

NRS/CSO: Patient and Public Involvement Event

Dundee, 12 March 2024



Co-producing research with people with living/lived experience of substance use

AILEEN O'GORMAN - Professor of Substance Use and Social Policy,
Director: Social, Health and Environmental Inequalities Research (SHEI) Centre,
University of the West of Scotland.

WEZ STEELE - Senior Training and Development Officer, Drug Death Prevention -
Peer Naloxone Supply, Scottish Drugs Forum (SDF).

Experience of PPI with PWLE



Focus on recent experience of two social science drugs research studies:

1. 'Understanding the Role and Potential of Primary Care in the Prevention of Drug Deaths' (funded by the Scottish Government Drugs Death Task Force)
2. 'Using foil for drug administration: exploring the views and experience of people who use drugs' (funded by the CSO).

Both studies approved by NHS Scotland Research Ethics Committees.

PPI - What do **we** mean?



- Recognition of power hierarchies in research and knowledge production, and lack of inclusion of affected communities.
- People who use drugs (PWUDs) heavily stigmatised, othered and marginalised community.
- ***‘Nothing about us without us’*** saying originated from disability activism in 1990s, adopted by PWUD advocacy groups e.g. Manifesto 101, VANDU <https://www.iowaharmreductioncoalition.org/wp-content/uploads/2019/04/Final-Manifesto-for-Ethical-Research-in-the-DTES.pdf>
- Research, policies and practice should explicitly include those affected —→ community engaged research.

WHO and HOW to involve?



WHO?

- People with **living** as well as lived experience (PWLLE)
- Reflect sex/gender, class/SES, age, sexual identity, intersectionality, housed/homeless, urban/rural, type of drug(s) used etc.
- Check whose voices are missing?

HOW?

- From the beginning – more opportunity to influence. Regular meetings.
 - co-production / partners /peer researchers
 - members of research team or advisory group
 - Participants as stakeholder / ‘expert’ to translate research into policy/practice.

Our PPI process



- Recruited **paid** PWLLE as research team /advisory group members through our networks for the duration of the research. All interested in research and advocating for improvements in policy and practice + well connected to PWUD communities.
 - participated in development of initial proposal and grant application,
 - assisted with ethics application by reviewing and advising on study materials (e.g. interview schedules, information sheets, lay summaries),
 - member of interview panel for appointment of the study researchers,
 - advise on all aspects of the research process including analysis, recommendations, dissemination activities, public engagement and impact strategies.

The PI's perspective



- PWLLE co-production enhances the quality of our research:
 - Language: question academic terms, language and assumptions.
 - Relevance: ensures we are asking the right questions, in the right way, to the right people.
 - Participant recruitment: publicise and advocate for research through community networks; provide local knowledge of sites where most relevant voices can be found.
 - Fieldwork: provide briefing and support for fieldworkers, pilot materials.
 - Data analysis: identify gaps, offer in-depth insight, and different perspectives.
 - Stakeholder/Expert working groups: inspire new approaches for translation to policy, practice and impact.

The PWLLE perspective



Research – why bother being involved...?

- To inform research with real life experiences
- Empowerment – A chance to influence change
- Gain insight into academia and how research can affect policy and practice
- Develop new skills; reviewing and critiquing research materials
- Acknowledgment of the value of our expertise and skills

Involving people – barriers



- Tokenistic involvement, non-inclusive approach.
- Lack of preparatory work (establish rapport, explain how things will work, meeting etiquette, offer training if necessary).
- Unclear focus on what input is sought.
- Not paying people, or offering vouchers 😞
 - ensure adequate for time and expertise.
 - ensure your organisation has an effective and timely PPI payment system compliant with HMRC and impact on tax, Universal Credit etc.
- Unrealistic expectations of experience & time available.
- Technological barriers: online meetings, edit/review comments, live docs etc.

Conclusion: best practice



Involving people – it's not rocket science!

- Provide inclusive environment - use plain English where possible.
- Ensure people's experience is relevant to the research.
 - Do we rely on the same people time and again & miss out on other voices?
- Pay people MONEY for their time and expertise.
- Nominate liaison person from academic team to provide informal support or calls prior to start of work and meetings to help folk feel at ease.
- Check people are comfortable with the way documents will be shared and how online meetings will run (Zoom/Teams).
- Acknowledge input – publications etc.

Thank you!

Primary Care study colleagues: Anne Whittaker, Betsy Thom, Katie Colliver, Roy Robertson, Stewart Mercer, Wez Steele, Joan Love.

Funders: Scottish Government

Foil study colleagues: Karen Dunleavy and Laura Roe + Advisory group including Wez Steele

Funders: CSO

Scottish Drugs Forum: <https://www.sdf.org.uk/what-we-do/involving-users-peer-research/>

Aileen.O’Gorman@uws.ac.uk

Wezs@sdf.org.uk