Working with patients to analyse data

What this involves

PPI Contributors and researchers working together to analyse and interpret qualitative or quantitative data whether they have been part of the data collection process or not.

What are the benefits of working with patients to analyse data?

1. PPI Contributors can add value to a study by bringing their own perspectives and identifying further areas for the researcher to look for in qualitative research.

2. PPI Contributors may be able to provide an in-depth understanding of the broader community context and how it should shape the meaning of the quantitative results and qualitative results.

3. Co-analysing may help researchers to keep a more open mind and be open to more possibilities.

4. Researchers and the public working together can result in a richer analysis than would have been possible from either alone.

When this might be a useful/appropriate approach:

This could be a useful approach in any research project.

How can you work with patients to analyse data?

Please note that this may involve some one-to-one or small group training.

Research staff and PPI Contributors could conduct the analysis separately or together. In either case they will conduct analysis in the usual way (e.g. reading and rereading the transcripts to identify potential codes, convening to create a common coding system and coding frame, and then assigning agreed-upon codes to relevant text.)

Another option is the Framework Method; a systematic and flexible approach to analysing qualitative data and is appropriate for use in research teams where not all members have previous experience of conducting qualitative research.

Using the Framework method Gale et al 2013

“An essential aspect of creativity is not being afraid to fail”

— Edwin Land, inventor of polaroid camera
What are the drawbacks of this approach?

Researchers may have to deal with the potential loss of control over analysis of their data and possible disagreements over the interpretation.

Researchers may feel that their professional role is undermined by having unqualified people do what they have trained for years to learn.

Resources

- Internal—John MacArtney asked PPI Contributors to analyse qualitative data in his colorectal cancer study in 2016.
- ‘Lay involvement in the analysis of qualitative data in health services research: a descriptive study’ Research Involvement and Engagement August 2016 S. Garfield et al
- ‘The Power and the Promise: Working With Communities to Analyze Data, Interpret Findings, and Get to Outcomes’ American journal of Public Health 2007 Suzanne B. Cashman et al
- ‘Hearing the voices of service user researchers in collaborative qualitative data analysis: the case for multiple coding’ Health Expectations September 2012 Angela Sweeney et al

The CBTp study employed multiple coding to analyse service users’ discussions of CBT for psychosis (CBTp) from the perspectives of a service user researcher, clinical researcher and psychology assistant. They concluded that multiple coding is an appropriate and important means of hearing service users’ voices in qualitative data analysis.

- Unpublished case study -Mirror on Mirror review of the PPI within the RAPPORT study CLAHRC East of England, Elspeth Mathie
  Involved lay people in the qualitative analysis of transcripts - the individuals had no training or background they simply read the anonymised transcripts and pulled out what they saw as important themes - this worked well.
- ALOIS community at John Radcliffe Hospital http://alois.cochrane.org/ caroline.struthers@ndm.ox.ac.uk
  The volunteers read reports of dementia research and extracted key pieces of information to enter into the trials register, a task referred to as ‘coding’.

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