With the growing trend towards involving patients in clinical decision-making, one trust has been looking at how to make this approach part of routine practice.

Enabling patients to share decisions about their care

This article...

- What shared decision-making means
- Barriers to shared decision-making
- Tools available to support this approach

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Health professionals are increasingly expected to ensure patients are actively involved in making decisions about their care, sharing the responsibility with them. This article explains what shared decision-making is, why health professionals should increase patients' involvement in decisions about their care, sharing the responsibility with them. It explores some of the reasons why professionals may not be enabling shared decision-making as much as they think they are, and suggests how to overcome some of the perceived barriers to implementing this approach.

Recent years there has been an increasing move towards a form of clinical decision-making that engages patients (Coulter, 2010; Elwyn et al, 2010). Although research into shared decision-making has been taking place for more than 15 years, until recently, many developments in this field have been theoretical and largely based in a research setting.

The NHS, in both primary and acute care, is now looking at how health professionals can make shared decision-making a part of routine practice to ensure patients and their families are appropriately engaged in discussions about their care. Shared decision-making is an important feature of the white paper Liberating the NHS (Department of Health, 2010), and health secretary Andrew Lansley's NHS mantra, “no decision about me without me”, has been given new prominence in a drive to ensure that shared decision-making becomes the norm rather than the exception.

What is shared decision-making?

There is a continuum of decision-making found in clinical practice, from paternalism at one extreme, through shared decision-making, to informed decision-making by patients (Charles et al, 1999a) (Fig 1).

In the paternalistic approach to decision-making the information exchange is one way, from health professionals to patients, with the professionals determining what information is given and which treatment should be pursued. With fully informed choice, the flow of information is still largely in the same direction, from health professionals to patients. Health professionals are the main, but not always the only source of information about the risks and benefits of different treatment options.

With informed choice, patients make their own decisions and professionals act as sources of expert clinical information, and with no further active role in decision-making (Charles et al, 1999b).

What defines shared-decision making is its interactive nature. Both parties acknowledge that, while health professionals hold the expert clinical and technical knowledge, patients are experts about their own lives and treatment objectives, and also what is important to them when making decisions. This sharing of essential information enables a more informed discussion and evaluation of treatment choices leading to a jointly agreed decision (Edwards and Elwyn, 2009).

While there are several definitions of...
shared decision-making, the generally accepted one is “the involvement of both patient and doctor with a sharing of information by both parties taking steps to build a consensus about preferred treatment and reaching an agreement about which treatment to implement” (Charles et al, 1997). Sharing information about options available, their risks and benefits, and patients’ values is vital for individuals to be able to fully participate in the process.

Components of shared decision-making

Clarifying the decision to be made

This requires a discussion between the health professional and patient about the decision concerned, including, for example, how quickly it has to be made. Some decisions may be discussed and decided over time, such as whether to have a hip replacement. Others will be more urgent, involving choices that must be made within a set time, either to resolve symptoms or stop a disease progressing, for example whether to have a lumpectomy or a mastectomy for early stage breast cancer. Once parameters have been set around the decision, patients and health professionals know how much time they have to deliberate.

Clarifying options available

Patients need to be aware that there is a choice of treatments and options available based on their clinical condition, comorbidities and the services on offer in their locality. If appropriate, these choices should include the option of doing nothing and what effect this would have on their health.

Communicating risks and benefits of the treatment options

There should be a description of what the different options involve, including a balanced presentation of the risks and benefits of each. These should be communicated in a way the patient understands. It is important to check that the patient understands all available options and their implications, because they are often being given complex information while in an emotional state about their health condition.

Exploring what is important to the patient

A vital element of shared decision-making is to explore what is important to the patient – sometimes referred to in the literature as “values clarification” (Edwards and Elwyn, 2009). Finding out what matters to patients allows health professionals to explore how this may affect the decisions they make. For example, one woman facing the choice of treatment for breast cancer may opt for a mastectomy to be reassured the tumour has been fully removed and the risk of recurrence minimised, whereas another may elect for lumpectomy because retaining her breast is important to her. Often health professionals identify this aspect of the decision-making process as the area in which they could do better and would value guidance and education, for example in how to communicate with patients about their values.

Decision support tools

Interventions to inform patients about healthcare options and to involve them in decisions about their care are now widely advocated (Elwyn and Edwards, 2001). A variety of interventions have been developed to support better shared decision-making, from patient booklets to interactive CDs and computerised decision support tools (Edwards et al, 2000). Patient involvement, information on options and discussions to clarify what is important to individual patients can be supported by the use of patient decision aids. These are tools designed to guide patients through the information on what is available, helping them to clarify what it important to them and to then reach a decision that fits closely with their values (O’Connor et al, 2006). One example is the Ottawa Personal Decision Guide (O’Connor et al, 2004). There is also a growing number of decision-specific patient decision aids to support shared decision-making, some of which are available online (www.nhs.uk/choices) or in booklet form, such as the NHS Direct tool for enlarged prostate. The aim is to determine which decision closely matches with what is important to the patient.

Health professionals aim to help patients identify which treatment option best matches what is important to them. However, often this is not straightforward and patients may need support to reconcile conflicting values. For example, if a pregnant woman values being mobile during her labour, but also seeks the degree of pain relief offered by an epidural,
she needs to understand there is a trade-off between mobility and pain control.

**Why don't we practise shared decision-making?**

While many health professionals are carrying out many elements of shared decision-making, there are barriers to fully implementing them in practice.

Health professionals work in increasingly busy clinical settings with many demands on their time. They worry that shared decision-making done well will add time to an already pressured environment. However, involving patients does not necessarily increase the time needed, although it may change the focus of communications between health professionals and patients.

Health professionals will be familiar with many of the risks and benefits of the treatment options they routinely discuss with patients, but need to ensure this is up-to-date with current evidence, and that it is clearly relayed and personalised as much as possible. Decision tools and information leaflets that have been developed and updated on a regular basis will help to illustrate these risks to patients and may also support ready access to relevant data for professionals. A list of decision aids, along with an internationally developed checklist for determining the quality of decision aids is freely available to support clinical practice from the International Patient Decision Aid Standards Collaboration (www.ipdas.ohtri.ca).

Our experience with working with health professionals has shown that to encourage shared decision-making it is important to develop their skills in this area. These skills are not widely taught at any stage of professional education, but examples of training to support shared decision-making are emerging.

We also need to find ways to embed shared decision-making in current systems. For example, in Newcastle Hospitals Foundation Trust, the importance of shared decision-making is discussed in the staff induction process, and the trust is introducing shared decision-making into communication skills training for clinical staff.

There will never be a specific decision support tool for every treatment option or clinical condition. In the absence of specific decision aids, generic tools such as the Ottawa Personal Decision Guide, supported by effective skills development, can help to structure a shared decision-making conversation.

There is a need to consider how decision support can best be aligned with current care pathways, or whether they need to be adapted to integrate shared decision-making into routine care.

**Why should we be doing more?**

Evidence of the effectiveness of shared decision making is growing. The NHS patient survey found that 48% of inpatients and 30% of outpatients want more involvement than they currently have in decisions about their care (Garratt, 2009). This figure has remained constant over several years, suggesting that, despite recent initiatives, we are still not involving patients effectively.

A Cochrane review of randomised controlled trials of patient decision aids identified that they not only improve knowledge, but also reduce the number of people who are passive in decision-making (O'Connor et al, 2006). These aids increase participation and the degree of comfort with the decision, and there is emerging evidence that their use also reduces the uptake of elective surgery in favour of more conservative options. These are all goals which we as health professionals strive to achieve to improve our patients’ healthcare.

In 2008, Joosten and colleagues advocated shared decision-making with patients who have long-term conditions. Patients who were engaged in shared decision-making about their treatment plan for anti-depressants were more likely to adhere to their medication than those who were not (Joosten et al, 2008). If patients understand the reason for the treatment they are offered, and are fully conversant with the possible side-effects before they begin treatment, they are more likely to adhere to the treatment regimen than if they had no active part in the decision-making process.

**How has shared decision-making been implemented?**

One example of putting shared decision-making into practice is at Newcastle upon Tyne Foundation Trust. A midwifery-led unit opened in June, offering women a choice of giving birth either at home, within the unit, or on a consultant-led obstetric unit. From an early stage in developing the service, the team wanted to embed shared decision-making as a way of supporting women in making this choice. A detailed information leaflet has been developed stating why women are being given options, and what they are, along with their associated risks and benefits. The community midwives who will pass this information to pregnant women are being trained in shared decision-making and in using the Ottawa Personal Decision Guide as a structure for their consultations. By implementing this approach from the start of a service we hope it will become embedded in routine practice and begin to have an impact on other decisions where community midwives support women.

**Conclusion**

In an ideal world, patients would have sufficient and appropriate knowledge, and clarity about their own personal values, along with the ability and desire to engage in a shared decision; in turn health professionals would support them through this (Barnato et al, 2007). As yet, this is far from a reality. There are considerable opportunities to enhance the quality of care within the health service, through implementing effective shared decision-making processes consistent with professional practice, but there are many challenges to address if we are to see this approach become the norm rather than the exception.

References


tinyurl.com/liberating-the-nhs


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