DRNS
DRUGS RESEARCH
NETWORK SCOTLAND

How can we support meaningful engagement with community stakeholders in substance use research?

May 2025

Executive summary

On 29th January 2025 we organised an event around meaningful engagement in research. The aim was to explore experiences and practices of Patient and Public Involvement and Engagement (PPIE) in research in Scotland.

This report is a summary of discussions among 37 people representing lived/living experience, academia, public and third sector who attended the event. They told us about their experiences and thoughts on PPIE in drugs research. We hope this document will be informative for those planning to engage with PPIE for future drugs research projects. We thank each person who was in attendance for their contribution.

What meaningful engagement looks like

Participants said that for PPIE to be meaningful, researchers need to reach out to people and engage with their research. It is important for researchers to hold engagement activities in familiar and comfortable places. Building trust is key and people should be included in all parts of the process—not just as a box-ticking exercise. This requires researchers to talk with people who have lived/living experience in respectful, open conversations without judgment. Engagement should be accessible to everyone, and researchers need to be flexible about how people can engage.

Participants also pointed out that the same people are often asked to engage in multiple projects, which can become overwhelming so researchers should keep that in mind. To make PPIE easier and more effective, researchers should use clear, simple language and explain their process from the start. Fair payment for people's time and input is important, as is keeping participants updated on how their contributions are being used.

Challenges to meaningful engagement

Participants shared several things that make it hard for researchers to properly involve people with lived experience. One major issue is funding—researchers need money to include people in early discussions, but funding applications often require engagement to already have happened.

The purpose of PPIE

Participants felt the purpose of PPIE groups is that it provides opportunities for people with lived/living experience, and it gives people a sense of purpose and that they are being listened to. They also felt that their purpose is to drive research, elevate community research, democratising the research process, and holding the research accountable and true to its aims. In the long-term and more broadly participants felt PPIE can change research practices and push the boundaries beyond academic norms and change policy.

Next steps

The event showed that there are many organisations already engaged in some form of PPIE, and instead of creating a new network, finding ways to amplify the work already going on would be the best focus. This might include work around good practice, ethics, and collaborative working between agencies which is something the DRNS can support going forward.

Introduction

Background

Many of us in drug research engage with stakeholders in developing research projects, in particular people with lived/living experience of individuals and families, so the idea of Patient and Public Involvement and Engagement (PPIE) is not new. What may be new is the focus on involving those with lived experience at the developmental, or agenda setting stage of research, as opposed to having them involved as participants or peer researchers.

Involvement of stakeholders in the development of research and policy is not a new concept in drugs policy, although it has been implemented inconsistently over the years. In Scotland, a major push to involve those with lived and living experience started in 2015 with the publication of the *National Research Framework for Problem Drug Use and Recovery* (Scottish Government, 2015). This framework aimed to implement recommendations from the *UK Drug Policy Commission Report* (UK Drug Policy Commission, 2012). This included moving drug policy from criminal justice to health, creating an executive group to oversee the implementation of evidence-based drugs policy (Partnership for Action on Drugs in Scotland – PADS), and, for the purposes of this report, commitment to broadening the policy advisory landscape:

> *With a focus on a collaborative way of working between Government, sponsored organisations, academics, ADPs and drug services, the priorities identified within this document will inform the new groups making up the advisory landscape, articulate a clear direction of travel for those working in the drugs field and directly influence Government policy"* (Scottish Government, 2015: p.10).

Commitment to this resulted in the development of the Lived and Living Experience (LLE) advisory group facilitated by the Scottish Recovery Consortium and set up to support the development of PADS. A significant outcome of this group was the changing of the 2018 drugs strategy from 'Seek, Keep and Treat', to the *Rights, Respect and Recovery* drug strategy (Scottish Government, 2018), following a day long LLE event. Alongside this many organisations in Scotland developed their own LLE groups, for example the Scottish Drugs Forum, who have been instrumental in supporting and developing peer researchers in this area.

What is 'patient and public engagement'/'public involvement'?

PPIE is a one of several terms representing the involvement of stakeholders in the development of research and policy. The term originates from the National Institute for Health Research (NIHR) (NIHR, 2025), and has become an important aspect of research development, especially for NIHR or UKRI funding.

Public Involvement involves research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. The "public" refers to patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

National policy is increasingly encouraging public involvement in research (NHS Scotland, 2025) and the NIHR and other funding bodies now require researchers to have already undertaken PPIE, or to present a plan for involvement in the proposed research or if they do not intend to involve patients or members of the public, they must explain why not.

Patients and members of the public bring an expert insight into individual research projects because of their experiences of living with a particular condition or using health services. Involving PPIE contributors in research allows different types of knowledge to be valued and to improve research. Involving those with lived experience enables researchers to access a fuller understanding.

This report

There are many 'in-house' examples of good practice and meaningful engagement of stakeholders in the development of research and policy, however, this event was initially inspired by the DRNS Network Planning meeting in September 2024, combined with members feedback, in recognition that meaningfully engaging people with lived experience does not always take place, and there are unique challenges and benefits from including these experiences right from the start.

On 29 January 2025 we organised an in-person event which brought together people with interest in research and engaging key stakeholders (including people with lived/living experience) in research process. The aim of this event was to have open discussions and learn from experiences around Scotland on meaningful engagement. We hope that this event and report will be useful in bringing together some of the current practices, barriers and opportunities for engagement.

There were 37 people representing lived/living experience, academia, and public and third sector who attended the event and this report is a summary of the discussions and notes these people contributed to. We thank each person who was in attendance for their contribution that is included here.

Experiences of meaningful engagement in practice and what works well

What meaningful engagement looks like

- Reaching out: participants felt that researchers need to meet people where they are at, going out to them to engage. This included making sure that engagement is held in informal settings that people with lived/living experience are known to attend. The threshold to engage needs to be low and there needs to be focus on building trust. People need to be able to engage regardless of their situation, e.g. if they are experiencing homelessness. Good ways to create engagement is to partner with local charities.
- Being genuine and respectful: showing consideration, curtesy, and mutual respect were felt to be essential to having meaningful engagement. This means really listening to people and being non-judgmental about their experiences and showing genuine interest in what people have to say. Participants highlighted that it is important for researchers to listen to people with lived experience as they think about things in different ways to how academics think about them.
- Not just a tick-box exercise: participants felt that engagement needs to be more than a tick-box exercise, be realistic, and needs to not just "extract" people's experiences. The focus should be on co-creation.
- Participants also felt that it was important to realise that it can empower people, so it is important to talk *with* rather than talking *to* people. Engagement with people with lived/living experience should take place before the agenda is set.
- Ethically judged: it is important that the engagement does not patronise people into being 'vulnerable' but also ensuring that the process is ethically informed and protect people.

- Participants felt that meaningful engagement needs involvement from the outset and at all levels. People need to feel involved in the project or process they are being asked to engage with their views and experiences on.
- Participants mentioned a few things that they felt can hinder or works less well when it comes to engagement. One thing is that it can end up being same people and those can become quite burdened with participating in engagement around multiple research projects. Individuals may be on a journey and not want to repeatedly tell story/share experience.

Practical ways to enable engagement

- A very common area mentioned by many participants was making sure language is accessible and avoiding jargon, acronyms, and otherwise inaccessible ways of communicating. Using plain English was highlighted as key. It is also important to be upfront with the standard academic process, structure, and administration as this can be a is a barrier. It is also important to manage the expectations of the engagement. Things like having engagement in a neutral space, such as community drop-in facilities, was seen to create meaningful engagement.
- Participants highlighted some practical areas that makes engagement work well: setting boundaries, allowing ownership, and exploring what is realistic from a lived/living experience angle. They also noted that engagement needs to be accessible, inclusive, and be informal and comfortable. This might mean having to be creative with how people can take part and be flexible in helping people engage in meetings or groups.
- For engagement to be meaningful, those taking part need to understand the purpose, the impact and the outcome of engagement activities and researchers need to make these clear. This also includes making it clear how the final input will be impacted by what people engaged in the research process say. Practical ways to ensure this happens is to set terms of reference or group rules from the outset and provide specific and clear guidance for those taking part. Participants also highlighted that feedback from people with lived/living experience needs to be taken onboard and that for those participating in the process, seeing the input PPIE members contribute makes a difference.
- Renumeration and compensation: to ensure that engagement is not tokenistic there needs to be appropriate remuneration for individuals to compensate them for their time.
- Build understanding of the research: educate people about the research process and how it relates to policy and practice. It is also important to be honest of where the data is going and how it will be used. To build trust and understanding it is also important to keep people informed or involved to see the outcome of the research, for some people this will be the first time they see the outcomes of research on topics relating to their lived experience.
- One important point some participants made was that researchers should show how research makes difference in the real word, but that it takes a long time to get a body of evidence developed.
- Good practice should be visible so it can be replicated; participants suggested giving examples of good practices of engagement to help future research projects being able to follow such examples. Some participants also highlighted that people engaged in the research process and advising on it have a “finger on the pulse” meaning they can help researchers shape their research.

What are barriers to meaningful engagement?

We asked participants how researchers can engage with people with lived/living experience and other stakeholders who are relevant to their research. We also asked them to tell us what, in their experience, meaningful engagement looks like in practice and what the barriers are. Participants identified a range of **structural barriers**, meaning things within systems and processes of doing research that create barriers for meaningful engagement. This included:

- The funding process: to involve people in engagement around developing new research questions researchers need funding to compensate people they engage with, but funders expect engagement to have happened to inform the research question in a grant application. This means people with lived/living experience don't get their say.
- Language used by researchers: jargon, acronyms and definitions might not align with people's perceptions and using 'academic' language can be inaccessible to many people.
- Safeguarding: engaging with young people with lived/living experience, specifically, can be difficult due to safeguards surrounding them. Others felt that research ethics committees sometimes place barriers on doing research relating to people with lived/living experience of substance use as their views do not align with charities of who is a "vulnerable person"
- Approvals: participants felt that if PVGs and research passports are needed for people with lived/living experience this can create barriers for engagement. This is typically not an issue for PPIE involvement due to this taking place at the research development stage, as opposed to actually carrying out work. However, clarity on this, and guidance on how to deal with this should it arise in the course of PPIE development, would be good.
- Biases, stereotyping and stigma: personal biases such as towards type of substances people use and stereotyping of people in 'addiction' can create barriers on who can and does engage. Various types of stigma, including mental health stigma, can also create barriers to engagement. Differing views on what lived/living experience is can also impact on who can/does engage.
- Relationship-related barriers: sharing of information, lack of trust between people with lived/living experience and researchers, and misinformation (do we know about what??) can hinder meaningful engagement. Some participants also mentioned that people might not like the answers to the questions they ask.
- Individual circumstances: researching those with lived/living experience who are using "recreational" drugs can be a challenge due to how those drugs can impact on engagement. It can also be difficult to find people with experience who want and can engage.

The purpose of PPIE groups

Participants discussed the purpose of engagement and highlighted that there is purpose and benefit for **individuals engaged in the process** and for **researchers/the wider research community**:

- Participants felt that engagement allows people to be exactly where they are, when it comes to their current drug/alcohol use and researchers should not put expectations on them.

- It provides opportunities for people with lived experience, and it gives people a sense of purpose. Participants also mentioned that engagement activities can be an outlet for expression and challenging oppression.
- The purpose for research includes agenda setting, participants gave the example of *European Network of People Who Use Drugs*. Participants also felt it helps driving research, elevate community research, democratizing the research process, and holds the research accountable and true to its aims. Engaging with key stakeholders also helps with understanding where and how to disseminate knowledge generated in research projects.
- More broadly, participants felt that engagement can change research practices and push the boundaries beyond academic norms. It is also important for future developments and service funding. Participants also believed that engagement in the research process can change policy.

Next steps

In regards the question of whether a new PPIE group should be set up it was felt that there are currently several organisations that already have aspects of the PPIE setup, and going forward the focus should be on how to create a collaborative inter-agency PPIE network.

We will explore more about the types of PPIE going on across Scotland with the aim of this will be to have an overview of ongoing activities.

We will explore what resources could be useful to enhance the impact of PPIE by engaging with our membership, wider networks, and exploring current funding landscapes.

We will share good practice examples of PPIE that can help others develop approaches for their own research projects.

References

NHS Scotland (2025). *Patient and Public Involvement (PPI) Guidance and Training*. Available at: https://www.nhsresearchscotland.org.uk/public/help-shape-research/patient-and-public-involvement-guidance-and-training

NIHR (2025) *Guidance for applicants on working with people and communities.* Available at: *https://www.nihr.ac.uk/research-funding/application-support/working-with-people-and-communities*

Scottish Government (2015). Scottish National Research Framework for Problem Drug Use and Recovery. Available at: https://www.gov.scot/publications/scottish-national-research-framework-problem-drug-use-recovery/

Scottish Government (2018). *Rights, respect and recovery: alcohol and drug treatment strategy.* Available at: https://www.gov.scot/publications/rights-respect-recovery/

UK Drug Policy Commission (2012) *A Fresh Approach to Drugs: final report of the UK Drug Policy Commission.* Available at: https://www.ukdpc.org.uk/publication/a-fresh-approach/