

SILENCE Project, Nuffield Department of Clinical Neurosciences (NIHR-funded via 'Research for Patient Benefit' stream)

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What was your study about?

The SILENCE project was a two-fold study looking at how to improve the intensive care unit (ICU) environment. We used patient interviews and in-situ observations (ethnography) to identify key sources of noise and how patients and staff reacted to their environment. Using the Accelerated Experience Based Co-Design (AEBCD) approach we invited staff and patients to discuss how best to reduce noise and disturbance in the clinical environment. With their help we designed an experiential teaching session so that staff could understand what it was like to be a patient. We also developed an e-learning module to accompany this.

Finally we designed a real-time visual display of sound levels. This focused on 'loudness', which is a measure of perceived sound rather than simply volume levels. Loudness takes into account the pitch of the noise as well as the volume. Higher pitched sounds are more intrusive and humans have a tendency to find them more annoying. An alarm is usually perceived as louder than low-frequency air conditioning for example, although they are often the same volume.

How did you involve patients and/or the public?

Our PPI plan was comprehensive and included patients embedded in the research team throughout the project. The original plan also included peer-to-peer interviews (including data analysis) but this didn't happen (see below).

Patients who were already part of the Oxford University Hospitals ICU Patient Forum Group agreed to join a wider meeting that also included staff and researchers. Discussion during this meeting was directed by the AEBCD framework.

What was the impact of involving patients and/or the public?

Patients rejected the original proposal put forward (to change the alarm system in the ICU). The alternative option that was suggested (multi-disciplinary complex intervention that included bespoke teaching and new display of real-time sound levels) may well have been more readily accepted because it had included patients and staff in the early stages.

What were the challenges and how did you overcome these?

We consistently struggle to engage patients to be truly part of the research team. They don't really have the time and they often feel it is not their role to assist with

research tasks (such as conducting interviews/completing data analysis). We also struggled to 'hand over' practical aspects from the joint meeting to anyone outside of the immediate research team. In the end we compromised. Researchers discussed analysis with patients and the research team took forward the various outputs from the joint meeting.

What advice do you have for other researchers considering patient and public involvement activities?

Plan well and be ambitious but be prepared to change plans if it becomes clear that they will be impractical. Remember to cost in time as well as expenses. Keep your patient friends updated regularly.