

ISICEM15: Setting Research Priorities with Community Involvement



Setting priorities for healthcare research involves a number of stakeholders, including patients and the public. Involving intensive care patients and families can be hard, but it can be done, and this was the theme of a talk by Stephen Brett (London, UK), speaking at the Intensive Care and Emergency Medicine Symposium in Brussels this week.

In the UK the James Lind Alliance (named after the doctor who discovered how to treat scurvy), brings patients, carers and clinicians together in research Priority Setting Partnerships (PSPs).

They set out to [determine priorities for research in patient care](#).

Brett explained this process was undertaken as it had several benefits, namely opportunities for:

- clinical staff who do not usually set the research agenda to have their say;
- find out what patients and relatives feel is important, especially as they have not been involved before;
- raising the profile of ICU research;
- influence research strategy and funding by a transparent and fair process.

Brett noted that this project is likely to determine the calls for grants from the National Institute for Health Research and the Intensive Care Foundation.

Using surveys they collected ideas (1200 suggestions in total, from 484 participants with experience of intensive care units), which were then ranked by more than 500 respondents in order of importance, and aimed to determine the most important suggestions for research to improve intensive care. They then agreed the 'top 10' priorities for intensive care research through democratic discussion and ranking. It was not only about supporting personal interests or discarding important research topics. It was to priorities the most important uncertainties through consensus between patients, families and clinical staff. The results have been published in the Journal of the Intensive Care Society ([Reay et al. 2014](#)).

The top three priorities were:

1. How can patients who may benefit from intensive care be identified early and admitted to the ICU at the right time?
2. How can patients and their families be best supported as they start living at home (e.g. health and social care services, ICU support groups, long term follow up)
3. What is the best way to identify patients with, or at risk of, delirium or agitation - how should the immediate and long term effects of delirium or agitation be monitored and managed?

The Enhancing Recovery after Critical Illness Programme's Patient and Carer Advisory Board has come up with several ideas:

- Rehabilitation must start in critical care
- Move to a normal ward is challenging and there are fracture points
- Plans should be individualised
- All elements should be available 7 days and everywhere
- Recovery has no discrete end
- Social structure and motivation are important
- Determine the population - how to engage people for benefit, how not to demotivate those whose recovery might be limited
- Information forms part of this and is often poor, both to patients and to receiving staff

Patient suggested outcomes are:

- Physical recovery
- Emotional assessment, concentration span and psychological recovery
- Motivational level (and collaboration and buddy system)
- Social structure assessment for each patient

- Individualised Quality of Life reporting for each patient
- Time on ventilator as metric of “ICU exposure”

Brett concluded that community involvement is not easy, but it is essential. It challenges your skills as a communicator, is suprisingly expensive. There are some very hard to reach groups as well as “too easy” groups that might have their particular hobby horses.

Brett concluded that it cannot be the only way of prioritising research otherwise you miss translational research. However, it is important to involve the community.

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