



**The  
10 for 10  
Project**

Celebrating 10 Years  
of McPin



# Research Involvement Groups

Reflections and learnings over 10 years

# Foreword

**Welcome to our resource, Research Involvement Groups: Reflections and learnings over 10 years. 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 research involvement groups and others in the series useful, and we welcome feedback. Turning to this resource specifically, we explain what involvement groups are and explore the different types; look at the five stages of setting up a group that you need to think about; and lay out our considerations for inclusive groups.

We have found that our staff bring a huge diversity of strengths and skills into the workplace when they actively draw upon their lived experience. We hope that our learnings can help you to embrace the intrinsic value of lived experience in research.



**Vanessa Pinfold**

Co-founder and Research Director

## The resources in our 10 for 10 collection are:

1. 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
5. Research Involvement Groups: McPin's models and learning, and linked resource on 'recruiting for diversity'
6. 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)

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## Acknowledgments

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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 the resources in our 10 for 10 series. Illustrations are by Kremena Dimitrova and design work is by Mark Teagles at White Halo.

# Introduction

**McPin aims to bring together people's lived experiences to inform and shape the research studies that we work on. We continually advocate for people with lived experience of mental health issues to contribute to all stages of research studies.**

One way we do this is by supporting and facilitating lived experience involvement groups on research studies. We have put this resource together drawing on experiences over the years running these groups with advisory and collaborative elements, to share our learning. Our hope is that this resource will enable readers to plan and run successful research projects working with people with lived experience.

We are continually learning and trying to change our own practices, so do contact us if you have recommendations to share.

## McPin's key thinking around research involvement groups:

⑥ **They primarily have an advisory or collaborative function.**

Researchers will do the core research work, and lived experience members will support the delivery of the study through advice or co-design.

⑥ **They are all different.**

Each group is unique, put together around the needs of a research project, and the interests, preferences, expertise and needs of the people with lived experience and researchers who are involved.

⑥ **They require effort to develop and sustain.**

At the centre of research involvement groups are clear roles and expectations alongside strong relationships built on trust. This requires skill, time, money, commitment, and support.

⑥ **Members should be properly recognised for their contributions, including payment for time.**

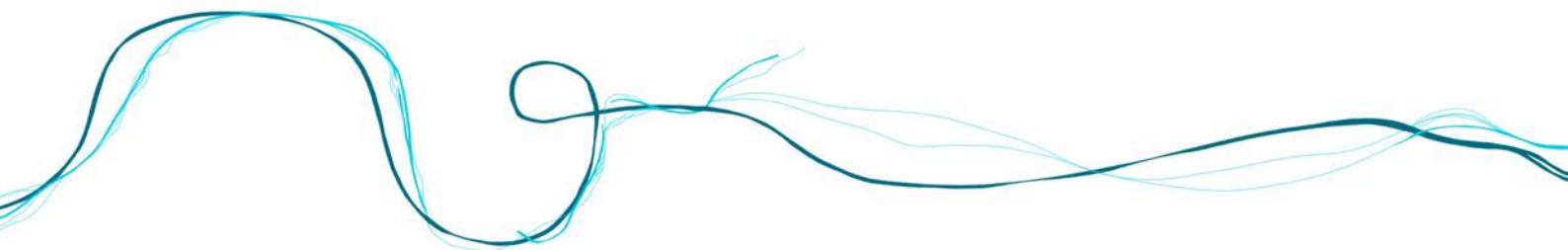
Recognition can also include training and providing a range of opportunities to ensure people can contribute across the lifetime of a research study.

⑥ **It is important to consider agency in decision making.**

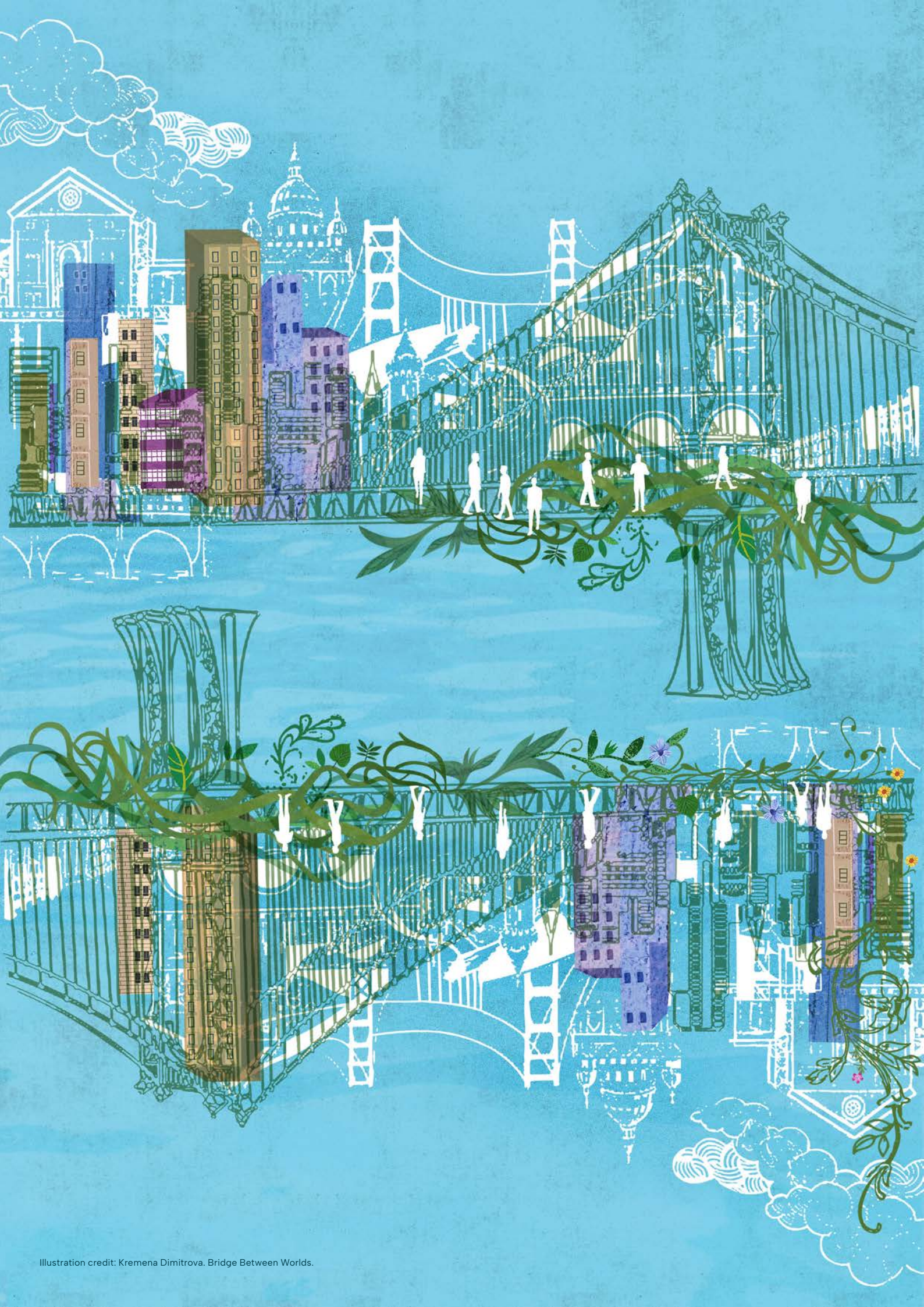
Will the group be involved in any decision making? If so, how and to what extent? Often groups record recommendations made and review how many were taken on board by research teams using an impact log. Clarity about processes and sharing of power is essential.

⑥ **Research involvement groups are only one way of involving lived experience in research.**

Please see our Public and Patient Involvement resource for more information of other types of involvement.









# What is a research involvement group?

**A research involvement group is formed of people with relevant lived experience who share their expertise to help improve a research study. Research studies and organisations use different terms to refer to research involvement groups.**

These terms can include:

- 🕒 Advisory Group
- 🕒 Lived Experience Advisory Panel (LEAP)
- 🕒 Patient and Public Involvement (PPI) group
- 🕒 Lived Experienced Working Group (LEWG)
- 🕒 Service User Advisory Group (SUAG)
- 🕒 Patient Advisory Group (PAG) and Young Peoples Advisory Group (YPAG)
- 🕒 Reference Groups
- 🕒 Research Forums

We use 'research involvement group' in this resource as an umbrella term to cover all the various terms and formats.

Research involvement groups should have an active role in a research project, rather than only receiving updates on a study's progress. These groups work with study teams to ensure the views and knowledge of people with lived experience informs, shapes, and improves research. Groups will meet to work together across in person and online formats depending on what is most convenient for people, the study's needs and the budget available.

Members may also work independently on tasks that need input between meetings. We build in a specific budget for this ad-hoc work into all funding proposals we work on. Most groups at McPin have budgets, and some have formal 'terms of reference'. Research involvement groups are not research participants, and group meetings should not be confused with focus groups. However, members may be asked to participate in evaluations of processes and share experiences of being involved in the group. They may also be asked to join a workshop for user development testing.

## What is the difference between involvement and participation?



**Involvement** is when people with lived experience are involved with designing and/or carrying out that research, alongside (or as part of) the research team.

**Participation** is when individuals take part in the research, by answering questions and supplying data, for example.

## What is lived experience in research?

In mental health research, members of research involvement groups have expertise that they have gained through lived experience of mental health issues. This can include people caring for someone with these experiences. Lived experience will also be intersectional – this means that most people’s mental health experience intersects or overlaps with other experiences such as their age, sex, gender, race, culture, sexual orientation, socio-economic background, geography.

Group members bring unique and important knowledge to research. Experiencing problems personally provides a very different perspective than can be gained from observation or clinical practice, reading a textbook, or attending a lecture.

For some groups, the lived experience will match up to a certain degree with what’s being explored in the research study. For example, a study exploring depression might have a group with members that also have lived experience of depression. However, this is not always the case. For most studies, members do not need to prove their lived experiences. Groups should be appropriately inclusive and include a diversity of people with different backgrounds and characteristics, even if they share the same mental health experience or diagnosis.

We try to ensure that in each group there will be some people who have had little or no experience of research. This is to ensure that new people are given the opportunity to get involved in research, using their unique skills and experiences to influence knowledge production.



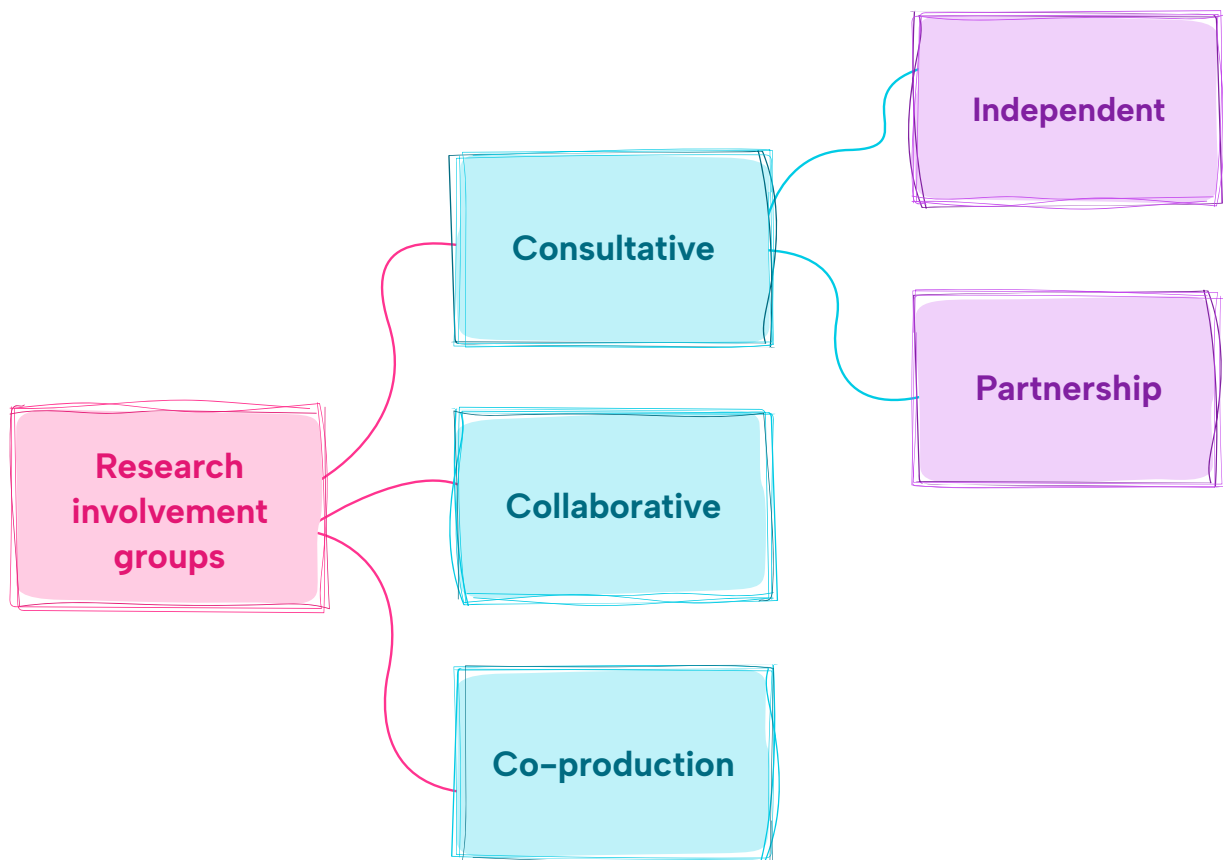




# Different kinds of research involvement groups

## Types of research involvement groups in action

At McPin, we recognise that our work so far has evolved into **five main types of groups**. These types are not mutually exclusive. We have found many projects use a combination of different elements.



### Independent consultation

Independent consultation groups generally work separately to the study team. They are often hosted by an external organisation, like McPin, without high levels of core research study staff involvement. They can assess parts of the project and give advice to the research team from a lived experience perspective. In this case, members of the study team will usually attend meetings to present documents and to hear the group's feedback.

Members of the group respond to information provided. These groups often meet at specific timepoints during a study, around the needs of the study team. This tends to be more frequently at the beginning and end of a study as this is when involvement can make the most difference. When there is a long gap in the middle of a study it's important to keep the members of the group informed of progress and engaged ready to reconvene at a point where there is more activity. For example when study data becomes available following the end of participant recruitment.

A **consultative** approach is most appropriate for short term projects with a low budget. When working towards lasting, embedded involvement, it is not an ideal model.

When using a consultative model, it is important to ensure that there is regular communication and feedback. This allows the group to know how and where their contributions have or have not been applied in a research study, and the reasons why. It is important to set any boundaries for the group early to avoid disappointment and ensure people understand the role of the group.

## What do we mean by independent?



Sometimes people believe independence equals neutrality, a role that provides oversight without bias and in turn must be kept separate. We believe that it is not possible to be completely neutral in an advisory group. People join because they are passionate about the topic or being involved in research and this is a positive thing!

When we say independent, we mean the model or structure; that the group is not embedded in the research team and has limited scope for work outside of providing their expert advice.

### Case study: TOSCA – example of a consultative independent group

TOSCA (Trial of Sertraline versus Cognitive behaviour therapy for generalised Anxiety) was a study designed to see if a drug called Sertraline could help people with Generalised Anxiety Disorder (GAD). The opportunity to take part was offered to people whose symptoms of anxiety who had not improved after having a specific form of psychological therapy in the NHS.

The study included the involvement of a three-person group all with lived experience of using mental health services, and a member of McPin staff who chaired the group, referred to here as a Clinical Academic Group or CAG.

The design of the study was set by the funder (National Institute of Health Research) through the application for tender process. Both the study team and CAG had some concerns from the beginning about the design of the study. CAG members reported

that they would have liked to have been informed better about what could be measured as part of the study and what could not.

One key point the CAG made was that recruiting people to the group that took the sertraline, rather than the group who had the therapy, would be challenging. It was felt that people would prefer to be in the group that received the therapy. This ultimately proved to be correct, and the study was closed early in 2016 due to poor recruitment.

The CAG met six times in total and operated relatively independently from the main study team. The small size of the group was seen to be appropriate by members in this context. Despite the study failing in its intended aims the CAG felt that there were some very valuable lessons to be learnt for other studies which were written up for publication. Recommendations for future research were also made.



## Consultative partnership

Consultative partnership groups have closer relationships with the core study staff and are considered part of the research team. Group members may be invited to be part of other study committees such as a management group or smaller working groups linked to specific modules in bigger studies.

These groups may meet ad-hoc or regularly. However, the core activities are consultation and advice work, they are generally not asked to make study decisions. The advice they give can be acted upon or may not be taken forward.

### Case study: Data Linkage – example of a consultative partnership model

Data science is a complex topic that affects anyone who has used NHS services. Data science in mental health is a specialist area. Our Data Science Advisory Group is relatively small compared to most research advisory groups; it has six members and was set up to support one university department, but is now an open-access group for interested researchers.

The members have all used secondary mental health services. They have also all been involved in other mental health involvement activities and are familiar with the research environment. This was intentional, members were chosen based on their experience and interest around data science, and their willingness to ask strategic and operational questions about how data science is done.

Meetings are not booked in advance but are convened when there is a topic to discuss. Membership of the group has remained consistent. The format of the meetings tends to involve presentations given by researchers (often early-career researchers), who present their project's early findings. The group gives feedback on how a project could be improved or what the findings might mean.

Discussions between service users, clinicians and data science researchers often highlight different perspectives on that data. The ethos is of shared learning, so researchers (usually data scientists) learn alongside service users and clinicians. Everyone improves their knowledge and how it can be applied. Over time, the group has developed more experience and expertise in data science and can offer advice at a more detailed and technical level.

## Collaborative

Collaborative groups are run with the intention that all the members will be actively involved in the study, helping to make decisions and delivering aspects of the project. They have an advisory function, but they also shape meeting agendas and co-chair sessions – they are not solely responding to questions from the core study team.

This requires group members and staff to work more closely together. All parties work in collaboration, each offering their own skills, with complementary roles and responsibilities.

Collaborative groups can have more influence on how a study is shaped, and they tend to be involved in the work in significant ways, such as data analysis. They are likely to have a dedicated coordinator. In this model, everyone in the group may work on the same things or take on different tasks aligned with their interests and skills.

Sometimes a collaborative approach will have elements of co-production or co-design.

### Case study: EYE-2 – example of a collaborative group

The EYE-2 Lived Experience Advisory Panels (LEAPs) were one part of a multi-levelled approach to Patient and Public Involvement (PPI) within a Randomised Controlled Trial (RCT). Five sites each had their own LEAP, with members consisting of service users and carers from the Early Intervention in Psychosis (EIP) service, facilitated by a lived experience PPI lead.

McPin's role was to support the five PPI site leads. The LEAPs met as needed at key points throughout the study, both in person and online. Initially it was anticipated these would be closed membership, with the same members regularly attending, however we found this difficult due to changing needs of group members and the nature of EIP services.

We moved to a more open membership model to help us maintain a minimum number of 4-5 attendees per meeting. This change proved positive as we heard the views of, and had increased input from, a more diverse group of people than we would have with closed membership.

As the facilitators were delivering parts of the intervention, they were a bridge between the central research team and the LEAPs and had significant knowledge about the study they could share and discuss with LEAP members.

This built a sense of team where people felt included and could ask questions or get updates. At subsequent LEAP meetings, the PPI leads would update members on how their input had been used and share any updated documents, ensuring good communication with the members.

All materials for activities were shared with LEAP members before meetings, allowing time to prepare. This approach also facilitated access for people who felt more confident providing written input rather than in-meeting input.

The EYE-2 LEAPs were unique as they had a lot of opportunities to co-design aspects of the trial. They were involved in making decisions about the direction of the study and delivering aspects of the project, not just responding to questions.

Across the LEAPs people drew on both their lived experience and knowledge of design, communications, and counselling to inform their contributions. This project showed that even in a randomised controlled trial with specific methods and limitations research involvement groups can have a key role and be involved in both design and delivery of the research.



## Co-production

Co-production groups have similar elements to collaborative groups, but they build a project together, from start to finish, based upon co-production principles and values<sup>1</sup>. Members of these groups will have mixed expertise, for example lived experience, academic and practitioner. The group works alongside each other in every aspect of the project, with the ambition that all members within the group have an equal say in what happens.

These groups are set up to undertake activities such as co-developing materials, co-creating interventions, engaging in training of project staff, and co-delivering research. Due to issues such as funding and need, the way coproduction groups work may be different across projects. However, they should all be operating as far as possible on a round table basis, working to limit the impact of system hierarchies, and exploring how power can be shared.

For more information on co-production see our resource [here](#).

### Which membership type for which model?



Some groups meet regularly throughout the lifetime of a research project. Others may have variable membership. We also run one-off groups or workshops to help shape projects before they apply for funding in the hope the people involved can form the ongoing group once funded.

We have found that consultative models work with either continuous or open membership, while collaborative and co-production models would work best with a fixed group of members to help develop the longer-term relationship required.

### Case study: **gameChange-** example of consultative-partnership group with elements of co-production

Eleven people with lived experience of psychosis and social anxiety were selected from across England to join a Lived Experience Advisory Panel (LEAP).

The four-year research project developed the use of a virtual reality (VR) therapy to help treat people who had a problem with visiting places outside of their home. The LEAP was run by McPin, with the PPI co-applicant as Chair. A PPI co-ordinator employed at McPin administered the group. Members of the gameChange study team attended LEAP meetings and there was good level of interaction between research staff and lived experience advisors.

As the study progressed, the LEAP was consulted at every stage. By the end, nine LEAP members were still fully engaged and we had held over 30 meetings.

LEAP members were involved in user-testing workshops to help inform the design of the virtual reality intervention, as well as attending LEAP meetings writing blogs about the involvement process. LEAP members also worked closely with the peer research team at McPin who carried out a piece of qualitative research to explore service user experiences of the gameChange VR therapy.

The peer researcher on the study had originally been part of the gameChange LEAP, and another LEAP member gained employment in a local study team. The gameChange LEAP was a springboard into other roles in the study.

1. National institute for health Research (NIHR). (2021, April). Guidance on co-producing a research project. Retrieved 12th July, 2023 from <https://www.learningforinvolvement.org.uk/content/resource/nihr-guidance-on-co-producing-a-research-project/>

# What influences how research involvement groups work?

There are lots of different influences on how groups operate; we list a few below.

## Study design

The length of the study, methodologies, location, how it is anticipated that those with lived and research experiences will work together, and what outputs are needed will all influence how a group runs. It is important to explore this before recruitment, so people know what they are getting involved with.

## Availability of non-staff budget

Budget is a key factor in determining what a group can do. Your budget will determine how often a group can meet, whether this is face to face with travel covered, how many members it has, how much paid activity you can have in between meetings (for example writing blogs, going to conferences, attending extra meetings), and whether you can fund digital inclusion and data allowances.

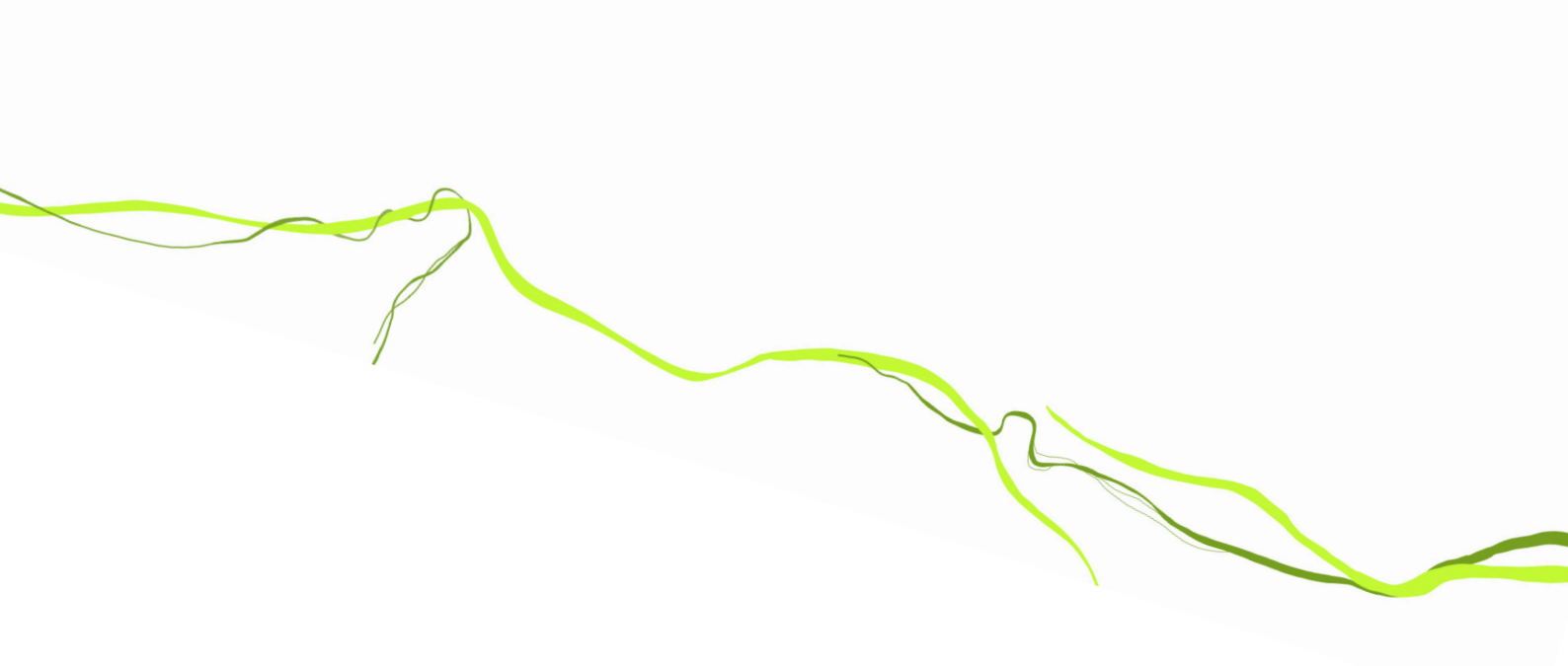
## Knowledge about research involvement groups

Understanding the parameters, expectations and relationships between the study team and lived experience group members is important for decision making throughout your project. This will also help you determine how much staff time and resource you need to guide, inform and develop the research team and group members about involvement throughout all stages of the study.

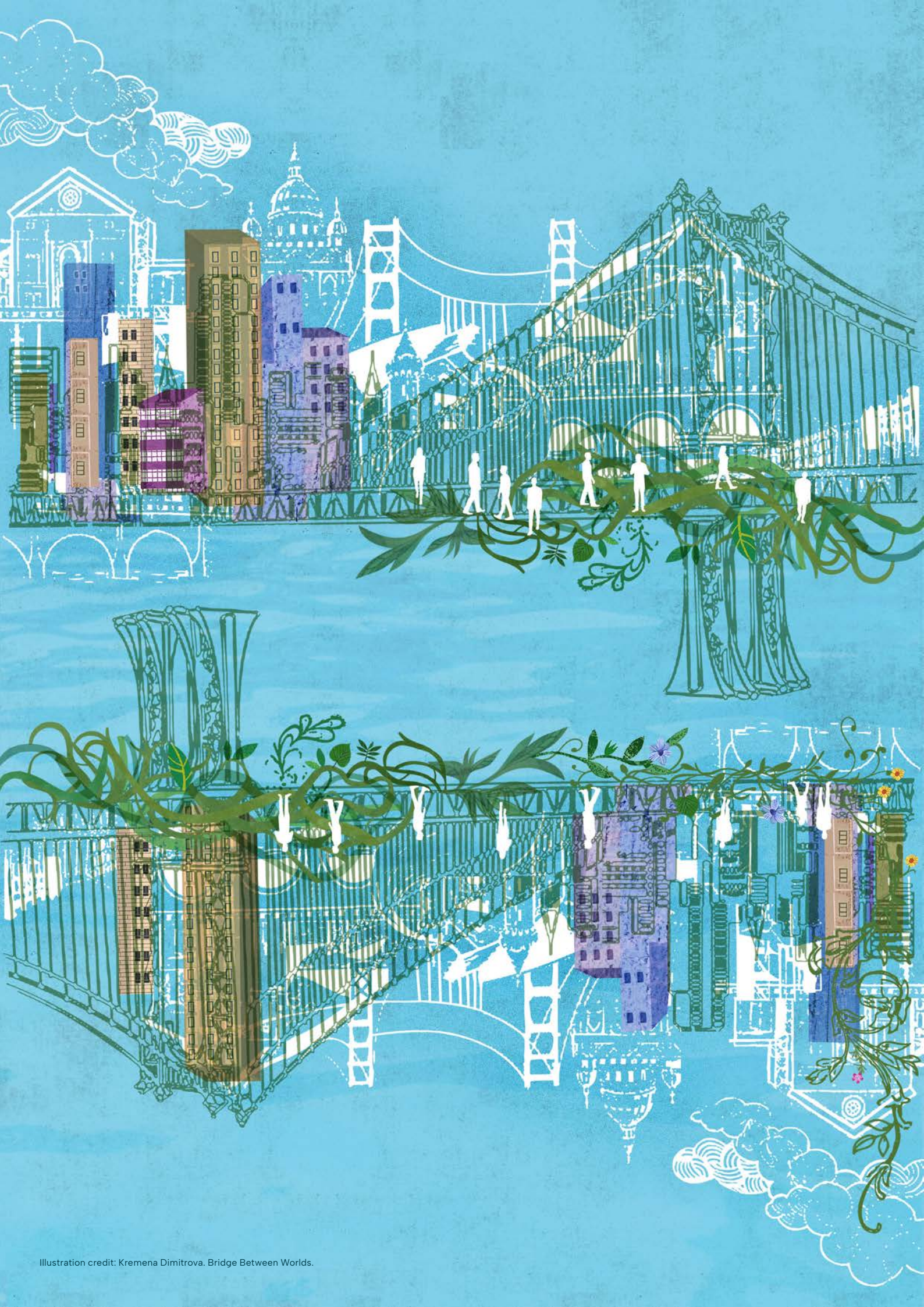
## Who is coordinating the group?

In our work, McPin staff often coordinate research involvement groups, but there may be partners who are already designated to deal with some aspects of public involvement.

From the inception of the project, it's important to be clear about roles and where they cross over, or where there is flexibility. Also, group members may be able to take on roles, for example co-facilitation or co-chairing sessions, report writing and editing. This structure will have some influence on how you conduct a group.









# Setting up a group: five stages to consider



## How to plan for a group

🔗 **Develop collective agreement on how you want to work:** Ensure there is a mutual understanding of the model the group will use between all people involved in the project. At the beginning of a study, asking partners what they want and how they want to work can help identify what group type would be most appropriate.



**Make sure you provide enough relevant and useful information about the group before someone considers joining.”**

LEAP Member

🔗 **Have a recruitment plan:** You will need to recruit group members. How many people should make up the group, what skills and experiences are needed, and how can you achieve diversity of perspectives among group members?



**Being organised should be a top priority, this would include developing clear documentation in regard to meetings (minutes, agendas, invites), making sure that meetings are organised in good time and taking into consideration everyone’s individual schedules.”**

YPAG Member

🔗 **Organisation, project management and timelines:** Project management involves administration, operations and coordination. This means managing people’s time and needs; helping project members understand and fulfil responsibilities; day-to-day communication, broader dissemination and communications planning and organising practical elements such as payment and technology support.

Coordination means keeping everyone informed about what they are being asked to do, where and how things are happening and aiding communication between people that usually don’t have contact. Timelines help to ensure everyone has a shared goal, and are aware of how project work impacts wider things around it (for example, is there an upcoming event the project could contribute to? Are there internal deadlines from the funder?).

- 🔗 **Begin involvement early:** Involving the group facilitator/lead and group members in study team meetings and conversations as early as possible, including when developing the project, helps embed good involvement. It is vital in co-production. Coming together helps you to map out where groups can be involved in the study, and how best to support a research involvement group.
- 🔗 **Safeguarding:** This is an essential part of working with people, especially young people. At McPin we have a policy for both young people and adults we use internally, and a Lead Safeguarding Officer to help facilitators if any issues arise. All staff undertake safeguarding training. We also have some practices that we use across all groups that help us ensure people's safety, that also help us in creating a welcoming space.



**When meetings at McPin are held, the beginning of the meeting has housekeeping points which include... what should happen if we begin to feel triggered and who to contact. Being triggered by a difficult topic may always be an issue and it's important for young people to understand that this is okay and there is support available."**

YPAG Member



**When you advertise your group be clear about the time commitment required and what you are looking for and what you can offer in return for people's work and time."**

LEAP Member

## What resources can your budget afford?

Understanding what resources you need at the beginning of a project, and making the case for these to the funder is critical. This can help you to avoid running out of time, overspending on your budget or not having enough to do the activities your project needs to ensure good lived experience involvement. We find that the beginning and end of studies are both intensive periods. At the end you tend to need a dissemination budget to produce quality outputs by involvement group members as well as payment for involvement fees.

- 🔗 **Payment** for group member's time and expertise must be part of the budget. Time that group members spend on the project, such as meeting time and doing ad-hoc tasks, should be acknowledged via the offer of payment. Consider the availability of your members and level of commitment they can give to the project. People's lives differ, and involvement should be flexible<sup>2</sup>. Your organisation may operate on a per hour or per meeting basis.
- 🔗 **Staff resource** to support groups and administration (e.g. recruitment, coordination, organising, invoices), time to engage people with different needs or preferences (e.g. verbal vs written communication, group vs one-to-one settings), time to build rapport with each member and understand their motivation, interests, personal development goals and access to technology for online activities. There also needs to be research staff resource that allows the team to plan and engage with the group.
- 🔗 **Tools** such as digital hardware, venues for in-person meetings and stationery are essential for keeping groups and meetings running and should be factored into your budget.

2. National Institute of Health Research (Version 1.4, July 2023). Payments guidance for members of the public. Retrieved on 24th July 2023, from Payment guidance for members of the public considering involvement in research | NIHR.



## Questions to ask about resources to help plan a project



1. Is the group included in project planning, allowing time for members to review, create and feedback? Might members need childcare, or carer costs covered? Add resource for all stages and adaptations that you might require.
2. How much will members be remunerated for time and expertise? Projects need to be clear on rates of pay, including for preparation for meetings or tasks.
3. How will the project build and support different skills, knowledge and experiences in the group? Include resource to cover support and training, mentoring and supervision.

## What support might be needed?

Providing **support for groups** to ensure you are working in an accessible way can include some of the following considerations. At McPin we ask these questions during recruitment, group set up and regularly through project delivery.

- Ⓞ Are carers or friends needed to accompany someone to a group?
- Ⓞ Do members need childcare or have carer responsibilities?
- Ⓞ Do the documents, media or hardware you work with, or activities included in your involvement work take into consideration neurodivergent ways of communication and learning?
- Ⓞ Is there a plan in place for when wellbeing issues arise – do members have personal networks, or have you signposted them to relevant organisations if external help is needed?
- Ⓞ Do members have access to the technology involved in your work, or do they need to work in different ways? Do they need support downloading software or logging into meetings? Will you need to support with hardware such as a tablet or laptop?
- Ⓞ If the meeting is online do people have affordable, reliable internet access and a private space to join meetings from?
- Ⓞ Do people need meeting reminders, and when and how is this best done?
- Ⓞ Support based on setting: have you considered accessibility needs for in person, online, and hybrid meetings?
- Ⓞ Can you make any adjustments base on literacy and language requirements such as allowing for both written and verbal contributions?
- Ⓞ Do materials or meetings require content warnings?



**I think the most important thing for helping members feel supported is allowing them to feedback in the way that works best for them. I think that members being able to choose their medium of response frees them up to contribute to their full potential as they may not freely tell you about challenges that they have in responses/confidence at the beginning.”**

YPAG Member

## Chairing

A Chair is the person that leads a meeting. Often, they are responsible for organising the agenda and facilitating the group in meetings. Essentially, a Chair makes sure that meetings run to time and that everyone can have their say. Sometimes the Chair will also be responsible for setting up the meeting including date, location and invites, taking attendance and ensuring minutes are sent out, but this is not always the case. These tasks might be allocated to group members, or someone who supports in an administrative role.

We have found we tend to use **four** chairing models at McPin:

- ④ Having a Chair external to all organisations and teams
- ④ A Chair from the study team (which could be a member of McPin staff)
- ④ A rotating Chair from within the research involvement group (lived experience member)
- ④ Co-chairing, which can be a mix of a member from the involvement group and a person from the staff team (McPin or the study team).

Sometimes we find that projects use a combination of these or start with one model and move to another as the group develops. It is important to think through what role the Chair will have no matter what model you use. One of the main things to consider is if your Chair will be neutral, where their main role is to facilitate and undertake administrative tasks but are not usually involved in decision making or sharing their personal views. Alternatively, the Chair might be actively involved in the group using their lived experience and other forms of expertise, so they are both member and Chair simultaneously.

It is worth considering the strengths and weaknesses of each chairing model, and why they may be suitable to your project. This can and should be discussed with all members concerned and be flexible to group needs. Chairing is a critical function in a group. It helps with ensuring different voices are heard, that key tasks and discussions are covered and for managing any conflicts that arise in meetings. It also ensures meetings start and finish on time. Chairs help facilitate fair process, ensuring the group over time achieves its purpose. Sharing chairing amongst

the group is a great opportunity for others to grow their confidence and skills and is a mechanism for power sharing. It can also help reduce 'them and us' dynamics between academics and people using their lived experience (group members).

## Impact, evaluation and feedback

In research involvement work, there is currently a useful discussion about measuring impact and importantly, how to do that appropriately. At McPin we favour collecting feedback from group members and evaluating our work using reflective practices and qualitative methods, to improve our models of involvement. We also commonly use impact logs to track decision making. Our impact logs tend to be a simple spreadsheet in which suggestions made, and their corresponding actions are recorded. The date of the suggestion and who made it is additionally recorded.

We are interested in the difference lived experience can make to a study, and the challenges with this work. That means engaging research involvement group members and the wider academic study team as well. For individual group members we have recently started developing Personal Development Plans with goals set early on and progress tracked over time.

Feedback on how group members feel they have impacted on a study, or how they have experienced their role can be collected in several different ways including online polls or surveys, online pinboards (after meetings and at key project development points) and informal feedback through emails or conversation.



**It can feel daunting talking about your most intimate and personal experiences (sometimes, those which you have never told anyone before!), so facilitating a space which nurtures individuals and is free of judgement is paramount."**

LEAP Member







# What skills are needed for group members, facilitators, and co-ordinators?

Below are some examples of the broad attributes and skills we have found are helpful when taking part in research involvement work for both members and facilitators. Importantly, some members will come with these skills and knowledge developed through their life or professional experiences (for example, other groups). Others will develop them as part of the reciprocal learning that should be embedded in a group. Not all members need to have all these skills; different people will have different strengths they contribute to a group.

## Group member attributes

### Experience

- ④ Having experience of **how mental health impacts day-to-day life**.
- ④ Experience of **mental healthcare systems**, whether through institutions such as the NHS or more local systems like community support.
- ④ Experience of **caring for other people** who live with the impacts of mental health issues.
- ④ Being **able to identify relevant parts of your experience** and offer them to meet the needs of the project. For example, to improve mental health support approaches and systems.

### Practical

- ④ **Open-mindedness** is key. You may come across situations you haven't yet encountered, opinions you are unsure about or things you disagree with. Having an open mind can help you to see the bigger picture and be more flexible to change where it might be needed.
- ④ **Curiosity**, asking questions and helping explore possibilities within a study.
- ④ **Investment** in the topic being explored and in participating as a member of the group.
- ④ **Being aware of other group members**. It is important to know that what you say may have

an impact on others; being conscientious and aware of this is crucial to group working.

- ④ A **willingness to engage** in activities that the project needs to function.
- ④ **Understanding** that group rules or safeguarding are in place to help everyone.
- ④ Being **willing to connect** with others and to share your thoughts.
- ④ Being willing to **communicate in different ways** in a meeting. This includes engaging outside of the meeting by email, phone, and other modes of contact.



Being in an Advisory Group has shown me the importance of taking on board people's opinions. There are many of us in the advisory group I am in and we all have such different opinions on every topic. People will say things that would never have crossed my mind and it is so important to hear these opinions in order to be able to have a well-rounded understanding of a topic. It is because of this that I have learnt the significance of advisory groups in general, as they provide researchers with vital information from all walks of life."

LEAP Member

# Facilitators and/or co-ordinator attributes

## Practical

- ④ **Administration** is key to keeping groups running smoothly.
- ④ An ability to **establish** ground rules and understand protocols for safeguarding.
- ④ **Making activities accessible** for group members and seeking out accessibility needs. Remembering to adapt to the members' needs rather than invite them into an unsuitable situation or space.
- ④ **Identifying and using your strengths.** As a facilitator you may be better at time keeping or establishing a connection with group members. It is also important to identify where you might need more help and support from team or group members.
- ④ **Knowledge of research, policy and evaluation** where relevant.

## Interpersonal

- ④ Listening.
- ④ Being able to **manage distress** and have a **caring approach**.
- ④ Being resilient.
- ④ Being empathetic and non-judgemental.
- ④ Understanding the **balance between relatability and having a neutral role** as a facilitator, and when these roles are most appropriate.
- ④ An ability to **coach and encourage others**, drawing people in and creating a welcoming environment for people to share their thoughts and concerns.

## Communication

- ④ Being able to **communicate ideas to different audiences** (for example between scientists and frontline workers, or people with lived experience).
- ④ Having **good engagement skills.** Knowing how to make topics interesting to people and being able to express the benefits of the work.
- ④ **Being honest** and sticking to the truth even when it's inconvenient.
- ④ **Being receptive** to the contributions of the group members.
- ④ **Good facilitation** skills include helping group members share the space when voicing their opinions; helping people see the value in their thoughts and suggestions; and using these skills across online, in person and hybrid meetings.
- ④ **Co-ordination** being able to keep in touch with people throughout a project, helping them stay involved practically.

## Skills across both

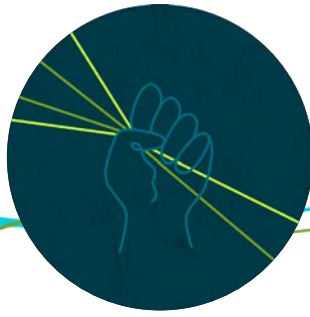
Some of the skills cross over both group members and facilitators. For example, effective listening, being open to lived experiences and opinions that are different to your own and accepting that the groups decisions might not always be ones you agree with. Be open to people taking on different responsibilities and tasks in groups based on their strengths and interests rather than their roles!

## What types of activities can research involvement groups work on?

Groups can contribute to a range of research activities. We believe that research studies should facilitate the inclusion of lived experience as much as practically possible within the study design and research process. The following table shows some of the activities advisory groups can be involved in, as well as the ways lived experience expertise can enhance these activities.

Activity	How lived experience can enhance these activities
<b>Defining or refining research questions</b>	Knowing what is important to those with lived experience or where research might have impact on the ground. Knowledge of the most pressing needs/wants of the community being studied.
<b>Choosing an appropriate methodology</b>	Knowing what approaches might be best suited to exploring lived experience of an issue. Knowing where a methodology might align or conflict with a community's values.
<b>Data collection tools</b>	Modifying language (stigmatising words/sentences and inclusivity), shortening surveys to reduce time commitment, piloting tools to check for efficacy. Knowing how to make tools engaging and not overwhelming for people. Suggesting which order to use when implementing assessment tools which use a sequence of standardised questions. Knowing what questions get to the heart of lived experiences.
<b>Scoping work, including literature reviews</b>	Looking at a variety of information and connecting it to lived experiences – access to non-traditional forms of knowledge, embedded in community places (support groups, peer support, places of worship etc.). Literature reviewing – suggesting search terms.
<b>Study materials (e.g. consent, information sheets, summaries)</b>	Advising on how to make these engaging and accessible. Ensuring these explain the study in a lay manner. Spotting acronyms and jargon. Reviewing language for triggers and inclusivity. Putting oneself in the research participants position, helping to draft careful wording. Thinking about using audio and video instead of written information.
<b>Participant and staff recruitment</b>	Knowing who will most benefit from the project, and who will best fit the project recruitment criteria. Able to communicate aims and benefits in ways that the participants can relate to. Common culture, knowledge of cultural and social context. Rapport building.
<b>Data collection, often qualitative interviews</b>	Rapport building, empathy because of similarity of experiences. Able to connect with participants to allow richer experience sharing and knowledge. Knowing which questions to ask to further explore narratives.
<b>Contributing to/reviewing analysis</b>	Using lived experience to understand results and how themes connect. Asking searching questions and ensuring clear narrative emerges. Interpreting themes that people without lived experience might miss or deprioritise. Adding depth to results.
<b>Writing</b>	Knowing how to translate complex information into understandable language – such as through blogs or summaries. Knowledge of how to present information that reflects the complex messages in a readable way.
<b>Dissemination</b>	Knowing how to ensure results make it back to the community at the focus of the research. Suggesting different formats and leading the creation of some outputs. Able to translate research content into a format that is accessible that is meaningful for the audience. Able to better understand how to give back in the dissemination process. Knowing who may be interested in the work. Active dissemination through own service user networks and social media.
<b>Implementation</b>	Knowing the barriers to engagement and how these might be overcome. Motivating key stakeholders such as clinicians to take note of evidence base. Knowing what types of things might be helpful for people in improving wellbeing, and how best to describe a programme.





## Being a critical friend

A key feature of research involvement is being what McPin calls a 'critical friend'. This is where the members provide critique and challenge to a research study with the intention of supporting it to improve and have maximum impact. Being a critical friend is a set of skills. It can also require a level of resilience and ability to deal with discomfort and rejection of suggestions, as well as positive feedback.



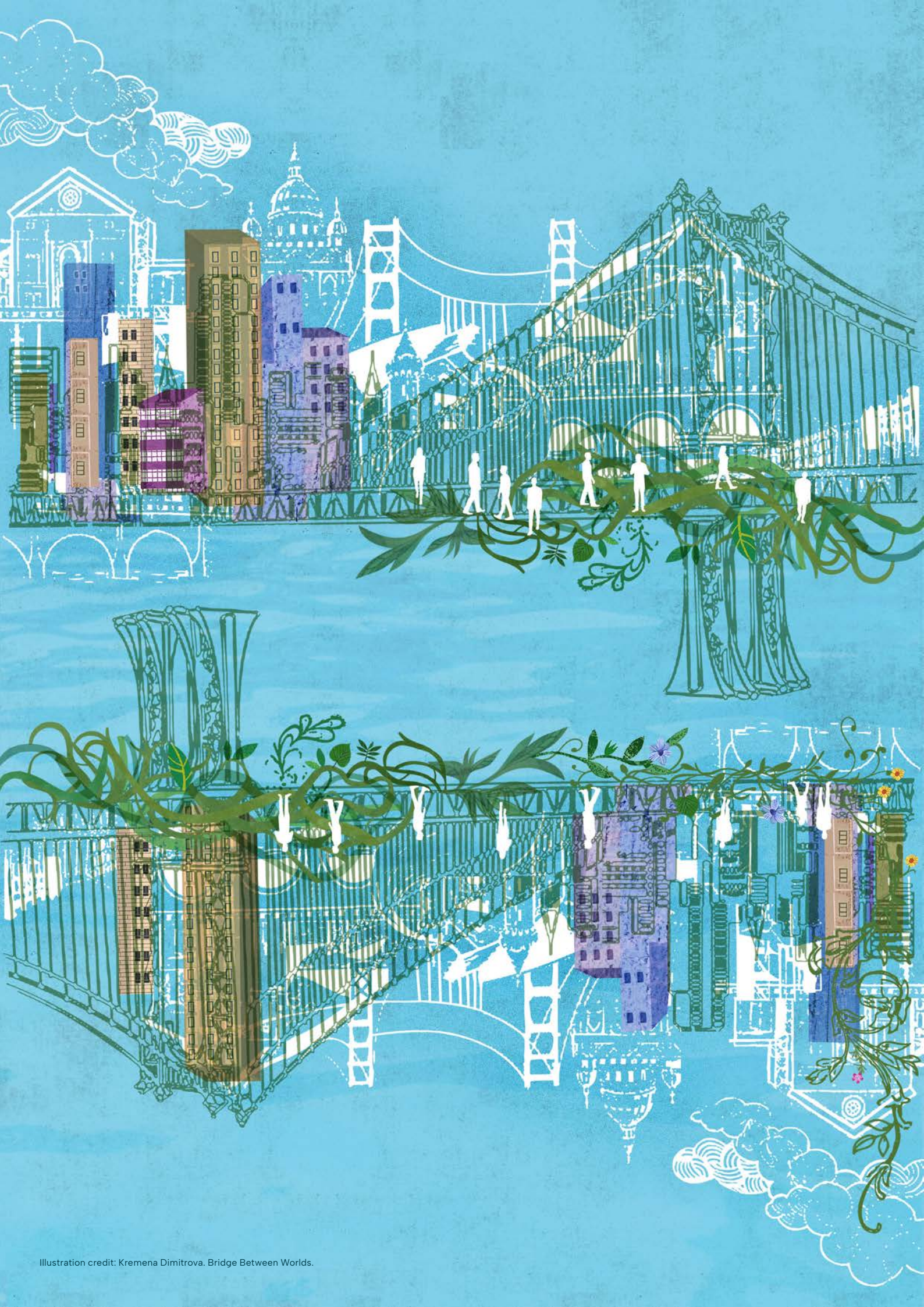
**Being both a LEAP member and then a Service User Researcher on a major mental health study has given me two distinct perspectives and involved striking a balance between being a critical friend and a colleague. As a LEAP member, I was able to enjoy a critical distance from the study, attending quarterly meetings, being updated with a 'snapshot' of progress, and making suggestions that might otherwise have been passed over by the research team. I felt more independent as a LEAP member than as a member of staff and, on reflection, also felt able to be bolder in my feedback than when working on a daily basis with colleagues drawn from the academic and clinical fields.**

**"When I became a Service User Researcher, it felt a daunting prospect to begin working alongside clinicians from a treatment system that has inherent power imbalances embedded within its practice. The very language employed by both clinicians and academics, with its copious use of acronyms and jargons, seemed to serve as a signifier of exclusivity. Negotiating the fluctuations in power dynamics within a research hierarchy consisting of academics, clinicians and people with lived experience was a challenging yet fascinating aspect of my role.**

**"As a staff member I was much closer to day-to-day decision making which in theory gave me more 'power' to shape and direct the project, yet also made me far more aware of the need for compromise and pragmatism than when I was a LEAP member."**

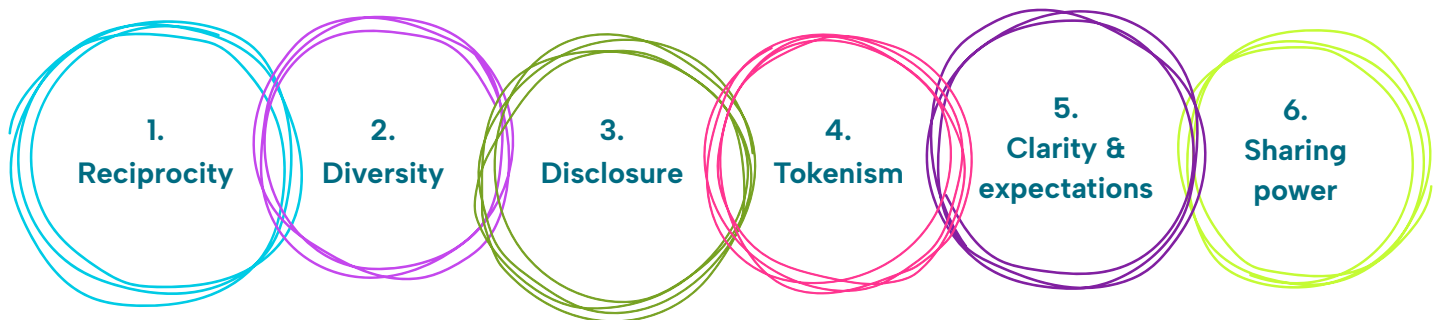
Staff member







# Considerations for inclusive research involvement groups



## Reciprocity



Reciprocity is the idea that all people involved should benefit. This means members contribute their experiential expertise and skills, and researchers provide something in return. Research involvement groups are not for extracting people's opinions or stories about their lived experience. They are about valuing people as experts with unique insights into issues and systems that enhance research. This can lead to researchers benefitting by learning from people with different skills and perspectives, and group members also acquiring new knowledge or developing positive relationships with other members and academics.

One way to avoid being extractive is to build reciprocity into groups, and at McPin we believe this is a foundational part of running good groups. Adequate payment is one form of recognition. The types of things that can be built into groups to enhance reciprocity could include:

- ④ Establishing the basic ground rule that everyone in a group is treated with equality.
- ④ Discovering members' skills and strengths, building upon them and offering opportunities to utilise them.
- ④ Ensuring good and meaningful communication

with regular updates. Inviting members to shape meeting agendas or suggest ideas. Sharing what is learnt with people and communities in lay-friendly and accessible formats.

- ④ Getting to know people – both the research team and those bringing lived experience. This might be through chats at the start of meetings or during breaks. Some groups like to have social events, like a dinner after a meeting.
- ④ Providing training and development about research methods, skills or even more about the topic being researched and putting this new learning into practice within the project.
- ④ Having buddy systems, community building or peer connections where people can learn from the study team or others on the project.
- ④ Opportunities for connecting with other studies or groups sharing tips or ways of working.

Recognise that members don't just bring their lived experience – they also have other skills and knowledge. Good groups should explore how this can contribute to a study or group. Although at their core the function of research involvement groups is for people to draw on experiential expertise around mental health, viewing people as only this can be harmful and limits the potential of what the group can achieve. We often find people in our groups are very creative so can help with illustrations, blog writing, or making podcasts.



They know about community development, and addressing inequality, stigma and discrimination. Some people in our groups are experts in recruitment, accessibility and writing.



**Sometimes researchers get caught up in only considering the longer term, transactional purpose of a YPAG: to offer advisory support on a research project. All group involvement is therefore a means to this end. However, the best and most productive groups that I have sat on have been those that foster an environment of mutual support and community. For members to feel heard, involved, and like their voice is making a difference on both a micro and macro level, is really important."**

YPAG Member

## Diversity



Diversity means several things in research involvement groups. It can be about protected characteristics such as age, sex, race, disability, sexual orientation

etc. It can also be diversity of experiences about a specific mental health diagnosis, or services, or diversity in how much experience someone has with research or being in groups. It can also be about diversity in thinking. Groups work best when they have people with different opinions and perspectives on an issue. This helps with preventing 'group think' which is when everyone shares the same view. We recommend trying to ensure diversity across all these elements as this will enrich and bring different perspectives to your group.

Many group members will come with knowledge collected from their personal and professional networks and can advocate and share expertise based on this. However, it is important that individuals are not seen to have the definitive views of a group of people, as each person's lived experience is unique to their own lives and overlapping identities. This is why having a diverse group is so important.

A common problem is aiming for diversity but not creating a working environment that supports it. Is the study working with culturally diverse people? Does it consider how those from different socioeconomic or educational backgrounds might experience things differently? Is it clear how people can look for support if they feel they have been excluded from the group or any other aspects of the study based on aspects of their character? At McPin we ensure this information is covered during our group set up phase.

People often develop their skills and knowledge over time across different groups and become skilled group members. Although members with highly developed skills may make the process simpler for a researcher, only recruiting these people to your group will limit the voices and experiences you hear and exclude people who may have new and unique perspectives. We would recommend always aiming for a mix of new and experienced group members.



**I was learning how I could contribute to a rich discussion as a service user without mastering the English language and provided invaluable experience-led insight and advice that may shape the general direction in a way a survey would not provide if the panel answered a questionnaire."**

LEAP Member

## Questions to ask about diversity of experience



- ④ What experiences does the project require?
- ④ What does 'diversity' mean in context?
- ④ Are you creating an environment that sustains and supports diversity?

## Disclosure



People in groups bring expert knowledge gained through their lived experience, as well as other learned skills. Due to the nature of these groups, there

is an implied level of disclosure about having a relevant lived experience just from being involved. However, members should always be allowed to choose what details they share and how to use/share this in safe and comfortable ways.

It is an important issue to consider the effect of disclosing details around background and experience when involving people. Few people (if any) fit a neat box. Most people have more complex backgrounds and outlooks. You may have people with lived experience who also have similar experiences to the study team. For example, group members might have professional qualifications, academics can also be clinicians, or a mental health professional can have their own lived experience of mental health issues.

It's important for everyone involved to reflect on where they are drawing their knowledge from and how it informs their views. Although it is not necessary to disclose this, it can be helpful to share this with the group. However, preferences for privacy should also be respected. Groups work best when people feel they are equals, and sharing of qualifications and status can sometimes result in inadvertent ranking or be difficult for those who had their studies of careers cut short by mental health issues.

Sharing personal health details can also be difficult at times, especially with more stigmatised experiences. A balance of relevant disclosure to inform the task at hand, and respect for privacy and dignity is required. People must be allowed to describe their experiences in their own words and terms and should not be introduced to the group as "this is X and they suffer from Y" for example.

3. *Equalities Act (2010)*, c. 15., p. 2., c.1.  
<https://www.legislation.gov.uk/ukpga/2010/15/part/2/chapter/1>

## Tokenism



Tokenism is the act of including someone in an activity (specifically from a misrepresented or underrepresented background) without any tangible support,

to give the appearance of equality. One of the biggest criticisms of research involvement groups is where they have limited engagement in a study and become a tick box for meeting requirements for lived experience input<sup>3</sup>. This is often connected to lack of decision-making power, limited feedback mechanisms, poor communication and not implementing any or much of the group's advice.

### Ways of avoiding tokenism



- 📌 The best way to avoid tokenism is to **ensure good planning** for your group.
- 📌 Don't shy away from **addressing power imbalances**; once these are identified, it is easier to find ways to resolve and instil balance.
- 📌 **Consistent feedback loops** ensure the continued involvement of group members and respect for their input. Where feedback and updates aren't given, communication can get lost, and engagement is harder to maintain.
- 📌 **Reciprocity** (as mentioned on page 26) helps to restore balance.
- 📌 **Understanding the community/communities** you are working with. Does your research team have any connection to the community? If not, have you considered speaking to those within the community to understand how best to approach involvement, e.g. what needs and norms you should consider?
- 📌 **Not treating people as a monolith.** Remember, even if you are working with a specific community, not everyone in that community has the same views and experiences.

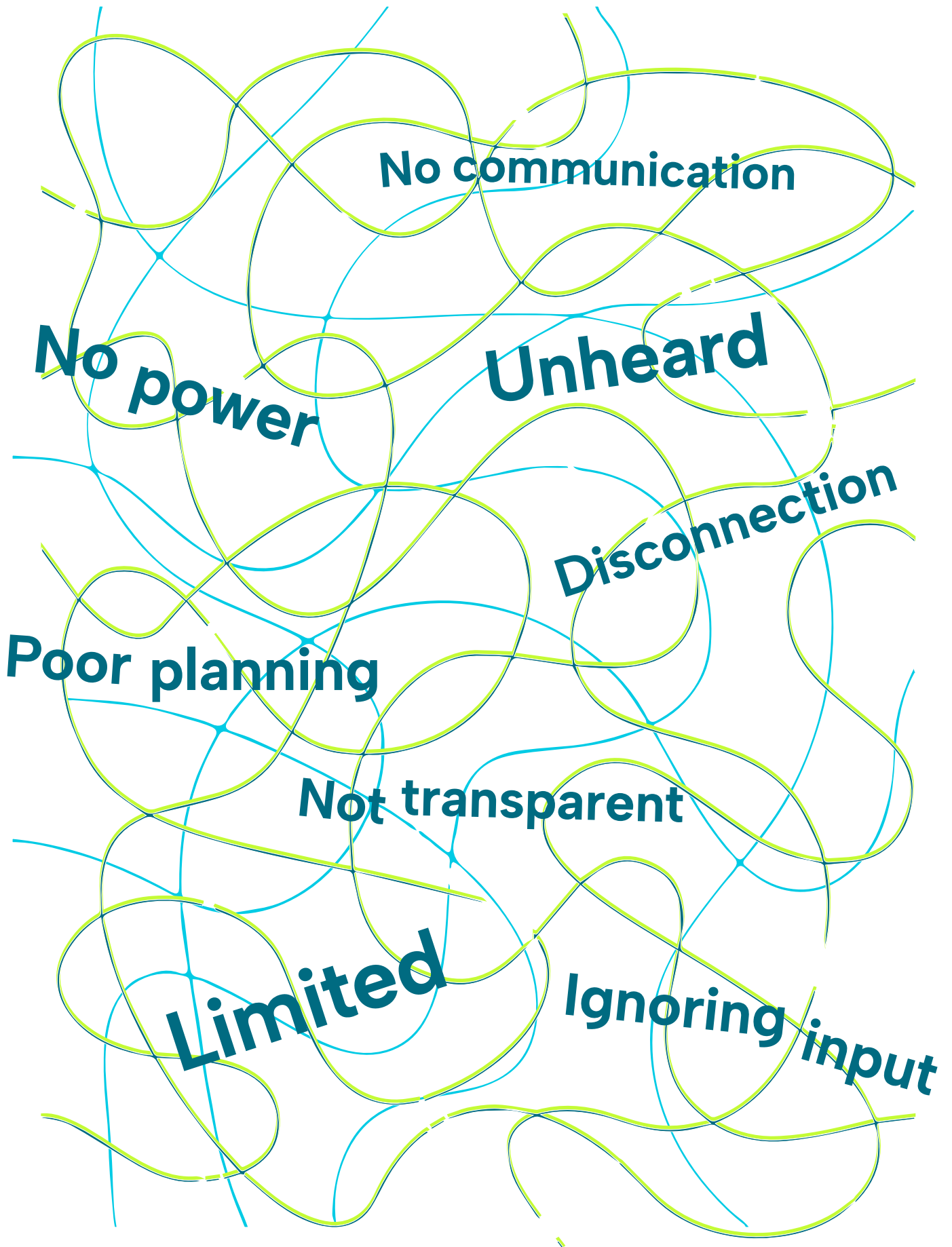


Figure 1: What makes groups tokenistic? This word cloud shows some the ways the McPin team have heard people describe their experiences of groups that were tokenistic



## Clarity and expectations



Clarity of objectives, agreements and outcomes are essential to ensure cohesion and comprehension for people in the research team

and involvement group. It is natural that people have different perspectives. A shared goal, understanding of limitations, and what is expected of everyone can help things run smoothly.



**I've learnt working in an advisory group is a real team effort and means being tolerant of different people's views. You get the best from the group, and this is due to the range of different experiences and beliefs that the group share, more often than not. People may disagree, and the most important thing is to deal with differences in views gently and fairly. Everyone's views are important."**

YPAG Member

## Sharing power



A key part of any research study is decision making. Being open and transparent about how study decisions are made and by whom is essential for

building trust. In particular, being clear on how the work of the research involvement group impacts study team decision-making is vital.

Some groups use an impact log to track group recommendations and decisions taken in the research study. Power sharing is central to a co-production group model but less so in other types. A terms of reference document, detailing all of the agreed parameters for a study, can help clarify, ensuring expectations are clear from the beginning.

### Questions to ask yourself to ensure clarity



- ⑥ What can be changed in your research?
- ⑥ What cannot be changed in your research?
- ⑥ Do people understand what your research is about?
- ⑥ Do you understand what your research is about?
- ⑥ What are the deadlines, limitations and motivations at play for various people around your project?

### Questions to ask yourself when considering power

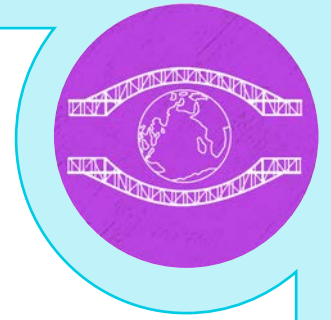


- ⑥ Who makes decisions for the study?
- ⑥ How do groups make decisions? What model of decision-making are you using?
- ⑥ What will you do if people disagree?
- ⑥ How can you allow other people to share their expertise?
- ⑥ Who holds responsibility for what?





# Top ten tips for research involvement groups



- 1 Create an open and inclusive environment, with respect and without judgement.** Co-developing ground rules that apply to everyone helps with this.
- 2 Include people from a range of backgrounds in your group.** Hearing from different voices can help avoid biases or one-sided perspectives. Remember that not all people with the same background or mental health issue have the same experience.
- 3 Support research involvement groups well;** both in terms of budget and staff time. Usually at McPin meetings we have at least two members of staff – one to chair, and one to take minutes and/ or provide one-to-one assistance to anyone in the meeting who needs it.
- 4 Make meetings accessible.** Find out and note all participants' access needs. You can do this at the start of a group and check in regularly during the project. As well as health-related needs, financial and time considerations should be made so that all who want to contribute to the group can do so equally.
- 5 Every person in a project and their views should be given the space to be heard and valued.** Differences in opinion should be welcomed, not silenced. Disagreements should always be expressed respectfully.
- 6 Plan meetings carefully.** Share information well in advance before meetings; agendas, timelines and minutes are key to making a project go smoothly. Objectives should be clearly outlined for each meeting, and actions should be noted and accounted for.
- 7 Ensure members' contributions to a project are acknowledged.** This should include naming and thanking the group in any publications.
- 8 Develop group members.** Provide ongoing training and support that contributes to people's goals as well as the project. Some people may want to take on research roles or further study.
- 9 Build a shared understanding of the project limitations and expectations.** Regular, circular feedback processes will ensure mutual understanding through the project. This can help everyone feel included, and manage expectations from the outset.
- 10 Record impact and act on feedback.** If you cannot trace involvement to any outcomes, you are not properly embedding involvement principles.



# Planning for a group: flow chart

The following flow chart is a tool that might help you when planning for a group. It is built on the learning in this resource, and key decisions we make when setting up groups.



# McPin Foundation

Transforming  
mental health  
research

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.

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