

Patient and Public Involvement (PPI) in Research – Case Study

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How patients and the public were involved

The Surgical Interventional Trials Unit (SITU) is currently working on its PPI strategy. This will include having an introductory evening which is open to patients, carers and members of the public, where the work that SITU is currently doing will be outlined, and then the main body of the event will involve a presentation on the PPI SITU wants to do, e.g. host a regular Research User Group (RUG), and to get feedback from the public on whether this is a good idea, achievable etc.

All studies run through SITU have some elements of PPI included within them, such as contact through disease groups, members of the public on trial steering committees etc. Studies on the SITU portfolio before the creation of the RUG do involve some PPI, all future studies will have their PPI coordinated through SITU, from the inception of the idea through to the dissemination of the findings.

SITU has been involved in several NIHR Oxford Biomedical Research Centre (BRC) public events and continues to seek opportunities to present the work that it does to the public.

The impact of involving patients and public in the study

Impacts on outcomes and numbers of study visits - patient involvement can ground researchers to what is realistic for patients.

The importance of involving patients and the public in research

Surgical trials are notoriously hard to recruit to and retain participants in. There is arguably a greater issue of equipoise (genuine uncertainty about whether the treatment being tested will be beneficial and hence the assignment of patients to different arms of a given trial) in surgical trials, for both the clinicians and the patients. Involving patients and the public in the whole process of surgical trials may ease the difficulties currently faced. By making sure that patient information sheets are clear and easy to read, patients might be more inclined to agree to join a trial, and more likely to stay in it to completion. Patients are in a unique position to advise on what they would feel about study documents if they were presented to them, offering a chance to amend them for the better.

By involving patients and the public in the design of research, you can also help to ensure that outcomes are more relevant to patients, and that they will benefit from the results of the trials. They are also best placed to advise on dissemination of findings.

The biggest challenges in PPI and what might help to overcome them

- Knowing what (if anything) needs ethical approval.
- Gathering momentum to host events
- Knowing where to go to encourage patients to get involved (other than the Patients Active in Research – Thames Valley website).