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RESPECT

Give a little RESPECT:

Public and Patient Involvement in Research

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Leeds and York Partnership NHS
NHS Foundation Trust

NHS
National Institute for
Health Research

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)

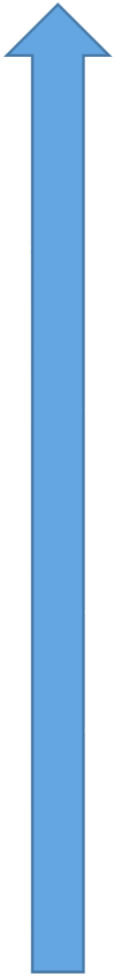
PPI in health research

- 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

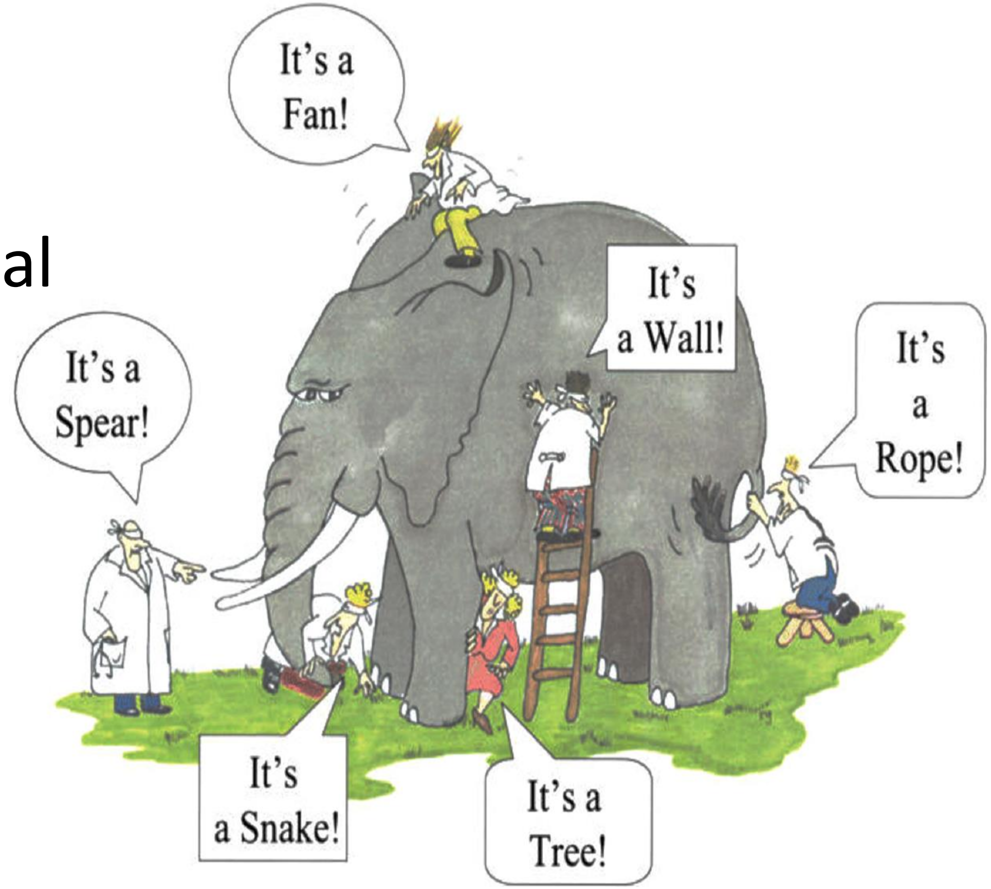
Principles of PPI

- 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

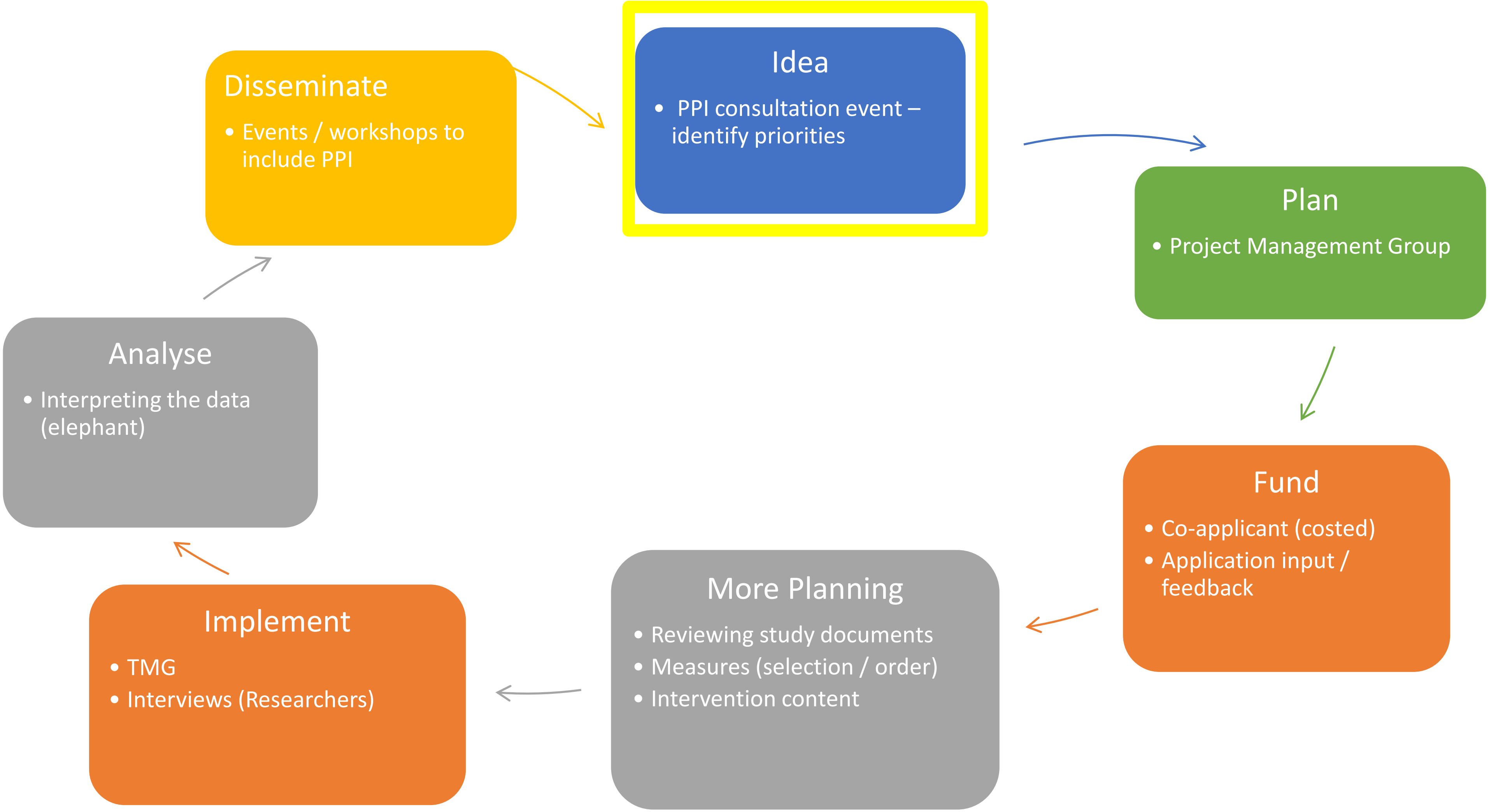
That's great… but PPI is challenging to do well!

- **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

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



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)

Analyse

- Interpreting the data (elephant)

Disseminate

- Events / workshops to include PPI

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…