McPin Methods Workshop series session 1: Integrating lived experience expertise within mental health research teams

Summary of group discussions

This short report summarises the main points raised in our discussion groups at the McPin Foundation's first Methods Workshop on 30th November 2016. It was attended by around 65 researchers from academia and the third sector, including researchers who actively use their expertise from experience of mental health problems in their work, and other professionals with an interest in PPI (Public and Patient involvement) and mental health research. Conversations were rich and there was much appetite and passion in the room for moving PPI methods forward, with plenty of expertise represented too. This report captures some headlines from the discussions held as a recording of what people feel are the priorities for the sector, and to provide us with ideas for future methods workshops – we will return to this latter point in the conclusion.

Throughout this document we use PPI to refer to both the infrastructure of involvement and to peer research methods in line with our wider approach to language.

Theme 1: How might models for involving people with lived experience in research evolve?

This theme had three separate discussion groups from which the following themes emerged:

- **Addressing power imbalances and hierarchies**: Academia is a hierarchical environment and practical steps to address this would help integrate lived experience in research more effectively. Decision making power needs to be shared within research teams more for lived experience expertise to better impact on how research is designed and delivered. This includes making involvement part of planning and design in studies, rather than involving people only once key decisions have been made.
- **Advancing research methods:** The sector needs to develop more approaches to integrate lived experience expertise, valuing different types of research knowledge and perspective, broadening out from the current research designs like RCTs.
- **Be more discerning**: The sector needs to be critical of poor examples of PPI, for instance through peer review, reflect on challenges in reports and other outputs, and highlighting good PPI practice, for example through funding processes, awards, writing up methods in peer review journals.
- **Diversity**: It's vital that researchers actively seek out and listen to diverse voices to broaden involvement and make it more inclusive. There is a lack of black and minority ethnic voices in PPI; we need to address the barriers to involving a wider variety of people in research. This includes providing better training and support for people with lived experience who are interested in becoming involved in
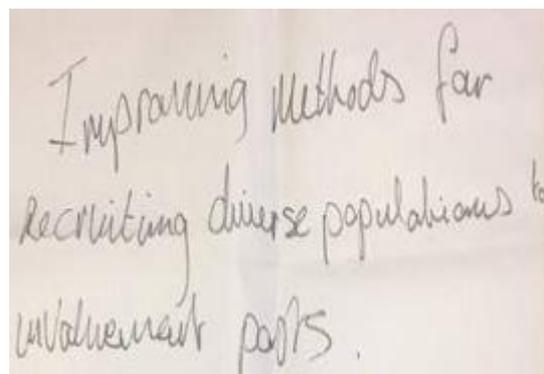
Improving Methods for Recruiting diverse populations to involvement parts.

research.

- **Acknowledgement:** Service users who have been involved in research need to be acknowledged better in journal papers and conference presentations, as well as other research outputs – and to be actively involved in writing or designing them. Opportunities to contribute to outputs should be better prioritised.

- **Strengthening the voice of lived experience**: Too often survivor/service user/peer researchers are lone voices in research teams. There is a need to develop larger teams of people or networks so that these voices can develop a different departmental culture and encourage more shared learning.

- **Clarity and transparency around PPI roles**: The sector would benefit from a shared understanding about what different types of involvement mean and how these different roles contribute to research studies.

- **Infrastructure**: The infrastructure around PPI such as decision making processes, funding, best practice guidance, training and support for researchers, needs to be strengthened and developed further to support public advisory roles and peer research in the long term.

- **Building continuity in expertise**: Some PPI is developed within time limited projects and expertise may be lost when funding ends. Planning how to maintain expertise to benefit other studies, supporting other researchers to develop research ideas and design studies needs greater attention. This will also build a culture within departments and teams that integrated lived experience is essential not optional.

- **Demystifying research**: It is important to create a more open and nurturing environment within research teams to combat the sense many service users have that research is intimidating. This includes avoiding overuse of jargon.

- **Ensuring that PPI in practice reflects plans in bid**: Funders may need to institute post project reviews to make sure meaningful PPI actually happens when it is promised in bids. Research teams should be required to justify changes to these plans, rather than PPI being turned into a meaningless tick box exercise.

- **Create targets to raise standards**: Some studies are perceived to cut PPI budgets and recycle the savings elsewhere. To better address this, and raise standards, a target to spend 10% of the total budget on all research studies on PPI could be trailed. The impact of the investment should be monitored and evaluated.

- **Evidencing the value of involvement:** Building an evidence base around PPI should be a priority in order to drive up standards in terms of methods and approaches, as well as conceptual work explaining the value and 'how to' mechanisms. This evidence gathering could be built into involvement methods. The principled argument of 'nothing about me without me' is complemented by work addressing the specific impacts of PPI.
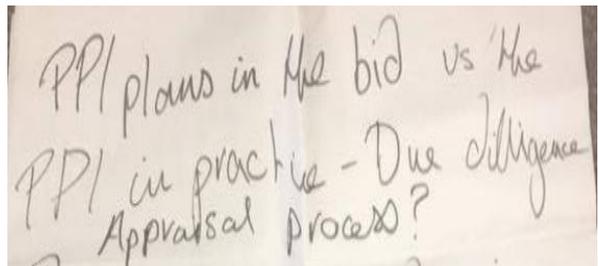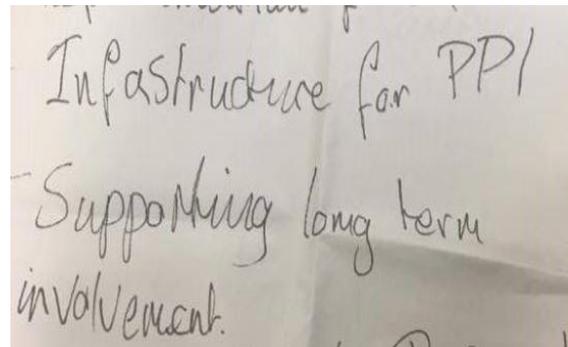
Theme 2: How do we define lived experience in a research context and how closely must it fit with research topics?

The group discussing this theme had a wide ranging discussion about lived experience identities, authenticity and methods, with some key themes emerging:
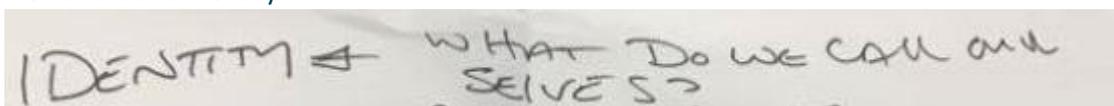
- **The need for more reflexive practice**: All researchers (and people) have lived experience of some sort which influences their reaction to a research topic, and multiple identities along class, ethnicity, gender, sexuality and many other groups. The sector needs to address and be reflexive about these potential biases or assets.
- **Respect and acknowledgement of lived experience:** As an asset to be valued, rather than simply something which defines an individual. In mental health research, lived experience of mental health problems is a particularly valuable type of lived experience.
- **Authenticity and relevance:** Guidance and best practice on matching types of lived experience to different research topics is needed as there is no agreed or easy answer to how closely we need to match, or to how important this is to the involvement process or the quality of the research.
- **Avoiding tokenism or exploitation:** Some people with lived experience have come away from their involvement in a research study with the feeling of being used for their lived experience in a disempowering or transactional way. Others have had the experience of their presence feeling like a tick box exercise. The sector needs to be mindful of both these risks when asking people to join a research team and share their lived experiences in research contexts.
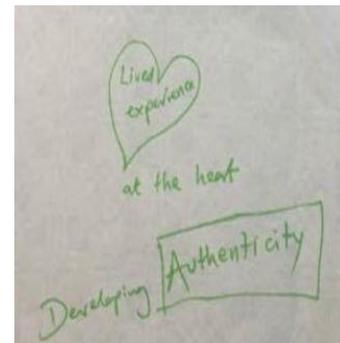
Theme 3: How do mental health researchers with lived experience develop their careers and what barriers do they face?

Participants in this group didn't have a problem identifying important career barriers for people involved in PPI, but the discussion developed into a constructive debate about solutions that should take priority:

- **The need for diverse training options**: from general research literacy for people starting in PPI through to professional PhD level training. A formalised training scheme is needed to skill up the sector, as well as resource for training being built into funding bids. All research team members need appropriate training in PPI, not just those with lived experience.
- **Guidance on disclosure and identity**: There is also a need for guidance around disclosure of personal mental health experience in research contexts and how we make this an asset as well as around identity.
- **The need to develop leadership in the PPI researcher community:** Leadership is an important element of the development of researchers with lived experience as a career

path. We have some and we need more – a key challenge being how we develop new leaders in the sector to drive forward progress.

- **Addressing access barriers and codes of behaviour**: ways of working in academic settings are barriers to involvement, from unspoken codes of behaviour, language and dress that are unfamiliar and intimidating to people who may have been out of work for some time, to a perceived reluctance of academics to come out and work in the community, rather than asking people to come into their institutions – academic researchers need to go where people are, not expect people to come to them.

- **Making transition from benefits or adherence to benefits guidelines easier to navigate**: Guidelines around benefits entitlement while working in a PPI role are complicated and confusing, while juggling ad hoc income with benefits seen as very risky; more guidance is needed to reduce the impact of this barrier.
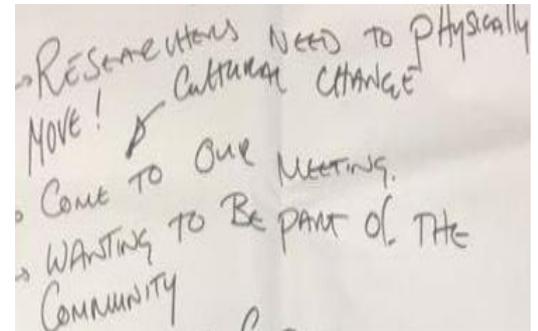
Where next?

This was the first in what we hope will be a new series of methods workshops aimed at providing a space for innovation, collaboration and knowledge sharing in the sector. The key points above will help guide our choice of future topics. Some themes emerged from the discussions as potential future workshop topics:
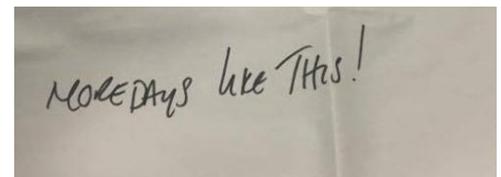
1. **Improving access and involvement**: sharing good practice in reaching a wider diversity of voices**.**
2. **Methodological innovations**: developing best practice guidelines for the effective use of lived experience within existing research methods as well as developing new methods with lived experience at their heart.
3. **Methodological guidance for researchers with lived experience**: such as using lived experience during analysis and disclosing lived experience during data collection.
4. **Developing the evidence base**: How the sector provides quality evidence that PPI is worth doing.

We will be progressing plans for our future workshops over the coming months subject to funding. We would be interested in talking to other organisations about collaborating on future workshops. If you have any other ideas about future workshop topics or would like to speak with us about the series, get in touch with Daryl Sweet at darylsweet@mcpin.org