NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

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| Quality standard topic: Decision-making and mental capacity  Output: Prioritised quality improvement areas for development.  Date of Quality Standards Advisory Committee meeting: 5 September 2019 |

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for decision-making and mental capacity. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[Decision-making and mental capacity](https://www.nice.org.uk/guidance/ng108). NICE guideline NG108. Published October 2018.

1. Overview
   1. Focus of quality standard

This quality standard will cover decision-making in people using health and social care services who are 16 years and over and may lack capacity to make their own decisions (now or in the future). It aims to support implementation of the ethos and principles introduced by the [Mental Capacity Act 2005](https://www.legislation.gov.uk/ukpga/2005/9/contents) (MCA 2005) and relevant codes of practice but does not substitute these.

* 1. Context

It is estimated 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. The MCA 2005 was designed to empower and protect individuals in these circumstances. In 2014 the CQC identified serious issues with the practical implementation of the Act which was subsequently reported on by a House of Lords Select Committee, adding further momentum towards the need for improvement in practice.

NICE guideline on decision-making and mental capacity (NG108) helps to ensure that people are supported to make decisions for themselves when they have the mental capacity to do so, and where they lack the mental capacity to make specific decisions, they remain at the centre of the decision-making process. The guideline supports the empowering ethos and principles introduced by the MCA 2005 and explained in the Code of Practice. These are:

1. A person must be assumed to have capacity unless it is established that he lacks capacity

2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because he makes 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 his 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.

The Mental Capacity Act applies to all professions – doctors, nurses, social workers, occupational therapists, healthcare assistants, and support staff. These staff and their employers have a duty to ensure they know how to use it.

Most trusts and local authorities will have a Mental Capacity Act lead who provides specialist advice on how the Act works.

More information about Mental Capacity Act and its implementation is available on NHS website[[1]](#footnote-1).

* 1. Resource impact

NICE guideline NG108 supports the Mental Capacity Act (MCA), 2005, and its code of practice. The challenges to implementation which may have a resource impact depending on current local services are:

* Access to independent advocacy (MCA, 2005; Mental Health Act, 2007; Care Act, 2014). This is affected by a range of factors including a shortage of well-trained advocates, uncertainty (among commissioners, public bodies, practitioners and people who use services) around advocacy and the different types of advocacy, practitioners being unaware of the duty to refer for advocacy and advocacy services being under-resourced and in high demand (commissioned by local authorities). Ensuring a greater focus on supporting decision-making.
* Ensuring a workforce is well-trained and well-developed in supporting decision-making and implementing the MCA.
* Cost of re-training staff on the concept of supporting decision-making and the emphasis on advance care planning.

The resource impact does not result directly from the guideline as it reflects existing legislation and associated codes of practice.

Implementing legislation properly and involving people appropriately may reduce the risk of challenge to decision-making and may reduce costs associated with this.

Services where people may need support with decision-making activities are commissioned by local authorities, NHS England and clinical commissioning groups. Providers are health and social care practitioners, independent advocates and practitioners working in services (including housing, education, employment, police, immigration and criminal justice).

1. Summary of suggestions
   1. Responses

In total 14 registered, 1 non-registered stakeholder and 1 individual responded to the 2-week engagement exercise 5/07/19 - 19/07/19. We also received comments from 9 specialist committee members. The responses have been merged and summarised in table 1 for further consideration by the committee.

Full details of all the suggestions provided are given in appendices 3 - 4 for information.

### Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders |
| --- | --- |
| Supporting decision making   * Person centred process * Communication * Independent advocacy | AS, BASW, Birthrights, CBF, CMHP, Mencap, MIND, NMCF, RCN, RCOT, RCSLT, SBPFT, SCM1, SCM2, SCM3, SCM5, SCM6, SCM7, SCM8 |
| Advance care planning | AS, Birthrights, Mind, SCM3, SCM4, SCM7, SCM9 |
| Assessment of mental capacity   * Assessing mental capacity * Decision specific assessment | BASW, Birthrights, BRC, Mencap, MIND, NMCF, RCN, RCOT, RCP, RCSLT, SBPFT, SCM1, SCM4, SCM5, SCM7 SCM9, |
| Best interest decision making   * Person centred decision making * Involving families * Best interest decision-making process | AS, BASW, Birthrights, BRC, CBF, CMHP, Luton CCG, Mencap, MIND, NMCF, SCM1, SCM4, SCM5, SCM7, SCM9 |
| Additional areas   * Training * MCA Champions * Hospital food * Pharmacy dispensing | CD, CMHP, Mencap, RCN, RCOT, SBPFT, SCM2, SCM5, SCM6, SCM8 |
| Abbreviations:   * AS, Alzheimer’s Society * BASW, British Association of Social Workers * Birthrights * BRC, British Red Cross * CBF, The Challenging Behaviour Foundation * CD, Compassion in dying * CMHP, College of Mental Health Pharmacy * Luton CCG, Luton Clinical Commissioning Group * Mencap * NMCF, National Mental Capacity Forum * RCN, Royal College of Nursing * RCOT, Royal College of Occupational Therapists * RCP, Royal College of Psychiatrists * RCSLT, Royal College of Speech and Language Therapy * SBPFT, Surrey and Borders Partnership NHS Foundation Trust * SCM 1 - 9, Specialist Committee Member | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1066 papers were identified for decision-making and mental capacity. In addition, 72 papers were suggested by stakeholders at topic engagement and 28 papers internally at project scoping.

13 papers have been included in this report and are included in the current practice sections where relevant. Appendix 2 outlines the search process.

1. Suggested improvement areas
   1. Supporting decision making
      1. Summary of suggestions

Stakeholders highlighted that practitioners were required to support the person to make their own decision before deciding that they lack capacity to make that decision. They suggested that despite being a key principle included within the Mental capacity Act, this is still an area where improvement is necessary.

Person centred process

Stakeholders suggested that assumptions were made about peoples' capacity to make decisions. This was particularly applicable to people with a learning disability, dementia or those in long term residential care. As a result, people may not be receiving care they would have chosen had they been supported and given the opportunity to express their preferences.

Stakeholders suggested simple steps such as ensuring people had their glasses or hearing aids, including relevant supporters, using communication aids or the best time of day, could substantially enhance peoples' understanding of the conversations and their capacity to make a decision.

Making Decision Passport prepared prior to admission to hospital was suggested as a valuable tool that could support decision making process.

Stakeholders highlighted the importance of recording all steps taken to support the person to make a decision before deciding that they lacked capacity.

Communication

Stakeholders highlighted that communication difficulties could mask individual’s inherent decision-making abilities. They suggested that people were seen or assessed as lacking capacity because they couldn't communicate their views or understand the information provided in a standard format. Stakeholders suggested that currently used leaflets and materials were often inaccessible to people with as well as without communication difficulties and that presenting information in an accessible format would benefit everyone using services.

Stakeholders suggested that communication strategies and communication aids, including digital options, could reduce barriers, facilitate effective communication, support people with exercising choice and making decisions about their own care.

People with communication problems may need to work with professionals such as speech and language therapists who can support them during the decision-making process.

Independent advocacy

Stakeholders suggested that people with cognitive impairment who lack or may lack capacity were often not aware of the benefits or could not access support from Independent Mental Capacity Advocates (IMCA). Stakeholders highlighted that an advocate could support the person to make a decision or they could represent them if they were unable to make a decision. Support from advocacy services helps to ensure that people are treated fairly and are not discriminated against.

* + 1. Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

### Table 2 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Person centred process | NICE NG108 Recommendations 1.2.4, 1.2.14, 1.2.17, 1.2.18 |
| Communication | NICE NG108 Recommendations 1.2.4, 1.2.7. 1.2.10, 1.2.16 |
| Independent advocacy | NICE NG108 Recommendations 1.1.7, 1.1.8, 1.1.10 |

### Person centred process

NICE NG108 Recommendation 1.2.4

Practitioners should take a personalised approach, accounting for any reasonable adjustments and the wide range of factors that can have an impact on a person's ability to make a decision. These should include:

* the person's physical and mental health condition
* the person's communication needs
* the person's previous experience (or lack of experience) in making decisions
* the involvement of others and being aware of the possibility that the person may be subject to undue influence, duress or coercion regarding the decision
* situational, social and relational factors
* cultural, ethnic and religious factors
* cognitive (including the person's awareness of their ability to make decisions), emotional and behavioural factors, or those related to symptoms
* the effects of prescribed drugs or other substances.

They should use this knowledge to develop a shared and personalised understanding of the factors that may help or hinder a person's decision-making, which can be used to identify ways in which the person's decision-making can be supported.

NICE NG108 Recommendation 1.2.14

Practitioners should increase the person's involvement in decision-making discussions by using a range of interventions focused on improving supported decision-making.

NICE NG108 Recommendation 1.2.17

Practitioners should make a written record of the decision-making process, which is proportionate to the decision being made. Share the record with the person and, with their consent, other appropriate people. Include:

* what the person is being asked to decide
* how the person wishes to be supported to make the decision
* steps taken to help the person make the decision
* other people involved in supporting the decision
* information given to the person
* whether on the balance of probabilities a person lacks capacity to make a decision
* key considerations for the person in making the decision
* the person's expressed preference and the decision reached
* needs identified as a result of the decision
* any further actions arising from the decision
* any actions not applied and the reasons why not.

NICE NG108 Recommendation 1.2.18

Organisations should ensure they can demonstrate compliance with principle 2, section 1(3) of the Mental Capacity Act 2005 by monitoring and auditing:

* person-reported outcomes, including the extent to which the person experiences collaboration and empowerment when making important decisions and the extent to which they experience support for their decision-making
* practitioner-reported outcomes, including the frequency and quality of steps they have taken to support decision-making
* process outcomes, including the frequency and quality of formal recording of steps taken to support decision-making and the use of overt and covert coercion during decision-making.

### Communication

NICE NG108 Recommendation 1.2.7

When providing the person with information to support a particular decision:

* do so in line with the NHS Accessible Information Standard
* support them to identify, express and document their own communication needs
* ensure that options are presented in a balanced and non-leading way.

NICE NG108 Recommendation 1.2.10

Support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with paragraphs 3.10 and 3.11 of the Mental Capacity Act Code of Practice.

NICE NG108 Recommendation 1.2.16

Health and social care practitioners should refer to other services (for example speech and language therapy, clinical psychology and liaison psychiatry) that could enable the person to make their decision when their level of need requires specialist input. This is especially important:

* when the person's needs in relation to decision-making are complex
* if the consequences of the decision would be significant (for example a decision about a highly complex treatment that carries significant risk).

### Independent advocacy

NICE NG108 Recommendation 1.1.7

Practitioners should tell people about advocacy services as a potential source of support for decision-making, including:

* enabling them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs
* facilitating their involvement in decisions that may be made or are being made under the Mental Capacity Act 2005.

NICE NG108 Recommendation 1.1.8

As a minimum, independent advocacy must be offered by local authorities as described in the [Care Act 2014](https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted), [Mental Capacity Act 2005](https://www.legislation.gov.uk/ukpga/2005/9/contents) and [Mental Health Act](https://www.legislation.gov.uk/ukpga/2007/12/contents) 2007.

[This recommendation is adapted from the NICE guideline on learning disabilities and behaviour that challenges: service design and delivery]

NICE NG108 Recommendation 1.1.10

Commissioners, public bodies and providers of statutory advocacy services should work closely to ensure that:

* statutory duties on public bodies to refer to and involve advocacy are consistently adhered to and monitored and
* failures in the duty to refer to statutory advocacy are addressed.
  + 1. Current UK practice

### Person centred process

The National Mental Capacity Forum stated in its latest report that principle 2 of the MCA 2005 (Provide support) was the area where least progress had been made. The report states that too much focus has been placed on capacity assessments with greater emphasis on testing rather than on giving support and information[[2]](#footnote-2).

A CQC complaints review found that patients felt that their opinion was not considered when deciding on treatment and that staff lacked compassion and ignored simple requests. Patients also felt that they were not appropriately involved in their own care, not informed about services, and that staff were too busy to speak to them. This was experienced in several ways but included not having their rights explained, not discussing medication with the appropriate clinician or a health clinician talking with them for a few minutes and then basing their treatment on previous medical records[[3]](#footnote-3).

Everyday decisions project which interviewed 15 intellectually disabled people, six supporters, and 25 care professionals found that front-line care and support staff were often extremely good at supporting intellectually disabled people to make everyday decisions. In contrast, difficult decisions were less well supported. Many of the care professionals in the research reported medical decisions being made using the ‘best interests’ framework under the MCA, rather than supporting disabled people to make their own choices about care and treatment[[4]](#footnote-4).

However, CQC highlighted this as an area of the greatest improvement. The data shows:

* 10% increase in evidence of patients’ involvement in care plans between 2014-16 and 2016-18
* 5% increase in care plans showing consideration of the person’s view about their treatment
* 4% increase in consideration of the person’s diverse needs in care plans increased[[5]](#footnote-5).

### Communication

How the information is provided to patients was the most frequently raised area of concern in CQC visits in 2017/18. Recording attempts to provide patients or relatives with information about their legal position or repeated attempts to explain rights to patients who do not initially understand them was a common problem. In many cases, patients may struggle to understand information given to them on admission because they are most ill at this point. However, the data indicates a 2% increase in further attempts to explain rights, or to explain rights to nearest relatives and 2% improvement in rates of discussions about rights and assessments of the patient’s levels of understanding[[6]](#footnote-6).

### Independent advocacy

Under the MHA, providers are required to take practicable steps to make sure that patients subject to the MHA are aware of the help that is available from Independent Mental Health Advocates (IMHAs). In 2016/17 CQC found that 85% (544) of 639 wards were following the Code’s advice. In 2017/18 automatic referrals were found in 91% (985) of 1,080 wards asked about advocacy arrangements for incapacitated patients[[7]](#footnote-7).

* 1. Advance care planning
     1. Summary of suggestions

Stakeholders suggested that people should be supported to make advance care plans that would include their wishes and preferences should they lose capacity. Advance care planning allows people to prepare for a time when they may lack capacity to make decisions, improve the care team’s understanding of the person’s needs and wishes and result in more positive experience for the person. Advance care planning is particularly important for people whose capacity may fluctuate as the condition progresses or when they are in a crisis situation. This may be particularly important for people with mental health problems, dementia or people with life limiting illness or long-term condition.

Stakeholders suggested that identifying a specific health or social care professional who would be responsible for supporting the person to develop the advance care plan has the potential to improve implementation.

Stakeholders also suggested that advanced care plans must be reviewed regularly to ensure that they are a true reflection of a person's wishes at the time when they no longer have capacity.

Stakeholders' suggestions also included making advanced statements around specific areas such as end of life care and DNACPR.

* + 1. Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

### Table 3 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Advance care planning | NICE NG108 Recommendations 1.2.15, 1.3.9, 1.3.15, 1.3.16 |

### Advance care planning

NICE NG108 Recommendation 1.2.15

Where possible and relevant, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time.

NICE NG108 Recommendation 1.3.9

Health and social care practitioners should help everyone to take part in advance care planning and co‑produce their advance care plan if they choose to have one (including people with fluctuating or progressive conditions). They should:

* work with the person to identify any barriers to their involvement, and investigate how to overcome these
* help them to communicate by providing communication support appropriate to their needs (for example communication aids, advocacy support, interpreters, specialist speech and language therapy support, involvement of family members or friends).

NICE NG108 Recommendation 1.3.15

Review advance care plans at reviews of treatment or support, while the person has capacity, and amend as necessary, if the person wishes.

NICE NG108 Recommendation 1.3.16

When people are reaching the end of life, give them the opportunity to review or develop an advance care plan if they haven't already done so.

* + 1. Current UK practice

### Advance care planning

The National Audit of Care at the End of Life found within the case note review documented evidence of an advance care plan prior to admission in 7% of cases (6% for England, acute trusts only). There was documented evidence that the advance care plan had been reviewed in 19% of cases, and taken into account in decision making, in 59% of cases[[8]](#footnote-8).

A National survey of 544 people with clinical diagnosis of bipolar disorder and 650 psychiatrists who manage people with bipolar disorder found that 403 (74.1%) believed making plans about their personal welfare if they lost capacity to be very important. 199 (36.6%) participants knew about the MCA but only 91 (16.6%) had made any form of advance directive. Barriers included not understanding its different forms, unrealistic expectations and advance plans being ignored by services. 144 (22%) psychiatrists refused to discuss the MCA with people with bipolar disorder[[9]](#footnote-9).

A report based on reflections from supporting 25,000 people planning for the end of life highlighted that 20% of over 65-year olds said they wanted to set out their wishes to refuse treatment in an Advance Decision but said they hadn’t got around to it yet. Whilst 87% of people think it is important that healthcare professionals know about their preferences for treatment and care, only 4% of people have made an Advance Decision and just 7% have appointed someone they trust to make decisions on their behalf through a Lasting Power of Attorney for Health and Welfare[[10]](#footnote-10).

207 Clinical Commissioning Groups responded to the freedom of information request on end of life care. 21 CCGs responded to say they did not hold the requested information and five CCGs explained that they were in the process of developing strategies on end-of-life care. Key findings include:

* 74 CCGs noted the availability of online resources for advance care planning on their website
* 106 confirmed that advance care planning is considered a free service
* 96 stated that the GP practices in their area have a system for recording the existence of a person’s Advance Decision
* 57 did not respond to the question on whether they commission training for GPs on advance care planning and the Mental Capacity Act
* 85% of CCGs (177 out of 207) provide GP practices with information on Do Not Attempt Resuscitation orders
* 46% of the CCGs (96 out of 207) reported that GP practices in their area have systems for recording the existence of a person’s Advance Decision and 32 of those responses mentioned the use of Electronic Palliative Care Co-ordination Systems (EPaCCS)[[11]](#footnote-11).
  1. Assessment of mental capacity
     1. Summary of suggestions

Assessment of mental capacity is strongly linked with the previous section on supporting decision making. Effective communication, putting the person at the centre of the assessment process and supporting the person to enhance their capacity are necessary to ensure the results of the assessment truly reflect individual's capacity.

Assessing mental capacity

Stakeholders highlighted the importance of identifying individuals who may need support with decision-making and an assessment of their mental capacity to make specific decisions. Professionals such as psychologists, speech and language therapists, occupational therapists and specialists in learning disability may need to work as a team to assess capacity.

An admission to hospital or a care setting was suggested as the first opportunity to establish if the person has capacity to consent to the admission and putting suitable safeguards in place to ensure appropriate support for decision-making.

Capacity assessments within inpatient mental health services and capacity assessments for people detained under the Mental Health Act were highlighted as being particularly important due to the disempowering context of the circumstances.

Decision specific assessment

Stakeholders highlighted that people may have capacity to make only some decisions and that their capacity to make decisions may fluctuate. Mental capacity assessment should be specific to a decision, yet people are often assessed and classed as lacking capacity and subsequently not involved in decision making at all.

Stakeholders also highlighted the importance of recording the process of assessing capacity to ensure that the decisions were made in line with the empowering ethos of the Mental Capacity Act. They suggested what should be documented as a minimum record to support the assessment process.

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

### Table 4 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Assessing mental capacity | NICE NG108 Recommendations 1.1.4, 1.4.3, 1.4.10, 1.4.17 |
| Decision specific assessment | NICE NG108 Recommendations 1.4.7, 1.4.23, 1.4.27, 1.4.28, 1.4.29 |

### Assessing mental capacity

NICE NG108 Recommendation 1.1.4

Practitioners involved in making decisions regarding individuals who lack capacity or supporting decision-making in individuals who have capacity must follow the 5 key principles set out in section 1 of the Mental Capacity Act 2005. As a starting point they must assume capacity unless there is evidence to suggest an assessment is required.

NICE NG108 Recommendation 1.4.3

Organisations should ensure that assessors can seek advice from people with specialist condition-specific knowledge to help them assess whether, on the balance of probabilities, there is evidence that the person lacks capacity – for example clinical psychologists and speech and language therapists.

NICE NG108 Recommendation 1.4.10

In preparing for an assessment, the assessor should be clear about:

* the decision to be made
* if any inability to make a decision is caused by any impairment of or disturbance in the functioning of the mind or brain in that person
* the options available to the person in relation to the decision
* what information (the salient factors) the person needs in order to be able to explore their options and make a decision
* what the person needs in order to understand, retain, weigh up and use relevant information in relation to this decision, including the use of communication aids
* how to allow enough time for the assessment, giving people with communication needs more time if needed
* how to introduce the assessment and conduct it in a way that is respectful, collaborative, non-judgmental and preserves the person's dignity
* how to make reasonable adjustments including, for example, delaying the assessment until a time when the person feels less anxious or distressed and more able to make the decision
* how to ensure that the assessment takes place at a location and in an environment and through a means of communication with which the person is comfortable
* how to identify the steps a person is unable to carry out even with all practicable support
* whether involving people with whom the person has a trusted relationship would help the assessment.

### Decision specific assessment

NICE NG108 Recommendation 1.4.7

While the process applies to all decisions that fall within the scope of the Mental Capacity Act 2005, both large and small, the nature of the assessment and the recording of it should be proportionate to the complexity and significance of that decision.

NICE NG108 Recommendation 1.4.23

Practitioners should understand that the person has to retain information only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision.

NICE NG108 Recommendation 1.4.27

If the outcome of the assessment is that the person lacks capacity, the practitioner should clearly document the reasons for this. The documentation should also make clear what impairment/disturbance of the mind or brain has been identified, the reasons why the person is unable to make a decision (with reference to section 3 of the Mental Capacity Act 2005) and the fact that the person's inability to make a decision is a direct consequence of the impairment or disturbance identified.

NICE NG108 Recommendation 1.4.28

The person assessing mental capacity should record:

* the [practicable steps](https://www.nice.org.uk/guidance/ng108/chapter/recommendations#practicable-steps) they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved
* whether the person has capacity to make the decision
* if the person is assessed as lacking capacity, why the practitioner considers this to be an [incapacitous](https://www.nice.org.uk/guidance/ng108/chapter/recommendations#capacitous) decision as opposed to an unwise decision

NICE NG108 Recommendation 1.4.29

All assessments of mental capacity must be recorded at an appropriate level to the complexity of the specific decision being made at a particular time. This may be as a stand-alone assessment document, contained within the individual's health or social care record or in care and support plans, following local policy. The timescale for review of the assessment should be specified and recorded.

* + 1. Current UK practice

### Assessing mental capacity

An audit of referrals received by the King’s College Hospital Liaison Psychiatry Team, South London and Maudsley NHS Foundation Trust (SLaM) was carried out over the 3 sampling months. At the time of the audit guidance by the Care Quality Commission recommended that assessments regarding decision making capacity (DMC) to consent to treatment and admission should be made on all patients at the point of admission to a psychiatric hospital. It aimed to clarify whether it was an admission authorised through the consent of a patient with decision making capacity or under the ‘best interests’ procedures in a patient who is assenting but lacking decision-making capacity. The audit found that decision making capacity was assessed only in 7.6% of referrals (72 out of 949 referrals)[[12]](#footnote-12).

The National Audit of Care at the End of Life found that in 43% of cases, there was documented evidence that the dying person had their capacity assessed to be involved in their end of life care planning. In 49% of cases there was documented evidence that the dying person lacked capacity to be involved in their care planning[[13]](#footnote-13).

The Select Committee on the Mental Capacity Act 2005 report included statements highlighting that in the majority of cases the process of conducting a formal capacity assessment was not completed and not formally recorded. The report highlighted concerns about quality of the assessments and lack of support for the individual[[14]](#footnote-14).

### Decision specific assessment

An audit of adherence to the mental capacity act and deprivation of liberty safeguards was carried out across 9 hospitals in Wessex. 188 inpatients (57%) under the care of geriatricians across the region had cognitive impairment, predominantly due to dementia (60%) or delirium (22%). For 67 of these patients (36%), there was evidence that a capacity assessment had been carried out. This proportion varied widely between trusts (10-73%). In 122 of these 188 patients (65%), the clinical team felt that the patient did not have capacity to decide to remain in hospital, yet there was evidence of the use of the MCA or DoLS in only 41 cases (39%). Again, there was wide regional variation (0-100%)[[15]](#footnote-15).

* 1. Best interest decision making
     1. Summary of suggestions

Person centred decision-making

Stakeholders highlighted that wishes of the individual should always be at the centre of the decision-making process. Whilst other factors and people should be considered when the decision is being made, where possible, precedence should be given to the individual’s previously expressed wishes and needs even when those are at odds with family members/carers wishes. The person should not be put under pressure or coerced to something just because of what the family or professionals think is best for them. Stakeholders suggested that decisions were often taken from medical best interest perspective rather than what the person would have wanted.

Involving families

Stakeholders raised concerns that family members who were likely to have the best knowledge and understanding of the person were often excluded from best interest decisions or involved but not listened to. They suggested it was very important for the families to be consulted and involved (as they wanted to be) when best interests decisions were being made to ensure true ‘best interests’ decisions are being made by professionals. Stakeholders also highlighted lack of clarity around: the family being involved in best interest decision-making, obtaining lasting power of attorney or being a court appointed deputy.

Best interest decision making process

Stakeholders highlighted that the best interest decision making process should ensure that people who lack capacity have their wishes, feelings, beliefs, and values respected and reflected in the care they receive. They also emphasised that people who may lack capacity to make a decision may still be able to contribute to it. Stakeholders raised concerns over lack of consistency and robust processes in best interest decision-making processes. They suggested that best interest decision making framework, toolkits or checklist would help to improve current practice. They also highlighted the importance of recording the process of making the decisions and the need to review them on regular basis.

Some specific decision-making areas were highlighted by stakeholders:

* Covert administration of medication
* Do not Attempt Cardiopulmonary Resuscitation orders
* Dental treatment
  + 1. Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after the table to help inform the committee’s discussion.

### Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Person centred decision-making | NICE NG108 Recommendations 1.5.3, 1.5.6 |
| Involving families | NICE NG108 Recommendation 1.5.7 |
| Best interest decision making process | NICE NG108 Recommendations 1.5.12, 1.5.14, 1.5.15, 1.5.17 |

### Person centred decision-making

NICE NG108 Recommendation 1.5.3

As part of the best interests decision-making process, practitioners must take all reasonable steps to help the person to provide their own views on the decision.

NICE NG108 Recommendation 1.5.6

Health and social care services should have clear systems in place to obtain and record the person's wishes and feelings in relation to a relevant decision, as well as their values and beliefs, or any other factor that would be likely to influence such a decision. Services should:

* have mechanisms in place to make these available in a timely way
* ensure that the person's personal history and personality is represented in the above.

### Involving families

NICE NG108 Recommendation 1.5.7

Unless it would be contrary to the person's best interests to do so, health and social care practitioners should work with carers, family and friends, advocates, attorneys and deputies, to find out the person's values, feelings, beliefs, wishes and preferences in relation to the specific decision and to understand the person's decision-making history.

### Best interest decision making process

NICE NG108 Recommendation 1.5.12

When making a decision on behalf of the person who lacks capacity, practitioners should use a range of approaches, as needed, to ensure that the person's best interests are served. This might include:

* a less formalised approach for day-to-day decisions – that is, recurring decisions being recorded in support or care plans
* a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments
* formal best interests meetings for significant decisions:

- if this is the most appropriate way to undertake the required consultation or

- if the outcome of the decision is likely to have a serious impact on the person's health or wellbeing or

- if there are likely to be conflicting opinions about the person's best interests.

NICE NG108 Recommendation 1.5.14

Health and social care organisations should provide toolkits to support staff to carry out and record best interests decisions. These toolkits should include:

* how to identify any decision-making instruments that would have an impact on best interests decision-making occurring (for example a Lasting Power of Attorney, advance decisions to refuse treatment, court orders)
* when to instruct an Independent Mental Capacity Advocate
* a prompt to consult interested parties (for example families, friends, advocates and relevant professionals) and a record of who they are
* guidance about recording the best interests process and decision. This may include, for example, a balance sheet, which may assist in documenting the risks and benefits of a particular decision
* instructions on what information to record, ensuring this covers:
* a clear explanation of the decision to be made
* the steps that have been taken to help the person make the decision themselves
* a current assessment concluding that the person lacks the capacity to make this decision, evidencing each element of the assessment
* a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including any advance statements
* the concrete choices that have been put to the person
* the salient details the person needs to understand
* the best interests decision made, with reasons.

NICE NG108 Recommendation 1.5.15

When making best interests decisions, explore whether there are less restrictive options that will meet the person's needs. Take into account:

* what the person would prefer, including their past and present wishes and feelings, based on past conversations, actions, choices, values or known beliefs
* what decision the person who lacks capacity would have made if they were able to do so
* all the different options
* the restrictions and freedoms associated with each option (including possible human rights infringements)
* the likely risks associated with each option (including the potential negative effects on the person who lacks capacity to make a decision – for example trauma or disempowerment).

NICE NG108 Recommendation 1.5.17

As people's circumstances change, review the decisions regularly to ensure that they remain in a person's best interests.

* + 1. Current UK practice

### Person centred decision making

The analysis of 27 Safeguarding Adults Reviews (SARs) completed by authorities in London found an absence of explicit best-interest decision-making and missing or poorly performed capacity assessments. It also found:

* Lack of personalised care and focus on needs, wishes and preferences
* Insufficient contact and reliance on views of others
* Lack of curiosity about the meaning of behaviour
* Lack of time to engage and build trust and continuity[[16]](#footnote-16)

A research study of professional practices in best interests decision making under the Mental Capacity Act (MCA) was carried out in four contrasting areas of England amongst health, social care and legal professionals. The data were drawn from online surveys (N = 385 valid responses), telephone interviews (N = 68) and interviews (25 cases, with multiple or single interviews). The research found:

* over half of all decisions involved a series of meetings between the decision-maker, the person and usually others who knew the person; however health care decisions were significantly more likely than other types of decisions to be made at a single meeting, or at meeting(s) that did not involve the person lacking capacity
* 47% of people lacking capacity were involved in best interests meetings with multiple participants; people with learning disabilities were significantly less likely to be invited to a formal meeting, and those with dementia were more likely
* Although most people said they had taken into account the wishes and values of the person lacking capacity, there were only a few clear examples where wishes and values were influential in the best interests decision, or where past values had been explored[[17]](#footnote-17).

### Involving families

The analysis of 27 SARs completed by authorities in London found an absence of explicit best-interest decision-making and missing or poorly performed capacity assessments. It also found:

* Failure to involve carers and to recognise their needs
* Absence of attention to complex family dynamics[[18]](#footnote-18)

A research study of professional practices in best interests decision making under the Mental Capacity Act (MCA) was carried out in four contrasting areas of England amongst health, social care and legal professionals. The data were drawn from online surveys (N = 385 valid responses), telephone interviews (N = 68) and interviews (25 cases, with multiple or single interviews). The research found:

* 88% of respondents in the online survey felt that people close to the person lacking capacity had been consulted, and 86% felt that their views had been taken into account.[[19]](#footnote-19)

### Best interest decision making process

This research study of professional practices in best interests decision making under the Mental Capacity Act (MCA) was carried out in four contrasting areas of England amongst health, social care and legal professionals. The data were drawn from online surveys (N = 385 valid responses), telephone interviews (N = 68) and interviews (25 cases, with multiple or single interviews). The research found:

* 70% (271) of the best interests processes in the online survey were preceded by an assessment that someone lacked capacity. However, one in ten best interests decisions did not follow an assessment that showed the person lacked capacity.
* Determining whether or not someone had capacity, even for a specific decision, was considered the most difficult aspect of the Act. Despite this, there was good practice reported in giving good support, prompts, and repeated chances to ‘regain’ capacity with some groups of people.
* About one quarter of best interests decisions were made on the basis of a capacity assessment relating to history, diagnosis or disability, age, appearance or behaviour, or the fact that someone was making an unwise decision[[20]](#footnote-20).
  1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 5 September.

### Training

Various specific examples of training for health and social care staff were suggested as an area for quality improvement. These included training around:

* Understanding key components of advance care planning and best interest decision making
* Assessing capacity
* Covert administration of medication
* Dosage form manipulation

Stakeholders also suggested that improvements to current training is needed to be more effective in day to day practice. They suggested training needs to be more interactive, include people who use services and scenarios.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee should consider which parts of care and support would be improved by increased training. Training may be referred to in the audience descriptors.

### MCA Champions

Collating information for job descriptions for MCA champions was suggested as an area for quality improvement. This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the recruitment that enables the actions to take place. However, MCA champions and information gathering may be referred to in the audience descriptors.

### Hospital food

Nutritious food in hospitals was suggested as an area for quality improvement. This suggestion has not been progressed as it is seen to be outside of the scope of this quality standard. NICE has published a quality standard on nutrition support in adults (QS24) that specifically focuses on nutrition in hospital setting.

### Pharmacy dispensing

Improving response times to the dispensing of medication on hospital discharge was suggested as an area for quality improvement. This suggestion has not been progressed as it is seen to be outside of the scope of this quality standard.

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# Appendix 1: Additional information

## Assessing mental capacity

Capacity is the ability of a person to make their own choices and decisions. In order to do this, a person needs to be able to understand and remember information and communicate their decision clearly, either verbally or non-verbally. A person may lack capacity because of a mental health problem, dementia or a learning disability[[21]](#footnote-21).

The MCA 2005 sets out a 2-stage test of capacity:

1) Does the person have an impairment of their mind or brain, whether as a result of an illness, or external factors such as alcohol or drug use?

2) Does the impairment mean the person is unable to make a specific decision when they need to? People can lack capacity to make some decisions but have capacity to make others. Mental capacity can also fluctuate with time – someone may lack capacity at one point in time but may be able to make the same decision at a later point in time.

Where appropriate, people should be allowed the time to make a decision themselves. The MCA says a person is unable to make a decision if they can't:

* understand the information relevant to the decision
* retain that information
* use or weigh up that information as part of the process of making the decision[[22]](#footnote-22)

## Helping people make their own decisions

Before deciding a person lacks capacity, it's important to take steps to enable them to try to make the decision themselves. For example:

* does the person have all the relevant information they need?
* have they been given information on any alternatives?
* could information be explained or presented in a way that's easier for them to understand (for example, by using simple language or visual aids)?
* have different methods of communication been explored, such as non-verbal communication?
* could anyone else help with communication, such as a family member, carer or advocate?
* are there particular times of day when the person's understanding is better?
* are there particular locations where the person may feel more at ease?
* could the decision be delayed until they might be better able to make the decision?

## Best interest decisions

If someone lacks the capacity to make a decision and the decision needs to be made for them, the MCA states the decision must be made in their best interests. The MCA sets out a checklist to consider when deciding what's in a person's best interests. It says you should:

* encourage participation – do whatever's possible to permit or encourage the person to take part
* identify all relevant circumstances – try to identify the things the individual lacking capacity would take into account if they were making the decision themselves
* find out the person's views – including their past and present wishes and feelings, and any beliefs or values
* avoid discrimination – don't make assumptions on the basis of age, appearance, condition or behaviour
* assess whether the person might regain capacity – if they might, could the decision be postponed?

It's vital to consult with others for their views about the person's best interests. In particular, try to consult:

* anyone previously named by the individual
* anyone engaged in caring for them
* close relatives and friends
* any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney
* any deputy appointed by the Court of Protection to make decisions for the person[[23]](#footnote-23).

## Advance statements and decisions

An advance statement is a written statement that sets down a person's preferences, wishes, beliefs and values regarding their future care. It's not legally binding. The aim is to provide a guide for anyone who might have to make decisions in a person's best interests if that person has lost the capacity to make decisions or communicate their decision.

An advance statement can cover any aspect of a person's future health or social care. This could include:

* how they want any religious or spiritual beliefs they hold to be reflected in their care
* where they would like to be cared for – for example, at home or in a hospital, nursing home or hospice
* how they like to do things – for example, if they prefer a shower instead of a bath, or like to sleep with the light on
* concerns about practical issues – for example, who will look after their pet if they become ill

An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT, or a living will) is a legally binding decision that allows someone aged 18 or over, while still capable, to refuse specified medical treatment for a time in the future when they may lack capacity to consent to or refuse that treatment.

An advance decision must be valid and applicable to current circumstances. If it is, it has the same effect as a decision made by a person with capacity – healthcare professionals must follow the decision. If the advance decision refuses life-sustaining treatment, it must:

* be in writing, signed and witnessed
* state clearly that the decision applies even if life is at risk

People who make an advance decision may wish to consider letting their family, friends and carers know about it[[24]](#footnote-24).

## Lasting Powers of Attorney

People can grant a Lasting Power of Attorney (LPA) to another person (or people) to enable them to make decisions about their health and welfare, or decisions about their property and financial affairs. Separate legal documents are made for each of these decisions, appointing one or more attorneys for each.

An Enduring Power of Attorney (EPA) under the previous law was restricted to making decisions over property and affairs, which includes financial affairs and accessing the person's information. An EPA made before the Mental Capacity Act came into force on 1 October 2007 remains valid.

Powers of attorney can be made at any time when the person making it has the mental capacity to do so, provided they're 18 or over.

Both an EPA and LPA must be registered. An LPA can be registered at any time, but a personal welfare LPA will only be effective once the person has lost the capacity to make their own decisions. When acting under an LPA, an attorney (the appointed person) must:

* make sure the MCA's statutory principles are followed
* check whether the person has the capacity to make that particular decision for themselves – if they do, a personal welfare LPA can't be used and the person must make the decision [[25]](#footnote-25)

In addition, the Court of Protection will be able to appoint deputies who can also take decisions on health and welfare and financial matters if the person concerned lacks the capacity to make a decision. They'll come into action when the court needs to delegate an ongoing series of decisions rather than one decision.

If the person concerned already has an LPA appointed, they won't normally need a deputy as well. The Office of the Public Guardian registers LPAs and EPAs and supervises court-appointed deputies. It provides evidence to the Court of Protection and information and guidance to the public. The Public Guardian works with a range of agencies, such as the financial sector, police and social services, to investigate concerns[[26]](#footnote-26).

# Appendix 2: Review flowchart

Records identified through topic engagement  
[n = 72]

Records identified through ViP searching  
[n = 1066]

Records identified through IS scoping search  
[n = 28]

Records excluded  
[n = 1019]

Records screened  
[n = 1166]

Citation searching or snowballing

[n=42]

Full-text papers excluded  
[n =176]

Full-text papers assessed   
[n = 189]

Current practice examples included in the briefing paper  
[n = 13]

# Appendix 3: Suggestions from stakeholder engagement exercise – registered stakeholders

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| ID | Stakeholder | Key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? |
| 1 | SCM3 | Supporting healthcare decisions for patients with intellectual disabilities in acute care | It is estimated that 1,200 people with an intellectual disability (ID) die avoidably in the NHS each year. Of those 1,311 deaths reported in the national Learning Disabilities Mortality Review (LeDeR) for 2016-17, 27% had mild learning disabilities and 33% had moderate learning disabilities, raising the question as to how half this group had been supported to make decisions regarding their treatment and care. People with IDs have a right to be facilitated in making choices about care and treatment, where possible. People with IDs are particularly vulnerable and can be excluded from conversations that they may be able to have which could help plan the care that they wish to receive. There is evidence that medical decision making is sometimes based on misguided assumptions about the quality of life of people with intellectual disabilities, their ability to comply and cope with treatments, or their ability to consent to treatment and be involved in the decision making process. This can lead to people with IDs not receiving good quality person-centred care and not receiving potentially lifesaving treatment. | 1. Processes for identifying and responding adequately to people with IDs in acute and other healthcare services appear inadequate. In 2018, Heslop et al found that a substantial minority of NHS trusts were unable to provide data about people with IDs using services and that it was doubtful whether the data provided by some trusts was accurate. Approximately a half of trusts (49% of NHS foundation trusts and 54% of NHS trusts) explicitly stated that they did not undertake audits of learning disability services or did not make any such reports publicly accessible. 2. The 2013 Conﬁdential Inquiry into premature deaths of people with learning disabilities (CIPOLD), reviewing the patterns of care that people received in the period leading up to their deaths, found that people with IDs were signiﬁcantly more likely to have had problems with the Mental Capacity Act being followed than other comparator groups.  3. Consistent with the wider literature, Bradbury-Jones et al found that a number of healthcare professionals have limited knowledge of the issue of IDs and that key strategies to promote health, safety and welfare of patients with IDs include ID liaison services and the availability of resources such as videos, accessible booklets, augmentative and alternative communication and pictures/symbols. 4. While there is a significant absence of research and evidence regarding care and treatment planning (including end-of-life) with people with intellectual disabilities, Wagemans et al found no evidence in their study of people with IDs being asked for his or her own opinion in making end-of-life decisions.  5. Tuffrey-Wijne et al’s study conﬁrmed ﬁndings from previous studies and inquiries that acute hospital trusts fail to deliver services that are consistently accessible to patients with intellectual disabilities, noting multiple barriers and enablers to providing reasonable adjustments. Tuffrey-Wijne et al provide an empirical framework of barriers and enablers to providing reasonably adjusted health services to people with ID in acute hospitals including those that are cross-organisational and staff (individual and team) focused. This area of quality improvement should consider both barriers and enablers considered in this framework. (see. P4. The barriers to and enablers of providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a mixed-methods study). A key question consistent with the literature and raised directly by Tuffrey-Wijne et al is: what is the most effective training to prepare staff to provide individualised reasonably adjusted services [for people with IDs] and to use the Mental Capacity Act effectively? |
| 2 | SCM5 | Supported Decision Making to be encouraged and facilitated in Hospitals/ in the NHS | Hospitals are busy places, often with limited time and tools for people who need support to make decisions. A Making Decision Passport prepared prior to admission/ visit would be invaluable. | It would promote people’s human rights – it would enable people to be much more involved in decisions about their health and it would save health staff time. |
| 3 | SCM5 | Supported Decision Making to be encouraged and facilitated in Care Homes | People live in care homes usually for several years. There is time to do more in-depth work in relation to supporting decision making skills. We should develop a series of tools/forms to be used in long term care plans – documenting what decisions a person CAN make, showing how they make them and how they can be supported to make more decisions. | It would promote people’s human rights – it would enable people to be much more involved in decisions about their care and it would document people’s abilities and people’s past decisions. This would also be an important element of any best interests decisions that are needed later on when a person loses much of their capacity to make decisions. |
| 4 | Mencap | including accessible information and emphasis on supported decision-making |  | It needs to be clear that supported decision making is a central principle of the United Nations Convention on the Rights of Persons with Disabilities. People with a disability should receive the support necessary to enable them to make and implement the decisions that affect them. The Government said in response to the Law Commission review into DoLS and MCA: ‘We intend to strengthen the MCA Code of Practice to improve supported decision-making in the future.’ It is important the quality standard includes an important focus on supported decision-making, including who supports the person, how they do it and type/format of information. There needs to be an explicit link between principle 2 and with the Equality Act and the associated Accessible Information Standard. We know the Accessible Information Standard has not been fully implemented. Last review in 2017 showed major issues. Mencap’s Treat Me Well data showed variable approaches towards reasonable adjustments. Only 23% of hospital trusts said they routinely offered people with a learning disability easy read information, and only a third routinely offered longer appointments. |
| 5 | Alzheimer’s Society | Involving people affected by dementia in decisions about their care | It should not be assumed that just because someone has dementia, they lack capacity to make their own decisions. People with dementia should be supported in making their own decisions about their care and day to day life for as long as possible. Involving people from the beginning of the decision making process makes it more likely that people would agree with their proposed care. | The Mental Capacity Act 2005 (MCA) must underpin the decision-making process, and it sets out how people can be supported to make decisions. If implemented fully the MCA can support and protect people with dementia who lack capacity to make decisions for themselves, and ensure that any decisions made on their behalf are made in their best interests, and always with regard to the least restrictive option. However, we heard from people affected by dementia that they are not always supported to make decisions for themselves. People have told us that they do not feel practitioners spend sufficient time speaking to them about their care options. There needs to be a culture shift where it becomes the norm that people are involved and supported to make decisions about their care. In addition better training for health and care staff on the MCA and dementia would improve the decision making process. |
| 6 | Birthrights | Personalised decision-making support for individuals | Individuals who need additional support to make decisions about their care should be offered personalised support based on best practice models, and taking all appropriate reasonable adjustments. | Best practice models of care might include continuity of carer or support from a known supporter, provision of accessible communication aids and the use of role play (e.g. to illustrate options in labour care). Some aspects of best practice are included within section 1.2 of the NICE guideline, including 1.2.15: “Where possible and relevant, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time.” This is likely to be particularly pertinent to maternity settings where an individual may need to be supported to make a number of inter-related decisions over an extended period of time. |
| 7 | British Red Cross | Greater prominence and focus on the ‘supported decision making model’ including the use of \*supported decision making agreements to ensure the focus person has genuine opportunities to maximise their decision making capacity prior to there being a ‘reasonable belief’ that a person lacks the capacity to make one or more of their own decisions and the subsequent capacity test. | Whilst the NICE guideline [NG108], October 2018 refers to supporting people’s decision making and providing information to support decision making, the rights of the focus person would be better served by the setting of an expectation that providers will work within the framework of a supported decision making model. The need for it is underlined by the omission of a ‘supported decision making scheme’ which would be consistent with international best practice, into the MCA by the Mental Capacity (Amendment) Act 2019 as had been proposed by the Law Commission. | As the Mental Capacity Act was introduced in 2005 as rights based piece of legislation, we cannot risk losing or undermining principle 2: A person is not to be treated as unable to make a decision, unless all practicable steps to help him do so have been taken without success. Embedding supported decision making models in the ways we operate are essential and adopting a model or scheme which is consistent with international best practice is key to making maximising people’s capacity a reality alongside assuming capacity as our starting point.  In common with other organisations such as People First (Scotland) we entirely support the idea of self-determination of all people including people with intellectual impairments and also see supported decision-making as a crucial step in that direction. |
| 8 | SCM7 | Addressing the near- absence of service user views and experiences | To enable audit, monitoring and service quality assurance across the whole domain covered by this Guideline, and its individual elements e.g. ACP, capacity assessments, supporting decision-making etc Few studies considered by the GC reported the views and experiences of people who may lack capacity (or their families/carers). | Addressing the near- absence of service user views and experiences, in terms of qualitative data, monitoring and service quality and assurance, can ensure person-centred service delivery, assessments, and enable increase compliance with the Act’s and its Code of Practice provisions. Local policies and guidance should be developed and specific tools, which meet the requirements of the Act and are appropriate to different decisions. A collaborative approach across agencies, including advocacy services, may assist. Measurable in engagement outputs, and potential outcomes from views and expressed adjustments communicated. |
| 9 | Royal College of Nursing | Reasonable adjustments | NICE guidance recommends that healthcare practitioners support people 16 years and over who may lack capacity now or in the future, to make their own decisions where they have the capacity to do so. NICE also recommends that practitioners keep people who lack capacity at the centre of the decision-making process. | In learning disabilities and autism, people can make assumptions about capacity. It is so important that it is impressed upon professionals to provide information about any particular decision in an accessible format. The interest of the person requiring support is paramount in determining reasonable adjustments that is to be made for them to meet their needs whether this takes longer to achieve, or involves more professionals such as speech and language therapists and advocates for example. |
| 10 | The Challenging Behaviour Foundation (CBF) | Seeking and taking into account views of people who cannot communicate verbally or have limited communication, in best interest decisions made on their behalf. | The principles of decision making are clear that when people lack capacity to make a decision for themselves, their views and preferences should be sought and taken into account in best interest decisions. | Anecdotal evidence from family carers at the CBF tells us that often very little effort is made to seek the views of people with severe learning disabilities. Personalised communication methods can be used to ascertain the individual’s preferences in relation to the decision, however this rarely occurs. The CBF hears of many best interest meetings where the views of the person are not represented. |
| 11 | BASW | Supporting people to make their own decisions. | The Quality Standard needs to address competence and clear recording of the support given and the reasoning for deciding that the person lacks capacity. | This is variable in practice however essential to ensuring the best outcomes for individuals. |
| 12 | The Challenging Behaviour Foundation (CBF) | Good quality training for health and social care staff in decision making. | Health and social care staff need to appropriately support decision making of people who may lack capacity, on a day to day basis and for significant decisions in the person’s life. | The CBF are told about direct support staff in health and social care services (or in education), who misunderstand capacity and decision making to the detriment of the individual they support. Regarding day to day decisions, they may allow the individual to make decisions that they do not have the capacity to make, for example choosing to eat unhealthy food when they do not have the capacity to understand the health implications of the decision, or choosing to not take part in an activity or leave their room, when they do not understand the consequences so lack capacity to make the decision. Regarding significant decisions, staff and professionals may not have enough knowledge to trigger capacity assessments and decision making processes. |
| 13 | BASW | Application of the key principles of the Mental Capacity Act (2005). | There is evidence that the key principles set out in the Mental Capacity Act (2005) are poorly understood and applied in practice. BASW are concerned that the "presumption of capacity" and the specificity of "this decision, for this person at this time" have still to be incorporated into mainstream consciousness and action. | The Mental Capacity Act is intended to be positive with a focus upon enabling people to make decisions. Application of the key principles outlined are essential to supporting decision making. |
| 14 | MIND | Supporting decision-making in community and inpatient mental health services | Supporting people to make decisions about their health and care is important in all contexts, but there are aspects of mental health care and treatment that make this a key area to focus on:  • we hear from IMCAs that health care professionals are much less familiar and comfortable with the MCA than social care professionals;  • a recent court ruling means that people may be subject to both a community treatment order and DOLS – we are concerned that in these circumstances, the community mental health team may overlook a person’s capacity to make some decisions, while the restrictions on the person mean they are likely to require more proactive support to do so; • many people who are inpatients are detained under the Mental Health Act (MHA) and so there will be some decisions they cannot make, and some will lack capacity to make at least some health and care decisions. In such a disempowering position it is all the more important to support people to make the decisions they can take, and it is still necessary to enable people to express their wishes and preferences so that decisions made under the MHA are properly informed, person-centred and least restrictive of the person; • the restrictive nature of detention affects the inpatient environment for everyone, so actively supporting people to make decisions is important for all inpatients. | The independent review of the Mental Health Act shows how disempowered people detained under the Act often are, not only through the lawful use of the Act’s powers but by “being disparaged, disbelieved or ignored and [being] subject to judgemental and paternalistic behaviour from those caring for them” or subject to unnecessary restrictions.  The Review is recommending various legislative and other changes to strengthen people’s say in their care and build capacity considerations into the MHA including best interests decision-making.  A quality standard on supporting people to make their own decisions under current law and guidance would promote people’s existing rights and help create the culture change that will be required to implement any legislative change made in response to the Review. |
| 15 | NMCP | Supporting those who lack capacity | There is inadequate awareness of support for those who lack capacity - with support their capacity can be enhanced dramatically. Only when every effort to provided support in decision making has failed should one then proceed to assess lack of capacity |  |
| 16 | SCM7 | Ensuring a greater focus on supported decision making. | Ensuring a greater focus on supported decision making.  Supported decision-making can ensure people get the support they need to make decisions for themselves, or to express their wishes or preferences if someone is making a decision on their behalf. As a key rights-based feature of the Act and Guideline, increased understanding of the advantages of supported decision making, and collaborative practice, may add value to health and social care practitioner roles, and ensure a positive care culture; over, protecting a person’s autonomy and rights, and enhancing person-centred care. Plus, compliance with the MCA 2005 can be achieved. [Full Guideline NG108 - 1.2.18 Organisations should ensure they can demonstrate compliance with principle 2, section 1 (3) of the Mental Capacity Act 2005 by monitoring and auditing: person-reported outcomes, including the extent to which the person experiences collaboration and empowerment when making important decisions and the extent to which they experience support for their decision-making • practitioner-reported outcomes, including the frequency and quality of steps they have taken to support decision-making • process outcomes, including the frequency and quality of formal recording of steps taken to support decision-making and the use of overt and covert coercion during decision-making.] | Supported decision making is an implementation area identified as possibly requiring additional thought for commissioners and providers following the Guideline’s publication. Particularly helpful for supporting e.g. treatment-specific decision making, the Committee recommended ‘alongside local policies and training, organisations need to ensure their procedures and forms for capacity and best interests assessments are congruent with an emphasis on supported decision making’.[1] Increasing understanding, and delivery of supported decision making can be done in conjunction with tackling ‘consistent evidence of a lack of understanding amongst commissioners, public bodies, practitioners and people who use services of the critical role independent advocacy can play in upholding rights and providing an ultimate safeguard from abuse’. A number of types of advocacy services can be voluntary schemes e.g. Citizen Advocacy; the Expert witness testimony highlighting the Swedish ‘Personal Ombudsman’ peer support scheme, for instance, could also ‘benefit people who, although retaining capacity, may need support to make a decision’.[3] Utilising imaginative solutions with partners in a tight budgetary envelope may be required. [(1.2 Supporting decision-making: ‘A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success’ (Principle 2 section 1(3), Mental Capacity Act 2005)] As a start, ensuring gaps in statutory advocacy services are filled will be required. |
| 17 | SCM1 | Implementing supported decision making | The NICE guidance stress the importance of supported decision making and the NHS have published an information standard on inclusive communication.  The third key principle of the MCA 2005 is supported decision making. | The average literacy level in the UK is extremely low, and many written leaflets are inaccessible to people with and without communication difficulties.  Making resources accessible for everyone- inclusive to people with all types of communication difficulty will ensure equitable access and will support decision making. |
| 18 | SCM1 | Use of communication aids use to support decision making and capacity assessments. | The UN convention on the rights of people with disabilities (CRPD) emphasise the need to support decision making. There are a number of communication aids, and communication strategies that can support this process. The third key principle of the MCA 2005 is supported decision making. | People with dementia, stroke related aphasia, brain injury and progressive neurological conditions most commonly fail an assessment based on their difficulties in understanding information given to them. Using communication aids, total communication strategies and other means can reduce these barriers. |
| 19 | College of Mental Health Pharmacy |  | There is a need for development of tools/guidance for health care staff and patients to access in relation to supporting decision making and medication. Such tools could be designed to help patients with a mental health diagnosis to agree their individualised “relapse signature” after collaboration with their healthcare staff. This “relapse signature” should be consulted during times of relapse in patients with fluctuation capacity. Another area where such tools need to be developed are for use in patients diagnosed with dementia. The tools should provide evidence- based information to aid decision-making for the patient. Information about medication should be provided in the right way (e.g. tone, with others or not, right materials, verbal/non-verbal etc), in the right place and at the right time. | There are few centrally available resources currently to support high quality, consistent practice in this area. There would be opportunities to work with external organisations such as Mencap, Alzheimer’s Society, Mind, etc when developing these materials. |
| 20 | SCM6 |  | Communication aids - Different approaches can be used to support people with communication disorders to understand and express information during capacity assessments. | Expert testimony presented to the NICE guideline committee identified tools aids and approaches which may be effective in supporting capacity assessment, based on doctoral research focused on mental capacity assessment practice within acute hospital and intermediate care settings and clinical experience of Speech and Language Therapist involved in multidisciplinary mental capacity assessment in acute hospital and specialist rehabilitation settings. |
| 21 | SCM8 | Use and consideration of digital technology including Apps | Responsive and effective use of data collection including both physical/mental health including mood and capacity. Providing evidence to support decision making and outcomes that supports a much more transparent MDT involvement in a person centred manner and identifying long term conditions to prevent relapse. It would I believe improve risk factors for both the patient and staff in terms of identifying triggers resulting in aggressive behaviour. | SCIE Digital technology working group 2019. |
| 22 | SCM8 | Additional info | Use of digital technology | Move away from paper records and it improves capacity. |
| 23 | Royal College of Speech and Language Therapy | Use of communication aids and equipment use to support decision making and capacity assessments | Many people undergoing capacity assessments will have complex communication needs which require support via access to communication aids or equipment. A specific speech or language impairment does not mean that the person with that need lacks capacity to make a decision. A person with a communication difficulty may have capacity to make decisions, but not the means to demonstrate it if their communication needs are left unsupported. Speech and language therapists support people’s individual communication style including the use of Augmentative and Alternative Communication (AAC), aids and equipment. | Our members tell us that assessors often mistake communication difficulties for a lack of capacity. With the right communication support people can demonstrate their capacity.  Professionals too frequently fail to recognise that an individual with communication needs requires support to make decisions. As a result people with communication needs may be asked to make uninformed decisions.  People with complex communication needs in receipt of the correct communication support may be perfectly capable of exercising choice and making decisions. |
| 24 | Surrey and Borders Partnership NHS Foundation Trust | Understanding the need to enhance capacity | One of the key principles of the MCA is that people should be supported to make their own decisions and that every endeavour should be made to enhance people’s capacity | CQC and LeDeR and other reports have found that there is often little evidence of how staff have worked to enhance people’s capacity – e.g. through ensuring people have their glasses or hearing aids, for including relevant supporters, through using communication aids e.g pictures, Easy Read, and through thinking about time of day and other personal issues that may affect capacity |
| 25 | Royal College of Speech and Language Therapy | Implementing supported decision making | Our members report that more work needs to be done to place the client at the centre of the process and to ensure that every step is taken to determine their views and wishes. Demographic changes are resulting in an increasing need for mental capacity assessments. People having a capacity assessment have difficulties with communication and thinking skills, including:  ☛ comprehension  ☛ expression  ☛ retention and recall  ☛ reasoning | Demographic changes are resulting in an increasing need for mental capacity assessments. People with communication needs are at risk of being wrongly deemed as lacking capacity and, in some extreme cases, being deprived of their liberty (having decisions about their care or treatment made on their behalf in hospitals, care homes and other settings) unnecessarily because their individual needs have not been properly assessed and supported. |
| 26 | SCM2 | Developing health and social care staff’s awareness of, and ability to respond to, communication needs of individuals to support decision making | NICE Guidance [NG108] recommends that practitioners should support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with paragraphs 3.10 and 3.11 of the Mental Capacity Act Code of Practice. | Individuals with speech, language, and communication needs are vulnerable because communication difficulties may mask an individual’s inherent decision making abilities or make an assessment of their mental capacity more complex (Brady et al, 2013). Inaccurate mental capacity assessment puts this population at risk, either of being excluded from decision making or of making uninformed decisions (Ferguson et al, 2010). |
| 27 | Royal College of Speech and Language Therapy | Referral to key professionals who can support decision making and capacity decisions. | People requiring a capacity assessment will have a broad range of communication needs arising from head injury, stroke, dementia, progressive neurological conditions, learning disability or mental health problems. All of these can have a significant impact on an individual’s understanding, expression and thinking skills. People need access to key professionals such as speech and language therapy to support their communication during this process. Improving communication support will help people to express their wishes and preferences and maximise client participation in decision-making. This also increases access to high quality assessments. There are excellent examples of speech and language therapists supporting and facilitating communication during capacity assessment but this referral does not happen as often as it should. The person’s needs for decision-making and making sure that their wishes sit at the heart of decision making. | Our members report that assessors do not recognise or know how to support communication difficulties. Without expert support from a speech and language therapists communication difficulties can mask decisions of capacity. We have evidence that shows that assessors too infrequently seek professional support from speech and language therapists to assist in capacity assessments of individuals with communication difficulties (Jayes, Palmer & Enderby (2016).  In cases where the individual has a significant communication need, the support from a speech and language therapist must be sought to aid decisions around capacity and consent. |
| 28 | SCM1 | Referral to key professionals who can support decision making and assess capacity. | There are certain professionals who are able to support decision making such as psychology, speech and language therapy, OT and specialist learning disabilities professionals (this list is not exhaustive) and the NICE guidelines emphasise the need to work as a team to assess capacity. The third key principle of the MCA 2005 is supported decision making. | There are a number of professionals who have expertise in the area who may be consulted in regard to this. People with these diagnosis may not always be referred to in a timely manner (esp those with dementia) |
| 29 | Alzheimer’s Society | Improving awareness of advocacy | Advocacy can be very helpful for people with dementia. An advocate will represent the person with dementia in decisions where they are not able to represent themselves. Where they are used they are particularly valued because of their independent nature, acting solely in the interests of the person with dementia rather than the services that they use or their family. | Independent Mental Capacity Advocates (IMCAs) were introduced as part of the MCA. We have heard from people affected by dementia that they were not aware of IMCAs. This suggests there is low awareness of the existence of IMCAs and the benefits of using them in England and Wales. Better awareness of the MCA and safeguards within it needed amongst the public and health and care professionals. |
| 30 | Mencap | Individuals must be able to access independent advocacy - statutory and non-statutory |  | Independent advocates can be hard to access. Statutory and non-statutory independent advocacy have an important role under MCA. Note – not all decisions are major ones that would meet the criteria for accessing statutory advocacy under the MCA (IMCAs), however independent advocacy can be very important in order to support people with a learning disability with decision-making and get their voices heard. We suggest contacting IHAL/ NDTi in relation to research around access to statutory advocacy under the MCA (IMCAs) and non-statutory independent advocacy. |
| 31 | SCM6 |  | There is some evidence that independent advocacy services benefit individuals who lack or may lack capacity but there is a recognised shortage of such advocates, whether they are offered by local authorities or other public bodies under the Care Act 2014, the Mental Capacity Act 20005 and the Mental Health Act 1983 | The evidence suggests that there are increasing numbers of individuals who suffer from cognitive impairment for example through dementia and/or increasing awareness of impaired decision making because of conditions such as autism who would benefit from support from advocacy services to enable, support and facilitate their decision making; Availability and access to independent advocates is very variable, yet many of the difficulties which individuals suffering from these conditions face can be ameliorated by access to such advocacy services |
| 32 | SCM8 | Legal requirements Human Right | Because Advocacy services are becoming difficult to access particularly in rural areas. Can help prevent poor decision making by being more responsive and effective in dealing with social issues such as benefit advice, housing Etc. Triggers to poor Decision Making can be Welfare Benefit Reforms that can result in psychosis so important to invest in good robust advocacy services that are accessible to all. |  |
| 33 | Royal College of Occupational Therapists | Expansion of existing statutory independent advocacy roles | To increase provision/access to advocacy for people who use services | To try to ensure that people are treated fairly and are not discriminated against, whether or not they lack capacity related to a specific decision. |
| 34 | Alzheimer’s Society | Recognising fluctuating capacity | This is an area particularly relevant for people with dementia whose capacity can fluctuate as the condition progresses. | Better awareness amongst health and care staff on dementia and fluctuating capacity is needed. As a person’s dementia progresses they are more likely to lose capacity; however capacity can fluctuate, even within the space of a day. Awareness and understanding of how capacity fluctuates will help to ensure that steps can be taken to support a person to make decisions, for example putting off making decisions until a later time in the day when a person might regain capacity for a period of time. |
| 35 | MIND | Advance care planning in a mental health treatment context | Advance care planning is especially important in mental health when capacity may fluctuate and people may become unable to articulate their wishes, for example when in crisis. Where this is done well we hear very positive feedback, about how it cuts out things that people find unhelpful and how it improves the care team’s understanding of the person’s needs and wishes. | Although crisis plans have become a routine part of care planning, it is not evident that they are routinely co-produced with, or written by, the patient, or that they include an advance statement. Issues people have raised with us are: • not knowing the plan had been written (until seeing it in notes) • being present but too unwell to contribute to the plan • staff not having time to go beyond a tick-box exercise • the plan being inaccessible when needed eg by A&E • the plan being accessible but not followed. The independent review of the Mental Health Act has recommended (and the Government accepted) introducing Advance Choice Documents (ACDs) as a way for people to set out their preferences, which can then inform care and treatment decisions in detention. As well as enabling people in the community to make advance decisions and have their wishes and preferences taken into account, should they lose capacity, a quality standard on advance planning of mental health care should also bring practice more in line with what will be needed when ACDs are introduced. |
| 36 | SCM4 | Where a person has a long term condition or life limiting illness a health or social care professional will be identified (?At a specified point in care?) to support the person to develop an advance care plan | There is good evidence in the NICE guideline to support collaborative advance care planning.  To identify a specific professional ensures that the work is owned by someone and will be completed | The NICE guideline has recommendations specifically arising from the evidence of the effectiveness that advance care planning with people who have life limiting and long term conditions has on positive patient experiences The MHA code of practice identifies that advance care planning should be part of good discharge planning for people who have been subject to the MHA 1983, though there is little evidence that this is occurring. Advance care planning has risen in status within the Independent Review of the MHA with an early Government response that these recommendation will be supported |
| 37 | SCM9 | Advance care planning directives must be up to date and recent enough to have validity | Health professionals and family members/carers need to be confident that the advance plan is a true reflection of a person’s wishes at a time when they lose capacity | Advance planning directives should be revisited at intervals in order to ensure that wishes expressed are up to date and valid |
| 38 | SCM4 | All advance care plans are reviewed with the person a minimum of every 6 months to determine if the content remains in keeping with the persons capacitious wishes | The only guidance available in the MCA cop regarding the review period for advance care planning comes at 9.29 – 9.30 where it states ‘Anyone who has made an advance decision is advised to regularly review and update it as necessary’ There is a need to ensure that where advance care plans are in place, that the plan to be followed remains valid and applicable, not being superseded by a further decision or have been retracted. Without formal review there is a risk that the wrong plan is followed | Having a clear structure for a review process will support good quality and collaborative care planning. Ensures that the correct advance care plan is recorded (including refusal of life sustaining treatment) and remains valid and applicable. Reduces the risk of following an out of date or retracted decision |
| 39 | Alzheimer’s Society | Improving advance care planning for people with dementia | Planning in advance allows people to plan for a time when they might lack capacity to make a decision. | Advance care planning can be very beneficial for people with dementia. It allows them to put their affairs in order and provides reassurance that the right decisions about their care and treatment will be made in the future, even if they lack capacity to make that decision themselves. However, we have heard from people affected by dementia that they are not given enough opportunities to talk about advance care planning. We are aware that some practitioners do not feel it is their role to speak about advance care planning, or do not feel qualified to do so. Better training for health and care staff is needed to ensure they feel confident to talk to people about how they would like to be cared for at a time when they lose capacity. |
| 40 | SCM3 | CPR and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) orders | CPR and DNACPR have been the subject of a number of high profile legal cases in recent years and subsequent public and professional debate, with the 2016 ‘joint statement’ by the BMA and RCN, revised guidance on DNACPR decisions and the introduction of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process, which is now at an unspecified stage of ‘adoption’ by health organisations nationally. Emphasis has been placed on ensuring high-quality timely communication, decision-making and recording in relation to decisions about CPR. However, there is evidence to show that this area of clinical decision making is not meeting current legal standards, while at the same time patients having DNACPR ‘status’ may be at higher risk due to the wider implications for clinical decisions relating to their care and treatment. | 1. Multiple legal cases in the UK involving DNACPR discussions and the Human Rights Act: Tracey vs Cambridge University Hospital NHS FT (2015); Montgomery vs Lanarkshire Health Board (2015); Winspear vs City Hospitals Sunderland NHS Foundation Trust (2015); Andrew Waters vs East Kent Hospitals NHS trust (2015) 2. Concerns raised regarding GMC guidance for CPR and DNACPR. 3. UK research indicating that discussions regarding CPR does not meet preferences of patients, families or carers and that the “experience of CPR decision-making discussions are at odds with the current legal state in the UK”. 4. The consideration that the presence of DNACPR has wider implications for clinical decision-making with clinicians being less likely to provide a range of interventions for those with CNACPR status. 5. A recent published audit evidenced ongoing variability in practice, in some cases with no consultation taking place with patients / families and no documentation of clinical reasoning for a DNACPR decision as well as consultation leading to potentially avoidable patient distress. |
| 41 | SCM7 | Advance Care Planning (ACP) – training for registered managers of care homes and home care services but not restricted to senior-level staff. | Advance Care Planning (ACP) – training for registered managers of care homes and home care services but not restricted to senior-level staff. NICE quality standard: Decision-making and mental capacity overview (July 2019): Relevance for Existing Indicators cf NHS Digital, 4, P3; P2 – existing NGs - NG108(2018), NG53(2016), NG31(2015), CG136(2011), with ability to inform future NG in development and its QS P3: ‘Shared decision-making: practical guidance for health and social care professionals’. Advance Care Planning is the process of discussing your preferences and wishes about future treatment and care with those close to you and your health/care team. Understanding and following an individual’s own choices and decisions if they may not have capacity is empowering and ensures quality person-centred approaches. It’s particularly relevant therefore for people at risk of losing mental capacity - for example, through progressive illness. People whose mental capacity varies at different times - for example, through mental illness. | There is no set way to plan in advance but there are different elements that can be combined to ensure people know how you would like care to be delivered. For instance: ’The number of older frail nursing home residents is increasing in the UK. Advance Care Planning (ACP) for this population provides an opportunity to empower older people by discussing and documenting their wishes and preferences for their future care. The nursing home workforce is well placed to carry out ACP but lack confidence and training’.[1] The NICE ACP Quick Guide was produced to inform and enable care services’ staff, and public, and couple with the Guideline itself, identifies further a need for pan-sector training. However, training itself without outcome measures can become a lost opportunity (e.g. staff, service user and supporters’ satisfaction and improved adherence to an ACP leading to potential wider health economy and wellbeing gains) |
| 42 | Birthrights | Personalised decision-making support for individuals and advanced care planning | Individuals who need additional support or where there are queries about capacity in the context of ongoing care (e.g. maternity) should be provided with continuity of carer and support and the opportunity to discuss/consider care options ahead of time, as described in para 1.2.15 and section 1.3 of the NICE guideline. | See above re. 1.2.15. Continuity of carer and support will be particularly important for women making decisions around birth where they may wish to make a number of decisions about potential options in advance (birth planning) but where these decisions may change – as a result of preference, circumstance or other factors – when in labour. When considering intrapartum care, midwives deal with much of the care of pregnant women regardless of obstetric risk status and may often be better placed to build an understanding of a woman’s preferences and risk tolerance than other members of the care team. They are well-placed to develop a trusting relationship that is conducive to supporting a woman to make decisions about her care. In Birthrights and Birth Companions’ recent research, healthcare professionals highlighted the importance of continuity of carer for supporting women with decision-making: “There’s no way you would be able to understand the layers of that person and their communication needs, their social needs, their support needs – how they’ve managed their condition, how they live their life unless you have seen them [on] multiple occasions” [ref next column]. |
| 43 | SCM3 | Advance care planning including end-of-life in key areas, i.e. for i) frail and older people; ii) people with MCI-Dementia; iii) patients with a diagnosis of life-threatening, life-limiting or progressive illness; and iv) patients with a terminal prognosis | Despite conversations about end-of-life care being an important component of the national End of Life Care Strategy, Sharp et al found there is a marked disparity between the majority of frail and older people who would like to discuss advance care plans, and the minority who currently have this opportunity.  Dening et al (1) cite several studies showing that family members and carers are often relied upon as ‘surrogate decision makers’ in relation to care and treatment decisions where a person with dementia is considered to lack capacity. There is little evidence about the experiences of patients following the disclosure of a terminal prognosis in relation to planning for end-of-life care. How physicians support patients to transition from anticipating being cured from disease to preparing for death is paramount in promoting patients’ quality of care. Studies evidence patients with a terminal prognosis not recollecting any conversations about forward planning for end-of-life care with the consultant or physician who disclosed their prognosis. | 1. Sharp et al (1) found a marked disparity between the majority of older individuals who would like the opportunity to discuss their end-of-life care and the minority that have the opportunity to do so. 2. Trice and Prigerson highlight key unresolved considerations specifically in relation to end-of-life care remain regarding:  i) what information individual patients truly want; ii) when; iii) how best to convey that information; iv) how patient preferences may change over time; v) how to provide medical information while avoiding or reducing distress and maintaining hope; vi) how to effectively and efficiently translate information exchange into patient and clinician decision-making that honors patient choice and avoids unwanted or inappropriate outcomes; and vii) how the above questions are best approached at EOL in minority populations. 3. Dening et al (1) note that there is on-going debate on when the best time is to offer ACP to people with dementia and patients with a diagnosis of progressive illness or a terminal prognosis; many professionals feel that entering into discussions about ACP for end-of-life care is both too soon and insensitive within the initial diagnostic process. This conflicts with the need for professionals to initiate ACP conversations with the person in a timely and effective way.  4. Whose role it is to initiate ACP or conversations about future care is still ambiguous and this impacts upon the timeliness of ACP. Horne et al’s findings suggest that patients with advanced lung cancer have little or no recollection of physician-led discussions about end-of-life care, matching similar findings. This calls into question whose role and responsibility it is to initiate conversations about concerns and goals of care, or to make offers to engage in ACP or what the best timing for such initiation to occur. 5. Furthermore, the reliance upon family and carers to act as surrogate decision-makers in the absence of effective ACP does not reliably result in decisions which match those that the person would make. In a study using the Life Support Preferences Questionnaire (LSPQ) to explore whether family carers’ choices showed agreement with the end of life care preferences of a person with dementia, Dening et al (2) found that in hypothetical illness scenarios family carers had a low to moderate agreement with the person they were making decisions on behalf of in terms of their preferences for end of life treatment. 6. There remains an unresolved tension between the benefits of ‘standardisation’ and ‘tailoring’ of ACP discussions between professionals and patients: A survey of GPs by Sharp et al (2) found that GPs feel it would be helpful if discussing ACP was more ‘standardised’ in practice (together with a public awareness campaign), while a systematic review of evidence of patients’ experiences of ACP by Zwakman et al showed that patients’ ‘ambivalence’, ‘readiness’ and ‘openness’ play an important role in their willingness and ability to participate in an ACP conversation, leading to calls for a more personalised approach to ACP being developed, which is reflectively tailored to the individual patient’s needs, concerns and coping strategies. |
| 44 | SCM4 | Additional info | 2018 Independent review of the MHA – We know that the Government has accepted some recommendations in respect of advance care planning Governments response to the Independent Review of the MHA (due for publication in December 2019) |  |
| 45 | Mencap | Decision-making 16 and 17 year olds |  | It is important there is clarity in the quality standards around decision-making concerning 16 and 17 year olds. There should be reference to relevant legislation eg. Children and Families Act 2014 and how the MCA works alongside that other legislation. |
| 46 | Surrey and Borders Partnership NHS Foundation Trust | Understanding specific decisions and the requirements to have capacity | Some decisions give rise to more specific issues in deciding whether the person has capacity and greater awareness is needed to guide staff and families.  E,g, Suporting people to make decisions about having sex. | Some decisions are more complex in practice to decide if the person has capacity than others. These include decisions about capacity to consent to sex, financial decisions, where to live etc. Evidence suggests that individual clinicians / staff have different standards as to whether a person has capacity – having expectations of greater understanding than others. This leads to inequity in practice. |
| 47 | Royal College of Occupational Therapists | Awareness by all involved in assessing an individual’s capacity that the assessment MUST be decision-specific, and not a generic assessment | Many people who lack capacity regarding a specific decision are assumed to ‘lack capacity’ in many/all areas of their lives and are treated accordingly. | We all have a duty to respect the autonomy of the people we work with, and enable choice and participation. |
| 48 | SCM9 | Recognition of   the impact of fluctuating capacity | Health professionals must understand that in some situations people may have periods of lucidity and clarity and permanent loss of mental acuity should not be assumed | It may be necessary to revisit decisions made within a best interests context and those decisions should not be considered unalterable. |
| 49 | Royal College of Nursing | Decision making and capacity for people who are detained under the Mental Health Act (MHA) | NICE guidance recommends that healthcare practitioners support people 16 years and over who may lack capacity now or in the future, to make their own decisions where they have the capacity to do so. NICE also recommends that practitioners keep people who lack capacity at the centre of the decision-making process. | People with learning disabilities and autism may represent a small number of the general population often face challenges here. In this regard, we would like some representation for this group of the population in this quality standard. People in secure services are protected by the Mental Health Act; and although the Mental Capacity Act (MCA) is a separate legal framework; decisions around this can become intertwined (i.e. the assessment of capacity to consent to take medications on a T2 (certificate of consent to treatment) or T3 (certificate of second opinion), whether the person has capacity to understand their rights etc.). The MHA Code of Practice is excellent at covering decision-making and mental capacity in terms of Advanced Decisions, care planning, restrictive interventions; however, there are issues specifically for people with learning disabilities and autism. This is also covered in Code of Practice on reassessment of capacity over time and how to record this. We are, however, aware that some professionals think that capacity is static and if someone lacks capacity then they always will. A quality standard covering this issue would be most beneficial for this group of people. |
| 50 | Surrey and Borders Partnership NHS Foundation Trust | Introduction of a real time mental capacity assessment tool | Staff need to be supported to record accurately their capacity assessment ensuring that they meet all the requirements of the MCA Act | Often people undertake a capacity assessment and then transcribe the responses onto forms / or the Electronic Patient Record. Audits show that these are often incomplete/ variable in quality and miss out important factors.  We were awarded £85,000 from the Nurse Technology Fund to develop a web based assessment tool that allows the clinician to input the information contemporaneously, supports the clinician / member of staff to address all the requirements of the Act re decision making, and produces a pdf report immediately on completion |
| 51 | Mencap | Recording decision-making - driving the right practice |  | The Law Commission recommended that professionals should have to prepare a written record containing required information for certain important decisions they have taken where the person lacks capacity to make that decision. The Government’s response to this was ‘Health and care workers should already record these decisions in care and treatment records and this will continue in the system.’ However, too often we are seeing professionals not making decisions in line with the MCA and there being no evidence that they have followed the MCA, eg. around supporting people to make decisions, assessing capacity, and if they are assessed as lacking capacity, evidence that they have followed the best-interests checklist. |
| 52 | Royal College of Psychiatrists | Documentation of decision making and mental capacity | The documentation is often poor, general hospital medical notes often just say ‘has capacity’ or ‘lacks capacity’ and best interests are rarely mentioned. | We suggest a minimum documentation of  • the decision to be made (including choices if applicable),  • who is assessing capacity and why,  • the process used to reach the decision (including how capacity was optimised and who else was consulted to assist the assessment),  • how best interests were assessed • and finally a clear statement about capacity and what the next steps are now a determination has been reached. |
| 53 | NMCP | Decision specific capacity | Lack of capacity is for ‘that decision at that time’ – all too often blanket assessments are made |  |
| 54 | SCM5 | Collecting MCA audit materials and tools that can be used across an organisation | The House of Lords stated that the MCA was poorly embedded – and that people did not know it. Audit material would help. | It is about thinking big – how do we embed it in a whole CCG or LA? How do we know it is embedded or not? Do we have strategies for whole organisations? Can we hold whole organisations accountable for embedding the MCA? |
| 55 | Royal College of Speech and Language Therapy | Training all health and social professionals in communication strategies to support capacity assessments. | Decisions regarding mental capacity will often concern people with complex communication needs. Mental capacity assessment findings impact directly on people’s ability to retain independent control over different aspects of their lives. It is essential that any professional involved in mental capacity assessment, supported decision making and advance care planning is competent to do this. Assessors must understand communication needs and be trained to have these skills to result in more accurate assessments.  Research has demonstrated that communication training can improve the communication of groups of health professionals. Assessors of mental capacity who were trained in facilitative and supportive communication techniques were able to assess decision-making capacity more accurately. | Assessors of capacity need to be able to identify and be able to respond to communication or cognitive difficulties in order to complete accurate assessments. However, assessors often do not recognise or know how to support communication difficulties. Our members tell as that too often assessors mistake communication problems for a lack of capacity.  Professionals without specialist knowledge, or experience of working with people with communication difficulties, make assumptions about peoples decision making abilities based on their own perceptions of communication skills.  Our members frequently tell us that people with communication difficulties have inaccurate mental capacity assessment which puts them at risk of either being excluded from decision making or of making uninformed decisions. |
| 56 | British Red Cross | Compliance with the Convention on the Rights of Persons with Disabilities (CRPD) –  ‘Article 12 recognizes that persons with disabilities have legal capacity on an equal basis with others. In other words, an individual cannot lose his/her legal capacity to act simply because of a disability. (However, legal capacity can still be lost in situations that apply to everyone, such as if someone is convicted of a crime.) The Convention recognizes that some persons with disabilities require assistance to exercise this capacity, so States must do what they can to support those individuals and introduce safeguards against abuse of that support. Support could take the form of one trusted person or a network of people; it might be necessary occasionally or all the time.’ | Ensure that practice in capacity and decision making embeds respect for human rights, autonomy and agency and is compliant with the CRPD so that people who are receiving support and care are seen and treated as:  • active agents with autonomy and  • partners with human rights | For our work at the British Red Cross this is a key area as it’s closely aligned with our humanitarian principles i.e. ensuring that respect for human rights, autonomy and agency is embedded in all our services and for all the people we support who are disempowered including people with disabilities, people with mental health issues, older people, people who are refugees or seeking asylum and vulnerable children and young people |
| 57 | MIND | Cultural competence in capacity assessments, supporting decision-making and best interest decision-making | Assessment of capacity requires some understanding of the person’s world view and best interests decisions are informed by the person’s wishes and feelings.  It is therefore important for the assessor and decision-maker to work in a culturally competent way and be conscious of any biases they may have. | While we (Mind) were working on the Mental Health Act review we heard from people with lived experience about the importance of antidiscriminatory practice and cultural competence in decision-making. Race on the Agenda (ROTA) and the Racial Equality Forum (REF) noted, in their submission to the review, the imprecision of the term ‘mental disorder’ and the room this allows for racial stereotypes or cultural misunderstandings can influence diagnostic decisions made by practitioners. Similar issues are likely to apply in decisions about capacity and best interests. People from BAME communities experience barriers to the right care and support; culturally competent practice in this area should improve people’s experiences and outcomes. |
| 58 | SCM7 | Equalities – Process improvement, and satisfaction measures – ensuring service user views are recognised, and empowering workforce. |  | The Guideline Committee found little published evidence of how a person’s cultural background, ethnicity or religion, including where English is not their first language - influenced outcomes following best interest and capacity assessments, and in particular questioned whether the processes themselves were acceptable to service users and health and social care practitioners. Whilst research in this subject-area has been recommended, it would be possible, and practical, for commissioners and providers to survey and review their current processes and day-to-day policies and practice, (including the use or otherwise of interpreter services), encouraging engagement from partner agencies in this improvement exercise. Intended outcomes being, (ahead of formal research or contributing to it), increased understanding of service user (and carer) experience and quantified levels of satisfaction. Plus, measuring levels of acceptability for service users and carers from current services’ delivery, and gaining information to enable swift commissioning and/or service changes to accommodate equalities’ needs. |
| 59 | Birthrights | Identification of individuals with a need for decision-making support. | It is vital to identify individuals who need decision-making support and to ensure that proper capacity and cognitive assessments are carried out. NHS Trusts may be in breach of Articles 8 and 14 of the European Convention on Human Rights if they fail to provide equal access to care which promotes women’s autonomy in decision-making. In meeting this quality improvement need, it is vital that assumptions about capacity are not made based solely on the decisions an individual is making. A mentally competent patient has an absolute right to decline medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death. A mentally competent pregnant woman may decline treatment even where that might lead to death or serious harm to her or her baby (St George’s Healthcare NHS Trust v S (1997)). The fact that a woman may have made a decision that health professionals believe is not in her or her baby’s best interests is not a reason by itself to decide that she lacks capacity. Conversely, women should not be denied or not offered decision-making support because they are making ‘recommended’ decisions. | Recent research by Birthrights and Birth Companions raised concerns about whether women with learning disabilities that might impact their capacity to make decisions about their maternity care were not consistently identified and supported. Healthcare professionals felt that “doubts about capacity may be less likely to be followed up” if women consented to their care team’s preferred plans, or if they had family support. As noted in section 1.2 of the NICE guideline, “'A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.' (Principle 2, section 1(3), Mental Capacity Act 2005)”; individuals should not miss out on assessment and support to make the decisions that are right for them solely because they are appearing to agree with, or acquiesce to, care provider’s recommendations. It is not sufficient to assume that, because an individual has family support, they are therefore receiving sufficient support to fulfil this requirement and are not coming under coercion or pressure to make a particular decision. |
| 60 | MIND | Capacity assessments in inpatient mental health services | In the disempowering context of an inpatient admission, which may be involuntary, it is important that capacity assessments are done well in line with law and guidance. | The CQC has previously been critical of the quality and frequency of capacity assessments in inpatient units, while the independent review of the Mental Health Act refers to concerns about misuse whereby disagreement with the clinician may lead to an assessment that the person lacks capacity. In particular there is the risk of conflating ‘insight’ and capacity. |
| 61 | SCM1 | Training health and social care professionals in communication strategies to support capacity assessments. | There is evidence that health and social care professionals can benefit from training to improve their communication skills. The NICE guidance on decision-making and mental capacity highlights training (inclusive communication) as a recommendation. | Evidence on training re communication skills in professionals indicates that practice, role play, inclusion of service users are all key components of this type of training and should be followed up with mentoring and support. Training should be based on the research around what is effective, it should not be tokenistic. |
| 62 | SCM4 | As part of the process of admission to hospital or residential care setting, there will be a record of the persons capacity to consent to the admission | There is good evidence in the CQC annual monitoring reports that people are subject to defacto detentions and therefore denied access to safeguards and rights  There is inconsistency between the MHA and MCA codes of practice which may add to confusion by clinical staff. | CQC annual reports continue to highlight the identification of defacto detentions in a range of settings DoLS and LPS are dependent on the provider to make the application. Having the written record would be a good start to preventing defacto detentions and prompting staff to employ the correct legal framework to manage admissions – MHA,Consent, MCA, DoLS/LPS and ensure people have appropriate safeguards and rights. |
| 63 | BASW | Assessment of Capacity | The quality of assessment of capacity needs to improve and be consistent. This should include competencies for capacity assessors, engagement of the person with the process, clarity on the legal requirements of each assessment such as who is the decision maker, what is the relevant information for the decision etc. It is essential to acknowledge that capacity may vary depending upon a given situation and the importance of understanding the needs of adults with learning disability and autistic people. | Evidence suggests variable practice and at times widespread confusion around processes for the assessment of capacity. |
| 64 | Alzheimer’s Society | Improving the way that Best Interest decisions are made for people with dementia | When a decision is made on behalf of a person who lacks the ability to make it themselves, it must always be made in the person's best interests. | The Best Interest checklist shows the rights that the person, and those close to them, have in decision-making:  - When appropriate, the person has a right to be involved in decisions made about them. - Family, friends, and carers also have a right to be consulted and involved in the decision, where appropriate. This is vital as they often know the person best and can share what they feel is in the person's best interests, as well as what the person's preferences and views are. We have heard from people affected by dementia and their families that they do not feel that they are consulted enough, and decisions are often taken from medical best interest perspective rather than what the person would have actually wanted. Past and present wishes should be taken into consideration when making best interest decisions, and it should be considered whether the person will regain capacity later, and if the decision can be put off until then. This is crucial as a person with dementia may have good and bad days and they may be able to make the decision on another day. Better training for health and care practitioners on best interest decisions is needed. |
| 65 | MIND | Best interests decision-making and giving particular weight to the wishes of the individual | Throughout the quality standards we think it would be very helpful to emphasise the importance that should be placed on the wishes of the individual; while there are other factors in best interests decisions it is imperative that the person’s wishes are given due weight. |  |
| 66 | SCM5 | Tools to help address the interface between capacity and ‘self neglect’. | Practitioners struggle with what is called self neglect – when a person refuses personal care or chooses to live in poor conditions or refuses help. This is a very difficult area to get the balance between freedom and security. | Another human rights issue – for a small group of people, but a group who are very hard to support in accordance with human rights law. |
| 67 | SCM9 | Best interests decisions should, where possible, give precedence to the individual’s previously expressed wishes and needs even when those are at odds with family members/ carers wishes | Supported best interests can enable people to participate in the process given the use of aids such as communication/story boards. Health professionals and decision makers need to be assured that the person is not being coerced or being put under pressure to agree with the decision. | An assessment of lack of capacity is decision specific and cannot be assumed based on a person’s behaviour or attitude. For example, someone may have capacity to make a decision such as where they want to live but may not have capacity to deal with their own finances. |
| 68 | SCM1 | Proper consideration of what the person would have considered in their best interest decisions. | The MCA (2005) and the CRPD emphasise the importance of not using a substituted decision making process but making a decision in the best interests of the person involved. There are a number toolkits reported in the NCIE guidelines to support best interest decisions. | In my clinical experience there are few toolkits being used to address this issue, nor are the will and preferences, wishes and beliefs or a person being documented. |
| 69 | SCM4 | Peoples views, wishes and preferences are sought and recorded within 1 month of admission to a health or social care service provision | The MCA 2005 formalises the importance of acting in the person’s best interests when they are unable to make the decision for themselves. In order to complete this action it is vital to understand what is important to the person. | Whilst there is regular reference throughout a range of guidance documents as to why it is important to collect information regarding the persons views wishes and preferences, and how to use them when making decisions on behalf of the person, there is no standard around the collection of this information. The information becomes pertinent at the point a person lacks capacity to make the decision, therefore this information needs to be collected prior to it becoming crucial to decision making for or on behalf of that person. |
| 70 | Birthrights | Best interests decision-making | Best interests decisions should not only focus on all medical risks and benefits but the psychological and ethical, social and welfare (e.g. trust in medical professionals, ongoing engagement with services) impacts of the options being considered. It is vital that “all reasonable steps” are taken to help the woman in question provide her own views on the decision being made (NICE guideline para 1.5.3) – and that those views are then fed appropriately into the best interests decision-making. For pregnant and labouring women, foetal outcomes should not be conflated with maternal ones: for example by making assumptions that the mental health of the woman is best served by ensuring a healthy infant. | It is not always clear that women’s broader best interests and views on decisions are being taken into account when best interest decisions are being considered around labour and birth.  It is vital to recognise the broader impacts of best interest decisions; for example, carrying out any intervention on a pregnant woman judged to lack mental capacity is likely to be profoundly distressing for a woman who is already vulnerable even if this is deemed to be in her best interests: “While lack of capacity may justify intervention in extreme circumstances, all those involved in such cases need to explore every option for ensuring that incapacitated women’s choices about their births are respected.” E Prochaska and S Lomri, The Practising Midwife, Nov 2014 |
| 71 | NMCP | Keeping the person ath the heart of all thinking | There is a need for support in many areas – finance etc being very prominent – and the line between protecting from harm and maximising independence is difficult to clarify for some – but the key is to keep the person at the heart of all thinking. All too often the service and its rules overtake what is best for a person and the person is disempowered by that. |  |
| 72 | Mencap | Best interest decision making |  | Too often families, who in many cases have the most knowledge about their family member, are being excluded from best interests decisions or are involved but not listened to. The professionals involved in people’s lives change. Families will often be the ones who are consistently there who are able share important knowledge and information needed to make proper ‘best interests’ decisions. We have not seen an improvement since the House of Lords Select Committee (2014) criticism that: “The general lack of awareness of the provisions of the Act has allowed prevailing professional practices to continue unchallenged, and allowed decision-making to be dominated by professionals, without the required input from families and carers about P’s wishes and feelings (paragraph 107).” It is very important that families are consulted and involved (as they want to be) when best-interests decisions are being made, in-line with the MCA, and that proper ‘best interests’ decisions are made by professionals. Families should not have to become a Health and Welfare Deputy in order to ensure that they are properly involved in decision-making and/or a proper ‘best interests’ decision is made for their son or daughter. Even when they are involved in decision-making, families have reported to us how they can feel disempowered during the process and find themselves on the back foot in best interest meetings. In some cases family members have not received the appropriate paper work prior to the meeting and in others families talked about how they felt that the decision had already been made before they walked in the room. Poor involvement of families in best interests decisions is a theme that comes up in lots of Mencap’s work eg. evidence from campaigning around health and Transforming Care The Mencap training has highlighted that best interest decisions are regularly made without any assessment of capacity (see also LeDeR; CIPOLD; CQC report 2017/18 and Social care ombudsman report 2017 as supporting this finding) and without using the best interest checklist provided by MCA Principle 4 Evidence at Mencap that best interest decisions may be made, but then not followed through e.g. helpline dental cases. |
| 73 | Mencap | Clarity and understanding around LPAs, and Deputyship and Advance decisions |  | There is confusion around LPAs and deputyship amongst professionals and families, which can cause a number of issues. In line with the MCA families should be involved in best-interests decisions about their loved ones’ care, and professionals should be making best-interest decisions which are genuinely in the person’s best interests. Unfortunately, we see that too often this is not happening. Many families want to become welfare deputies as they believe that is the only way to ensure they are involved in decisions about their loved one’s care and a genuine ‘best interests’ decision is made for their loved one. The Mencap training has found time and again that professionals do not know or understand about LPAs, deputyship or advance decisions. (See also LeDeR; CIPOLD; CQC report 2017/18 and Social Care Ombudsman report 2017 as supporting this finding). |
| 74 | Surrey and Borders Partnership NHS Foundation Trust | Supporting families to understand the MCA | Families, especially those in transition from child to adult services, and those supporting people with dementia need a better understanding of the MCA | Clinicians find that families often do not understand the requirements of the MCA and their role once the person has become an adult. There needs to be more publicity and information for families at transition points to support them in understanding decision making under the MCA |
| 75 | The Challenging Behaviour Foundation (CBF) | Involving family carers in a meaningful way in best interest decisions and giving sufficient weight to their views | Professionals must understand and follow best interest procedures and guidance, to fully inform families of their rights in decision making, involve them meaningfully and not disadvantage or exclude them from the process in any way. | The balance of power within decision making usually lies with the health and social care services working for the individual, as they lead the process. The family are often pushed out or only involved in a tokenistic, ‘tick box’ way. The CBF hears of families who have attended a best interest meeting, disagreed with the course of action being put forward, but not been informed or enabled to use other routes to follow up this failure to agree. The decision of the majority is pushed through, often using a voting system for example, where there are many people in the room from a care provider but only one family carer. |
| 76 | The Challenging Behaviour Foundation (CBF) | Informing family carers about their rights and the rights of their relative who lacks capacity, from age 16. | People who lack capacity to make a decision are at a disadvantage if their family are not well informed about their rights. Social services, CCGs, schools/ colleges and transition services should proactively inform families of decision making and capacity policy and law from age 16. | Families may suddenly face a conflict in decision making and have to learn about this complex legislation in an urgent and stressful situation. The CBF regularly inform families of their rights regarding decision making when their relative lacks capacity to make a decision. Family carers are often scared and intimidated by the processes. They miss opportunities to uphold their relative’s rights if they are not informed in advance. Families are often given misleading information about best interest decisions and legal deputyship. |
| 77 | The Challenging Behaviour Foundation (CBF) | Consistent practice and meaningful involvement of families in the initial approval and ongoing review of deprivation of liberty. | When individuals who lack capacity to make decisions about their care are deprived of their liberty, there should be a consistent and fair process to assess and agree to the restrictions. This is particularly important when restrictive practices such as restraint, seclusion or use of psychotropic medication are being proposed. Relevant professionals should be involved who have an awareness of both best practice and the implications of the restriction for the individual. Families should be fully informed, involved and their views (as relevant person’s representative) fully included. | For some individuals deprivations of liberty are approved without sufficient scrutiny or consideration of the least restrictive option for the person.  When approving restrictive practices, there is often no expert opinion or consideration of less restrictive options for support. Families concerns about use or restrictive practices are not taken seriously. |
| 78 | NMCP | Lasting Power of Attorney | LPAs are poorly understood and poorly used – the development of IT based systems will help this over the next year or so |  |
| 79 | NMCP | Involving people who know the person | Best interests decision making is a last resort and MUST involve consulting those who know the person and focus on what the person would have wanted NOT what others think they ought to have wanted. |  |
| 80 | Luton CCG | The prescribing of Covert Medication and decision making/evidence/documentation around this. | A Mental Capacity Act assessment and best interest’s decision should be completed by the prescriber for prescribing medication to be administered covertly to evidence that the prescriber reasonably believes that the patient lacks the capacity to consent to their medication. This would improve outcomes for the individual to ensure they have essential prescribed medication. Robust recording will be encouraged and GP’s should ask for evidence on a MAR chart of how many times medication has been refused in the last week/two weeks etc., rather than just taking it on face value when a care provider asks for it. We need to see evidence to back up and justify our actions.  We also really need to ask the question is this medication actually essential? | In the local area, The Mental Capacity Act Manager/Lead has been involved in a number of safeguarding cases, where a capacity assessment has not been evidenced by the prescriber and covert medication has still been prescribed. This can potentially be a breach of human rights. It is good practice for prescribers to work in collaboration with the care provider, pharmacy and involve the patient as much as possible. An MCA assessment could be used to coordinate and document everyone’s views who have the person’s well-being at heart. The prescriber takes full responsibility for the assessment but all interested parties have input. Many MCA assessments that have been audited have had very scant information documented on the forms, they need to be more robust and collaborative working should improve the quality of these assessments. Meds management teams in the CCG’s could possibly offer such support in this area? |
| 81 | British Red Cross | Improve understanding of ‘best interests decision making’ and use of tools such as best interests checklist | Important that our use of the best interests decision making framework is robust and fit to stand up to criticism of being a patronising approach, a criticism levied against it for example by thinkers and practitioners involved in the implementation of the Incapacity Act in Scotland where the concepts of benefit and preferences are promoted and in article to right from the Medical Law Review. My understanding is that the best interests decision making process (MCA and code of practice) promotes and supports the wishes, feelings, beliefs, and values of people who have decision making capacity and people who lack the capacity to make one or more decisions at the time they need to be made. As such I don’t see it as disempowering. However I think more work needs to be done on this area and note that the NICE guidance [NG 108] includes recommendations in this area to support good and compliant practice in this area so presume that was one of your findings prior to preparing the guidance. In my working life as a person primarily engaged with safeguarding adult matters I’m regularly needing to challenge two common misunderstandings:  1. Best interest decisoin making applies equally to people who have and don’t have the capacity to make one or more of their own deisions  2. Best interest decision making is the same as working out what you think is the best thing for that person  Example: a relative of ours has dementia. When she was young she had thick long hair and never had it cut short. Now 10 years on from her diagnosis and living in a care home, the staff team asked her husband for some money for a hair cut as they said now that her hair was thin it would be much better for her to manage it if it was cut in a shorter style. Her husband was adament that despite practicalities, she had always had her hair long and never wanted a shorter hair cut so said it was fine for a trim but the money was not to be used for a shorter haircut as that isn’t what her preference was. | This is a key area for quality improvement because where best interests decision making is not understood or poorly understood, the risk of disempowering people and stripping them of their rights is high. We don’t want to go back in time where we thought that doing our best for people was the best we could do and also need to comply with the Convention on the Rights of Persons with Disabilities which, as a state, we have signed up to. |
| 82 | SCM4 | All best interest decisions are supported by a care plan that is reviewed at a minimum of every 6 months | The MCA code of practice guidance for recording in respect of a BID is limited to how the decision was made.   Furthermore the cop’s guidance for the frequency of review of BID’s is that they ‘should be reviewed regularly’ (5.14) | The NICE guidelines links BIDs to care plans in respect of reoccurring decisions (1.5.12) It is however common for BID’s to be standalone documents that are not clearly linked to care plans to support on-going or day-to-day care and treatment for a person who lacks capacity to make these decisions. Setting a standard will improve the quality of record keeping across health and social care, enabling consistency of care as a person transfers between services and service providers. |
| 83 | Mencap | DNACPR decisions |  | In Mencap’s health campaigning there have been examples where DNACPR orders have been applied to people who lack capacity to make this decision, without knowledge or involvement of family or the person’s support team, and situations where DNACPR orders have been applied hastily in inappropriate situations, solely on the basis of the person’s learning disability. Legislation must be followed around DNACPR orders. They must only be in place if they have been appropriately agreed, in line with the law. This process must involve family and carers, where the person lacks capacity to make a decision themselves. Concerns in the latest LeDeR (Learning Disability Mortality Review) Annual Report around DNACPR orders. The main concern was about using learning disabilities as justification. 3 out of 12 recommendations in the report were around DNACPR orders:  -The Department of Health and Social Care, working with a range of agencies and the Royal Colleges to issue guidance for doctors that ‘learning disabilities’ should never be an acceptable rationale for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order, or to be described as the underlying or only cause of death on Part I of the Medical Certificate Cause of Death. -Medical Examiners to be asked to raise and discuss with clinicians any instances of unconscious bias they or families identify e.g. in recording ‘learning disabilities’ as the rationale for DNACPR orders or where it is described as the cause of death. - The Care Quality Commission to be asked to identify and review DNACPR orders and Treatment Escalation Personal Plans relating to people with learning disabilities at inspection visits. Any issues identified should be raised with the provider for action and resolution. |
| 84 | Luton CCG | Improved MCA Implementation for consent for dental treatment - for Dentists especially for those with a learning disability, acquired brain injury or a dementia for example | A Mental Capacity Act assessment and best interest’s decision should be completed by the Dentist to ensure that people do not unnecessarily have all their teeth taken out for example. | A number of cases in the locality have raised concerns via safeguarding and via a LeDeR review where improvements were identified in applying the Mental Capacity Act in practice and in Dentistry on the whole. This would ensure that patients w/should be safeguarded from having treatments imposed upon them and they would receive treatment in their best interests when they have been deemed as lacking the capacity for that particular decision at the time it needs to be made. |
| 85 | College of Mental Health Pharmacy |  | With regard to covert administration of medication, there is a need to improve the quality and frequency of documentation. Documentation of the practice is often absent and specific policies are not always in place. It is reported that sometimes the administering nurse makes the decision to administer medicines covertly without consulting other members of the multidisciplinary team. | Covert medicines administration appears to be a common practice in nursing homes affecting 1.5–17% of institutional patients. Usually medication is mixed with food or drink. Covert administration is only appropriate in patients who lack capacity and following a discussion with the multidisciplinary team, relatives and carers. In England and Wales a Mental Capacity Act (2005) best interests checklist should be completed before administering medicines covertly. |
| 86 | SCM7 | Health and social care organisations should provide toolkits to support staff to carry out and record best interests decisions. | When a person lacks capacity, decisions may be made on behalf of the person, ensuring their best interests are served, which crucially means ‘a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments’ is adopted.  In doing so, this can assist the person, practitioners, and other relevant persons to uphold the person’s rights, and their wishes and feelings as far as possible. | The circumstances for best interests’ decision making may be formal or otherwise, and further consistent support for practitioners was identified. As likely no ‘standardised’ formats exist or would be universally acceptable, local development is desirable. Such development can additionally meet equalities and language/interpreter challenges identified previously. Measurable Quantitative & Qualitative outcomes from toolkit outputs: Service user (and carer) experience and level of satisfaction, the latter quantitative measure of satisfaction. Acceptability to service users and carers. Service user views and experiences regarding mental capacity assessment and best interests decision processes. Health and social care practitioner views and experiences regarding mental capacity assessment and best interests decisions processes. |
| 87 | BASW | Best Interests Decision Making | There is a presenting need for competence, clarity around who is taking the decision, legal literacy, recording, and clear standards for how to make decisions when the person is objecting. | Evidence suggests different approaches to decision making including the application of the law. |
| 88 | SCM5 | Collate/ Research information for job descriptions for Mental Capacity Champions | The NICE Guideline advocated the use of MCA Champions. This is likely to be a ‘hot topic’ in 2020 when both the NHS and LAs will start recruiting for staff to take forwards the new LPS. If we could develop some guidance on how Champions most effectively influence change – both in relation to the LPS but more broadly in relation to the MCA – then we could give the Champions a boost. | Champions drive change Champions needs job descriptions – so that they focus on driving change, not just administering a new Dols/ LPS system It is topical right now – a one off opportunity to influence the JDs of Champions in all parts of England and wales. |
| 89 | BASW | Training of professionals and audit processes. | Health and Social Care agencies should have processes for supporting workers to have necessary capabilities. There should also be multi agency processes to audit the quality of capacity assessments, supporting decision making and best interest decisions. | This is a key area for quality improvement due to the need for consistently good practice across health and social care. |
| 90 | College of Mental Health Pharmacy |  | There is a need for development of an up-to-date policy and mandatory training at a national level for use by all health care organisations relating to mental capacity, decision making and covert administration of medication | Organisations tend to develop their own guidelines and many useful ones are available |
| 91 | College of Mental Health Pharmacy |  | In relation to dosage form manipulation by health care staff and carers there is a need to increase awareness and improve training to ensure this is appropriately supported and safe. | Research evidence highlights evidence of risk in this area. https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2648.2011.05700.x |
| 92 | Compassion in Dying | Training and support for health and care professionals to understand the key components of advance care planning and best interest decision making as set out in the Mental Capacity Act 2005 and to offer person-centred care that is in line with individuals’ goals, preferences and values. | 1. People place great value on choice and control over decision-making and as we have learned from our service users, planning ahead gives people peace of mind and allows them to live well now.  (Compassion in Dying, I wish I had known…2018). 2. 68% of Britons would like more control over decisions about their health (Ipsos Mori, Global Trends – Health, 2017) 3. Data collected from the Compassion in Dying information line shows that those who want to plan ahead in line with the Mental Capacity Act often face many barriers because healthcare professionals are unaware of the law and their responsibilities and find person-centred as opposed to paternalistic approaches to care very difficult. https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/ 4. The NHS Long Term Plan places great emphasis on person-centred care. Therefore it is vital that  a. accurate information on the legal mechanisms available for planning ahead such as Advance Decisions, Advance Statements and Lasting Powers of Attorney is widely disseminated b. all health and care professionals are supported to have the necessary knowledge, skills, attitudes and behaviours needed to realise the empowering principles of the Mental Capacity Act. | The Government’s response to a House of Lords Select Committee Report on the Mental Capacity Act stressed the urgency to: “promote better understanding among health care staff of Advance Decisions, in order to ensure that they are followed when valid and applicable [and] promote early engagement between health care staff and patients about Advance Decisions” We know from recent cases such as that of Brenda Grant and Jillian Rushton that Advance Decisions as provided for under the Mental Capacity Act are still poorly understood and inconsistently implemented with tragic consequences. In the case of Brenda Grant (https://compassionindying.org.uk/statement-response-payout-warwickshire-woman-kept-alive-will/), life-sustaining treatment was provided against the patient’s wishes for 22 months because those responsible for her care did not pay attention to her legally binding Advance Decision. Jillian Rushton (https://www.bailii.org/ew/cases/EWCOP/2018/41.html) also received life-sustaining treatment over several years even though she had taken great pains to refuse it. This was because her GP failed to ensure that her legally-binding Advance Decision was properly communicated to hospital staff. The current NICE guidelines on Decision Making and Mental Capacity do not sufficiently clarify the tools available for planning ahead (Advance Statements, Advance Decisions and Lasting Powers of Attorney); how they are to be implemented and how they work alongside best interest decision making. Improving this element would greatly benefit the practical value of these guidelines. |
| 93 | SCM2 | Developing a culture within health and social care services where the principles of the MCA underpin all interactions | NICE Guidance [NG108] states that service providers and commissioners should ensure that practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. However, training around the MCA often focuses on the procedural aspects of completing and recording the assessment. The focus should instead be on conversations about the ‘whys’ of MCA: Why is it important to support people to make their own decisions? Why is a capacity assessment set out in this way (i.e. diagnostic + cumulative functional test)? Why do we even have an MCA? Such conversations lead to deeper understanding of the ‘hows’, greater motivation to bring about the MCA’s vision and, in turn, to better, more proportionate, practice. | A survey designed to explore how well the MCA is being implemented in care homes by Goldman, S (2019) highlighted that over-reliance on formal, classroom MCA training appeared to be a major barrier to implementing the legislation in practice. While training is a vital starting point for creating a care team who understand the MCA, mental capacity awareness should not be confined to training days, but embedded in every day decisions. Marshall & Sprung (2018) reviewed the literature regarding the MCA and found that 10 years after becoming legislation, the underpinning principles and vision of MCA is not embedded in to practise as was initially intended. |
| 94 | Mencap | Training for health and social care professionals |  | CIPOLD said ‘professionals in both health and social care commonly showed a lack of adherence to and understanding of the Mental Capacity Act 2005, in particular regarding assessments of capacity, the processes of making ‘best interest’ decisions and when an Independent Mental Capacity Advocate (IMCA) should be appointed’. One of the recommendations in the Confidential Inquiry report was that Mental Capacity Act training and regular updates should be mandatory for staff involved in the delivery of health or social care. Both the 2016/17 and 17/18 LeDeR reports have highlighted issues with understanding of the Mental Capacity Act. Our own training has found great confusion between the interplay between consent and the Mental Capacity Act |
| 95 | SCM6 |  | Training of assessors/practitioners in assessing capacity | Inconsistent and variable quality of training Royal Colleges and various professional groups have indicated the difficulty in understanding of the MCA and its application; different toolkits and approaches can lead to lack of understanding; GC recognised for good quality training easily accessible to a wide range of professionals. |
| 96 | SCM8 | Empowerment of Service Users and Carers  Learning outcomes | Improving Quality standards for the involvement of service users & carers in educational co-production within Higher & Further Education speciality within faculties delivering Social Work education. Delivering on the principles of “Making a Real Difference” from a Lived Experience Perspective enhancing CPD for student Social Workers involved in the assessment process and decision making. | HQIP recommendations. CSIP MARD. |
| 97 | SCM8 | Additional info | The increasing use of service users in developing training modules to support CPD in Further and Higher Education when training staff and students. |  |
| 98 | Royal College of Nursing | Staff training | The Care Quality Commission produced guidance to ensure that provider are aware of the duties and responsibilities placed on them by the Mental Capacity Act, so they are able to judge whether they are meeting these. | We are aware that some professionals are not confident in the application of the MCA and are generally hesitant to take lead on the decision maker role in capacity decisions/best interest meetings. A training framework would be useful for providers and what as a minimum it should include. This may already be available and if so, published as part of the Quality Standard. |
| 99 | Royal College of Occupational Therapists | All employees should attend mandatory training regarding decision-making and mental capacity | To try to ensure that people are treated fairly and are not discriminated against, whether or not they lack capacity related to a specific decision. | We all have a duty to respect the autonomy of the people we work with, and enable choice and participation. |
| 100 | Royal College of Occupational Therapists | Assurance that employers/service providers, etc provide quality training for its staff | To try to ensure that people are treated fairly and are not discriminated against, whether or not they lack capacity related to a specific decision. | To ensure that training provision, quality, and cost is monitored and audited. |
| 101 | Surrey and Borders Partnership NHS Foundation Trust | Training for staff | There is good evidence that current training for staff is not effective in day to day practice. Training needs to be more interactive, include people who use services and scenarios. | The LeDer Work in people with learning disabilities has consistently found issues with understanding and implementing the mental capacity act in their reviews of deaths of people with learning disabilities. |
| 102 | SCM8 | 1-6-14 Food in hospital | I do not believe it is acceptable to just include patient choice, consideration should be given to nutritional food content in line with good quality standards. This wording should be included in the document. It is a well-known fact that a well-balanced nutritional meal will improve memory and concentration and ultimately decision making. Combined with the intervention of a professional Nutritionist a person’s well-being can be enhanced in an educational manner | NICE Guidelines on Obesity and Diet. |
| 103 | SCM8 | Pharmacy Dispensing | Improve response times to the dispensing of medication on hospital discharge. Often patients can wait all day for medication to be provided resulting in bed blocking and general frustration for the patient and their families. | Personnel narrative July 2019 |
| 104 | British Red Cross | Not sure if it’s relevant to this consultation or not but would it be possible to take steps for practitioners and commentators from other jurisdictions (i.e. outside of England and Wales) to consider the standards which are written following the consultation so that if there are lessons we need to be learning from the implementation of the capacity legislation in the other UK jurisdictions there is an opportunity to hear and learn and consider them? We appreciate this may be out of remit and also has resource implications but thought it was worth an ask. |  |  |
| 105 | Mencap | General |  | Mencap’s health campaigning has highlighted how serious the consequences can be when the Mental Capacity Act isn’t followed. See Mencap’s ‘Death by indifference’, ‘74 deaths and counting’ and ‘Treat Me Well’ reports. Particular concerns include discriminatory assumptions, not involving families in best interests decision-making and flawed best interest decision-making. Other concerns related to the MCA include: not providing the right support to enable someone to understand and make their own decisions – for example, not providing information in an accessible format or providing an advocate to support the person to understand information, if needed; not doing a full enough capacity assessment and allowing someone to consent to treatment, when they are not able to weigh up the options and understand the consequences. There is now a strong evidence-base that failure to comply with the MCA is contributing to avoidable deaths of people with a learning disability eg. the Confidential Inquiry into the premature deaths of people with a learning disability (CIPOLD) report 2013 and the Learning Disability Mortality Review programme (LeDeR), which started in 2015. We welcome that the MCA Code of Practice is being updated and it is important that this quality standard reflects the updated Code. |
| 106 | MIND | Additional info | Referencing point (not a key area) – NICE refers to the Mental Health Act 2007, but this was an amending Act and the amended legislation is the Mental Health Act 1983 - https://www.legislation.gov.uk/ukpga/1983/20/contents |  |
| 107 | SCM7 | Additional info | Link to Liberty Deprivation Safeguard provisions - cohort of citizens currently receiving DoLS, to be placed under LPS if re-assessed as requiring, have assessed lack of capacity. Presumption from Mental Capacity Act (MCA) 2005 is a citizen has capacity until/unless assessed as otherwise. The MCA’s first two principles being: 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 to do so have been taken without success. | The Mental Capacity (Amendment) Act 2019 Previous assessments can be relied upon in the transition period, so the quality of these is important. A confident and trained workforce can ensure both the MCA, and LDS work in a person’s best interests, hence the link back to the Guideline’s Quality Standards’ development. ECHR Article 5 definitions of liberty deprivation are maintained, hence a broad-based rights-based approach required. The consultation on the new Code has ADASS at its heart, and it is heavily involved. It will be responsible for front-line implementation, as will NHS England…“The Government recognise the importance of providing people with information. We amended the Bill in the other place to clarify that people should be informed of their rights under the liberty protection safeguards process and provided with a copy of their authorisation record. [Hansard April 2019] [n.b. PhilR: not clear how the consultation will be enacted….] |

1. [NHS website](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/) Making decisions for someone else [↑](#footnote-ref-1)
2. National Mental Capacity Forum (2019) [Chair's annual report](https://www.scie.org.uk/mca/directory/forum)  [↑](#footnote-ref-2)
3. Care quality commission (2019) [Monitoring the Mental Health Act report](https://www.cqc.org.uk/publications/major-report/monitoring-mental-health-act-report) [↑](#footnote-ref-3)
4. Professor Rosie Harding & Dr Ezgi Tascioglu (2017) [Everyday Decisions. Supporting legal capacity through care, support and empowerment.](https://www.legalcapacity.org.uk/research-findings/) [↑](#footnote-ref-4)
5. Care Quality Commission (2019) [Monitoring the Mental Health Act report](https://www.cqc.org.uk/publications/major-report/monitoring-mental-health-act-report) [↑](#footnote-ref-5)
6. Care Quality Commission (2019) [Monitoring the Mental Health Act report](https://www.cqc.org.uk/publications/major-report/monitoring-mental-health-act-report) [↑](#footnote-ref-6)
7. Care Quality Commission (2019) [Monitoring the Mental Health Act report](https://www.cqc.org.uk/publications/major-report/monitoring-mental-health-act-report) [↑](#footnote-ref-7)
8. HQIP (2019) [National Audit of Care at the End of Life (NACEL)](https://www.hqip.org.uk/resource/national-audit-of-care-at-the-end-of-life-nacel-2019/#.XVUWDKZ8C9I) [↑](#footnote-ref-8)
9. Bartlett P. et al (2016) [Planning for Incapacity by People with Bipolar Disorder under the Mental Capacity Act 2005](https://www.tandfonline.com/doi/abs/10.1080/09649069.2016.1228145?journalCode=rjsf20) [↑](#footnote-ref-9)
10. Compassion in Dying (2018) [I wish I had known](https://compassionindying.org.uk/library/i-wish-i-had-known/) [↑](#footnote-ref-10)
11. Compassion in dying (2018) [Advance care planning in general practice – does policy match reality?](https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/) [↑](#footnote-ref-11)
12. B.W.J spencer et al. (2016) [Capacity in vacuo: an audit of decision-making capacity assessments in a liaison psychiatry service](https://www.cambridge.org/core/journals/bjpsych-bulletin/article/capacity-in-vacuo-an-audit-of-decisionmaking-capacity-assessments-in-a-liaison-psychiatry-service/421C48664A43C3C36D6A6E3CAFFFF6AE) [↑](#footnote-ref-12)
13. HQIP (2019) [National Audit of Care at the End of Life (NACEL)](https://www.hqip.org.uk/resource/national-audit-of-care-at-the-end-of-life-nacel-2019/#.XVUWDKZ8C9I) [↑](#footnote-ref-13)
14. Select Committee (2014) [Select Committee on the Mental Capacity Act 2005 - Report](https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm) [↑](#footnote-ref-14)
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16. ADASS (2017) [Learning from SARs report](https://londonadass.org.uk/learning-from-sars-report/) [↑](#footnote-ref-16)
17. Williams V. et al. (2013) [Best interests decisions: professional practices in health and social care](https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12066) [↑](#footnote-ref-17)
18. ADASS (2017) [Learning from SARs report](https://londonadass.org.uk/learning-from-sars-report/) [↑](#footnote-ref-18)
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20. Williams V. et al. (2013) [Best interests decisions: professional practices in health and social care](https://onlinelibrary.wiley.com/doi/full/10.1111/hsc.12066) [↑](#footnote-ref-20)
21. [Decision-making and mental capacity](https://www.nice.org.uk/guidance/ng108) NICE guideline NG108 (2018) [↑](#footnote-ref-21)
22. [NHS website](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/) Making decisions for someone else [↑](#footnote-ref-22)
23. [NHS website](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/) Making decisions for someone else [↑](#footnote-ref-23)
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25. [NHS website](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/) Making decisions for someone else [↑](#footnote-ref-25)
26. [NHS website](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/) Making decisions for someone else [↑](#footnote-ref-26)