**Editorial for Nursing in Critical Care**

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**Involving patients and families in critical care research and quality improvement**

Undertaking ethical research and innovation practice, which informs and enhances healthcare delivery, is a priority for me as a clinical-academic nurse and for all healthcare staff. I hope that sharing my reflections in this editorial on the growing practice of public involvement in the field of critical care will contribute to a critical consideration of its use and a curiosity that leads to high quality, safe and effective practice.

Public involvement is defined as when research is “*carried out with or by members of the public rather than to, about or for them*” (INVOLVE, 2012). In practice this means researchers and/or healthcare staff working with lay people to design and/or to carry out research. INVOLVE, the National Institute of Health Research (NIHR) funded national advisory group for public involvement in England use the term public to mean patients, service users, survivors, carers and family members (NIHR, 2018). Within critical care, the public specifically refers to patients (and their carers/family members) who have experienced a critical illness. Although related, public involvement is a different concept from public engagement, which focuses on the active sharing of knowledge with the public, and from research participation, where people are involved in research as subjects (INVOLVE, 2012).

Public involvement is applicable to both research and quality improvement (QI). The term ‘experts by experience’ describes the input of the public in reviewing health and social care and related improvement activities (CQC, 2018). Many critical care units now have a patient and family group guiding local improvement work. In addition, the use of experienced based co-design or other methods of coproduction are recommended as ways of enabling patient representatives, clinicians and researchers to work together to identify and implement practice improvements and/or to carry out research (Locock et al., 2014; Staniszewska et al., 2018a). Outside of specific projects, critical care patient representatives also sit on or chair committees and/or stakeholder events, run critical care support groups and/or undertake volunteer work in local units (Bench et al. 2018b).

The involvement of the public in the design and delivery of research is now commonplace in the United Kingdom (UK) (Staniszewska et al., 2017); indeed, large scale funding for research is unlikely without a clear explanation of how members of the public contributed to its development and how they will be involved throughout the project. However, outside of the UK, public involvement is less well developed (Pearson et al., 2013; Staniszewska, 2018b). A stakeholder event I co-hosted highlighted this, with non-UK researchers noting the additional value of public involvement they observed over and above the extensive reviews of the literature already undertaken to inform the proposal. Within critical care, the guidelines for the provision of intensive care services (FICM, 2018) actively support and encourage involvement activities and I have personally experienced the benefits of involvement during my own PhD and post-doctoral work. I have witnessed the contribution that former patients and their family members can make to shaping research according to user needs (Bench et al., 2012). For example, I amended the timing of my data collection and the number of questionnaires after listening to people’s views about how they felt immediately post discharge from the intensive care unit. I have also listened to people talking about the therapeutic benefits, such as reduced feelings of social isolation and the improved psychological well-being that can come from sharing experiences during project involvement.

Despite the perceived benefits, as healthcare researchers and practitioners we have a moral obligation to question whether we should be dedicating so much resource to a practice, which can be viewed as tokenistic and which, to date has a limited evidence base of its impact. Whilst my own research work highlights people’s desire to give something back (Bench et al., 2018b), we need to question the need for public involvement for every project and debate how best to utilise people’s experiences in a way that maximises benefit whilst limiting potential risks to the individuals involved. We also need to consider the potential for patient representatives to become ‘professionalised’ and the impact of this, particularly where people take part in many different studies over an extended period (Bench et al., 2018b).

The effect of involvement on the health of critical illness survivors and their family members also remains unclear. Although involvement can help people to positively reflect on their own experiences, a process which can be therapeutic, it also has the potential to negatively affect people’s psychological well-being, due to the need to relive traumatic emotional experiences (Bench et al., 2018b). Moreover, the impact on service delivery and health outcomes within critical care remains largely unknown, with most publications reporting research and/or QI lacking detail about their methods of involvement (Bench et al., 2018a).

What can we learn from work conducted in other healthcare settings? A growing body of evidence suggests that public involvement has a positive impact on the design and delivery of research (for example, Boote et al., 2015; Brett et al., 2014; Evans et al., 2015; Mockford et al., 2012; Staniszewska et al., 2018a). However, a review of the barriers and enablers to progressing public involvement published by Staniszewska et al. (2018a) identified problems related to attitudes, resources, infrastructure, training, support and leadership. The use of medical jargon and technical language, which is not understood by everyone also inhibits effective involvement (Bench et al., 2018; Pearson et al., 2013). To address some of these issues, based on findings from a narrative review of the literature, Gradinger et al. (2015) recommend that research teams should articulate the values they attach to public involvement and consider how to optimise benefits for the researchers, the ‘experts by experience’ and the research.

My own research focused on critical care patients’ and family members’ views also suggests that both practitioners and researchers still have some way to go to get things right. Interviews with patient representatives across England (Bench et al., 2018b) highlight the challenges faced by survivors and their family members in relation to involvement activities. Challenges include those related to people’s physical health status, such as weakness, fatigue and limited mobility. These are common problems after a critical illness (NICE, 2009), which impact on the ability to travel to meetings or other events and to complete the necessary tasks. My research emphasises the vital role of project leads in making people feel valued and equal partners in the process. In addition, it highlights the need to enable and support people to make informed choices at a time when they are ready to do so and the importance of gatekeepers, to avoid vulnerable people contributing before they are ready, a practice, which could negatively affect their health status (Bench et al., 2018b).

Public involvement in critical care continues to engage a minority of survivors, of a particular demographic (Bench et al., 2018b). This is also evident in other population groups (Staniszewska et al., 2018a). We need further investigation around how best to involve for example, those with disabilities that affect their ability to communicate or bereaved families, and the best time to invite people to become involved. Furthermore, although there are examples of people undertaking wider activities (such as collecting data and co-authoring publications), people’s involvement both in critical care and more widely is generally limited to advising on project aims and methods and reviewing documents (Bench et al., 2018b).

Improvement science is all about investigating the best and most appropriate methods through which to ensure the quality and safety of health services and exploring factors that can encourage or impede improvement. Identifying the best methods by which to involve critical illness survivors is an important research priority in itself (Bench et al., 2018a; Menzies et al., 2016). In March 2018, the NIHR published the first set of UK national standards for public involvement. Six generic standards focus on inclusivity, working together, support and learning, communications, impact and governance (NIHR 2018). Guidance for reporting involvement generally is also available (Staniszewska et al., 2017). Whilst these publications are applicable to all areas of practice, it is imperative that they are used in way that addresses the particular needs of people with previous experience of critical illness.

So, what does this mean for critical care research, practice and quality of care? Should we advocate public involvement in critical care? Based on current literature and my own experience, my answer would be a resounding yes. However, it is important that we use an ethical, equitable, flexible and supportive approach, which enables people to contribute in different ways, depending on their circumstances (Bench et al., 2018b; Denegri, 2015; Pearson et al., 2013). Although challenging, we should strive to achieve broader representation from all sectors of our community. We must also develop an infrastructure, which enables us to mitigate the potential risks of involvement, both for the individuals and for the projects on which people are working. For example, while INVOLVE and the English Health Research Authority acknowledge that public involvement helps to produce more ‘*ethically acceptable’* research, guidance on the ethical conduct of public involvement at the research design stage is lacking (Pandya-Wood et al. 2017).

Both within and outside of the UK, as critical care academics and practitioners, it is our responsibility to consider how best we can apply and build upon the national standards for public involvement (NIHR, 2018) in our patient group, both in research and quality improvement. We must also consider how we align our public involvement priorities with those of clinical practice, the budget and efficiency. To date, several issues remain unresolved, potentially leading to patient safety concerns. As advocates for our patients and their families, nurses, along with the wider healthcare profession, have a responsibility to ensure that public involvement in our work offers benefit for all those involved and that, as noted by Staniszewska et al. (2018a), it is underpinned by a robust evidence base.

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