

The Alchemy of Involvement:

TRANSMUTING LIVED EXPERIENCE INTO EXPERIENTIAL KNOWLEDGE
TO ENRICH MENTAL HEALTH RESEARCH



"It is a truth universally acknowledged, that an organisation with the stated goal of self-improvement, must be in want of a lived experience advisory board."

(Adapted from Jane Austen)

Contributions include

- Draft Mental Health Bill submission (cited 5 times)
 - Community Mental Health Inquiry submission (cited 5 times)
 - Dolly's dolls/social security commentary
 - Research Methods Toolkit
 - Centre EDI task and finish group including development of Code of Conduct and co-facilitating Away Day to operationalise it
 - Contributed to funding applications, including successful £500K Wellcome Trust Mental Health Innovation Fund application
 - Spoken at a range of public events, conferences, teaching, involvement in LEI recruitment best practice
 - KERA Award 2025
 - SSPP Impact Award 2025
 - IoPPN Faculty Award 2025
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What value does lived experience bring to research?

- RESEARCH THAT MAKES A DIFFERENCE
 - POSITIVE OUTCOMES FOR PEOPLE'S MENTAL HEALTH AND WELLBEING
 - NO POLICY SHOULD BE DECIDED BY ANY REPRESENTATIVE WITHOUT THE FULL AND DIRECT PARTICIPATION OF MEMBERS OF THE GROUP(S) AFFECTED BY THAT POLICY
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4 Key Areas of Strength

Accountability

‘stay with the trouble’, sit with other’s distress, do not strive for simplistic explanations over nuance

Perspective and Insight

Both outsiders and insiders within research culture, re-grounding research in experiential knowledge, enhancing research that holds relevance and meaning for the people it is most likely to affect

Inclusion and Impact

Making things accessible, a focus on impact, motivation to improve things for us and our peers

Inspiration

Enthusiasm, capacity to support others to express themselves

The Importance of Power

When we talk about people with lived experience, we believe we have a shared understanding of what it means to be powerless, both within and beyond mental health services

- Position Paper

Power operates in research contexts too, due to the academic hierarchy. People in positions of power have some responsibility to be aware of that power and to make efforts to be both transparent about the power they hold, and to share it along with the resources that underpin it

- Position Paper

It is also critical to be aware of who researches who: who has the power to direct the research and who is in the position of being researched. This is because, “In academic research there are powerful norms surrounding who gets to study whom” (Sweeney and Beresford 2019) which lived experience involvement challenges; this can lead to powerful resistance.

- Position paper

What do research programmes and centres need to do to be able to hear us and accept change to their work?

- INFORM AND EDUCATE PEERS, REDUCE AMBIGUITY
 - EMBRACE DISAGREEMENT AND THE CRITICAL EYE
 - BUILD SUPPORT ROUTES IN TO PROJECTS
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“If people make the space for change to happen, then the added value that people with lived experience bring can flourish”

-Position Paper Excerpt

Thank you
