



UNIVERSITY OF
LIVERPOOL

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

Lucy Brading
PhD Student



@Brading_Lucy

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



Conclusion

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



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