

Patient comment: shared decision making

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The notions of shared decision making (SDM) and support for self-management (SSM) seem completely right and unquestionable from a patient perspective. It is hard to argue against people having as much involvement as possible in making decisions about their own health, and in managing their own health. In an ideal world wouldn't we all wish to understand what is happening and what the options are when we are unwell?

On the grounds of ethical and moral clinical practice, as well as effectiveness, SDM and SSM make perfect sense. Logically, greater patient involvement, with patient and clinician working in partnership, would lead to greater mutual understanding, fewer misunderstandings and an inclination to work together to manage illness, promote health and achieve an optimum quality of life for the patient.

Many of us will know from our own life experiences and those of our loved ones that the extent to which patients are involved in decisions about their health seems to vary along a continuum between two extremes. I was fortunate to have been witness to an excellent example of SDM when I accompanied a patient to a meeting with a senior clinician. We sat alongside the consultant in his office. He shared with us a research paper about his management of patients with similar conditions; all of us were then involved in the discussion about treatment options available. At the other end of the spectrum, I have seen hospital doctors discussing a patient's condition around a hospital bedside without involving the patient, and even refusing to answer the patient's questions.

The Patients Association¹ analysed data from its national helpline, focus group research, listening events and surveys. Their report identified 'information and communication' as a crucial area and highlighted that there is a lack of openness and transparency that needs to be addressed. It concludes that:

Evidence from our Helpline indicates that our callers are finding that the systems and processes that are meant to work for them are getting in the way of the patients receiving patient-centred care. (Page 63)

This report entitled *Why our NHS should listen and be human; this is what the public are telling us* reveals that many patients did not feel they knew what options were available to them, nor what was happening to them. The findings suggest that people do want to be included in any decisions about their

care and wish to be kept informed about events affecting their health.

Dr Nick Lewis-Barned² highlights that while only about half of patients feel involved in healthcare decisions, a much higher proportion of healthcare professionals feel they involve patients in their care. This mismatch in perception is fascinating and hints at a disparity between the level and quantity of involvement sought by those people receiving healthcare and those giving healthcare. The article sets out in clear detail the three areas that need investment if SDM and SSM are to become the predominant reality. It makes apparent not only the enormity and complexity of this challenge, but also the very practical steps that need to be taken.

At a fundamental level of culture, 'ways of seeing' patients and health professionals and 'ways of being' with patients and health professionals need to be re-orientated. Beyond an explicit rationale this will require attitude changes on behalf of both patients and health professionals. Not all patients will automatically expect or want greater involvement, and of those who would like greater involvement, they may not have had the experience of 'being' like this, of working in partnership with health professionals. The same may be said of health professionals; the wish to work in a way that promotes greater patient involvement on its own is not sufficient to achieve this change.

Atul Gawande conveys eloquently his experiences of changing to an SDM approach and the qualitative difference this made to his patients. Through the use of powerful stories he illustrates how clinicians can, by asking 'vital' questions, trigger conversations that actually enable a patient-centred and partnership approach to making decisions.³

Lack of time might at first sight appear to be a barrier to the implementation of SDM, but this is probably more an expression of the way we are all used to things being organised and communicated. This valuable work on SDM and SSM shows how it is possible to promote greater patient involvement through the creation of an environment that actively supports the development of the necessary skills and attitudes of the key players at the level of the consultation, as well as at local and national levels.

Changing to a culture of greater patient involvement will require patients and health professionals to change. Preparation of people for SDM and SSM is crucial and the decision support tools and aids will undoubtedly be very helpful. Ultimately, the level of partnership working will be the result of a dynamic interaction between the patient, the health professional, and the surrounding policy and organisational context. The fact that

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the Royal College of Physicians and a growing number of health organisations are supporting greater patient involvement in SDM and SSM is to be applauded and is in itself a positive signal that this culture change is really starting to happen. ■

References

- 1 The Patients Association. *Why our NHS should listen and be human: This is what the Public are telling us*. Harrow: The Patients Association, 2015.

- 2 Lewis-Barned N. Shared decision making and support for self-management: a rationale for change. *Future Hospital Journal* 2016;3:117–120.
- 3 Gawande A. *Being Mortal. Illness, Medicine and What Matters in the End*. London: Wellcome Collection, 2014:100–1;234;259.

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