

Presentation by

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Research Fellow

Making it matter, Involving seldom heard groups in research.

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Patient and Public involvement in health research (PPI)

Patient and Public Involvement and Engagement (PPI/E) is integral to the work of the Health protection research unit and we ensure we ask patients and the public to advise us on what research we should do, how we should do it and what we should do with the findings: setting research agendas, designing studies, communicating with the public, and overseeing the HPRU and research within it.

Why involve: a matter of perspective



Seldom heard groups

- 'Seldom heard' - groups who may experience barriers to accessing services or are under-represented in healthcare decision making.
- Traditionally includes rural communities, black and minority ethnic (BME) groups, gypsies and travellers, lesbian, gay, bisexual and transgender, asylum seekers and refugees and young carers.
- IV drug users

Possible barriers to inclusion

- **The communities**

- Access to communities
- Lack of 'buy in'
- Cultural reasons
- Socio economic status
- Do people ask?

- **The Researchers**

- Good PPI is time consuming
- Unfamiliar territory
- New language, skills, focus, approaches required.
- Buy in from senior academics

MRSA Swabbing project

Simon Packer – Epidemiologist in
Public Health England

Health Protection Research Unit,
Evaluation of Interventions

Bristol Drugs Project



User group Involvement

THE PLAN

- Convene a service user group to inform and develop a questionnaire that would be used for the MRSA swabbing study
- Recruit 8-10 men and women to participate
- To meet twice.

THE REALITY

- Problematic access to participants
- Chaotic lifestyle of service users
- Ethical dilemmas
- Health protection researchers work in areas including; modelling, epidemiology and laboratory research. They can be uncomfortable in becoming 'patient facing' even if only for a short time.

Collaborative working

Service providers at BDP

Research collaborator

Co facilitator



The group

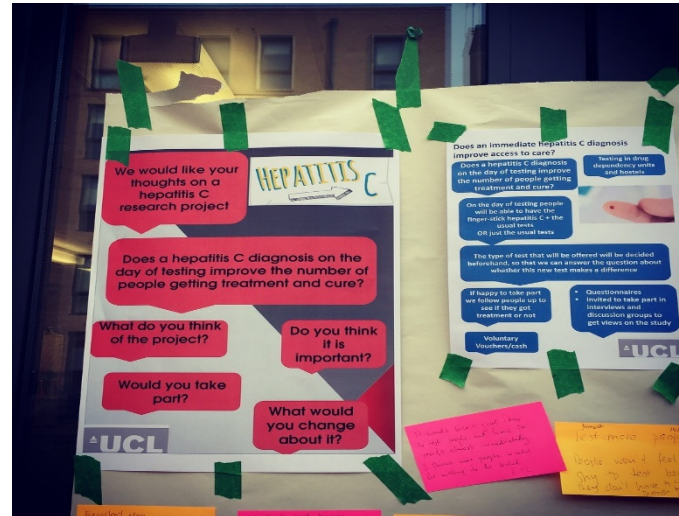
- 5 men
- Age range between 24 and 60
- All IV drug users
- Paid for their involvement
- Group discussion that lasted 1.5 hours
- Contributions were used in the questionnaire
- Return visit to service providers for context

Highlights

- Include free text boxes to gather information about feelings
 - Anonymity required clarification
 - Information leaflets for signposting
 - Time frames needed to be different
 - Options were missing in questions about place of residence
 - Simplification of wording required
 - Doubts over the necessity of some questions
 - Questions considered too probing were removed
 - Terminology was unclear
 - Accessible Handouts were required.
- **People felt involved, valued and heard.**
 - **We learnt a lot.**

Ongoing collaborations

- i. Shooting stars
- ii. Fellowship applications
- iii. HEP C events
- iv. Stakeholder meetings



Public involvement training



Lessons learnt

- Ask the experts
- Be brave
- Be flexible
- Don't give up
- Laugh
- Remember why you are doing it

Thankyou for listening

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