

Information about how the guideline was developed is on the [guideline's webpage](#). This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

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1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in this guideline and [NICE's information on 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.

2 1.1 Embedding shared decision making at an organisational 3 level

4 High-level leadership

5 1.1.1 Make a board member (or a member of the senior leadership team if there
6 is no board) accountable and responsible for the leadership and roll out of
7 [shared decision making](#) across the [organisation or system](#).

8 1.1.2 Consider appointing a patient director (from a healthcare service user
9 background) to work with the board member and be responsible for:

- 10 • raising the profile of the service-user voice in shared decision making,
11 especially from those in under served populations
- 12 • supporting the embedding of shared decision making at the highest
13 level of the organisation.

14 1.1.3 Appoint 1 or more senior [practitioners](#) to work with the board member and
15 patient director as organisation-wide 'champions' responsible for shared
16 decision making.

17 1.1.4 Identify 1 or more people who use services as organisation-wide 'service-
18 user champions' for shared decision making.

1 **Planning and implementing shared decision making**

2 1.1.5 Develop an organisation-wide plan to put shared decision making into
3 practice. As part of this plan:

- 4 • Identify existing good practice in departments or teams where shared
5 decision making is already being practised routinely, and use their
6 experience.
- 7 • Identify departments or teams where shared decision making can be
8 put into practice most easily next. Continue this process across the
9 whole organisation.
- 10 • Identify key staff and service-users to train as shared decision making
11 trainers and suitable providers to deliver the training (see
12 recommendation 1.1.8).
- 13 • Review how information systems might support shared decision
14 making. This could be by providing ready access to patient decision
15 aids or information about risks, benefits and consequences during the
16 consultation. It could also provide the healthcare provider and the
17 person using services with knowledge of that person's past decisions,
18 past preferences, values, and other information discussed during
19 appointments (for example through a patient-held record).
- 20 • Set out how people who use services will be involved in supporting
21 implementation.
- 22 • Plan internal or external monitoring and evaluation (including service-
23 user and staff feedback activities) and how to feed back the results to
24 staff at individual, team and management level.
- 25 • Establish a support network within the organisation for shared decision
26 making trainers (including service-users who are trainers) and
27 practitioners.
- 28 • Consider joining up the support network with others in the wider system
29 and across the region.

1 **Supporting practitioner skills and competences**

2 1.1.6 Organisations should ensure that knowledge, skills and confidence to
3 support shared decision making are included in the training and
4 continuing professional development of all healthcare staff.

5 1.1.7 Ensure that training and development for practitioners in shared decision
6 making includes the following:

- 7 • understanding the principles that support shared decision making
8 based on the [three-talk model](#) (see recommendations 1.2.6 to 1.2.15)
- 9 • communicating with people in a way they can understand, using clear
10 language, avoiding jargon and explaining technical terms
- 11 • sharing and discussing the information people need to make informed
12 decisions, and making sure they understand the choices available to
13 them (including the choice of doing nothing or not changing the current
14 plan)
- 15 • drawing out what is important to people
- 16 • communicating with and involving family members, carers, advocates
17 or other people if the person chooses to include them.

18 1.1.8 Provide access to 'train-the-trainer' style workshops (where practitioners,
19 and potentially service-users, are taught to train other practitioners) for
20 key shared decision making champions in the departments where shared
21 decision making is being rolled out.

22 1.1.9 Ensure that training is practical (for example, using role play), rather than
23 solely theoretical, so that practitioners can put into practice the skills
24 needed for shared decision making.

25 **Promoting shared decision making to people who use services**

26 1.1.10 Organisations should actively promote shared decision making to people
27 who use their services, for example offering people training, and using
28 posters or other media to prompt people to ask questions such as:

- 29 • 'What are my options?'
- 30 • 'What are the possible benefits and risks of those options?'

- 1
- 'How can we make a decision together that is right for me?'

For a short explanation of why the committee made these recommendations 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](#) and [evidence review E: effective approaches and activities to normalise shared decision making in the healthcare system](#).

2 **1.2 Putting shared decision making into practice**

3 1.2.1 Offer people interventions that support [shared decision making](#) at different
4 stages, including before, during and after discussions with a healthcare
5 professional, so that they are fully involved throughout their care.

6 1.2.2 Select the methods that are best suited to support shared decision making
7 in the care setting where the decision is being made, for example in
8 primary care, an outpatient clinic or a ward round. Tailor the methods to
9 that setting if needed.

10 1.2.3 Ask the person if they want to involve family members, friends or
11 advocates (being aware of safeguarding). If so, include them in
12 discussions as a way to help the person:

- 13
- actively engage in the consultation
 - 14 • explain what is important to them
 - 15 • make decisions about their care
 - 16 • remember information they have been given during discussions.

17 **Before appointments**

18 1.2.4 Before an appointment where a decision will be discussed, offer the
19 person access to resources in their preferred format (for example a
20 booklet, flyer or app) to help them prepare for discussing options and

1 making shared decisions. It should encourage them to think about what
2 matters to them and what they hope to gain from the appointment (the
3 'preparation stage'). Resources could include links to relevant NICE
4 guidance or NICE-endorsed information.

5 1.2.5 If a person might find it difficult to share in decision making, for example if
6 they have a mental health condition, English is not their first language or
7 they have sensory difficulties, offer to arrange additional support for them
8 if they do not have, or do not want, support from a partner, friend or carer.
9 Support could come from a nurse, social worker, translator or volunteer
10 (for example, an advocate) who can:

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

15 **During appointments**

16 1.2.6 Agree an 'agenda' at the start of each appointment to prioritise together
17 what to discuss. Say how long the appointment will last.

18 1.2.7 Ensure the person understands they can take part as fully as they want in
19 making choices about their treatment or care (the 'choice talk' stage of the
20 three-talk model).

21 1.2.8 When discussing decisions about tests and treatments, do so in a way
22 that encourages people to think about what is important to them, and to
23 express their needs and preferences.

24 1.2.9 When offering tests, treatments or other healthcare services:

- 25 • explain the healthcare aims of each option and how they align with the
26 person's aims
- 27 • openly discuss the risks, benefits and consequences of each option,
28 making sure the person knows this includes choosing no treatment, or
29 no change to what they are currently doing (the 'option talk' stage)

- 1 • clarify what the person hopes to gain from the treatment or intervention
2 and discuss any misconceptions
- 3 • set aside enough time to answer questions, and ask the person if they
4 would like a further opportunity to discuss options.
- 5 1.2.10 Support the person when they are considering options by:
- 6 • checking they understand the information
7 • discussing what is important to them in light of the information provided,
8 and checking that their choice is consistent with this.
- 9 1.2.11 Give people (and their family members or carers, as appropriate) enough
10 time to make decisions about tests and treatments.
- 11 1.2.12 Accept and acknowledge that people may vary in their views about the
12 balance of risks, benefits and consequences of treatments, and that they
13 may differ from those of their healthcare professionals.
- 14 1.2.13 Make a joint decision or plan about treatment or care and agree when this
15 will be reviewed (the ‘decision’ or ‘planning’ stage).
- 16 1.2.14 At the end of an appointment, state clearly what decisions have been
17 made to make sure the person agrees with and understands what has
18 been decided, what happens next, what the timescales are, and when it
19 will be reviewed.
- 20 1.2.15 When writing up the consultation, record any decisions made along with
21 details of what the person said was important to them in making those
22 decisions.

23 **After or between appointments**

- 24 1.2.16 Give people resources to help them understand what was discussed and
25 decided in their appointment. This could be a printout summarising the
26 options and decisions or plans made, and links to high-quality online
27 resources (for example, relevant NICE guidelines). Ideally, give people
28 this material to take away, or provide it very soon after the appointment.

1 1.2.17 In secondary or tertiary care, consider asking the person if they would like
2 a letter detailing the information from their appointment to be sent to them
3 and copied to their GP. Letters should be written in line with [Academy of](#)
4 [Medical Royal Colleges guidance on writing outpatient clinical letters to](#)
5 [patients](#).

6 1.2.18 Offer to provide additional support to people who are likely to need extra
7 help to share in making decisions. This could include encouraging them to
8 record the discussion during their appointment, explaining in writing the
9 decisions that have been made, or arranging follow-up by a clinical
10 member of staff or a suitable alternative.

11 **Sharing information between services**

12 1.2.19 Practitioners should ensure they are providing consistent information to
13 people by sharing expertise and information with all relevant services and
14 agreeing how to align their messages.

For a short explanation of why the committee made these recommendations 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](#).

15 **1.3 Patient decision aids**

16 **Practitioners**

17 1.3.1 Use [patient decision aids](#) as one part of an overall 'toolkit' to support
18 [shared decision making](#) alongside the other skills and interventions
19 outlined in sections 1.2 and 1.4 of this guideline. If a relevant decision aid
20 is not available, continue to use the shared decision making principles
21 outlined in this guideline.

22 1.3.2 Only use a patient decision aid if it is:

- 23
- up to date and reflects evidence-based best practice

- 1 • relevant to that discussion, and the decision that needs to be made
- 2 • relevant to that clinical setting.

3 1.3.3 Healthcare professionals should make sure they are familiar with a
4 particular decision aid and how it will help people to understand which
5 option is best for them before using it.

6 **Organisations**

7 1.3.4 Provide access for all staff in the [organisation or system](#) to a database of
8 quality assured patient decision aids (assessed against the [International
9 Patient Decision Aid Standards](#)). Ensure the database is maintained so
10 that decision aids are regularly reviewed and updated.

11 1.3.5 Organisations should ensure their facilities and systems support staff to
12 provide patient decision aids in multiple ways to suit people's needs, for
13 example, printed or online and available in different languages and
14 formats.

For a short explanation of why the committee made these recommendations 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](#).

15 **1.4 Communicating risks, benefits and consequences**

16 1.4.1 Discuss risks, benefits and consequences in the context of each person's
17 life and what matters to them. Be aware that risk communication can often
18 be supported by using good quality decision aids (see recommendations
19 1.3.1 to 1.3.3).

20 1.4.2 Personalise information on risks, benefits and consequences as much as
21 possible. Make it clear to people how the information you are providing
22 applies to them personally and how much uncertainty is associated with it.
23 For more on dealing with uncertainty, see the [General Medical Council's
24 guidance on decision making and consent](#).

1 1.4.3 Organisations should ensure that staff presenting information about risks,
2 benefits and consequences to people have a good understanding of that
3 information and how to apply and explain it clearly (see [recommendations](#)
4 [1.1.6 and 1.1.7](#)).

5 1.4.4 If information on risks, benefits and consequences specific to the person
6 in front of you is not available, continue to use the [shared decision making](#)
7 principles outlined in this guideline.

8 **Discussing numerical information**

9 1.4.5 Think about using a mixture of numerical and pictorial formats (for
10 example, numerical rates and pictograms or icon arrays) to allow people
11 to see both positive and negative framing at the same time.

12 1.4.6 Use numerical data to describe risks if available. Be aware that different
13 people interpret terms such as 'risk', 'rare', 'unusual' and 'common' in
14 different ways.

15 1.4.7 Use absolute risk rather than relative risk. For example, the risk of an
16 event increases from 1 in 1,000 to 2 in 1,000, rather than the risk of the
17 event doubles.

18 1.4.8 Use natural frequencies (for example, 10 in 100) rather than percentages
19 (10%).

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

23 1.4.10 Present a risk over a defined period of time (months or years) if relevant.
24 For example, if 100 people are treated for 1 year, 10 will experience a
25 given side effect.

26 1.4.11 Use both positive and negative framing. For example, treatment will be
27 successful for 97 out of 100 people and it will be unsuccessful for 3 out of
28 100 people.

For a short explanation of why the committee made these recommendations 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](#).

1

2 **Terms used in this guideline**

3 This section defines terms that have been used in a particular way for this guideline.

4 **Organisation or system**

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

9 **Patient decision aids**

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

13 Patient decision aids do not advise people to choose one option over another, nor
14 are they meant to replace practitioner consultation. Instead, they prepare people to
15 make informed, values-based decisions with their practitioner.

16 (Adapted from the [International Patient Decision Aid Standards \(IPDAS\)](#)
17 [Collaboration website](#)).

18 **Practitioner**

19 For the purpose of this guideline, this refers to all healthcare workers who come into
20 contact with people using healthcare services, including healthcare professionals
21 and other staff such as reception staff and some administrative and management
22 staff.

1 Shared decision making

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

6 Three-talk model

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

9 The model has 3 steps:

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

13 Recommendations for research

14 The guideline committee has made the following recommendations for research.

15 1 Differing intervention effects in different groups

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

For a short explanation of why the committee made this recommendation 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](#).

18 2 Measuring shared decision making

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

For a short explanation of why the committee made this recommendation 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](#).

1 **3 Sustaining shared decision making**

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

For a short explanation of why the committee made this recommendation 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 and evidence review E: effective approaches and activities to normalise shared decision making in the healthcare system](#).

5 **4 Acceptability of shared decision making**

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

For a short explanation of why the committee made this recommendation 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](#).

8 **Rationale and impact**

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

11 **Embedding shared decision making at an organisational level**

- 12 [Recommendations 1.1.1 to 1.1.10](#)

1 **Why the committee made the recommendations**

2 Although a reasonable number of quantitative studies were identified, their
3 usefulness was limited because it was often unclear whether or not interventions
4 were effective, so the committee could not recommend specific interventions. The
5 committee also heard qualitative evidence, as well as expert evidence about the
6 ways shared decision making had been implemented internationally. Using this
7 evidence and their own expertise, they recommended ways organisations could
8 embed shared decision making into everyday practice.

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

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

24 The committee agreed with expert evidence that digital technology could be used to
25 support shared decision making, for example through patient held records.

26 The committee also used the opinions from the expert witnesses and their own
27 experience to make other recommendations about embedding shared decision
28 making into organisations, including how to involve people who use services, and
29 ways to monitor and evaluate its use in practice.

30 The committee agreed that an organisation-wide plan for implementing shared
31 decision making was important and made a series of recommendations based on

1 expert evidence from organisations that had successfully implemented shared
2 decision making. They noted that, in the short term, the roll-out of shared decision
3 making might create further inequalities in services where it had not yet been
4 implemented, but they were content that this was temporary and unavoidable.

5 The evidence matched the committee's own experience and the expert evidence
6 supporting the use of 'train-the-trainer' style training. They agreed this was the most
7 useful way to approach shared decision making training because it brought the
8 necessary expertise in-house.

9 Due to the lack of published evidence about rolling out shared decision making
10 across organisations, and about sustaining shared decision making in organisations,
11 the committee made a [recommendation for research on sustaining shared decision](#)
12 [making](#).

13 **How the recommendations might affect services**

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

19 [Return to recommendations](#)

20 **Putting shared decision making into practice**

21 [Recommendations 1.2.1 to 1.2.19](#)

22 **Why the committee made the recommendations**

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

1 The committee also wanted to highlight that shared decision making interventions
2 will need to be adapted to specific settings and populations. For example, the same
3 intervention would need to be tailored differently to be used in a GP appointment and
4 in an outpatient clinic.

5 The committee recommended when extra support might be needed for people
6 before and after appointments based on both their own experience and expert
7 evidence, which highlighted the groups who might find it more difficult to engage in
8 shared decision making. The committee noted that good-quality translation services
9 were also important for people who don't speak English well.

10 ***Before appointments***

11 There was some support in the evidence for offering interventions before
12 appointments. Even though the studies that looked specifically at pre-appointment
13 interventions did not show an increase in shared decision making itself, there was
14 some evidence that these kinds of interventions increased people's knowledge and
15 their satisfaction with their appointment. The committee agreed that while knowledge
16 alone is not enough for shared decision making to take place, it is a necessary part
17 of it.

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

21 The committee recommended arranging third party support only for people who
22 might need additional support to engage in shared decision making, either by a
23 professional or by a friend or family member. This was because the evidence was
24 not strong enough to offset the potentially large resource impact of arranging
25 professional third party support. The committee agreed that everybody should be
26 offered the opportunity to bring a friend or family member to appointments if they
27 choose to.

28 ***During appointments***

29 The studies looking at what was effective in shared decision making showed the
30 strongest support for eliciting people's expectations, values, priorities and goals as

1 part of interventions based on key stages of shared decision making from the three-
2 talk model. These include ‘choice talk’ (also called team talk) where the practitioner
3 and person work together to describe choices and talk about goals, and ‘option talk’,
4 where they discuss alternatives using risk communication tools. The committee
5 agreed that it was useful to think in terms of these key stages of shared decision
6 making.

7 The committee heard expert evidence about using the three-talk model as a way to
8 structure the shared decision making process and they agreed that the interventions
9 that showed an effect were all consistent with one or more of the stages of the three-
10 talk model. As well as this, the committee agreed that the three-talk model was
11 simple to understand and use and that made it useful in all healthcare settings.

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

16 The committee also updated the recommendations on shared decision making from
17 [NICE’s guideline on patient experience in adult NHS services](#) and brought them into
18 this guideline.

19 ***After or between appointments***

20 The committee highlighted that interventions to support shared decision making
21 should carry on after appointments because they should be part of a continuing
22 process. They agreed on some methods to support people who might need
23 additional help, such as suggesting that they record the appointment on their phone
24 or other electronic device to help them remember discussions and think about their
25 options.

26 ***Future research***

27 The committee made research recommendations to fill the most notable gaps in the
28 evidence. They agreed that research was needed into how the same shared
29 decision making interventions differ in effectiveness between different populations
30 and different care settings so they made a [recommendation for research on differing](#)

1 [intervention effects in different groups](#). The committee also noted from the evidence
2 that it was unclear what the best measures of shared decision making are and how
3 acceptable different interventions are to people who receive them, so they also made
4 [recommendations for research about measuring shared decision making](#) and [the](#)
5 [acceptability of shared decision making](#).

6 **How the recommendations might affect services**

7 The recommendations will help to increase the use of shared decision making in
8 day-to-day clinical practice by indicating which methods to support it are effective.
9 Some of the options in the recommendations may require additional resources, for
10 example using a healthcare worker to provide third party support, but others can be
11 integrated into current practice, for example encouraging a person to record their
12 appointment. There is also a potential that, in some healthcare settings,
13 appointments may need to be longer and this could represent a substantial resource
14 impact.

15 [Return to recommendations](#)

16 **Patient decision aids**

17 [Recommendations 1.3.1 to 1.3.5](#)

18 **Why the committee made the recommendations**

19 There was strong evidence to support using patient decision aids before, during and
20 between appointments. However, the committee wanted to make it clear that
21 decision aids alone do not deliver shared decision making but should be seen as one
22 component of a wider approach. There would never be a patient decision aid
23 available to support every conversation, and healthcare professionals still need to
24 have the skills described in this guideline to engage people in making shared
25 decisions even when decision aids are available.

26 The committee agreed that for patient decision aids to be most useful, they had to be
27 drawn from a maintained library to ensure they are of high quality and up to date.
28 They also highlighted that even though the evidence favoured using patient decision
29 aids, it is crucial to provide them to people in formats they can use and understand
30 otherwise they would not be useful. In the committee's view, organisations have a

1 responsibility to make sure that a database of good-quality decision aids is available
2 to their staff in many different formats and that systems support using them in
3 different ways. In the committee's experience, accessing decision aids in suitable
4 formats is not always possible – for example, facilities to print out decision aids are
5 not always available in consulting rooms across organisations, and some decision
6 aids cannot be printed because of their format, for example if they have a block
7 colour background that uses a lot of ink.

8 **How the recommendations might affect practice**

9 The committee agreed that there were many good quality patient decision aids that
10 practitioners could use and that more were being developed all the time. Many of
11 them are freely available. Setting up and maintaining a library of decision aids could
12 have a moderate resource impact, but the committee noted that these could be set
13 up in collaboration with other organisations to maximise 'economies of scale'. The
14 committee also noted that there might be some resource impact of printing more
15 material for people.

16 [Return to recommendations](#)

17 **Communicating risks, benefits and consequences**

18 [Recommendations 1.4.1 to 1.4.11](#)

19 **Why the committee made the recommendations**

20 The committee updated recommendations on communicating risks and benefits from
21 [NICE's guideline on patient experience in adult NHS services](#) and brought them into
22 this guideline. They agreed to broaden the wording of the recommendations to risks,
23 benefits and consequences, because the term 'risk' can have negative connotations
24 when used on its own in discussions with people using services. Some implications
25 are neither risks nor benefits, but are still important for decision making (for example,
26 whether a particular treatment option will affect the person being able to drive).

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

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

11 The committee wanted risks and benefits to be personalised using high-quality
12 numerical data where these are available. Ideally, healthcare professionals would be
13 able to provide personalised risk calculations. However, the committee
14 acknowledged that personalised risk information is often not available. This means
15 healthcare professionals often need to use generalised information about risks,
16 benefits and consequences (often available in good quality decision aids) and
17 explain to the person how it relates to them (for example, above average, average or
18 below average levels of risk). In this case, explaining how much uncertainty
19 surrounds these estimates will help people interpret that information and what it
20 means for them.

21 **How the recommendations might affect practice**

22 These recommendations will help practitioners explore risk, benefits and
23 consequences of healthcare decisions with people. The committee noted that since
24 these recommendations have been in place since 2012, there should be no resource
25 impact.

26 [Return to recommendations](#)

27 **Context**

28 Shared decision making is a collaborative process that involves a person and their
29 healthcare professional working together to reach a joint decision about care. It could
30 be care the person needs straightaway or care in the future, for example through

1 advance care planning. It involves choosing tests and treatments based both on
2 evidence and on the person's individual preferences, beliefs and values. It means
3 making sure the person understands the risks, benefits and possible consequences
4 of different options through discussion and information sharing. This joint process
5 empowers people to make decisions about the care that is right for them at that time
6 (with the option of choosing to have no treatment always included).

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

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

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

30 The [General Medical Council's guidance on decision making and consent](#) (published
31 in 2020) says that healthcare professionals should discuss 'risks of harm and

1 potential benefits that the patient would consider significant for any reason. These
2 will be revealed during your discussion with the patient about what matters to them'.
3 It also states that they should discuss 'any risk of serious harm, however unlikely it is
4 to occur'.

5 **Finding more information and committee details**

6 To find out what NICE has said on topics related to this guideline, the [NICE web](#)
7 [page on patient and service user care](#).

8 For details of the guideline committee see the [committee member list](#).

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