

Centring Young People in Mental Health Research

McPin
Foundation

Transforming
mental health
research



Youth-led Approach

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Research
England

About this resource

This resource has been produced through a partnership between The University of Birmingham (UoB), its Institute for Mental Health (IMH) and their Youth Advisory Group (YAG), and the McPin Foundation's own Young People's Advisory Group (YPAG).

Our aim is to put young people at the centre of mental health research that directly affects them through promotion of **best practice** and **shared learning** in youth involvement. Through scoping work, 1-1 consultations, surveys, joint meetings between the UoB IMH YAG and McPin YPAG, youth-led presentations/discussions and smaller working group meetings, we have reviewed current practices in youth involvement in mental health research. We've put those learnings into practice ourselves, and now we're sharing what we have learnt in the form of **three resources**.

The purpose of this resource is to share our learnings and act as a talking point for the **youth-led approach** when involving young people in mental health research. This resource could be useful for other youth involvement leads, those planning on setting up their own YPAG, those already running a YPAG, researchers planning on working with YPAG members, as well as young people interested in involvement work. We note that this resource should not be used as definitive guidelines, with youth involvement in mental health research continually evolving and ultimately highly context-dependent.



What have we learnt?

The youth-led approach engages young people in decision-making, and ensures they have the skills to feel confident in such roles and beyond through appropriate training and development.

“

Being a YAG member has given me so many new skills and abilities; understanding the research process, problem-solving, being reflective, offering constructive feedback on proposals and article drafts etc, confidence and communication skills. By using my experiences to shape research, it's taught me to believe in myself and the power of my own lived experiences. It's never felt like 'work' – it's always felt fun, interesting and engaging due to meetings being relaxed, informal, inclusive spaces where everyone is welcomed regardless of lived experience, personal characteristics or existing research knowledge. When a group of engaged young people all come together to help develop research, it's a very empowering and special thing to be a part of!

-Lizzie

”

When in doubt, just ask the young people!

In the context of mental health research, what does 'youth-led' mean to you?



The following pages cover the **4 key messages** young people highlighted as important for achieving a youth-led approach when involving young people in mental health research:

1. Maintaining Engagement

ENGAGE

- Ensure a welcoming and **inclusive atmosphere**, and the creation of a space in which young people **feel safe** to disclose their lived experiences - see also “Ensuring Diversity & Inclusivity” and “Creating Safe Spaces” resources.
- Involve young people as **early as possible**, ideally at the research proposal development stage allowing them to shape the research from start to finish.
- Ensure the knowledge, skills and experiences of young people are being **listened to, acknowledged, valued and utilised**.
- **Thoroughly plan** meetings / involvement activities to avoid them lacking objectives, meaning or purpose, which could leave it feeling tokenistic – dedicate the majority of the time to the involvement activity and listening to the young people, striking a balance in discussion points between those that may require disclosure of lived experience and those that don't.
- **Be aware of young people's other commitments** and **manage expectations** – make it clear in advance what the commitments for each involvement activity will be, guide young people on what level of involvement is required e.g., advisory, co-design, co-production, young person co-researcher, and be transparent throughout.



“

Researchers should have genuine beliefs that they need something from us – not just something they ought to do. What do they want us to add to the conversation?

”

1. Maintaining Engagement

“ You don't want to feel used for your information – it feels extractive. ”

- **Listen to the needs of young people**, with **accessibility and flexibility** across the board - from communications, to meeting timing, travel, location, environment and other practical arrangements, to the involvement activity itself with a range of different ways to get involved.
- Put structures in place that will help **build relationships** between the youth-involvement leads / researchers and young people e.g., ground rules, terms of engagement, introductions, icebreakers, consistency of facilitators, facilitators sharing their own experiences, integration into the research community; as well as optional formal and informal opportunities / social events for young people to get to know each other too.
- Ensure the time and effort of young people is **appropriately reimbursed, and recognised**.
- **Reciprocity and mutuality** – provide additional opportunities that are not always solely seeking lived experience contributions from young people e.g., mentoring, training and development.
- In the longer-term, having the opportunity to be involved in a variety of different projects and involvement activities.
- Foster a culture of reflection and improvement – actively encourage feedback from young people on facilitation and involvement activities and reassure that it will be taken constructively for improvement, and not seen as a complaint.
- Aim for a feeling of being a part of something / having a group identity e.g., McPin YPAG / UoB IMH YAG.

“ We have time to spend time with the researchers and break down the power dynamics between us, which means that we are able to contribute more – and can in some cases mean more valuable research. ”



2. Good Communication

- **Variety of methods of communication** for during and between involvement activities - email, videos, audio / WhatsApp voice notes, online space / discussion board for more informal advice and asks e.g. Slack or Discord.
- It is important to ask young people which method of communication they would prefer to increase accessibility and engagement.

**Establish
ways of
working**

Accessible

“ Young people can have lots of different skills and experiences, but this does not mean they will automatically understand industry terms or jargon. Be sure that language does not become a barrier. If any resources are shared that include jargon, there ought to be an explanation of specific terms at the start of the document - like a glossary. ”

- **Avoid academic jargon and acronyms.**
- Ensure the language used is **understandable** so young people have the context to be able to meaningfully contribute, it's **appropriate** for the age range, and **inclusive**.
- Consider the use of **various formats**.

2. Good Communication

- Provide **follow-up** for young people to know where their input fits in, what it is contributing to, and how it is informing decision-making, research plans and other activities.
- This extends to once the project has finished with sharing of results and overall impact of their involvement.

- **Keep in touch** and provide regular updates between meetings / involvement activities letting young people know what's going on in the background in a consistent way so young people know when and where to expect it e.g., monthly newsletter / involvement bulletin via email.
- **Provide reminders** of what was previously discussed for longer projects with larger gaps between meetings / involvement activities e.g. taking and sharing of minutes, which can also help keep young people included if they were unable to attend.
- Consider the **frequency** of communications / meetings / involvement activities: too often is a burden, too seldom and young people will lose interest.
- **Transparency** is appreciated, can help to manage expectations and avoid disappointment in the long-run, and facilitate shared decision-making.
- E.g. what can and cannot be changed about a project, changes in involvement plans and why, if a situation has come up or indecisive about something ask the young people!

Complete
the feedback
loop

Consistent &
transparent

“ We need to know where we are at, bring us into the project, otherwise you feel detached from a project by only meeting 4 x a year. ”

3. Collaboration

“Don't underestimate young people - whatever role there is in involvement of young people in mental health research, if you provide appropriate training and support, young people can do it.”

- **Shared-decision making** from the beginning is important. However, there needs to be good preparation and enough of an initial plan to get started on for young people to feel confident to take more of a lead, especially in light of their other commitments.
- Find a balance between pre-planning / putting structures in place and the flexibility required for young people to also be involved in decisions.
- There should still be opportunities for young people to get **involved at whatever level they feel comfortable**, only taking more of a lead if they want to.
- Of those young people interested in youth-led opportunities many expressed that, rather than researchers coming to young people, young people could proactively pitch projects to researchers, who would then help them to formulate the research proposal.
- Use the youth-led approach as an opportunity to unleash imaginations and **work more creatively** – ask the young people how they would like to be involved and the best approaches to use.

“Young people should have the option to lead/take part in youth-led opportunities - but, if they don't want to, that's also fine!”



What are the current challenges and barriers that we need to overcome to achieve more youth-led activities?



4. Training and Development

During

- Provide more **project-specific training** as and when required, as well as additional training and development opportunities working to the young peoples' strengths and interests.
- Ideally training with an award scheme and/or leads to widely recognised qualification / accreditation providing tangible evidence of skills developed e.g. Mental Health First Aid.
- It is important to regularly ask young people what training and development opportunities they would be interested in.
- However, youth-involvement leads and/or researchers who have been in the roles and know what training and development would be required for such roles should also take some initiative.
- Focus on **up-skilling and transferable skills** that are beneficial to all young people no matter their background or what future goals or careers they may have.

“

Young people don't yet know exactly what youth-involvement leads and/or researchers do day-to-day having not been in the role – hard to know what training they would need without “a menu” as such e.g., “research skills training” is so vague and broad. Sometimes youth-involvement leads and/or researchers need to take the initiative with what training they could provide. I also think this is where shadowing is so important – seeing what they do day-to-day can help young people know what training they'd require and like to focus on.

”



4. Training and Development

Up-skilling and transferable skills

- **Shadowing or mini-placement opportunities** to learn more about the day-to-day responsibilities of youth involvement leads / researchers and develop practical experience.
- Inclusive and accessible to those with non-academic backgrounds.

- **Peer support / mentoring** of newer or younger members of a YPAG or of those new to youth involvement in mental health research.
- Researcher-young person 2-way mentoring to enable both parties to work closely together and learn from one another.




- Allow young people to **take on responsibilities** and roles e.g., co-facilitating meetings / involvement activities, which can also help to ensure young people's voices are heard and integrated.

- If presenting mental health research with a large youth involvement component at local, national, or international conferences – invite the young people involved to attend and **co-present** their work.
- Involvement in increasing awareness of and training in youth involvement in mental health research.

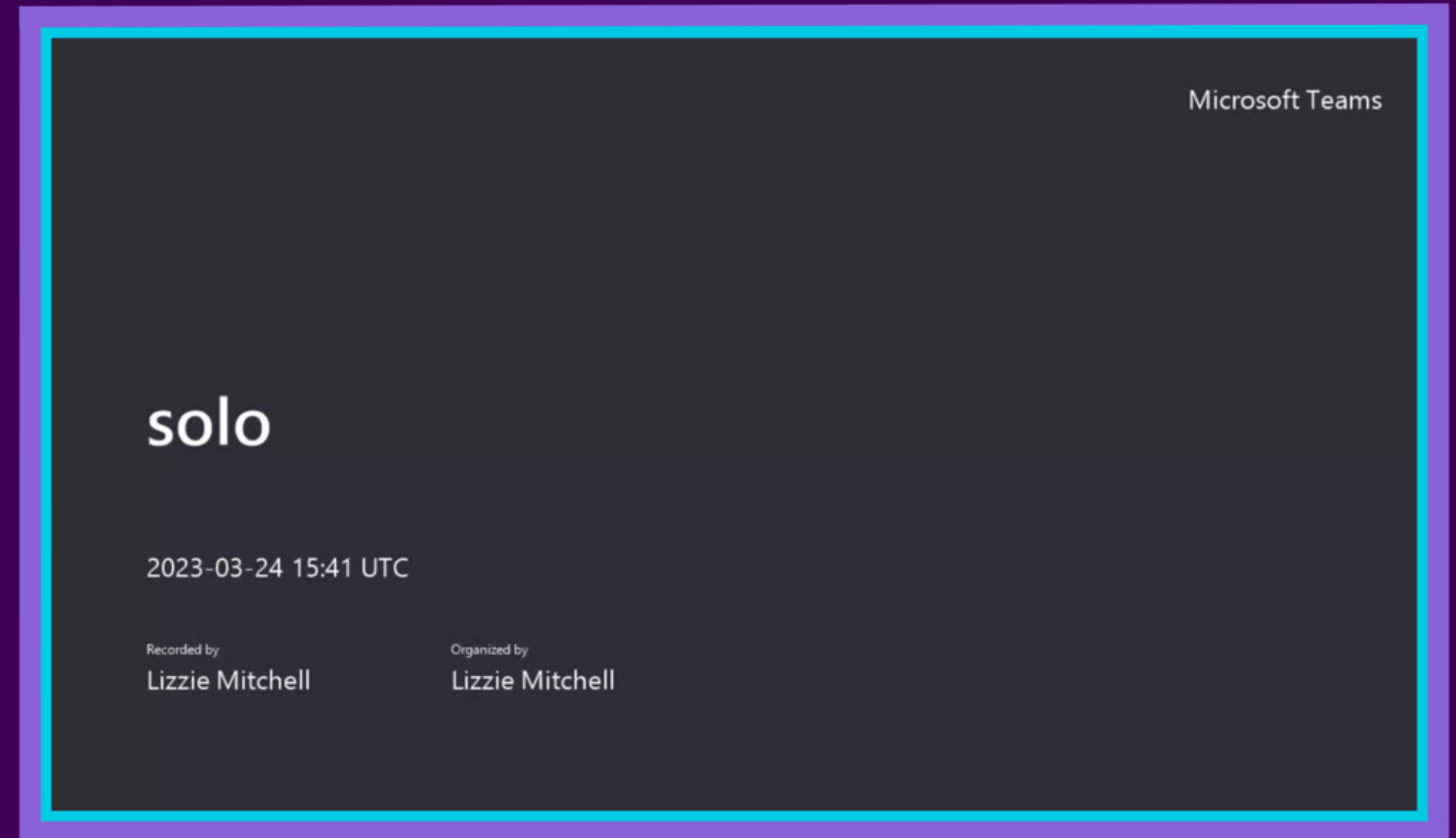
- **Review** research proposals, contribute to publications as co-authors, write blogs.

4. Training and Development

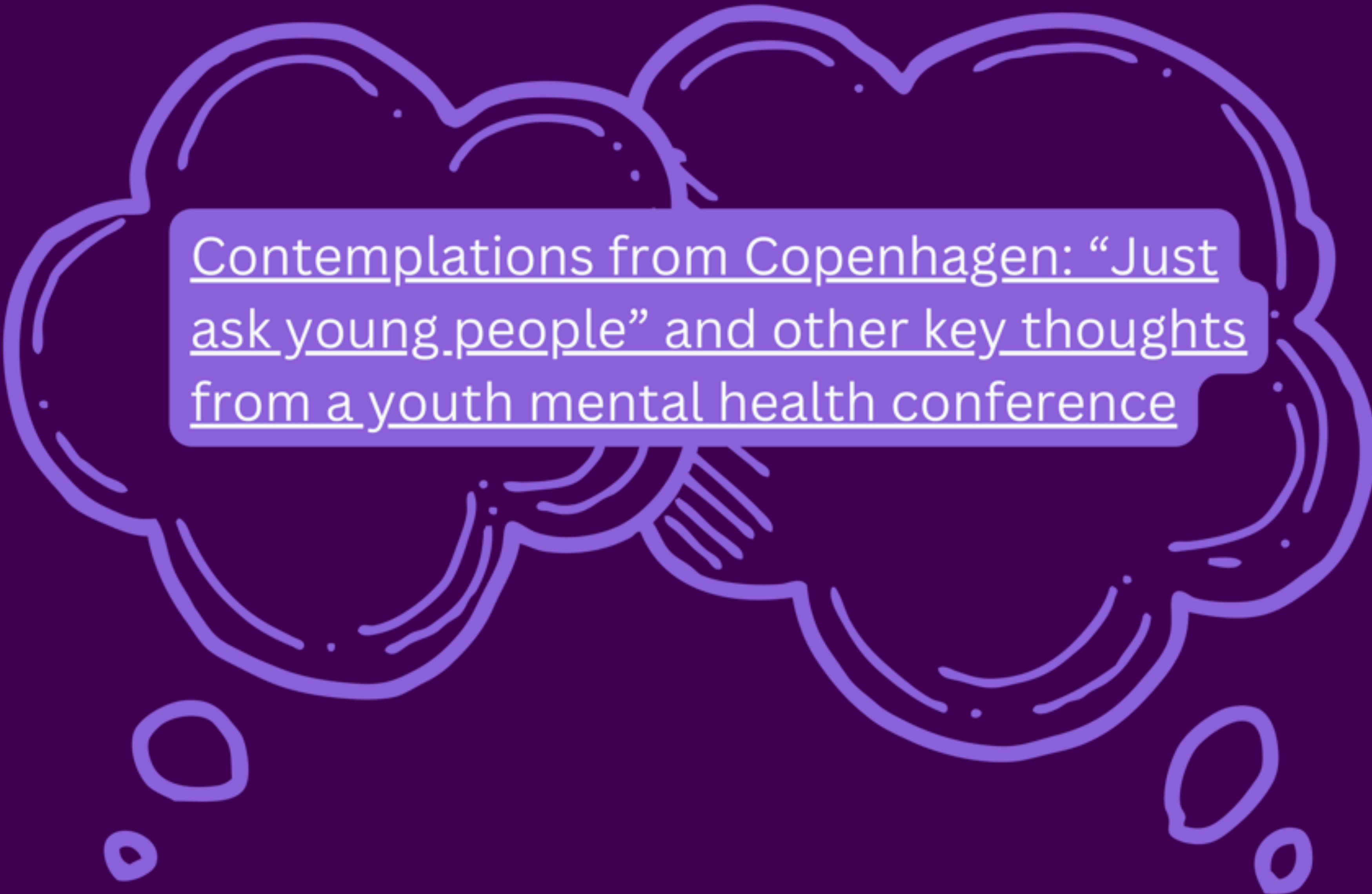
During this project, UoB IMH YAG and McPin YPAG members had the opportunity to attend and co-present at the International Association for Youth Mental Health Conference 2022, Copenhagen - young people and staff members share their reflections here in a poem, presentation and blog.



Flying on a plane to a destination unknown,
To a capital city that's near yet far from home,
Surrounded by my YAG homies, we're all full of joy,
Not gonna lie I was gassed, it was as if I was a little boy,
The experience was amazing,
The gym, conference and more,
Although the conference food left something to be desired,
Most under-25s felt it was poor,
It was beautiful to represent my group,
In a presentation that was youth led,
We overcame the nerves and excitement,
That were running through our heads,
During the conference we looked around and,
There weren't many like us,
But we stayed hanging out in the back,
And we didn't make much fuss,
We made Birmingham proud,
As we stood tall and spoke,
At the end everyone clapped and cheered,
They even enjoyed our bad jokes,
So the future is bright,
As we will always stand together,
Because even though some subjects are heavy,
Our bond makes them float like a feather,
Whatever the journey holds,
We will always stay ready and busy.



-Lizzie



Contemplations from Copenhagen: “Just ask young people” and other key thoughts from a youth mental health conference

4. Training and Development

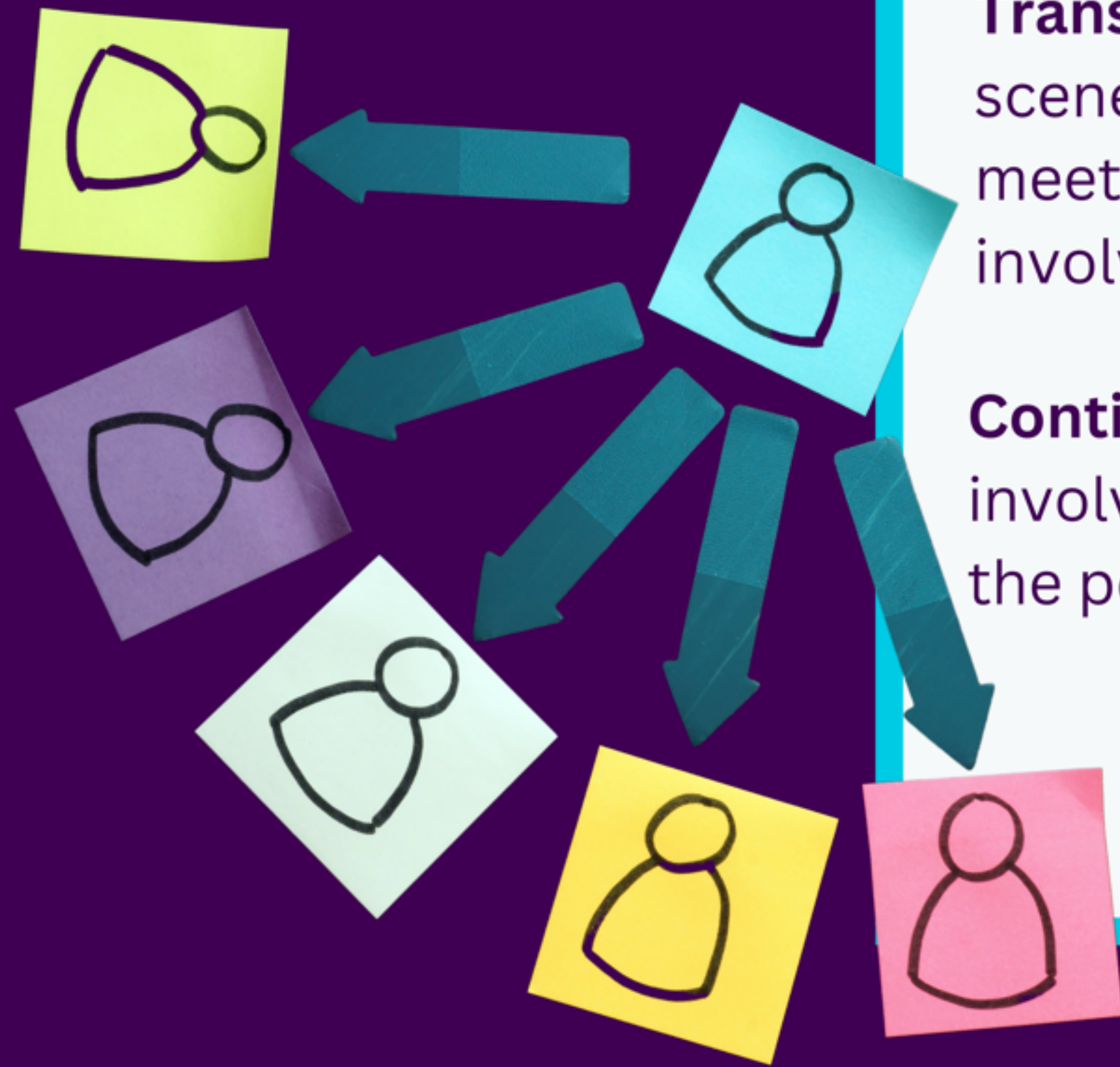
Transition

The term “young people” typically refers to the age group 14 – 25 years, with transition referring to the period where a young person turns 25+, aging-out of a YPAG into more “adult spaces”, be it older advisory groups, researchers or youth-involvement leads themselves or other employment. Young people discussed the ways in which youth involvement leads and/or researchers can support this transition period:

Transitional / alumni roles – older young people starting to take on more responsibilities e.g. behind the scenes running of a YPAG, helping recruitment and sitting on interview panels, planning and co-facilitating meetings / involvement activities, peer support / mentoring those of a younger age and/or new to youth involvement in mental health research.

Continued support and advice - once transitioned into sometimes less welcoming and accessible adult involvement spaces, where lived experience seems to be more operationalised and the worth and value of the person is based solely on their lived experience.

Alumni newsletter - updating those young people who have aged-out what work is going on, progress, other involvement opportunities.



4. Training and Development

Transition continued

Careers guidance – from youth-involvement leads / researchers, careers coaches, contact and hold workshops with those working in different careers across the mental health sector, portfolio / CV development, YPAG career support group.

Career opportunities:

- Including young people as co-applicants / young people as co-researchers on long-term projects.
- Paid apprenticeships supporting university functions across research and professional services.
- Possibility of these becoming formalized positions, “Research Ambassadors”, and/or more formalized progression routes into desired careers, both research and non-research e.g., inclusion in internal recruitment.
- Particularly focusing on young people from non-academic backgrounds, helping them to enter certain fields via non-traditional routes.
- Make use of any established networks of contacts and keep an eye on and share relevant resources, opportunities and job posts with young people.



Entering employment in mental health research, services, or charities is highly competitive. Many people use voluntary work to gain experience and bolster their CV. Working with McPin’s YPAG offered a brilliant alternative opportunity to gain experience, and develop insight in the mental health sector. There are no educational or skill barriers to engaging with involvement work, because all you need to take part is lived experience. Academic research, in particular, is considered a highly prestigious area. Without engaging in involvement work, there is no way I would have the insight, or input into, the kind of research projects I’ve been involved with. As such, involvement work can carve out a really useful space for younger, less experienced people. I would hope it could also offer opportunities for people with less social or educational privilege. Involvement experience was definitely valuable in showing my engagement with, and interest in mental health, when applying for my first job as a Support Worker at a local Mind. Often it’s these first steps into a sector which are the hardest. And doing involvement work was so beneficial in making that first step.

-James





The McPin Foundation
McPin Young People's Network
UoB IMH
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Sign-up to the McPin YPN
Research involvement opportunities
Involve young people in your research

Make sure to take a look at our 2 other resources on youth involvement in mental health:

[Ensuring Diversity & Inclusivity](#)
[Creating Safe Spaces](#)

Acknowledgements

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Further resources

NIHR INVOLVE Guidance on co-producing a research project

NIHR INVOLVE A Guide to Actively Involving Young People in Research: For researchers, research commissioners, and managers

NIHR INVOLVE Involving children and young people as advisors in research: Top tips and essential key issues for researchers

NIHR INVOLVE Reward and recognition for children and young people involved in research – things to consider

NIHR Oxford Health BRC - Patient and Public Involvement - Young People's Involvement

Co-producing research with youth: The NeurOx young people's advisory group model

NeurOX YPAG: Focus on Impact

NeurOX YPAG: Summary of Projects & Outputs

Independent Storytelling Evaluation of Involvement in the NeurOX YPAG

Knowledge Institute on Child and Youth Mental Health and Addictions - Walking the talk: A toolkit for engaging youth in mental health

Knowledge Institute on Child and Youth Mental Health and Addictions - Quality standard for youth engagement

NCB Guidelines for Research with Children and Young People

NCB Young People in Research: How to involve us

Barnardo's - Young Researchers: Guidance

Barnardo's - Young Researchers: Toolkit

Barnardo's - Involving children and young people in recruiting new staff

Barnardo's - Recognising, rewarding and remunerating young people

Wellcome Trust - Involving young people in health research

camh INNOVATE Research Youth Engagement Guidebook for Researchers

Emerging Minds enuture Youth Engagement Guide

Orygen - Resources - Youth Partnerships in Research Toolkit

A guide to peer research with young people

Young co-leads share insights from shaping a peer-led research project

The Mental Elf - Coproducing qualitative mental health research with young people

From participants to partners: reconceptualising authentic patient engagement roles in youth mental health research

The Youth Patient and Public Involvement Café-A youth-led model for meaningful involvement with children and young people

Reflections, impact and recommendations of a co-produced qualitative study with young people who have experience of mental health difficulties

Involving young people in health promotion, research and policy-making: practical recommendations

Co-designing for mental health: creative methods to engage young people experiencing psychosis

Getting it right! Enhancing youth involvement in mental health research

Mind/nef - Co-production in mental health: A literature review

