Please see below for a link to the webinar recording for the Trials Methodology Research Partnership:

PPI in Trials Methodology Research

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19 November 2020

On behalf of the MRC Hubs for Trials Methodology Research

The slides are also available below.

For any queries, please contact uktmn@nottingham.ac.uk

https://www.youtube.com/watch?v=MfugSHO-N28
Resources and links

• NIHR INVOLVE is currently transitioning to NIHR Centre for Engagement and Dissemination.
  INVOLVE: https://www.invo.org.uk/
  CED: https://www.nihr.ac.uk/news/nihr-launches-new-centre-for-engagement-and-dissemination/24576

• CED recognition payments for public contributors:


• INCLUDE Ethnicity Framework: https://www.trialforge.org/trial-forge-centre/include/
Resources and links

• COMET POPPIE Group: https://www.comet-initiative.org/Patients/POPPIE

• The Peoples Trial: https://thepeoplestrial.ie/

• TMRP PPI resources: https://www.methodologyhubs.mrc.ac.uk/about/tmrp-what-trials-methodology/

• Consider local RDS funding for PPI involvement. This is an example from RDS London: https://www.rds-london.nihr.ac.uk/patient-public-involvement/public-involvement-fund/

• International PPI Network Webinars: https://training.cochrane.org/international-ppi-network-learning-live-webinar-series
Involving the Public with Trials Methodology Research

Webinar Presentation 19th Nov 2020
Katie Gillies & Heather Barrington

MRC NIHR Trials Methodology Research Partnership (TMRP) – Patient, Public Involvement & Engagement (PPIE)
Webinar content

• What is trials methodology research?
• Patient and Public involvement (PPI) in trials methodology research – a background
• Examples of PPI in methods research

• Questions / Over to you!
Nuts and Bolts

Photo by Chris Yates on Unsplash

Photo by Tekton on Unsplash
research on research
A note on definitions

Patient and public involvement (PPI) in research is where research is “being carried out ‘with’ or ‘by’ members of the public” not just “‘to’, ‘about’ or ‘for’ them”


Image provided by PRIMER, University of Manchester
Why is PPI in methods research important?

**Main arguments**

**Epistemological** — Patients / the public have knowledge of their own health condition / community that can benefit researchers who may not have first hand experience.

**Moral** — Patients / the public have the right to be involved in publicly funded research that may impact any future research that they are invited to take part in.

**Consequentialist** — To improve the quality, relevance and impact of trials methodology research, improve the transparency of the process and accountability to the wider community.

**Policy** — PPI may well be policy with many trials methodology funders, so funding may depend on getting PPI right at the grant application stage.

Modified from a Slide provided by PRIMER, University of Manchester.
Planning for patient involvement in your methods research

“Planning is bringing the future into the present, so that you can do something about it now”.

Alan Lakein
Are we asking a relevant and important research question?

Photo by Matt Walsh on Unsplash
Which outcomes for methods research and potential ways of measuring those outcomes?
Is your methods study well designed from the perspective of a potential participant? What about your participant information resources?
What do you think we should do about this ........?
Views on your data and how best to present the study results
What ways do patients get involved?

- Advisory groups
- Public panel
- Priority setting partnerships
- Study management groups
- Co-applicants
- User led research

Different roles / different experience & skills
What are the benefits of patient involvement?

- Identifying topics for research
- Making the research design more relevant and accessible
- Improving the consent process by producing clearer, more accessible information
- Enhancing the ethical acceptability of research
- Increased participation and response rates
- Identify research themes that researchers may miss
- Make research findings more accessible and messages more powerful

Impact on the public contributor

• Increased knowledge and skills
• **Personal rewards** (eg. making friends, feeling of making a difference)
• **Financial reward**

Impact on the researcher

• **Fresh insights** into the issues of the study
• **Better understanding** of and **relationships** with the community
• Potentially **enhanced career benefits**
• **Positive challenges** to beliefs and attitudes

• “I think the biggest impact that their involvement has had is to keep the group of methodologists constantly aware of the patient and public perspective during our discussions and our work.” Methodology researcher

• “I can easily list things such as commenting on PIS and topic guides etc and that has been really useful. But a list like that would hardly begin to capture the ways that working with research partners has changed how I think about my research, the questions it asks, how I do studies and how I understand the purpose of the work. Everything really – plus keeping me orientated and grounded in what really matters”. Qualitative researcher.
Facilitating good PPI

• Offering support to patients who are involved
• Effective communication, so people understand what, where, how and when they might be involved
• Providing acknowledgement for involvement
• Appropriate funding for PPI
• Adequate resources for PPI (especially time)
Resources to support PPI

• NIHR Centre for Engagement and Dissemination (INVOLVE resources) https://www.invo.org.uk/ (including the NIHR Public Involvement Standards)

• People in Research https://www.peopleinresearch.org/

• Toolkits for PPI in research

• Methods research organisations eg. COMET / Cochrane

Avoid re-inventing the wheel!

Photo by Jon Cartagena on Unsplash
Challenges of PPI

ChALLENGES
Key considerations

- Both researchers and PPI partners must:
  - Be committed to making PPI work
  - Communicate freely and frequently
  - Have clear and realistic expectations
  - Respect each other: remember that a meeting between a researcher and a PPI partner is a meeting between experts with different areas of expertise
Examples from trials methodology research
Involving
Involving
An evidence base to optimise methods for involving patient and public contributors in clinical trials: a mixed-methods study

Carol Gamble, Louise Dudley, Alison Allam, Phila Bell, Deborah Buck, Heather Goodare, Bec Hartley, Jennifer Preston, Alison Walker, Paula R Williamson and Bridget Young
Researching

Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis

Joanna C Cocker, 1,2 Ignacio Ricci-Cabello, 3,4,5 Adwoa Parker, 6 Jennifer A Mirski, 7 Alan Chant, 7 Sophie Petit-Zeman, 7 David Evans, 7 Sian Rees 7

ABSTRACT

OBJECTIVE

To investigate the impact of patient and public involvement (PPI) on rates of enrolment and retention in clinical trials and explore how this varies with the context and nature of PPI.

METHODICAL


Engaging
A word on funding for PPI in Trials Methodology Research ....
Any questions?

Photo by Marcel Strauß on Unsplash
How do you / might you involve patients in your methods research?
What challenges have you faced / might you face?
How did you / might you address these challenges?

Over to you!