

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### Decision-making and mental capacity

#### *Topic*

The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 and over<sup>1</sup>. The guideline will help health and social care practitioners to:

- support people to make their own decisions as far as possible
- assess people's capacity to make specific health and social care decisions
- make specific best interests decisions when people lack capacity, and maximise the person's involvement in those decisions.

This may include decisions about where and how people live, their support, care and treatment and their security or safety.

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

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

#### ***Who the guideline is for***

- People using health and social care services who may (now or in the future) lack mental capacity, and their families and carers.
- Health practitioners working with people who may lack mental capacity.

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<sup>1</sup> The definition of adults includes young people aged 16 and 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

- Social care practitioners (including personal assistants) working with people who may lack mental capacity.
- Advocates, including independent mental capacity advocates, Care Act advocates and independent mental health advocates.

The guideline will also be relevant for:

- Practitioners working in services (including housing, education, employment, police and criminal justice) who may come into contact with people who lack mental capacity.
- Local authorities and clinical commissioning groups.
- Social care and health providers.
- Community and voluntary organisations representing or supporting people who may lack mental capacity, and their families and carers.
- Guardians (under the Mental Health Act), court appointed deputies and those who hold power of attorney.

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.

The guideline will look at inequalities relating to:

- people who may lack mental capacity and who also have a sensory, cognitive or physical impairment
- people with mental health problems, including those subject to the Mental Health Act
- people detained under the Mental Health Act or those who are subject to Deprivation of Liberty Safeguards (DoLS) or are under court order

- people with communication difficulties
- people with complex needs and long-term conditions
- people at risk of self-neglect
- people for whom English is a second or additional language
- people who do not have support from family members
- young people (aged 16 and 17 years) who may lack mental capacity, as practitioners may not be aware that they are covered by the Mental Capacity Act
- young people and young adults aged up to 25 years who may lack mental capacity and are making a transition from children's to adults' services.

## **1 What the guideline is about**

### **1.1 *Who is the focus?***

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

All people aged 16 years and over:

- who may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions.
- whose capacity to make specific decisions about aspects of their care may need to be assessed.
- when specific best interest decisions are being made on their behalf if they are assessed as lacking capacity.

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
- the symptoms of alcohol or drug use.

### **Groups that will not be covered**

- Children aged under 16 years who lack the capacity to make decisions their care, support or treatment.

## **1.2 Settings**

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

Any settings where health and social care practitioners are involved in supporting decision-making by, or making best interests decisions on behalf of, people who may lack the mental capacity to make particular decisions for themselves.

- Community settings including:
  - The person's own home.
  - Extra care, supported housing, shared lives schemes.
  - Primary healthcare, outpatients and day hospitals.
- Care homes of any type (including specialist homes).
- Inpatient settings including:
  - Secondary and acute healthcare settings.
  - Mental health inpatient settings.
- Hospices and palliative care settings.
- Educational settings.
- Criminal justice settings, including prisons.
- Family courts.

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

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

## Key areas that will be covered

- 1 Support for people who need help from health or social care professionals to make their own decisions.
- 2 Support for people to plan in advance for decision-making, especially if they have a condition likely to cause changes in mental capacity.
- 3 Interventions, tools and approaches to involve and support people, on the presumption of capacity, to make decisions for themselves wherever possible, including:
  - how to provide information
  - how to involve family members, carers, independent advocates and other people with an interest in the person's welfare, with the person's consent
  - safeguarding in the context of supporting decision-making, including consideration of risk.
- 4 Approaches to assessment of mental capacity when a decision needs to be made, including:
  - when assessments should be considered
  - the nature of the decision
  - the timing of the assessment
  - who should carry out assessment
  - methods and tools for conducting and recording assessments
  - the possibility that an assessment may be refused.
- 5 Involvement in best interests decision-making, when people have been assessed as lacking capacity, to make decisions about:
  - where they live
  - personal choices about how they live, including relationships
  - day to day decisions about daily living
  - care and support
  - treatment options
  - medical tests
  - assistive technologies and equipment
  - safety and risk management.

- 6 Interventions, tools and approaches to support making best interests decisions on behalf of people who have been assessed as lacking capacity to make a particular decision, including:
  - how to maximise the person's involvement in making the decision
  - approaches to determining what is in the person's best interests
  - ways of identifying family members, carers, independent advocates and others with an interest in the person's welfare, and supporting them to participate in decision-making
  - approaches to providing independent advocacy (independent mental capacity advocates, independent mental health advocates or Care Act advocates) for the person
  - how to use DoLS and applications to the Court of Protection as needed
  - safeguarding, including consideration of risk and in relation to the person's best interests

#### **1.4 Economic aspects**

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an individual and societal perspective, as appropriate.

#### **1.5 Key issues and questions**

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

- 1 Planning in advance, including for people who experience fluctuating capacity
  - 1.1 What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity?

- 1.2 What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
- 2 Supporting decision-making on the presumption of mental capacity
  - 2.1 What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?
  - 2.2 What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
- 3 Assessment of mental capacity
  - 3.1 What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity?
  - 3.2 What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
- 4 Best interests decision-making for those who have been assessed as lacking the mental capacity to make a specific decision.
  - 4.1 What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making?
  - 4.2 What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?

## **1.6 Main outcomes**

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

- 1 Person-focused outcomes.
  - People being enabled to make decisions about their own lives.

- Participate as fully and effectively as possible in a decision made in their best interests.
  - Dignity, human rights and rights under the [Mental Capacity Act 2005](#).
  - Independence and social inclusion.
  - Consideration of least restrictive options.
- 2 Service outcomes.
- Competence and confidence of practitioners to uphold the principles of the Mental Capacity Act and the [Care Act 2014](#).
  - Transparency and quality of recording.
  - Efficient and effective use of resources.

## 2 Links with other NICE guidance, NICE quality standards and NICE Pathways

### 2.1 NICE guidance

#### **NICE guidance about the experience of people using NHS services**

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to supporting people who may lack mental capacity.

- [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

#### **NICE guidance that is closely related to this guideline**

##### ***Published***

NICE has published the following guidance that is closely related to this guideline:

- [Transition between inpatient mental health settings and community and care home settings](#) (2016) NICE guideline NG53

- [Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes](#) (2015) NICE guideline NG5
- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31
- [Developing and updating local formularies](#) (2014) NICE guideline MPG1
- [Managing medicines in care homes](#) (2014) NICE guideline SC1
- [Service user experience in adult mental health; improving the experience of care for people using adult NHS mental health services](#) (2011) NICE guideline CG136
- [Dementia: supporting people with dementia and their carers in health and social care](#) (2006) NICE guideline CG42

### ***In development***

NICE is currently developing the following guidance that is closely related to this guideline:

- [Mental health problems in people with learning disabilities](#) NICE guideline. Publication expected September 2016
- [Dementia: assessment, management and support for people living with dementia and their carers](#) (update) NICE guideline. Publication expected September 2017
- [Managing medicines for adults receiving social care in the community](#) NICE guideline. Publication expected March 2017
- [Care and support of older people with learning disabilities](#) NICE guideline. Publication expected May 2018
- [Supportive and palliative care in adults](#) (update) NICE guideline. Publication expected January 2018
- [People's experience in adult social care services: improving the experience of care for people using adult social care services](#) NICE guideline. Publication expected January 2018

## **2.2 NICE quality standards**

- [Medicines optimisation](#) (2016) NICE quality standard 120
- [Medicines management in care homes](#) (2015) NICE quality standard 85
- [Dementia: independence and wellbeing](#) (2013) NICE quality standard 30

- [Service user experience in adult mental health services](#) (2011) NICE quality standard 14
- [Dementia: support in health and social care](#) (2010) NICE quality standard 1

## **2.3 NICE Pathways**

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

# **3 Context**

## **3.1 Key facts and figures**

This guideline is about supporting people to make their own decisions when they are able and assessing people's capacity to make specific decisions about their health and social care. It is also about best interests decision-making on behalf of people who are assessed as lacking the mental capacity to make specific decisions for themselves. People's capacity may fluctuate for a number of reasons. Lack of mental capacity may be a temporary result of illness, treatment or substance abuse, or an ongoing organic impairment, such as dementia, learning disability or brain injury.

The [Care Quality Commission](#) estimates that around 2 million people in England and Wales may lack the capacity to make certain decisions for themselves at some point because of illness, injury or disability. Many of these people will be supported to make those decisions, or have best interests decisions made on their behalf, as part of their routine care and support. A smaller number need specific supports and safeguards in relation to mental capacity.

The [Independent Mental Capacity Advocacy Service: 7th annual report](#) states that 13,301 referrals were received in 2013–14: more than double the number in 2007–2008. The majority of referrals (64%) were for adults aged 66 and over. The most common mental impairments associated with a referral to the Independent Mental Capacity Advocacy service were dementia (42%), learning disability (14%) and mental health problems (13%).

Similarly, [statistics from NHS Digital](#) (formerly the Health and Social Care Information Centre) report that there has been a year-on-year increase in applications to local authorities for deprivation of liberty under the DoLS since their introduction in 2009–10, with 137,540 applications made in 2014–15. The majority of applications (61%) in 2012–13 were completed on behalf of people with mental health conditions, with dementia accounting for more than half (51%).

It is difficult to estimate the costs of supporting decision-making people who may lack mental capacity, particularly as many of the costs will be embedded in the overall provision of support and services. Some research (Shah et al. Deprivation of Liberty Safeguards in England: implementation costs, 2011) suggests that the cost of undertaking a DoLS assessment is higher than the initial government estimate of £600, with an average cost in 5 DoLS offices of £1,266 (95% confidence interval £506 to £2,048). But clearly this relates to only one aspect of practice in this area.

### **3.2 Current practice**

Practice under the [Mental Capacity Act 2005](#) must be underpinned by 5 statutory principles:

1. a person must be assumed to have capacity unless it is established that they lack capacity
2. a person is not to be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success
3. a person is not to be treated as unable to make a decision merely because they make an unwise decision
4. an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests
5. before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

A key additional element of practice is applying DoLS or making applications to court if restrictions and restraint used in the best interests of a person who

lacks mental capacity may deprive the person of their liberty. Under DoLS, it is illegal to restrict a person's liberty unless authorised by due legal process, which involves either the Court of Protection or the DoLS process, in hospitals and care homes.

In 2014 the House of Lords Select Committee on the Mental Capacity Act published its [post-legislative scrutiny report](#). Its key findings were that the Mental Capacity Act is not widely and adequately implemented. In particular:

- the 'empowering ethos' of the Act has not been widely implemented
- the prevailing culture is one of risk aversion and paternalism
- the wishes, thoughts and feelings of the person are not routinely prioritised.

The Select Committee report suggests that there is a general lack of awareness of the provisions of the Act, as well as of the rights and responsibilities of different stakeholders as conferred under the Act. It also suggests that many practitioners misunderstand the presumption of mental capacity. Particular concern was expressed about the assessment of capacity in adults with specific conditions such as Down's syndrome, autism and brain injury.

The report also identified that DoLS are frequently not applied when they should be, and that the complexity of the legislation can cause confusion.

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

#### **Policy, legislation, regulation and guidance**

The [Mental Capacity Act 2005](#), including DoLS (and its accompanying [Code of Practice](#)), provides the legal framework around decision-making and mental capacity. This includes acting and making a decision on behalf of people who have been assessed as lacking the mental capacity to make decisions for themselves.

But, as highlighted by the [Select Committee report](#), practitioners can struggle to implement the provisions of the Act. This guideline aims to provide evidence-based recommendation on how best to apply the Act and Code of

Practice, focusing on interventions, practices and approaches that have been shown to be effective.

In developing the guideline, we will need be aware that the Law Commission has undertaken a consultation on DoLS, and is expected to publish a report and draft Bill proposing changes to these arrangements in 2016.

In developing the guideline we will also need to be aware of the following pieces of legislation:

- the [Care Act 2014](#) which introduced new legislation to ensure that people's wellbeing and the outcomes that matter to them are at the heart of every decision made. It also introduced new rights to advocacy. The principles of the Care Act could be said to underpin the legislation on supporting decision-making
- the [Mental Health Act 1983](#) (amended by the [Mental Health Act 2007](#)), which governs the involuntary admission, treatment and detention of people in mental health inpatient settings.

Practice in this area is also influenced by international law, including:

- the UN [Convention on the Rights of Persons with Disabilities](#), article 12 of which sets out the right to legal capacity on an equal basis with others
- the [European Convention on Human Rights](#), article 5 of which guarantees the right to personal liberty and provides that no-one should be deprived of their liberty in an arbitrary fashion.

## **Commissioning**

People who may lack mental capacity will be supported through a range of commissioning relationships, including:

- services provided directly by local authorities or the NHS
- independent sector providers commissioned by local authorities or clinical commissioning groups
- providers commissioned by people who use services, for example through the use of personal budgets or self-funding.

The guideline will need to reflect this range of commissioning relationships.

## Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in July 2018.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.