

Patient and Public Involvement (PPI) in Research – Case Study**Provided by:**

Julie Darbyshire, Critical Care Research Programme Manager & Training Bursary holder (DPhil project), Nuffield Department of Clinical Neurosciences, University of Oxford

How patients and the public were involved

Patients and non-research staff are at the heart of the SILENCE project which is part-funded by the Oxford BRC in the form of a personal training bursary.

The aim of the SILENCE project is to reduce noise levels in the intensive care unit (ICU). To do this we have convened a mixed staff/patient group to review data collected by the research team and to use this information to design/develop noise reduction strategies which will be implemented on the local ICU later this year.

We hosted a mixed group meeting which included patients, staff (nurses and doctors), and the research team.

The focus of the data presentation was a collection of film clips extracted from patient interviews conducted by the Health Experiences Research Group. These clips were part-selected by a patient who has fairly recently been treated in the ICU. This ensures that the clips shown to the group have real validity for the project and are not simply 'juicy' quotes selected by the research team. The film was prepared for us by the Oxford-based DIPEX charity, who run the website healtalkonline.org which provides information and support for a range of health issues from real-life experiences. We supplemented these clips with reports of observations that the research team had conducted in the ICU. These observations were to identify the key sources of noise in the ICU, and the effect that noise seemed to have on the patients and staff.

Over the course of an afternoon this mixed group concluded that noise levels were a problem in the ICU, and drafted the outline of a plan to address the problem. These changes will be introduced in the autumn of this year and noise levels will be monitored. There will be a follow up meeting to review results in about twelve months' time.

The impact of involving patients and public in the study

We are following the principles of Accelerated Experience-Based Co-Design (AEBCD) which has been shown to be effective [Locock L, Robert G, et al. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. *Health Serv Deliv Res* 2014;2(4)]

The new policies have been designed, and will be developed and implemented by service users (patients and ICU staff). The expectation is that the changes will be better accepted than if they were imposed, either by the research team, or hospital management.

It was interesting to note that both staff and patients who attended the meeting were very positive about the experience.

The importance of involving patients and the public in research

For this project the end point is to completely change the environment of the intensive care unit. This can only be achieved through culture change, and this level of change is unlikely to occur through 'top down' enforcement of guidelines. For me, bringing patients and non-research staff into the design and implementation of the project is a way of ensuring that change comes from within.

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

It has been difficult to explain the need for an evidence base, and baseline measures from which any change can be measured. Both staff and patients are keen to implement changes immediately!