



# DRNS Annual Conference – Nov 2018

Morning workshop:

*Democratising drugs research? Navigating the evidence and building on people's experience to make it work for everyone*

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# Aims of workshop

- ▶ To explore the underpinning values, ethics and principles of involving people who use/d drugs and affected family members;
- ▶ To explore different models of involvement we have been involved with, raising associated benefits and challenges;
- ▶ To explore the tricky and challenging issues in this work and how these connect to, and can reinforce, power imbalances and structural inequalities;
- ▶ To share insights and practices that can support involvement working for all involved.



# Leeds Addiction Unit

## Service user involvement in research: a two way process

- ▶ Making questions meaningful
- ▶ Making questions comprehensible
- ▶ Promoting the art of everyday language
  
- ▶ An example: steps in the development of the  
**Addiction Recovery Questionnaire**

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# Notes

- ▶ What was good about it? We started with a blank sheet of paper, asked service users in different contexts and different stages of their treatment/recovery journey, their families and friends what it meant to get better
- ▶ Developed the questions and went back to them to modify and shape up
- ▶ Validated the resulting questionnaire using other service user groups
- ▶ Produced an instrument to measure progress that has good face validity, takes two minutes to complete and covers these areas: involvement in substance use, everyday functioning and psychological health

# NIHR SHARPS Experts by Experience group

- ▶ Meets quarterly through the 2 year project - people with lived experience of substance use and homelessness - uses **INVOLVE guidance** as basis
- ▶ **Lessons learned**
  - ▶ Ensuring time for people to get to know each other and the researchers – trust and feeling comfortable together means the time needed together is longer – build in process as well as study working time – this is still work!
  - ▶ Insights very significant re things to include and to avoid
  - ▶ Importance of giving people a choice in reimbursement for their time and expertise
  - ▶ Seeing the enjoyment people get from being involved meaningfully and their contribution being valued
  - ▶ Importance of involving people in other events and opportunities, not just the study related work, if they are interested – helping people extend their networks
  - ▶ Importance of encouragement, being sensitive to individuals, anxieties/concerns and practical barriers to involvement (e.g. phones, emails, travel, speaking out in a group)



## Research can contribute to disempowerment

*'... researchers have to learn how to put their knowledge and skill at the disposal of their research subjects, for them to use in whatever ways they choose'.*

Mike Oliver. 1992, p11.



### **Standard 1: INCLUSIVE OPPORTUNITIES**

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

### **Standard 2: WORKING TOGETHER**

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

### **Standard 3: SUPPORT & LEARNING**

We offer and promote support and learning that builds confidence and skills for public involvement in research.

### **Standard 4: COMMUNICATIONS**

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

### **Standard 5: IMPACT**

To drive improvement, we capture and share the difference that public involvement makes to research.

### **Standard 6: GOVERNANCE**

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.