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# Power imbalance prevents shared decision making

Providing information is not enough to enable shared decision making, argue **Natalie Joseph-Williams and colleagues**. Action is required to change the attitudes of both patients and doctors

## KEY MESSAGES

Many patients currently feel they can't participate in shared decision making  
Power imbalances in the clinical encounter are a key barrier even if patients have the required knowledge  
Patients need to know that their input is valued and won't damage their care  
The attitudes of both patients and clinicians need to change to enable shared decision making

**A**doption of shared decision making into routine clinical settings has been slow.<sup>1</sup> Large scale implementation programmes in the UK have delivered valuable lessons on how best to embed shared decision making,<sup>2-5</sup> but few programmes have actually considered what helps or stops patients from being involved in healthcare decisions. Organisational and clinician perceived barriers are important,<sup>1 3 6</sup> but shared decision making is unlikely to become the norm if we do not also deal with the barriers that patients perceive. Our recent systematic review of patients' perceptions highlighted deeper rooted attitudes that need to be changed in order to prepare patients for a new type of clinical encounter.<sup>7</sup> Here we highlight the main findings and discuss how to prepare patients for shared decision making.

### Patients find it hard to speak up

There is good evidence that attitudinal barriers are hindering progress in implementing shared decision making.<sup>1 7</sup> Even when patients are well educated and well informed, many still find it difficult to use this knowledge to participate meaningfully in decisions about their healthcare.<sup>8</sup> The Francis report into failings at Mid Staffordshire trust revealed that patients often feel prohibited from speaking up, even when they are extremely concerned about safety or the quality of care they are receiving.<sup>9</sup> Online blogs, publications, and social media campaigns (such as #hellomynameis)<sup>10</sup> show that even doctors are not immune to the power imbalance when they become patients, feeling that they represent a disease rather than that they are an individual and aware of a pressure to be compliant and passive.<sup>10-12</sup> How then can we expect people to express their preferences about treatment options—especially when they often observe doctors assuming that they can act in their best interests, displaying unquestioned

confidence in being able to make the best decision on their behalf?

### Knowledge is not enough

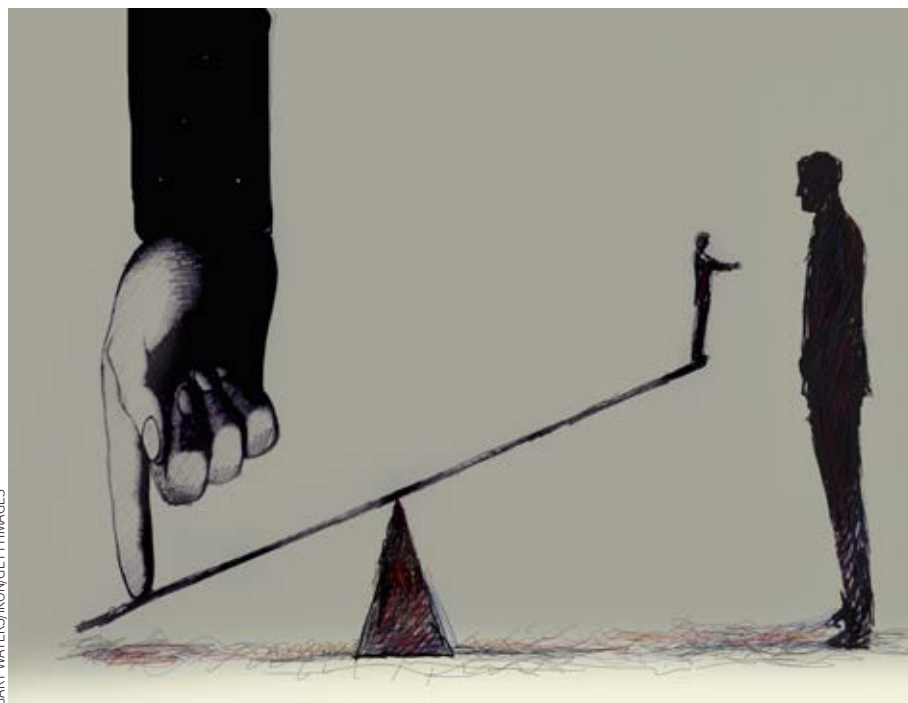
The 44 studies in our review of patient barriers suggest that many patients currently feel that they can't participate in shared decision making rather than that they don't want to, as many clinicians believe. Unsurprisingly, having information needs met in an appropriate way was a key facilitator for many patients. If patients do not know about their condition, and they do not know or understand their available options, they cannot take part in decision making. However, many patients also undervalue their abil-

### Power imbalances in the clinical encounter are a key barrier even if patients have the required knowledge

ity to understand the information given to them and underplay their knowledge gain relative to that of the clinician. Therefore, they tend to defer the decision to the expert who "owns" the knowledge.

Many patients also do not recognise the unique expertise that they bring to the clinical encounter—that is, knowledge about their personal preferences. Until patients believe that they are capable of understanding the information provided to them and believe that personal expertise and medical expertise are equally important, they are unlikely to become actively engaged.

Alongside this problem are the covert contracts that some patients develop with clinicians in which they feel compelled to adopt the role of a "good" patient. This role is characterised by passivity and compliance. Many



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patients believe that they cannot or should not be involved in decisions, often out of fear of annoying the clinician and the potential repercussions it might have, such as being labelled difficult or receiving less or lower quality care.<sup>8</sup> Such views and beliefs are long engrained in many patients, especially older people and those with lower educational attainments.

Fundamentally, knowledge provision, knowledge acquisition, and expectation to contribute personal preferences occur in the context of a power imbalance between the clinician and the patient. Therefore, a patient's capacity to participate seems to be linked not only to how much knowledge she has but also to how much power or influence she feels she has in the decision making encounter (that is, her perceived ability to use this knowledge).

### How to overcome passivity

Although great strides have been made to ensure that patients are informed about their treatment options,<sup>13-15</sup> patient passivity has been neglected; the focus has been on supporting the process if and when a patient becomes engaged, rather than working out how to engage patients. A shared decision making encounter is considerably different from the appointments that many patients are used to, and may even be comfortable with. We cannot expect patients to change their long established behaviours just because they are given an opportunity to participate in decision making. Both implementation researchers and healthcare systems have invested substantial efforts in trying to shift the attitudes of clinicians but have not invested the same efforts in preparing patients for these new types of social interaction.

Some researchers have, however, recognised the importance of preparing patients for a shared decision making clinical encounter, partly by changing attitudes towards participation.<sup>4 16-20</sup> There are relatively few evaluated interventions, and their use tends to be restricted to decision specific research settings (such as preparation for a cancer consultation), but they offer a platform for designing further interventions. The earliest example was developed in 1985 and aimed to alter the traditional patient role through decision coaching before the appointment.<sup>21</sup> Other coaching interventions have since been developed,<sup>18-20 22</sup> and most report some success at increasing patient engagement in trial settings (as measured by, for example, asking questions, seeking information, and taking an active role in decision making). However, decision coaching is both time and resource intensive—typically comprising a 20-45 minute session with a trained research nurse or counsellor before a clinical

appointment—and is unlikely to be sustained in already pressurised healthcare systems.

Other campaigns, such as Ask Share Know (<http://askshareknow.com.au>) and Ask 3 Questions (<http://personcentredcare.health.org.uk>),<sup>4</sup> try to increase participation by encouraging patients to ask: what are my treatment options, what are their benefits and harms, and how likely are they to happen to me? They use brochures and other media (videos, websites, etc) to explain why this is important. Although these campaigns show promise,<sup>3 23</sup> patients are often not aware of them until they are given leaflets in waiting rooms. This does not provide sufficient time for patients to change attitudes and beliefs, especially when they are so deeply entrenched.

### Better preparation

Another problem with current interventions aimed at patients is that they do not do enough to overcome two important barriers to participation—patients' perception that their knowledge is inferior to medical knowledge and desires to act like a good patient out of fear that they will receive worse care otherwise. Interventions aimed at changing long established behaviours are most likely to be effective if they are based on evidence from patients rather than what researchers or clinicians think is likely to work.<sup>24 25</sup> Early work suggests that interventions should be delivered in two stages: preparation, followed by enablement. Patients should be sent a preparation intervention, such as a booklet with an accompanying website link, with their appointment letter. In primary care the intervention could be posted to all registered patients. At a minimum it should

- Inform patients about shared decision making—what it is, what to expect, and why it is appropriate
- Explain that there are two experts in the clinical encounter— describe the different but complementary knowledge
- Challenge attitudes that there are right and wrong decisions
- Redefine perceptions of a good patient and reassure patients that participation will not result in retribution
- Promote social acceptability of this role—confirm that clinicians want patient participation
- Build patients' belief in their ability to take part.

Once the patient has made an informed decision to be involved, the focus moves on to enablement. This is helping patients to take

part in the shared decision making process by offering appropriate decision support tools<sup>13</sup> and question prompt lists (pre-populated or for self completion).<sup>22</sup> Importantly, the interventions need to be promoted from within the organisation—for example, by framing messages as “your local health board/doctors/nurses want(s) to know what is important to you”; this indicates to patients that the local

health organisation and the clinicians are giving them permission to participate.<sup>1 4</sup> Experts in shared learning recently remarked that skills training trumps tools for clinicians, and attitudes trump

skills. The same can be said for patients. This is why attitudinal change is important before we make attempts to support the decision making process.

Achieving shared decision making in routine practice will require interventions targeted at both clinicians and patients. We acknowledge that clinicians will not be able to change the experience of every patient, but we should try to make it easier and safer for them to feel included and respected.<sup>26</sup> Patients need to believe that they can and should be involved, and clinicians need to ensure that they make efforts to understand what matters most to patients.<sup>27</sup> Tackling structural and process barriers, such as time to do shared decision making and tools to do it, is important, but unless we address deep rooted “white coat silence”<sup>28</sup> through appropriate interventions, routine shared decision making in healthcare is unlikely to become a reality.

**Natalie Joseph-Williams** research associate

**Adrian Edwards** professor, Cardiff University, School of Medicine, Cochrane Institute of Primary Care and Public Health, Cardiff, UK

**Glyn Elwyn** professor and senior scientist, Dartmouth Center for Healthcare Delivery Science and the Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, NH, USA

Correspondence to: N Joseph-Williams [josephnj1@cf.ac.uk](mailto:josephnj1@cf.ac.uk)

**Contributors and sources:** This paper originated from discussion around the results of a systematic review of patient reported barriers and facilitators to shared decision making (Joseph-Williams et al, 2014). NJ-W is a research associate conducting patient centred care implementation research at Cardiff University. AE is professor of general practice with research and teaching interests in healthcare communication and quality improvement. GE is a physician-researcher and professor and senior scientist at the Dartmouth Health Care Delivery Science Center and the Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth College, USA. NJ-W drafted the manuscript, and all authors worked collaboratively to contribute to the content, and to edit and agree the final version.

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