

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Decision-making and mental capacity

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?

(Please specify if the issue has been highlighted by a stakeholder)

The following equality issues were identified during the development of the scope by the NCCSC.

There may be a wide population of adults who lack mental capacity: Some will be affected by long-term learning disabilities or conditions, which impact their decision making abilities throughout their lives, while others, for example those who experience mental health problems can be affected by a temporary lack of capacity. People with conditions like dementia may be experiencing or expecting a decline in their capacity and others may be subject to episodic lapses in capacity to make specific decisions. People that fit into this group may include those who are affected by substance misuse issues or experience confusion, drowsiness or unconsciousness as a result of medication or treatment.

People with communication difficulties, and/or sensory impairment:

Communication strategies maximising choice and control, and safeguarding are important issues for people with communication difficulties. Sensory impairment and communication difficulties, including profound deafness and age-related sight degeneration and dysphasia, may also develop with or be exacerbated by age. Communication is potentially further hampered if the person's first language is not English.

People with mental health problems including those subject to the Mental Health Act:

People who are detained for treatment under the Mental Health Act may not be considered as subject to the provisions of the Mental Capacity Act or Deprivation of Liberty Safeguards. It is not clear what support to make decisions,

some of which may be life-changing, is available to people in secure mental health settings.

In most cases, loss of capacity caused by mental illness is temporary, and there may be capacity to take some decisions but not others. People with mental health problems may also have a right to an Independent Mental Health Advocate. Some individuals who lack capacity due to a learning difficulty, may also be more likely to “experience psychiatric disorders than adults generally.” (British Institute of Learning Disabilities).

People who are not known to care services: “Up to 25% of people with learning disabilities living with older family carers, are not known to services until there is a crisis” (Department of Health, 2001, quoted by the British Institute of Learning Disabilities). Not being identified as having learning disabilities may reinforce inequity of access to support to make important decisions, especially those which arise when family carers die or are no longer able to care.

People of minority ethnic background: Research suggests that minority status in cultural, religious and language characteristics among some people from black and minority groups disadvantages them in accessing social and health care and support. Within this population, disadvantage will be exacerbated by having a learning disability. Services should be sensitive and responsive to different cultural and religious requirements and the difficulties in accessing services that these groups may face. Recent migrants, including refugees and asylum seekers, and people who do not speak English as their first language are likely to have reduced knowledge of, and hence access to, social care services.

People with learning disability and other co-morbidities: Certain conditions such as cerebral palsy, autism and epilepsy, are associated with learning disability because people with these conditions are more likely to have a learning disability. “All people with learning disabilities are at greater risk of developing dementia than the general population (22% vs 6% aged 65 and above) (British Institute of Learning Disabilities). People with learning disabilities are also more likely to develop other health conditions common in older age – such as osteoporosis and diabetes – when they are younger, and services to address these conditions may not provide appropriate support to people who also have learning disabilities to take decisions. People with some categories of learning disability who may lack capacity may be necessarily involved in more complex choices about clinical care than are people in the general population.

People on the autism spectrum who do not have a learning disability, people with neurodegenerative diseases (such as Parkinson’s Disease and people with acquired injuries may find themselves in situations where they are discriminated against due to the **fluctuating** nature of these conditions and how they might be perceived.

People at end of life: People who lack capacity will approach end of life, and are possibly less likely than the general population to have been supported to make advance decisions. Providing end of life care which accords with their wishes, needs and comfort may be a particular challenge for services.

People who live alone: Older people who live alone and may lack capacity to determine their own best interests may not come to the attention of services until a crisis occurs. People who live alone may then be particularly vulnerable to unmet need in all aspects of daily living and care and be at risk of neglect or self-neglect.

People in prison: Older people with learning difficulties may be over-represented in the prison population, which is known to be ageing. Where evidence is available, the support needs of this group will be considered as Local Authorities have responsibility for their wellbeing (Care Act, 2014).

Family carers and other supportive carers: Although there may be no review area that concerns only carers, the role of carers is in scope because:

- They are often involved in accessing, monitoring and critiquing care and support services, and acting as informal advocates for a person who lacks capacity.
- The care of adults with cognitive impairment is often supplied by parents, by children or other relatives, which means that they may be experts in the person's needs and probable wishes.
- Decisions in the best interests of the person may depend on the presence of a willing carer to give insight into what the person might have wanted.
- Costs of unpaid care will be included in the economic approach.

People who lack capacity and do not have family or other unpaid carer support may then be disadvantaged by not having this source of informal advocacy.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

The population included in the scope for this guideline is broad. The guideline will take into account adults and older people who lack the capacity, or will lack the capacity in the future to make decisions about aspects of their care and support. The focus of the guideline is on adults and so children and young people under 16 are excluded from the scope. The stakeholder workshop agreed that young people 16-18 years is a high risk group, especially those in transition between children's and

adults' services, and supported their inclusion in the scope. It was further noted that early intervention services for psychosis start at 14 years with planning for three years. However, it was agreed that this, in itself, did not justify inclusion of people younger than 16 within the scope of this guideline.

Plans for incorporating material on people who may be disadvantaged in being supported to make decisions include sensitivity to equality and diversity issues, and search strategies specifically oriented to seek out material on these groups. The identified groups may have difficulty in accessing general care services, advocacy and other support, because there is no provision of support to make decisions to do so. The guideline will address the organisation and delivery of decision-making support that can work in health, social care and housing, including the provision of appropriate advice and information to maximise participation and support access to personalised services. The guideline will attempt to uncover and address some of the areas where there is well-documented discrimination. The Guideline Committee may also make recommendations specifically in relation to particular service users and carers.

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?

Yes, stakeholders requested that specific reference should be made in the scope to ethnicity and cultural considerations, literacy issues, socio-economic status, multi-morbidities, LGBT specific issues, pregnant women, young people and those whose first language is not English.
Stakeholders also argued that stroke survivors and those with an acquired brain injury should be included as a group for special consideration.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

These issues have not been added to the scope document. In some cases stakeholders were signposted to their existing presence in section 1.0 (for example, the challenges for those who do not speak English are already addressed in section 1.1 of the EIA) or their addition to the EIA in section 2.2 (see below).

Ethnicity and cultural issues: It is key that the particular cultural needs of BAME communities and other migrant groups are considered in relation to mental capacity. There is evidence that some groups are more likely to develop capacity limiting mental health issues than other populations. The needs of carers from BAME communities should also be considered and cultural sensitivity is necessary.

Literacy issues: literacy issues may be linked to a disability, communities that experience low levels of literacy (including BAME communities) and can affect a person's ability to engage in decisions about their care and support and their ability to access information made appropriate for their needs.

LGBT groups: There was concern from stakeholders that assumptions may be made about personal relationships and LGBT individuals may wish to specify who they wish to provide support, this may be an independent person.

Socio economic status: The inequalities relating to socio-economic deprivation should be considered; in terms of the susceptibility of people from more deprived backgrounds to develop mental health issues and their access to services, carers from poorer socio economic backgrounds may also struggle to provide unpaid care.

Acquired brain injury, including those resulting from a stroke. Those who are affected by an acquired brain injury may experience a sudden loss of capacity, and also increase their likelihood of developing of co-morbidities, such as the relationship between stroke and dementia. Stakeholder identified the importance of recognising the importance of differentiating between someone who lacks the capacity to make a decision, and someone who has capacity but is unable to articulate that decision.

Pregnant women: Pregnant women (who have a condition that may limit their capacity) may be making decision for herself and in the interests of her child.

Young people: Young people (aged over 16) may be experiencing conditions that can affect their capacity, such as Anorexia Nervosa. Stakeholders had concerns that parents and caregivers can be excluded form decision making, due to confidentiality issues, despite sometimes providing a significant amount of care. There may be a lack of guidance on how to support caregivers in this situation.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need?

If so, is an alternative version of the 'Information for the Public' document recommended?

If so, which alternative version is recommended?

The alternative versions available are:

- large font or audio versions for a population with sight loss;
- British Sign Language videos for a population who are deaf from birth;
- 'Easy read' versions for people with learning disabilities or cognitive impairment.

Yes, the population for this guideline may include older people and a wide range of people who may lack capacity. Some members of this group may have conditions that make them more likely to have communication difficulties and other sensory impairments, including sight loss.

Updated by Developer: Carolyn Denne

Date: 03 August 2016

Approved by NICE quality assurance lead: Fiona Glen

Date: August 2016

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

People with communication difficulties, and/or sensory impairment: The importance of taking steps to support people making advance care plans who may find it difficult to communicate their wishes is stressed throughout the Guideline. For example draft recommendation 1.3.9 states that health and social care practitioners should empower everyone to make advance care plans by providing communication support appropriate to their needs. Draft recommendation 1.2.3 states that practitioners supporting a person's decision making should build and maintain a trusting relationship with them, so that they have specialist knowledge of the person's communication needs which they can use to support the person's decision making. Draft recommendation 1.1.1 states that practitioners should have communication skills for building trust to support decision making. And draft recommendation 1.2.7 states that when providing information to support a particular decision, practitioners should assess the person's communication needs by supporting the person to identify, express and document their communication needs.

People with mental health problems including those subject to the Mental Health Act: While there are not currently specific recommendations about working with people with mental health problems including those who are subject to the Mental Health Act 1981, draft recommendation 1.4.17 does state that when a person's capacity is being assessed there should be clear referral routes for practitioners to seek advice from or assessments by colleagues from other relevant disciplines such as clinical psychology, old age psychiatry, speech and language therapists, occupational therapists and autism specialists.

People who are not known to care services: There are no recommendations specifically for working with people who are not known to care services. However, recommendations aimed at ensuring that any practitioner from any background is competent and supported to discuss or initiate advance care planning, that people

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

can easily access information about advance care planning, and that advance care planning is available to people who are newly diagnosed, are all aimed at ensuring ACP is widely available to as many people as possible, whether they are previously known to care services or not.

People of minority ethnic background: While there are no specific references to decision making and mental capacity with people of minority ethnic background in the draft guideline, draft recommendation 1.4.17 recommends the use of other professionals, for example an interpreter in order to facilitate communication during capacity assessments.

People with learning disability and other co-morbidities: While there are no specific references to decision making and mental capacity with people with learning disability and other co-morbidities in the draft guideline, recommendation 1.2.4 highlights that a range of factors, which may affect a person's ability to make decisions, should be taken into account, including their physical and mental health.

People on the autism spectrum who do not have a learning disability, people with neurodegenerative diseases (such as Parkinson's Disease and people with acquired injuries: While the draft guideline does not specifically address supporting people with these conditions, in terms of decision making and future capacity, it does recommend that people should be offered information on specific conditions, capacity and future planning (draft rec 1.3.2 and 1.3.3). Draft rec 1.1.1 states that all practitioners should receive condition-specific training related to advance care planning.

People at end of life: This is specifically addressed in the draft guideline, with statements that practitioners should consider using advance care plans to encourage people to have conversations about future treatment and end of life care with carers, family, friends and practitioners if they wish, and a recommendation that when

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

people are reaching the end of life they should be given the opportunity to review or develop an advance care plan (draft rec 1.3.16).

People who live alone: The issue of decision making and mental capacity with people who live alone is not specifically addressed in the draft guideline. However draft recommendation 1.3.10 does include the person's personal history and social circumstance as factors that should be taken into consideration when developing advance care plans. Draft recommendation 1.2.11 stresses the importance of including significant and trusted people in decision-making, and seeking the views of family, carers and friends if the person can't identify who they want to be included in the process. Recommendation 1.1.7 recommends telling people about advocacy services as a potential source of support for decision-making. Even if the person lives alone, the recommendations aim to ensure that they are supported with decision making from within their social network or by an advocate.

People in prison: The issue of decision making and mental capacity with people who are in prison is not specifically addressed in the draft guideline. However recommendation 1.3.10 does include the person's personal history and social circumstance as factors that should be taken into consideration when developing advance care plans.

Family carers and other supportive carers: The draft Guideline does take account of family carers and other supportive carers with regard to decision making and mental capacity. There is a sub section in 'best interests decision making', which is dedicated to helping and supporting families during the best interests process. For example recommendation 1.5.11 states that the 'decision maker' should ensure families are consulted and involved and give time to express themselves.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

No other potential equalities issues have been identified.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

The committee's considerations of the equalities issues described are explained in the LETR tables in the full guideline.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

The draft recommendations do not make it more difficult for some groups to access services compared with others.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

The committee do not believe that the draft recommendations will have an adverse impact on people with disabilities because of something that is a consequence of the disability.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

There are no further explanations.

Completed by Developer: Beth Anderson

Date: March 2017

Approved by NICE quality assurance lead:

Date:

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

People with fluctuating capacity: a number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.

Young people aged 16-17 years: stakeholders expressed concern that there is no explicit reference to young people aged 16-17 years. Some stakeholders said that in practice difficulties arise due to the overlap between the Mental Capacity Act 2005 and the Children Act 1989 and that the guideline ought to specifically address these issues. The committee discussed these concerns at GC11 and were not in agreement that difficulties in supporting this age group necessarily arise from the overlap in relevant legislation. Although they did not feel they had reviewed evidence that provided a basis on which to make specific recommendations about this group, the committee did agree it was important to describe in the context the intended practical application of the Mental Capacity Act to people aged 16-17 years, in particular the potential role of parents in best interests decision making. The group also agreed the context section should recognise the existence of other legislation (such as the Children Act 1989 and Children and Families Act 2014) and to acknowledge that they provide an additional framework for the way in which children and young people should be supported in decision making.

People with prolonged disorders of consciousness: one stakeholder wanted the guideline to make specific reference to people with prolonged disorders of consciousness to help with appropriate best interests decision making for this group. The committee discussed this suggestion at GC11 and they concluded that the recommendations already apply to this group of the population, in particular the subsection on best interests decision making, which is clear about the role of the

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

decision maker and the safeguards in place to protect people assessed as lacking capacity (which would be likely to apply in the case of people with prolonged disorders of consciousness). The committee did however agree that it would help to highlight Lasting Power of Attorney (LPA) as a legally binding means of planning in advance for treatment or care and support. They achieved this through adding an introductory paragraph to section 1.3 on advance care planning.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, none of the post consultation changes to the recommendations could be said to introduce barriers to services for any group within the guideline population.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No. Changes to the recommendations following consultation have had the effect of clarifying the wide-ranging application of the Mental Capacity Act, ensuring safeguards for people who may lack decision making capacity.

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

The changes to the recommendations made after consultation do not give rise to any barriers to access and therefore it is not necessary to make further recommendations that would address this issue.

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

Not applicable.

4.5 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

The LETR table for recommendation 1.3.9 highlighted the importance of helping everyone to be involved in advance care planning, including those with fluctuating or progressive conditions.

Updated by Developer: Stephen Goulder

Date: 14 March 2018

Approved by NICE quality assurance lead:

Date: