

Patient & Public Involvement at the McPin Foundation: An overview

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A resource for our staff and partners

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www.mcpin.org

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Introduction: About us



The McPin Foundation is a specialist mental health research charity, established in 2007 and operating as a research unit since 2013.

Our Mission

To champion expertise from experience in research so people's mental health is improved in communities everywhere

Our Vision

A world where the value of expertise based upon experience is recognised and is at the heart of all stages of mental health research

Our Values

1. We work with passion
2. We deliver quality work
3. We include and listen to others
4. We collaborate
5. We care

To see examples of our work please visit our website www.mcpin.org

Introduction: About these slides



- Mental health research is vital to improving the lives of people with mental health problems. Our work complements that delivered elsewhere, and focuses upon the contribution that people with mental health problems can make to the research agenda themselves.
- These slides are intended to provide our staff and collaborators with an introduction to the language we currently use to describe our work and the principles that underpin it.
- It also explains why ‘expertise from experience’ is at the heart of the McPin Foundation’s work.
- Our thinking on how to describe patient and public involvement (PPI) in research has and will continue to evolve. **We recognise that the definitions we use are not universally recognised, but we think it is important for us as an organisation to be consistent and transparent about the choices we make and the language we use.**

Introduction: Language and terms



- We don't have fixed terminology at McPin to describe mental health. We adapt to context but are explicit about the choice of language we use (e.g. service user, patient, person with a diagnosis of bipolar, people experiencing a mental health crisis, mental health issues).
- In these slides we tend to use the phrase “people with mental health problems”.
- The terms we have defined over the next 4 slides are central to our work
 - **Patient and Public Involvement (PPI) in research** – an overarching term used to describe all the ways in which people with lived experience of the topic being studied are able to use this experience and knowledge to influence all aspects of the research process, including study design, conduct and dissemination.

Language and terms: different aspects of PPI

Patient and Public Involvement (PPI) in research

Advising on research

**Public Advisory
Work**

Doing research

**Co-produced
Research**

**User-led or user-
controlled
research**

Peer Research Methods may be used.

All involve expertise from experience – people with relevant experience of mental health problems directly involved in all aspects of the research process from study design, delivery to dissemination.

Language and terms: Expertise from experience



- Expertise from experience **describes the particular kind of knowledge and skills developed through everyday living**, for example, managing a mental health problem or being a grandparent. While each experience is unique, this term emphasises the value of expertise gained in this way. It is sometimes known as ‘lay’ experience.
- **We make explicit the central place of mental health expertise from experience in our work, but that does not exclude other lived experiences being relevant as well.** Other perspectives are also valuable. We believe that the best research harnesses a range of different perspectives and forms of expertise.
- This is valuable in research because **experiencing a problem personally provides a different perspective than can be gained from observation or clinical practice, or from reading a text book or attending a lecture.** This is especially relevant in mental health research as mental health problems are poorly understood and those experiencing them have traditionally been marginalised.
- **The process of carrying out research requires us all to reflect on how our lived experiences may impact on our work.** This is as important for the basic scientist as the qualitative researcher. Everyone in a research team is influenced by their past experiences, and all researchers need to be reflexive about it not just those involved in PPI.

Language and terms (cont.)



- **Public advisory work** – ways in which people with lived experience of the topic being studied provide advice to researchers at any or all stages of a research project. They provide advice, inform or influence the conduct of a study but do not usually undertake the research themselves in this role.
- **Co-produced research** – describes research that involves a range of stakeholders who all work together collaboratively by drawing on their individual and collective expertise and knowledge (practitioner, academic, lay, service user, carer) to design and deliver a research study.
- **User-led or user-controlled research** – describes research that has been initiated, designed and carried out by people using their lived experience of the topic being studied.
- **Peer research methods** – describes a methodological approach in which people actively and reflexively draw on their lived experience of the topic being studied to influence and improve the research they conduct.

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A way of working



In this section we outline some of the key issues that we have to think about when carrying out patient and public involvement in research.

It is important to emphasise this is work in progress. As a team we have reflected on and discussed the issues in these slides in light of our and others' experience carrying out mental health research. Our approach will continue to evolve in dialogue with others. We will continue to review the way we describe our work, and update these slides accordingly.

Feedback or offers to collaborate in developing these ideas are very welcome – please email contact@mcpin.org, sign up to our newsletter at www.mcpin.org, or follow our twitter (@McPinFoundation) for announcements about future publications and methods workshops.

Experience, identity and roles: A way of working



- Patient and Public Involvement (PPI) in research draws upon **expertise from experience** but how this is done will change depending on the nature of the study and role individuals want to take.
- PPI requires **decisions to be made about disclosure** – how to share experiences, what to share, support provided (both to others and person in PPI role), short and long term impact on self and others.
- Working in this way **requires everyone involved in a piece of research to reflect** on their life experiences, a sense of their own identity and the role they take on in any project or team. This is good research practice in all studies; it is essential for PPI in research.
- We actively **encourage reflexivity** to help individuals and teams decide on their position and appropriate approach.

Experience, identity and roles: What do we mean?



- **Experience** – may refer to any of the things that happen to us during our lives. In the work of the McPin Foundation, **these are often lived experiences related to mental health, but may include any number of experiences** relevant to the research being conducted such as being an immigrant or single mother.
- **Identity** – **how we see ourselves and sometimes how others see us.** This can often be linked to experiences, including our background, upbringing, impact of group membership, as well as characteristics such as race or sexual orientation. Our identities change through our lives, and we focus on different identities in different contexts.
- **Role** – **what we do in relation to a specific task or tasks.** People are recruited to a job role based on their skills and experience. Staff at McPin may use their lived experiences, of mental health or any other issue, in different ways on different projects depending on their role, as a researcher, as an adviser or as a manager.

For example, applying this to peer research methods ...

A peer research approach ...

Experience

Researchers using a peer research approach actively and reflexively draw on their lived experience of the topic being studied to influence and improve the research they conduct.

Identity

Researchers using a peer research approach may explicitly draw on an identity that they believe they share with people taking part in the study by telling them something about their own experience.

Role

People recruited to a research post will have the relevant research skills necessary for the role. If the project is using peer research methods, the researcher must also be willing to use their lived experience of mental health issues within the research study. But how they do this will vary.

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Most of the research we do is co-produced



- We define **co-produced research** as research that involves a range of stakeholders, including people who have mental health expertise from experience. They work collaboratively, drawing on their individual and collective expertise and knowledge (e.g. as practitioner, academic, service user or carer) to design and deliver a research study.
- **In a co-produced study, some of the researchers will have relevant mental health expertise from experience.** They play an active part in the process of designing the study, collecting and analysing data, and writing up results; they therefore need relevant research skills. When recruiting researchers for a role on a co-produced study we may make relevant expertise from experience, and the ability to use it in research, an essential criteria.
- Ideally co-produced research projects will have **public advisors and researchers with relevant expertise from experience from their inception through to completion**, although they might not always be the same people.
- Our aim is for **thriving research teams** that respect each other's research and life experiences. Integrating a range of skills and knowledge is the objective.

Peer research as a methodology



- **We use ‘peer research’ to describe a methodology** not as an alternative to ‘co-produced’ or ‘user-led’ research
- It is a **method whereby a researcher explicitly draws on their own relevant lived experience** of what is being studied to inform their research. This can be as part of a co-produced or user-led study.
- **The use of ‘peer’ deliberately emphasises a shared experience or identity** between researcher and research participant, and de-emphasises the power differential that has traditionally existed between the researcher and their subjects.
- **Sharing an experience may not be sufficient to make people peers.** Differences in background, other life experiences or characteristics such as race or gender may be as or more important in some contexts.
- Using a peer methodology can help establish rapport with participants and put them at ease, help a researcher ask more relevant questions and place the answers into a broader context. **It implies some level of disclosure of the nature of the researcher’s relevant experience.** What is disclosed, how and when will depend on the specific project and the individual researcher.

Being reflexive

- Being open about the influence of lived experience on research is not unique to mental health. Like all people, researchers use their personal experience all the time. We:
 - Make assumptions about participants based on their cultural background, job, age or other characteristics. These are shaped by previous experience of people who share these characteristics, and are sometimes wrong.
 - Try to build rapport with participants by behaving in ways that we think will put the person at ease based on our own social skills and experience.
 - Are drawn to topics that we think are interesting and important.
 - Interpret data drawing on our own assumptions, cultural background and previous experiences.
- Avoiding bias in research is always a challenge. **We believe that the best way to avoid this is by encouraging all our researchers to be constantly reflexive about how their experiences may influence their work, whether they are of mental health problems or not.** This means examining how their personal experiences may consciously or unconsciously shape how they respond to the people and issues they encounter in their work.

Do peer research methods require researchers to talk about their mental health?



- People with experience of mental health problems are found in all areas of mental health research: statisticians, trial managers, professors, researchers, data managers, administrators. A researcher may have relevant lived experience of a topic being studied but choose not to disclose, although they should still be reflexive about how it might influence them.
- Where a peer research approach is used it is implicit that the researcher will have to be open about some of their relevant experience. **But what they disclose and how is a personal decision.** How, and to whom, they disclose will vary from project to project and person to person.
- In making a disclosure to a participant during an interview or recruitment conversation researchers need to think about:
 - **What they disclose** – it should be relevant to the topic, and done for a specific reason. It does not mean sharing everything.
 - **When they should disclose** – e.g. before, during, or after an interview / recruitment conversation.
 - **How they should disclose** – in some cases it is better to do it in person, other researchers may be more comfortable with doing it in writing in the information given to participants.
- **Whatever approach is taken should be recorded and reflected as appropriate in the analysis and reporting of results.**

Researchers using their lived experience face particular challenges around stigma and discrimination



- **Discrimination** against people with mental health problems across society persists and many also experience **anticipated discrimination** (also known as self-stigma). The health and research professions are not immune to these problems.
- We recognise, and respect, that some researchers choose not to be explicit about their personal experiences in public or in published work, and that they may have many reasons for doing so. Others are comfortable being open about their experiences, and using them as a way of challenging prejudice.
- Researchers may also choose to be explicit in one setting, and not in another. An individual researcher's preferences for using lived experience may also change over time.
- **As an organisation we try not make assumptions about what people are comfortable disclosing.** We ask our collaborators and staff similarly to be sensitive to individual's wishes and to respect their privacy.
- We also try to be sensitive to those occasions outside of formal research projects where some form of disclosure is inherent or implied in what we ask people to do, and agree how to manage them with individuals before committing to them.

Peer research methods: Support, supervision and training?



- Using peer research methods on mental health topics often requires the researcher to think about personal experiences that are, or were, distressing. As an organisation **we must support all our researchers to think carefully about how they will use their experience safely, and provide them with ongoing support to do so.** We must also support them to think through the implications of disclosing aspects of their experience to others.
- In McPin the main formal routes are through regular 1:1 supervisions with line managers, and project group meetings. We also have an external mentor who works with staff who actively draw on their lived experience in their job role.
- However, we also endeavour to create an atmosphere that allows all our staff to feel able to voice concerns openly, or identify issues that are difficult for them, and ask for support at any time. We also promote informal learning and mentoring between the team.
- In the future we want to provide more structured training around these issues, including disclosure, for both researchers and their managers. This is something we are looking at developing within our own team, but also intend to explore with others through our methods workshops.

Our principles on using peer research methods continue to evolve



Based on our experience we have developed organisational principles for using peer research methods:

- **We no longer use “Peer Researcher” in job titles.** All our researchers are expected to be reflexive about using their lived experience. On some projects they may explicitly use a peer research methodology.
- Being able to use peer research methods, including **having the relevant expertise from experience, may be an essential competency for some roles on specific projects.** This will be agreed with the researcher before they are recruited or assigned to the project, including what they are comfortable disclosing.
- **What researchers disclose is ultimately a personal decision,** and can change. Nobody will be forced to disclose their lived experience of mental health, or other issues.
- No assumptions will be made about what a researcher may be comfortable disclosing outside of a project – **just because an individual disclosed in one context does not mean their experience is public.**
- **We will be explicit where a peer methodology has been used in our work** – but this does not necessarily mean being explicit about which of the research team had the relevant expertise from experience.

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Public advisory work at McPin



Public advisory work: Key features



- **Public advisory work does not tend to involve actually doing research**, but involves people with relevant lived experience drawing on their expertise to *advise* research teams in order for projects to directly address the issues that matter to patients and the public, and to run efficiently.
- **Public advisors always disclose some of their relevant experiences to the researchers, and often to other advisors** and use expertise from experience actively in their role. Working out how to do this safely, and how to integrate public advisory expertise into research teams takes time and effort.
- **People who do public advisory work may also do research**, including using peer research methods. They are different roles but we work with people who've moved from an advisor to researcher within studies.
- This is an **evolving field of work**, and we are continuing to learn how to do public advisory work well.

Examples of public advisory activities

Member of a Lived Experience Advisory Panel (LEAP) - this can involve many different activities (e.g. study promotion, producing material for study website, writing blogs, reviewing study materials, commenting on data findings, chairing meetings, minute taking).

Co-applicant on a research funding application, taking on role of PPI project lead, developing entire PPI plan for the study and delivering the plan with colleagues.

Expertise from experience

Being recruited to a study's external steering group such as a trial steering committee or data monitoring committee.

Taking part in a consultation group, prior to submission for funding, to help shape the research topic, outcome measures, or provide practical advice to the team on how to recruit participants.

Lived Experience Advisory Panels (LEAPs)



- We support Lived Experience Advisory Panels (LEAPs) for a range of different studies. They are a group of people with relevant lived experience, usually facilitated by a McPin staff member but sometimes chaired by a LEAP member, who provide advice and input to the research team.
- We have evolved two main types of LEAPs:
 - **A critical friend model** which works as a reference group feeding advice to the research team. It runs independently from the team. Members of the research team attend to hear the advisors' feedback.
 - **A co-production approach** where members of the LEAP are involved in making decisions about the direction of the study, not just responding to questions. This requires the LEAP to be more embedded within the team. In some cases they may cross over into doing co-produced research.

Public advisory work: Some principles



- Over the last three years the McPin Foundation has worked with academics from across the country to help a range of different studies to benefit from expertise from experience. Our practice continues to evolve, but we have identified some principles:
 - **Public advisory input should be part of a study from inception**, not a last minute add-on. Structures and methods for involving the public should be decided between collaborators, and ideally written into project plans, before applying for funding – and many funders now require it.
 - Public advisory work is often facilitated by people with expertise from experience, and we encourage this, although others can support the process and provide relevant input including brokering collaborative working. **The crucial aspect of PPI leadership is partnerships, and integrating and respecting each other’s expertise within the team.**
 - **It is important that academic teams think carefully about what expertise from experience they require in their study, from general to highly matched experience.** All Public Advisors are expected to disclose their lived experience to the group, so care must be taken to arrange settings and brief other people at meetings so this can be done safely and respectfully.

Public advisory work: Principles (cont.)



- **People with relevant expertise from experience should be at the heart of the process.** The time and resources necessary to recruit them needs to be included in project plans. Sometimes that may require people to be mentored or supported to acquire the skills they need to take a full part.
- **A clear structure for how public advisory work will operate in any study needs to be decided prior to applying for funding.** Often adjustments are needed to ensure public advisory work can be effectively integrated within studies.
- **It is important to try to ensure people from a range of backgrounds are involved.** Again this may require additional investment in recruitment and support for advisors, and ensuring that the methods of involvement are accessible.
- **Those providing advice should be properly remunerated.** What they will be asked to do, including the time commitment, should be clear from the start. They should be kept informed of how their input is being used and what can and cannot be changed as a result of their advice.

Public advisory work: Ultimately our goal is to build capacity in the sector



- Our ideal would be for every research study to benefit from PPI. It is increasingly a requirement of research funders, but it needs dedicated resources to do it well.
- Our aim is to build capacity within university research departments to be able to deliver high quality public advisory work for their own studies.
- We see our role as being to facilitate, support and establish sustainable systems for PPI beyond the life of individual projects by building local capacity and expertise for this way of working.
- We actively seek to learn from others and share our own insights to help develop and test models for delivering different approaches to public advisory work to meet the needs of different types of studies. Research in basic science will require different advisory expertise to public health and wellbeing studies.

Public advisory activities: How we work



- **Carefully:** we try to work out what we can offer to meet the needs of both research teams and the people we work with as public advisors. This involves **balancing the needs of different groups** but always being focused on how best to deliver quality mental health research.
- **Transparently: we are clear with partners about what public advisory work involves, and on our preferred ways of working to ensure quality:** We will work with any partner who shares our values, but will not take on work that would involve compromising our commitments to quality and to respect for the people we ask to share their expertise from experience.
- **Cautiously:** we know **we have more to learn** across the field of public involvement and that public advisory work takes time to do well.

Contact us



- If you would like more information on our work or are interested in collaborations please do get in touch – contact@mcpin.org

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Website: www.mcpin.org