

Public involvement in Systematic Reviews

Andy Gibson, Kate Boddy
PenCLAHRC PPI Team



Today we will cover...

- What is Patient and Public Involvement (PPI)?
- Why include PPI in a systematic review?
- How can I meaningfully include PPI in my review?

What is PPI in Research?

Public involvement in research is research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them, for example:

- Working with research funders to prioritise research,
- Offering advice as members of a project steering group,
- Commenting on and developing research materials,
- Undertaking interviews with research participants.
- PPI is **not** qualitative research!

Who are the 'public'?

- patients;
- unpaid carers; parents/guardians;
- users of health services;
- disabled people;
- the potential recipients of health promotion/public health programmes;
- groups requesting research due to concerns about potentially harmful circumstances, products/services;
- groups requesting research because they may have been denied products/services from which they may have benefited;
- organisations that represent service users and carers.

What are the potential benefits of Public Involvement?

- Ensuring research addresses public concerns and issues
- Improving the quality of the research design and instruments
- Improving the applicability and utility of research findings
- Importantly patients and members of the public are the final decision makers when it comes to putting research into practice

Why involve the public in systematic reviews?

- Considered best practice by review authorities: e.g. Cochrane & CRD etc;
- To address questions that are important to people;
- To investigate outcomes that are important to those affected;
- To ensure reviews are accessible to people making decisions.

Different models for different contexts



*National Institute for
Health Research*

- A user led systematic review of consumers' perspectives on ECT. Impact on all stages of the review including the type of evidence used and the findings.
- Review to develop evidence-based policy in the National Newborn Screening Programme. Involvement in the interpretation and implementation of the findings to form guidance.
- Involving users via an advisory group in a review of Peer Support for parents of disabled children

The Peer Support Review

- Setting the research question
- Public advisory group formed:
 - Focussing the question
 - Defining the outcomes
 - Setting the inclusion/exclusion
 - Contributing to the search strategy
- Will comment on the drafted paper
- Will be involved in dissemination

The practical side of involvement: How do I involve the public in my review?

- Build time and resource into the project for meaningful involvement
- Involve people as early as possible
- Be clear about what is expected of people
- Provide ongoing support
- Ensure materials and communications are accessible
- Involve everyone in dissemination
- Report PPI using the GRIPP guidance

Frequently asked questions...

- How do I meet people to involve in my review?
- How do I manage meetings with the public and researchers?
- How do I manage the frequency and content of written communications with the public?
- Help...I'm worried about over burdening the lay members of the team
- Should I pay people and if so what?

Come and talk to us!

Our next clinic is on Thursday 24th February 2- 4 pm

Kate.Boddy@pms.ac.uk

Andy.Gibson@pms.ac.uk