Lived Experience Influence and Participation Policy: Ensuring that people with mental health problems drive all that we do

Summary

- This policy sets out Mind’s principles of lived experience influence and participation that should inform the work of all Mind staff.
- The policy explains why lived experience influence and participation is important and the importance of ensuring opportunities are accessible to a diverse range of people.
- Payment information outlining who we pay, for what and how is included in this policy.
- The policy should be read in conjunction with the Engagement Toolkit. The Toolkit provides practical guidance and templates to support Mind staff to deliver engagement in their day-to-day work.

Policy agreed on: 23rd March 2017

By: Quality and Safeguarding group

Review due: March 2018
Contents page

1. About this policy………………………………………………………………………………p3
2. Why lived experience influence and participation is important...............p5
3. Payment..............................................................................................................p6
4. Who takes part....................................................................................................p10
5. Monitoring.........................................................................................................p10
6. How....................................................................................................................p12
7. Support...............................................................................................................p13
8. Resources...........................................................................................................p15

Appendix 1 - Participation at Mind – Diagram.................Intranet – Toolkit Tab
1. **About this policy**

1.1 We are here to provide advice and support to anyone experiencing a mental health problem and to campaign to improve mental health services, raise awareness and promote understanding.

To do that effectively, it is essential that a deep understanding of the needs and experiences of people with mental health problems drives everything that we do and that, wherever we can, we actively seek opportunities for people with experience of mental health problems to lead and guide our work. Of course, this includes using our own personal experience, where we have it.

It should be noted that much of our resilience work is based on the assumption that we want to prevent people developing mental health problems. There will be times when we need the insights of a particular group e.g. students, African Caribbean men, women with experience of perinatal period in order to understand how to engage with them meaningfully, regardless of whether or not they have a mental health problem. Under these circumstances this policy will also apply.

People’s experience can take many different forms. As we plan, develop and implement our work, it is vitally important that we actively consult, discuss, meet with, research, involve, listen to and understand the views and opinions of as wide a range of people with experience of mental health problems as we can.

1.2 Mind defines *Lived experience influence and participation* as:

> 'The development and promotion of opportunities in order that a diverse range of people, with lived experience of a mental health problem, influence and participate in our work. This recognises that people want to take part in a variety of different ways and there is not a ’one size fits all’ approach.‘

**Lived experience influence** – Initiatives and activities that sit within this category give people with lived experience the opportunity to shape and develop our work; this includes what is prioritised and how it is planned, delivered and evaluated. In other words people are influencing decision making, this could be through completing a survey, taking part in a focus group, contributing to decision-making on an advisory group or leading a project.

**Lived experience participation** – Initiatives and activities that are in this category give people with lived experience the opportunity to work alongside us in a practical way to achieve our aims. People might volunteer at an event sharing their experience of mental health problems, share their stories as part of a training session, support out online campaigns.
**Lived experience leadership** – This relates to the skills, experience, confidence and networks that people can develop through influencing and participation activities. Every influencing and participation activity at Mind should support individuals to develop their leadership skills in some way. The aim is that everyone has an opportunity to grow through their influencing and participation experience at Mind which supports their wellbeing, career development and ability to effectively contribute to other mental health work nationally and locally.

Other related terms include involvement, co-production, co-design – see The Engagement Toolkit for more information on these concepts.

We have moved from the use of the word engagement to influencing and participation as the latter two are more specific and the former is often used more broadly in the areas of communication and fundraising.

*Please see appendix 1 for a visual representation of ways people can participate in Mind’s work.*

There are other ways for people to participate in Mind’s work; these opportunities are open to people who do and don’t have lived experience of mental health problems. Areas include research, volunteering, campaigning and fundraising. These are included in appendix 1 however for further information please read the relevant Mind policy.

Influence and participation permeates everything we do. For example, many of the people who work or volunteer for us and the people involved in governing and representing Mind (our trustees and patrons, for example) have personal experience of living with mental health problems.

1.3 It is not enough to rely on our own experience and the experience of those around us. Everybody’s experience is different and we must actively seek out opportunities to engage with as wide a range of people as we can. By working together in this way, we will make Mind more representative and more effective.

1.4 This policy explains why we enable / empower people to influence and participate in our work and who should take part. It will also signpost you to resources to support you to do this. It is written to explain our ethos of influence and participation to employees of Mind and to everyone with a mental health problem who wishes to use their experience to influence the work of Mind and to work alongside us.
2. **Why is this important?**

2.1 Influence and participation must be part of our organisational DNA. It is all of our responsibility: as employees and volunteers. Simply put, if what you do affects people with mental health problems you can’t do it effectively unless you widely engage with people with mental health problems. It is every bit as integral to our work as complying with regulations, properly managing budgets and delivering high quality projects.

Influence and participation not only brings enormous benefits to Mind, it also provides benefits to those who work alongside us.

<table>
<thead>
<tr>
<th><strong>Benefits to Mind</strong></th>
<th><strong>Benefits to people</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaningfully engaging people in our work ensures it is informed by a broad range of experiences and will effectively meet diverse needs.</td>
<td>Validates the experiences people have had and values this in order to makes improvements</td>
</tr>
<tr>
<td>Our projects and services will be more effective at meeting the needs of a wide range of people.</td>
<td>Helps people to practice existing skills and develop new ones, such as public speaking, leading and contributing to meetings and editing/reviewing documents.</td>
</tr>
<tr>
<td>Mind becomes more representative of the diverse audiences that influence our work – this can be seen in the way we look, speak, and the methods we use</td>
<td>Taking part helps people to be more effective in their everyday lives and to be more able to contribute and feel connected to their local communities and contribute to other national work.</td>
</tr>
<tr>
<td>Our advice will be more insightful and more likely to benefit those who receive it.</td>
<td>Sharing and talking about experience helps people to meet others with similar experience, to make more sense of their experiences and develop their views.</td>
</tr>
<tr>
<td>Our information will be more useful to the people who receive it and easier to understand.</td>
<td>Feel valued and respected and challenging self-discrimination.</td>
</tr>
<tr>
<td>Our campaigning will be backed by better evidence and will ring true with more people.</td>
<td>Our projects and services, information, advice and campaigning will more effectively meet their needs</td>
</tr>
<tr>
<td>Our fundraising will demonstrate more clearly how donations transform more lives.</td>
<td></td>
</tr>
</tbody>
</table>


Our organisation will have more credibility with the general public, government and with funders.

Our staff and volunteers will be more connected to the everyday issues of living with a mental health problem.

Our staff and volunteers will become more familiar with issues of multiple disadvantage and will be more confident in addressing intersectional discrimination.

3. Payment

3.1 We are able to pay people who share their expertise to influence our plans or who contribute expertise to the work we deliver. [Please see the table below for more detail on the types of activities where we are able to pay]

3.2 As it is our policy to make payments to people with lived experience, it is essential that all teams ensure that payments are appropriately budgeted for within their programme budgets as part of our financial planning process. We advise a budget line is allocated to this and money phased as appropriate.

3.3 Sometimes it is appropriate to employ consultants with lived experience to complete work on behalf of Mind. This is usually when a piece of work needs someone with specific skills and experience. This person will complete the work independently. Examples include a lived experience expert chairing a conference or process, or undertaking a specific piece of research or consultation.

The skill level of people working with Mind in this way needs to be higher and experience in the relevant area more extensive than would be required for regular activities. Therefore Mind contracts with individuals on a consultancy basis. Fees are payable via eRequest once an invoice, including a purchase order, for the agreed amount has been received. This should be after completion of work.

The table below states when and how much we are able to pay people.
## Payment table

<table>
<thead>
<tr>
<th>Influence</th>
<th>Examples:</th>
<th>Payment:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Discussion / focus groups, information reviews, user testing (in person), recruitment process (short listing &amp; panel), interviews, survey’s (these are likely to take less than 1.5hrs and no travel will be required)</td>
<td>Less than 1.5hrs – expenses only&lt;br&gt;1.5 – 3 hrs - £25&lt;br&gt;3.5 – 5 hrs - £50&lt;br&gt;5.5 – 7 hrs - £100&lt;br&gt;Travel is remunerated; staff to book in advance where possible&lt;br&gt;Accommodation if length of journey requires this&lt;br&gt;Subsistence costs in line with Mind’s allowable expenses e.g. Breakfast, lunch, dinner&lt;br&gt;&lt;b&gt;No payment is due&lt;/b&gt; if the initiative or activity took less than 1.5hrs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participation</td>
<td>Examples: Speaking to the media, taking part in our campaigning work, Time to Change Champion on database, being a trustee, attending an event, photoshoot</td>
<td>Payment:&lt;br&gt;No payment&lt;br&gt;Travel is remunerated; staff to book in advance where possible&lt;br&gt;Accommodation if length of journey requires this&lt;br&gt;Subsistence costs in line with Mind’s allowable expenses e.g. Breakfast, lunch, dinner</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteers</td>
<td>Examples: Administrative role, data entry, community events volunteers, retail role in our shops, carrying out tasks that don’t relate to lived experience</td>
<td>Payment:&lt;br&gt;No Payment&lt;br&gt;Please see the Volunteer policy for full details on required remuneration of expenses</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional engagement expertise - consultants</td>
<td>Examples: Advisory group&lt;br&gt;Steering / working group, Influence &amp; Participation Coach, Lived experience / Peer researcher</td>
<td>Payment: £200&lt;br&gt;£230 dependent on skills and level of experience needed. There may be occasions where a higher rate of pay is required, this should not exceed £400. Please consult with Mind Engagement Manager for support in deciding on the correct fee.&lt;br&gt;A flat rate can be defined for specific pieces of work, this should be discussed with the Influence &amp; Participation Manager during planning.</td>
</tr>
<tr>
<td>Training</td>
<td>Example:</td>
<td>Payment:</td>
</tr>
<tr>
<td>----------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td></td>
<td>Independently leading development of and delivering training</td>
<td>£400 per day</td>
</tr>
<tr>
<td></td>
<td>Delivering training (lead or co-trainer)</td>
<td>£200 per day (both) Travel, accommodation and subsistence where relevant</td>
</tr>
<tr>
<td></td>
<td>Contributing your story to training session</td>
<td>Always check with the training department &amp; Engagement manager before commencing, this is a guide only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Influence and participation fee</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research</th>
<th>Example:</th>
<th>Payment:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Participating in research</td>
<td>No payment – An incentive can be offered</td>
</tr>
<tr>
<td></td>
<td>Planning and designing research / peer researcher</td>
<td>E.g. £20 gift voucher for taking part</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Please see Research policy for more information</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Travel is remunerated; staff to book in advance where possible</td>
</tr>
<tr>
<td></td>
<td></td>
<td>See consultant fees above</td>
</tr>
</tbody>
</table>

3.4 All payments must be made in line with this policy, if you are unsure what the appropriate payment is for your activity please contact the Mind Influence and Participation Manager. Hourly payments must **not** be made under any circumstances; the level of payment must be agreed before opportunities take place and be clearly stated in all promotion and relevant correspondence. It is recommended that when you promote influencing and participation opportunities that you state the length of the task and the related fee e.g. £25 for 2 hours of reviewing an information booklet.

3.5 Travel should be pre-booked by Mind staff wherever possible to minimise this barrier to taking part. Some people are on low incomes. Accommodation should be offered if the participant has to travel over 3.5 hours to take part. We should not be requiring people to leave home before 7am or return after 9pm, if this is likely to happen accommodation should be offered.
All accommodation should be booked by Mind staff in line with Mind’s Expenditure, purchase order and budget management policy:

Maximum £75 per night outside of London

Maximum £100 per night in London

Subsistence should also be offered, at the same rate as Mind staff if a person needs to travel over 3.5 hrs. Please ensure receipts are kept and the non-staff expense form is completed.

3.6 Mind cannot accept responsibility for the impact that accepting a payment may have on someone’s benefits and / or HMRC tax responsibilities. Due to the individuality and complexity of this, Mind cannot provide advice to individuals. It is staff’s responsibility to ensure participants understand they are responsible for declaring their income to HMRC and the Department of Works & Pensions, and that they are responsible for paying any tax and National Insurance due.

A statement highlighting this is included in the Mind invoice template which participants need to sign to show acknowledgement.

You may find the following paragraphs helpful if you are asked questions about tax and benefits by people engaging in your work:

"Payments are made in recognition of a contribution of time and expertise, they count as income and are therefore covered by the tax and benefit rules around declaration of earnings. It is important to understand that they may impact the amount of tax you need to pay and the amount of benefits that you are entitled to. We cannot give advice on individual tax and benefit positions and therefore it is your responsibility to ensure that you are aware of the tax and benefit implications.

If you need advice speak to your local Benefits Advisor, Citizens Advice Bureau or see the information on the gov.uk website

3.7 Remuneration of young people

We are able to pay young people who take part in activities which influence our work if they are aged 16+.

We are not able to make payments to children younger than this; where we do engage with children under 16 we are able to offer a £20 gift voucher as a thank you for taking part. Payments made to a mixed age group of participants should
be defined by the age of the youngest person taking part; all participants must be offered the same payment / voucher.
If you are engaging with children please inform the Mind Influence and Participation Manager to discuss how best to support them and thank them for their insights.

4. **Who takes part**

4.1 It is very important that we consult with people who have experience across the whole spectrum of mental health problems.

4.2 Equally, it is essential that we include people who come from different backgrounds and have different experiences of health and social care, and who may have encountered different degrees of social exclusion, stigma and discrimination.

4.3 We are here for **anyone** with a mental health problem, which means we must meet the needs and experiences of all. When selecting people to take part you should aim to work alongside people from a diverse range of backgrounds and experience.

When planning your Influence and Participation work it is important to think about who is affected by the topic and what the barriers to them influencing this work are. Effective planning can help you and participants get the best from the opportunity.

Remember, you may need to hold a variety of different activities targeted at specific demographic groups; their needs understanding or language around mental health or experiences may be very different. Speak to your Engagement Coach and the Equality Improvement team for support.

5. **Monitoring**

5.1 To help us understand and evidence who is influencing and participating in our work staff are required to enter monitoring and demographic data into the Influence and Participation database.

In doing this we are able to build a picture of who is, and subsequently isn’t influencing our work, so we can improve our approaches in the future.

The database is located on the shared drive and needs completing for each activity by the end of each quarter. You can enter at any time, but your entry needs to take place by the end of each quarter.

As the capacity of our CRM system is developed this will become an additional tool for data monitoring.
Resources to guide you are located on the intranet under the Engagement Toolkit tab. Please ensure you ask all participants to complete a demographic monitoring form and feedback form at the time of the activity as you will need this information to complete your entry.

Below are the levels of ‘Influence and Participation’ used to do this.

**Mind Levels of Influence and Participation**

- **Level 5 - Leading**: Leading projects and making decisions independently
- **Level 4 - Deciding together**: Working as partners & contributing to decision making
- **Level 3 - Doing together**: Working together towards common objectives
- **Level 2 - Working Together**: Contributing within fixed roles and boundaries
- **Level 1 - Consultation**: Giving feedback within fixed boundaries

All heads and managers are required to write an annual Influence and Participation plan; support will be provided by the Influence and Participation Coaches and Manager between Jan – March. Targets will need to be set by each team; activity will be monitored against the targets each quarter and reported to MET and Trustees.

Organisation wide accountability resides with the Lived Experience Influence and Participation Manager; compliance with this policy by all staff is essential and will be monitored closely to ensure high standards are maintained.
6. **How we do this**

6.1 It is our policy to:

- Engage regularly and often with people with mental health problems at all stages of our work (priority setting, planning, delivery and review) and in all that we deliver.

- Be inclusive to ensure that we understand the needs of a broad spectrum of people with mental health problems, and proactively support people to overcome barriers to participation.

- Use practical and cost effective methods, making sure that we build influence and participation into our plans and our budgets, being absolutely certain that we can do what we say. It is recommended that a small budget is always ring-fenced for reasonable adjustments E.g. being able to offer an interpreter, paying for childcare or for PA support for disabled people.

6.2 We do this by:

- Building Influence and Participation into all of our programme and communication plans.
- Ensuring that we provide for it in all of our departmental budgets.
- Ensuring that we continually identify influence and participation opportunities to improve our ongoing work.
- Using a range of tools and techniques to meet the needs of people from different backgrounds and life circumstances.
- Adapting the techniques we use to work with new audiences e.g. children and young people, people with learning difficulties and older people.
- Identifying groups of people who might face barriers to accessing our work and engaging with us, and proactively taking steps to overcome those barriers so that we learn from their experiences and make our work as inclusive as possible. This often involves going to where people already meet and feel comfortable, rather than asking them to come to us.
- Ensuring that we provide adequate support for those who take part, as sharing a mental health related experience can be painful.
- It is your responsibility to ensure that you get the support you need, this is especially important when exploring sensitive issues with people.
- Completing a risk assessment so we understand potential risks to participants and staff and manage these as effectively as possible.

6.3 Opportunities to influence and participate in our work should be promoted as widely as possible. We must do our best to ensure as diverse a range of
people have the opportunity to take part, as well as people new to Mind, in order to achieve this our promotion should be distributed as widely as possible.

**Mind Membership** is the primary place to promote opportunities and has regular postal and e-communications. Other places to promote opportunities include:

- People who fundraise for Mind
- Digital supporters
- Time to Change champions network
- Peer Support mailing list
- Leadership and engagement’s list of lived experience consultants
- People you have previously worked with who have given you permission to contact them again.

External organisations such as National Survivor User Network (NSUN) and National Voices are useful places to promote opportunities.

Your engagement coach and Equality Improvement partner can help you think through which promotion channels to use, as well as how to promote to less heard groups.

When specifically seeking input from people from marginalised communities, it is sometimes useful to send opportunities to specific contacts, groups and organisations that you or your colleagues may have already developed or know about. The Equalities Improvement team can support you to plan this type of promotion.

6.4 Ensure you are not working with the same people every time you run an activity, it is important to let others have their say. They may have very different experiences to the people you regularly work with that would change the way your work progresses.

The Mind Influence and Participation Manager can advise on participant selection processes.

7. **Support**

7.1 It is important to offer those taking part appropriate and relevant support, this can take many forms and will differ depending on the method you are using, topic being discussed and age of those taking part.

The Engagement Toolkit covers this topic in more depth and includes tools and templates to help you offer the most appropriate support.
Consider:

- What support is feasible for you to offer e.g. A quiet break out space, having a MHFA on site, offering to complete a WAP plan if the opportunity is long term
- Is training appropriate? Training gives people more confidence in their abilities and can help build their understanding of topics concepts
- What will you do if someone becomes distressed whilst taking part? Your coach can help you plan for this too

The support you offer a young person taking part will need to have a higher level of formality and planning. Please read the **Working with groups of young people** policy for additional guidance.

Always speak to the Mind Influence and Participation Manager and your engagement coach before undertaking activities with under 18's; they will be able to support your planning and ensure you are thinking through all risk factors.

Always:

- Ask for the relevant written consent from parents / guardian / responsible adult of anyone under the age of 18 taking part. Please see the **Children and Young People Consent Procedure**.
- Ensure children and young people (16 and under) are accompanied to your event by a parent or guardian (always reimburse the travel costs for all attending); parents don’t need to take part or be present during your event however they do need to be present at the beginning and end.
- Ensure you are aware of parent / guardian contact details should you need to reach them during an event. Make sure the child or young person taking part is aware you may contact them should they become distress or unwell and are no longer able to take part.
- You have read the relevant safeguarding policy
- Consider who the best people to facilitate are and be present at your event. Would a facilitator experienced at working with young people be better placed to run the session? Do you need support from youth workers during the session?
- Ensure there are a minimum of 2 members of staff (Mind staff / external facilitator) who have been DBS checked present at all events. This ensures you have enough people to support anyone in need whilst also continue the event.
• Think of methods and language that will be appropriate and length of sessions.

You may find some useful information on engaging children and young people in the following resource from SCIE.

Involving children and young people in developing social care

8. Resources to support your work

8.1 To help you apply this policy in practice, we have produced an online Engagement Toolkit which outlines Mind’s ethos and provides a series of tools and templates to help us all bring this policy to life. You can access the Toolkit via the intranet by clicking the tab on the home page.

8.2 Engagement coaches are allocated to all teams across Mind, they are able to help staff with planning as well as giving advice on the best methods to use. Information about Engagement Coaches can be found on the intranet in the Engagement toolkit tab.

8.3 Influence and Participation training is mandatory for all staff and runs a minimum of 4 times per year.

Monitoring and payment training runs 3 times per year. You can also invite the Mind Influence and Participation Manager to your team meetings to discuss this in more detail.

8.4 Support is also available from the Leadership and Engagement team; contact engagement@mind.org.uk with all queries.

8.5 Safeguarding policy

8.6 Volunteering Policy

8.7 Equality Improvement resources and support are also available to ensure your work is fully inclusive and accessible. Contact equality@mind.org.uk with all queries about equality and inclusion
## Document Control

<table>
<thead>
<tr>
<th>Security Classification</th>
<th>UNCLASSIFIED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author</td>
<td>Influence and Participation Manager</td>
</tr>
<tr>
<td>Owner Role</td>
<td>Influence and Participation Manager</td>
</tr>
<tr>
<td>Approved by</td>
<td>Quality and Safeguarding team</td>
</tr>
<tr>
<td>Approval Date</td>
<td></td>
</tr>
<tr>
<td>Distribution</td>
<td>All staff</td>
</tr>
<tr>
<td>Availability</td>
<td>Mind intranet</td>
</tr>
<tr>
<td>Next Review Date</td>
<td></td>
</tr>
<tr>
<td>Related Policies &amp; Procedures</td>
<td>Participation at Mind - diagram</td>
</tr>
<tr>
<td></td>
<td>Expenditure Policy</td>
</tr>
<tr>
<td></td>
<td>Working with groups of young people policy</td>
</tr>
<tr>
<td></td>
<td>Children &amp; Young People Consent Procedure [pending]</td>
</tr>
<tr>
<td></td>
<td>Risk assessment policy [pending]</td>
</tr>
<tr>
<td>References</td>
<td></td>
</tr>
</tbody>
</table>