Patient and carer involvement in healthcare education, service delivery and research: avoiding tokenism

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We are delighted to have been invited to write this editorial on patient and carer involvement in health education, service delivery and research. Within developed countries, the involvement of patients and carers has become central to healthcare delivery. Health services, research and education policy directives, particularly with the UK, are explicit that patient and carer input is an integral part of healthcare. Input ranges from service design and delivery, across the research processes to the development, delivery and evaluation of programs of study offered to healthcare students. The overarching aim is to ensure healthcare delivery, research and the preparation of health professionals is more responsive to the needs of the patient and their carers. Valuing and listening to patients and carers is central to the quality agenda, including ensuring care is patient and family-centred, and there is appropriate use of resources that meets patient needs.

The potential benefit of patient and carer involvement in healthcare education, service delivery and research include an opportunity to influence the healthcare agenda from service developments to identifying research priorities, becoming empowering to influence change and having greater ownership of services. In relation to healthcare delivery, a move away from a paternalistic to more inclusive approach is essential as patients, and carers as appropriate, increasingly take responsibility for, and share in decisions about care interventions, particularly in the context of long-term conditions.

Although patient and carer involvement is central to the success of healthcare delivery, research and preparation of health professionals, concerns particularly in relation to research that their involvement can be tokenistic have been highlighted. While the origins were about the inherent power struggles within society, and who holds the power when important decisions are being made, Arnstein’s ladder of involvement remains of value when considering participating. Application of Arnstein’s ladder of involvement to healthcare is presented in figure 1.

Who are patients and carers? Individuals who use or are involved with all aspects of health and social care and can play an important role in shaping the way healthcare is delivered, research is undertaken and healthcare professionals are prepared for practice. Patients and carers do this by using their ‘lived experiences’ derived from numerous situations and circumstances. A patient or carers’ observation of a situation can enable them to reflect on and share the facts and events of that experience, including the practical, clinical and physical aspects of care, which can trigger a variety of emotions in relation to the experience. The reality of an experience from the patient or carers perspective can be a powerful resource in improving the quality of a service.

Figure 1: Dimension of quality care.

Involvement and collaboration occurs when professionals work together with the lived experience bringing another perspective to the research, and service development or education of health professionals. This frame of reference includes opinions, suggestions, views and ideas on all aspects of the subject in question. The lived experience generates an abundant and diverse range of examples in healthcare that can, coupled with research, develop and improve new and existing areas of care and procedures.

Participation acts as a catalyst for further development and may also include talking to students in the university or in their own home. Participation can involve handling prototypes of a new health resource that the professionals need objective views on such as the weight and feel of materials and any perceived barriers that a person may have in being able to use the equipment. Engagement and interaction between professional and patient and carers is a mutually rewarding experience. From a patient and carers perspective sharing experiences with professionals is an extremely vital, enjoyable and rewarding part of participating and offers patient and carers a sense of satisfaction that their input can improve healthcare for all. Understanding the experiences of patients and carers provides professionals with a deeper understanding of the impact of services and the way care is delivered for the patient and can improve patient-centred care and patient outcomes. Similarly, engaging patient and carers in setting research agendas and the conduct of research will ensure research is relevant to their needs.

There are challenges for patient and carers sharing their lived experiences with professionals. In Annie’s role as visiting lecturer working with students and
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Figure 2  Examples of involvement and engagement.

contributing to the research agenda and participating in research, it is important to ensure every contact counts; tokenism can be a barrier and to a certain degree been reduced by the Carers Rights Act, The Act into force in 2014 with an expectation that patients and carers are at the centre of future healthcare plans and care delivery. Working as a patient and carer generates useful and constructive questions, discussions and debates with health professionals, educators and researchers, which are all part of student learning outcomes along with finding solutions to health-related issues. Involvement in whatever capacity, the experience for patients, carers and professionals should be meaningful to all parties. In addition, expectations for all parties should be clear and concise. Trust and confidentiality are imperative especially if a patient or carer is talking about a very personal, sensitive and emotional issue. This does not have to be a challenge providing both parties are aware that the interaction can stop if it is too uncomfortable or distressing to continue. Student nurses and social workers, for example, report that hearing the lived experiences has given them a deeper insight into the person’s life and the barriers they face. Challenges for patients and carers taking part in projects are many, mainly in terms of the practicalities of being able to attend when a patient is not well enough, along with times and dates that are difficult to arrange around caring responsibilities. Finally, Annie’s personal lived experiences of 40 years has contributed to her being an invaluable part of the education of health professionals and knowing she is part of the successful preparation of future professionals in healthcare. She his hopeful that students will take with them the very poignant messages of the patients and carers stories into their future career.

To conclude, the pinnacle of patient and care involvement in all aspects of healthcare, research and the preparation of health professional is achieving an outcome based on activities that are undertaken with the patient and carer as opposed to on the patient and carer. Professionals who include patients and carers in an educational setting should have policy, guidelines and procedures that are proactive in the way they engage and work with the public.

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