NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

How might patient and public involvement (PPI) improve recruitment and retention in surgical trials?

Exploring the views of trial staff and PPI contributors

Summary of research findings presented at the 4th International Clinical Trials Methodology Conference, Liverpool, May 2017 • Joanna Crocker, University of Oxford.

Our findings in a nutshell...

The participants that we interviewed suggested a variety of ways in which PPI might improve recruitment and retention in surgical trials. They also gave some examples of when PPI might be unhelpful or even detrimental. People who design trials should think carefully about how to involve patients and members of the public most effectively and as early as possible.

What's the problem?

For clinical trials to be successful, they need to recruit enough patients and keep those patients in the trial once they have been recruited. However, trials often struggle to recruit patients, so they take longer than expected and end up being more expensive. Sometimes recruited patients (participants) drop out, which is also a problem. Trials involving surgery or patients who are undergoing surgery can be especially difficult to recruit patients to.

Involving patients and members of the public in designing and/or carrying out trials could help to solve these problems. But patient and public involvement (PPI) is often done with little planning or idea as to what the role of PPI contributors might be and how their input might benefit the trial.

We are developing a PPI programme for surgical trials aimed at improving recruitment (the number of people who agree to take part in surgical trials) and retention (the number of people who stay in the trial once they have agreed to take part). As part of this, we asked surgical trial staff and PPI contributors about how input from patients and the public might help improve recruitment and retention in trials.

What we did

We invited surgical trial staff and PPI contributors to take part in a group interview called a focus group. We ran six focus groups (four with surgical trial staff and two with PPI contributors) at four locations across the UK. We also offered one-to-one interviews (in person or by telephone) to PPI contributors who were unable to attend the focus groups. We invited all participants, as well as those unable to attend focus groups, to submit comments in writing.

We recorded the focus groups and interviews, typed up the recordings, and analysed the typed-up documents, looking for relevant things that people said.

Who took part

54 people took part: 31 surgical trial staff, 21 PPI contributors and two PPI coordinators. Staff took part in focus groups at four surgical research centres: Oxford, Aberdeen, Bristol and Birmingham. 14 PPI contributors took part in two focus groups at the Library of Birmingham and seven had a one-to-one interview. 11 people provided written comments.

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What we found

The participants suggested several ways in which PPI could improve recruitment and retention to trials, which included:

Improving recruitment:

- making sure the research question is important to patients;
- influencing how the trial is designed, for example making it as patient-friendly as possible, and making sure the information makes sense to patients;
- judging whether or not patients will want to take part in the trial;
- directly recruiting participants; and
- publicly endorsing the trial.

Improving retention:

- changing what information is collected from participants and how;
- influencing how the trial is designed, for example making it as easy to take part as possible, and giving participants something to say "thank you" for taking part; and
- communicating with participants during the trial, for example explaining why it is important to stay in the trial, and sending them regular updates.

However, participants also suggested that PPI contributors could be unhelpful in some situations, for example, if they are involved too late (e.g. only in designing patient information sheets), or if they are different from the people being recruited to the trial. Occasionally PPI could have a negative effect, for example if it led to more expensive or time-consuming ways of recruiting patients, without increasing the actual number of recruits.

For more information, visit our study website: www.phc.ox.ac.uk/pirrist

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