



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

Jason Wallace

Gillian Tober

Tessa Parkes



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

Gillian Tober PhD Consultant Addiction Psychologist

www.result4addiction.net



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.