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

Provided by:

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How patients and the public were involved

With the support of the Research Design Service (RDS) South Central PPI officer, the critical care research study team invited a small number of public representatives to attend a focus group to discuss the design and development of the study.

We recruited participants through follow-up clinics and patient groups (ICU steps: an online support charity, and CritPAL: the Intensive Care Society's patient liaison committee). All participants volunteered in response to a targeted advert which invited people to become part of the research team. One of these is a member of CritPAL who has a good understanding of the political and strategic aspects of our work, and three previous intensive care unit (ICU) patients, two of whom had no previous experience of PPI involvement. 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. The group were consulted on the design of the study, with a focus on patient and relative interviews and the direction of the pilot work.

Several suggestions were made which included:
- Using interviews rather than focus groups to ensure patients and their relatives felt able to talk openly and honestly.
- Separating 'clinicians' from interviews, again to encourage openness.
- Accessing medical notes for some of those interviewed to contrast their experience with what was documented.
- Including a relative in future user group meetings.
- The group felt that there was already a body of evidence to suggest what was wrong with the care of patients following ICU discharge (evidenced by the presence of NICE and NCEPOD guidelines) but that the focus of this and future work should be on why and how to improve.
- They disliked the initial title of the study and associated acronym, feeling that the focus on mortality was too negative.

Members were invited to form a PPI group that will be involved in the design and management of the study through its full term. Unfortunately the grant application was not successful but we have remained in contact with the group via email and will be asking them if they would like to be involved in a new funding application later this year.

The impact of involving patients and public in the study

The main aim of the project did not change as a result of the PPI initiative but the detail of the methodology was adjusted as per the group's suggestions. Although not included in the list above, research team were keen to do approach relatives of patients who had died, but were worried about causing upset or offence. The patients felt that this was an important group to include and that although the initial approach might be difficult, they felt that people would be interested to help. Advice from other sources agreed, and suggested including a bereavement counsellor on these interviews.

Perhaps of particular note was their intense dislike of our original title (Mortality After Critical Care: MACC). 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 on the issue.

The importance of involving patients and the public in research

It can be hard to efficiently explain the reason and purpose, and often the methodology, behind research projects. Having lay people involved ensures that explanations are clear, and this also helps to focus the aims, leading to better designed projects. Where patients will be asked to volunteer for projects, having the patient viewpoint at the outset can help to improve recruitment by better wording of information sheets and consent forms. Better recruitment rates = faster projects = economic benefits and quicker dissemination. Researchers can have a tendency to distil patients to data points. Having a ‘real person’ in the room can bring a sense of humanity to the research.

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

The hardest challenge for us has been finding people for individual projects. Currently it seems to be a requirement to establish a PPI group for every project, and that there are some very specific expectations. Where multiple projects run within the same research group this is hard to achieve. There seems to be a limited cohort of ‘professional patients’ within the ex-ICU patient community and they are at the point where they cannot take on more responsibilities. An acknowledgement from funding bodies that there could be alternative methods of introducing PPI into research projects would be helpful.