Centring Young People in Mental Health Research

McPin Foundation | Transforming mental health research

YOUNG PEOPLE'S NETWORK

Ensuring Diversity & Inclusivity

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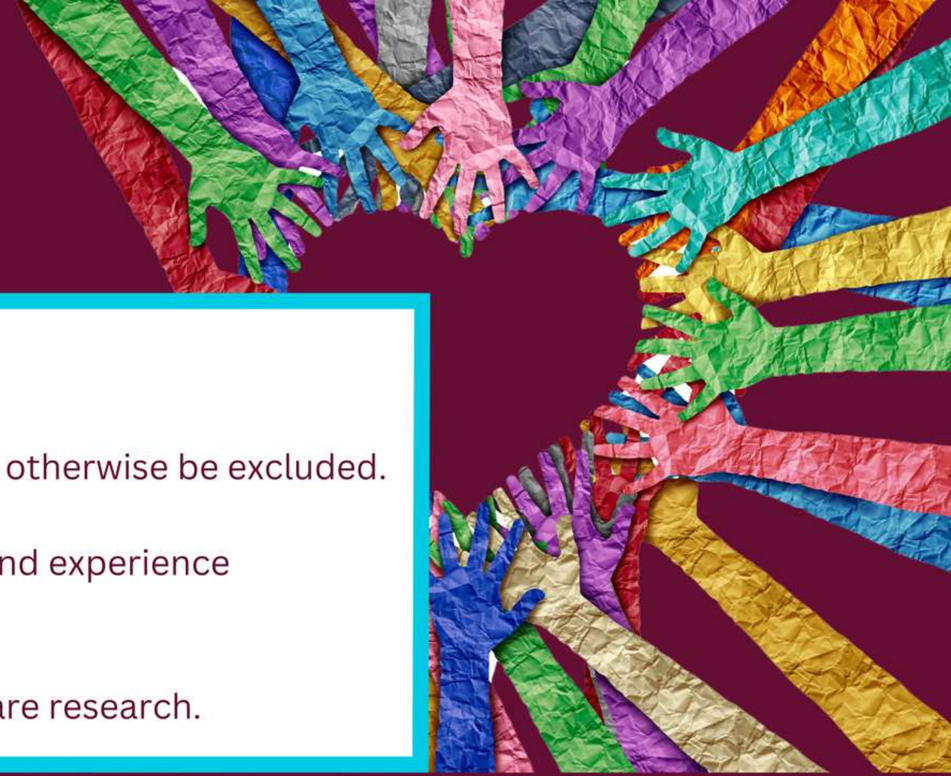
About this resource

This resource has been produced through a partnership between The University of Birmingham (UoB), it's 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 & 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 **ensuring diversity and inclusivity** 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?



A few definitions

Diversity - involving people from a range of different backgrounds.

Inclusivity - providing equal access to opportunities and resources for people who might otherwise be excluded.

Intersectionality - consideration of all the factors that might impact a person's identity and experience together, rather than considering each in isolation.

Under-represented – those groups of people who are frequently excluded from health care research.

Which groups of young people are currently under-represented in youth involvement in mental health research?

Without diversity and inclusivity, the research that emerges is limited in scope as it excludes the perspectives of the most marginalised members of our society, who often bear the greatest burden of poor mental health outcomes.

Recruiting Under-represented Groups

Young people highlighted the following **4 key messages** for recruiting young people from all walks of life to involvement opportunities in mental health research:

1. Proactive Outreach

- Whilst it's tempting to focus on the same avenues that have proved successful for the recruitment of young people, they primarily reach well-represented groups of young people who know about mental health research and where to find youth involvement opportunities.
- More targeted recruitment strategies often still only reach "the most represented of the under-represented".
- We need to do more to raise awareness of mental health research and youth involvement opportunities, with **proactive outreach** to individuals, groups and networks who may not have otherwise known these opportunities exist.
- Make the effort to go to where the young people are.
- Additionally, recruitment should not be limited to a single strategy e.g., just in schools or on social media, as this excludes those who do not attend school, and contributes to digital exclusion.

> **“I don’t like the term ‘hard-to-reach’” – “it’s not ‘hard-to-reach’, it’s easy to ignore.”**

2. Build long-term, reciprocal relationships

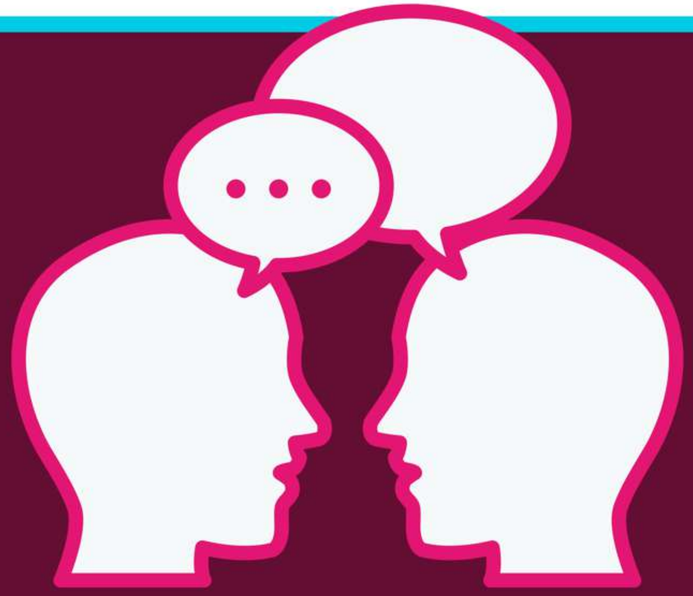
- When engaging with individuals, groups and networks in the community and online, ensure to connect in meaningful ways with the **aim to build long-term, reciprocal relationships.**
- Be aware of the kind of power dynamics that may emerge between a large organisation such as a university or hospital trust and a smaller grassroots organisation, an ensure **roles are equitable.**

> **“It can sometimes be difficult to make sure that groups are identified and represented without it just being a box ticking exercise.”**

Recruiting Under-represented Groups

3. Language

- **Avoid academic jargon and acronyms** - include a lay project summary, and clearly set out what the opportunity would involve, what would be provided, and how to apply.
- Ask others outside of your academic field, and young people themselves as a paid task, to review recruitment materials to ensure the language is appropriate.



4. Unintimidating application process

- Emphasise that the application does not need to be written in an academic way, possibly broadening the scope beyond written applications to **other formats** e.g., audio, video, call to go through the questions verbally for those who do not have access to a computer / word processing software, informal 1-1 chat.
- Provision of a **description or video of what a YPAG meeting** is like so young people know what to expect and may be more likely to apply as a result.

Where are the best places to advertise involvement opportunities in order to recruit under-represented groups of young people?

youth spaces in community
schools colleges and unis
student unions
community centres
sign-up to email bulletin
student societies
3rd-sector organisations
grassroots organisations
youth-groups
flyers
posters
places of worship
social media
forums eg care leavers

Creating an Inclusive Atmosphere

Whilst reviewing recruitment strategies is an essential part of ensuring diversity, the voices of under-represented groups still cannot be heard in an environment that fails to amplify them. Young people highlighted the following **5 key messages** for creating an inclusive atmosphere in which all voices are heard:

1. Robust leadership and facilitation

- The youth involvement leads and/or researchers have a large role in creating a friendly and inclusive atmosphere, facilitating in such a way that **all voices are heard equally.**
- Remain impartial, acknowledge and note everyone's contributions, encourage contributions in alternative ways, and reassure that it's **ok to make mistakes as long as everyone is open to learning.**
- **Continuous learning** - opportunities during/after involvement activities for young people to feedback, and all reflect on what went well, what didn't, what could be done better.
- Consider **reflective practice** - the ability to reflect on one's own actions to engage in a process of continuous learning, including reflecting on personal biases and how these may impact discussions.
- Young people emphasised the importance of **ground rules, introductions** (including pronouns either spoken or included in online name) and **icebreakers** in helping to create an inclusive atmosphere.
- It was also consistently mentioned that **diversity within the youth involvement / research team itself** goes a long way to helping young people from under-represented groups feel welcome.

> **Researchers need to want to learn, and be willing to have uncomfortable conversations. It's important in breaking down barriers.**

> **Expecting a team with little diversity to connect with young people is not going to work that well. You need diversity within the team itself. A team who can relate to young people on a certain level.**

Creating an Inclusive Atmosphere

2. Asking and listening to the needs of young people

- It is not always obvious who may require accommodations, and each young person may be different in how they want to be supported – **suspend your assumptions and really listen to the needs of young people.**
- Ask young people about their needs prior to any involvement activity.
- Young people on a YPAG or working on a specific project over a period of time could be asked to complete individual well-being plans indicating their needs, that could be shared with consent to appropriate team members for the relevant accommodations to be made, and should be reviewed regularly in case individual needs have changed.

Listen and adapt!

> As a young person representing an ethnic minority in research projects it is a challenge not to sometimes feel that my role in research projects is to fulfil the need for diversity within participants, rather than actually valuing my personal view and experiences. However McPin is an organisation who are great at engaging and supporting underrepresented groups and truly valuing our input. They always acknowledge the struggles of each community by having an open conversation, listening to feedback and adapting which makes a big difference.

Creating an Inclusive Atmosphere

3. Accessibility at every step

Communications

- Any communication (emails, research project summaries, involvement activity materials, task instructions etc.) needs to be accessible to a wide range of young people with varying backgrounds.
- Ensure the language used is:
  - **Understandable** for young people to have the context to be able to meaningfully contribute – avoid academic jargon and acronyms.
  - **Age-appropriate** – avoid patronising or infantilising young people; if there is a large age range there may need to be different communications for younger and older groups.
  - **Inclusive**
- Consider **legibility** – text size and alignment, easy-to-read colour, visual cues e.g., bold / highlighted text.
- Consider use of **various formats** – written, audio, video.
- Turn on **closed captions** in online meetings / presentations.
- Encourage young people to ask questions or if they need assistance.
- With lived experience of mental health illness and/or neurodivergence, it is also helpful to **eliminate unknowns** – send out involvement activity materials and a clear schedule with as much detail as possible in advance where possible to allow young people to mentally prepare and help manage expectations and levels of anxiety.

Involvement

- Offer a **range of options** for young people to respond to an involvement activity:
  - During a meeting – speaking, writing, drawing, responding to a poll, contributing to a whiteboard, typing responses in the chat rather than speaking out loud, collating thoughts into a document to email later.
  - Ad-hoc task – track changes, answer discussion points in separate document, email, 1-to-1 call, video response, audio response, WhatsApp voice notes.
- When there are quiter voices amongst more dominant ones, **avoid singling them** out as it can feel embarassing and may discourage further engagement; instead provide reminders of the different ways to respond.
- Consider sending a follow-up email with minutes / outcomes and a final opportunity for young people to contribute.

Creating an Inclusive Atmosphere

3. Accessibility at every step

Meetings

Travel:

- Help to **organise transport** – pre-book and pay in advance or provide travel expenses.
- Offer to **meet young people** at a designated point and walk them to the building / travel with young people to support them in navigating a potentially unfamiliar space and help alleviate anxiety.

Location:

- Make use of **local community spaces** – go into the community instead of expecting them to come to you.
- Ideally close to **public transport links.**
- Provide **information on accessibility** in advance – disabled parking / wheelchair-accessible taxi booking, wheelchair accessible building and meeting room, accessible toilets close to the meeting room, hearing loop?

> **Coming to an academic institution which is posh and fancy may bring up systemic trauma.**

University setting?

- Young people have sometimes found YPAGs / involvement activities to be geared towards academics, which can influence the power dynamics.
- Those young people from non-academic backgrounds felt uncomfortable and excluded through technical or inaccessible language and an emphasis on researchers' credentials and qualifications.
- Holding meetings in a university setting:
  - Could be intimidating and bring up systemic trauma.
  - But could also be a positive experience for young people who haven't gone to university or are getting ready to go to university, especially if there are opportunities offered e.g., campus tours, shadowing/training, integration of the YPAG into the research community.
- Young people agreed that an inclusive atmosphere can be creating in a university setting through seemingly small-scale changes.

> **I feel universities can be quite intimidating. [Although they] can also be encouraging for people who haven't experienced it before.**

Creating an Inclusive Atmosphere

3. Accessibility at every step

Meetings

Currently, many "disability / neurodivergent friendly meeting" guides lump different types of disability / neurodivergence together, as well as assuming people with the same type of disability / neurodivergence require the same things, when this may not necessarily be the case - this brings us back to simply asking, assessing and listening to the needs of young people.

Environment:
Whilst there may be limitations on the chosen location e.g., restricted to university room bookings, the environment can and should be adapted to suit the needs of the young people:

- Consider the **lay-out of the room / composition of break-out rooms** – if there is limited discussion and/or a few voices dominating, try mixing it up during the meeting.
- Consider the **sensory environment** – not too loud, limit harsh bright lighting, no strong smells, room size is appropriate for the amount of people, regular breaks especially if there is a lot of social interaction.
- **Allow items** that can minimise sensory stimulation and/or allow the young person to self-regulate e.g. earplugs, noise cancelling headphones, sunglasses, stim toys, stress balls.
- **Availability of a "quiet room"** – helpful for those young people who need respite from sensory overload / social interaction, get anxiety attacks, have fluctuating energy levels, need to pray at certain times of the day, or have certain medical conditions e.g. T1 diabetics that need to inject insulin.
- Provision of a range of **refreshments** covering all dietary requirements, checked in advance.

- If there are multiple meetings, there should be **consistency** in the chosen location, environment, facilitators and other attendees in order to develop a community feeling that contributes to the creation of a safe space, in which young people feel comfortable disclosing their lived experience.
- McPin have also started requesting **dedication of funds to digital inclusion** in all project budgets, for provision of a laptop, webcam, internet access expenses etc. to those young people who wouldn't otherwise have been able to attend meetings increasingly held online.

Creating an Inclusive Atmosphere

4. Flexibility

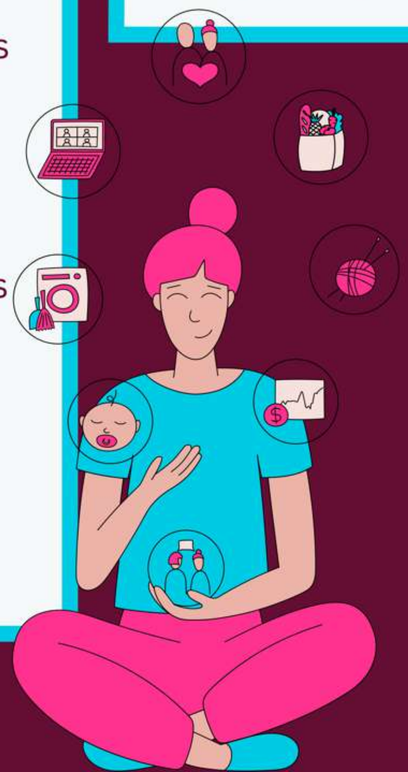
Avoid one-size-fits all approaches and **be flexible** to accommodate the needs of young people from all walks of life:

- From communications, to meeting timing, travel, location, environment and other practical arrangements, to the involvement activity itself.
- Consider the young peoples' **pre-existing commitments and other priorities** e.g., school / work, family life, caring responsibilities etc.
- Meetings organised well in advance and at times that work for the young people rather than at the convenience of the study team.
- Consider **hybrid meetings** with both in-person and online options to allow young people who may struggle to attend in-person to still be involved.
- **Limit pressure** to attend every meeting and, particularly for longer-term involvement activities, provide options for young people to catch-up, which may also serve as reminders for others if there are long gaps between involvement activities – comprehensive minutes, meeting recording with consent, 1-to-1 chat, newsletters.
- **"Guest seat" spaces** for those young people who's capacity has changed but they still want to contribute when they can, or for those who may want a taster of what being on a YPAG is like.

5. Safety

Youth involvement in mental health research must be meaningful, inclusive and safe. There are 3 key considerations when it comes to safety:

- **Organisational safeguarding policies and procedures.**
- **Robust safety plans** that young people should be aware of in advance – individual well-being plans, an emergency contact on file, who young people can contact if they are feeling unsafe, transparent emergency procedures.
- **Safe space** - environment in which young people feel comfortable disclosing their lived experience without fear of discrimination, breach of confidentiality, or risk to their wellbeing.



> **Safety can impact the conversation i.e. how safe men feel speaking in a group of mainly women.**

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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:

Youth-led Approach
Creating Safe Spaces

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Further resources

Shaping Our Lives Inclusive Involvement Matters: Tickboxes and Tokenism?

How can young people in the UK play a bigger role in health and science research?

Promoting the participation of seldom heard young people: A review of the literature on best practice principles

NIHR Oxford Health BRC EDI Project: Widening involvement of young people in mental health research

Orygen - Resources - Trans and Gender Diverse Young People

Triumph - Why we need to talk about 'jargon' in mental health research

Guidance on development and operation of Young Persons' Advisory Groups

Generation R Alliance/eYPAGnet Toolkit for setting up and running a YPAG

McPin YPN Involving Young People in Research Work: 10 things everyone needs to know about running a meeting with young people

Inclusion and involvement of young people in research: moving to digital YPAG meetings

McPin Blog Finding my voice: hacks for neurominorities in meetings