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Give a little RESPECT: Public and Patient Involvement in Research

Claire Paul, Amanda Edmondson, Liz Hughes, Ceri Owen, Isaac Samuels and Sheena Foster
Objectives

• Get you thinking about public and patient involvement (PPI) in research

• Gain insight into PPI in the real world – RESPECT case study

• Be inspired, challenged and encouraged by first hand accounts of working in a PPI role

• Reflect on your own research practice and PPI
What is public and patient involvement (PPI) in health research?

• **Involve** define public and patient involvement in research as...

  “...research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (Involve 2012)

• PPI excludes participation in research as subjects for the purposes of data collection

• In the context of PPI, the public are patients, potential patients, carers and people who use health and social care services (Involve 2012)
PPI in health research

• The Research Governance Framework states,

  “Relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research” (DOH 2005 p. 8)

• All major funding organisations in the UK expect evidence of PPI in all or some research activities in order to secure funding (NIHR 2006)
PPI Activities

**User-led research**
Power, initiative and decision-making lies with the patient/service user e.g. Chief Investigator

**Collaborating throughout the process**
Active, on-going partnership with the patient and/or public. Decisions are shared and the PPI perspective is valued throughout the research process e.g. Steering group member, Co-applicant

**Consulting or commenting on research**
The views of patients and/or public are sought and may influence decisions e.g. reviewing and commenting on study documents
Principles of PPI

• Shifting the balance of power between the research participant and the researcher (Brett et al. 2010).

• “PPI brings...different perspectives to research decision-making spaces, based on... experiential expertise” (Thompson et al. 2012 p.603).

• From expertise lying solely with academics and clinicians towards valuing and integrating the expertise gained from lived-experience, caring or citizenship.
Benefits of PPI

What are the potential benefits of PPI to?

• The research study
• The researchers/professional members of research team
• The person(s) providing a patient, carer or public perspective
PPI in the real world

That’s great... but PPI is challenging to do well!

- **Resource constraints** – lack of specific funding, capacity, PPI recruitment
- **Tokenistic approaches to PPI** - ticking the box for funding
- **Culture/context** – attitudinal barriers, lack of organisational support/policy
Randomised Evaluation of Sexual health Promotion Effectiveness informing Care and Treatment (RESPECT): a feasibility study of an intervention aimed at improving the Sexual Health of People with Severe Mental Illness
PPI & RESPECT

**Idea**
- PPI consultation event – identify priorities

**Plan**
- Project Management Group

**Fund**
- Co-applicant (costed)
- Application input / feedback

**More Planning**
- Reviewing study documents
- Measures (selection / order)
- Intervention content

**Implement**
- TMG
- Interviews (Researchers)

**Disseminate**
- Events / workshops to include PPI

**Analyse**
- Interpreting the data (elephant)
Take home messages

1) Start early – Ideas stage (and keep going)

2) Ensure PPI costs are included (and realistic). See INVOLVE for guidance [http://www.invo.org.uk/frequently-asked-questions/](http://www.invo.org.uk/frequently-asked-questions/)

3) Be flexible & responsive

4) Evaluate the impact of PPI activities
What now?

Take a minute to reflect on the workshop today

Identify one thing you will do differently to promote public and patient involvement in health research...