

Editorial

The importance of service users in healthcare quality and research: from involvement to emancipation

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Service user involvement has become a watchword of health research and quality improvement over the past few years. The introduction of systematic changes designed to encourage researchers to consider whether, how and to what extent service users should be involved in the design, conduct and dissemination of research has made this an essential consideration for investigators. Many funding bodies now require explicit statements about the level of involvement and include funded lay members on decision making groups and interview panels.

This has undoubtedly led to a sea-change in the quantity and quality of user involvement in improvement and research activity in the United Kingdom, supported by organisations such as INVOLVE, a national advisory group funded by the National Institute for Health Research (NIHR), which supports greater public involvement in NHS, public health and social care research (www.invo.org.uk/). Despite attempts to similarly embed better support for service users in health services, for example through Patient Advice and Liaison Services (PALS: www.pals.nhs.uk/) and Local Involvement Networks (LINKs: www.nhs.uk/NHSEngland/links/Pages/links-make-it-happen.aspx) formed by individuals and community groups working to improve health and social care services, systematised patient and service user input into maintaining and improving local services is sadly lacking.¹

Unfortunately, although there are many cases of excellent leadership, optimal clinical practice, good teamwork and exemplary care, there are also many instances of care that fall short of this. This is reflected in the very serious breakdown in quality of care experienced by patients in NHS facilities in some areas of the country and in some units within hospitals or other health service providers. Although this is epitomised by the stories recounted by patients experiencing lack of care at Mid Staffordshire,² other examples of

poor communication, uncaring attitudes, lack of organisation and failures of care are sadly commonplace.

A recent episode in a tertiary centre where I experienced first hand repeated admissions for procedures which were cancelled at the last moment, poor communication from doctors, nurses and administrative staff, apparent and expressed conflicts between staff members, failure to provide adequate analgesia, uncaring attitudes from some staff and poor processes suggests that poor care, rather than being episodic, is endemic in the health system.

The importance of systematically supporting and emancipating patient groups and movements in the pursuit of improving healthcare quality is the subject of a new book by Charlotte Williamson.³ Williamson's broad vision and clarity in developing her argument are a triumph. She makes sense of patient groups and the patient movement as a wider social movement engaged in radical activism which opposes the status quo of poor standards of care. The middle chapters of the book are concerned with the core values, principles and standards that lie at the heart of radical patient activism. The key value is autonomy and the 10 principles that are discussed in detail from the point of view of patients include respect, equity, access to information, safety, choice, shared decision making, support, representation and redress.

Rather than dismissing the uncertainties, shortcomings and challenges of the patient movement, Williamson explores these issues; she explains why patient representation is important, describes the developing knowledge base of the patient movement and focuses on its contribution to better services. In doing so she explains the basis for radicalisation and activism among patient groups and individuals, and enlightens the reader on where the movement is in conflict internally and where it finds its external support and opposition. The closing chapters are devoted to the

achievements and failures of the patient movement to date and finally look to future directions, challenges and the ultimate goal of improving healthcare.

If commissioners of research consider service user involvement as critical to its success then the commissioned systematic involvement of service users in the delivery and improvement of existing health services may be what is missing. Unless we make this happen, we will continue to bemoan the variations in care experienced by some patients and the reality of poor care for some in the NHS. In the meantime, for those interested in understanding how the patient movement is making a difference to health services, Williamson's book is a very readable and expert account of the subject.

REFERENCES

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