

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:
<https://www.nihr.ac.uk/documents/centre-for-engagement-and-dissemination-recognition-payments-for-public-contributors/24979>
- Public contributor definition: https://www.invo.org.uk/wp-content/uploads/2020/05/Including-perspectives-Version-A_final-v2.pdf
- PPI Toolkit: <https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0029-8>
- 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



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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”

INVOLVE – What is public involvement in research? <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

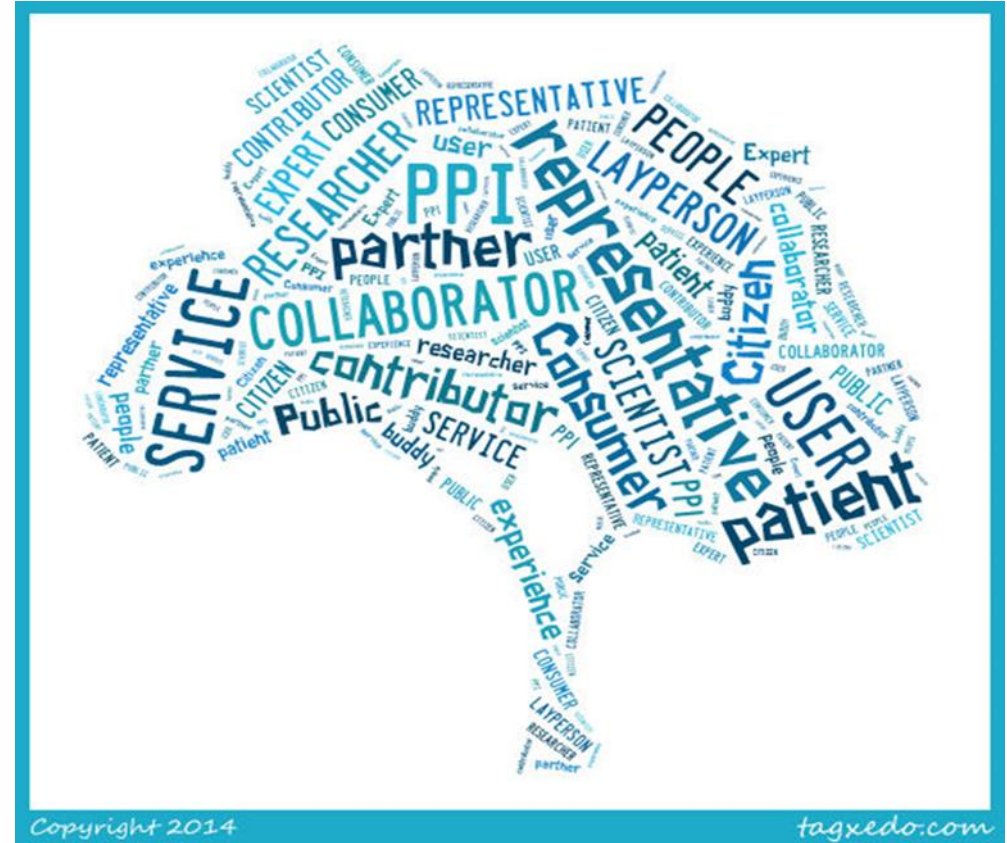
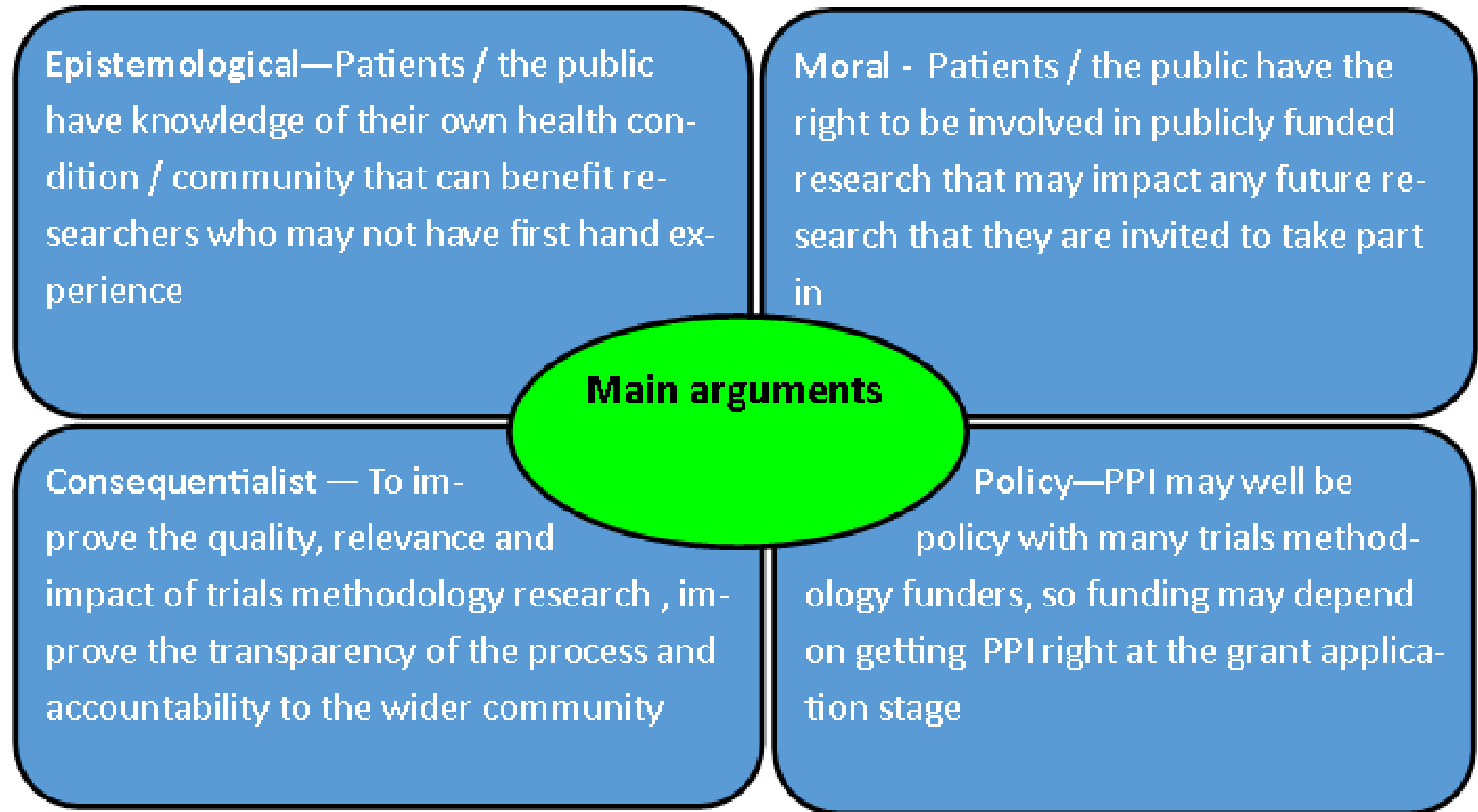


Image provided by PRIMER, University of Manchester

Why is PPI in methods research important?



Planning for patient involvement in your methods research

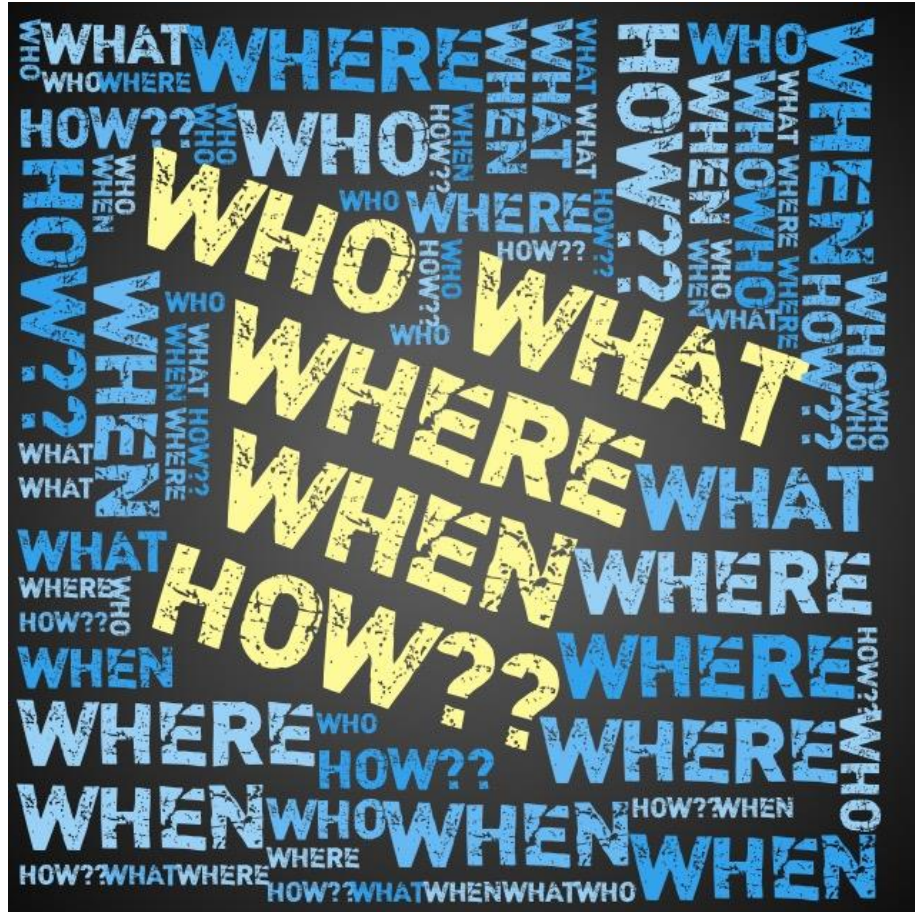


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“Planning is bringing the future into the present, so that you can do something about it now”.

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
.....?



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Views on your data and how best to present the study results



Image created using Image Chef

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**

<http://www.piaf.org.uk/documents/impacts-summary-1113.pdf>

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

<http://www.piaf.org.uk/documents/impacts-summary-1113.pdf>

- *“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!



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Challenges of PPI



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

COMET
INITIATIVE
PoPPIE



School of Health and Related Research

**Limited Budgets
Does it work?
Value for money?
Adaptive Designs**



MANCHESTER
1824
The University of Manchester

Patient Centred Trials

Involving



Researching

HEALTH SERVICES AND DELIVERY RESEARCH

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An evidence base to optimise methods for involving patient and public contributors in clinical trials: a mixed-methods study

Carrol Gamble, Louise Dudley, Alison Allam, Philip Bell, Deborah Buck, Heather Goodare, Bec Hanley, Jennifer Preston, Alison Walker, Paula R Williamson and Bridget Young



Researching



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!



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