# Involving people with experience of problem drug use and their families in the Drugs Research Network Scotland

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## 1    Introduction

The Drugs Research Network Scotland (DRNS) exists to generate knowledge about problem drug use in Scotland to inform the development of increasingly effective policies and practices.  The DRNS is a partnership that includes academics, technical experts, policy makers, service providers, and people affected by problem drug use.

This document sets out the DRNS' approach to the meaningful involvement of people with both lived and living experience of problem drug use and their families in our work.  We provide definitions for key terms, describe our values and principles, outline a rationale for including stakeholders in research, and how we will support this in our work.

## 2    Definitions

**Problem drug use** is defined as any psychoactive drug use which is associated with negative effects on a person's social, financial, psychological, physical or legal well-being , and the well-being of those around them (adapted from DrugWise, 2017).   We refer to people with **lived or living experience** when describing those who have personal experience of problem drug use.  This includes people in recovery, including medication-assisted recovery, people who are currently using illicit drugs and people who regard themselves as ex-users.  The abbreviation **LEAF** refers to people with Lived or living Experience and Affected Family members.

**Drugs research** is the study of problem drug use.  Methods are chosen to collect or generate new information which is then analysed to make evidence-based conclusions and recommendations.  There are two broad types of research:

- *Quantitative* research uses information in the form of numbers that are collected by measuring things.  Statistics, mathematics, and computational methods are used to make sense of these numbers and explain patterns in data (numbers).
- *Qualitative* research uses information that is generated by interviewing people or by observing their behaviour.  Sometimes written text, pictures or videos are used.  This information is examined to identify themes that tell us something about how people understand the world and why they behave the way that they do.

A **recovery-oriented** approach is one that recognises and supports people's "hope, self-determination, self-management, empowerment and advocacy [and their] right to full inclusion and to a meaningful life of their own choosing, free of stigma and discrimination" (Australian Health Ministers' Advisory Council, 2013, p. 13). Involvement in recovery-oriented research can provide people with opportunities to meet a range of personal goals related to citizenship, social participation and autonomy (Davidson et al., 2017; Frost et al., 2017).

> "For me the relationship was built out of respect for me and my experience and respect for my colleagues who also had their own experiences.  I felt that I had an equal input into the process which empowered me to collaborate and utilise our collective experiences.  My role became more than a former service user, to being a valued member of a group with an equal part in the process.
>
> This type of involvement really empowered me and the members of the institute to work together to bring about a change in all our thinking on what recovery and its real potential really could mean to all of our practices, and the recovery pathway for people…"
>
> Service user researcher.  From (McGowan et al., 2009, p.208).

## 3    Our values and principles

As well as our commitment to work in a way informed by international evidence of best practice, our stated values are to:

- Commit to the highest possible standards of excellence and ethical conduct.
- Ensure that all DRNS-sponsored research is delivered in accordance with the Research Governance Framework for Health and Social Care (Health Research Authority, 2017).
- Foster a culture of respect, dignity, transparency, and fairness in all our activities.
- Advocate dialogue as a means of balancing the diverse views on drug use, misuse, and dependence.
- Be sensitive to the diversity of our membership and commit to consensus decision-making.

We approach drug use as a phenomenon that can have negative health and social consequences for individuals, families, communities, and society.  Problem drug use does not affect all social groups equally; it is a socially-patterned, inequitably-distributed issue that reflects the unequal distribution of economic and other resources in society.  As well as the social determinants of drug dependence, people who use drugs and their family members can be further disempowered through stigmatising social attitudes and institutional responses (Belle-Isle et al., 2014; Popay et al., 2008). We have a responsibility to recognise these experiences and take steps to avoid further disempowerment or stigmatisation of people as a result of their involvement in research.

The DRNS aims to contribute to a reduction in health and social inequities through our public engagement activities.  We will apply an 'equity lens' to the development of our policies and practices by recognising the structural disadvantages experienced by people who have living experience of substance use and their affected family members (Pauly et al., 2013).

> Community members have traditionally been excluded from the production of academic knowledge and have had little or no decision-making power in this regard.
>
> By democratising knowledge production by including community members in the research process, power is distributed through more equitable community-academic relationships…
>
> Inclusion of community members in the research process can be enhanced by valuing their lived experience, providing training and mentoring opportunities, financial compensation, building trust and accommodating their needs.
>
> (Belle-Isle et al. 2014 pp. 182, 186)

We also recognise that the categories of academic researchers and people with lived/living experience/family members are not mutually exclusive.  There are professional researchers with experience of problem drug use and substance use services.  There are also trained peer researchers across Scotland; people with experience of problem drug use who are trained to design and conduct research.  Involving those with 'dual identities' has the potential to further enhance approaches to drugs research in Scotland (for associated work in the area of mental health see Rose: 2014, 2017).

## 4    Why involve people with living experience and family members in research?

The rationale for involving affected communities in research has been described under four main areas (Neale et al., 2017; University of Sheffield, 2017).  At the most basic level, there is a **policy imperative since** funders and research governance bodies require evidence of collaboration as a condition of supporting research projects.  A **moral approach** suggests that those with experience of problem drug use have a right to be involved in research that affects them, especially when research findings could impact on social policies and attitudes or shape the services they receive.  An approach informed by **theories of knowledge** recognises that people with personal experience of problem drug use and its consequences "have valuable first-hand information that researchers tend not to have but need to know" (Neale et al., 2017, p. 2085).  For example, they can:

- Advise on research topics and questions, ensuring that efforts are directed towards the most relevant and impactful areas of inquiry;
- Ensure that appropriate language is used in surveys and study information sheets, resulting in participants being more able to give informed consent and the collection of more meaningful data;
- Make recommendations on research methods and designs that are likely to be most acceptable to target populations;
- Provide knowledge and networks to help recruit participants who may otherwise be considered difficult to reach. These community links can also be used to disseminate research findings to target populations, increasing the reach and impact of new knowledge.

Finally, several **results-based reasons** suggest a range of potential benefits for researchers, community members and the research itself. Meaningful involvement can enhance a research project with greater credibility that supports participant recruitment and trust in the findings. Researchers can learn how to describe their work more clearly and accessibly to a wider range of people which can benefit knowledge exchange and impact of research.

Participation can also provide real benefits for community members. Previously, their voices may not have been heard, especially by professionals working in large institutions. They may wish to see improvements in drugs policy, health and social care services informed by their experience as service users, patients, or carers. They may also seek to develop their skills and self-confidence. (Davidson et al., 2017; Frost et al., 2017; Neale et al., 2017).

> Collaboration is, however, much more than a list of 'involvement' activities. It is a mind-set, requiring all parties to trust, respect and value each other and to function as a team.
>
> People who use substances need to recognize that there are rules and conventions of research, including deadlines, over which researchers may not have control.
>
> Researchers must be willing to change their views and amend study designs depending on what people who use substances tell them.
>
> (Neale et al., 2017, p. 2084)

## 5 How the DRNS will support and evaluate involvement activities

A number of UK-wide and Scottish frameworks exists to support the development of community involvement in publicly-funded organisations and health research, with many commonalities in principles and approach (INVOLVE, 2014; National Institute for Health Research et al., 2018; Scottish Governement, 2015; Scottish Government, 2017).

The DRNS is working to the **National Standards for Public Involvement** (National Institute for Health Research et al., 2018) as the NIHR is a key health and care research funding organisation and these standards were developed by a partnership that includes the Chief Scientists' Office of the Scottish Government Health Directorate. The following table (adapted from National Institute for Health Research et al., 2018) outlines the standards, their rationale and actions the DRNS will take to implement them.

| Public involvement standard: | The DRNS will achieve this by: |
|---|---|
| **1. Inclusive opportunities**<br><br>Standard: We offer public involvement opportunities that are accessible and that reach people and groups according to identified needs.<br><br>Rationale: We want research to be informed by a diversity of experience and insight so that it leads policies and practices which reflect identified needs. | Actively seeking out evidence of international examples of best practice in LEAF involvement.<br><br>Reaching out to LEAF representatives through a range of channels including existing service user and family support groups, addiction services and third sector organisations.<br><br>Developing flexible opportunities for LEAF involvement at all stages of the research process.<br><br>Using a range of media to make information and engagement accessible including, face-to-face meetings telephone conversations and electronic communications. |
| **2. Working together**<br><br>Standard: We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.<br><br>Rationale: We deliver better research when we work together on a common purpose. Different perspectives are respected and embraced through clearly defined roles and responsibilities. | Ensuring that everyone involved in the network is aware of and agreed to work towards our stated values.<br><br>Provide clear, accessible information on opportunities for involvement in research. This will include information on the roles available, what people would be expected to contribute, and an idea of the time commitment required.<br><br>Describing what people can expect from the DRNS. This includes training and support, clear accessible information, reimbursement of expenses, and recognition for their time and contribution.<br><br>Being open and honest with peers about the opportunities for them to be involved in research, and areas where this may not be possible. |
| **3. Support and learning**<br><br>Standard: We offer and promote support and learning that builds confidence and skills for public involvement in research.<br><br>Rationale: We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research. | Regularly asking those involved about their training and support needs. We will work with peers, and their organisations, to ensure they receive the training and support they need to be involved in research.<br><br>We will engage with drug services, mental health organisations and family support groups to ensure that peers have access to information and support that will help them identify and manage any difficulties that arise because of their involvement in research.<br><br>As well as training LEAF representatives in drugs research we will offer training to academic researchers on peer involvement. This will enable traditional researchers to understand the contribution that community members and peer-led research can make to the field, and how they can more effectively engage with community partners. |
| **4. Communications**<br><br>Standard: We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.<br><br>Rationale: Plain language helps develop shared understanding in research. Free flow of information and adapting communication for particular needs helps keep the focus of involvement on improving research and outcomes. | We will provide peers with written information in plain English that is clear, understandable and explains any technical language or abbreviations.<br><br>We will use a range of channels to make our information and engagement accessible including email, our website, Twitter, and Facebook pages.<br><br>We will provide printed copies of information to peers who do not have access to a computer or printer. We will offer telephone, on-line, and face-to-face meetings to engage with people.<br><br>We aim to give all network members enough time to read information and paperwork, to think about it, and respond in a way that suits them.<br><br>We will address geographical and physical barriers to engagement and will hold engagement events in venues across Scotland. |

| Public involvement standard: | The DRNS will achieve this by: |
|---|---|
| **5. Impact**<br><br>Standard: To drive improvement, we capture and share the difference that public involvement makes to research.<br><br>Rationale: We can learn from both positive and negative impacts of public involvement in research. By sharing this learning, we can improve what we do. | We will encourage research teams to record involvement activities using the GRiPP2 checklist. (Staniszewska et al., 2017). As a minimum this captures information on: the aim, methods, and outcomes of involvement activities in the study, and a critical reflection on things that went well and those that could be improved.<br><br>The DRNS' involvement activities, outcomes and opportunities will be made publicly available on our website and actively promoted to peer and family support organisations and peer researchers across Scotland. |
| **6. Governance**<br><br>Standard: We involve the public in our governance and leadership so that our decisions promote and protect the public interest.<br><br>Rationale: Public involvement in research needs visible leadership and clear lines of responsibility so that it is transparent and gains public trust. | We will establish a network of LEAF members who would like to be kept informed about, and are seeking opportunities to be involved in, our work.<br><br>This group will be invited to identify representatives to represent them and their interests on the DRNS Steering Group. Two places will be made available on the Steering Group to encourage representation from someone with lived/living experience of problem drug use and an affected family member/carer. |

**Resourcing involvement activities**

We will help to ensure that public involvement costs are included in all DRNS-supported funding bids. This will ensure research projects have the funds to:

- reimburse peers for travel and other expenses that result from their involvement;
- compensate peers for their time and the work they do for research;
- provide training and support;
- fund peers to attend conferences and policy development meetings;
- hold accessible meetings with peers to consult, involve and engage them in research.

We recognise that receiving cash payments or other compensation (e.g. supermarket vouchers) can have implications for LEAF contributors who receive state benefits. We will take steps to ensure that they are not penalised for their involvement and follow best practice in this area. We will recommend and signpost participants to sources of expert advice to ensure their benefits are not affected.

We will also encourage network partners such as universities and service providers to offer formal education and work placement opportunities to peers who wish to build on their skills and develop their portfolio of skills and experience. The network already has representation from the Scottish Drugs Forum and Society for the Study of Addiction who support skills development through training and bursaries.

The DRNS is committed to the meaningful engagement of people with experience of, and those personally affected by, problem drug use in Scotland. We will use emerging evidence of best practice to inform our approach to LEAF involvement in the development of the network and delivery of our activities.

We will review this document annually and encourage feedback to help us to improve our policy and approaches in this area. If you have any comments on this document, please feel free to contact us by emailing admin@drns.ac.uk or calling us on 01786 467611.

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## Appendix A. Examples of levels and stages of peer involvement in research.

| Stage of research process | No involvement | Consultation | Contribution | Collaboration | Control |
|---|---|---|---|---|---|
| **Identifying research topics** | Identified by traditional researchers or funders. May reflect issues that peers have raised with service providers. | Peers asked their views of (usually pre-identified) research topics. Traditional researchers decide whether to adopt their ideas. | An employed peer may work with others to identify research topics. Traditional researchers usually take final decisions. | Peers and traditional researchers jointly identify topic for research. | The research topic is identified by peers. |
| **Designing research** | Study designed by traditional researchers. May include a focus on peers' experiences. | Peers asked for their views on existing study design. Traditional researchers take the final decision. | Peers may contribute to a specific part of study design. Traditional researchers take the final decision. | Peers and traditional researchers jointly design the study. | Peers design the entire study. Traditional researchers may be consulted for technical advice. |
| **Outcome measures** | Traditional researchers select outcomes they believe it is important to measure. | Peers' views of outcome measures are sought. Traditional researchers take the final decision. | A peer may be tasked with generating outcome measures that reflects peers' concerns. | Peers and traditional researchers jointly identify, select and modify outcome measures. | Peers select all outcome measures, generating additional peer-focussed outcome measures if needed. |
| **Data collection** | Peers are research participants with no influence over how data are collected. | Peers' views of data collection are sought. Traditional researchers take the final decision. | Peers may be employed to collect data. | Peers and traditional researchers jointly decide on data collection strategy and collect data. | Peers develop data collection strategy and collect all data. Peers may commission others to collect data. |
| **Data analysis and interpretation** | Traditional researchers analyse and interpret data. Interpretations may be checked with peers (validation). | Peers are asked their opinion of analysis and interpretation strategies. Traditional researchers have the final say. | Peers may be employed to analyse and interpret data. | Peers and traditional researchers jointly engage in data analysis and interpretation, each bringing their unique perspectives. | Peers analyse and interpret data. They may consult traditional researchers for technical advice. |
| **Write-up** | Traditional researchers write up the results and retain editorial control. | Peers are consulted on (near) final draft e.g. for accessibility. Traditional researchers have the final say. | Peers may contribute to write-up but traditional researchers retain editorial control. | Peers and traditional researchers jointly undertake writing and share editorial control. | Peers undertake write-up and ideally have full editorial control, but constraints may be set by funders / commissioners. |
| **Dissemination** | Traditional researchers plan dissemination strategy. This may include dissemination to peer audiences. | Peers are consulted on dissemination strategy, often how to reach a peer audience. Traditional researchers make the final decision. | Peers have a key role in disseminating research findings to other peers. | Peers and traditional researchers jointly plan dissemination strategy. | Peers plan dissemination strategy, typically seeking to reach a wide peer audience in a variety of innovative ways. |

(Adapted from Sweeney and Morgan, 2009).