

# INVOLVING YOUNG PEOPLE IN RESEARCH WORK



**THINGS  
EVERYONE NEEDS  
TO KNOW ABOUT  
RUNNING A  
MEETING WITH  
YOUNG PEOPLE**

Rachel Kimberley Temple,  
Anja Hollowell and the McPin  
Young People's Advisory Group

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# 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 since 2017. The answer is we have learnt a lot. And 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 chose to focus the guide on running meetings because this is a core part of any research work. We will cover other aspects of working with young people in research in a different guide, such as working as a co-researcher. Meetings provide the chance for us to meet, discuss research, and bounce ideas off each other. 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 is written by Rachel Kimberley Temple and Anja Hollowell together with the McPin YPAG. Rachel leads our young people's work. Anja works with Rachel and supports our work with young people. There is more about our team at the end of this document.

**This guide 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 fourteen young people aged 16-25 and includes those with direct or indirect lived experience of mental health difficulties.

The YPAG was originally formed in 2016 to support our [Right People Right Questions 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 meetings, though there is regular contact and input given outside of meetings. 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 (RPRQ) project, and currently consists of over 200 young people aged 13 to 25 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. And 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.



# 10

## 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

**1** Provide enough time for preparation and set-up before meetings.



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



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



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



**7** Ensure there are plenty of breaks.



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



**6** Make sure sessions are interactive and engaging.



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



### TRAINING AND SUPPORT

**9** Provide training for both researchers and young people.



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



### RUNNING THE GROUP



# PROVIDE ENOUGH TIME FOR PREPARATION AND SET-UP BEFORE MEETINGS

“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

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 value 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:

- Agenda
- Ground rules
- Prep work reading and task
- 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.

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](#).

“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



## Young People’s Advisory Group Meeting

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	<b>Break</b>
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

**“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

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 sixteen to twenty-five years old, and we’ve had members as young as thirteen 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 problems – but what these are varies from person to person.

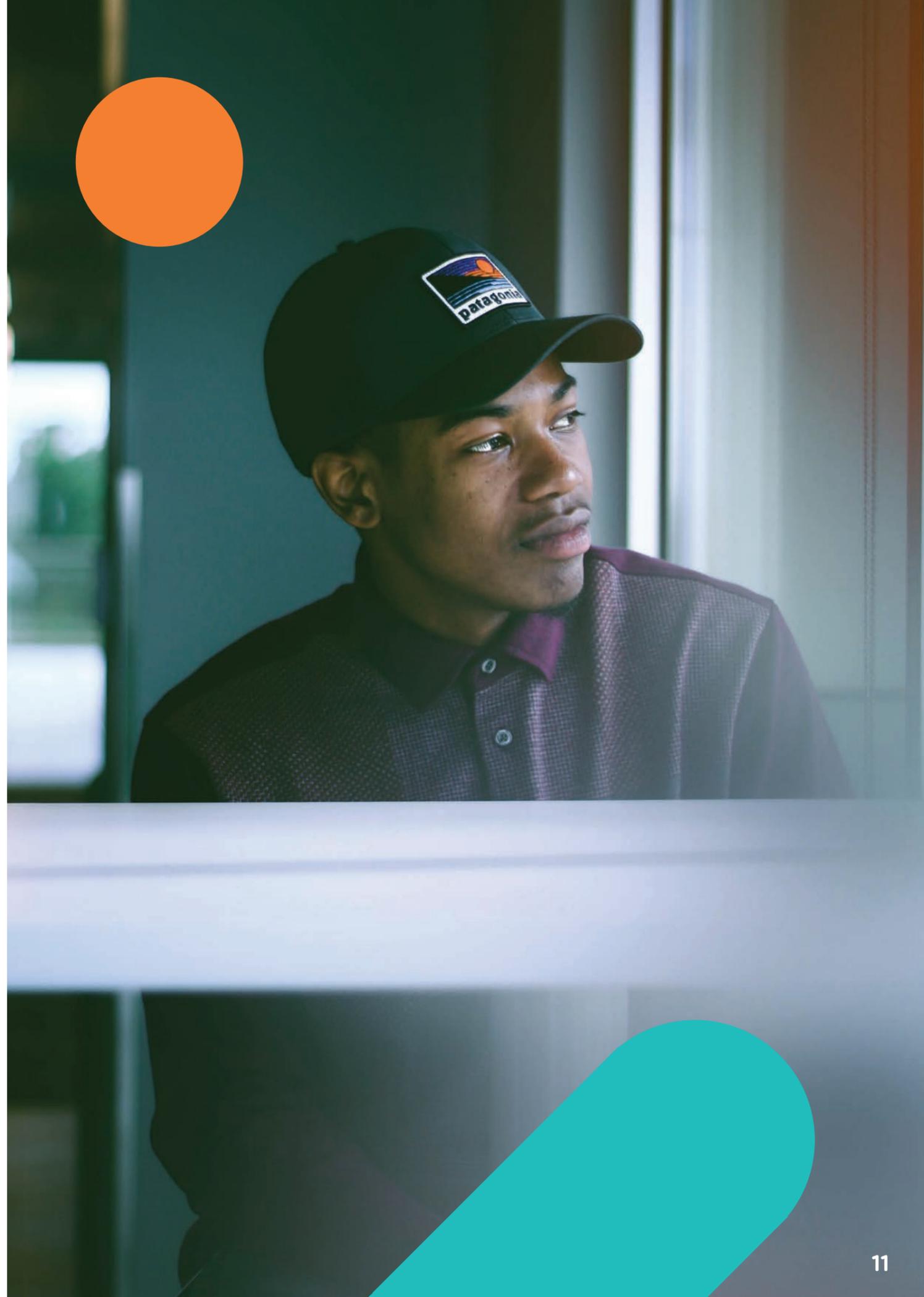
It is so important not to make generalisations about what it means to have lived experience of mental health conditions. For example, one person’s experience of anxiety might look quite different to another person’s, and different people are at different points in their recovery. There can also be a huge variation in the kinds of mental health difficulties 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 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.





## 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’](#).

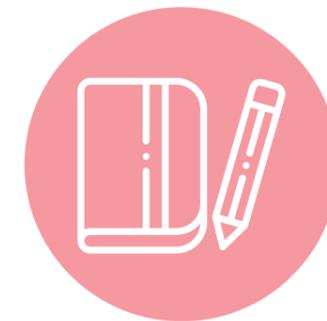


## WORK AROUND YOUNG PEOPLE’S AVAILABILITY WHEN SETTING MEETING DATES AND TIMES

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 jobs or work 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	✓	✓	✓		✓	✓		✓		✓		

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## ENSURE ALL YOUNG PEOPLE IN THE GROUP HAVE A VOICE AND A CHANCE TO INPUT

**“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 facilitator

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 usually 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.

### Menti feedback

#### One good thing about the meeting and one thing you would change

**Loved using breakout rooms and speaking to everybody.**

**I would have liked longer in the breakout rooms.**

**Great that everyone had a chance to contribute.**

**I liked using the chatbox.**

**Super interesting but wish it was longer.**

**I liked the good thing and didn’t like the bad thing!**



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 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. And 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.

**“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





## 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 [Menti](#) 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



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](#).



**“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

**“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



## BE MINDFUL OF THE ATMOSPHERE – MAKE SURE IT'S COMFORTABLE, WELCOMING, INFORMAL AND SUPPORTIVE

“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

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, 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.

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 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

“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



## PROVIDE TRAINING FOR BOTH 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-bite sized 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<sup>1</sup> 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. This also goes for making sure people understand the basic science methods and the jargon. One does not want to throw around acronyms like RCT<sup>2</sup>, HRA<sup>3</sup> or NIHR<sup>4</sup> 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 difficulties 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

1. 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>
2. “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. “Health Research Authority” – this is part of the NHS. They make sure research follows strict guidelines to protect patients and public.
4. “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.

# 10

## PROVIDE SUPPORT, ESPECIALLY WHEN DEALING WITH DIFFICULT SUBJECTS, AND MAKE PEOPLE AWARE OF WHAT WILL BE DISCUSSED IN ADVANCE



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.

**“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

# 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 guide 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](#).



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



Our YPAG's first advisory role was shaping the Right People Right Questions project. Read more [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](#).

# ABOUT THE AUTHORS



**Rachel Kimberley Temple** 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 difficulties to ensure that involvement work is as inclusive, appropriate and engaging as possible.



**Anja Hollowell** 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.



The **McPin Young People's Advisory Group** was founded in 2017 and is made up of fourteen young people aged between 17–25. 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 guide would not exist without their work.



# OTHER YPAGS

1

## 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](http://www.oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/young-peoples-involvement)

2

## 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](http://www.ypmhag.org)

3

## 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](http://www.generationr.org.uk)

# 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.  
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## About the McPin Foundation

This document was published in December 2021 and can be cited as: McPin Young People's Advisory Group, 2021. 10 things everyone needs to know about running a meeting with young people. Involving young people in research work. McPin Foundation. We are a mental health research charity. We believe research is done best when it involves people with relevant personal experience that relates to the research being carried out. We call this expertise from experience and integrate this into our work by:

- Delivering high-quality mental health research and evaluations that deploy collaborative methods
- Supporting and helping to shape the research of others, often advising on involvement strategies
- Working to ensure research achieves positive change

Research matters because we need to know a lot more about what works to improve the lives of people with mental health difficulties, their families and ensure people's mental health is improved in communities everywhere.

Sign up to our newsletter:  
[www.mcpin.org/stay-in-touch/](http://www.mcpin.org/stay-in-touch/)

Want to find out more about our work?  
Visit [www.mcpin.org](http://www.mcpin.org)  
Email [contact@mcpin.org](mailto:contact@mcpin.org)

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