



May 2022

Sort the Switch

The experiences of young people moving from Specialist Child and Adolescent Mental Health Services to Adult Mental Health Services in Wales



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About Mind

- We are **Mind**.
- We **connect** minds - bringing together an unstoppable network of individuals and communities – people who care about mental health to make a difference.
- We **support** minds – offering help whenever you might need it through our information, advice and local services.
- We **change** minds – across England and Wales by making mental health an everyday priority. By standing up to the injustices – in healthcare, in work, in law – which make life harder for those of us with mental health problems.
- Join us in the **fight for mental health**.
- We won't stop until everyone experiencing a mental health problem gets both **support and respect**.



Acknowledgements

We would like to thank all the young people that took part in this research - through the survey, interviews and the workshops. Your insights have been invaluable.



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* See [page 6](#) for definitions

Background

Definitions

Specialist Child and Adolescent Mental Health Services (SCAMHS): SCAMHS are secondary mental health services for young people whose main purpose is to provide specialist mental healthcare. These services are made up of mental health professionals who offer targeted specialist support.

Adult Mental Health Services (AMHS): Adult Mental Health Services are specialist NHS services that support adults with mental health problems.

Transitioning: Moving from specialist child and adolescent mental health services to adult mental health services.

Care and treatment plan: A comprehensive plan that everyone receiving secondary mental health services must have. It should assist a young person's recovery. When it is made, it should consider at least 8 areas of a person's life, including personal care and physical wellbeing, education and training, and social, cultural or spiritual needs.

Definitions (continued)

Signposting: When an individual is given information or guidance to help them get help from somewhere or someone else.

Thresholds: A definitive level at which an individual must reach so that they can receive the service available/offered.

Advocacy: Advocacy means getting support from another person to help you express your views and wishes, and help you stand up for your rights. Someone who helps you in this way is called your advocate.



A point to note for decision-makers:

These terms are used regularly by mental health services in Wales. Young people asked us to explain and simplify them. We have done our best to do this.

Service terminology may always be needed, yet it is vitally important that professionals ensure that young people and their family/carers, fully understand what these terms mean for them.

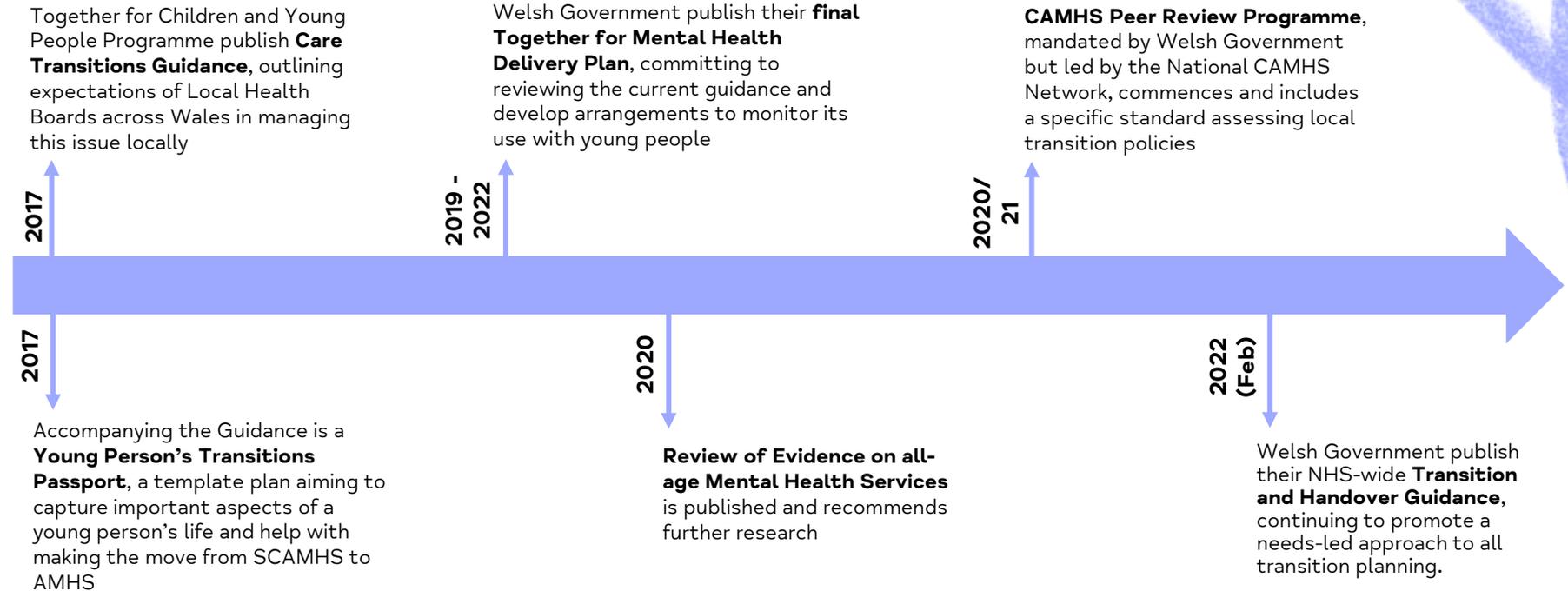
Why this issue?

- Our **Youth Voice Advisory Panel**, made up of 12 people aged 14-24 with lived experience, worked with us to develop and refine [Mind's strategy](#).
- We aimed to ensure that young people with lived experience fed into every stage of strategy development, and that **our plans for 2021-2024 reflect the realities that young people with mental health problems** across England and Wales face today.
- Young people identified six priority areas for our campaigning work. Campaigning for a **flexible transition from CAMHS to adult services for 18-24 year olds** was one of these.
- Our research objectives ([see page 15](#)) reflect our commitment to **improve our understanding** of young people's experiences of this in Wales, and to develop, with them, a campaign that **amplifies their voices** and includes specific calls for **positive change**.

Content warning

Some of the quotes and stories within this report mention self-harm and suicide.

Timeline of policy developments on moving from SCAMHS to AMHS in Wales since 2017



Current national policy in Wales

Care Transitions Guidance (2017)¹

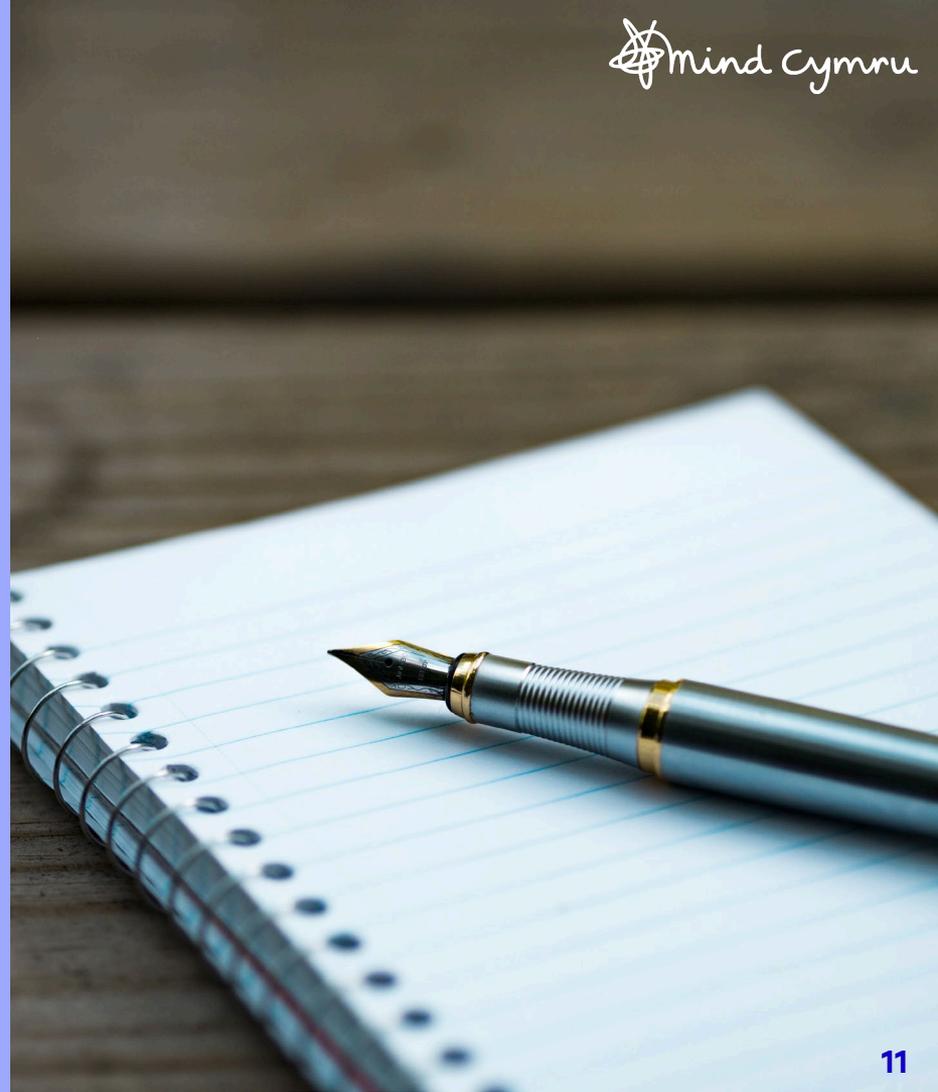
Aimed at supporting services involved in planning for young people's move from SCAMHS to AMHS locally, this document promotes a process which:

- is shared & inclusive
- is based on needs and not age
- explains why moving to AMHS is being considered
- includes a period of joint working between SCAMHS and AMHS
- secures continuity of care
- ensures SCAMHS remains available to young people (*for a reasonable period while they move*)
- includes information explaining the process, engagement, rights and expectations
- includes agreed timescales with young people
- ensures communication methods are understood
- includes the development of a 'Passport', in conjunction with a Care & Treatment Plan
- outlines how to raise any potential concerns
- considers the potential need for AMHS training on child development
- includes governance arrangements and a commitment to review.

¹ Together for Children and Young People Programme (2017) *Care Transitions Guidance*. Wales: currently unavailable online.

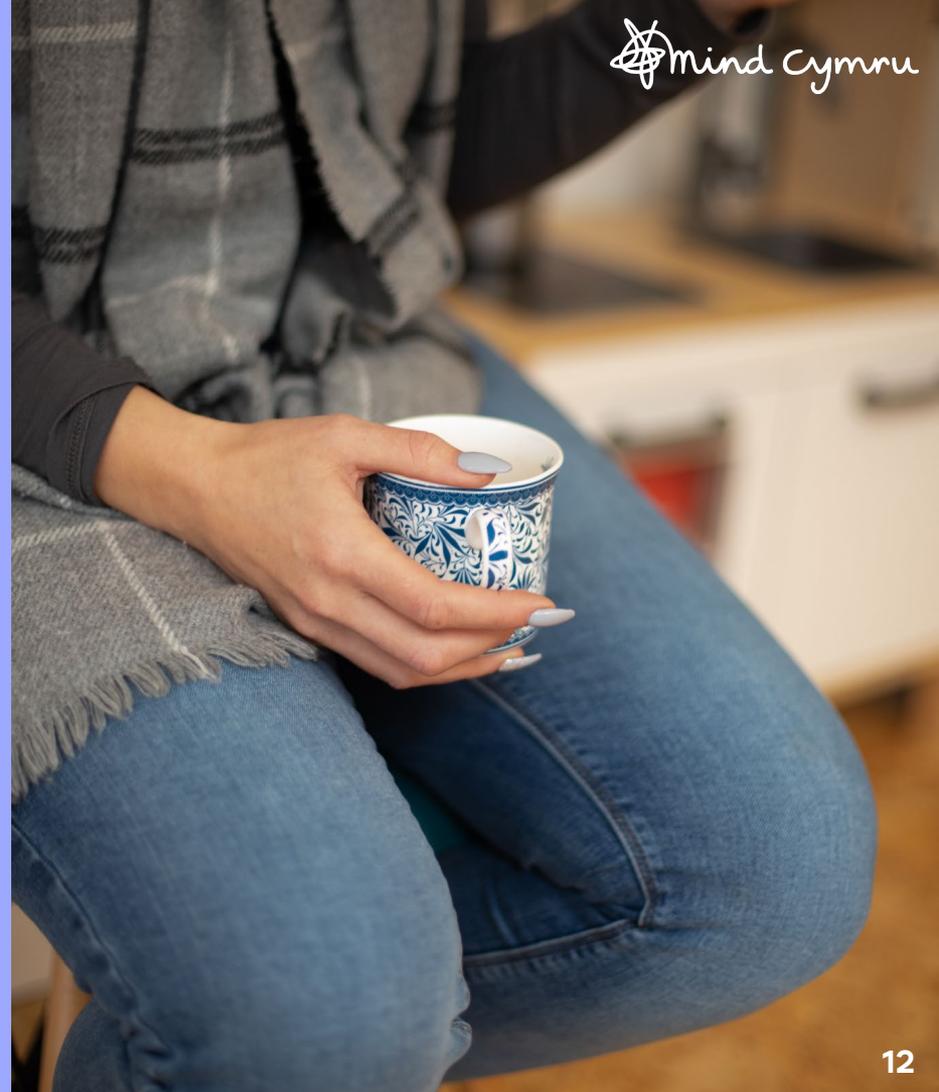
The Mental Health (Wales) Measure 2010²

- The Mental Health (Wales) Measure 2010 is the **law** that sets out the support that children, young people and adults living in Wales should receive from **primary and secondary mental health services**.
- Everyone receiving secondary mental health services must have a written **care and treatment plan (CTP)** prepared and regularly reviewed by a care co-ordinator.
- When an **adult is discharged** from secondary mental health services, they have a **right to request an assessment** of their mental health that would allow them to be **referred back** to secondary services without going to a GP. They must be informed of this right in writing.
- Once a **young person** turns 18, they also have a **right to request an assessment**, even if they were **discharged from SCAMHS** and now wish to access AMHS.
- If a young person is **discharged** from secondary services **within 3 years** of their **18th birthday**, they must be informed of this right in writing.



Rights of children and young people in Wales

- The **United Nations Convention on the Rights of the Child (UNCRC)**³ is a comprehensive statement of children's rights. It has 54 articles which list all the rights that children and young people have, including:
 - The **best interests** of the child must be a top priority in all decisions that affect them (article 3)
 - Right to be **heard** in all matters affecting them and to have their views taken seriously (article 12)
 - Right to the **best possible health** and **access to good quality healthcare** (article 24)
- The **Rights of Children and Young Persons (Wales) Measure 2011**⁴ puts a duty on Welsh Ministers to consider the UNCRC whenever they develop legislation and policy. Wales is currently the only country in the UK to have a law like this.



³ United Nations Human Rights: Office of the High Commissioner: *Convention on the Rights of the Child (UNCRC)*. Available at: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child> (Accessed: 18 February 2022)

⁴ Legislation.gov.uk. *The Rights of Child and Young People (Wales) Measure 2011*. Available at: <https://www.legislation.gov.uk/mwa/2011/2/contents> (Accessed: 18 February 2022)

Voices of young people with lived experience of moving from SCAMHS to AMHS

What we knew:

- Sources of available data on the number of young people who have lived experience were unknown.
- Sources of available data on outcomes or patient experiences were also unknown.
- Of the only quantitative data sources available, we knew that 578 patients in receipt of secondary mental health services across Wales at the end of September 2021 were recorded as under 18 years old⁵.

What we learnt:

- The means available to us, of engaging with these young people proved worryingly difficult.
- Previous research suggests limited involvement of young people on this issue.
- This difficulty was worthy of highlighting within this report.



⁵ StatsWales.gov.wales. *Care and treatment plan (CTP) compliance, by LHB, service, age, and month*. Available at: <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Mental-Health/Mental-Health-Measure/Part-2/careandtreatmentplancompliance-by-lhb-service-month> (Accessed: 18 March 2022)

About this research

Objectives

- To hear from young people about their experiences of moving from SCAMHS to AMHS in Wales between 2017-2021.
- To identify the ‘pain points’ in the process of moving from SCAMHS to AMHS for young people, identifying which are most common and impactful.
- To co-produce recommendations for decision makers in Wales with young people on how to improve this experience.
- To identify the focus of Mind Cymru’s campaign for young people moving from SCAMHS to AMHS.

Our approach

Sign up form

- We created a sign-up form hosted online on the survey platform Qualtrics.
- The sign-up form was shared amongst our network of local Minds in Wales, as well as key partners working with young people. It was also shared on our social media platforms.
- We had a total of 33 responses.
- 16 young people expressed interest in speaking to us further.

Interviews with young people

- We spoke to 8 young people through semi-structured interviews in November 2021. The full sample can be found on [page 18](#).
- Interviews were conducted over Zoom and on the phone.
- Young people had to have moved from SCAMHS to AMHS, tried to move or be in the process of moving in Wales between 2017-2021.
- A sampling matrix was used to ensure diversity across location in Wales, gender, ethnicity and sexual orientation.
- Interviews were professionally transcribed.

Identifying themes

- Data was initially analysed thematically using the Framework Approach to identify emerging themes.
- Transcripts were read by all analysts independently so they could code them and check if the emerging themes were accurate.
- Regular meetings were held to discuss and amend the themes.
- Finally, a concise thematic structure was developed.

Young people involvement

- Mind works hard to understand the needs and experiences of people with mental health problems. This drives everything we do, and, wherever possible, we actively seek opportunities for people with lived experience of mental health problems to get involved and guide our work.
- We sought young people's involvement at every opportunity, including:
 - The issue of moving from SCAMHS to AMHS was identified by young people themselves.
 - 2 young people from Mind's Youth Voice Network (YVN) reviewed the discussion guides.
 - A workshop was conducted with 5 young people in January 2022 to review the thematic framework and shape the recommendations. Another 2 young people contributed remotely.
 - 3 young people reviewed this report and provided feedback and comments.

Sample



Age: 18
Gender: Female
Ethnicity: Mixed
Location: Denbighshire
Transition status: Moved from SCAMHS to AMHS



Age: 18
Gender: Male
Ethnicity: White or White British
Location: Cardiff
Transition status: Moved from SCAMHS to AMHS



Age: 20
Gender: Female
Ethnicity: White or White British
Location: Cardiff
Transition status: Referral was unsuccessful to AMHS



Age: 18
Gender: Male
Ethnicity: White or White British
Location: Anglesey
Transition status: Moved from SCAMHS to AMHS



Age: 20
Gender: Female
Ethnicity: White or White British
Location: Vale of Glamorgan
Transition status: Moved from SCAMHS to AMHS



Age: 19
Gender: Female
Ethnicity: White or White British
Location: Pembrokeshire
Transition status: Referral to AMHS accepted but been on waiting list for 18 months



Age: 19
Gender: Female
Ethnicity: White or White British
Location: Conwy
Transition status: Moved, but treatment broke down as AMHS didn't suit needs



Age: 22
Gender: Female
Ethnicity: White or White British
Location: Swansea
Transition status: Not sure* but now receiving support from AMHS

*Those who may not have gone through a formal process of moving but are now in receipt of AMHS support

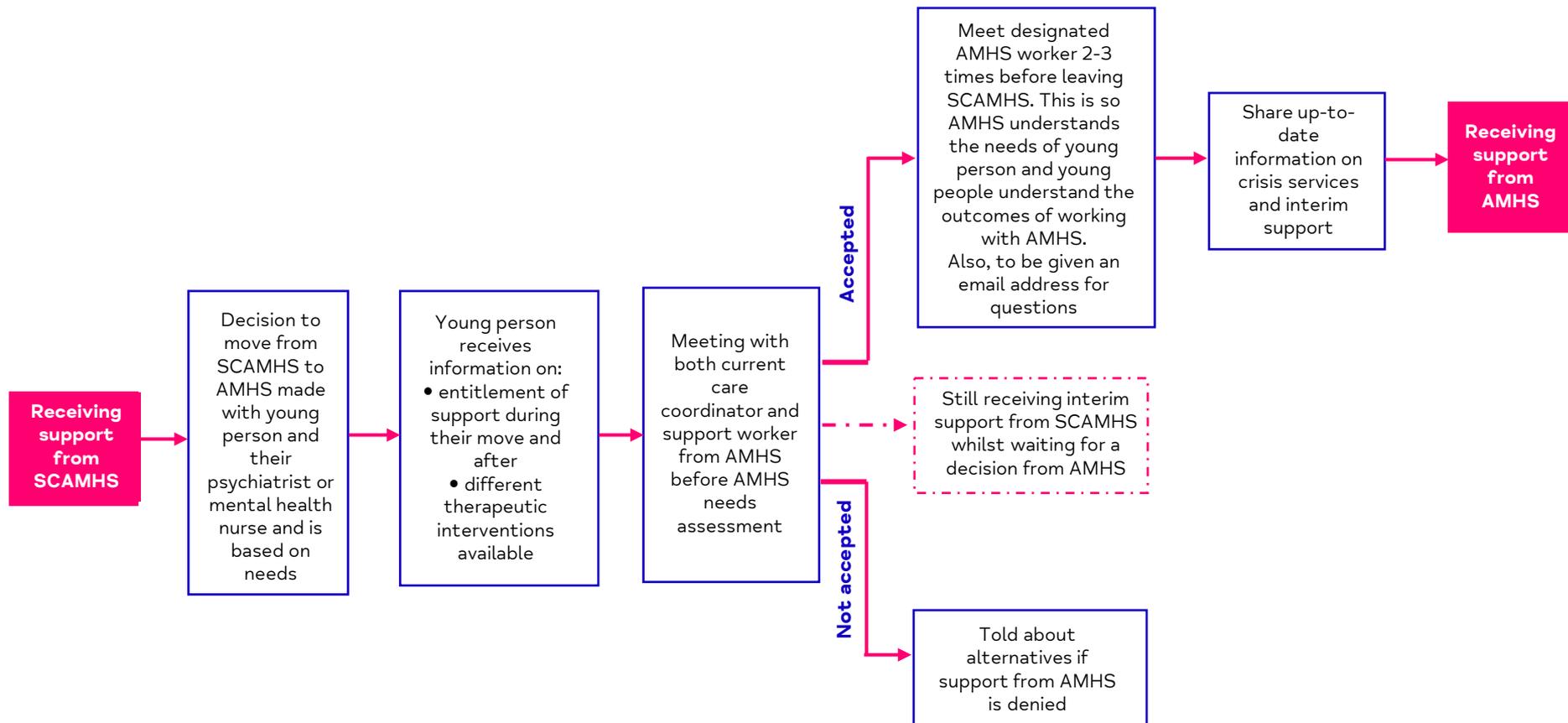
About this report

- This report outlines the **key themes** which were identified from interviewing young people about their experiences of moving from SCAMHS to AMHS.
- The themes can be used in order to **provide challenges** and **opportunities for the improvement** of this process for young people.
- Themes are structured according to what young people felt was most **important to them**.
- Young people's 'ideal' move is used throughout to identify the **pain points*** in the current process for each theme. You can find an outline of young people's 'ideal' move on [page 21](#).
- Each theme has an identified **design challenge** with some key questions.
- There are also some **proposals for change** which were shaped by young people which help to answer these key questions.
- **Recommendations** are then included for the attention of Welsh decision-makers.

Limitations of this research

- Engaging with young people with lived experience was **difficult** due to the particular criteria we required young people to have met (young people had to have moved from SCAMHS to AMHS, tried to move or be in the process of moving in Wales between 2017-2021) and the **limited means available**. However, the promotion strategies used helped us reach those young people who did meet the criteria.
- In addition to the particular criteria, reaching young people from **minority ethnic backgrounds** also proved to be difficult. This is a continued challenge for Mind and Mind Cymru. However, this is a situation that we are **committed to addressing** and improving through developing meaningful long term partnerships with a range of organisations. Mind is committed to ensure the voices of people from minority ethnic backgrounds are included in our work.
- We interviewed 8 young people out of the 33 people who completed our survey. While this is a small number, given the scope and nature of the research, and the fact that there is **limited data available** on the number of young people who have lived experience of moving from SCAMHS to AMHS in Wales, we believe the insights from these 8 young people have provided a **strong basis for improvement and change in the process**.

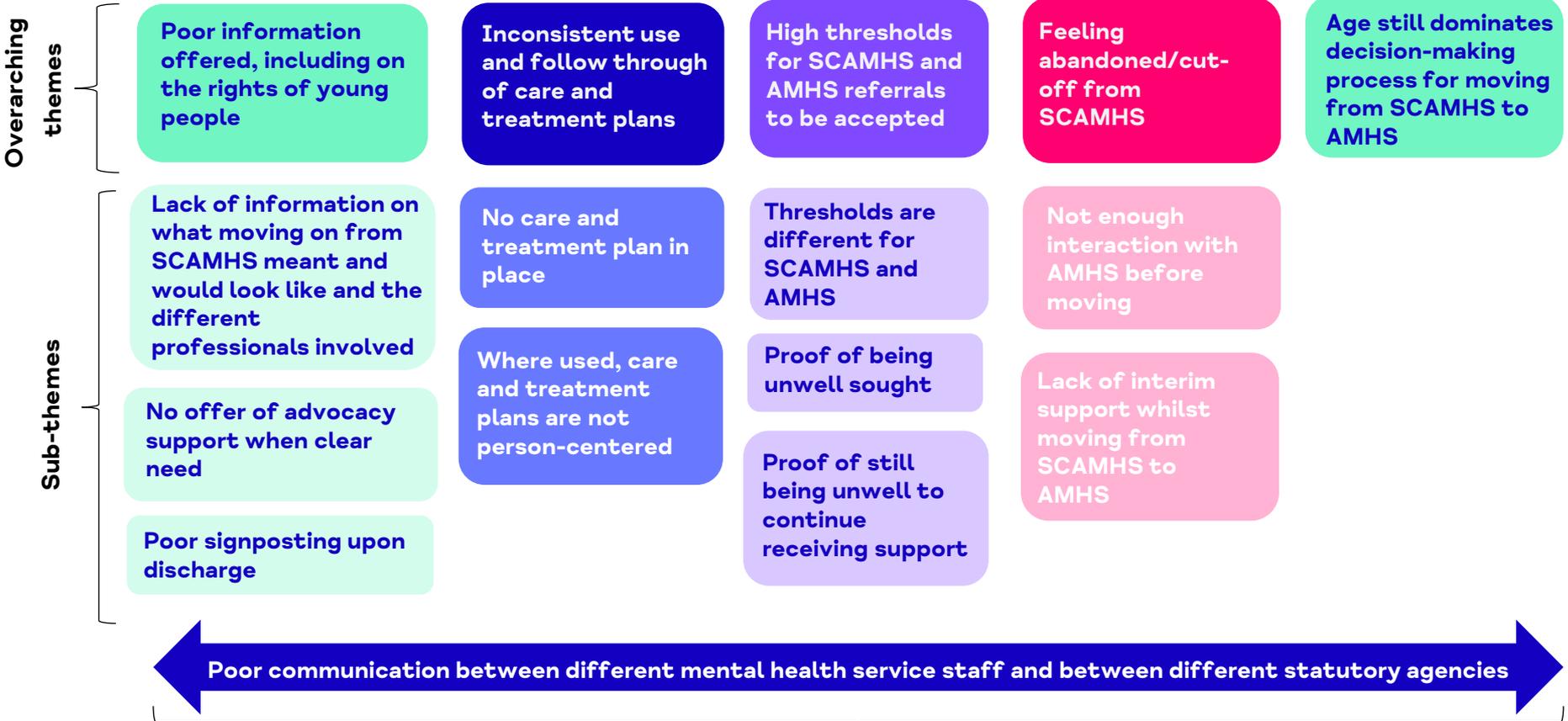
An 'ideal' move for young people



Themes



Overview of themes



Poor information offered, including on the rights of young people

- Young people are often unclear about what moving from SCAMHS to AMHS means and what to expect
- Some young people are unaware of their rights and that they can have an adult with them when conversations about moving on are taking place
- Variable information is provided to young people when they are discharged

Lack of information on what moving from SCAMHS to AMHS meant and would look like and the different professionals involved

Young people are unsure of the stages of the process



Lack of information on what moving on from SCAMHS meant and would look like and the different professionals involved

Young people are being told they need to move on from SCAMHS services and are being introduced to the term 'transitioning'.

Yet, they don't feel like they have enough information on what this means and what this could look like for them.

Key findings:

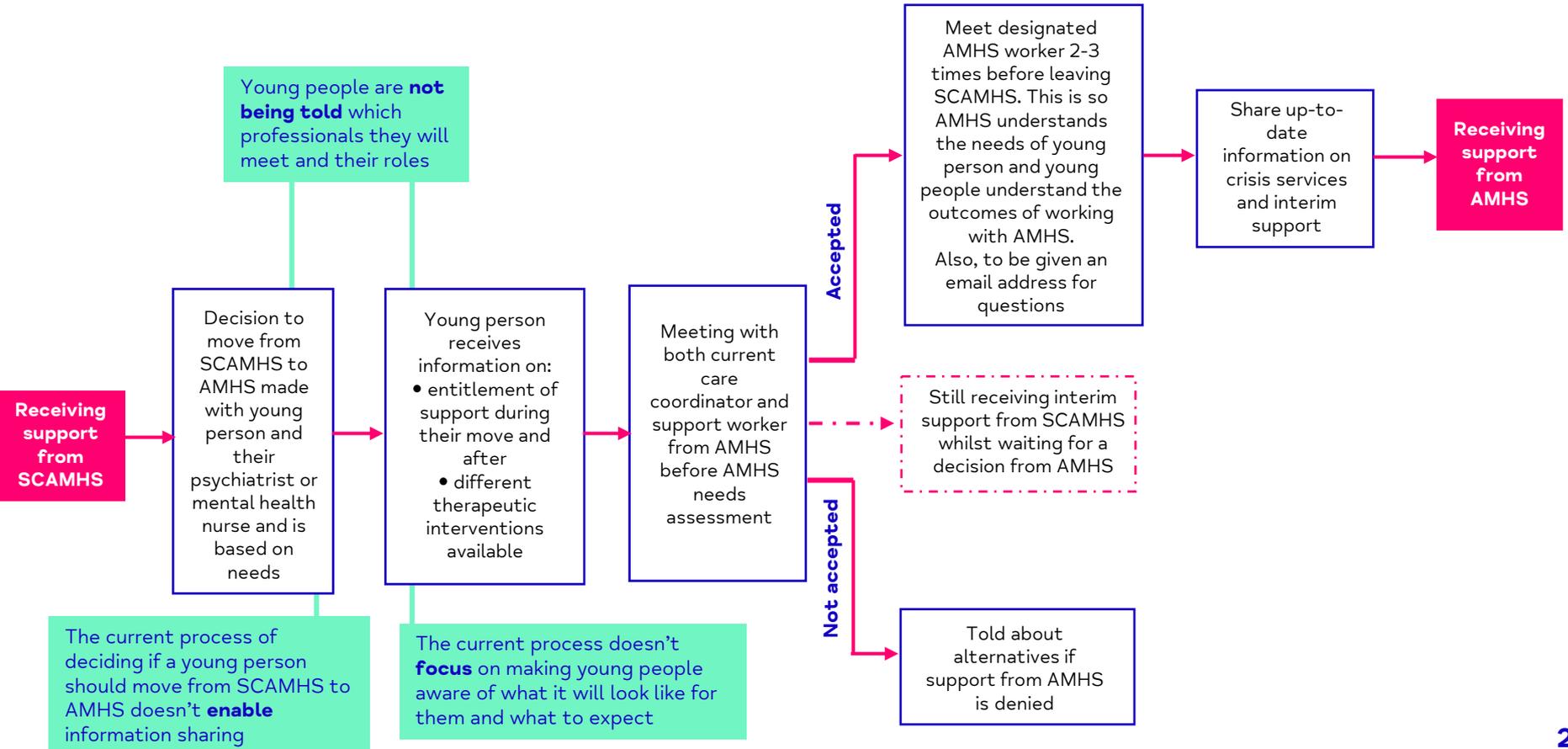
- Some young people feel that the information about what moving from SCAMHS to AMHS or the term 'transitioning' is and what it could look like for them isn't given to them by default
- Young people struggle to ask for more information due to feeling overwhelmed or too unwell. Sometimes they don't know what to ask for or what they need
- The process of moving from SCAMHS to AMHS involves different professionals at each stage. It can get confusing for young people to know their specific roles in relation to their move

“

I definitely could have done with some more information. I think at the time I didn't really know that I would have needed that. I didn't really know that was a thing. I can't explain it very well, but I didn't know, yes. And I don't know, I didn't have the head-space to think to ask for it.

”

PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why information on moving on from SCAMHS is not routinely offered to young people

Welsh guidance says young people should be given all the information they need to make decisions. It's important to find out why this isn't always the case and ensure the process of moving from SCAMHS to AMHS makes this a priority.

Suggested key questions

- What types of information do young people want and need?
- What format do young people want to receive this information in?
- Who should provide this information to young people?
- What is the best time in the process of moving on from SCAMHS to AMHS for young people to receive information?

Proposals for change from young people...

 Ensure information is accessible and easy to understand for young people

 Explain what transitioning is, who is involved in person but also provide a booklet to young people

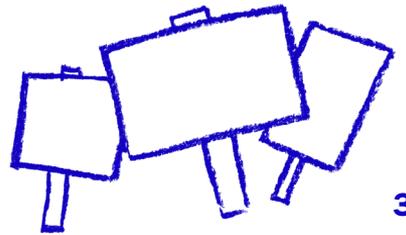
 Provide young people information on what crisis services are available to adults a week prior to turning 18

 Tell young people what is on offer to them before their AMHS assessment

 Give young people information on what to expect in the AMHS assessment

 Give young people a designated person they can ask questions to

 Review the language that is used by SCAMHS healthcare professionals to describe AMHS to young people so that young people don't have a negative view of it

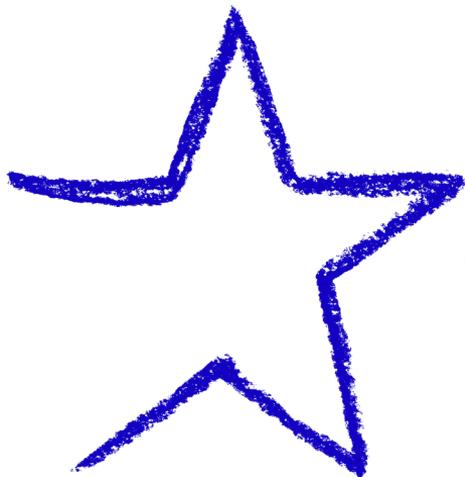


What it can look like if young people are told what to expect



Well actually, I had that conversation with the head coordinator about a year before I got transitioned, so it's quite far off from when I was being transitioned and [he] explained to me what will happen and what the plan in place was. So, it's, kind of, reassuring. But I was always quite nervous of transitioning to adult services, so when he first told me about it I, kind of, got quite anxious about it all the time. But, the care coordinator, my care coordinator made it very sure that I won't be anxious and there's a plan in place to help me.

I always had that conversation about once a week with my care coordinator about, you know, what was going to happen when I turn eighteen and all that. And he just made me feel reassured so that I could, kind of, like, have a good experience of transitioning and not have a negative one.



No offer of advocacy support when clear need

Young people are not offered support when they have additional needs



No offer of advocacy support when clear need

Getting support from another person to help them voice their views and wishes and stand up for their rights can be incredibly valuable to young people.

The current process does not make it clear to young people when they have a statutory right to advocacy. It also doesn't make it clear what their options are when they don't have a statutory right.

Key findings:

- Being told that you will be moving on from SCAMHS can be quite an overwhelming conversation to have for young people
- Young people are already managing their mental health needs, or they might have additional needs which can impact how much information they can take in and process
- Some young people aren't aware that they can have an independent advocate to accompany and support them in meetings or appointments
- Young people are also not aware that this person doesn't have to be a family member and will be completely independent

‘Maria’, 20 Vale of Glamorgan

Transitioning status:

‘Maria’ moved from
SCAMHS to AMHS

Maria was diagnosed with a tumour for which she received proton beam therapy. As a result, Maria doesn’t produce her own hormones. This impacted her mental health and she started to become depressed. Another symptom of the tumour is memory problems. Maria got a referral to CAMHS through the GP and felt that without the support of the hospital, she wouldn’t have got referred or accepted.

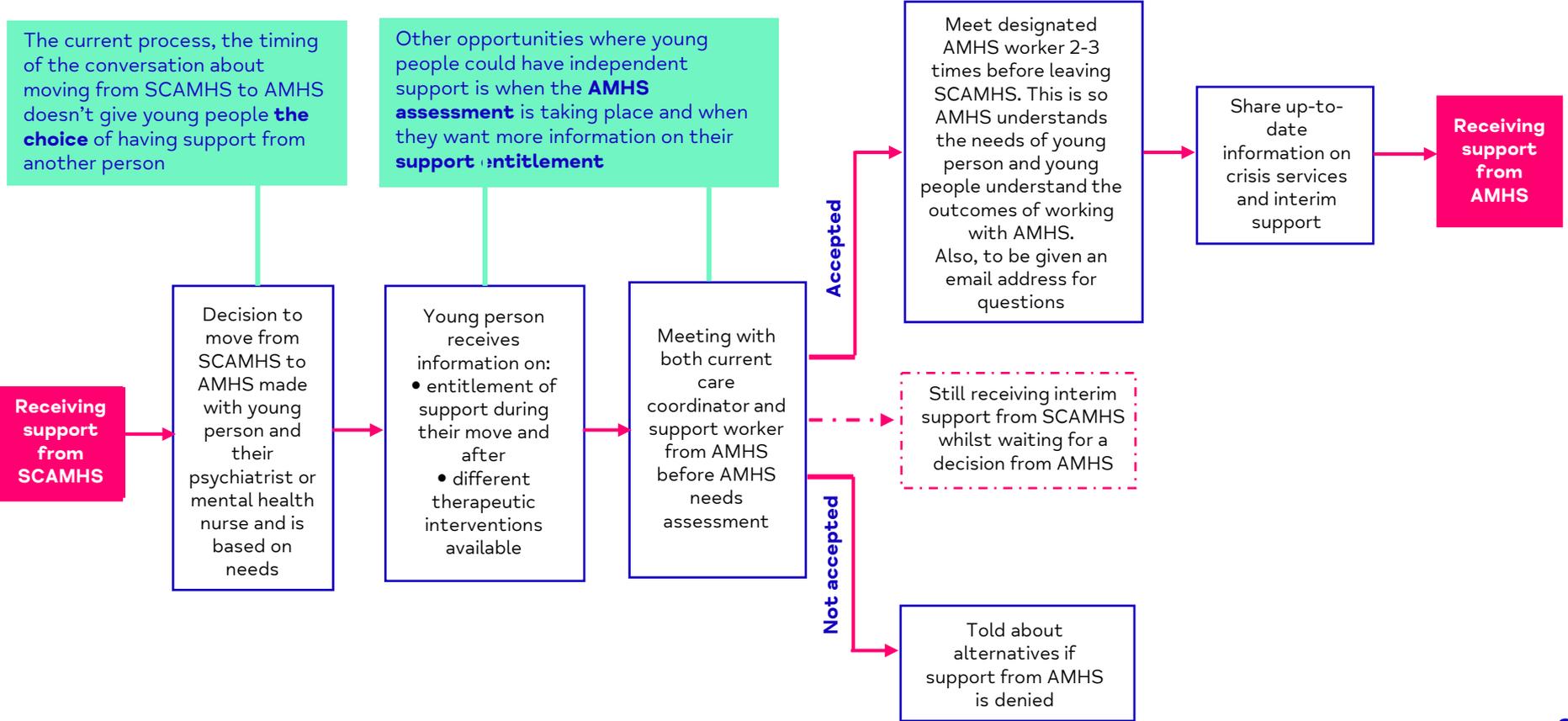
Overall, Maria felt she had a positive experience of CAMHS. The conversation about moving on from SCAMHS to AMHS happened before Maria turned 18. However, there was a lot of confusion about who Maria would be under the care of due to her physical needs. ‘Maria’ and her mum both felt that the move happened in a rush. Eventually, Maria was told to go back to her GP and her mental health needs were being looked after by the specialist school she currently attends.

Maria and her mum both felt like they did not understand what was going on well enough and in Maria’s case, her memory problems added to this. Maria’s mum felt on many occasions that due to her additional needs; she shouldn’t have been there [in meetings/appointments] on her own.

66 **Maria definitely didn't understand it [transitioning] well enough. Maria's not great at, if she's gone in a room with somebody on her own, to contain the information, which I totally understand because she's at that age. I was never concerned about her going in, chatting, you know, having counselling with somebody on her own, but if they discussed with her in there about transitioning, she has not been able to relay that to me coming out afterwards.**

When she was fourteen, they said, could they speak to Maria on their own. Then I was like, I went out because I thought I had to. Then I sat in the waiting room, and I thought, 'Hang on a minute. She's got additional needs. She's only fourteen. She shouldn't be in there on her own.' So, I went back in, and they sort of said, 'Well, she'll be sixteen soon,' and I said, 'Well, she's not even fifteen yet.' ♪ - ‘Maria’s mum’

PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why young people who have a clear need for advocacy are not offered it

Welsh guidance says young people should have access to an advocate where it is needed although there is no legal right to it. The UNCRC says that young people have a right to be listened to in all decisions about them. Having someone help a young person express their views and wishes (when they find it difficult to do this on their own) is key to them feeling empowered.

Suggested key questions

- What types of information on advocacy do young people want and need?
- What format do young people want to receive this information in?
- Who should provide this information to young people?
- How can the process of moving from SCAMHS to AMHS ensure that healthcare professionals actively offer advocacy support where young people could benefit from this?

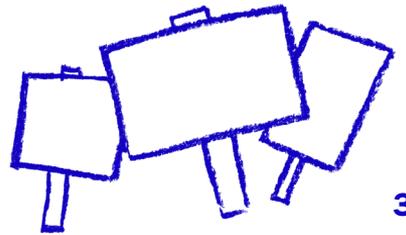
Proposals for change from young people...

 Provide young people with a leaflet on advocacy with the contact details when they enter SCAMHS services

 Provide healthcare professionals training so they understand the circumstances when young people would benefit from having an advocate

 Tell young people about the different types of advocacy available to them

 Remind young people of their right to advocacy at different stages of the transition process



Poor signposting upon discharge

Discharge information is
generic and unsuitable



Poor signposting upon discharge

Giving young people and their parents and carers tailored and relevant information on where to get support after being discharged can help young people be informed and empowered about what their options are.

Young people and their parents/carers are being signposted. However, this feels generic and not particularly useful.

Key findings:

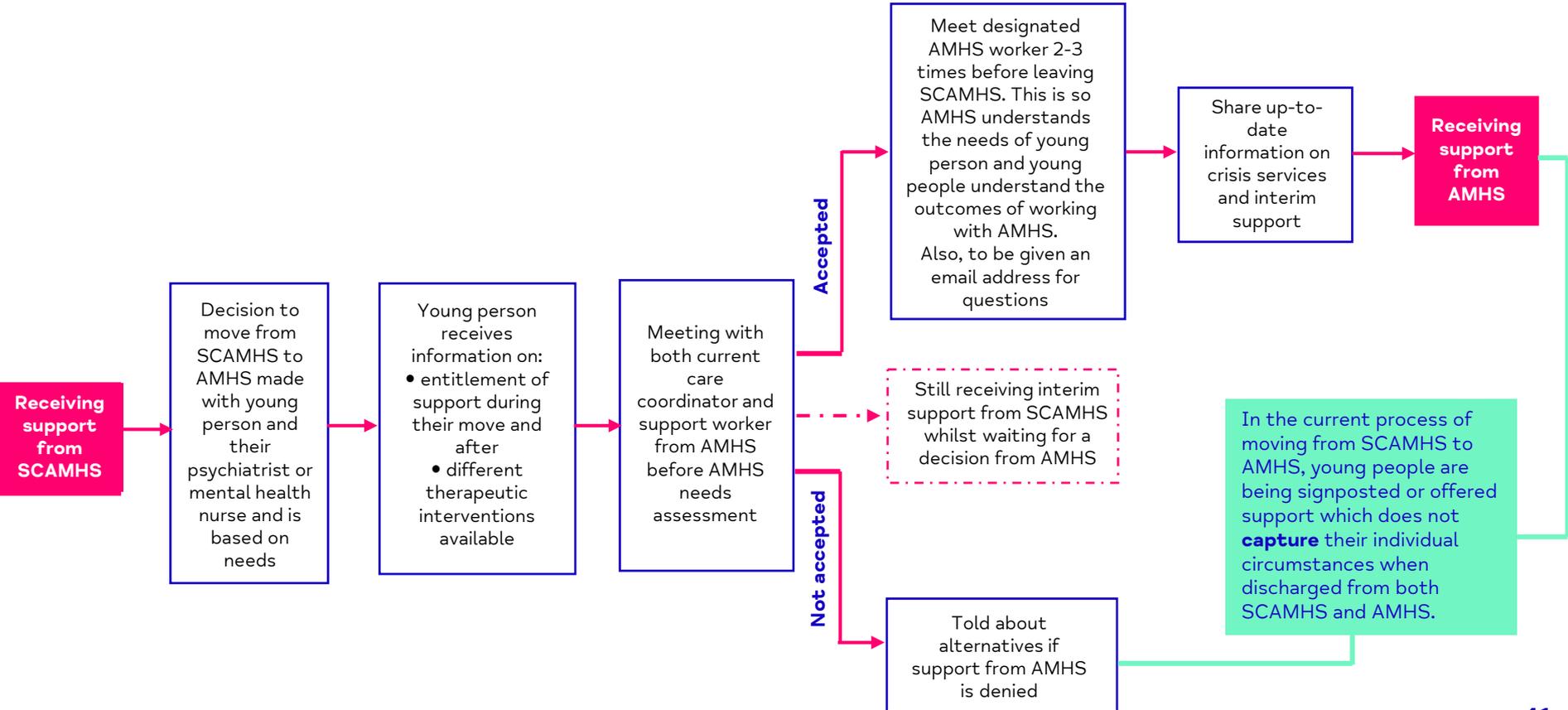
- Most young people are being told how to re-refer themselves to AMHS
- Some young people and their parents/carers are being signposted. However, the information is too generic, unsuitable and/or not specific to the young people
- Some young people feel because they have demonstrated they can 'find stuff' themselves, healthcare professionals don't pay particular attention to signposting



I think they [adult services] might have offered some talking therapy slots, but it was like a stress relief programme or something, and I kind of knew what it was, because I'm pretty certain that my mum had been recommended it from her GP after I'd attempted... It was not really working in my mind that you had me who was on quite serious antidepressants, had three diagnosed mental health conditions, a disability and had been actively suicidal for a very long time and had been given the same courses of treatment as my mum, who was stressed.



PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why information offered upon discharge is not relevant or useful to young people

Young people must be given personalised information on where they can go for support and the specific services available to them. This is important for building trust in mental health services among young people.

Suggested key questions

- What are the barriers for healthcare professionals not offering tailored information on services for young people once they are discharged?
- What information would be most helpful for young people when they are discharged from SCAMHS or AMHS services?
- What format do young people want to receive this information in?
- When do young people want to receive this information?

Proposals for change from young people...



Create a personalised list or booklet of further services and support for each young person so it is clear these services are based on their needs



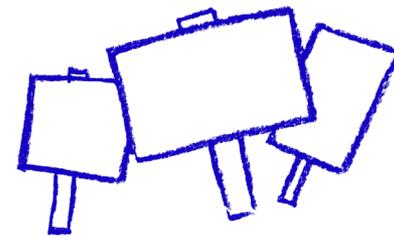
Build in time to create a more personalised list of services and support into the transition process



Have a named key contact that young people can email about services and support or if they have any questions about the services and support offered to them



Update young people's safety plans with what crisis services are available to them and the key contact details



Inconsistent use and follow through of care and treatment plans

- Part 2 of the Mental Health (Wales) Measure (2010) states that every young person receiving secondary mental health services (SCAMHS) must have a comprehensive care and treatment plan to assist their recovery
- However, not all young people could recall having a care and treatment plan in place
- Those young people who did have a care and treatment plan in place, did not feel that these were not created with them

No care and treatment plan in place

Care and treatment plans are not offered to every young person



No care and treatment plan in place

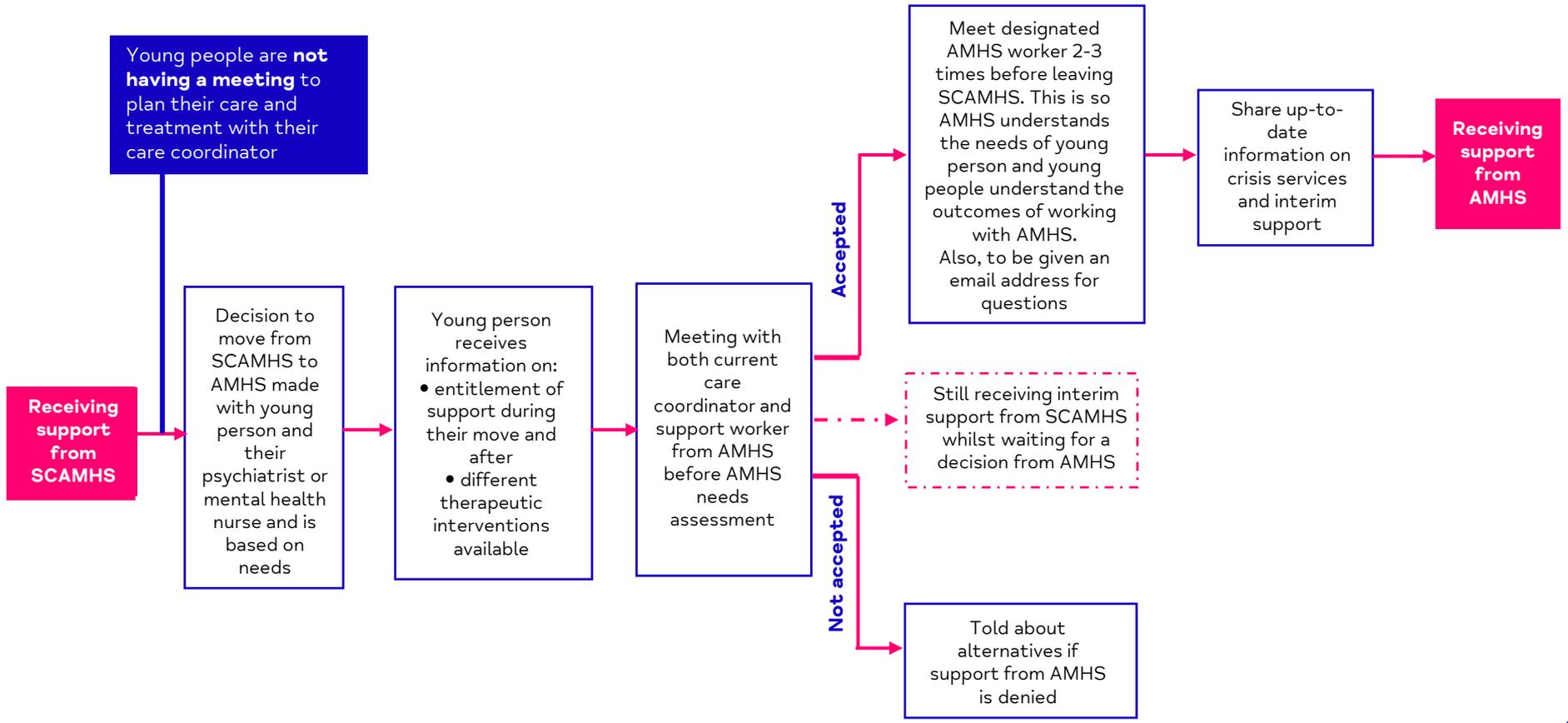
A care and treatment plan sets out what mental health support a young person will receive to help them recover.

Despite this being a legal entitlement in Wales, many young people did not know what this was.

Key findings:

- Many young people could not recall having a care and treatment plan in place
- It is not always clear to young people what is meant by a 'care and treatment plan'
- Without a care and treatment plan in place, there is no formal way of knowing if the young person's wishes are being met or if they are meeting any outcomes

PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why some young people do not have a care and treatment plan

The Mental Health (Wales) Measure (2010) states that all young people who are receiving secondary mental health services must have a comprehensive care and treatment plan. The UNCRC says that all young people have the right to the best possible health and access to healthcare. It is important to find out why young people are not receiving one and ensure having one is made a priority.

Suggested key questions

- What are the barriers that exist to young people having a care and treatment plan?
- How can the language used to describe a care and treatment plan and what's involved be more accessible to young people?
- How can we ensure that having a care and treatment plan in place, meets the needs of young people and is considered useful?

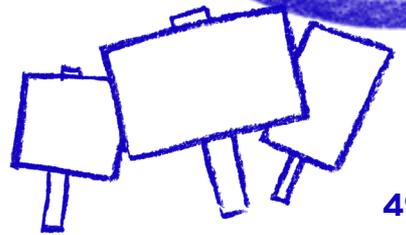
Proposals for change from young people...

 Think about alternate language that can be used to describe a care and treatment plan which is more accessible to young people

 Provide information to young people on what a care and treatment plan is and its purpose

 Ensure care coordinators are aware of the legal entitlement of young people having a care and treatment plan

 Let young people know that they are entitled to a care and treatment plan and that if they don't have one, they can ask for it



Where used, care and treatment plans are not person- centered

Care and treatment plans
don't include the young
person's voice



Where used, care and treatment plans are not person-centered

Care and treatment plans should be written with both the young person and their healthcare professional and be updated regularly.

However, young people don't feel they are involved in creating them.

Key findings:

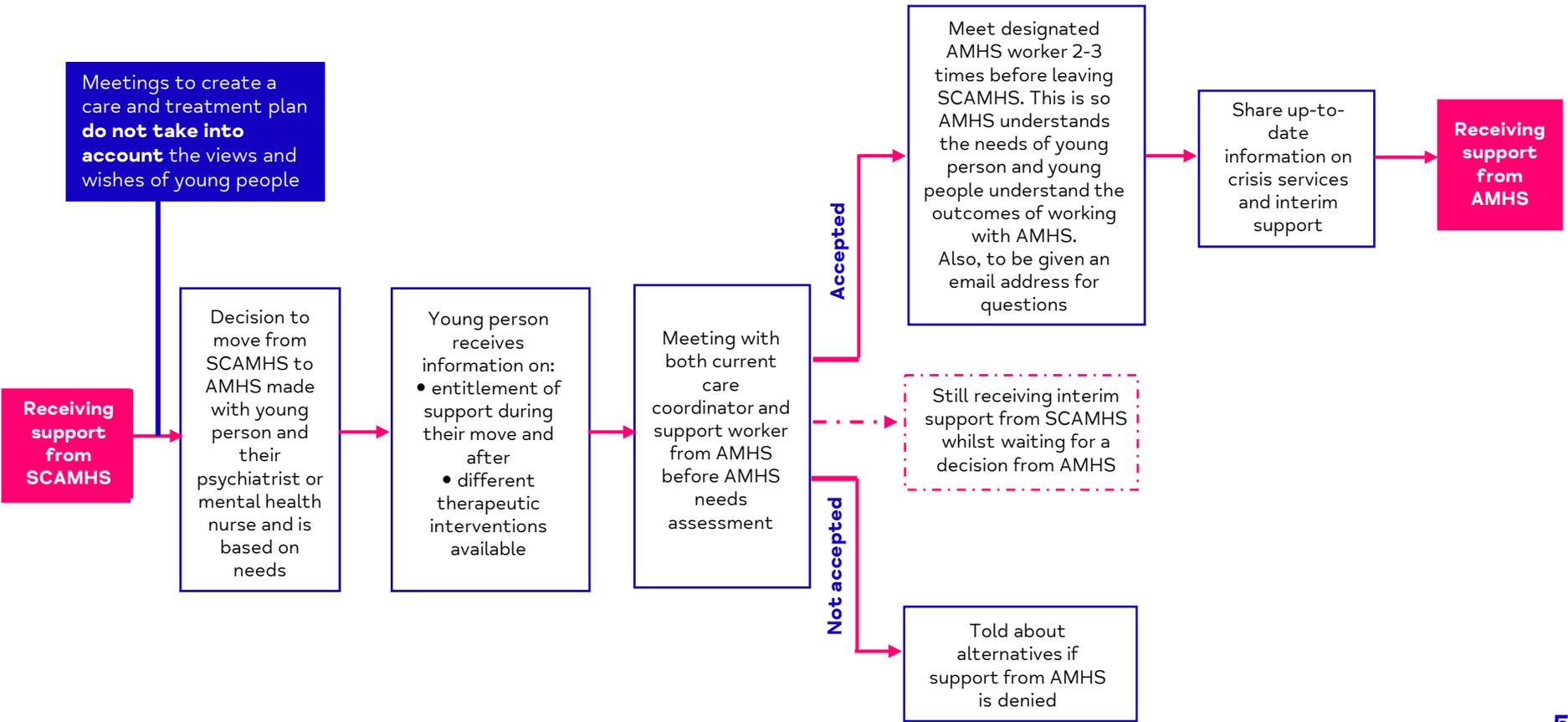
- Those young people who could recall having a care and treatment plan described this as something that wasn't created with them
- Young people don't feel the care and treatment plan meetings are person-centred, with some feeling that they only focused on their weaknesses
- There is also a lack of follow through of care and treatment plans, with young people not knowing where to even access them if they wanted to



I remember the meeting when we made it and I found that really difficult when we were making the care and treatment plan. I don't think I ever really used it that much, I don't know, I don't think it was that useful. I think I felt like it was just looking at all my weaknesses and I found that really hard.



PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why the care and treatment plans of young people are not person centered

The Mental Health (Wales) Measure 2010 states that all young people and their parents and carers should be involved in the planning, development and delivery of their care and treatment plan. The UNCRC says that young people have a right to be listened to in all decisions about them.

Suggested key questions

- What are the barriers that exist to young people and their carers being involved in the planning, development and delivery of their care and treatment plan?
- How can the meeting to develop the care and treatment plan ensure it doesn't focus on the weaknesses of young people?
- How can young people easily access their care and treatment plan?

Proposals for change from young people...

 Make young people aware of where they access their care and treatment plan

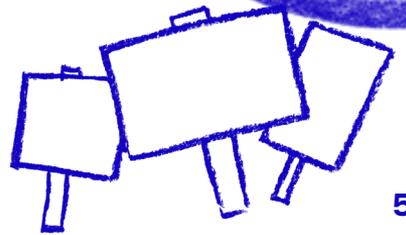
 Ensure care and treatment plans are flexible to change and that young people know this

 Ensure care and treatment plans are written in the young person's words

 Ask young people what format they want their care and treatment plan to be in

 Ensure care and treatment plans are always individualised and not generic

 Let young people know that their carers should also be involved in the planning stage



What it can look like if young people have a good care and treatment plan

“Yes, it [care and treatment plan] was quite useful because I could put my needs on it and my-, what kind of problems I need to address on it. And also, what to do if I was in a crisis. That kind of thing is quite reassuring to look at. My care and treatment plan, if there was a need of needing to go back into hospital or something.”



High thresholds for SCAMHS and AMHS referrals to be accepted

- Young people feel it is difficult to get accepted into SCAMHS and AMHS when it is clear they need support
- Meeting these high thresholds feels traumatic for young people, and if they are moving from SCAMHS to AMHS, this trauma is experienced twice

Thresholds are different for SCAMHS and AMHS

SCAMHS and AMHS having different criteria for acceptance



Thresholds are different for SCAMHS and AMHS

Young people should be receiving support from SCAMHS and AMHS when they have a clear need for support.

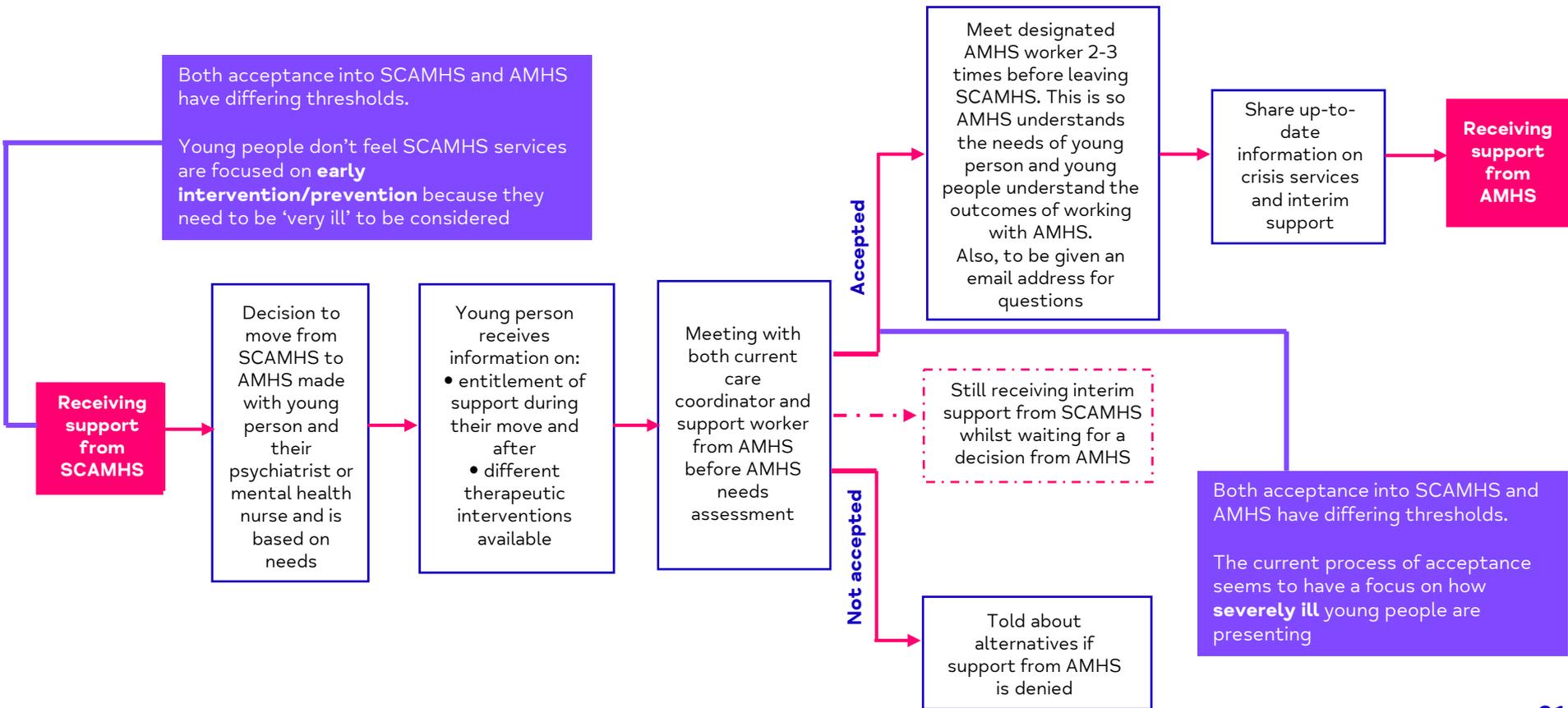
However, young people feel that the criteria to get accepted into both SCAMHS and AMHS is high, and they are often different from each other.

Key findings:

- Young people are aware of how difficult it is to get accepted into SCAMHS and AMHS
- Young people feel that while it is difficult to get accepted into SCAMHS, they do accept people with a range of mental health problems
- Whereas acceptance into AMHS feels like it is based on how severe and enduring a young person's mental health problem is
- Young people feel both services expect them to be very unwell to even be considered

“..It's weird because you're trying-, you know that the discharge date is coming up. So, you're trying to get everything in your head in order so that you're mentally well enough to be discharged. It's not going to be great, but at least you'll be able to survive it. But then you've also got to be a level of unstable so you can have that assessment appointment and then get care. There is the motivation for you to get well enough to be unsupported, but then also you know that if you're engaging with that successfully then you're not going to get support and it's just this weird little catch 22. Because if you're in therapy, you're kind of wanting to be getting better, or trying to. But then you have to go to those assessment appointments and have to be as ill as possible. ”

PAIN POINTS along the journey



DESIGN CHALLENGE > Review the criteria young people need to meet for acceptance into SCAMHS and AMHS and communicate this

The UNCRC says that all young people have the right to the best possible health and access to healthcare and it's important that the criteria for acceptance into SCAMHS to AMHS is as flexible as possible to take into account the variability of young people's mental health. Young people should be made aware of the criteria.

Suggested key questions

- How can the criteria for acceptance into SCAMHS and AMHS be flexible enough to meet the needs of young people?
- How can information on the expected criteria for acceptance be communicated to young people?
- What format do young people want to receive this information in?

Proposals for change from young people...



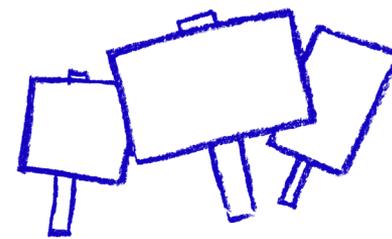
Develop a document or leaflet for young people which outlines clearly what the criteria to acceptance into both SCAMHS to AMHS is



Speak to a range of young people to understand the range of mental health problems they experience. This can help inform what the criteria for acceptance into SCAMHS and AMHS should be



If young people aren't accepted into SCAMHS and AMHS, explain the decision-making process and sign post them to other services that can support them



Proof of being unwell is sought

Young people are having to prove their mental health problems



Proof of being unwell is sought

Young people come across many barriers when seeking help for their mental health.

They feel they are being asked to prove they have mental health problems, yet another barrier they face when trying to move to AMHS.

Key findings:

- Some young people feel the process of moving from SCAMHS to AMHS allows healthcare professionals to ask them for proof of how unwell they are during the AMHS assessment
- This can be traumatic for young people as it leads to them thinking that they aren't 'mentally unwell' enough, and will ultimately be denied support

‘Sally’, 20 Cardiff

Transitioning status:

‘Sally’ was referred to AMHS, but her referral was unsuccessful

Sally accessed CAMHS services twice; first at the age of 12 and the second time when she was 15 following a suicide attempt and seeing the crisis team.

After trying multiple therapies and treatment for her PTSD, such as Eye Movement Desensitisation and Reprocessing (EMDR), Sally was assessed for autism, and went on to receive an autism diagnosis. Sally felt that because of this, CAMHS decided EMDR was no longer successful even though she was seeing a positive benefit and wanted to pass her onto autism services.

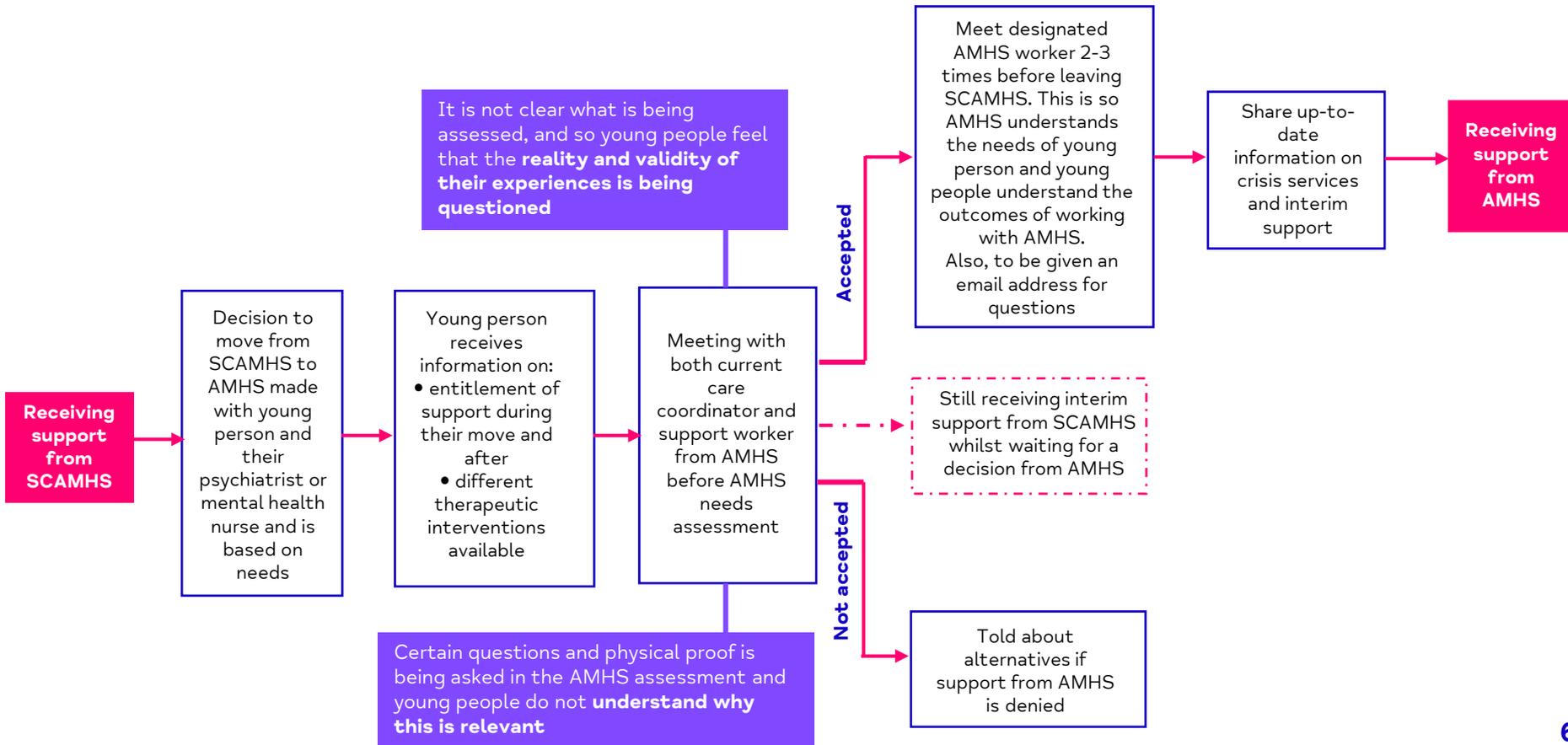
Sally managed to fight this and got referred to family therapy. Through family therapy, Sally realised there were a lot of blocks around PTSD and started individual trauma-based work. This worked significantly for Sally, but she felt aware that her time was running out in CAMHS as she was 17.

Sally was being prepared to move from SCAMHS and eventually had her meeting with AMHS. Sally was asked to show her self-harm scarring and felt like she could tell that AMHS thought ‘it wasn’t very much’. Sally came out of the meeting feeling like she wasn’t ‘mentally ill’ enough and was subsequently not accepted into AMHS.

“I remember being asked about self harm, or maybe I brought it up, I don't know, and how I'd been clean of it since my suicide attempt. But, you know, intrusive thoughts and all that still there. They asked if I had any scarring from it, and I'd, sort of, said, 'Like, it's very light.' Like, on the wrist, but I know it's there. They asked to see it and I was like, 'Okay.' And kind of rolled up my sleeve a bit and showed it to them and I could just, sort of, see in her face the, kind of, like, 'Well, that's not very much.' That was interesting to me. I left the appointment, kind of, like, knowing that I hadn't been mentally ill enough for it to have been a success. ☹️

Please note, pseudonyms have been assigned to young people for anonymity purposes

PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why young people are being asked to show proof of being unwell during the AMHS assessment

The UNCRC says that the best interest of the child must be the primary consideration in all decisions about them. Proof (through certain questions or physically) should not be sought or be a determining factor for future support.

Suggested key questions

- How can young people be reassured that their mental health condition is not in doubt particularly if they have been receiving treatment from SCAMHS?
- How can questions be framed so that they help healthcare professionals make an accurate judgement of the young person's needs without making them feel they are having to show proof of being unwell?

Proposals for change from young people...



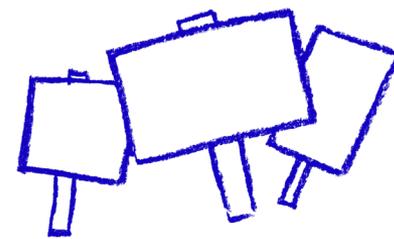
Reassure young people that their mental health condition is not in doubt



Ensure assessors have specialist mental health training



Think about the framing of questions that are asked in the AMHS assessment



Proof of still being unwell to continue receiving support

Good and bad days are
not being captured



Proof of still being unwell to continue receiving support

Many mental health problems fluctuate throughout young people's lives.

Young people feel that the assessments in SCAMHS and AMHS do not focus on how the presentation of their mental health problems can vary.

Key findings:

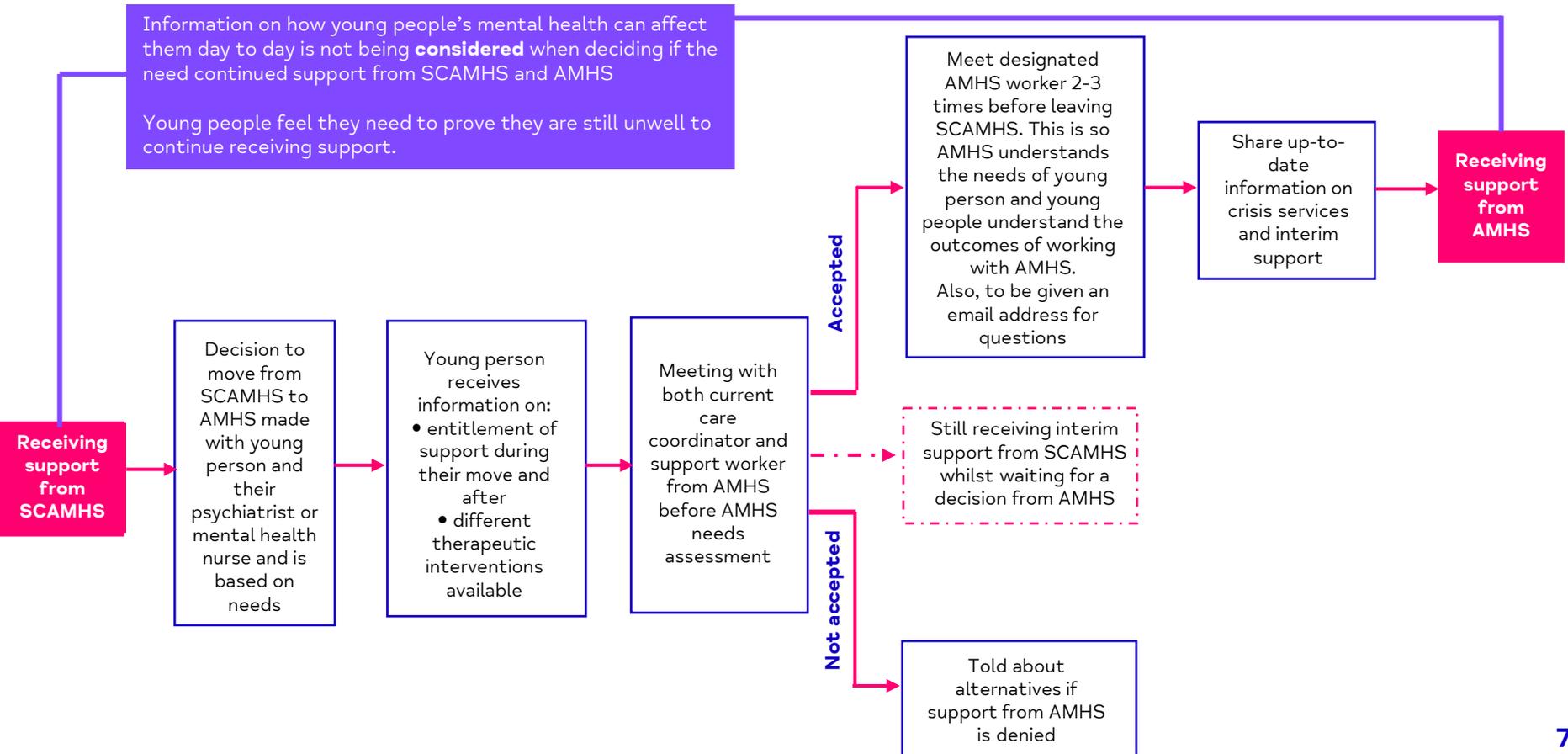
- Young people who do get accepted into SCAMHS and AMHS are made to feel 'lucky' that this is the outcome for them
- Young people's experience of having good and bad days is not being captured or considered
- Some young people avoid talking about their good days because if they are seen as 'engaging successfully' then the support will stop
- Young people feel they need to show they are still unwell otherwise their support will be cut off

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I think I've kind of got on a bit better since [being discharged from CAMHS and waiting for AMHS] because I've been doing stuff. I'm kind of scared that they'll say that I don't need the help, but for me I'm very up and down so I can be fine most of the time but then something will happen, and I'll be where I was, or I'll be much worse. Like I yo yo a lot, so I can be fine, or I can be really really happy, or I can be really, really sad and it's very mixed. So, what they might see on one day doesn't represent what I am the whole time and I'm kind of-, I'd say I was a bit scared that they'd see that and just be like, 'Well, you're fine, you don't need it' [support from AMHS].

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PAIN POINTS along the journey



DESIGN CHALLENGE > Enable young people's mental health fluctuations to be considered when deciding if they still need support

It's important that the process of deciding if a young person continues to receive support from SCAMHS to AMHS captures their realities of having good and bad days. The UNCRC says that all young people have the right to the best possible health and access to healthcare. Young people should not have to feel like they need to show healthcare professionals they are 'still unwell' to continue receiving support

Suggested key questions

- How can healthcare professionals be accurate when assessing how much a young person's mental health varies and how this impacts on their need for support?
- How can a culture be created where young people don't feel they will be negatively impacted if they are seen to be engaging with treatment before an assessment?
- How can healthcare professionals ensure that young people can communicate the varying presentations in their mental health?

Proposals for change from young people...



Provide a space where young people can speak openly about their good and bad days before an assessment



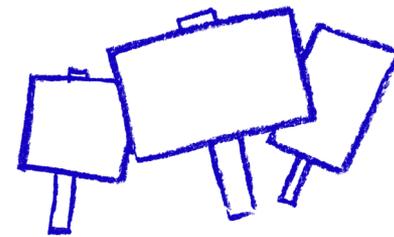
Understand that young people might mask their symptoms around assessors who they don't know. Therefore, consider having the young person's care team present so the young people feels more comfortable



Develop questions that capture the frequency and impact of bad days for different mental health problems



Ensure and guarantee young people that them talking about their good days or about how well they are engaging in treatment will not have a negative impact on the outcome of the assessment



Feeling abandoned and cut-off from SCAMHS

- Feelings of abandonment are felt by young people when they move from SCAMHS to AMHS due to not meeting their new care team enough
- Young people are left in limbo whilst waiting to hear back from AMHS with no one appearing to have responsibility for their ongoing support needs because they have been discharged from SCAMHS

Not enough interaction with AMHS before moving on from SCAMHS

Young people are meeting
their new AMHS team very
briefly



Not enough interaction with AMHS before moving on from SCAMHS

Young people are not having enough contact with their new care team in AMHS before they move from SCAMHS.

The process of moving from SCAMHS to AMHS does not always support multiple meetings and interactions which is what young people want and need.

Key findings:

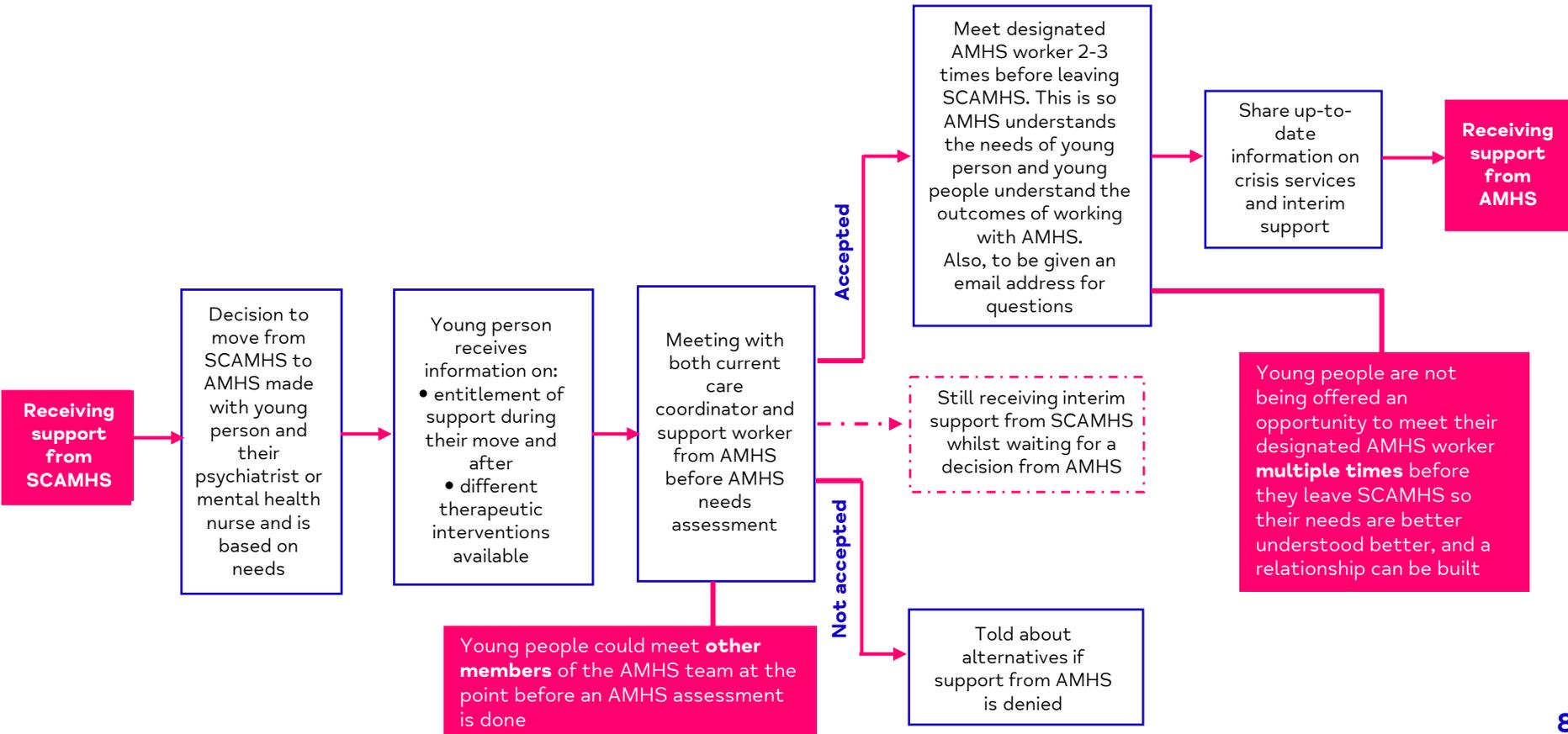
- Some young people feel that they are only meeting their new adult care coordinator briefly
- This doesn't feel sufficient for young people as they want to ensure that AMHS know what they need for their mental health needs
- The process of moving from SCAMHS to AMHS does not explicitly allow young people to meet their new care team from AMHS more than once
- Young people have already built a rapport with their care team within SCAMHS and moving onto AMHS can already feel daunting for young people

“

I did meet my adult care coordinator, I think, did I meet her once before I transitioned. My CAMHS coordinator and my new adult care coordinator in a room, kind of, met them both for about fifteen minutes and then that was it.

”

PAIN POINTS along the journey



DESIGN CHALLENGE > Find multiple points in the process of moving on from SCAMHS where young people can meet their new AMHS care team

Young people should be given the opportunity to meet their new AMHS care team more than once so they can start building a relationship with them before moving on from SCAMHS. This also provides an opportunity for young people to communicate their mental health needs.

Key questions

- What are the barriers to allowing young people to meet their new AMHS care team more than once?
- What time points do young people want to meet them?
- How often do young people want to meet them?
- How long do young people want to meet them for?
- What will help young people build a rapport with their new AMHS care team?

Proposals for change from young people...

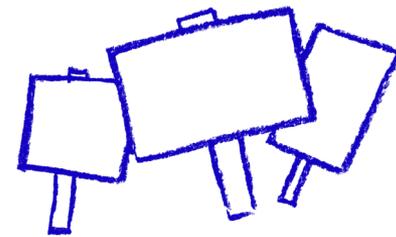


Work out the different time points in the transition process at which young people can meet their new AMHS care team



Have a designated lead person who provides 121 transition support to young people and is a link worker between SCAMHS and AMHS.

Ensure this lead person has knowledge of both SCAMHS and AMHS



What it can look like if young people get to know their new AMHS care coordinator before moving on from SCAMHS

  I got discharged from the PICU and all that. I then went to see my care coordinator in the community first time. That was, kind of, quite daunting. But also, my care coordinator, I also got to know her before I transitioned to adult services. So, I think about February I actually met my care coordinator when I was in child services, met my care coordinator who I'd have for adult services, so that was really helpful. I got to know her and all that and it was very good, really, because I didn't expect that to happen. I thought, when I'd go to adult services I would meet that person for the first time, but that wasn't the case with my transitioning period. I was getting to know my care coordinator in adult services. 

Lack of interim support between moving from SCAMHS to AMHS

Young people are left on
their own between moving
from SCAMHS to AMHS



Lack of interim support between moving from SCAMHS to AMHS

The process of moving from SCAMHS to AMHS is not as seamless as it appears for some young people.

Young people waiting to hear back about whether they are accepted into AMHS don't feel they receive enough support from SCAMHS.

Key findings:

- Young people feel that the support from SCAMHS is 'cut off' because they have turned 18, despite still waiting on a decision from AMHS
- For other young people, especially those on waiting lists, there doesn't appear to be anyone they can contact for support in the interim
- For other young people, the lack of interim support from SCAMHS has led to their mental health getting worse

‘Melissa’, 19 Conwy

Transitioning status:

‘Melissa’ did move from SCAMHS to AMHS but her treatment broke down as AMHS didn’t suit her needs

Melissa accessed CAMHS services and didn’t feel like she had a good or bad experience. She was given support but didn’t find it overly beneficial for her in the way she wanted.

Melissa described herself as someone who found it difficult to open up and talk and it took her a while to start getting comfortable in group therapy and counselling. The therapy was stopped just as Melissa got a chance to gain the benefits.

A month before turning 18, Melissa had the conversation about moving from SCAMHS to AMHS. She was told it was because she was turning 18 and ‘Melissa’ didn’t think she had a choice about the matter.

Melissa was referred to AMHS in February 2020, turned 18 in March 2020 but never met or spoke to anyone from AMHS. Melissa was not in a great place with her mental health and her mum called up AMHS in April and was told that they ‘hadn’t discussed it [the referral] yet’.

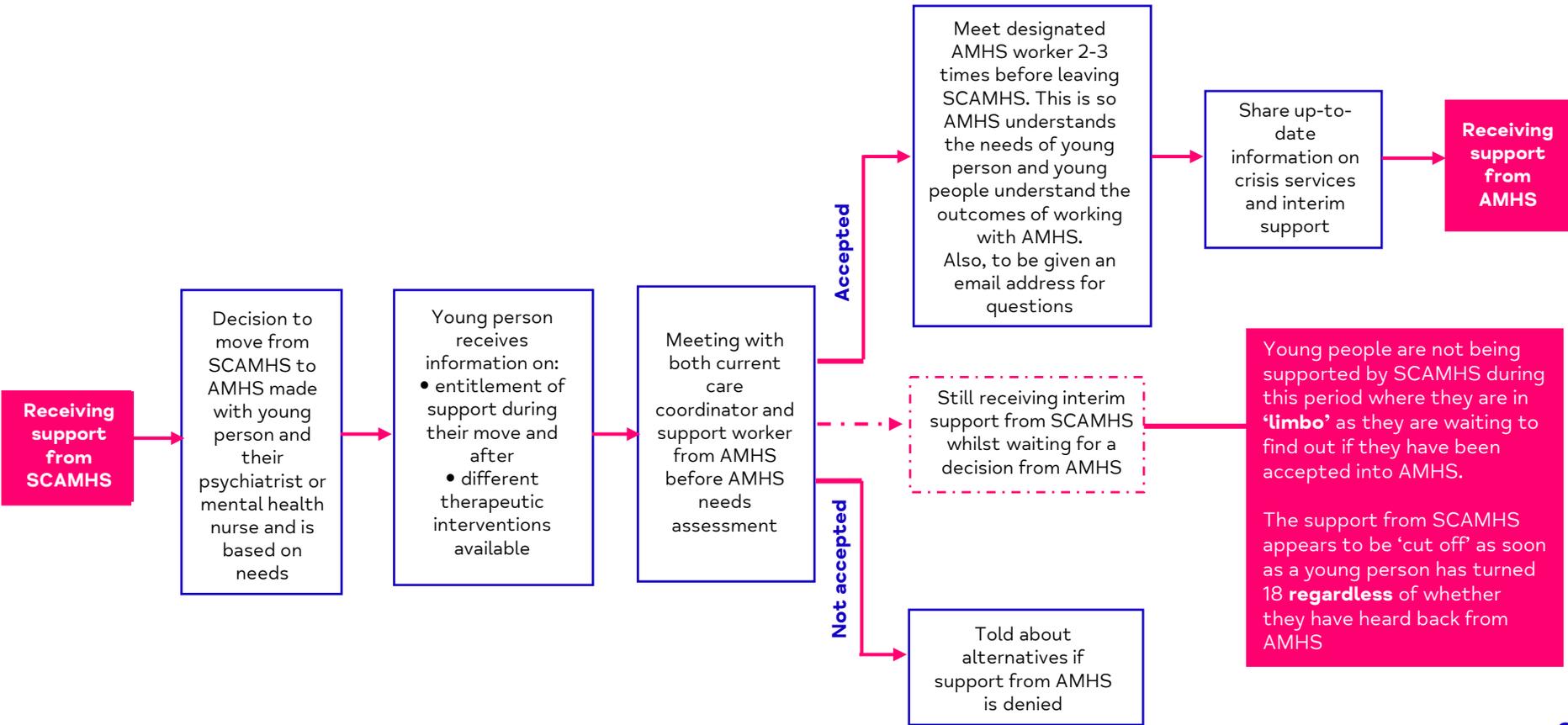
Melissa was subsequently hospitalised, and despite being put through as an emergency case, she still had no contact from AMHS. The first time Melissa heard from AMHS was in July 2020 following two hospital admissions.

Melissa received no interim support from CAMHS since she turned 18 and felt like she was ‘floating around’. After Melissa’s first hospitalisation, she was advised by the hospital to stop taking her medication (which she had been on from CAMHS and had a repeat prescription for) as it wasn’t appropriate for her.

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I was on medication from CAMHS and the only thing I had really was a repeat prescription, that was all that was left from’ CAMHS. But, after the first hospitalisation, I can't remember if it was April or May, it was one of those two, the hospital actually told me to stop taking the medication because they said that I shouldn't be on that medication. So, they told me to stop, and so I was receiving no support and I'd just stopped my meds. ☹

PAIN POINTS along the journey



DESIGN CHALLENGE > Enable young people to be supported with their mental health needs while they await a decision from AMHS

The Mental Health (Wales) Measure 2010 guidance says that a young person's care and treatment plan should continue until it's decided that they no longer need secondary mental health services. It is important that the process of moving from SCAMHS to AMHS ensures young people are provided continuous support and not left to feel abandoned. A lack of support from SCAMHS during the interim period should not be dictated by a young person's age or left so their mental health deteriorates.

Suggested key questions

- How can we make sure that the process of moving from SCAMHS to AMHS enables young people to feel supported when they are awaiting a decision from AMHS?
- What could this support look like for young people?

Proposals for change from young people...



SCAMHS continue to provide support to young people to the minute AMHS take over



Have a designated lead person who provides 121 transition support to young people and is a link worker between SCAMHS and AMHS.

Ensure this lead person has knowledge of both SCAMHS and AMHS



Ensure young people have a solid support in the community so young people feel supported if there is a gap between support.

This support bubble should include people the young person sees at least once a week and someone who would be able to notice behaviour changes without having to be told.



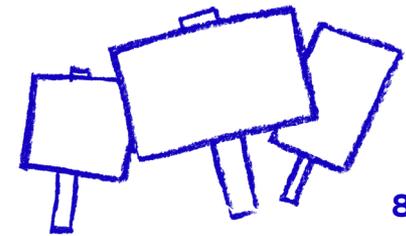
Provide support to parents and carers so they can best support their child if there will be a gap in support



Ensure conversations take place with the school if there is going to be a gap in support



Have the young person's old SCAMHS care coordinator check in with the young person 1-3 months after they have transitioned to AMHS





There should be some sort of system there where you have an adult team waiting, you have your old team, and there is a period of time where there's some meetings between the two of you.

A smoother transition, a graded transition where maybe you have a couple of appointments with one team, and then another. There needs to be no drop, I feel like that period of time where things drop is really hard.



Age still dominates decision-making process for moving from SCAMHS to AMHS

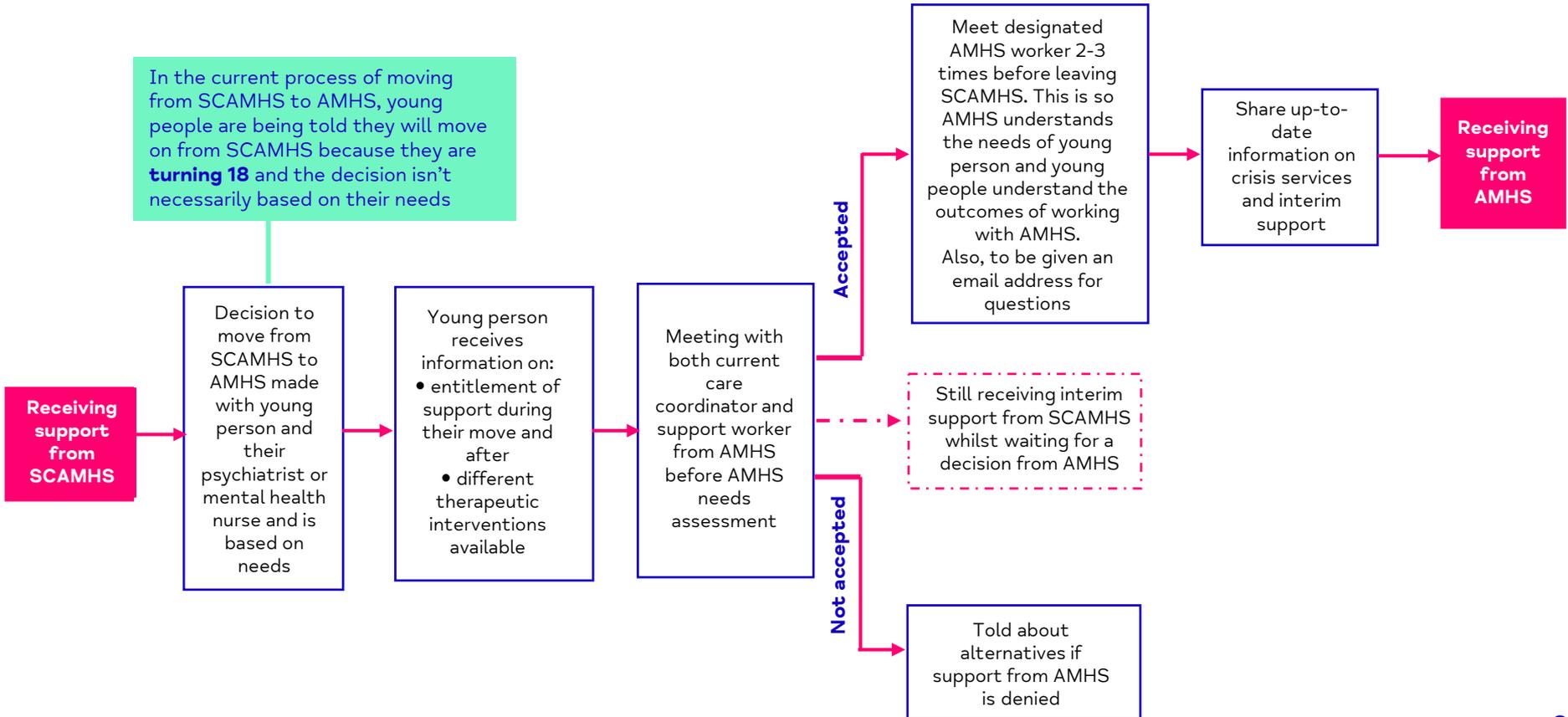
- Conversations about moving from SCAMHS to AMHS are taking place with young people before their 18th birthday
- Young people feel this isn't always the right thing for them, but feel they have a lack of choice because they are turning 18
- Young people don't feel heard as part of the process of moving from SCAMHS to AMHS and any decisions made about their care



It [the conversation about transitioning] was literally about a month before I actually transitioned because of Covid...my psychiatrist, he told me that I was going to be moving. They [SCAMHS] just, kind of, said that they were just moving me over and I didn't really have any say about it. They were just, like, 'Well we are moving you now.'

I don't agree that everybody should have to transition at the exact same time, because I don't agree that everyone who turns eighteen, is mature enough to transition. I know I definitely didn't think I was, because I think when you're in, like, a lot of pain, and your mental health is not great at all, you can't really process the change as much as somebody who maybe isn't in so much pain. 

PAIN POINTS along the journey



DESIGN CHALLENGE > Find out why the decision to move from SCAMHS to AMHS is more often than not based on young people turning 18 and not their specific needs

Welsh Government guidance says that the decision to move from SCAMHS to AMHS should be based on needs and not age.

Suggested key questions

- How can we make sure Welsh Government guidance is followed so the process of moving from SCAMHS to AMHS ensures that any decision to move on from SCAMHS is based on the young person's individual needs and not because they are turning 18?
- How can we ensure that the needs and wishes of the young person are taken into account when this conversation is taking place?
- How can we ensure young people feel they have a choice and feel comfortable challenging the decision to move from SCAMHS to AMHS if they don't think it isn't right for them right now?

Proposals for change from young people...



Support for young people should continue until they are 19/20 years old rather than stopping immediately at age 18



Have three separate services so young people don't transition straight from SCAMHS to AMHS. These could be:

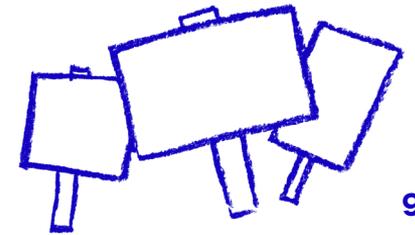
- SCAMHS
- Young adults
- AMHS



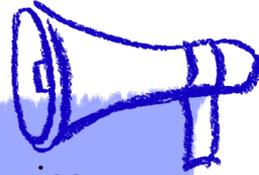
Tell young people that they do have a choice in the decision-making process



Think about the other changes going on in the lives of young people and take these into account when making decisions about transitioning



Conclusion

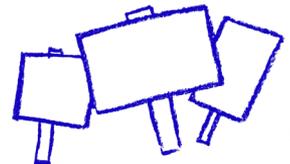


- Overall, the young people we spoke to told us that change needs to happen in the following areas:
 - a) The **information** giving process to young people
 - b) The **care and treatment plan** developing process
 - c) The **criteria for acceptance** into SCAMHS and AMHS
 - d) The **support offer** to young people when there is a **gap** between SCAMHS and AMHS
 - e) The **decision-making process** for moving from SCAMHS to AMHS
- Seeking **proof of being unwell** and **proof of still being unwell** to continue receiving support are indicators of a system which isn't currently meeting the needs of young people. This is how the process and system of moving from SCAMHS to AMHS is **making young people feel**. Achieving **positive change** in the areas mentioned by young people within this report has the **potential to avoid continuing this significant impact**.

Detailed recommendations

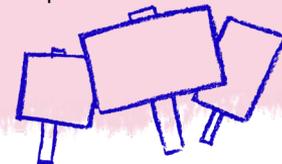
Overarching recommendation:

- Given its non-statutory status, it is vital that **Welsh Government and Local Health Boards** improve their ability to monitor and demonstrate that all principles and aspects of the Care Transitions Guidance are fully implemented. This is particularly important when ensuring that the process of moving from SCAMHS to AMHS for young people is based on their needs, and not on their age.



Underpinning recommendations

- **Right to be heard and taken seriously:**
- **Welsh Government and NHS Wales** should ensure that the current Care Transitions Guidance is amended to better reflect the importance of the voice of young people being listened to and heard. An explicit reference to Article 12 of the UNCRC should be included, alongside how this can and will be achieved in practice.
- **Welsh Government** should immediately ensure that:
 - a. As a matter of urgency, local transition workers guarantee that the voices of young people are sought, listened to, and inform both their own care pathway and service improvement locally.
 - b. Each local transition protocol includes a participation strategy and platforms/opportunities for young people's voices to be heard are developed immediately.
 - c. Local Health Boards use processes currently available to them to enable the sharing of good practice on involving and listening to young people and ensure the workforce is supported to achieve real change.
- **Welsh Government** should also work to ensure that:
 - a. Local Health Boards are required to audit and monitor the level of involvement of young people, both in their individual care journeys and in service improvement processes. SCAMHS and AMHS should regularly collect patient satisfaction surveys and use these to improve service planning and delivery. Young people should also form part of service review measures and contribute to co-designing service improvements.
 - b. Local Health Boards develop appropriate systems to ensure learning is implemented. A reporting requirement should be secured to achieve this under any revised national strategy for mental health in Wales.



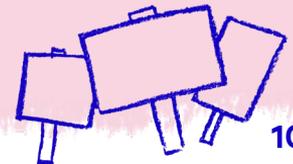
Underpinning recommendations

- **Right to be heard and the role of Advocacy:**

- **Welsh Government** should explore all avenues to extend the right to advocacy to young people receiving secondary care mental health services, with clear and urgent timescales for delivery. For example, Welsh Government could consider extending Part 4 of the Mental Health (Wales) Measure 2010 to ensure that young people moving from SCAMHS to AMHS can access support from an advocate. Welsh Government should commit to comprehensively resourcing this expansion.

- **Right to Information:**

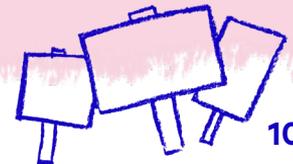
- **Local Health Boards** should urgently audit the information available to young people on moving from SCAMHS to AMHS in their area.
- **Local Health Boards** should ensure that the information available to young people on moving from SCAMHS to AMHS in their area is always co-produced and reflects what information young people say they want and need.
- **Local Health Boards** should better enable transparency and accountability by ensuring that their local transition protocol is known and understood by young people and their families/carers, and is made available and accessible upon request.
- **Welsh Government** should better enable transparency and accountability by ensuring that the results of any co-review of the current guidance are communicated to young people and their families/carers to ensure a good understanding of national service requirements.



Underpinning recommendations

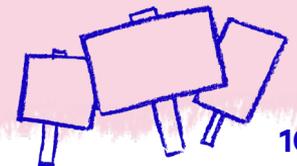
- **Right to good health and healthcare:** (support on discharge)
 - **Local Health Boards**, alongside all relevant partners, should ensure that a comprehensive, needs-led package of support is guaranteed for any young person discharged from SCAMHS. Built around their care and treatment plan (CTP), this should be developed, with the young person, to identify the best options available to them through good discharge planning.
 - **Local Health Boards** must ensure that all care and treatment plans for young people are fully co-produced, understood and include information, tailored to the particular needs of the individual, on where and how to access support when required. The care and treatment planning process should effectively prepare young people for discharge and assure them that they remain fully supported by the wider mental health system, whenever they need it.
- **Right to good health and healthcare:** (High thresholds from SCAMHS and AMHS)
 - **Local Health Boards** should ensure that thresholds for accessing both SCAMHS and AMHS are known and well understood amongst young people and their families/carers.
 - **Welsh Government and NHS Wales** must look at how thresholds align between SCAMHS and AMHS to ensure young people with continuing mental health support needs don't fall through any arbitrary service gap.
 - **Welsh Government and NHS Wales** must urgently bring forward proposals for a mental health service that supports children, adolescents, and young adults up to the age of 25
 - **Welsh Government, alongside all relevant partners**, should ensure that the principles of a 'no wrong door' approach⁶ are extended to young people aged 18 and over, moving from SCAMHS to AMHS.

⁶ Children's Commissioner for Wales (2020) *No Wrong Door: bringing services together to meet children's needs*. Available at: <https://www.childcomwales.org.uk/publications/no-wrong-door-bringing-services-together-to-meet-childrens-needs/>



Underpinning recommendations

- **Right to good health and healthcare:** (Feeling abandoned/cut-off from SCAMHS)
 - **Welsh Government and Local Health Boards** should ensure that no young person assessed as in need of AMHS is discharged from SCAMHS before this support is actively in place.
 - **Local Health Boards and NHS Wales** should work at pace to ensure that the period of joint working expected of both SCAMHS and AMHS is clearly enforced and guaranteed for every young person.
 - **Local Health Boards** should ensure that young people moving from SCAMHS to AMHS are not negatively impacted by the existence of AMHS waiting lists, but instead receive continued support from SCAMHS and are fast tracked, as appropriate.
- **Right to a Care and Treatment Plan:**
 - **Welsh Government with Local Health Boards** must review local compliance with Part 2 of the Measure in its application amongst young people in receipt of SCAMHS. This should support local capacity through exploring compliance by case numbers per care co-ordinator to identify gaps, areas for improvement, and ensure that the necessary actions are undertaken to guarantee full compliance.
 - **Welsh Government** should action at pace, the specific recommendation set out within the Duty to Review Final Report to improve the accessibility and applicability of CTPs to all service user groups.
 - **Welsh Government with Local Health Boards** should provide suitable training on how to co-produce a SMART CTP and ensure mechanisms to monitor its application in practice are in place.



If you need support:

Mind's Information Hub for Young People

When you're living with a mental health problem, or supporting someone who is, having access to the right information is vital.

<https://www.mind.org.uk/information-support/for-children-and-young-people/>

Mind's Information on Moving to Adult Services

Mind's guide on what to expect when moving from child to adult mental health services, and what to do if things don't go the way they should:

<https://www.mind.org.uk/information-support/for-children-and-young-people/moving-to-adult-services/>

**For any questions or further detail
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