NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Decision making and mental capacity

Date of quality standards advisory committee post-consultation meeting:
16 January 2020.

1. Introduction

The draft quality standard for decision making and mental capacity was made available on the NICE website for a 4-week public consultation period between 5 November and 4 December 2019. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 25 organisations, which included service providers, national organisations and professional bodies. We also received comments from 2 individuals.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices [1 to 3].

1. Questions for consultation

Stakeholders were invited to respond to the following general questions:

1. Does this draft quality standard accurately reflect the key areas for quality improvement?

2. Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be to be for these to be put in place?

3. Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

4. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* The quality standard and areas prioritised were supported by the stakeholders.
* Stakeholders highlighted the need to ensure the quality standard refers to the most up to date legislation and may need updating before publication – they highlighted Mental Capacity (Amendment) Act which passed in law in May 2019 and the revised MCA Code of Practice which is due to be published in Spring 2020.
* Stakeholders raised concerns about the lack of clarity around the particular position of those aged 16-17 years old within the quality standard. They highlighted parallel decision-making routes for this age category in the medical treatment context based upon the Mental Capacity Act 2005 or upon parental responsibility.
* Stakeholders highlighted that the statements would be very difficult to implement in emergency situations or in the “hear and treat” environment of NHS111 and suggested it should be acknowledged throughout the document.
* Stakeholders suggested adding more detail around training for health and social care staff in line with the new commitment to mandatory training of health and social care workers, reflecting the learning disability core capabilities framework which has various learning outcomes on MCA.
* Stakeholders suggested that there should be more references to advocacy throughout the quality standard. It is important that the quality statements reflect the importance of both IMCAs, and community (non-statutory) advocacy.
* Stakeholders highlighted that sensory needs alongside mental and physical needs should be recognised in the quality standard.
* Stakeholders suggested that using term “adults/people at risk” rather than “vulnerable people” better reflects current safeguarding legislation and up to date terminology.
* Stakeholders raised concerns about using the term allied health professionals and asked for it to be amended or removed.

### Consultation comments on data collection

* Stakeholders raised concerns that for the process measures, any result other than 100% would be an admission of unlawful practice.
* Stakeholders raised concerns that data collection will require lengthy audit of notes and free text information relating to every patient contact, meaning a low probability of this work being undertaken due to limited time and resources.
* Stakeholders suggested that to make the data collection more manageable, the committee should consider making the numerators and denominators more specific, for example, include narrowing the denominator down to a specific diagnosis (e,g. dementia)

### Consultation comments on resource impact

* Stakeholders highlighted that resources would be required to provide training around the application of Mental Capacity Act.
* Stakeholders suggested that fully implementing the existing NHS Accessible Information Standard would be a cost saving to services having to create their own resources.
* Stakeholders suggested standardised digital images and a searchable database should be available for all services to use across health and social care services.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

People aged 16 and over who may lack capacity to make decisions receive support for decision making that reﬂects their individual circumstances and meets their particular needs.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

* As we are assuming capacity, and the starting point is working with people to maximise their capacity, talking about people who may lack capacity rather than people who need support to make their own informed decisions, risks confusing and conflating the two.
* Access to independent advocate should be added to the statement.
* The definition of IMCA and their role will need updating to take account of the new role of approved mental capacity professional under the Mental Capacity Amendment Bill.
* The role of family carers should be highlighted more.
* Stakeholders made numerous comments on measures suggested within this draft quality statement. We will review these comments in line with the final statement wording and committee discussions.
	1. Draft statement 2

People aged 16 and over at risk of losing capacity to make decisions, and those with fluctuating capacity, are given the opportunity to discuss advance care planning at each health and social care review.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

* Statement should go beyond discussion; discuss and develop/record so that actions are taken after the discussion.
* Advanced care planning has different meaning across health and social care. Planning for the future may be more suitable terminology.
* The statement needs to be explicit about what is included in planning for the future – Lasting Power of Attorney, Advanced Decisions to Refuse Treatment, Advance Statements etc. - term ‘advance care planning’ encompasses a wide range of decisions
* There is a need to clarify the limits of advanced decision making in those aged 16 and 17 within this statement.
* Concern about regularly reviewing advance care plans in people with certain conditions especially mental health conditions. It may be suitable to discuss their future care once they have recovered but not when their capacity is fluctuating due to the condition – eating disorder provided as an example.
	1. Draft statement 3

People aged 16 and over who are assessed as lacking capacity to make a decision have a clear record of the practicable steps taken to support them and the reasons why they lack capacity.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

* As supported decision-making has been covered in Statement 1 it may be more useful to focus Statement 3 on assessing capacity.
* It should be made more clear that an assessment is not a one off action - whenever decision is made there should be a review of the person’s ability to take that decision.
* Temporality of lack of capacity, deferring referral, regaining capacity and reassessment should be mentioned in this statement.
* The statement should refer to “specific decision”.
* Stakeholders also made comments on measures suggested within this draft quality statement. We will review these comments in line with the final statement wording and committee discussions.
	1. Draft statement 4

People aged 16 and over who lack capacity to make a decision have their wishes and feelings reflected in best interest decisions made on their behalf.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

* The statement should also include beliefs and values to more accurately reflect the language of the MCA 2005
* Suggestion to remove decisions ‘made on their behalf’ – it moves the statement in the right direction of people’s will and preferences and away from ‘substitute’ decision making
* As currently drafted, this section refers to the need to talk to the person about their wishes and feelings, but does not highlight the centrality of the person’s wishes and feelings to the best interests decision making process - greater emphasis could be given in this section to the legal concept of best interests.
* Term “Best interest” is often misunderstood by healthcare professionals who take it as “medical best interest” rather than the wider ranging meaning given to the term under the Metal Capacity Act and subsequent case law.
* Suggestion to add “and have access to independent advocates where needed” to the statement.
* Stakeholders made numerous comments on measures suggested within this draft quality statement. We will review these comments in line with the final statement wording and committee discussions.
1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Role of support staff in assessing capacity - there is a need for staff to understand that capacity assessments are not something that should only be carried out by doctors and psychologists and to become more aware of the everyday assessments that they are already engaging in and recognise their everyday assessments of capacity as part of implementing the MCA.
* Access to advocacy – having a separate quality statement around access to advocacy would address the issues identified in the decision making and mental capacity guideline.
* Safeguarding – having a separate statement on safeguarding referrals to the local authority if a person aged 16 or over has the capacity to say if they want it to happen or not.
* Advance care planning - where a person aged 16 or over lacks capacity to make relevant decisions, appropriate advance care planning is undertaken in relation to healthcare interventions that may be required (and/or treatment escalation decisions).
* Court of protection - cases that require determination by the Court of Protection are brought appropriately to the Court of Protection
* Mental Capacity Act Code of Practice - decision-makers have regard to the current version of the Mental Capacity Act Code of Practice (including, if separate, the Code relating to the Liberty Protection Safeguards) when making decisions.

© NICE [2020]. All rights reserved. Subject to [Notice of rights](https://www.nice.org.uk/terms-and-conditions#notice-of-rights).

# Appendix 1: Quality standard consultation comments table – registered stakeholders

|  |  |  |  |
| --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Statement number** | **Comments** |
| 1 | British Geriatrics Society | General | Consider referring to NICE delirium guideline and QS |
| 2 | British Red Cross  | General | The list (on page 8) needs to be broadened so that it also includes and takes account of: • the impact on capacity of abuse and/or trauma e.g. following torture, trafficking, war, bereavement or significant change in health or social circumstances |
| 3 | British Red Cross  | General | A request to use the term adult/people at risk instead of vulnerable person/people (similar to the distinction between social and medical models of disability) to acknowledge: • the learning from the consulation on the review of No Secrets when many self-advocates using services asked not to be referred to as ‘vulnerable people’• that many people are at risk in relation to their circumstances and the actions of other people • that if a person is at risk using the language and concept of risk rather than vulnerability is more likely to support and lead to effective engagement and reflect:• current safeguarding legislation which avoids the use of ‘vulnerable person’ and ‘vulnerable people’ |
| 4 | Compassion in Dying | General | The quality standard would benefit from greater specificity around the documentation of, rather than only the discussion of, personal preferences, particularly with reference to the options available under the Mental Capacity Act 2005: – Advance Statements, Advance Decisions and Lasting Powers of Attorney.Compassion in Dying runs a free Information Line, which over the years has supported over 44,000 people to discuss and record their care preferences. Our experience reveals the urgent need to support individuals to understand their rights and choices regarding future treatment and care. For example, some of the questions we get asked on our free information line include:“How do I make sure I am not given artificial nutrition when I have dementia?”“How can I make sure that the paramedics know I don’t want to be resuscitated?”To help reflect real people’s experiences in the quality standard please see our report - “I wish I had known…”- https://compassionindying.org.uk/library/i-wish-i-had-known/ the launch of which was attended by representative of NHS England, the British Medical Association and the Royal College of Physicians (2018).We also strongly recommend referring to recent case law which highlights the importance of documented and legally binding care preferences:- Briggs v Briggs & Ors [2016] EWCOP 53 - Mr Justice Charles noted that if Mr Briggs had made an advance decision it would have been decisive.- Brenda Grant (2017) - Mrs Grant was given life-prolonging treatment against her previously documented wishes for 22 months following a severe stroke, when the hospital caring for her lost her legally binding Advance Decision to Refuse Treatment https://www.hsj.co.uk/end-of-life-care/the-tragic-brenda-grant-case-should-be-a-wake-up-call/7021361.article - NHS Cumbria CCG v Rushton [2018] EWCOP 41 – Mr Justice Hayden noted that the medical profession must give advance decisions the utmost care, attention and scrutiny.Our recent report on GPs also reveals the urgent need for supporting healthcare professionals to implement the key principles of the Mental Capacity Act 2005: https://compassionindying.org.uk/library/advance-decisions-uncovering-what-gps-need/ (2019).This observation was also made in the recent Care Quality Commission report The state of health care and adult social care in England 2018/19 which noted that they “…see providers that do not understand the wider legal principles of the MCA” https://www.cqc.org.uk/sites/default/files/20191015b\_stateofcare1819\_fullreport.pdf Finally, a recent YouGov survey of 502 people living with terminal or advanced illness revealed that people need more support to document their preferences. For example:• 33% of respondents say that they would like to complete an LPA but have not done so yet. • 43% say they want to refuse treatments at the end of life but only 12% have completed an Advance Decision.• 37% don’t know what Advance Decisions and Advance Statements areNot including the fact that decisions can be recorded if the person chooses to do so, is a very concerning oversight. Clearly for a person’s care and treatment preferences and decisions to be known about and respected they need to be recorded in a way that is accessible to healthcare professionals beyond the person they discussed their wishes with. Therefore, if person-centred care is to become a reality, we suggest utilising every opportunity to promote people’s rights and choices to plan ahead and to enable health and care professionals’ to facilitate this.  |
| 5 | Compassion in Dying | General | We suggest including an additional bullet point to the outcomes about health and care professionals being supported to implement personalised care. |
| 6 | Court of Protection Practitioners | General | We agree that the statements accurately reflect the issues that we would have wanted to highlight in this area. We advocate for no changes to the wording of the statements themselves.  |
| 7 | Mencap | General | Training for health and social care staff – This does not form a statement in itself but is reflected within the detail for each statement. We would suggest more detail in terms of training outcomes in line with the new commitment to mandatory training of health and social care workers, reflecting the learning disability core capabilities framework which has various learning outcomes on MCA. |
| 8 | Mencap | General | This standard must be updated soon to be reflective of any updates to the MCA Code of Practice next year (2019).  |
| 9 | Mencap | General | DNACPR decisions – This is a particular issue for people with learning disability (LeDeR 2019, CIPOLD). This may not be appropriate for a distinct recommendation, but it would be helpful if this could be addressed in the examples.  |
| 10 | NHS Sheffield CCG | General | Bearing in mind that the Mental Capacity (Amendment) Act was passed in law in May 2019 and a revised MCA Code of Practice is due to be published Spring 2020, the current draft may appear to be outdated as it refers to the Mental Capacity Act 2005. Will this impact on the statements within this QS and should publication be delayed to ensure this reflects the most up to date legislation and guidance |
| 11 | Royal College of General Practitioners | General | Overall this is a very difficult topic to measure. It is not common to code or document those who “are at risk of losing capacity” or who “may lack capacity” in the clinical notes.Capacity measurement is a continuum not an isolated point in time and one must always assume a patient has capacity with every interaction as determined by the Mental Capacity Act 2005.In primary care, capacity is checked each time patient-healthcare professional contact occurs. No ‘formal’ mental capacity assessment is undertaken. Many of the quality measures listed will require lengthy audit of notes and reading of free text information relating to every patient contact, meaning a low probability of this work being undertaken due to limited time and resources in primary care. The committee should consider making the numerators and denominators more specific than those currently detailed in order to collect data that is more readily available. For example this could include narrowing the measured field down to a specific diagnosis (e,g. dementia) |
| 12 | Royal College of Psychiatrists | General | There is no clear approach on what actions to take of mental capacity constantly fluctuates and ongoing decision making is required. This is currently a court decision that is open and subject to appeal. A clear guide on actions to be taken would be useful.  |
| 13 | Royal College of Psychiatrists | General  | Some specific mental disorders can affect identity and wishes, not just the intellectual capability to make decisions. For example, it has been established in 5 court of protection cases that patients with severe anorexia nervosa can lack capacity to make decisions about refusing treatment for their eating disorder. It is very important in these cases that ‘the person’s wishes’ are carefully disentangled from their expressed wishes due to the impact of the mental disorder, for example a wish to lose weight even if they died is driven by the eating disorder. So although it is critical to always respect individuals and their (authentic ie true to themselves) wishes it is important to be able to qualify a directive to always put the person’s expressed wishes above the views of families and professionals.  |
| 14 | Skills for Care | General | We think the document should mention deprivation of liberty as it’s important in respect of when someone has had capacity to consent and has consented to care arrangements. This is key if those arrangements mean they are under constant supervision and not free to leave, but they aren’t technically deprived of their liberty as they have given capacious consent but then lose the capacity to consent at which point they are technically deprived of their liberty and best interest decision and an authorisation would be needed. This is the case now and will be under the new LPS; it’s just the process for the authorisation that changes. |
| 15 | Skills for Care | General | Need to include sensory needs alongside mental and physical as from experience working with the people with sensory impairments, this isn't always recognised or addressed as well as it could and also from a recording prompt perspective to include who was involved, again regularly missed and then not knowing who to follow up with at review or as something changes. |
| 16 | Skills for Care | General | A wider point that’s omitted is about people consenting to anything and then either changing their mind (and being able and encouraged to). People consenting to anything ongoing or repetitive and then losing capacity and generally about revisiting decisions that have ongoing effects to check for either of those things. |
| 17 | The British Dietetic Association (BDA) | General | The BDA Mental Health specialist group and BDA Older People specialist group welcome the development of the quality standard. The statements are clear and should be easy to demonstrate within MDT documents and relevant to all dietitians.  |
| 18 | The British Psychological Society | General | The Society welcomes reference to access to psychologists, though we would strongly recommend that this is not restricted to Clinical Psychologists. The HCPC regulates seven protected titles of practitioner psychologist, many of which work in healthcare and may work in contexts with people who may lack capacity.  |
| 19 | The British Psychological Society | General | We welcome the advice that training should be tailored to the role and responsibility of the practitioner.  |
| 20 | The Challenging Behaviour Foundation | General | The Challenging Behaviour Foundation (CBF) works to support the lives of children, young people and adults with severe learning disabilities whose behaviour challenges and their families. Following our response to the previous consultation on this quality standard, we welcome the changes that have been made to the quality statements to reflect the needs of people with severe learning disabilities who are at particular risk of not being engaged in decision making. They face a range of complex issues, including barriers to integration and the inappropriate use of restrictive interventions and medication. Often, they can live in places far from the family home with people they do not like. Therefore, it is encouraging to see the quality statements take into consideration making reasonable adjustments to communicate with individuals and understand their wishes, as well as taking practicable steps to ensure mental capacity decisions are not made too hastily. However, the important involvement of family carers is still not clear in the quality standards. For individuals with severe learning disabilities whose behaviour challenges, while health and social care practitioners are important, family carers often know the individual best, including having an understanding of their communication, and are often the best advocate for their loved one. The input of family carers is an invaluable resource that should be reflected and respected in the quality standards.  |
| 21 | The Law Society | General | The Law Society is the professional body for solicitors in England and Wales, representing registered legal practitioners. The Society represents the profession to parliament, government and regulatory bodies and has a public interest in the reform of the law. This response has been prepared by the Mental Health and Disability Law Committee of the Law Society of England and Wales.  |
| 22 | The Law Society | General | Nevertheless, our support is conditional on all four quality statements reflecting the particular position of those aged 16-17 years old, where at present, the Mental Capacity Act Code of Practice and other relevant guidance states that there are parallel decision-making routes for this category of people in the medical treatment context based upon the Mental Capacity Act 2005 or upon parental responsibility. We consider that it is necessary that this position is resolved by NICE prior to finalising the Quality Standard as otherwise it will not be possible appropriately to monitor compliance with the statements. |
| 23 | The Law Society | General | The Law Society is not best placed to provide comment on implementation or monitoring matters, however we consider that any monitoring must include a qualitative audit element in addition to a significant element of monitoring by experts by experience. The four quality standard statements proposed by NICE are not fully accommodated by quantitative auditing, nor do the three further ones that the Law Society recommends below.  |
| 24 | NHS England – Specialised Commissioning | Measures | I am not overly familiar with the approach taken by NICE in building these measures but it seems odd to me that against every statement, the measure is looking for numerator and denominators which ought be 1:1 in every case. In all cases, in order to be legally compliant the person’s communication needs should be taken into account, trusted and significant people must be involved, practicable steps must be taken, it must be recorded why the person lacks capacity, the person must be involved in a best interests decision wherever this is appropriate, the best interest checklist must be followed and. To report any other numbers would be an admission of unlawful practice – is this what the team expects? |
| 25 | British Red Cross  | Question 1 | Does this draft quality standard accurately reflect the key areas for quality improvement? We welcome the four-fold focus on 1) supported decision making; 2) advance care planning; 3) practicable steps and 4) best interest decision making and suggest the need for a 5th and a change in order so that for example best interests does not come before practicable steps as it needs to be the other way round. The statements would therfore be: 1 (stays as 1)Supported Decision Making 2 (instead of 3) Practicable Steps3 We think there is the need for an additional statement about the role of support staff (and volunteers?) in assessing capacity so that good best interest decisions can be made for everyday decisions e.g. what to have for breakfast, what clothes to wear for going shopping on a cold and frosty day which take account of the person’s wishes (past and present), will and preference. There is a need for staff to understand that capacity assessments are not something that should only be carried out by doctors and psychologists and to become more aware of the everyday assessments that they are already engaging in and recognise their everyday assessments of coapacity as part of implementing the MCA. 4 (as before) Best interest decisions 5 (instead of 2) Advance care planning  |
| 26 | Royal College of Occupational Therapists | Question 1 | Yes, it reflects some areas needed for improvement. However, there are also quality improvements needed to identify responsibility for funding and provision of resources to ensure the Mental Capacity Act (MCA) requirements of ‘all practicable steps’ to help an individual to make a decision is met.  |
| 27 | Royal College of Speech and Language Therapists | Question 1 | RCSLT is pleased to see the focus on taking steps to ensure that communication is supported and highlighting an individual’s potential communication needs. It is absolutely essential that supported decision making, including support for all people with communication difficulties, is at the heart of this Quality Standard. RCSLT is pleased to see that commissioners will be encouraged to consider how people are supported. This measure will help to drive forward person-centred decision making.  |
| 28 | Sussex Partnership NHS Foundation Trust | Question 1 | We consider the draft quality standard accurately reflect key areas for quality improvement. |
| 29 | The Law Society | Question 1 | In principle, we agree that the four quality statements accurately reflect the key areas for quality improvement, which we understand to relate to the making of decisions by health and social care professionals.  |
| 30 | British Red Cross  | Question 2 | Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?No I don’t think that local systems and structures are in place to collect this data for the proposed quality measures. For us as an organisation putting the necessary training and infrastructure in place to support the effective implementation of the MCA is more of an important pre-requisite for quality improvement than putting local systems for data quality measures in place. Once this is in place and we move towards quality assurance at this stage we’d be asking about understanding of i) the principles of the act; ii)supported decision making to maximise people’s decision making capacity; iii) your role in assessing capacity for everyday decisions; iv) the role of advocates including IMCAs and how to access them; v) best interest decision making and vi) advance care planning.  |
| 31 | Royal College of Occupational Therapists | Question 2 | There are practical steps recommended pertinent to all Statements:1. Capacity key worker. There needs to be a nominated ‘Responsible Capacity Worker’ so that assessments and data is shared. People who lack capacity or who may lack capacity are often those whose needs are broad and across a range of services and there is often poor sharing of information between services because people simply do not know what previous assessments have been undertaken. 2. Responsibility defined for identifying and funding of specialist assessment and education programmes. Without these the ‘all practical steps’ cannot be implemented.  |
| 32 | Royal College of Speech and Language Therapists | Question 2 | Currently there is not adequate infrastructure to support the collection of the data that the quality measures suggest. Local data collection initiatives may exist and will be able to provide snapshots and examples of a particular way of working, which may or may not reflect information relating to the quality standard. However, this is not systematic and is unlikely to extract information that could be collated across localities. In particular, data coding for therapy interventions, approaches and types of support is not centralised and therefore this evidence cannot be extracted. A joined up informatics system across health and social care will be required for this, in which NICE has a role in supporting the delivery of. The Royal College of Speech and Language Therapists Online Outcome Tool supports speech and language therapists with collecting and collating TOMs data and generating reports. |
| 33 | Sussex Partnership NHS Foundation Trust | Question 2 | Local systems are in place for recording this information. Reporting mechanisms could, potentially, be developed. |
| 34 | British Red Cross  | Question 3 | Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.No, I think that many local services are grappling with the complexity and challenge of meeting people’s essential support needs in a climate of shrinking service provision and budgets. We think that alignment to these quality statements would require some substantial shifts in priorities and that asking staff to prioritise data collection over direct service delivery would be an unfair ask though we do appreciate the value of good data collection alongside improvement activity. One of the service managers who was given an opportunity to contribute to this submission made the following comments on the subject of case complexity and its impact: ‘I agree with the standards, but what sort of training will frontline workers get on how to assess capacity? Both of our independent living services are dealing with people in far more complex and chaotic situations than originally anticipated, where there have been no formal assessments of mental capacity and people’s unwise or poor decisions e.g. in relation to medication, drugs and alcohol are having a serious impact both on the people themselves and on the staff and volunteers supporting them.’  |
| 35 | Royal College of Occupational Therapists | Question 3 | By enabling that he existing NHS Accessible Information Standard is fully implemented. Experience across many different services and trusts is that it remains poorly understood and poorly implemented. If implemented fully this would be a cost saving to services having to create their own information each time. What would help – standardised digital images and a searchable database available for all services to use across health and social care services.  |
| 36 | Royal College of Speech and Language Therapists | Question 3 | Adequate speech and language therapy services will need to be in place across the country to delivery consistent care to achieve these standards. Government predictions show a rapid increase in the number of mental capacity assessments being carried out. This will lead to increased future demand for speech and language therapy which needs to be considered in workforce planning.  |
| 37 | Sussex Partnership NHS Foundation Trust | Question 3 | Availability and delivery of quality training, in a format that is easily accessible by clinical staff is key to enhancing Mental Capacity Act knowledge and its practical implementation in daily clinical practice. |
| 38 | Sussex Partnership NHS Foundation Trust | Question 3 | To implement a mechanism for data gathering/auditing and reviewing the data would require allocation of additional resources. |
| 39 | Royal College of Occupational Therapists | Question 4 | Page 7 Supporting decision making. Example from practice: Individual following severe brain injury then diagnosed with cancer requiring treatment. He had previously been assessed as lacking capacity for health and care needs. Individual was advised surgery was needed to save his life. He immediately refused. Specialist Speech and Language assessment identified complex communication disorder and need for information to be provided in accessible format. Decision to be made was of high importance and high risk. Joint working with Medical team, nursing team, Speech and Language Therapist(s) and Occupational Therapist(s) to agree an education programme. Individualised Accessible documents were prepared and 4 x education sessions provided by different therapists over 1 week. A further capacity assessment was then arranged with the neuropsychologist. With use of communication support client was able to demonstrate ability to understand, recall, weigh up and communicate his wishes. The process involved shared working across a range of services. But it was very time intensive and needed to be undertaken in a short timescale given the nature of the treatment needed. If the hospital had pre-prepared accessible information this would have reduced some of the time needed. |
| 40 | Royal College of Speech and Language Therapists | Question 4 | Throughout the Quality Standard the term “allied health professionals and practitioners” is used. RCSLT recommend this is either clarified or changed. Allied health professionals bring together 14 professions, and their title is recognised by NHS England and protected by Law. There is no professional title called ‘allied health practitioner’ and the RCSLT ask that you remove this from the guideline |
| 41 | Sussex Partnership NHS Foundation Trust | Question 4 | We have developed and launched a Trustwide care plan that incorporates a prompt for the patient to be asked about Advance Care planning. This conversation is held at an early stage in their contact with services and as part of the core Care Plan document will be early accessible by all mental health services and subject to regular review. |
| 42 | Sussex Partnership NHS Foundation Trust | Question 4 | We have developed and launched a Trustwide capacity and consent form that includes a prompt for staff around supported decision making. It includes the ability to record what supports were given to the patient to enable them to make the decision. |
| 43 | Sussex Partnership NHS Foundation Trust | Question 4 | Our Trustwide capacity and consent form is programmed to support the process and recording of Best Interest decision making, requiring the views of the patient, family, carers and others to be recorded, along with details of the decision taken and why. |
| 44 | Royal College of Speech and Language Therapists | Question 5 | No comment  |
| 45 | Alzheimer’s Society | 1 | This statement accurately reflects an area for quality improvement. People affected by dementia have told us that they do not feel they are provided with adequate support to help them to make decisions on their own. When people are supported properly to make a decision, it is not only beneficial for the person with dementia, but it is also less likely to result in appeals and therefore would reduce costs and save time. |
| 46 | Alzheimer’s Society | 1 | This statement should be achievable by local services, as supporting people with dementia who lack capacity to help them to make their own decisions should be built into the care planning process. This section provides a helpful overview of how to support people to make their own decisions. There are additional areas that should be included which would be of benefit to people with dementia including the following: * People with dementia must not be rushed to make a decision and must be given sufficient time to respond to questions about their care
* Some people with dementia may benefit from information being given to them at different times of the day, for example some people are at their best in the morning while others prefer to receive information in the afternoon. The person should be asked at what time of the day they would prefer to receive information
* The use of pictures could help some people with dementia to understand information
* Information presented in video form that the person with dementia could review at a time of their choosing may be beneficial for some people
* Providing easy read versions of complex information is helpful for some people with dementia
* If the person with dementia wears a hearing aid or glasses, reminding them to put these would be helpful
 |
| 47 | Alzheimer’s Society | 1 | One way to measure this quality statement is via the annual DoLS statistics published by NHS Digital which records the number of DoLS applications which have been rejected on the basis that the person was found to have capacity. The lowering of this number would suggest that improvements are being made to support people to make their own decisions. |
| 48 | Alzheimer’s Society | 1 | (Process measure) Alzheimer’s Society recommends including a line here stating that a person’s ‘significant and trusted person’ should know the person well, including their feelings and wishes about their care arrangements. |
| 49 | Alzheimer’s Society | 1 | It would be useful to include a line to clarify that mental capacity is decision specific. A person only needs to understand information for a specific decision. For example, a person may not be able to make a decision about their care arrangements but could be able to decide what they would like to eat or how they would like to dress. Therefore, it should not be assumed that if a person is unable make a decision about one matter that they cannot make decisions about other matters. |
| 50 | Alzheimer’s Society | 1 | (Process measure) It is unclear from this statement, what are ‘significant consequences’, therefore there is a risk that this could be interpreted in different ways by people thus impacting on the type of decisions that are recorded for measurement purposes. It would be helpful to provide examples of significant consequences for clarity. |
| 51 | Alzheimer’s Society | 1 | This section would benefit from including the first principle of the Mental Capacity Act which states that a person must be assumed to have capacity unless it is established that they lack capacity. This is important because we have heard from people living with dementia that they are often treated as if they do not have capacity just because of their diagnosis of dementia. |
| 52 | Alzheimer’s Society | 1 | Independent advocacy p.8. This section could be improved upon by explaining the benefits of advocacy for people who may lack capacity including people living 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. We have heard from some people affected by dementia that they were not aware of Independent Mental Capacity Advocatess. 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 Mental Capacity Act and safeguards within it are needed amongst the public and health and care professionals. |
| 53 | Birthrights | 1 | Birthrights welcomes the recognition of the importance of accessible communication and the support of a trusted person. In maternity care this should also include support from a midwife providing continuity of care, who is able to build up a trusted relationship. For women under a multi-disciplinary team, it may also be appropriate to include doctors and other HCPs within the continuity team. |
| 54 | British Geriatrics Society | 1 | Could an should specifically comment on the need to review capacity regularly where capacity may fluctuate rapidly such as in people with a delirium |
| 55 | British Red Cross  | 1 | Original Statement 1 People aged 16 and over who may lack capacity to make their own decisions receive support for decision making that reﬂects their individual circumstances and meets their particular needs.Proposed Statement 1 People aged 16 and over who may lack capacity to make one or more of their own informed decisions receive support to maximise their decision making capacity that reﬂects their individual circumstances and meets their particular needs, including access to independent advocates where needed.We support this statement and suggest that: • the addition of one or more of their own informed decisions makes it clearer from the beginning that the lack of capacity is always decision specific and highlights our responsibility to ensure that people have the information they need to make informed decisions. • including maximising decision making capacity strengthens the commitment to supported decision making from the beginning and highlights the importance of this second principle of the MCA • reference to independent advocates where needed in the first statement is helpful and prompts people to make themselves aware of advocacy services that the person they are supporting may need to access. It is not clear to us whether you are talking about supported decision making to maximise people’s decision-making capacity or if you are talking about people who may lack the capacity to make one or more of their own decisions with support. We think it’s confusing and have suggested an alternative but appreciate that may have strayed away from your intention. As we are assuming capacity and our starting point is both this and working hard with people to maximise their capacity it risks confusing (us and perhaps others) to conflate the two and talk about people who may lack capacity rather than people who need support to make their own informed decisions. We question whether it’s helpful to conflate people who need support to make their own decisions with people who lack capacity to make one or more of their own decisions. Some people need help to make many of the decision they need to make and have capacity. Using the terms loosely/interchangeably risks people making the assumption that if you need support with making decisions you lack capacity when that is absolutely not the case and appreciate this wouldn’t have been your intention. Everyone who needs support to make their own informed decisions should have access to this support and if people are after that not able to make one or more of their decisions they should still be involved and informed (as appropriate to their needs and preferences) in and about the decision-making process so their perspective, past and current wishes, will and preferences are informing the best interest decision. This latter principle needs to be reflected in your statements as this is one of the areas of practice that needs strengthening so that we are not left with it being OK to ignore or side step people’s preferences if they lack the capacity to make one or more of their own informed decisions. |
| 56 | British Red Cross  | 1 | We suggest an amendment to the role of advocates so it’s clear they both support people to speak for themselves and speak out on people’s bealf where this is needed: From: Together with their provider organisations they work in partnership with the people they support to speak out on their behalf.To: Together with their provider organisations they work in partnership with the people they support to enable people to speak out for themselves and to and speak out on their behalf where needed. |
| 57 | Compassion in Dying | 1 | Within the data source for quality measure (b) please note that voluntary sector organisations can also support people to make decisions and with greater emphasis being placed on social prescribing we recommend that this is included as a source of support. |
| 58 | Court of Protection Practitioners | 1 | There ought to be a clear statements of the following in the rationale section:• The person must be given the relevant information;• It may be necessary to optimise the person’s ability to take a decision, as part of the overall assessment of their capacity, for the person to be visited on more than one occasion, perhaps at different times and in different places depending upon their profile. • Sufficient time must be allowed for the assessment so as to provide the person with the space to demonstrate their understanding.Wrapping up the giving of relevant information with the accessible format loses the emphasis that this is an essential prerequisite to assess capacity. Otherwise we support the content set out therein.  |
| 59 | Mencap | 1 | Supporting decision-makingWe welcome the specific quality statement on supporting decision making.Quality measure: Structure a)In the Data source section it would be helpful if it could say ‘for example evidence of service providers and health and social care practitioners implementing the tools and approaches in local practice’ (as we want all health and social care workers to know it applies to them).Quality measure: Process a)In the Data source section it would be helpful to be more specific eg. ‘local data collection for example, local audit of patient records or care plans, checking local protocols or recording templates have been completed and appropriate interventions have been made/tools used.’ If we want to drive practice improvements, then it would be helpful to encourage data to be collected around situations where people who wanted an advocate had no advocate involved and why not, and where people have reported not feeling supported, why this is. This will be useful information for providers, practitioners and commissioners to use to improve support for decision-making.  |
| 60 | Mencap | 1 | In the ‘what the quality statement means for different audiences’ section, we suggest including in each of the audience paragraphs, reference to principle 2 of the Mental Capacity Act, as well as the Accessible Information Standard (2016), as these must be followed by service providers, health and social care practitioners and commissioners, and it is helpful for people aged 16 and over who may need help with making decisions to be aware that they should get the support they need in line with this legislation.  |
| 61 | Mencap | 1 | Definition of terms usedWe suggest including in this list ‘any needs related to disability’ |
| 62 | NHS Cambridgeshire and Peterborough Clinical Commissioning Group  | 1 | ‘To approach decision making in a way that is suitable to the person’s circumstances, the practitioner needs to understand what is involved in a particular decision…’ Perhaps it also needs to mention that the practitioner needs to be clear about identifying the relevant information in relation to the specific decision. |
| 63 | NHS England – Specialised Commissioning | 1 | Feedback collected from a cohort who lack capacity to understand a decision, regarding their experience of making the decision, will be challenged for reliability |
| 64 | NHS England – Specialised Commissioning | 1 | Feedback regarding whether people ‘feel’ involved in a process intended to enhance involvement is an outcome measure of the effectiveness of the process, rather than a measure of whether the process is in place.  |
| 65 | NHS England – Specialised Commissioning | 1 | On this point: “Proportion of people aged 16 and over who may lack capacity to make decisions, who feel supported to make their own decisions.Numerator – the number in the denominator who feel supported to make their own decisions.”Given the fact that the person lack a capacity to make the decision, there will be relatively few people who can reliably be called upon to answer the rather more abstract question of whether they feel supported to make a decision that they may well not fully understand. Whilst there will be exceptional cases in which this is easy to determine – in most cases this will be subject to a fair amount of interpretation – such that the assessor is ‘marking their own homework’ |
| 66 | NWAS | 1 | We acknowledge that the Quality Statement is aimed at those of 16 years of age or older. However, we would like to note that adulthood does not legally commence until the age of 18, and the gap between the ages of 16 and 18 are vulnerable to be missed as they will not fit into the criteria. |
| 67 | NWAS | 1 | We acknowledge that it may be required to include others such as specialist service and independent advocates, but as an emergency service this is not always feasible due to the limited time that we are supporting the individual. It would be helpful to include some guidance in this case. We also undertake a high percentage of ‘hear and treat’ functions through both our 111 service and our 999 service and assessing capacity can be very complex and challenging when not face to face with the individual, as would providing support in terms of decision making. |
| 68 | NWAS | 1 | We agree that recoding of decision making processes should be proportionate to the decisions being made. Audits of this within an ambulance service may present a challenge, we do not typically use care plans and in an emergency situation there may not be access to significant and trusted people to involve. In addition to this for our ‘hear and treat’ conversations are usually with one person at a time and the discussion with those who are significant and trusted are not always feasible. It would be helpful if the guidance could include advice for emergency service personnel in terms of their potential role to advocate for the individual in an emergency situation when the person is deemed to lack capacity.  |
| 69 | NWAS | 1 | We would welcome that training is commissioned and ensuring that this is competency based and includes assessment of communication skills and we acknowledge that current training is not standardised and varies in terms of standards. |
| 70 | NWAS | 1 | From a pre-hospital emergency medicine service perspective, we feel that training should focus on the individual’s capacity when there has been a lack of previous experience, as this is often the case in the event of a trauma. |
| 71 | Royal College of Occupational Therapists | 1 | Robust protocols need to be in place to access professionals in a timely manner.  |
| 72 | Royal College of Occupational Therapists | 1 | Covers information clearly in line with MCA.  |
| 73 | Royal College of Occupational Therapists | 1 | ‘Support may include (but is not limited to) helping the person to communicate’ |
| 74 | Royal College of Occupational Therapists | 1 | ‘Responsibilities of the practitioner and cover new staff (as part of their induction)’ |
| 75 | Royal College of Occupational Therapists | 1 | ‘Continuing development and practice supervision for existing staff (with additional training and support regarding the needs of the individual being supported)’ |
| 76 | Royal College of Speech and Language Therapists | 1 | The numerator for point a) Proportion of decisions made by a person aged 16 and over who may lack capacity where the decision-making process took into account their communication needs. Is the number in the denominator where communication needs of the person were taken into account?  |
| 77 | Royal College of Speech and Language Therapists | 1 | Questions about the individual quality statementsThe numerator for point a) Proportion of decisions made by a person aged 16 and over who may lack capacity where the decision-making process took into account their communication needs. Is the number in the denominator where communication needs of the person were taken into account? This measure is very ambiguous and RCSLT is concerned that this would be open to bias and varied interpretation. Evidence shows that too infrequently assessors seek support to accommodate people’s communication needs. Yet decisions regarding mental capacity often concern people with complex communication and cognitive needs. The RCSLT recommend this is changed so it is explicit that people with communication needs are supported during the assessment process to: “the number in the denominator where communication needs of the person were identified and provided with appropriate expert support.”This is the only measure of communication support, and as the Quality Standard and the Equality Impact Assessment identifies effective engagement with people with communication difficulties as a key area for improvement, we recommend that this is quantified.  |
| 78 | The British Psychological Society | 1 | On page 8 the document refers to Independent Mental Capacity Advocates (IMCAs) – this will need updating to take account of the new role of approved mental capacity professional under the Mental Capacity Amendment Bill (http://www.legislation.gov.uk/ukpga/2019/18/enacted). At this stage it is probably a question of noting the new role and changes this may bring to the IMCA role. |
| 79 | The Challenging Behaviour Foundation | 1 | It is encouraging to see that the quality statement reflects the need to make reasonable adjustments. Supporting an individual who may lack capacity to make a decision should include consulting family carers. For individuals with severe learning disabilities whose behaviour challenges, family carers often have a lifelong knowledge of the individual and their methods of communication. In addition, the introduction of new people into decision-making discussions can be overwhelming for an individual and may impact on communication and, therefore, assessment of capacity. |
| 80 | Alzheimer’s Society | 2 | This statement accurately reflects an area for quality improvement. Advance care planning is incredibly important for people affected by dementia. However, we have heard from people affected by dementia that they are not given enough opportunities to talk about their future care. 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.Someone with dementia may not want to speak about future care arrangements when they have recently been diagnosed with dementia, so it is important to ask this question regularly, and also let the person know that they can bring this subject up whenever they wish to discuss it. |
| 81 | Alzheimer’s Society | 2 | We have become aware of instances where GPs have been charging people for appointments to discuss advance decisions. Alzheimer’s Society feels it is completely wrong for GPs to charge for these appointments as it is every adult’s right to refuse medical treatment in advance, providing they have capacity. Therefore, it should be part of the role of healthcare professionals, and not something that they can charge for.  |
| 82 | Birthrights | 2 | Birthrights welcomes the recognition of the role of advance care planning. It is not clear whether the phrase ‘each health and social care review’ in the QS would mean each appointment with e.g. maternity services, or whether it is envisaged that this standard would cover only more formal reviews which may be more common in other contexts. For maternity care – a time-limited period of quite intense engagement with services – it would not be appropriate to set formal review points on a one-size-fits-all basis. Women must be supported to consider whether they wish to make advance planning decisions and review them as and when their wishes, preferences, or medical/other circumstances change. Circumstances and preferences may change throughout pregnancy and also in labour and continuity of carer plays a role in supporting decision-making where this occurs. Any advance planning process needs to anticipate and include planning for different circumstances and developments during pregnancy and labour as far as reasonably practicable. Birthrights is not aware of significant use of advance planning in maternity contexts, and – if correct - suggests that healthcare practitioners and service providers may need support in developing capacity and skill in this area. |
| 83 | British Geriatrics Society | 2 | Is it worth mentioning overlap with similar dementia QS |
| 84 | British Geriatrics Society | 2 | Worth mentioning palliative care settings and staff |
| 85 | British Red Cross  | 2 | Original Statement 2 People aged 16 and over at risk of losing capacity to make decisions and those with flucatuating capacity, are given the opportunity to discuss advance care planning at each health and social care review. Proposed Statement 2 People aged 16 and over at risk of losing capacity to make decisions, and people with fluctuating capacity, are given the opportunity to discuss and develop advance care plans at each health and social care review.We support this statement and suggest: • people instead of those as it’s more person centred in tone • the addition of giving people the opportunity to develop advance care plans as well as discuss them so it’s clear that the expectation goes beyond discussion.  |
| 86 | Compassion in Dying | 2 | If the decisions made are to be meaningful and practical, then it is vital that this quality statement is amended to include the documentation of preferences.“People aged 16 and over at risk of losing capacity to make decisions, and those with fluctuating capacity, are given the opportunity to discuss and document their care preferences advance care planning at each health and social care review.” |
| 87 | Compassion in Dying | 2 | Structure – please include text as follows “…have ongoing opportunities to discuss and document their advance care plans while they have capacity.” |
| 88 | Compassion in Dying | 2 | The numerator that on the number of people who have an advance care plan must necessarily include a definition that explains what documents are considered advance care plans (Advance Statements, Advance Decisions, Lasting Powers of Attorney, DNAR forms, ReSPECT) and which documents can be made by those who are 18 and over (Advance Decisions, Lasting Powers of Attorney). Not being specific about these methods risks diluting the strength and value of this quality statement. |
| 89 | Compassion in Dying | 2 | Within the list of service providers, please include Ambulance Trusts/paramedics. |
| 90 | Compassion in Dying | 2 | We are pleased that the document highlights the importance of Commissioners organising training on the Mental Capacity Act including on Advance Decisions and Lasting Powers of Attorney. Our research among all 207 CCGs revealed that this is an area that requires greater investment - https://compassionindying.org.uk/library/advance-care-planning-in-general-practice-does-policy-match-reality/ (2018). For example, only 35% of the CCGs that responded to our question on GP training made specific reference to training on the Mental Capacity Act.Data gathered through our free information helpline and through our interviews with GPs in 2019 revealed that GPs had significant gaps in knowledge about Advance Decisions and how they can benefit people. This included a lack of awareness that a valid and applicable Advance Decision is legally binding and must be followed and, conversely, an assumption it requires the involvement of a solicitor. For more information, including examples of the distress this causes individuals, please see - https://compassionindying.org.uk/library/advance-decisions-uncovering-what-gps-need/  |
| 91 | Compassion in Dying | 2 | With reference to the fact that there is no single mechanism for an “advance care plan” we recommend that the options available for documenting preferences are included as below:People aged 16 and over who may not be able to make decisions in the future are helped to develop a plan that sets out their preferences for their future care, called an ‘advance care plan’. They can update their advance care plan every time their treatment or support is reviewed. These plans can include an Advance Statement, a DNAR form, and/or a ReSPECT form for people aged 16 and over and an Advance Decision and/or Lasting Power of Attorney for Health and Welfare for those aged 18 and over. |
| 92 | Compassion in Dying | 2 | Definition of advance care planning – please note that it is insufficient to document only the discussion of preferences. The treatment and care decisions made must also be documented if advance care planning is to be a meaningful and practical activity.Please see amended sentence below:“…With the person's agreement this discussion and the decisions made are documented…” |
| 93 | Court of Protection Practitioners | 2 | The rationale section does not refer to fluctuating capacity at all it focusses upon advance decisions. We suggest that the following points are made about fluctuating capacity• Where a person has fluctuating capacity and a decision can await a time that they are capacitous to take it then that should be preferred course. • The type of decision being made needs to be considered as either a macro decision which encompasses numerous micro-decisions i.e. a group of connected micro-decisions or a micros decision, i.e. a separate decision made independently of the others: Royal Borough of Greenwich v CDM [2019] EWCOP 32• An assessment of capacity ought to await the time or should mirror the circumstances in which the person is most likely to be capacitous to take the relevant decision. Reviewing advance care plans- we agree that a review is appropriate however some of these are decisions taken by a person often with great care and after considerable consideration i.e life sustaining treatment or measures. There ought to be no expectation that they will change it and the review must not be perfunctory or cursory rather reflect the gravity of the decision taken particularly where they relate to life sustaining treatment or measures.  |
| 94 | NHS Cambridgeshire and Peterborough Clinical Commissioning Group  | 2 | needs to be explicit about planning for the future – LPA’s / ADRT’s / Advance Statements etc. NB: ‘Advance care planning’ has different meanings across health and social care. Perhaps call it planning for the future. See compassion in dying guidance - https://compassionindying.org.uk/library/planning-ahead-treatment-care/  |
| 95 | NHS England – Specialised Commissioning  | 2 | The denominator for all of the quantitative measures is the population ‘at risk’ of losing capacity to make decisions. It is impossible to define this population, as it could be considered to include all people. There is a risk that the analysis of this measure will be based on a retrospective analysis of people who have lost capacity, as to whether there was advanced decision making, which would be a different metric. The danger is that this measure will either reflect a different metric, or essentially monitor the reliability of identification of people at risk of losing their decisional capacity. |
| 96 | NWAS | 2 | This statement is not relevant to an ambulance service as we would not be involved in supporting the person to develop advance care plans. However it is essential that emergency services are aware of the presence of any advance care plans and that these are accessible if the person is not able to inform they exist. |
| 97 | Royal College of Occupational Therapists | 2 | Assessment regarding capacity should be routine. |
| 98 | Royal College of Occupational Therapists | 2 | ‘Continual’ and ‘regular review’ of advance care plans and who should be the primary person driving needs to be clarified locally. |
| 99 | Royal College of Occupational Therapists | 2 | ‘and accessible information to help them make these decisions. They also perform regular reviews of the person, and with the person’s consent,’ |
| 100 | Royal College of Psychiatrists | 2 | There is a need to clarify the limits of advanced decision making in those aged 16 and 17 within this statement. According to the Mental Capacity Act 2015, advance decisions to refuse care can only be made by those aged 18+, and any refusal of life-saving care in someone under 18 is likely to be over-ruled by a judge. It is very positive that those aged 16 and 17 should be supported to make advance decisions about their care, in so far as this does not amount to an advance refusal of treatment that is potentially life-saving. Clarity about this is important as it is may influence the discussions around the care plan in young people aged 16/17, the content of the care plan, and the young person's experience of being supported in making it.  |
| 101 | Royal College of Psychiatrists | 2 | “Quality Statement: People aged 16 and over at risk of losing capacity to make decisions, and those with fluctuating capacity, are given the opportunity to discuss advance care planning at each health and social care review. Rationale: Advance care planning for people who are at risk of losing decision-making capacity or have fluctuating capacity enables them to exercise their autonomy as much as possible. It involves helping people to plan for their future care and support needs while they have capacity to make decisions. Reviewing advance care plans regularly enhances their utility and quality and ensures that the recorded wishes of the person stay valid, applicable and up to date.”Given the concerns stated above in comment 1, we would be very concerned about patients with eating disorders being asked at each and every review to be asked to express their wishes for future care. It is the nature of many cases of severe eating disorders (and some other severe mental disorders) that without treatment these persons often wish to reject treatment and deny illness. It is sometimes (and often early in treatment before recovery starts) really important to ‘cross each bridge as you get to it’ rather than have patients, in addition to being in conflict with families and professionals about current treatment, to also be invited enter into conflict and disagreement about future treatment. This is not least because as treatment progresses patients can often change their minds about whether treatment was needed in hindsight, and can often take a long time before they are able to express this. For us as eating disorder psychiatrists, it is often unhelpful to attempt to ask people to ‘betray their eating disorder’ and overtly agree with families and professionals which they may feel unable to do.This is not to say we do not think that there is no role for Advance Care Planning in eating disorder treatment. When patients have had considerable experience of compulsory treatment or are remitting and relatively well, it can be extremely helpful to have discussions with them about what their wishes are if their condition deteriorates again.As a result we have problems with the idea of counting the number of patients who would have a risk of fluctuating incapacity (which would be nearly all) and then counting the number who have Advance Care Planning, as if it would be better if this number were higher. In many cases, pushing for Advance Care Planning can be very harmful to our patients. |
| 102 | The British Dietetic Association (BDA) | 2 | We would like to highlight the importance of advance care planning being communicated across primary and secondary care settings as well as, mental health and community services and palliative care teams.  |
| 103 | The Challenging Behaviour Foundation | 2 | This is an important statement for individuals with severe learning disabilities whose behaviour challenges as they are at particular risk of not being ‘heard’ or engaged. This means that they can often be unfairly discriminated against when it comes to assessing capacity, and decisions about their lives can be taken with little effort made to effectively communicate and understand their wishes. Therefore, it is good to see in the statement that efforts to understand the individual’s wishes for the future are encouraged. Hopefully, this will mean that should capacity to make a decision change, the individual’s needs can still be met. However, the CBF knows from the families we support that individuals with severe learning disabilities whose behaviour challenges do not always receive timely Care and Treatment Reviews and Annual Health Checks. If the review of advance care planning is reliant on health and social care reviews, measures need to be in place to ensure that this quality statement is still adhered to in the absence of regular reviews so that the person’s needs and wishes for the future can be reflected if capacity is lost at a later date |
| 104 | The Law Society | 2 | We encourage NICE to consider the use of the term ‘advance care planning’ in Statement 2, as this term encompasses a wide range of decisions, including making a Health and Welfare Lasting Power of Attorney (‘HW LPA’). Further to this point, we note that it is only commissioners who NICE appear to have indicated as needing to be aware of LPAs. However, it is not merely, or even primarily commissioners, who need to be aware of LPAs. Rather, it is important those actually making decisions on the front line understand how HW LPAs interrelate with other forms of advance care planning. For example, there is a need to consider how a HW LPA interacts with an advance decision to refuse treatments, and what role an attorney under an HW LPA has in relation to decisions about treatment escalation and/or the placing of “Do Not Resuscitate” recommendations in the donor’s clinical records.  |
| 105 | Alzheimer’s Society | 3 | This statement accurately reflects an area for quality improvement. Data published on the Deprivation of Liberty Safeguards for 2018/2019 shows that 3,890 people had their application rejected on the basis that they were found to have capacity. This suggests that people are not being provided with enough support to make their own decisions. Having a written record of the steps taken to help some to make their own decision would be useful. Alongside this it would be helpful for practitioners to have a list of the type of support that should be offered to someone. The list provided in comment two of this response would be a good starting point for the type of support people who may lack capacity should receive. |
| 106 | Birthrights | 3 | Birthrights welcomes the explicit requirement for practitioners to record why “the decision they [the person] have made to be incapacitous as opposed to unwise. They record what impairment or disturbance of the mind or brain has been identified and the reasons why the person is unable to make a decision.” However, Birthrights remains concerns that capacity may be called into question in maternity care where a woman has made a different choice to that recommended by her care team. Whilst Birthrights agrees that it is important to ensure that “everything practicable” is done to support a person to have capacity, this should not tip over into coercion into agreeing with proposed care plans, or ignoring doubts about support needed because a woman is agreeing with recommended care. 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 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 (and therefore were not necessarily making a decision for themselves but having decisions made for them by family members). (Birthrights and Birth Companions (2019). Holding it all together: Understanding how far the human rights of woman facing disadvantage are respected during pregnancy, birth and postnatal care. London [online]).  |
| 107 | British Geriatrics Society | 3 | Wonder about measurement. Not every capacity assessment needs additional support/advice. Some assessments are more straightforward than others |
| 108 | British Red Cross  | 3 | Original Statement 3 People aged 16 and over who are assessed as lacking capacity to make a decision have a clear record of the practicable steps taken to support them and the reasons why they lack capacity.Proposed Statement 3 People aged 16 and over who are assessed as lacking capacity to make a specific decision have a clear record of the practicable steps taken to support them to maximise their decision making. This record includes the reasons why the person assessing them concludes they lack capacity to make the specific decision they need to make at the time it needs to be made.We support this statement; although our suggestion will make it longer we think it will make the ask of practitioners clearer.  |
| 109 | British Red Cross  | 3 | Suggest that where the term incapacitous is used is is explained so it isn’t added to the jargon jar!They also record the practicable steps they or other parties have taken to help the person make a decision for themselves, whether the person has capacity to make the decision and, if the person is assessed as lacking capacity, why the practitioner considers the decision they have made to be made without capacity (‘incapacitous’) as opposed to unwise. |
| 110 | British Red Cross  | 3 | Suggest ‘their reasons for making that decision’ rather than ‘why they decided that’ in this paragraph, to prompt people to explain their decision making. People aged 16 and over who have an assessment of their mental capacity to make a decision have an assessor who knows them well enough to talk to them easily. The assessor can explain what is involved in the decision and find out what the person’s preferences are. If the assessor decides that the person is not able to make this decision, they write down their reasons for making that decision. why they decided that. They also write down the person’s preferences so that these can be taken into account when the decision is made.  |
| 111 | Compassion in Dying | 3 | As supported decision-making has been covered in Statement 1 it may be more useful to focus Statement 3 on assessing capacity. |
| 112 | Court of Protection Practitioners | 3 | • It must be borne in mind that an assessment that a person lacks capacity is not once and for all time decision. This ought to be made clear. • Whenever decision is made there should be a review of the person’s ability to take that decision and at the very least such review may illuminate mechanisms that may enable a person to participate in the decision making more fully.  |
| 113 | Mencap | 3 | Assessing capacityIt might be helpful to be clear in the rationale section that assumption of capacity is the starting point. |
| 114 | NHS Cambridgeshire and Peterborough Clinical Commissioning Group  | 3 | People aged 16 and over who are assessed as lacking capacity to make a specific decision have a clear record of the practicable steps taken to support them and the reasons why they lack capacity.  |
| 115 | NWAS | 3 | We acknowledge that it is crucial that people aged 16 and over who are assessed as lacking capacity to make a decision have a clear record of the practicable steps taken to support them and the reasons why they lack capacity. We feel that documentation used to record care and in particular decision making needs to be aligned to support this nationally, and would suggest that consideration be given in relation to national templates to record the voice of the service user which will also support more comprehensive and streamlined audits that can be compared and benchmarked. |
| 116 | NWAS | 3 | We would advocate that there needs to be more robust training in terms of assessing where the decision made by the individual are unwise or uncapacious, especially for those experiencing mental health problems where there is a lot of ‘grey areas’.  |
| 117 | Royal College of Occupational Therapists | 3 | Temporality – the temporal nature of capacity is only referenced as ‘fluctuating’ and could read as relating to longer term conditions. There is no reference to an estimation of the time that any potential loss of capacity might apply and the need to estimate when capacity might be regained as there is in the MCA.  |
| 118 | Royal College of Occupational Therapists | 3 | Deferral – there is no mention of the deferral of capacity assessment to a more appropriate time, especially when capacity is likely to be regained or when the decision is not ultimately time sensitive. |
| 119 | Royal College of Occupational Therapists | 3 | Regaining capacity – again no mention of the ability to regain capacity and how this impacts on previous decisions made under the provision of the MCA when they lacked capacity. |
| 120 | Royal College of Occupational Therapists | 3 | Further assessment of capacity – there is no reference as to when capacity should be reassessed, thus, the quality standard takes many practicable steps to improve the immediate assessment but neglects the need to revisit capacity and how frequently capacity should be revisited depending on the person and their condition. |
| 121 | Royal College of Occupational Therapists | 3 | The documentation of capacity and the best interests meeting need to be completed correctly. Responsibilities regarding advanced care plans need to be identified locally.  |
| 122 | Royal College of Psychiatrists | 3 | The standards are helpful and clear. However some may be difficult for general hospital staff to apply in urgent situations. A fairly common situation is for general hospital staff to incorrectly assume capacity and then not deliver treatment in people with temporary lack of ability to weigh information due to emotional distress - for example regarding physical treatment for an overdose in someone whose capacity is impaired due to temporary high emotional distress due to emotionally unstable personality disorder. To ensure accurate reflection of assessments in addition to reviewing capacity assessments where capacity was lacking, it would be helpful if audits could also review capacity assessments for treatment of overdose where capacity was assessed as present and so treatment did not occur. |
| 123 | Royal College of Psychiatrists | 3 | “Quality statementPeople aged 16 and over who are assessed as lacking capacity to make a decision have a clear record of the practicable steps taken to support them and the reasons why they lack capacity. Rationale Having mental capacity involves being able to make a particular decision at the time it needs to be made. To lack capacity within the meaning of the Mental Capacity Act 2005, a person must be unable to make a decision because of an impairment or disturbance in the functioning of the mind or brain. The assessment of capacity must show how this impairment or disturbance prevents the person from being able to understand the relevant information, retain it for long enough to make the decision, weigh up the important information or communicate their decision. Lack of capacity can only be established if everything practicable has been done to support the person to have capacity. Quality measuresStructurea) Evidence of local protocols to ensure mental capacity assessments are collaborative, person centred, thorough and aligned with the Mental Capacity Act 2005 and its Code of Practice. b) Evidence of local arrangements to ensure that assessors can seek advice from people with specialist knowledge to help them assess whether there is evidence that the person lacks mental capacity.”As case law demonstrates, the assessment of mental capacity in severe eating disorders is complex. While we agree that it would be good to more great use of capacity assessments as well as to properly document and standardise assessments, we wish to stress strongly that the determination of mental capacity or lack of capacity specifically in people with eating disorders must involve a psychiatrist who has expertise in eating disorders. This is because research and case law demonstrate that these patients have very specific decision-making problems around specific treatment decisions (typically about treatments to gain weight) but are often fully capacitous in terms of other decisions as well as highly articulate and intellectually high functioning. This makes the assessment of capacity more complex and requires professionals who have a very good understanding of these specific deficits and are able to identify them. We strongly advocate the final quality recommendation of: “b) Evidence of local arrangements to ensure that assessors can seek advice from people with specialist knowledge to help them assess whether there is evidence that the person lacks mental capacity.”Specialist eating disorder psychiatrists are relatively rare. Given the high profile that capacity in severe eating disorders has obtained in past cases, we would suggest a specific requirement for people with eating disorders for a specialist eating disorder psychiatrist to be involved in a capacity assessment as we do not have full confidence that other consultant psychiatrists would have the required expertise. |
| 124 | The British Psychological Society | 3 | The Society welcomes this standard. Providing an audit of the practicable steps taken to support people should be best practice. |
| 125 | The British Psychological Society | 3 | This section refers to getting a Makaton signer. However, we believe that other obvious things should be used such as simplifying ideas, repetition, writing down key words and drawings to keep in line of sight of the person, things to make the decision more concrete and tangible for the person (perhaps photos of the locations of care homes, visits to them, etc.).  |
| 126 | The Challenging Behaviour Foundation | 3 | This quality statement is important because individuals with severe learning disabilities whose behaviour challenges are particularly at risk of not being ‘heard’ or engaged. It is encouraging to see that practicable steps are specified in the quality statement to ensure this happens even where capacity is lacking. Practicable steps to support an individual with learning disabilities whose behaviour challenges who may lack capacity should include engaging with families who often have an in-depth knowledge of their loved one’s communication, in addition to working with professionals who support the individual |
| 127 | Alzheimer’s Society | 4 | This statement on improving the way that best interest decisions are made accurately reflects an area for quality improvement. 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. |
| 128 | Alzheimer’s Society | 4 | If a best interest decision has been made and it goes against something that the person previously wanted before they lost capacity, it should be clearly noted why this decision was made.  |
| 129 | Birthrights | 4 | Birthrights welcomes the inclusion in the rationale that “the person should be placed at the heart of the decision-making process”. However, the wording in the QS itself is not as strong and suggests that only the person’s “wishes and feelings [be] reflected”. This should be strengthened. Both the QS and the rationale should require wishes and feelings – and an understanding of why the person has those wishes and feelings – to be central to best interests decision-making. Making decisions – particularly those which impact on bodily autonomy – which are not in line with a person’s wishes and feelings may be profoundly traumatic, have long term impact on women’s psychological health and engagement with health services. It is vital to put a full understanding of a person’s wishes and feelings (and why they hold these wishes and feelings) at the heart of the decision-making process. |
| 130 | Birthrights | 4 | “They ensure that any best interests decision made reflects the person’s wishes, values and preferences unless it is not possible or appropriate to do so, such as in an emergency”. Birthrights is concerned that a number of cases have come to the Court of Protection, with the Court given the impression that the situation was an emergency when this was not correct. This has led to decisions in favour of Caesarean birth, either against the woman’s wishes or in the absence of information about her wishes, being made “in great haste” due to a “temptation in cases concerning pregnancy and childbirth to believe that the baby might emerge at any second and that decisions therefore have to be rushed” (Prochaska 2013: https://www.birthrights.org.uk/2013/12/05/views-on-the-forced-cesarean-judgment/). Whilst these QSs are clearly aimed at clinicians and healthcare providersand not the Court, it is vital to ensure that this clause is specified as narrowly as possible, to ensure that women do not have decisions made without regard to their best interests in situations which are urgent but where best interests decisions are still possible (the Courts have commented on a number of recent cases which have been brought as emergency, out of hours, applications but which could appropriately be listed the next day to allow for the woman to be represented in the hearing and hence the best interests decision-making process (e.g. Guys and St Thomas’s and X [2019] EWCOP 35)). It is also vital to ensure that this clause is specified narrowly to ensure that women do not have decisions made without regard to their best interests in situations which could reasonably have been foreseen, or situations which might be an emergency for the foetus – which at that point has no legal rights – but not for the mother. |
| 131 | British Geriatrics Society | 4 | Again consider in more detail how this will actually be measured in practice. The guidance could be interpreted in a variety of ways giving variation in data quality. |
| 132 | British Red Cross  | 4 | Original Statement 4 People aged 16 and over who lack capacity to make a decision have their wishes and feelings reflected in best interest decisions made on their behalf.Proposed Statement 4 People aged 16 and over who lack capacity to make a decision have their wishes and feelings (past and present), will and preference reflected in any any best interest decisions made and have access to independent advocates where needed.On the whole we support this statement and have added past and present wishes in as well as will and preference. We suggest the removal of ‘on their behalf’ to avoid confusion which can take us away from the principles underpinning the MCA and best interest decision making and risks people thinking they can make decisions on other people’s behalf outside of or separate to the best interest decision making framework, perhaps because they think the decision is the ‘right one’ from their perspective. We think the removal of decisions ‘made on their behalf’ moves us in the right direction of people’s will and preferences and away from ‘substitute decision making.’  |
| 133 | British Red Cross  | 4 | Suggest ‘what they would have chosen for themselves if they had capacity’ rather than ‘what they would want’ to make it clearer. People aged 16 and over who are not able to make decisions are involved as much as possible when decisions are made about their care and support. Health and social care staff use the information they have about the person’s wishes and feelings to make sure that decisions made on the person’s behalf are what they would have chosen for themselves if they had capacity want. |
| 134 | Compassion in Dying | 4 | Rationale – With reference to the evidence mentioned above about health and care professionals not understanding the Mental Capacity Act and the mechanisms for recording care preferences, we strongly suggest that the rationale includes a note about the legally binding nature of some care plans so that due attention is placed on them and tragedies such as those mentioned in comment 1 are prevented. A suggested amendment is below“…It also means using information within the advance care plans, paying special attention to legally binding Advance Decisions and/or Lasting Powers of Attorney, consulting with the person’s family…” |
| 135 | Compassion in Dying | 4 | Structure – “Evidence of local protocols to ensure that best interests decisions are being made and documented in line with the Mental Capacity Act 2005.” |
| 136 | Compassion in Dying | 4 | With reference to the evidence mentioned above, it is vital that health and social care practitioners have a good understanding of which advance care planning documents are legally binding and which are not. The Compassion in Dying information line has received calls from distressed relatives who have been told by health and care practitioners that their Advance Decision refusing CPR (legally binding) will be ignored and that they needed a DNAR form (not legally binding).We suggest adding a second sentence as below:“They have a comprehensive understanding of which advance care planning documents are legally binding (Advance Decisions and Lasting Powers of Attorney) and which carry legal weight but are not binding (Advance Statements, DNAR forms, ReSPECT forms).” |
| 137 | Court of Protection Practitioners | 4 | The term ‘best interests’ is often misunderstood by healthcare professionals, and is taken to mean ‘medical best interests’ rather than the wider ranging meaning given to this term under the Mental Capacity Act and subsequent case law (in particular Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67). As currently drafted, this section refers to the need to talk to the person about their wishes and feelings, but does not highlight the centrality of the person’s wishes and feelings to the best interests decision making process. Greater emphasis could be given in this section to the legal concept of best interests, for example by reference to Lady Hale’s judgment in the Aintree case, in which she said: ”in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.” |
| 138 | Mencap | 4 | Best interests decision-makingWe think it would be helpful to include the Best interest checklist from the MCA in this section. So people are really clear about the legal requirements, including the person making the decision must consider the person’s past and present wishes and feelings…they must take into account, if it is practicable and appropriate to consult them, the views of anyone engaged in caring for the person or interested in his welfare..In the rationale it would also be helpful to include: ‘It also means being aware when the person has a Deputy or Lasting Power of Attorney to make certain decision on behalf of the person. It is good to see best interest decision making framed in such a person-centred way with the person being placed at the heart of the decision-making process. It would be helpful to be clear that the person’s wishes and feeling should be central and particular weight should be given to them in the best interest decision-making process (or whatever wording is in line with updated MCA Code of Practice).  |
| 139 | Mencap | 4 | Involvement of families and others in best interest decision making. We are glad to see that NICE have included a quality measure around involvement of family but suggest this is strengthened to reflect the legal duty of practitioners to do so. It is an area where too often we hear of poor practice with families being excluded from or not listened to during the decision making process, particularly around medical decisions. Quality measures:Process - as well as collecting data about whether the person was involved in the best-interest decision making process, it would be helpful to understand how they were involved, what approaches were used and why they were appropriate. To ensure that involvement is "meaningful" not just a tick-box exercise. We welcome measures to help ensure the involvement of carers, family, friends or advocates. However, we think there should be separate measures for involvement of each of these groups in line with the best interest checklist.  |
| 140 | Mencap | 4 | In the ‘What the quality statement means for different audiences’ section we think it is important in the health and social care practitioners section to include ‘GPs and other doctors’ in the list of examples or just say ‘doctors’. From our health campaigning work, we are concerned about lack of adherence to the MCA amongst doctors in hospitals. Definitions of termsIn the list of instructions on what information to record, it would be helpful to include who has been consulted (in line with the Best interests checklist) and what their views were.The toolkit should also include information for practitioners about what to do if there is a disagreement ie the steps set out in the MCA code of practice around this, eg second opinion, involvement of an advocate and ultimately escalation to the Court of Protection.We suggest discussion with the Court of Protection around a quality measure to help ensure cases are escalated appropriately. |
| 141 | NWAS | 4 | We feel that guidance needs to acknowledge that in an emergency situation such as someone standing on the edge of a bridge there is not the opportunity to assess capacity and offer guidance in terms of acting in the patient’s best interest. |
| 142 | NWAS | 4 | It would be very difficult as an emergency service and other practitioners to some extent to audit how practitioners have made decisions in accordance with advance care plans unless the practitioner was aware they existed and accessible to shape their best interest decision making and record this. |
| 143 | NWAS | 4 | We welcome the fact that advice is given in terms of decision making in an emergency but feel this needs to be referenced throughout the Quality Standard. |
| 144 | The British Psychological Society | 4 | This statement refers to evidence around the involvement of carers etc. in best interest discussions where it wasn’t appropriate to include the person themselves. We believe that clearer documenting of the reasons why it wasn’t appropriate should be included and this could be added to the suggested bullet points on page 21 rather than as a separate standard to audit.  |
| 145 | The Challenging Behaviour Foundation | 4 | It is encouraging to see the quality statement take into consideration the best interest decisions and the fact that capacity is decision specific. This will allow individuals with severe learning disabilities whose behaviour challenges to ensure that they are given an appropriate amount of choice and autonomy in their lives, even if it is for small decisions. Best interest decisions for individuals with severe learning disabilities should also include the family carers who will know the individual best and have a firm understanding of their needs and wishes |
| 146 | The Law Society | 4 | We would also expect to see Statement 4 amended to insert ‘people aged 16 and over who lack capacity to make a decision have their wishes, feelings, beliefs and values reflected in best interest decisions made on their behalf.’ The addition of the words ‘beliefs and values’ accurately reflect the language of the Mental Capacity Act 2005.  |
| 147 | British Red Cross  | Additional statements | We think the standard would benefit from an explicit reference to the principle in child protection of making referrals even where the child is unhappy with this (i.e. the child has capacity and says “I don’t want you to tell anyone”) not least because other children may be at risk. The new standard needs to address this question:“If we are working within the framework of the MCA does it mean that if a child of this age has capacity they can dictate whether we make a safeguarding referral to the local authority or not?”  |
| 148 | Mencap | Additional statements | Access to advocacy – Please consider having a separate quality statement around access to advocacy in order to address the issues identified in the decision making and mental capacity guideline itself. In addition, we would like to see more references to advocacy in the discussion of all the quality statements. It is important that the quality statements reflect the importance of both IMCAs, and community (non-statutory) advocacy.  |
| 149 | The Law Society | Additional statements | We recommend that NICE adopt three further quality statements in line with the below:Statement 5: Where a person aged 16 or over lacks capacity to make relevant decisions, appropriate advance care planning is undertaken in relation to healthcare interventions that may be required (and/or treatment escalation decisions). This statement would ensure that the Quality Standard covers people with and without capacity, reflecting the quality of initiatives such as the ‘ReSPECT’ initiative.  |
| 150 | The Law Society | Additional statements | Statement 6: Cases that require determination by the Court of Protection are brought appropriately to the Court of Protection. This statement would respond, in the clinical context, to the requirements set down by the Supreme Court in NHS Trust v Y [2018] UKSC 46 in relation to situations of disagreement or doubt. It would also respond to the position in relation to issues considered so serious that court consideration is required, to be addressed further in the next iteration of the Code of Practice. It would further ensure that cases arising under the Deprivation of Liberty Safeguards (‘DoLS’) / Liberty Protection Safeguards (LPS) are brought to court, including by commissioning/treating bodies. The word ‘appropriately’ is proposed in this statement to reflect the duty of the public body to bring a case to court alongside situations where the duty would be that of an individual, such as a Relevant Person’s Representative (or in due course, an Appropriate Person) challenging a DoLS/LPS authorisation on behalf of the person.  |
| 151 | The Law Society | Additional statements | Statement 7: Decision-makers have regard to the current version of the Mental Capacity Act Code of Practice (including, if separate, the Code relating to the Liberty Protection Safeguards) when making decisions. This statement would ensure that the Code of Practice is accounted for when decisions are made and reflect the fact that (1) the main MCA Code of Practice is undergoing revision; and (2) an entirely new Code (possibly to be included within the umbrella of the main Code) is being produced to accompany the LPS. The Lord Chancellor is also required by the Mental Capacity (Amendment) Act 2019 to review (that part of) the Code relating to LPS within 3 years of the Act coming into force, and then at 5 yearly interviews, so there is for the first time a statutory commitment to reviews at specific points in time. We believe that this statement would allow NICE to monitor the use of the Code(s) of Practice in decision-making, which is extremely important to ensure that legislation is being properly implemented in a consistent manner. That the specific requirement is to have regard to the current version of the Code(s) will enable monitoring of the extent to which commissioners/staff are appropriately updated as to the law.  |
| 152 | Royal College of Nursing | No comments | Thank you for the opportunity to contribute to this quality standard, we don’t have any comments from the RCN on this occasion |
| 153 | Royal College of Physicians | No comments | The RCP is grateful for the opportunity to respond to the above consultation.We would like to endorse the response submitted by the British Geriatric Society (BGS). |

## Registered stakeholders who submitted comments at consultation

* Alzheimer’s Society
* Birthrights
* British Geriatrics Society
* British Red Cross
* Compassion in Dying
* Court of Protection Practitioners
* Mencap
* NHS Cambridgeshire and Peterborough Clinical Commissioning Group
* NHS England – Specialised Commissioning
* NHS Sheffield CCG
* NWAS
* Royal College of General Practitioners
* Royal College of Nursing
* Royal College of Occupational Therapists
* Royal College of Physicians
* Royal College of Psychiatrists
* Royal College of Speech and Language Therapists
* Skills for Care
* Sussex Partnership NHS Foundation Trust
* The British Dietetic Association
* The British Psychological Society
* The Challenging Behaviour Foundation
* The Law Society