

---

## Volume 16 - Issue 1, 2016 - Management Matters

### Don't Forget to Ask! The Patient and Relative Perspective



**Catherine White**

\*\*\*\*\*@\*\*\*icusteps.org

Information Manager - ICUsteps  
Warwick, UK

---

*There has been good progress in the last decade to ensure that the patient voice is heard at all levels, including in research and service planning. However there is still more to be done, and this article sets out the case for meaningful intensive care patient and relative involvement and how this can be achieved.*

#### Why Involve Former Intensive Care Patients and Relatives?

The short answer is because we have a perspective that no amount of training or clinical experience can provide. We know what it is like to have intensive care treatment and the profound effect that it has. Any strategic or research project that does not involve patients and relatives will be lacking this depth of understanding, and will be poorer for it. Healthcare professionals can have a good awareness of what patients and relatives go through, and this is especially so if they have spent time talking to both about their experiences, but only from being there can you truly know what it means to be critically ill. And all initiatives, whether research or strategic planning, are about improving intensive care treatment, so how can former patients and relatives not be asked to contribute towards this?

The many unique elements to being critically ill mean it is not comparable to any other type of illness or hospital stay. If you require emergency ICU admission, you have no time to prepare or understand what will happen to you. You often cannot engage in your treatment or discuss with the medical staff what is required and why. Additionally, a complete inability to make sense of your surroundings can cause you profound distress. Critically ill patients can experience:

- Partial awareness when under light sedation;
- Delirium;
- Paranoia;
- Confusion, disorientation and an inability to retain information;
- Inability to communicate;
- Alien environment;
- Lack of real sleep.

Patients often cannot understand and process what is happening to them at the time, and this leaves a legacy of psychological distress, which needs support and rehabilitation afterwards to enable them to come to terms with it.

Relatives' experience of critical illness is different than that of the patients, but it is also deeply distressing. They feel powerless to help their family member, not knowing if they will even survive. This is combined with a desperate worry about what is going to happen in the future, and uncertainty over the care that the patient may need once discharged. For many families, critical illness brings significant changes, which may be permanent; the psychological and physical after effects may mean that the patient is unable to return to normal activities, including their work, and there is an increased care burden placed on family members. Both patients and relatives need significant support and information to help them with their recovery and to understand what has happened. Sadly, in the UK this support is often not provided.

It was the recognition of this need that inspired the founding of [ICUsteps](http://www.icusteps.org), the UK patient and relative intensive care support charity. Mo Peskett, a Senior Sister at Milton Keynes General Hospital, was responsible for the hospital's follow-up clinic and saw first-hand the after effects of intensive care treatment. In 2005 she and Peter Gibb, a former ICU patient, set up the first support group for intensive care patients and relatives in Milton Keynes. The idea was to provide patients and relatives with a place to come where people truly understood, sharing 'empathy, not sympathy', where those further along the journey of recovery could support those just beginning it. It is hard to overstate just what this means to patients and relatives in their early recovery, hearing from others who have been there and had similar experiences, learning about what helped them and that recovery after critical illness is possible.

Since that small beginning, it has been quite an extraordinary journey. We now have over twenty affiliated support groups across the country. We provide high quality information for patients and relatives, and since our information booklet [Intensive Care: a guide for patients and relatives](#) was first printed in 2008, we have distributed 150,000 copies to UK hospitals. It is also available in sixteen languages on our website, and we have received requests from numerous countries around the world for permission to adapt it for their use. In 2013 we held our first conference, attended by over two hundred healthcare professionals and last year our website had 21,000 visitors. We are proud of our achievements, not least because we have no paid staff; our charity is run entirely by patient, relative and healthcare professional volunteers.

Although the scope of our work has changed over the last ten years, our aims have stayed true to our original principles, which are to:

- support patients and relatives affected by critical illness;
- promote recognition of the physical and psychological consequences of critical illness through education of the medical profession and the general public; and
- encourage research into treatment and the prevention of these issues.

The secret of our success is not only that we identified an unmet need, but also because our work is a true partnership between patients and relatives and critical care healthcare professionals. As patients and relatives, we have immeasurable respect for intensive care staff and their skill and dedication that saved our lives. We also know that our personal experiences provide a unique perspective to strategic work to improve the care and treatment for future patients. As an ICU patient, you have no voice (you are often unable to communicate and are confused), so many patients are therefore unable to contribute to their care and express their wishes while in intensive care. This is why it is so vital that the voices of former patients and relatives are heard at all levels to help fill this gap.

### **How Can You Involve Patients and Relatives?**

There are many ways to do this, but there is a caveat to be added first. Not all patients and relatives want to, or are able to contribute after their critical illness. Especially in early recovery, many are deeply distressed, and may want to cope by not thinking about their critical illness. Even many years later, they may feel unable to participate in projects that revive such distressing memories. Some patients also suffer cognitive impairment from their illness, and find it hard to read and process complex information.

Despite these difficulties, some who have survived critical illness want to put their experiences to good use to try and help those yet to become critically ill. It is therefore important that the opportunities to contribute are provided, but there must be no compulsion to help. Additionally, patients and relatives have different skills depending on their previous experiences, and not all will be interested or will be able to participate at a strategic level, so it is important that different levels of involvement are offered, and that training and support is available to enable participation. Below are some ideas about the ways that patients and relatives could be involved:

#### **• Local feedback: Ask about quality of treatment provided in individual units**

Provide the opportunity for patients and relatives to feed back to the intensive care unit about their treatment and the care they received. Many hospitals do not do this, and it means intensive care professionals miss the opportunity of dialogue and improving care for future patients. Unlike other types of hospital treatment, ICU patients and relatives are often unable to discuss their experience while they are in the critical care unit, and both may need time to reflect and understand what happened to them, so a mechanism for contacting them afterwards is required. This could happen via the critical care follow-up service, or by a paper or telephone survey. Not all patients and relatives will want to engage in this way, but it is vital that they are offered the opportunity to do so.

#### **• Patient and relative talks**

These are a very powerful training tool for healthcare professionals. Asking patients and relatives to talk about their experiences can significantly increase staff understanding about how best to care for intensive care patients as well as improve awareness of the legacy and impact of critical illness.

#### **• Strategic participation in service planning**

The UK has made good progress in the last ten years in improving the engagement of patients and relatives, and there are areas of good practice. For example the National Institute for Health and Care Excellence (NICE) has two patient representatives for the development of all clinical guidelines, and the National Institute for Health Research (NIHR) has two lay members on its research funding boards. Patient and relative trustees from ICUsteps have been involved with the development of three NICE Clinical Guidelines (National Institute for Health and Care Excellence 2007; 2009; 2016), the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) investigation into sepsis, Just Say Sepsis (Goodwin et al. 2015), and the executive board of the National Outreach Forum; National Health Service (NHS) England (through the Critical Care Clinical Reference Group), the patient and relative group of the Intensive Care Society and the Critical Care Leadership Forum. We have also commented on numerous documents, including the Guidelines for the Provision of Intensive Care Services (GPICS) (Faculty of Intensive Care Medicine and Intensive Care Society 2015) and the National Competency Framework for Adult Critical Care Nurses (Critical Care Network-National Nurse Leads 2015). Involving patients and relatives at this level of strategic planning brings a new perspective to the process, but also ensures that the end result will be relevant for future patients.

#### **• Research Management**

It is now acknowledged that engaging former ICU patients and relatives in research is extremely valuable. Only in that way can we be sure that the research is both acceptable and relevant to the end user and worth the considerable investment of time and money. Again, there has been good progress in the UK with one of the main funders, the National Institute of Health Research, recognising and encouraging public and patient involvement. However, there can still be a tendency for some researchers to make this a 'tick box' exercise rather than a meaningful one. Yet involving patients and relatives as part of the research team brings significant benefits to good quality research.

They ensure that:

- the research question has meaning for intensive care patients/relatives;
- the outcomes tested are relevant;
- the research team is sensitive to areas that may cause participants on the trial distress, and can work towards ways to mitigate these;
- that the researchers know the reality of ICU treatment for patients and relatives and can shape their study accordingly;
- a different perspective is brought to the project.

There are various points that may be helpful when thinking about engaging patients and relatives in research. Many of these are also relevant for effective patient and relative participation in areas other than research too:

#### **1) Start Early**

Meaningful public and patient involvement (PPI) does not come from making a token gesture just before the funding application is due in. Researchers need to engage with patients and relatives as soon as they have the idea of the research topic — well before the application is written. This ensures that PPI input makes a difference and shapes the proposal.

#### **2) Provide Funding**

© For personal and private use only. Reproduction must be permitted by the copyright holder. Email to [copyright@mindbyte.eu](mailto:copyright@mindbyte.eu).

Allow money in the budget for the time given by patients and relatives, as well as travel and subsistence expenses. PPI representatives should not be expected to contribute their time voluntarily, because this discriminates against those who cannot afford to do so. Participating can mean loss of earnings, or having to pay for childcare or for other types of care, and therefore a contribution should be paid for their time.

### 3) Provide Training and Development

Offer training and development opportunities to ensure that patients and relatives can fully participate. Medical research is an unknown world to many members of the public. The jargon can be off-putting and the processes unclear. Training can demystify research, as well as help patient representatives to fully participate and benefit from their involvement. This does not have to be on a formal training course, but can be from a member of the research team who is responsible for support and mentoring.

### 4) Enable Participation

Patients and relatives have different backgrounds and experiences. Some may find it daunting to participate in focus groups or research board meetings. It is vital that the chairperson is sensitive to these issues, that they ensure that medical jargon/abbreviations are not used during the meeting, that the lay members feel comfortable, and that they give plenty of opportunity for questions to be asked.

### 5) Be Sensitive to How PPI Members May Feel

Former ICU patients and relatives may find it difficult to discuss some aspects of intensive care treatment as it may bring back distressing memories.

There are also other ways for patients and relatives to be involved with research. In the UK the James Lind Alliance ([jla.nihr.ac.uk](http://jla.nihr.ac.uk)) helps Priority Setting Partnerships work with patients, carers and health professionals to identify gaps in evidence and agree jointly on the priority topics for research. They are also facilitating this process in other countries such as the Netherlands and Canada. An Intensive Care Priority Setting Partnership has recently been completed, which has produced the top ten areas for research, details of which can be found at [jla.nihr.ac.uk/priority-setting-partnerships/intensive-care-top-ten](http://jla.nihr.ac.uk/priority-setting-partnerships/intensive-care-top-ten).

There are numerous common themes amongst the experiences of intensive care patients and relatives, but there are many individual experiences too, some of which will not necessarily be representative of standard practice. This is why it is important that patient involvement is not tokenistic and that having one representative does not presume coverage of all issues. It is important to engage as many patients and relatives as possible.

#### So how can you access patient and relative help?

- Find out what PPI groups are already established in your local area – universities and hospitals may have patient and relative groups that can help.
- If your hospital provides ICU follow-up support, the lead nurse may know of patients and relatives who might like to be involved.
- Consider forming a long-term PPI intensive care research group, in collaboration with other researchers, which meets to discuss new projects and asks for feedback. Requests for new members could be advertised on hospital noticeboards.
- Engage with charities and special interest health groups.

### Conclusion

Patient and relative involvement in many areas of healthcare has made significant progress in the last decade, but there is still more to be done. There are examples of good practice, but it is now time for meaningful involvement to be the norm, not the exception. Good quality patient and public involvement takes time, especially to ensure that their participation is enabled, but it will pay dividends in ensuring that research and strategic planning will make a real and lasting difference to future intensive care patients. Patients and relatives can make a significant contribution, but don't take my word for it – ask them!

**Catherine White** is a former intensive care patient and is a Trustee and Information Manager for [ICUsteps](http://ICUsteps.org), a UK charity.

### Further Information

- For more information about the work of ICUsteps, visit [icusteps.org](http://icusteps.org)
- For information about what patients and relatives experience during ICU treatment, and ways to help, see: White C (2013) intensive care and rehabilitation — a patient's perspective. Journal of the Intensive Care Society, 14: 299-302.

Published on : Fri, 11 Mar 2016