Priorities for Methodological Research on Patient and Public Involvement in Clinical Trials: A Modified Delphi Process

For which topic were research priorities identified?
clinical trials

In which location was the research priority setting conducted?
Europe - United Kingdom

Why was it conducted at all?
Despite increasing international interest, there is a lack of evidence about the most efficient, effective and acceptable ways to implement patient and pub lic involvement (PPI) in clinical trials.

What was the objective?
to identify the priorities of UK PPI stakeholders for methodological research to help resolve uncertainties about PPI in clinical trials

What was the outcome?
a ranking list of 10 research topics

How long did the research prioritization take?
November 2015 - March 2016

Which methods were used to identify research priorities?
Delphi

How were the priorities for research identified exactly?
Step 1: literature review to develop list of potential methodological research topics, 58 potential research topics were identified from literature, reduced to 39 distinct topics. Step 2: pilot study to check clarity and understanding of topics, 3 topics were excluded. Step 3: Delphi round 1: list of 36 topics, participants were asked to rate each topic, 81 additional topics were suggested. Step 4: Delphi round 2: list of 42 topics, participants were asked to re-rate topics. Step 5: Delphi round 3: in form of a consensus meeting, discussion of each topic, ranking of 40 topics. Step 6: written report circulated

Which stakeholders took part?
Patient representatives, research partners in clinical trials, clinical trial funding boards, chief investigators, trial managers, researchers, lay people. Delphi round 1: 219 participants. Delphi round 2: 187 participants. Delphi round 3: 25 participants: 12 participants lay and 13 non-lay.

How were stakeholders recruited?
Snowball sampling was used to identify stakeholders using personal contacts and Internet searches to develop a database of individuals, organizations and networks under each of the seven stakeholder groups. For the consensus meeting, the team allocated thirty places to equal numbers of lay and non-lay stakeholders with broad representation across the seven stakeholder groups. The METHODICAL study team were invited to attend and participate in the consensus meeting. Three study team members helped to facilitate the meeting and did not take part. Ten other study team members registered to attend as participating stakeholders and were allocated either lay or non-lay places based on their primary PPI roles. Survey participants were invited at random within their stakeholder group.

Were stakeholders actively involved or did they just participate?
Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.