

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Shared decision making

NHS England has asked NICE to develop a guideline on shared decision making.

The guideline will be developed using the methods and processes outlined in [developing NICE guidelines: the manual](#).

This guideline will also be used to develop the NICE quality standard for shared decision making.

1 Why the guideline is needed

Context

- Shared decision making is a collaborative process. It involves healthcare professionals and people who use services working together to choose tests, treatments, management or support packages, based on evidence and the person's personal informed preferences 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 a decision about the treatment and care that is right for them at that time.
- Shared decision making is applicable in all healthcare settings (acute, chronic, palliative and preventative care) whenever there is more than one NHS treatment or management option available (options include doing nothing).

Current practice

- Although the benefits of shared decision making are increasingly being recognised it is not yet routinely practised. National surveys have shown

1 that people want to be more involved in decisions about their care (44% of
2 inpatients and over 30% of primary care patients).

- 3 • The benefits of involving people in decisions about their care may include:
 - 4 – fewer regrets about decisions
 - 5 – less uncertainty in making a choice
 - 6 – people being better informed and making decisions aligned with their
 - 7 values
 - 8 – better communication between people and their clinicians
 - 9 – better adherence to an agreed treatment plan
 - 10 – people reporting a better experience, including more satisfaction with the
 - 11 outcome
 - 12 – reducing unwarranted variation in clinical practice.

13 **Policy, legislation, regulation and commissioning**

- 14 • A landmark ruling was made in 2015 by the UK Supreme Court following
15 the Montgomery v Lanarkshire case. A new legal standard set out that
16 adults ‘of sound mind’ are entitled to make informed decisions when giving
17 or withholding consent to treatment. Consent ‘must be obtained before
18 treatment interfering with bodily integrity is undertaken’, and it should only
19 be gained when patients have shared a decision informed by what is
20 known about the risks, benefits and consequences of all reasonable NHS
21 treatment options. It is the doctor’s duty to ‘take reasonable care’ to make
22 sure patients are ‘aware of any material risks involved in proposed
23 treatment, and of reasonable alternatives’. A risk is considered ‘material’ if
24 ‘a reasonable person in the patient’s position would be likely to attach
25 significance to it, or if the doctor is or should reasonably be aware that their
26 patient would be likely to attach significance to it’.
- 27 • 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
29 to be given information and support to enable this. In line with this, the
30 [Health and Social Care Act 2012](#) makes clear the duties on the NHS
31 Commissioning Board and the clinical commissioning groups to promote

1 the involvement of patients and carers in decisions about their care and
2 treatment, and to enable patient choice. The Department of Health and
3 Social Care's [NHS Choice Framework](#) sets out the choices that people can
4 expect to be offered, and information to support these choices.
5 Correspondingly, the General Medical Council provides guidance to
6 support doctors in making shared decisions with their patients about
7 treatment and care. NHS England is supporting the implementation of
8 shared decision making across care pathways at national and local level
9 through its NHS RightCare [shared decision making programme](#).

10 **2 Who the guideline is for**

11 This guideline is for:

- 12 • Adults, young people and children using healthcare services, their families,
13 carers and advocates, and the public
- 14 • Everybody who delivers healthcare services
- 15 • Commissioners of health and public health services

16 It may also be relevant for:

- 17 • Social care professionals

18 NICE guidelines cover health and care in England. Decisions on how they
19 apply in other UK countries are made by ministers in the [Welsh Government](#),
20 [Scottish Government](#), and [Northern Ireland Executive](#).

21 ***Equality considerations***

22 NICE has carried out [an equality impact assessment](#) during scoping. The
23 assessment:

- 24 • lists equality issues identified, and how they have been addressed
- 25 • explains why any groups are excluded from the scope.

1 **3 What the guideline will cover**

2 **3.1 Who is the focus?**

3 **Groups that will be covered**

- 4 • Adults, young people and children using healthcare services
- 5 • Families, carers and advocates of adults, young people and children using
- 6 healthcare services

7 **Circumstances that will not be covered**

- 8 • Unexpected life-threatening emergency needing immediate life-saving
- 9 care.
- 10 • Situations in which people lack mental capacity^{1,2} to make their own
- 11 decisions about healthcare at that time.

12 **3.2 Settings**

13 **Settings that will be covered**

14 The guideline will cover all settings, including people's own homes, where
15 publically funded healthcare services are commissioned and provided.

¹ The [Mental Capacity Act code of practice](#) states that lack of mental capacity can fluctuate. It says that examples of an impairment or disturbance in the functioning of the mind or brain may include: conditions associated with some forms of mental illness, dementia, significant learning disabilities, the long-term effects of brain damage, physical or medical conditions that cause confusion, drowsiness or loss of consciousness, delirium, concussion following a head injury, and the symptoms of alcohol or drug use.

² This guideline will cross refer to NICE's guideline on [decision-making and mental capacity](#) which covers people 16 years and over who may lack capacity now or in the future. It aims to help health and social care practitioners support people to make their own decisions where they have the capacity to do so. It also helps practitioners to keep people who lack capacity at the centre of the decision-making process.

1 **3.3 Activities, services or aspects of care**

2 **Key areas that will be covered**

3 We will look at evidence in the areas below when developing the guideline,
4 but it may not be possible to make recommendations in all the areas.

5 1 Supporting and promoting shared decision making

6 2 Shared decision making in the healthcare system

7 **Areas that will not be covered**

8 1 Whether shared decision making is required

9 2 Areas covered by NICE's guideline on [patient experience in adult NHS](#)
10 [services](#). NICE guideline CG138

11 3 Areas covered by NICE's guideline on [service user experience in adult](#)
12 [mental health](#). NICE guideline CG136

13 4 Areas covered by NICE's guideline on [decision-making and mental](#)
14 [capacity](#). NICE guideline NG108

15 **Related NICE guidance**

16 ***Published***

- 17 • [Decision-making and mental capacity](#) (2018) NICE guideline NG108
- 18 • [People's experience in adult social care services](#) (2018) NICE guideline
19 NG86
- 20 • [Care of dying adults in the last days of life](#) (2015) NICE guideline 31
- 21 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 22 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 23 • [Service user experience in adult mental health](#) (2011) NICE guideline
24 CG136
- 25 • [Medicines adherence](#) (2009) NICE guideline CG76

26 ***In development***

- 27 • [Infant, children and young people's experience of healthcare](#). NICE
28 guideline. Publication expected 2021

- 1 • [Shared decision-making: practical guidance for health and social care](#)
- 2 [professionals](#). NICE quality standard. Publication date to be confirmed
- 3 • [Supporting decision-making for people who lack mental capacity](#). NICE
- 4 quality standard. Publication date to be confirmed

5 **3.4 Economic aspects**

6 We will take resource impact into account when making recommendations.

7 **3.5 Key issues and draft questions**

8 While writing this scope, we have identified the following key issues and draft
9 questions related to them:

- 10 1 Supporting shared decision making
- 11 1.1 What are the most effective approaches and activities to support the
- 12 following groups to engage with shared decision making:
- 13 (a) people using services, and their families, carers and advocates?
- 14 (b) healthcare providers?
- 15 1.2 What are the barriers to, and facilitators for, engagement with shared
- 16 decision making by:
- 17 (a) people using services, and their families, carers and advocates?
- 18 (b) healthcare providers?
- 19 1.3 What are the core components of effective shared decision making
- 20 approaches and activities?
- 21
- 22 2 Shared decision making in the healthcare system
- 23 2.1 What are the most effective approaches and activities to embed
- 24 shared decision making into the healthcare system?
- 25 2.2 What are the most effective approaches and activities to embed
- 26 shared decision making into patient culture?
- 27

28 The NICE guidelines on [patient experience in adult NHS services](#) and [service](#)
29 [user experience in adult mental health](#) contain related recommendations. The
30 guideline will cross-refer to these recommendations as appropriate.

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2 The key issues and draft questions will be used to develop more detailed
3 review questions, which guide the systematic review of the literature.

4 **3.6 Main outcomes**

5 The main outcomes that may be considered when searching for and
6 assessing the evidence are:

- 7 1 engagement in shared decision making by healthcare providers' and
8 people who use services and their families, carers and advocates
- 9 2 wellbeing and quality of life (including physical health, mental health and
10 social wellbeing)
- 11 3 changes in knowledge, intentions, ability and confidence about
12 undertaking shared decision making for healthcare providers' and people
13 who use services and their families, carers and advocates
- 14 4 satisfaction with shared decision making of people who use services
15 (including perceptions of how satisfied they are from their family
16 members, carers and advocates)
- 17 5 unintended consequences

18 **4 NICE quality standards and NICE Pathways**

19 **4.1 NICE quality standards**

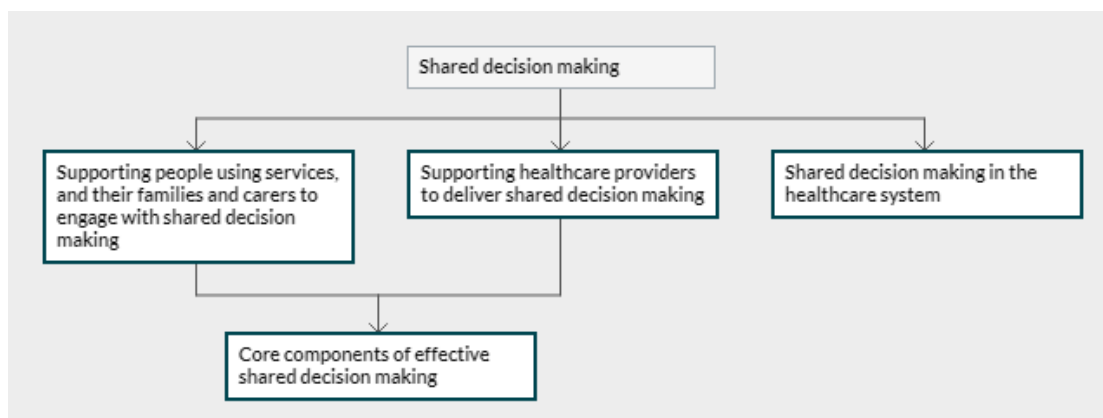
20 **NICE quality standards that will use this guideline as an evidence source**
21 **when they are being developed**

- 22 • [Shared decision-making: practical guidance for health and social care](#)
23 [professionals](#). NICE quality standard. Publication date to be confirmed

24 **4.2 NICE Pathways**

25 [NICE Pathways](#) bring together everything we have said on a topic in an
26 interactive flowchart. When this guideline is published, the recommendations
27 will be included in the NICE Pathway on shared decision making (in
28 development).

1 An outline based on this scope is included below. It will be adapted and more
2 detail added as the recommendations are written during guideline
3 development. Links will be added to relevant NICE Pathways, for example
4 [decision-making and mental capacity](#), [patient experience in adult NHS](#)
5 [services](#), and [service user experience in adult mental health services](#).



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8 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 18 January to 15 February 2019.

The guideline is expected to be published in April 2021.

You can follow progress of the [guideline](#). Our website has information about how [NICE guidelines](#) are developed.

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