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Editorial for Evidence Based Nursing March 2019

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

Authors: Joanna Smith[1], Annie Dransfield[2]

[1]Dr Joanna Smith, Associate Professor Child Nursing, School of Healthcare, University of Leeds, j.e.smith1@leeds.ac.uk

[2]Annie Dransfield, Carer and Retired Further Education Lecturer

Correspondence: Dr Joanna Smith

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 health care delivery. Health services, research and education policy directives, particularly with the United Kingdom (UK), are explicit that patient and carer input is an integral part of healthcare, from service design and delivery, across the research processes to the development, delivery and evaluation of programmes 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.[1] 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 (Figure 1).

Figure 1: Dimension of quality care[2]

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.[3] 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.[4]

Although patient and carer involvement is central to the success of healthcare delivery, research and preparation of healthcare professionals, concerns particularly in relation to research that their involvement can be tokenistic have been highlighted.[5] 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.[6] Application of Arnstein’s ladder of involvement to health care is presented in Figure 2.

Figure 2: Examples of Involvement & Engagement

Public Led Take the lead in decision making about the planning, delivery & evaluation of services Being a Principal Investigator of a research study Lead a service	**PATIENT/ CARER CONTROL**
Co-Production Delivering services in an equal & reciprocal relationship between professionals, people using services Being a co-investigator on a research study Co-plan, deliver & evaluate an activity such as peer patient support group	
Involvement Work that is carried out *with* or *by* members of the public rather than *to* or *about* them Contribute to educational curriculum planning meeting Contribute to service re-configuration planning meetings	**TOKENISM**
Engagement Public opinion & ideas are sought Participate in university public engagement / recruitment events Participate in service improvement project	
Participation People take part in an activity Attend opening of a new service Complete a questionnaire or participate in a focus group evaluating a service Research participant	**NON-PARTICIPATORY**

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 delivery, 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.

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, which can, coupled with research, develop and improve new and existing areas of healthcare 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 the materials it is made from or 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 there input can improve health care 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 patients-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.[7]

There are challenges for patient and carers sharing their lived experiences with professionals. In Annie's role as visiting lecturer working with students and 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 which came into force in 2014 and 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 being an invaluable part of the education of health professionals and knowing that she has been part of successful preparation of future professionals in healthcare, and that the 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.

References

[1]Hall A.E., Bryant J., Sanson- Fisher R.W., Fradgley E.A., Proietto A.M., Roos I. Consumer input into health care: Time for a new active and comprehensive model of consumer involvement Health Expect 2018; 21(4): 707-713.

[2]Institute of Medicine (IOM) Crossing the Quality Chasm. Crossing the Quality Chasm: A New Health System for the 21st Century. 2001; Washington D.C, National Academy Press.

[3]Crawford MJ, Rutter D, Manley C, et al. Systematic review of involving patients in the planning and development of health care. BMJ. 2002; 325 (7375): 1263.

[4]Smith J., Kendal, S. Parents' and health professionals' views of collaboration in the management of childhood long-term conditions. Journal of Pediatric Nursing, 2018; 43: 36-44.

[5]Esmail, L., Moore, E., & Rein, A. Evaluating patient and stakeholder engagement in research: moving from theory to practice. Journal of Comparative Effectiveness Research, 2015; 4; 133-145.

[6]Arnstein S.R. A Ladder of Citizen Participation. Journal of The American Institute of Planners, 1969; 35 (4); 216-224.

[7]Harrison J.D., Auerbach A.D., Anderson W., et al. Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities. Health Expect, 2019; 1-10.

Resources

Carer Act Fact Sheet:

https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets

Health Expectations is an open access international journal that focussed on public participation in healthcare and health policy:

https://onlinelibrary.wiley.com/journal/13697625

The National Health Service five year forward plan:

https://www.england.nhs.uk/publication/nhs-five-year-forward-view/

INVOLVE, the is a national advisory group that brings together expertise, insight and experience in the field of public involvement in research:

https://www.invo.org.uk

Picker Institute, is a not-for-profit organisation that makes patients' views count in healthcare, and helps health professionals understand, measure and improve patient experience and satisfaction in health and social care:

https://www.picker.org

James Lind Alliance, is a non-profit making initiative that brings patients, carers and clinicians together in priority setting partnerships to identify and prioritise unanswered questions that they agree are the most important to address:

http://www.jla.nihr.ac.uk