

Establishing a Patient and Public Involvement (PPI) Group in ICU Research

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What is Patient and Public Involvement?

The NIHR (2018) define Patient and Public Involvement (PPI) as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”. Recruiting patients to research does not constitute PPI but collaborating with them in a meaningful way throughout the research process and considering patients and members of the public integral members of the research team ensures effective PPI. Furthermore, PPI has gained global attention with evidence of PPI now a prerequisite for securing funding and gaining favorable ethical approval (NIHR, 2018). PPI provides a unique perspective on research, using personal insights and experiential knowledge (NIHR, 2018). The expertise of PPI representatives improves the quality of research, through strengthening the research design and enhancing its relevance (Bench et al., 2017).

Aim: to formally establish a PPI group within the Edinburgh Critical Care Research Group

Launch Event

The Edinburgh Critical Care Research Group (ECCRG) held a ‘launch event’ in June 2018 to bring together researchers, former ICU patients and family members. This event acted as a forum whereby the future direction of patient and public involvement could be discussed in an open manner.

- 13 previous ICU patients and one family member attended; each with varying levels of PPI experience
- 12 healthcare professionals and researchers attached to the ECCRG attended
- Patients and family members were identified through ‘ICU Steps’ (a patient and family support group) (ICU Steps Edinburgh, 2018) and patients who had previously been involved in PPI activities were invited to attend
- The event began with presentations from a researcher experienced in PPI, a researcher whose aim was to include PPI in a future project and a patient with extensive experience of PPI
- The second half of the launch event involved round table discussions. There were 3 groups, each had a chair (one patient and two researchers acted as chair)
- Notes were taken throughout the discussions
- Refreshments were provided with breaks at regular intervals
- Travel expenses were offered to all patients and family members

“Personally, I am here to give something back for all the care I received whilst in ICU.. don’t use the bursary to pay for our travels costs, use it to arrange more face-to-face meetings so that we can help shape the future of research” -Former ICU patient

Challenges



Practical
 Organising a time, date and venue that was suitable for patients and family members as well as researchers who have clinical responsibilities required advanced planning and thought. The event was held in the evening to accommodate this. We chose a seminar room in the hospital as it incurred no additional cost, had good transport links and parking making it accessible for everyone. There was a cost associated with organising this event. The ECCRG had been awarded a bursary of £500 to aid in integrating PPI into the research group and without this bursary this event would not have been possible.

Time
 In conjunction with a full-time job as a Clinical Research Nurse we needed to allocate time to organising this event. Working as part of a team of Clinical Research Nurses made this possible.

Psychological Impact
 Having been patients in ICU there was the potential for patients to ‘relive’ their experiences during the round table discussions. It is essential to be aware of what stage patients are at in their recovery. Some patients were still ‘coming to terms’ with their experience. Attendance at ICU steps was advocated to patients requiring support.

Managing Expectations
 It was necessary to delineated the purpose of PPI for both the patients and researchers. With a shift towards making PPI an essential criterion for obtaining funding, researchers need to avoid considering it a ‘tick box’ exercise but ensure meaningful involvement. Educating patients on the research process is necessary so patients do not expect instant change.

Lack of formal guidance
 Throughout the literature there is minimal guidance on how to conduct PPI activities. In 2018 the NIHR published standards for PPI which were pivotal as a benchmark in ensuring this event was effective and meaningful.

Outcomes

Two patients became **co-applicants** on grants

Lay summaries reviewed

Face-to-face meetings were patients have influenced:

- primary outcome setting
- reviewed study paperwork
- protocol design

One participant has since sat on an **ethics review panel**

Collaboration with other PPI leads

- Shared experiences and expertise
- Training event was organised

Formal sign-up sheet

- Database of patient contact details
- ‘Opt-in’ to varying levels of involvement

Empowerment

“Being involved in PPI makes me feel empowered..something I lost during my illness”

-New PPI member and former ICU patient

Building relationships

“This event was the perfect opportunity to meet patients and start to work alongside them”

-Researcher

Reflections

- The NIHR has promoted strategic and infrastructure change so researchers can incorporate PPI into research activities. Conversely, PPI activities begin prior to grants being awarded leaving a cost deficit in the pre grant stage of the research process. Without our locally awarded bursary this launch event and subsequent PPI activities would not have been possible. Funding for future PPI events needs to be secured and the infrastructure to enable PPI developed.
- The group of patients attending the PPI event commonly had time to invest, were highly motivated and not afraid to ‘speak up’. In accordance with the PPI standards (NIHR, 2018) a wider group of patients need to be engaged
- Feedback was sought from patients and researchers and in the absence of guidance on how to measure the impact of PPI and more specifically the launch event, future PPI activities and patient empowerment were thought to be indicators of success.
- The event generated interest in PPI and to prevent patients becoming overburdened with PPI requests the research nurse took on the role of ‘gatekeeper’. This also allowed for more meaningful involvement.

References

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