

# Choosing, deciding, or participating: what do patients want in primary care?

Choice is a concept of increasing importance in healthcare policy. While politicians, health professionals, and service managers argue about the advantages and disadvantages of choice in terms of quality of care, efficiency, and equity, the patient perspective has received less attention.<sup>1</sup> In this issue of the *BJGP*, Ogden and colleagues illuminate patient perceptions of choice using both qualitative and quantitative methods.<sup>2,3</sup>

Essentially, their quantitative research found that it was possible to distinguish attitudes towards 'having choice' from attitudes towards 'making choices', and that patients were more positive about the former than the latter.<sup>3</sup> Nearly two-thirds responded positively to questions about having a range of options in health care (for example, 'I like to know all the possible ways in which I could be treated'), whereas far fewer were positive about making choices about health care (for example, 'I prefer to make my own mind up about what treatment I will have').

As with any good research study, this study raises as many questions as it answers. Implicit in their approach is the idea that it is possible to measure general attitudes to choice. They found that attitudes to choice within and outside of health care loaded similarly in the factor analysis, which supports this approach to a degree. However, it is noteworthy that many responders answered 'not sure' to questions about 'making choices', which may have reflected the difficulties of responding to general items on choice without context.<sup>4</sup> Making a decision on whether or not to take antibiotics for a sore throat is different from deciding between chemotherapy and surgery for a malignant tumour. Similarly, making a choice between different providers of care (such as different hospitals or GPs) may be different from making decisions about treatment.<sup>1</sup>

Responders were limited to agreeing

that the patient should make the choice, or the doctor should make it on their behalf. This somewhat crude dichotomy ignores the option for shared decision making, which recent research by Cox *et al* has shown is the most popular model for both doctors and patients.<sup>5</sup>

The authors also conducted qualitative interviews with 22 participants and identified a number of themes related to choice.<sup>2</sup> There was agreement with the principle of choice, and concern about having choice removed, an issue which has been identified previously in relation to MMR.<sup>6</sup> Having choices available allowed expressions of patient autonomy and empowerment, and was not restricted to providing options, but included the right to query judgments, express preferences, and highlight non-medical factors that should be taken into account. However, making choices was seen as potentially problematic, as it could undermine the trust placed in the health professional.

We would argue that the gap between 'having choices' and 'making choices' is best filled by the notion of patient participation, which has been defined as:

*'... an interaction, or series of interactions ... in which the patient is active in providing information to aid diagnosis and problem-solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best meet his/her needs, preferences or priorities'.<sup>7</sup>*

This definition raises an important distinction between the concept of choice in current policy discourse, and the concepts of shared decision making and participation. Choice can be conceptualised as a decision between a range of predetermined options (such as between different healthcare providers, or

between different options for treatment), and is best viewed as an outcome. Decision making and participation are concerned with the collaboration between professional and patient required to develop that list of options, and are best conceptualised as a process.<sup>8</sup> Engaging patients effectively in that process avoids the problems of disempowerment and 'personal identity threat' that underlie patients' dissatisfaction with health care.<sup>9</sup>

Thinking in terms of participation avoids the false dichotomy of 'choice' versus 'no choice' and focuses attention on the middle ground of the interaction between patient and health professional. However, achieving success in that middle ground is not easy. Coulter's 2007 editorial in the *BJGP* outlined how not all patients wish to be involved to the same degree and how GPs are not very good in predicting what role patients want to play.<sup>5,10</sup> Patients actively participating in their care tend to be younger, female, educated, articulate patients of higher socioeconomic status, who may share the background and values of their healthcare providers.<sup>11</sup>

What are the barriers to effective participation? Some barriers reflect the particular context of health care. Acute or severe illness and the anxiety it engenders may make patients adopt a more passive role. Additionally, previous encounters with healthcare professionals may have resulted in a learned expectation of passivity, which may require active intervention to overcome.

Health literacy (that is, the cognitive and social skills that allow individuals to understand and use health information) may also be an issue. Research evidence has shown that doctors are more comfortable asking patients about their sexual behaviour, than whether or not they can read and write.<sup>12</sup> Low health literacy affects both understanding of the written word and the ability of patients to communicate about their illness and its

management. People with low health literacy may be least likely to make use of the opportunities afforded by policies aimed at increasing public participation in their health care.

Increasing participation in health care requires change at the level of the patients, the professional, and the healthcare system.<sup>13</sup> Training in shared decision making and participation is possible, but achieving change is difficult. A recent systematic review of intervention strategies designed to enhance patient participation in consultations found that the most commonly used interventions were patient-completed questionnaires eliciting information about health status or quality of life issues (such as pain scores). These 'patient reported outcome measures' are then returned directly to their healthcare professionals and were reported to have a 'substantive positive impact' on some processes of care (that is, communication between patient and healthcare provider and management).<sup>7</sup> However, their full potential in clinical practice remains unknown, as insufficient attention has been given to the mechanisms by which they work and their contribution to changing the nature of the relationship between patients and health professionals over time.<sup>14</sup>

Another important concept is clarification of values, an exercise intended to help patients to think about, and then communicate, the personal importance of different negative and positive features of 'options', to improve the match between what is personally most desirable and which option is actually selected. There are a number of ways in which values clarification has

been achieved. These include describing the features and likely outcomes of the options in sufficient detail to enable the patient to fully understand what is involved; describing how other patients' values led them to make certain choices; or explicitly measuring the patients' individual values for options. This process can be facilitated by decision aids and other interactive health communication applications.<sup>15</sup>

Research on the subject of choice indicates that it is important to patients and has a place as a marker of quality in primary care. However, it is important that we listen carefully to what patients are describing when they talk about 'wanting choice'. It seems likely that they are talking as much about the quality of the doctor-patient relationship and their experience of the process of care, as issues to do with access to a menu of different providers and treatments.

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