

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

- Shared decision making is applicable across all healthcare settings, in situations where there is more than one possible NHS care or treatment option (options include doing nothing).

### **Current practice**

- Although the benefits of shared decision making are increasingly being recognised it is not yet routinely practised. National surveys have shown that many people want to be more involved in decisions about their care (44% of inpatients and over 30% of primary care patients).
- The benefits of involving people in decisions about their care may include:
  - greater satisfaction with decisions
  - greater understanding about the risks and benefits of the available options
  - people being better informed and making decisions aligned with their values
  - better communication between people and their healthcare practitioner, including people feeling that they have ‘been heard’
  - facilitating trust between people and their healthcare practitioner
  - better concordance with an agreed treatment plan
  - people reporting a better experience of care, including more satisfaction with the outcome

### **Policy, legislation, regulation and commissioning**

- A landmark ruling was made in 2015 by the UK Supreme Court following the Montgomery v Lanarkshire case. A new legal standard set out that adults ‘of sound mind’ are entitled to make informed decisions when giving or withholding consent to treatment. Consent ‘must be obtained before treatment interfering with bodily integrity is undertaken’, and it should only be gained when patients have shared a decision informed by what is known about the risks, benefits and consequences of all reasonable NHS treatment options. It is the healthcare professional’s duty to ‘take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative

or variant treatments'. A risk is considered 'material' if 'a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it'.

- 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. In line with this, the [Health and Social Care Act 2012](#) makes clear the duties on the NHS Commissioning Board and the clinical commissioning groups to promote the involvement of patients and carers in decisions about their care and treatment, and to enable patient choice.
- Shared decision making links in with personalised care, which is one of the practical changes to the NHS that will take place over the next 5 years, as set out by the recently published [NHS Long Term Plan](#). This will see people have more choice and control over how their mental and physical healthcare needs are met. To achieve personalised care, people will need to be involved in the decision-making process and be supported to elicit the outcomes that matter most to them and how best to achieve these outcomes. NHS England is supporting the implementation of shared decision making across care pathways at national and local level through its Personalised Care Group's [shared decision making programme](#).
- The General Medical Council provides guidance on [consent](#) to support doctors in making shared decisions with their patients about treatment and care, and to help make sure they have informed consent from their patient.

## 2 Who the guideline is for

This guideline is for:

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

It may also be relevant for:

- People who use social care services
- Social care practitioners

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

### ***Equality considerations***

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

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

## **3 What the guideline will cover**

### **3.1 *Who is the focus?***

#### **Groups that will be covered**

- Adults (aged 18 years and over) using healthcare services, and their families, carers and advocates if they choose to involve them

#### **Circumstances that will not be covered**

- Unexpected life-threatening emergency needing immediate life-saving care.

- Situations in which people lack mental capacity<sup>1,2</sup> to make their own decisions about healthcare at that time.

## **3.2 Settings**

### **Settings that will be covered**

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

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

### **Key areas that will be covered**

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

- 1 Supporting and promoting shared decision making in healthcare
- 2 Shared decision making in the healthcare system

### **Areas that will not be covered**

- 1 Whether shared decision making is required
- 2 Areas covered by NICE's guideline on [service user experience in adult mental health](#)
- 3 Areas covered by NICE's guideline on [decision-making and mental capacity](#)

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<sup>1</sup> The [Mental Capacity Act code of practice](#) gives examples of impairments or disturbances in the functioning of the mind or brain that affect capacity as including: 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. The code also states that mental capacity can fluctuate so that people may be able to make decisions at some times but not others.

<sup>2</sup> 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.

## Related NICE guidance

### *Published*

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

### *In development*

- [Infant, children and young people's experience of healthcare](#). NICE guideline. Publication expected April 2021
- [Shared decision-making: practical guidance for health and social care professionals](#). NICE quality standard. Publication date to be confirmed
- [Supporting decision-making for people who lack mental capacity](#). NICE quality standard. Publication date to be confirmed

### *NICE guidance that will be updated by this guideline*

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138  
(When this shared decision making guideline is published, the recommendations relating to shared decision making in [patient experience in adult NHS services](#) (NICE guideline CG138) will be stood down)

## **3.4 Economic aspects**

We will take resource impact into account when making recommendations.

### **3.5 Key issues and draft questions**

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

- 1 Supporting shared decision making in healthcare
  - 1.1 What are the most effective approaches and activities to support the following groups to engage with shared decision making:
    - (a) people using healthcare services, and their families, carers and advocates?
    - (b) healthcare providers?
  - 1.2 What are the barriers to, and facilitators for, engagement with shared decision making by:
    - (a) people using healthcare services, and their families, carers and advocates?
    - (b) healthcare providers?
  - 1.3 What are the core components of effective shared decision making approaches and activities?
- 2 Shared decision making in the healthcare system
  - 2.1 What are the most effective approaches and activities to normalise shared decision making in the healthcare system?

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

### **3.6 Main outcomes**

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

- 1 engagement in shared decision making by healthcare providers and people who use healthcare services and their families, carers and advocates

- 2 wellbeing and quality of life (including physical health, mental health and social wellbeing)
- 3 changes in knowledge, intentions, culture, norms, ability and confidence in relation to undertaking shared decision making among healthcare providers and people who use healthcare services and their families, carers and advocates
- 4 satisfaction with shared decision making of people who use healthcare services (including perceptions of how satisfied they are from their family members, carers and advocates)
- 5 unintended consequences

## **4 NICE quality standards and NICE Pathways**

### **4.1 NICE quality standards**

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

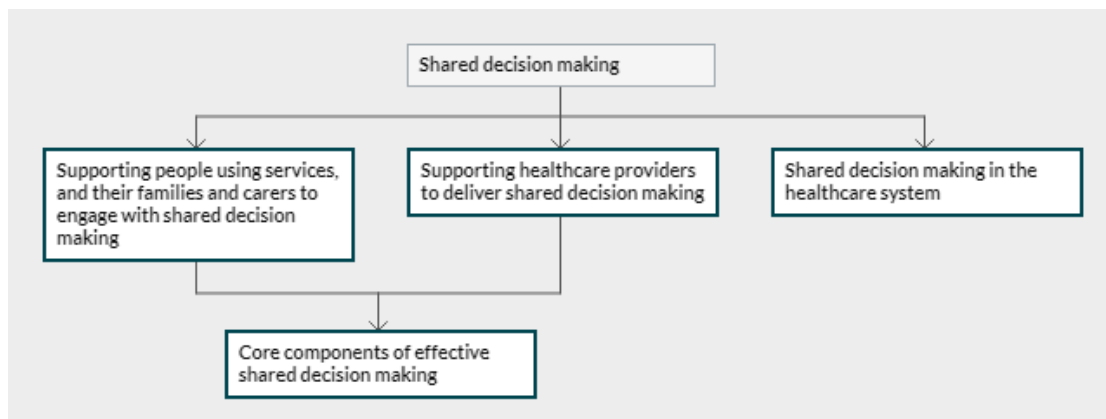
- [Shared decision-making: practical guidance for health and social care professionals](#). NICE quality standard. Publication date to be confirmed

### **4.2 NICE Pathways**

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

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





## 5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

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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