Distinctive challenges of patient and public involvement in core outcome set development: qualitative study

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Background

Participation
where patients take part in a COS study, and give data on their opinions regarding what outcomes are important

Involvement
where patients are involved in designing and overseeing a COS study
Aim

- Explore the experiences of PPI partners and researchers involved in COS development
Methods

Qualitative interviews:
- Semi-structured interviews
- 14 PPI partners
- 12 COS studies

Analysis:
- Transcribed interviews
- Thematic analysis
Methods

Ethnography
- 4 COS studies

Observations:
48 hours

Interviews:
9 PPI partners
7 Researchers
1. Blurring of participation and involvement

“No, we won’t [participate in the Delphi]. […] it’s because we’ve helped to formulate them, I think it will be wrong for us to take part really.”

P9 Qualitative Interview Study

“…I thought, is it like having a prejudice? [But I] answered all the questions and then there was no problem at all.”

P14 Qualitative Interview Study
It is a shame I can’t use her for everything, because now she is a **participant**. [...] it wasn’t necessarily her **informed decision**, maybe I should have explained it clearly, you can **take part** if you want, but that will mean, your role will be **limited** later on. [...] maybe I didn’t make sure she was **aware of the consequences**.

Case Study Two

I think maybe **completely understanding** the decision that you’re making [...] so you can make, a much more **informed choice** about whether you want to be a **participant or, involved** [...].

P12 Qualitative Interview Study
2. Training or finding the ‘right’ person

- Challenge of understand COS
- ‘Right’ PPI partner
  Previous PPI experience
- No formal training
3. Nature of involvement

- Feedback on study documentation
- Impactful
- Valued
3. Nature of involvement

- Systematic review
- Qualitative interviews
- Focus groups
- Delphi survey
- Consensus meeting
3. Nature of involvement

- Systematic review
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Conclusion

1. Blurring
2. ‘Right’ PPI partner over training
3. Involvement:
   - Feedback
   - Delphi
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