/Asian British Chinese	0 (0.0)	0 (0.0)	0 (0.0)	3 (1.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	3 (0.4)
Asian/Asian British other	0 (0.0)	0 (0.0)	0 (0.0)	6 (3.8)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.2)	0 (0.0)	7 (1.0)
Mixed White & Black African	0 (0.0)	0 (0.0)	3 (4.0)	0 (0.0)	0 (0.0)	1 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.7)	5 (0.7)
Mixed White & Asian	0 (0.0)	0 (0.0)	1 (1.3)	0 (0.0)	0 (0.0)	1 (2.3)	0 (0.0)	0 (0.0)	2 (2.4)	1 (0.7)	5 (0.7)
Mixed White & Black Caribbean	0 (0.0)	0 (0.0)	0 (0.0)	6 (3.8)	0 (0.0)	1 (2.3)	1 (1.8)	0 (0.0)	2 (2.4)	1 (0.7)	11 (1.6)

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MISSING			2						4		6	
Other	0 (0.0)	1 (2.4)	1 (1.3)	2 (1.3)	2 (2.9)	0 (0.0)	2 (3.6)	2 (11.1)	11 (12.6)	4 (2.9)	25 (3.6)	
Middle Eastern	0 (0.0)	0 (0.0)	0 (0.0)	3 (1.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (1.1)	0 (0.0)	4 (0.6)	
Eritrean	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	4 (4.6)	0 (0.0)	4 (0.6)	
Somalian	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	20.0 (23.0)	0 (0.0)	20 (2.8)	
Mixed other	0 (0.0)	0 (0.0)	0 (0.0)	2 (1.3)	0 (0.0)	0 (0.0)	1 (1.8)	0 (0.0)	0 (0.0)	0 (0.0)	3 (0.4)	

Table A4.3: Baseline descriptive statistics for outcome measures, employment and clinical variables

Row		Suffolk n=16	Coventry n=49	Northamp tonshire	Leeds N=143	Blackpool n=67	Southamp ton n=42	Plymouth n=61	Middlesbr ough	Kensington & Chelsea	Elefriends n=98	Total n=649
		11-10	11-49	n=70	N-145	11-07			n=20	n=83	11-30	11-049
Admitted to hospital in previous 3 months for mental health	Yes	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.8)	1 (1.9)	3 (8.6)	0 (0.0)	0 (0.0)	1 (1.7)	7 (7.4)	13 (2.6)
	MISSING	2	8	12	23	14	7	22	17	25	3	137
Taken medication in previous month for mental health	Yes	6 (42.9)	17 (56.7)	24 (44.4)	44 (53.0)	28 (56.0)	23 (67.6)	19 (48.7)	1 (50.0)	17 (53.1)	68 (71.6))	247 (57.0)
	MISSING	2	19	16	60	17	8	22	20	51	3	216
Employment	Full-time	4 (28.6)	2 (12.2)	11 (20.4)	15 (18.1)	1 (20)	2 (5.9)	13 (33.3)	0 (0.0)	7 (21.9)	20 (21.1)	79 (18.2)
status*	Part-time	4 (28.6)	3 (10.0)	8 (14.8)	9 (10.8)	5 (10.0)	7 (16.7)	4 (10.3)	0 (0.0)	5 (15.6)	10 (10.5)	55 (12.7)

	Voluntary	6 (42.9)	5 (16.7)	19 (35.2)	31 (37.3)	13 (26.0)	13 (38.2)	9 (23.1)	0 (0.0)	9 (28.1)	11 (11.6)	116 (26.8)
	Work-related training	1 (7.1)	0 (0.0)	1 (1.9)	2 (2.4)	0 (0.0)	2 (5.9)	0 (0.0)	0 (0.0)	1 (3.1)	1 (1.1)	8 (1.8)
	Unemployed	1 (7.1)	8 (26.7)	10 (18.5)	20 (24.1)	16 (32.0)	11 (32.4)	12 (30.8)	0 (0.0)	3 (9.4)	15 (15.8)	96 (22.2)
	Not working due to illness	1 (7.1)	5 (16.7)	12 (22.2)	27 (32.5)	14 (28.0)	9 (26.5)	11 (28.2)	0 (0.0)	8 (25.0)	30 (31.6)	117 (27.0)
	Retired	1 (7.1)	2 (6.7)	6 (11.1)	11 (13.3)	3 (6.0)	0 (0.0)	4 (10.3)	0 (0.0)	4 (12.5)	6 (6.3)	37 (8.5)
	Student	2 (14.3)	3 (10.0)	5 (9.3)	8 (9.6)	4 (8.0)	9 (26.5)	0 (0.0)	0 (0.0)	4 (12.5)	19 (20.0)	55 (12.7)
	Homemaker	0 (0.0)	4 (13.3)	7 (13.0)	8 (9.6)	5 (10.0)	6 (17.6)	3 (7.7)	0 (0.0)	3 (9.4)	13 (13.7)	49 (11.3)
	Family	0 (0.0)	4 (13.5)	7 (15.0)	0 (9.0)	5 (10.0)	0(17.0)	5(7.7)	0 (0.0)	5 (5.4)	15 (15.7)	45 (11.5)
	caregiver	1 (7.1)	2 (6.7)	6 (11.1)	9 (10.8)	2 (4.0)	1 (2.9)	0 (0.0)	0 (0.0)	2 (6.3)	7 (7.4)	30 (6.9)
	MISSING	2	19	16	60	17	8	22	18	51	3	216
Wellbeing	Mean (S.D.)	22.2 (2.9)	21.6 (4.6)	21.2 (4.3)	21.1 (5.3)	19.7 (4.5)	21.3 (4.5)	20.5 (4.8)	21.8 (3.1)	21.2 (4.3)	17.9 (3.6)	20.5 (4.6)
	MISSING	0	0	2	0	0	0	0	0	0	0	2
Lubbens Social Network Subscales	Family Mean (S.D.)	7.3 (2.7)	6.3 (4.0)	5.6 (3.3)	5.7 (3.5)	5.4 (3.9)	6.2 (3.3)	5.4 (3.4)	2.5 (2.1)	5.2 (3.2)	4.7 (2.5)	5.5 (3.3)
	Friends Mean (S.D.)	10.1 (3.0)	6.9 (3.8)	6.6 (3.9)	6.8 (3.7)	6.9 (4.0)	7.3 (4.2)	4.9 (3.4)	7.0 (4.2)	5.5 (3.0)	5.1 (3.6)	6.2 (3.8)
	Neighbours Mean (S.D.)	5.9 (3.1)	3.8 (3.5)	3.3 (3.6)	3.7 (3.4)	3.1 (3.4)	3.6 (3.3)	2.9 (2.6)	5.5 (0.7)	2.8 (3.1)	2.7 (2.7)	3.3 (3.2)
	MISSING	0	11	1	54	6	1	0	18	33	0	124
Herth Hope Index	Mean (S.D.)	36.3 (4.6)	33.4 (6.3)	32.6 (6.9)	32.7 (6.7)	31.9 (6.7)	31.4 (5.3)	31.6 (6.7)	40.5 (2.1)	32.2 (6.4)	27.9 (5.9)	31.6 (6.6)
	MISSING	0	11	2	55	6	1	0	18	33	1	127

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Mental Health Self	Mean (S.D)	43.3	33.9	33.7	34.3	30.9	33.9	33.9	48.5	32/8	25.6	32.3
Efficacy Scale		(11.8)	(14.4)	(13.5)	(13.4)	(13.0)	(12.0)	(14.3)	(10.6)	(12.7)	(11.3)	(13.4)
	MISSING	0	11	2	57	6	1	0	18	33	1	129

				Northampt			Southampt		Middlesbor	Kensington &	£	
		Suffolk	Coventry	onshire	Leeds	Blackpool	on	Plymouth	ough	Chelsea	Elefriends	
-	n	16	49	70	143	67	42	61	20	83	98	649
Informal peer support	Giving	11 (68.8)	20 (40.8)	33 (47.1)	52 (36.4)	33 (49.3)	24 (57.1)	24 (39.3)	9 (45.0)	46 (55.4)	65 (66.3)	317 (48.8)
	Receiving	11 (68.8)	26 (53.1)	42 (60.0)	63 (44.1)	42 (64.2)	26 (61.9)	30 (49.2)	11 (55.0)	29 (39.9)	67 (68.4)	348 (53.6)
One-to-one peer support	Giving	4 (25.0)	15 (30.6)	24 (34.3)	45 (31.5)	24 (35.8)	16 (38.1)	8 (13.1)	8 (40.0)	14 (16.9)	24 (24.5)	182 (28.0)
	Receiving	4 (25.0)	18 (36.7)	29 (41.4)	37 (25.9)	27 (40.3)	21 (50.0)	19 (31.1)	8 (40.0)	17 (20.5)	31 (31.6)	211 (32.5)
Peer support pairs	Giving	8 (50.0)	8 (16.3)	15 (21.4)	32 (22.4)	20 (29.9)	11 (26.2)	5 (8.2)	7 (35.0)	8 (9.6)	12 (12.2)	126 (19.4))
	Receiving	9 (56.3)	13 (26.5)	21 (30.0)	28 (19.6)	25 (37.3)	15 (35.7)	8 (13.1)	12 (60.0)	6 (7.2)	12 (12.2)	149 (23.0)
Peer support groups	Giving	9 (56.3)	19 (38.8)	30 (42.9)	48 (33.6)	30 (44.8)	13 (31.0)	18 (29.5)	7 (35.0)	40 (48.2)	23 (23.5)	237 (36.5)
	Receiving	9 (56.3)	25 (51.0)	46 (65.7)	52 (36.4)	33 (49.3)	17 (40.5)	32 (52.5)	10 (50.0)	34 (41.0)	24 (24.5)	282 (43.5)
Peer-led or facilitated	Giving	5 (31.3)	17 (34.7)	22 (31.4)	57 (39.9)	24 (35.8)	14 (33.3)	18 (29.5)	6 (30.0)	12 (14.5)	12 (12.2)	187 (28.8)
groups	Receiving	6 (37.5)	24 (49.0)	34 (48.6)	65 (45.5)	35 (52.2)	23 (54.8)	27 (44.3)	9 (45.0)	18 (21.7)	16 (16.3)	257 (39.6)
Peer support networks	Giving	9 (56.3)	10 (20.4)	17 (24.3)	21 (14.7)	14 (20.9)	14 (33.3)	6 (9.8)	6 (30.0)	13 (15.7)	14 (14.3)	124 (19.1)
	Receiving	10 (62.5)	12 (24.5)	24 (34.3)	4 (2.8)	18 (26.9)	13 (31.0)	11 (18.0)	6 (30.0)	10 (12.0)	16 (16.3)	141 (21.7)
Elefriends online peer	Giving	0 (0.0)	4 (8.2)	4 (5.7)	4 (2.8)	4 (6.0)	3 (7.1)	4 (6.6)	3 (15.0)	3 (3.6)	77 (78.6)	106 (16.3)
support network	Receiving	1 (6.3)	7 (14.3)	10 (14.3)	4 (2.8)	5 (7.5)	3 (7.1)	3 (4.9)	3 (15.0)	4 (4.8)	77 (78.6)	117 (18.0)
Other online peer support	Giving	1 (6.3)	8 (16.3)	7 (10.0)	6 (4.2)	10 (14.9)	3 (7.1)	5 (8.2)	4 (20.0)	6 (7.2)	21 (21.4)	71 (10.9)
	Receiving	1 (6.3)	10 (20.4)	8 (11.4)	2 (1.4)	11 (16.4)	5 (11.9)	6 (9.8)	4 (20.0)	5 (6.0)	17 (17.3)	69 (10.6)

Table A4.4: Baseline use of peer support by region, values are frequency (%)

Outcome	Change in Peer Support	Cha	nge in number of type	es of PS - G	iving	Chan	ge in number of types	s of PS - Rec	eiving	Cha	nge in number of PS	projects atte	nded
	Peer Support	n	Mean (95% Cl)	p-value	ES	n	Mean (95% CI)	p-value	ES	n	Mean (95% CI)	p-value	ES
Wellbeing	Decreased	353	-0.16 (-0.70, 0.38)	0.005		413	-0.04 (-0.57, 0.48)	0.113		250	0.73 (0.19, 1.26)	0.040	0.17
	Same	706	0.23 (-0.22, 0.69)	_		604	0.31 (-016, 0.78)	_		505	0.05 (-0.41, 0.52)	-	
	Increased	339	0.84 (0.28, 1.40)	_	0.20	381	0.55 (0.00, 1.09)	_		249	0.13 (-0.41, 0.67)	-	
Self-efficacy	Decreased	289	-0.58 (-2.24, 1.08)	0.252		337	0.21 (-1.34, 1.77)	0.668		191	1.20 (-0.49, 2.89)	0.252	
	Same	434	0.44 (-1.03, 1.91)	_		375	0.76 (-0.77, 2.29)	_		323	-0.43 (-1.88, 1.04)	-	
	Increased	285	1.12 (-0.61, 2.84)	_		296	-0.15 (-1.87, 1.57)	_		193	0.20 (-1.49, 1.89)	-	
Норе	Decreased	283	-0.63 (-1.34, 0.09)	< 0.001		334	-0.47 (-1.13, 0.20)	0.002		187	0.40 (-0.32, 1.13)	0.661	
	Same	431	0.20 (-0.44, 0.85)	_		369	0.26 (-0.40, 0.92)	_		318	0.07 (-0.58, 0.71)	-	
	Increased	281	1.00 (0.27, 1.74)	_	0.20	292	0.92 (0.20, 1.65)	_	0.19	192	0.11 (-0.61, 0.83)	-	
Contact	Decreased	289	-0.01 (-0.29, 0.27)	0.319		337	0.03 (-0.23, 0.29)	0.586		191	0.38 (0.09, 0.66)	0.050	0.17
with family	Same	434	0.05 (-0.18, 0.28)	_		375	0.06 (-0.18, 0.30)	_		323	-0.07 (-0.29, 0.16)	-	
	Increased	285	0.28 (-0.01, 0.57)	_		296	0.22 (-0.07, 0.52)	_		193	0.00 (-0.28, 0.29)	-	
Contact	Decreased	289	-0.33 (-0.72, 0.06)	0.053		337	-0.21 (-0.59, 0.16)	0.222		191	0.27 (-0.13, 0.67)	0.039	
with friends	Same	434	-0.01 (-0.37, 0.35)	_		375	0.16 (-0.22, 0.53)	_		323	-0.08 (-0.43, 0.28)	-	
	Increased	285	0.22 (-0.19, 0.63)	_		296	-0.10 (-0.51, 0.30)	-		193	-0.31 (-0.71, 0.09)	-	
	Decreased	289	-0.04 (-0.42, 0.35)	0.837		337	0.03 (-0.34, 0.37)	0.943		191	0.26 (-0.13, 0.65)	0.160	
	Same	434	-0.01 (-0.35, 0.34)			375	0.03 (-0.33, 0.40)	_		323	-0.08 (-0.42, 0.27)	-	

### Table A4.5: Association between change in overall peer support access and change in outcomes

Contact with neighbours	Increased	285	0.09 (-0.30, 0.49)		296	0.04 (-0.43, 0.36)		193	-0.13 (-0.52, 0.26)		
Health	Decreased	359	-0.08 (-0.34, 0.19)	0.141	418	0.00 (-0.25, 0.26)	0.494	254	0.20 (-0.06, 0.46)	0.049	
status	Same	710	0.07 (-0.14, 0.29)	-	612	0.16 (-0.07, 0.38)	_	511	-0.12 (-0.34, 0.10)		
	Increased	345	0.25 (-0.03, 0.52)	-	384	0.01 (-0.25, 0.27)	-	250	0.16 (-0.10, 0.43)		

Outcome	Change in Peer		Change in use of informa	al PS - Giving		Cł	nange in in use of informal	PS - Receiving	g
	Support	n	Mean (95% CI)	p-value	ES	n	Mean (95% CI)	p-value	ES
Wellbeing	Decreased	297	0.52 (-0.54, 0.64)	0.060		316	-0.06 (-0.67, 0.54)	0.554	
	Same	505	-0.12 (-0.67, 0.43)	_		481	0.17 (40, 0.73)		
	Increased	314	0.60 (0.00, 1.20)	_		312	0.26 (-0.36, 0.87)		
Self-efficacy	Decreased	230	-0.15 (-1.98, 1.68)	0.728		255	-0.16 (-1.96, 1.64)	0.615	
	Same	359	0.40 (-1.27, 2.06)	_		326	0.89 (-0.90, 2.68)		
	Increased	267	0.68 (-1.12, 2.49)	_		270	0.14 (-1.69, 1.97)		
Норе	Decreased	227	-0.09 (0.80, 0.62)	0.487		251	-0.48 (-1.15, 0.19)	0.146	
	Same	355	-0.06 (-0.66, 0.55)	_		323	0.34 (-0.29, 0.98)		
	Increased	265	0.40 (-0.29, 1.08)	_		268	0.20 (-0.48, 0.87)		
Contact with family	Decreased	230	0.14 (-0.17, 0.44)	0.011		255	-0.00 (-0.29, 0.29)	0.124	
	Same	359	-0.17 (-0.41, 0.07)	_		326	-0.02 (-0.27, 0.23)		
	Increased	267	0.40 (0.11, 0.69)	_	0.17	270	0.34 (0.05, 0.63)		
Contact with friends	Decreased	230	-0.24 (-0.66, 0.17)	0.001		255	-0.27 (-0.67, 0.13)	0.006	
	Same	359	-0.21 (-0.59. 0.17)	_		326	-0.12 (-0.52, 0.28)		
	Increased	267	0.56 (0.15, 0.96)	_	0.19	270	0.45 (0.05, 0.86)		0.16
Contact with	Decreased	230	0.06 (-0.37, 0.48)	0.863		255	-0.08 (-0.49, 0.33)	0.230	
neighbours	Same	359	-0.04 (-0.44, 0.36)	_		326	0.26 (-0.15, 0.67)		

### Table A4.6: Association between change in informal peer support access and change in outcomes

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	Increased	267	0.78 (-0.34, 0.50)		270	-0.11 (-0.52, 0.31)	
Health status	Decreased	300	-0.2 (-0.30, 0.26)	0.596	319	-0.12 (-0.40, 0.16)	0.134
	Same	509	0.12 (-0.13, 0.38)		489	0.12 (-0.13, 0.38)	
	Increased	319	0.13 (-0.16, 0.42)		313	0.20 (-0.09, 0.49)	

Outcome	Change in Peer		Change in use of OTO/Pai	rs PS - Giving		Ch	ange in in use of OTO/Pai	rs PS - Receivi	ng
	Support	n	Mean (95% CI)	p-value	ES	n	Mean (95% CI)	p-value	ES
Wellbeing	Decreased	216	-0.06 (-0.72, 0.60)	0.010		230	-0.09 (-0.74, 0.57)	0.587	
	Same	645	-0.05 (-0.56, 0.46)	_		634	0.23 (-0.28, 0.75)	_	
	Increased	265	0.87 (0.23, 1.51)	_	0.21	260	0.23 (-0.43, 0.89)	_	
Self-efficacy	Decreased	165	0.24 (-1.91, 2.39)	0.894		184	-0.02 (-2.08, 2.03)	0.080	
	Same	495	0.43 (-1.10, 2.05)			471	1.09 (-0.52, 2.70)	_	
	Increased	205	-0.11 (-2.16, 1.94)			210	-1.53 (-3.63, 0.58)	_	
Норе	Decreased	161	-0.33 (-1.15, 0.50)	0.018		180	-0.90 (-1.69, -0.11)	0.014	-0.18
	Same	494	-0.20 (-0.75, 0.35)	_		469	0.24 ( -0.31, 0.79)	_	
	Increased	201	0.96 (0.19, 1.73)	_	0.19	207	0.53 (-0.26, 1.33)	_	
Contact with family	Decreased	165	0.18 (-0.17, 0.53)	0.087		184	-0.09 (-0.43, 0.25)	0.248	
	Same	495	-0.07 (-0.28, 0.14)			471	0.04 (-0.17, 0.25)	_	
	Increased	205	0.34 (0.01, 0.66)	_		210	0.31 (-0.03, 0.64)	_	
Contact with friends	Decreased	165	-0.21 (-0.69, 0.28)	0.105		184	-0.06 (-0.52, 0.41)	0.252	
	Same	495	-0.05 ( -0.41, 0.31)			471	-0.08 (-0.44, 0.28)		
	Increased	205	0.36 ( -0.10, 0.82)			210	0.33 (-0.15, 0.80)	_	
Contact with	Decreased	165	-0.20 (-0.69, 0.29)	0.374		184	0.04 (-0.42, 0.51)	0.869	
neighbours	Same	495	-0.08 (-0.30, -0.46)			471	-0.00 (-0.38, 0.38)		

### Table A4.7: Association between change in one-to-one/pair peer support access and change in outcomes

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	Increased	205	0.15 (-0.32, 0.61)		210	0.13 (-0.35, 0.60)		
Health status	Decreased	221	-0.12 (-0.44, 0.20)	0.104	236	-0.24 (-0.55, 0.07)	0.025	
	Same	648	0.06 (-0.18, 0.30)		639	0.24 (0.00, 0.47)	_	0.11
	Increased	269	0.27 (-0.04, 0.58)		261	-0.03 (-0.35, 0.29)	_	

Outcome	Change in Peer	r Change in use of Group PS - Giving					Change in in use of Group	PS - Receiving	
	Support	n	Mean (95% CI)	p-value	ES	n	Mean (95% CI)	p-value	ES
Wellbeing	Decreased	287	0.06 (-0.54, 0.66)	<0.001		324	0.30 (-0.29, 0.88)	0.445	
	Same	463	-0.37 (-0.93, 0.20)			407	-0.07 (-0.65, 0.50)		
	Increased	379	0.85 (0.29, 1.42)	_	0.20	397	0.30 (-0.26, 0.87)		
Self-efficacy	Decreased	228	-0.70 (-2.53, 1.13)	0.039		246	0.15 (-1.63, 1.93)	0.970	
	Same	343	32 (-2.02, 1.39)			303	0.09 (-1.71, 1.88)		
	Increased	294	1.73 (0.05, 3.51)	_	0.14	318	0.34 (-1.42, 2.09)		
Норе	Decreased	225	-0.51 (-1.22, 0.20)	0.008		243	-0.20 (-0.88. 0.49)	0.378	
	Same	340	-0.16 (-0.79, 0.47)			301	-0.06 (-0.73, 0.62)		
	Increased	291	0.80 (0.013, 1.48)		0.16	314	0.38 (-0.28, 1.04)		
Contact with family	Decreased	228	0.07 (-0.23, 0.37)	0.074		246	-0.02 (-0.30, 0.27)	0.763	
	Same	343	-0.13 (-0.38, 0.12)			303	0.08 (-0.19, 0.34)		
	Increased	294	0.30 (0.02, 057)			318	0.13 (-0.14, 0.40)		
Contact with friends	Decreased	228	0.06 (-0.37, 0.48)	0.012		246	0.18 (-0.24, 0.59)	0.039	
	Same	343	-0.31 (-0.71, 0.08)	_		303	-0.33 (-0.75, 0.09)		
	Increased	294	0.42 (0.01, 0.83)	_	0.15	318	0.29 (-0.12, 0.69)		
Contact with	Decreased	228	0.05 (-0.38, 0.47)	0.956		246	0.08 (-0.33, 0.50)	0.682	
neighbours	Same	343	-0.02 (-0.42, 0.39)	_		303	0.08 (-0.34, 0.49)		

### Table A4.8: Association between change in group peer support access and change in outcomes

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	Increased	294	-0.05 (-0.37, 0.47)		318	-0.09 (-0.49, 0.32)	
Health status	Decreased	292	-0.04 (-0.33, 0.25)	0.067	327	0.01 (-0.27, 0.28)	0.322
	Same	466	-0.04 (-0.31, 0.22)		410	0.22 (-0.05, 0.49)	
	Increased	383	0.28 (0.01, 0.55)		327	-0.02 (-0.28, 0.25)	

Outcome	Change in Peer		Change in use of online	PS - Giving		Change in in use of online	PS - Receiving		
	Support	n	Mean (95% CI)	p-value	ES	n	Mean (95% CI)	p-value	ES
Wellbeing	Decreased	149	-0.24 (-1.06, 0.58)	0.432		163	-0.32 (-1.12, 0.48)	0.264	
	Same	850	0.25 (-0.25, 0.74)	_		834	0.29 (-0.20, 0.79)	_	
	Increased	127	-0.22 (-1.09, 0.65)	_		128	-0.30 (-1.19, 0.59)	_	
Self-efficacy	Decreased	143	-0.97 (-3.34, 1.40)	0.055		152	-1.14 (-3.49, 1.21)	0.013	
-	Same	604	0.90 (-0.57, 2.37)	_		598	1.10 (-0.40, 2.60)	_	
	Increased	118	-2.30 (-4.84. 0.24)	_		114	-3.12 (-5.81, -0.43)	_	-0.25
Норе	Decreased	142	-0.45 (-1.37, 0.47)	0.484		151	-0.71 (-1.62, 0.19)	0.145	
	Same	596	0.15 (-0.36, 0.66)	_		590	0.20 (-0.32, 0.71)	_	
	Increased	118	0.11 (-0.88, 1.10)	_		114	0.32 (-0.73, 1.37)	_	
Contact with family	Decreased	143	-0.20 (-0.58, 0.19)	0.220		152	-0.14 (-0.52, 0.24)	0.418	
	Same	604	0.08 (-0.11, 0.27)	_		598	0.08 (-0.11, 0.27)	_	
	Increased	118	0.30 (-0.12, 0.72)	_		114	0.23 (-0.21, 0.68)	_	
Contact with friends	Decreased	143	-0.18 (-0.72, 0.37)	0.562		152	-0.07 (-0.61, 0.47)	0.828	
	Same	604	0.03 (-0.31, 0.36)	_		598	0.02 (-0.33, 0.36)	_	
	Increased	118	0.17 (-0.42, 0.75)	_		114	0.14 (-0.48, 0.76)	_	
Contact with	Decreased	143	-0.17 (-0.71, 0.37)	0.303		152	-0.26 (-0.79, 0.28)	0.418	
neighbours	Same	604	0.01 (-0.34, 0.36)			598	0.12 (-0.23, 0.48)		

### Table A4.9: Association between change in online peer support access and change in outcomes

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	Increased	118	0.30 (-0.28, 0.87)		114	-0.10 (-0.70, 0.51)		
Health status	Decreased	152	-0.01 (-0.41, 0.39)	0.165	166	-0.05 (-0.43, 0.34)	0.037	
	Same	859	0.14 (0.08, 0.36)		843	0.17 (-0.05, 0.39)	_ ·	
	Increased	127	-0.30 (-0.73. 0.14)		128	-0.44 (-0.88, 0.01)		

Table A4.10: Association between change in peer support access and change in outcomes – subgroup	
analyses	

Outcome	Change in Peer	Subgroup		Change in number of ty	pes of PS - G	iving
	Support		n	Mean (95% CI)	p-value	ES
Health status	Decreased	Male	139	-0.24 (-0.66, 0.18)	0.041	
		Female	207	-0.02 (-0.37, 0.33)	_	
	Same	Male	297	0.01 (-0.32, 0.35)	_	
		Female	384	0.10 (-0.20, 0.39)		
	Increased	Male	145	0.48 (0.07, 0.90)	_	0.21
		Female	191	-0.07 (-0.45, 0.30)	_	
Subgroup = Ha	s a learning disabili	ty				
				Change in number of p	rojects atten	ded
Self-efficacy	Decreased	No	148	0.72 (-1.17, 2.60)	0.027	
		Yes	41	2.78 (-0.96, 6.52)	_	
	Same	No	286	-0.88 (-2.40, 0.65)	_	
		Yes	34	1.41 (-2.90, 5.72)	_	
	Increased	No	157	0.87 (-0.97, 2.70)	_	
		Yes	34	-3.40 (-7.39, 0.60)	_	
Subgroup = Ha	s a physical disabili	ty				
				Change in number of ty	pes of PS - G	iving
Health status	Decreased	No	217	0.17 (-0.17, 0.51)	0.036	
		Yes	132	-0.58 (-1.00, -0.16)	_	-0.25
	Same	No	485	0.13 (-0.13, 0.39)	_	
		Yes	202	-0.04 (-0.42, 0.35)	_	
	Increased	No	207	0.54 (0.19, 0.89)		0.24
		Yes	130	-0.39 (-0.84, -0.06)		-0.17
Subgroup = Us	es formal mental h	ealth services				
				Change in number of ty	pes of PS - G	iving
Self-efficacy	Decreased	No	169	2.03 (-0.08, 4.14)	0.006	
		Yes	113	-4.93 (-7.51, -2.34)	_	0.40
					_	

226

0.96 (-0.99, 2.91)

Same

No

		Yes	199	-0.13 (-2.23, 1.98)		
	Increased	No	179	1.59 (-0.54, 3.72)	-	
		Yes	98	0.12 (-2.76, 3.00)	-	
				Change in number of typ	pes of PS - Gi	ving
Contact with	Decreased	No	169	0.15 (-0.36, 0.65)	0.003	
friends		Yes	113	-1.10 (-1.72, -0.47)	_	-0.38
	Same	No	226	0.06 (-0.42, 0.53)	_	
		Yes	199	-0.10 (-0.63, 0.43)	_	
	Increased	No	179	0.10 (-0.42, 0.61)	_	
		Yes	98	0.38 (-0.30, 1.07)	_	
			(	Change in number of typ	pes of PS - Gi	ving
Contact with	Decreased	No	169	0.45 (-0.05, 0.95)	0.003	
neighbours		Yes	113	-0.65 (-1.27, -0.04)	_	-0.23
	Same	No	226	0.35 (-0.12, 0.82)	_	
		Yes	199	-0.41 (-0.93, 0.11)	_	
		105				
	Increased	No	179	-0.00 (-0.51, 0.50)	-	
	Increased				-	
Subgroup = Ag		No	179	-0.00 (-0.51, 0.50)	-	
	e Change in Peer	No	179 98	-0.00 (-0.51, 0.50)	- - rojects atten	
Subgroup = Ag Outcome	e	No Yes	179 98	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07)	- ojects atten p-value	ded ES
Outcome Contact with	e Change in Peer	No Yes	98	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr	-	
	e Change in Peer Support	No Yes Age group	179 98 	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl)	p-value	ES
Outcome Contact with	e Change in Peer Support	No Yes Age group 18-34	179 98 <u>n</u> 52	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80)	p-value	ES
Outcome Contact with	e Change in Peer Support	No           Yes           Age group           18-34           35-54	179 98 	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38)	p-value	ES
Outcome Contact with	e Change in Peer Support Decreased	No Yes Age group 18-34 35-54 55+	179 98 	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97)	p-value	ES
Outcome Contact with	e Change in Peer Support Decreased	No           Yes           Age group           18-34           35-54           55+           18-34	179 98 <b>n</b> 52 80 57 75	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37)	p-value	ES
Outcome Contact with	e Change in Peer Support Decreased	No Yes Age group 18-34 35-54 55+ 18-34 35-54	179 98 <b>n</b> 52 80 57 75 143	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37) 0.05 (-0.49, 0.60)	p-value	ES
Outcome Contact with	e Change in Peer Support Decreased Same	No Yes Age group 18-34 35-54 55+ 18-34 35-54 55+	179 98 7 52 80 57 75 143 102	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37) 0.05 (-0.49, 0.60) -0.34 (-0.98, 0.31)	p-value	ES
Outcome Contact with	e Change in Peer Support Decreased Same	No Yes Age group 18-34 35-54 55+ 18-34 35-54 55+ 18-34	179 98 7 52 80 57 75 143 102 51	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37) 0.05 (-0.49, 0.60) -0.34 (-0.98, 0.31) 0.18 (-0.58, 0.94)	p-value	ES 0.36
Outcome Contact with	e Change in Peer Support Decreased Same	No           Yes           Age group           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54	179 98 7 52 80 57 75 143 102 51 81 81 59	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37) 0.05 (-0.49, 0.60) -0.34 (-0.98, 0.31) 0.18 (-0.58, 0.94) -0.87 (-1.50, -0.23)	<b>p-value</b> 0.010	ES 0.36
Outcome Contact with	e Change in Peer Support Decreased Same	No           Yes           Age group           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54           55+           18-34           35-54	179 98 7 52 80 57 75 143 102 51 81 81 59	-0.00 (-0.51, 0.50) 0.40 (-0.27, 1.07) Change in number of pr Mean (95% Cl) 1.04 (0.27, 1.80) -0.25 (-0.88, 0.38) 0.24 (-0.48, 0.97) -0.34 (-1.05, 0.37) 0.05 (-0.49, 0.60) -0.34 (-0.98, 0.31) 0.18 (-0.58, 0.94) -0.87 (-1.50, -0.23) -0.07 (-0.78, 0.65)	<b>p-value</b> 0.010	ES 0.36

35-54       339      02 (-0.67, 0.63)         55+       178       0.76 (-0.12, 1.65)				
35-54         339        02 (-0.67, 0.63)           55+         178         0.76 (-0.12, 1.65)           eased         18-34         88         0.79 (-0.37, 1.96)           35-54         152         0.71 (-0.12, 1.54)		55+	97	0.37 (-0.66, 1.40)
55+         178         0.76 (-0.12, 1.65)           eased         18-34         88         0.79 (-0.37, 1.96)           35-54         152         0.71 (-0.12, 1.54)	Same	18-34	161	0.35 (-0.60, 1.29)
eased 18-34 88 0.79 (-0.37, 1.96) 35-54 152 0.71 (-0.12, 1.54)		35-54	339	02 (-0.67, 0.63)
35-54 152 0.71 (-0.12, 1.54)		55+	178	0.76 (-0.12, 1.65)
	Increased	18-34	88	0.79 (-0.37, 1.96)
55+ 90 1.02 (-0.03, 2.07)		35-54	152	0.71 (-0.12, 1.54)
		55+	90	1.02 (-0.03, 2.07)

Subgroup = Loo	cation					
Outcome	Change in	Location		Change in number of p	rojects attend	led
	Peer Support		n	Mean (95% CI)	p-value	ES
Health status	Decreased	City	144	0.22 (-0.12, 0.56)	0.046	
		Medium town	78	-0.02 (-0.49, 0.46)	_ ·	
		Rural	27	0.33 (-0.50, 1.17)	<u> </u>	
	Same	City	356	-0.07 (-0.33, 0.20)	<u> </u>	
		Medium town	105	-0.27 (-0.72, 0.17)		
		Rural	29	-0.33 (-1.21, 0.55)	<u> </u>	
	Increased	City	142	-0.01 (-0.36, 0.33)	_ ·	
		Medium town	78	0.53 (0.05, 1.01)	_ ·	0.23
		Rural	24	-0.61 (-1.48, 0.26)	_ ·	
			Cł	nange in number of type	es of PS - Rece	eiving
Self-efficacy	Decreased	City	160	0.27 (-1.88, 2.41)	0.054	
		Medium town	125	0.01 (-2.60, 2.62)		
		Rural	46	-0.27 (-4.51, 3.98)		

209

125

32

151

105

31

0.35 (-1.72, 2.41)

1.06 (-1.45, 3.56)

2.26 (-2.51,7.03)

1.81 (-0.56, 4.18)

-3.75 (-6.60, -0.90)

1.10 (-3.84, 6.04)

Same

Increased

City

Rural

City

Rural

Medium town

Medium town

-0.30

Outcome	Change in	Location		Change in number of ty	pes of PS - Gi	ving		
	Peer Support		n	Mean (95% CI)	p-value	ES		
Contact with	Decreased	Group	196	-0.03 (-0.52, 0.46)	0.018			
friends		One to One	37	-1.54 (-2.68, -0.48)	_	-0.54		
		Elefriends	46	-0.84 (-1.81, 0.12)	_			
	Same	Group	271	0.25 (-0.20, 0.70)	_			
		One to One	94	-0.47 (-1.31, 0.36)	_			
		Elefriends	58	-0.50 (-1.45, 0.45)	_			
	Increased	Group	200	0.17 (-0.33, 0.66)	_			
		One to One	37	0.90 (-0.16, 1.94)	_			
		Elefriends	42	-0.01 (-1.16, 1.15)	_			
Subgroup = Etl	nnicity							
Outcome	Change in	Ethnicity		Change in number of p		orojects attended		
	Peer Support		n	Mean (95% CI)	p-value	ES		
Self-efficacy	Decreased	White	168	0.42 (-1.39, 2.23)	0.007			
		Black	8	3.78 (-4.03, 11.59)	_			
		Asian	6	7.84 (-1.03, 16.71)	_			
		Other	5	11.45 (1.35, 21.55)	_	0.92		
	Same	White	278	-0.36 (-1.93, 1.20)	_			
		Black	19	-2.57 (-8.45, 3.31)	_			
		Asian	12	1.68 (-5.66, 9.01)	_			
		Other	10	-7.31 (-15.13, 0.51)	_			
	Increased	White	167	-0.23 (-2.03, 1.58)	_			
		Black	14	3.26 (-2.90, 9.41)	_			
		Asian	4	-7.11 (-17.89, 3.66)	_			
		Other	5	6.73 (-3.38, 16.83)	_			
Норе	Decreased	White	165	0.20 (-0.56, 0.96)	0.002			
		Black	7	-0.68 (-4.10, 2.74)	-			
		Asian	6	4.81 (1.17, 8.44)	-	0.99		
		Other	5	2.12 (-2.06, 6.30)	-			
	Same	White	275	-0.36 (-1.02, 0.31)	_			

	Black	18	4.48 (1.95, 7.01)		0.90
	Asian	12	0.69 (-2.43, 3.80)	_	
	Other	10	-0.06 (-3.38, 3.27)	_	
Increased	White	166	-0.05 (-0.80, 0.71)	_	
	Black	14	1.62 (-0.95, 4.19)	_	
	Asian	4	-4.24 (-8.62, 0.14)	-	
	Other	5	2.53 (-1.65, 6.71)	_	
Decreased	White	168	0.25 (-0.05, 0.56)	0.024	
	Black	8	1.81 (0.42, 3.20)	_	0.79
	Asian	6	0.54 (-1.07, 2.15)	-	
	Other	5	1.29 (-0.47, 3.05)	-	
Same	White	278	-0.14 (-0.38, 0.10)	-	
	Black	19	-0.24 (-1.14, 0.67)	_	
	Asian	12	0.82 (-0.31, 1.96)	_	
	Other	10	-0.13 (-1.38, 1.11)	_	
Increased	White	167	-0.04 (-0.35, 0.26)	_	
	Black	14	1.08 (0.03, 2.14)	_	0.47
	Asian	4	0.17 (-1.80, 2.14)	_	
	Other	5	-2.69 (-4.45, -0.93)	_	-1.17
Decreased	White	168	0.24 (-0.19, 0.67)	0.043	
	Black	8	1.96 (0.14, 3.78)	_	0.68
	Asian	6	0.00 (-2.07, 2.07)	_	
	Other	5	-0.05 (-2.44, 2.34)	-	
Same	White	278	0.04 (-0.35, 0.42)	_	
				_	-0.57
	Black	19	-1.64 (-3.07, -0.20)		
	Black Asian	19 12	-1.64 (-3.07, -0.20) -1.56 (-3.34, 0.23)	_	
				_	
Increased	Asian	12	-1.56 (-3.34, 0.23)	-	
Increased	Asian Other	12 10	-1.56 (-3.34, 0.23) -0.09 (-2.01, 1.84)	- - -	
Increased	Asian Other White	12 10 167	-1.56 (-3.34, 0.23) -0.09 (-2.01, 1.84) -0.22 (-0.65, 0.21)	- - -	-0.89
	Decreased Same Increased Decreased	AsianOtherIncreasedWhiteBlackAsianOtherDecreasedWhiteBlackAsianOtherSameWhiteBlackAsianOtherIncreasedWhiteBlackAsianOtherIncreasedWhiteBlackAsianOtherIncreasedWhiteBlackAsianOtherIncreasedWhiteBlackAsianOtherOtherDecreasedWhiteBlackAsianOtherDecreasedWhite	Asian12Other10IncreasedWhite166Black14Asian4Other5DecreasedWhite168Black8Asian6Other5SameWhite278Black19Asian12Other10IncreasedWhite167Black14Asian4Other5DecreasedWhite167Black14Asian4Other5DecreasedWhite168Black8Asian4Other5DecreasedWhite168Black8Asian6Other5DecreasedWhite168Black8Asian6Other5	Asian         12         0.69 (-2.43, 3.80)           Other         10         -0.06 (-3.38, 3.27)           Increased         White         166         -0.05 (-0.80, 0.71)           Black         14         1.62 (-0.95, 4.19)           Asian         4         -4.24 (-8.62, 0.14)           Other         5         2.53 (-1.65, 6.71)           Decreased         White         168         0.25 (-0.05, 0.56)           Black         8         1.81 (0.42, 3.20)           Asian         6         0.54 (-1.07, 2.15)           Other         5         1.29 (-0.47, 3.05)           Same         White         278         -0.14 (-0.38, 0.10)           Black         19         -0.24 (-1.14, 0.67)           Asian         12         0.82 (-0.31, 1.96)           Other         10         -0.13 (-1.38, 1.11)           Increased         White         167         -0.04 (-0.35, 0.26)           Black         14         1.08 (0.03, 2.14)         Asian           Asian         4         0.17 (-1.80, 2.14)         Other           Other         5         -2.69 (-4.45, -0.93)         Decreased           White         168         0.24 (-0.19, 0.67) <td< td=""><td><math display="block">\begin{tabular}{ c c c c c c c c c c c c c c c c c c c</math></td></td<>	$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$

Change in number of types of PS - Giving

Норе	Decreased	White	242	-0.97 (-1.73, -0.21)	<0.001	-0.20
		Black	14	4.56 (1.67, 7.45)	-	0.92
		Asian	15	-1.63 (-4.85, 1.52)	_	
		Other	6	0.19 (-3.83, 4.20)	_	
	Same	White	362	-0.10 (-0.78, 0.58)	-	
		Black	33	2.93 (0.41, 5.44)	-	0.59
		Asian	11	0.89 (-3.14, 4.91)	_	
		Other	12	1.52 (-2.11, 5.15)	-	
	Increased	White	241	0.84 (0.07, 1.61)	-	0.17
		Black	11	-4.59 (-8.88, -0.29)	_	-0.92
		Asian	10	5.58 (1.84, 9.31)	-	1.12
		Other	10	1.32 (-2.89, 5.53)	-	
Contact with	Decreased	White	246	-0.03 (-0.32, 0.27)	<0.001	
family		Black	15	-0.22 (-1.39, 0.96)	-	
		Asian	15	0.90 (-0.40, 2.19)	_	
		Other	6	-1.14 (-2.73, 0.46)	-	
	Same	White	364	0.04 (-0.20, 0.28)	-	
		Black	33	0.11 (-0.68, 0.90)	-	
		Asian	11	0.26 (-1.21, 1.73)	_	
		Other	12	-0.95 (-2.33, 0.42)	_	
	Increased	White	243	0.05 (-0.26, 0.35)	_	
		Black	12	5.29 (3.55, 7.03)	_	2.30
		Asian	10	0.72 (-0.87, 2.31)	-	
		Other	11	1.15 (-0.44, 2.74)	-	
			Cł	ange in number of type	s of PS - Red	eiving
Wellbeing	Decreased	White	309	0.05 (-0.55, 0.65)	0.005	
		Black	41	1.53 (-0.54, 3.60)	-	
		Asian	38	-2.58 (-4.17, -0.99)	_	-0.61
		Other	16	-0.18 (-2.52, 2.17)	_	
	Same	White	329	0.29 (-0.31, 0.89)	-	
		Black	113	1.91 (0.80, 3.03)	-	0.45
		Asian	113	-1.01 (-2.23, 0.20)	_	

		Other	27	-1.48 (-3.54, 0.57)		
	Increased	White	270	0.48 (-0.16, 1.13)	_	
		Black	42	0.94 (-0.55, 2.44)	_	
		Asian	33	0.04 (-1.63, 1.72)	_	
		Other	24	0.14 (-2.02, 2.30)	_	
Норе	Decreased	White	289	-0.67 (-1.40, 0.05)	0.039	
		Black	14	3.61 (0.39, 6.83)	_	0.73
		Asian	16	-1.49 (-4.60, 1.63)	_	
		Other	9	0.41 (-3.18, 4.00)	-	
	Same	White	307	-0.02 (-0.73, 0.69)	_	
		Black	33	1.87 (-1.00, 4.73)	-	
		Asian	10	1.86 (-3.45, 7.17)	_	
		Other	6	0.87 (-3.61, 5.35)	_	
	Increased	White	249	0.55 (-0.23, 1.33)	_	
		Black	11	2.48 (-1.08, 6.04)	_	1.20
		Asian	10	5.98 (2.19, 9.77)	_	
		Other	13	2.36 (-1.57, 6.28)	_	

*Table A4.11: Association between change in peer support access and change in outcomes – for specific subsamples* 

Elefriends on	ly						
Outcome	Change in Peer	Change in number of types of PS - Giving					
	Support	n	Mean (95% CI)	p-value	ES		
Норе	Decreased	46	-0.69 (-2.25, 0.87)	0.029			
	Same	58	-0.61 (-2.16, 0.93)				
	Increased	42	1.99 (0.08, 3.90)	·	0.40		
		Ch	ange in number of types	of PS - Receiv	ving		
Норе	Decreased	49	-1.36 (-2.83, 0.10)	0.024			
	Same	52	0.27 (-1.29, 1.84)				
	Increased	45	1.52 (-0.32, 3.36)				
		(	Change in number of pro	ojects attende	d		
	Decreased	24	0.69 (0.06, 1.33)	0.021	0.30		

Contact with family	Same	55	-0.40 (-0.82, 0.03)		
таппту	Increased	19	-0.03 (-0.77, 0.71)		
Leeds only					
		Change in number of types of PS - Giving			
Self-efficacy	Decreased	40	1.02 (-3.08, 5.13)	0.045	
	Same	59	-3.62 (-7.26, 0.01)		
	Increased	46	1.57 (-2.37, 5.52)		

#### Appendix 5.1: Draft 1 Core principles and values - following consultation work

**Universal characteristics of Peer support** – we considered these characteristics to be core, to or underpin all peer support, and without these characteristics the service or support could not be considered peer support.

#### 1. Shared Lived Experience

- Peers will all have experienced mental health difficulties
- These experiences will be unique to the peer and to their personal circumstances, however there is a willingness to share elements of this experience with others in peer support.
- The sharing of experiences may be very specific in relation to a particular mental health difficulty, community or activity. E.g. asian women's peer support group, group peer support for people with depression, walking group.

#### 2. Mutuality

- All peers are involved in giving and receiving support, sharing experiences and encouraging others
- The giving and receiving of support may fluctuate over time in response to a peer's mental health or other life circumstances

#### 3. Purpose

- The peer support has a defined reason for existing
- This purpose guides its activities
- All peers are aware of the purpose and agree to work towards that aim

**Values** – We considered these as overarching qualities that peer support should have, while maintaining respect for diversity and difference. These values formed the basis of a basic understanding about how peers may conduct themselves when involved in peer support, to ensure that peer support embodies these qualities

#### 1. Inclusive

- An attitude of acceptance of peers as they are (from others)
- Respecting each peer's individual differences and uniqueness
- Warm and caring approach to other peers
- Peers feel they can be themselves and are not required to put up a front

#### 2. Empathy

- Understanding what it feels like for other peers, without them having to personally explain their life story
- Feeling of being understood without having to explain one's mental health history
- Feeling of being understood without analysis or judgement
- Seeking commonalities of experience, rather than differences

### 3. Equality

- There are equal opportunities to give and receive support, to talk and listen
- Responsibilities for the group are shared amongst all peers
- Decisions are made collectively through a democratic process

### 4. Valuing experience

- The mental health experiences that peers share are explicitly valued by themselves, and other peers and any organisation involved in supporting the peers.
- Through sharing, peers recognise their experiences as a form of expertise with a positive outcome.

#### 5. Being Human

- Peers are motivated by compassion a genuine interest and commitment to the wellbeing of others
- Peers work together to produce a culture of companionship which lessens feelings of isolation
- Peer support enables a culture of belonging to a group with a positive identity

**Principles** – We considered these to be guiding rules that peers could use to 'run' their peer support. For peer support to be effective these principles needed to be upheld.

#### 1. Peer Ownership

- Peers have the freedom to make their own choices about their involvement in peer support, this includes joining, participation and length of commitment
- Peers have the space and opportunity to reflect on, make independent decisions about, and take personal responsibility for their mental health
- Peers feel they can be can be unwell and still contribute

# 2. Feeling safe

- Feeling safe to talk openly about one's mental health the good, bad and ugly
- Ground rules are set by and understood by all peers
- Peer support is held in a space that is easily accessible and comfortable to all
- Peer support is funded sufficiently, ensuring on-going consistency of support
- All peers maintain confidentiality of the group/relationship
- Confidentiality may have to be broken to protect individual or a group in the circumstances where there is a significant risk of harm
- Peers who consistently use homophobic/racist/stigmatizing/ abusive language, or who makes other peers feel unsafe through their behaviour, may be asked to leave by a group-decision of remaining peers

# 3. Flexibility

- The way peer support operates in any given context can be adapted or modified to meet the needs of the peers involved
- Peer support is flexible and person-centred/ responsive to needs of individual peers
- Peer involvement happens at peer's own pace

- Peers may drop in and out of support, being mindful to uphold the groups agreed ground rules
- Peers would not be excluded from support on basis of failure to attend

#### 4. Active sharing

- Peers actively share their personal experiences of mental health, service use, and overcoming everyday difficulties
- By being open, peers encourage other peers to feel they may be able to overcome difficulties and build on their own strengths and resources
- Peers demonstrate ways of coping using their own resources in a positive way which can inspire hope and optimism for other peers
- Peers enable each other to develop skills that can be used in paid work

### 5. Support

- Practical help such as sharing lifts, providing refreshments
- Emotional support expressed through active listening, reassuring or commiserating responses
- Peers supporting each other to discover and achieve their goals