Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
20/12/2017 to 05/02/2018

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Age UK	Full	General	General	There is some uncertainty as to the audience the guidelines were being produced for, how they would be implemented and how they would be communicated to health and social care professionals.	Thank you for your comment. The audiences for the guideline are specified in the section titled 'Who is it for?' which refers to: health and social care practitioners working with people who may (now or in the future) lack mental capacity to make specific decisions; independent advocates with statutory and non-statutory roles; practitioners working in services; people using health and social care services who may (now or in the future) lack mental capacity to make specific decisions, as well as their families, friends, carers and other interested parties.
Age UK	Full	7	168 – 173	Recommendation for all health and social care organisations to develop local policies, guidance and tools about which interventions, tools and approaches will be used to support decision-making and to assess the mental capacity of the people they are working with. Development of local toolkits, rather than national guidance could lead to local variation and therefore a lack of clarity around legal compliance.	Thank you for your comment. The Guideline Committee acknowledge that there will be local variation to meet local needs and we have also made a research recommendation to address this issue.
Age UK	Full	10	272 - 278	The recommendation calls for practitioners to 'involve significant and trusted people' in supported decision making and then goes on to say that their 'wishes and preferences' should be free 'from coercion or undue influences'. There is a lack of clarity for professionals as to what they should do were they to suspect coercion or undue influence on a person's decision-making.	Thank you for your comment. The Guideline Committee felt that this recommendation was clear and needed no further expansion on the issue of coercion. However, an example of coercion has been added as follows: …'for example that it does not undermine the person's ability to understand, retain, use and weigh information and express a choice'.
Age UK	Full	11	270 – 285	The recommendations call for practitioners to 'talk to the person and their carer, family and friends, as appropriate, about the potential consequences of supported decision-making'. As in the previous comment, there is a lack of substantive guidance for professionals in how they should deal with cases where they suspect coercion.	Thank you for your comment. This issue is now addressed in recommendation 1.2.11
Age UK	Full	18	497 - 501	This recommendation has a lack of clarity and assumptions are made about the decision making of those with a traumatic brain injury.	Thank you for your comment. The recommendation has been edited to clarify that no assumptions are being made and acknowledging that capacity may be more difficult to assess in people with executive dysfunction and so structured assessments need to be supplemented by real world observation..
Age UK	Full	22	597- 599	The recommendation for health and social care organisations to 'provide toolkits to support staff to carry out and record best interest's decisions'. As in the earlier comment, development of local toolkits, rather than national guidance could lead to local variation and therefore a lack of clarity around legal compliance.	Thank you for your comment. The committee is aware that some health and social care organisations already produce guidance and toolkits to support best interests decision making so this recommendation aims to ensure that this practice is rolled out more widely. The recommendation aims to improve consistency and compliance with the law, good practice and the evidence by listing the important elements of those locally produced toolkits. The committee believe this will improve practice in this area.
Alternative Futures Group	Short	4	21 - 25	We are concerned that this recommendation might imply that there is or needs to be a shared electronic information/records system accessible by in the example paramedics and care staff. This would be difficult to implement across different providers e.g. NHS and third sector providers of social care. However, if it is referring to something more basic such as a paper record like a hospital/health passport – a document commonly used in the support of people with learning disabilities this is achievable. But from experience it would be unlikely that NHS colleagues such as hospital nurses or paramedics would update or contribute to a document drawn up and held by e.g. a third sector provider of health/social care	Thank you for your comment. This is intended to relate to shared electronic information systems, which although aspirational, were also deemed by the committee to be achievable *and* incredibly important. However, as a reflection of the potential difficulties and associated costs where electronic systems are not in place, the committee agreed not to explicitly state that the systems 'should' be electronic.

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Alternative Futures Group	short	4	11 - 13	This sentence is not clear. Could it be re-phrased to make the meaning more plain?	Thank you for your comment. The committee considered the suggestion but concluded that changing the wording would affect the intended meaning.
Alzheimer's Society		4	25	This should include reference to due regard for data protection, information governance, confidentiality and consent.	Thank you for your comment. The Context section now makes clear that practitioners should read the guideline recommendations alongside 'the specific requirements of…legislation, codes of practice and other guidance relevant to their work.' This would include a wide range of requirements including, for example, those in respect of data protection, governance, confidentiality and consent.
Alzheimer's Society		12	9	The use of the term 'mental disorder' is very medical specifically aligned with the Mental Health Act. Alternative language would be more appropriate.	Thank you for your comment. This term was used to reflect the specific terminology used in the evidence that underpinned this recommendation, and for consistency with the legislation as you point out. The Guideline Committee considered your comment at the post-consultation meeting but decided to retain the existing wording, for this reason.
Alzheimer's Society		12	18	'Should be able to seek' should be changed to 'can seek.'	Thank you for your comment. We have made this amendment.
Alzheimer's Society		14	6	This section refers to the need to 'not cause distress' but this is often used by practitioners as a reason to not include the person in the decision or to bypass capacity assessments. The guidelines need to be clear that emotional distress is a factor when considering the best way to carry out the assessment and not the over-riding factor. The approach to capacity assessments should also reflect the individual's desire to be involved, as well as the extent of their family or carers.	Thank you for your comment. The Guideline Committee discussed this and agreed with the point you made. The recommendation has been edited to make clear that assessors should be mindful that assessment may be distressing but that every reasonable step should be taken to minimise this and encourage participation.
Alzheimer's Society		14	17	Advocacy should be included here.	Thank you for your comment. This recommendation makes a specific point about helping people to communicate and the suggestions included in the recommendation are derived from the evidence and from committee expertise. Advocacy is not specifically intended to aid communication (although obviously it has a role to play) so it has not been added to this recommendation. However, the committee recognised the value of advocacy in the context of decision making and mental capacity and developed a number of specific recommendations about advocacy, including about expansion of the role.
Alzheimer's Society		17	1	It is unclear whose role it is to do this and must be clarified.	Thank you for your comment. The section now has an introductory statement which indicates how it relates to existing guidance and legislation.
Alzheimer's Society	Short	General	General	• More information is needed on the context for the guidance. This guidance was originally intended to provide practical assistance for healthcare professionals to support individuals with decision-making. This would improve implementation of the MCA and also align with the approach in the UN Convention on the Rights of Persons with Disabilities. This guidance is a missed opportunity for doing this. • In general, the guidance is vague, repetitive and difficult to follow and it does not bring new additional information. Most of what is included can be found elsewhere (e.g. in the MCA Code of Practice). What is needed is *practical* guidance to support healthcare professionals when implementing the MCA, particularly around supporting people to make decisions. This guidance does not provide that. • We are concerned that the guidance does not fully consider fluctuating capacity and this is evident in many areas throughout the document. The	Thank you for your comment. The introduction section has been updated following consultation and now provides a clearer description of the relationship between the guideline and the mental capacity legislation. The overall structure of the guideline has also been reviewed by the Guideline Committee to take into account yours and other consultation comments. Each separate section of the guideline now has an introductory paragraph highlighting related sections or principles of the MCA and Code of Practice. We hope this goes some way to addressing your concerns about the structure and clarity of the guideline. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the

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				overall approach the guidance takes implies that whether or not a person has capacity is an all or nothing situation. The first page states that the guideline covers people 'where they have capacity' and later people 'who lack capacity', but does not acknowledge people who have fluctuating capacity. This is an area particularly relevant for people with dementia whose capacity can fluctuate as the condition progresses, and even at different times of day. Practical guidance is needed for people working in these situations, which can often be the most challenging for healthcare professionals. • The guidance overall does not seem to fully appreciate the different types of advocacy which may be relevant in this context and how they interact for example, Care Act advocacy and Relevant Person's Representatives. It also doesn't appreciate the current on the ground situation that advocacy services are in regarding limited resources. • There is not enough in the guidance around unwise decisions, which is an area that healthcare professionals require further practical guidance around. • The guidance frequently uses unclear language including jargon with references to 'autonomy' and 'empowerment' without explanation of what these mean or how to enhance them for the individual. • The guidelines state they are for everyone, practitioners and service users alike. Both of these audiences require guidance that is clear and concise whereas this is vague. At the same time, it is not clear who the guidance covers as 'health and social care practitioners' and 'practitioners working in services' is vague and used inconsistently throughout the guidance. • Throughout the guidance, responsibilities are set out but not assigned to particular people – there are numerous areas of the document where the subject is not stated. • It needs to be clearer throughout the document which guidance refers to a legal obligation i.e. is a 'must' and what is good practice i.e. 'should.' These terms are used inconsistently throughout.	particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions. The committee acknowledge that the draft recommendations on advocacy lacked clarity and have made revisions accordingly. In revising the recommendations post consultation, the committee clarified references to unwise decisions by emphasising that this is a subjective judgement made by practitioners. They added that during capacity assessments, the practitioners view about the decision should be recorded, including whether they consider it to be unwise. They also revised the context section to highlight the 3rd principle of the Mental Capacity Act. In terms of providing any further practical guidance as you suggest, the committee felt unable to do this because they did not review any evidence which would provide a basis for specific recommendations on this issue. The committee reviewed the language of the recommendations and worked with the editor to ensure clarity. They also added items to the 'terms used' section and improved the descriptions already provided. In relation to the population and audience, the committee endeavoured to clarify this by revising the wording of some of the recommendations, reviewing the context section and adding introductory paragraphs to each section. Finally, the committee revised the recommendations to ensure that any that are legally binding include 'must' and any that are not but which are supporting by strong evidence and committee expertise, would include 'should'. This should now be clear and consistent.
Alzheimer's Society	Short	1 – intro/ context	13	This sentence needs to be amended to reflect fluctuating capacity, rather than solely referring to adults who 'may in the future lose, or have already lost mental capacity.'	Thank you for your suggestion. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.

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Alzheimer's Society	Short	2	5	Include 'past and present wishes, feelings, beliefs and values' in this sentence.	Thank you, this has been amended in the recommendations for consistency.
Alzheimer's Society	Short	3	General	It is not clear what "your care" is. This section refers to 'overarching principles' but then goes on to state the application of these principles – it would be clearer to just state principles then go into practical application afterwards. One of the overarching principles should be 'acknowledge an understanding of and regard to benefits of advocacy.'	Your care is a NICE resource encouraging and guiding people to be involved in their health and care, particularly in relation to decision making. The importance of the role of advocacy is explained in detail in 1.1.7 – 1.1.11 in the overarching principles section.
Alzheimer's Society	Short	3	2	Consideration of fluctuating capacity and unwise decisions needs to be added here.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
Alzheimer's Society	Short	3	5	It is unclear whose responsibility it is to decide what is 'appropriate' training – this needs to be clarified.	Thank you for your comment. This recommendation has now been reworded to clarify that training should be tailored to the role and responsibilities of the practitioner.
Alzheimer's Society	Short	3	13	'Loss of autonomy' in this context is unclear. It would be better to state 'loss of capacity.'	Thank you for your comment. The Guideline Committee confirm that the term 'autonomy' is correctly used in the third bullet in Recommendation 1.1.1. Furthermore, the committee note that the MCA refers to autonomy in the sense of the second principle of the Mental Capacity Act.
Alzheimer's Society	Short	3	16	It is unclear what 'roles and responsibilities' are being referred to here.	Thank you for your comment. This recommendation is in the overarching principles section. The term refers to all roles and responsibilities relating to decision making and mental capacity
Alzheimer's Society	Short	4	8	This sentence sets out a responsibility regarding co-developing policies and training programmes but it does not state whose responsibility this is. If it is health and social care organisations as per the previous paragraph, this should be stated.	Thank you for your comment. The committee did not want to be overly directive with this recommendation. The target audience is the organisation or practitioners with responsibility for developing training in this area.
Alzheimer's Society	Short	4	20	Advocacy should be added here.	Thank you for your comment. Advocacy is dealt with in some detail in recommendations 1.1.7 – 1.1.11.
Alzheimer's Society	Short	4	21	This section is not clear on who it is that must record and update this information. If it is staff, more detail and guidance is needed to support staff to do this in practice. This guidance is an important opportunity for providing practical support to staff who are producing advance care plans with individuals and their families so more practical detail is needed.	Thank you for your comment. The committee did not make any edits to this recommendation because they felt it is clear that practitioners working with the person, for example to support them to make their own **decisions, would be the people recording and updating information.** 'Past and present wishes' have been added to the recommendation.

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				'Past and present wishes' also needed to be included along with preferences, values and beliefs.	
Alzheimer's Society	Short	5	8-14	This section needs to be strengthened to start with 'practitioners must' in line with legal obligations. The section does not reflect the different types of advocacy – this needs to be clarified, and not be limited to IMCA. It also needs to be made clearer that support from advocacy services can be obtained for people with fluctuating capacity.	Thank you for your comment. This recommendation – along with the others on advocacy – has been substantially revised in light of yours and other comments. The legally binding obligations have been clarified as have the 'consider' recommendations.
Alzheimer's Society	Short	5	17-22	These are things that should be happening anyway.	Thank you for highlighting this. The committee agrees with you and they anticipate that this recommendation will improve practice in this area by ensuring it is rolled out more widely.
Alzheimer's Society	Short	5	5-7	This section displays a lack of understanding of the current pressure facing advocacy services on the ground which are severely under-resourced. Expanding existing services is not feasible given the current practical issues facing advocacy services. This section also does not consider the different types of advocacy roles and how they interact.	Thank you for your comment. The advocacy recommendations have now been substantially revised and the one to which you refer is now a 'consider' recommendation, which gives commissioners flexibility around implementation and now relates to statutory advocacy.
Alzheimer's Society	Short	5	15	The Care Act contains specific legal obligations for when advocacy is required to support during safeguarding. The use of the word "consider" therefore needs to be much stronger and recognise these legal obligations. This section should also be clearer about which types of advocacy must be provided.	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised and the elements that are legally binding are now much clearer.
Alzheimer's Society	Short	5	25	This should state the particular types of advocacy as many are relevant for this group of people, not just IMCA.	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised to clarify the elements that are legally binding.
Alzheimer's Society	Short	6	General	This comment also applies to page 7. The titles and content of pages 6 and 7 are similar but are phrased differently, which makes it unclear. The language is also very academic and should be rewritten as more practical with a focus on how to optimise capacity. For example, instead of saying 'relational factors' say 'who has the best relationship to support the person' rather than situational say 'would somewhere quieter or more familiar help?'	Thank you for your comment. Following consultation the recommendations, including the structure and title headings were revised. We hope this addresses your concerns.
Alzheimer's Society	Short	6	1	This guidance should be broader than just Independent Mental Capacity Advocacy as these issues are relevant to all types of professional statutory advocacy that may be relevant in this context.	Thank you for your comment. You are right that the guideline applies more broadly that independent mental capacity advocates – also to other advocates and practitioners supporting people to make their own decisions.
Alzheimer's Society	Short	6	3	"Dementia" should be added as an example here as particular skills and experience is key to effectively supporting someone with dementia.	Thank you for your comment. The Guideline Committee agreed that this recommendation will be edited to include wording to cover people with impaired executive function, so it will cover groups more broadly (while addressing the specific issue of 'executive dysfunction' which was the aim of this recommendation. This will thereby pick up the issue of dementia.
Alzheimer's Society	Short	6	15	It is unclear what this means and needs to be clarified. If it means support or help that the person has received in the past, then this should be made more explicit.	Thank you for your suggestion but the committee believe this point is already covered by the term 'situational, social and relational factors'.
Alzheimer's Society	Short	6	21	"Environmental factors" should be added to this list to include things like background noise and time of day. These can be particularly important for supporting a person with dementia.	Thank you for your suggestion but the committee believe this point is already covered by the term 'situational, social and relational factors'.
Alzheimer's Society	Short	6	28	It is not clear what "process and principles" are being referred to here as there isn't an established system for supported decision-making outside of the MCA, and the MCA principles are not limited to supported decision-making.	Thank you for your comment. This section is about supporting decision making. The link between these recommendations and the MCA and Code of Practice is clearly explained in a new introduction to this section.

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Alzheimer's Society	Short	7	18-19	This section needs more detail in order to practically support healthcare professionals who are supporting someone with making an unwise decision.	Thank you for your comment. The recommendation has been revised to provide some more clarity but the committee point out that people should be supported to make decisions following the same principles, regardless of whether it is judged to be an unwise decision.
Alzheimer's Society	Short	7	3	Information should be tailored to the person's individual needs. This requires a personalised approach that may require further consideration than just the NHS Accessible Information Standard.	Thank you for your comment. The point you make is actually addressed in the recommendation before this one, which refers to tailored, accessible information.
Alzheimer's Society	Short	7	6	Reference to unwise decisions should be included here, as personal opinions of the person's decision may affect the way the practitioner presents information.	Thank you for your comment. The committee feel your point is addressed in the recommendation, which refers to 'balanced and non-leading way'.
Alzheimer's Society	Short	7	24	This should include a suggestion of advocacy where there is conflicting needs e.g. an exhausted carer may need for the person to go into respite against wishes of the individual.	Thank you for your comment. The committee made a number of detailed recommendations about advocacy in the overarching principles of the guideline. These have been clarified and strengthened in light of stakeholder comments.
Alzheimer's Society	Short	8	10	This sentence refers to a 'range of interventions,' which is too vague and makes it unclear and confusing. Specific examples of interventions must be added to address this vagueness.	Thank you for your comment. There was not sufficient evidence to recommend specific interventions.
Alzheimer's Society	Short	9	16	It is not clear what training is being required here and who the audience is. More clarity and detail is needed.	Thank you for your comment. The recommendation relates to training for advance care planning. This should be provided to relevant health and social care practitioners.
Alzheimer's Society	Short	9	20	It is not clear whose responsibility it is to do this. If it is commissioners as per the previous paragraph, this needs to be clearly stated.	Thank you for your comment. The text has been edited for clarity.
Alzheimer's Society	Short	9	24	As above it is not clear whose responsibility this is. If it is commissioners as per the previous paragraph, this needs to be clearly stated. This should not be limited to people who have been 'recently diagnosed.' Conversations about advance care planning should be ongoing and tailored to the individual's needs, who may not be inclined to have these conversations soon after diagnosis. Healthcare professionals may interpret this guidance as a duty to initiate conversations immediately which could have huge impact on emotional wellbeing of person and effectiveness of future planning. This section should therefore be amended to reflect the importance of a personalised approach as well as the ongoing nature of conversations.	Thank you for your comment. The text has been edited for clarity.
Alzheimer's Society	Short	10	8	As above, this should not be limited to people who have been 'recently diagnosed.' Conversations about advance care planning should be ongoing and tailored to the individual's needs, who may not be inclined to have these conversations soon after diagnosis. Healthcare professionals may interpret this guidance as a duty to initiate conversations immediately which could have huge impact on emotional wellbeing of person and effectiveness of future planning. This section should therefore be amended to reflect the importance of a personalised approach as well as the ongoing nature of conversations.	Thank you for your comment. We believe that the importance of a personalised approach is covered adequately by reference to 'at the most suitable time.'
Alzheimer's Society	Short	10	16	This section should also include reference to the ability of the person to change their mind, either during the conversation or later on.	Thank you for your comment. This is covered in the recommendation numbered 1.3.3 in the draft guideline.
Alzheimer's Society	Short	10	22	It is unclear what 'needs for autonomy' means in this context – it is vague jargon and alternative wording should be used.	Thank you for your comment. We have edited the text for clarity.

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Alzheimer's Society	Short	11	2	References to co-production are important and positive but healthcare professionals need clearer guidance if they are to do this. This section needs much more practical detail on how this would happen if it is to be useful.	Thank you for your comment. We believe that this issue is adequately covered in this recommendation.
Alzheimer's Society	Short	11	19	The use of the word "contemporaneous" is jargon and simpler, clearer language should be used.	Thank you for your comment. The committee believe that this phrase is appropriate and understood by practitioners within this context. The writing of contemporaneous notes is described in the Mental Capacity Act. However in acknowledgment of the need for clarity the committee added a definition of the term 'contemporaneous' in the term used section of the guideline.
Alzheimer's Society	Short	11	22	It is unclear whose responsibility this is.	Thank you for your comment. The recommendation is aimed at all health and social care practitioners. We have edited the recommendation to clarify this.
Alzheimer's Society	Short	11	29	The use of the word 'consent' here is unclear. More detail is needed on this.	Thank you for your comment. The guideline includes a section on 'terms used' where a definition of consent is provided.
Alzheimer's Society	Short	12	4	Add in "or the person requests it" to when to review an advance care plan so it is not just at particular times of review.	Thank you for your comment. We have edited the text accordingly.
Alzheimer's Society	Short	12	6	For a person with dementia, they may lack capacity but not be approaching the end of life. This needs to be reflected in the guidance so that revisiting care plans is not only relevant to people approaching the end of life.	Thank you for your comment. The recommendations are not specific to end of life care.
Alzheimer's Society	Short	13	1-30	This contains virtually the same title as the previous page which is unclear. This section just repeats the detail found in the Code of Practice. It does not add new, practical information which is what is needed.	Thank you for your comment. The guideline has been reviewed to minimise duplication. The recommendations are based on the best available evidence. The text has been edited to make clear where there is an overlap with the code of practice.
Alzheimer's Society	Short	14	8	'Empowering and proportionate' is unclear jargon. More detail is needed on what this means and how healthcare professionals do this.	Thank you for your comment. We believe that the meaning of these terms is clear.
Alzheimer's Society	Short	14	11	The reference to voting here is unclear as voting is not relevant in the context of the MCA. Further, if stating that for certain areas there is no legal requirement to establish capacity, it needs to be clear what these areas are.	Thank you for your comment. Voting rights are covered in Section 29 of the Mental Capacity Act – this recommendation reflects this aspect of the legislation.
Alzheimer's Society	Short	15	1	It is unclear what "functioning capacity" means – alternative language should be used such as "capacity."	Thank you for your comment. The reference to functional capacity has been removed.
Alzheimer's Society	Short	16	25-29	This section should include detail on the importance of seeing whether the person may regain capacity to make the decision.	Thank you for your comment. The committee believe that this is implicit in the recommendation.
Alzheimer's Society	Short	16	10	Recording whether it is an "unwise decision" or not is entirely inappropriate. This is a subjective judgment – what should be recorded is the outcome of the capacity and assessment and the decision-making process, it is irrelevant whether the person assessing capacity feels it is an unwise decision.	Thank you for your comment. The committee agree that this text was confusing and this has now been edited to be clear that practitioners should record whether the person has capacity to make the decision and the decision that they make.
Alzheimer's Society	Short	16	11	It is unclear here what the person has given "valid consent" to. It needs to be clarified whether it is consent for the assessment or for the particular decision or intervention.	Thank you for your comment. The committee agree that this text was confusing and this has now been edited to be clear that practitioners should record whether the person has capacity to make the decision and the decision that they make.
Alzheimer's Society	Short	17	27-28	Advocacy should be added in here.	Thank you for your comment. The use of advocacy is recommended as an overarching principle in recommendation 1.1.7
Alzheimer's Society	Short	17	21	This demonstrates lack of understanding of advocacy services as it will not necessarily only be an IMCA that is relevant here. It is also unclear whose role it is to do this.	Thank you for your comment. Advocacy is now covered in more detail in recommendations 1.1.8 to 1.1.11.

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Alzheimer's Society	Short	18	6-8	Advocacy should be added in here.	Thank you for your comment. This recommendation has now been replaced with recommendation 1.5.9 that includes advocates.
Alzheimer's Society	Short	18	24	If 'reasonable adjustments' are to be included, practical examples should be given.	Thank you for your comment. The committee did not feel that it was necessary to include practical examples in this recommendation.
Alzheimer's Society	Short	19	4	It is unclear what 'toolkits' are relevant here. This guidance is intended to provide practical guidance on implementing the MCA.	Thank you for your comment. The recommendation is based on evidence reviewed by the committee which suggested that checklists and tool-kits can help to improve best interests practice. However, there was a lack of clarity on the form that these might take and the committee were unable to provide further detail on the issue.
Alzheimer's Society	Short	19	23	Fluctuating capacity should be added in here.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
Alzheimer's Society	Short	20	1-11	This section just repeats the detail found in the Code of Practice. It does not add new, practical information which is what is needed.	Thank you for your comment. Other stakeholders requested that the Code of Practice was referred to in the guideline, in order to make clear how the guideline sat alongside the Code.
Alzheimer's Society	Short	20	27-28	This section does not acknowledge the practicalities of going to the Court of Protection, which should be a last resort after other avenues of conflict resolution have been explored (aside from situations where there is a legal requirement to refer to the Court of Protection).	Thank you for your comment. The committee considered your suggestion but felt it would be better for people to refer to Court of Protection guidance, which would avoid any changes to those rules making this guideline out dated.
Alzheimer's Society	Short	20	11	It is not clear what is meant by 'disempowerment' as a negative effect. This is unclear jargon and needs to be clarified.	Thank you for your comment. The committee believe the meaning of the term to be clear.
Alzheimer's Society	Short	21	19-24	This definition is unclear and inconsistent as it starts with 'advance decisions to refuse treatment' then in the body of the definition refers to 'advance decision – sometimes known as advance decision to refuse treatment.' Use of the term 'living will' is also unclear – the correct term from the MCA is 'advance decision to refuse treatment.' This definition also needs to make clear that advance decisions to refuse treatment are legally binding if they are 'valid and applicable', and then provide detail of what makes them so.	Thank you for your comment. By 'advance decisions to refuse treatment', we mean 'advance decision'. Regarding a 'living will', to avoid confusion, this term has been removed from the heading for advance decision. A little more detail has been added to the 'advance decision' definition.
Alzheimer's Society	Short	21	25-28	This definition is unclear, and should reflect other terms people may use such as 'advance statement' or 'statement of wishes.'	Thank you for your comment. The term 'advance directive' has been removed from the guideline because it does not appear in the recommendations. However the introduction to the advance planning section refers to advance directive and

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				Use of 'mentally incapacitous of giving consent to treatment' is unclear and not used at any other point in the document. It should be changed to 'lack capacity.'	other advance care planning tools and we hope this description addresses your concerns.
Alzheimer's Society	Short	21	9	As above, this section does not acknowledge the practicalities of going to the Court of Protection, which should be a last resort after other avenues of conflict resolution have been explored (aside from situations where there is a legal requirement to refer to the Court of Protection).	Thank you for your comment. The committee considered your suggestion but felt it would be better for people to refer to Court of Protection guidance, which would avoid any changes to those rules making this guideline out dated.
Alzheimer's Society	Short	21	12	This definition needs more detail to reflect the different things that can be part of advance care planning including what is legally binding.	Thank you for your comment. This is just intended to be a definition of how the terms are used in this guideline. The committee did not agree to make any changes to the definition but they did agree to revise the introduction to the advance care planning section, which now makes references to the legal status of various advance care planning tools.
Alzheimer's Society	Short	22	4-8	'Duty of care' has not been mentioned anywhere else in the document so it is unclear why it is included here. The definition is also wordy and unclear.	Thank you for highlighting this. 'Duty of care' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Alzheimer's Society	Short	22	15-19	This definition needs more detail. In particular, it does not state that there are two different types of LPA which is a key consideration in this context.	Thank you for this suggestion. The definition of LPA has been edited to align with the Office for the Public Guardian definition, which makes clear the distinction between the two types of LPA.
Alzheimer's Society	Short	22	2	References to capacity are not needed here. It should be changed to 'when a person gives permission to someone to do something to them.'	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent does not consent to treatment or care and support, even if they co-operate with the treatment or actively seek it'.
Alzheimer's Society	Short	22	24	This definition does not take into account fluctuating capacity. Further, the MCA is relevant to everyone including people who have capacity (sections on Lasting Powers of Attorney and Advance Decisions to Refuse Treatment for example).	Thank you for your comment. We acknowledge that the Mental Capacity Act (MCA) is relevant for people with and without capacity. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
Alzheimer's Society	Short	23	15-18	'Proxy' has not been mentioned anywhere else in the document so it is unclear why it is included here. Further, the definition is misleading as legal authority can only be given to make decisions on behalf of someone who lacks capacity through a Lasting Power of Attorney.	Thank you for your comment. We have now deleted this definition of 'Proxy'.

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Alzheimer's Society	Short	23	25-28	'Substitute decision-making' is not included anywhere else in the document so it is unclear why it is included here. The definition is unclear as 'substitute decision maker' is not a recognised role.	Thank you for your comment. We have now deleted this definition of 'Substitute decision-making'. Thank you for highlighting this error in the draft guideline.
Alzheimer's Society	Short	23	8	'Unfit' is entirely inappropriate and offensive language. The correct wording of the MCA principle from the MCA should be used i.e. 'unable to make a decision.'	Thank you for your comment. This has been amended to 'unable'.
Alzheimer's Society	Short	24	1-3	As above – 'supporter' is not a recognised role within the MCA so including it here is misleading and unclear.	Thank you for your comment. The term does not appear in the recommendations (nor in the context section) and therefore is not defined in the short guideline. It is only defined in the full guideline because it is mentioned in the included evidence. The term is described in line with how it has been used in that study. The term cannot be removed from the definitions in the full guideline because it is intended to help people understand how it used in the cited study.
Alzheimer's Society	Short	24	20	This states 'training' but provides no detail of what training is required.	Thank you for your comment. This section of the short guideline is intended to highlight some of the issues that will need particular thought when implementing the recommendations and training is one of those. Some suggestions as to what might be covered are provided, but it is not possible to state definitively what training is required given the very wide audience for this guideline.
Alzheimer's Society	Short	25	4-7	This does not show an appreciation of the current challenges faced by advocacy services, which are seriously under-resourced and over-stretched.	Thank you for your comment. Text to reflect the range of challenges in accessing advocacy services has been added to this section.
Alzheimer's Society	Short	25	28	'May' should be changed to 'need'.	Thank you for your comment. The text in this section is standard in NICE guidelines and cannot be amended.
Association for Family Therapy and Systematic Practice in the UK	Short	general	general	It would be helpful to clearly define what is meant by supported decision-making and shared decision-making.	Thank you for your comment. The committee reviewed the guideline following consultation and it no longer refers to shared decision making. Instead, the committee agree to refer to 'supporting decision making' and this is clearly explained in an introductory paragraph at the start of section 1.2
Association for Family Therapy and Systematic Practice in the UK	Short	general	general	Our membership expressed concerns that this guideline will lead to increased bureaucracy; and take frontline practitioners away from their face to face work with service users and their families. This could impact negatively on the capacity of services to meet their clinical responsibilities, representing a cost of this guideline.	Thank you for your comment. The Guideline Committee considered carefully the need to develop recommendations that improve practice and that retain focus on the person being at the centre of their care. They agreed that the recommendations are aspirational but achievable.
Association for Family Therapy and Systematic Practice in the UK	Short	general	general	We welcome the focus on collaboration and centring the views and wishes of the person concerned, and supporting decision-making in everyday decisions, not just at times of conflicting views.	Thank you for your comment and support for the guideline.
Association for Family Therapy and Systematic	Short	1 cover page	5	"This guideline covers decision-making in people over 16…" Does it aim to cover all decision-making? That might be regarded as patronising for people who have the capacity to make autonomous decisions for themselves. Perhaps it should cover "supported" decision-making, so long as it is clear what that means, as stated in the rest of the document.	Thank you for your suggestion. This section now refers specifically to 'people 16 years and over who may lack capacity now or in the future'.

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Practice in the UK					
Association for Family Therapy and Systematic Practice in the UK	Short	3	14	This point is not clear; should it be 'required communication skills for building trust to **support** decision making'?	Thank you for highlighting this typo, which has now been corrected.
Association for Family Therapy and Systematic Practice in the UK	Short	4	5	Refers to health and social care organisations identifying or devising specific tools to help assess mental capacity, yet the use of mental capacity assessment tools is identified as an area for research on page 29. This could potentially lead to organisations devising a range of untested tools which could be potentially unhelpful so we are not sure that this is a sound recommendation. For example, our membership have reported a so-called capacity assessment which consisted of a cognitive test used to screen for dementia – this is not an appropriate tool to use to assess mental capacity in relation to decision-making. Perhaps a statement about ensuring any capacity assessment tools used are not used as a 'stand-alone' or decontextualized proxy for deeming capacity. The importance should be underlined, here about using multiple sources of assessment and triangulating sources to ensure better accuracy of any assessment. Any idiosyncratic tools developed or existing tools identified for this process should have a system of evaluation in place to audit the fitness of these tools for purpose, and a means to share results across services.	Thank you for your comment. The committee felt that local organisations are already developing policy and guidance to support decision making and that this recommendations would encourage the wider roll out of this. However acknowledging your point about potential inconsistencies and development of idiosyncratic tools, they have reviewed the recommendation to now say that those tools should be audited in terms of their adherence to the Mental Capacity Act Code of Practice.
Association for Family Therapy and Systematic Practice in the UK	Short	5	15	"consider" providing independent advocacy when there is a safeguarding concern. This statement may be too weak. There will be safeguarding concerns where it might be appropriate for family to support an individual but there will be others where it will be inappropriate, and we feel the recommendation should lean towards involving an independent advocate in those cases where both safeguarding and mental capacity concerns exist.	Thank you for your comment. Following consultation feedback and a legal review of the guideline, the recommendations on advocacy have now been revised to clarify when advocacy should be provided and the use of advocates is included in recommendations related to situations that might result in best interests decision-making, such as recommendations 1.5.7 and 1.5.9.
Association for Family Therapy and Systematic Practice in the UK	Short	7	8-9	The recommendation to give the person opportunity to review and comment on what is recorded and write down their views, may not be inclusive of people who aren't able to write down their views. It is important to think about and describe ways in which people can be involved in sharing their views when reading and writing may not be accessible to them.	Thank you for your comment. To clarify, it is intended that the practitioner record the person's views after they have communicated them, through whatever means suits their needs. The practitioner is doing the recording, not the person.
Association for Family Therapy and Systematic Practice in the UK	Short	7	18-19	The phrasing here implies that services and professionals are likely to know best what is 'wise' or 'unwise. A less paternalistic way of phrasing this could be: 'Support the person with decision-making even if they wish to make a decision that services or professionals disagree with or believe to be unwise'. In these situations it can be difficult for services and professionals to be fully supportive, and in these cases independent advocacy may be important to consider.	Thank you for your comment. The committee agree with you and have revised the recommendation to say that a person should not be treated as unable to make a decision merely because he or she makes an unwise decision.
Association for Family Therapy and Systematic	Short	8	15-23	Family therapy would be another example of a health and social care practitioner with significant expertise in supporting people to reach shared decisions when there are conflicting views and complex situations, especially when these arise within the context of family support.	Thank you for your comment. The examples given in the recommendation are based on the evidence reviewed and this did not provide any basis for specifically referring to family therapists.

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Practice in the UK					
Association for Family Therapy and Systematic Practice in the UK	Short	15	24-27	This is about how people need to retain the most important points long enough to make a decision. There are some occasions when people who appear to make a capacitous decision then retain no knowledge of that decision. If someone goes through the process with them again, they again appear to retain material and make a capacitous decision but it can be a different decision. Our membership reports knowledge of people going through the process several times, making different decisions. We think that vacillation may demonstrate impaired decision-making capacity, even though each assessment might demonstrate capacity is present; the guideline does not cover what to do in this situation where capacity concerns come from taking a meta-view of multiple assessments.	Thank you for your comment. The committee acknowledge your point and highlight that an earlier recommendation in the section on capacity assessment states that the assessor should take into account the person decision making history when preparing for an assessment and this would include the nature and outcome of the decisions they reached.
Association for Palliative Medicine	Short	General	General	The NICE guideline: short version on Decision-making and mental capacity fails to provide clear and supportive guidelines to allow health care practioners to implement care under the mental capacity act . The guidelines don't appear to refer to the core principles of mental capacity, or clearly reference those guidance They are vague and unsupportive	Thank you for your comment. The committee revised the recommendations following consultation, aiming to make them as clear and useful as possible. The context section has also been revised and now includes the principles of the MCA and each relevant section of the guideline contains an introductory paragraph citing the relevant principle and section of the MCA and Code of Practice. We hope this addresses your concern.
Association for Palliative Medicine	Short	General	General	The Association for Palliative Medicine of Great Britain and Northern Ireland have major concerns should this be released as guidance . We believe they will create additional confusion for individuals and organisations rather providing the clarity and quality of which we are assured by NICE	Thank you for your comment. Following consultation the committee reviewed the recommendations, clarifying their intended meaning as well as some crucial terminology. The context section has also been revised and now includes the principles of the MCA and each relevant section of the guideline contains an introductory paragraph citing the relevant principle and section of the MCA and Code of Practice. We hope this addresses your concern.
Association for Palliative Medicine	Short	16-21	General	As with earlier section, 1.5 lacks clarity. It does not clearly identify the role of the Best Interest Decision Maker with particular reference to end of life treatments and ACP	Thank you for your comment. The guideline has been edited to provide clarity and we have included more detail on the links to advance care planning and best interests processes (including the importance of identifying a decision-maker).
Association for Palliative Medicine	Short	12-15	General	1.4 the guidance fails to explicitly identify the the 4 principals upon which capacity assessment is based.	Thank you for your comment. Following consultation the context section was revised as was the introduction to the section on capacity assessment. The relevant principles are now clear.
Association for Palliative Medicine	Short	1-3	General	What do these guidance add above or beyond the Mental Capacity Act Code of Practice. The guidance offers no supplementary, new or evidence based guidance.	Thank you for your comment. Following consultation the context section was revised and new introductions to individual sections of the guideline were added in order to clarify the relationship between the guideline and relevant legislation.
Association for Palliative Medicine	Short	9-11	General	Section 1.3 Advance Care Planning fails to clearly identify or reference the types of advance care planning identified within the MCA and opens the way for inconsistent practice. This provides no standards. Nor does it provide any evidence base or quality assurances	Thank you for your comment. The guideline has been edited to include more details regarding advance care planning and links to relevant sections of the code of practice have been provided where appropriate. Further details regarding the evidence on which these recommendations are based can be found in appendix B.
Association for Palliative Medicine	Short	4	General	A number of the recommendations are vague e.g. 1.1.2 and add nothing to the Mental Capacity Act Code of Practice.	Thank you for your comment. The recommendations have been revised to improve clarity. In addition the context has now been revised to provide a clear link between the guideline, the relevant legislation and the Code of Practice. Further references to the MCA and Code of Practice have also been added to the guideline.
Association for Palliative Medicine	Short	6	General	Where tools or interventions are suggested their is no guidance as to what they might be e.g. 1.2.14 or how their quality might be ascertained.	Thank you for your comment. Unfortunately the committee did not review any evidence which would provide a basis for recommending specific tools and guidance.

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Association for Palliative Medicine	Short	23	15	The glossary has reference to terms that are no used used in the application of the MCA such as proxy whilst failing to identify statutory roles such as Lasting Power of Attorney and Court Appointed Deputy. This is inconsistent and will create additional confusion	Thank you for your comment. We have now removed the term 'Proxy' from the revised version of the guideline.
Association for Palliative Medicine	Short	23	19	Psychiatric Advance Statements is referenced which does not appear within the MCA	Thank you for your comment. Psychiatric Advance Statements are no longer referred to in the guideline.
Berkshire Healthcare NHS Foundation Trust	Full and short	General	General	On reading the guideline, there is a suggestion that Psychologists will be available to support mental capacity assessments. If this were taken to the letter, it could place significant pressure on our Psychology staff as many of our services (e.g. district nursing, community wards etc) would potentially be asking for this support. Is the guideline suggesting that psychologists should always be consulted, or that we should only draw in support when required? (e.g. if the assessment shows the need for psychologist input?)	Thank you for your comment. Rec 1.2.16 (numbering as per consultation draft) makes reference to seeking the input of different practitioners being as needed: 'when the person's level of need requires specialist input'. The practitioners listed in 1.4.3 are examples only and others' expertise could be drawn on.
Betsi Cadwaladr University Health Board	short	17	1.14.20	Over-estimating capacity is a common problem and can have serious ethical and clinical consequences. I suggest this is pointed out clearly and not just mention in the context of acquired brain disorders. I suggest the following publications for research in this regard. Systematic review on the prevalence of lack of capacity in medical and psychiatric settings. **Lepping P**, Stanly T, Turner J. Clin Med (Lond). 2015 Aug;15(4):337-43 Overestimating patients' capacity. **Lepping P**. Br J Psychiatry. 2011 Nov;199(5):355-6 Paternalism v. autonomy - are we barking up the wrong tree? **Lepping P**, Palmstierna T, Raveesh BN. Br J Psychiatry. 2016 Aug;209(2):95-6	Thank you for your comment. The prevalence of a lack of decision-making capacity is not within the scope of this guideline.
Betsi Cadwaladr University Health Board	Short	23	1.15	It would really help to point out that taking a calculated risk can be in the patient's best interest in order to facilitate the least restrictive option. This may be in conflict with safeguarding, which often seems to trump best interest. The advice could point out as 1.15.24: Safeguarding proceedings cannot replace best interest decisions. Calculated risk should be taken if it is in keeping with the patient's wishes and the least restrictive option, even when it may be in conflict with safeguarding concerns.	Recommendation 1.5.15 highlights that practitioners should take into account their restrictions and freedoms with each option to allow for risks that might be in the person's best interest.
Brain Injury Social Work Group	Short	6	1.2	Re The involvement of others. BISWG is particularly concerned that this should include the involvement of specialist providers who have experience of Brain Injury, in particular any aspects of frontal lobe damage and consequent lack of insight. This includes Independent Brain Injury Case Managers	Thank you for your comment. This recommendation is intended to be sufficiently broad to prompt all practitioners to consider the wide range of factors that can have an impact on a person's ability to make decisions.
Brain Injury Social Work Group	Short	5	1.1.	BISWG is concerned that training regarding Acquired Brain Injury is made available and that experts in this area should be consulted and respected in this respect. BISWG has experience of providing training to social services departments across the country and would be willing to extent this training and to share information for the NICE database .	Thank you for your comment and suggestion for implementation support.

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Brain Injury Social Work Group	Short	7	General	Our experience would suggest that ' the involvement of others" can involve malevolent influences if the person with brain injury has been assessed as being suggestible. Considering this may be time consuming and difficult to establish but opinions should be sought from all involved.to establish any undue influence , More clarification is needed regarding " undue influence" particularly where someone might have a financial compensation award . Involving " carers ' should also mean professional care providers who might have know a client for many years .	Thank you for your comment, which the committee believe is addressed in the recommendation about ensuring support is free from coercion and undue influence. In terms of providing any further detail about this, the committee did not feel they had the basis to do so from the evidence they reviewed.
Brain Injury Social Work Group	Short	12	1.4	BISWG is aware of many cases where specialist knowledge has been challenged if it does not comply with social care workers opinion. Several of these cases have considered that members of a social care team with generic knowledge are perfectly able to assess capacity. BISWG] and other specialist Brain Injury groups] are willing to be consulted for advice . See BISWG and BASW " Practice Guidance for Social Workers working with people where there may be an Acquired Brain Injury "	Thank you for the information provided. Recommendation 1.4.3 states that 'Organisations should ensure that assessors can seek advice from people with specialist condition-specific knowledge to help them assess whether, on the balance of probabilities, there is evidence that the person lacks capacity '. It is therefore hoped that this recommendation will help to improve practice in this area.
Brain Injury Social Work Group	Short	13	1.4 general 1.4.20	'Assessors should have sufficient knowledge of the person being assessed to be able provide tailored information " Many people with acquired brain injury may sound competent to state intentions but actually have poor insight into their difficulties and unable to put intention into practice. It should be stressed that it is essential to gain 3rd party evidence and to consider <u>actual</u> functioning and vulnerability. BISWG is aware of cases where assessors have refused to include providers in assessments of a person's functioning and ability. Social service assessors and independent advocates have been known to dismiss capacity assessments by specialist professionals . This can leave the person with a brain injury very vulnerable and at risk	Thank you for your comment. 'Sufficient knowledge' could include knowledge gained from conversations with others.
British Association of Brain Injury Case Managers	Full	General	General	The British Association of Brain Injury Case Managers (BABICM) welcome these guidelines. BABICM provided considerable evidence and examples to the House of Lords Select Committee in 2014, along with other organisations, citing the complexities in understanding the nuanced issues of people with acquired and traumatic brain injury and the consequent variance in quality of capacity assessment and best interest decisions. Indeed, the report produced by the House of Lords specifically drew examples of the particular vulnerabilities that result from assumptions by uninformed professionals within the process. There is record of the difficulties associated with 'structured' assessments as providing a framework of scaffolding which leads to a belief that a person has capacity which they are unable to maintain when influenced by other factors or environments and decisions are made 'on line'. There was evidence that often professionals, such as case managers, as well as family members/others that know the client well are not consulted and that questions asked are poorly formulated. Additionally, there was provided evidence and comment regarding the use of capacity as a means to withhold, withdraw or limit service provision.	Thank you for your comment, support for the guidelines, and helpful examples of evidence that supports the expert testimony from Dr Jackson (University of Liverpool) which informed the guideline.

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				It is encouraging, therefore, to note that all of these areas have been noted within the document and that the expert testimony has also highlighted the difficulties that people with brain injury often have as a result of executive functioning (Dr Howard Jackson) It is encouraging that there is discussion regarding the need to involve assessors with relevant skills and that consideration be given to screening mechanisms to ensure that the specific needs of these individuals are identified and met. It is also encouraging to note that there is particular mention of consultation with those who know the person in various setting and in different circumstances when formulating a decision regarding mental capacity. Of particular note is the emphasis that a finding of capacity does not mean that vulnerability, risk and service provision can be avoided. Given the importance of this document to our membership and the people that we serve, BABICM commissioned a recent study in association with the University of Plymouth, to investigate the experience of Case Managers when working with people with acquired brain injuries, specifically to better inform our response to this consultation. A questionnaire circulated amongst the membership of BABICM has revealed similar continuing issues (BABICM, University of Plymouth – in preparation). A total of 93 respondents took part in the survey. Of those 66.7% completed the survey fully with 33.3% completing it partially. The survey has resulted in both quantitative and qualitative data detailing experiences with brain injured people that they have case managed within the past 5 years. There is to be further follow up interview and evaluation later in the year, however, when asked to rank the domains in which participants felt their clients would be most likely to demonstrate a lack of capacity 'weighing up and using the information' was ranked the highest, whilst capacity to communicate was the least likely area of concern. This would reinforce the expert testimony of Dr Howard Jackson, absorbed into the guidelines, with respect to ability to maintain intention in decision making in fast moving, complex or emotional situations in everyday life.	
British Association of Brain Injury Case Managers	Full	3	79-83	There is note that the document is as a consequence of the concerns of CQC that lead to the House of Lords review. It is BABICM's understanding that this was also related to consideration of the UN CRPD (as identified by Expert Testimony – Lucy Series) and considerations regarding compliance. It is noted that there has been discussion regarding the need for Health and Social Care Professionals to understand the implications of the UN CRPD and wonder if reference to this should be included in this part of the document.	Thank you for your comment. You are right to highlight the important link with the House of Lords Review but the UN CPRD did not in itself contribute to the evidence base reviewed for this guideline and the committee agreed there was no particular argument to refer to UNCPRD over and above any other specific legislation or guidance.
British Association of Brain Injury Case Managers	Full	6	162 -164	Conduct of decision – specific capacity assessments. It is experience of BABICM members that often those placed in the position of decision making do not recognise the specific nature of the needs of brain injured individuals for the reasons above; competent verbal presentation within a structured environment but lack of 'on-line capacity'. BABICM welcome comment that an overarching principle is condition specific knowledge and staff also need training in considering decision specific questions and consideration of interrelation of decision making within everyday environments	Thank you for your comment and for your support about our focus on people with acquired brain injury and executive dysfunction.

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British Association of Brain Injury Case Managers	Full	7	187-191	BABICM welcomes the concept of shared information regarding people's wishes, beliefs and preferences, along with indicators regarding decisions that have been made in best interest and with whom. BABICM would wish to stress that there should be a continued need to emphasise that professionals should seek out opinion of others that know the person well and that all viewpoints considered. Perhaps there is need to stress that such documentation is to inform the process and a reminder that decisions are time specific. (see 5 above)	Thank you for your comment. These areas are covered in the rest of the guideline, for example a number of recommendations which specifically focus on supporting the involvement of family members in best interests decision making. The recommendations also emphasise the importance of ensuring that everyone concerned with best interests decision making are fully involved and that their views are encouraged, respected and heard.
British Association of Brain Injury Case Managers	Full	7	171-173	It is noted that there is a reference later in the document advising that there were concerns regarding "tick-box" screening tools. BABICM would endorse the premise that screening tools are only as good as the individual undertaking the screening, however note that tools such as the BINI (Brain Injury Needs Indicator) developed by the Brain Injury Rehabilitation Trust (www.thedtgroup.org/brain-injury/) is a screening tool devised for use by social workers when assessing needs. This is designed to highlight to the assessor specific awareness that the individual may have unrecognised need as a consequence of their brain injury. This screening tool, or an adapted version, may become a useful asset to a tool box to highlight to the assessor that this person may need specialist assessment.	Thank you for your comment and link to the resources, which we can consider during the implementation phase. However, please note that the Guideline Committee cannot endorse tools for which they have not reviewed any evidence.
British Association of Brain Injury Case Managers	Full	7	177-179	BABICM endorse that decision-making capacity should be considered within all care planning and consent approaches. It is the experience of our members that there continues to be generalisation across all decisions regarding capacity with case managers being asked the generic question of "does he have capacity" without regard to the decision to be made. There is clearly a training need across social workers and care assessors with inherent cost implications. This difficulty appears to increase with appointment of generic social work departments where individuals may have had limited experience of assessment that are now being asked to conduct assessments of complex individuals.	Thank you for your comment and you support for the guideline. The potential resource impact of implementing the guideline, including through activities such as training, were considered as part of guideline development. The recommendations were considered to be aspirational but achievable.
British Association of Brain Injury Case Managers	Full	8	192	BABICM very much welcome the suggestion that there should be further investment into independent advocacy. There is an inherent cost implication in this expansion.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation now reads that the expansion of statutory advocacy commissioning should be commissioned and as a consider recommendation this is not legally binding. The committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
British Association of Brain Injury Case Managers	Full	9	236-243	Comment is made with regards to the hierarchy of presentation that the recent BABICM questionnaire presents regarding these needs. In the experience of our membership this list is almost the reverse in priority with regards to outcome of capacity. Nonetheless all of these factors are important to consider.	Thank you for comment. Please note that this list is not presented in order of priority, but we have qualified this recommendation by acknowledging that practitioners should take a personalised approach, accounting for any reasonable adjustments.
British Association of Brain Injury Case Managers	Full	9	246-249	Very important point. Reference is made to current experience of generalisation of capacity across questions by practitioners, interaction of complex decisions in everyday decision-making being considered and lack of clear definition regarding decisions to be made.	Thank you for your comment and support for the guideline.

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British Association of Brain Injury Case Managers	Full	9	224-226	This section regarding supported decision making is welcome. Again, comment is made with regards to the longevity of a case management relationship and knowledge that this provides of the individual.	Thank you for your comment and support for the guideline.
British Association of Brain Injury Case Managers	Full	9	224	It should also be stressed that there is also a training need in regard to independent advocates with regards to specific brain injury needs as highlighted in earlier responses. It is also often difficult to find independent advocates. Providers and Case Managers are often seen as having an interest in the outcome of decision making and their views not given emphasis despite their detailed knowledge and experience of the individual.	Thank you for your comment. In response to this, we have now expanded the point about training for IMCAs to read: 'for Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with impaired executive function, arising from acquired brain injury, mental illness, dementia, or other illness'.
British Association of Brain Injury Case Managers	Full	10	250-252	It would very useful for there to be increased emphasis on the need to record a structure regarding a person's decision making, shared responsibilities and how to structure information within shared documentation. Whilst this may not remove the need for further discussion and consideration around new decisions it would assist in formulation and assist processes. This would be a cost-effective measure that would greatly assist. This should be incorporated within the care plan and risk assessment documentation.	Thank you for your comment. We have addressed the importance of recording decisions and structuring information in the final version of the guideline.
British Association of Brain Injury Case Managers	Full	10	270-271	The concept of assisting a person with an unwise decision is understood, along with taking account of preferences. Emphasis is drawn to repeated unwise decisions and the indicator that this may be a demonstration of poor functional capacity as demonstrated above. The difficulties a person may have within an environmental context maintaining a decision and weighing up their past experience. Within the recent study conducted by BABICM there were qualitative concerns expressed that people were deemed to have capacity when they made repeated unwise decisions – '*placing themselves at risk of harm by their impulsive behaviour, unable to sustain stable or consistent place to live, behaviour that places themselves or others at harm', Client repeatedly made the same unwise decisions, often states that he has learnt from previous occasions…but does not..'* In fact acquired brain injury often results in repeated unwise decision making, and this remains a significant prominent factor and grave concern. Ref :(Lennard.C.(2016). Fluctuating capacity and impulsiveness in acquired brain injury: the dilemma of 'unwise' decisions under the mental capacity act. *The Journal of Adult Protection, 18,* 229-239	Thank you for your comment, the information you provide and your support for the recommendations.
British Association of Brain Injury Case Managers	Full	10	262	Training programmes are considered helpful and important but education is not necessarily going to assist in functional decision making. Approaches to assist with decision making in context of the environment in which the decision is to be made and rehabilitative and functional approaches by staff trained in brain injury may be more helpful. Emphasis is drawn to the testimony of Dr Jackson with regards to executive functioning and the difficulties of accessing decision making in the fast flowing, unpredictability of everyday life as opposed to the classroom. Emphasis is drawn to strategies discussed within his report.	Thank you for your comment. The recommendation is based on evidence and committee discussions about the benefits of using educational and training programmes to improve the person's understanding about the particular area in which they may be required to make decisions. The point was that providing training and education in a tailored way would add further support to the person in making their own decisions because it would improve their understanding and knowledge in the specific area.
British Association of Brain	Full	10	272	Whilst it is important to ensure that a person has opportunity to discuss preference in who is asked with regard to decision making, it is also important that views of those who know the individual well are considered within complex	Thank you for your comment. The issue of involving relevant practitioners is addressed in the recommendations as well as ways of increasing the involvement of families/ friends.

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Injury Case Managers				decision making. There are concerning reports from BABICM membership of family members and professionals being disregarded when decisions are made, either because the individual is under the influence of maleficent others, or where the individual considers that the person who knows him best may oppose a decision. It is felt that emphasis should be given to the assessor also seeking out information from those who know the person where necessary, even if this is not the preference of the person but is necessary to inform the decision.	
British Association of Brain Injury Case Managers	Full	11	296	It is again emphasised that consideration should be given to the person's ability to weigh up and maintain their decision, and particularly that their behaviour echoes the verbal decision made in a structured setting.	Thank you for your comment. These issues are covered in the guideline but it was not the intention to address them within this recommendation, which refers to the involvement of other services to support the person. There is a recommendation in the section on capacity assessment, which refers to the importance of ensuring the person has what they need in order to weigh up and use information.
British Association of Brain Injury Case Managers	Full	11	286 – 288	It is considered essential that the person with brain injury develops a relationship and meets more than on one occasion	Thank you for your comment and support for the guideline.
British Association of Brain Injury Case Managers	Full	13	341	Should reference/cross reference be made to other guidelines in relation to decision making with regards to people with prolonged disorders of consciousness here or elsewhere within the document?	Thank you for your comment. The guideline has been reviewed to ensure that references to other guidance is included where appropriate.
British Association of Brain Injury Case Managers	Full	15	405-409	This would also be useful to document and evolve as part of the process regarding people with fluctuating capacity. People with neurobehavioural difficulties may not be in ready contact with services or be accepted by mental health services. A plan, could, however, be drawn up with the individual as part of supported decision making regarding measures to be taken at times of crisis and could form part of shared documentation regarding decision making referred to earlier.	Thank you for your comment. The evidence on which this recommendation was based suggested that joint crisis plans may be suitable for people with mental health issues. It was not therefore appropriate for the GC to recommend that joint crisis plans be used to support other groups.
British Association of Brain Injury Case Managers	Full	15	415	This recommendation is endorsed. It is imperative that assessors have brain injury knowledge and experience.	Thank you for your support.
British Association of Brain Injury Case Managers	Full	17	460	In reflection of the above comments regarding globalisation of decision making, perhaps it should be stressed that it is best practice that choice and capacity should be reflected and documented throughout all written care plans and considered within risk assessment.	Thank you for your comment. The committee revised this recommendation following consultation and between this and other recommendations about capacity assessment they believe your point is addressed by the guideline.
British Association of Brain Injury Case Managers	Full	18	497	BABICM fully endorses this section. This is clearly in line with the Expert testimony of Dr Jackson and reflects the experience of case managers. Participants in BABICM's recent study (in preparation) have indicated that the process does not take account of '*the interrelated, complex and emotional aspects of decision making'*	Thank you for your support.
British Association	Full	18	502	The concept of assisting a person with an unwise decision is understood, along with taking account of preferences. Emphasis is drawn to repeated unwise	Thank you for your comment. Just to highlight, this recommendation has now been revised and refers to 'a decision that the practitioner perceives as risky or

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of Brain Injury Case Managers				decisions and the indicator that this may be a demonstration of poor functional capacity as demonstrated above. The difficulties a person may have within an environmental context maintaining a decision and weighing up their past experience. Within the recent study conducted by BABICM there were qualitative concerns expressed that people were deemed to have capacity when they made repeated unwise decisions – '*placing themselves at risk of harm by their impulsive behaviour, unable to sustain stable or consistent place to live, behaviour that places themselves or others at harm', Client repeatedly made the same unwise decisions, often states that he has learnt from previous occasions…but does not..'* In fact acquired brain injury often results in unwise decision making, and this remains a significant prominent factor and significant concern. Ref: (Lennard.C.(2016). Fluctuating capacity and impulsiveness in acquired brain injury: the dilemma of 'unwise' decisions under the mental capacity act. *The Journal of Adult protection, 18,* 229-239	unwise'. In terms of your point about taking into account repeated 'unwise decisions', this is addressed elsewhere in a recommendation, which states that the assessor should record their own view about the person's decision, including whether they perceive it to be unwise.
British Association of Brain Injury Case Managers	Full	19	506	Whilst this principle is understood within the context of the Act in considering retention, this has a bearing when considering ability to maintain 'on line' capacity in those with executive difficulties. Fluidity, speed and environmental factors will all impact upon a person's ability to maintain their decision in everyday life over time. Emphasis is placed upon the Expert testimony of Dr Jackson which correlates with the experiences of our membership who cite this ability as the key factor in decision making of people with brain injury who lack capacity.	Thank you for your comment. This recommendation is intended to be understood within the context of the Act and to relate broadly to the issue of retention of information. The committee chose not to make any revisions in light of your comment.
British Association of Brain Injury Case Managers	Full	19	510	This statement is agreed in principle, however, this also was addressed within Dr Jackson's testimony where he considers metacognition and a person's ability to weigh up information cognitively may differ to their behaviour. Lack of insight into inability to make decisions as a consequence of brain injury, to anticipate and to reflect on decision making are all critical and are not fully reflected in this paragraph	Thank you for your comment. Following consultation the committee revised this recommendation to make clearer that if a practitioner believes an assessment of insight is relevant to a capacity assessment they must clearly record what they mean by insight in this context.
British Association of Brain Injury Case Managers	Full	19	521	Importance of recording in care plans as well as stand alone documentation of assessment should be stressed as identified above. Documents should record time specificity to avoid generalisation of assessments over many years.	Thank you for your comment. We believe that the recommendation covers these points adequately.
British Association of Brain Injury Case Managers	Full	20	539	The concept of decision maker often causes conflicts, particularly where an independent service is calling a best interest decision meeting. It seems that the Chairperson is often the budget holder which can lead to decisions being resource lead and best practice guidelines not being followed. Perhaps this paragraph requires expansion, if only to state that the decision maker should be familiar with this role and ensure that all parties are able to express their view.	Thank you for your comment. The recommendation has now been revised to highlight that the decision maker may need support to undertake this role effectively.
British Association of Brain Injury Case Managers	Full	20	559	BABICM endorse this point but again raise the difficulty in finding advocates with experience and knowledge of acquired brain injury. Specialist providers are required with inherent cost implications and training needs.	Thank you for your comment. The GC considers the recommendation to be aspirational but achievable.
British Association of Brain	Full	21	586	Agreed. The need to translate decision making into the core of key documentation has already been raised. This raises the need for training for support staff/carers and inclusion within inspection by regulatory bodies.	Thank you for your support for this recommendation.

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Injury Case Managers					
British Association of Brain Injury Case Managers	Full	22	597-616	BABICM welcome the development of clear tools for practitioners to use – providing this includes clear screening and direction around brain injury as detailed above. (BINI and other screening tools)	Thank you for your support.
British Association of Brain Injury Case Managers	Full	23	637-639	BABICM welcome this suggestion but note again the shortage of appropriate Mental Capacity Advocates, and that when an advocate is instructed this is anecdotally often late in proceedings and merely for the purpose of the decision making. It is important that they remain involved until the decision is implemented fully	Thank you for your comment. The GC believe the recommendation to be aspirational but achievable
British Association of Brain Injury Case Managers	Full	23	640	BABICM welcomes this but reiterates comments above regarding generalisation of decision making and acceptance of capacity assessments that are not timely in current practice	Thank you for your comment. The committee with you about this important point and feels that the recommendations as a whole will help to address the problem you highlight.
British Association of Brain Injury Case Managers	Full	24	651	BABICM welcome this. Review is not always timely or often does not occur.	Thank you for your support for this recommendation.
British Association of Brain Injury Case Managers	Full	27	743	Training and Support for practitioners – BABICM would welcome research into this area. Initial results from the questionnaire presented to BABICM membership provides evidence that there remains variance in understanding and practice amongst our own membership and other practitioners and that this varies with level of experience.	Thank you for your comment. We agree it is useful to highlight the initial results from the questionnaire presented to BABICM. We will feed this back to NICE as part of their work with research commissioners and funders, to ensure this in taken into account in any future research on the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions.
British Association of Brain Injury Case Managers	Full	30	804	BABICM would also concur with the view that advance planning processes do not currently assist those with executive functioning difficulties. Throughout our recent study, within the House of Lords Select Committee recommendations and this document this remains a theme.	Thank you for your comment and your support for the guideline.
British Association of Brain Injury Case Managers	Full	31	820	BABICM endorse this view. The level of evidence requirement is acknowledged although it is considered that there is considerable qualitative and practice evidence beyond RCT to support cognitive, social and neurobehavioural best practice in this area, and that perhaps the current search could be widened or appropriate research commissioned.	Thank you for your comment in respect of the proposed research recommendation to examine the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups. We will feed this back to NICE for them to take account of in any future research that is commissioned in this area.
British Association of Brain Injury Case Managers	Full	32	834	It is considered that more work could be undertaken to explore supported decision making models versus substituted decision making where possible.	Thank you for your comment and your support for the guideline. In the updated version of the short guideline, we have also expanded the suggested methodology to propose that the effectiveness component will ideally include 3 arms; usual care, usual care plus advocacy and usual care plus support with enhanced advocacy.

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British Association of Brain Injury Case Managers	Full	35	875	BABICM would endorse the use of standardised forms that would promote the specialised needs during assessment for people with acquired brain injury. There is a risk of standardised forms that do not promote investigative questioning and this would need to be carefully considered in development.	Thank you for your comment in respect of the proposed research recommendation to examine the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation). We will feed this back to NICE for them to take account of in any future research that is commissioned in this area.
British Association of Brain Injury Case Managers	Full	39	890	BABICM would share concerns regarding a 'tick box' approach, however reiterate the importance of considering executive functioning and wider aspects of neurofunction within decision making. There is a need to ensure appropriate people are involved in this process. This will require additional training needs.	Thank you for your suggestion. Assuming your comment refers to research recommendation 2.8 then please be assured that this is intended to apply to everyone lacking capacity and being supported in the context of best interests decisions making.
British Association of Social Workers	Full	All	All	The comments from the British Association of Social Workers (BASW) are confined to general ones. There is little in the detail that we disagree with, but our concerns are about the length of the full document and accessibility and relevance of the guidance for social workers. The guidance provides very comprehensive detail about the MCA and decision making, but we are concerned that the guidance tries to be relevant to too many constituencies - see lines 93 - 109 – a large number of professions and people affected by decision making, who are by no means homogenous. They will have different levels of knowledge, experience and expertise and operate in a variety of situations. We were wandering if NICE would be better would be better advised to produce a number of smaller documents, customised to specific audiences? We feel that there the guidance for social workers replicates much of what is expressed more succinctly elsewhere (such as the Code of Practice). The "economic impact" material that is offered says very little about the cost of all the training that is recommended or the extra tasks that are promoted. Given the pressures in the system to do the basics of complying with Cheshire West implications we fear that social work practitioners will not engage with the guidance, coupled with other more succinct documents being available. (Code of Practice, SCIE). We are also of course waiting for the Government response to the review of the Mental Capacity Act and the Deprivation of Liberty Safeguards (DoLS), which will have a significant impact on Decision-making and mental capacity.	Thank you for your comment and your support for the guideline. As part of the work to support dissemination of the guideline, NICE will be producing some additional targeted products. The Guideline Committee recognised that this guidance sits within a complex array of existing guidance and legislation. The introduction has been updated following consultation to make this clearer. The Guideline Committee tried to keep repetition to a minimum. Where details have been included that repeat those found elsewhere, this was thought to be important for improving practice or for emphasis. Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to assess likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
British Psychological Society	Short	3	20	The Society believes that this should include training on how cognitive issues can impact on capacity. We believe that a practitioner with training and expertise in cognitive assessment and rehabilitation should always be involved in the training of advocates. Such practitioners might include: Speech & Language Therapists, Clinical Psychologists, Clinical Neuropsychologists and Occupational Therapists. The practitioner should have expertise in the clinical condition concerned (e.g. learning disability, dementia, stroke, acquired brain injury, mental health)	Thank you for your comment. This is part of a recommendation in overarching principles and is not intended to be so specific. The committee did not review evidence that would provide a basis for prescribing who should be involved in training but obviously it would need to be someone with appropriate skills for condition specific training.
British Psychological Society	Short	5	8	The Society welcomes the recommendation and would support the intent to ensure service user's rights are protected and we welcome attempts to clarify the responsibilities of local authorities in relation to advocacy. This recommendation will be a challenging change in practice because it can be difficult to get access to advocates who have training and experience in brain injury, and it can be difficult to involve advocates without training/experience in a useful way.	Thank you for your comment and for your support. The advocacy recommendations have actually been substantially revised and definitions added to 'terms used'. The guideline is now much clearer about which recommendations in this section are legally binding and which are not.

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				The recommendations for training of advocates in 1.1.9-1.1.11 are very important and would need to be implemented to make this a useful recommendation. Also, the recommendation that a referral should be made to an advocate every time a person lacks capacity has considerable resource implications, both for the availability of advocates and in relation to the time of the staff team, family and patient. This may be difficult to implement. For example, in an 18 bed inpatient unit, it is not uncommon for 12 patient's to lack capacity and be subject to a DOLs. There are a lot of decisions made in the patients best interests in a working day. The current advice is that an advocate is used in situations where there is no suitable family member, when there is disagreement within the team/between team and family or when there is a decision to be made with very significant implications for the person (such as long term change in placement). This is a more practical use of advocates. Sometimes there is an expectation that family members will act as advocates, which they either refuse, or agree to do but then do not always act. Suggestions around timely action from advocates, professionals and family members, would be helpful. It is important that advocacy services provide consistent documentation around their involvement that follows the patient when they are treated in different services/teams.	
British Psychological Society	Short	8	15	The Society believes that it is helpful to refer to specialist practitioners in order to inform the mental capacity assessment. We welcome the specificity in the guideline in relation to SALT and clinical psychology and recommends that clinical neuropsychology is added to this list. Further to this, the MCA Code of Practice states that "If the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition)." (emphasis added; MCA Code of Practice, p59 - ISBN 9780117037465 https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice) The Society believes that the spirit of this statement should be replicated in the guideline, as different patient groups have different aetiologies and different presentations that affect reasoning and decision-making in different ways. The Society recommends that the guideline should state that clients should be referred to practitioners (such as SALT and clinical psychology/neuropsychology) who have experience and expertise in the client's condition (e.g. dementia, learning disability, acquired brain injury, stroke, etc). The Society also recommends that referrals to specialist practitioners are made for people with executive dysfunction (see 1.4.20 of the draft guideline). In more complex cases, (e.g. where there is dispute and/or complex decisions are involved and/or where there are complex executive functioning issues), The Society recommends that a referral is made to clinical neuropsychology services	Thank you for your comment. The professionals mentioned are intended as examples only.

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				(neuropsychologists, clinical psychologists or educational psychologists who have further specialist training and expertise in neurological conditions, and how these affect the cognitive processes involved in decision-making; Neuropsychologists are members of the British Psychological Society Specialist Register of Clinical Neuropsychology - SRCN).	
British Psychological Society	Short	12	13	The Society has produced a mental capacity audit tool that could be useful for this purpose. http://www.bps.org.uk/sites/default/files/documents/audit-tool-mental-capacity-assessments_0.pdf The Society has a Mental Capacity Act Advisory Group that is currently working on reviewing this tool and providing some best practice documents on capacity assessment	Thank you for your response. We will pass this information to our local practice collection team. More information on local practice can be found here.
British Psychological Society	Short	12	18	The Society recommends that the guideline states that clients should be referred to practitioners (such as SALT, clinical psychologists/neuropsychologists) who have experience and expertise in the client's condition (e.g. dementia, learning disability, acquired brain injury, stroke, etc.)	Thank you for your comment. We believe the recommendation adequately covers these issues.
British Psychological Society	Short	14	3	'Taking into account the person's decision-making history' – As a stand-alone point, this statement is ambiguous. We believe that the following needs to be taken into account, (i) unwise decisions, but with full capacity, (ii) decisions that have not been reasoned, and therefore represent behavioural evidence of reduced reasoning, or (iii) understanding the person's previous wishes.	Thank you for your comment. The committee agree that the recommendation lacks clarity and detail has been added regarding the importance of the type of decisions the person has made.
British Psychological Society	Short	15	15	The Society welcomes this recommendation and believes it to be a very important inclusion in the guideline. Society members have highlighted many instances where executive dysfunction has either been missed by the MCA assessor, or the nature of the condition and its implications for decision-making have not been fully understood by the MCA Assessor. The Society welcomes the following good practice points for an MCA Assessor in carrying out a mental capacity assessment where there are (i) difficulties with executive functioning and/or (i) lack of insight - The assessor should routinely ask whether there are any potential issues with executive functioning or lack of insight - A practitioner with training and expertise in executive functioning / insight should always be involved in the assessment / supporting the assessor - Such practitioners might include: Speech & Language Therapists, Clinical Psychologists, Clinical Neuropsychologists, and Occupational Therapists. The practitioner should have expertise in the clinical condition concerned (e.g. learning disability, dementia, stroke, acquired brain injury, mental health) - We welcome the statement that 'structured assessments should be supplemented by real-world observation of the person's functioning and ability'. This does not necessarily need to be directly observed by the assessor themselves, as this may not be practical/possible. Existing records (e.g. observation records, care record entries) and the observations/descriptions of care staff/family members should routinely be	Thank you for your comment, and for your support for the guideline.

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				sought out and taken into account. It is important to include the views of those with direct experience of the person's real world behaviour over a period of time (i.e. family, professionals, and care staff). - These 'real world observations' could include comparing patient's self report with their actual performance on functional tasks and/or structured questionnaires to be completed by relatives/staff members (e.g. the Dysexecutive Questionnaire (Burgess et al., 1998) - A person's behaviour in one environment (e.g. a ward, care home) does not necessarily predict their behaviour in other settings (e.g. on the high street, in a social gathering, in a crowd). As such, 'real world observations' should not be limited to highly structured environments if there are concerns regarding executive dysfunction/lack of insight. Community visits and home visits (supported by care staff, Occupational Therapists, etc) should be considered. - Good performance on neuropsychological tests of executive tests does not necessarily mean that executive function is intact, and the results of such test should be considered in the context of clinical observations and the views of significant others. Ideally, clinical psychologists/neuropsychologists should be involved in the interpretation of these tests - In relation to insight, the assessor should consider whether the person uses the knowledge about their condition in their everyday life - there can be a distinction between having the knowledge and using it at the right time (Owen et al, 2015; https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5080972/). - In assessing patients with executive problems, the person's impulse control should be considered when making a judgement on capacity (Owen et al., 2015) - An attempt to assess/improve insight should be considered. This guideline may provide some helpful suggestions for ways to do this (inCOG guidelines): https://www.ncbi.nlm.nih.gov/pubmed/24984096	
British Psychological Society	Short	24	20	The Society believes that practitioners with expertise in specific conditions (e.g. dementia, learning disability, acquired brain injury, stroke, etc.) should be involved in training people in mental capacity. Such practitioners might include: Speech & Language Therapists, Clinical Psychologists, Clinical Neuropsychologists, and Occupational Therapists.	Thank you for your comment. We will consider it as part of the implementation work.
British Psychological Society	Short	27	19	The Society has practitioner members who have developed training programmes in the MCA and how to assess capacity. These could be collated to provide examples of practice in this area.	Thank you for your comment and signposting the training programmes in the MCA and how to assess capacity developed by members of the British Psychological Society. We will pass this information to the resource endorsement team.
British Psychological Society	Short	28	6	The Society has practitioner members who would be willing to evaluate the effectiveness and cost effectiveness of different targeted interventions to support and improve decision-making capacity for treatment in specific groups.	Thank you for your comment and signposting the capacity of the British Psychological Society, which we will consider as part of our research recommendation on targeted interventions to support and improve decision-making capacity for treatment.
British Psychological Society	Short	29	16	The Aphasia Institute in Canada publish a useful tool for assessing capacity in people with Aphasia. It is Canadian, so does not cover all aspects of UK capacity law, but does provide some useful materials.	Thank you for your comment and signposting the resources.

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				https://www.aphasia.ca/wp-content/uploads/2012/11/Communication-Aid-to-Capacity-Evaluation-CACE.pdf	
British Psychological Society	Short	29	17	The Society has practitioner members who would be willing to evaluate the utility of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005.	Thank you for your comment and for your support.
British Psychological Society	Short	30	2	The Society has practitioner members who would be willing to evaluate what constitutes an effective assessment of mental capacity to make a decision, and the practicality of developing checklists, memory aids and standardised documentation to assist with this.	Thank you for your comment.
Care Quality Commission	Short	General	general	We would welcome the insertion of lines 72-83 from the full version into the beginning of the short version to add prominence to the breadth of the issue.	Thank you for your comment. The Context section at the beginning of the short and full guideline has now been substantially reworded to ensure that both versions of the guideline give full detail of the breadth of the issue.
Care Quality Commission	Full	General	general	1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why. *CQC answer: As the guideline principally reflects existing legislation and associated codes of practice, individual practitioners, commissioners and providers would presumably be expected to review any change impacts on an individual basis.*	Thank you for your comment. The guideline seeks to complement existing legislation while providing some flexibility for practitioners, commissioners and providers to implement the good practice recommendations at a local level.
Care Quality Commission	Full	General	general	2. Would implementation of any of the draft recommendations have significant cost implications? *CQC answer: This is difficult to estimate but in the main the guideline reflects existing legislation and associated codes of practice. There would perhaps be some costs for providers to deliver on co-production of policies and materials if this is not already an activity they undertake.*	Thank you for your comment. The Guideline Committee acknowledge the potential resource implications and challenges involved in the co-production of policies, however, the benefits are judged to outweigh the costs.
Care Quality Commission	Full	General	general	3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.) *CQC answer: There is an opportunity to link to existing resources, including SCIE, Skills for Care/Health and CQC's own guidance. Good practice examples from CQC's State of Care report and other CQC programme reports could also be reference points. Major CQC publications can be found here: http://www.cqc.org.uk/search/site/publications?f%5B0%5D=im_field_publication_type%3A49*	Thank you for your comment and for your suggestions about how to link with ongoing good practice work happening nationally. We will consider this issue in our post-publication engagement work.
Care Quality Commission	Full	403	7399	We note that more recent data/reference is available with respect to CQC's statutory responsibility to report on DoLS. Please see for 16/17 http://www.cqc.org.uk/sites/default/files/20171123_stateofcare1617_report.pdf Please see for 15/16 http://webarchive.nationalarchives.gov.uk/20161107112611/https://www.cqc.org.uk/content/state-of-care	Thank you for your comment. We agree it is useful to highlight CQC's statutory responsibility to report on DoLS and have added a cross-reference to this as per your suggestion.
Care Quality Commission	Short	24	8	Suggest that in such proposed hyperlinked tools and resources, reference to CQC Regulation compliance is made with respect to registered services, including reference to the guidance attributable to the regulation: http://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-11-	Thank you for your comment. The committee decided to make clearer links between the guideline and the principles and sections of the Mental Capacity Act and Code of Practice. In terms of your additional suggestions, these will be passed to the implementation team.

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				need-consent with respect to the Mental Capacity Act and http://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-13-safeguarding-service-users-abuse-improper with respect to DoLS	
Care Quality Commission	Short	General	general	It is not always clear from the guideline what is a 'must', what is a 'should', and what constitutes good practice.	Thank you for your comment. The committee reviewed the recommendations to ensure that all of those referring to a legal requirement use the term 'must' and those underpinning by strong evidence and committee expertise use the term 'should'.
Care Quality Commission	Short	General	general	Although the guideline makes reference to involving people, it does not always cohere as person-centred, and there is an opportunity to more strongly reference the assumption of capacity, and to reflect that the outcome of an assessment can be and should sometimes surely be that the person does have capacity following the two stage test. This could be partly addressed by setting the guideline in its opening statements in the context of empowerment, rights and respect and promoting principle 1.	Thank you for your comment. The committee took account of your helpful suggestion and reviewed and revised certain recommendations to ensure they are as person centred and empowering as possible, in line with the ethos of the Mental Capacity Act, which is also reiterated in the revised context section.
Care Quality Commission	Short	General	general	The emphasis on advocacy in the main guideline, whilst being positive, is not then supported by p. 28, line 28's reference to the lack of evidence of its importance in improving outcomes for people. It would be helpful to include under the Terms used in this guideline section, descriptions or links to the different kinds of advocate, or to define this at the first mention.	Thank you for your comment. The committee revised the advocacy recommendations substantially, including providing a definition in the 'terms used' section of the guideline.
Care Quality Commission	Short	General	generalk	The chosen order of presentation of the guideline has led to instances of repetition, both in specific references made, for example for the need for communication support and involved professionals (e.g. Speech and language therapy) and in how the guideline is set out in the sections it covers. We would welcome the 5 principles being reflected in the short version of the guide as they are in the full version. A different more balanced approach could be taken by setting the guideline against each of the 5 principles in the order in which they appear in the Act, and using flowcharts to visualise practice/actions to take against each of the principles. In its present form the guidance provides a series of helpful pointers, particularly around supported decision making but could be strengthened by drawing attention to the most pertinent points of the Code of Practice per principle, rather than in some sections repeating the broad meaning and content of the Code. Reference to fluctuating capacity could be strengthened throughout. Good practice examples of mental capacity assessments and other relevant templates could be gathered and presented.	Thank you for your comment. Following consultation the committee revised the structure and the recommendations to ensure they are as clear and logical in their presentation as possible. The context section has also been revised and now contains the 5 principles of the MCA. We hope this addresses your concerns.
Care Quality Commission	Short	General	general	We note that DoLS are out of the stated scope of this guidance but feel there is an opportunity here to develop the guidance so that DoLS are presented as part of the continuum of measures under the Mental Capacity Act that exist to balance rights and duties with protections and freedoms, and so clarify their link to the broader purpose. Reference could be made to CQC's role in monitoring the use of the DoLS scheme across sectors, and in discharging our duties to assess provider's compliance of Regulation 11 and Regulation 13 in registered settings (refer feedback point 23). There is an opportunity to clarify the interface between the Mental Capacity Act and the Mental Health Act in relation to DoLS and restrictions to liberty/detention under both Acts.	Thank you for your comment. In revising the guideline the committee did take the opportunity to clarify the interface between the Mental Health Act and Mental Capacity Act, although not specifically in relation to DoLs, as DoLs was out of scope for this guideline.

Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
20/12/2017 to 05/02/2018

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Care Quality Commission	Short	3	6	Can the context of the meaning of "pre-registration" be clarified – does this refer to CQC registration, or other types of professional registration?	Thank you for your comment. The Guideline Committee confirm that by "pre-registration" in recommendation 1.1.1, we mean other types of professional registration.
Care Quality Commission	Short	3	12	Suggest insertion of acknowledgement of fluctuating capacity as a key principle to take account of, and not just for complex decisions.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
Care Quality Commission	Short	3	14	Should 'to supported decision making' read "for supported decision making?	Thank you for highlighting this typo, which has now been corrected.
Care Quality Commission	Short	4	15-16	Should reference be made here to information accessibility standards even though it is made later at page 7 https://www.england.nhs.uk/ourwork/accessibleinfo/	Thank you for your suggestion. The committee did not agree to make this change. They feel the recommendations already comprehensively address issues of accessibility and link with the NHS accessible information standard.
Care Quality Commission	Short	4	21-23	Should mention/consideration be given to issues of confidentiality/data protection and as to how other professionals have access to personal data?	Thank you for your comment. The guidelines should be implemented within the context of data protection law and the committee did not believe this needed stating within the detail of this recommendation.
Care Quality Commission	Short	5	12	Unintentional colloquialism/incomplete sentence? "Otherwise, think about…"	Thank you for your suggestion. The advocacy recommendations have been substantially revised and this wording no longer appears.
Care Quality Commission	Short	6	4-21	Suggest this section would be improved by acknowledging fluctuating capacity and the need to consider best time/circumstances of the person to best facilitate supported decision making both in specific contexts and more generally.	Thank you for your comment. The committee felt the recommendations to ensure that decisions should are best supported at certain times and in certain places – and the same is the case with the assessment of capacity. They also believe that the principles set out in the recommendations apply equally whether the person's capacity is fluctuating or stable. They clarified this in the new introduction to the section on advance care planning.
Care Quality Commission	Short	6	11	Suggest sentence revision to "Practitioners should take into account the wide range of factors that can have an impact on a person's ability to make a decision *at the time it needs to be made*"	Thank you for your suggestion. The committee believed this edit to be unnecessary because it is implied that these factors would be taken into account at the time the decision needed to be made – or when the person was being supported to make their decision.
Care Quality Commission	Short	8	19-21	Suggest the 'or's' are not needed.	Thank you for your comment. The recommendation has been amended as you suggest.
Care Quality Commission	Short	8	7	Suggest change '1' to 'one'	Thank you for your comment. It is NICE house style to use numerals for all numbers.
Care Quality Commission	Short	13	15	Suggest insertion of a bullet point making reference to considering fluctuating capacity, and that consideration should be made of being responsive to the best times for the person to have their capacity assessed for the particular decision at hand.	Thank you for your comment. The committee have edited this recommendation to make clear that capacity assessments can be postponed until a point at which the person is more likely to have capacity.

Decision making and mental capacity

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Care Quality Commission	Short	16	28-29	Suggest this paragraph presents an opportunity to reference advance decisions and also reference http://www.respectprocess.org.uk/ in life saving treatment scenarios and DNACPR arrangements.	Thank you for your comment. The introduction of this section has been amended to include details regarding the links between advance care planning and best interests processes.
Care Quality Commission	Short	17	24	Can the context of the meaning of "pre-registration" be clarified – does this refer to CQC registration, or other types of professional registration?	Thank you for your comment. The recommendation has been edited to clarify that this relates to professional registration.
Care Quality Commission	Short	19	4-7	Opportunity to clarify that the toolkit should contain a template/space for the specific decision to be made recorded, rather than the toolkit containing a definition of the decision itself.	Thank you for your comment. The Committee felt that the current wording was sufficient to imply that the decision should be recorded.
Care Quality Commission	Short	20	12-14	We acknowledge that the Deprivation of Liberty Safeguards (DoLS) are not designed as in scope of this guideline. However, we suggest that DoLS could be covered in more depth at this point. There is an opportunity to use this guideline to point to DoLS legislation and the code of practice as a minimum. DoLS is a known area of inconsistent practice and difficulty/complexity with significant risks and benefits in its application.	Thank you for your comment. The guideline has been reviewed to ensure that references to relevant legislation and guidance are included where appropriate.
Care Quality Commission	Short	22	15	Suggest this is an opportunity to define LPA for Property and Financial Affairs; and LPA for Health and Wellbeing, here on in the Terms Used in this Guideline section.	Thank you for your comment. We have revised the definition of this term so that it includes the following wording: '…There are 2 types of LPA; health and welfare and property and financial affairs and either one or both of these can be made…'
Care Quality Commission	Short	22	20	Suggest as reference is made to deprivation of liberty at p.20, lines 12-14, that the DoLS and their code of practice are referenced here also.	Thank you for your comment. This recommendation has now been removed following a legal review of the guidance and as DoLS was out of scope for this guideline, we have not made reference to DoLS in this section of recommendations. .
Care Quality Commission	Short	23	15	Proxy is stated here as a term used in the guideline but is not used in the short version of the guideline that precedes it.	Thank you for your comment. We have now removed the term 'Proxy' from the revised version of the guideline.
Care Quality Commission	Short	23	19	Psychiatric advance directive is stated here as a term used in the guideline but is not used in the short version of the guideline that precedes it.	Thank you for your comment. Psychiatric Advance Directives are no longer referred to in the short guideline.
Care Quality Commission	Short	23	25	Substitute decision-making is stated here as a term used in the guideline but is not used in the short version of the guideline that precedes it	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
Care Quality Commission	Short	24	20-30	Line 27 – clarification over pre-registration; it would appear this refers to clinical registration in which case clarification could be made, together with an opportunity to link to the Care Certificate standard 9, and other relevant guidance e.g. http://www.skillsforcare.org.uk/Standards-legislation/Care-Quality-Commission-regulations/Recommendations-for-CQC-providers-guide.aspx And with regard to cross-referencing training to the Care Certificate and other guidance in CQC registered services: http://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-18-staffing	Thank you for your comment. We will pass this information to the endorsement team.
Care Quality Commission	Short	12	14-15 Rec	Clarification suggested on who is a health and social care organisation in this context. In other parts of the guidelines, reference is made to practitioners and providers. Suggest that reference to CQC Regulation compliance is made with	Thank you for your comment. The guideline and recommendations have been edited to provide clarity on these issues.

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				respect to registered services, including reference to the guidance attributable to the regulation: http://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-11-need-consent	
Coma and Disorders of Consciousness Research Centre	Short	General		The Coma and Disorders of Consciousness Research Centre (http://cdoc.org.uk) has built up a considerable body of research, knowledge and experience about best interests decision-making concerning people who previously had capacity to make their own medical decisions but lost it – usually quite suddenly – as a result of a catastrophic brain injury. Such injuries are caused by (for example) a stroke or cardiac arrest, a road traffic collision, assault, fall, or sporting accident. One key research finding is that, after emergency treatments and stabilization, people who do not recover consciousness – or who do so only minimally or with profound neurological disabilities – are often given life-prolonging treatment 'by default' without ongoing consideration of their best interests including addressing whether or not they would want such treatments. This is so in relation to all potentially life-prolonging treatments – including clinically assisted ventilation, antibiotics for infection, CPR, screening and preventative treatments – but our research finds it particularly prevalent in relation to clinically assisted nutrition and hydration. We are concerned, therefore, to ensure that decision-making about people in prolonged disorders of consciousness [PDoCs] and those who 'emerge' from PDoCs but with permanent profound neurological injuries should take full account of the person's own prior wishes, values, feelings and beliefs in relation to ongoing treatments, including clinically assisted nutrition and hydration. One reason for treatment by default is the absence of any identified 'decision-maker' to consider best interests for these patients. This is clearly contrary to the Mental Capacity Act 2005, but our research finds it to be routine (e.g. Kitzinger, J and Kitzinger, C (2012) 'The "window of opportunity" for death after severe brain injury: Family experiences', *Sociology of Health and Illness*). **We would like the NICE Guideline to incorporate guidance to help support appropriate best interests decision-making for these patients by requiring, in the guidelines, that all treatments are subject to proper best interests decision-making – including treatments such as clinically assisted nutrition and hydration that may have been provided for years – and that the 'decision-maker' is identified and identifiable to professionals and to families**. We also have experience of supporting people who ask how they could refuse all life-prolonging treatments if they were ever severely brain injured – this experience has built up because some people with relatives with such injuries involved in our research have asked for help about how to protect themselves from being kept alive in a similar situation (and research with a variety of populations shows that 70%-80% of people would not want to be kept alive in a permanent vegetative or minimally conscious state). We have conducted a detailed investigation of Advance Decision making in Wales (see Kitzinger, J and Kitzinger, C (2016) 'Increasing Understanding and Uptake of Advance Decisions', PPiW Report for Welsh Government) which explores the challenges of	Thank you for your comment. The committee felt they have addressed best interests decision making comprehensively and that while the recommendations do not necessarily refer to people with specific conditions or to decisions about specific interventions, the recommendations do cover all relevant situations, including the ones you describe. The committee also feel they have covered advance care planning, which also addresses the situations you highlight. However in light of your comment the committee agreed to place greater emphasis on Lasting Power of Attorney and advance decisions to refuse treatment, including revised definitions of both in the 'terms used' section of the guideline.

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				implementing ADRTs in practice and makes concrete recommendations for implementation. We are concerned that advance decisions (and Lasting Power of Attorney) are not properly integrated into Advance Care Planning in this document. **We would like the NICE Guidelines to cover the full range of Advance Care Planning tools – including advance decisions and Lasting Power of Attorney.**	
Coma and Disorders of Consciousness Research Centre	Short	17-18	Whole section	This is incomplete. In addition: An agenda should be agreed in advance and relevant documentation provided to family/friends (those who care for the patient and are interested in his/her welfare). Minutes should be taken and circulated to all who attended the meeting and agreed, or corrected, or disagreements about the content of the meeting noted. The agenda and minutes should be added to the person's medical records.	Thank you for your comment. The recommendations are based on the evidence reviewed by the GC. This did not provide the basis for drafting such a recommendation.
Coma and Disorders of Consciousness Research Centre	Short	4	33	This is challenging in practice. Recording and updating ACP in a form that can be accessed by relevant practitioners at the appropriate time is a systematic failing across the NHS. For example there is no central register for Advance Decisions to refuse treatment, documentation gets lost, and NHS computers are not always set up with compatible systems that can access stored information (see Kitzinger, J and Kitzinger, C (2016) 'Increasing Understanding and Uptake of Advance Decisions', PPiW Report for Welsh Government). In a recent case, settled out of court, a hospital mislaid an ADRT and delivered treatment that had been lawfully refused for nearly 2 years (http://www.bbc.com/news/uk-england-coventry-warwickshire-42240148).	Thank you for your comment. The committee agrees with the point you make, which is why they drafted the recommendation.
Coma and Disorders of Consciousness Research Centre	Short	9	7-10	We are concerned that this reads as though Lasting Power of Attorney (LPA) and Advance Decisions to Refuse Treatment (ADRTs) are not part of Advance Care Planning (ACP). Both LPAs and ADRTs are an integral part of ACP and should be presented as integral to it and not as "other ways". Rewrite lines 8-10 to reflect this, e.g. "One way of doing this is to set out wishes and preferences in a document that doctors can use to make decisions in your best interests in the future if you lose the capacity to make these decisions for yourself. Another way is to appoint someone you know and trust to work with doctors to make these decisions – this should be someone who knows you well and who understands what your wishes would be if you were unable to express them yourself. You must formally appoint this person via Lasting Power of Attorney for Health and Care and you can do so using this website: https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney. You can also make decisions about treatments you want to refuse right now and put them in writing in the form of an Advance Decision to Refuse Treatment – sometimes known as a 'living will': for example, you may say that you want to refuse all life-prolonging treatments if you are in a severely brain injured state and unlikely ever to regain the ability to make your own medical decisions or need 24/7 care; or that you do not want blood products, or cardio-pulmonary resuscitation under any circumstances. These refusals are legally binding if you (a) are over 18 and have mental capacity and are not under duress at the time that you make them, (b) put them in writing and sign the document, with a witness to your signature, and (c) include a sentence to the effect that you make these refusals knowing that your life might be shortened as a result. There is a website	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.

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				that can help here: https://compassionindying.org.uk/making-decisions-and-planning-your-care/planning-ahead/advance-decision-living-will/	
Coma and Disorders of Consciousness Research Centre	Short	9	16	This should be amended to read "including Lasting Power of Attorney and Advance Decisions to refuse treatment"	Thank you for your comment. The recommendation has been edited to include details on lasting powers of attorney.
Coma and Disorders of Consciousness Research Centre	Short	9	19	This should be amended to read "advance care planning (including Advance Decisions to refuse treatment and Lasting Power of Attorney) in audits"	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.
Coma and Disorders of Consciousness Research Centre	Short	9	27	This should be amended to read "…the process of advance care planning (including Advance Decisions to refuse treatment and Lasting Power of Attorney)"	Thank you for your comment. We have edited our introduction to this section to include reference to ADRTs and LPAs.
Coma and Disorders of Consciousness Research Centre	Short	10	16-23	Evidence suggests that many people are keen to talk about ACP and that it is health and social care practitioners who may find 'the conversation' difficult. Suggest adding some acknowledgement that practitioners may feel uncomfortable about starting 'the conversation' and may not know how to manage it – and in that case they should seek training and/or refer the patient to someone else who is comfortable with talking about these issues. Practitioners may also feel very uncomfortable when someone's views about ACP differ from their own – e.g. when the person wants all possible treatments under circumstances when the practitioner considers palliative care alone to be more appropriate, or when the person wants to refuse life-prolonging treatments that the practitioner considers worthwhile. These situations (and conscientious objection) can cause real moral distress in practitioners. Some guidance on how to manage health and social practitioner's anxieties and discomfort – while upholding patients' rights - would be welcome.	Thank you for your comment. The following text has been added to the introduction to this section: 'Skilled practitioners to have sensitive conversations with people in the context of a trusting and collaborative relationship, and provide the person with clear and accessible information to help them make these important decisions.'
Coma and Disorders of Consciousness Research Centre	Short	10	2 (whole section)	We are concerned at the implication that ACP is always "collaborative" with health and social care professionals. Not all LPAs or ADRTs will be developed "collaboratively" with health and social care practitioners, and there is no legal requirement for them so to be. Suggest inserting an acknowledgement that sometimes ACP tools such as these will come to light after the person has lost capacity, and without professionals having been involved in collaboratively creating them (e.g. ADRTs completed on the Compassion in Dying website or other online tools). These are still potentially valid and applicable ACP tools. This whole section is written very much as though the impetus and rationale for ACP comes from professionals and as though they 'own' the process and are inviting patients in. That may often be the case in practice – but it is also often the case that citizens create their own ACP documents and then they (or their families) inform practitioners. When patients have taken the initiative in this way it can come as a shock to health and social care practitioners (we've even heard doctors say they feel "bullied" by such documents) – but since this is happening in	Thank you for your comment. You are right to highlight that not all advance planning is or should be initiated by practitioners. The point you raise has now been made in general terms in the revised introduction to the section on advance care planning. The introduction explicitly states that individuals can initiate some advance care planning, for example advance statements however for others such as advance decisions, specialist input is required.

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				practice and people have the legal right to do this, it's important that health and social care practitioners are supported to respond appropriately.	
Coma and Disorders of Consciousness Research Centre	Short	16	22-23	Excellent that you have pointed out that ADRTs are excluded from the provisions of best interests decision-making. This is a point that many health and social care professionals do not actually understand and it is worth spelling out that if there is a valid and applicable ADRT then there is no need for a best interests decision because the person has already made the decision for themselves (and whether or not anyone thinks it is in their best interests is irrelevant).	Thank you for your comment and support. The introduction to this section and that of the advance care planning section have been edited to provide further information in relation to these types of issues.
Coma and Disorders of Consciousness Research Centre	Short	17	28	You say "wishes and preferences' but the Mental Capacity Act is more inclusive – it includes "values", "feelings", "beliefs" and the "other factors the person would take into account". Suggest expanding to make compliant with the Act.	Thank you for your comment. Reference to values, feelings and beliefs has been added to this recommendation.
Coma and Disorders of Consciousness Research Centre	Short	18	13-15	This implies (and elsewhere) that the Chair of the Best Interests meeting and the 'decision-maker' are one and the same person. This is not in fact always the case – and may not represent best practice.	Thank you for your comment. The recommendation has been edited to provide greater clarity on identifying a decision maker.
Coma and Disorders of Consciousness Research Centre	Short	18	14-15	This is incorrect. Not all views should be simply "encouraged, respected and heard". Families/friends need to understand that what is needed is their views about WHAT THE PATIENT would have wanted, i.e. THE PATIENT'S values, wishes, feelings beliefs etc. What family members would want for themselves in that situation is not relevant for best interests decision-making. Nor is what family members want for the person in that situation. Equally, health and social care practitioners' views about 'sanctity of life' or their judgment that the patient has a 'poor' quality of life, or that they themselves would/wouldn't want treatment under these circumstances are NOT relevant and should NOT influence the decision. What is needed is confident support and guidance of relevant views for the process of best interests decision-making. This can include the strategy of listening to – and putting on the table – the irrelevant views – but it should be clear that irrelevant views will *not* inform the decision to be made about the patient precisely because it is the patient's wishes etc that are at the centre of decision-making – not anyone else's. (NB Equally it should be acknowledged that the patient may have taken into account suffering caused to the family and those they love – so family views that "he wouldn't want to do this to US" may well be relevant. This is often not understood.)	Thank you for your comment. This is an important point and the committee feel it is already implied that in line with the Mental Capacity Act this recommendation refers to other people's views about what the person (P) would have wanted, after all this is the basis on which they are concerned with the best interests decision.
Coma and Disorders of Consciousness Research Centre	Short	18	25-26	This is not inclusive and not compliant with the Mental Capacity Act wording - "views and beliefs" – see comment for page 17, line 28	Thank you for your comment. Values and feelings have now also been added to this recommendation although it should be noted that the committee did not try to simply replicate the wording of the Mental Capacity Act within this guideline.
Coma and Disorders of Consciousness Research Centre	Short	18	3	This will prove challenging in practice because of uncertainty about who "the decision-maker" is. It would be worth addressing this head-on. One of the biggest problems in the health care area that we have researched is that it is radically unclear to everyone who 'the decision-maker' is. This can mean that no decision gets made (or that decisions are not reviewed after they have been	Thank you for your comment. Thank you for this information. Unfortunately the committee did not feel they had a basis on which to make any specific recommendations about who the decision maker should be over and above the advice provided in the Mental Capacity Act Code of Practice. It will vary according to the decision and according to the situation.

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				implemented) because everyone thinks the decision-making responsibility belongs to someone else. For example, when a patient in a prolonged disorder of consciousness moves to a long-term care home, it is often not clear who is 'the decision-maker' concerning on-going delivery of clinically assisted nutrition and hydration. The doctors who initially decided to operate to insert the feeding tube and initiate artificial feeding are no longer involved (even if the intervention had been intended as a temporary trial to see if the patient could improve over the first six to twelve months before, for example, a diagnosis of Permanent Vegetative State can be confirmed). In the care home the decision-maker for ongoing treatment could be seen as: the carer who connects the bag of nutrition/hydration to the feeding tube, the patient's GP, the care-home manager, or the case manager for the Clinical Commissioning Group (England) or Health Board (Wales) - and sometimes it is somehow (wrongly) assumed that the decision-maker is 'the family' or someone else. It would be helpful to have a section somewhere that says (a) how important it is that there IS a named decision-maker identified for each medical decision and (b) that decisions should be regularly reviewed so a decision that might have been right at one moment in time is not simply replicated by default under changing circumstances. Without an identified, named, 'decision-maker' and attention to the fact that 'decisions' need to be taken – including reviewing decisions taken in relation to ongoing treatments that may have been decided upon months, years or even decades earlier - there are unlikely to be adequate best interests decisions. It is also important that the family are not left not knowing who they should be talking to about decision-making concerning their relatives – and not feeling that the decision is up to them.	
Coma and Disorders of Consciousness Research Centre	Short	18	9	This is incomplete. Not just 'to make a decision' but 'to make a decision about X' – i.e. the decision which needs to be made should be explicitly identified.	Thank you for your comment. The recommendations have been reviewed to ensure that it is clear that decisions must be specific.
Coma and Disorders of Consciousness Research Centre	Short	18	16 whole section	This does not provide sufficient information. More information is needed about when a best interests meeting should be held. These should not be only at 'crisis' points or when family raise concerns. It's important to recognise that ongoing treatments such as CANH are medical interventions on a daily basis which require best interests decisions to GIVE (and not only - or even primarily - to withhold).	Thank you for your comment. We have added details on these issues to provide clarity about the importance of responding proportionately.
Coma and Disorders of Consciousness Research Centre	Short	19	13-14	This is incorrect. The existence of an LPA does NOT prevent best interests decisions from occurring – it mandates best interests decision-making (with the Attorney(s) as the 'decision-maker'). The existence of an ADRT does not in and of itself prevent best interests decisions – it is only that those decisions already made by the person in a valid and applicable ADRT are excluded from best interests decision-making. There may be plenty of decisions not covered by a valid and applicable ADRT.	Thank you for your comment. The guideline as a whole and this section specifically have been reviewed to ensure that the links between lasting powers of attorney, ADRTs, and best interests procedures are clarified.
Coma and Disorders of Consciousness Research Centre	Short	19	16	Typo: Should be Advance statements (not 'advanced')	Thank you for your comment. This has been corrected.

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Coma and Disorders of Consciousness Research Centre	Short	21	25	Confusing section – Advance Directives are the Scottish version of English 'Advance Decisions'	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Compassion in Dying	Full	General	General	Compassion in Dying is a national charity working to inform and empower people to exercise their rights and choices around their treatment and care at the end of life and in advance of a potential loss of capacity. We do this by: • providing information and support over our free phone Information Line; • supplying free Advance Decision to Refuse Treatment (ADRT) and Advance Statement forms and publications which inform people how they can plan ahead for the end of their lives; • supplying a free resource www.mydecisions.org.uk so that people can make an Advance Decision to Refuse Treatment online; • running information sessions and training for professionals, community groups and volunteers on a range of end-of-life topics, including accredited Continuing Professional Development (CPD) modules; and • conducting and reviewing research into end-of-life issues to inform policy makers and promote person-centred care. As such, our comments focus on strategies we believe are needed to ensure that people have the information and support they need to plan ahead and receive the care that is right for them. We welcome this guidance, yet feel that the overall tone of it remains rather paternalistic with an assumption that people do not want to proactively discuss their views and preferences regarding their care. In fact, our experience shows that while there are some individuals needing support to consider end-of-life care, the unwillingness of healthcare professionals to engage in advance care planning is a significant barrier to planning ahead. Reflecting this diversity of preference amongst both healthcare professionals and the public within the guidance would add value to this document. Additionally, greater clarity in the text about the ways in which those who have capacity and those who lack capacity to make specific health and care decisions should be supported would contribute to a more user-friendly document. Wherever possible, these general comments have been addressed in the relevant sections below.	Thank you for your comments and for your support as well as the information provided about your services. Following consultation the committee revised the wording of the recommendations to ensure the language is more empowering and less paternalistic. In addition, some revision were made to the context section, including an explicit reference to the person centred, empowering ethos of the Mental Capacity Act. In relation to the reluctance of some practitioners to engage in advance care planning, the committee aimed to help address this through the specific recommendations on advance care planning, for example recommending that commissioners and providers develop joint protocols to help practitioners undertake advance planning and recommending exactly when and in what way practitioners should support people to have those discussions and make important decisions.
Compassion in Dying	Short	General	General	The guidance would benefit from practical information for healthcare professionals and members of the public. We suggest the following: For professionals - Mental Capacity Act Code of Practice – https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice - Social care institute for excellence - https://www.scie.org.uk/mca/ For individuals	Thank you for your comment. The committee reviewed the guideline following consultation and have made a much clearer link between the recommendations and the Mental Capacity Act and Code of Practice. In terms of the other guidance, we will pass these to our endorsement team.

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				- For Powers of Attorney - https://www.gov.uk/power-of-attorney - Compassion in Dying – for those wishing to plan ahead https://mydecisions.org.uk/?utm_source=cidwebsite&utm_medium=planningahead&utm_campaign=CIDPLANAHEAD; - Advance Decisions Assistance –resources include case studies and examples of Advance Decisions: http://adassistance.org.uk/write-it/	
Compassion in Dying	Short	16 - 21		There is a lot of repetition in section 1.5, particularly within the subtitles – ***Helping practitioners to deliver best interests decision-making*** and ***Undertaking best interests decision-making.*** We suggest that all the recommendations concerning systems, toolkits and training be collated within the subtitle ***Helping practitioners to deliver best interests decision-making*** which should subsequently be moved to the end of section 1.5.	Thank you for your comment. The guideline and recommendations have been edited to ensure clarity and focus.
Compassion in Dying	Short	18 - 21		We suggest reordering this section on ***Undertaking best interests decision-making.*** This section should be placed immediately after 1.5 Suggest order: - Start with the current point 1.5.15 - Followed by 1.5.16 - Then 1.5.12 and 1.5.13, 1.5.18, 1.5.17, 1.5.19, 1.5.20, 1.5.21, 1.5.22, 1.5.23	Thank you for your comment. The guideline and recommendations have been edited and reordered to provide greater clarity.
Compassion in Dying	Short	3	17	The purpose of the 6th bullet point is not clear. Firstly, it mentions "disadvantages" of advance care planning. As it is the different tools available for planning ahead (Advance Decisions to Refuse Treatment, Advance Statements, Lasting Powers of Attorney for Health and Welfare) that have disadvantages rather than advance care planning as a whole it would be useful to change this to "challenges" which would then include the barriers to planning ahead such as obtaining accurate information on the different tools, costs of registering an LPA and discussing preferences with family members. Secondly, it is unclear what is meant by the term "ethics" in this context is also unclear and does not add value to the bullet point. If the mention of ethics is intended to address that some healthcare professionals may find some patient decisions (e.g. to refuse treatment) emotionally difficult, or to touch on conscientious objection, this should be dealt with in a separate bullet point. We would recommend amending the bullet point to read as follows: The advantages and disadvantages of the different tools available for planning ahead; the challenges that people may face when doing so; and how to discuss these with the person and their carers, family and friends.	Thank you for your comment. The committee discussed this and agreed they would not edit the recommendation as you suggest because they wanted to retain the original meaning, which included that there can, in some circumstances be perceived disadvantages associated with advance care planning. They recognise that this is not straightforward and is certainly debatable and therefore wanted to ensure that the subject is explored in training.
Compassion in Dying	Short	4	11	It would be useful to include a note explaining that healthcare professionals need to be prepared for people making decisions that they do not agree with or that they consider unwise, and particularly that this in itself is not evidence of a lack of capacity.	Thank you for your comment. Although it is not explicitly stated in this recommendation, your point is addressed comprehensively in the rest of the guideline, namely in the capacity assessment and best interests sections.
Compassion in Dying	Short	4 12	21 3	The recommendation about appropriately recording and sharing advance care plans is very important and should be strongly made in 1.1.6 and 1.3.14 The lack of a central register for Advance Decisions to Refuse Treatment, the fact that documentation can be misplaced and the lack of compatible systems across	Thank you for your comment. The committee believes that this issue is adequately covered in the recommendations.

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				the NHS enabling easy storing and sharing of information is serious challenge for advance care planning. The recent case of Brenda Grant in which a hospital mislaid an ADRT and delivered treatment that had been lawfully refused for nearly 2 years is a good example of how important these systems are. (See http://www.bbc.com/news/uk-england-coventry-warwickshire-42240148)	
Compassion in Dying	Short	4	26	This section would benefit from some clarification about the different types of advocacy (an advocate, IMCA, IMHA etc) available for those who do and do not lack capacity.	Thank you for your comment. This has been addressed through an update of and links to the definitions in 'terms used'.
Compassion in Dying	Short	5	10	We would recommend adding a note that before a referral is made to an IMCA for those who lack capacity, practitioners should find out whether the person has appointed a Lasting Power of Attorney and/or has an Advance Decision (Advance Decision to Refuse Treatment).	Thank you for your comment. The advocacy recommendations have now been substantially revised and the wording of this recommendation has actually changed.
Compassion in Dying	Short	7	10	The example of sexual education is based on programmes undertaken for those living with a learning disability and do not seem to correspond to the principles within this section. It may be better placed under 1.2.16 which relates to specialist services.	Thank you for your comment. The recommendation is intended to apply to the population generally on the basis that tailored education on a particular topic would help the person to be able to make their own decision on the issues because they would have a greater understanding.
Compassion in Dying	Short	9	9	We recommend stating that other ways of advance care planning include LPA and/or ADRTs as both documents can be completed to complement each other.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.
Compassion in Dying	Short	9	10	Please include a sentence to state that, advance care planning can be initiated by a healthcare professional or by individuals. The implication of subsection 1.3 overall is that advance care planning is for healthcare professionals to initiate.	Thank you for your comment. We have edited the introduction to the section on advance care planning to clarify that people can initiate some advance care planning (such as advance statements) independently, without the input of practitioners.
Compassion in Dying	Short	9	13	We recommend that the first bullet reads: be prepared to work with and support people who have completed Advance Decisions and/or Lasting Powers of Attorney independently of healthcare professionals.	Thank you for your comment. The committee considered your point and felt that it wasn't necessary to make this specific edit to the recommendation because the point has now been made in general terms in the revised introduction to that section. The introduction explicitly states that individuals can initiate some advance care planning, for example advance statements however for others such as advance decisions, specialist input is required.
Compassion in Dying	Short	9	27	The second bullet should preferably read – the process of advance care planning including the legally binding tools available to do so such as Advance Decisions and Lasting Powers of Attorney for Health and Welfare.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.
Compassion in Dying	Short	10	2 (whole section)	We suggest including an introductory section to recognise that not all LPAs or ADRTs will be developed in collaboration with health and social care practitioners. In fact, there is no legal requirement for them to do so but these are still valid tools which need to be taken seriously particularly if they become known about after the person has lost capacity.	Thank you for your comment. We have reviewed the introduction to provide details on the legal status of LPAs and ADRTs.
Compassion in Dying	Short	10	18	We recommend amending the 1st bullet to read: recognise that while some people may prefer not to talk about this or prefer not to have an advance care plan, others may have strong preferences about their treatment, care and quality of life	Thank you for your comment. We believe that the recommendation adequately covers this issue.
Compassion in Dying	Short	10	24	We recommend amending the 4th bullet to read: talk about the purpose, advantages and disadvantages of the different types of planning tools available and explain which ones are legally binding	Thank you for your comment. The recommendation was designed to provide general principles in relation to advance care planning.

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Compassion in Dying	Short	12	8	We recommend adding a final recommendation to the end of this section as follows – In addition to recording and sharing advance care plans that have been developed collaboratively, practitioners must ensure that they record and share Advance Decisions, Advance Statements and Lasting Powers of Attorney that have been prepared independently by individuals, or prepared previously with other professionals.	Thank you for your comment. We have edited this section to clarify that advance decisions, advance statements, and lasting powers of attorney are all types of advance care plan.
Compassion in Dying	Short	13	2	Before setting out the assessment process, it is important to reiterate that the reasons for the assessment of capacity must be met in line with the two stage process provided for in section 2 of the Mental Capacity Act, and that capacity is decision specific.	Thank you for your comment. We believe that this is covered by the wording of the recommendation.
Compassion in Dying	Short	13	12	We are concerned about the message convened by recommendation 1.4.8. Capacity assessments can be distressing when people fear that their preferences will be ignored, or fear it is not a true assessment, as the practitioner has already decided they don't have capacity (the current wording implies that that a practitioner has already decided). We recommend deleting or re-writing this recommendation	Thank you for your comment. The committee agree that the recommendation as currently drafted implies that a decision may already have been made. The text has been edited to clarify that this is not the case.
Compassion in Dying	Short	13	15	We recommend adding a bullet point to the start of this list to read: the reasons for the capacity assessment	Thank you for your comment. The committee agree that there is a need to be clear about this. The recommendation has been edited to include details regarding the importance of such issues.
Compassion in Dying	Short	14	7 & 8	To be practical and useful recommendation, we suggest including a few sentences explaining what "a structured, person-centred, empowering and proportionate approach to assessing a person's capacity" means or including an example of when an assessment does not meet those criteria. If this is not possible, 1.4.12 could be deleted as it does not add significant content to the section.	Thank you for your comment. We believe that this is covered adequately in the recommendation as it is currently drafted.
Compassion in Dying	Short	14	11 & 12	We recommend deleting the sentence relating to voting as this does not fit well within the current context	Thank you for your comment. The committee felt that it was important to include this here.
Compassion in Dying	Short	15	13 14	We recommend amending the first bullet point to read: that their capacity is being assessed, <u>the reasons for the assessment</u> **and…** We recommend inserting a sentence such as: Where appropriate, the same information should be provided to the person's carer and/or attorney. Please also include a recommendation that systems need to be in place for addressing disagreements between carers/attorneys and practitioners about the capacity assessment including recourse to an independent assessor.	Thank you for your comment. The committee agree that the person should be provided with accessible information explaining why their capacity is being assessed and the recommendation has been edited accordingly. We have revised these recommendations and both 1.4.27 and 1.4.28 now address these issues.
Compassion in Dying	Short	15	19	Alongside the example of when capacity is over-estimated, it may be useful to include examples of when capacity may be under-estimated such as in cases of dementia, anorexia, and young people as included within the Mental Capacity Act.	Thank you for your comment. The recommendation is based on the evidence reviewed and this did not provide the basis for the inclusion of this issue.
Compassion in Dying	Short	16	19 - 23	We suggest moving the text relating to when best interest decisions are not made (as per sections 27 – 29 of the MCA) to the end of this section (to pg. 21)	Thank you for your comment. The recommendations have been edited and reordered to provide greater clarity.
Compassion in Dying	Short	16	17	Capacity assessments can be distressing when people fear that their preferences will be ignored. Disempowerment and alienation would occur if the assessment is done inappropriately. As such , we suggest rewording 1.4.27 to read as follows: - In order to minimise feelings of distress, the person should be reassured that decisions will only be made in their best interests which include taking	Thank you for your comment. This recommendation focuses on the process of assessment rather than the outcome and the committee believe that the recommendation covers this issue adequately.

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				into account their previously expressed preferences and being provided with emotional support and other relevant information as needed.	
Compassion in Dying	Short	16	19	Section 1.5 should preferably start with a statement referring to principle 4 of the MCA - If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests.	Thank you for your comment. This section has been edited to provide clarity on these issues.
Compassion in Dying	Short	16	24	Following an introduction on when and why best interest decisions are made, we suggest including a section on Lasting Powers of Attorney and Advance Decisions to Refuse Treatment as below: - If a person lacks capacity and has previously appointed a Lasting Power of Attorney for Health and Welfare, the healthcare professional in charge of their care must check whether their attorney has been given power to make the decision in question (when you make your LPA you must choose if you want your attorney to make decisions about life-sustaining treatment). If your attorney does have that power then they must make the decision. If you lack capacity and have previously made an Advance Decision refusing a medical treatment, the healthcare professional in charge of your care must decide if it is valid and applicable. If it is, they must follow it.	Thank you for your comment. The guideline has been edited to ensure that clarity is provided in relation to the legal status of lasting powers of attorney and ADRTs and the links between these and best interests processes.
Compassion in Dying	Short	16	25	If the introductory statements have been made as suggested above, 1.5.1 could be deleted	Thank you for your comment. The section has been edited for clarity and to avoid duplication.
Compassion in Dying	Short	17	1 3-7 14 21 28	1.5.2 could be moved to a bullet point within 1.5.14 In light of the sections that precede this, 1.5.3 and 1.5.4 are redundant and can be deleted 1.5.6 is dealt with in 1.5.14 1.5.7 We suggest including a recommendation for knowledge about the role of Attorneys as provided for by a Lasting Power of Attorney within this training. 1.5.8 The Mental Capacity Act includes “values”, “feelings”, “beliefs” and the “other factors the person would take into account” and we recommend expanding this point to ensure compliance with the Act	Thank you for your comment. We have reviewed these recommendations and made the following decisions: - Recommendations 1.5.2, 1.5.3, 1.5.4 and 1.5.6 in the draft guideline for consultation have been retained - Recommendation 1.5.7 in the draft guideline for consultation has been deleted We have amended 1.5.8 as was in the draft guideline for consultation and now is 1.5.7 to make reference to values, feelings and beliefs.
Compassion in Dying	Short	18	13 25	We suggest moving 1.5.11 to become the last bullet point within 1.5.9. This point should also clarify that families/friends are there to discuss what the patient would have wanted and what the patient's values, wishes, feelings and beliefs were. 1.5.13 - The Mental Capacity Act includes “values”, “feelings”, “beliefs” and the “other factors the person would take into account” and we recommend expanding this point to ensure compliance with the Act	Thank you for your comment. We believe that this recommendation should remain separate. We have edited this recommendation in response to your comment.
Compassion in Dying	Short	19	23	The toolkit should also include guidance on how to resolve disagreements about a best-interest decision.	Thank you for your comment. The recommendations are based on evidence reviewed by the committee and in this instance the committee did not believe that there was a basis on which to include detail regarding resolution of disagreements about best interests decisions.

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Compassion in Dying	Short	21	12	Advance care plans can only contain decisions that the person was able to make themselves, as such ACP cannot take place with someone who currently lacks capacity. We suggest using this definition: (https://compassionindying.org.uk/library/advance-care-plans/) Advance Care Planning is the process of discussing your preferences and wishes about future treatment and care with those close to you and your healthcare team. This process may include talking about where you want to be cared for, identifying the people you would like to be consulted about your care, or making treatment decisions in advance. The process enables health and care professionals, and those close to you, to understand how you want to be cared for if you become too ill to make decisions or speak for yourself. You can also formally document your wishes as part of this process.	Thank you for your comment. Although the definitions in the 'terms used' section have not been revised, the committee did agree to edit the introductory paragraph in section 1.3, which now explains: Advance care planning involves helping people to plan for their future care and support needs, including medical treatment, and therefore to exercise their personal autonomy as far as possible. This should be offered to everyone who is at risk of losing capacity (for example through progressive illness), as well as those who have fluctuating capacity (for example through mental illness). Some approaches involve the production of legally binding advance decisions, which only cover decisions to refuse medical treatment, or the appointment of an attorney. Others, such as joint crisis planning and advance statements, which can include any information a person considers important to their health and care, do not have legal force, but practitioners must consider them carefully when future decisions are being made, and need to be able to justify not adhering to them. People can initiate advance care planning (such as advance statements) independently, without the input of practitioners. However, in some circumstances, professional input from a clinician with the appropriate expertise may assist a person to consider the matters they wish to address either by way of an advance care plan, an advance refusal of treatment and/or creation of a formal proxy decision-making mechanism such as a Lasting Power of Attorney. Skilled practitioners are required to have sensitive conversations with people in the context of a trusting and collaborative relationship, and provide the person with clear and accessible information to help them make these important decisions. '
Compassion in Dying	Short	21	25	Advance Directives is the name given to Advance Decisions in Scotland. They are not legally binding in the same way as in England and Wales. Please see our factsheet on this - https://compassionindying.org.uk/library/advance-directives-living-wills-scotland/ . We recommend deleting "Advance Directive" and inserting the following definition of Advance Decisions to Refuse Treatment https://compassionindying.org.uk/library/advance-decisions-living-wills-introduction/ *An Advance Decision is a legally binding document that allows you to write down any medical treatments that you do not want to have in the future, in case you later become unable to make or communicate decisions for yourself. It will only be used if you cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is also sometimes called a Living Will. If an Advance Decision includes a refusal of life-sustaining treatment it must be in writing, signed, witnessed, and include a statement to the effect "I maintain this refusal even if my life is at risk/shortened as a result".* This will help health and care practitioners and members of the public to know exactly what an Advance Decision is and what it needs to be valid	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Compassion in Dying	Short	22	1	In light of the fact that valid consent requires capacity to make that decision, please update the definition of consent to read as follows: (https://www.nhs.uk/conditions/consent-to-treatment/)	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives

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				Consent to treatment is the principle that a person must give permission before they receive any type of medical treatment, test or examination. For consent to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision.	to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Compassion in Dying	Short	23	25	As the role of "substitute decision-maker" is not usually a clearly defined person and as this term does not appear within the core recommendations we recommend deleting this definition.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
Compassion in Dying	Short	24	1	As the role of "supporter" is not a legally defined role, we would recommend deleting this definition	Thank you for your comment. The term does not appear in the recommendations (nor in the context section) and therefore is not defined in the short guideline. It is only defined in the full guideline because it is mentioned in the included evidence. The term is described in line with how it has been used in that study. The term cannot be removed from the definitions in the full guideline because it is intended to help people understand how it used in the cited study.
Court of Protection Practitioners Association	Full/Short	General	General	CoPPA welcomes the overall aims and approach of the draft guideline, in particular the emphasis on supported decision making. It is anticipated that, once implemented, this guideline will significantly improve awareness, understanding and implementation of the principles of the Mental Capacity Act within the healthcare field.	Thank you for your comment and support for the guideline.
Court of Protection Practitioners Association	Short	1	16	It should be the Mental Health Act 1983 not 2007	Thank you, this has been changed.
Court of Protection Practitioners Association	Short	5	8	Support the recommendation that practitioners should tell people about advocacy services as a potential source of support for decision making but this is assuming any advocacy services specifically provide this, not aware this is the current situation.	Thank you for your comment. The advocacy recommendations have been substantially revised and definitions added to 'terms used'. The recommendation to which you refer is now much clearer about the legal obligation to tell people about advocacy services as a potential source of support.
Court of Protection Practitioners Association	Short	5	12	Could there be reference to independent advocacy that is NOT funded by local authority commissioners? There is a growing trend towards independent privately commissioned advocacy, be it by the CCG, local authority, property and affairs deputy or attorney e.g. 'this could include spot purchasing / sourcing independent advocacy that may be privately funded'. Those with property & affairs deputy's / attorneys may not meet a statutory criteria, there is minimal non statutory advocacy but privately funded arrangements can be put in place.	Thank you for your suggestion. The advocacy recommendations have been substantially revised and there is now a recommendation, which states that expansion of statutory advocacy commissioning should be considered.
Court of Protection Practitioners Association	Short	6	1	Appreciate there cannot be an exhaustive list but training is not just about communication skills or diagnostic awareness, it should also include report writing, challenging decisions, non instructed advocacy.	Thank you for your comment. The committee felt there was a basis to make these specific references to important elements of the advocacy role. Broader elements are covered in the overarching training recommendation at the start of the guideline.
Court of Protection Practitioners Association	Short	6	20	Should there be a reference to undue influence being part of someone's ability – or inability to make decisions.	Thank you for your query. The committee feel this is covered by involvement of others but they agreed to add '…and the possibility that the person may be subject to undue influence, duress or coercion regarding the decision'.
Court of Protection	Short	7	25	I understand the point being made that one might 'think' about involving an advocate if there is no one else trusted or otherwise but this appears to diminish the role of an advocate, it is not a last resort, it is about having an independent	Thank you for your comment. The committee made a number of detailed recommendations about advocacy in the overarching principles of the guideline. These have been clarified and strengthened in light of stakeholder comments.

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Practitioners Association				voice / support. A person can have trusted people in their lives and still benefit from an advocate. Can it not simply say 'advocacy should always be considered in terms of supported decision making'.	
Court of Protection Practitioners Association	Short	8	6	'Be aware this may mean meeting with the person for more than 1 session'. Query the use of the words 'be aware', isn't the point of supported decision making meant to be about getting to know an individual which is more than likely going to take more than one session. Should this statement reflect that SDM takes time as oppose to instilling a fear that practitioners may have to actually get to know an individual?	Thank you for your comment. The importance of building relationships is referenced in recommendation 1.2.3.
Court of Protection Practitioners Association	Short	8	15	Add - Involvement of advocacy?	Thank you for your comment. Advocacy is covered elsewhere in the recommendations, including recommendations 1.1.7 and 1.1.8 in the section on 'Overarching principles'.
Court of Protection Practitioners Association	Short	10	2	There is a lot of reference to advance care planning which is good but no reference to advance decisions to refuse treatment, appreciate this may be part of advance care planning but it doesn't state that. Can this specifically state within this section 'and this can or may include supporting someone to make an ADRT or signposting to an organisation that supports those in making ADRTs'	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that more detail is included regarding ADRTs.
Court of Protection Practitioners Association	Short	15	20	Could something be added to this that states 'this includes practitioners being aware / mindful of their own values or the values / culture of an organisation'. For example there may be a particular policy in place that goes against an unwise decision, public health guidance on flu vaccines for example may recommend increasing the uptake of it and that must be considered against the values of an individual who does not want a vaccine. Values are very important to specifically state as oppose to just 'perceive'.	Thank you for your comment. We believe that this concept is adequately covered by the current wording of the recommendation.
Court of Protection Practitioners Association	Short	16	1	The word 'insight' being used in a mental capacity document ?? What does insight mean? That the person has a different view to that of an assessor or practitioner? It's a lazy way to describe capacity or the fact a person disagrees with others.	Thank you for your comment. The committee discussed the use of the word 'insight' in detail. Whilst they agree that it can sometimes be misused they believe that its continued use in practice suggests that it is useful to refer to it here. The text of the recommendation has been edited to make clearer that this relates to the practitioners perception.
Court of Protection Practitioners Association	Short	22	1	The definition of 'consent' is incorrect and needs to be re-worded. Persons with capacity may give consent. Decisions made for persons who do not have the capacity to consent to those decisions must be made in their best interests.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Critical Care National Network Nurse Lead Forum	Full	13	12-13	The use of a double negative here is confusing and I had to read it several times for clarity. I think it should say : Practitioners should be aware that people may find capacity assessments distressing, particularly if the practitioner strongly believes that the person has capacity.	Thank you for your comment. The recommendation has been edited for clarity.
Critical Care National	Full	22	5-8	I think this needs breaking up into chunks to aid comprehension. It's not a major objection- it does make sense but it's quite a long statement.	Thank you for your comment. The recommendation has been edited to provide clarity.

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Network Nurse Lead Forum					
Critical Care National Network Nurse Lead Forum	Full	22	2	I find this sentence misleading. Surely consent is simply 'permission to do something'. Anyone can give consent- a person with capacity can give consent and a person without capacity can give consent. We have to determine if that consent is valid. I think the bit about having capacity is not relevant to the definition.	Thank you for your comment. The definitions in the 'terms used' section have been revised and hopefully now provide far better clarity and compliance with relevant legislation.
Critical Care National Network Nurse Lead Forum	Full	22	18	I did not know this ! although it makes sense it can be confusing and people might think we are talking about organ donation ! Not that this is likely but anything is possible. Do we need to know these terms? Would it be better to say that a person 'appoints' a representative on their behalf to make such decisions and this person will be known as their 'attorney' I think a few template forms might be useful that individual Trusts might personalise to suit their own needs. It could give a good clear example of a best interest decision, and an example of an advanced decision etc.. and how it ought to be documented.	Thank you for your comment. The definitions in the 'terms used' section have been revised and hopefully now provide far better clarity and compliance with relevant legislation.
Cumbria County Council	Short	General	General	I wonder if it would be helpful to clarify some of the terminology further (section 'Terms used in this Guidance'): Advance care planning/directive – confusing in my as the Mental Capacity Act uses Advance statement Substitute decision maker–isn't this an American term (essentially another term for a Lasting Power of Attorney)?	Thank you for your comment. The term 'advance directive' was included in the full guideline where this specific term was used in the research reviewed (Bisson et al 2009, Dixon et al 2015, Elbogan et al 2007, Pearlman et al 2005, Robinson et al 2013). It has not been included in the recommendations and we will remove this from the 'Terms used' section of the short guideline. The same applies to the term 'advance directive'.
Cumbria County Council	Short	6	11	I agree awareness of these issues is important, but at the same time if we are questioning capacity at every decision, is there a risk of moving toward a presumption in incapacity rather than capacity. Should we not assume capacity and only question this in light of evidence to the contrary?	Thank you for your comment. This section of the guideline focuses on supporting decision making. At this point in a decision making process, capacity is of course still assumed although there may be factors that affect decision making (not necessarily capacity) and examples are provided in this recommendation. However, for information a new recommendation has been added to the guideline which emphasises the important principle of the presumption of capacity.
Cumbria County Council	Short	14	13	Guidance on assessing capacity- would it be worth mentioning that a good capacity assessment should include (or would be good practice to include) direct quotes relating to what was said at the time of the assessment. So for example recording the actual questions asked and answers given. These would be a good way of providing evidence. Also, might it be worth mentioning here about the 'balance of probabilities'? I.e. the assessor of capacity doesn't have to be 100% certain that the person lacks capacity in relation to the issue at hand, but it is on a scale of 'balance of probabilities' (need to be around 51% certain to put a number on it…)	Thank you for your comment. The committee believe that the issue of assessment is adequately covered by the recommendation.
Cumbria County Council	Short	20	3	'If a Best Interest decision maker is calling a best interests meeting…' – this is absolutely correct, but I wonder if this paragraph might be a chance to add about the fact that best interests meetings are not necessarily required. I find that there is a belief amongst many professionals that when making a best interests decision, a best interests meeting needs to be conducted. Naturally, this is not the	Thank you for your comment. We have added details on these issues to provide clarity about responding proportionately and the importance of identifying a single decision-maker. The reference to a best interests meeting has also been amended and the current wording acknowledges that a meeting may not be necessary or the only way to consult.

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				case. And while in some cases a meeting might indeed be the best way of consulting with relevant parties, it is by no means the only way of doing this. Another myth that appears to circulate among professionals is that best interest meetings are a collective decision making process, rather than being about the decision maker consulting and then arriving at their decision. So I wonder if there might be a chance to clarify these myths here? I.e. the decision maker makes the decision, but must consult before making their decision.	
Cumbria County Council	Short	21	4	Might be worthwhile adding here that any options looked as part of best interests decision making process should be concrete, real life options (i.e. no point making a best interests decision if a particular option is not concretely available)	Thank you for your comment. This recommendation relates to review of implementation of best interests decision making.
Cumbria County Council	Short	23	1	Review of best interest decisions -As above, this seems to suggest that a best interest meeting is the only way to proceed (as opposed to the decision maker reviewing their decision by whichever means appropriate)	The reference to a best interests meeting has been amended and the current wording acknowledges that a meeting may not be necessary or the only way to consult.
Department of Health and Social Care	Full	General	general	I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you for your time reviewing the guideline.
Derbyshire County Council	Short	general	General	The Care Act principles of proportionate and more simple assessments. The need to evidence a myriad of capacity related activities and advanced decisions undermines proportionate strength based assessments which is both enabling and client led. Instead it will force a return to a deficit and risk adverse model	Thank you for your comment. The committee reviewed the recommendations following consultation to ensure they are as strengths based and empowering as possible, while still ensuring safeguards for people who may lack capacity.
Derbyshire County Council	Short	general	general	For those 16 moderate LD and or complex needs they typically already lack capacity in many areas yet have not reached their majority. Legally and in practice parental views hold sway until 18. Due to lack of opportunity and life experiences what is 'important to' the young person will invariably be based solely what they are familiar with (this is likely to be quite limited based on existing family and home networks). The challenge will then be to not just accept the status quo but to expose young people to greater life opportunities and improve autonomy in line with the changed legal position of becoming an adult at 18 and what is necessary to enable them to take their place in the adult world (through positive risk taking) rather than risk adverse arrangements based on parent/carer fears. Consequently, greater autonomy and in some cases capacity may be achievable through encouraging practice in decision making over time	Thank you for your comment. The committee reviewed the guideline and added a paragraph to the context section to explain the specific legal framework surrounding mental capacity and decision making among people aged 16-18 years.
Derbyshire County Council	Short	General	general	Social model of disability through increase emphasis on SALT and psychologists as key people in Capacity Assessments thereby medicalising this process and undermining the role of Social Care staff (including OT's) in both taking this forward and defending the rights of individuals. Courts will inevitably take the views of more risk adverse medical professionals	Thank you for your comment. The committee recognise the importance of taking a multi-disciplinary approach to supporting decision making and assessing capacity to make decisions. Some practitioners (e.g. speech and language therapists) are given as examples but this is not to suggest they are the only practitioners who make an important contribution.
Derbyshire County Council	Short	3	22	The Mental Capacity Act 2005 in that capacity is decision specific and capacity should be assumed unless there are indicators to the contrary. This will force a multitude of MCA for almost everything. This has already been a major failing of the CQC approach to MCA who insist that MCA's are in place for almost every decision in a person's life if they are using a registered service.	Thank you for your comment. This recommendation is not intended to suggest that advocates should be involved in every capacity assessment – instead the recommendation is about training for all practitioners.
Derbyshire County Council	Short	5	2	The statutory requirement for IMCA under the Mental Capacity Act only relates to long term accommodation moves, serious medical treatment and adult protection. There is also a statutory requirement for LA's under the Care Act to provide advocacy in relation to assessment, care planning and reviews and safeguarding.	Thank you for your comment. Following consultation feedback, the recommendation on advocacy has been reworded to clarify the need for statutory advocacy and take into account stakeholder concerns regarding the resource implications of the previous recommendations.

Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
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				Any advocacy needs outside of these processes would be considered non-statutory and most LA's are not commissioning this due to continued funding pressures. Derbyshire County Council are funding non-statutory advocacy but many other LA's are not.	
Derbyshire County Council	Short	14	5	While at first sight the emphasis in section 1.411 that practitioners take reasonable steps to ensure process of MCA does not cause a person distress or harm appears reasonable. In practice this opens up a can of worms and potentially is a licence for unscrupulous individuals to prevent MCA's of vulnerable adults who may be open to exploitation on the basis that they are making an informed choice and the MCA would prove too distressful for them. We are dealing with exactly this situation at the moment. We are not aware of a situation where an MCA has resulted in harm to an individual and though recognise this might be stressful there are ways to minimise this and there has to be a focus on the best outcome for that individual which may outweigh short term distress. Consequently, the wording should be along the lines that assessors should be mindful the MCA may be distressing for someone but every reasonable step should be taken to minimise distress and encourage participation short of not undertaking the MCA at all.	Thank you for your comment. The committee agree that the recommendation as currently drafted could be misinterpreted. The text has been edited to reflect that
Derbyshire County Council	Short	21	25	Advanced decisions: It is often too late to incorporate advanced decisions into MCA as the greater proportion of people we support are often only known at the point there capacity has deteriorated.	Thank you for your comment. These are just intended to be definitions of what the term is – not a recommendation for practice about the tool or intervention. However, some more detail has been added to help clarify the definition.
Derbyshire Healthcare NHS Foundation Trust	Full	general	General	Please could it be clarified within the guideline as to where the age that the MCA applies to as 16, and any difference around understanding of competence starting at 18? We understand that there have been recent legal cases around this.	Thank you for your comment. Following consultation, the Guideline Committee included some additional text that refers to legislation on decision-making and capacity in respect of 16-18 year olds.
Derbyshire Healthcare NHS Foundation Trust	full	general	general	Is there sufficient advice within the guidance to indicate the threshold of decisions seen as being appropriate to be considered as requiring a "Best Interest Meeting" or those which might be seen more as the responsibility of specific professional? For example, the balance of the expectation of the clinician to make a decision around DNAR, given that the ultimate responsibility for such decisions will be held by the clinician?	Thank you for your comment. This was discussed at the post-consultation committee meeting. The introduction to this section has been updated to make clear what a Best Interest decision is, how and when it may apply, and to cross-reference existing legislation and guidance. The guideline does not replace existing legislation and guidance.
Derbyshire Healthcare NHS Foundation Trust	Full	General	General	Might there be some clearer advice or directions about processes required when an appeal or challenge against an advance directive/advance care plan/advance decision/best interests decision needs to be considered?	Thank you for your comment. None of the review questions specifically focussed on this issue, which helps to explain why no related evidence was located and therefore why the committee did not draft any recommendations on this particular area. However, please note that one of the recommendations in section 5 in the guideline on best interests decision making, does refer to disputes about best interests decisions.
Derbyshire Healthcare NHS Foundation Trust	Full	general	General	Some case examples for each of the main issues would be really helpful	Thank you for your comment. The recommendations in the guideline are intended to be specific and action-focused. The follow-up work undertaken by NICE to disseminate the guideline and to develop Quality Standards informed by it can include more information to illustrate how recommendations could be implemented.

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Derbyshire Healthcare NHS Foundation Trust	Short	General	General	To aid accessibility given the topic, would it be helpful for there to be flow charts or diagrams to illustrate the main points of both the mental capacity act (stages 1 and 2) and its implementation (best interests meetings, DoLs, Advanced Decisions and statements, etc.). Derbyshire Healthcare NHS Foundation Trust has developed educational resources in this style for staff groups across the Trust attached below. Please contact Edward.Komocki@derbyshcft.nhs.uk or Lee.Smith@derbyshcft.nhs.uk for more information or if you would like to view these.	Thank you for your comment and for the information you provide, which will be passed to our endorsement team. The guideline will be published alongside a NICE pathway.
Derbyshire Healthcare NHS Foundation Trust	Short	3-21	General	Pages 3-21 (1.1.1 – 1.5.23) are needlessly repetitive in content and objectives and could be reduced significantly to a more succinct presentation for ease of access and reading for the intended audience. This will be aided further by diagrammatic presentations (see point 2 above).	Thank you for your comment. In light of yours and other stakeholder comments the committee revised the recommendations to improve the clarity of wording and structure of the guideline. We hope this has helped to address your concerns.
Dimensions	Short	General	General	Question 3: An awareness raising exercise with healthcare professionals would be beneficial. In particular, clarity around who should be assessing capacity for particular decisions across providers, commissioners, care managers and health professionals would be helpful. Simple guidance on this could be developed to support these guidance.	Thank you for your comment and suggestion for implementation support.
Dimensions	Short	General	General	Overall, the guidelines are process driven, using a significant amount of professional and sector relevant jargon. Whilst this is perhaps inherent in the nature of guidelines, the formal style detracts from the person centred nature of supported decision making and best interest decision making. This may make the guidelines poorly suited for reception amongst those who most need to understand and implement them.	Thank you for your comment. Following the consultation, the committee reviewed the recommendations to ensure they are as clear and accessible as possible, including adding and revising definitions in the 'terms used' section of the guideline. The committee were also careful to ensure the recommendations are as person centred and empowering as possible, in line with the ethos of the MCA.
Dimensions	Short	General	General	Question 3: Practical ways of thinking creatively about how people can come together to make best interest decisions would be helpful for those who live far apart from loved ones or have become over reliant on face-to-face meetings.	Thank you for your comment and suggestion for implementation support.
Dimensions	Short	General	General	Question 1: Applying the very good principles to a particular decision can take time. Often, the need is too pressing, or perceived to be too pressing, to apply principles in practice. Safeguarding concerns are especially typical of this. Protecting the person concerned (and themselves & their organisation) is deeply ingrained into *all* social care staff, providers' and local authorities' alike. So the first impulse is to report, and not consult the person effectively. This isn't altogether a bad thing; but sometimes the Care Act is allowed to trump the Mental Capacity Act where it shouldn't.	Thank you for your comment. Following consultation the committee reviewed the guideline and emphasised the relationship between the Mental Capacity Act, Care Act and the recommendations – as well as the Code of Practice and Mental Health Act. The recommendations also place great emphasis on the importance of supporting the person to make their own decision and we are confident that this will improve practice in this regard.
Dimensions	Short	5	23 - 26	Question 2: We believe there are high cost implications for introducing training for all practitioners and advocates in relation to mental capacity and supported decision making.	Thank you for your comment. The committee believes that this recommendation is affordable within current resources, even if this means using them slightly differently.
Dimensions	Short	5	26	Question 1: We believe implementing the appointment of Independent Advisors would be difficult given the current scarcity of trained advocates at this moment in time.	Thank you for your comment. To clarify, this is not what's being recommended in 1.1.11, it's about increased investment in training for advocates.
Dimensions	Short	7	3	Reference to the Accessible Information Standard make sense in terms of efficiency and consistency, however it may be unwise to mention this as a sole replacement of a more human and tangible description which is about the personal preferences and needs a person has when wanting to both understand information/others and be understood themselves.	Thank you for your comment. The point you make is actually addressed in the recommendation before this one, which refers to 'tailored, accessible information'.

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Dimensions	Short	8	24	Question 1: Whilst social care workers might offer good support around decision making, evidencing this can be problematic. In our experience, evidencing the process, even with the assistance of toolkits, can be hard for some. Indeed, this can demand that support worker are also excellent written communicators, above and beyond what might typically be asked of them in their role.	Thank you for your comment. We hope the guideline will support improvements to practice in this area.
Durham County Council	Short	General	General	Further funding would be helpful to overcome some of the challenges discussed to improve, expand and access to resources for service users. To improve access to information for people requiring intervention, their families and carers, for example information on lasting power of Attorney and Court of Protection Procedures	Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Durham County Council	Short	4	28	There may be increased difficulties accessing advocacy for practitioners due to the demands on the service and the availability to respond promptly (market pressures).	Thank you for your comment. In light of yours and other stakeholder comments the recommendations about advocacy have been substantially revised and we hope this addresses your concerns.
Durham County Council	Short	9	6	May be difficulties in developing a joint approach when using different systems, issues of who has access and ownership. Joint tools which are accessed from health and social care are not easily developed due to the pressures on both services.	Thank you for your comment. The committee believe these recommendations to be aspirational but achievable.
Durham County Council	Short	9	13	Cost of training and changes to compatible systems in sharing advanced care plans.	Thank you for your comment. The recommendations are designed to be aspirational but achievable.
Durham County Council	Short	9	24	Implications on responsibilities of providing sensitive information, would impact on social workers, who may not be the most appropriate professional to lead with this.	Thank you for your comment. The guideline makes recommendations for best practice and the committee believe that this is achievable.
Durham County Council	Short	10	3	Possible impact on social workers as consideration must be made on who is the most suitable practitioner to do this.	Thank you for your comment. We have edited the recommendation to clarify that all practitioners should be able to enable access to advance care planning.
Durham County Council	Short	10	16	Better understanding of the individual may have impact on training.	Thank you for your comment. The committee consider the recommendation to be aspirational but achievable.
Durham County Council	Short	10	16	Understanding the individual impact on training costs as increased awareness of specialism required.	Thank you for your comment. The committee consider the recommendation to be aspirational but achievable.
Durham County Council	Short	11	7	Implications to resources to ensure that support is available.	Thank you for your comment. The committee believe the recommendations to be aspirational but achievable.
Durham County Council	Short	11	7	Implications to resources to ensure that support is available and cost.	Thank you for your comment. The committee believe the recommendations to be aspirational but achievable.
Durham County Council	Short	11	22	There appears to be a need for clarification on who is responsible for completing, maintaining and distributing the document and that may have an impact on social workers.	Thank you for your comment. The recommendation is aimed at all health and social care practitioners. We have edited the recommendation to clarify this.
Durham County Council	Short	12	1	Need clarity on who would be responsible for ensuring confidentiality and responsibility of transferring documents.	Thank you for your comment. The committee acknowledge that different arrangements may be in place in different areas but that these would always comply with data protection legislation.

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Durham County Council	Short	12	18	Implications on how services are accessed and eligibility – seeking specialist input needs to be proportionate. Local authority would have no control over these services, accessing may be difficult or take too long.	Thank you for your comment. The committee believes the recommendations to be aspirational but achievable.
Durham County Council	Short	12	18	Impact on existing services, eligibility and accessing services.	Thank you for your comment. The committee believes the recommendations to be aspirational but achievable.
Durham County Council	Short	13	6	This may not be possible on occasions of emergency intervention.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Durham County Council	Short	14	11	Can this be made clearer with an explanation of what this means?	Thank you for your comment. The committee believe that the issue of assessment is adequately covered by the recommendation.
Durham County Council	Short	15	15	Social workers may need further guidance and knowledge on the specialist assessments available to people effected by brain injury, which would impact on training and possible costs of training.	Thank you for your comment. The committee believe that the recommendation is achievable within the current context.
Durham County Council	Short	15	15	Possible costs to training social workers who may need further guidance, knowledge and skills	Thank you for your comment. The committee believe that the recommendation is achievable within the current context.
Durham County Council	Short	16	19	Can further clarification be provided on this this guidance?	Thank you for your comment. The guideline should be read in conjunction with the MCA code of practice. References to specific paragraphs have been added where appropriate.
Durham County Council	Short	16	25	Can this be expanded to say if the person has been assessed as having capacity they do not require a best interest decision?	Thank you for your comment. We believe that this is implied in the recommendation.
East Sussex County Council	Full	26	726	We are concerned about the inclusion of psychiatric advanced directives (PAD) in this document and the definition given. They are not legal instruments.	Thank you for your comment. The term does not appear in the recommendations and therefore is not defined in the short guideline. It was only defined in the full guideline because it is mentioned in the included evidence. However to avoid confusion, this has now been deleted from the full guideline.
East Sussex County Council	Short	4	28	We are concerned that this implies that we could expand existing statutory independent roles to meet the recommendations. We believe that we already provide this within our statutory provision i.e. Independent Mental Health Advocates, Independent Mental Capacity Advocates and advocacy to meet the requirements of the Care Act.	Thank you for your comment. In light of yours and other stakeholder comments the recommendations about advocacy have been substantially revised and we hope this addresses your concerns.
East Sussex County Council	Short	5	5	We also want to highlight that the funding pressures local authorities are currently facing mean that if there are no new resources from Government, by 2021/22 it is unlikely we would be able to fund additional advocacy outside of statutory provision.	Thank you for raising this important point. Following consultation feedback, the recommendations on advocacy have been reworded.
East Sussex County Council	Short	5	23	We are concerned that this recommendation seems to assume that we have additional resources to invest in advocacy (see comment number 2). We would expect a provider to deliver a service with suitably qualified advocates and deliver their training and Continuous Personal Development within the contract financial	Thank you for raising this important point. Following consultation feedback, the recommendations on advocacy have been reworded to clarify the need for statutory advocacy and take into account stakeholder concerns regarding the resource implications of the previous recommendations. This is not a mandatory

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				envelope. Our existing provider is competent in the area of non-instructed advocacy and again we would expect an appropriate skills mix provision to cover the likes of need in the acquired brain injury community.	recommendation (does not use 'must') but the committee did believe it would be hugely beneficial for commissioners to work with public bodies and providers in order to increase investment in this important area.
Eastern Region MCA DOLs Leads Group	Question 1	General	General	*Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.* As the current MCA's Code of Practice is in a desperate need to be revised to incorporate all of the practice learnt in the last 10 years or so, this document may have to stand in as a substitute albeit only in the areas of supported decision making and best interests. It is still very much a challenge to get health colleagues in complex/continuing health care and GP's to take on board the basic requirements of the MCA let alone supporting decision making and establish best interests decisions. Time is a resource especially in acute hospital settings and when discharges have to be considered for quick turnover of beds say in the winter months. For practitioners in health and social care to be able to openly consider the 3rd principle of the Act versus risks i.e. how to adopt positive risk taking in a culture of blame! Self funders with LPAs or Court Appointed Deputies and how to get them subscribing to the requirements of the Act and also the same with the banking and commercial sectors.	Thank you for your comment and support for the guideline which seeks to complement, rather than replicate, existing legislation and guidance.
Eastern Region MCA DOLs Leads Group	Question 2	General	General	*Would implementation of any of the draft recommendations have significant cost implications* Time is a cost resource and so does training for new staff, on-going up dating training for existing staff, commissioning for more Care Act and IMCA advocates.	Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Eastern Region MCA DOLs Leads Group	Question 3	General	General	*What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)* To have one organisation like SCIE tasked to collect and organise practical resources and examples of best practice etc.	Thank you for your comment and suggestion for implementation support.
Eastern Region MCA DOLs Leads Group	Short	1	27	It would be beneficial to use words in keeping with section 4 of the MCA - this should be wishes, feelings, beliefs and values of the person.	Thank you, this has been amended in the recommendations for consistency.
Eastern Region MCA DOLs Leads Group	Short	1	28 & 29	Should this statement meant to have said ensuring people who lack the mental capacity rather than have capacity. This statement should reflect principle 1 of the MCA and support that people must be assumed to have the capacity to make their own decisions until proven otherwise.	Thank you for your comment. The context section has now been revised and no longer contains this sentence.
Eastern Region MCA	Short	2	3	This statement should reference principle 4 & 5 of the MCA and section 4 best interests checklist.	Thank you for your suggestion. The context has now been revised to provide a clear link between the guideline, the relevant legislation and the Code of Practice.

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DOLs Leads Group					Further reference to the MCA and Code of Practice have also been added to the guideline.
Eastern Region MCA DOLs Leads Group	Short	2	10	Why does this guidance not cover the Deprivation of Liberty processes in relation to the capacity assessment requirement?	Thank you for your comment. The scope of this guideline was specifically decision making and the decision was taken by the committee, during the scoping stage, that this therefore should not cover issues around deprivation of liberty. However, the recommendations are clearly intended to be implemented within the context of the whole of the Mental Capacity Act (as well as other legislation and guidance) so the focus on decision making is not intended to be at exclusion of the other statutory principles.
Eastern Region MCA DOLs Leads Group	Short	3	3	Despite the fact that the MCA came into being in 2007, there has been a disparity between health and social care's understanding of the practice implications of the Act, in particular with the former still lacking behind and especially with Continuing Health Care professionals, health practitioners and in general practices.	Thank you for your comment. The committee hoped to have addressed these and other problems relating to the implementation of the MCA within this guideline.
Eastern Region MCA DOLs Leads Group	Short	3	10	Consent is not only applicable to Advanced Care Planning – this should include all acts of care and treatment.	Thank you for your comment. The recommendation has been revised accordingly and now refers to the importance of consent more broadly, not just in relation to advance planning.
Eastern Region MCA DOLs Leads Group	Short	3	14	There should be more emphasis on the importance of using alternative communication styles/means.	Thank you for your comment. The committee feel that the guideline provides good detail about different means of communication and meeting people's communication needs – communication in this recommendation is used in a very broad, overarching way.
Eastern Region MCA DOLs Leads Group	Short	3	16	Clarity on roles – it needs to be clear what roles and responsibilities are being considered and the impact these have on decision-making. The role of decision-maker should be explored further to ensure the most appropriate person supports with decision-making and assesses capacity. There still remains confusion about who is decision-maker with assessments being delayed or completed by inappropriate persons.	Thank you for your comment. This is an overarching principle and applies to all roles and responsibilities so it wouldn't be appropriate to be specific.
Eastern Region MCA DOLs Leads Group	Short	3	22	Decision and time specific.	Thank you for your suggestion. In this overarching recommendation the committee felt it was appropriate to refer to the 'decision specific' nature of capacity assessments. However other recommendations in the capacity assessment section do address the importance of conducting assessments in a time and place that is suitable for the person.
Eastern Region MCA DOLs Leads Group	Short	4	1.1.4	It is important to highlight that very often in practice, a person's ability to give valid consent is called to question when he or she changes their mind about something they have agreed to earlier on. Such risks adverse practice should be addressed in this guidance.	Thank you for your comment. The committee were aware of the need to balance safeguarding of the person with being overly risk averse. Although not in this particular recommendation the committee do feel they have struck this balance across the whole guideline.
Eastern Region MCA DOLs Leads Group	Short	4	3 and 4	There are very few if any tools that exist currently to aid practitioners with supported decision making. Therefore, this guidance could be leading the way in this important area of work with the focus on ensuring this. This should include person centred approaches are applied to fully embrace principle 2 of the MCA. It would also be prudent to include the word "mandatory" when referring to training.	Thank you for your comment. Unfortunately it is not within the NICE remit to make training mandatory
Eastern Region MCA DOLs Leads Group	Short	4	26 & 27	There is a need to consider the interface between the Care Act 2014 and the MCA relating to the provision of IMCAs and Care Act Advocates and duties/powers to provide.	Thank you for your comment. The context section has been revised to provide a clearer explanation about the relationship between these recommendations and the relevant legislation. The recommendations on advocacy have also been

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					substantially revised and we hope that as a result your concerns have been addressed.
Eastern Region MCA DOLs Leads Group	Short	5	8	Again, despite the fact the MCA was implemented since 2007, knowledge on the statutory criteria for the engagement of IMCA services are still lacking especially with health professionals, it will be good for this guidance to spell them out.	Thank you for your comment. The advocacy recommendations have been substantially revised and definitions added to 'terms used'. The recommendation to which you refer is now much clearer about the legal obligation to tell people about advocacy services as a potential source of support.
Eastern Region MCA DOLs Leads Group	Short	5	8	Referral to IMCA is for a statutory reason that is not clear here.	Thank you for your comment. The advocacy recommendations have been substantially revised and definitions added to 'terms used'. The recommendation to which you refer is now much clearer about the legal obligation to tell people about advocacy services as a potential source of support.
Eastern Region MCA DOLs Leads Group	Short	5	15	This can be confusing to practitioners in mixing independent Care Act advocacy with IMCA which is discretionary to provide for safeguarding concerns.	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised and the elements that are legally binding (and those which are not) are now much clearer.
Eastern Region MCA DOLs Leads Group	Short	5	23	Any training for IMCAs and other statutory advocates in relation to their professional developments are down to the providers of such services.	Thank you for your comment. The emphasis in this recommendation is on commissioners increasing investment in training rather than being the direct providers.
Eastern Region MCA DOLs Leads Group	Short	5	21 & 22	How would this be achieved and by whom?	Thank you for your comment. Failures would be identified by the inspectorate.
Eastern Region MCA DOLs Leads Group	Short	6	23-26	At a minimum a person should be provided with the following information – the nature of the decision, why the decision needs to be made, what the available options are, the risk and benefits to each option and the foreseeable consequences. In practice this does not happen and records do not provide sufficient evidence to demonstrate what relevant information has been shared with the person and how.	Thank you for your comment. These aspects are actually covered in the recommendation about providing a written record of the decision making process as a means of supporting the person to make their own decisions. For example, the recommendation states that the record should include what the person is being asked to decide, steps taken to help them decide, key considerations for the person and others.
Eastern Region MCA DOLs Leads Group	Short	6	8 10-20	It will be good if the Guidance reinforces the issue of spending time to support decision making in order to build a trusting relationship. Supported decision making must not be seen as someone parachuting in from nowhere, rapport needs to be built up and this will take time to do.	Thank you for your comment, which the committee believe is already well covered throughout the guideline, especially in those recommendations about supporting decision making.
Eastern Region MCA DOLs Leads Group	Short	7	18	This is another good opportunity for this guidance to expand on the issue of unwise decision versus adverse risk taking. There is also a need to reference how a person should be supported to consider ways to reduce/mitigate risk where a person chooses to make unwise decisions and legal literacy.	Thank you for your comment. The committee did not feel they had the evidence that would provide a basis for making this addition.
Eastern Region MCA DOLs Leads Group	Short	8	5	Give the example of life changing decisions, such as moving from own home into residential care.	Thank you for your comment. We have not amended the recommendation as this should take place irrespective of the significance of the decision.
Eastern Region MCA DOLs Leads Group	Short	8	12	Some local authorities have stipulated in their commissioning of advocacy services that they would like to see Care Act Advocates to be also IMCA trained so that the same advocate could be involved should the statutory criteria for IMCA be met. In reality practice does not allow for the management of long term cases -	Thank you for your comment. The committee were aware that this would not always be possible, and included the wording 'where possible' in the

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				high caseloads and turnover of staff would make this difficult to achieve. It would be beneficial to focus on strategies that could be developed to guarantee there is continuity in applying practical steps and supported decision-making.	recommendation. There was insufficient evidence to recommend particular strategies.
Eastern Region MCA DOLs Leads Group	Short	8	22	Again, to give the example of life changing decision alongside complex treatment.	Thank you for your comment. We have reviewed the recommendation and think that this example is covered by the wording 'if the consequences of the decision would be significant'.
Eastern Region MCA DOLs Leads Group	Short	8	26	And how the steps have supported, enabled and empowered the person to make decisions and where other steps have been considered but not applied and why.	Thank you for your comment. The recommendation has been amended to make reference to 'any actions not applied and the reasons why not.'
Eastern Region MCA DOLs Leads Group	Short	9	7	It is important to remind that some elements of advance care planning is not legally binding but provides the person with a voice (to express their wishes, feelings, values and beliefs) at a stage when they are unable to make the decision and these views MUST be taken into account when best interests decisions are made. This guidance needs to explicitly define advance decisions to refuse treatment and advance statements.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of ADRTs and advance statements is made clear.
Eastern Region MCA DOLs Leads Group	Short	9	24	The guidance should stipulate who will be responsible for providing this information and also acknowledge the importance of counselling to help persons transition through the five stages of loss and grief.	Thank you for your comment. We have edited the text to clarify who this recommendation is aimed at.
Eastern Region MCA DOLs Leads Group	Short	10	27 & 29	It is important to recognise that there may be a need to continue reviewing who to consult and involve as a person has the right to withdraw consent at any stage.	Thank you for your comment. We believe this is adequately covered in this recommendation.
Eastern Region MCA DOLs Leads Group	Short	12	25	Other than resorting to triggering complaint procedures, this will be an opportunity for this Guidance to elaborate as to how someone or the family can challenge the outcome of capacity assessments whether it be lacking or having capacity.	Thank you for your comment. The recommendations are based on the best available evidence and as such the committee did not consider it to be appropriate to include further detail on these types of processes.
Eastern Region MCA DOLs Leads Group	Short	12	16 & 17	It would be beneficial for the guidance to offer suggestions on how data can be collected? Quantitative versus qualitative and how this should be used for monitoring purposes.	Thank you for your comment. The recommendation is not intended to be prescriptive.
Eastern Region MCA DOLs Leads Group	Short	13	25-26	The example of fluctuating/temporary incapacity should also be referenced with emphasis being placed on decision-makers justifying why an assessment cannot be delayed in these circumstances.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.

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Eastern Region MCA DOLs Leads Group	Short	13	1	This is an opportunity to provide clarity on who the decision maker is and especially for staff in health settings and therefore, it will be useful to cite different examples	Thank you for your comment. The decision-maker will depend on the setting and it would not be appropriate for the committee to specify this here.
Eastern Region MCA DOLs Leads Group	Short	13	6	The reality is that sometimes, assessors are required to assess capacity with little or no knowledge of the person concerned. We believe this is where time will be needed and in practice, this often poses a challenge in acute hospital settings with finite number of beds available. The guidance does not take into account pressures on front line practice.	Thank you for your comment. The committee believes the recommendation to be aspirational but achievable given current resources.
Eastern Region MCA DOLs Leads Group	Short	13	15	The guidance should include the word available when referring to person's options as this may raise expectations that cannot be met. There is a need to be mindful of resource implications and constraints imposed on public bodies.	Thank you for your comment. We believe that this is adequately covered in the recommendation.
Eastern Region MCA DOLs Leads Group	Short	13	18	In keeping to consistency and completeness of language, the MCA needs the person to understand, retain, use and weigh and communicate the decision and there is no mention of the use of communication aids.	Thank you for your comment. These concepts are all mentioned in the recommendation.
Eastern Region MCA DOLs Leads Group	Short	13	12 & 13	It would be useful to provide suggestions on how practitioners can manage these situations, especially where a person refuses to be engaged in an assessment in any shape or form and concerns/risks are high, for example, safeguarding concerns and unwise decision versus positive risk taking.	Thank you for your comment. The committee were unable to make further recommendations on this issue due to the lack of evidence in relation to the subject; however the recommendation numbered 1.4.10 in the draft guideline has been edited to include details about ensuring the risks of distress are minimised.
Eastern Region MCA DOLs Leads Group	Short	14	21-24	It would be useful for the guidance to share information/provide examples of where tools can be accessed, especially where there are delays in waiting for a formal assessment of communication. It would be excellent if there could be a central place for tools to be located.	Thank you for your comment. There was insufficient evidence to recommend any specific tools.
Eastern Region MCA DOLs Leads Group	Short	14	18-20	Will priority be given to person's who require this support? In reality a person may be placed on a waiting list with support not being delivered in a timely manner.	Thank you for your comment. The committee make evidence based recommendations regarding best practice. They believe that this recommendation is achievable within the current health and social care context.
Eastern Region MCA DOLs Leads Group	Short	14	13	Principle 2 requires all practicable steps to be taken to support the person to make their own decision. Its main aim is to ensure practicable steps are being taken and this may produce collaboration between the person and the assessor and possibly other people who know the person. It will be really good for this guidance to elaborate on what it means by taking all practical steps to meet the second principle of the Act. There should be emphasis on steps being taken to maximising decision-making.	Thank you for your comment. The committee believe that this issue is covered adequately by the recommendations in section 1.2.
Eastern Region MCA DOLs Leads Group	Short	15	8	It will be really useful if this guidance can touch on the issue of outright refusal to be engaged with practical suggestions.	Thank you for your comment. The committee discussed your point and agreed that in fact there are a few rare cases where someone refuses to engage with a capacity assessment (repeatedly) which will be a factor (amongst others) that is taken into account for the purpose of an interim declaration pursuant to section 48 of the MCA - the test being there is "reason to believe" P may lack capacity to make a specific decision. The court will then direct an independent expert or a special court visitor (with expertise in such cases) before a final declaration is made. So as you say, a person does not *have* to engage, but a refusal (against a background where a capacity assessment is being contemplated) *may*be a factor from which inferences about capacity could be made. Unfortunately and in

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					this context however the committee did not feel they had reviewed evidence which would provide a basis to make suggestions for practical solutions.
Eastern Region MCA DOLs Leads Group	Short	15	15	Executive functioning or the lack of for example, people with traumatic brain injury is a practice issue that warrants further guidance on.	Thank you for your comment. This would not be within the scope of this guideline.
Eastern Region MCA DOLs Leads Group	Short	15	13 & 14	This should also include explanation as to why there is doubt about the person's ability to make the decision and how decisions can be challenged. It is important to reinforce openness and transparency in all working relationships.	Thank you for your comment. The committee agree that it would be useful to include this detail and the recommendation has been edited accordingly.
Eastern Region MCA DOLs Leads Group	Short	16	7-9	The guidance should reinforce the need for records to evidence how practical steps have supported, empowered and enabled the person to make the decision as opposed to just describing what steps have been taken. This information will be beneficial if further assessments of capacity are required and will ensure continuity in person-centred planning. This is key where assessors have limited knowledge/information on the person, for example, when responding to crisis situations/safeguarding and discharge from acute settings.	Thank you for your comment. The committee believe that the recommendation covers these issues adequately.
Eastern Region MCA DOLs Leads Group	Short	16	1	It is good that the Guidance alludes to the lack of insight into a condition does not necessarily reflect lack of capacity and perhaps can go further to highlight the fact that insight is not mentioned at all in the Act and how this notion of insight is being used commonly in psychiatry and especially when a person declines to take their prescribed psychiatric medications on account of adverse side effects, for example.	Thank you for your comment. The committee agreed that it was important to highlight this issue however on the basis of the available evidence they were unable to make further recommendations.
Eastern Region MCA DOLs Leads Group	Short	16	23	Advance decisions to refuse medical treatment need to be valid and applicable. It would be useful to clarify how practitioners should determine this and action to take where there are concerns about validity/applicability.	Thank you for your comment. The guideline has been edited to ensure that clarity is provided in relation to the legal status of ADRTs and the links between these and best interests processes.
Eastern Region MCA DOLs Leads Group	Short	17	21-24	This should also include Care Act Advocates and the role they may play at the point of assessing capacity.	Thank you for your comment. The role of IMCAs is specifically focussed on in this recommendation because it is based on evidence about practitioners demonstrating a lack of understanding about that role.
Eastern Region MCA DOLs Leads Group	Short	17	12	The guidance should consider how written statements are shared amongst professionals and following consent of the person. There is also a need to remind that written statements are not currently legally binding and suggestions on the level of weighting that should be given when making best interests decisions.	Thank you for your comment. The guideline has been edited to ensure that clarity is provided in relation to the legal status of written statements and the links between these and best interests processes.
Eastern Region MCA DOLs Leads Group	Short	18	5	The guidance should provide examples of what may constitute to be 'harmful' as there is a risk this statement may be overused as a reason not to invite the person to the meeting. The guidance should also recognise that a person can be involved in other ways and provide suggestions as to how this can be achieved.	Thank you for your comment. This recommendation has now been amended and the reference to 'harm' removed. Recommendation 1.5.10 acknowledges that information could be gathered through other ways.
Eastern Region MCA DOLs Leads Group	Short	18	17	We hope the Guidance can include a narrative on the expectations of supported decision-making and undertaking best interests' decision making for people who are self-funding and may not have any professional involvements.	Thank you for your comment. The committee did not review any evidence specifically related to supporting decision making and self-funders but the same principles would always apply and independent advocates may have a particular role to play in this context.

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Eastern Region MCA DOLs Leads Group	Short	19	12-14	Best interests decisions are still required where a person has a LPA/Deputy but the substitute decision-maker will have the authority to make the best interests decisions. The guidance should reinforce the importance of ensuring the LPA/Deputy has access to all the relevant information in order to make an informed decision on behalf of the person. The guidance should also make reference to what actions to take where a LPA/Deputy is not acting in the person's best interests, for example, in self-funding cases.	Thank you for your comment. The guideline as a whole and this section specifically have been reviewed to ensure that the links between lasting powers of attorney, ADRTs, court orders, and best interests procedures are clarified.
Eastern Region MCA DOLs Leads Group	Short	19	4	It would be useful for the guidance to provide links on best practice toolkits currently employed by organisations.	Thank you for your comment. There was insufficient evidence to refer to particular toolkits.
Eastern Region MCA DOLs Leads Group	Short	20	25-28	It would be beneficial to refer to Chapter 15 of the MCA Code of Practice and the need to seek legal advice regarding applications to the Court of Protection.	Thank you for your comment. The guideline has been reviewed to ensure that readers are directed to the relevant sections of the code of practice (or other guidance and processes) at the start of each section.
Eastern Region MCA DOLs Leads Group	Short	20	12-14	Consideration should also be made to the interference of other human rights articles, for example, article 8 – the right to a private, family life.	Thank you for your comment. The recommendation has been edited on the basis of your comment.
Eastern Region MCA DOLs Leads Group	Short	20	1-2	It is important that the guidance stresses the importance that best interests decisions should maximise a person's right to autonomy, independence, choice and control.	Thank you for your comment. The guideline has been reviewed to ensure that these concepts are emphasised sufficiently.
Eastern Region MCA DOLs Leads Group	Short	20	20-21	It would be useful for the guidance to provide examples of best practice review timescales.	Thank you for your comment. The committee did not feel they had a basis on which to make a more specific recommendation about time scales, not least because the situation is so particular to the person, the circumstances and the decision.
Eastern Region MCA DOLs Leads Group	Short	20	4	Current conversations, actions, choices etc. should also be acknowledged.	Thank you for your comment. The committee believe that this is covered adequately by the recommendation.
Eastern Region MCA DOLs Leads Group	Short	20	7	It is essential here that this reads "available options' or realistic/viable option and not simply options.	Thank you for your comment. The committee believe that this is covered adequately by the recommendation.
Eastern Region MCA DOLs Leads Group	Short	21	19,25	Here, confusion may arise with advance directives and a statement of wishes and preferences versus advance decisions to refuse treatment.	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Eastern Region MCA DOLs Leads Group	Short	22	1	We question this definition of consent as it relates only here to those lacking or potentially lacking capacity. There is no mention of appointed LPA or Court appointed Deputy who can give consent on behalf the person concerned.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who

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					lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Eastern Region MCA DOLs Leads Group	Short	23	8	The word 'unfit' can evoke negative connotations.	Thank you for your comment. This has been amended to use the term 'unable'.
Eastern Region MCA DOLs Leads Group	Short	23	27	It would be useful to describe what is meant by substitute decision makers as often there is confusion that Next of Kin is able to make decisions on behalf of spouse etc.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
Eastern Region MCA DOLs Leads Group	Short	24	28-30	Will additional monies be made available to meet the training agenda?	Thank you for your comment. Training will need to be funded from within current resources.
Eastern Region MCA DOLs Leads Group	Short	25	11	This will be dependent on resource availabilities. It is widely accepted that frontline social and health care are under financial pressures with continued cuts from central government.	Thank you for your comment. The text in this section is standard in NICE guidelines.
Eastern Region MCA DOLs Leads Group	Short	25	18	It would be beneficial for the guidance to provide already existing links to on-line resources, for example, SCIE MCA directory, British Institute for Human Rights, ADASS/LGA, 39 Essex Street.	Thank you for your comment. This section of text is set by NICE and cannot be altered. We will pass this information to the resource endorsement team.
Edge Training and Consultancy	Short	General	General	General points: • Not clear on difference between the legislation and the Code of Practice – many staff don't appreciate this or the authority of the Code over and above professional guidance/policies or indeed that the Code will always supersede NICE guidance in law. • Direct reference to applicable Code of Practice chapters on advance decisions and assessing capacity would be appropriate to direct staff individually and organisations to incorporate the Code into their policies. • The document refers to 16 plus and adults – they are different in law. The law still allows those with parental responsibility to authorise treatment in some circumstances for those aged 16-17 which means the MCA will not always apply in that situation. • Consent is not properly explained or defined. The crucial link between consent and capacity is not properly explained. As a training company, this is one of the biggest problems we find with health staff. They see the MCA as something that stands alone and do not appreciate the link to consent. If a person lacks capacity they cannot consent to treatment/care and if a person is not able to give consent this may be because they lack capacity under the MCA (16+ and have impairment or disturbance).	Thank you for your comment, your individual points are addressed below: Following consultation, the committee revised the context section of the guideline to clarify the relationship between the guideline and the mental capacity legislation and Code of Practice. Thank you for this suggestion, which the committee acted upon in revising the guideline. They agreed to add introductory paragraphs to all relevant sections, highlighting the link with the appropriate section and principle of the Code and MCA. Thank you for highlighting this. The committee agreed to add a specific paragraph to the context section of the guideline which describes the specific legal framework for decision making, mental capacity and people aged 16-18 years of age. Thank you for raising this issue about consent, which other stakeholders also highlighted. One way in which the committee addressed this was to edit the first recommendation in the guideline so it refers to the importance of all practitioners being trained in consent (as it applies across decision making and mental capacity) as opposed to consent simply in relation to advance care planning, which it was felt was too narrow.

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Edge Training and Consultancy	Short	3	10	We are concerned that the Mental Capacity Act itself is not mentioned until line 10. This is the legal basis of the whole document and the historic concerns referred to stem from the House of Lords investigation into the Act/legislation (not decision making in a general sense).	Thank you for your suggestion. The context has now been revised to provide a clear link between the guideline, the relevant legislation and the Code of Practice. Further references to the MCA and Code of Practice have also been added to the guideline.
Edge Training and Consultancy	Short	3	10	*the importance of seeking consent for the process of advance care planning* What about seeking consent for all care (current or advance)? Further, there is no system of advance consent so many of these decisions will need to be made under best interests at the time which should include past wishes recorded in any advance care planning process.	Thank you for your comment. The recommendation has been revised accordingly and now refers to the importance of consent more broadly, not just in relation to advance planning.
Edge Training and Consultancy	Short	3	15	*practitioners must comply with the statutory functions of the agencies* This is misleading as any person or practitioner must comply with the legislation when working with people who lack may lack capacity. It is not related to the statutory function of the agency. It would be clearer and more accurate to say any practitioner must comply with the law/legislation that is relevant to their work.	Thank you for your comment. The context section has now been revised and no longer includes this sentence.
Edge Training and Consultancy	Short	3	22, 23	*the conduct of decision-specific capacity assessments* *the process of best interests decision-making in the context of section 4* Not clear why Best interests is referred to with reference to the Act section 4 and capacity assessments do not refer to Sections 2 & 3 of MCA?	Thank you for your comment. This specific mention is made because it was felt this was an area of unmet need in terms of training.
Edge Training and Consultancy	Short	5	8	*Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy. Where statutory criteria are met, practitioners must refer to the relevant advocacy service.* This implies that for all people lacking capacity a referral to IMCA should be made. Given reported lack of referrals to IMCA services it would be better to state that practitioners have a legal duty to refer for an IMCA in certain situations and state those situations or provide the reference to the Code of Practice where they can find this information. Another option is to say that practitioners must ensure they are aware of when they have a duty to refer for an IMCA.	Thank you for your comment. The advocacy recommendations have been substantially revised and definitions added to 'terms used'. The recommendation to which you refer is now much clearer about the legal obligation to tell people about advocacy services as a potential source of support.
Edge Training and Consultancy	Short	6	6	*Mental Capacity Act Code of Practice, principle 2.* This is the first direct reference to the Code and it is misleading. Principle 2 (which could be quoted directly) is in the legislation (see Section 1). The Code of Practice simply repeats it and then expands on the practical application of it.	Thank you for your comment. To avoid confusion, the Guideline Committee agree that we should be referring to both the MCA, and the Code of Practice. They are both cited at the start of the guideline, in the revised context section as well as in relevant sections of the guideline in new, introductory paragraphs.
Edge Training and Consultancy	Short	9	4	*Organisations should ensure they can demonstrate that they monitor compliance with principle 2, section 1 (3) of the Mental Capacity Act.* Needs to state what this is – the duty to take practicable steps.	Thank you for your comment. We have given further examples in the recommendation to clarify this.
Edge Training and Consultancy	Short	9	7	*Advance care planning is one way of discussing and setting out a person's wishes in relation to future care and treatment decisions. Other ways of doing this include*	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.

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				appointing a Lasting Power of Attorney or making an advance decision to refuse treatment. It is really important to note that advance care planning has no legal authority – a care provider can override advance care plans whereas LPA and Advance Decisions are legally binding and part of the Mental Capacity Act and failure to follow them would lead to action in Court of Protection. The whole 'chapter' here fails to explain the difference between an LPA, advance care plan or Advance Decision – this is very important. Example: a person with MS who would never want to have a peg feed inserted. They ask a professional how they can legally ensure this wish is followed even after they have lost capacity? The answer is NOT advance care planning but rather an Advance Decision under the MCA (or potentially an LPA).	
Edge Training and Consultancy	Short	11	17	*In line with the Mental Capacity Act Code of Practice practitioners* Give paragraph or chapter reference to the Code of Practice – this should be consistent throughout the whole document.	Thank you for your comment. The guideline has been reviewed to include references to relevant sections of the code of practice at the start of each section.
Edge Training and Consultancy	Short	12	22	*Organisations with responsibility for accessible care plans should ensure that they record that the person consents to the care plan and identifies if they are unable to consent.* Consent is never explained in the document (or the glossary, see later) – it should state what consent is or refer to case law and DoH guidance.	Thank you for your comment. Consent is defined in the 'terms used' section of both the long and short version of the guideline.
Edge Training and Consultancy	Short	13	2	*Assess mental capacity in line with the process set out in section 3 of the Mental Capacity Act.* It is Sections 2 and 3 of the Act. Section 2 states the single test and that the person must have an impairment or disturbance of mind/brain and the assessment is time and decision specific. Section 3 elaborates on the four part assessment process.	Thank you for your comment. We have edited the recommendation in response to your comment.
Edge Training and Consultancy	Short	15	8	*If a person refuses to engage in a capacity assessment,* Reference should be made to the Code of Practice paragraphs that cover this issue (statutory guidance)	Thank you for your comment. Each section of the guideline has been amended to include references where appropriate.
Edge Training and Consultancy	Short	15	18	This should match the law and say 'use or weigh'	Thank you for this suggestion. The committee sought to avoid simply repeating the wording of the Mental Capacity Act and felt it was simpler and more recognisable to say 'weigh up or use relevant information'.
Edge Training and Consultancy	Short	16	12	*All assessments of mental capacity must be recorded at an appropriate level to the complexity of the decision being made* Reference to the Code of Practice should be made – paragraph? As this states about repeated decisions and care plans and professional duties to record	Thank you for your comment. The committee agree that references to the code of practice would be helpful. These have been added to the introduction at the start of each section.

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Edge Training and Consultancy	Short	17	3	*Regardless of whether a person has capacity to make a specific decision, practitioners must take all reasonable steps to help them be involved in making decisions.* This is a statutory obligation under Section 4 of the Act – should be stated	Thank you for your comment. The recommendation has been edited to ensure clarity on this issue and references to the MCA code of practice have been included where appropriate.
Edge Training and Consultancy	Short	17	6	*Health and social care services should ensure that best interests decisions are being made in line with the Mental Capacity Act.* The wording – *should ensure* – is too vague. It is a legal requirement to follow Section 4 when a person lacks capacity. See case of Elaine Winspear v City Hospitals Sunderland NHS Foundation NHS Trust [2015] EWHC 3250	Thank you for your comment. The wording has been amended to 'must' ensure to reflect that this is a legal requirement.
Edge Training and Consultancy	Short	18		except in emergencies. Clarification that the exception relates to recording the assessment and not to the assessment itself. ie unconscious patient would fail the test immediately because they cannot 'understand info relevant to the decision'. In this example, the assessment would take a second so can be done in an emergency even though the recording will not.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Edge Training and Consultancy	Short	21	20	*An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT or a living will) is a decision people can make now to refuse a specific type* This fails to explain ADRT is part of the MCA and it should reference (for consistency across the guidance) the Section of the Act and the Code of Practice chapter that applies so that staff can get further information which this guidance does not provide.	Thank you for your comment. In light of yours and other stakeholder comments, there is now a much clearer description of advance decisions to refuse treatment in the introduction to the section on advance care planning. In addition the definition provided in the 'terms used' section has also been revised and we hope this addresses your concerns.
Edge Training and Consultancy	Short	22	2	*When a person who may lack mental capacity now or in future gives permission to someone to do something for them.* This is not the definition of consent. Reference should be made to DoH guidance or the case law on consent. Consent must be informed = information on the nature, purpose and consequences of treatment/care given to the person which they understand AND the consent is freely given (not coerced).	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Edge Training and Consultancy	Short	23	16	*When authority is given to a person to act for someone else, such as a person authorized to act on behalf of someone who lacks mental capacity to make decisions.* This is not at all clear as the question would be what legal authority do they have to make decisions for someone lacking capacity – they answer would not be proxy but they are an LPA, deputy, appointee (benefits). Only an LPA or Deputy for health and care (personal welfare) could make decisions for treatment.	Thank you for your comment. We have now removed the term 'Proxy' from the revised version of the guideline.
Edge Training and Consultancy	Short	23	16	*Psychiatric advance directive*	Thank you for your comment. We have now removed the term 'Psychiatric advance directive' from the revised version of the guideline.

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				These do not have a legal basis in the law of England or Wales and this term is not part of the MCA, Mental Health Act 1983 or their respective Codes of Practice. See Chapter 9 of the MHA Code of Practice which states in the preamble: *"Advance statements do not legally compel professionals to meet patients' stated preferences, though they should be taken into account when making decisions about care and treatment. Advance decisions to refuse treatment are legally binding."* By adding in additional ideas or terminology, the legal structure we already have often becomes diluted so staff are distracted by terms that are not based in law instead of focussing their minds on the legal position. An Advance Decision under the MCA can be used to refuse psychiatric treatment (although ultimately the use of the Mental Health Act 1983 can override this in the majority of cases).	
Edge Training and Consultancy	Short	23	25	*Substitute decision-making* As with previous comments immediately above- no legal basis in law and the guidance should adhere to the legal terms lasting power of attorney or deputy.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
Edge Training and Consultancy	Short	24	4-8	Says that duty of care is defined but where is this definition from? It does not accurately encapsulate the case law. The word 'may' should be deleted from line 6.	Thank you for your comment. 'Duty of care' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Faculty of Intensive Care Medicine	Short	General		The advance planning element, although good, may not give enough consideration to exploring what a person may wish in an emergency situation. In effect, the same status quo remains of acting in presumed 'best interests'. This could be a missed opportunity to emphasise that advance planning is not just about likely treatment decisions but about consideration of what would be consistent with wishes if an emergency arose.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Gloucestershire County Council	Full	General	general	We welcome the draft guidance and consider it will assist practitioners in their understanding of the MCA and how its principles should be enacted. One of the impediments to giving the full weight of the MCA in practice is time. A good capacity assessment requires good communication between the assessor and the individual. The evidence suggested that many individuals do not feel they are part of the assessment or best interest process and their views are not being listened to. Assessor and decision makers need to take the time to build a relationship with an individual to allow them to understand the views and wishes of that person. Good recording of the views of all relevant people is key to demonstrating good assessment and best interest decision making. If an individual whose capacity is in question is to be at the centre of the assessment and decision making it is important that practitioners accurately record the views of the individuals. Recording can be made in existing patient files without significant additional cost. One of the purposes of the MCA is to empower individuals to make decisions for themselves where they are able to do so. Research into costs implications for health and social care of taking decisions in full compliance of the MCA compared	Thank you for your comment and support for the guideline. The Committee agreed strongly on the importance of a person-centred approach and of appropriate recording. In relation to your suggestion for research, the committee do not believe that it would be ethical to recommend research in which people were purposefully disempowered.

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				to the costs of not empowering individual's choices (the state making decisions without due processes being followed) would be welcomed.	
Gloucestershire County Council	Full	8	194	The guidance could include a reference to the legal duties on LA's and Supervisory Bodies (DOLS) to commission and provide independent advocacy in appropriate circumstances.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation now reads that the expansion of statutory advocacy commissioning should be considered. The committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
Gloucestershire County Council	Full	9	227	The Guidance could include more examples of how communication must be accessible to individuals and families/carers, in line with principle 3 (Section 1(3) MCA 2005). The importance of this principle cannot be over estimated if the principles of the MCA are to be truly embedded in all professionals practice. An example is the use of this question in an assessment of a person with a learning disability's capacity regarding finances: "What are the disbenefits od someone having control of your finances?" The question may be in line with the language used in the MCA; however professional must use language appropriate communication if principle 3 is to be given its full effect.	Thank you for your comment. The examples of accessible communication for individuals and families/carers are covered by other recommendations, including one of the overarching principles, which states that when information given to the person should be accessible, relevant and tailored to their needs. In addition, there are specific recommendations about supporting families to be involved in best interests decision making including through the provision of a wide range of information in an accessible format.
Gloucestershire County Council	Full	12	316	6 1.3 Advance care planning We suggest that this section is confusing. We would suggest an alternative wording: Advance care planning is a term to describe various ways of planning ahead including; statements of wishes and preferences/Advance Decisions/End of life planning. A further option for planning ahead is to appoint a Lasting Power of Attorney Greater emphasis should be given to practitioners understanding of the role of Advance Directives (AD), which under the MCA 2005, must be followed where the AD is valid.	Thank you for your comment. The section relating to advance care planning has been edited to provide clarity and detail has been added regarding advance directives, advance statements, etc.
Gloucestershire County Council	Full	15	410	The auditing of the quality of mental capacity assessment is supported as an important measure to ensure consistency of good practice across professionals.	Thank you for your support for this recommendation.
Gloucestershire County Council	Full	25	675	The definition of Advance directive: *An advance directive is a way of making a person's views known if he or she should become mentally incapacitous of giving consent to treatment, or making informed choices about treatment, at some future time.* An advance decision is a statement of instructions about what medical treatment you want to refuse in case you lose the capacity to make these decisions in the future. It is legally binding.	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Gloucestershire County Council	Full	25	679	The definition of consent given here is incorrect. "*1 Consent 2 When a person who may lack mental capacity now or in future gives permission to 3 someone to do something for them.*"	Thank you for your comment. The definition of consent has been edited to address your comment.

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				A person lacking capacity on a particular decision now, would be unable to provide consent to relating that decision. The views of the incapacitated person are still an important and relevant part of the decision making process.	
Gloucestershire County Council	Full	26	726	*19 Psychiatric advance directive* - Further clarification is needed on the role of PAD's in relation to Advance Directive and LPA's. How does the PAD differ from the AD or LPA and which would have legal authority in cases of dispute? Clarification would be helpful on the interplay with the role of Nearest Relative under MHA 1983 and the PAD.	Thank you for your comment. The term does not appear in the recommendations and therefore is not defined in the short guideline. It was only defined in the full guideline because it is mentioned in the included evidence. However to avoid confusion, this has now been deleted from the full guideline.
Guy's and St Thomas' NHS Foundation Trust	Short	General	General	- It appears that no-one on Guideline committee nor co-opted is a clinician in an Acute NHS Hospital sector	Thank you for your comment, we felt that the committee provided a good representation in terms of practitioner expertise as well as experts by experience. Where a gap was identified among the group, a consultant psychiatrist from AWP NHS Trust was co-opted because he was able to provide vital clinical expertise.
Guy's and St Thomas' NHS Foundation Trust	Short	General	General	- The guideline reads very much as if aimed at those involved in decision making over medium to long term rather than more immediate requirements as in the acute NHS sector.	Thank you for your comment, the committee were determined to ensure that the recommendations apply to decision making across a broad spectrum, including significant decisions about health and welfare as well as every day decisions, for example in care home or other long term settings. Following consultation they reviewed the recommendations to ensure they address decision making across this spectrum.
Guy's and St Thomas' NHS Foundation Trust	Short	General	General	- A significant change in the emphasis on independent advocacy services (IAS)- far beyond the IMCA use criteria as per MCA. Define IAS. Costs of such an expansion at a time of financial restraint to ss and nhs. Those truly in need of these services might get less support as diluted down by others using the services when not necessary.	Thank you for your comment. The committee reviewed the recommendations following consultation with a particular focus on the advocacy recommendations. In the final draft, they refer to expansion of advocacy commissioning in terms of a 'consider' recommendation, thereby reducing the resource impact.
Guy's and St Thomas' NHS Foundation Trust	Short	General	General	- The concept of a "reasonable belief" of a lack of capacity for decisions as in the MCA and code of practice is not mentioned but this is important for day to day care delivery in some situations. It's applicability and use should be mentioned.	Thank you for your comment. The committee reviewed the guideline following consultation and made numerous changes including revising the context section to emphasise the relationship between the guideline and the mental capacity legislation, which is clearly the crucial legal context within which practitioners will implement this guideline.
Guy's and St Thomas' NHS Foundation Trust	Short	General	General	This document is also to be used by users of health and social care and their families but focuses very much on the role of providers. The public needs to be made aware of their right to advocacy, advance care planning etc. and empowered to engage in the decision making and advanced care planning. How are the general public made aware of the information in this document so that they do not view advanced care planning as something negative and health driven?	Thank you for your comment. The guideline does aim to improve practice and by doing so also ensure that people using services understand what they can expect in the context of decision making and mental capacity. However NICE also produces additional material to support the implementation of the guideline, including materials for people using services and their families. This can be found under the 'information for the public' 'tab' on the guideline page following publication.
Guy's and St Thomas' NHS Foundation Trust	short	3	3	Providing training within acute services has its challenges with it ever transient population and staff being available for lengthy training programmes. Such a key piece of legislation the formal and in-depth training should be undertaken at pre – registration where many of the suggested topics should be addressed. Practitioners must have a certain level of knowledge and will be supported with organisational training that refreshes and updates knowledge of the MCA requirements and introduces the procedures within the organisation. Despite all provider organisations providing training the MCA is still slow in being implemented, there needs to be more guidance or evidence based training programmes that are co-	Thank you for your comment and your support. This is certainly what the committee endeavoured to address in recommendation 1.1.1. However they recognise there is a gap in the evidence base on this issue and have therefore recommended that research is commissioned to address this.

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				developed with those who have experience of the MCA being used in their care, supported by central government.	
Guy's and St Thomas' NHS Foundation Trust	Short	4	21	Recording and updating information about people's wishes and preferences in a way that practitioners from other agencies can access will be challenging especially when not all health and social care systems are aligned in a way that information can be shared easily. People's wishes and belief may be situation specific and may vary with time. Keeping the information updated will be challenging especially if the person is being treated by a number of practitioners, within the organisation and other agencies	Thank you for your comment. The committee reviewed evidence, which was supported by their own expertise, which provided a sound basis for this recommendation. They agree that in areas where this is not already happening, the recommendation may be challenging and aspirational but they also believe it is achievable within current resources and that any costs outweigh the benefits of doing so.
Guy's and St Thomas' NHS Foundation Trust	Short	4	28	IMCA services are for people who lack capacity and are unbefriended. With friends, family and carers available to advocate for the person, what will be the role of the IMCA who are currently commissioned to represent those who are befriended	Thank you for your comment. The committee discussed your point and agree that IMCAs can be involved even if people have friends and family. The circumstances would be a) that the professional considered the friends/ family to be inappropriate or b) that there are safeguarding issues in which case the IMCA can provide additional, knowledgeable support.
Guy's and St Thomas' NHS Foundation Trust	Short	5	8	is that ALL people regardless of the complexity/ risk of the decision and regardless of their capacity status? And for those that lack capacity a referral should be made to IMCA……. This appears to be changing the MCA referral reasons for an IMCA, broadening it to any decision making for people that lack capacity to make that decision. Which decisions would the advocate be involved in	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to clarify the need for statutory advocacy and take into account stakeholder concerns regarding the resource implications of the previous recommendations..
Guy's and St Thomas' NHS Foundation Trust	Short	6	4	Needs clarity as to whether this applies to people with capacity for the decision, those without capacity or both. I suspect all. It is helpful to have a check list of considerations to be taken into account that may affect one's ability to make a decision required, but there may be limitations to how many of these factors can be considered when patient is acutely ill and decisions need to be made quickly	Thank you for your question. The process of supporting someone to make their own decisions must be in line with the principles of the Mental Capacity. The assumption is that they have capacity to do so and they should not be treated as though they do not have capacity unless all practicable steps have been taken unsuccessfully to help them. Therefore the recommendation applies to everyone – until they have been assessed as lacking capacity to make the decision.
Guy's and St Thomas' NHS Foundation Trust	Short	6	10	the list should include temporary factors such as delirium, sedatives, alcohol	Thank you for your comment. The committee agreed that your suggestion is best addressed by adding a bullet point to Recommendation 1.2.4 referring to the effects of prescribed medicines or other substances. They felt that delirium was addressed in the bullet point citing cognitive factors.
Guy's and St Thomas' NHS Foundation Trust	short	8	5	"one session" sounds institutional- "once" seems more appropriate and generic across all systems this guideline applies too.	Thank you for your comment. We have retained the original wording.
Guy's and St Thomas' NHS Foundation Trust	short	9	7	ACP is………."other ways of doing this are……. It's not an either or situation. Appointing a LPA or creating an advance refusal of treatment can be part of ACP or compliment other forms of ACP.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.
Guy's and St Thomas' NHS	short	10	3	Some clarity is required on what decisions health and social care practitioners would be supporting a person following a diagnosis. Health practitioners would be best placed to support people with their future health care needs	Thank you for your comment. We have edited the recommendation to clarify that all practitioners should be able to enable access to advance care planning.

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Foundation Trust				Not all health staff will be confident in co-producing an advanced care plan with a person, when would the right time, during an acute episode of care where there will be time constraints as people need time to consider all aspects of their lives before making decisions that will affect their life and family. What discipline or seniority of practitioner should be involved in co-producing advance care plans with people? Should personal assistants be involved in co-producing advance care plans as they are also considered social care practitioners? The GP will have a key role to play in this aspect of care.	
Guy's and St Thomas' NHS Foundation Trust	short	10	12	Practitioners should be able to provide information concerning disease trajectory and prognosis	Thank you for your comment. We believe that this point is adequately covered in the recommendation wording of 'their condition'.
Guy's and St Thomas' NHS Foundation Trust	short	11	22	Are accessible documents hand held records? What will the status of these documents be? To be implemented widely and recognised by all practitioners this will need to be nationally supported. It will require agreement and implemented nationally. This will require a public campaign to raise its awareness. There needs to be training for practitioners on advanced care planning if the role in supporting people produce their own care plans can be any health and social care practitioner.	Thank you for your comment. We hope that this recommendation will contribute to practice in this area. The training recommendations in the overarching principles of the guideline also help to address this issue.
Guy's and St Thomas' NHS Foundation Trust	short	12	22	"accessible care plans" is this National terminology? There needs to be clarity on "which organisations have a responsibility for accessible care plans"	Thank you for your comment. We have edited this text for consistency with the rest of the guideline.
Guy's and St Thomas' NHS Foundation Trust	Short	13	14	useful checklist	Thank you for your support.
Guy's and St Thomas' NHS Foundation Trust	Short	4	11	Should state all adults are presumed to have capacity unless proven otherwise. The current statement risks all adults capacity being questioned and might be misconstrued by some (124 line 1 of the main draft guideline does state this- just not in the short version which is likely to be the one read by most people)	Thank you for your comment. A new recommendation (1.1.4) has been added to emphasise the presumption of capacity.
Hampshire County Council	Full	General	general	Answer to question 1 - *Rather than "areas" as such, the biggest challenge will be changing culture. The other fundamental challenge will be the ability to have a sufficiently developed trusting relationship to enable these discussions to happen in a meaningful way e.g. rapid flow through hospital, the changing nature of primary care moving away from traditional general practice, new models of care that disperse support etc. could impair the relationship with individuals and prohibit meaningful discussions*.	Thank you for your comment and for highlighting a challenge that can be considered during implementation support work.
Hampshire County Council	Full	General	general	Answer to question 2 - Yes, insofar as a considerable cost relating to the implementation of universal workforce development to ensure consistent practice and the audit and evaluation to demonstrate the difference.	Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to assess likely resource impact which was

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				However, if practitioners are reminded to prepare for their capacity assessments from the start thoroughly it will reduce work and cost in the end, as managers/services will not send the assessments back asking for better evidencing etc.	shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Hampshire County Council	Full	General	general	Answer to question 3 - Having an assessor who is clear on the salient facts and details of the decision will help the client. Having an assessor who is using principle 2 correctly will help clients protect their adult autonomy. As regards resources, we need to use a diverse range of media and support – e.g. a You Tube video that showcases how the guidelines should be implemented; the personal feedback from people who understand the implications etc as well as national, standardised learning resources for reference. Also it may help for NICE to produce a Frequently Asked Questions document, supporting an online "chat room" where people can offer peer support.	Thank you for your comment. The Guideline Committee agreed that the guideline should help assessors be clear about what constitutes good practice in assessment, building on what they are required to do by law and the guidance and standards relating to their own professions. We will pass on your suggestions regarding resources to our implementation support team.
Hampshire County Council	Full	General	general	Positive feedback: It is good that the guideline emphasises principle 2 and a key point is that the practitioner should record what steps they have taken to help the person understand the information. It is good that the guideline advises the practitioner to record what information the person is actually given.	Thank you for your comment and support for the guideline.
Hampshire County Council	Full	General	general	Gaps in the guidelines: It would be helpful to emphasise the importance of telling the person what the actual decision at hand is and why you are meeting with them. Could it be emphasised that the 5 Principles actually apply at different times in the mental capacity process, so Principles 1, 2 and 3 must be applied at first aiming to help the person make their own decision. Then Principles 4 and 5 are only applied once a person has been deemed to lack capacity and a best interest decision is being made. We often see people say, 'the client has made their own decision in their best interests' – confusing principle 1 with Section 4. Or not uncommonly we might hear a practitioner say, 'we involved the client in the decision making process', thinking that they were the decision maker but actually it was the client's decision to make and so they should have been focusing on Principle 2 and not on Section 4 (4). The guideline talks about auditing the capacity assessments: could it give examples of good recording? We often see capacity assessments that just repeat the question and do not actually record clear evidence. Could the guideline provide clarity on evidencing Section 2 and 3 and why the person lacks capacity? Could the guideline remind practitioners to check if the client set up any 'future proofing' eg. Lasting Power of Attorney (LPA), when the outcome of the assessment is that they lack capacity. Could the guideline manage situations where the decision maker is a family LPA and they are not clear on their role or need support in using Section 4 to make a best interest decision? We also suggest including in the guideline a clear explanation of who the decision maker should be within the scope of the best interest decision making process.	Thank you for your comment. The Guideline Committee agreed on the importance of telling the person what the actual decision at hand is; this recommendation (numbered 1.2.5 in consultation version of guideline) seeks to address this by making reference to the need to provide the person with information about this specific decision being made, as well as about the process and principles of supported decision-making. We have updated the introduction in the full guideline to reflect your comments about the Five Principles and introductions have been added to each section to help make clearer how the guideline relates to the MCA and Code of Practice. The Guideline Committee agreed that it is important to monitor and audit the quality of assessments which drove recommendation 1.4.1 (numbering from consultation version of guideline). We did not explicitly search for evidence on best practice in respect of auditing and recording as part of the systematic review work. NICE guidelines also seek to allow some flexibility for implementation at the local level. Thank you for your suggestions about LPA, which the committee discussed. Instead of making this specific suggestion for practitioners to check whether LPA has been established, the committee agreed to make a general recommendation, ensuring that training for all practitioners should include the 'the processes and laws surrounding advance decisions to refuse treatment and LPA' – this is in recommendation 1.1.1. In relation to your suggestion about managing situations where a family member is an LPA, the committee agreed to address this in section 5 on best interests

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				In the past colleagues have sometimes found, when chairing best interest decision meetings, that no one was prepared to identify themselves as the decision maker, or were worried about taking on the responsibility, saying that the meeting was the decision maker, or that their manager would be the decision maker. Obviously this is not necessarily the case. It might be helpful to include guidance from the MCA Code of Practice about who a decision maker should be.	decision making. As well as ensuring that everyone know who the best interests maker is, the committee added that if the decision maker is a family member who requires support in their role, this should be provided in line with the recommendation sin section 2 on supporting decision making. Finally, in relation to your suggestion about the identity of the decision maker, this has been addressed through the addition of an introductory paragraph for section 5 on best interests decision making. Overall, the Guideline Committee sought to refer to and build on, rather than replicate, the MCA and Code of Practice so far as possible. The guideline introduction has been updated, following consultation, to make clearer the link with existing legislation and guidance. Introductions have been added to each section to support this.
Headway – The Brain Injury Association	Full	7	186	We suggest including memory aids in this list. Brain injury survivors often have memory problems, and may be reliant on the provision of memory aids to assist in decision making. For example, a brain injury survivor may be told some vital information regarding a decision that needs to be made, but fail to recall this information when asked about it a few minutes later. In this instance it would have been helpful to initially record the information provided, either orally or physically, as a memory prompt so that they can continue to be supported with making an informed and supported decision.	Thank you for your comment. Evidence in relation to memory aids was not identified in the systematic literature review.
Headway – The Brain Injury Association	Full	9	226	Headway delivers a range of training courses designed to educate people on the impact of brain injury. There are a number of training courses offered specifically to professionals to give them core skills required when working with a person with acquired brain injury. Readers of this guideline (IMCAs and otherwise) might benefit from being informed of such training opportunities. Headway also offers an award winning range of publications that can be referred to by readers to gain information and guidance on various aspects of brain injury. These are available to download free of charge from www.headway.org.uk/information-library. Please consider including this information or weblink in this section of the guideline or in an appendix further on.	Thank you for your comment, which we will consider as part of the work on implementation.
Headway – The Brain Injury Association	Full	9	243	Whilst we appreciate the inclusion of cognitive and emotional factors in this list, we feel there needs to be an explicit mention of the person's insight into their reduced capacity to make decisions. Brain injury can sometimes result in a person lacking insight into the impact of their injury (anosognosia), which can significantly impair the recognition of assistance needed for supported or best-interests decision making. We would therefore recommend a separate point to be listed regarding lack of insight, or a mention of this next to 'cognitive factors'	Thank you for your comment. In response to this, the Guideline Committee has suggested that we expand the bullet point on cognitive factors to include reference to your point about awareness of an individuals' reduced capacity to make decisions.
Headway – The Brain Injury Association	Full	10	259	We would recommend offering both audio or video recording as well as written recording of information that is given, to ensure an accurate record is made and there is clearer transparency with decisions made.	Thank you for your comment. The Guideline Committee feel that using the word 'recording' is sufficiently broad, covering whatever means of recording is most appropriate in the situation. They don't believe 'record' as it is used in this recommendation necessarily implies that it is done in writing.
Headway – The Brain	Full	13	335	We would suggest explicitly stating that the information provided should be printed as well as presented verbally in order to assist brain injury survivors who have memory problems or difficulties with concentration/attention/cognitive fatigue etc.	Thank you for your comment. Overarching principles about how to provide information, including ensuring that information is accessible and tailored to each person, are given in recommendations 1.2.6 to 1.2.7.

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Injury Association					
Headway – The Brain Injury Association	Full	15	408	Many brain injury survivors are not treated or supported by mental health teams due to the differences between mental health and brain injury and lack of recognition between the two services that these two conditions can overlap (further information on this is available in the Headway factsheet *Mental health and brain injury*). We would therefore recommend that this section also lists neurological services to ensure applicability to brain injury survivors.	Thank you for your comment. The evidence on which this recommendation was based suggested that joint crisis plans may be suitable for people with mental disorders. It was not therefore appropriate for the GC to refer to people with brain injuries or access to neurological services in this recommendation.
Headway – The Brain Injury Association	Full	16	443	Please also list memory aids in this line	Thank you for your comment. This example is intended to be illustrative rather than an exhaustive list.
Headway – The Brain Injury Association	Full	16	445	Please also list people with cognitive fatigue and information processing difficulties, as they may require more time for an assessment. Further, people with fatigue may require an assessment to be carried out over more than one session, or with breaks in between.	Thank you for your comment. The committee agreed to revise this recommendation and add greater detail, which should help to address your comment. Although there is no specific mention of 'cognitive fatigue', the recommendation does now refer to the need for reasonable adjustments, including delaying an assessment.
Headway – The Brain Injury Association	Full	17	450	Please also include when a person feels less fatigued in this list.	Thank you for your comment. This example is intended to be illustrative rather than an exhaustive list.
Headway – The Brain Injury Association	Full	17	475	Please also include here individuals with memory problems who may require memory aids.	Thank you for your comment. This example is intended to be illustrative rather than an exhaustive list.
Headway – The Brain Injury Association	Full	18	498	Executive dysfunction can be experienced by people with all forms of acquired brain injury, not just traumatic brain injury. Please consider changing traumatic brain injury to acquired brain injury.	Thank you for your comment. We have retained the phrase 'traumatic brain injury' to emphasise the link with executive dysfunction.
Headway – The Brain Injury Association	Full	18	501	Family members and carers can often also provide useful and insightful supplementary information about a brain injury survivor, especially with issues of executive dysfunction or where a lack of insight is an issue. Please consider stating that family members and carers should be consulted, alongside making real-world observations about behaviour.	Thank you for your comment. We believe that this is covered in the recommendation numbered 1.4.15 in the draft guideline.
Headway – The Brain Injury Association	Full	19	526	Please consider including an additional point 1.4.28 about providing follow-up emotional support and information after the assessment, as well as guidance on what to do if the person's decision has changed or if they need any further support.	Thank you for your comment. We believe that this is covered adequately in recommendation 1.4.27.
Headway – The Brain Injury Association	Full	31	826	Please change 'head injury' to 'brain injury' to make this more inclusive.	Thank you for your comment. We have now change 'head injury' to 'brain injury'.
Headway – The Brain Injury Association	Full	31	828	Please also mention here the fluctuating nature of these conditions.	Thank you for your comment. We have now made reference to the fluctuating nature of dementia, a learning disability, an acquired brain injury or a mental illness.

Decision making and mental capacity

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Headway – The Brain Injury Association	Full	32	833	Please change 'head injury' in this box to 'brain injury' to make this more inclusive.	Thank you for your comment. In the final version of the short guideline, we have deleted the box.
Headway – The Brain Injury Association	Full	38	930	Please change 'brain damage' to 'acquired brain injury' if this wording has not been directly lifted from Code of Practice.	Thank you for your comment. This wording was lifted from the Code so we have not made the change you suggested.
Headway – The Brain Injury Association	Full	400	7299	Further detail should be offered on the implementation and evaluation of this training, or further detail should follow publication of this guideline. In addition to this, despite the challenges that such training would present, it is of key importance that condition-specific training should be delivered as the nature of lacking capacity following a brain injury would differ to the nature of capacity issues of other conditions.	Thank you for your comment about condition-specific training, which we will consider as part of the implementation work.
Headway – The Brain Injury Association	Full	400	7309	Please consider specifying that advocates should be trained and have good understanding of specific conditions. General advocates without this specific knowledge would not be able to appropriately support an individual who lacks capacity, especially if the condition is fluctuating or if the individual lacks insight into their own issues. This specification is mentioned in line 226 in the Recommendations section, but should be included here as well for clarification.	Thank you for your comment about training, especially condition-specific training of advocates, which we will consider as part of the implementation work.
Hounslow and Richmond Community Healthcare NHS Trust	Short	3-4	all	Our Trust has made a 27 minute open source 'Show How to Know How' training film about using (and recording) principles of the MCA in the community. It has been well received so far across the UK (health and social care including carers). There is also an accompanying booklet for those who don't use Youtube. **Watch the film on our website here** Contact Sandie Cox sandie.cox@hrch.nhs.uk	Thank you for your response. We will pass this information to the resource endorsement team. More information on endorsement can be found here.
Hounslow and Richmond Community Healthcare NHS Trust	Short	5	25-28	I feel it would be more effective to encourage interprofessional working (IMCAs and other advocates encouraged to work with local professionals e.g. SaLTs as suggested on P8 line 15-8, P11 line 9 and P12 line 20-21.. There are no additional resources to invest in training advocates and the staff churn and lack of timely access to advocates in many areas would dilute this effort. Better to utilise the professionals who are up to date with research and training and can deliver effective outcomes in local partnerships.	Thank you for your comment. Thank you for your comment. The committee believes that this recommendation is affordable within current resources, even if this means using them slightly differently.
Hounslow and Richmond Community Healthcare NHS Trust	Short	8	12-14	This may be unrealistic, depending on the service. It also risks expertise not being built across teams.	Thank you for your comment. The recommendation states this should be done 'where possible', in recognition that this may be difficult in some areas.
Hounslow and Richmond Community Healthcare NHS Trust	Short	14	25-29	I am concerned that this is confusing to practitioners re consent provided to identify people to liaise with (given that valid consent must be capacitious) that it refers to 'functional capacity' and encourages practitioners to build a picture from family friends etc. This is a tricky area as while we must consult, wording should not encourage practitioners to rely on others to tell them whether this person can generally make decisions as this is likely to elicit previous unwise decision making (e.g. a young adult with LD or a parent with memory loss) Family and friends are	Thank you for your comment. The reference to functional capacity has been removed.

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				often protective and not aware of the person's right to make their own decision if they can.	
Hounslow and Richmond Community Healthcare NHS Trust	Short	15	15-19	Again, this is likely to be tricky for practitioners. Executive dysfunction should be encompassed within the weighing test. Legally, I don't think there is precedent for 'real-world observation' of the person's functioning and ability' This seems to contradict the decision and time specific element. Such observations felt to be of value should be very carefully worded (with legal oversight) and separated from the operational guidance.	Thank you for your comment. The recommendation has been amended following legal advice to ensure that the intention is clear and legally accurate.
Include	Short	3	14	Concerned that this statement implies the communication skills are required only for building trust, when the communication skills are also vital for facilitating informed decision making	Thank you for your comment. This bullet has been revised to make it clear that communication skills are also needed general terms for working with people who may lack capacity.
Include	Short	4	7	Concerned there is no mention of training practitioners to use the specific tools identified or devised	Thank you for your comment. The committee agreed that training was important, but felt that it was implicit in the need for those tools to be devised that would help practitioners.
Include	Short	6	14	Concerned there is no mention of the need to take into account what communication strategies have proved useful in the past	Thank you for your suggestion. The committee did not feel this addition was necessary because the recommendation already includes communication needs and as a whole the guideline places a lot of focus on communication strategies and approaches to support communication.
Include	Short	7	25	Concerned that the parantheses 'particularly if the advocate has worked with the person before' may be seen as a 'get-out' clause for not involving advocacy at all – something which is a real challenge in the current commissioning landscape	Thank you for your comment. The committee made a number of detailed recommendations about advocacy in the overarching principles of the guideline. These have been clarified and strengthened in light of stakeholder comments.
Include	Short	8	19	Concerned that 'when person has a 'communication impairment' isn't specifically mentioned as a condition when referrals to other professionals should be made	Thank you for your comment. This wording of the recommendation is deliberately broad to cover a number of reasons why decision needs in relation to decision making may be complex. Speech and language therapists are given as an example of a professional to whom people may be referred.
Include	Short	8	24	Felt that exactly what capacity is being assessed for / what decision is being made needs to be recorded in the written process too (it's often omitted, so even though this is mentioned elsewhere, feel it's worth stating clearly as part of written process)	Thank you for your comment. The Guideline Committee agree that recommendation 1.2.17 should include 'what is being decided as part of the written process. The committee also agreed that this is not a 'must' recommendation because the decisions could be really insignificant ones.
Include	Short	13	6	Felt assessors also need knowledge of and ability to meet additional communication needs	Thank you for your comment. The committee believe that this is covered adequately in the recommendation numbered 1.4.10 in the guideline.
JS Parker Ltd.	Full	General	General	We are delighted to see the need for IMCAs to have expertise in specialist areas such as acquired brain injury, a requirement that has been lacking in our experience.	Thank you for your comment and support for the guideline.
JS Parker Ltd.	Full	6	150	We would add that wherever possible training should be classroom based and relate specifically to the area that the learners are working in. For instance, if the training is being delivered to specialist brain injury workers, the training should relate specifically to the issues and challenges associated with that specific role. We would advocate such training to be classroom based rather than e-learning, but where e-learning is used, it should be relevant to the field of work.	Thank you for your comment. There was no evidence that training should be classroom based and furthermore, this may not always be practical. The recommendation already specifies ways in which training should be tailored to people's roles, for example through the provision of condition-specific information.
JS Parker Ltd.	Full	8	202	The use of statutory or non-statutory independent advocacy should be based on specialist knowledge of the advocate. Where an existing "advocate", such as a brain injury case manager, is already working with the client, and no conflict of interest exists, the benefits of the advocate having a pre-existing relationship with the person should be taken strongly into account.	Thank you for your comment. The Guideline Committee agree that the use of statutory or non-statutory independent advocacy should be based on specialist knowledge of the advocate. The guideline includes a training recommendation in the overarching principles about required specialist knowledge for practitioners

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					working with people who may lack capacity. Following consultation feedback, the recommendation on advocacy has been reworded.
JS Parker Ltd.	Full	9	224	We strongly agree that IMCAs should have expertise in specific areas that require additional skills such as acquired brain injury. We have many experiences of IMCAs without this knowledge where the client's needs have not been taken into account and decisions have, in our opinion, not been in the client's best interest. For IMCAs to acquire this level of expertise, they should be recruited/sourced from relevant fields and have experience of working with clients with brain injury in the community. Where this is not the case, specialist level training will be required.	Thank you for your comment and support for the guideline.
JS Parker Ltd.	Full	15	418	Brain injury case managers are also well placed to offer advice in this area.	Thank you for your comment. The examples provided are intended to be illustrative rather than an exhaustive list.
JS Parker Ltd.	Full	18	497	We strongly agree with this – executive dysfunction is often missed and under-estimated in assessment of clients with acquired brain injury. Real-work observations are so important with this client group.	Thank you for your support.
Kent County Council	Short	General	general	As an overall comment from Kent County Council we welcome the document and the references to working in partnership. In Kent the Local Implementation Network (LIN) has continued since the introduction of MCA/DOLS and has multiple benefits including sharing good practice and identifying challenging themes that arise, for multi-agency resolution. We would strongly recommend that the work completed by SCIE and ADASS is considered within the further development of this document by NICE. The lessons learned from our local authority experience of <u>some 18 DOLS</u> appeal cases under Court of Protection proceedings is that the principles need to be clearly evidenced as being considered, particularly with regard to ensuring that options have been provided and that the recommendation from best interests decision is absolutely the less restrictive. An further action from our Local Authority learning is that there is work being undertaken with practitioners to promote the recording of wishes, feelings, beliefs and values while persons have capacity.	Thank you for your comment and support for the guideline. Thank you also for the information you provide, which we will share with the endorsement team.
Kent County Council	Short	4	1	Our Mental Capacity Act (MCA)/ Deprivation of Liberty Safeguards (DOLS) service find that Lasting Power of Attorney (LPA) for health and welfare (H and W) is frequently not in place at the point a person loses capacity even if it has been previously recognised and LPA for health and welfare has been put in place as part of advance decision making. Would it be possible to highlight this e.g. including Lasting Power of Attorney for H and W and Property and Affairs.	Thank you for your comment. The inclusion of sources of advice and information has been left broad as this could include a range of possible advice sources. However, an earlier bullet highlights the need to explain processes including lasting powers of attorney.
Kent County Council	Short	4	11	1.1.4 – The recommendation would benefit from qualification regarding consent forms, our Best Interests Assessors (BIA) have frequently seen consent forms signed by another person without reference to any Mental capacity Assessment or Best Interest (BI) meeting decision making process for support.	Thank you for your comment. Although they considered your suggestion the committee decided not to edit this recommendation. They feel the issues you raise are addressed comprehensively in the rest of the guideline, namely in the capacity assessment and best interests sections.
Kent County Council	Short	4	14	1.1.5 – The challenge raised by practitioners is when giving information to a person is the time required, which would more clearly support sufficiency. Acknowledgement within the guidance of the practitioner requiring time should be considered. It is noted there is some reference at point 1.2.13.	Thank you for your comment. The committee acknowledge that more time may be required to ensure that people are fully supported in making their own decisions. In this context they believe the recommendations are aspirational but achievable.

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Kent County Council	Short	4	21	1.1.6 - Experience from legal cases highlights - *Record and update information about people's wishes, beliefs and preferences*, is essential to have some record of before there is any query regarding decision making and capacity. This can greatly inform best interest decisions that maybe required.	Thank you for your comment, with which the committee agrees. The point is emphasised in the guideline generally, especially in the sections on assessing capacity and best interests decision making.
Kent County Council	Short	5	5-7	1.1.7 – Our Authority has already undertaken all measures to achieve this locally, however out of area remains a challenge not only to KCC but many other local authorities when seeking advocacy due to limited pool of advocates.	Thank you for this information. The advocacy recommendations have now been substantially revised and the one to which you refer is now a 'consider' recommendation for expansion of statutory commissioning, which gives much more flexibility over whether it is implemented.
Kent County Council	Short	5	15	1.1.9 Consider providing independent advocacy when there is a safeguarding concern needs to be reworded in keeping with Care Act guidance 2014 chapter 14 e.g. *The local authority must arrange, where appropriate, for an independent advocate to represent and support an adult who is the subject of a safeguarding enquiry or Safeguarding Adult Review where the adult has 'substantial difficulty' in being involved in contributing to the process and where there is no other appropriate adult to assist.*	Thank you for your comment. Following consultation feedback, the recommendation on advocacy has been reworded and there is now a 'consider' recommendation for expansion of statutory commissioning, to reflect the potential resource impact of this recommendation.
Kent County Council	Short	6	3	1.1.2 – Our authority has recently launched a Mental Capacity Act and DOLS policy and practice guidance, that partner agencies including health found useful and it has been agreed that it will be placed on our external website to share – please advise should you wish for us to share this as an example.	Thank you for this information, which we pass to our endorsement team.
Kent County Council	Short	6	8	1.2.2 - "build and maintain trusting relationship" can be challenging within some settings and may not be possible to maintain, particularly within the acute sector. It may benefit from being expanded to acknowledge *whenever this is possible*	Thank you for your suggestion. The committee feel this is an important recommendation and do not believe that it would be appropriate to add this caveat.
Kent County Council	Short	6	23	Practitioners should clearly determine, at the start, what information they need to cover, based upon experience and audit - we would recommend that the practitioners should clearly determine *the decisions that are to be made* before moving to the information they need to cover.	Thank you for the suggestion. Although the point could arguably be made more explicit the committee addressed this point in a recommendation about recording the decision making process which starts with defining the decision.
Kent County Council	Short	7	13	1.2.9 – For guidelines to be more user friendly, it would in our view be beneficial to emphasise some of the key points as well as the cross-reference to the MCA code of practice for example: - *Try to understand the person's situation (eg to describe the person as challenging/their situation as 'challenging' does not usually convey what their experience actually is.* - *Allow time for the person (is there opportunities to delay decision-making process?)* - *Acknowledge that the following can impact on decision-making: - context - what we know and are familiar with* - *personal values - comparing the past with the present - external factors – choice* - *weighing up outcomes- understanding information and options - emotion-support from others- community presence*	Thank you for your comment. The committee were keen to avoid simply repeating the MCA however they have taken your advice and made a clearer description of the relationship between this guideline and the MCA and Code of Practice. They have also added introductions to the separate sections which link with relevant sections and principles in the Code and in the Act.
Kent County Council	Short	7	18	1.2.10 - Support the person with decision-making even if they wish to make an unwise decision. It may be beneficial to highlight that it is Principle 3 to reinforce *an important element of law, that we all have the right to make our own decisions where we have the capacity to do so*. Otherwise there is a risk where a person's values are incompatible with decision-makers or those of the environment they are in, that they are deemed to lack capacity.	Thank you for your comment. The committee have revised this and made a new recommendation that addresses your comment by referencing the 3rd principle.

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Kent County Council	Short	7	25	1.2.11 - think about involving an advocate indicates that it is an option while the Mental Capacity Act states that Independent Mental Capacity Advocates (IMCA) must be instructed by the 'responsible body', that is, the Local Authority or National health Service (NHS) (essentially the body responsible overall for making the decision) and by an authorised person. It may be useful to provide the criteria for instruction of an IMCA at this point.	Thank you for your comment. The committee made a number of detailed recommendations about advocacy in the overarching principles of the guideline. These have been clarified and strengthened in light of stakeholder comments.
Kent County Council	Short	8	15	1.2.16 – referrals to others would benefit from including legal advice as Court of Protection application may be required in some cases.	Thank you for your comment. The Guideline Committee do not think it is necessary to refer for legal advice in the context of this recommendation 1.2.16 as it will not help and will slow down the process.
Kent County Council	Short	9	3	Based upon recent Safeguarding Adults Review any further actions arising from the decision *including Court of Protection application* could support practitioners in identifying when this route may be considered.	Thank you for your comment. The wording of the recommendation in relation to 'any further actions' is deliberately broad and of course would include Court of Protection applications, but is not limited to them.
Kent County Council	Short	9	6	1.3 - Advance Care Planning …to future care and treatment decisions. It might be beneficial to advise that *The Mental Capacity Act enables people that have capacity to prepare for a time in the future when they may know they are likely to be unable to make certain decisions. It allows us to prepare for the unknown as well as the known through:* - *advance care planning* - *advance decision, and* - *advance decisions to refuse treatment* *Advance care planning should be person-centred and begin with a conversation about what is important to the person. It can be a record of what the person would like others to know as well as how they would feel if others had to make decisions on their behalf. Would they choose to nominate someone that knows them well to be a decision-maker through a Lasting Power of Attorney (LPA)for Health and Welfare for example, or would they find it beneficial to make a list of preferences*	Thank you for your comment. This section has been edited to provide further clarity on the links between these recommendations and the Mental Capacity Act.
Kent County Council	Short	9	9	1.3 - Lasting power of attorney would benefit from qualifying which is relevant within mental capacity assessment. The following may be beneficial to include *'A power of attorney for personal health and welfare is a legal document that gives a person the opportunity to give someone else the authority to make decisions on their behalf. There are also LPA's for property and affairs which do not provide the authority.'*	Thank you for your comment. Lasting power of attorney is defined in the 'Terms used' section and a clearer description of its role is now made in the context of the guideline as well as in the introduction to the section on capacity assessment.
Kent County Council	Short	11	16	1.3.10 - mention could be made regarding the requirement to consult with an attorney or court appointed deputy for health and welfare which could look like this: *' consult with a court appointed deputy or a lasting power of attorney for health and welfare if the individual has been assessed as lacking capacity to participate in advanced care planning to determine their wishes, values, beliefs, aspirations and anything else that they may consider important'.*	Thank you for your comment. This section is about advance care planning with people who may lack capacity now or in the future – that is, a capacity assessment has not been conducted so it is assumed the person can participate in advance care planning. The issue of identifying and consulting with an attorney (in the context of an LPA) is addressed in the section on best interests decision making.
Kent County Council	Short	13	3	1.4.6 - to provide a point of easy reference for practitioners would suggest adding *'and the guidance contained within the Code of Practice'.*	Thank you for your comment. The introduction of each section has been edited to include references to relevant sections of the code of practice.
Kent County Council	Short	13	13	1.4.8 - would suggest adding *'and you may want to offer the person the opportunity to have someone present for reassurance and support'.*	Thank you for your comment. Involving someone with whom the person has a trusted relationship is covered in recommendation 1.4.10.

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Kent County Council	Short	13	27	1.4.9 – could be clarified to accommodate decisions that may not be possible to delay further by adding *'but this may depend upon the urgency of the decision required'.*	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Kent County Council	Short	14	1-4	1.4.9 It depends: a trusted person, e.g. a family member, can be a distraction and it is common for P to defer to that person. In other cases, it is found that P is happy to be guided in making certain decisions by their trusted person. It might be useful for clarification	Thank you for your comment. The recommendation suggests that such a person could be involved if appropriate, rather than prescribing that they should always be involved.
Kent County Council	Short	14	5-6	1.4.11 – Practitioners are required to presume capacity, and in order to test capacity the relevant facts do need to be put to P. In some cases, P has not been told why they are in a hospital/care home, and the facts come as a shock and can affect P's mental state. To ensure that all reasonable steps were taken to prevent distress to P could undermine the validity of the capacity assessment if necessary information was withheld. It would benefit from the addition of an acknowledgement at the end of the point '*However this should not prevent or impede the sharing of the information P requires to make the decision'*	Thank you for your comment. The committee agree that a balance needs to be struck. The text of the recommendation has been edited to make this clear.
Kent County Council	Short	14	9	1.4.12 – may benefit from adding *'but each specific decision will be considered separately'.*	Thank you for your comment. The recommendations have been edited to ensure that it is clear that assessments of mental capacity are decision specific.
Kent County Council	Short	15	5	1.4.16 – To avoid mental capacity assessments being considered as covering all decisions consider that it is important to repeat how it relates to specific decisions based upon the balance of probability may be beneficial to add *'however it's useful to remember each view of capacity is decision specific and made on the balance of probability'.*	Thank you for your comment. The committee agreed to edit the recommendation to make clear that mental capacity assessments are always decision specific.
Kent County Council	Short	15	19	1.4.20 - As assessments take place in a range of settings it may benefit from adding *'as far as is practicable'.*	Thank you for your comment. The committee believe that the recommendation is achievable and do not consider the use of a qualifier to be necessary.
Kent County Council	Short	16	25-29	1.5.1 In practice many capacity assessments are complex and borderline requiring the practitioner to reflect on the evidence and observations before reaching a conclusion about capacity. It does not seem particularly onerous on P for a practitioner to ask questions related to the making of a best interests decision. Furthermore, sometimes information taken from P related to their best interests can be fed back to the care provider to resolve any issues relating to the care arrangements and accommodation. In more difficult capacity assessments where the practitioner needs time to reflect - additional visits to P might be needed. As the exception of emergencies are highlighted in support of practitioners and organisations to achieve good outcomes for P it may benefit from highlighting *…that more complex decisions may require several visits to P.*	Thank you for your comment. The committee did not feel that the wording in the draft recommendations at all implied that best interests decisions should be made within the context of a single conversation or visit. Therefore they did not make any changes in light of your comment although they did endeavour to clarify the meaning with some small edits, expanding on the issue of emergency situations. The recommendation now reads, 'In line with the Mental Capacity Act 2005, practitioners must conduct a capacity assessment, and a decision must be made and recorded that a person lacks capacity to make the decision in question, before a best interest decision can be made. Except in emergency situations this assessment must be recorded before the best interests decision is made.
Kent County Council	Short	18	22	1.5.12 - formal best interests meetings for significant decisions; the word 'significant' is not elaborated upon within this version and our experience is that practitioners believe a formal conference is required for all decisions e.g. flu jab and usual care planning or alternately may not realise when it is e.g. they may stop someone visiting because a close relative or partner has told them to or they may be using various levels of restraint during personal care.	Thank you for your comment. We have added details on these issues to provide clarity about the importance of responding proportionately.

Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
20/12/2017 to 05/02/2018

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Kent County Council	Short	19	8	1.5.14 following the second point steps that have been taken to help the person make the decision themselves may benefit from examples of *: how the Assessor has encouraged the participation of P in the assessment for example any communication aids used or consideration of venue or time assessment completed.*	Thank you for your comment. We have reviewed this bullet point and believe that it adequately captures this concept.
Kent County Council	Short	22	9	**Joint Crisis planning** How and when does this happen – is it different to **psychiatric advance directive**? May benefit from the difference being clarified and possibly located closer to page 23 line 19 30Is this the same as an advanced directive? If they are the same may benefit from being provided as an example opposed to different types of directives within the Mental Capacity Act 2005.	Thank you for your comment. We have revised the definition of this term as follows: 'A joint crisis plan enables the person and services to learn from experience and make plans about what to do in the event of another crisis. It is developed by seeking agreement between the person who may lack mental capacity now or in future and their mental health team about what to do if they become unwell in the future. When the person lacks capacity to make decisions regarding their care and treatment and is unlikely to gain or regain capacity, a joint crisis plan about what to do in the event of a future crisis may be developed through a best interests decision-making process. A joint crisis plan does not have the same legal status as an advance decision to refuse treatment.' Reference to advance directives has been removed from the guideline.
Kent County Council	Short	23	27	**Substitute Decision Maker'** it might prove beneficial to advise the Act or reference that this role has been developed from for ease of practitioner reference as it was not clear when searched on line – Canadian laws came up.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
Kent County Council	Short	24	20 -22	**Training for staff; -awareness of the nature and functional impact of the impairments that give cause to question whether the MCA applies and how it should be assessed. *Is this suggesting that some impairment's do not need to be considered? How does this sit with the legal definition in the Mental Capacity Act and Mental Health Act of mental disorder?***	Thank you for your comment. It was not the intention to suggest that some impairments do not need to be considered, and the text has been removed.
Kent County Council	Short	24	1	**Supporter**, how does this fit with legal definition related to the Person within the meaning of the Mental Capacity Act 2005?	Thank you for your comment. The term does not appear in the recommendations (nor in the context section) and therefore is not defined in the short guideline. It is only defined in the full guideline because it is mentioned in the included evidence. The term is described in line with how it has been used in that study. The term cannot be removed from the definitions in the full guideline because it is intended to help people understand how it used in the cited study.
Kent County Council	Short	25	5	May benefit from practitioners being immediately aware that it is not a recommendation but a *statutory requirement* relating to independent advocacy may be beneficial to include.	Thank you for your comment. The use of *recommendation* here relates to the recommendations about advocacy within the guideline, rather than suggesting that access to independent advocacy is not a statutory duty.
Kent County Council	Short	25	25	Links to tools that already exist maybe useful for ease of reference –(it has not been possible to access the links provided in the document). https://www.adass.org.uk/media/4307/l15_152-mental-capacity-act-liberty_41427.pdf https://www.local.gov.uk/topics/social-care-health-and-integration/adult-social-care/mental-capacity-act-including-dols	Thank you for your comment. We will pass this information to the resource endorsement team.
Kent County Council	Short	29	7	Advocacy: Whilst embracing the wider use of advocates in decision making this could mean a doubling up of resources and cause funding issues. It can at times be challenging within the current resource of available independent advocates to provide advocates for those who are un-befriended and lack mental capacity?	Thank you for your comment and your support for the guideline. High-quality mixed methods studies with a controlled effectiveness component (preferably randomised) are needed to evaluate the effectiveness and cost effectiveness of advocacy as a tool to support the decision-making of people who may lack

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				This is most notable for our Local Authority when a resident lives outside of the County and experienced by other authorities within the southern region.	capacity to make a decision (on the presumption of capacity). The effectiveness component will ideally include 3 arms; usual care, usual care plus advocacy and usual care plus support with enhanced advocacy. This would be beneficial to people who lack capacity, as it would force the research field to concentrate on developing and enhancing existing assessment and support methods, thus improving outcomes even more. By asking for three arm-trials, this would mean we would also get data on how well existing approaches and support methods work. Studies should also include a qualitative component that explores whether advocacy as a means of support to make decisions is acceptable to people using services and valued by practitioners.
Kent County Council	Short	30	9	**Point 4-using tools for capacity assessments**. Association of Directors of Adult Social Services (ADASS) provide tools already in national use for DOLS that includes Mental Capacity and Best Interest forms, would it be better to liaise with ADASS rather than develop a different set of tools, this way they could continue to be used nationally by health and social care practitioners, who are already familiar with them? https://www.adass.org.uk/mental-health-drugs-and-alcohol/public-content/new-dols-forms	Thank you for your comment and signposting the ADASS resources. There is a lack of evidence from the UK on the effectiveness and acceptability of approaches to capacity assessment that are in line with the meaning of mental capacity as outlined in the Mental Capacity Act. Although the guideline committee reviewed some evidence evaluating the accuracy of specific tools, these are not necessarily compatible with the definition of mental capacity. As such, there is a need for high-quality mixed methods studies that evaluate the accuracy or effectiveness of mental capacity assessment tools that are compliant with the Mental Capacity Act. We will include these tools as part of the search strategies carried out by Information Specialists for this research recommendation.
King's College Hospital NHS Foundation Trust	short	general	general	Further guidance to support clinicians support individuals with fluctuating capacity and where there is a complex decision to be made about their care/ treatment would be welcomed.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
King's College Hospital NHS Foundation Trust	short	5	15	Consider higher level of detail in consideration to this point	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised and the elements that are legally binding are now much clearer.
King's College Hospital NHS Foundation Trust	short	6	8	Acknowledgement of limitations in an Acute Trust setting	Thank you for your comment. The committee feel this is an important recommendation and do not wish to add any caveat about different settings as this may provide a get out clause. However they do recognise that challenges in acute settings and this is referred to in the revised context section.
King's College Hospital NHS	short	6	20	Include time sensitivity	Thank you for your suggestion but the committee believe this point is already covered by the term 'situational, social and relational factors'. The committee also

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Foundation Trust					point out that this not an exhaustive list and the issue of time sensitivity has been covered elsewhere in the guideline.
King's College Hospital NHS Foundation Trust	short	6	27	Explore a drive to increase accessible information as at present there is poor availability and many existing documents are out dated	Thank you for your comment and suggestion for implementation support. Unfortunately the committee did not feel they had a basis from the evidence to add this.
King's College Hospital NHS Foundation Trust	short	7	1	Consider whether there is a training need for accessible information at a National Level	Thank you for your comment. The committee agree that training to deliver this recommendation is an issue for commissioners/ providers at a local level.
King's College Hospital NHS Foundation Trust	short	7	10	The Trust welcomes further guidance on the decision-making and mental capacity and acknowledges the key role that health plays. It is felt that there should be some clarification / acknowledgement of the time limitations/ pressures on the Acute Health Provider and fulfilment of some of the recommendations may not be practicable but if picked up on during an in-patient admission could perhaps be referred out to the community health services to support.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
King's College Hospital NHS Foundation Trust	short	7	26	Consider adding Community Professionals	Thank you for your suggestion, however this was not intended in the drafting of the recommendation so the addition has not been made.
King's College Hospital NHS Foundation Trust	short	15	10	Please clarify whether this means involved in the assessment or involved in the decision making	Thank you for your comment. We have edited the recommendation to clarify that this refers to involvement in assessment.
King's College Hospital NHS Foundation Trust	short	17	9-13	Adult Safeguarding Boards could be tasked with overseeing this work / recommended best practice. Many service users access more than one agency/ provider so it is crucial that this information is accessible to more than one agency / provider.	Thank you for your comment. The committee believe that the issue of having the information accessible across services and between health and social care practitioners is already addressed in this recommendation and indeed in other recommendations about information sharing. It would be down to local areas to decide whether Adult Safeguarding Boards would be tasked with the things highlighted in the recommendation. The committee therefore did not make any edits to the recommendation in light of your comment.
King's College Hospital NHS Foundation Trust	short	18	4	Is this appropriate in all cases or should it be considered case by case if someone has been deemed to lack capacity to make a decision is it fair to bring them into a situation that may increase confusion	Thank you for your comment. We believe that the recommendation is clear that whilst this is generally best practice, a decision on this should be made on a case by case basis.
King's College Hospital NHS Foundation Trust	short	18	22	Consider rewording to say best interest meetings or discussions as meetings will not always be appropriate or practical due to time and attendees availability.	Thank you for your comment. We have added details on these issues to provide clarity about the importance of responding proportionately.

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King's College London	Short	1	12-14	"who may in the future lose, or have already lost, mental capacity to make specific decisions about…" – we think it is important to mention time-specificity of capacity assessment here as the wording does not acknowledge the potential to regain capacity re a certain decision.	It says 'to make certain decisions' – reflecting the fact that a lack of capacity is time specific
King's College London	Short	1	16-17	It is unclear how exactly these guidelines interact with the MCA code of practice, which is statutory. It would be helpful it this was delineated – there seems to be significant interaction. As useful as these guidelines are, they do not replace the need for a thorough review of the code of practice incorporating evidence from research studies and case law since 2007.	Thank you for your comment. The context section has been revised and introductions added to each section to clearly explain the relationship between the guideline and the relevant legislation.
King's College London	Short	1	1	**Title -** The title of the guidance could usefully either be changed to, or have a subtitle of "supporting legal capacity." The current title captures two aspects of the guidance and the task in hand: (1) supporting individuals to take their own decisions; and (3) decision-making in relation to individuals who do not have mental capacity to make their own decisions. It does not capture the third aspect: advance planning to enable individuals to exercise agency – and hence legal capacity – at points when they do not have the requisite decision-making capacity. "Supporting legal capacity" also conveys an important, but under-recognised, aspect of the Mental Capacity Act 2005, namely that it is entirely possible to characterise best interests decision-making which properly respects the individual's rights, will and preferences (or, in domestic terms "wishes, feelings, beliefs and values") as supporting their legal capacity. See, for an example of this, the decision in the *Briggs* case concerning the issue of whether life-sustaining medical treatment should be continued, where the constructed decision made on his behalf by the court undoubtedly supported his legal capacity to be recognised as an actor in respect of a critical question.	Thank you for your comment, which the committee discussed. They concluded that the title already accurately describes the areas covered, decision making in cases where the person may lack capacity now or in the future.
King's College London	Short	1	12	The guidance suggests that the recommendations will be useful in the context of financial matters. If it is to cover this, then it should provide considerably more detail about the issues that arise in this context, and should also signpost directly to the DH-funded guidance on this area: https://empowermentmattersweb.files.wordpress.com/2014/09/assessing-capacity-financial-decisions-guidance-final.pdf	Thank you for your comment. It is true that decisions about financial matters are not specifically mentioned in the guideline and this is owing to the nature of the evidence reviewed. However many of the recommendations are intended to refer in general terms to any decision that needs to be taken. Please also note that the context section has been revised and now refers to a range of decisions. In addition there is a specific description of Lasting Power of Attorney in the 'terms used' which highlights the two types, health/ welfare and financial.
King's College London	Short	4	21-25	"Record and update information about people's wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making. " This is a very interesting and potentially useful idea but what would it look like in practice? Do this mean recording a person's expressed wishes and preferences in clinical notes (is this accessible to everyone?) or in a separate personal document?	Thank you for your comment. This is intended to relate to shared electronic information systems, which although aspirational, were also deemed by the committee to be achievable *and* incredibly important. However, as a reflection of the potential difficulties and associated costs where electronic systems are not in place, the committee agreed not to explicitly state that the systems 'should' be electronic.
King's College London	Short	4	11-13:	Practitioners should think about decision-making capacity every time a person is asked for consent, or to make a decision, during care and support planning (that is, not only as disagreement resolution)."	Thank you for your comment. An additional recommendation has been developed by the committee, which should clarify the intended meaning in relation to the presumption of capacity.

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				Does it contravene the presumption of capacity to think about capacity issues every time a person encounters any decision re their health and social care? (see further the comment to page 13, line 2).	
King's College London	Short	4	11	This formulation has a difficult relationship to the presumption of mental capacity. It would be better to say that capacity should be considered in situations where there are good reasons to consider it and that health and social care professionals should be expected to know these reasons to a reasonable degree and according to their specialisation. Here research on prevalence and risk factors is important (see comments on recommendations for research below) as well as context specific triggers for thinking about mental capacity for a decision.	Thank you for your comment. This recommendation intends to encourage practitioners to think about capacity rather than doubt it. This is reiterated in the creation of a new recommendation which highlight the importance of the presumption of capacity.
King's College London	Short	5	1-2	"(using independent advocacy to)… enable them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs/ facilitate their involvement in decisions that may be made, or are being made under the Mental Capacity Act." Although it is clarified later we think it is worth clarifying from the outset that the role of the formal IMCA is only for those who have already been established to lack capacity, although part of their role is to support the person's involvement in decision-making and to help represent their interest in decision-making. Of course other non-IMCA advocates may assist in maximizing a person's capacity and this should be promoted.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation now reads 'Consider expanding statutory advocacy commissioning' and is a consider recommendation. Therefore, it is not legally binding. The committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money. In addition, the committee point out that in fact IMCAs can be involved even if people have friends and family. The circumstances would be a) that the professional considered the friends/ family to be inappropriate or b) that there are safeguarding issues in which case the IMCA can provide additional, knowledgeable support.
King's College London	Short	5	9-10	"for those who lack capacity, a referral should be made to an independent mental capacity advocacy." The MCA code of practice advises IMCA referral only in cases where a person who lacks capacity has no family or friends to consult re best interest decisions.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation now reads 'Consider expanding statutory advocacy commissioning' and is a consider recommendation. Therefore, it is not legally binding. The committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money. In addition, the committee point out that in fact IMCAs can be involved even if people have friends and family. The circumstances would be a) that the professional considered the friends/ family to be inappropriate or b) that there are safeguarding issues in which case the IMCA can provide additional, knowledgeable support.
King's College London	Short	6	5	It should be made clear that this section, as currently framed, is specifically about fleshing out what constitute "practicable steps" for purposes of s.1(2) MCA – indeed, it would be sensible to use this language. The way that this section is framed leads to some ambiguity as to whether it also covers the separate (if related) issue of supporting the person to participate in best interests' decision-making (see in particular the reference to "wishes and preferences" at page 7 line 23, which is ambiguously close to "wishes and feelings").	Thank you for highlighting this. The committee deliberately kept the supported decision making and best interests decision making sections separate. This was in order to emphasise the fact that best interests decision making must not occur unless and until a person has been assessed as lacking capacity to make a specific decision. In practice the two may happen close together but for the

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				It would be quite possible, and indeed arguably preferable, to re-frame this section to cover two aspects, which both require similar skills: (1) Taking practicable steps to support the person to take their own decision; (2) Supporting the person to participate in best interests decision-making in accordance with the requirements of s.4 MCA 2005	purposes of the guideline and to emphasise this point, the committee agreed to leave the sections organised as they appeared in the draft guideline.
King's College London	Short	6	10	The factors set out in the list starting at line 10 are relevant, but they are at a very high level. This is characteristic of the guidance, which – perhaps understandably – seeks to cover a very wide range of situations, including both settings and conditions which may impair a person's capacity. What is really required in this area is grounded/detailed guidance which assists practitioners to understand how best to translate the requirements of the law into practice in relation to specific settings. By way of example, what may be meaningful support in relation to a person with dementia is very different to what may constitute meaningful support for a person with an acquired brain injury. The same goes for assessment of capacity: the meaningful questions to probe whether a person with a learning disability understands or can use/weigh information are not going to be the same as the questions to probe whether a person with dementia can do so. One suggestion is that the NICE guidelines relating to specific conditions are revised in due course to incorporate the core elements from this guidance tailored to the particular conditions. This also feeds into the areas for further research, addressed below.	Thank you for your comment. The recommendations are intended to cover all those who may lack capacity – these factors would apply generally but in specific ways for individuals and it is down to practitioners to tailor their approach according to the person and their needs, which may or may not arise from their clinical condition.
King's College London	Short	7	22	In connection with the point above at p.6 line 5, it is unclear where the framing of support as "based on the person's wishes and preferences" has come from, or what it means in practice. In terms of the first concern, as noted above, the language of "wishes and preferences" is close to the language of "wishes and feelings" found in the best interests section of the MCA 2005 (s.4(6)). However, support at p.7 line 22 presumably refers also, or even primarily, to supporting the person's mental capacity, to enable them to make their own decisions as per the Care Act 2014 (s.67). In this context, it is not clear that support should be "based on the person's wishes and preferences". Rather, it would seem that support should be based on facilitating the person's ability to understand, retain, use and weigh relevant information, and to communicate their decision, in line with the MCA 2005. We note, however, that the language of "wishes and preferences" is also close also to the provision in Convention on the Rights of Persons with Mental Disabilities (CRPD) that support measures (as a measure relating to the exercise of legal capacity) must respect the "will and preferences" of the person (Article 12(4)). If the intention at p. 7 line 22 is to bring this requirement from the CRPD into the NICE guidance on support, then this should be made explicit. There are significant open questions about how to square the requirements of domestic mental capacity law with the requirements of the CRPD, including questions about how support should be conceived and implemented. For discussion, see Craigie (2015) below. We believe there is currently insufficient research available to offer meaningful guidance on this issue, and therefore we recommend that the NICE guidance avoids making recommendations, at this stage, that draw on the CRPD. However, the Mental Health Justice research initiative, especially the 'Enabling legal capacity through decision making support'	Thank you for your comment. The Guideline Committee agree that using the phrase 'based on the person's wishes and preferences' ties the recommendation too closely with best interests decision making (in the MCA) and therefore causes confusion. In the revised version of the guideline it is made explicit that this is about preferences regarding involvement of others not preferences generally.

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				stream, is working towards generating a research base for the development of guidance and policy in this area. See Craigie, J. (2015) 'A fine balance: reconsidering patient autonomy in light of the UN Convention on the Rights of Persons with Disabilities', *Bioethics* 29(6): 398-405. (PMID: 25492591) See also the Mental Health Justice website: https://mhj.org.uk/about/	
King's College London	Short	7	27	The advantages listed in this paragraph appear to conflate two things: (1) The statutory requirement on substitute decision-makers (as the term is used in the guidance) to take all practicable steps to support a person to take their own decision before proceeding on the basis of the defence in s.5 (2) The concept of advance care planning, including, in particular, the making of advance decisions/advance statements It is extremely important that the two concepts are kept separate, because one gives rise to legal consequences (including liability on the part of health and social care professionals – see, e.g. *Winspear*). The other may, or may not, give rise to legal consequences.	Thank you for your comment. The Guideline Committee have pointed out that the revised recommendation should be clear that we are talking about the process of supporting capacitous decision-making.
King's College London	Short	7	18	The notion of unwise decision features in the MCA as a principle specifically in the assessment of mental capacity. "A person is not to be treated as unable to make a decision merely because he makes an unwise decision." There is no requirement in the MCA, or in other UK statutes, to support the person to make decisions even if unwise. The phrasing may unhelpfully conflict with GMC guidance to "make the care of your patient your first concern" and in mental settings could conflict with the Mental Health Act. We advise deleting this guidance statement.	Thank you for your comment. We have reviewed this recommendation, and feel this is logically consistent with the Mental Capacity Act in that people who are making what a practitioner may deem to be an unwise decision should be offered the same support as others, on the basis that it should be assumeded that they have capacity. However your comment prompted the committee to further clarify the intended meaning of this recommendation and it now reads: 'At times, the person being supported may wish to make a decision that appears unwise. As confirmed by the 3rd key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.'
King's College London	Short	8	10	The reference to "shared decision-making" should either be unpacked or deleted. It is a concept which makes sense in clinical/social work terms, but does not have any statutory basis. Health and social care professionals need to be very clear whether the decisions that ultimately fall to be made are decisions that they are taking, or decisions for the individual concerned (directly, or by a proxy if they lack capacity).	Thank you for your comment. Reference to shared decision-making has been removed from the recommendations.
King's College London	Short	9	6	(1) It is suggested that "advance care planning" should not be distinguished from, but rather is the umbrella term for, facilitating individuals to make advance statements, advance decisions or grant proxy decision-making powers. All of these form part of advance care planning. (2) This section is predicated very firmly on advance care planning in relation to medical treatment. There is nothing, in and of itself, wrong with this (although it should be noted that advance care planning could be equally useful in relation to a person's social care needs), but if this is how the term is to be used here, it would be sensible to make this clear. (3) This section is predicated upon a person being on a one-way path to losing capacity (see in particular page 9, lines 24-28). Advance care	Thank you for your comments, which are addressed in turn below. (1) Thanks you for highlighting this, the text has been revised in line with the point you make. (2) Thank you, this section is not intended to only relate to planning around medical decisions. The introductory paragraph has now been revised and it gives a clearer description of the scope of the recommendations in this section. (3) Thank you, the introductory paragraph now highlights that advance care planning can be helpfully carried out with people experiencing fluctuating capacity. (4) With regard to the RESPECT protocol, the committee did not review any evidence relating to this so they were unable to develop related recommendations. Just to confirm, advance care planning is being used in this

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				planning is equally, if not more, useful for those with fluctuating capacity; this is then addressed at page 11 line 3, but it would be worth flagging this further up in this section). It is also possible (for instance under the ReSPECT protocol) for advance care planning to be done where the person has already lost capacity. This throws up considerable complexities in terms of the involvement, in particular, of attorneys: it is suggested that if the form of advance care planning considered here only relates to individuals with capacity this made clear (although note that the glossary at page 21 line 13 refers to individuals lacking capacity at the time of the planning).	guideline to refer to a process undertaken with and by people who have capacity to make decisions although they may lack capacity in the future. The definition in 'terms used' refers to people engaging in advance care planning who 'may lack capacity' only because their capacity is not at that point in question and an assessment has not been conducted. Therefore 'may' is being in the sense that it hasn't been established one way or the other via a capacity assessment.
King's College London	Short	11	10-1 and 22-25	It is extremely important that: (1) Practitioners make clear what can, and cannot, form part of an advance care document – in particular that it is not possible to demand care or treatment that is not available (*N v ACC* [2017] UKSC 22 as regards social/healthcare in general, and e.g. *Burke* as regards inability to compel medical professionals to provide clinically contra-indicated treatment) (2) The document clearly indicates what aspects constitute advance statements, and what aspects constitute advance decisions to refuse medical treatment (and that any aspect which constitute ADRTs relating to life-sustaining treatment comply with the requirements of s.24 MCA 2005) In the medical treatment context, the use of a graphic as on the ReSPECT form can be very useful to identify where an individual's priorities lie on the spectrum between being kept alive at all costs as opposed to being made comfortable.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that there is clarity regarding the legal status of advance care planning processes.
King's College London	Short	12	9-12	The guidance on joint crisis planning is so short here as, in reality, not to be of any assistance. In particular, it is not clear whether and how it is supposed to fit into the wider scope of the document relating to mental capacity, and leaves an ambiguity as to whether there is a necessary correlation between having a relapse/deterioration of a mental disorder with losing mental capacity. It is suggested that this is either removed or expanded.	Thank you for your comment. This recommendation was drafted on the basis of a small amount of evidence and as such the committee were not able to make further recommendations relating to the use of joint crisis planning.
King's College London	Short	12	25-26	"Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment." Could NICE provide any direction as to policies or guidance that might be helpful here?	Thank you for your comment. The committee did not review any evidence that provided a basis on which to recommend particular guidance or policies. They felt that the important message reflected in this recommendation was more to do with having policies and guidance, not necessarily that the content should be uniform across organisations.
King's College London	Short	12	18	The suggestion that condition-specific expertise is sought is very important, and should be reinforced. The meaningful questions to probe whether a person with a learning disability understands or can use/weigh information are not going to be the same as the questions to probe whether a person with dementia can do so. One suggestion is that the NICE guidelines relating to specific conditions are revised in due course to incorporate the core elements from this guidance tailored to the particular conditions. This also feeds into the areas for further research, addressed below. Page 12: 18-21 "seek advice from people with specific condition-specific knowledge to assist them to assess capacity – for example clinical psychology	Thank you for your suggestions. The examples of practitioners given in the recommendation are intended to be illustrative rather than exhaustive.

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				and speech and language therapists". We think that it is useful to mention psychiatry here also. Psychiatrists are frequently consulted for second opinion or joint capacity assessment when a person's decision-making appears to be impacted by symptoms of a mental health problem.	
King's College London	Short	13	2	The test for identifying whether a person has or lacks capacity is set out in s.2 (not s.3) MCA – see *PC & NC v City of York Council*. Section 3 amplifies s.2 but the test is not in s.2. The whole of the following section reads as something of a collation of miscellaneous points from case-law, the Code of Practice and practice. We suggest that it may be of use to have regard to the 39 Essex Chambers capacity assessment guide for a way in which to provide what practitioners actually require: i.e. how to translate the law into practice. http://www.39essex.com/content/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Capacity-Assessment.pdf. Further and in any event, the guidance needs to address wo critical points here: (1) The potential misapplication of the presumption of capacity highlighted in the House of Lords Select committee report, either because of a lack of understanding as to what it means or to avoid taking responsibility for a vulnerable adult. This is touched on at page 15, line 15, but not in terms, and requires amplification. (2) The 'causative nexus.' The guidance should make clear that a person can only be found to lack capacity where their relevant functional inability is because of an impairment or disturbance in the functioning of their mind or brain (*PC*). It is very important that the guidance makes clear how this is to be interpreted in the real world, and in particular in the context of those with mild impairments who are caught in complex social situations – perhaps making reference to *NCC v TB* where Parker J made clear that the test is whether the impairment/disturbance is a material cause, even if it is not the sole cause.	Thank you for your comment. The committee agreed that greater detail on this issue was needed and we have therefore included extra information in the recommendation numbered 1.4.10 in the guideline in relation to this.
King's College London	Short	13	18	It is not necessary that the person communicate specific information about the decision – the requirement is that the person is able to communicate their decision. Suggest breaking this out, because this is a different requirement to the requirement to be able to understand/use/weigh etc information.	Thank you for your comment. The committee believe that the recommendation covers the issue of communication appropriately.
King's College London	Short	14	7-12	"Health and social care practitioners should take a structured, person- centred, empowering and proportionate approach to assessing a person's capacity to make decisions, including everyday decisions. The assessment should show where a person has capacity and where they do not. However, they should be aware that for certain areas, such as voting, there is no legal requirement to establish capacity." The language here is worrying for a lack of decision-specificity, seeming to assume that a single capacity assessment could cover multiple decisions. The reference to capacity to vote is a little confusing at this point.	Thank you for your comment. The recommendations have been edited to ensure that there is clarity that assessments should be decision specific.

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King's College London	Short	14	3-4	"The assessor should take into account the person's decision-making history when preparing for an assessment." What is a person's decision-making history and how may practitioners access this?	Thank you for your comment. The recommendation has been edited to make clear what this relates to.
King's College London	Short	15	15-20	"Practitioners should be aware that people with executive dysfunction – for example, people with traumatic brain injury – may be at risk of having their decision-making capacity overestimated. Structured assessments of capacity should be supplemented by real-world observation of the person's functioning and ability. " Whilst this is true, there is a risk that real-world observation will cause emphasis on a person's disorder or global functioning rather than their capacity to make specific decision – this risk should be highlighted.	Thank you for your comment. The recommendation has been edited to make clear that this is not an additional test of capacity.
King's College London	Short	15	24-27	Overall in this section there is an emphasis on retaining and communicating information, but no guidance on the more difficult areas of 'understanding' and 'use or weigh'. In our view this should be identified as an important area for further research.	Thank you for your comment. The committee believe that these are all important areas for research; they felt however that it was inappropriate to focus on only one of these issues.
King's College London	Short	15	15	We would concur with this point about brain injury though the assessment will have to come back from real world behavioural observation to an analysis of decisional making abilities and a useful, evidence driven, framework for doing this is available. Clinical assessment of decision-making capacity in acquired brain injury with personality change: Owen, G., Freyenhagen, F., Martin, W. & David, A. 19 Jun 2015 In : Neuropsychological Rehabilitation.	Thank you for your response. We will pass this information to our resource endorsement team.
King's College London	Short	16	1	"Insight" is not a word which features in the MCA – it is important to make clear that practitioners need to explain how person's lack of insight can be related to an inability to understand/retain/use/weigh relevant information. It should also be noted that a person can have insight into their condition but still not be able to make a decision.	Thank you for your comment. The committee discussed the use of the word 'insight' in detail. Whilst they agree that it can sometimes be misused they believe that its continued use in clinical practice suggests that it is useful to refer to it here. The text of the recommendation has been edited to make clearer that this relates to the practitioners perception.
King's College London	Short	16	7	It is just as important that a practitioner records and explains why they have reached a decision that a person has capacity in circumstances where there have been objective reasons to question that person's capacity, not least to avoid misapplication of the presumption of capacity.	Thank you for your comment. The committee agree that this is important information that should be recorded. The recommendation numbered 1.4.28 in the draft guideline has been edited to include details on this.
King's College London	Short	17	1	The question of who the decision-maker is not straightforward at all given the way in which the MCA (deliberately) does not identify decision-makers, save in the case of attorneys/deputies. It would be very helpful to have more discussion of this – here and elsewhere in this section, it may be useful to have regard to the 39 Essex Chambers Best Interests Assessment guide: http://www.39essex.com/content/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Best-Interests.pdf	Thank you for your comment. NICE guidelines do not recommend specific tools unless there is evidence to support their effectiveness. The committee did not feel they had a basis on which to make a recommendation about who the decision maker should be over and above what is set out in the Mental Capacity Code of Practice.
King's College London	Short	20	3	The list of factors here should reflect the case-law from *Aintree* onwards, and the requirements of the CRPD, to make clear that the purpose of the exercise is to put oneself in the shoes of the person and that "[w]here the patient's views can be ascertained with sufficient certainty, they should generally be followed (***Briggs*** at [62] per Charles J) or afforded great respect (***M v N*** at [28] per Hayden J***)***, though they are not automatically	**Thank you for your comment.** You are right that the purpose of the exercise is to put oneself in the person's shoes. However, the evidence on which this recommendation is based showed that in only a very small number of cases the least restrictive option was explored. The committee agreed that in their experience practitioners do tend to lack understanding about the importance of exploring least restrictive options, which includes a judgement about associated risks and developing an understanding about the person's likely wishes.

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				determinative. '*...if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.* ***Briggs*** at [62ii] per Charles J.*'...the 'sanctity of life' or the 'intrinsic value of life', can be rebutted (pursuant to statute) on the basis of a competent adult's cogently expressed wish. It follows, to my mind, by parity of analysis, that the importance of the wishes and feelings of an incapacitated adult, communicated to the court via family or friends but with similar cogency and authenticity, are to be afforded no less significance than those of the capacitous.'* ***M v N*** at [32] per Hayden J" (*Salford Royal NHS Foundation Trust v P* [2017] EWCOP 23: http://www.bailii.org/ew/cases/EWCOP/2017/23.html) These observations relate to medical treatment, but are equally applicable to other best interests decisions, especially those which are intensely personal.	Recommendation 1.5.15 aims to provide guidance about exploring less restrictive options. Although the committee do not dispute the point you make, given the evidence on which the recommendation is based and the area of practice they were aiming to improve they did not agree to make any edits in light of your comment.
King's College London	Short	21	12-18	(1) It is suggested that "advance care planning" should not be distinguished from, but rather is the umbrella term for, facilitating individuals to make advance statements, advance decisions or grant proxy decision-making powers. All of these form part of advance care planning. As per the comments above, the bulk of the guidance relating to advance care planning relates to those who currently have capacity to participate, but this entry in the glossary suggests that it also covers those who currently lack it. The ReSPECT project shows that advance care planning in relation to those currently lacking capacity throws up considerable legal complexities, not least as regards the role of attorneys. In particular, it is unclear whether attorneys can purport to make what amount to advance decisions to refuse treatment (it is suggested that the answer is that they cannot, although if it is clear that that the attorney would, at the time the treatment is needed, refuse consent on behalf of the person, it will in almost all cases not be appropriate for that treatment to be included in the care plan, unless there is reason to believe that that the attorney is not acting in the best interests of the person). A decision needs to be taken as to whether advance care planning is intended to cover both types of situations, and, if so more detail should be given as to how to carry out advance care planning where the person currently lacks capacity to participate.	Thank you for your comment. In the glossary, 'advance care planning' is a process with people who may lack mental capacity now or in the future is a voluntary process of discussion about future care between the person and their care providers. If the person wishes, their family and friends may be included in the discussion. With the person's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.
King's College London	Short	21	19-24	(1) It is important to emphasise that "living wills" is not a statutory team, and risks misleading people as they may think that documents created prior to the MCA coming into force (or created in other jurisdictions where this is the term used, including Scotland) meet the relevant requirements in relation to life-sustaining treatment. (2) Specific reference should be made to the fact that particular requirements apply in relation to life-sustaining treatment.	Thank you for your comment. To avoid confusion, 'living will' has been removed from the heading for advance decision. A little more detail has been added to the 'advance decision' definition.
King's College London	Short	21	25	"Advance directive" is a very problematic term for three reasons: (1) It is not the statutory term in the MCA 2005, and risks confusion with what are now known as ADRTs; (2) If it is intended to refer to anything other than an ADRT, such statements are more generally known as "advance statements";	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.

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				(3) "Directive" risks misleading people into thinking that they can compel specific actions, for instance the administration of medical treatment or particular service provision by public bodies, when decision-making post-incapacity represents choices between available options (*N v ACC* [2017] UKSC 22 as regards social/healthcare in general, and e.g. *Burke* as regards inability to compel medical professionals to provide clinically contra-indicated treatment.	
King's College London	Short	22	1	"Consent" – this presumably means "advance consent," and it should also make clear that consent (including advance consent) has to be given freely. As it stands, the definition of consent is misleading.	Thank you for your comment. The definition of consent has been edited to read: ' The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
King's College London	Short	22	4	"Duty of care": this definition is problematic because conflates (at least) two different issues: (1) The common law concept of duty of care as an aspect of the law of negligence, which will only arise in certain circumstances; (2) The duty under s.1(5) MCA 2005 It is <u>very</u> important to emphasise that acting on the basis of either of these does not give rise to any <u>powers</u> on behalf of either public bodies or private individuals to act and/or a defence if they do act. There is a perennial issue (for instance) that care homes say that they are acting "under their duty of care" to compel/coerce/restrict actions of an individual with impaired capacity. That may explain <u>why</u> they are doing what they are doing, but it does not explain legally <u>how</u> they can do it. It may be worth making specific reference to s.5 MCA 2005 here	Thank you for your comment. This term is no longer used in the guideline.
King's College London	Short	22	15	The distinction between the two types of LPA should be made clear here, and the fact that only H&W powers of attorney operate in the way set out here (a P&A power of attorney could take effect immediately)	Thank you for your comment. We have revised the definition of this term so that it includes the following wording: '…There are two types of LPA; health and welfare and property and financial affairs and either one or both of these can be made…'
King's College London	Short	22	25	The definition of the MHA 1983 is rather charitable – it is not focused on telling individuals their rights, but is (primarily) about the regulation of compulsory admission for and treatment of mental disorder	Thank you for your comment. We have amended this definition to now read: 'The Mental Health Act 1983 provides for the detention of persons in hospital for assessment and/or treatment of mental disorder and for treatment in the community in some circumstances. The Act provides for the process of assessing individuals and bringing them within the scope of the Act, for treatment of individuals subject to the Act's provisions and sets out the rights and safeguards afforded to individuals who are subject to the Act's powers.'
King's College London	Short	23	3-4	There are multiple references to "people who may lack mental capacity" without caveats about decision-specificity and time-specificity. Some caveat needs to be made to ensure this is clear. The MCA Code of Practice uses the following: "In this chapter, as throughout the Code, a person's capacity (or lack of capacity)	Thank you for your comment. Following stakeholder consultation the recommendations were revised to improve clarity and there is now more specific references to 'capacity to make decisions'. Clearer explanations are now also provided in an updated context section and introductory paragraphs within the body of the recommendations.

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				refers specifically to their capacity to make a particular decision at the time it needs to be made."	
King's College London	Short	23	8	Suggest using the (statutory) term "unable," not "unfit" as the latter has different connotations	Thank you for your comment. This has been amended to 'unable'.
King's College London	Short	23	19	Suggest deleting "Psychiatric Advance Directives," as this risks seriously misleading service users and professionals. This a concept from other jurisdictions (most obviously the US) which does not – yet – exist in E&W. This definition also, as it stands, uses the wrong term ("competent" rather than "capacitous")	Thank you for your comment. We have removed the term 'Psychiatric advance directive' from the revised version of the guideline.
King's College London	Short	23	25	"substitute decision-maker". It is important to make clear that this is not a statutory term and can encompass three different categories of: (1) A proxy decision-maker (2) A person relying upon the provisions of s.5 MCA (nb, it is critical to make clear that s.5 does not give any single person or body the status of decision-maker A judge making a decision under s.16 MCA 2005	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
King's College London	Short	24	1	A supporter can: (1) Support a person with impaired decision-making capacity to make their own decisions; Support a person who lacks decision-making capacity in the process of constructing a best interests decision. This glossary should include reference to both	Thank you for your comment. The term does not appear in the recommendations (nor in the context section) and therefore is not defined in the short guideline. It is only defined in the full guideline because it is mentioned in the included evidence. The term is described in line with how it has been used in that study. The term cannot be removed from the definitions in the full guideline because it is intended to help people understand how it used in the cited study.
King's College London	Short	27	5-25	With regard to training on conducting capacity assessments, it remains difficult to define a gold standard for how capacity assessments should be conducted in practice. As mentioned in Recommendation 5 there is lack of clarity about how practitioners do or should carry out assessments. Research directed at exploring this further is important as this will inform: a) Content of education and training interventions b) Measures or standards to compare different training interventions in terms of 'effectiveness and cost-effectiveness'	Thank you for your comment and support for this research recommendation.
King's College London	Short	27	1	The research questions that are set out represent a start at exploring the terrain in a very complex and wide-ranging area. However, we suggest that there are other key research recommendations that are required: (1) Implementing mechanisms for supporting decision-making which go beyond advocacy (addressed in recommendation 3), including informal support through trusted family members and friends identified by the person in question. This research (and the research relating to advocacy as support) needs to address how safeguards are implemented to avoid undue influence and/or conflicts of interest; (2) Implementing broader mechanisms to support legal capacity, including through advance decision-making and the making of advance statements.	Thank you for your comment and signposting the various resources, including those in development, which we will consider as part of our research recommendation on training and support for practitioners. The Guideline Committee acknowledge the importance of epidemiological research, but the research recommendations set out in the guideline reflect the greater priorities identified by the committee in light of the evidence review underpinning the guideline.

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				(3) The theme of training is very important. We have shown that legal training alone (although improving knowledge of the law) does not change practice. Capacity in vacuo: An audit of decision-making capacity assessments in a liaison psychiatry service: Spencer, B. W. J., Wilson, G., Okon-Rocha, E., Owen, G. S. & Jones, C. W. 1 Feb 2017 In : Psychiatrist. 41, 1, p. 7-11 New approaches that engage directly with clinical and social care scenarios and concerns (and hard cases) need to be developed and evaluated and this is part of the programme for the Wellcome Trust funded 'Mental Health and Justice' project cited below. (4) Continuing epidemiological research, barely considered in the guidance, that provides prevalence and associations of mental capacity for relevant decisions in (e.g. treatment, residence, research participation) in relevant contexts (e.g. inpatient dementia, outpatient psychosis, ECT suites). This research helps trusts know what the extent of the mental incapacity need is in relevant contexts and helps to direct resources for assessment accordingly. For examples see Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study: Owen, G., Richardson, G., David, A. S., Szmukler, G., Hayward, P. & Hotopf, M. 2008 In : BMJ (International Edition). 337, 7660, p. 40 Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study: Raymont, V., Bingley, W., Buchanan, A., David, A. S., Hayward, P., Wessely, S. & Hotopf, M. 16 Oct 2004 In : The Lancet.364, 9443, p. 1421 - 1427 (5) Continue research which aims to link the generic decision making abilities in the MCA to the disorder specific decision making phenomena found clinically. This requires in depth interview studies to help practitioners bridge the law with the clinical or social care interview and the nature of the impairment of mind or brain. An example is the brain injury study cited above. These research areas are already being examined in work being undertaken by the Wellcome Trust funded 'Mental Health and Justice' project, which has been running since 2017 and is to run to 2022: www.mhj.org.uk.	
King's College London	Short	29	16	Workstream 6 of the Wellcome Trust funded 'Mental Health and Justice' project is looking at precisely this issue, and will be providing research outputs, including a pilot educational intervention by 2022.	Thank you for your comment and signposting your work.
King's College London	Short	30	1-14	With regard to the need for high-quality research that explores in detail how to conduct an effective capacity assessment – as previously mentioned, Workstream 6 of the Wellcome Trust funded Mental Health and Justice Project involves a qualitative study of practitioners experienced in capacity assessments focusing on	Thank you for your comment and signposting Workstream 6 of the Wellcome Trust funded Mental Health and Justice Project, which we will consider as part of research recommendation 5 'What are the components of an effective assessment of mental capacity to make a decision'?

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				their most difficult assessments of capacity as well as a review of capacity cases from the Court of Protection. This data will inform an educational intervention directed at practitioners carrying out capacity assessments.	
London Ambulance Service	Short	General	General	1. There is no mention to MCA and decision making in the pre-hospital setting and feel that this needs to be considered and added as a separate section. As it stands we are unable to make baseline assessments as we usually do not know the patient and would also not have access to professionals mentioned such as speech and language therapist or psychologists in an emergency situation.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
London Ambulance Service	Short	General	General	2. There is an on-going issue within Ambulance services around accessing care plans at present so as it stands we would not always be in a position to have sight of these in some cases.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
London Ambulance Service	Short	General	General	3. In terms of auditing use of MCA – this is something we would welcome and are currently in the process of starting a internal process for this – a suggestion would be that there is a national framework	Thank you for your comment and support for this recommendation.
Manor Community	Full	6	145 - 150	We recognise the importance and relevance of the Mental Capacity Act in this section. We recommend that the document makes reference to other legislation which is important to take into consideration in this area and from the outset. This would include Article 8 European Convention on Human Rights and UN Convention on the Rights of Persons with Disabilities (UNCRPD) in regard to supported decision making	Thank you for your comment. The context section has been reviewed to clarify the relationship between this guideline and the most relevant legislation. We have focused on legislation which is specific to mental capacity, so have not included all items you mention.
Manor Community	Full	7	180 - 181	Providing information to patients or people using health services can be challenging. Therefore, the points in this section will be helpful to practitioners. We feel that this section would also be enhanced by including a term which encourages practitioners to prioritise the information they provide, to that which is most would be most relevant to the to to the individual. This would be in line with case law set out in the case of Montgomery v Lanarkshire Health Board [2015] UKSC 11.	Thank you for your comment and your support for these recommendations. Following consultation the committee reviewed this recommendation and added that the information must be tailored and relevant. We hope this addressed your concerns.
Manor Community	Full	9	227	As providers of social care services, we often see supported decision-making being unsupported by practitioners, often due to lack of understanding of the importance and benefits of supported decision-making. We therefore support the inclusion here of a section on supported decision making. It will help practitioners understand their role in this and change the experience of people using services. It may however incur an economic element for service providers in training practitioners to properly understand the concept and its implementation. We feel this section would be enhanced with a reference, appendix or/and hyperlink to what the 'processes and procedures' referred to here, are of supported decision making. If NICE already has a separate guide on this then a sign post to that, or to areas within the UN CRPD	Thank you for your comment and support for the guideline. The GC believes that this recommendation is achievable within current resources. Thank you for your comment. This section has now been revised and the specific phrasing no longer appears. However, in principle, the processes referred to are those set out in the Mental Capacity Act and Code of Practice. The link with these is clarified in a new introductory paragraph in the section on supporting decision making.
Manor Community	Full	16	425	We feel that an appendix with reference to the parts of the Mental Capacity Act which are referenced throughout this guidance would help practitioners cross-reference to Mental Capacity Act and aid understanding of this guidance. If an appendix were to be included we also feel that a hyperlink to the area of the appendix, e.g. s3 Mental Capacity Act, would be beneficial as well. This would	Thank you for your comment. The introduction to each section has been redrafted to include reference to relevant parts of the Act.

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				help practitioners to use this guide as a tool to aid improvement in everyday practice in relation to mental capacity.	
Manor Community	Full	18	483	We commend the focus in this section on consulting with the person's support network. The dignity of the person will be respected by seeking their consent in doing this and presenting this advice in the guide. However, we recommend that the use of the term 'functional capacity' in this line could be misconstrued. The capacity tests of s3 Mental Capacity Act 2005 are often referred to (in training of practitioners and in law) as the 'functional tests' of capacity. This sentence may be confused with s3 Mental Capacity Act functional tests. If this is the case, this may lead practitioners to assume that consulting family is part of the 'functional test' rather than, consulting family to ascertain how the individual functionally communicates and usually makes decisions. In any case, we would recommend that the guidance makes clear that it is the person that the assessment should initially be conducted with not the family. The family and support network are correctly stated as valued supports in understanding the individual and in making best interest decisions, however, before a person's capacity is assessed, and best interests are concluded, it is important to put the individual at the centre of the assessment.	Thank you for your comment. The reference to functional capacity has been removed from the recommendation.
Manor Community	Full	18	493	We support the reference to providing accessible information. This can often be neglected either due to resource restraints or a lack of prior consideration to help an individual understand a discussion in a way in which they prefer. However, not all individuals with an 'impairment of, or a disturbance in the functioning of, the mind or brain' will require accessible information. In fact, from our experience some individuals with mental health illness do not like to be presented only with accessible information as they do not identify themselves as requiring it. The guidance may be enhanced by changing this sentence to read 'practitioners should always clear language in plain English (or through an interpreter if required). Practitioners should use an accessible format, where required by the person, to tell them:…'	Thank you for your comment. The committee did not make the changes you suggest because this recommendation is specifically about the importance of communicating in a way that is accessible to the person, whatever that may require. In other recommendations in the guideline, reference is made to 'tailored' and 'person centred' approaches so there is certainly no implication that everyone requires accessible information.
Manor Community	Full	20	552	It is required by the Act that the elements in this section should be address separately by practitioners. We recommend that this paragraph be reformulated by bullet pointing the areas to be captured in the practioner's assessment. This would benefit formation on paperwork to aid capacity assessment which is Mental Capacity Act compliant and which encourages practitioners to cover all aspects of Capacity correctly. We feel this section would benefit from being restructured in this way: 'Health and social care services should have clear systems in place to obtain and record the person's • wishes in relation to a relevant decision • feelings in relation to a relevant decision, • values • beliefs, • or any other factor that would be likely to influence such a decision.'	Thank you for your comment. We believe that the recommendation covers these points adequately.

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Manor Community	Short	1	30	We welcome further explanation of elements of Mental Capacity Act. However, we feel this section would be enhanced with an appendix to or hyperlink to referenced parts of the Mental Capacity Act so that people can easily read these parts of the Act themselves.	Thank you for your suggestion. The context has now been revised to provide a clear link between the guideline, the relevant legislation and the Code of Practice. Further reference to the MCA and Code of Practice have also been added to the guideline. Hyperlinks to the Code and to the legislation are provided.
Manor Community	Short	3	16	We recognise the importance and relevance of the Mental Capacity Act in this section. We recommend that the document makes reference to other legislation which is important to take into consideration in this area and from the outset. This would include Article 8 European Convention on Human Rights and UN Convention on the Rights of Persons with Disabilities (UNCRPD) in regards to supported decision making	Thank you for your suggestion. The committee revised the context section and although they did not agree to include article 8 on Human Rights and UNCRPD, they have ensured a much clearer explanation about the link between the guideline, the relevant legislation and the Code of Practice.
Manor Community	Short	7	15	We welcome focus on supported decition-making However we feel this section would be enhanced with actual examples or case studies of supported decision-making. As an organisation we have used Essential Lifestyle Planning and Person-centred care tools to help people understand decisions and express what is important to them	Thank you for this information. NICE do not include case studies in their guidelines but we will pass this information to the implementation team.
Marie Curie	Full	General	General	We are concerned at the strength of the recommendations being offered considering the amount of evidence available to support them. We would expect NICE to produce guidance based on demonstrable best practice, but the portfolio of evidence that has been drawn together to inform these guidelines seems too thin to support the recommendations being made by the guideline.	Thank you for your comment. NICE guidance is informed by best available evidence about effectiveness, cost-effectiveness and the views and experiences of people who use services and their carers. This is interrogated by the Guideline Committee members in the context of their experience. The Guideline Committee considered carefully the strength of each recommendation based on the evidence available. The recommendations comprise a mix of strong and weaker recommendations (indicated by use of the word 'consider') as a result of the Guideline Committee's extensive debates about the strength of the evidence.
Marie Curie	Full	General	General	The language of the guideline is inconsistent with the language of the Mental Capacity Act (MCA). The MCA refers to the individual receiving care as 'Person' or more frequently 'P', whereas this guideline switches between 'person' 'individual' and 'they'. Referring to the person at the centre of the process as 'person' or 'P' has the advantage of focussing the guideline on the person at the centre of the issue, in line with the MCA's principles. It also reduces the opportunity for confusion as the meaning of 'they' and 'individual' can become ambiguous in some contexts (does 'they' refer to the patient, the health professional or their carer, for example).	Thank you for your comment. The Guideline Committee agreed and the terminology has been updated throughout so that uses of the word 'individual' is now replaced with 'person' for consistency.
Marie Curie	Full	General	General	It would be helpful for the guideline to clearly define the specific clinical situations in which the guideline and its recommendations need to be applied, to ensure that health professional know when they need to take them into account.	Thank you for your comment. This guideline had a wide remit given that it is relevant to all people who may (now or in the future) lack capacity to make specific decisions, and to practitioners in health, social care, housing, education, employment, police and criminal justice. It would therefore not be feasible to define an exhaustive list of the situations to which this would apply. The Guideline Committee thought carefully about the wording of the recommendations to ensure they were broadly applicable.
Marie Curie	Full	6	143	The guideline's recommendations are fairly limited in terms of detail, which limits how useful they can be in a clinical setting. Basic information such as who needs to be involved at which points in the process or the practicalities of these recommendations are not explored in any detail.	Thank you for your comment. NICE guidelines make recommendations based on the best available evidence - the level of detail in the recommendations is constrained to some extent by the availability of evidence on particular aspects of practice. NICE guidelines are also not intended to replace practitioner judgement.

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				For example, on page 9 lines 231 and 232 state that *'Practitioners supporting a person's decision-making should build and maintain a trusting relationship with them'* without exploring the issue any further. To a clinician dealing with the person, this can only serve as a very general indicator of what constitutes best practice without providing any advice on how it can actually be achieved.	
Marie Curie	Full	6	144	We are concerned that the 'Overarching principles' section of the guideline makes no reference to the principles of the MCA. While those principles are listed in the section above, the fact that they are not reflected in the recommendations is a significant oversight. The MCA statement that people should be assumed as having decision making capacity until '*all practicable steps to help them do so have been taken without success*' is integral to how health professionals should be approaching mental capacity issues, and the guideline should make that explicit in its recommendations.	Thank you for your comment. The aim of this guideline is not to reproduce the principle of the Mental Capacity Act in the recommendations. However the committee agreed with you that there should be a clearer link with the principles of the Act and they achieved this through revising the context and adding introductory sections to the sections of the guideline.
Marie Curie	Full	12	316	The guideline offers little by way of practical guidance around Advance Care Planning (ACP), despite it being a challenging process which requires the involvement of multiple individuals involved in the person's care. The absence of practical guidance such as who needs to be involved in ACP, how to arrange meetings and recommended timeframes mean that these guidelines will not be particularly useful in a clinical setting. Basic, practical advice for how best practice in ACP can be achieved is what is needed and expected of this guideline.	Thank you for your comment, which the committee considered. The recommendations on advance care planning have been revised and now provide as much as detail as the committee believe they have a basis for and without being overly restrictive in terms of recommended practice.
Marie Curie	Full	25	676	The guideline does not adequately distinguish between terms such as Advance Care Planning and Advance Directives. Health professionals will not necessarily understand the intricacies of these terms, and the guidelines should be explicit that the two are very separate. ACP does not necessarily result in an Advance Directive, and the terms refer to very different processes. Currently the guideline fails to clarify exactly what these terms mean, and as a result the guidance is less useful for clinicians who may not have prior knowledge of mental capacity assessments.	Thank you for your comment. The committee do not feel the two terms are confused/ conflated in the 'terms used' section. If they appeared confused in the draft recommendations, this has now been addressed with a clear introduction to the section on advance care planning.
Marie Curie	Short	9	9	We are concerned that there is only one reference to Lasting Power of Attorney in the short version of the guideline outside of the definitions section. The guideline should have an explicit recommendation that health professionals should ascertain if Lasting Power of Attorney already exists in every case. Failure to find this out at an early stage can result in a person's wishes being ignored. The guidelines need to place more emphasis on the importance of Lasting Power of Attorney in cases where mental capacity is an issue.	Thank you for your comment. Reference to Lasting Power of Attorney has been added to recommendation 1.1.1, the introductions to sections 1.3 and 1.5 and recommendation 1.5.14.
Mencap	Short	General		We think the guideline will cause confusion in its current form. We think it needs to be much clearer what the purpose of the guideline is. We think it would be helpful for this guideline to focus on supported decision making: what it is, why you need to do it, how to do it; being clear that it should be done in implementing the MCA. The summary of what the guideline covers does suggest this focus, however, the title and content of the guideline do not. It says that this guideline is not a step by step guide to implementation of the MCA and it says guidance for decisions made under the MCA is published in the MCA Code of Practice. It would be helpful to be really clear that it is about supported	Thank you for your comment. Following consultation the committee reviewed the recommendations and structure of the guideline, including adding introductory paragraphs to the relevant sections. The revised context section also helps to clarify the relationship between the guideline and the MCA and Code of Practice as well as other relevant legislation. We hope that these revisions help to address your concerns. In light of yours and other stakeholder comments the committee agreed to only refer to 'supporting decision' making and this is defined in the 'terms used' section of the guideline. An introductory paragraph has also been added to this section to help explain what is meant.

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				decision-making and that it is to help practitioners with principles 2 and 4 of the Mental Capacity Act. The guideline needs to define the term 'supported decision-making'. At the moment it feels that supporting decision-making and supported decision-making are being used interchangeably and there is no definition of supported decision-making. It is really important the 'context' explains the need for the guideline. This will help practitioners understand why it is important and motivate them to follow it. The guideline refers to the serious issues with practical implementation of the MCA. It needs to be clear that supported decision making is a central principle of the United Nations Convention on the Rights of Persons with Disabilities. People with a disability should receive the support necessary to enable them to make and implement the decisions that affect them. And that this guideline shows how to ensure this happens. Some wording from page 24 could be used here: 'supported decision making is fundamental to effective implementation of the legislation.' There is a lot of useful context and findings in recent research from the University of Birmingham: Everyday Decisions: Supporting Legal Capacity through Care, Support and Empowerment https://www.legalcapacity.org.uk/research-findings/. It could be helpful to mention some of the points from their context and findings which bring to life why this guideline is needed, for example: 'difficult decisions were less well supported, overall, than everyday decisions and care professionals often defaulted to using the 'best interests' framework under the MCA to make substituted decisions in these areas.' (Pg 2, column 3, para 1, Research spotlight: www.legalcapacity.org.uk/wp-content/uploads/2017/12/EverydayDecisionsResearchSummary.pdf)	Thank you for your suggestion for implementation support.
Mencap	Short	1-6	General	It would be helpful for this list to include, in line with the Equality Act, reasonable adjustments should be made. Some practical examples would be helpful, for example, extra time, easy read. It could also be helpful to include in this list 'Avoid the use of jargon.'	Thank you for your comment. Following consultation the recommendations were revised to make them clearer. The committee ensured your point was addressed through recommendations about reasonable adjustments and accessible, tailored and person centred information and communication.
Mencap	Short	4-5	General	It would be helpful for the section on 'Using independent advocacy to support decision-making and assessment under the MCA' to link to what is said in the MCA Code of Practice as this will help give weight to this, and show that it is not a 'new' idea that the guideline is bringing in – it is just highlighting what should be done under the MCA. For example Pg 33 MCA Code of Practice: '3.10 To help someone make a decision for themselves, all possible and appropriate means of communication should be tried:…Would an advocate (someone who can support and represent the person) improve communication in the current situation?' The guideline should also remind practitioners of those situations when a statutory advocate should be involved (eg. IMCA, Care Act advocate).	Thank you for your comment. The committee believe this is already covered by the guideline. In addition they want to avoid simply repeating/ reproducing the MCA although obviously this is the legal and practice context in which the recommendations must be implemented. The context section has been revised and introductions added to each section to clearly explain the relationship between the guideline and the relevant legislation.

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Mencap	Short	6	5-7	It would be helpful for this section to start by explaining what supported decision making is (if it is not defined earlier in the guideline). It should also link to what the MCA Code of Practice says about supporting decision-making. It is confusing starting this section with 'Ask the person how they want to be supported and who they would like to have involved in decision-making.' Some people will just need accessible information and will not need someone involved to help them. The level of support should be tailored to the individual's needs – some people may just need accessible information, others may need more support eg. an advocate.	Thank you for this suggestion, which was acted on by the committee. They agreed to add an introduction to the section on supporting decision making, which addresses your concern.
Mencap	Short	22	2-3	Re: Definition of Consent – We suggest 'who may lack mental capacity now or in the future' is deleted so it reads 'When a person gives permission for something', as if someone does lack capacity to make a decision around consent then they are not able to consent.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Mind	Full (& short)	3 (& 1)	61-71 (& 12-14)	The inclusion of decisions around mental health in relation to joint crisis planning is welcome, however we recommend that mental health is referred to at other appropriate points in the guideline. Specifically, in laying out the purpose of the guidance, the guideline is described as intending to help practitioners to "assess people's capacity to make specific health and social care decisions". We recommend that this is amended to include mental health care and treatment, eg "assess people's capacity to make specific health and social care decisions, including decisions about mental health care and treatment". Good practice around decision-making should apply to mental health care and treatment too.	Thank you for your comment. The GC agree that good practice around decision-making should extend to mental health care and treatment however the recommendations are based on evidence reviewed by the GC and it was only in relation to joint crisis planning that the GC felt that the evidence was clear enough to refer to people with mental health diagnoses specifically.
Mind	Full	15	405-409	We welcome the inclusion of joint crisis planning under section 1.3, on advance care planning. The guidelines on advance care planning will be useful to practitioners co-developing joint crisis care plans (which are, of course, also advance care plans). We recommend that the section on joint crisis care planning is better joined up with the rest of the section on advance care planning, particularly on developing advance care plans collaboratively. Good practice in working collaboratively to develop advance care plans will also apply to joint crisis care planning, for example, in how a person is offered the discussion; in the approach to discussions; co-producing care plans and so on (as laid out in the guidelines). We recommend that joint crisis care plans are highlighted as being a type of advance care plan in the introduction to this section.	Thank you for your comment. The evidence on which this recommendation was based suggested that joint crisis plans may be suitable for people with mental disorders. It was not therefore appropriate for the GC to recommend that joint crisis plans be used to support other groups.
Mind	Full	15	405-409	This guideline states that joint crisis plans should be "recorded". In line with NICE clinical guideline (CG136) 'Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services', joint crisis care plans should be "respected and implemented, and incorporated into the care plan". We know from previous research that a key issue for the success of joint crisis care planning is a lack of follow-through (see Henderson C., Flood C., Leese M et al. (2004) Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised	Thank you for your comment. Unfortunately we cannot make any changes to other NICE guidelines although they will be considered for updating in due course. You can follow decisions about the review of the mental health transitions guideline via this link to the NICE website https://www.nice.org.uk/guidance/ng53

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				controlled trial, British Medical Journal; and Thornicroft G, Farrelly F, Szmukler G et al. (2013) Clinical outcomes of joint crisis plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. Lancet 381: 1634–41). NICE guideline [NG53] 'Transition between inpatient mental health settings and community or care home settings' also states that "practitioners involved in admission should refer to crisis plans and advance statements when arranging care". We recommend that this line is amended in line with good practice and other NICE guidelines to read, that "the plan should be recorded, respected and implemented". The Mental Health Crisis Care Concordat also includes specific guidance on joint crisis care planning. It states that people should be able to expect that: • In the case of urgent and emergency access to crisis care, staff "follow my wishes and any plan that I have voluntarily agreed to", as far as possible. • In receiving treatment and care when in crisis, "if my expressed wishes or previously agreed plan are not followed, the reasons for this are clearly explained to me". • In terms of recovery and staying well / preventing future crises, "I am supported to develop a plan for how I wish to be treated if I experience a crisis in the future and there is an agreed strategy for how this will be carried out." We recommend therefore that the following is also added: "An agreed strategy for how the joint crisis care plan will be carried out, is developed as part of the planning process." "If the person's previously agreed plan is not followed at the time of a crisis, the reasons for this are clearly explained."	
Mind	Full	15	405-409	As written, the guideline states that "anyone who has a mental disorder with an assessed risk of relapse or deterioration and who is in contact with specialist mental health services" should be offered joint crisis care planning. We recommend that the criteria given in the guideline as to who should be offered a crisis plan should be the same as that in NICE guidance (CG136). This guidance recommends that "people who may be at risk of a crisis" (and in touch with services) should be offered a crisis plan which is co-developed with their care coordinator. It is also worth noting that NICE guideline [NG53] recommends that people who have more than one admission should be offered a joint crisis care plan. Considering this, it would be helpful to develop a more inclusive statement, which would apply to someone who may not be using secondary/specialist services on an ongoing basis but where a joint crisis plan may be useful.	Thank you for your suggestion. The committee discussed this and felt that the recommendation in this guideline was closely tied with the evidence they reviewed and discussions about that evidence which took place in the committee. They were satisfied that this recommendation did not contradict the recommendations made in CG136 and NG53 and therefore agreed to make no changes.
Mind	Full	15	405-409	The inclusion of joint crisis care planning in this guidance on decision-making and mental capacity is an opportunity to provide support to health and social	Thank you for your comment. Unfortunately the systematic review underpinning this guideline did not locate a good amount of evidence about joint crisis planning.

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				care practitioners. We recommend that the section on joint crisis care planning is extended to include the key areas of good practice. From Mind's independent inquiry into acute and crisis mental healthcare, "Listening to Experience", we know that for joint crisis care planning to be successful, it should: • be negotiated in a structured way, which empowers the person whose care it is and allows them final sign off • involve any friend, family member or other supporter the person wishes to involve • ensures buy-in from the whole care team, including care co-ordinator and senior clinician This inquiry draws on the research, Thornicroft G, Farrelly F, Szmukler G et al. (2013) Clinical outcomes of joint 2380 crisis plans to reduce compulsory treatment for people with psychosis: a 2381 randomised controlled trial. Lancet 381: 1634–41. Other NICE guidelines also set out good practice in joint crisis care planning, for instance, • NICE guideline [NG53] states that crisis care plans should include: ○ relapse indicators and plans ○ who to contact in a crisis ○ coping strategies ○ preferences for treatment and specific interventions ○ advance decisions • NICE guideline [CG136] lays out that crisis plans should include: ○ possible early warning signs of a crisis and coping strategies ○ support available to help prevent hospitalisation ○ where the person would like to be admitted in the event of hospitalisation ○ the practical needs of the service user if they are admitted to hospital (for example, childcare or the care of other dependants, including pets) [QS] ○ details of advance statements and advance decisions (see 1.1.11) ○ whether and the degree to which families or carers are involved ○ information about 24 hour access to services ○ named contacts. Considering this, we recommend that the section on joint crisis planning should be extended to include the following: "Crisis care planning should be a voluntary, negotiated agreement between the person and the clinical team, with the patient having the final say."	The committee felt that they only had the basis for developing this one, general recommendation about joint crisis planning.

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				"The care coordinator and senior clinician should be involved, as should any friend, family member or other supporter the person wishes to be involved. Crisis care plans should include: • possible early warning signs of a crisis and coping strategies • support available to help prevent hospitalisation • where the person would like to be admitted in the event of hospitalisation • the practical needs of the service user if they are admitted to hospital (for example, childcare or the care of other dependants, including pets) • details of advance statements and advance decisions • preferences for treatment and specific interventions • named contacts, including whether and the degree to which families or carers are involved • information about 24 hour access to services"	
Mind	General	General	General	We welcome the development of this guideline. We are aware that people are often not supported to make their own decisions or properly involved in best interests decision-making, so this guideline should be very valuable. We support the guideline's aim of helping practitioners to keep people who lack (or may lack) capacity at the centre of the decision-making process. We particularly welcome the opportunity to make clear how good practice around capacity and decision-making should apply to decisions around mental health care and treatment too, including joint crisis care planning.	Thank you for your comment and support for the guideline.
National Childbirth Trust	Full	General	General	While there is some excellent work in this draft guidance, we are disappointed not to find any reference to maternity care or supporting the decision-making of pregnant women or new mothers, for example those with learning difficulties. Maternity care has a number of unique features, including the facts that: 1. the pregnant woman is not (usually) ill or injured, therefore may not need 'treatment' at all but if possible needs to understand that a situation can occur during the birth when rapid intervention may be recommended. If this happens, it can be extremely frightening (for any woman - but especially for those less able to understand explanations swiftly) if she doesn't feel involved in the decision, and the fear/anxiety can affect the physiological process of the labour and birth. the wellbeing and the interests of both the mother and the baby/babies are key, and must be taken into account in any decision-making.	Thank you for your comment and support for the guideline. The recommendations are intended to apply to a wide variety of people using services given that they are relevant to 'people who may (now or in the future) lack mental capacity to make specific decisions'. It was not possible to specify in detail all possible circumstances when this may apply.
National Childbirth Trust	Full	General	General	Both UK common law and the Human Rights Act enshrine women's decision-making rights as taking precedence over the needs of the baby: *'The fact that a woman may have made a decision that health professionals believe is not in her or her baby's best interests is not a reason by itself to decide that she lacks capacity'*	Thank you for your comment. The guideline is intended to complement rather than replicate existing legislation and guidance.
National Childbirth Trust	Full	General	General	We would suggest that the guidance should also cover topics related to maternity care such as: what happens when giving birth affects capacity to consent; the legal status of a birth plan; and decision-making about treatment for the baby, if needed, once it is born.	Thank you for your comment. The recommendations are intended to apply to a wide variety of people using services given that they are relevant to 'people who may (now or in the future) lack mental capacity to make specific decisions'. It was not possible to specify in detail all possible circumstances when this may apply. The guideline is intended to complement rather than replace existing legislation, guidance and professional guidelines.

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National Childbirth Trust	Full	General	General	We are aware of some of the high quality research completed in this area (and of further studies being carried out at the National Perinatal Epidemiology Unit) and would like to highlight the conclusions, with which we are in accord, drawn by the authors of the study by Malouf et al. 'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability. BMJ Open 2017;7: e015526. doi:10.1136/bmjopen-2016-015526. This says, in part: 'With support from family and services, learning disabled women can become confident and successful parents. Maternity services should make reasonable adjustments when providing care to this group, including adapting to their individual communication and learning needs: allowing sufficient time in appointments, offering clear explanations of each aspect of care and sensitive support for autonomy and fully informed choice.	Thank you for your comment. This article did not meet the inclusion criteria for our work as it was published in 2017 and the searches were conducted in 2016. A supplementary search was conducted in 2017, but this focused specifically on advance planning. This article will be considered in any future update to the guideline.
National Collaborating Centre for Mental Health	Short	3	3	Recommendation 1.1.1 – Should the guideline recommend that training is a standardised course delivered by a reputable organisation? There are a range of training courses available, however, the wording as it stands may allow for some service providers to manage this responsibility by providing below standard training to save money. Staff knowledge and training around mental capacity should also be linked to a competence framework for staff, to ensure that staff undergo regular supervision and professional development to maintain their skills in this area. If a relevant competence framework does not exist, then one should be developed to sit alongside the guideline.	Thank you for your suggestion. The committee was unable to recommend a specific training programme because they did not review evidence that would support this. However they recognise this as a shortcoming in terms of the evidence base and have therefore recommended that research is commissioned to address this.
National Collaborating Centre for Mental Health	Short	4	2	Recommendation 1.1.2 – There are concerns with this recommendation that the use of interventions, tools and approaches to support decision-making may not be consistent or standardised across services, meaning that the quality of care that people experience will be highly variable. The guideline should offer clearer advice on how local policy and guidance should be developed across services. The recommendation also states that health and social care organisations should identify or devise specific tools to assess mental capacity. This statement is too vague and is open to interpretation, possibly allowing organisations to develop vague policies around tools or to devise invalid or unreliable tools for assessment. While there is no one singular assessment tool to assess mental capacity, there needs to be clearer guidance on the parameters of any assessment tools, how the development of tools should occur, or the qualities that make up an ideal tool. Research questions 4 and 5 may address some of these concerns, however research needs to occur sooner rather than later.	Thank you for your comment. Unfortunately the committee did not feel they had a basis – from the systematic review evidence - to be more specific. They wished to ensure flexibility to suit local need. However they do recognise the shortcomings in terms of evidence in this area and have developed a research recommendation try and fill this gap.
National Collaborating Centre for Mental Health	Short	7	9	Sentence needs to be reworded for clarity; it is not clear whether the person will be supported to write down their own views, or if they will be supported to have their views noted down on their record (i.e. by somebody else).	Thank you for your comment. The committee felt it was sufficiently clear that the practitioner would write down the views expressed by the person.
National Collaborating Centre for	Short	12	14	Recommendation 1.4.1 – There needs to be clearer guidance around how monitoring and quality audits of mental capacity assessments should occur, what should comprise a quality audit, how often an audit should take place, and who would be involved in regular monitoring. There is a concern that organisations	Thank you for your comment. The recommendation has been edited to give greater detail regarding what features a good quality assessment of mental capacity to make a decision would have.

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Mental Health				may interpret or action this recommendation in many ways, with inconsistency across services as organisations may hold different quality thresholds for assessments and engage in variable monitoring.	
National Collaborating Centre for Mental Health	Short	12	16	Recommendation 1.4.2 – The current wording says 'consider' including people's views and experiences – this should be a stronger statement and indicate that organisations 'should' include people's views and experiences at all stages of monitoring. Involving people, service users, families, and carers, should be a central part of any mental capacity process, with co-production a key part of any health and social care organisation. An organisation could read this recommendation in its current form, consider including people's views, and choose not to. It would mean their capacity assessment activity may not be as transparent as it needs to be.	Thank you for your comment. The use of consider reflects the fact that the evidence base on this issue was not especially well developed and the committee therefore felt unable to make a stronger recommendation.
National Mental Capacity Forum Leadership Group	Short	General	General	The National Mental Capacity Forum leadership group have concluded that this draft is not fit for purpose and requires serious reconsideration. It needs correct information which is legally accurate and stated with consistency. As it currently stands, this draft would significantly undermine the reputation of NICE in this field.	Thank you for your comment. Following consultation, the committee conducted a careful review of the guideline to ensure legal compliance and provide a clear message about the link between the recommendations and existing mental capacity legislation. The final guideline has also benefited from further work with stakeholders with expertise in this field.
National Mental Capacity Forum Leadership Group	Short	General	General	This guidance seems overall to significantly miss the empowering ethos behind the Mental Capacity Act (MCA) and its focus on the individual person.	Thank you for your comment. The context section has been revised since consultation to place greater emphasis on the mental capacity act and its enabling, person centred ethos. In addition the committee reviewed the wording of the recommendations to ensure they are as empowering as possible.
National Mental Capacity Forum Leadership Group	Short	General	General	The evidence base is weak and there appears not to have been an adequate exploration of evidence found in the 'grey literature', there is a wealth of experience and reports on activities undertaken by Local Authorities in this area, including tools and other resources developed and disseminated through ADASS and LGA. This work is particularly strong in the area of Supported Decision Making which has been broadly overlooked in the draft guideline. Local Authority and other practitioners are beginning to explore new ways of working to support decision-making and this could provide a good opportunity to highlight leading-edge practice in this area.	Thank you for your comment. NICE guidelines are based on reviews of the best available evidence. These involve comprehensive literature searches of both published and 'grey' literature. The results of these searches are then screened to identify relevant papers, however if these do not have any methodological detail it is not possible to include them in the review. More details on the methodology used can be found in the NICE manual. The committee believes that supporting decision making has been addressed in detail in the guideline and during the post consultation committee meeting did add further detail to this section of the guideline, on the basis of consensus and in light of stakeholder comments. Changes to this section include an introductory paragraph which links with and spells out relevant sections and principles of legislation and the MCA Code of Practice.
National Mental Capacity Forum Leadership Group	Short	General	General	The National Mental Capacity Forum Leadership Group found it disappointing overall. In many places the guidance is vague and at times repetitive. There is inconsistency around the use of terms throughout (e.g. advocacy, support, advance care planning) and could be strengthened by further detail and guidance (or links to other resources).	Thank you for your comment. In light of yours and other stakeholder comments the committee reviewed the recommendations and the overall structure of the guideline, clarifying terms and links with legislation and the MCA Code of Practice. In particular, they reviewed the terms used throughout the guidance and the recommendations on independent advocacy and we hope these revisions help to address your concerns.
National Mental Capacity	Short	General	General	The fundamental principles of the Mental Capacity Act have not been reflected in the guideline, for example an absence of reference to the three principles that relate to capacity.	Thank you for your comment. In light of yours and other stakeholder comments the committee reviewed the guideline, partly with the aim of clarifying the relationship between the recommendation and the legislation and Code of

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Forum Leadership Group					Practice. This has been achieved through revising the context at the beginning of the guideline as well as adding introductory paragraphs to each relevant section.
National Mental Capacity Forum Leadership Group	Short	General	General	The sense of the rights of the person needs to be strengthened throughout. As currently drafted, the guideline in parts is actually disempowering of individuals.	Thank you for your comment. The committee reviewed the recommendations with the aim of ensuring that they are more person centred and empowering. For example in the section on supporting decision making there is now greater emphasis on 'supporting the person to make their own decision'. In addition, it should be noted that the guideline and recommendations have been drafted by a committee that included experts by experience.
National Mental Capacity Forum Leadership Group	Short	General	General	Throughout this guidance it may be helpful to use the term 'person' (or even 'P' as used in the MCA) to denote the person at the heart of the process. At times during guidance the term 'they' is confusing as it is unclear whether it refers to P/the person, or to the professionals or others involved in providing care. The term 'P' has been used in places in this response.	Thank you for your comment. The committee took account of your suggestion and ensured that where relevant, all reference were to the person rather than 'the individual'.
National Mental Capacity Forum Leadership Group	Short	General	General	It needs to be clearer throughout the document which guidance refers to a legal obligation i.e. is a 'must' and what is good practice i.e. 'should.' These terms are used inconsistently throughout.	Thank you for your comment. The committee reviewed the recommendations and made some changes to ensure that all of those referencing legal obligations use 'must' and all those based on strong evidence and committee expertise use the word 'should'.
National Mental Capacity Forum Leadership Group	Short	General	General	The guideline refers to both 'health and social care practitioners' and 'practitioners working in services' and are inconsistently used.	Thank you for your comment. The committee reviewed the recommendations to ensure that the term 'health and social care practitioners' is only used where this is the specific and main intended audience. In other recommendations, they removed 'health and social care' and only referred to practitioners – representing a more general audience, which may identify themselves as neither health nor social care.
National Mental Capacity Forum Leadership Group	Short	General	General	The guidance would be improved by assigning responsibilities to particular roles and people – there are numerous areas of the document where the subject the instruction is aimed at is not stated.	Thank you for your comment. The recommendations have been reviewed to ensure greater clarity in terms of intended audience.
National Mental Capacity Forum Leadership Group	Short	General	General	The guidance frequently uses unclear language including jargon with references to 'autonomy' and 'empowerment' without explanation of what these mean or how to enhance them for the individual.	Thank you for your comment. The committee reviewed the recommendations to ensure the language is clearer. Autonomy is only used in two recommendations and the committee believe that within the context of mental capacity legislation and practice, the meaning is widely accepted and understood. Please note that there is a Terms used section in the short guideline and a fuller glossary in the full guideline for those terms that need further explanation.
National Mental Capacity Forum Leadership Group	Short	General	General	The document seems to take a simplistic and uncritical view of advocacy. The circumstances in which advocacy is mandated should be clearly specified.	Thank you for your comment. The committee reviewed the advocacy recommendations in light of yours and other stakeholder comments. We hope the revisions address your concerns.

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National Mental Capacity Forum Leadership Group	Short	General	General	The role of advocates and the pros and cons of involving another stranger in the person's care needs to be much better explained. This guidance in parts extends the role of IMCAs beyond their legislative base. It does not differentiate between registered IMCAs and commercial organisations who can act as advocates but are not regulated in the same way, Care Act advocacy and Relevant Person's Representatives or peer-peer support organisations and the role they can play. It also does not acknowledge the current challenges facing advocacy services.	Thank you for your comment. The committee reviewed the advocacy recommendations in light of yours and other stakeholder comments. We hope the revisions address your concerns.
National Mental Capacity Forum Leadership Group	Short	General	General	There is a concerning gap around a role for relatives (who are so often 'gold dust' in their understanding of the person's communication, their wishes and feelings, and what makes them upset or happy) who are routinely denied their statutory right to be consulted. As suggested below, the statutory best interests checklist, with the strengthened protections suggested by the Law Commission in March 2017, should form the basis of the guidance.	Thank you for your comment. The committee reviewed the recommendations taking care to ensure that the role of relatives is emphasised while at the same time safeguarding the person from any potential undue influence. Examples of involving families and other trusted people include recommendations for commissioners and providers to develop protocols for information sharing between practitioners, people and families; recommendations about taking all reasonable steps to include families in advance care planning and a number of specific recommendations about supporting carers and families to be actively involved in best interests decision making.
National Mental Capacity Forum Leadership Group	Short	General	General	The guidance should do more to impress upon clinicians the importance overcoming challenges to instigating conversations about advance care planning and the potential benefits for the individual, those providing care to them and the wider healthcare system that can result	Thank you for your comment. The committee felt that the draft recommendations placed great emphasis on the importance and benefits of advance care planning. They also revised the introductory paragraph for this section to further emphasise the benefits.
National Mental Capacity Forum Leadership Group	Short	General	General	It would be helpful to refer to the core principles as laid out in the MCA, because the part of the process often least well assessed is the ability of the person to weigh up information decision-making and consider the implications of a decision for self and for others	Thank you for your comment. In revising the guideline after consultation the committee agreed to amend the context section, explicitly stating the core principles of the Mental Capacity Act in the way you suggest.
National Mental Capacity Forum Leadership Group	Short	General	General	The warning around the difficulties in people with executive dysfunction at 1.4.20 is important and its inclusion is welcomed.	Thank you for your comment and support for this recommendation.
National Mental Capacity Forum Leadership Group	Short	General	General	It is confusing to start with 'ask the person how they want to be supported and who they would like to have involved' as not everyone will need someone to be involved to help them. This section should explain that different people will need different amounts of support, ranging from ensuring that information given is clear, accessible, and jargon free through to highly specialised communication skills and aids	Thank you for your comment. The committee acted on your suggestion by changing the recommendation to say that people should be asked how they want to be supported. In a separate sentence the recommendation states that if the person wants someone to support them then 'ask who this should be'. In this sense there is no longer an implied assumption that they will want someone to support them.
National Mental Capacity Forum	Short	General	General	Practitioners have a responsibility to protect the person from coercion, which means identifying conflicting opinions and their relevance to that person.	Thank you for your comment. The committee highlighted that the identification of conflicting opinions was already covered in the draft recommendations – as something which practitioners should discuss with the person and their family in the context of supporting decision making. Following consultation they also amended the recommendations within the section on best interests decision

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Leadership Group					making to make clear that formal best interests decision making meetings may be helpful if there are conflicting opinions about the person's best interests.
National Mental Capacity Forum Leadership Group	Short	General	General	Paragraph 1.2.16 talks about referral to those with special skills who may help the person with communication difficulties, particularly when these are severe. At page 8 line 20 the text implies that somebody (not the person affected) is making a decision and someone else (again not the person) is providing support. This is confusing because the role of supported decision-making is to support the person in making a decision for themselves; such support may require intensive communication support to enable the person to express their view. It may also require intensive support to explain the issues to the person in such a way that the information can be used in the decision-making process.	Thank you for your comment. The committee acted on your suggestion and ensured that the final recommendations emphasised the role of the person in making their own decisions.
National Mental Capacity Forum Leadership Group	Short	General	General	There is not enough detail about unwise decisions, which is an area requiring further development and guidance	Thank you for your comment. When they revised the recommendations following consultation the committee clarified several referenced to unwise decisions and they also ensure that the revision of the context section highlighted principle 3 of the Mental Capacity Act.
National Mental Capacity Forum Leadership Group	Short	1	5	The title should reflect what the guideline actually covers- it currently doesn't. For example, be clear this guideline is about ensuring people are supported to make their own decisions and where someone lacks capacity their involvement in decision making is maximised, and refer specifically to the relevant principles of the MCA. Currently this seems to be focused on advance care planning more than the MCA, but does not draw adequately on the evidence base around advance care planning in health and social care.	Thank you for your comment. The title reflects the fact the guideline is about decision making and mental capacity. Advance care planning also falls under this description. (Making decisions in advance). Advance care planning is not meant to relate to absolutely everyone but only to people who may lack capacity now or in future.
National Mental Capacity Forum Leadership Group	Short	1	8	The guideline states that it is seeking to address historic concerns raised by the Care Quality Commission, and the forum's view is that this guideline does not achieve that, nor does it support practical implementation of the Mental Capacity Act as purported	Thank you for your comment. The text does not actually say the guideline seeks to address the concerns raised by the CQC, rather that the problems identified by the CQC form part of the context for the guideline. The committee feels the guideline does build on the MCA (and other relevant legislation), complementing it and supporting implementation. The relationship between the guideline, relevant legislation and the Code has now been clarified in a revised context section.
National Mental Capacity Forum Leadership Group	Short	1	17	Page 1 line 17 should provide a link to the Mental Capacity Act code of practice. The document in places appears incompatible with the Code of Practice of the MCA. Although the code of practice does need some updating in places this document does not address aspects that are in need of revision. This draft represents a missed opportunity to help health and social care staff make a step change around knowledge of and practice around people with impairments of decision-making capacity, particularly not where such impairments fluctuate.	Thank you for your suggestion. The context has now been revised to provide a clear link between the guideline, the relevant legislation and the Code of Practice. Further reference to the MCA and Code of Practice have also been added to the guideline.
National Mental Capacity Forum Leadership Group	Short	2	10	Although the guideline does not cover Deprivation of Liberty Safeguards processes, it seems extraordinary that protection from liability is not discussed, nor are the extra conditions that are required for restraint to be lawful in someone's best interests. Aligned with the final two statutory principles of the MCA, these are serious omissions.	Thank you for your comment. The scope of this guideline was specifically decision making and the decision was taken by the committee, during the scoping stage, that this therefore should not cover issues around deprivation of liberty. However, the recommendations are clearly intended to be implemented within the context of the whole of the Mental Capacity Act (as well as other legislation and guidance) so the focus on decision making is not intended to be at exclusion of the other statutory principles.
National Mental	Short	3		Overarching Principles: It is helpful that the guideline stresses the importance of role appropriate training and continuing professional development and supervision	Thank you for your comment and your support for the guideline.

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Capacity Forum Leadership Group				of staff and helpful that the importance of seeking consent for advance care planning is stressed.	
National Mental Capacity Forum Leadership Group	Short	3	12	This should be reworded because the term autonomy is incorrectly used here – the consideration in difficult conversations is the potential impairment of mental capacity. Autonomy is the ability to take decisions to self-govern and is a relational state between people, whereby a person's autonomy is enhanced or undermined by the way that they are behaved towards. Autonomy is not synonymous with mental capacity. The MCA aims to enhance and support the autonomy of the individual even in the face of the type of situations that might be envisaged in a care plan. It is not clear whether references have been made to work of an Onora O'Neill and others on defining autonomy, but these would be a useful addition to the document to the evidence base.	Thank you for your comment. The Guideline Committee confirm that the term 'autonomy' is correctly used in the third bullet in Recommendation 1.1.1. Furthermore, the committee note that the MCA refers to autonomy in the sense of the second principle of the Mental Capacity Act.
National Mental Capacity Forum Leadership Group	Short	4	26	It is unclear who the guidance considers to be appropriate advocates, standards for their training, quality control or to whom they are professionally accountable.	Thank you for your comment. The issues of appropriate advocates, standards for their training, quality control or to whom they are professionally accountable are beyond the scope of this guideline.
National Mental Capacity Forum Leadership Group	Short	5	17	There seems to be reliance on the role of commissioners to assure advocacy referral, but there is no reference to important role of the regulator, the Care Quality Commission. Recent changes at CQC are embedding the MCA into its work and building capability of inspectors; these will help to challenge risk averse and paternal practice. This responds to the evidenced detail to the House of Lords post-legislative scrutiny report that showed the problems originate in strong existing cultures in social care, health and safeguarding practice (the latter promoting risk aversion and paternalism).	Thank you for your comment. The advocacy recommendations have now been substantially revised and they no longer place a reliance on commissioners to assure referral to advocacy.
National Mental Capacity Forum Leadership Group	Short	5	23	The costs associated with advocate provision are not explicitly considered, and the strong focus on involving an advocate in decision-making (despite the weaker evidence for advocacy) dilutes and detracts from the responsibility on the HCPs and other carers to shoulder responsibility for implementing the MCA, which should be a primary aim of the guidance. The reference to training at 1.1.11 (p5 line 23) should require such training be provided to clinical staff at all grades who communicate with the person (e.g. all staff in stroke units, head injury units, rehabilitation units, mental health services particularly those dealing with addictions and all emergency services, particularly first responders).	Thank you for your comment. Training for other practitioners is addressed in other recommendations, especially the one in the overarching principles, 1.1.1. The committee believes that the guideline as a whole does place a good deal of emphasis on the ability of all practitioners to support decision making within this context.
National Mental Capacity Forum Leadership Group	Short	5	5, 6, 9, 10	It is unclear what the costs are of the recommendation line 5&6 or the evidence for relative cost efficacy and improved care compared with increased skills in the health and social care teams	Thank you for your comment. The advocacy recommendations have now been substantially revised and the recommendation to which you refer is now phrased with 'consider' expanding statutory advocacy commissioning, to highlight that it is not legally binding and will not have a prohibitive resource impact.

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National Mental Capacity Forum Leadership Group	Short	6	4 onwards	This guidance should reiterate that supported decision making is a central principle of the United Nations Convention on the Rights of Persons with Disabilities - people with a disability should receive the support necessary to enable them to make and implement the decisions that affect them. This underpins the MCA requirement for support in decision making.	Thank you for your comment. The Guideline Committee agree that this recommendation covers all people, i.e. people with capacity for the decision, and those without capacity.
National Mental Capacity Forum Leadership Group	Short	6	8	1.2 .2 rightly stresses the importance of the relationship of trust in supported decision-making, but should be reworded to state that 'practitioners supporting a person's decision-making should work to build a relationship of trust and to ensure that such trust is never betrayed	Thank you for your suggestion, which the committee discussed. They did not make the change to the recommendation because they felt their draft wording is clearer.
National Mental Capacity Forum Leadership Group	Short	7	8	text reads: 'for those who lack capacity, a referral should be made to an independent mental capacity advocacy'. This suggests a lack of understanding of the IMCA remit.	Thank you for your comment. Reference to making a referral to an Independent Mental Capacity Advocate has been removed from the recommendation.
National Mental Capacity Forum Leadership Group	Short	7	20	1.2.11 and 1.2.12 tells practitioners to involve 'involve significant and trusted people' in supported decision making, and that professionals need to be aware of coercion or undue influence. It states that 'if there are no significant trusted people, think about involving an advocate, particularly if the advocate has worked with the person before.' This is a dangerous assumption that the advocate will always be trusted. In the following paragraph it states that practitioners should talk to carers, family and friends. These two paragraphs appear confusing as there is no guidance given to how staff should deal with suspected abuse/ coercion.	Thank you for your comment. The committee agreed to review these two recommendations and highlighted that the recommendation states 'ensure that this support is free from coercion or undue influence, in addition 1.2.1 states 'Be aware of the possibility that the nominated person may be exercising undue influence, duress or coercion regarding the decision, and take advice from a safeguarding lead if there is a concern.' We hope this helps to address your concerns.
National Mental Capacity Forum Leadership Group	Short	7	27	1.2.12 appears to deal with the consequences of care planning rather than supported decision-making. The sentence at page 7 line 29 could be rewritten state 'These could include ways to enhance the individual's autonomy, to ensure the person is better informed about the options available. Topics that may need to be covered include the benefits of sharing decisions with others interested in the person's welfare and the need to confront potentially upsetting issues including to declining health or end-of-life. Advance care planning can help mitigate a person feeling overwhelmed by having to make the difficult decision to difficult time, but it must be made clear that any such plan can be altered or abandoned at any time should the person so wish	Thank you for your comment. The recommendation does refer to supported decision-making. It has been amended to refer to 'capacitous decision-making' to clarify this.
National Mental Capacity Forum Leadership Group	Short	8	5	In 1.2.13 the possible need to be present more than one session is stated. In reality supported decision-making can only occur when a relationship of trust and understanding has been established; it is unusual for this to happen in a single session. Paragraph 1.2.15 rightly identifies the need for continuity with the same practitioner providing support, which should be stressed.	Thank you for your comment. We have reviewed the recommendations and feel that your points are covered. The importance of building relationships is also referenced in recommendation 1.2.3.
National Mental Capacity Forum	Short	9	6	The section could be strengthened by more emphasis on the practical issues around advance care planning and supporting professionals have these conversations. There is concern that clinicians may come to view planning as an	Thank you for your comment. We believe that these points are addressed adequately in the advance care planning section of the guideline and the evidence reviewed did not provide a basis from which to make further recommendations.

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Leadership Group				optional extra for individuals rather than a key component of providing care to a person.	
National Mental Capacity Forum Leadership Group	Short	9	6	The MCA does not cover advance care planning per se directly. It deals with two aspects: advance decisions to refuse treatment and an advance statement of wishes. The latter form the basis of care planning, which must be considered in best interests decision making when a person has lost capacity. An advance care plan may incorporate an ADRT. This needs to be stressed more clearly (short version)	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the links between advance care planning and ADRTs and advance statements of wishes are made clearer.
National Mental Capacity Forum Leadership Group	Short	9	6 onwards	As much of this guidance is taken up with advance care planning may be more helpful to divide it into three sections: 1. When a person becomes unwell with advancing disease that is likely to result in some difficulties with decision making capacity in the future. 2. When a person has some impairment of mental capacity, leading to a requirement to support in decision-making . 3. When a person lacks capacity for a major decision and others must take that decision on the person's behalf	Thank you for your comment. This section has been edited to provide greater clarity.
National Mental Capacity Forum Leadership Group	Short	9	13	This section at page 9 line 13 speaks about developing standard protocols, but protocols are rigid. The term guidance would allow standard of best practice to be developed without the risk of a rigid protocol cutting across P's right to privacy	Thank you for your comment. The committee believed that protocol was the most appropriate term to use.
National Mental Capacity Forum Leadership Group	Short	10	15	the term 'they' is particularly confusing because it should refer to both the professional and to P, recognising they may have compatible but different information needs	Thank you for your comment. This recommendation relates solely to the information needs of practitioners.
National Mental Capacity Forum Leadership Group	Short	12	13 onwards	The entire section on assessment seems wilfully to omit the crucial elements: the 2-stage test and the 'balance of probabilities' nature of decision-making, in favour of aspirational but vague injunctions to proceed respectfully. Other guidance is available on Capacity Assessments (e.g. from 39 Essex Chambers) which should be referred to strengthen this part of the document.	Thank you for your comment. The recommendations are evidence based and the committee were therefore unable to add further detail to these recommendations.
National Mental Capacity Forum Leadership Group	Short	12	13 onwards	The guidance does not acknowledge that a person's capacity can often fluctuate. This is an area particularly relevant for people with dementia whose capacity can fluctuate as the condition progresses, and even at different times of day. Practical guidance is needed for people working in these situations, which can often be the most challenging for healthcare professionals. No reference has been made to ways in which capacity can be improved.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions**.**

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National Mental Capacity Forum Leadership Group	Short	16	18 onwards	The document does not adequately stress the role of someone holding lasting power of attorney. In the section on best interests (P16 line 18 onwards), it fails to stress that whoever holds an LPA must still undertake the best interests decision process when taking a decision on behalf of the person.	Thank you for your comment. The guideline has been edited to make the links between lasting powers of attorney and best interests processes.
National Mental Capacity Forum Leadership Group	Short	16	18 onwards	Under best interests decision making it is not clearly stated that a best interests decision must be taken in the interests of P, not the interests of others or of the care system. This guidance must reflect the MCA that clearly states that a best interests decision must never be motivated by a desire to bring about death.	Thank you for your comment. This section has been edited to provide clarity on these issues.
National Mental Capacity Forum Leadership Group	Short	16	18 onwards	It is helpful that the importance of a timely review is stressed at 1.5.23. It would be helpful to recommend that at the time of the first decision being made, the timeframe should be agreed to review the decision.	Thank you for your comment and support. The recommendation was drafted in response to the evidence reviewed by the committee and this did not provide a basis on which to make such a statement.
National Mental Capacity Forum Leadership Group	Short	18	3	P 18 line 3 1.5.9 seems to fall into the commonly held error of believing that best interests must be decided via a 'meeting'. There is no such suggestion in the Act.	Thank you for your comment. We have added details on these issues to provide clarity about responding proportionately.
National Mental Capacity Forum Leadership Group	Short	18 20	4 1	The bullet points would be better replaced by the statutory checklists contained in MCA s.4. The order of consideration should start from the person, for example, the person's use of lawful ways to remove decision-making from professionals should come up the list to an early point in any list of factors to consider.	Thank you for your comment. These recommendations were drafted on the basis of the evidence reviewed by the committee. We have reviewed the guideline to ensure that the introduction to each section includes references to relevant parts of the Mental Capacity Act.
National Mental Capacity Forum Leadership Group	Short	19	4	1.5.14 (as often in this document) falls back on demanding tool-kits and protocols: this emphasis on process rather than practice risks creating tick-box lists.	Thank you for your comment. The recommendation is based on evidence reviewed by the committee which suggested that checklists and tool-kits can help to improve best interests practice.
National Mental Capacity Forum Leadership Group	Short	19	12	P 19 line 12 could be read to imply that an attorney under an LPA can block a best interests decision, but such a person is obliged to undertake the best interests process. A Court Appointed Deputy can only operate within the powers given by the Court.	Thank you for your comment. The guideline as a whole and this section specifically have been reviewed to ensure that the links between lasting powers of attorney and best interests procedures are clarified.
National Mental Capacity Forum	Short	21	11	The Definitions section needs to be rewritten. It is inaccurate. NICE need to ensure that it does not redefine legislation	Thank you for your comment. We have revised this section to take into consideration comments received from a range of stakeholders.

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Leadership Group					
National Mental Capacity Forum Leadership Group	Short	21	19 and onwards	The MCA clearly states that an Advance Decision to Refuse Treatment (ADRT) is a refusal of consent, made in advance. It must fulfil the requirements of consent to be valid (be informed, be made by a person with capacity to make that decision and it must be voluntary and free of coercion). It must be specific to the situation it refers and must be properly documented and signed. A good example is Jehovah's witnesses who refuse a treatment (blood products) in advance	Thank you for your comment. We have defined this in the Terms used section as: 'An advance decision to refuse treatment (sometimes known as an ADRT or a living will) is a decision an individual can make when they have capacity to refuse a specific type of treatment, to apply at some time in the future when they have lost capacity. It means that families and health professionals will know the person's decisions about refusing treatment if they are unable to make or communicate the decisions themselves. An advance decision must be valid and applicable before it can be legally binding. For example, one of the conditions is that the individual is aged 18 or over at the time the decision is made. To establish whether an advance decision to refuse treatment is valid and applicable, practitioners must have regard to sections 24-26 of the Mental Capacity Act 2005. If the advance decision purports to refuse life-sustaining treatment, additional requirements apply.'
National Mental Capacity Forum Leadership Group	Short	21	19 and onwards	The term 'living will' should not be used. It does not exist in law and is misleading	Thank you for your comment. To avoid confusion, 'living will' has been removed from the heading for advance decision. More detail has been added to the 'advance decision to refuse treatment' definition and we hope this addresses your concern.
National Mental Capacity Forum Leadership Group	Short	21	19 and onwards	Specific issues around refusal of life-sustaining treatment should be covered	Thank you for your comment. In light of yours and other stakeholder comments the definition of 'advance decisions to refuse treatment' has now been revised although there is still no specific reference to 'refusal of life-sustaining treatment' because the definition is intended to cover all decisions about treatment, care and support.
National Mental Capacity Forum Leadership Group	Short	21	19 and onwards	The guidance should stress that when a person has an ADRT in place, all care of the person must continue and problems or risks of distress arising from the refusal must be minimised.	Thank you for your comment. These are just intended to be definitions of what the term is – not a recommendation for practice about the tool or intervention. However, some more detail has been added to help clarify the definition.
National Mental Capacity Forum Leadership Group	Short	21	19 and onwards	The guidance should state that a person can revoke their ADRT at any time	Thank you for your comment. These are just intended to be definitions of what the term is – not a recommendation for practice about the tool or intervention. However, some more detail has been added to help clarify the definition.
National Mental Capacity Forum Leadership Group	Short	21	25	Advance Directive **:** this term should also not feature in this guidance. A person cannot direct something to be done to them. This does not exist in UK law. The Mental Capacity Act provides for an Advance Statement of Wishes (ASW), which must be considered when a person is making a decision on behalf of a person who lacks capacity for that decision at a specific time.	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.

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National Mental Capacity Forum Leadership Group	Short	22	4	The definition of 'duty of care' is confusing as written. It reflects 'prudent healthcare principles'.	Thank you for your comment. This term is no longer used in the guideline.
National Mental Capacity Forum Leadership Group	Short	22	15	P22 Line 15 defines a lasting power of attorney. This section needs expansion to explain that the LPA is only valid if registered with the Office of the Public Guardian and the different types of LPA should be clarified, including the importance of aspects specified in the LPA document (Health and Welfare; Finance) It is also important that health and social care staff know how to challenge when the attorney appointed by a person is not appearing to act in that person's best interests and is not undertaking due process in formulating decisions on behalf of that person	Thank you for your comment. We have revised the definition of this term as follows: 'A legal instrument that allows a person (the 'donor') to appoint one or more people (known as 'attorneys') to make decisions on their behalf. There are 2 types: health and welfare, and property and financial affairs, and either one or both of these can be made. To have legal force, LPAs must be created in accordance with section 9 and section 10 of the Mental Capacity Act 2005. The attorney must have regard to section 4 of the Mental Capacity Act 2005, the Mental Capacity Act Code of Practice, and must make decisions in the best interests of the person.'
National Mental Capacity Forum Leadership Group	Short	23	15	There is no legal role of proxy decision maker in England and Wales. This is a very misleading subsection as written. The term should not be used.	Thank you for your comment. We have now removed the term 'Proxy' from the revised version of the guideline.
National Mental Capacity Forum Leadership Group	Short	23	19	These bring together ADRTs and ASW's to guide management in future relapses in patients in psychiatry. They are not 'directives'. See http://www.psychiatrycpd.co.uk/learningmodules/advancedecisionsinpsychiatr.aspx	Thank you for your comment. Reference to psychiatric advance directives has been removed from the guideline.
National Mental Capacity Forum Leadership Group	Short	23	25	The term substitute decision-maker is not lawful in England or Wales. It should not be used.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
National Mental Capacity Forum Leadership Group	Short	25	22	The reference to a named MCA lead requires clarification. Such a post is weakened when seen and structured as part of adult safeguarding. Problems then arise due to the tension between the empowering ethos of the MCA and the frequent tendencies within Safeguarding towards risk-aversion and paternalism	Thank you for your comment. This section provides standard advice from NICE about implementation of its guidelines, which includes identifying someone who would lead implementation of the guideline. This is not intended to mean the MCA lead, although they may be an appropriate person.
National Mental Capacity Forum Leadership Group	Short	28	23 and onwards	Advocacy and support for decision-making on the presumption of capacity: The document draws attention to the lack of evidence, as already referred to above. Given the lack of evidence, the strong recommendations over providing advocates, as referred to above, would seem misleading for health and social care system that is already struggling financially. Decisions to divert funds to pay for the large number of advocates that would be required if the earlier parts of this	Thank you for your comment and your support for the guideline. High-quality mixed methods studies with a controlled effectiveness component (preferably randomised) are needed to evaluate the effectiveness and cost effectiveness of advocacy as a tool to support the decision-making of people who may lack capacity to make a decision (on the presumption of capacity). The effectiveness component will ideally include 3 arms; usual care, usual care plus advocacy and

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				guidance were implemented, would inevitably jeopardise the health, well-being and life chances of large numbers of patients	usual care plus support with enhanced advocacy. This would be beneficial to people who lack capacity, as it would force the research field to concentrate on developing and enhancing existing assessment and support methods, thus improving outcomes even more. By asking for three arm-trials, this would mean we would also get data on how well existing approaches and support methods work. Studies should also include a qualitative component that explores whether advocacy as a means of support to make decisions is acceptable to people using services and valued by practitioners.
National Mental Capacity Forum Leadership Group	Short	30	10	The guidelines correctly state (P 30 line 10) was there is little evidence about any particular standardised forms. However the Appelbaum criteria set out some principles which have not been disputed or disproved and therefore it would seem important that some of the core principles laid out. It is extremely unlikely that any single assessment format will be adequate given the wide range of capacity impairments and the almost infinite combinations of these with the type of decision has to be made. It is right to call for further research in this area.	Thank you for your comment and support for the guideline. There is a need for high-quality mixed methods studies that evaluate the accuracy or effectiveness of mental capacity assessment tools that are compliant with the Mental Capacity Act. We have expanded this research recommendation so that the controlled effectiveness component will ideally include 3 arms; usual care, usual care plus mental capacity assessment tools and usual care plus support with enhanced assessment tools. Studies should also include a qualitative component that explores whether such tools and approaches are acceptable to people using services and valued by practitioners.
NHS England	Full	General	General	We are supportive of its content and have nothing overtly critical to add to the consultation. We note with interest the specific reference to learning disabilities in the full guidance and found this a very positive inclusion in the overall guidance One area that isn't noted and perhaps it's out of scope, is the interface between restricted sections , capacity and planning care, as recently surfaced by the MM judgement, however I note this is a specific issue and maybe out of scope of guidance of this type.	Thank you for your comment and support for the guideline. The introduction has been updated to make clearer how the guideline relates to existing legislation, case law, guidance and professional guidelines. In relation to your specific point, you are correct that this would be beyond the scope of this guideline. Restricted sections are more to do with Deprivation of Liberty than with the elements of decision included within the guideline scope. The Mental Health Act and DoLS guidance would provide advice on this subject. It is also important to note that the case you mention is being appealed to the Supreme Court so any recommendations based on this judgement might eventually become obsolete.
NHS England	Full	general	general	1. *Would implementation of any of the draft recommendations have significant cost implications?* Multidisciplinary meetings may require longer time away from clinical practice and organisation of meetings at times when general practitioners may have to arrange locums to cover their clinical work. Development of IT and clinical tools may require investment of time (individual commitments) and financial support. Development of advocacy services may also have cost implications. Training and learning material and dissemination of training programmes may add significant financial burden in primary care.	Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable. The section on advocacy was reviewed by the Guideline Committee and has been updated. Following consultation feedback, the recommendation on advocacy has been reworded to take account of stakeholder concerns regarding the resource implications of the previous recommendations. The recommendations now relate to statutory advocacy that legal authorities have a duty to provide.
NHS England	Full	General	General	2. *What would help users overcome any challenges?* Development of accessible electronic templates Sharing of good practice	Thank you for your comment and suggestion of tools to support implementation of the guideline recommendations.

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				Provision of online training and learning resources.	
NHS England	Short	6	20	Visual materials, visual aids, communication aids could be further qualified by adding that such tools should meet the standards of NHS Accessible Information Standards.	Thank you for your comment. The NHS Accessible Information Standard is included in another recommendation (1.2.7 in the draft guideline).
NHS England	Short	7	11	It is concerning that practitioners are obliged to refer patient to relevant advocacy service, could be difficult to implement in areas where such advocacy services are not well established, it may be best to changed the recommendation to consult relevant advocacy service.	Thank you for your comment. The wording of the recommendation is clear in that if the person has no trusted people then the practitioner supporting their decision should think about the involvement of an advocate.
NHS England	Short	7	15	Recommendation to consider providing independent advocacy is in contrast with earlier recommendation under 1.1.8 where practitioners are required to refer to relevant advocacy service.	Thank you for your comment. The recommendations on advocacy have been substantially revised and we hope this addresses your concern.
NHS England	Short	8	9	When supporting a person making decision, practitioners should build and maintain a trusting relationship and also make sure that they are not breaching the issues of equality and diversity – ensuring practice does not prejudice against patients with any of protected characteristics defined under equality and diversity act.	Thank you for your comment. The importance of building relationships is referenced in recommendation 1.2.3.
NHS England	Short	9	11	Repetition of guidance already included under 1.1.11	Thank you for your comment. Recommendation 1.1.11 (in the consultation version) focuses on the provision of advocacy services whereas this section deals with advance care planning.
NHS England	Short	11	16	Needs to clarify the intended audience for training on advance care planning practitioners or patients and their advocates?	Thank you for comment. The recommendation on training relates to practitioners. The text has been edited to clarify this.
NHS England	Short	13	21	Needs to clarify intended audience of "other people" carers or practitioners.	Thank you for your comment.
NHS England	Short	14	8	Joint crisis planning seems to refer to mental health services only, whereas crisis planning may be needed in terminal illnesses where patients condition may deteriorate significantly (malignant or non-malignant conditions).	Thank you for your comment. This recommendation is based on evidence showing that joint crisis planning may be beneficial to people diagnosed with a mental health issue. The committee did not review evidence relating to the use of crisis planning with other groups.
NHS England	Short	14	17	Need clarification: Organisations capacity assessment activity – perhaps means organisation's mental capacity assessment activity.	Thank you for highlighting this, it how now been amended to reflect that it refers to mental capacity assessment activity.
NHS England	Short	14	21	Recommended assistance could also include patients with protected characteristics or other disabilities.	Thank you for your comment. We believe that this issue is covered adequately by the guideline's emphasis on person-centred care.
NHS England	Short	16	6	Point is repetition of recommendations under 1.4.8 (page 15 line 26)	Thank you for your comment. The recommendations have been edited to ensure that there are no overlaps.
NHS England	Short	16	24	It should add that tools should also meet NHS Accessible Information Standard	Thank you for your comment. We have edited the recommendations to include reference to the NHS Accessible Information Standard.
NHS England	Short	17	14	It should include the outcome and implication of the assessment	Thank you for your comment. Recommendation 1.4.14 states that people should be informed of the outcome of the assessment in accessible language or an accessible format.
NHS England	Short	17	15	People with learning disability could also be included to make sure awareness of their special needs are equally raised just as those people with executive dysfunction.	Thank you for your comment. A number of recommendations make clear that support and interventions should be tailored to the needs of the person (for example, recommendations 1.1.5, 1.2.4, 1.2.6, 1.2.9 and 1.4.8). The aim of this was to cover a range of people with particular or complex needs.
NHS England	Short	18	18	A definition of best interests decision-making would be useful to include	Thank you for your comment. This section has been edited and the introduction expanded to provide clarity on this.
NHS England	Short	21	19	A record of who interested parties are could be improved by adding that their level and nature of interest and engagement should be understood before consulting them.	Thank you for your comment. These are just intended to be definitions of what the term is – not a recommendation for practice about the tool or intervention. However, some more detail has been added to help clarify the definition.

Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
20/12/2017 to 05/02/2018

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
NHS England	Short	23	5	Implementation of multi-agency meetings in primary care settings particularly for general practitioners and their teams may prove to be challenging area to organise, because of the reasons as follows Firstly difficulty of coordination of care planning with wider services for example secondary care and social services is difficult. Secondly lack of standardised methods for recording of the information for examples templates and IT support for recording of the information. Thirdly lack of coordinated sharing of information between social services, secondary care services and primary care services.	Thank you for your comment about condition-specific training in primary care settings. This area is not in scope for this guideline.
NHS England	Short	24	2	Definition of consent is not fully clear.	Thank you for your comment. This is defined as 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
NHS England	Short	26	14	MCA – could improve by adding full word 'Mental Capacity Act'	Thank you for your comment. This has been amended to 'Mental Capacity Act' in full.
NHS England	Short	29	5	Implementation of considerations about training of individuals involved in care planning may restrict the involvement to only those who are trained to conduct such assessments leading to limited opportunities of contributions from those who may have knowledge of the patients but may not have been trained.	Thank you for your comment and your support for the guideline. We acknowledge your concern that implementation of considerations about training of individuals involved in care planning may restrict the involvement to only those who are trained to conduct such assessments. In our research recommendation about training and support for practitioners, the guideline committee agreed that effective training and support on the Mental Capacity Act and how to apply its principles in practice is essential for practitioners working with people who may lack capacity to make a decision. A better understanding of what training and support increases compliance with the Act could improve outcomes for people who may lack capacity to make a decision. This training and support would not be restricted to those only involved in care planning.
NHS England	Short	5, 26	(5) 6 (26) 7	Training for doctors may need to be expanded to undergraduate education in order to help develop their skills for writing care plans. This may have significant implications for financial and educational resources.	Thank you for your comment. This is a recommendation for further research, rather than a recommendation for practice.
NHS Harrogate and Rural District CCG	Short	general	general	It would be helpful to have more clarity between the documentation and resources needed for smaller everyday decisions as opposed to more significant decisions. The recommendations seem to imply that each time an everyday decision is made on the person's behalf this should be recorded?	Thank you for your comment. Introductory text has been included in each section to make clear how this fits with existing legislation, guidance and practice requirements.
NHS Harrogate and Rural District CCG	short	General	General	Appropriate training is welcomed but rather than being left to individual organisations or commissioners would a national program be more appropriate?	Thank you for your comment which will feed into the ongoing work on guideline implementation and the quality standard.
NHS Harrogate	Short	4	11-13	There is a general principle included in the MCA code of practice and the MCA that people should be assumed to have capacity unless there is a reason to suspect otherwise. Could this be included in the recommendation? This	Thank you for your comment. The Guideline Committee agree that this recommendation is just about being aware of capacity issues, and is not about

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
and Rural District CCG				recommendation currently appears to read as if everyone's capacity should be suspected for every decision.	doubting people's capacity. Please note that we have added a separate recommendation highlighting the importance of the presumption of capacity.
NHS Harrogate and Rural District CCG	Short	5	10	Should this read advocacy **service** or **advocate**? The recommendations appear to imply an advocate should be used for all decisions eg on medical treatment. This would be a move away from using an advocate for significant medical interventions and may restrict providing the best care for a patient if independent advocacy services were not available in a reasonable time frame or were not available locally.	Thank you for highlighting this typo, which has been corrected although the wording of the recommendation has also been changed.
NHS Harrogate and Rural District CCG	Short	5	15	This recommendation does not provide any information on who it is aimed at. It would be helpful to do so.	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised. Although the recommendations have changed, as a basic principle, they are aimed at the practitioner supporting the person to make a decision.
NHS Harrogate and Rural District CCG	Short	10	5-6	Please clarify who "they" refers to in this sentence. I suspect that it means the person rather than the practitioner?	Thank you for your comment. We have edited the recommendation to clarify that all practitioners should be able to enable access to advance care planning.
NHS Harrogate and Rural District CCG	Short	14	9-11	The recommendation appears to imply that the capacity assessment is of the person's capacity to make decisions in general whereas the code of practice is clear that it is a specific decision at a specific time. This is particularly evident in the sentence in the lines quoted. Can this be clarified?	Thank you for your comment. The recommendations have been edited to ensure that it is clear that assessments of mental capacity are decision specific.
NHS Harrogate and Rural District CCG	Short	22	2	If the person lacks capacity to make a specific decision can they actually give consent?	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Norfolk County Council	Short	8	general	Supported decision-making – In Norfolk the principles of the Mental Capacity Act are well understood by practitioners and our current practice is such that adults are regularly involved with decisions made. Involving adults in decision-making where there are questions around mental capacity is clearly covered in existing policies and legal guidance; we should of course involve the adult in any decisions making even where they lack the capacity to make a decision on a specific issue. A specific supported decision making assessment prior to an assessment of capacity could be problematic as this should be part of an existing mental capacity assessment assessment. The proposed Guidance does raise the question about whether a specific supported decision-making assessment is necessary prior to the completion of a mental capacity assessment and if so, we would be concerned that this would extend the length of time in which decisions could be made as well as placing an additional burden on social care resources.	Thank you for your comment. The committee were clear that they were not recommending a 'supported decision making assessment' should be conducted first. Instead the person should be supported to make their own decisions because they should not be assumed to lack capacity until and unless all steps have been taken to help them to do so. In this sense and given that it is line with the law, they did not feel they were placing a burden on local resources.
Norfolk County Council	Short	10	general	**Advanced Care planning** – This is the biggest single proposed change to current practice in Norfolk. Currently, if an adult makes their views known in respect of advanced care planning, the Adult Social Services will record those wishes however, this is not a practice which is currently promoted. Advanced care planning decisions could be formally recorded in 'Advance Decisions to Refuse	Thank you for your comment. We hope the guideline will support improvements to practice in this area.

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				Treatments' or with 'Lasting Power of Attorney's'. The Care and Compassion website has a very good guide on detailing advance care planning decisions to be taken into account at a later date (should an adult be unable to express their wishes). There is a concern about the impartiality of social work practitioners being involved in these decisions and regular care reviews should remove the need to spend time and resources on specific assessments related to advance care planning. The local authority would certainly expect practitioners to provide advice to people on where they can get more information/obtain documents should they wish to set up LPAs/ADRTs. If implemented on a wider scale, we would be concerned that current computer technology and software programmes would need adjustment for specific advanced care planning so that advance wishes were accurately recorded in a way that is easily accessible by all of those to whom this information relates. Active promotion of this is likely to increase the length of time taken to complete Care Act Assessments and place additional burdens on social care budgets. There would also be concerns about a need to review advanced care planning decisions so that this information was kept up to date. That is to say not only would practitioners be reviewing current care needs under the Care Act but may also end up reviewing future needs. There are also implications where family members have not been told of advanced care planning decisions, leaving the local authority vulnerable to potential legal challenges and potential criticism of workers with regard to impartiality (as mentioned above).	
Norfolk County Council	Short	15	18	Ensuring that structured mental capacity assessments are accompanied by real world observations is clearly good practice. The Care Act generally requires a more reflective evidence-based approach to meeting needs and the Mental Capacity Act requires the same. Of course, 'real world' observations can take time to observe as well as to document and again, depending on levels of detail required, this could have an impact on frontline resources.	Thank you for your comment and support for the recommendation. The committee believe that the recommendation is achievable within current resource constraints.
Norfolk County Council	Short	19	24	**Best Interest recording** – This section talks specifically about recording the adult's wishes and feelings, the steps taken to involve the person in the best interest meeting and recording why the person was not included where they were not present. Whilst this is already good practice and the Council's current Best Interest Assessments already allow for this information to be noted, additional requirements relating to documenting the reason for non-involvement may prove burdensome.	Thank you for your comment. The committee believe based on their experience of practice that the recommendation is achievable.
North Middlesex University Hospital	Full	General	General	The Trust has general comments regarding this document: Negative comments 1) It is not clear how or why the guidance will replace documents such as the Code of Practice, a statutory resource with legal status and the Bournemouth Competency Framework which is best practice for training 2) Use of the word 'Proxy' is misleading – there is no such role defined in the Act	Thank you for your comment. In relation to our specific points: 1) The guideline is intended for use by practitioners to enhance the specific requirements of such legislation, codes of practice and other guidance relevant to their work. The guideline does not seek to repeat these, or be a step-by-step guide to their implementation. 2) The term 'proxy' has been removed from the guideline

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				3) The document is far too long. For it to be read and utilised in practice it needs to be much shorter and to the point 4) The guidance advises all persons who lack capacity to be referred to an IMCA. This is not necessary where a person has an appointed emergency contact or family/friends who are willing to be involved Positive comments 4) NICE guideline will place the MCA within the medical sphere.	3) There is a short version of the guideline (c. 37 pages) that is intended for use by professionals. The full guideline provides more information for those wishing to know more. 4) NICE has a statutory remit to produce guidelines in social care as well as health.
Northern, Eastern, Western Devon CCG	Full	6	150	Involving experts by experience in training would have cost implications. There are also challenges in recruiting service users with experience of having their capacity assessed.	Thank you for your comment. The committee were aware of the cost implications of involving experts by experience, and have included the words 'where appropriate' in the recommendation to allow appropriate targeting of resources. The benefit of involving experts by experience in training outweighs the costs. These have already been considered in the development of the recommendations, as recorded in the Evidence to Recommendations tables.
Northern, Eastern, Western Devon CCG	Full	6	152	It is not clear why ACP should be covered as part of MCA training as well as ACP training. MCA training would usually include the importance of recording wishes and advance decisions, but not wider best practice around ACP. It is not clear why MCA training should specifically include consent for the ACP process.	Thank you for your comment. The committee revised this recommendation, which now refers to the importance of seeking consent as a general principle, rather than specifically related to advanced care planning.
Northern, Eastern, Western Devon CCG	Full	6	154	It is not clear that this should sit within MCA training.	Thank you for your comment. The Guideline Committee suggest that we should not split MCA-specific training from the aspect of 'difficult conversations' as this latter issue is an important part of MCA training, where evidence shows there is reluctance to do this.
Northern, Eastern, Western Devon CCG	Full	6	156	Communication skills training is important, but would sit separately to MCA training – communication skills being its own competency affecting many areas of practice.	Thank you for your comment. The Guideline Committee suggest that we should not split MCA-specific training from other aspects such as communication as this latter issue is an important part of MCA training.
Northern, Eastern, Western Devon CCG	Full	6	159	The guidance could include further rationale for inclusion of ACP in this NICE guidance and not having a separate guidance for best practice in ACP which refers to the MCA guidance.	Thank you for your comment. The scope of this guideline is decision making and mental capacity so the Mental Capacity Act clearly constitutes the significant legislative framework but is certainly not the only focus of the guideline.
Northern, Eastern, Western Devon CCG	Full	6	162	Conditions specific training would be better placed separately from MCA training – any condition-specific training as it relates to MCA or ACP would not fit easily in the time of training courses or the expertise of MCA trainers.	Thank you for your comment. Recommendation 1.1.1 is an overarching training recommendation and as such the committee aimed for it to be as broad and comprehensive as possible.
Northern, Eastern, Western Devon CCG	Full	7	175	Co-production of policies has resource implications and there are noted difficulties in recruiting - especially since the concept of "supported decision-making" is relatively new in these terms.	Thank you for your comment. The Guideline Committee acknowledge the potential resource implications and challenges involved in the co-production of policies. However, having discussed the trade-off between costs and benefits in this context the committee felt that involving experts by experience in delivering training, represents value for money.
Northern, Eastern, Western Devon CCG	Full	7	177	This is very useful to include in the guidance for clarity of expectation.	Thank you for your comment and support for the guideline.
Northern, Eastern, Western Devon CCG	Full	8	194	The requirement of commissioners to arrange advocacy outside their current statutory requirement will need to be made clear with consideration of resources if the remit and use of advocacy is to be expanded.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation to expand

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					statutory advocacy commissioning is a consider recommendation and therefore not legally binding however the committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
Northern, Eastern, Western Devon CCG	Full	8	200	Existing statutory advocacy (IMCA) are already under-funded and over-stretched and it is unrealistic that they would be expanded for a non-statutory role unless new funding is found by the government to support this additional work	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation to expand statutory advocacy commissioning is a consider recommendation and therefore not legally binding however the committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
Northern, Eastern, Western Devon CCG	Full	10	250	There are resource implications for production of accessible information in every case relating to the specific decision to be made. Information is usually adapted according to a person's specific needs as required.	Thank you for your comment. The Guideline Committee agree with your point and the revised recommendation now makes reference to 'tailored' accessible information.
Northern, Eastern, Western Devon CCG	Full	10	251	The principles of supported decision-making are not well known or publicised. Although they were muted in the law commissions proposed reform of DoLS, this is not at present a legal concept. The line between a supported decision and upholding a person's wishes although they do not have capacity to make their own decision requires further clarification before this can be put regularly into practice.	Thank you for your comment. The committee were very well aware of the problem you highlight and they aimed to address this in the structure of the guideline and the specific content of the recommendations on supporting decision making.
Northern, Eastern, Western Devon CCG	Full	10	258	This may seem reasonable; however, in practice, there is usually persuasion toward the practitioner's perceived safer option involved in discussions around the assessment of capacity and inevitable testing of the person's reaction to professional advice. Requiring these to be kept completely separate would increase the time needed to spend with the individual and have a significant impact, for example, on the practice in hospital discharge teams who are already pressured for time in carrying out discussions about onward care and assessing capacity to make decisions about the same. Increasing expectations may lead to reduced compliance.	The recommendation to which you refer is about the provision of information to the person to support the decision making process. The committee felt this was a fundamental principle and certainly achievable and they agreed not to make any changes to it in the final guideline.
Northern, Eastern, Western Devon CCG	Full	11	277	See previous comments (9 and 10) about availability of advocates to become involved at this level.	Thank you for your comment. The committee certainly believe the revised recommendations are achievable within current resources. The recommendations on advocacy have been revised in response to stakeholder concerns regarding resource implications and now relate to statutory advocacy.
Northern, Eastern, Western Devon CCG	Full	11	280	It would be useful to set out what these are or to refer to other resources.	Thank you for your comment. The committee believes they have set out examples of the possible consequence of supporting decision making and did not feel there was a basis to make further additions.
Northern, Eastern, Western Devon CCG	Full	11	287	This is useful guidance; however, has an implication in pressured health and social care services and would require change at the organisational level. It would be useful to make this clear so that it is not interpreted as placing unachievable requirements on individual professionals in relation to best practice expectations.	Thank you for your comment. The committee considered your comment but felt that organisational change should not be required in order for practitioners to be able to listen to the person being supported to make their own decision, even if this involved meeting the person on more than one occasion.
Northern, Eastern,	Full	11	291	Is shared decision-making different to supported decision-making?	Thank you for your comment. The term 'shared decision-making' has now been removed from the guideline.

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Western Devon CCG					
Northern, Eastern, Western Devon CCG	Full	11	293	Is this the advocate? It is not clear how this is achievable as systems are currently designed.	Thank you for your comment. This recommendation does not relate exclusively to advocates but to the practitioner supporting the person to make their own decision.
Northern, Eastern, Western Devon CCG	Full	12	326	It would be useful to cross reference this to any other NICE guidance where this requirement is set out	Thank you for your comment. The guideline has been reviewed to ensure that references to relevant guidance are included where appropriate.
Northern, Eastern, Western Devon CCG	Full	14	387	These 3 points are not set out explicitly in quite this way in the current code of practice	Thank you for your comment. The recommendation was not intended to simply repeat the Mental Capacity Act. However the committee agreed to revise the recommendation, which now makes it clear which elements are legally binding, namely that notes are taken contemporaneously.
Northern, Eastern, Western Devon CCG	Full	15	405	It would be useful to cross reference this to any other NICE guidance where this requirement is set out	Thank you for your comment. The guideline has been reviewed and references to other guidance included where appropriate.
Northern, Eastern, Western Devon CCG	Full	15	413	Having attempted to collect this information on several occasions in several different ways, there are considerable challenges in collecting this meaningfully and effectively.	Thank you for your comment. Whilst the GC recognises that collecting these data may not always be straight-forward, they believe the recommendation to be achievable.
Northern, Eastern, Western Devon CCG	Full	16	422	This is very useful to include in the guidance for clarity of expectation.	Thank you for your support.
Northern, Eastern, Western Devon CCG	Full	18	482	References to functional capacity need to be used cautiously as the phrase is not present in the current legislative framework and arguably sits outside the statutory test of capacity.	Thank you for your comment. The reference to functional capacity has been removed from the recommendation.
Northern, Eastern, Western Devon CCG	Full	19	506	Better to use "salient points" in keeping with the language in case law.	Thank you for your comment. The committee agreed to use 'salient details' because it is clearer language and more immediately comprehensible.
Northern, Eastern, Western Devon CCG	Full	20	540	Although decision-maker has developed as a term in understanding section 5 protection, it is not defined in the code of practice and the code of practice does allow for MDT decisions where that is appropriate, so it is not necessarily helpful to mention this here without appropriate definitions and caveats.	Thank you for your comment. The recommendations have been edited to make clear that a single decision-maker must be identified, regardless of whether a number of different people are involved in the decision making process.
Northern, Eastern, Western Devon CCG	Full	22	615	The courts have indicated that not all decisions require a balance sheet and though it is sometimes helpful, it is not always the most helpful way to approach certain decisions. In my experience, having this in the proforma leads to it being completed only partially where it is not required - and is better as a free-standing tool that can be used as required by practitioners.	Thank you for your feedback. This recommendation describes the range of elements that the committee believe should be included in the toolkits although it is not to say that every single item will always be relevant in every single situation. It would be down to local organisations to decide how toolkits are configured to address the issue you raise.
Northern, Eastern,	Full	23	639	I am not sure this is consistent with the current guidance - that they need to remain involved through implementation. I believe that is currently at the discretion of the IMCA.	Thank you for your comment. NICE guidelines include best practice recommendations. The GC believe that better outcomes will be achieved where an IMCA is involved in the process until a decision has been implemented fully.

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Western Devon CCG					
Northern, Eastern, Western Devon CCG	Full	24	669	The use of the phrase living will dilutes the legally binding nature of an advance decision because living will is often used to refer to a larger document containing wishes which are not legally binding and issues relating to funeral, etc. see *Robinson L, Dickinson C, Bamford C et al. (2013)*	Thank you for your comment. To avoid confusion, 'living will' has been removed from the heading for advance decision. A little more detail has been added to the 'advance decision' definition.
Northumberland Healthcare NHS Trust and Northumberland County Council	Full	9	6	We would like to offer suggestion that there is a clear legal distinction between Advanced care planning and making an Advanced decision to refuse treatment. The former having no legal standing in terms of guaranteed provision (i.e. a person can say what they would like to have included in a care plan but there is no legal duty to provide that service unless it is the only way to meet an eligible need) the latter having a legal standing provided it is valid and applicable to the circumstances (i.e. it must be followed). This is not clear as it could be in the guidance with terms interchanging If it was more defined this would assist all stakeholders, staff to have a full understanding of supporting the Advanced decision process without fully understanding this.	Thank you for your comment. In light of yours and other stakeholder comments, a clear introduction to the section on advance care planning has now been added. A fuller definitions are in the Terms Used section of the guideline and together we hope that these revisions address your concern.
Office for the Public Guardian	Short	7	7-9	We would like to add another consideration here, which is to - consider re-arranging for another day or time of day, when the person may have better capacity.	Thank you for your suggestion. The committee did not feel there was a basis to make this specific addition although the issue of conducting assessments and supporting decision making at a time that is more appropriate for the person is well covered by the guideline.
Office for the Public Guardian	Short	7	21	'Involve significant and trusted people in supporting decision-making, in 21 line with the person's preferences'. Add - Eg an attorney or court appointed deputy	Thank you for your suggestion, however the committee did not feel it was necessary to make this specific reference.
Office for the Public Guardian	Short	11	16	We support the proposal to commission training on advance care planning, particularly in regard to the option of creating a lasting power of attorney – there are many myths in the public and professional domain about how this can be done; we would urge practitioners to communicate that anyone can set up a power of attorney whilst they have the mental capacity to make that decision. The process can be completed by individuals themselves using the forms issued by the Office of the Public Guardian. The forms can be completed online, or on paper, and do not require the involvement of a solicitor, unless the person creating the lasting power of attorney feels they need legal advice. For people on lower incomes or certain benefits the fees for registering lasting powers of attorney can be reduced or waived altogether.	Thank you for comment. The recommendation on training relates to practitioners.
Office for the Public Guardian	Short	12	22	We are concerned that the emphasis on the importance of consent is not highlighted here. This is a decision.	Thank you for your comment. We believe that the issue of consent is covered adequately in this recommendation.
Office for the Public Guardian	Short	19	4-6	We support the development of a toolkit to enable health and social care workers to request, identify and verify the validity of lasting power of attorney documents and court orders. Including best practice examples of how to record this information so that everyone involved in the person's care is aware that a lasting power of attorney or court order is in place.	Thank you for your comment. The guideline as a whole and this section specifically have been reviewed to ensure that the links between lasting powers of attorney, court orders, and best interests procedures are clarified.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Office for the Public Guardian	Short	21	12-13	We are concerned that a lasting power of attorney is described as one of a type of *'decision-making instruments that would prevent best interests decision-making occurring'*. The appointment of lasting power of attorney enables the donor (the person who has lost capacity) to choose a person who is able to speak for them and represent their views if they are unable to do so. Similarly a deputy for health and welfare may have been appointed by the Court of Protection via a court order. The deputy's role would be similar to that of an attorney, although there may be specific decisions that the court order indicates they can make. The person who holds power of attorney (or deputyship) for health and welfare - who will often be a relative or close friend - should be very much involved with any best interests decision making in relation to health and social care to put across the wishes and preferences of the donor. The lasting power of attorney document or court order may contain specific instructions or preferences that need to be taken into account, but these should aid best interests decision making processes and not prevent them taking place.	Thank you for your comment. In the revised guideline, we have not referred to the lasting power of attorney as one of a type of 'decision-making instruments that would prevent best interests decision-making occurring'. The definition of LPA has been edited to align with the Office for the Public Guardian definition, which makes clear the distinction between the two types of LPA.
Office for the Public Guardian	Short	22	15-19	We recommend that the language used to describe a last power of attorney remains consistent with our publications and suggest the following edit. 'A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if you have an accident or an illness and can't make your own decisions (you 'lack mental capacity'). You must be 18 or over and have mental capacity (the ability to make your own decisions) when you make your LPA. You don't need to live in the UK or be a British citizen. There are 2 types of LPA: • health and welfare • property and financial affairs You can choose to make one type or both'	Thank you for this suggestion. The definition of LPA has been edited to align with the Office for the Public Guardian definition, which makes clear the distinction between the two types of LPA.
Office for the Public Guardian	Short	22	2-3	We are concerned with the way this is worded as it may imply that a person who lacks capacity 'now' is able to make decisions. Recommend to reword this part to '***When a person who may lack mental capacity in the future gives permission to someone to do something for them'***.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Older People's Advocacy Alliance	Short	25	4-7	We believe that the statement that there is lack of understanding about the critical role of independent advocacy in upholding rights and safeguarding is very true. The subsequent sentence in lines 4 – 7 about ensuring the recommendations relating to independent advocacy are acted upon, and to support implementation, should include a form of wording about this being "best practice".	Thank you for your comment. The text has been reviewed but the guideline committee did not feel a reference to 'best practice' needed to be added.
Premier Care	Short	5	10	Just a missing word: end of line should read "advocacy service" or alternatively "advocate".	Thank you for highlighting this typo, which has been corrected although the wording of the recommendation has also been changed.

Decision making and mental capacity

Consultation on draft guideline - Stakeholder comments table
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Premier Care	Short	19	12-14	If there is an LPA then it should have been identified before the best interests decision commenced. I suggest that this reference to an LPA should be made separately, perhaps before 1.5.12. It might also be worth distinguishing between LPAs for property and financial affairs and LPAs for health and welfare. In addition I am not sure whether an LPA precludes a best interests decision taking place, if the attorney agrees (and is willing to participate).	Thank you for your comment. The final guideline provides far greater clarity about LPAs through editing the recommendations, through adding an introduction to this section of the guideline and through improving the definition of LPA in the terms used section. To address you specific point about an LPA preventing best interests decision making, this wording has now been removed from the recommendation because as you rightly say, it was misleading.
Premier Care	Short	19	4 ff	I am not sure that the word "toolkit" is appropriate for this recommendation. A toolkit is a general set of documents or other aids to assist a practitioner. What is listed in 1.5.14 is rather a template or a list of information to record during the course of a particular best interests decision making process. Only the last three items in the list can be described as part of a toolkit.	Thank you for your comment. The term 'toolkit' has been retained as is being used in a broad sense to refer to supporting materials.
Royal College of Anaesthetists	Short	General	General	From the point of view of anaesthetists, this aspirational document will impact on a number of areas of care, specifically pre-operative assessment clinics, maternity units, and emergency departments. The resource implications if these recommendations are to be fully implemented in these areas will require considerable commitment with respect to finance and staffing levels, and may make them unachievable, especially in the short term. We would particularly highlight the likely impact upon the provision of surgical dental services to patients with 'special needs'. For further information on national standards for provision of information prior to anaesthesia and surgery, we would highlight the Royal College's "Guidelines for the Provision of Anaesthesia Services 2017" (GPAS). Those relating to consent and provision of patient information can be found in Section 9 of GPAS for Pre-Operative Assessment and Preparation, at https://www.rcoa.ac.uk/system/files/GPAS-2017-02-PREOP.pdf. The greatest impact on practice is likely to found in the Critical Care Unit, but we anticipate that the Faculty of Intensive Care Medicine will comment in more detail in this regard.	Thank you for your comment and your support for the guideline. The committee acknowledge that some of the recommendations may be aspirational but they believe that they are achievable within current resources even though this may mean organising resources in different ways.
Royal College of Anaesthetists	Short	General	General	We are concerned that this document is very much predicated on English and Welsh law alone, and does not appear to take into account the important differences in capacity-related legislation in Scotland and Northern Ireland. See Adults with Incapacity (Scotland) Act (http://www.gov.scot/Publications/2008/03/25120154/1) and Mental Capacity Act (Northern Ireland) (http://www.legislation.gov.uk/nia/2016/18/contents/enacted)	Thank you for your comment. The way NICE was established in legislation means that NICE guidance is officially England-only. Devolved administrations make their own decisions about how NICE guidance applies.
Royal College of Anaesthetists	Short	General	General	We are concerned that the authors have not taken account of the differences relating to young people aged between 16 and 18. While in England and Wales (the situation differs in other home countries), 16-18 year olds are able to make decisions relating to their healthcare, parental rights still apply, especially when patients in this group lack capacity for other reasons. We note that other NICE documents use 18 years as the cut-off point for adults (e.g. guidance on safeguarding) and it is not clear why this approach has not been taken here.	Thank you for your comment, which the committee took into account in reviewing the guideline. They revised the context section to include a paragraph describing the legal framework surrounding decision making and mental capacity for people aged 16-18 years.
Royal College of Anaesthetists	Short	General	General	Throughout the document, there is a supposition that the reader is dealing with patients who have lost or are losing capacity. There is a failure to take into account the group who may never have had capacity e.g. as a sequel to severe neurodevelopmental delay. This is an increasing problem in health care and could	Thank you for your comment. The committee believe they have covered the population you highlight in that the recommendations apply to all people who may or do lack capacity, whether or not this is a permanent. Additional detail has been provided to clarify the population and this can now be found in introductory paragraphs for each of the relevant sections of the guideline.

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				have been addressed by this guidance, especially as clinicians and families can find the law and guidance around it particularly confusing in this population.	
Royal College of Anaesthetists	Short	4	11	The Mental Capacity Act rightly places great emphasis on the importance of always assuming that an adult has capacity until and unless it can be demonstrated to be lacking. This section, along with others, appears to imply that practitioners should take a neutral stance when assessing a patient's capacity, and this does not accurately reflect the legal and ethical position in the UK.	Thank you for your comment. This recommendation intends to encourage practitioners to think about capacity rather than doubt it. This is reiterated in the creation of a new recommendation which highlight the importance of the presumption of capacity.
Royal College of Anaesthetists	Short	6	10	With regard to the factors which can impact upon a person's ability to make a decision, we would suggest adding "The influence of drugs and/or other therapy". Even when not under the full effects of general anaesthesia (during which time capacity is, of course, absent), patients who have had sedatives, pain-killers or other medication may have their faculties impaired to the point at which capacity may be in question.	Thank you for your comment. The committee agreed that your suggestion is best addressed by adding a bullet point to Recommendation 1.2.4 referring to the effects of prescribed medicines or other substances.
Royal College of Anaesthetists	Short	12	13	Under the heading "Assessment of Mental Capacity", we feel that it should be clearly stated that patients must be informed in advance that they are to undergo a mental capacity assessment and given the opportunity to refuse. We have encountered circumstances in which such tests are randomly administered without prior discussion to patients undergoing minor surgery, as part of 'target-hitting' exercises.	Thank you for your comment. The recommendations on assessment have been amended to include detail regarding the ability to refuse an assessment.
Royal College of Anaesthetists	Short	15	6	"conduct an assessment at a level proportionate to the decision being made" It is disappointing that the guidance does not offer examples of what "proportionate" might mean.	Thank you for your comment. Each section of the guideline now includes an introduction that directs readers to relevant sections of the code of practice where examples can be found.
Royal College of General Practitioners	Short	General		32 pages is lengthy for a short guideline and it is doubtful if many busy GPs, will have the opportunity to look at it in detail. Can it can be distilled down to a "5- 10 minutes for GP and primary care Health care professionals (PCHCPs)" format or the Clinical Knowledge summary format ? Examples of good practice would be useful particularly for high risk situations in primary care. It may also potentially formalise consultation manners to become a tick box when the skills of informal consultations may be most useful. It is will increase the consultations time for GPs and PCHCPS. The recording of the information will require a considerable increase in written details in the clinical notes and primary care do not have any work capacity to do this at present. It needs also as below to be clear that patients are responsible for updates with agencies, not GPs and PCHCPs and that there is a named carer or loved one. Families and friends have to sort themselves out over who is speaking on behalf of patients if necessary, as they reasonably frequently don't agree and this is not clear in the draft. Some of this guidance may leave GPs and PCHCPs more vulnerable to complaint by relatives than at present.	Thank you for your comment which will inform the work to consider the most useful implementation products to develop. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. The potential impacts on primary care was also discussed by the Guideline Committee. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Royal College of General Practitioners	short	General	general	The guidance suggests organisations carry out a baseline assessment and developing a tiered action plan. This plan would need to detail where there is no/little evidence (e.g. Telephone toolkit for capacity assessment) and agree a "reasonable" approach. This plan would need to be pragmatic in terms of how much resource to devote to this and where within maximum benefit would be achieved (Plan should also make clear what elements of guidance are beyond the	Thank you for your comment. The recommendation was worded to enable flexibility for implementation at the local level.

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				primary care organisations scope to fix and ensure appropriate liaison with stakeholders.	
Royal College of General Practitioners	short	1	1	Add to title: for over 16 year olds	Thank you for your suggestion. The age of the guideline population is explained upfront in 'this guideline covers' and the committee did not feel it would be necessary to add it to the guideline title. They did however add further explanation about the specific legal framework, which applies to decision making and mental capacity with people aged 16-18 years.
Royal College of General Practitioners	short	3	all	Training: for GPs this appears to more mandatory training in an overworked time short profession and as GPs receive this in undergraduate and early postgraduate training there is concerns this will become yet another 3 yearly cyle of management-proving training, unpopular and unhelpful. For GPs the best way of improving practice in this area may be to record MCA in all educational modules and publications, paper or online - so that it is situated in contexts. A guideline to ask publication bodies to include MCA and decision making routinely in articles would be more helpful than a tick box eLfH module every 3 years. There are quite a lot of these for a variety of non-clinical subjects and the time taken to complete removes GPs from time to see patients. The basic assumption that this and other legal entities are more important than clinical knowledge is debatable as a 3-yearly update	Thank you for your comment. The training recommended in 1.1.1 is not mandatory and providers/ responsible bodies are free to decide the best way of ensuring practitioners learn and maintain those skills.
Royal College of General Practitioners	short	4	21	***Record and update information about people's wishes*** This should be clearer. So, an ACP in a GP notes: how long is it valid for if the patient does not seek re-approval or change of it? As an ACP can actually occur at any age if people have strong views, they do not need to have terminal illness, then this is very important as professional actions may occur which are subsequently outdated and we may then be complained about for instituting outdated wishes. Many people change their minds. The responsibility on updating ACPs should lie with the patient, the LPA for health and care decisions or nominated proxy by the patient and the responsibility to share their wishes with the various agencies should also lie with them. LPA is useful but not everyone can afford one for both finances and health wellbeing and there is potential for conflicts of interest and abuse. The guideline could achieve a lot by recommending free fees or minimal for LPA creation?	Thank you for your comment. The reference to recording and updating information about people's wishes made in the overarching principles does not cover detailed examples, which are made throughout different points of the guideline.
Royal College of General Practitioners	short	5	8	***Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy*** Should GPs and primary care HCPs should have this role? It is likely to be more appropriate through the adult social work service. Currently the wording could make GPs and PHCHPs liable for this if they don't enact this. It should be part of the social care record of the patient and held primarily by SW depts. So the pathway is GPs refer to SW depts. and they take on this action.	Thank you for your comment. The advocacy recommendations have been substantially revised and definitions added to 'terms used'. The recommendation to which you refer is now much clearer about the legal obligation to tell people about advocacy services as a potential source of support. The practitioner working with the person at the time a decision needs to be made will be the one best placed to tell them about advocacy services, whether this is a GP or social worker.
Royal College of General Practitioners	short	6	4- 29	Supported decision making- There is a lack of guidance in the document for an emergency situation or one where an independent advocacy is not available. The principles of the MCA must apply here.	Thank you for your comment. Unfortunately there was a lack of evidence about decision making and mental capacity in emergency situations. However, the committee is in agreement with you about the importance of following the

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				- Staff must be clear about documenting the capacity assessment in a clearly recognised format in the patient records particularly those shared with other agencies. - How Patient Transport staff would assess capacity if a patient refused to travel to an appointment (e.g. cancer treatment). If capacity test is not documented the rationale for refusal must be recorded and reported on.	principles of these recommendations, even in emergency situations. This has been further clarified in the revised context section of the guideline.
Royal College of General Practitioners	short	6	4-29	Supported decision making – timely access to support i.e. independent advocacy/different modes of communication will be extremely challenging in a telephone assessment environment for Duty GPs and front-line emergency working environment with potential for significant operational impact if decision making is to be delayed until this can be achieved.	Thank you for your comment. The guideline is clear that assessment and recording should be proportionate to the decision being made and recognises that in emergencies practitioners may need to provide rapid assistance. One of the recommendations in the section on capacity assessment also acknowledges it may not be possible to have as much knowledge about the person as is otherwise being recommended – either because the person may not be known to services or because it may be an emergency situation.
Royal College of General Practitioners	short	7	7	***Record the information that is given to the person during decision-making*** Each consultation has a number of decisions with patients and this guideline assumes "big decisions" but is not clear how this is practical for all the decisions involved in an average GP consultation especially those involving multimorbidity and or multiple problems. In deciding a management plan, or any investigations, GPs bring MCA, consent issues, pros and cons, evidence bases and patients autonomy to the consultation and to write views down for all consultations will be unachievable. It needs to state if this is for ACPs, ADRTs, patients who want to follow a management plan which the GP or PCHCP (primary care HCP) does not agree with.	Thank you for your comment. The committee did not agree that a change needed to be made to this recommendation in light of your comments however they did add an introduction to the section in order to fully explain what is meant by supporting decision making and how it should apply.
Royal College of General Practitioners	short	8	12	***Where possible, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time*** The present generation of GPs have been herded into large practices by governments, reducing continuity of care with various HCPs employed to duplicate roles. There are a multiplicity of providers, increased part-time GP workforce too so it is increasingly impractical to now expect continuity of care. Putting this in appears to be an ideal but is not realistic in normal practice and so reduces the face validity of the guideline	Thank you for comment. The Guideline Committee suggest that we keep this recommendation as is, acknowledging it is aspirational but realistic, qualified by the words 'where possible'.
Royal College of General Practitioners	short	9	11-12 (1.3.1)	ACPs are useful though identifying the best person to do this might be helpful. The guideline at present means a number of agencies may do their own and duplicate. Can it be more stream lined and have online site or forms at appendix?	Thank you for your comment. The committee thought that the most appropriate person would differ depending on the situation or individual circumstances, so this has not been specified.
Royal College of General Practitioners	short	9	1.3	ACPs are relevant to the local health Frequent Caller Teams and requires effective multi-agency working to develop care plans to meet patient need. For this to be effective there is a need to be able to access joint records and pathways. This is also relevant for joint crisis planning (1.3.16) these plans should be available to staff in 111 and 999. Accessing care plans/wishes – previous pace of summary care record work, challenges in these being kept up to date and these being visible to practitioners	Thank you for your comment. We agree with this point and have aimed to address in the recommendations, for example 1.3.1.

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				using different IT systems remain a huge issue. Also in the front-line emergency environment.	
Royal College of General Practitioners	short	12	18 -21	section 1.4.3–how practical and realistic is for primary care to ensure our staff (assessors) are able to seek advice from people with specialist condition specific knowledge to assist them to assess capacity- this would be relevant if the patient was transferred to a mental health professional within the Clinical Hub or a pharmacist for drug related concerns. 1.4.4 How will this consent be recorded	Thank you for your comment. Whilst the recommendations are intended to outline best practice, the committee believe them to be achievable.
Royal College of General Practitioners	short	12	14-15	There needs to be a recommended quality improvement tool which has been validated in primary care	Thank you for your comment. The committee hope that the recommendation will lead to developments in this area.
Royal College of General Practitioners	short	12	Section 1.4	Telephone triage – guidance is aimed at practitioners (inferred face to face) - there is no specific mention of guidance in the difficult area of telephone triage. We assume capacity unless there is something in the assessment that might suggest capacity is in question. Assessing of capacity – there is mention of a toolkit to record capacity assessment. What is evidence base for this particularly wrt telephone triage? How would that work from a system point of view? How long will that take in addition to rest of the telephone assessment	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Royal College of General Practitioners	short	13	3	***Be aware that the process applies to all decisions, large and small, though the measures adopted and recording will be proportionate to the complexity and significance of that decision.*** You might as well ask GPs to have GP training. As above, it is not practical to document everything in every consultation at this level of detail and most consultations are important. I find this unrealistic and risks devaluing the guideline	Thank you for your comment. The recommendation was drafted to make clear that recording should be proportionate to the significance of the decision taken.
Royal College of General Practitioners	short	14	3-6	1.4.10 – not possible for 111/999 or emergency front line practitioners. 1.4.16 – not practical for 111/999 or front-line workers. There is no guidance included for when restraint is required.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
Royal College of General Practitioners	short	15	8	***If a person refuses to engage in a capacity assessment, the assessor should give them a choice about who else could be involved or any other changes that can be made to help them*** Please recognise that if someone doesn't want an assessment they don't have to have one It is very concerning that patients who do not follow a modern health model, and there are a number, are not accounted for in the draft guide.	Thank you for your comment. The committee discussed you point and agreed that in fact there are a few rare cases where someone refuses to engage with a capacity assessment (repeatedly) which will be a factor (amongst others) that is taken into account for the purpose of an interim declaration pursuant to section 48 of the MCA - the test being there is "reason to believe" P may lack capacity to make a specific decision. The court will then direct an independent expert or a special court visitor (with expertise in such cases) before a final declaration is made. So as you say, a person does not ***have*** to engage, but a refusal (against a background where a capacity assessment is being contemplated) *may*be a factor from which inferences about capacity could be made. Unfortunately and in this context however the committee did not feel they had reviewed evidence which would provide a basis to make suggestions for practical solutions.

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Royal College of General Practitioners	short	16	18	Best Interests and decision making Section 1.5.1 refers to (except in an emergency situation) – the whole document needs more clarity re emergency situations or a standalone chapter as it currently feels like an afterthought- The guidance should be clear that it is aimed at children aged 16 and 17 and not refer to them as 'people' or 'adults'. Has thought has been given to the prehospital emergency environment and indeed to the patient transport service?	Thank you for your comment. This section has been edited to provide clarity on these issues.
Royal College of General Practitioners	short	17 onwards re best interests		***Best interest meetings*** needs better definition. In GP clinics best interests are discussed all the time re driving, homes, meals etc with patients and their loved ones. It is not practical to invite or delay many of these and they are routine GP work esp. in the elderly or those with problems like alcoholism or those with cognitive difficulties. Needs to be greater clarity between a MCA "Best Interest Assessment" decision and a decision that is made in the *best interest* of a patient (who lacks capacity to make the decision themselves) in an emergency care setting. The two are very different.	Thank you for your comment. In order to more clearly describe best interests decision making and meetings, an introduction has been added to this section. Exceptions relating to decisions taken in emergency situations are also referred to and we hope this addressed your concerns.
Royal College of General Practitioners	short	17	1	***Ensure that everyone involved in the best interests decision-making process knows who the decision maker is.*** This is ideal but as families are scattered about, this is not always apparent and changing this to agreeing with the patient or their agreed LPA for health and care or their named decision maker should suffice, No GP or PHCP can check with everyone involved	Thank you for your comment. The committee make evidence based recommendations regarding best practice, however they recognise that in some specific circumstances this may not always be possible.
Royal College of Nursing	Full	General	General	The Royal College of Nursing (RCN) welcomes proposals to develop guidelines to aid decision making and mental capacity. The RCN invited comments from those involved this area of work. The comments below reflect the views of our reviewers.	Thank you for your comment and the time you have taken to review the guideline.
Royal College of Nursing	Full	General	General	The following publication, published by the RCN in collaboration with a multi-disciplinary group based in Northern Ireland: the Royal College of Psychiatrists, the Northern Ireland Association of Social Workers and the College of Occupational Therapists. contains some useful information on this topic: Three Steps to Positive Practice: A rights based approach when considering and reviewing the use of restrictive interventions https://www.rcn.org.uk/professional-development/publications/pub-006075 The publication is designed to assist health and social care professionals who are involved in practices where people in their care may be restricted in some way.	Thank you for your comment and link to the publication. This practice guidance did not meet the inclusion criteria for our work as it was published in 2017 and the searches were conducted in 2016. A supplementary search was conducted in 2017, but this focused specifically on advance planning.
Royal College of Nursing	Question	Question 2		*Would implementation of any of the draft recommendations have significant cost implications?*	Thank you for your comment. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was

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				Significant time is required for practitioners to attend education and training in this area. Currently there are great number of nursing vacancies which means that the ability for nurses to access required training is significantly reduced. Similarly, the turnover of staff in the independent sector, which is approximately 30%, means that practitioners could be attending more than one course in a short space of time in order to meet organisations' mandatory requirements. There is also a significant cost implication for training. Our reviewers have informed us that many clinicians will struggle with having time to practice mental capacity assessments under supervision. To ensure training is effective, training programmes would benefit from supervised practice which in turn would increase costs. We are aware that in some practices, there have been attempts to train staff but despite this many staff in Health and Social Care lack the confidence to make actual assessments for patients. The number of independent mental capacity advocates need to be increased to ensure that there is a greater recognition of the need of this service which should be addressed, also a recognition of the potential for this to delay discharge or transfer should be acknowledged.	shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Royal College of Nursing	Questions	Question 1		*Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why?* The guidance will be very useful for practitioners at all levels and across all settings, particularly those devising and delivering training programmes.	Thank you for your comment and support for the guideline.
Royal College of Nursing	Questions	Question 3		*What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)* Two areas have not been sufficiently brought to the fore in this guidance, firstly, the acknowledgement that mental capacity can fluctuate and is time specific. Support needs to be given to practitioners to manage this. Secondly, the issue of consent to sexual activity is a very important consideration in any guidance in this area as this is an emotive issue and requires careful professional education from both mental capacity and legal view. The RCN is writing its guidance on sexual intimacy in care homes and will be publishing this guidance shortly.	Thank you for your comment. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions. The lack of focus upon sexual activity in these recommendations reflects a lack of evidence located by the systematic review which underpins the guideline. However we note the work you are currently publishing and will pass this information to our implementation team.
Royal College of Nursing	Questions	Question 3		There is good work starting in practices both nationally and locally, we are aware that some practices have been looking at Advanced Decision Making. This is making best interest decision making easier and certainly would be a good area to build on nationally.	Thank you for your comment, support for the guidance and indication of ongoing work taking place in practice.

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Royal College of Occupational Therapists	Short	General	General	It would be useful to restate the overarching principles of the capacity legislation at the beginning of the document.	Thank you for your comment. The introduction section has now been updated. In addition, text has been inserted at the start of each section to make clear how it relates to existing legislation and guidance.
Royal College of Occupational Therapists	Short	General	General	It could be made clearer in the body of the document which statements are for clinicians and which are for organisations and commissioners.	Thank you for your comment. The guideline has a broad remit and therefore it was not possible to list all groups of professionals to whom it applies. The Guideline Committee carefully considered the wording of recommendations; where recommendations are directed as specific groups of professionals (e.g. health and social care practitioners), this has been made clear.
Royal College of Occupational Therapists	Short	General	General	The recommendations could be reordered so that they start with the assessment of mental capacity, then either has (decision-specific capacity) supported decision making or (lacks decision specific capacity) best interests decision making, and finishes with advance care planning. This better reflects the clinical decision making pathway.	Thank you for your comment. The structure of the guideline was discussed at length by the Guideline Committee. The rationale for the current structure was to emphasise the importance of having advance care planning discussions early (not solely after assessment of mental capacity).
Royal College of Occupational Therapists	Short	General	General	Consideration regarding carers related to capacity; e.g. moving and handling issues which are decision-specific	Thank you for your comment. This guideline focuses on the person using services. There is a separate NICE guideline on carers' in development. **https://www.nice.org.uk/guidance/indevelopment/gid-ng10046**
Royal College of Occupational Therapists	Short	General	General	Consideration regarding Technology Enabled Care (TEC) e.g. trackers, safeguarding	Thank you for your comment. The effectiveness of these interventions was not in scope for this guideline.
Royal College of Occupational Therapists	Short	3	3-24	Q2: Costs of training, review and refresher training. Reminder to professionals regarding specific decisions review.	Thank you for your comment and suggestions regarding implementation issues.
Royal College of Occupational Therapists	Short	4	11-13	Q1: Very important good practice consideration	Thank you for your support.
Royal College of Occupational Therapists	Short	4	19-20	Q1: Occupational therapists can provide assessments regarding adaptations	Thank you for your suggestion, which we will pass to our endorsement team.
Royal College of Occupational Therapists	Short	5	23-26	Q2: Cost implications regarding increasing 'investment in training for statutory independent mental capacity and other statutory advocates in key areas'	Thank you for your comment. The committee believes that this recommendation is affordable within current resources, even if this means using them slightly differently.
Royal College of Occupational Therapists	Short	5	5-7	Q2: Cost implications regarding 'expansion of existing statutory independent advocacy roles'	Thank you for your comment. The advocacy recommendations have now been substantially revised and the one to which you refer is now a 'consider' recommendation, which gives much more flexibility over whether it is implemented.
Royal College of	Short	6	10-21	Q1: Occupational Therapists can assess all of these areas	Thank you for your comment and suggestion for implementation support.

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Royal College of Occupational Therapists	Short	7	10-12	Q2: Cost implications regarding providing additional training	Thank you for your comment. The committee acknowledge the resource implications but they do believe on the basis of evidence and their expertise that the recommendation is achievable within current resources.
Royal College of Occupational Therapists	Short	8	8-11	Q1: Good practice; involving people in shared decision making	Thank you for your comment.
Royal College of Occupational Therapists	Short	8	12-14	Q1: Service implications/practice	Thank you for your comment.
Royal College of Occupational Therapists	Short	8	5-7	Q2: Possible cost implications for some services if meeting for more than one session	Thank you for your comment. The committee took in to account the potential resource impact of the recommendations, and believe the recommendations to be aspirational but achievable.
Royal College of Occupational Therapists	Short	9	4-5	Q2: Possible costs related to auditing compliance with the Mental Capacity Act	Thank you for your comment. The committee took in to account the potential resource impact of the recommendations, and considered them to be aspirational but achievable.
Royal College of Occupational Therapists	Short	10	7-11; 12-15; 16-29	Q1: Example of good practice that should already be in place	Thank you for your comment. The committee make recommendations regarding best practice in an attempt to address variations in quality.
Royal College of Occupational Therapists	Short	11	17-21	Q1: Training needed to ensure that professionals are aware of these requirements	Thank you for your comment. We believe that this is adequately covered in the recommendation numbered 1.3.1 in the draft guideline.
Royal College of Occupational Therapists	Short	12	13-26	Q2: Cost of training, monitoring and audit - assessment of mental capacity	Thank you for your comment. The committee recognise that there may be some costs associated with this recommendation however the committee believes it to be achievable.
Royal College of Occupational Therapists	Short	13	14-30	Q1: Occupational therapy assessments related to reasonable adjustments	Thank you for your comment. The recommendation relates to assessment of mental capacity to make a specific decision.
Royal College of Occupational Therapists	Short	13	1-13	Q2: Cost of training, monitoring and audit - accessing capacity to make decisions	Thank you for your comment. Whilst the committee aimed to draft aspirational recommendations they believe these to be achievable given current resources.
Royal College of Occupational Therapists	Short	14	1-12	Q1: Example of good practice/training implications to ensure professionals are following recommendations	Thank you for your comment. We have reflected this challenge in the 'Putting this guideline into practice' section.

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Royal College of Occupational Therapists	Short	15	1-27	Q1: Training implications. Occupational therapists can assess a person's 'functioning and ability' (line 19)	Thank you for your comment. The committee believe the recommendations to be aspirational but achievable.
Royal College of Occupational Therapists	Short	15	20-27	Q2: Cost of training, monitoring and audit - professional's perception	Thank you for your comment. The committee believe the recommendations to be aspirational but achievable.
Royal College of Occupational Therapists	Short	15	20	Sentence could read 'structured assessments of capacity should be supplemented by real world observation of the person's functioning and ability by, for example, an occupational therapist'	Thank you for your comment. The recommendation is based on the evidence reviewed and this did not provide a basis for the committee to include such details.
Royal College of Occupational Therapists	Short	16	1-17	Q2: Cost of training, monitoring and audit - professional's awareness and good practice	Thank you for your comment. The committee took in to account the potential resource impact of the recommendations and considered them to be aspirational but achievable.
Royal College of Occupational Therapists	Short	17	8-13;	Q2: Cost of training, monitoring and audit - professional's awareness and good practice	Thank you for your comment. The committee gave careful consideration to the resource impact of the recommendations, and considered them to be aspirational but achievable.
Royal College of Occupational Therapists	Short	19	4-23	Q2: Cost of training, monitoring and audit - provision of toolkits	Thank you for your comment. The committee took in to account the potential resource impact of the recommendations, and considered them to be aspirational but achievable.
Royal College of Occupational Therapists	Short	21; 24-26	11; 6-21	The 'Terms used in this guidance' section (p21) and 'Putting this guidance into Practice' (p24-26) could be swapped over; i.e. into practice section first, terms second.	Thank you for your comment. The order of the sections is set by the NICE template for all guidelines.
Royal College of Occupational Therapists	Short	24	13-30	Q2: Cost of training, monitoring and audit - resource implications	Thank you for your comment. The guideline committee took in to account the potential resource impact of the recommendations, and considered them to be aspirational but achievable.
Royal College of Occupational Therapists	Short	25	1-28	Q1 Challenges: access to independent advocacy	Thank you for your comment. The guideline committee agreed that access to independent advocacy will be a particular challenge to the implementation of this guideline.
Royal College of Occupational Therapists	Short	26	1-16	Q1 Challenges: access to independent advocacy	Thank you for your comment. The guideline committee agreed that access to independent advocacy will be a particular challenge to the implementation of this guideline.
Royal College of Psychiatrists	Full	General	General	We understand space may be limiting, but we would suggest including some case scenarios to illustrate the practical application of the advice for both emergency and less urgent assessments.	Thank you for your comment. The recommendations in the guideline are intended to be specific and action-focused. The guideline has been revised in light of consultation and is it now much clearer that the principles behind the recommendation apply to emergency as well as non-urgent situations, while at the same time recognising the need to be proportionate. There are specific recommendations which acknowledge that emergency situations to represent

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					exceptions, for example the one about assessors needing to have specific knowledge of the person they're assessing and another about recording capacity assessments before best interests discussion take place. However please also note that the follow-up work undertaken by NICE to disseminate the guideline and to develop Quality Standards informed by it can include more information to illustrate how recommendations could be implemented.
Royal College of Psychiatrists	Full	9	244	Feedback from our Carer representative highlights difficulty in assessing usual decision making in someone with a disturbed mental state who may superficially appear rational. We suggest adding involvement of families or close friends may aid understanding of a person's wishes and help assess whether their current decision making reflects impairment of their normal state to those who know them well.	Thank you for your comment. Later recommendations in the same section highlight the importance of involving significant and trusted people in decision making and that with the person's consent, a written record of their decision making should be shared with other appropriate people (which may include families).
Royal College of Psychiatrists	Full	11	296	Reference to others who may help assess capacity is good but would benefit from acknowledgement that time does not always permit such as for people wanting to self-discharge from hospital. We suggest adding 'or Liaison Psychiatry' to other professionals who may help assessment, especially for people in a general hospital who are refusing serious or life sustaining treatment.	Thank you for your comment. The updated guideline now includes reference to 'liaison psychiatry'.
Royal College of Psychiatrists	Full	24	669	RCPsych understands and supports the aim of the document to support people making their own decisions. However, in a general hospital, capacity is easily over-estimated. This is especially important where capacity assessments of someone with emotional or mental health difficulties relate to refusal of medically beneficial or life sustaining treatment, decisions are urgent and there is little background information. In these cases, the balance of assessment, whilst supporting capacious disagreement with professionals, also needs to ensure the needs of vulnerable patients are protected. Whilst we understand space may be limiting, we would suggest including some case scenarios to illustrate the practical application of the advice for both emergency and less urgent assessments.	Thank you for your comment. In light of yours and other stakeholder comments the definition of this term has been revised and this hopefully addressed your concern.
Royal College of Psychiatrists	Short	General	General	This draft Guidance does not have any specific reference to young people 16-17 years even though this age group is covered by the Mental Capacity Act 2005 and the Code of Practice devotes the whole of Chapter 12 to children and young people. The draft Guidance needs to be revised to include specific guidance on young people including how professionals need to manage the overlap between the Mental Capacity Act 2005 and the Children Act 1989. For example, there are some cases whereby decision making in relation to a 16 or 17-year-old who lack capacity may be more appropriately made by a person with parental responsibility. These overlaps between the Mental Capacity Act 2005 and the Children Act 1989 cause substantial difficulties for front-line clinicians; hence it would be important to use the opportunity provided by this draft to provide adequate guidance on this specific matter.	Thank you for your comment. Following consultation, the Guideline Committee included some additional text that refers to legislation on decision-making and capacity in respect of 16-18 year olds.
Royal College of Psychiatrists	Short	4	11-13	There is a presumption of capacity in the MCA; this paragraph suggests that that presumption should be questioned every time a person makes a decision which is not within the spirit of the MCA.	Thank you for your comment. The Guideline Committee agree that this recommendation is just about being aware of capacity issues, and is not about doubting people's capacity. Please note that we have added a separate recommendation highlighting the importance of the presumption of capacity.

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Royal College of Psychiatrists	Short	6	4	Is this for everyone or just those who may lack decision making capacity?	Thank you for your query. This is intended to refer to all those who may lack capacity (in line with the Code of Practice guidance)
Royal College of Psychiatrists	Short	7	27	This statement is suggestive of paternalism. It should be explicitly stated that consent should be sought from the individual themselves before talking to family, carers and friends if appropriate (as suggested on page 10 line 27)	Thank you for your comment. The preceding recommendation makes clear that involvement of other people should be in line with the person's preferences.
Royal College of Psychiatrists	Short	8	15	Reference to others who may help assess capacity is good but would benefit from acknowledgement that time does not always permit such as for people wanting to self-discharge from hospital. We suggest adding 'or Liaison Psychiatry' to other professionals who may help assessment, especially for people in a general hospital who are refusing serious or life sustaining treatment.	Thank you for your comment. Reference to liaison psychiatry has been added to recommendation 1.2.16.
Royal College of Psychiatrists	Short	9	7-10	N.B. LPA and advance decision to refuse treatment are legally binding under the MCA. Advance care planning is not legally binding but good practice.	Thank you for your comment. The guideline as a whole and this section specifically have been edited to ensure that the status of LPAs and ADRTs is made clear.
Royal College of Psychiatrists	Short	9	24-25	Need to specify which patients are being targeted with advance care planning? Many patients with long term or life limiting conditions will continue to be capable of making decisions about their care.	Thank you for your comment. The recommendation is intended to have relevance to a broad range of service users. The committee believe the recommendation to be suitable in its current form.
Royal College of Psychiatrists	Short	9	16	Has the training of staff and audit been costed? What would no longer be provided to pay for this? Is there any evidence that patient's benefit from advance care planning?	Thank you for your comment. Whilst the committee recognise that there may be costs associated with training and audits, the recommendation is believed to be aspirational but achievable.
Royal College of Psychiatrists	Short	10	18-19	This is a really important and useful paragraph- should it come earlier?	Thank you for your comment. The committee believed that this point fits most clearly with the recommendation numbered 1.3.7 in the draft guideline.
Royal College of Psychiatrists	Short	12	9 and 12	Under joint planning, the we suggest adding another scenario – to include both mental and physical health specialists when advance care planning is being developed for the physical care of people with mental health conditions. This should help ensure the scenario specified includes all relevant information and that clear capacity at the time of writing is documented. In addition, there should be a clear mechanism for storing and communicating the plan, especially as relapse and contact with services can occur out of hours when clinical records are not always easily accessible. Should the person themselves have a copy with them as an example? All patients open to secondary care mental health services and who have a care co-ordinator should have a jointly agreed care plan in place.	Thank you for your comment. The recommendation is based on the available evidence and the committee did not believe that this supported further recommendations.
Royal College of Psychiatrists	Short	13	1-5	It would be helpful to explain how mental capacity is defined in the MCA. N.B.- not all processes are covered by the definition in the MCA e.g. capacity to conduct court proceedings and make a will have specific criteria as set out in case law.	Thank you for your comment. We have edited the introduction to the guideline to provide greater clarity on this issue.
Royal College of Psychiatrists	Short	13	6	Section 1.4.7 Feedback from our Carer representative highlights difficulty in assessing usual decision making in someone with a disturbed mental state who may superficially appear rational. We suggest adding involvement of families or close friends may aid understanding of a person's wishes and help assess whether their current decision making reflects impairment of their normal state to those who know them well.	Thank you for your comment. We believe that this issue is covered adequately in the recommendation numbered 1.4.10 in the draft guideline.

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Royal College of Psychiatrists	Short	14	7-12	I would suggest re-wording this paragraph is it suggests that a person "has" or doesn't have capacity. Mental capacity is decision specific.	Thank you for your comment. The recommendations have been edited to ensure that it is clear that assessments of mental capacity are decision specific.
Royal College of Psychiatrists	Short	15	15-19	what is the evidence for this? Suggest re-wording to say that all factors should be taken into account including an opinion from a person who cares for the patient, if the patient lacks insight into their condition or functioning.	Thank you for your comment. The recommendation has been edited to provide clarity.
Royal College of Psychiatrists	Short	15	15	RCPsych supports highlighting the need to be aware of the risk of overestimating capacity for a number of mental disorders including someone with an acquired brain injury; those in an emotional crisis and those with emotionally unstable personality disorder.	Thank you for your comment. This recommendation makes reference to executive dysfunction as an overall category, and includes the example of traumatic brain injury.
Royal College of Psychiatrists	Short	15	20	when referring to the MCA please use section and para number.	Thank you for your comment. The committee agreed to add references to relevant sections of the MCA in the introduction to each section.
Royal College of Psychiatrists	Short	16	18-23	Reference to section in MCA would be helpful here.	Thank you for your comment. The committee agreed to add references to relevant sections of the MCA in the introduction to each section.
Royal College of Psychiatrists	Short	16	12-14	Not sure what this para is trying to say.	Thank you for your comment. The committee believe that the recommendation is clear in its current form.
Royal College of Psychiatrists	Short	17	14-17	This may be a multidisciplinary decision which should include family/carers rather than a sole decision maker.	Thank you for your comment. The guideline is very clear about the important role of family members and carers and there are specific recommendations aimed at providing support for them to be actively and meaningfully involved in the best interests decision making process.
Royal College of Psychiatrists	Short	18	3	Does this mean best interests assessor?	Thank you for your comment. This refers to the best interests decision maker.
Royal College of Psychiatrists	Short	21	19	RCPsych supports recommendations regarding advance care planning. However, it suggests balancing the advice that, before the document is viewed as legal, there is a need to ensure the person had capacity when it was written and that the specific features of the situation are covered – this is especially important for cases of refusal of life saving treatment.	Thank you for your comment. These are just intended to be definitions of what the term is – not a recommendation for practice about the tool or intervention. However, some more detail has been added to help clarify the definition. In addition, the introduction to the section on advance care planning has been revised to provide a clearer explanation.
Royal College of Psychiatrists	Short	22	1-3	This is not a definition of consent.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Royal College of Psychiatrists	Short	23	19-24	Not legally binding. Advance decisions in the MCA can be overruled by the Mental Health Act.	Thank you for your comment. We have now deleted this definition of 'Psychiatric Advance Directive'.
Royal College of Psychiatrists	Short	25	1-2	Reference evidence	Thank you for your comment. This section has since been reviewed and there is no longer any reference to 'consistent evidence'.

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Royal College of Psychiatrists	Short	29	26	Cairns et al., assessed the use of the MacCAT-T which is consistent with the definition of capacity in the MCA and found high inter-rater reliability. (BJPsych)	Thank you for your comment. The committee nevertheless agreed that there is a need for a greater volume of evidence about mental capacity assessment tools, including their effectiveness, cost-effectiveness and acceptability.
Royal College of Speech and Language Therapists	Short	5	14	RCSLT believe it is crucial that practitioners receive training in communication skills. Speech language therapists (SLTs) already train other practitioners on how to support people with communication needs, to overcome their disability and to help practitioners and the individual to make informed decisions about their care and support. The RCSLT would be happy to work with you to develop this training.	Thank you for your support and suggestion for implementation support.
Royal College of Speech and Language Therapists	Short	6	19	All verbal information must be supported by written information, and information tailored to the needs of the individual. SLTs support communication by using augmentative and alternative communication – using writing, pictures, gestures, signing, symbols and pictures to support or replace spoken word.	Thank you for your comment. The committee did not feel this point fitted within the recommendation but they do believe the point is covered elsewhere in the guideline, which recognises the important role of specialists such as speech and language therapists.
Royal College of Speech and Language Therapists	Short	7	27	We agree that practitioners should have training around communication. SLTs already train other practitioners on how to support people with communication needs, to overcome their disability and to help practitioners and the individual to make informed decisions about their care and support. The RCSLT would be happy to work with you to develop training.	Thank you for your comment and suggestion for implementation support.
Royal College of Speech and Language Therapists	Short	8	14	We believe it is important to take someone's communication needs into account as many people with communication disability do have the capacity to make decisions when their communication is supported.	Thank you for your comment. Communication needs are covered in recommendation 1.4.18.
Royal College of Speech and Language Therapists	Short	9	5	Speech and language therapists have a key role in supporting people with communication needs to express their wishes. Without support with their communication, people are often unable to express their wishes and to make decisions.	Thank you for your comment. The committee recognises the important role that speech and language therapists can play and have made reference to this where appropriate.
Royal College of Speech and Language Therapists	Short	10	16	The RCSLT is pleased to see that health and social care practitioners should refer to speech and language therapy. Support for decision making is crucial and speech and language therapists can demonstrate if someone has decision making capacity. SLTs also reduce the potential risk of someone with communication needs being wrongly deemed as lacking capacity and in some extreme cases being deprived of their liberty.	Thank you for your comment and support for the guideline.
Royal College of Speech and Language Therapists	Short	13	8	The RCSLT is pleased to see that communication support will be provided including communication aids and speech and language therapy support.	Thank you for your support for the recommendation.
Royal College of Speech and	Short	14	21	The RCSLT is pleased to see that speech and language therapists will be called to support capacity assessments and support decision making.	Thank you for your support. The guideline has been edited to make clear that the recommendations should be read in conjunction with the code of practice.

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Language Therapists				The Mental Capacity Act Code of Practice recommend that the professional guidance of speech and language therapists is sought to support capacity assessments of people with communication difficulties. SLTs undertake detailed assessments of an individual's current and likely future ability to communicate including their ability to understand, express themselves and retain and recall information.	
Royal College of Speech and Language Therapists	Short	16	17	We support a multidisciplinary approach to assessing capacity. SLTs carry out and contribute to multidisciplinary capacity assessments of people with communication needs.	Thank you for your comment. The important role of SLTs is referenced in recommendation 1.4.17
Royal College of Speech and Language Therapists	Short	17	11	The RCSLT is pleased that information will be accessible to the needs of the person. Speech and language therapists are experts in inclusive communication, removing barriers to communication and advising others to do so. This includes supporting others to adapt their communication style to meet people's individual needs.	Thank you for your support.
Royal College of Speech and Language Therapists	Short	25	10	SLTs support people who cannot make informed decisions to express their preferences and wishes in relation to any decision made on their behalf. SLTs support people to understand how to communicate with individuals who have been found to lack decision making capacity.	Thank you for your comment. The committee acknowledge the important role of Speech and Language Therapists in the context of decision making and mental capacity and make several specific reference to this within the recommendations.
SeAp Advocacy	Short	4	28	It is our experience that the commissioning of non-statutory advocacy is variable. Whilst the MCA is very clear about when an IMCA must be instructed, there is no such guidance for the provision of non-statutory advocacy. There are discussions around whether non-statutory advocacy can be non-instructed as well as instructed. Clearer guidelines will help commissioners.	Thank you for your comment. The recommendations about advocacy have been substantially revised and we hope this addressed you concerns.
SeAp Advocacy	Short	5	15	It is worth noting at this point that the MCA for IMCA involvement in safeguarding has been superseded by the mandatory requirement under the Care Act 2014 which widens the remit to support people who have substantial difficulties in engaging with the process.	Thank you for your suggestion. The advocacy recommendations have been substantially revised and we hope that this addresses you concern.
SeAp Advocacy	Short	5	17	We agree with this and in our contract with local authorities we work hard to raise awareness of the duties to refer to statutory advocacy. However, it is our experience that knowledge amongst practitioners is still poor and with high turnover of staff and pressure of work it can be difficult to keep teams fully informed. We believe that more work needs to be done during the training and induction of practitioners in health and social care to ensure that advocacy is embedded in their thinking, rather than just another thing to remember to do. This should include helping practitioners understand how advocacy can support them in their work as well as the person at the centre. Even if referrals are made, they often show poor understanding of the need to have a decision and time specific mental capacity assessment and what constitutes family members or friends being considered 'available and appropriate'.	Thank you for your comment. The committee concur with your point and have tried to address this in the overarching training recommendation, 1.1.1.

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SeAp Advocacy	Short	5	23	We agree with this recommendation but in practice would suggest that current contracts are so tightly resourced that there is little time and money for training outside the mandatory requirements.	Thank you for your comment and your support. The committee acknowledge the financial constraints but they do believe the recommendation is achievable.
SeAp Advocacy	Short	7	14 to 26	It is worth noting under this section that the Care Act 2014 provides for advocacy when a person is going through needs assessments and care and support planning. There is now a duty to provide advocacy in certain circumstances as set out in your recommendation which is more directive than 'thinking about' involving an advocate. By setting this out as a duty, it will encourage staff to comply.	Thank you for your comment. Provision of advocacy is covered in recommendations 1.1.7 to 1.1.11.
SeAp Advocacy	Short	20	15	We agree with this recommendation however our experience shows that, in practice, reduced commissioning budgets can restrict the amount of follow up an IMCA is able to do and there is variation in practice as to whether the IMCA is invited to the follow up review.	Thank you for your comment. The committee believe the recommendation to be achievable within current funding contexts.
SeAp Advocacy	Short	25	1	This summary of independent advocacy confirms our views as stated above. We believe that raising the profile of advocacy through these guidelines will help implementation and go some way towards ensuring that people who lack capacity get the appropriate level of support.	Thank you for your comment. The guideline committee agreed that access to independent advocacy is important.
Sheffield Health and Social Care NHS Foundation Trust	Easy read	1		Is this document just about fluctuating capacity? Shouldn't it deal with mental capacity in general.	Thank you for your comment. We can confirm that the guideline is for: 'people who may (now or in the future) lack mental capacity to make specific decisions' (Short guideline). This wording is reflected in the boxed text at the beginning of the short guideline, which sets out what the guideline covers; the full guideline Introduction section, with more detail provided: 'people aged 16 years and over who - may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions'. The Easy Read document aimed to simplify and summarise information about the programme of work to develop the guideline. The guideline introduction and context has been revised to make clear that people with fluctuating capacity are in scope.
Sheffield Health and Social Care NHS Foundation Trust	Easy read	1		The easy read does not define what capacity is…. it is in itself a jargon term and needs a plain English definition.	Thank you for your comment. The Guideline Committee considered this at the post-consultation meeting. The Easy Read document aimed to simplify and summarise information about the programme of work to develop the guideline.
Sheffield Health and Social Care NHS Foundation Trust	Easy read	1		I think that the use of the terminology "fluctuating mental capacity" is confusing in this context. I think this document should refer to people who "may lack mental capacity to make decisions" or similar wording.	Thank you for your comment. Thank you for your comment. We can confirm that the guideline is for: 'people who may (now or in the future) lack mental capacity to make specific decisions' (Short guideline). This wording is reflected in the boxed text at the beginning of the short guideline, which sets out what the guideline covers; the full guideline Introduction section, with more detail provided: 'people aged 16 years and over who - may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions'. The Easy Read document aimed to simplify and summarise information about the programme of work to develop the guideline. The guideline introduction and context has been revised to make clear that people with fluctuating capacity are in scope.
Sheffield Health and	Full	7	187	I am concerned about the practical difficulties for services in being able to meet this recommendation – primarily due to separate note keeping systems. Further	Thank you for your comment which we will consider as part of the implementation work. The Guideline Committee acknowledge your concerns in respect of the

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Social Care NHS Foundation Trust				work would need to be done nationally on how to develop a system around this that is robust and safe	practical difficulties, but stress that the recommendation is essentially about the principle with the onus being on the professionals organising services to decided how best to achieve this.
Sheffield Health and Social Care NHS Foundation Trust	Full	9	227	Whilst this recommendation is appropriate for most people, I think that there is a need for further guidance around how to practically approach these issues with people for whom even the knowledge that a decision needs to be made (or the uncertainty around there even being a decision that needs to be made) would cause them to be extremely anxious/lead to significant risks to themselves and others	Thank you for your comment and support for the guideline. We did not review evidence about this issue as it is not in scope. However, this is covered in another NICE guideline on learning disabilities and behaviour that challenges: service design and delivery.
Sheffield Health and Social Care NHS Foundation Trust	Full	10	250	The principle of providing accessible information is an important facilitating action. More attention should be given to providing centrally supported and validated (by service users as well as staff) accessible information library/resources. This will save a great deal of time in the process and support consistency.	Thank you for your comment and support for the guideline.
Sheffield Health and Social Care NHS Foundation Trust	Full	10	270	To make an unwise decision requires capacity. This statement is a bit ambiguous and could be used inadvertently to justify a supporter influencing a person to make an unwise decision. The decision in this case needs to fully belong to the person, better to word it that the supporter supports a consideration of all decision options.	Thank you for your comment. In order to address the point about ambiguity, this recommendation has now been revised as follows: 'At times, the person being supported may wish to make a decision that appears unwise. As confirmed by the 3rd key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision'.
Sheffield Health and Social Care NHS Foundation Trust	Full	11	289	Does this need a caveat about 'unless there is a known reason (e.g., a safeguarding concern) not to involve friends, family or carers in shared decision making.'	Thank you for your comment. This point has already been addressed in the recommendations e.g. 1.2.11, undue influence.
Sheffield Health and Social Care NHS Foundation Trust	Full	11	293	I think that there will be practical problems around the same practitioner being involved around different decisions – for example, when the decision maker is a different person or where a service operates an episodic model of care. The recommendation is also based on the assumption that that person is an appropriate person to be fulfilling that role and their involvement is actually supportive for the person, so this would need to be assured. However, I think it is a good aim if it is possible and appropriate.	Thank you for your comment. To address the issue you have raised, we have added 'where possible and relevant' to this recommendation.
Sheffield Health and Social Care NHS Foundation Trust	Full	12	316	I think that there are practical challenges around advance care planning, particularly around the transfer of information between services (point 1.3.14) and of keeping documents current (particularly when services offer an episodic model of care).	Thank you for your comment. The committee recognises that there may be challenges regarding implementation of some recommendations however they are intended to be aspirational but achievable.
Sheffield Health and Social Care NHS	Full	13	338	I think that there needs to be more clarity about the status of information in "advance care plans" if people already lack the capacity to make such decisions when they express their opinions	Thank you for your comment. This section has been edited and further detail provided regarding the legal status of particular advance care planning tools.

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Foundation Trust					
Sheffield Health and Social Care NHS Foundation Trust	Full	13	342	This point of the guidance makes reference to "after diagnosis". I think that this may be confusing, as it seems more applicable to people with e.g., dementia than to a wider population covered by this guidance	Thank you for your comment. The recommendation was designed to cover anyone who may receive any diagnosis although it is more likely to be relevant for people with a diagnosis of a life limiting of fluctuating illness.
Sheffield Health and Social Care NHS Foundation Trust	Full	15	405	Does this need a definition or reference to what a 'joint crisis plan' is?	Thank you for your comment. The guideline includes a 'terms used in this guideline' section in which joint crisis planning is defined.
Sheffield Health and Social Care NHS Foundation Trust	Full	16	419	And if the person cannot consent should there be a formal record that the plan is being pout into place in their best interest?	Thank you for your comment. Although the recommendation does not precisely address your point the committee feel that advice in the event of best interests decision making is covered in the best interests section. In addition the committee agreed to include an introductory paragraph at the beginning of the capacity assessment section to clarify the link with what is stipulated in the Mental Capacity Act.
Sheffield Health and Social Care NHS Foundation Trust	Full	18	478	I think that guidance is needed about what to do if you think the person lacks capacity to consent to the decision to involve others in the capacity assessment. I think that it can all get quite circular if there is not clear advice given.	Thank you for your comment. The committee did not feel they had the basis on which to make this specific recommendation although they are confident that issues around consent and involving families and others as well as advocates are well covered by the guideline.
Sheffield Health and Social Care NHS Foundation Trust	Full	18	490	I think there is a need for further advice about what to do if a person continues to refuse a capacity assessment	Thank you for your comment. The committee added some more detail to the recommendation and this hopefully addresses your concern.
Sheffield Health and Social Care NHS Foundation Trust	Full	20	549	I think that this could present practical problems – it would be likely to be feasible within the same organisation, but much more difficult between organisations currently	Thank you for your comment. The GC believes the recommendations to be aspirational but achievable.
Sheffield Health and Social Care NHS Foundation Trust	Full	21	572	Practitioners may sometimes feel it is not appropriate to involve certain other people in best interests processes. Some guidance is needed as to any circumstances as to when that would be appropriate and procedures needed if relevant people are not consulted.	Thank you for your comment. This recommendation focuses on the importance of ensuring the person has the appropriate help and input to support their communication during the assessment. It is vitally important that if the person has communication needs, those needs are met.

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Sheffield Health and Social Care NHS Foundation Trust	Full	21	582	A definition of who is the decision maker – this is obvious but often avoided. E.g., the anaesthetist or dentist in the example of complex tooth extraction under anaesthetic. (i.e., they both have BI responsibilities for different aspects of the procedure).	Thank you for your comment. The importance of being clear about whom the decision-maker is covered in the recommendation numbered 1.5.2 in the draft guideline.
Sheffield Health and Social Care NHS Foundation Trust	Full	26	726	I think that the guidance has the potential to cause confusion as to appropriate terminology in relation to decisions made in advance. I think it is particularly highlighted here by the use of the term "Psychiatric advance directive". It is my understanding that this is terminology from the USA. Whilst it appears in the research review, I think it is confusing to have it in the body of the text, as it implies that it is terminology in use in this country. I think that this guidance is a good opportunity to provide clarity around a shared and consistent terminology.	Thank you for your comment. The term does not appear in the recommendations and therefore is not defined in the short guideline. It was only defined in the full guideline because it is mentioned in the included evidence. However to avoid confusion, this has now been deleted from the full guideline.
Shropshire County Council	Short	General	general	As an overall comment from Shropshire Council and informed by the West Midlands region we find this a great disappointment, there is too great an emphasis on Advance Care Planning and too great focus on ideas of consent. We welcome some greater clarity around those with a brain injury but have some concerns as to how it is written. We find that Local Authority practice has been almost completely ignored as have practice improvements driven by ADASS and the LGA and sector led improvements which they have supported over the last few years. The voice of the person is missing entirely from this document and the assumption of capacity is overlooked.It seems to be a great opportunity missed to provide a lead on what supported decision making is and to drive improvement in this area.	Thank you for your comment. The review questions and protocols made explicit reference to the presumption of capacity. This has now been included more clearly in the introduction and recommendations in the final guideline. The Guideline Committee agreed strongly on the importance of putting the person at the centre of the guideline. The overall tone of the guideline was reviewed at the post-consultation meeting and edits made throughout to ensure it is person-centred. The committee did not aim to single out advance care planning by giving it greater emphasis and in the context of the recommendations in the other sections do not believe that this has been the end result. There are actually more recommendations, for example, which relate to the assessment of capacity.
Shropshire County Council	Short	1	25	There is intermittent different use of the things to consider. This should be wishes, feelings, beliefs and values consistently not with different ones omitted.	Thank you, this has been amended in the recommendations for consistency.
Shropshire County Council	Short	1	28	This statement is fundamentally flawed. It ignores the assumption of capacity as it is written. Supported decision making may mean that someone begins the process lacking capacity but after they receive appropriate and relevant support they gain capacity for the specific decision.	Thank you for your comment. The context section has been revised and no longer contains this sentence.
Shropshire County Council	Short	3	1	A statement is written advising of a right but it is unclear in what way this is a recommendation. This could be much more forward thinking.	Thank you for your comment. This isn't actually a recommendation – it's a statement and the reader is encouraged to follow the hyper link for more info.
Shropshire County Council	Short	3	3	Line 1.1.1 this has a heavy focus only on training. Training in MCA has been provided since 2007 and yet many health and care professionals still do not know even the 5 key principles. There is much more able to be provided in this area, support tools, methods of embedding learning, competency frameworks, use of audit tools, shadowing and reflective practice as well as hearing from those affected by the MCA on a personal level. There are existing tools to support improvements in practice which were completely overlooked by the working group. These are mainly those arising from Local Authorities and are provided on the ADASS website and the LGA website for example.	Thank you for your comment. The committee is aware of these training tools, from their own expertise and from the evidence. The recommendations do go on to cite these in the overarching principles section.

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Shropshire County Council	Short	3	10	Consent is not only applicable to ACP and neither is consent the only application of MCA principle	Thank you for your comment. The recommendation has been revised accordingly and now refers to the importance of consent more broadly, not just in relation to advance planning.
Shropshire County Council	Short	3	14	The guidance also has a leaning heavily towards communication as the only aid to support capacity or support decision making	Thank you for your comment. The evidence – combined with the committee's expertise highlighted the importance of communication and addressing communication needs as a means of supporting decision making although of course it's not the only important element and these are addressed in great detail throughout the guideline, especially in the section on supporting decision making.
Shropshire County Council	Short	3	16	Clarity on roles – the report could have taken the opportunity to expand on the roles particularly the role of decision maker. This is often confused in health settings and is often seen as multi-disciplinary rather than vested in a person's role. More could also be said about the role of LPA and Deputy.	Thank you for your comment. This is an overarching principles section and applies to all roles and responsibilities so it wouldn't be appropriate to be specific.
Shropshire County Council	Short	4	3/4	Very few if any tools exist to aid practitioners with supported decision making. The guidance could have used the opportunity to go further and provide more guidance as to what this would contain. Local Councils do have examples of good practice	Thank you for your suggestion. Unfortunately the committee did not feel they had the evidence – from the systematic review – on which to base specific recommendations for particular tools.
Shropshire County Council	Short	5	8	Referral to IMCA is for a statutory reason that is not clear here	Thank you for your comment. Following consultation feedback, the recommendations on advocacy has been reworded to make clear the statutory responsibilities.
Shropshire County Council	Short	5	15	This is restating the clear requirements and option sin relation to IMCA referrals	Thank you for your comment. In some places in the guideline, direct reference is made to relevant elements of the MCA and Code of Practice, which helps emphasise the legal requirements. The context section of the guideline has been revised to emphasise the connection with the relevant legislation.
Shropshire County Council	Short	5	23	LA's commission the IMCA service but do not have the facility to provide specific training for them. This would fall to the provider although commissioning guidelines could include specific requirements for training and quality to be evidenced by the provider.	Thank you for your comment. The emphasis in this recommendation is on commissioners increasing investment in training rather than being the direct providers.
Shropshire County Council	Short	6	10 -20	There are additional factors t be considered such as the type of decision maker the person is, their experience of decision making, whether they feel they have the right to make a decision, how much time is needed	Thank you for your comment. The recommendation now makes reference to the person's previous experience (or lack of experience) in making decisions, their awareness of their ability to make decisions), emotional factors (which we think covers whether they feel they have the right to make the decision).
Shropshire County Council	Short	7	13 - 29	An opportunity is missed to describe support for decision making in a more forward thinking way. The emphasis is on communication and the support of professionals. Support and skills may actually be present in the person's friendship group or family/carer the idea of programmes of support could be explored further and examples of Local Authority Adult Social care practice could have been used as a starting point for innovation in these areas.	Thank you for your suggestion, which the committee feels is covered in the guideline by recommendations about involving significant and trusted people and where relevant and appropriate, families and carers. However, we will also pass this information to the endorsement team.
Shropshire County Council	Short	12	22,23,24	There could be more here about collaborative working with the person and their strengths it is not simply about consent to a care plan.	Thank you for your comment. We believe that the issue of collaborative working has been adequately covered in the recommendations.
Shropshire County Council	Short	13	1	This is an opportunity to provide clarity on who the decision maker is especially in health settings	Thank you for your comment. The decision-maker will depend on the setting and it would not be appropriate for the committee to specify this here.

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Shropshire County Council	Short	13	6	Sometimes assessors are required to assess capacity with little or no knowledge of the person. This statement is perhaps an ideal. It is often used as a reason not to assess capacity because the practitioner concerned feels they do not have adequate knowledge of the person but in many settings this will be the case.	Thank you for your comment. The committee believes the recommendation to be aspirational but achievable.
Shropshire County Council	Short	13	18	Again this is about consistency and completeness of language. The MCA needs the person to understand, retain, use and weigh and communicate.	Thank you for your comment. These concepts are all mentioned in the recommendation.
Shropshire County Council	Short	14	13	Principle 2 requires all practicable steps to be taken to support the person to make their own decision. Its focus is on those practicable steps this will produce a collaboration between the person and the assessor and possibly others. There is currently quite a knowledge gap about this kind of support, there is a lack of a model/s and very few support tools to aid recording and evidence.	Thank you for your comment. The committee hope that the recommendations will improve practice in these areas.
Shropshire County Council	Short	15	1 - 27	Overall this repeats much of what is currently available it is also repetitive of information written elsewhere particularly the existing Code of Practice. It does not appear to take innovation or developments in practice into account. As throughout the report it does not draw on any local authority practice, expertise, guidance documents, practice improvement tools etc.	Thank you for your comment. The recommendations are based on the best available evidence.
Shropshire County Council	Short	15	15	The mention of those with executive dysfunction e.g. traumatic brain injury is welcome however the wording of this section leads to an additional test for those people. It implies that capacity should be assessed and then a supplementary test should be added of observation. It is much better to think of it as real world observation providing the evidence to satisfy the use and weigh requirement of MCA. The test is a functional one and therefore includes not just what the person can tell you they would do, but does the person actually do what they can tell you they would do. This is particularly so in TBI and any new Code of practice or practice examples and support materials arising out of this guidance should reflect that but to describe it as "supplemented by" is applying an additional test.	Thank you for your comment. The words 'supplemented by' have been removed from the recommendation to make it clear that there is no additional test for this cohort.
Shropshire County Council	Short	8,9	1-29 and 1-5	The assumption of capacity and the onus of proof should be made more clear here.	Thank you for your comment. Recommendation 1.2.2 emphasises the importance of presumption of capacity.
Shropshire County Council	Short	17	1	Opportunity to clarify who the decision maker is	Thank you for your comment. This section has been edited to make it clear that for best interests decisions there can only be one decision-maker and that all parties should be clear about who this is. Reference to the relevant sections of the code of practice will also be included in the introduction.
Shropshire County Council	Short	18	4	Most local authorities do provide such tool kits. It is an omission of the research base. A desk top review at the least of local authority practice in this regard would greatly have aided this guidance and its recommendations.	Thank you for your comment. The evidence review underpinning this guideline focuses on research evidence that can be appraised in terms of quality. This is not feasible in relation to local toolkits already in use.
Shropshire County Council	Short	20	7	It is essential here that this reads "available options' and not simply options. There is no reference either to public law duties such as the Care Act and this role in relation to best interests decision making. Much greater clarity is needed as to when best interests decisions are needed and when decisions arise out of other duties. More needs to be said about the role of LPA or Deputy in relation to decision making.	Thank you for your comment. The committee believe that this is covered adequately by the recommendation. The text of the guideline has been edited to provide more details in relation to lasting powers of attorneys.
Shropshire County Council	Short	21	19,25	These terms are confused Advance Directive particularly is confused with a statement of wishes and preferences.	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline.

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					The term only appears in the full guideline because it is a term used within an included study.
Shropshire County Council	Short	22	1	Query this definition of consent, as it relates only here to those lacking or potentially lacking capacity. There is no definition of a Court appointed Deputy and no mention of such either. Some of the items on these pages such as practicable steps do not lend themselves to a definition.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.
Shropshire County Council	Short	24	29	There are a variety of documents in existence which aim to set a competency framework for MCA theses have not been included in the research but such a document them provides a framework for a minimum standard.	Thank you for your comment. We will pass this information to the implementation team.
Shropshire County Council	Short	25	25	An excellent Self-Assessment tool exists to provide a baseline for organisations https://www.adass.org.uk/media/4307/l15_152-mental-capacity-act-liberty_41427.pdf and https://www.local.gov.uk/topics/social-care-health-and-integration/adult-social-care/mental-capacity-act-including-dols materials are here also on restrictive practice as well as MCA commissioning and other support for the care and health sector.	Thank you for your comment. We will pass this information to the resource endorsement team.
Shropshire County Council	Short	30	1 - 14	Many of these comments seem to ignore improvements in practice in Adult Social Care there are some excellent resources on the SCIE website as well as those mentioned above. There is some excellent practice in relation to engaging with people who use services to inform and advise of their rights under the MCA.	Thank you for your comment and signposting these resources.
South Gloucestershire Council	Short	general	general	Overall I think this is a useful document, although I think that large parts simply repeat what is already in the MCA Code of Practice. My main concern is that whilst this pulls together principles from the MCA and Care Act, the delivery off knowledge in this format may fail to achieve real change on the ground. Locally, a modular practice based approach to MCA training delivery seems to be more effective than earlier e-learning and knowledge based approaches. There is a local MCA champions meeting where care home managers and staff are encouraged to attend to discuss MCA practice issues in their work setting, which has had some success in changing local practice. If this guideline is to have an impact on non-statutory health and social care staff, particular effort will be needed to introduce the guideline in a way that properly engages them and makes sense for them in their day to day work. I wonder if an even shorter version will be necessary for some settings. I think one of the main challenges will be to get health and social care staff to engage effectively in the process of advanced care planning. It may be necessary to raise the profile of this section.	Thank you for your comment and support for the guideline. There will be a range of supporting materials to assist implementation of the guideline, including a NICE pathway, a Quick Guide, and costing statement. The guideline committee also noted the importance of training, which is highlighted in recommendation 1.1.1 of the guideline.
South Gloucestershire Council	Short	22	1-3	I am concerned that as a result of how this is worded this statement might lead people to believe that a person who lacks capacity can give consent	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given

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					under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
South Gloucestershire Council	Short	23	19	My understanding is that these are not used in the UK	Thank you for your comment. We have removed the term 'Psychiatric advance directive' from the revised version of the guideline.
South West London and St George's Mental Health NHS Trust	Short	24	9	Joint crisis planning discussed in way that relates to integrated health and social care services. 4/5 local authorities under our Trust are no longer integrated and some guidance around that consideration or what that might need to look like would be necessary in our view.	Thank you for your comment. Issues regarding service configurations at authority/Trust level are not within the scope of the guideline.
South West London and St George's Mental Health NHS Trust	Short	24	26	We are concerned that this does not cover anything in relation to fluctuating capacity which is the main area of practice concern. There is only a one line whip in the Code that peoples capacity may fluctuate. There is no guidance as to how to address this in a way that is helpful to range of staff to which this applies across health and social care.	Thank you for your comment. Reference to capacity has been added to the text and we will consider this issue as part of the implementation work.
South West London and St George's Mental Health NHS Trust	Short	25	22	Lead – Our ultimate lead is the Executive Director of Nursing & Quality. Day to day Trust lead Head of Social Work who works with the Clinical Director identified lead (psychiatrist) & Compliance & MH Law Manager in overseeing all aspects of MH law including MCA leads and chairing the committee that reports to Board. In practice terms, each ward and team should have a MCA lead who attends higher level training to support practice and audit. These leads are a range of professional disciplines that have a specific interest and motivation to ensure that policy and protocols to support MCA/Code are implemented locally and report up any concerns.	Thank you for your comment. This section of text is common across guidelines and who is best placed to act as the lead will vary according to the setting.
South West London and St George's Mental Health NHS Trust	Short	25	25	This recommendation will be challenging in practice due to the largescale of our organisation working in different settings. The onus upon each organisation developing their own tool will have an implication for understanding impact across the different Trusts for shared learning. We would see a benefit to one shared tool as a pro forma.	Thank you for your comment. This text is common across guidelines and cannot be altered. The suggestions may be more or less suitable depending on the individual settings.
South West London and St George's Mental Health NHS Trust	Short	27	5	We have run a number of training analyses over the years providing bespoke training for inpatient & community to ensure tailored for their needs. We are currently developing training further and refreshing with a plan to make on line e-training session mandatory on the dashboard. We are also developing step by step guidance on using the form on the system which is intuitive and only opens fields that are required.	Thank you for your comment and signposting the various resources, including those in development, which we will consider as part of our research recommendation on training and support for practitioners.
South West Yorkshire Partnership NHS Foundation Trust	Full	General	General	The Trust welcomes and supports this NICE Guideline	Thank you for your comment and support for the guideline.

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South West Yorkshire Partnership NHS Foundation Trust	Full	General	General	The Trust supports and welcomes the research recommendations	Thank you for your comment and support for the research recommendations in the guideline.
South West Yorkshire Partnership NHS Foundation Trust	Full		704	The Trust believes the definition to be incomplete and suggests the following alternative wording; The Mental Health Act (MHA) 1983 is a piece of legislation (in England and Wales) which sets out the scope and limitations for professionals providing care and treatment for people with mental disorders. It also informs people with mental health problems what their rights are regarding: assessment and treatment in hospital, treatment in the community and pathways into hospital, which can be civil or criminal.	Thank you for your comment. The committee reviewed their definition of the Mental Health Act and although it is not worded in exactly the same way as you have suggested, they feel that it highlights the same most important elements.
South West Yorkshire Partnership NHS Foundation Trust	Full	6	145 - 150	The Trust has experience of implementing a mandatory MCA training programme for all staff and would be willing to submit its experiences to the NICE shared learning database. Contact Yvonne French, Assistant Director Legal Services	Thank you for your response. We will pass these details to the local practice collection team. More information on local practice can be found here.
South West Yorkshire Partnership NHS Foundation Trust	Full	6	150	The Trust is committed to the involvement of experts by experience, however their involvement can be challenging because of difficulties accessing people who have the skills, confidence, availability and support to ensure that their mental health is not disturbed. The commitment to supporting a complex annual plan of training is a significant pressure. Solutions such as the use of recording and audio visual technology are being explored as a means of partially resolving this challenge.	Thank you for your comment. The guideline does not recommend annual training plans, as no evidence was found in relation to this issue. Thank you for describing your innovative solutions such as the use of recording and audio visual technology.
South West Yorkshire Partnership NHS Foundation Trust	Full	7	171	The Trust has templates and guidance tools to assist clinical staff in assessing capacity; however the challenge is that the Trust works across 4 Local Authorities who each wish to use their own suites of documentation. Trust services comprise of health and social care staff and confusion arises as to which suite of tools should be used be clinicians at which times.	Thank you for your comment. The committee recognised the problem you highlight. They revised this recommendation following consultation and it now refers to the importance of auditing the tools and guidance, against adherence to the Mental Capacity Code of Practice. Although this may not completely resolve the problem you highlight the committee believe that it should help to achieve better consistency, potentially rationalising the range of tools made available.
South West Yorkshire Partnership NHS Foundation Trust	Full	7	174	The Trust is committed to the involvement of experts by experience, however their involvement can be challenging because of difficulties accessing people who have the skills, confidence, availability and support to ensure that their mental health is not disturbed. The commitment to supporting a complex annual plan of training is a significant pressure. Solutions such as the use of recording and audio visual technology are being explored as a means of partially resolving this challenge.	Thank you for your comment. The Guideline Committee acknowledge the challenges with involving experts by experience, but felt that there significant benefits associated with doing this. It is also encouraging to know that solutions such as the use of recording and audio visual technology are being explored.
South West Yorkshire Partnership NHS Foundation Trust	Full	7	185	The Trust has experience of developing materials to support people who have learning disabilities in their decision making. The Trust would be willing to submit materials to the NICE shared learning database. Contact Yvonne French, Assistant Director Legal Services	Thank you for your response. We will pass these details to the local practice collection team. More information on local practice can be found here.

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South West Yorkshire Partnership NHS Foundation Trust	Full	8	200 -202	The Trust would welcome an expansion of the role of the IMCA to support and advocate for patients in respect of property and affairs issues. The Trust believes that the challenge for Commissioners will be a financial matter and would question if this recommendation is achievable given our experience of withdrawal of non-statutory advocacy	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act.
South West Yorkshire Partnership NHS Foundation Trust	Full	9	218 - 222	The Trust is concerned that this recommendation may imply that the Trust should be funding the training of agencies that we do not commission	Thank you for your comment. The recommendation refers to increasing funding for training – although working with public bodies and providers to achieve this.
South West Yorkshire Partnership NHS Foundation Trust	Full	12	232	The Trust is concerned that this recommendation places the responsibility for the creation and sharing of advanced decision-making on the Trust. Patients have the right to make advance decisions and LPA's without the involvement of their treating clinical team.	Thank you for your comment. The committee wanted to clarify that the recommendation instead places responsibility on commissioners and providers to have standard protocols for joint working and info sharing where advance care plans have been developed.
South West Yorkshire Partnership NHS Foundation Trust	Full	12	314	The Trust is concerned that this recommendation implies that the 2nd principle has greater weighting than the other 4 principles. Further the Trust considers this recommendation to be challenging by being insufficiently specific enough to determine what should be monitored, under what circumstances, where this is reported to and any consequences arising from the findings of this monitoring.	Thank you for your comment. The committee agreed with the point you raise and this recommendation has now been significantly expanded to address the points you have raised.
South West Yorkshire Partnership NHS Foundation Trust	Full	15	414	The Trust is concerned that this recommendation to monitor the quality of assessments of capacity will be of particular challenge in the absence of a tool to determine what a quality assessment should look like, what a minimum standard would be and whether there would be different criteria or standards for different decisions or assessments made by different professionals	Thank you for your comment. Whilst the GC recognises that collecting these data may not always be straight-forward, they believe the recommendation to be achievable on the basis of their professional experience. The committee also believe it is absolutely crucial that the views of people who have had their capacity assessed are included in monitoring activity connected with capacity assessments.
South West Yorkshire Partnership NHS Foundation Trust	Full	16	429	The Trust is concerned that this recommendation will be challenging as it does not take account of first or early contact with services and where those services are crisis related.	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
South West Yorkshire Partnership NHS Foundation Trust	Full	17	456	The Trust has concerns that this recommendation may be challenging because it assumes that the assessment of capacity will take place when the patient is well known to services. This is often not the case and the history available may be very limited or self-reported	Thank you for your comment. The committee have revised the guideline to clarify the importance of taking an appropriate, proportionate approach to the application of mental capacity legislation, for example according to the urgency of the situation.
South West Yorkshire Partnership NHS	Full	20	547	The Trust is concerned that this recommendation may imply that all decisions in respect of a person who lacks capacity to make the decision must be made and recorded in compliance with the MCA. This recommendation does not take	Thank you for your comment. The committee did not agree to make any changes in light of your comment but they did revise the context section of the guideline as well as adding an introductory paragraph to this section. Together these changes

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Foundation Trust				account of the different process in respect of decision-making under the MHA 1983	should help to clarify the relationship with the guideline and with other relevant legislation including the Mental Capacity Act and Mental Health Act 1983.
South West Yorkshire Partnership NHS Foundation Trust	Full	20	549	The Trust is concerned that this recommendation may imply that the Trust has responsibility to hold all advance decisions, statements and LPA's that have been made by the patient. The nature of health care is such that it is unlikely that this will be the case. The Trust would suggest that this recommendation be reworded to reflect that we should be able to 'identify and locate any relevant written statement made by the person with the support of the responsible service or that has been shared with the service by the person'	Thank you for your comment. We believe that the recommendation is clear that this relates to the process of identifying advance statements and LPAs rather than managing these.
South West Yorkshire Partnership NHS Foundation Trust	Full	20	552	The Trust has had experience of implementing this approach and would be willing to submit its experiences to the NICE shared learning database. Contact Yvonne French Assistant Director Legal Services	Thank you for your response. We will pass these details to the local practice collection team. More information on local practice can be found here.
South West Yorkshire Partnership NHS Foundation Trust	Full	25	680	The Trust believes this definition to be incorrect. The Trust suggests the following alternative wording; Consent is the on-going agreement or permission of a person who has capacity to make the decision for the act or intervention to be made.	Thank you for your comment. The definition of consent has been edited to address your comment.
South West Yorkshire Partnership NHS Foundation Trust	Full	25	690	The Trust believes this definition to be incorrect. The Trust suggests the following alternative wording; A Joint Crisis Plan enables the individual and services to learn from experience and make plans about what to do in the event of another crisis. It is developed by seeking agreement between the mental health team and person when the person has mental capacity for their care both now or for a time in the future when they may lack mental capacity. When the person lacks mental capacity and is unlikely to gain or regain mental capacity a Joint Crisis Plan about what to do in the event of a future crisis may be developed through a best interest decision-making process.	Thank you for your comment. Thank you for this suggestion. The definition of Joint Crisis Planning has been amended to take account of your alternative wording.
South West Yorkshire Partnership NHS Foundation Trust	Full	25	697	The Trust believes the definition to be incomplete and would suggest the following is added to the end of the current definition; The attorney may only make decisions within the scope of the decision-making authority the donor has set out in the LPA.	Thank you for this suggestion. The definition of LPA has been edited to align with OPG definition, which makes clear the distinction between the two types of LPA.
South West Yorkshire Partnership NHS Foundation Trust	Full	26	726	The Trust believes this definition to be incomplete and suggests that the following words are added; PAD's are not legally binding in England and Wales.	Thank you for your comment. The term does not appear in the recommendations and therefore is not defined in the short guideline. It was only defined in the full guideline because it is mentioned in the included evidence. However to avoid confusion, this has now been deleted from the full guideline.
South West Yorkshire	Full	27	734	The Trust believes this definition to be incomplete and suggests that the following words are added;	Thank you for your comment. We have now deleted the term 'substitute decision-making' from the Terms Used section of the guideline and expanded the definition

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Partnership NHS Foundation Trust				…do so under the law (e.g LPA or Court Appointed Deputy). This 'Substitute Decision Maker' …	of a 'lasting power of attorney (LPA)', which should address your comment. This definition makes reference to the person or 'donor' being able to appoint one or more people known as 'attorneys' to help them make decisions or to make decisions on their behalf.
St George's University Hospitals NHS Foundation Trust	Short	General	general	A very encouraging piece of work that highlights the role of the Mental Capacity Act (MCA) as a piece of legislation to enable people to fulfil their human rights, which in our experience is an aspect of the legislation that is often lost in some areas of clinical practice. We are particularly pleased to see: The emphasis on promoting patient involvement and an individualised approach. The best interest guidance as recorded in this document gives more concrete advice on what to consider and how to consult compared to the existing checklist in the code of practice. The aspects of the guidance that highlight the value and importance of working as an MDT when applying the MCA. Highlighting and clarifying the support that Psychology and SLT can bring to aspects of applying the MCA.	Thank you for your comment and support for the guideline.
St George's University Hospitals NHS Foundation Trust	Short	General	General	We are concerned that the purpose of the document is unclear (i.e. is it setting out what should be best practice that all practitioners follow or what we aspire to achieve as best practice with acknowledgement that the proposed support mechanisms do not currently exist and require investment?). Currently, the document appears to be a mixture of both of these things. For example: 1. P5 line 8-9 recommends that practitioners should tell people about advocacy services, as a potential source of support for decision-making, but our clinical experience is that only patients who do not have a family member to advocate for them will be accepted via such services. Therefore, this recommendation cannot be implemented currently). 2. Greater clarification is required regarding the recommendations related to advance care planning. We understand this is about developing local pathways, however, we believe a general national framework is required to ensure equity of service delivery in relation to this issue. 3. Regarding best interest decisions – clarification is required about who is the ultimate decision maker (i.e. is it a majority rules decision? What happens when the majority are health professionals and family disagree?). Clarification regarding when to defer decisions to the court of protection [COP] is needed. 4. Clarification is required about what to do when there is a dispute between professionals (i.e. social services and acute health professionals treating the patient about the outcome of the capacity assessment) and who is responsible for paying for the COP costs to resolve these disputes. Our experience is that payment disputes delay decision-making and negatively affects patient care. Clarification is required about what should happen in the interim period (i.e. do the treating team continue to implement their care plan assuming their assessment of capacity is correct until a decision is proven to the contrary via the COP?).	Thank you for your comment. The guideline has now been revised including an updated context section which clarifies the status of the guideline as well as its relationship with the Mental Capacity Act, Code of Practice and other relevant legislation. The guideline sets out recommendations for practice in the context of current policy and practice. They are aspirational but achievable. In relation to your specific points: This recommendation has actually now been revised and says that practitioners must tell people about advocacy services as a potential source of support for decision making – this is a legal requirement. The recommendations about advance care planning have been reviewed and hopefully now provide greater clarity about what is being recommended. More clarity has been provided about the role of decision maker. The guideline recommends that referrals to the court of protection should be made in the event of a dispute over best interests that cannot be resolved locally. The committee did not believe there was a basis on which to stipulate more precisely. The committee did not review evidence nor hear expert testimony which provided a basis for making these specific recommendations.

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St George's University Hospitals NHS Foundation Trust	Short	General	General	We are concerned that these are large documents that are not laid out in a very accessible format, which might add to the perception that assessing capacity is an overwhelming and onerous task for a lot of professionals. The layout of the document needs to be significantly improved if it is to be a user-friendly reference resource for practitioners.	Thank you for your comment. The document layout follows NICE's standard format. NICE also produce a 'pathway' which is an interactive online version of the recommendations with links to more information if people want it. The structure of the guideline was reviewed by the Guideline Committee following consultation and sections have been revised, with introductory text added with the intention of making the document more user-friendly.
St George's University Hospitals NHS Foundation Trust	Short	P10	3-6	It is unclear whether the recommendation is that practitioners "should" (line 4) help advanced care planning or can choose to do this if they "wish to". Please clarify. While we agree that advanced care planning should be addressed by a practitioner, consideration needs to be given to which practitioners are best placed to do this when and where. It is not appropriate to suggest that anyone can do this or should do this. We feel that this is an example of making the use of the MCA onerous and setting unrealistic expectations (i.e. it would be unhelpful if every practitioner who comes in contact clinically with a patient after they have been given a degenerative diagnosis prompted the person to make an advanced directive). There are skills involved in having such conversations and therefore appropriately trained clinicians (e.g. psychologists, clinical nurse specialists, etc.) should be identified to perform this role. Currently, there is insufficient investment to conduct such work as part of normal clinical practice, thus funds would need to be made available nationally to support implementation of this recommendation.	Thank you for your comment. The committee did feel strongly that there needs to be much greater focus on enabling people to undertake advance care planning. To try and maximise the chance of people being offered this opportunity, the committee felt that it should be presented as being the business of everyone in contact with the person following diagnosis, otherwise practitioners may work on the assumption that someone else will address this with the person. However they do recognise that it may not be appropriate for all practitioners to enable those discussions themselves so they have now revised the recommendation to say that if the person wants to carry out advance care planning then the practitioner should facilitate it.
St George's University Hospitals NHS Foundation Trust	Short	5	8-14	We are concerned that the recommendations regarding the role of independent advocacy services (i.e. statutory and non-statutory) is unclear throughout the document but specifically in lines 8-14 where it suggests all people who lack capacity should be referred for an Independent Mental Capacity Advocacy (IMCA), but this is not currently possible; our experience is such services will not accept a referral if there are family members able/willing to support the person. There is also substantial variability regarding access to IMCA services dependent on postcode. The document needs to clarify if it is suggesting IMCA services should take up referrals even when families are involved? If so, this would require substantial investment in the recruitment, training, and management of IMCAs. This would need to be managed by an independent body, as our experience is that IMCAs employed via social services can be biased towards the financial objectives of the local authority they work for rather than the best interests of the patient. Our experience is that the quality of IMCAs is very variable and some can be poorly trained and educated regarding diagnoses and the impact it has on reasoning abilities (e.g. brain injury and impact of executive dysfunction). In addition, some have poor professional boundaries and do not aid the process of decision-making but in fact hinder it by imposing their personal views on the decision-making process and there is little or poor procedures for addressing such governance issues related to their professional behaviour. Therefore, in our opinion, the whole IMCA system would require a substantial overhaul and investment if IMCA were to be used in the manner proposed.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded in response to stakeholder concerns regarding the resource implications of the previous recommendation. The recommendations now make clear what the statutory obligations are regarding advocacy.
St George's University Hospitals	Short	15	15-19	We strongly support inclusion of this section, as it addresses an area we commonly find certain professions fail to comprehend (i.e. the need to consider observational evidence, not just information gathered at interview). Often a person	Thank you for your comment, and for your support for the guideline.

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NHS Foundation Trust				who suffers executive dysfunction may express a capacitous opinion in an interview but when faced with the decision in real life, where impulsive behaviours are triggered, they are unable to maintain behaviour in accordance with their decision, thus at that moment they lack capacity.	
St George's University Hospitals NHS Foundation Trust	Short	15	8-10	This section is not clear. If a person is suspected to lack capacity to make a decision, the person can't decide who should assess their capacity. Please clarify whether the recommendation is that if someone refuses to engage, that you have to assume they lack capacity by virtue of their failure to be able to communicate a decision and therefore the recommendation is to initiate a best interest meeting involving stake holders that the person recommends should be consulted. Much clearer guidance is required as to what practitioners should do when someone refuses to engage in a capacity assessment.	Thank you for your comment. This recommendation has been edited to clarify that the recommendation refers to steps that can be taken to help a person engage in an assessment.
St George's University Hospitals NHS Foundation Trust	Short	16	1-3	We strongly support the inclusion of this statement but feel it also needs to be highlighted that if a person lack insight into their condition, and therefore fails to understand or accept the risks posed by their disorder of mind on their decision-making, then they will lack capacity. Often we find that patients who lack insight are seen as making an unwise decision when in fact they do not understand the information relevant to the decision (e.g. a patient who is at risk of falls following a brain injury but believes they can walk normally may express that they don't care about the risks of falling, thus is deemed as making an unwise decision, but when questioned about how likely the risk of falls is, they report it to be very low because they are basing this decision on their premorbid knowledge of themselves).	Thank you for your comment. In recognition that, in some instances, lack of insight can be a material consideration in assessing capacity, we have added text to this recommendation to state '' If a practitioner believes a person's insight/lack of insight is relevant to their assessment of the person's capacity, they must clearly record what they mean by insight/lack of insight in this context and how they believe it affects/does not affect the person's capacity.'
Stockport Council	short	4	27	Could this section reference NDACPR as there appears to be little understanding of this as a serious medical decision.	Thank you for your comment. The principles promoting through the recommendation are intended to apply to all decision making so this would be included.
Stockport Council	short	15	8	Further guidance would be helpful if person still refuses to engage	Thank you for your comment. The committee discussed your point and agreed that in fact there are a few rare cases where someone refuses to engage with a capacity assessment (repeatedly) which will be a factor (amongst others) that is taken into account for the purpose of an interim declaration pursuant to section 48 of the MCA - the test being there is "reason to believe" P may lack capacity to make a specific decision. The court will then direct an independent expert or a special court visitor (with expertise in such cases) before a final declaration is made. So as you say, a person does not *have* to engage, but a refusal (against a background where a capacity assessment is being contemplated) *may*be a factor from which inferences about capacity could be made. Unfortunately and in this context however the committee did not feel they had reviewed evidence which would provide a basis to make suggestions for practical solutions.
Stockport Council	short	16	20 & 21	The issue of capacity to vote is not properly understood and clearer guidelines for Care Homes would be helpful to ensure people are not unnecessarily disenfranchised.	Thank you for your comment. This issue is not within the scope of this guidance.
Stockport Council	short	21	11	Clarification on which advanced decision/planning are legally binding and which should be taken into consideration would be helpful	Thank you for your comment. These are just intended to be definitions of how the terms are used in this guideline. The committee did not agree to make any changes to the definition but they did agree to revise the introduction to the advance care planning section, which now makes references to the legal status of various advance care planning tools.

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Stockport Council	short	22	1	Definition of consent is confusing it implies a third party can give consent for someone who lacks capacity now or in the future rather than make decisions in the person's best interest	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
Stockport Council	short	23	15, 19,25,	Clarification on the legal standing of these powers would be a useful addition.	Thank you for your comment. These terms have been removed from the guideline.
Surrey County Council	Easy Read	General	General	Unclear why this highlights people with 'fluctuating' capacity, where the short document for consultation does not specifically refer in detail to this? If the Easy read links to the short and full documentation out for consultation, isn't it for 'people who may have difficulty in making some decisions'.	Thank you for your comment. We can confirm that the guideline is for: 'people who may (now or in the future) lack mental capacity to make specific decisions' (Short guideline). This wording is reflected in the boxed text at the beginning of the short guideline, which sets out what the guideline covers; the full guideline Introduction section, with more detail provided: 'people aged 16 years and over who - may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions'. The Easy Read document aimed to simplify and summarise information about the programme of work to develop the guideline. The guideline introduction and context has been revised to make clear that people with fluctuating capacity are in scope.
Surrey County Council	Full	General	General	With apologies we do not feel able to comment on the full document due to time restraints to look at this. We acknowledge it is over 400 pages long, but recognise it will be much reduced for the final document. We feel the comments relating to the short version may be applicable generally for the full document as well.	Thank you for your comment and the time you have taken to review the work. The recommendations in the short version are indeed identical to those in the full version.
Surrey County Council	Short	General	General	We thought there were many great recommendations in the guidelines around support-decision making, MCA training, quality assurance of compliance with the MCA, wishes and feelings, and promotion of advocacy knowledge. However, we believe that the implementation of these recommendations would be challenging both in terms of cost and, in particular, embedding in practice, as in some organisations where MCA compliance is currently poor, (as our Senior Manager with responsibility for DOLS/MCA has experienced - often in hospitals and care homes). This would mean a significant cultural and practice shift, and would require additional time spent, where resources are already stretched.	Thank you for your comment and support for the guideline. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable.
Surrey County Council	Short	General	General	We thought references to 'independent advocacy' were at times vague, and wasn't clear regarding circumstances where advocacy was proposed to be used more widely (which isn't covered by current requirements under the Care Act or Mental Capacity Act).	Thank you for your comment. The issue of independent advocacy was discussed with the Guideline Committee post-consultation. The recommendations on advocacy have been updated to address your concerns. The 'Terms used in this guideline' section has also been reviewed and updated.
Surrey County Council	Short	General	General	We generally thought some of the language could be better/clearer. For example '1.4.9 'what information, knowledge and experience the person needs about their options'.	Thank you for your comment. The wording of all recommendations has been reviewed by the Guideline Committee and by NICE, and updates have been made throughout.
Surrey County Council	Short	21-23	General	We thought some of the definitions at the end of the short guideline were not accurate. For example the Mental Health Act is not just about telling people with mental health problems about their rights. References to Lasting Power of Attorney should distinguish between Health and Welfare LPA and Property and Affairs LPA (and doesn't in the definitions section). We felt that the explanation of	Thank you for your comment. We have revised the Mental Health Act definition in light of stakeholder suggestions, although it still refers to the fact that the Act tells people their rights in relation to the relevant pathways. In addition, references to Lasting Power of Attorney now distinguish between Health and Welfare LPA and Property and Affairs LPA. 'Duty of Care' is no longer included in the guideline. The

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				what 'Duty of Care' meant (does not just apply to those who lack capacity), and 'consent', were not well explained/accurate. Advance directive should be Advance decision. ADRTs says applies when valid, but doesn't mention they need to be applicable to the circumstance.	definition of 'consent' and 'ADRT' have also been edited. Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
Surrey County Council	Short	18	17-24	The short guidance seems to presume that a best interest meeting is always required, and this is not the case. At times they are useful, at others they can be counterproductive. We think it need to be made clearer that currently there is no provision/ necessity for best interest meetings and that they should only be held where the decision maker thinks they will be useful for them in determining best interest for the relevant person.	Thank you for your comment. We have added details on these issues to provide clarity about responding proportionately.
Surrey County Council	Short	5 of 33	8-14	IMCA referrals - this is not clear in terms of correct referral criteria for IMCA's / Care Act Advocates - this may be clearer in the full version?	Thank you for your comment. This recommendation has been amended to be clearer about the criteria for referral.
Surrey County Council	Short	14 of 33	21-24	Note should be made that the assessor should be trained (where relevant) and able to use such communication tools.	Thank you for your comment. We have edited the recommendation on the basis of your suggestion.
Surrey County Council	Short	19 of 33	4-23	Developing decision making support tools/training is a great idea, but we think this would have time and resource implications for many Health providers as well as in Adult Social Care.	Thank you for your comment. The recommendations are intended to be aspirational but still achievable within current resource constraints.
Surrey County Council	Short	20 of 33	12-14	We felt the language should be altered slightly as it can't be expected that a person who identifies a 'likely' DOLS is responsible for ensuring the appropriate legal authority is obtained (but they could refer the case as appropriate)	Thank you for your comment. The committee considered your suggestion but they felt it was reasonable to expect a best interests decision maker to ensure appropriate legal authority is obtained, albeit that their role is likely to involve referring the case.
Surrey County Council	Short	9 to 12 of 33	General	Advance Care Planning - good suggestions, sharing of highly regarded resources for this would be helpful.	Thank you for your comment. There was insufficient evidence to support recommending specific resources.
Surrey County Council	Short	21 of 33	9	There is mention of the need to consider application to the Court of Protection, but not the process or responsibility for who progresses this. This would be very useful and might be worth considering a case study to offer as an example. Apologies we don't know if this is covered in greater detail in the full document.	Thank you for your comment. The committee considered your suggestion and agreed that it would be much more helpful if people referred to the Court of Protection rules for this information, which would address any updates to those rules and avoid this guideline becoming out-dated. NICE Guidance doesn't routinely present case study examples.
Surrey County Council	Short	23 of 33	20 - 24	We don't like the use of the word – competent / incompetent in relation to people who have mental health problems/ disorders, and think that by still using the terms living wills, this confuses things. We think we should talk about ADRT or Advance Statements, to help with understanding what has legal authority and what needs to be taken into account by decision makers.	Thank you for your comment. To avoid confusion, 'living will' has been removed from the heading for advance decision. A little more detail has been added to the 'advance decision' definition.
The Challenging Behaviour Foundation	Full	General	General	It would be useful to acknowledge that specific groups of people including people with severe learning disabilities and complex needs are particularly at risk of not 'being heard' or engaged. People with severe learning disabilities are often faced with a range of complex issues. They can expect to achieve less than other people, to face more barriers and discrimination and to struggle to become socially integrated. Individuals with learning disabilities and behaviour perceived as challenging are likely to:	Thank you for your comment. The guideline is intended to cover a wide range of people using services who may (now or in the future) lack mental capacity to make decisions. The Guideline Committee agreed that people with learning disabilities are a particularly important group to include in the work and, accordingly, ensured this was detailed explicitly within the Population section of the review protocol (please see full guideline) and two papers were included for review that related specifically to people with learning disabilities (Dukes and McGuire 2009; Goldsmith et al. 2013). These informed four evidence statements (SDM1, SDM4, SDM6, SDM9) which focused on supporting and engaging people with learning disabilities in decision-making.

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				• Live in places or with people they don't like, often a long way from their family home [1] • Be given too much medication, or inappropriate medication [2] • Be subjected to restraint [3] • Be secluded and have their movement restricted [4] Reasonable adjustments and special consideration needs to be given to enable them to participate in decision making.	
The Challenging Behaviour Foundation	Full	General	General	There is little explanation throughout of the role of family members and carers in the decision making process. Approaches to seeking the views of people with complex needs including those with severe learning disability should include the support of people who know the individual well.	Thank you for your comment. The Guideline Committee agreed that family members and carers are important. Recommendations 1.2.11 and1.2.18 refer to the need to involve trusted people, family and carers in supported decision-making. The involvement of carers, family and friends is also referenced in the over-arching principles (1.1.1. and 1.1.3) and in the section on advance care planning (1.3.1, 1.3.8, 1.3.9 and 1.3.12) and the section on assessment (1.4.10, 1.4.13 and 1.4.21) and the section on best interests decision-making (1.5.7 and 1.5.9).
The Challenging Behaviour Foundation	Full	General	General	As the guidance covers young people over 16, it would be useful to be clear about the importance of including young people in decision making. Young people across the country are often left out of decisions and processes that impact their lives. This is particularly true for individuals with learning disabilities and even more so for young people with severe learning disabilities or profound and multiple learning disabilities. All young people are able to tell us what they think and feel in many ways and have a right to be heard. *"Valuing the Views of Children with a Learning Disability"* [4] developed by the Challenging Behaviour Foundation and Mencap gives examples of how organisations have actively sought and responded to the views of children with severe or profound and multiple learning disabilities in ways that other people can replicate.	Thank you for your comment. Thank you for the link to the publication. This did not meet the criteria for inclusion in the search strategy for this work as it was published in 2017 and the searches were conducted in 2016 with a follow-up search focused specifically on advance planning conducted in 2017. Following consultation, the Guideline Committee included some additional text that refers to decision-making among 16-18 year olds.
The Challenging Behaviour Foundation	Full	5	121	As the guidance covers young people over 16, it would be helpful to include the Children and Families Act (2014) as an additional act requiring children and young people to be involved in decision – making	Thank you for your comment. We agree it is useful to highlight how the guideline relates to the Children and Families Act (2014) and have added a new paragraph and explanation to the context of the guideline, as per your suggestion.
The Challenging Behaviour Foundation	Full	6	150	It would be helpful to include the importance of specific specialised training for working with people with complex needs such as people with learning disabilities and behaviours described as challenging. No one is too challenging to be listened to. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person's needs or wishes are understood.	Thank you for your comment. These recommendations apply to all practitioners, which would include those working with people with complex needs. The recommendation has been amended to state that the training should be tailored to people's roles. Please note that there are specific NICE guidelines on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, and Learning disabilities and behaviour that challenges: service design and delivery.

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[1] Mansell, J. (2010). Raising our sights: services for adults with profound intellectual and multiple disabilities.
[2] Department of Health (2015). Government response to No voice unheard, no right ignored.
[3] Public Health England (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England.
[4] Care Quality Commission (2014). Review of Learning Disability Services.

[4] Valuing the Views of Children with a Learning Disability, *CBF and Mencap, 2017* http://pavingtheway.works/whats-new/valuingtheviewsblog/

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The Challenging Behaviour Foundation	Full	8	200	It is important to note there needs to be timely availability of high quality specialised independent advocates. Any issues around lack of availability / funding of advocacy will need to be resolved.	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation to expand statutory advocacy commissioning is a consider recommendation and therefore not legally binding however the committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
The Challenging Behaviour Foundation	Full	8	204	It would be useful to recognise that some people including those with a learning disability may have capacity but need support to uptake advocacy and recognise how it can help them. An initial meeting with an advocate would give an opportunity for the advocate to inform people of their rights and explain what advocacy is and how it could help – those who have capacity could then make a decision to proceed after this initial meeting if they want.	Thank you for your comment. The committee substantially revised the advocacy recommendations, which now refer to 'enabling' and 'facilitating' people in the context of being told about advocacy.
The Challenging Behaviour Foundation	Full	8	224	It would be helpful to include people with severe learning disabilities and behaviours described as challenging as another group who are likely to require advocates with specific specialised skills and knowledge to meet their needs.	Thank you for your comment. The examples provided in this recommendation are not exhaustive. Please note that there are specific NICE guidelines on Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges, and Learning disabilities and behaviour that challenges: service design and delivery.
The Challenging Behaviour Foundation	Full	9	233	It would be helpful to include that approaches should be personalised, with the support of people who know the individual well.	Thank you for your comment. The Guideline Committee agreed with your comment and the recommendation now states that a personalised approach should be taken in this context.
The Challenging Behaviour Foundation	Full	9	234	It would be helpful to include the person's behaviour. Challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person's needs or wishes are understood.	Thank you for your comment. The Guideline Committee suggested that the wording of this recommendation be revised to include the issue of an individual's physical and mental health condition or state.
The Challenging Behaviour Foundation	Full	11	305	It would be useful to include that this written record will be shared with the individual and appropriate others.	Thank you for your comment. The Guideline Committee agree with your comment and this recommendation has been revised to include reference to the written record being shared with the individual and appropriate others.
The Challenging Behaviour Foundation	Full	21	585	It would be useful to acknowledge that a person's behaviour could serve to communicate a decision; with people with challenging behaviour, the challenging behaviour itself is often communication of an unmet need, so understanding the function of behaviour can help to improve the way a person's needs or wishes are understood.	Thank you for your comment. We believe that this is covered adequately by the recommendation, which refers to ensuring that decision-making approaches are appropriate to the circumstances of the individual, which would include behaviour that challenges.
The hallenging Behaviour Foundation	Short	1	14	It would be useful to include education as the guidance covers young people aged 16 who may be making decisions about their education.	Thank you for your comment. The lack of recommendations specifically about education is owing to a lack of evidence on this topic. However the committee recognised a gap in this area and added a specific paragraph to the context section to explain the specific legal framework surrounding decision making and mental capacity for people aged 16-18 years.
The Law Society of	Short	General	General	We think that it is important that the relationship between this Guidance and the Mental Capacity Act Code of Practice (which is statutory) is made clear. If and to	Thank you for your comment. The context section has been revised and now includes the principles of the MCA as well as a clear description of the link

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England and Wales				the extent that this Guidance ends up giving different guidance to that in the Code, then which should health and social care professionals follow?	between the recommendations and MCA and Code of Practice, as well as other relevant legislation. In addition, each relevant section of the guideline contains an introductory paragraph citing the relevant principle and section of the MCA and Code of Practice. We hope this addresses your concern.
The Law Society of England and Wales	Short	1	1	**Title -** The title of the guidance could usefully either be changed to, or have a subtitle of, "supporting legal capacity." The current title captures two aspects of the guidance and its purpose: (1) supporting individuals to take their own decisions; and (2) decision-making in relation to individuals who do not have mental capacity to make their own decisions. It does not capture the third aspect: advance planning to enable individuals to exercise agency – and hence legal capacity – at points when they do not have the requisite decision-making capacity. "Supporting legal capacity" also conveys an important, but under-recognised, aspect of the Mental Capacity Act 2005 (MCA), namely that it is entirely possible to characterise best interests decision-making which properly respects the individual's rights, will and preferences (or, in domestic terms, "wishes, feelings, beliefs and values") as supporting their legal capacity. See, for an example of this, the decision in the *Briggs* case concerning the issue of whether life-sustaining medical treatment should be continued, where the constructed decision made on his behalf by the court undoubtedly supported his legal capacity to be recognised as an actor in respect of a critical question.	Thank you for your comment, which the committee discussed. They concluded that the title already accurately describes the areas covered, decision making in cases where the person may lack capacity now or in the future.
The Law Society of England and Wales	Short	6	4	Given the confusion over the meaning of 'supported decision making' in the wake of the Convention on the Rights of Persons with Disabilities (CRPD), it may be useful to clarify what NICE mean by this term. The CRPD Committee uses the term 'supported decision making' to mean something closer to the meaning of 'supporting the exercise of legal capacity'. This is a very broad term, and can even include making decisions for the person based on their will and preference. 'Supported decision making,' given its more *intuitive* meaning, is usually defined along the lines of 'a series of relationships, practices, arrangements and agreements… designed to assist an individual with a disability to make and communicate to other's decisions about the individual's life.' (Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making* (2012) 19 Human Rights Brief 8).	Thank you for your comment. In light of yours and other stakeholder comments this section heading no longer refers to supported decision making, instead to 'supporting decision making'. Supporting decision making in line with the Mental Capacity Act is then described in a new introductory paragraph for this section.
The Law Society of	Short	6	4	It may be helpful to begin this section by reiterating the duty to provide support for decision making under s1(3) MCA, and then separately to state that this should begin by asking the person how they wish to be supported. It may also be	Thank you for your comment. The term 'supported decision making' has now been replaced with 'supporting decision making'. Section 1.2 provides explicit detail, with reference to principle 2 of the MCA 2005.

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England and Wales				important to remind practitioners at this stage that they must have regard to Chapter 3 of the MCA Code of Practice.	
The Law Society of England and Wales	Short	6	5	The section should clarify that it provides guidance on "practicable steps" to support the person to make a decision under s1(3) MCA. Whilst supporting capacity and making a best interests decision are conceptually separate, and at no point should a best interests decision precede a capacity assessment. This section could add that the information gleaned whilst supporting a person to make a decision about their wishes, feelings, values and beliefs may also usefully inform a best interests decision should it become apparent later on that this needs to be made. The fact that the person has been properly supported to express their views will assist in ensuring they have been given opportunities to participate in a best interests decision under s4(4) MCA, although it is possible that further steps may need to be taken in this regard.	Thank you for this suggestion, which is hopefully addressed now that the committee added an introductory paragraph to the section on supporting decision making. 'Practicable steps' is also defined in 'terms used'.
The Law Society of England and Wales	Short	6	10	The guidance in this section identifies a broad range of factors that may be relevant to supporting decisions. In due course – perhaps once a stronger research base is established - it would be helpful for NICE to produce guidance on the specific support that may be appropriate for people with different conditions. The practical support that might be needed for a person with a learning disability, or dementia, or brain injury or a mental health problem, such as bipolar or a personality disorder, is likely to differ significantly.	Thank you for your comment. This recommendation has been revised and now provides more detail. However in terms of being condition specific, those would be addressed in other NICE guideline focussing on those particular populations, for example people living with dementia or learning disabilities.
The Law Society of England and Wales	Short	6	23	Practitioners should also determine before setting out any reasonable adjustments that they may be required by law to make under the Equality Act 2010.	Thank you for your comment. The committee did not agree that the recommendation should be changed to cover reasonable adjustments. However, they felt the issue is covered in other recommendations, for example about tailoring support and information, ensuring it is person centred and complies with the NHS Accessible Information Standard. There are also detailed recommendations about ensuring the person has the support needed – including from other professionals – to communicate during decision making and capacity assessments.
The Law Society of England and Wales	Short	7	7	Where reference is made to the need to record the information provided to the person, it may be helpful to distinguish between those decisions where it is important to have a record of the support and assessment, and decisions where support may still be important but where it is impracticable or inappropriate to document it.	Thank you for your suggestion. The committee discussed this but felt it would make an unhelpful distinction because the information given to a person during decision making should always be recorded.
The Law Society of England and Wales	Short	7	27	This paragraph seems to conflate supporting a person to make a decision in the here and now, with advance care planning. Although there may sometimes be overlap in practice between these, they give rise to legally distinct duties and will apply in different circumstances.	Thank you for your comment. The recommendation has been amended to refer to 'capacitous decision-making'.
The Law Society of	Short	8	10	In this context the term 'shared decision-making' is confusing. It sows confusion in the important question of whether the person – appropriately supported – has made the decision for themselves, or a substitute decision is being made.	Thank you for your comment. Reference to shared decision-making has been removed from the recommendations.

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England and Wales					
The Law Society of England and Wales	Short	8	11	This paragraph should include reference to the wishes and feelings of the person regarding the involvement of third parties.	Thank you for your comment. Reference to involvement of third parties has been removed from this recommendation.
The Law Society of England and Wales	Short	8	24	The written record should also include reference to the person's expressed preferences regarding a) how they wish to be supported, and b) their expressed preference regarding the decision. The latter will be important if a best interests decision must be made on their behalf under s4(6) MCA.	Thank you for your comment. Reference to how the person wishes to be supported, and their expressed preference, have been added to recommendation 1.2.17.
The Law Society of England and Wales	Short	9	6	(4) It is suggested that "advance care planning" should not be distinguished from, but rather is the umbrella term for, facilitating individuals to make advance statements, advance decisions or grant proxy decision-making powers. However, all of these form part of advance care planning. (5) This section is predicated very firmly on advance care planning in relation to medical treatment. There is nothing, in and of itself, wrong with this (although it should be noted that advance care planning could be equally useful in relation to a person's <u>social</u> care needs), but if this is how the term is to be used here, it would be sensible to make this clear. (6) This section is predicated upon a person being on a one-way path to losing capacity (see in particular page 9, lines 24-28. Advance care planning is equally, if not more, useful for those with <u>fluctuating</u> capacity; this is then addressed at page 11 line 3, but it would be worth flagging this further up in this section). It is also possible (for instance under the ReSPECT protocol) for advance care planning to be done where the person has already lost capacity. This throws up considerable complexities in terms of the involvement, in particular, of attorneys: it is suggested that if the form of advance care planning considered here only relates to individuals <u>with</u> capacity that this is made clear (although note that the glossary at page 21 line 13 refers to individuals lacking capacity at the time of the planning).	Thank you for your comments, which are addressed in turn below. (1) Thanks you for highlighting this, the text has been revised in line with the point you make. (2) Thank you, this section is not intended to only relate to planning around medical decisions. The introductory paragraph has now been revised and it gives a clearer description of the scope of the recommendations in this section. (3) Thank you, the introductory paragraph now highlights that advance care planning can be helpfully carried out with people experiencing fluctuating capacity. (4) With regard to the RESPECT protocol, the committee did not review any evidence relating to this so they were unable to develop related recommendations. Just to confirm, advance care planning is being used in this guideline to refer to a process undertaken with and by people who have capacity to make decisions although they may lack capacity in the future. The definition in 'terms used' refers to people engaging in advance care planning who 'may lack capacity' only because their capacity is not at that point in question and an assessment has not been conducted. Therefore 'may' is being in the sense that it hasn't been established one way or the other via a capacity assessment.
The Law Society of England and Wales	Short	11	10-1 and 22-25	It is extremely important that: (3) Practitioners make clear what can, and cannot, form part of an advance care document – in particular that it is not possible to <u>demand</u> care or treatment that is not available (*N v ACC* [2017] UKSC 22 with regard to	Thank you for your comment. The committee developed these recommendations on the basis of evidence reviewed and discussions in about the evidence in light of their own expertise. The recommendation was certainly not intended to imply that people could demand care or treatment and having reviewed the wording the committee were content that this is not the message that's conveyed. In relation to documenting what is an advance statement and constitutes advance decisions,

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				social/healthcare in general, and e.g. *Burke* with regard to the inability to compel medical professionals to provide clinically contra-indicated treatment) (4) The document clearly indicates what aspects constitute advance statements, and what aspects constitute advance decisions to refuse medical treatment (and that any aspect which constitute ADRTs relating to life-sustaining treatment comply with the requirements of s.24 MCA 2005) In the medical treatment context, the use of a graphic as on the ReSPECT form can be very useful to identify where an individual's priorities lie on the spectrum between being kept alive at all costs as opposed to being made comfortable.	the committee did not feel there was a basis to add this specific detail from the evidence they reviewed.
The Law Society of England and Wales	Short	12	9-12	The guidance on joint crisis planning is so short here as, in reality, not to be of any assistance. In particular, it is not clear whether and how it is supposed to fit into the wider scope of the document relating to mental capacity, and leaves an ambiguity as to whether there is a necessary correlation between having a relapse/deterioration of a mental disorder with losing mental capacity. It is suggested that this is either removed or expanded.	Thank you for your comment. Unfortunately the committee did not feel that the evidence they reviewed provided the basis to make any more detailed recommendations about joint crisis planning.
The Law Society of England and Wales	Short	12	18	The suggestion that condition-specific expertise is sought is very important, and should be reinforced. Meaningful questions to probe whether a person with a learning disability understands or can use/weigh information are not going to be the same as the questions to probe whether a person with dementia can do so. One suggestion is that the NICE guidelines relating to specific conditions are revised in due course to incorporate the core elements from this guidance tailored to the particular conditions.	Thank you for your comment. Recommendation 1.4.3 states that 'Organisations should ensure that assessors can seek advice from people with specialist condition-specific knowledge to help them assess whether, on the balance of probabilities, there is evidence that the person lacks capacity', so should contribute to improving practice in this area. NICE guidelines that have recently been developed that have relevance to this topic cross-refer to this guideline.
The Law Society of England and Wales	Short	13	2	The test for identifying whether a person has or lacks capacity is set out in s.2 (not s.3) MCA – see *PC & NC v City of York Council*. S. 3 amplifies s.2, but the test is not in s.2. It is important to note that *PC* also made clear that the Code of Practice was wrong in placing a 'diagnostic threshold' (which does not appear in the Act) before the 'functional test' (again, a term which does not appear in the Act): see also in this regard *Kings College NHS Foundation Trust v C and V* [2015] EWCOP 80 at para 33 (considering *PC* at paras 58-59). The whole of the following section reads as something of a collation of miscellaneous points from case-law, the Code of Practice and practice. We suggest that it may be of use to have regard to the 39 Essex Chambers capacity assessment guide for a way in which to provide what practitioners actually require: i.e. how to translate the law into practice.	Thank you for your comment. The committee agreed with your comments and the recommendations have now been revised to highlight the issues around presumption of capacity and the difficulties of assessing capacity, in particular in recommendation 1.4.6 that relates to sections 2 and 3 of the Act and recommendation 1.4.10 that emphasises the need for practitioners to be clear about a person's inability to make a decision being caused by any impairment of or disturbance in the functioning of the mind or brain.

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				http://www.39essex.com/content/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Capacity-Assessment.pdf. Further and in any event, the guidance needs to address two critical points here: (3) The potential misapplication of the presumption of capacity highlighted in the House of Lords Select committee report, either because of a lack of understanding as to what it means or to avoid taking responsibility for a vulnerable adult. This is touched on at page 15, line 15, but is not in clear terms, and requires amplification. The 'causative nexus.' The guidance should make clear that a person can only be found to lack capacity where their relevant functional inability is due to an impairment or disturbance in the functioning of their mind or brain (*PC*). It is very important that the guidance makes clear how this is to be interpreted in the real world and, in particular, in the context of those with mild impairments who are caught in complex social situations – perhaps making reference to *NCC v TB* where Parker J made clear that the test is whether the impairment/disturbance is a material cause, even if it is not the sole cause.	
The Law Society of England and Wales	Short	13	18	It is not necessary that the person communicate specific information about the decision – the requirement is that the person is able to communicate their decision. We suggest taking this out, because this is a different requirement to the requirement to be able to understand/use/weigh etc information.	Thank you for your comment. The Mental Capacity Act refers to all five concepts in relation to decision-making (that is, understand, retain, weigh up, use and communicate). These are therefore all included in the recommendation.
The Law Society of England and Wales	Short	16	1	"Insight" is not a word which features in the MCA – it is important to make clear that practitioners need to explain how a person's lack of insight can be related to an inability to understand/retain/use/weigh relevant information. It should also be noted that a person can have insight into their condition but still not be able to make a decision.	Thank you for your comment. The committee discussed the use of the word 'insight' in detail. Whilst they agree that it can sometimes be misused they believe that its continued use in clinical practice suggests that it is useful to refer to it here. The text of the recommendation has been edited to make clearer that this relates to the practitioners perception.
The Law Society of England and Wales	Short	16	7	It is just as important that a practitioner records and explains why they have reached a decision that a person has capacity in circumstances where there have been objective reasons to question that person's capacity, not least to avoid misapplication of the presumption of capacity.	Thank you for your comment. The committee agree that this is important information that should be recorded. The recommendation that is numbered 1.4.24 in the draft guideline has been edited to include details on this.
The Law Society of England and Wales	Short	17	1	The question of who is the decision-maker is not straightforward at all, given the way in which the MCA (deliberately) does not identify decision-makers, save in the case of attorneys/deputies. It would be very helpful to have more discussion of this – here and elsewhere in this section, it may be useful to have regard to the 39 Essex Chambers Best Interests Assessment guide: http://www.39essex.com/content/wp-content/uploads/2017/11/Mental-Capacity-Guidance-Note-Best-Interests.pdf	Thank you for your comment. NICE guidelines do not recommend specific tools unless there is evidence to support their effectiveness. The committee did not feel they had a basis on which to make a recommendation about who the decision maker should be over and above what is set out in the Mental Capacity Code of Practice.
The Law Society of England and Wales	Short	20	3	The list of factors here should reflect the case-law from *Aintree* onwards, as well as the requirements of the CRPD, to make clear that the purpose of the exercise is to put oneself in the shoes of the person and that:	Thank you for your comment. You are right that the purpose of the exercise is to put oneself in the person's shoes. However, the evidence on which this recommendation is based showed that in only a very small number of cases the least restrictive option was explored. The committee agreed that in their experience practitioners do tend to lack understanding about the importance of exploring least restrictive options, which includes a judgement about associated

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				“[w]here the patient’s views can be ascertained with sufficient certainty, they should generally be followed (***Briggs*** at [62] per Charles J) or afforded great respect (***M v N*** at [28] per Hayden J), though they are not automatically determinative. ‘...*if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.* ***Briggs*** at [62ii] per Charles J.‘*...the 'sanctity of life' or the 'intrinsic value of life', can be rebutted (pursuant to statute) on the basis of a competent adult's cogently expressed wish. It follows, to my mind, by parity of analysis, that the importance of the wishes and feelings of an incapacitated adult, communicated to the court via family or friends but with similar cogency and authenticity, are to be afforded no less significance than those of the capacitous.’* ***M v N*** at [32] per Hayden J” (*Salford Royal NHS Foundation Trust v P* [2017] EWCOP 23: http://www.bailii.org/ew/cases/EWCOP/2017/23.html) These observations relate to medical treatment, but are equally applicable to other best interests decisions, especially those which are intensely personal.	risks and developing an understanding about the person’s likely wishes. Recommendation 1.5.15 aims to provide guidance about how to explore less restrictive options. Although the committee do not dispute the point you make, given the evidence on which the recommendation is based and the area of practice they were aiming to improve they did not agree to make any edits in light of your comment.
The Law Society of England and Wales	Short	21	12-18	(2) Again, it is suggested that “advance care planning” should not be distinguished from, but rather is the umbrella term for, facilitating individuals to make advance statements, advance decisions or grant proxy decision-making powers. All of these form part of advance care planning. As per the comments above, the bulk of the guidance relating to advance care planning relates to those who currently have capacity to participate, but this entry in the glossary suggests that it also covers those who currently lack it. The experience of one committee member involved with the ReSPECT project shows that advance care planning in relation to those currently lacking capacity throws up considerable legal complexities, not least in regard to the role of attorneys. In particular, it is unclear whether attorneys can purport to make what amounts to advance decisions to refuse treatment (it is suggested that the answer is that they cannot, although if it is clear that that the attorney would, at the time the treatment is needed, refuse consent on behalf of the person, it will in almost all cases not be appropriate for that treatment to be included in the care plan, unless there is reason to believe that that the attorney is not acting in the best interests of the person). A decision needs to be taken as to whether advance care planning is intended to cover both types of situations, and if so, more detail should be given	Thank you for your comment. In the glossary, ‘advance care planning’ is a process with people who may lack mental capacity now or in the future is a voluntary process of discussion about future care between the person and their care providers. If the person wishes, their family and friends may be included in the discussion. With the person’s agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.

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				as to how to carry out advance care planning where the person currently lacks capacity to participate.	
The Law Society of England and Wales	Short	21	19-24	(3) It is important to emphasise that "living wills" is not a statutory team, and risks misleading people as they may think that documents created prior to the MCA coming into force (or created in other jurisdictions where this is the term used, including Scotland) meet the relevant requirements in relation to life-sustaining treatment. Specific reference should be made to the fact that particular requirements apply in relation to life-sustaining treatment.	Thank you for your comment. To avoid confusion, 'living will' has been removed from the heading for advance decision. A little more detail has been added to the 'advance decision' definition.
The Law Society of England and Wales	Short	21	25	"Advance directive" is a very problematic term for three reasons: (4) It is not the statutory term in the MCA 2005, and risks confusion with what are now known as ADRTs; (5) If it is intended to refer to anything other than an ADRT, such statements are more generally known as "advance statements"; "Directive" risks misleading people into thinking that they can compel specific actions, for instance the administration of medical treatment or particular service provisions by public bodies, when decision-making post-incapacity represents choices between available options (*N v ACC* [2017] UKSC 22 in regards to social/healthcare in general, and e.g. *Burke* in regards to the inability to compel medical professionals to provide clinically contra-indicated treatment).	Thank you for your comment. 'Advance directive' is not used in the recommendations nor is it defined in the terms used section of the short guideline. The term only appears in the full guideline because it is a term used within an included study.
The Law Society of England and Wales	Short	22	1	"Consent" – this presumably means "advance consent," and it should also make clear that consent (including advance consent) has to be given freely.	Thank you for your comment. The definition of consent has been edited to read: 'The voluntary and continuing permission of the person to receive particular treatment or care and support, based on an adequate knowledge of the purpose, nature, likely effects and risks including the likelihood of success, any alternatives to it and what will happen if the treatment does not go ahead. Permission given under any unfair or undue pressure is not consent. By definition, a person who lacks capacity to consent cannot consent to treatment or care and support, even if they co-operate with the treatment or actively seek it.'
The Law Society of England and Wales	Short	22	4	"Duty of care": this definition is problematic because conflates (at least) two different issues: (3) The common law concept of duty of care as an aspect of the law of negligence, which will only arise in certain circumstances; and (4) The duty under s.1(5) MCA 2005. It is <u>very</u> important to emphasise that acting on the basis of either of these does not give rise to any <u>powers</u> on behalf of either public bodies or private individuals to act and/or a defence if they do act. There is a perennial issue (for instance) that care homes say that they are acting "under their duty of care" to compel/coerce/restrict actions of an individual with impaired capacity. That may	Thank you for your comment. This term is no longer used in the guideline.

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				explain why they are doing what they are doing, but it does not explain legally how they can do it. It may be worth making specific reference to s.5 MCA 2005 here.	
The Law Society of England and Wales	Short	22	15	The distinction between the two types of lasting power of attorney should be made clear here, and the fact that only health and welfare powers of attorney operate in the way set out here (a property and affairs power of attorney could take effect immediately).	Thank you for your comment. We have revised the definition of this term so that it includes the following wording: '…There are two types of LPA; health and welfare and property and financial affairs and either one or both of these can be made…'
The Law Society of England and Wales	Short	22	25	The definition of the Mental Health Act 1983 is rather charitable – it is not focused on telling individuals their rights, but is (primarily) about the regulation of compulsory admission for, and treatment of, a mental disorder.	Thank you for your comment. We have expanded this definition to now read: 'The Mental Health Act 1983 provides for the detention of persons in hospital for assessment and/or treatment of mental disorder and for treatment in the community in some circumstances. The Act provides for the process of assessing individuals and bringing them within the scope of the Act, for treatment of individuals subject to the Act's provisions and sets out the rights and safeguards afforded to individuals who are subject to the Act's powers. '
The Law Society of England and Wales	Short	23	8	Suggest using the (statutory) term "unable," not "unfit" as the latter has different connotations.	Thank you for your comment. This has been amended to use the term 'unable'.
The Law Society of England and Wales	Short	23	19	Suggest deleting "Psychiatric Advance Directives," as this risks seriously misleading service users and professionals. This a concept from other jurisdictions (most obviously the US) which does not – yet – exist in England &Wales. This definition also, as it stands, uses the wrong term ("competent" rather than "capacitous").	Thank you for your comment. Psychiatric Advance Directives are no longer referred to in the short guideline.
The Law Society of England and Wales	Short	23	25	"substitute decision-maker". It is important to make clear that this is not a statutory term and can encompass three different categories: (3) A proxy decision-maker (4) A person relying upon the provisions of s.5 MCA (NB, it is critical to make clear that s.5 does not give any single person or body the status of decision-maker) A judge making a decision under s.16 MCA 2005.	Thank you for your comment. The term 'Substitute Decision Maker' does not appear in the recommendations and therefore is not defined in the short guideline. Thank you for highlighting this error in the draft guideline.
The Law Society of England and Wales	Short	24	1	A supporter can: (2) Support a person with impaired decision-making capacity to make their own decisions; and Support a person who lacks decision-making capacity in the process of constructing a best interests decision. This glossary should include reference to both.	Thank you for your comment. The term does not appear in the recommendations (nor in the context section) and therefore is not defined in the short guideline. It is only defined in the full guideline because it is mentioned in the included evidence. The term is described in line with how it has been used in that study. The term cannot be removed from the definitions in the full guideline because it is intended to help people understand how it used in the cited study.
University College London Hospitals NHS Foundation Trust	Full	General	general	UCLH is submitting our overall view of the proposed guideline. Whilst we welcome the principle by NICE to develop a guideline for decision making and mental capacity, the general feedback by UCLH Safeguarding Adults Steering Group is that this version requires a re-write. These are some of the reasons: 1. The MCA is statutory and there is national work ongoing to embed it 2. It has been recognised by the epartment of Health & the Ministry of Justice that the	Thank you for your comment. 1. and 2. The guideline intends to build on, rather than replicate existing guidance and legislation. It aims to help improve practice in respect of mental capacity and supporting decision-making more broadly than the MCA. 3. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also

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				MCA has been poorly implemented from the onset 3. Services, providers, commissioners, higher education, deaneries, royal colleges are grappling with embedding it into training, practice and local guidance. This work is ongoing and may take more years to fully embed. Until this is achieved with appropriate capacity, resources and funding, this guidance will serve to unsettle services, especially referenced by regulators 4. Having a NICE document in response to CQC's concerns about poor implementation is not a solution to the problem. We do not need another document to tell us what MCA involves. If the intention is to have specific standards that we can measure up against, then this document does not achieve that. 5. There are inconsistencies and repetition throughout the document 6. It is not useful to repeat the MCA Code of Practice. Some of the links are not comparable with the Code. 7. There are terminologies in it that is not relevant and outdated eg "proxy" 8. It does not have the similar quality, robust framework and evidence based references compared to other NICE guidance 9. The terminology of autonomy and advocacy needs to be clearly defined, with explicit legal responsibilities 10. The reference to groups of professionals requires clarity. There appears to be some confusion and many groups have been missed out 11. The description and criteria of the capacity assessment and best interest process requires close scrutiny to ensure its accuracy 12. The term Living Will and Advance Directive is obsolete 13. There is a lack of clarity as to which groups this guidance is for although it is stated on the first page. The broad brush approach across all services is not useful. The fundamental principle is that all staff across all services must adhere to the MCA 2005 and the Code of practice is a guideline. The Law Society has stated that the sands are shifting with the Code as case laws emerge. This needs to be noted. 14. It would not be helpful if this document were to progress without drastic amendment , further work and scrutiny by the legal teams	undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable. 4. The guideline was developed on the basis of a referral from the Department of Health, rather than in response to CQC concerns. The aim of the guideline is to provide best available evidence about what works. A NICE Quality Standard on this topic will be developed following publication of the final NICE guideline. NICE Quality Standards, informed by NICE Guidance, set out the priority areas for quality improvement in health and social care. Each standard comprises: a set of statements to help improve quality and information on how to measure progress. 5. As part of the work to revise the guideline to take into account consultation comments, we have sought to correct errors and reduce unnecessary duplication. 6. The Guideline Committee sought to keep repetition to a minimum. Where elements of the MCA Code of Practice are included, this was thought to be particularly useful, e.g. for emphasis, ease of reference or for improving practice. 7. The term 'proxy' was included in the full guideline where this specific term was used in the research reviewed (Bravo et al 206, Pearlman et al 2005, Klingler et al 2016, Lai et al 2008). It has not been included in the recommendations and has now been removed from the 'Terms used' section of the short guideline. 8. The guideline was developed in accordance with Developing NICE guidelines: the manual (NICE 2014) and was quality assured in accordance with NICE processes. This included peer review. The section on Linking Evidence to Recommendations in the full guideline summarises and links to the evidence underpinning each recommendation. 9. The section on advocacy has been updated following post-consultation review by the Guideline Committee. The Committee felt that they did not want to redefine terms that are already in legislation. 10. The guideline has a broad remit and therefore it was not possible to list all groups of professionals to whom it applies. The Guideline Committee carefully considered the wording of recommendations; where recommendations are directed as specific groups of professionals (e.g. health and social care practitioners), this has been made clear. 11. The sections on assessment and best interest decision making have been reviewed and updated, including having some introductory text added. 12. The term 'living will' was included in the full guideline where this specific term was used in the research reviewed (Barnes et al 2007, Pearlman et al 2005). It has not been included in the recommendations and we will remove this from the 'Terms used' section of the short guideline. The same applies to the term 'advance directive' (Bisson et al 2009, Dixon et al 2015, Elbogan et al 2007, Pearlman et al 2005, Robinson et al 2013). 13. The Guideline Committee were working within the parameters of a Scope agreed through a process of Scope development which involved a wide range of stakeholders from across health and social care. The primary audience for NICE guidance is health and social care practitioners 14. The guideline has been revised to take into account the extensive feedback from consultation and has been reviewed by legal experts. There is legal

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					representation on the Guideline Committee and the recommendations were reviewed additionally as part of the process of finalising the guideline.
VoiceAbility	Short	General	General	We believe that a recommendation ought to be made that "Local Authorities provide information to Relevant Persons Representatives (RPRs) about RPR's role, duties and powers". RPRs play a critical role in supporting the person in all matters relating to the operation of the DoLS upon their lives, well-being and best interests and this is not merely a matter of "DoLS process." It is common sense to ensure that RPRs have the information which they require in order to performs their role, yet this is frequently not the case. This recommendation might be located under the heading for 'Helping and supporting family members' as many RPRs will be family members.	Thank you for your comment. The committee did not review any evidence or hear any expert testimony specifically relating to RPR and this explains why they have not developed specific recommendations on this. However as you say there are a number of recommendations about the provision of support to families and we hope this will cover the situations you describe.
VoiceAbility	Short	General	General	We are concerned that the recommendations provide no specific guidance for practitioners supporting people with fluctuating capacity	Thank you for your comment, which the committee considered. A number of stakeholders commented that people with conditions that led fluctuating capacity were not adequately covered by the draft recommendations. The guideline committee discussed these concerns and felt that the draft recommendations in fact apply regardless of whether a person's capacity is fluctuating e.g. whether or not they are likely to regain capacity to make the particular decision. Although the committee agreed therefore agreed that no changes to specific recommendations were necessary, they did agree to add an explanatory introduction to the section on advance care planning to clarify that advance care planning should be offered to everyone who is at risk of losing capacity as well as those who have fluctuating capacity. The committee also noted that recommendation 1.3.9 already highlights that practitioners should help everyone to take part in advance planning including people with fluctuating or progressive conditions.
VoiceAbility	Short	General	General	The guidance does not take sufficient account of the role both Care Act advocates and Independent Mental Health Advocates play in supporting a person to make a decision	Thank you for your comment. The committee revised all the advocacy recommendations following consultation and we hope this addresses your concerns.
VoiceAbility	Short	2	10	Whilst understanding that there are proposals for legal reform, we remain concerned about the exclusion of DoLS processes from the Guidelines. These were not excluded from the scope – which explicitly includes "how to use DoLS".	Thank you for your comment. The scope of this guideline was specifically decision making and the decision was taken by the committee, during the scoping stage, that this therefore should not cover issues around deprivation of liberty. However, the recommendations are clearly intended to be implemented within the context of the whole of the Mental Capacity Act (as well as other legislation and guidance) so the focus on decision making is not intended to be at exclusion of the other statutory principles.
VoiceAbility	Short	3	5	We are concerned that this recommendation does not go far enough and that practitioners should undergo training in the Care Act 2014 as well as the Mental Capacity Act 2005. There is a very close working relationship between these two Acts. Where a person would experience substantial difficulty in doing one or more of tasks outlined in the Care Act s67(4), which would encompass people who may lack capacity to make decisions about their care, they will receive the support of either an appropriate individual or an independent advocate or both, under certain circumstances defined in the Regulations, to support them to make decisions.	Thank you for your comment. The committee feel they have gone as far as possible within the limits of the scope and the evidence reviewed. However they do recognise the shortcomings in terms of evidence in this area and have developed a research recommendation try and fill this gap.
VoiceAbility	Short	4	1	We believe a further recommendation is needed: "When and how to request, appoint, make a referral for an independent advocate"	Thank you for your comment. The recommendations on independent advocacy have been substantially revised and this should address your concern.
VoiceAbility	Short	5	5-7	Paragraph 1.1.7 is directed at Commissioners yet they do not have the power to expand existing statutory independent advocacy roles which can only be done by	Thank you for your comment. Following consultation feedback, the recommendations on advocacy have been reworded to emphasise the statutory

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				the Minister or Parliament. This point should be clearer – Commissioners have the power to supplement statutory advocacy provision by commissioning appropriately resourced non-statutory independent advocacy. The latter is particularly valued as being preventative or where longer term advocacy support is needed.	responsibility to provide independent advocacy in accordance with the Mental Health Act, Mental Capacity Act and Care Act. The recommendation to expand statutory advocacy commissioning is a consider recommendation and therefore not legally binding however the committee discussed the benefits compared with the costs of recommending this and felt that on balance it provided good value for money.
VoiceAbility	Short	5	3-4	We believe this recommendation should include decisions made under the Care Act 2014 as well	Thank you for your comment. The committee wished to focus this recommendation specifically on advocacy for decisions being made under the Mental Capacity Act.
VoiceAbility	Short	5	10	We believe this recommendation should include ….” A referral should be made to an independent Mental Capacity Advocate or a Care Act advocate” depending on the decision being made.	Thank you for your comment. The advocacy recommendations have now been substantially revised and the wording of this recommendation has actually changed. However the committee would point out that referral to an independent mental capacity advocate does not depend on the nature of the decision being made.
VoiceAbility	Short	5	15	This recommendation needs to be clearer. Under the Care Act a person who experiences substantial difficulty in doing one or more of the tasks outlined in s68(3), which encompasses people who may lack capacity to make decisions about their protective measures, has a right to an advocate if there is no appropriate person to support them. Under the Mental Capacity Act an Independent Mental Capacity Advocate (IMCA) only 'may be involved'. The squeeze on funding for IMCA services means a person may well not get an advocate under the MCA where as they would under the Care Act. The wording – 'consider providing independent advocacy' is just not strong enough.	Thank you for your comment. On the basis of yours and other stakeholder comments, the recommendations on advocacy have been substantially revised and the elements that are legally binding are now much clearer.
VoiceAbility	Short	5	20	This recommendation should be made stronger requiring 'recording' as well as 'monitoring'	Thank you for your comment. The committee discussed your suggestion but did not agree to make the change. They felt the recommendation was already sufficiently strong in its draft form.
VoiceAbility	Short	5	22	We believe a further recommendation is needed; "…and Commissioners allow for sufficient time within their commissioning provision so as to enable independent advocates to support a person to make a decision and fulfil the functions of independent advocacy as set out under the respective Acts."	Thank you for your suggestion. The committee did not feel they had a basis on which to make this specific recommendation. However, the committee felt that commissioners reading the guideline will know they have to commission in such a way the recommendations can be achieved in practice.
VoiceAbility	Short	9	4	1.2.18 We would recommend moving this point so that it comes at the very beginning of this section rather than at the end	Thank you for your comment. We have reviewed the recommendations. All the recommendations describe how to take practicable steps; it is appropriate to have this recommendation at the end of the section which outlines how compliance ought to be monitored.
VoiceAbility	Short	21	General	Under the 'Terms used in this guideline' section, we would further recommend adding in a definition of the term Independent Advocacy. Our experience suggests that their remains many practitioners who are unaware of what independent advocacy is and the functions of an independent advocate under the Mental Capacity Act and Care Act and Mental Health Act.	Thank you for your comment. This has been added to the list of terms used.
West Sussex County Council	Full	general	general	WSCC notes that the committee have possibly overestimated the legal literacy of practitioners who might use these guidelines. The guidelines do not have a strong narrative structure and do not define tightly enough some terms. The glossary (661) even contains a term that only pertains to other legal jurisdictions without	The guideline does not replace existing legislation and guidance. The Guideline Committee sought to avoid duplication so far as possible. The guideline introduction has been updated, following consultation, to make clearer the link with existing legislation and guidance. Introductions have also been added to each section of the guideline to support this.

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				this being mentioned in the definition. This may to lead to confusion and misinterpretation, rather than improved practice. WSCC notes that he Guideline Committee appears to have no members currently working at a senior level in statutory social care. The guidelines state that they are intended for use by Health and Social Care practitioners, but do not appear to reflect this. Where examples are given of how practice relates to the guidance, those examples reference health decisions. No consideration is given to the economic impact on local authorities of some recommendations (1.1.7). WSCC would like to see guidelines that are more inclusive of social care staff WSCC believes that the extensive review of relevant supporting evidence will be of value to all working to improve the experience of decision making, and the implementation of the Mental Capacity Act. WSCC supports the research recommendations made in the draft guidelines. In particular WSCC believes that research into the efficacy of training and support for practitioners is needed urgently. The House of Lords report into MCA implementation demonstrated that most initial training programmes had not achieved the level of understanding required by practitioners.	The recommendations and the structure of the guideline have also been reviewed to improve clarity and more of the words used in the recommendations have been defined in the 'terms used' section. The recommendations are intended to cover decision making across the broad spectrum of health, care and support as well as finances and other life choices. The committee tried to avoid providing specific examples of likely decisions and in the new introductions to the separate sections of the guideline, it has been made clearer that the recommendations have broad relevance. There is now a deliberate emphasis on 'care and support needs' as well as medical treatment. In terms of social care expertise, the committee did provide this, both in terms of the perspective of practitioners and also people with experience of decision making and mental capacity in a personal capacity. The Guideline Committee considered the likely resource impact of implementing the guidance throughout the development process. NICE also undertook work to consider likely resource impact which was shared with the Committee following consultation. In conclusion, the Guideline Committee considered the recommendations to be aspirational but achievable. Thank you for your support for the review work undertaken as part of the guideline development process.
West Sussex County Council	Full	9-12	228 -315	Supported Decision Making The section on supported decision making would be difficult to implement, as the guidelines do not define what it is meant by supported decision making. Recommendation 1.2.5 refers to the "principles of supported decision making" but makes no reference as to what they consider these principles to be or where they are found. WSCC see this lack of clarity as an unhelpful omission. Supported decision making can have specific legal meanings in some jurisdictions. The Mental Capacity Act works on substitute decision making, and does not allow for supported decision making as envisaged by the UN Convention on the Rights of Persons with Disabilities. However supported decision making can instead be used as an inclusive term to describe both the process of taking all practicable steps to help the person make their own decision, and the process of helping the person to take part in the decision if they are unable to make their own decision. If NICE wishes to promote the term "Supported Decision Making", then the guidelines should be clear about what is meant. The committee may find this document produced by the Mental Welfare Commission for Scotland helpful. http://www.mwcscot.org.uk/media/348023/mwc_sdm_draft_gp_guide_10__post_board__jw_final.pdf	Thank you for your comment and for the link to resources which we will consider as part of our implementation work. During discussion with the Guideline Committee, we agreed that the term 'supported decision making' would be changed to 'supporting decision making' which we acknowledge is principle 2 of the MCA. The term 'substitute decision making' has been removed from the guideline.

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West Sussex County Council	Full	8 -9	192-226	AdvocacyThese recommendations would have significant cost implications for local authorities, and would be extremely difficult to implement. Furthermore the recommendations appear very unclear. Recommendation 1.1.7 envisages an expansion of independent advocacy services. The recommendation fails to specify how it proposes advocacy provision would differ from the current statutory requirements. Is it recommending that independent advocacy be available for those who are "befriended", or that advocacy should be available for a wider range of issues, or both? The recommendation suggests expanding "existing statutory independent advocacy roles", but this would require changes in regulations, which does not appear to be the remit of these guidelines. A second suggestion is to commission non statutory advocacy. The recommendation fails to identify which bodies should commission these services. All statutory advocacy services are currently the responsibility of local authorities. It appears a presumption is being made that local authorities will fund these extra services. There is no examination of the economic impact, or the practicality of implementing this recommendation given the impact of the Supreme Court decision of March 2014. WSCC would like to suggest that the Committee might consider the comments made by Charles J in various court cases in relation to the current insurmountable difficulties facing local authorities in the provision of advocacy. http://www.mentalcapacitylawandpolicy.org.uk/deckchairs-on-the-legal-titanic-the-re-x-saga-continues/ Recommendation 1.1.8 appears to add to the confusion for practitioners on when to instruct different advocates. Independent Mental Capacity Advocates have a specific statutory role. A referral should not be made simply because somebody lacks capacity to make a particular decision. A person who lacks mental capacity may be entitled to other statutory advocacy, such as Independent Care Act Advocacy, or not entitled to statutory advocacy. WSCC would like to suggest removing "and for those who lack capacity, a referral should be made to an independent mental capacity advocacy (sic)". This recommendation would then reflect the law as it stands, and not lead practitioners into making errors that may result in them acting unlawfully.	Thank you for your comment. The Guideline Committee gave careful consideration to the resource impact of these recommendations. In reviewing the recommendations after consultation the committee substantially revised the advocacy recommendations. The recommendations about extending statutory advocacy commissioning use the term 'consider' to allow greater local flexibility. The committee therefore agree that in this context the recommendations are achievable within current resources.
West Sussex County Council	Full	5	120	120 – Consider adding "Practitioners should consider the impact of the Human Rights Act 1998 on any proposed actions." .	Thank you for your comment. It was out of scope to search the literature on the impact of the Human Rights Act 1998.
West Sussex County Council	Full	6	152	152 – This line might be better shortened to "the importance of seeking consent". The need to seek consent applies to all situations where care or treatment is proposed.	Thank you for your comment. The Guideline Committee agree to your suggestion to shorten this bullet point in Recommendation 1.1.1 to 'the importance of seeking consent'.

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West Sussex County Council	Full	6	156	156 – Replace "supported" with "support".	Thank you for your comment. We have now amended this bullet to read: 'required communication skills for building trust and working with people who may lack capacity'.
West Sussex County Council	Full	9	233-243	233-243 Please add "the possibility that the person may be subject to undue duress or coercion regarding the decision."	Thank you for your comment. The Guideline Committee agree that this wording "the possibility that the person may be subject to undue duress or coercion regarding the decision" should be added to the bullet point in this recommendation about the involvement of others.
West Sussex County Council	Full	9	224	. 224 – Consider replacing "Independent Mental Capacity" with "Statutory". (All statutory advocates work with people who may have the communication difficulties)	Thank you for your comment. The Guideline Committee agree that there is no need to replace IMCA with 'statutory advocates' because the recommendation already refers to 'and others'.
West Sussex County Council	Full	9	231	231 – This recommendation may be practically difficult to implement and not necessarily produce the best outcome for the person. What is meant by this? Is this for the duration of the decision? Different practitioners in different settings will need to support people with different decisions, and assess mental capacity as necessary. The practitioner most able to support the person by providing the relevant information may not be able to build a relationship over time.	Thank you for your comment. The recommendation refers to practitioners plural. Anyone working with the person to support the decision should build a trusting relationship with them. The committee recognises that this will not always be the same practitioner but the principle of trust is an important one in this context.
West Sussex County Council	Full	10	271	271 – Please add at the end "if they have mental capacity to do this."	Thank you for your comment. The recommendation now reads: 1.2.2 At times, the person being supported may wish to make a decision that appears unwise. As confirmed by the 3rd key principle of the Mental Capacity Act 2005, a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision
West Sussex County Council	Full	11	293-5	293 -295 – This is not possible in many health and social care settings. Furthermore the practitioner best suited to supporting the person by providing the information they need to make the decision may change depending on the decision.".	Thank you for your comment. This recommendation has been revised to include the word 'relevant' to reflect the issue of potentially different staff involved in different decisions.
West Sussex County Council	Full	12	319	319 – Consider adding after "Lasting Power of Attorney" the words "for Health And Welfare".	Thank you for your suggestion. We have used the broad term 'lasting power of attorney' throughout the guideline. The definition in the 'terms used' section makes clear the two types of lasting power of attorney.
West Sussex County Council	Full	12	325	325 – Consider replacing "families" with "those interested in their welfare	Thank you for your suggestion. We have used the term 'families' in the guideline but in recognition that this might not be relevant in every case, there are also references to 'people with whom the person has a trusted relationship'. There is certainly no assumption that families will always be involved and in most instances, the recommendations refer to them as being one of a number of different people that the person may wish to involve in some way.
West Sussex County Council	Full	13	337	337 – Please consider adding an additional point; • The status of advance care plans and how they differ from appointing a Lasting Power of Attorney for Health and Welfare, or making an Advance Decision to Refuse Treatment.	Thank you for your comment. We have added text to cover these issues.
West Sussex County Council	Full	13	347	347 -348 This point needs a minor rewrite to make the sense clear.	Thank you for your comment. We have edited the text for clarity.

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West Sussex County Council	Full	15	395	395 - The issue of who the person wishes to share and advanced care plan with should come at the beginning, not the end. There is little point making an advance care plan if the person does not want anybody to know about it.	Thank you for your comment. The recommendations earlier in this section also relate to securing the person's consent for advanced planning. This was included again in this recommendation as a reminder to practitioners about the importance of consent for information sharing.
West Sussex County Council	Full	17	456	456 – Consider clarifying what is meant by this point as it is open to a variety of interpretations.	Thank you for your comment. The recommendation has been edited for clarity and to avoid misinterpretation.
West Sussex County Council	Full	19	519	519 -520 These two points imply that any decision that is different from that advocated by the professional is unwise. Please consider replacing with one point; • If the person has capacity, detail clearly what decision they have made, and any action they may have consented to.	Thank you for your comment. The recommendation has been edited to make clear that a decision should not be considered unwise just because it differs from the decision that the practitioner thought was most appropriate.
West Sussex County Council	Full	19	531	531 – Consider replacing "divorce" with "marriage". (Divorce can happen lawfully if one person lacks capacity and has the required representation, but no decision can lawfully be made about marriage.).	Thank you for your comment. This introductory paragraph has been substantially revised and it no longer refers to divorce.
West Sussex County Council	Full	21	577	577 – This point appears unclear. Please consider further explanation.	Thank you for your comment. We have edited the text to provide clarity.
West Sussex County Council	Full	23	633	633 – A section needs to be added here about restraint. This document nowhere references the requirements of section 5 and 6 of the MCA. This is a major omission that must be corrected.	Thank you for your suggestion. The committee did not believe they had a basis (from the evidence and expert testimony) on which to make this addition. However the guideline is now very clear about the link with the relevant legislation, which would provide the basis for guidance about the issue you identify.
West Sussex County Council	Full	25	693	693 – Consider adding information about the two sorts of LPA. Many practitioners do not understand the difference and presume LPAs for Property and Affairs can make all decisions	Thank you for this suggestion. The definition of LPA has been edited to align with OPG definition, which makes clear the distinction between the two types of LPA.
West Sussex County Council	Full	26	722	722 – It is not clear why "Proxy" is included. This term is not used in the guidelines, and is not used in the context of the Mental Capacity Act. Consider removing this definition.	Thank you for this suggestion. The definition of "Proxy" has been removed from the Terms Used section of the guideline.
West Sussex County Council	Full	26	726	726 – It is not clear why "Psychiatric Advance Directive" is included. This term is not used in the guidelines. It refers to a legal instrument used in some US states, but the definition does not mention this.	Thank you for your comment. The term does not appear in the recommendations and therefore is not defined in the short guideline. It was only defined in the full guideline because it is mentioned in the included evidence. However to avoid confusion, this has now been deleted from the full guideline.
West Sussex County Council	Full	27	732	732 – Please define this further. Make it clear what this means within the Mental Capacity Act 2005. Do not leave it open to interpretation.	Thank you for your comment. We have not defined the term 'substitute decision-making' because it is does not appear in the recommendations.
West Sussex County Council	Full	27	735	735 – Consider adding a relevant definition for "Supported Decision Making"	Thank you for your comment. We have now introduced a detailed wording below in the introduction to Section 1.2 on supported decision making ''A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success' (Principle 2 section 1(3), Mental Capacity Act 2005) Principle 2 of the Mental Capacity Act 2005 requires practitioners to help a person make their own decision, before deciding that they are unable to make a decision. Supporting decision-making capacity effectively requires a collaborative and

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					trusting relationship between the practitioner and the person. It does not involve trying to persuade or coerce a person into making a particular decision, and must be conducted in a non-discriminatory way. It requires practitioners to understand what is involved in a particular decision, and to understand what aspects of decision-making a person may need support with, and why. **This may mean helping a person with their memory or communication, helping them fully understand and weigh up the information relevant to a decision, or helping to reduce their distress. Various ways to support decision-making capacity are described in Chapter 3 of the Mental Capacity Act 2005 Code of Practice.''**
West Sussex County Council	Full	27	736	736 – Consider rewriting the definition to reflect the suggested additional definition for supported decision making. Alternatively consider removing this definition as it is not a term used in the context of the MCA	Thank you for your comment. We have deleted the term 'Supporters' from the Terms Used section of the guideline.
Westcountry Case management	short	4-5	general	Regarding advocacy- there is nothing specified about the experience or knowledge of advocates being considered for specific client groups. Our experience of advocates (sometimes volunteers) who have been involved with individuals with brain injury, and therefore experiencing a unique set of difficulties in terms of assessing capacity and establishing wishes and needs- in particular a lack of insight and a 'cloak of competence' (being able to present as articulate and more capable in terms of processing and weighing up information, than may be the reality). An advocate with no knowledge of brain injury- and sometimes no desire to learn, or to listen to specialist professionals either, can cause irreversible damage and a great deal of angst to all involved. Maybe advocates should also be aware of point 1.4.20- as this applies when considering someone's expressed wishes- can be extremely impulsive, ill thought out and lacking insight, or intent can be difficult to follow through to action. Acquiescence is also common, as is suggestibility. Brain injury experience is essential for anyone assessing capacity **or** advocating for an individual with an ABI	Thank you for your comment. The Guideline Committee stress that the point about advocates for specific client groups, such as individuals with brain injury has been addressed in Recommendation 1.1.11. See second bullet: '•Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with impaired executive function arising from acquired brain injury'.
Westcountry Case management	short	15	general	Some guidance about what to do when practitioners disagree about a capacity assessment would be helpful.. we have experience of submitting an assessment from an experienced professional, only to be told by social services that they disagree, find the person has capacity and will proceed to action a major decision- where to live, without regard for the capacity assessment made by a clinical psychologist. I believe the MCA sets out the first assessment stands, and capacity must be resolved before either best interest, or action are taken- but this is not always the case. Guidance about professional disagreement would be helpful- in this case the services who disregarded the assessment had no specialist experience in brain injury, undertook their own assessment and disregarded that of the ABI specialist.	Thank you for your comment. Recommendation 1.4.5 suggests that organisations should develop local policies or guidance on how to resolve disputes about the outcome of the capacity assessment, including how to inform the person and others affected by the outcome of the assessment.

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*