National Institute for
Health and Care Excellence

Shared decision making

NICE guideline
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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS15.

Overview

This guideline covers how to make shared decision making part of everyday care in all healthcare settings. It promotes ways for healthcare professionals and people using services to work together to make decisions about treatment and care. It includes recommendations on training, communicating risks, benefits and consequences, using decision aids, and how to embed shared decision making in organisational culture and practices.

The guideline does not cover unexpected emergencies in which immediate life-saving care is needed. It also does not cover situations when, at the time a decision needs to be made, an adult does not have mental capacity to make a decision about their healthcare. For more information, see the NICE guideline on decision-making and mental capacity.

Who is it for?

- Everybody who delivers healthcare services
- Commissioners of health and public health services
- Adults (aged 18 and over) using healthcare services, their families, carers and advocates, and the public

It may also be relevant for:

- Social care practitioners
- Voluntary, community and social enterprise organisations
- People who use social care services

Recommendations

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. It could be care the person needs straightaway or care in the future, for example, through advance care planning. See the full definition of shared decision making.

For more information on what shared decision making means for people receiving care and treatment, see making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Embedding shared decision making at an organisational level

NICE has produced a guideline on babies, children and young people's experience of healthcare.

High-level leadership

1.1.1 Make a senior leader accountable and responsible for the leadership and embedding of shared decision making across every organisation or system regardless of its size. This should be a board member or, if the organisation does not have a board, a leader at the highest level of the organisation.

1.1.2 Consider appointing a patient director (from a healthcare service user background) to work with the senior leader and be responsible for:

- raising the profile of the service user voice in planning, implementing and monitoring shared decision making, especially from those in under-served populations

- supporting the embedding of shared decision making at the highest level of the organisation.

1.1.3 Appoint one or more senior healthcare professionals to work with the senior leader and patient director as organisation-wide 'champions' responsible for shared decision making.

1.1.4 Identify one or more organisation-wide 'service user champions' to work with the senior leader, patient director and professional champions for shared decision making. They should be recruited from people who use services.

Planning and implementing shared decision making

1.1.5 Develop an organisation-wide improvement plan to put shared decision making into practice, based on recommendations 1.1.6 to 1.1.10.

1.1.6 In developing the improvement plan, identify:

- existing good practice in departments or teams where shared decision making is already being practised routinely, and use their experience
- departments or teams where shared decision making can be put into practice most easily next; continue this process across the whole organisation
- key staff and service users to train as shared decision-making trainers, and suitable providers to deliver the training (see recommendation 1.1.13).

1.1.7 Review how information systems might support shared decision making, for example, by:

- providing ready access to patient decision aids or information about risks, benefits and consequences during discussions with a healthcare professional
- showing the person's past decisions and preferences, values and other information from previous discussions, for example, through a patient-held record (see recommendation 1.2.17).

1.1.8 Set out in the improvement plan how people who use services will be involved in supporting its implementation.

1.1.9 Plan internal or external monitoring and evaluation (including service user and staff feedback activities) and how to present the results to staff at individual, team and management level.

1.1.10 Establish a support network within the organisation for shared decision-making trainers (including service users who are trainers) and healthcare professionals. Consider joining up the support network with others in the wider system and across the region.

Sharing information

1.1.11 Ensure that expertise and information can be shared effectively both within and between organisations so that healthcare professionals provide people with consistent information. See recommendation 1.1.7 and section 1.4 of the NICE guideline on patient experience in adult NHS services.

Supporting healthcare professionals' skills and competencies

1.1.12 Organisations should ensure that knowledge, skills and confidence to support shared decision making are included in the induction, training and continuing professional development of all healthcare staff. This should include access to clinical supervision.

1.1.13 Ensure that training and development for healthcare professionals in shared decision making includes the following:

- encouraging people to talk about what is important to them
- understanding the principles that support shared decision making based on an evidence-based model (for example, the three-talk model)
- communicating with people in a way they can understand, using clear language, avoiding jargon and explaining technical terms
- sharing and discussing the information people need to make informed

decisions, and making sure they understand the choices available to them (including the choice of doing nothing or not changing the current plan)

- communicating with and involving family members, friends, carers, advocates or other people who the person chooses to include
- using patient decision aids.

1.1.14 Provide access to 'train-the-trainer' style workshops (where healthcare professionals, and potentially service users, are taught to train other healthcare professionals) for key shared decision-making champions in the departments where shared decision making is being rolled out.

1.1.15 Ensure that training is practical (for example, using role play), rather than solely theoretical, so that healthcare professionals can put into practice the skills needed for shared decision making.

Promoting shared decision making to people who use services

1.1.16 Organisations should actively promote shared decision making to people who use their services, for example, offering people training, and using posters or other media (such as appointment letters or websites) to prompt people to ask questions such as:

- What are my options?
- What are the possible benefits and risks of those options?
- How can we make a decision together that is right for me?

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on embedding shared decision making at an organisational level.

Full details of the evidence and the committee's discussion are in:

- evidence review A: effectiveness of approaches and activities to increase engagement in shared decision making and the barriers and facilitators to engagement
- evidence review E: effective approaches and activities to normalise shared decision making in the healthcare system.

1.2 Putting shared decision making into practice

1.2.1 Support shared decision making by offering interventions at different stages, including before, during and after discussions, so that people are fully involved throughout their care.

1.2.2 Tailor the methods used to support shared decision making to the care setting and context in which the decision is being made, including whether the discussion is happening in person or remotely by video or phone.

1.2.3 Ask the person if they want to involve family members, friends, carers or advocates (being aware of safeguarding). If so, include them as a way to help the person:

- actively engage in the discussion
- explain what matters to them
- make decisions about their care
- remember information they have been given during the discussion.

1.2.4 When providing information and resources:

- only use reliable, high-quality sources such as NICE-accredited information, links to the NHS website, information from appropriate patient organisations, or relevant NICE guidelines and quality-assured patient decision aids
- take into account accessibility and the requirement to meet the NHS Accessible Information Standard.

Before a discussion

1.2.5 Before a discussion, offer the person access to resources in their preferred format (for example, a booklet, flyer or app) to help them prepare for discussing options and making shared decisions. It should encourage them to think about:

- what matters to them
- what they hope will happen as a result of the discussion
- what questions they would like to ask (see recommendation 1.1.16).

1.2.6 Offer to arrange additional support for people who might find it difficult to share in decision making, especially if they do not have, or do not want, support from a family member, friend or carer. Support could come from a nurse, social worker, interpreter or volunteer (for example, an advocate) who can:

- help them to understand the resources provided
- encourage the person to take an active part in decision making
- reassure them that shared decision making will be supported by the healthcare professional they see.

During a discussion

1.2.7 Agree an 'agenda' at the start of each discussion to prioritise together what to discuss. Say how long the discussion will last.

1.2.8 Ensure the person understands they can take part as fully as they want in making choices about their treatment or care.

1.2.9 When discussing decisions about tests, treatments and interventions, do so in a way that encourages people to think about what matters to them, and to express their needs and preferences.

1.2.10 When discussing tests, treatments or other healthcare services:

- explain the healthcare aims of each option and discuss how they align with the person's aims, priorities and wider goals
- openly discuss the risks, benefits and consequences of each option, making sure the person knows this includes choosing no treatment, or no change to what they are currently doing
- clarify what the person hopes to gain from a treatment or intervention and discuss any misconceptions
- set aside enough time to answer questions, and ask the person if they would like a further opportunity to discuss options.

1.2.11 Support the person when they are considering options by:

- delivering information in manageable chunks (chunk and check)
- checking they understand the information (for example, using the teach back technique)
- discussing what matters to them in light of the information provided and checking that their choice is consistent with this.

1.2.12 Give people (and their family members, friends or carers, as appropriate) the time they need to make decisions about tests, treatments and interventions.

1.2.13 Accept and acknowledge that people may vary in their views about the balance of risks, benefits and consequences of treatments, and that they may differ from those of their healthcare professionals.

1.2.14 Make a joint decision or plan about treatment or care, and agree together when this will be reviewed.

1.2.15 At the end of a discussion, state clearly what decisions have been made to make sure there is a shared understanding between the person and their healthcare professional about what has been agreed, what happens next, what the timescales are, and when it will be reviewed.

1.2.16 Explain to the person that they can review their decision earlier than the agreed review date if they want to, and can change their mind about a decision they have made at any time.

1.2.17 When making a record of the discussion (for example, in a person's clinical notes or care plan), record any decisions made along with details of what the person said was important to them in making those decisions. Offer to share this with the person, for example, in a post-clinic letter.

After or between discussions

1.2.18 Offer people resources in their preferred format to help them understand what was discussed and agreed. This could be a printout summarising their diagnosis, the options and decisions or plans made, and links to high-quality online resources. Ideally, give people this material to take away, or provide it very soon after the discussion.

1.2.19 Ensure that information provided after discussions includes details of who to contact with any further questions.

1.2.20 When writing clinical letters after a discussion, write them to the patient rather than to their healthcare professional, in line with Academy of Medical Royal Colleges' guidance on writing outpatient clinic letters to patients. Send a copy of the letter to the patient (unless they say they do not want a copy) and to the relevant healthcare professional.

1.2.21 Offer additional support to people who are likely to need extra help to engage in shared decision making. This could include encouraging them to record the discussion, explaining in writing the decisions that have been made, or arranging follow up by a clinical member of staff or a suitable alternative.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on putting shared decision making into practice.

Full details of the evidence and the committee's discussion are in evidence review B: interventions to support effective shared decision making.

1.3 Patient decision aids

Healthcare professionals

1.3.1 Use patient decision aids as one part of an overall 'toolkit' to support shared decision making alongside the other skills and interventions outlined in section 1.2 and section 1.4 of this guideline. If a relevant decision aid is not available, continue to use the shared decision-making principles outlined in this guideline.

1.3.2 Only use a patient decision aid if it is:

- quality assured and reflects evidence-based best practice
- relevant to that discussion and the decision that needs to be made
- relevant to that clinical setting.

1.3.3 Before using a particular decision aid, healthcare professionals should make sure they are familiar with it, including how it will help people to understand which option is best for them.

Organisations

Also see recommendations 1.6.10 to 1.6.12 in NICE's guideline on medicines optimisation on making patient decision aids available for consultations about medicines.

1.3.4 Think about ways to give staff in the organisation or system access to quality-assured patient decision aids (assessed against NICE's standards framework for shared decision making support tools, including patient decision aids, or the International Patient Decision Aid Standards). This could be by maintaining a database of decision aids that are regularly reviewed and updated, or signposting staff to decision aids produced by national bodies such as NICE.

1.3.5 Organisations should ensure their facilities and systems support staff to provide patient decision aids in multiple ways to suit people's needs, for example, printed or online and available in different languages and formats.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on patient decision aids.

Full details of the evidence and the committee's discussion are in evidence review C: decision aids for people facing health treatment or screening decisions.

1.4 Communicating risks, benefits and consequences

1.4.1 Discuss risks, benefits and consequences in the context of each person's life and what matters to them. Be aware that risk communication can often be supported by using good-quality patient decision aids or graphical presentations such as pictographs (see recommendations 1.3.1 to 1.3.3).

1.4.2 Personalise information on risks, benefits and consequences as much as possible. Make it clear to people how the information you are providing applies to them personally and how much uncertainty is associated with it. For more on dealing with uncertainty, see the General Medical Council's guidance on decision making and consent.

1.4.3 Organisations should ensure that staff presenting information about risks, benefits and consequences to people have a good understanding of that information and how to apply and explain it clearly (see recommendations 1.1.12 and 1.1.13).

1.4.4 If information on risks, benefits and consequences specific to the person is not available, continue to use the shared decision making principles outlined in this guideline.

Discussing numerical information

1.4.5 Think about using a mixture of numbers and pictures, for example, numerical rates along with pictograms or icon arrays, to allow people to see both positive and negative framing (see recommendation 1.4.11) at the same time.

1.4.6 Use numerical data to describe risks if available. Be aware that different people interpret terms such as 'risk', 'rare', 'unusual' and 'common' in different ways.

1.4.7 Use absolute risk rather than relative risk. For example, the risk of an event increases from 1 in 1,000 to 2 in 1,000, rather than the risk of the event doubles.

1.4.8 Use natural frequencies (for example, 10 in 100) rather than percentages (10%).

1.4.9 Be consistent when using data. For example, use the same denominator when comparing risk: 7 in 100 for one risk and 20 in 100 for another, rather than 1 in 14 and 1 in 5.

1.4.10 Present a risk over a defined period of time (months or years) if relevant. For example, if 100 people have treatment for 1 year, 10 will experience a given side effect.

1.4.11 Use both positive and negative framing. For example, treatment will be successful for 97 out of 100 people and it will be unsuccessful for 3 out of 100 people.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on communicating risks, benefits and consequences.

Full details of the evidence and the committee's discussion are in evidence review D: risk communication.

Terms used in this guideline

Chunk and check

A technique to break down information into smaller, more manageable chunks rather than providing it all at once. In between each 'chunk', methods such as teach back are used to check for understanding before moving on.

Discussion

In this guideline, a discussion is any interaction (in person or remote) between a healthcare professional and a person using services in which a healthcare decision might be made.

Organisation or system

For the purpose of this guideline, this could refer to any organisation or network of organisations, for example, a general practice, a single hospital or clinic, a network or cluster of clinics, practices or services, or an integrated system or partnership between services, for example, a local dental network.

Patient decision aids

Patient decision aids are tools designed to help people take part in decision making about healthcare options. They provide information on the options and help people to think about, clarify and communicate the value of each option to them personally.

Patient decision aids do not advise people to choose 1 option over another, nor are they meant to replace healthcare professional consultation. Instead, they support people to make informed, values-based decisions with their healthcare professional.

(Adapted from the International Patient Decision Aid Standards Collaboration website.)

Shared decision making

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. It could be care the person needs straightaway or care in the future, for example, through advance care planning. It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the options of choosing to have no treatment or not changing what they are currently doing always included).

Teach back

The teach back method is a useful way to confirm that the information provided is being understood by getting people to 'teach back' what has been discussed and what instruction has been given. This is more than saying 'do you understand?' and is a check of how well things have been explained and understood.

Three-talk model

The three-talk model is a practical model of how to do shared decision making that is based on following choice, option and decision talk stages during the consultation. The model has 3 steps:

- introducing choice
- describing options, often by integrating the use of patient decision support
- helping people explore their preferences and make decisions.

Recommendations for research

The guideline committee has made the following recommendations for research.

1 Differing intervention effects in different groups

How do the same shared decision-making interventions differ in effectiveness between different groups of people and different care settings?

For a short explanation of why the committee made the recommendation for research, see the rationale section on putting shared decision making into practice.

Full details of the evidence and the committee's discussion are in evidence review B: interventions to support effective shared decision making.

2 Measuring shared decision making

What are the best ways to measure the effectiveness of shared decision making in different contexts (in different settings and involving different people)?

For a short explanation of why the committee made the recommendation for research, see the rationale section on putting shared decision making into practice.

Full details of the evidence and the committee's discussion are in evidence review B: interventions to support effective shared decision making.

3 Sustaining shared decision making

What interventions are most effective at transferring shared decision-making skills between people and departments, and in sustaining the implementation of shared decision making in an organisation and in clinical teams?

For a short explanation of why the committee made the recommendation for research, see the rationale section on embedding shared decision making at an organisational level.

Full details of the evidence and the committee's discussion are in:

- evidence review A: effectiveness of approaches and activities to increase engagement in shared decision making and the barriers and facilitators to engagement
- evidence review E: effective approaches and activities to normalise shared decision making in the healthcare system.

4 Acceptability of shared decision making

What influences the acceptability of shared decision making in populations that predominantly believe in the authority of the healthcare professional?

For a short explanation of why the committee made the recommendation for research, see the rationale section on putting shared decision making into practice.

Full details of the evidence and the committee's discussion are in evidence review B: interventions to support effective shared decision making.

5 Shared decision making in remote discussions

How do shared decision-making skills and techniques need to be modified for remote discussions?

For a short explanation of why the committee made the recommendation for research, see the rationale section on putting shared decision making into practice.

Full details of the evidence and the committee's discussion are in evidence review B: interventions to support effective shared decision making.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice.

Embedding shared decision making at an organisational level

Recommendations 1.1.1 to 1.1.16

Why the committee made the recommendations

Although a reasonable number of quantitative studies were identified, their usefulness was limited because it was often unclear whether or not interventions were effective, so the committee could not recommend specific interventions. There was qualitative evidence and evidence from experts on the ways shared decision making had been implemented internationally. Using this evidence and their own expertise, the committee recommended ways organisations could embed shared decision making into everyday practice.

The importance of strong leadership was a particularly prominent theme in the expert evidence and this was supported by the committee's views. In their experience, having a commitment from senior managers and leaders to shared decision making is essential because they can make sure resources are prioritised to support it and help to instil a culture of involving people who use services across the whole organisation. This could also be supported by choosing staff to be champions within the organisation and appointing patient leaders. These people would provide a strong voice to advocate for this approach and could act as 'influencers', passing on their knowledge and training in shared decision making to their colleagues.

The committee also agreed that appointing a person who uses services to a patient director post enabled service-users' voices to be heard at the highest levels of the organisation. Although the committee agreed this was a good idea, they were also aware that appointing a director-level post in an organisation was a large financial investment that might not be possible, especially in smaller organisations. For this reason, they agreed only to recommend this as an option to consider.

The committee discussed the importance of an organisation-wide plan for implementing shared decision making and made recommendations based on expert evidence from organisations that had successfully achieved this. These included using digital technology to support shared decision making (for example, through patient-held records) and putting in place 'train-the-trainer' style training. The committee agreed this was the most useful way to approach shared decision making training because it brought the necessary expertise in-house. Based on expert evidence and their own expertise, the committee recommended establishing support networks for these trained healthcare professionals and service users. This can improve how the implementation of shared decision making is monitored and communicated across organisations and areas.

The committee also used the expert evidence and their own expertise to recommend how to involve people who use services in implementing shared decision making and monitoring and evaluating its use in practice.

The committee was aware of national resources that might support developing a plan to implement shared decision making, such as the NHS England and NHS Improvement shared decision making summary guide and implementation checklist. In the short term, the roll-out of shared decision making might create further inequalities in services where it had not yet been implemented, but the committee agreed this was temporary and unavoidable.

Although shared decision making is most often carried out between people and their healthcare professionals, other practitioners (for example, healthcare assistants and some administrative and management staff) may also need to have shared decision-making skills, training and support. The committee noted resources and e-learning that might support this, such as the health literacy e-learning resource produced by Health Education England and NHS Scotland.

Because of the lack of published evidence about rolling out shared decision making across organisations, and about sustaining shared decision making in organisations, the committee made a recommendation for research on sustaining shared decision making.

How the recommendations might affect services

The committee hopes these recommendations will help increase the use of shared decision making in organisations by overcoming common barriers. Implementing the recommendations could have a modest impact on resources (for example, training or monitoring), but some changes, for example, appointing a patient director, could have a much larger impact.

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Putting shared decision making into practice

Recommendations 1.2.1 to 1.2.21

Why the committee made the recommendations

In the committee's view, shared decision making should be treated as an ongoing process rather than a one-off event. Using excellent communication and shared decision-making skills alongside a combination of other interventions that support shared decision making is likely to be most effective because no single intervention can be a one-size-fits-all solution, and the evidence supported this. The best available evidence was for multicomponent rather than individual interventions.

The committee also wanted to highlight that shared decision-making interventions may need to be adapted to specific settings and populations. The same intervention would need to be tailored differently to be used in a GP appointment, an outpatient clinic and inpatient hospital admission. In the committee's view, this also applies to remote discussions (for example, by phone or video). The committee agreed that the same skills and principles would be relevant even though the exact methods would be context dependent.

The committee noted the importance of the 'digital divide', with some people being unable to access or less familiar with things like online discussions. The committee did not see strong evidence about this and agreed it was an important area for research because of the increase in remote discussions in response to COVID-19. As a result, they made a recommendation for research on shared decision making in remote discussions to explore this further.

Providing information is important, but the committee wanted to emphasise that it needs to be of good quality, for example, NICE-accredited. The committee was aware that other quality standards exist, like the PIF TICK quality mark for patient organisations. There are also useful resources, such as 'ask 3 questions' and other tools to help people prepare, on the NHS England website.

Before a discussion

There was some evidence supporting offering interventions before discussions. Even though the studies that looked specifically at pre-discussion interventions did not show an increase in shared decision making itself, there was some evidence that these kinds of interventions increased people's knowledge and their satisfaction with their discussions. The committee agreed that, although knowledge alone is not enough for shared decision making to take place, it is a necessary part of it.

Supporting evidence also came from studies looking at other types of interventions that were offered before discussions: support from another person ('third party support') and eliciting people's preferences and values.

The committee recognised the benefits of arranging third party support for people who might need additional support to engage in shared decision making. This could include, for example, people who have a condition or disability that makes it more difficult for them to participate. The committee agreed that everybody should be encouraged to bring a family member, friend or carer to discussions if they choose to.

The committee acknowledged that intervention before a discussion was not always practical, for example, if the person needed care unexpectedly or urgently, so these recommendations would be best suited to non-urgent discussions.

During a discussion

The committee updated recommendations on shared decision making in NICE's guideline on patient experience in adult NHS services using the evidence and their expertise, and brought them into this guideline.

The studies looking at what was effective in shared decision making showed the strongest support for eliciting people's expectations, values, priorities and goals as part of interventions based on key stages of shared decision making from the three-talk model. These include 'choice talk' (also called 'team talk') that introduces the fact that there are options, and that the right option will depend on what matters to each person, and 'option talk', when they discuss alternatives addressing the risks, benefits and consequences of each option. These then lead onto 'decision talk', which makes sure a decision is made that is right for each person. The committee agreed it was useful to think about these key stages of shared decision making, but acknowledged that other models of shared decision making were in common use.

Evidence suggested using the three-talk model as a way to structure the shared decision-making process and the committee agreed that the interventions that showed an effect were all consistent with 1 or more of the stages of the three-talk model. In their view, the three-talk model was simple to use and that made it useful in all healthcare settings. The committee agreed, however, that any evidence-based model for shared decision making is useful so they were not prescriptive in the recommendations.

Agenda setting, explicitly stating decisions, the option of no treatment (that is, not choosing any of the treatments offered), and agreeing when to review a decision were not captured in the effectiveness evidence, but the committee considered them to be key aspects of shared decision making.

The committee noted that some people may not want to be involved in shared decision making. They also noted that not all decisions can be shared. People have a right to refuse any treatment, and similarly, healthcare professionals are not obliged to provide any treatment that in their clinical opinion is medically futile (this may need a second opinion or discussion with a senior colleague). Healthcare professionals cannot provide access to treatments that are not available.

The committee talked about documenting discussions. They agreed that recording which options have been discussed and what is important to the person is the best evidence that a meaningful shared decision making dialogue has taken place.

After or between discussions

The committee highlighted that interventions to support shared decision making should carry on after discussions with a healthcare professional because they should be part of a continuing process. They agreed on some methods to support people who might need additional help, such as suggesting that they record the discussion on their phone or other electronic device to help them remember what was said and think about their options.

Future research

The committee made recommendations for research to fill the most notable gaps in the evidence. They agreed that research was needed into how the same shared decision-making interventions differ in effectiveness between different populations and different care settings so they made a recommendation for research on differing intervention effects in different groups. The committee also noted from the evidence that it was unclear what the best measures of shared decision making are and how acceptable different interventions are to people who receive them, so they also made recommendations for research about measuring shared decision making and the acceptability of shared decision making.

How the recommendations might affect services

The recommendations will help to increase the use of shared decision making in day-to-day clinical practice by suggesting effective methods to support it. Some of the options in the recommendations may need additional resources, for example, using a healthcare worker to provide third party support, but others can be integrated into current practice, for example, encouraging a person to record their discussion. There is also a potential that in some healthcare settings, appointments or consultations may need to be longer and this could represent a substantial resource impact, but might lead to fewer subsequent appointments and will ensure that the right decisions are made with people.

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Patient decision aids

Recommendations 1.3.1 to 1.3.5

Why the committee made the recommendations

There was strong evidence to support using patient decision aids before, during and between discussions. However, the committee wanted to make it clear that decision aids alone do not deliver shared decision making but should be seen as 1 component of a wider approach. There would never be a patient decision aid available to support every discussion, and healthcare professionals still need to have the skills described in this guideline to engage people in making shared decisions irrespective of whether decision aids are available.

The committee agreed that for patient decision aids to be most useful, staff should have access to quality-assured patient decision aids either via a maintained database or signposting to those produced by national bodies. They also highlighted that even though the evidence favoured using patient decision aids, it is crucial to provide them to people in formats they can use and understand otherwise they would not be useful. In the committee's view, organisations should think about ways to make sure that a database of quality-assured decision aids is available to their staff in many different formats and that systems support using them in different ways. In the committee's experience, accessing decision aids in suitable formats is not always possible – for example, facilities to print out decision aids are not always available in consulting rooms across organisations, and some decision aids cannot be printed because of their format, for example, if they have a block colour background that requires a lot of ink.

How the recommendations might affect practice

The committee agreed that there were many good-quality patient decision aids that healthcare professionals could use and that more were being developed all the time. Many of them are freely available. Maintaining a database of decision aids could have a moderate resource impact, but the committee noted that these could be set up in collaboration with other organisations to maximise 'economies of scale'. The committee also noted that there might be some resource impact of printing more material for people.

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Communicating risks, benefits and consequences

Recommendations 1.4.1 to 1.4.11

Why the committee made the recommendations

The committee updated recommendations on communicating risks and benefits from NICE's guideline on patient experience in adult NHS services and brought them into this guideline.

The committee agreed that people's interpretation of risks, benefits and consequences is fundamentally embedded in their values and priorities, which explains why people do not weigh risks, benefits and consequences in the same way as others, or indeed in the same way as professionals.

The committee agreed that a person can only make an informed decision if they are given enough information to do so, and if the risks, benefits and consequences presented to them relate directly to their circumstances and what is important to them. Information about risks and benefits will be weighed differently in different situations and depending on a person's prognosis and the decisions they have to make. They discussed the evidence about presenting absolute risks compared with relative risks and noted that absolute risks are much clearer, especially when accompanied by visual summaries. They agreed that presenting relative risks alone was misleading and that relative risk should only be introduced as a supplement to absolute risks.

The committee wanted risks and benefits to be personalised using high-quality numerical data when these are available. Ideally, healthcare professionals would be able to provide personalised risk calculations. However, the committee acknowledged that personalised risk information is often not available. This means healthcare professionals often need to use generalised information about risks, benefits and consequences (usually available in good-quality decision aids) and explain to the person how it relates to them (for example, above average, average or below average levels of risk). Explaining how much uncertainty surrounds these estimates will help people interpret that information and what it means for them. The committee highlighted guidance from the General Medical Council (GMC) for more information – although GMC guidance is written for doctors, they agreed it provided an example of good practice for all professionals.

How the recommendations might affect practice

These recommendations will help healthcare professionals explore risk, benefits and consequences of healthcare decisions with people. The committee noted that because the recommendations in NICE's guideline on patient experience in adult NHS services have been in place since 2012, there should be no resource impact.

Return to recommendations

Context

Shared decision making is a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care. It could be care the person needs straightaway or care in the future, for example, through advance care planning. It involves choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. It means making sure the person understands the risks, benefits and possible consequences of different options through discussion and information sharing. This joint process empowers people to make decisions about the care that is right for them at that time (with the options of choosing to have no treatment or not changing what they are currently doing always included). In line with NHS England's personalised care and support planning guidance: guidance for local maternity systems, in maternity services this may be referred to as 'informed decision making'.

Shared decision making is enshrined as a principle in the NHS Constitution, with principle 4 stating that, 'Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment'.

Some people prefer not to take an active role in making decisions with their healthcare professionals, but they should always be given the opportunity to choose to what degree they want to engage in decision making and the extent to which decisions that are made on their behalf are discussed and communicated with them, including the reasons for selecting a particular treatment. Involving people in decisions about their care may result in:

- greater satisfaction with the decisions made
- greater understanding about the risks and benefits of the available options
- better communication between people and their healthcare professional, including people feeling that they have 'been heard'
- improved trust between people and their healthcare professional
- better concordance with an agreed treatment plan
- people reporting a better experience of care, including more satisfaction with the outcome.

After the Montgomery v Lanarkshire case (2015), a new legal standard was set to protect people's rights to make informed decisions when giving or withholding consent to treatment. Healthcare professionals should discuss the risks and benefits of each course of action that are meaningful to the particular person. Consent 'must be obtained before treatment interfering with bodily integrity is undertaken', and it should only be gained when a person has shared a decision informed by what is known about the risks, benefits and consequences of all reasonable NHS treatment options. As set out in the NHS Constitution for England, people have the right to be involved in planning and making decisions about their health and care, and to be given information and support to enable this.

The General Medical Council's guidance on decision making and consent (published in 2020) says that healthcare professionals should discuss 'risks of harm and potential benefits that the patient would consider significant for any reason. These will be revealed during your discussion with the patient about what matters to them'. It also states that they should discuss 'any risk of serious harm, however unlikely it is to occur'.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on patient and service user care.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the guideline committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

Update information

Minor changes since publication

October 2021: We added a link to NICE's guideline on babies, children and young people's experience of healthcare in section 1.1.

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