

Recovery following intensive care treatment: REFLECT

Case Study

Background

With the support of the NIHR Research Design Service, the critical care research study team invited a small number of patient and public representatives to attend a focus group to discuss the design and development of the study on improving care for people after leaving intensive care units (ICU) in

What we did

We recruited people to become part of the research team with a targeted advert via follow-up clinics and patient groups (ICU Steps: an online support charity, and CritPAL: the Intensive Care Society's patient liaison committee). One person is a member of CritPAL and has a good understanding of the political and strategic aspects of our work, three people were previous ICU patients. With this dynamic group we were able to have a wide-ranging discussion about the work we planned to do and how this would impact both at a patient and strategic level. We focused on the design of the study, on patient and relative interviews and the direction of the pilot work. The group made suggestions which included:

- Using interviews rather than focus groups, so patients and their relatives could talk openly and honestly.
- Separating 'clinicians' from interviews, again to encourage openness.
- Accessing medical notes for some interviewees to contrast their experience with what was documented.
- Including a relative in future group meetings.
- Focusing this study on why and how to improve, because there is already evidence around wrong with the care of patients following ICU discharge (evidenced by the presence of NICE and NCEPOD guidelines)
- Changing the study name from 'Mortality After Critical Care: MACC' as the focus on mortality was too negative.

We invited the contributors to form a PPI group to be involved in the design and management of the study through its full term.

What difference did it make?

We adjusted the detailed methodology as per the group's suggestions. The research team were keen to do approach relatives of patients who had died but were worried about causing upset or offence. The group felt that this was an important group to include and that although the initial approach might be difficult people would be interested to help. Advice from other sources agreed and suggested including a bereavement counsellor in these interviews.

The group intensely disliked MACC and with hindsight it is obvious why this was a terrible title, and the revised version (Recovery following intensive care treatment: REFLECT) very clearly describes a different viewpoint.

Although this grant application was not initially successful, we have remained in contact with the group via email and will invite them to be part of a new funding application.

As researchers, we felt that having a 'real person' in the room brings a sense of humanity to the research.