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Give a little RESPECT: Patient and Public Involvement in Research

### Original Citation

Paul, Claire, Edmondson, Amanda J., Hughes, Elizabeth, Samuels, Isaac, Foster, Sheena and Owen, Ceri (2016) Give a little RESPECT: Patient and Public Involvement in Research. In: Leeds and York Partnership NHS Trust Research and Development Forum, Nov 15th 2016, Leeds, UK. (Unpublished)

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# RESPECT

## 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

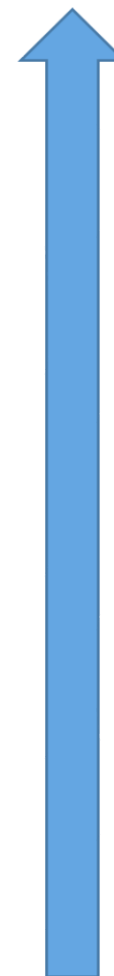
## Collaborating throughout the process

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

Ladder of participation





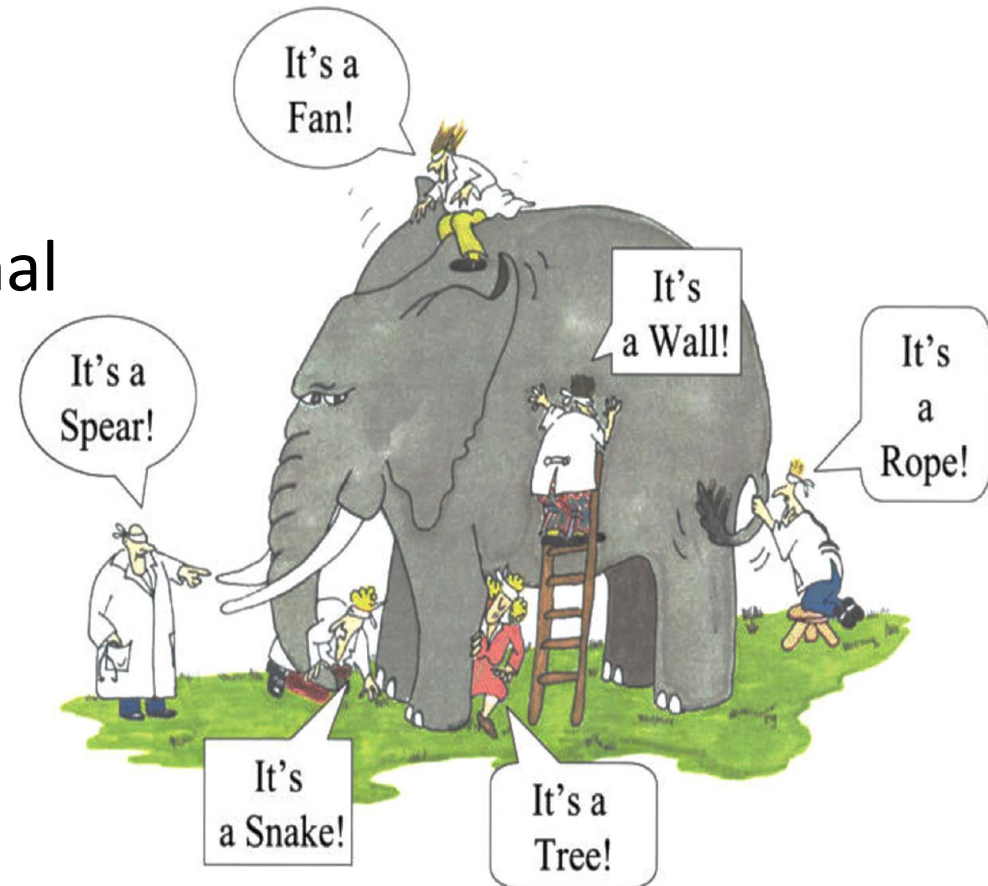
# Principles of PPI

- 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!**

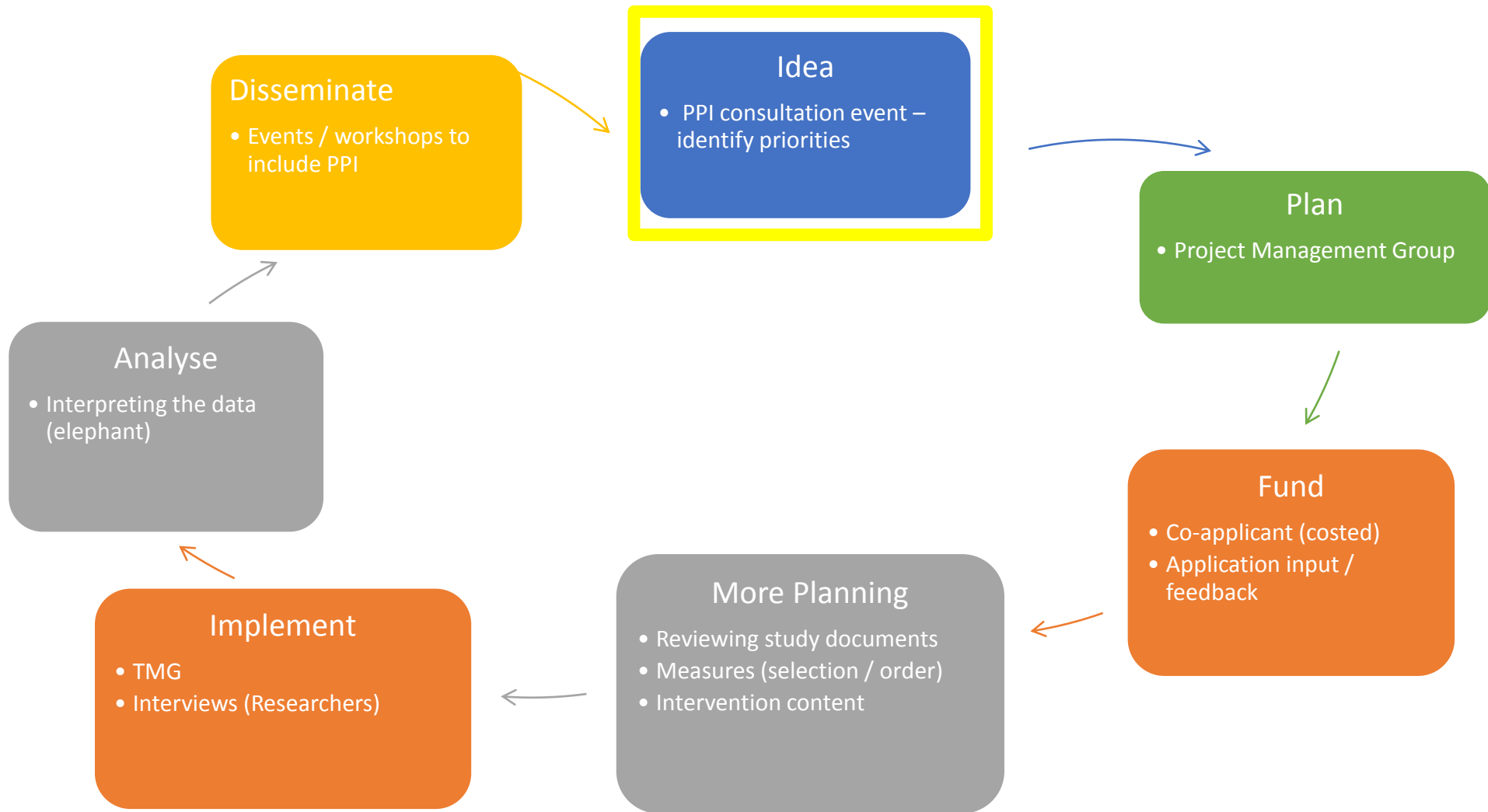
- **Resource constraints** – lack of specific funding, capacity, PPI recruitment
- **Tokenistic approaches to PPI** - ticking the box for funding
- **Culture/context** – attitudinal barriers, lack of organisational support/policy



# RESPECT

**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





# 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/>
- 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...

