

Involving young people in research work

10 things you need to know about running a meeting with young people

Foreword

Welcome to our resource, Involving young people in research work: 10 things you need to know about running a meeting with young people. This is one of ten resources we've produced to celebrate ten years of the McPin Foundation.

For those new to us, we are a small mental health research charity that has been delivering on our mission to transform mental health research by placing lived experience at the centre of research since April 2013. In this time, we have changed and grown from a six-person team to a network of staff, collaborators and partners covering the UK, with friends across the globe. To mark our anniversary we have produced a collection of ten resources that explain our approach to working in collaboration with lived experience expertise to lead and shape research, evaluations and public involvement work.

The '10 for 10' resources showcase our learning and reflections from working across a wide range of projects. They are not 'how to' guides but instead present our thinking and learning to date. Two years in the making, this collection has encouraged us to navigate differences of opinion, even amongst co–authors. We value the conversations this process sparked, and we believe the results are a collection of resources with more depth and nuance.

Now that we've published these resources, we'd like to continue that conversation. We don't have all the answers. At McPin, we are continuing to develop our expertise in co-production, public involvement in research, peer research and supporting lived experience roles in the workplace. By sharing how we approach these issues and what we have learnt over the decade we hope the resources spark passionate conversations amongst the wider mental health research community, and beyond.

We do hope you find this resource on involving young people in research work and others in the series useful, and we welcome feedback. Turning to this resource specifically, we take you through how we run meetings with young people at McPin, from the set-up and planning stage, to running the group itself and how you can provide training and support.

We hope that our learnings can help you to embrace the intrinsic value of lived experience in research.

Vanessa Pinfold

Vanessa Kihrd

Co-founder and Research Director

The resources in our 10 for 10 collection are:

- Using lived experience in the workplace: How staff lived experiences are shaping work at McPin
- **2.** Co-production at McPin: Reflections and learning over 10 years
- **3.** Peer Research at McPin: Our approach, reflections and learning over 10 years
- **4.** Public Involvement in mental health research at McPin: Reflections and learning over 10 years
- Research Involvement Groups: McPin's models and learning, and linked resource on 'recruiting for diversity'
- Working as a co-researcher at McPin: Shaping young people's mental health research
- 7. Young People meeting guide
- 8. Wellbeing at work: What does it mean at McPin? and linked resources: Mentors and mentees (podcast); Neurodivergent meeting guide: A McPin lived experience perspective
- 9. McPin's journey towards antiracism
- 10. An Ode to Peer Research at McPin: You got the Power!: Dedicated to those who have crafted their pain into power (video)

Contents

About this resource							
About the Young People's Advisory Group							
Young peop	ole's involvement at the McPin Foundation	5					
10 things everyone needs to know							
Set-up	and planning						
	1. Provide enough time for preparation and set-up	8					
	2. Ensure there is diversity within the group	10					
	3. Timely payments	12					
	4. Work around young people's availability	13					
Runnin	g the group						
	5. Ensure all young people in the group have a voice	14					
	6. Make sure sessions are interactive and engaging	16					
	7. Ensure there are plenty of breaks	17					
(w)	8. Be mindful of the atmosphere	18					
Training and support							
-(4)	9. Providing training for researchers and young people	20					
	10. Providing support and dealing with difficult topics	22					
Learnings		23					
Hear more from our young people							
About the authors							
Useful resources							

About this resource

At McPin, the Young People's Involvement In Research team are regularly asked what we have learnt from working with young people for over four years now. The answer is we have learnt a lot. We decided to try and summarise this learning in a resource that could help others who want to work with young people.

As much as we consider ourselves to have expertise, we are not the experts. To make this resource, we turned to the people who would know best: young people themselves. We asked our Young People's Advisory Group (YPAG) to share what they believe are the most important tips for researchers engaging and involving young people in research through advisory groups.

Together, through a process of discussion, collaboration and a final vote, we have compiled a list of the most important things that everyone needs to know when running a meeting with young people. We did this in 2019 prior to the pandemic. Our list still stands but we do have to consider every thing in a new context including running meetings online (using Zoom) or in a hybrid format, both online and in person.

We chose to focus the resource on running meetings because this is a core part of any research work. We cover another aspect of working with young people in research in a different resource: Working as a co-researcher.

We will cover other aspects of working with young people in research in a different resource, such as working as a co-researcher. We do involve young people in our work outside of meetings too, such as over the telephone, by email and using other digital means, but meetings remain at the heart of what we do.

This summary was first written by Rachel Kimberley Temple and Anja Hollowell together with the McPin YPAG in 2019. Rachel leads our young people's work. Anja used to work with Rachel and supported our work with young people. It has been updated by Rachel, Emma, Annie and the YPAG in 2023. There is more about our team at the end of this document.

This resource is aimed at anyone interested in involving young people in research. This will include researchers, people working in public involvement in research, and others who work with young people.

About our Young People's Advisory Group

Our Young People's Advisory Group (YPAG) is made up of twenty five young people aged 15–28 and includes those with direct or indirect lived experience of mental health issues.

The YPAG was originally formed in 2016 to support our Right People Right Questions (RPRQ) project. It meets regularly and provides input into a wide variety of mental health research studies.

Most of the work that the YPAG does is through online or hybrid research meetings, though there is regular contact and input given outside of these sessions. For example, people can contribute by writing blogs and research papers, reviewing research documents (like information sheets and study proposals), creating graphics and speaking on podcasts.

Young People's involvement work at the McPin Foundation

Our Young People's Network was formed in 2018 after our Right People Right Questions project, and currently consists of over 300 young people aged 13–28 who are interested in mental health research.

Network members include young people with a variety of different life and mental health experiences from all over the UK, and even some from outside the UK. Members hear about the latest involvement in research opportunities as sent to us by researchers who are seeking young people's input on their mental health research projects. They shape our own work at McPin too. We also have a co-researcher programme, with young people employed on projects. This is something we will be developing further.

Learn more

Learn more Find out we mean by co-research and look at examples of it in action at McPin in our other resource, Working as a co-researcher.

Acknowledgments

We would like to thank all the people who have worked with us in shaping this resource. We would specifically like to thank staff at McPin (past and present) who shared their expertise in our workshops, and our Communications team for their support in editing and design. Raj Hazzard, Senior Researcher at McPin, to whom we owe a particular thanks for the care and kindness brought to this project, has co-ordinated the production of all 10 resources in our series

Illustrator and visual storyteller Kremena Dimitrova and 10 for 10 project lead Raj Hazzard collaborated to create two visual metaphors that captured the essence of McPin's work. 'Bridge Between Worlds' speaks to McPin's commitment to connect the knowledge, experience and expertise from a variety of differing and overlapping communities and spaces. 'Valuing Vulnerability' speaks to McPin's commitment to nurture and empower the knowledge and skills embedded in mental health experiences. Design work is by Mark Teagles at White Halo.

This document was first published in December 2021 and has been updated to add more information on virtual meetings. It can be cited as: Involving young people in research work – 10 things you need to know about running a meeting with young people.



things everyone needs to know about running a meeting with young people

We've listed them here and grouped them into three categories.

Set-up and planning Work around young people's availability when setting meeting dates and times.



Ensure there are plenty of breaks.

Running

the group



Make sure sessions are interactive





Provide enough time for preparation and setup before meetings.



Have payment guidelines to ensure young people get paid well and promptly.



Be mindful of the atmosphere - make sure it's comfortable, welcoming, informal and supportive.



Ensure all young people in the group have a voice and can input.



Ensure there is diversity within the group of people you are involving in your research.



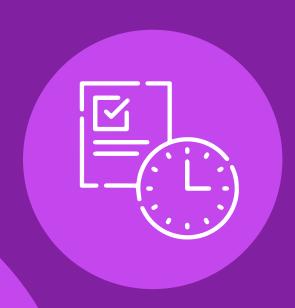


Provide training for both researchers and young people.





Provide support, especially when dealing with difficult subjects, and make people aware of that will be discussed in advance.



Setup & planning









Provide enough time for preparation and set-up before meetings



Young people's meetings can take different forms and can cover different stages of the research process. For example, meetings might involve:

- Introducing researchers and their project proposal to the YPAG and seeking their input
- Continually working with a researcher and their team to shape and advise throughout all stages of their project. This may include developing recruitment or design materials, carrying out research analysis, helping to make sense of the study findings and producing communication materials.
- Young people themselves joining a meeting with researchers and their wider team as a research advisor: discussing research strategy or problem solving (e.g. as a steering group member).

There is nothing worse than feeling unprepared for a meeting: not knowing what will happen, how it will happen, and who will be there. This dreaded feeling of uncertainty may not seem like a big deal to everyone – especially not for some researchers, who are probably more than used to dancing continuously between different meetings! However, our YPAG values being kept in the loop as much as possible, as early as possible. This can help to alleviate any anxieties about the work.

As a rule, we will always send out a preparatory email at least a week before the meeting. These preparatory emails can be packed with content, so we are careful to bold, number and highlight any key tasks and deadlines. The email includes the following materials:

- 4 Agenda
- Prep work reading and task
- Ground rules
- Invoice form

The **agenda** will outline the structure of the session, who will be there, and when breaks will happen. Young people can then contact us if they have any concerns about how the session will run, or simply give us a heads up about things that they might find helpful or parts of the meeting that they might find difficult. An example agenda can be found on the opposite page.

I have found communicating with the McPin Foundation before all of our meetings has helped me to feel prepared and confident walking into the building each time. An agenda is released before the meeting so we all know what each session involves and staff are very quick and helpful in addressing any concerns of ours."

Amelia, YPAG member Personally, I strongly appreciate knowing what will be asked of me before an event: will I be speaking in front of a large group? Will we be discussing a topic that I'm not so familiar or comfortable with?"

Rachel, YPAG facilitator The **prep work** will usually include reading a summary of the research that we will be discussing. If there are a few key topics that we will be discussing, we will send out some questions for people to think about in advance. These also serve as prompts for the things that people might want to have in mind while reading. Some people may prefer to use these questions to give written feedback rather than giving it verbally in meetings. Or if members prefer, they can have a call with us before the meeting to share their thoughts.

Not everyone is confident thinking on the spot (especially not in a group setting), so preparation gives people time to get their head around complicated projects and proposals. Providing young people with the opportunity to adequately prepare for a meeting isn't just helpful – it's essential. Remember that, unlike researchers, they aren't working on these projects day in, day out. They will appreciate some time to digest the information so that they feel able to contribute fully. It also means that meeting time can be spent productively and everyone can get the most out of it.

At the end of a meeting, we'll always communicate plans for the next meeting where possible. There's no harm in sending out email reminders about upcoming meetings, either. We outline what young people can expect from our meetings here.

An example agenda for a young people's advisory meeting

Young People's Advisory Group Meeting Saturday 20 February 2021, 11:00 to 13:00

The meeting will be held on Zoom: (Zoom link goes here)



Agenda

Time	Item
11:00	Hello! Introductions, ground rules and updates
11:20	Engaging young people in schools: presentation
11:30	Engaging young people in schools: breakout rooms
12:10	Break
12:25	Feedback on anxiety research proposal: whole group discussion
12:55	AOB, feedback, payment and expenses
13:00	Goodbye!

Ensure there is diversity within the group of people you are involving in your research



Our YPAG members have found there are ample benefits to having a diverse group, but primarily it's about promoting the voices of different perspectives. We've got a wide age range in our YPAG; from 16–28, and we've had members as young as 13 join us in the past. The group should include the views from people of different genders, ethnicities and sexualities too. Our YPAG also differ in their life experiences and backgrounds; many identify as having lived experience of mental health issues – but what these are varies from person to person.

It is so important not to make generalisations about what it means to have lived experience of mental health conditions. For example, one person's experience of anxiety might look quite different to another person's, and different people are at different points in their recovery. There can also be a huge variation in the kinds of mental health issues people have experienced: someone's experience of having depression as a child will differ greatly to someone who was hospitalised with an eating disorder in their teens.

Some members are familiar with mental health research, whereas for others this is an entirely new experience. All of these voices are equally valuable. It is vital to include each one.

Maintaining this balance of perspectives has been an essential part of what makes our YPAG work so well. During recruitment, we actively seek people from all walks of life. We know it can sometimes be very helpful to work with community groups and places where young people feel comfortable and already have established relationships. You don't always need to set up new structures; there may be opportunities to work with other organisations. Additionally, we do not solely select people based on the quality of their written application.

While it may be tempting to recruit people specifically on the depth of their prior understanding of research, it is important to provide the opportunity to those who might have less experience of being involved in research but who would like to learn.

And besides, who else is going to call out researchers on any jargon-loaded dissemination materials? Diversity within the group ensures that the session reflects real life as closely as possible. The benefits of this are endless.

It is always interesting to meet young people from different cities and backgrounds but with similar interests. The diversity of life experiences means everyone gets the benefit of insights from different perspectives."

Syinat, YPAG member



It's great to see that in our meetings there is a wide range of individuals who can each offer a different yet equally valuable perspective on the topic at hand."

Lucy, YPAG member



Have payment guidelines to ensure young people get paid enough and in a timely manner

Sometimes researchers can lose sight of the fact that young people have outgoings as well and need to be paid for our time. This is especially important when we are paying for travel before getting paid for the event, which makes it really helpful when travel is paid in advance. There is an assumption that just because we are young, we may not have the same need for money as those older than us. However, this is not the case, in fact, we potentially rely upon this money even more."

Niamh, YPAG member It is unsurprising that this point made our top ten list – and rightfully so. Sometimes we forget that outside of the YPAG, young people have other commitments. They have their own studies or other roles. When they complete some work for us, they are giving us their time and expertise – just like researchers do when they are employed to work on a project. Just like researchers and other paid experts, young people are remunerated sufficiently for the work they do with us.

It's important to make it clear to the young people about when they can expect to receive their payment. At McPin our group members are paid by invoice and we make sure payment is received within 30 days of submitting it. We try to reimburse travel expenses in a meeting or immediately afterwards, which helps to ensure that no young person is out of pocket financially. That's why we also offer to book travel for young people ahead of the meeting. It's just one less expense they have to worry about.

It's also important to consider the different tax situations for young people. For younger members who may not have a bank account, include the option to pay directly into a parent/guardian's account. For further guidelines on payment please have a look at the 2016 NIHR INVOLVE document entitled 'Reward and recognition for children and young people involved in research – things to consider'.



Work around young people's availability when setting meeting dates and times



Our YPAGs are always held on Saturday afternoons, unless they are outside of term time. As Niamh says, all of the young people in our group have different commitments – some are in school, some in university, some have full-time, or multiple, jobs. It's vital to be flexible around people's timetables. If not, we risk excluding voices from the conversation.

The priority is to give people choice: we will always send out a Doodle poll when we're arranging a meeting. Another key aspect is giving people as much notice as possible, which means confirming dates a few weeks in advance. If we notice that someone has repeatedly missed out on attending a meeting with us due to other commitments, we will try to prioritize their availability (where possible) next time.

The same guidance occurs when we have an opportunity to offer to someone in the group (for example, to take part in a podcast). If two people express an interest but the opportunity is only for one, we will try to prioritise the individual who misses out the next time an opportunity comes up.



I feel that being flexible around times and dates is a very important aspect for the YPAG. There are so many people, from various backgrounds, with different jobs and this makes it difficult to find a time that suits everyone. However, the Doodle polls make this much easier and give us all enough notice to keep a particular day aside. Taking this into consideration makes life so much easier."

Niamh, YPAG member

Doodle poll

	APR 24 SAT 11.00 13.00	APR 24 SAT 17.00 19.00	APR 26 SAT 11.00 13.00	APR 26 SAT 17.00 19.00	APR 27 SAT 11.00 13.00	APR 27 SAT 17.00 19.00	APR 28 SAT 11.00 13.00	APR 28 SAT 17.00 19.00	APR 29 SAT 11.00 13.00	APR 29 SAT 17.00 19.00	MAY 1 SAT 11.00 13.00	MAY 1 SAT 17.00 19.00
5 participants +	✓ 5	✓3	✓2	~ 4	~ 1	✓ 2	✓ 2	~ 4	✓ 2	√ 3	✓ 2	√ 3
Thomas	/	~	~	✓	✓			✓	✓			✓
Oli	~			~			✓					✓
Faith	~			~		✓	✓	✓	✓	✓	✓	✓
Anja	✓	~		~				✓		✓	✓	
Rachel	✓	~	~		/	~		~		/		



Running the group









Ensure all young people in the group have a voice and a chance to input



During our YPAG meetings, we divide the session into smaller group-work activities which provides people with more space to have their say. In face-to-face meetings, this means that we break people up into smaller groups, though we try to stay in the same room. In virtual meetings it is usually possible to place groups of people into smaller 'break-out' rooms.

If you divide people into groups, try to rotate the groups around and give everyone the chance to talk to different people. Some feedback we often get is that people would have liked to talk to everyone in the group.

Another strategy is to place post-its and A3 paper onto tables so that people can jot down their thoughts throughout the meeting. This is especially handy if someone is not comfortable voicing their views, or if someone doesn't get to say a point because there isn't enough time. In virtual meetings there are ways for people to use electronic 'sticky notes' or a chat function to do this.

Sharing feedback

At McPin, we often use Menti Meter – online software that allows you to create polls, quizzes and word clouds – to gather feedback. Using Menti Meter can be a good way to hear from people who might not feel comfortable speaking in large groups.

Everyone has
the chance to
input in group
conversations
and are actively
encouraged to do
so by the McPin
staff; by fostering
an environment
where everyone
can be heard, some
really interesting
conversations
come up."

Lucy, YPAG member

Menti Meter feedback examples

Loved using breakout rooms and speaking to everybody.

I would have liked longer in the breakout rooms.

Super interesting but wish it was longer.

Great that everyone had a chance to contribute.

I liked using the chatbox.

I liked the good thing and didn't like the bad thing!

As a facilitator with social anxiety, I fully recognise how daunting it can be to speak in front of an entire group, let alone feel like I'm making sense! Imposter syndrome is no simple issue. And it doesn't disappear because you are in an environment with fellow young people."

Rachel, YPAG member We strongly encourage using the chat feature in our Zoom meetings, which works particularly well when people are worried about interrupting each other, have a question, or simply feel more comfortable contributing in this way. There are also virtual whiteboard options like Padlet, Jamboard and Miro, and there are ways to submit anonymous thoughts and questions, like with presentation software Menti. Be wary of overcomplicating things with too many technology options at once – this can detract from the meeting!

After a meeting, we will draft up some minutes and bring all of these notes together. The chance to provide input doesn't stop once the meeting is over. We're always open to receiving any follow-up thoughts that the young people have, which they can send via email, voicenote or any other medium. This could include giving feedback using artwork, or exchanging text/video/audio WhatsApp messages.

Using different methods for providing feedback enables those who are not as confident to talk in sessions or meetings to share their thoughts, and is more inclusive of the needs of a neurodiverse group.



Make sure sessions are interactive and engaging

We're eager to make our involvement work as enjoyable and as effective as possible. We do this in several ways:



When meeting face to face

One way in which we commonly run sessions is via the world café style which involves small groups working on a particular question for a set period of time, and then rotating from table to table. We ask guest researchers to get involved by hosting a table or acting as facilitators. This method seems to be popular with the YPAG and it's a great way to stick to time! Using different formats for the meetings helps to break up a long meeting, especially when there is a lot to get through, by setting apart each of the tasks that we're working on.

Working virtually

If you're holding meetings remotely, you can make use of Zoom's breakout room feature, allocating people to small groups. The share screen tool is a great way to involve everyone in the note-taking process during the discussion. People can make annotations of their own – and there's even a drawing feature! If you want to write notes collaboratively, you could all work together on a Google doc – this way people can write things in their own words, instead of you having to paraphrase.

We have experimented with other interactive methods such as the <u>Menti</u> method, where people answer questions using a live survey and we display all anonymous answers on screen. This works especially well when we need to quickly come to a decision as a group, which can be done using the Menti voting feature.

After the session

Even after the meeting has finished, it is important to keep the group updated with the study's progress: what impact have their contributions made? Whether it's to the study proposal, design, interpretation of findings, young people value the opportunity to hear about it. In fact, we have heard that this is one of the major reasons why young people choose to get involved in the first place – to make a difference. So it's important to show them how they have done this.

Over the years of being part of the YPAG, certain traditions have evolved such as feedback at the end of the meeting being done by throwing bits of paper around the room. It sounds a bit crazy but it makes the meetings fun and exciting."

Amelia, YPAG member

When there is a group with a mixture of young people at various ages who are friends that go quite a long time without seeing each other (such as the YPAG), the meetings can be quite chatty. It is important that the sessions have a balance of being interactive and engaging, to ensure that we are concentrating, interested and not chatting, and also having enough breaks to allow us to catch up."

Niamh, YPAG member



Ensure there are plenty of breaks

I find that taking regular breaks during meetings helps my concentration, helping me to get my thoughts together and contribute in the best way possible."

Lucy, YPAG member

For me, the session can get overwhelming at times, as switching from topic to topic requires me to switch accordingly as well. This drains me as the session goes on. Having multiple breaks helps me to recover and mentally organise the topics we have discussed."

Ashad, YPAG member We really enjoy the YPAG meetings. But no one likes a meeting that drags on, especially without breaks! YPAG meetings take a lot of concentration because they can touch on some pretty difficult subjects and are asking a lot from everyone involved: young people, researchers and McPin staff.

While this may seem obvious, it is worth mentioning because meeting fatigue can be one of the biggest impediments to working well. When organising the agenda, we place the more complex items before a break. In our experience this helps people to not feel overwhelmed while also making sure it is a productive use of everyone's time. We also make it clear at the start of a meeting that if someone feels uncomfortable then they can leave the room at any point or leave the session completely.

We often use Zoom to host online meetings, and the need for breaks in these meetings is especially important.

Usually, in face-to-face meetings, it's perfectly reasonable to pop out of the room to get a cuppa or go to the loo. But people can feel far less comfortable doing this in a Zoom meeting than when they're there in person. It's really important to schedule breaks in Zoom meetings and to adjust timings to account for the new (online) setting.

- The NIHR School for Primary Care research has produced a helpful video and a blog on running a meeting virtually. The video can be accessed here.
- The NIHR School for Primary Care research has produced additional resources and guides about running virtual meetings which can be accessed here.



Be mindful of the atmosphere – make sure it's comfortable, welcoming, informal and supportive





Having a good atmosphere during meetings is probably one of the most difficult things to define in terms of what works in meetings and what does not. Often it is personal preference, but many things already discussed contribute to a positive atmosphere: having plenty of breaks, ensuring there's diversity in the group, and providing support for difficult subjects.

When we recruit new members we will have a one-to-one conversation with them to check if there are any adjustments or support that we can put in place for them ahead of their first meeting.

At McPin we have **ground rules** that we use in all our advisory groups to make sure that meetings are safe and comfortable spaces. We ask researchers or guests to read these in advance of our meetings and will run through them at the beginning of every session.

We find it is always helpful to say at the start of meetings that, just because we're discussing something from a lived experience perspective, it doesn't mean anyone needs to disclose anything. We have had times when we could tell that everyone in the room was a bit more tense than usual. This can happen, for example, when there is something difficult happening in the news. When this is the case, we make sure to accommodate this.

We do not continue discussions if people seemed too tired, we take lots of breaks, and we might even finish the meeting a bit earlier than usual. Figuring out 'atmosphere' is often a matter of putting yourself in other people's shoes and making continual assessments of the feeling in the room.

I've noticed that the atmosphere or mood shifts throughout the day. This may depend on the topic being discussed or how a researcher may be behaving. It's always helpful to be aware of the atmosphere and the research officers who lead the YPAG meetings do a wonderful job of reading the room and checking/ adapting to the young people and their needs."

Ashad, YPAG member



The atmosphere of a session dictates how productive it will be. A comfortable, supportive environment means many different opinions will be voiced freely. A simple cup of tea and a friendly attitude go a long way."

Syinat, YPAG member It can also be good to have the researchers present in meetings. That way they can hear feedback first-hand and they can discuss how to talk about their research in a way that is accessible. However, something we pay a lot of attention to is how the presence of researchers in the room might affect the atmosphere. Always consider why they're there – what's the purpose? Do they need to be there to discuss the research first-hand or can this be done by someone else?

We have been told that sometimes having researchers there can mean young people feel less able to contribute, especially if their feedback is at all critical. However, we have also been told that sometimes having the researcher present is really nice, as the young people feel it is a valuable opportunity to speak directly to them. Either way, we try never to have staff outnumber young people.

Example of ground rules and tips for young people's meetings

- Everyone in the room is equal
- Respect one another
- Avoid jargon or overly scientific language
- When drawing from your own expertise and knowledge, whether that is talking about academic research or lived experience, try to do so in a way that encourages constructive discussion without anyone being excluded from the conversation
- Ask questions if you need to, no question is a silly question –
 if you're thinking it, someone else probably is too
- Take as many breaks as you need to. If you're leaving, please let a member of staff know so that we're not worried.
- All sensitive information will remain confidential. No one is expected to disclose anything that they do not want to.







Providing training for researchers and young people

I think the idea that disclosure is always necessary is a false assumption that people often make. If you have lived experience, it's going to inform the perspective that you bring to a meeting - and that's all that matters! Of course, people are also very welcome to discuss specifics, it's just not a requirement. Generally, being aware of the atmosphere is about being sensitive to other people's needs, while also understanding that it is very variable. You can only work with what you have got – so there is no need to go overboard."

Anja, YPAG facilitator Not only do young people need to have an understanding of research in order to contribute well to what is discussed at meetings, but they often want to expand their knowledge and are keen to learn new skills. Providing training in research methods and topics for the young people does not have to be a daunting task to organise and can happen within meetings or separately. It does not mean you have to spend a huge portion of the involvement budget sending people on academic courses. Short, bitesized video presentations (followed by a discussion) work very well.

The point of training for people involved in research is threefold in our experience:

- 1. People are better equipped to make meaningful contributions to research meetings
- 2. It will mean that the experience of involvement work is more mutually beneficial for both young people and researchers
- **3.** We are upskilling young people and providing work experience, which may help them in future careers

When we asked the YPAG what they thought was important in relation to training, they came up with the following things:

Give young people options

Some people will be more interested in learning about the background of the research topic, some will be more interested in learning research methodologies. You never know until you ask. For the YPAG, we gave everyone copies of a book about research methods for them to see what might interest them in terms of training.

Provide training in advance and throughout the project

Even though you are not trying to train young people to do the research itself (though this is an option!), it's still important to make sure they are adequately equipped to contribute by explaining the research.

Bee, P., Brooks, H., Callaghan, P., & Lovell, K. (Eds.). (2018). A research handbook for patient and public involvement researchers. Manchester, England: Manchester University Press. Retrieved Apr 21, 2020, from https://www.manchesteropenhive.com/view/9781526136527/9781526136527.xml



This also goes for making sure people understand the basic science methods and the jargon. One does not want to throw around acronyms like RCT², HRA³ or NIHR⁴ without explaining what they mean because this will only make it harder for people to contribute. If people understand the research, they're more likely to be able to make suggestions that can be followed through. Of course, training should be adapted to the specific needs of the group members and project(s) that it advises on.

It is important to appreciate that training should be ongoing

There are always more skills and knowledge that can and should be developed. The world of research is so large that it is unlikely that anyone would have all the training that they could benefit from.

Ideally, training should be freely accessible so that others can benefit from it. Training does not need to be given formally, it can be given via an app, or integrated throughout a meeting.

Training opportunities should be available for researchers and young people alike

An important point that the young people raised was that the need for training doesn't just apply to the young people. Training should also be provided for researchers on how to work with young people with lived experience. As we have tried to illustrate in this resource, there are a lot of things to consider when working with young people.

Of note, anyone working with young people with lived experience of mental health issues can benefit from training on how to discuss difficult or triggering subjects.

Training is
essential for young
people taking part
in research as it
empowers them to
be well informed
about the
task at hand and
therefore in a
position to offer
their best opinion."

Lucy, YPAG member

 [&]quot;Randomised Control Trial" – this is the sort of research where you're trying to see if something (like a
drug or therapy) has the desired effect. You randomly assign participants to either receive the treatment
or be the control (no treatment). At the end, you see what the difference is between the groups.

^{3. &}quot;Health Research Authority" – this is part of the NHS. They make sure research follows strict guidelines to protect patients and public.

 [&]quot;National Institute for Health Research" – this is a UK government body that funds a lot of health
research. It funds all sorts of research, from small projects to huge multi-million pound studies.



Providing support and dealing with difficult topics

All of the staff at McPin are very attentive to the needs of the young people and their potential mental health needs, guiding us through essential, yet sensitive, topics in a responsible and non-triggering way."

Lucy, YPAG member YPAG meetings are by nature going to cover topics that may be difficult to discuss. It's important not to shy away from these topics. But it's equally important to be able to provide support when dealing with challenging subjects.

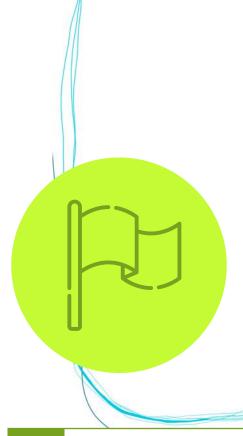
The people on our YPAG have joined knowing that, or even because, we will be discussing mental health. Even so, advanced warning of topics under discussion gives people the chance to mentally prepare. People really appreciate knowing about whether certain topics will be discussed in meetings so that they're not taken by surprise.

There should also always be the option to take a short break from the meeting if it is required. We tend to apply a similar rule to these emotionally difficult subjects as we do to other types of challenging subjects – we don't overload the agenda!

Most of the YPAG are also part of the McPin Young People's Network. This is a mailing list of over 200 young people who we contact about involvement opportunities. Given that these emails are about mental health research, it's sometimes the case that they contain triggering topics. As such, we make sure to put content warnings in these emails.

Whenever we work with a new young person, we arrange a one-to-one chat with them, to find out what support they may have already in place, what topics they may find difficult, and what support we could offer in those situations.

Ultimately, we have to remember that, just because young people have signed up to get involved with mental health research and draw from their lived experience, does not mean that they will feel able to engage with all topics at all times.



Making your meeting hybrid

We've recently moved to making our meetings hybrid: a combination of in-person and Zoom meetings. This improves accessibility of our meetings because if our group members aren't able to travel to our London office, they can join the meeting online. Here are some quick-fire tips for running hybrid YPAG meetings:

Have plenty of staff at hand

We always recommend at least two staff members for YPAG meetings, but for hybrid meetings, we've found it essential to have at least three: a meeting Chair, a notetaker/person on hand for support, and someone to manage all things tech.

Get the appropriate equipment

Our meeting spaces are fixed up with cameras, microphones and big screens that capture the entire room. This helps everyone online to feel part of the conversation, and the large screen can be used to display the Zoom participants.

Include ground rules that address the online setting

At McPin, it is a requirement for attendees to show themselves on camera (WiFi-permitting). This not only improves engagement in the meeting, but is a safeguarding requirement, as we can verify the individual's identity. For more Zoom ground rules see below.

Assign someone as online facilitator

Our YPAG have said that, for attendees joining online, it's really handy to have one 'dedicated' staff member to be online facilitator. It is especially vital to have a staff member present online where any participants are 16 and under. Whilst the meeting is running, this individual should be the 'go-to' person for any private chat queries from the young people; to ensure screen sharing of any meeting documents runs smoothly, to admit people into the meeting and breakout rooms, and to lead the small group discussion online (whilst the other small groups are carried out in person). Note that for big online groups, you might

need two staff members to facilitate separate breakout rooms/take notes. The online facilitator could benefit from a separate room/space whilst facilitating their breakout room, so that they have a private space to address the online group. Otherwise be sure that the main room microphone is muted – it can disrupt the online group!

Two staff members to log into the Zoom meeting

You'll need one Zoom account to open and run the meeting, and another Zoom account for the dedicated online facilitator. This is essential because any private messages to the online facilitator won't then be displayed on the main big screen within the room, and instead will be seen on the facilitator's own private laptop. Later in the meeting, this account can be admitted into the private breakout room whilst the main account keeps the Zoom meeting running.

Think about meeting duration

Our in-person meetings (12:30-4pm) are typically longer than our online meetings (11-1pm). We do this because it's tiring to be on screens all day, and because our in-person meetings include more time for chit-chat and friendly breaks. Zoom participants may not be required to stay online for the full duration of an in-person meeting; they could join after the in-person group have had lunch, and are encouraged to take more breaks.

Zoom participants need lunch too

Just because they are unable to join in person, does not mean that Zoom participants should miss out on lunch (if the meeting runs during lunch hours). We send our online YPAG members a delivery voucher (e.g. JustEat).

Tips for joining a Zoom call

- Please accurately label yourself in the waiting room by your name (first name is fine).
- Please keep your camera on. We ask that you keep your camera on throughout the meeting, but we do understand that you may need to turn it off for short periods from timeto-time (for example, to answer your door, go the toilet, etc.).
- Be wary of background noise; please mute your microphone if not in use.
- Privacy: if you can, please either find a private space or wear headphones while in a call with us. This will help limit the chances of disturbance and distractions.
- Please do not record or take screenshots during the meeting. McPin staff may ask to record the meeting but this will always be optional, and any recording will be deleted after the notes have been written.

- © Contribute in the way that you feel most comfortable. Use the 'chat' option to type responses if you would prefer. The chat will be saved so even if points don't get raised, they will still be accounted for.
- You can use the private function to message the Chair of the meeting if you would like to raise a point to add to the notes or for them to bring into the discussion, or if you have any concerns.
- Please do not use the private chat feature to contact group members (other than staff). If you receive an unwanted private message from another group member, please contact the responsible McPin member of staff.
- You can use the raise your hand feature (or actually raise your hand) to speak/vote.

A round up of some of the tech we use

There are many applications that can make our work in research easier. Here are some of the things we use:



- Mentimeter
 Interactive presentation software that helps you generate polls, quizzes and word clouds Interactive presentation software mentimeter.com
- O Doodlepoll
 A free online scheduling tool to help you find a meeting date that suits everyone doodle.com
- Padlet
 Make visually interesting and interactive idea-gathering boards online padlet.com

Learnings

Working with young people in an effective, appropriate and engaging way is our mission at the McPin Foundation. If you want to do the same, we recommend you:

- Listen to those that you work with
- Regularly seek feedback and advice. It seems obvious,
 but it's easily neglected especially when you're busy
- Always make time to check in with the young people that you work with to see if there's a preferred way of doing things

We have also found it helpful to speak with other Young People's Advisory Group leaders across the country to compare notes.

Ultimately, we all have a shared mission: to improve the quality of mental health research by putting young voices at the heart of it.

We hope this resource will serve to support that goal.

Hear more from our young people



Want to know about one young advisor's experience of developing a digital audio tour for the National Gallery? Read Hannah Roberts' blog here.



We ask for feedback from researchers, helping us to improve how the YPAG can best work. For the perspective of one researcher, click here.



Read Lucy's blog here about how members of the YPAG supported a research project on screen time use.



We were invited to a youth mental health research conference in 2022. You can read about our experience here.



Our YPAG's first advisory role was shaping the Right People Right Questions project. Read more here.



Listen to the Agency podcast on a project that explores young people's sense of agency during mental health interactions.



Read Hemlata's blog about attending a youth festival in Edinburgh and supporting the #mentalhealthresearchmatters campaign.

About the authors



Rachel Kimberley Temple

Rachel is a Public Involvement in Research Manager at the McPin Foundation.
As the young people's lead, she is passionate about drawing from her own lived experiences as a young person with mental health issues to ensure that involvement work is as inclusive, appropriate and engaging as possible.



Emma Garavini

Emma is a Youth Public Involvement in Research Officer at the McPin Foundation. She co-ordinates and supports a number of young people's projects at McPin. Emma aims to use her own lived experience, and the views and experiences of the young people she works with, to create meeting spaces that are comfortable, accessible and engaging.



Anja Hollowell

Anja was formally a Senior Public Involvement in Research Officer at the McPin Foundation. She joined McPin in May 2019 and worked on a number of projects, including working with Rachel on the young people's work. She is passionate about making sure that people with lived experience have a say in mental health research and that research is accessible to everyone.



Annie Walsh

Annie is a Public Involvement in Research Manager at the McPin Foundation working across several projects. With her own lived experience, she is a strong advocate for the involvement of those with lived experience in all aspects of mental health research. Her research background in early intervention led to a particular interest in youth involvement and highlighted the importance of involvement that is meaningful, safe and inclusive.



The McPin Young People's Advisory Group was founded in 2017 and is made up of 14 young people aged 13–28.

The YPAG co-produced this document: they were involved in the process every step of the way, from providing the top ten points, to the content and design. This resource would not exist without their work.

Other YPAGs

NeurOx Young Person's Advisory Group (YPAG)

"The NeurOx Young Person's Advisory Group (YPAG) is a group of about 30 young people (between 14 and 18 years old) who work with the Neuroscience, Ethics and Society (NEUROSEC) team at the University of Oxford to help develop methods for working with young people to better understand their views."

Please visit the NeurOx webpage using the link below. The webpage includes a series of podcasts, blogs by members of the group, and useful forms including a term of reference, and a safeguarding document.

www.oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/young-peoples-involvement

Young Persons Mental Health Advisory Group (YPMHAG)

"We are a group of 16-25 year olds with lived experience of using mental health services, or caring for someone who has used these services. We meet every six to eight weeks and invite researchers or research teams who would like our advice and support to come and discuss their projects."

Please visit the YPMHAG webpage.

www.ypmhag.org

GenerationR

"GenerationR is a National Network (GenerationR Alliance) of Young People's Advisory Group's (YPAGs) based across the UK."

Please visit the GenerationR web pages using the link below. The web pages contain a series of videos, games, and useful documents such as a research agreement form, and a young person's agreement form.

www.generationr.org.uk

University of Birmingham Institute for Mental Health YAG

The YAG is made up of 18 young people aged between 18–25 with experience of or a strong interest in youth mental health. Members are paid, and take part in monthly meetings to discuss research ideas, contributing to work on research grants and taking part in training. Please visit their website:

www.birmingham.ac.uk/research/mental-health/youth-advisory-group.aspx

Wolfson YAG

The Wolfson Centre wants to put the experiences and voices of young people at the heart of its work. They are regularly looking to recruit young people aged 14–25, with lived mental health experience, to join their two Youth Advisory Groups. Group members get a chance to be an active part of a major new research initiative in young people's mental health.

Please visit their website:

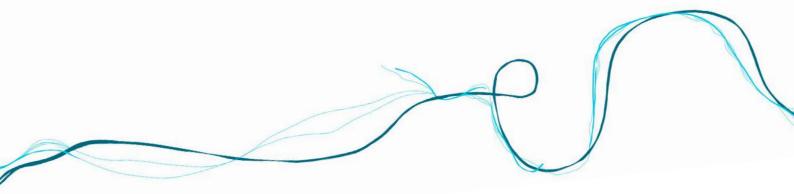
Youth Advisory Group - Wolfson Centre for Young People's Mental Health - Cardiff University

Useful resources

- Young people's advisory groups in health research: scoping review and mapping of practices, Sellars et al, Archives of Disease in Children, published online in 2020. This research paper gives a very useful overview of how YPAGs across the country operate. Please note that, at the time of writing, the full text of this paper is currently not freely available. www.dx.doi.org/10.1136/archdischild-2020-320452
- Report on involving children and young people in research, INVOLVE, 2019. www.invo.org.uk/wp-content/uploads/2019/06/77620-YPv3-Booklet-WEB.pdf
- Involving children and young people as advisors in research: Top tips and essential key issues for researchers, INVOLVE, 2019.

 www.invo.org.uk/wp-content/uploads/2019/10/Involving-children-and-young-people-as-advisors-in-research.pdf
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 www.invo.org.uk/posttypepublication/involving-children-and-young-people-in-research-top-tips-and-essential-key-issues-for-researchers
- Reward and recognition for children and young people involved in research things to consider, INVOLVE, 2016.
 www.invo.org.uk/wp-content/uploads/2016/05/CYP-reward-and-recognition-Final-April2016.pdf
- NCB Guidelines for Research with Children and Young People, National Children's Bureau, 2011. www.ncb.org.uk/sites/default/files/field/attachment/NCB%20guidelines%20CYP.pdf
- Young researchers guidance commissioned by the Charity Barnardo's, June 2002 authored by Dr Louca-Mai Brady and Berni Graham. https://uhra.herts.ac.uk/bitstream/handle/2299/25987/Young_Researchers_Guidance_FINAL. pdf?sequence=1





We want mental health to be better understood. Our mission is to improve everyone's mental health through research informed and directed by lived experience expertise. We want the value of lived experience of mental health issues to be upheld and embraced, which is why we put it at the heart of all our work.

Stay in touch

Sign up to our newsletters mcpin.org/get-involved/sign-up-to-our-networks

Find out more about our work

www.mcpin.org contact@mcpin.org

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