

MRC-NIHR Trials Methodology Research Partnership

Patient and Public Involvement & Engagement – June 2020

Thank you to those of you who have been involving and engaging patients and the public in your different trial methods and with research on those methods. Firstly, it is great to see that there are an increasing number of you finding creative ways in which patients, carers and members of the public can help. There are many really good examples but we need more, please.

A report on the workshop we held last year about PPIE and Trials Methodology Research is now on the TMRP website

https://www.methodologyhubs.mrc.ac.uk/files/5715/9016/6157/FINAL_2020513_TMRP_PPI_Workshop_Ver_2.pdf

Key points from the report:

- PPIE isn't really any different from any other research
- The challenge seems to be more about trying to help people make that next step from intervention research to methodology research
- It is about enabling people make sense of what research methodology research is and does
- It is often more about the 'patient experience' in general rather than someone's personal experience.
- There are some useful questions to help you think (copied below)
- Examples - There are numerous embedded links to good practice
- Please consider using [GRIPP2](#) for writing-up and reporting for PPIE

Next steps: a further Tweetchat on the topic of Involvement with TMR; a webinar being planned for the PhD awards; and writing some help for patient/public partners. The Animation being planned by Evidence Synthesis Ireland is partially delayed due to Covid.

A 'patient's perspective

I have tried to identify what I see as the important points about Trials Methodology Research for patients. It is on my blog at...

<https://involveddotblog.wordpress.com/2020/03/24/what-is-trials-methodology-research-a-patients-viewpoint/>

Finally during Covid - Please remember that the heart of Patient & Public Involvement and Engagement is a relationship. It relies on social interaction if we are to learn from each other. As we increasingly use online-meetings we need to pay special attention to the personal aspects of care, helping people take part and sometimes having a telephone call or separate email before or after the formal meeting.

Derek C Stewart, TMRP PPIE Lead

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Patient, Public Involvement & Engagement for Trials Methodology Research

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Extract from Workshop Report

Top Questions around designing and conducting methodology research

The group identified a number of top tips for patient & public involvement. These were translated into questions following a suggestion made by Mike Robling. We present below for comment

- What is the aim and **purpose** of actively involving patients and the public with your Methodology Research?
- What is **distinct** about this involvement with Methodology Research or methodologies and how will it ultimately **benefit** patients?
- How do we best explain the **complexity** of this research?
- What planning are you doing to define specific **roles, expectations, perceptions** and **assumptions** people might have in this context?
- What **examples** and **case studies** of similar work can we draw upon?
- What **questions** would we like to explore together with patient contributors?
- Do we have the **community capacity** to carry this out?
- How are we **communicating** the task (language and style)?
- What **planning** and **resources** are required and how will the impact be measured??
- How might we identify and overcome any **challenges** and leave **preconceptions** aside?
- How might we tell others and **disseminate** the way we have involved patients & the public to different audiences?

Thank you to everyone who attended, provided notes and gave of their time.