

Shared decision making

Key therapeutic topic

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www.nice.org.uk/guidance/ktt23

Key points

- In the context of medicines optimisation, shared decision making involves healthcare professionals and patients (patients should be understood to include all people who use NHS services), working together to make choices about medicines based on clinical evidence and the patient's informed preferences about what they hope to gain from the treatment.
- When discussing the risks and benefits of treatment, the law now requires healthcare professionals to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment and of any reasonable alternatives.
- The first principle in the Royal Pharmaceutical Society's [good practice guidance on medicines optimisation](#), published in 2013 is 'Aim to understand the patient's experience'. Professional codes of practice recommend a shared decision-making approach to care, including those of the General Medical Council, General Pharmaceutical Council and Nursing and Midwifery Council.
- All NICE guidance recommends shared decision making, and several NICE quality standards identify and define shared decision making as part of good quality care.
- The NHS England document [Universal personalised care: Implementing the comprehensive model](#), published in January 2019 has shared decision making as 1 of the 6 core components of personalised care.
- **Options for local implementation:**
 - Encourage and support a shared decision-making approach to care. Visible

- – organisational buy-in and support are essential for this to succeed. Individual healthcare professionals need support and training to incorporate and develop shared decision making in their practice.
- Consider patient empowerment, activation and preparation campaigns, such as the [Ask 3 Questions](#) or [Choosing Wisely](#) campaigns, to explain what shared decision making involves, why it might help, and provide interventions such as question prompt lists.

Evidence context

This medicines optimisation: key therapeutic topic is intended to highlight the area of shared decision making and some key resources to help local teams involved in medicines optimisation think about how shared decision making can feature in their work. It is closely related to the medicines optimisation: key therapeutic topic on [multimorbidity and polypharmacy](#). NICE is also developing a guideline on [shared decision making](#). It is expected to publish in April 2021 and will give formal NICE guidance on implementing shared decision making.

In this medicines optimisation: key therapeutic topic, the term 'patient' should be understood to include all people who use NHS services. Healthcare professionals should follow the Department of Health's [advice on consent](#) and take account of the NICE guidance on [decision-making and mental capacity](#). If someone does not have capacity to make decisions, healthcare professionals should follow the [code of practice that accompanies the Mental Capacity Act](#). However, the statutory principles in the Act make clear that a person must be assumed to have capacity unless it is established that they do not. Moreover, they should not be treated as unable to make a decision merely because they make a decision that others consider unwise.

Shared decision making: what it is and what it is not

The scope for the NICE guideline on [shared decision making](#) states:

Shared decision making is a collaborative process through which a healthcare professional supports a person to reach a decision about their care, now or in the future (for example, through advance care planning). It involves healthcare professionals working together with people who use services and their families and carers to choose tests, treatments, management or support packages, based on evidence and personal informed preferences, health beliefs, and values. This involves making sure the person has a good understanding of the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the treatment and care that is right for them at that time (including doing nothing).

The scope notes that some people prefer not to take an active role in making decisions with their healthcare professionals, but states that they should always be given the opportunity to choose to what degree they want to engage in decision making. It states that shared decision making is applicable across all healthcare settings, in situations where there is more than one possible NHS care or treatment option (options include doing nothing).

The shared decision-making approach to care recognises that both the healthcare professional and patient bring 2 different but complementary forms of expertise to the process (see table 1).

Table 1 Sharing expertise

Healthcare professional's expertise	Patient's expertise
<ul style="list-style-type: none"> • Diagnosis • Disease aetiology • Prognosis • Treatment options • Outcome probabilities 	<ul style="list-style-type: none"> • Experience of illness • Social circumstances • Attitude to risk • Values (what matters to them) • Preferences
<p>Adapted from King's Fund 2011.</p>	

Shared decision making is particularly relevant for what has been described as preference-sensitive decisions ([Wennberg et al. 2010](#)). These are decisions in which more than 1 valid treatment or care option exists (including the possibility of no treatment) and the choice between options involves the individual person concerned weighing up trade-offs according to their preferences and values. Many clinical decisions in healthcare can be described as preference-sensitive ([King's Fund 2011](#)). In emergency situations, to save life or limb, shared decision making may not be appropriate or even possible, but most clinical decisions are not so urgent. A shared decision-making approach to care is particularly, but not only, important when people have several health problems; see the medicines optimisation: key therapeutic topic on [multimorbidity and polypharmacy](#). However, shared decision making is important for all prescribing and medicines optimisation, including deprescribing.

Shared decision making does not involve simply providing information and then handing decision making entirely to the patient, in a highly consumerist approach. Nor are all conceivable options

open to the patient – the healthcare professional helps the patient choose from a selected range of options, usually those recommended by NICE guidance. This range of options is restricted by any contraindications relevant to the patient's individual clinical circumstances.

It has been stated that there are 2 main tasks in shared decision making ([Elwyn et al. 2012](#)):

- to ensure that individuals are not making decisions in the face of avoidable ignorance
- to support patients to deliberate about their options by exploring their reactions to information.

The first of these applies in 2 main ways. Firstly, there is evidence that patients tend to underestimate the potential harms of treatment and overestimate the likely benefits, as discussed in NICE's [evidence commentary on patients' expectations of the benefits and harms of treatments and tests](#). Moreover, doctors are likely to do the same ([Hoffmann and Del Mar 2017](#)). Thus, without an accurate and realistic assessment of the possibility of harms and benefits, people may accept or reject 1 option over another, which they might not have done had they been in full possession of the facts.

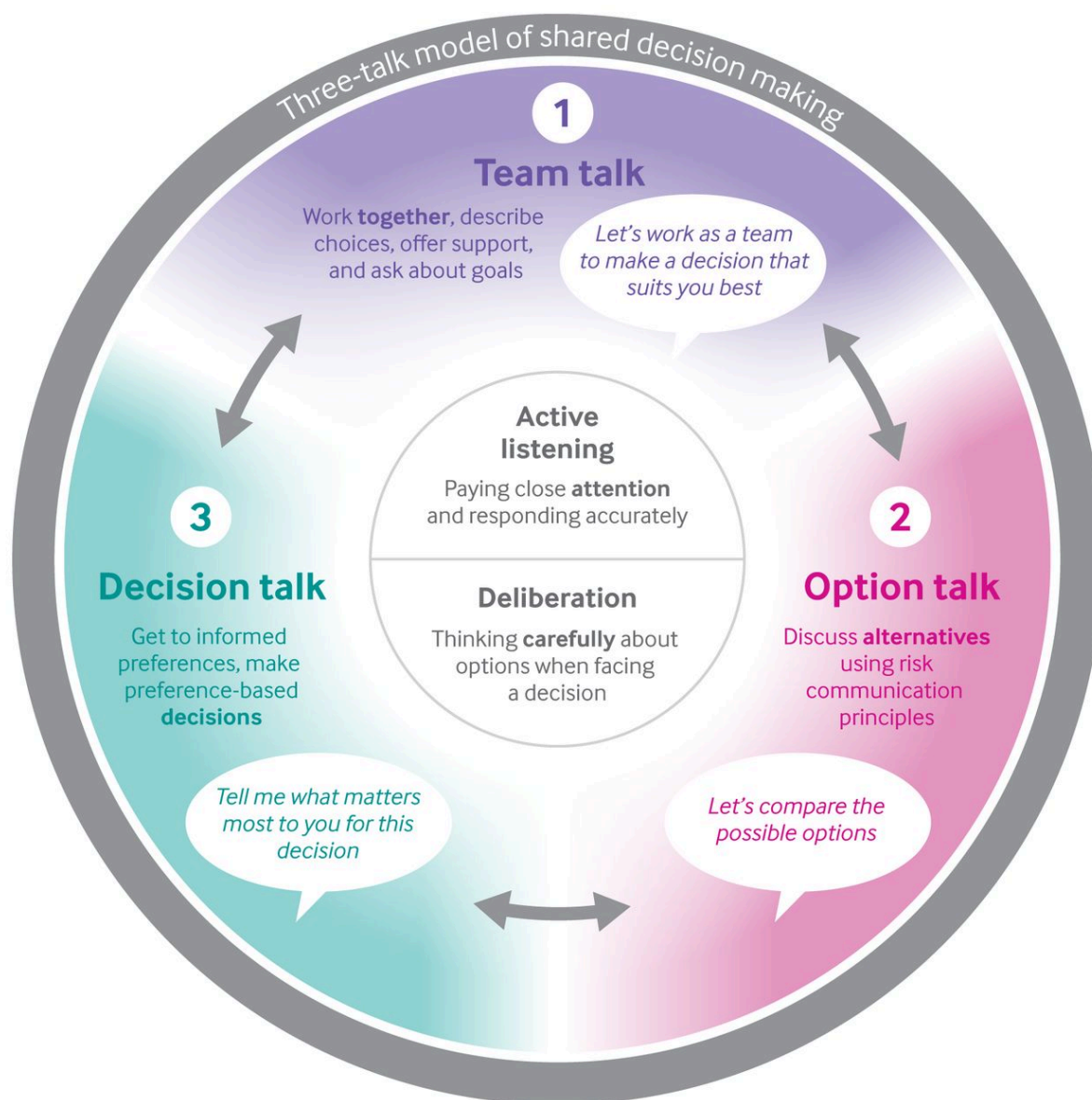
Secondly, there may be substantial differences between what patients want and what healthcare professionals think patients want. This has been described as preference misdiagnoses. It has been stated that this is common and that healthcare professionals are rarely made aware that they have made such a preference misdiagnosis ([Mulley et al. 2012](#)). In the context of medicines optimisation, it is important that healthcare professionals find out what the patient hopes to gain from taking or using the medicine. They need to communicate clearly what likely benefits and possible harms the patient may experience.

For example, a study conducted in the UK found a wide range of attitudes among people as to the amount of benefit they felt a fictional, side-effect free, 'ideal' tablet would have to produce to offset the inconvenience of taking it every day. More than a quarter of people required a greater increase in lifespan to justify such daily medication than a statin is likely to produce. The results of this study are discussed in more detail in NICE's [evidence commentary on cardiovascular primary prevention: trading off the inconvenience of taking medicines against the expected benefits](#). Similar results were seen in a systematic review of studies from the UK and other countries, as discussed in NICE's [evidence commentary on patient preferences: minimum likely benefits required from cardiovascular preventative medication](#).

The second task – supporting patients to deliberate about their options – is equally important – some people feel surprised or unsettled by the offer of options and uncertainty about what might

be best. If all responsibility for decision making is transferred to patients they may feel abandoned. A practical approach to implementing shared decision making in the consultation for single decisions is described in an article discussed in NICE's medicines evidence commentary on [shared decision making: an updated three-talk model for the clinical consultation](#) (see figure 1 below).

Figure 1 Three-talk model of shared decision making (Elwyn et al. 2017)



The NICE guideline on [patient experience in adult NHS services](#) gives guidance on shared decision making and on presenting information about risks and benefits, including the need for healthcare professionals to accept and acknowledge that patients may vary in their views about the balance of risks, benefits and consequences of treatments, and may have a different view from the healthcare professional.

Drivers for shared decision making

Practising and enabling shared decision making are supported by ethical, legal and professional considerations, NICE guidance and NICE quality standards.

Firstly, there is an ethical imperative for shared decision making. Coulter and Collins ([King's Fund 2011](#)) state that 'The most important reason for practising shared decision making is that it is the right thing to do'. This is based on the fundamental moral principles of respecting the patient's autonomy (the ability to make one's own decisions) and the duties for healthcare professionals of beneficence (doing good) and non-maleficence (not doing harm; [Gillon 1994](#)).

Secondly, offering shared decision making is a legal requirement. The ruling by the UK Supreme Court in the case of *Montgomery versus Lanarkshire Health Board* has important implications for all healthcare professionals ([Sokol 2015](#)). The law now requires healthcare professionals to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is:

- a risk to which a reasonable person in the patient's position would be likely to attach significance or
- a risk that the healthcare professional knows – or should reasonably know – would probably be deemed of significance by this particular patient.

The [judgment](#) notes that the assessment of whether a risk is material depends both on what it is and its importance to the person; it is not just a matter of the probability of the risk. Moreover, it is important that the person understands the likely risks and consequences – simply providing lots of technical information is not sufficient.

There are exceptions to this general principle, if the person makes it clear that they do not want to discuss the risks of treatment, or treatment is urgent and the person is not able to make a decision (for example, because they are unconscious), or if they lack capacity. In addition, a healthcare professional can withhold information about a risk if they reasonably consider that its disclosure would be seriously detrimental to the patient's health. However, this exception is limited and the judgment makes clear that it does not allow the healthcare professional to withhold information because they think that the person might make an informed choice with which they disagree.

Professional codes of practice also recommend a shared decision-making approach to care, including those of the [General Medical Council](#) (2008, currently being [updated](#)), [General](#)

[Pharmaceutical Council \(2017\)](#) and [Nursing and Midwifery Council \(2015\)](#). The first principle in the Royal Pharmaceutical Society's [good practice guidance on medicines optimisation \(2013\)](#) is 'Aim to understand the patient's experience'.

NICE guidelines should be understood as 'guidelines, not tramlines'. Every guideline states clearly that although healthcare professionals are expected to take its recommendations fully into account when exercising their judgement, they should do so alongside the individual needs, preferences and values of their patients or service users. The application of the recommendations in NICE guidelines is not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient or their carer or guardian. Several NICE single-condition guidelines specifically highlight shared decision making within their recommendations, such as the guideline on [lipid modification](#), and several NICE guidelines make cross-condition recommendations for shared decision making. They are:

- [Medicines adherence \(2009\) NICE guideline CG76](#)
- [Service user experience in adult mental health \(2011\) NICE guideline CG136](#)
- [Patient experience in adult NHS services \(2012\) NICE guideline CG138](#)
- [Medicines optimisation \(2015\) NICE guideline NG5](#)
- [Multimorbidity \(2016\) NICE guideline NG56](#)

NICE's quality standards on [service user experience in adult mental health services](#) and [patient experience in adult NHS services](#) also support shared decision making.

Although the [quality and outcomes framework \(QOF\)](#) rewards general practices for certain measures, this should not drive a 'one size fits all' approach to care. Full points can be achieved without the QOF indicator being achieved for all relevant patients. Moreover, patients who make an informed decision not to take up the offer of the care in the QOF indicator can, from 2019/20, be removed from the indicator denominator through a 'personalised care adjustment' (this was previously known as 'exception reporting'). This ensures that a practice is not penalised by offering patient-centred care.

Barriers to shared decision making and possible approaches to address these

In 2010, the Health Foundation in the UK commissioned the [MAGIC \(making good decisions in collaboration\) programme](#) to design, test, and identify the best ways to embed shared decision

making into routine primary and secondary care using quality improvement methods. The learning from the programme and subsequent experience about the key challenges of implementing shared decision making, and some possible practical solutions, was summarised by [Joseph-Williams et al. \(2017\)](#). The authors identified 5 challenges:

Challenge 1: We do it already

Many patient-facing professionals feel that they already involve patients in decisions about their care, so often do not see how shared decision making differs from their usual practice. The MAGIC programme found that the most successful approaches were role-play-based training, which emphasised practical skills, and using exercises that challenged embedded attitudes and promoted discussion around them. The training helped the healthcare professionals understand how shared decision making differed from their current ways of working, by helping them improve their communication of risk and the way they explore what matters to patients. Some clinicians reported changing their view from we do this already to we could do this better.

Challenge 2: We don't have the right tools

There is good evidence that patient decision aids can help shared decision making. A Cochrane review ([Stacey et al. 2017](#)) found that, compared with usual care, using decision aids helps people become better informed, take a more active role in decision making and be more likely to make choices in line with their values. However, merely having a decision aid does not ensure that shared decision making takes place, nor is it necessary to have a decision aid before shared decision making can occur. A key learning point from the MAGIC programme was that "skills trump tools, and attitudes trump skills." It is unlikely that there will be a decision aid for every decision; and even if there is 1 for the particular decision in question, not every patient will want to use it or find it helpful. It is important that healthcare professionals do not substitute decision aids for consultation skills that will enable them to find out and discuss what really matters to the patient.

Challenge 3: Patients don't want shared decision making

Healthcare professionals often report that patients do not want to be involved in making healthcare decisions. This can sometimes be the case and that this desire should be respected. But not to be involved in those decisions is in itself a decision that should be informed, and not be based on what the healthcare professional assumes the patient wants, or what the patient thinks the healthcare professional wants. In the Care Quality Commission's [Adult inpatient survey 2018](#) only just over half of patients (54%) said they were involved as much as they wanted to be in the decisions surrounding their care. Moreover, if a patient decides to hand decision making wholly or mainly to the healthcare professional, it is important that the professional understands what the

patient's priorities are, so as to make a decision that is truly in the patient's best interests.

Some patients may think they will annoy healthcare professionals by trying to be more involved – their desire to be a 'good' patient over-rides their desire for sharing decisions. Patient empowerment, activation and preparation can increase the likelihood of mutually useful conversations between patients and professionals. Such campaigns focus on changing patients' attitudes about involvement in healthcare decisions, explaining what shared decision making involves, why it might help, and provide interventions such as question prompt lists. Interventions such as the [Ask 3 Questions](#) or [Choosing Wisely](#) campaigns can help patients know what to expect and give 'permission' and encouragement to be involved. Addressing health literacy is also important – those with low health literacy may have much to gain from a shared decision-making approach to care.

Challenge 4: How can we measure it?

Measuring how much shared decision making has taken place is not straightforward. However, Joseph-Williams et al. state that the 3-item [CollaboRATE measure](#) shows promise. In the MAGIC programme, focusing on quality improvement helped embed shared decision making more readily with some clinical teams, and suggest linking with local health improvement programmes.

Challenge 5: We have too many other demands and priorities

Visible organisational buy-in and support are essential for shared decision making to succeed. During the MAGIC programme, key organisational leaders showed healthcare professionals that shared decision making was an important organisational priority to drive improvement, and clinical leadership was critical to implementation. This led to greater engagement because healthcare professionals then saw shared decision making as part of the organisation's underpinning values and principles, rather than as yet another initiative being imposed on them to compete with other demands. Teams sometimes needed support from the organisation to adapt clinical pathways to support effective shared decision making.

Practice examples and shared learning

The NICE website has a dedicated page that covers all aspects of NICE's work on [shared decision making](#). This includes links to NICE's own decision aids and those produced by others. NHS England has a section of its website devoted to [shared decision making](#), including advice and ideas for supporting and developing shared decision making locally. The NHS England Right Care website also has resources relating to [shared decision making](#). Several [online courses relating to shared decision making](#) are available on the e-Learning for Healthcare website.

There are several [shared learning case studies](#) relating to shared decision making, showing how NICE guidance and standards have been put into practice by some NHS organisations:

- [Improving the quality of care for men with lower urinary tract symptoms: shared decision making](#)
- [My Birthplace®: A computerised place of birth decision support tool for women and midwives](#)
- [Medicines Optimisation: Stroke prevention in atrial fibrillation in practice](#)

A selection of [virtual patients \(avatars\)](#) have been developed by Keele University to help students or healthcare professionals improve their clinical and communications skills. These include cases on shared decision making and atrial fibrillation.

Prescribing data, metrics or supporting resources

At this point, no relevant prescribing data, metrics or resources have been identified to support this topic.

Update information

September 2019: This topic was retained for the 2019 rapid update of medicines optimisation: key therapeutic topics. Minor editorial changes have been completed and the definition of shared decision making has been updated.

About this key therapeutic topic

This document summarises the evidence base on this key therapeutic topic that has been identified to support medicines optimisation. **It is not formal NICE guidance.**

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