Supporting decision making for people who lack mental capacity

Consultation on draft scope

Stakeholder comments table

18/05/2016 to 15/06/2016

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Behind The Mask Foundation	General	general	The document covers every option for mental capacity and our foundation fully agrees with its contents.	Thank you for your support.
College of Occupational Therapists	3	63	Should this read 'now and/or in the future'?	Thank you for your comment. The scoping group opted to retain the existing wording in this section. We will search for evidence that informs decision making in the present and in the future, and in the case of fluctuating capacity.
College of Occupational Therapists	10	251	Should the first box read 'Person aged 16 or over who may lack mental capacity to make (specific) decisions? i.e. To reiterate that the mental capacity assessment should be 'decision-specific'.	Thank you for raising this. We note your point and agree that mental capacity assessment should be decision-specific. A decision has been taken, in collaboration with colleagues at NICE, to remove this diagram. An updated version of the pathway will be developed at a later stage in the development process.
College of Occupational Therapists	general	general	Staff training regarding the assessment of mental capacity could be mentioned. It would be useful if there was a reminder that all staff should be able to assess capacity and that the responsibility is not automatically passed on to one individual e.g. care co-ordinator/keyworker. Raising staff confidence and effective supervision and support could reduce costs as people who use services would receive faster and more efficient assessments and decisions regarding their care would be made more quickly.	Thank you for your comment, this is noted. The outcomes section of the scope states that the 'competence and confidence of practitioners to uphold the principles of the Mental Capacity Act 2005 and the Care Act 2014' (Decision Making and Mental Capacity Scope p.7). are key outcomes sought from the final guideline.
Compassion	General	General	Compassion in Dying welcomes this guidance because a focus on supported	Thank you for your support.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
in Dying			decision-making is vital to making sure that everyone is able to participate in decisions about their own health and care. We are a national charity working to inform and empower people to exercise their rights and choices around their treatment and care. We do this by: • providing information and support through our Information Line; • supplying free Advance Decisions to Refuse Treatment (ADRT) forms and publications which inform people how they can plan ahead for the end of their lives; • delivering one-to-one support to older people through our outreach service, My Life, My Decision (MLMD); • 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 patient-centred care. Although we appreciate that the Department of Health has asked NICE to look at this particular issue, we feel the guidance needs to be clearer about who the intended audience is and who it is intended to support. The wording 'people who may lack capacity' is vague, as every individual will potentially lack capacity at some point in the future. We are concerned that if the guidance retains this wording it will be difficult for healthcare professionals to determine who should be receiving support. On the other hand, if the guidance is intended only for people who *already* have a condition that may impair their capacity, there is potential to go against the presumption of capacity by implying that because a person has a diagnosis, they are more likely to lack capacity. Furthermore, this leads to the focus on supported decision-making being too restrictive as it leaves out a large group of people who may benefit from varying means of support to make a decision and yet do not have a specific diagnosis. An example of this would be people for whom English is not a first language, who often benefit from additional support to understand information and communicate, but do not necessarily already have an impairment of the mind or brain that could affect their capacity. The guidance could potentially alternatively be described as guidance for people	Thank you for your comment, We agree that additional clarity is needed around the subject of the guideline. The scoping group took into account comments about this and have reformulated wording to add clarity to the population of, and audience for, the guideline. These are now clarified in the introductory section.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			who may need support with decision-making, in order to ensure that professionals don't feel that there *has* to be an impairment of the mind or brain in order for them to use this guidance.	
Compassion in Dying	2	49	It is important that people who have difficulties with literacy are also included at this point in the list of equality considerations. This may be in English or their own language if they have English as an additional language. Learning from our MLMD project where we worked with people from BAME communities who had low literacy levels demonstrated that this has a significant impact on their ability to engage in decisions about their healthcare. This is because their access to appropriate information is limited, as well as their ability to communicate what they want. One of the participants commented, "we are already at the stage where we cannot communicate our wishes" when discussing how they could be supported to plan ahead for a loss of capacity. Types of support that would be appropriate in this context (for example the use of visual information and tools) must also therefore be considered in the full guidance.	Thank you for your comment. Literacy issues are now considered in the equality impact assessment (EIA). The EIA already acknowledges the challenges for those who do not speak English as their first language in terms of how they are able to communicate their wishes. We have now highlighted that lack of or poor literacy can create a barrier to planning ahead. The GC will consider any appropriate evidence that may emerge from the search to decide whether they wish to make recommendations in this area.
Compassion in Dying	4	98	We would like this section to emphasise that capacity is decision-specific. This is because the level and type of support that is required to help a person make a decision will depend on what the decision is that needs to be made. Experience from MLMD has shown for example that while some people lack capacity to make a decision about their finances, they can, with the appropriate support, make a decision about their care preferences.	Thank you for highlighting this. The scoping group have changed the wording of the scope in this section to introduce more clarity and show that the guideline will relate to decision making around specific health and social care related decisions. We note your point and agree that mental capacity assessment should be decision-specific.
Compassion in Dying	4	106	It is important to make sure that support is also available to enable people to plan ahead in ways that are appropriate to them. Support is relevant not only in the decision to engage in advance care planning, but also in the method that is used to allow people to record their preferences. Using tools that are appropriate for the person will help them to engage more proactively in their own care and can be especially helpful in cases where the person has fluctuating capacity. During our work with a group of older Somali women as part of MLMD for example, we created a template visual advance statement form. The women did read or write in English, and most did not speak English, so the form used images rather than	Thank you for your helpful comments, drawing upon your learning from working with people in different circumstances. We have ensured that the examples you identify – of people who do not speak English, people with dementia, those with complex needs and with visual impairments are addressed in the equality impact assessment. It is our intention to search for evidence of

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			words to convey the women's preferences for their future care and treatment. It is also important that conversations about planning ahead happen early, particularly if the person has a condition that will progressively impair their capacity. This is partly because providing someone with the appropriate level of support can often take time. For example, in MLMD, we have seen that people with a diagnosis of dementia may require a series of conversations to confidently be able to make a decision about planning ahead. This can be because their capacity is fluctuating, or their ability to remember and understand information is affected by various external factors. MLMD has also worked with service users who have visual impairments where explaining complex medical information for the purpose of making a decision about treatment requires a series of conversations to make sure the person is able to understand and retain the information.	interventions, tools and approaches that relate to planning ahead and fluctuating capacity. The potential for capacity to fluctuate is recognised and a key part of the scope. Search for appropriate tools and helping people plan ahead and key parts of the proposed guideline.
Compassion in Dying	5	113	It is important that the person themselves is consulted as far as possible about who they would like to be involved in decisions about their care. There is a risk from the current wording that healthcare professionals will immediately assume that a person wants their family members to be involved, but this is not always necessarily the case. Learning from MLMD has demonstrated that this can be of particular concern for the LGBT community, where assumptions about personal relationships can lead to the right people not being involved. We would suggest that the wording is altered to put the person's wish first – for example, "the person is consulted about who they would like to be involved, for example, family members, carers and other people interested in their welfare." Also, although those close to the person may provide significant support, it is important to remember that sometimes an independent person can be more appropriate. For example, the use of an independent interpreter in situations where the person does not speak English, is often more appropriate than using a family member, in order to make sure that the person's decision is not being influenced. This is also acknowledged at paragraph 3.10 of the MCA Code of Practice.	Thank you for highlighting this. We agree that people who may lack capacity may as far as possible want to choose who is or is not involved in decisions about their care and support The scoping group agreed to add; advocates, guardians, those who hold power of attorney and other interested parties to the' who is the guideline for' section of the scope. We have also noted your point about concerns that LGBT people may have and have added this to the equality impact assessment.
Compassion in Dying	5	122	It is important that the full guidance includes at this point reference to anything the person has previously expressed or recorded. This could include an Advance Statement or Statement of Wishes which contains important information about their beliefs, values and preferences and which must be considered in any best interests decision being made on their behalf.	Thank you for your comment, the guideline will aim to make recommendations as person centred as possible – including taking past recorded wishes into account. The Key Areas

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
				section says that the guidance will include 'interventions, tools and approaches to involve and support people'. And one of the main outcomes is person centred outcomes, including involvement in best interests' decision making. As recommendations are developed the guideline committee will bear in mind the preferences of the person, as far as is possible.
Compassion in Dying	6	145	Many methods of support do not require significant additional cost. Learning from MLMD has demonstrated that even minor adjustments can have a huge impact on the person's ability to engage in decision-making. For example, some service users take medication at particular times of the day and this can make them drowsy. Making sure that the conversation occurs at a time when the person is more alert is a key way of supporting them without incurring significant cost. Making sure that people get the right support to make decisions about their care and record their preferences in advance is also a more cost-effective way of approaching supported decision-making. This reiterates comments made earlier at point 3 regarding the significance of having conversations about preferences early, particularly if the person has a diagnosis of a condition that may impair capacity. We commissioned think-tank the International Longevity Centre-UK, to conduct a review of the literature and data analysis on the impact of advance care planning on care. The results showed that when people record their preferences in advance, it can reduce the need for avoidable hospital admissions. For example, studies demonstrated that for people with a diagnosis of dementia, advance care planning can reduce the need for hospital admission in the later stages of the disease. Reducing the number of hospital admissions (particularly towards the end of life) can have a significant impact on the costs associated with dying in hospital.	Thank you for your comment and for providing this information. The guideline development includes consideration of economic analysis based on a search for cost effectiveness data in relation to tools and interventions aimed at decision making and mental capacity. Depending on what evidence emerges there may also be some further economic modelling. We will ensure that the review team are aware of the study to which you refer.
Compassion in Dying	7	181	We feel that the use of 'best interests' in this statement is misleading. Best interests is a concept that applies when a person lacks capacity. If people have capacity, they can make the decision they would want (with appropriate support if necessary), even if objectively it could be construed as not in their best interests. This also reflects Principle 3 of the Mental Capacity Act (reiterated at line 293 of the Draft Scope),	Thank you for your comment. The scoping group have sought to add more clarity to this section. The guideline is aimed to assist people who may lack capacity, so will provide guidance on

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			which acknowledges that people have a right to make an unwise decision.	supporting people to make decisions when they have capacity and also on make decisions in the best interests of those who are assessed as lacking capacity to make a specific decision.
Compassion in Dying	10	251	We feel that the way the diagram is currently presented is unclear as it suggests that support for decision-making is a last resort. For example, considering the different types of support may be relevant when providing a person with information and yet it is presented at the end of the pathway. We would suggest that support is something that should be considered at each stage noted on the diagram (providing information, assessing mental capacity, advance planning and safeguarding), rather than as something that comes at the end of all of these and the diagram should be amended to reflect this.	Thank you for your comment. A decision has been taken, in collaboration with colleagues at NICE, to remove this diagram. An updated version of the pathway will be developed at a later stage in the development process.
Department of Health	General	General	Substance misuse sits oddly with the other categories which are conditions rather than behaviours. People may have impaired decision-making capacity when intoxicated, whether by alcohol, illicit drugs or by high doses of opioids taken for therapeutic reasons. These people don't in general lack capacity on a continuous basis, even those who are using dependently. And lots of non-dependent people are frequently intoxicated by alcohol. Care will be needed in distinguishing between people who make unwise decisions and those who lack capacity, i.e. is someone that chooses to misuse substances any different in principle from someone making unwise decisions about their food intake, their lack of exercise, their friends and associates?	The 'groups that will be covered' section has been reworded in accordance with the Mental Capacity Act Code of Practice which includes mention of 'the symptoms of alcohol and drug use'. Wording has also been changed on page two, to make clear that the subject of the guideline is those who are using health and social care services. As such we are including those with substance misuse issues in the scope.
Kent and Medway NHS and Social Care Partnership Trust	10	251	Reference should be made to assessments of capacity being specific to a particular decision. This should be reflected in the pathway	Thank you for highlighting this. The scoping group have added more clarity to the scope in order to show that mental capacity assessments are decision specific. This diagram has now been removed and an updated version of the pathway will be developed at a later stage in the development process.
Kent and Medway NHS	7	181/182	Contradictory " being enabled to make decisions about their own lives and in their best interests"	Thank you for your comment. The scoping group agreed to amend the

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
and Social Care Partnership Trust				wording in the Outcomes section, to better illustrate that the guideline is aimed at supporting decision making for people who have capacity and also best interests decision making when people as assessed as not having capacity.
Kent and Medway NHS and Social Care Partnership Trust	4	118	Should include how / where to document and who has access to assessment	Thank you for your comment. Assessment will be a central part of the guideline. Approaches to assessment is on of the key areas detailed in the scope (page 5).
Kent and Medway NHS and Social Care Partnership Trust	general	General	There could be a flow chart of process of assessment of capacity	Thank you for your suggestion. We hope that, through guideline development, we will be able to identify approaches and tools that are effective in supporting assessment of capacity for the guideline committee to draw upon in making recommendations. We may also be able to signpost to or create new implementation support tools. In the pathway, that will be developed later in the process, there will be a visual representation of the recommendations, potentially including the assessment process.
Kent and Medway NHS and Social Care Partnership Trust	general	general	There could be a flow chart of process of best interest decision	Thank you for your suggestion. As above, we hope to identify evidence about approaches and tools to support best interest decision-making through guideline development to inform recommendations that we may be able to also signpost to in future. Best interests decision making is one of the key areas to be addressed in the guideline and the pathway, which will be developed later in the process, there will be a visual representation of the

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
				recommendations.
Kent and Medway NHS and Social Care Partnership Trust	general	general	There could be a flow chart of process of DoLS	Thank you for this suggestion. As above, we hope to identify approaches and tools that are effective in supporting DoLs process to inform guideline development. The pathway, which will be developed later in the process, will be a visual representation of the recommendations, including information about DoLs.
Kent and Medway NHS and Social Care Partnership Trust	2	43	DoLS should be referred to here as well as on line 47/48	Thank you for your comment. We are satisfied that it is sufficient to include DoLs just once in the section of the scope that relates to equality considerations
Kent and Medway NHS and Social Care Partnership Trust	3	66	Difficulty would be better wording than problem	Thank you for your comment. We recognise that some people may prefer your suggested wording. However, this wording has been retained to be consistent with that used in the Mental Capacity Act Code of Practice document.
Kent and Medway NHS and Social Care Partnership Trust	3	67	Instead of illness put condition	Thank you for your comment. This wording has been amended.
Kent and Medway NHS and Social Care Partnership Trust	5	133	There should be reference as to when to reassess capacity as it may fluctuate	Thank you for your comment. It is our intention to search for evidence about planning ahead and fluctuating capacity. The potential for capacity to fluctuate is a key part of the aims of the scope. The wording in key area 5 has been amended to reflect this more clearly.
Kent and Medway NHS	6	160	The two stage test of mental capacity should be here.	Thank you for your comment. We recognise that is set out in the MCA code

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
and Social Care Partnership Trust				of practice. At this stage specific approaches cannot be detailed. The review process and search will look for good quality evidence based on specific tools and interventions.
Kent and Medway NHS and Social Care Partnership Trust	10	251	Should be box in flow diagram showing review	This diagram has now been removed and an updated version of the pathway will be developed at a later stage in the development process.
Kent and Medway NHS and Social Care Partnership Trust	11	265	Support not supports	Thank you for your comment and for highlighting this. This wording has been changed.
Kent and Medway NHS and Social Care Partnership Trust	11	267	Should say year of report	Thank you for your comment. Full details of all references are found in the bibliography section.
Kent and Medway NHS and Social Care Partnership Trust	7	general	Add a point about about considering diverse opinions and equality and diversity in relation to decisions	Thank you for your comment. Equalities issues are dealt with in depth in the Equality Impact Assessment (EIA) that accompanies the guideline.
Medicines and prescribing programme, NICE	8	219	The guideline 'Managing medicines for adults receiving social care in the community', expected March 2017 is also related to this guideline and should probably be included in this list.	Thank you for highlighting this. This guideline has been added to the list.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
Mencap	2	27-29	Suggested addition: the guideline will also be relevant for practitioners working in banks/ financial services	Thank you for your comment. Following discussion with the scoping group, it was agreed that banks and financial institutions fall outside the scope of a NICE guideline on this topic, which has a focus on decisions within health and social care.
Mencap	2	33	Suggested addition: DWP – in relation to decisions about Appointees	Thank you for your comment. Following discussion in the scoping group, it was decided that the DWP falls outside the scope of this topic as an intended audience, as its focus is on decisions within health and social care. However, the DWP have been identified as a stakeholder, in order for them to contribute to consultation on the guideline.
Mencap	2	47-48	Suggested clarification: People detained under the MHA, people who are subject to DoLS (A person won't be under MHA and subject to DoLS)	Thank you for your comment, In response the wording on this point has been altered to make clear that we are referring to those who are detained under the MHA, or are subject to DoLs.
Mencap	4	99-105	Suggest for clarification to re-word 'Supporting people who may lack capacity, or have been assessed as lacking capacity, to make decisions about' to 'Supporting decision-making for people who may lack capacity, in relation to decisions about'	Thank you for your comment. This section has been reworded following consultation with the scoping group. It is felt that the new wording better separates the concepts of supported decision making and best interests decision making,
Mencap	4	83	Suggested addition: Dentists	Thank you for your comment. Following discussion in the scoping group it was decided that 'dentists' can be considered as included under 'health professionals'
Mencap	4	99-105	Suggested addition: Finances	Thank you for your comment. Following discussion in the scoping group, it was decided that finances fall outside the scope off this topic, as its focus is health and social care.
Mencap	4-5		In the Key areas that will be covered section, we think it would be helpful to include	Thank you for your suggestion. We have

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			'roles and responsibilities in relation to supporting decision-making (referencing different settings)'.	made a number of revisions to this section in the light of stakeholder comments. However, we have not specified roles and responsibilities in the scope. Where there are clear roles and responsibilities, these are likely to emerge from the evidence that the guideline committee will be asked to consider in making their recommendations.
Mencap	5	117-118	Suggested addition: when assessing mental capacity the importance of using open ended questions.	Thank you for your comment. At this stage specific approaches cannot be detailed. The review process and search will look for good quality evidence of specific tools and interventions, and assessment is one of the key areas that will be focused on.
Mencap	6	167-168	Suggest 'Supporting decision-making for those who have been assessed as lacking mental capacity to make a particular decision' is changed to 'Supporting involvement in the decision-making process for those who have been assessed as lacking mental capacity to make a particular decision.'	Thank you for your comment. In consultation with the scoping group this wording has been amended to reflect your comment and similar ones from other organisations. The new wording is clearer in stating that best interests' decision making is necessary when someone is assessed as lacking capacity, but that the person should be supported to be involved as much as possible.
Mencap	6	169-171	Suggest this is changed to 'what interventions, tools and approaches are effective and cost effective in supporting involvement in the decision-making process for people who have been assessed as lacking capacity.'	Thank you for your comment. In consultation with the scoping group this wording has been amended in response to your comment.
Mencap	6	174-176	Suggest this is changed to '…acceptability of interventions, tools and approaches to support involvement in the decision-making process for people who have been assessed as lacking capacity?'	Thank you for your comment. The wording of question 4 has been changed to make clear that best interests decision making is necessary when a person is assessed as lacking capacity.
Mencap	7	181-182	Suggest this is changed to 'People being enabled to make decisions about their own lives'	Thank you for this comment. The wording in the outcomes section has been

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				changed to reflect your comment.
Mencap	7	182-183	Suggest new line inserted between 182 and 183: 'Where a person lacks capacity to make a decision, a 'best interests' decision is made, which is truly in the person's best interests'	Thank you for the comment. The wording in the outcomes section has been changed to reflect your comment.
Mencap	7	186-187	Suggest 186-187 is changed to two bullets instead: - 'Use of least restrictive options where some degree of restriction is required' - 'People supported in the least restrictive way possible where a deprivation of liberty is required'	Thank you for your comment. The scoping group have formulated new wording for this section. The scoping group made the decision to retain one bullet point and amend the wording to - Use of least restrictive options
Mencap	10	255-257	Suggest 'or participate in decision-making' is deleted as I think this is confusing as people won't 'lack capacity' to participate. So suggest this is 'People may lack capacity to make decisions for a number of reasons'.	Thank you for your comment. The scoping group have formulated new wording for this section. The scoping group formulated a description of the topic area that was clearer about the distinction between supporting people to make decisions and best interests decision making when a person lacks capacity.
Mencap	10	264	Suggest 'taken on their behalf' is changed to 'made on their behalf'.	Thank you for your comment, this wording has been amended.
Mencap	11	290-291	Suggest this is changed to 'a person should be presumed to have mental capacity unless they are assessed as lacking it after having been supported to try to make that decision.'	Thank you for your comment. The scoping group made the decision to retain this wording as it corresponds to that of the Mental Capacity Act
Mencap	12	294-295	Suggested addition: 'an act done or decision made under the Act or on behalf of the person who lacks mental capacity must be in the person's best interests, using the best interest checklist'	Thank you for your comment. The scope document is intended to identify the parameters of the project. At this stage we can not make reference to any specific assessment tools. But evidence on best interests decision making will be sought during the review process.
Mencap	12	298	Suggest a few lines are added after the 5 principles saying: 'When a person is assessed as lacking capacity to make a decision and a best interests decision is made, the person making the decision must consider the person's past and present wishes and feelings.' As this makes clear that when a person is assessed as lacking capacity the person must still be involved as much as possible.'	Thank you for your comment. The scoping group made the decision to include reference to 'past and present wishes' in this section. The scoping document is designed to identify the parameters of the project and identify areas where the review team

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				should search for evidence. Until later in the process we cannot make recommendations around practice. Past and present wishes are discussed in the Mental Capacity Act Code of Practice, and our scope makes clear that the guideline will aim to person centred in its focus.
Mencap	12-13	321-324	Suggest this is changed to 'The Mental Capacity Act 2005, including DoLS (and its accompanying Code of Practice), provides the legal framework for acting and making decisions on behalf of people who have been assessed as lacking the mental capacity to make decisions for themselves.'	Thank you for highlighting this. The text has been amended as you suggest. The review team recognises the need for the guideline to emphasise that an assessment of capacity is important around each decision made.
Mencap	13	340	Suggest there is also a reference to the revised MHA Code of Practice 2015.	Thank you for your comment. The existing hyperlink to the MHA 1983 and MHA 2007 also leads to the code of practice documents. As such the current wording will remain the same.
Mencap	General		For information – Mencap and BILD's Involve Me project/ resource is about how to creatively involve people with profound and multiple learning disabilities in decision-making processes and consultation. It shows how, where a person lacks capacity to make a decision, creative approaches can be used to find out and capture people's preferences and ensure these are used to influence decisions made about the person's life (eg. film showing a person enjoying an activity could influence a decision about how they spend their time). It has a number of principles to support involvement: www.mencap.org.uk/involveMe	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.
Mind	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.	Thank you for your support
Mind	General	General	Overall we strongly support the content of the draft scope, in particular that it covers present and advance decision-making, and that it is inclusive in that it is about people who **may** lack capacity to make decisions about health and social care (currently or in the future) as well as people who have been assessed to lack capacity to make specific decisions.	Thank you for your support. We have amended the wording throughout the scope to better reflect the Mental Capacity Act and supporting those who may lack mental capacity, affecting their ability to make decisions at certain times.
Mind	1	9	The principle that mental capacity is in relation to a specific decision is very important and not always well understood. Therefore we recommend that the	Thank you for your comment. The Scoping group agreed that health and

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			opening sentence states '… who may lack capacity to make decisions about their health and social care needs' rather than leaving this to the second paragraph. Although it would be cumbersome to use in every reference, it would be helpful to reiterate the decision-specific and time-specific nature of capacity at more points in the scope.	social care should be introduced earlier in the introduction to make the aims of the scope clear. Reference to the decision-specific and time specific nature of capacity has also been strengthened at points. The review questions now relates more clearly to making particular decisions.
Mind	3	63	Should it be 'or in the future' not 'and…'?	Thank you for highlighting this. The scoping group felt that the current wording better demonstrates that a person who may experience limited capacity can be supported to make decisions at the present time and also in the future, if there is a risk of them losing capacity. This may be particularly pertinent for some conditions, such as Dementia.
Mind	3	78-79	We welcome the emphasis on supporting people to make their own decisions: health and social care professionals should support people to make their own decisions as far as possible and maximise their participation where best interests decisions are being made. Therefore in general it is good to see 'decision-making **by** people….' However there are some discrepancies between references to decision-making by or for people, and at some points, such as here and 97-98, the text appears to be contradictory, ie implying that the person who has been assessed to lack capacity [to make a decision] is making the decision. We are interested in seeing exploration of supported decision-making as the model for all these decisions, but in the current legal context, people who are assessed to lack capacity to make a specific decision have that decision made for them, albeit (though not always in practice) with their participation. We recommend having an introductory statement to the effect that the guideline is about supporting people to make their own decisions as far as possible, assessing people's capacity to make specific health and care decisions and maximising people's participation where best interests decisions are being made for them.	Thank you for your comment and your support. Following several comments similar to yours we have reworded the introduction and several other sections of the guideline to better describe the distinction between supporting decision making and making decisions in the best interests of a person who is assessed as lacking the capacity to make a decision. We have drawn upon your suggested text to do this.
Mind	4	97-98	Please see comment 5	Thank you for your comment. This is an important point. We have clarified within

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			Although it is implicit in the scope, we think it is important to address explicitly the fact that people may lack capacity to make a specific decision but be able to make other decisions – for example they may lack capacity to decide about a course of treatment but be able to make day to day decisions about what they do, where they go and who they see. This could be included in this section and/or in the introduction.	the scope that decision making in this context is around specific individual decisions related to health and social care.
Mind	5	141-176	We agree with this framework and the questions posed.	Thank you for your support.
Mind	7	181-182	This conflates own and best interests decision-making – we recommend saying 'People being enabled to make decisions about their own lives and to participate as fully and effectively as possible in decisions made in their best interests'.	Thank you for your comment. The scoping group agreed to amend the wording to make this point clearer. We have opted to simplify the first point, change the wording and add a second bullet with the wording you have suggested.
Mind	7	192	Efficient **and effective** use of resources	Thank you for your comment. The scoping group agreed to change the wording as you have suggested.
Mind	General	General	Cost savings – we would expect that better involvement in decision-making and understanding of people's wishes and preferences will lead to more consensual and effective treatment and care. For example (subject to the care and treatment available) it should make it more likely to get the right treatment or care first time, fewer complaints/challenges and, in the case of advance decision-making that is honoured, access to preferred treatment before reaching crisis point.	Thank you for your comment, we have tried to make the scope reflect that supporting people to make decisions and best interests decision making needs to be as person centred as possible. The outcomes section is specific in the focus on person centred outcomes. The review work will include some economic analysis and we will be seeking evidence of cost-effective interventions.
RCGP	General	General	This is a thoughtful document with a sharp analysis of the present situation and in particular how poor present information is on the people involved, and how well or badly the system works-audit is of great importance. (PS) Plainly maximum autonomy and support is ideal. (PS) Suggesting techniques to enable people to be involved in decision making regarding their care, even if they have some degree of mental impairment, seems a good	Thank you for your comments and your support for the guideline. The scoping document is designed to illustrate the parameters of the project and suggest the areas in which recommendations may be made. The review evidence will inform which tools, approaches and interventions are recommended in the

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			objective of this guideline. (MJ) Over emphasis on the use of 'tools' may undermine its value. Mental capacity is a sensitive topic, individual and nuanced that it may be challenging to transform in a computer algorithm. Stressing the importance of trying to get people to contribute to decisions about their care would be a more valuable aim. (MJ) Capacity assessments are complex and can lead to conflict with patients/family/carers. The guideline should include how to involve patient/family/carers with the tools allowing the mental capacity assessment of a person. Promoting unity and understanding between those assessing capacity and the patient/family/carers is really important. (MJ) From the point of view of the clinician it may be useful to consider Planned and Emergency intervention, and negative and positive decisions about treatment. A life saving surgical intervention in an emergency will be regarded differently to a planned sterilisation. (PS) There is also the complication where the person lacking capacity is pregnant and another human life is involved. (PS)	final guideline. We agree that this is a very important topic that will touch upon some complex and sensitive areas. We look forward to working with a group of guideline committee members who will bring a wide range of expertise to consider the evidence based recommendations. The review process will search for material exploring the views and experiences of people who may lack capacity and hopefully emphasise their participation, as far as possible, in best interests decision making. This point is included in key area 6 and section 1.6 of the scope. The involvement of families and carers is also an area of importance and the views of families and carers will be sought in response to question 3.2 relating to assessments. Key area 5 shows the variety of different types of decisions that may be taken account of by the guideline. This includes clinical decision making in 'treatment options'. Treatment options may also include decision making around pregnancy.
RCGP	1	21	There needs to be a focus to support frontline health and care workers. The guidance needs to be clear and straightforward to support all GP and practice staff particularly to support newly qualified doctors, who are faced with complex care decisions particularly in out of hours situations, (MH)	Thank you for your comment. We agree that all health and social care practitioners working directly with people should benefit from this guideline. We have noted those audiences that you feel may find it particularly helpful such as newly qualified staff and those dealing with complex care decisions, especially out of hours. We will record this in the adoption issues log which we maintain throughout development.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
RCGP	3	66	There should be explicit mention of Autism or Neurodevelopmental Disorders. I do not think it suffices to cover it under 'mental health problem' since NDD should not be considered as such but rather consistent with a person's pattern of behaviour. Dr Ken Courtenay (MH)	Thank you for your comment. At this stage we cannot make an exhaustive list of groups covered by the guideline, due to the risk of omissions. The 'who is the focus' section borrows wording from the Mental Capacity Act Code of Practice to broadly set out the groups that may be included.
RCGP	4	102	It would be helpful to further categorise care decisions where a single response is required and complicated care decisions. This subdivision is used in Deciding Right App from NHS England Clinical Network. Under 1.3 It would also be useful to include how to document capacity assessments both on paper and in electronic clinical records. The RCGP has a mental capacity decision toolkit (http://www.rcgp.org.uk/clinical-and-research/a-to-z-clinical-resources/~/media/Files/CIRC/Learning%20disabilities/Learning%20disabilities%20resources/CIRC_Mental%20Capacity%20Act%20Toolkit%202011.ashx) (MH)	Thank you for your comment and for bringing these resources to our attention. We have added some further detail to the key areas and will be searching for all available good quality evidence relating to assessing mental capacity. Key area 2 details some of the areas in which decision may be made in relation to health and social care.
RCGP	5	115	The Mental Capacity Act suggests the capacity assessments are not intended to be global mental capacity assessments but are time and decision specific. (MH)	Thank you for your comment. The scoping group have amended the wording in several places within the scope to reflect the 'decision' specific nature of decision making and mental capacity.
RCGP	6	148	How can parents and significant carers be involved in care and decision making for young people 16-25 years with mental health issues such as anorexia nervosa. At present confidentiality considerations often mean carers and parents are excluded despite providing a significant amount of care, often 24 hours a day. The Somerset mental health Partnership uses a model of triangulation of care which could be considered. (MH)	Thank you for highlighting this point and the example of triangulation of care. During the review process we will be looking for evidence around the experiences of carers as well as interventions and approaches that improve outcomes for young people 16-25 where there are mental capacity issues.
RCSLT	1	12/13	The guideline scope states it will help practitioners support people to make decisions on topics such as where they live, their support, care and treatment and their security or safety. It does not state anything about finances – the RCSLT believes it would be worth being explicit here as this is one of the most common and pressing issues for people who may lack decision making capacity due to issues such as stroke, brain injury or dementia (Aldous et al, 2014).	Thank you for your comment. The scoping group discussed the inclusion of finances and financial services but it was decided that this is outside the scope of this NICE guideline, which focuses specifically on health and social care.
RCSLT	2	32/33	This guideline should also be relevant for people who have been nominated as	Thank you for your comment. The

Stakeholder	Page no.	Line no.	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			power of attorney, deputy or guardian who may need to make a decision on the behalf of someone else. These people may benefit from this guidance to support someone to contribute to different types of decisions or express their preference. There is very little guidance beyond that issued by some charities, (such as Mencap), for these groups. Yet it is often this group who are making decisions for people who lack capacity	scoping group agreed that those with power of attorney and guardians be specifically named in the scope and the wording has been amended to reflect this.
RCSLT	4	103	We question whether this should include a clear statement to demonstrate both pharmaceutical and procedural and other non-invasive interventions.	Thank you for your comment. We have revised one of the key areas to be covered which now includes decisions about 'medical tests, assistive technologies and equipment
RCSLT	4	104	"Diagnostics and devices" – The RCSLT are a little unclear what this means, could NICE possibly clarify please?	Thank you for your comment. The scoping group took your comment on board and changed the wording to 'medical tests, assistive technologies and equipment'.
RCSLT	4	105	The RCSLT believe it would again be important to include finances in this section. This is one of the most common areas of decision making assessed by health professionals in health settings (Aldous et al, 2014).	Thank you for your comment. The scoping group discussed the inclusion of finances and financial services but it was decided that this is outside the scope of this NICE guideline, which focuses specifically on health and social care.
RCSLT	5	122	'How to maximise best interests' – the RCSLT believe this should include supporting people to express a preference even if they do not have capacity. As stated in the Mental Capacity Act code of practice (pg.76) *"…a trusted relative or friend, a full-time carer or an advocate may be able to help the person to express wishes or aspirations or to indicate a preference between different options."*	Thank you for your comment. The scoping group discussed whether this section clearly describes the importance of maximising the involvement of the person in best interests decision making and it was decided that the current wording is sufficient for the scope. The MCA and its Code of Practice are clearly key documents and, as stated in the context section 3.3, the guideline aims to provide evidence based recommendations on how best to apply them.
RCSLT	5	124	The RCSLT again think it is extremely important the scope document includes people who have been nominated as power of attorney, deputy or guardian as these are often family, friends or others who have no experience of supporting people with communication or cognitive difficulties, and will need a significant amount to support	Thank you for your comment. The scoping group agreed that those with power of attorney and guardians be specifically named in the scope and the

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			to do this.	wording of key area 5 has been amended to reflect this.
RCSLT	Pg 5-6		Adjustments and supports for communication and cognitive difficulties should be mentioned more specifically in this document, as these are cited in the Mental Capacity Act code of practice (pg.32). as a specific method to support someone in decision making	Thank you for highlighting this. The Equality Impact Assessment that accompanies this guideline has a much fuller account for the equalities considerations in the scope, which does mention and address communication difficulties.
RCSLT	10	259	"Severe learning disability" – lack of mental capacity to make a specific decision may be a result of even a mild learning disability, so the RSCLT recommend that the word "severe" be removed.	Thank you for your comment the wording 'severe' has been removed.
Real Life Options	2	33	Although social care provider organisations are specified later in the guideline scope we feel they should also be listed here.	Thank you for your comment. The wording in this section of the scope has been amended to include Local authority and health commissioners and social care and health providers.
Real Life Options	4	112	As well as how to provide information this should include 'signposting' to other sources of information.	Thank you for your comment. The scoping group discussed the addition of 'signposting' but opted to retain the current wording.
Real Life Options	6	152	We are very supportive of the emphasis on the presumption of mental capacity.	Thank you for your support
Real Life Options	7	183	We feel this should go beyond 'people being safe' and talk about approach to risks and managed risks.	Thank you for your comment. The scoping group decided to remove 'people being safe' from the outcome section because it does not fit with the assertion that people can be supported to make potentially unwise decisions. Mention of safeguarding concerns and managing risks is found in the Key Areas section
Royal Borough of Kensington and Chelsea	1	4 and 5	I find the heading confusing – originally I thought this was solely about supporting people to make their own decisions, but it seems that it covers best interests decision-making too. I also don't find 'may lack mental capacity' a helpful term – I think it risks perpetuating the myth that having or lacking capacity is a status, rather than it being in relation to a specific decision at a specific moment in time.	Thank you for your comment. The scoping group have reworded some parts of the scope to make clear that this guideline will make recommendations around supporting people to make decisions when they have capacity and to

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			A suggested alternative title (although it's wordier) is 'Supported decision-making with people who have difficulty decision-making; and best interests decision-making for people who lack mental capacity to make the decision in question'	initiate best-interests decision making around specific individual decisions when they are assessed as lacking mental capacity. We feel that the wording: people who may lack capacity, describes how capacity can fluctuate. We also accept that the title is misleading and have simplified it to ''Decision-making and mental capacity'
Royal Borough of Kensington and Chelsea	General	General	The term 'lack mental capacity' or 'may lack mental capacity' is used on many occasions throughout the document. As stated above, this risks perpetuating the myth that having or lacking capacity is a status, rather than it being in relation to a specific decision at a specific moment in time. It also sounds negative. Suggested alternatives are 'people who have difficulty making some of their own decisions' or 'people who have difficulty decision-making' or 'people who need extra support with decision-making'.	Thank you for your comment. Please see our response above. Our wording was chosen to match that of the Mental Capacity Act and the related code of practice.
Royal Borough of Kensington and Chelsea	3	62 and 63	The phrase 'who may lack the capacity to make decisions about their care, support or treatment' is too broad. Someone may lack capacity to make a decision about one aspect of their care but have capacity to make a decision about another aspect of their care. I think that this sort of blanket statement contradicts the first 3 principles of the Mental Capacity Act.	Thank you for your comment. The scoping group have agreed new wording for this section. The new wording makes clear that the guideline will relate to specific decisions about care and support, not decision making more generally.
Royal Borough of Kensington and Chelsea	4	97 and 98	I think it would be clearer if the two areas of 1) the person being supported to make their own decision, and 2) a decision being made by someone else in the person's best interests because they lack capacity to make it themselves, should be separated, as someone who has been assessed to lack capacity to make the decision in question is not then being supported to make the decision themselves (although, following the best interests checklist, they need to be involved in the decision-making process as much as they are able, and their views, wishes and feelings are a very important factor). Area 1) could be amalgamated with key area 3). Area 2) could be amalgamated with key area 5).	Thank you for your comment. The scoping group have agreed new wording for this section. The new wording makes clear that the guideline will relate to specific decisions about care and support, not decision making more generally. The scoping group agreed to keep the 5 separate key areas. The review team felt that each of these areas describes activities related to decision making, from supporting those who have capacity to make decisions to tools associated with best interests decision making,
Royal	4	107	The term 'lose capacity' risks implying that having or lacking capacity is a status.	Thank you for highlighting this, this

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Borough of Kensington and Chelsea			Suggested alternatives are, 'should they have difficulty decision-making in the future' or 'should they, at a future date, need extra support decision-making'.	wording has been changed. The term 'lose capacity' has been removed from key area 2.
Royal Borough of Kensington and Chelsea	5	131-133	I think that Safeguarding should be a separate key area.	Thank you for your comment. The scoping group felt that safeguarding concerns are included across the current key areas and so a separate key area is not necessary. However, we have made it clearer how it should apply to this guideline in the context of supporting decision-making as well in best interest decision-making.
Royal Borough of Kensington and Chelsea	6	167 and 168; 170	'Supporting decision-making for those who have been assessed as lacking mental capacity to make a particular decision' is a difficult phrase to understand. I wonder if phrasing it simply as 'best interests decision-making for those who have been assessed as lacking mental capacity to make a particular decision' would be better. It is very important that the person themselves is as involved as possible in the decision-making process and that their own views, wishes, feelings and beliefs are given great weight by the decision-maker, but the legal position (whether or not it agrees with the UNCRPD) is that the person is not making their own decision, but someone else is making a decision in their best interests.	Thank you for your comment. The wording in question 4 has been amended by the scoping group following your comment and others like it. The scoping group aimed to make it clearer that best interests' decision making applies when a person is assessed as lacking mental capacity.
Royal Borough of Kensington and Chelsea	7	181 and 182	There needs to be a separate bullet-point about a decision being made in the person's best interests, maybe, 'Person-centred best interest's decisions being taken about people who lack capacity to make the decision in question'.	Thank you for your comment. The scoping group decided to add a new bullet point to emphasise the importance of involving the person as much possible in best interests decision making.
Royal Borough of Kensington and Chelsea	7	183	I don't think 'people being safe' is a useful statement as an outcome (at least on its own). If the person has capacity to make the decision in question, they have the right (unless use of the Mental Health Act can and is being considered) to decide to do something which leaves them unsafe. If the person lacks capacity to make the decision in question, it might be in their best interests not to be safe (for example, if they would be physically unsafe at home but so miserable in a care home that it is their best interests to remain at/return home)	Thank you for your comment. The scoping group discussed this point and opted to remove 'people being safe' from the Main Outcomes section.
Royal Borough of Kensington and Chelsea	7	186	Use of least restrictive options – this should be in all circumstances, not just where deprivation of liberty (or even restraint or restriction of liberty) is required.	Thank you for your comment. The scoping report discussed your comment and agreed to remove reference to DoLs from outcome 1 to make clear that the least restrictive options should apply to all

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				circumstances.
Royal Borough of Kensington and Chelsea	10	256 and 257	'People may lack capacity to make decisions' – this shouldn't be in the plural. 'People who may lack capacity to... participate in decision-making' – I don't think the statement that someone lacks capacity to participate in decision-making can be correct – lacking capacity is about not being able to make the decision, not about not being able participate in the decision-making process. Someone may lack capacity to make the decision but be able to participate, at least to some degree, in the decision-making process, or they may not have the ability to participate in the decision-making process at all (but using the term 'capacity' rather than 'ability' confuses things).	Thank you for highlighting this. This wording has been amended in response to your comment. The wording was changed to make clear that this guideline will be about decision making around specific issues. The scoping group agreed that people can participate in best interests' decision making. We hope that the new wording is clear and reflects the rationale for the guideline.
Royal Borough of Kensington and Chelsea	13	323	'people who lack the mental capacity to make decisions for themselves' – this is not correct legally – maybe the phrase from 1.1 of the Code of Practice could be used – 'on behalf of individuals [or people] who lack the mental capacity to make particular decisions for themselves'.	Thank you for your comment. The wording in this section has been amended to make clear that an assessment is needed to ascertain a person's capacity.
Royal College of Nursing	General	General	The Royal College of Nursing welcomes proposals to develop this guideline. It is topical. The draft scope seems comprehensive.	Thank you for your comment and for your support
Royal College of Nursing	General	General	The RCN has some guidelines on supporting decision making which might inform the development of this guidance: 'Making it work - Shared decision-making and people with learning disabilities' https://www.rcn.org.uk/about-us/policy-briefings/pol-4112	Thank you for your comment and for this information
Royal College of Psychiatrists	general		In general the purpose of this guideline is not clear. The Mental Capacity Act (MCA) sets out the law governing decision making for people who lack mental capacity. There is very little evidence about what helps good implementation of this law which at present is poorly understood and inconsistently used. What could help are clear decision making tools that could be applied to make decisions once someone has been assessed as lacking mental capacity. Also forms to clearly document advanced preferences and choices about refusal of	Thank you for your comments. We have now added text at the beginning of the scope that seeks to clarify the purpose of this guideline. The guideline seeks to support decision making when people have capacity and best interests decision making when they do not. The guideline will also offer guidance on the application of the Mental Capacity Act. The status of this scope is to set out the parameters of what the guideline will cover. It is not guidance in itself. Those

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			treatments. This guidance does not help clarify the laws as they stand and some parts of it are wrong.	aspects which may have appeared accurate or misleading we have sought to clarify following consultation.
Royal College of Psychiatrists	1	7-9	The GMC has excellent guidance about this; the law is currently under review; this applies to England only	Thank you for your comment and for this information.
Royal College of Psychiatrists	2	42-49	Most of these are the groups covered by the MCA; this is not about inequality, it is human rights law	Thank you for your comment. The final guideline will take into account the legal context of decision making and mental capacity.
Royal College of Psychiatrists	3	60-72	This is basic mental capacity knowledge and not disputable in a guideline	Thank you for your comment. All NICE guidelines clarify which populations are to be covered in the scope before development starts and this informs the search strategy.
Royal College of Psychiatrists	3	74-75	Reference should be made to Gillick competence and guardianship	Thanks you for your comment. As young people under 16 do not fall within the scope of this guideline we have not added reference to Gillick competence. However, we have added Guardians as one of the primary audiences for this guideline since they are also people with an interest in a person's welfare.
Royal College of Psychiatrists	4-5	96-133	This is muddled; the Mental Capacity Act (MCA) is much clearer. Why not follow the MCA code of practice, in particular reference to sections 4 and 5.	Thank you for your comment. The scoping group have reformulated and reworded some sections of section 1.3 to improve clarity. We have also added introductory text which serves to improve clarity from the outset.
Royal College of Psychiatrists	4	105	MCA is not really about safety and risk management which is an institutional concern. MCA is about helping individuals make their own decisions and therefore make their own choices about safety and risks. This is a human right and judgements about this are made by people with mental capacity all the time. The MCA provides a legal framework for non-capacitous people to have some of this right retained.	Thank you for your comment and for this information. Safety and risk management remains in scope precisely in so far as it relates to enabling individual choice about those things. We agree that the MCA provides the framework for those

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				choices for all people who use health and social services and support. However, stakeholders report that not everyone experiences it at present.
Royal College of Psychiatrists	5	134	Economic analysis is fine but this guidance relates to human Rights law in England and Europe and therefore economic options may not be legal	Thank you for your comment. The economic element of the guideline is designed to present evidence on the costs and effectiveness of tools and interventions related to decision making and mental capacity. We do not anticipate that economic analysis will result in any recommendations that fall outside of UK Law,
Royal College of Psychiatrists	5		Key issues and questions – many of these are not necessarily relevant to applying this law effectively. The outcomes should be related to good use of this law not service outcomes. What could help would be a clear format/or forms for documenting decision making processes for transparency and for future reference. The GMC has an excellent flow chart which if implemented would cover most of this scope. Good decision making should be part of all health and social care and not specifically relevant to the NICE guidance listed.	Thank you for your comment. The guideline aims to provide evidence based recommendations on how to support decision making and how best to apply the Act and its Code of Practice, focussing on interventions and approaches that have been shown to be effective. The main purpose of the guideline is to assist practitioners to support decision making, to assess capacity and also offer recommendations around best interests decision making for people who lack capacity. The focus is on using views and experiences data, as well as the best available evidence on tools and interventions to inform recommendations. You will note that the service outcomes include competence and competence of practitioners in upholding the principles of both the MCA and the Care Act 2014 – both of them pertinent to health and social care practitioners.
Royal College of Psychiatrists	6	144-151	This is not relevant to this guideline; it is a tautology. This guideline is about decision making for people when they lack capacity. Planning in advance can only be done when someone has capacity. QED.	Thank you for your comment. The guideline is about best interests' decision making when people lack capacity and

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				also supporting people who are using health and social care to make decisions when they do have capacity. This includes planning for the future – particularly for people who have conditions where their capacity may fluctuate.
Royal College of Psychiatrists	10		This flow chart is wrong; if someone may lack capacity this should be assessed. Information should be given to capacitous people/patients who can also make advanced statements. Neither of these two apply to safeguarding.	Thank you for your comment. A decision has been taken, in collaboration with colleagues at NICE, to remove this diagram. An updated version of the pathway will be developed at a later stage in the development process.
Royal College of Psychiatrists	11		This is the law, it is not "practice … should be underpinned by …"	Thank you for highlighting this. This section is designed to highlight the current legal obligations on practice around mental capacity and decision making. So here 'practice' refers to how practitioners carry out their duties under the law.
Royal College of Psychiatrists	12	317-318	DoLS legislation is under review and will be radically changed.	Thank you for your comment. Section 3.3 acknowledges the forthcoming changes to DoLs, due to be announced later in 2016
Royal College of Psychiatrists	13	330-332	They have issued an interim statement available on the LC website.	Thank you for your comment and for this information.
Skills for Care Ltd	7	181	The draft scope states that one of the main outcomes that will be considered when searching for and assessing the evidence is people being enabled to make decisions about their own lives and in their best interests. It should be explicit that the ability to make these decisions often changes, sometimes from day to day, for a variety of reasons.	Thank you for your comment. The fluctuating nature of capacity is a key element of the guideline and the scoping group have reworded some sections in the introduction, key areas and focus sections to make this clearer.
Skills for Care Ltd	7	190	Should take into account the 2016 (and ongoing) Care Act amendments.	Thank you for your comment. The Care Act is now listed in the key legislation section.
Skills for Care Ltd	13	325	Social Care providers and their staff (including Personal Assistants) sometimes struggle to interpret formal guidance. They will often understand how to implement best practice when they have an opportunity to discuss it with other practitioners /	Thank you for your comment. Implementation issues will be identified throughout the guideline development

Stakeholder	Page no.	Line no.	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			experts face to face. Having the opportunity to put it into context with their own 'local' case studies is very effective.	work. The Guideline Committee (GC) will be given the opportunity to identify key implementation issues early on in the process and later the GC will decide on three priority areas of the implementation chapter in the final guideline.
Stroke Association	General	General	The issue of capacity is extremely important in the context of stroke, both in the acute stage and throughout the rehabilitation pathway. At the acute stage, the impact of a stroke on the brain can impair the capacity of a person to make decisions regarding their treatment; for example, a stroke may have such an impact on an individual's capacity that they are deemed unable to make a decision on whether they should receive thrombolysis. The issue of capacity remains important right throughout the care pathway. Stroke can impact on a person's ability to choose, for example, whether or not they have a feeding tube, where they are discharged to, and what rehabilitation support they receive. It is extremely important that health professionals are able to identify and manage capacity issues as appropriate, and know when to take control and make a decision that is deemed to be in the patient's best interests. Because stroke can so often have a profound effect on ability to communicate, it can reduce capacity not only to make decisions, but also to convey them. 33% of stroke survivors are affected by communication problems, including receptive aphasia (difficulty understanding what is being said), expressive aphasia (difficulties expressing oneself), or a mix of the two.[1] Our recent survey of stroke survivors found that 27% of them have either severe or moderate communication difficulties (aphasia), and this percentage is sure to be higher for individuals in the immediate aftermath of their stroke, as aphasia tends to be worst in the first days and weeks following a stroke. [2] Stroke can also affect short-term memory which can make communication slower and more difficult. It is very important that professionals recognise the different between a stroke survivor who lacks the capacity to make a decision, and one who has capacity but is unable to articular that decision.	Thank you for your comment and support for this guideline. Special consideration of issues for stroke survivors and those with communication difficulties were discussed by the scoping group and it was agreed that this issue will receive attention in the equalities impact assessment (EIA) that accompanies the guideline.

---

[1] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

[2] *A New Era for Stroke,* conducted by The Stroke Association in March 2016. 1,174 stroke survivors in England, Scotland, Wales and Northern Ireland responded to the survey.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			Appropriate safeguards need to be in place to ensure that those who do have capacity, but are experiencing communication difficulties, are able to express themselves as effectively as possible. Under the Mental Capacity Act, a person must be given all practicable help before they are treated as if they cannot make their own decisions. Speech and language therapy is can be a vital lifeline for stroke survivors to recover their communication skills, but we are aware that access to speech and language therapy is hugely variable across the country. According to the most recent Sentinel Stroke National Audit Programme (SSNAP) statistics, stroke units are only providing 44.7% of the minutes of speech and language therapy that they should be (in accordance with NICE guidelines).[3]	
Stroke Association	1	19	We are pleased to see that this draft scope includes a focus on carers. Over a third of stroke survivors in the UK are dependent on others, and 1 in 5 are cared for by family or friends.[4] Carers need to understand the principles of the Mental Capacity Act in order to effectively support the one they care for in the instance that that person has a lack of capacity due to their stroke, as, under the Mental Capacity Act, there is an obligation for health professionals to consult people who are involved in caring for anyone who lacks capacity. Carers, family and friends should also be involved in any assessments of mental capacity which take place. It is particularly important to consult with family and friends when assessing capacity of a stroke survivor due to the communication difficulties that can arise as a result of stroke. We've heard from carers about the frustration they feel about the different ways health professionals communicate with stroke survivors who may lack capacity: "*While his speech is now reasonable he can't take things in quickly. We find NHS staff ignore me as a carer and speak to my husband as though he can understand and make decisions immediately. Consequently we don't get the correct information after hospital appointments*" "*We continually struggle to get medical professionals to recognise that he is not stupid when he gets treatment. He is ignored when he tries to communicate*".[5]	Thank you for your comment and support for the guideline. The special requirements of stroke survivors will be discussed in the equality impact assessment (EIA) that accompanies this guideline. We have highlighted the importance of involving carers, with the person's consent, in the scope. We will be looking for evidence about the views and experiences of carers as well as of people who use services as part of our review work. The examples you have quoted help to illustrate why this is important.

---

[3] Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx

[4] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

[5] Stroke Association, 'Feeling Overwhelmed', Summer 2013, https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web.pdf

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			Carers often report that they know stroke survivors want to express their feelings, but are simply unable to. Because of this, carers, family and friends play a key role in helping to understand what stroke survivors may be feeling and thinking, and their role in conveying this should not be underestimated.	
Stroke Association	1	22	We are pleased to see that this guidance will apply to social care practitioners. We often hear from stroke survivors that they feel social care staff do not understand the impact of stroke. If social care staff do not understand that communication difficulties can arise as a result of stroke, they may assume that someone who is unable to communicate lacks mental capacity. A consideration of social care staff in this guidance may help social care staff to understand how to engage with stroke survivors who have communication difficulties, and therefore reduced capacity to effectively communicate their decisions. This will help to safeguard against any assumptions about lack of mental capacity when, in fact, a stroke survivor may just need support to express their wants and needs when it comes to care.	Thank you for your comment and support for this guideline. One of the primary audiences for this guideline are staff working in health and social care, whether they are arranging or providing care and support for people who may lack mental capacity, and to help them identify and react to issues of capacity versus communication.
Stroke Association	2/3	42 – 58	This scope currently does not examine inequalities relating to their socio-economic deprivation, or ethnicity. Black people are twice as likely to have a stroke as white people, and Black and South Asian people have strokes at a younger age than white people. People from the most economically deprived areas of the UK are around twice more likely to have a stroke than those from the least deprived areas.[6] Because of the increased likelihood of stroke amongst these demographics, we would like to see an increased emphasis on them in the draft scope. In particular, there needs to be a consideration of culturally-specific issues for Black or South Asian people who may lack mental capacity, and for their carers. Decisions taken by an individual in the context of their cultural framework may seem illogical or irrational to someone with a different cultural background, and safeguards must be in place to prevent certain decisions or desires being misinterpreted as a lack of mental capacity. We would also welcome more of a consideration of equalities issues associated with age. Age is the single most important risk factor for stroke - the risk of having a stroke doubles every decade after the age of 55.[7] Communication difficulties may be	Thank you for your comment. The scoping group discussed your suggested additions to the equalities section and it was decided that additions will be made to the Equalities Impact Assessment (EIA). The EIA already contains reference to older people, but new additions have been made around socio economic groups, cultural considerations and multi-morbidities.

---

[6] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

[7] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			exacerbated by age (for example, profound deafness or blindness may be present in older individuals) and this may have an impact on an older stroke survivor's capacity to communicate. The existence of multi-morbidities may also impact on a stroke patient's capacity, and the guidance should involve some consideration of how a lack of capacity due to multi-morbidities can be managed. For example, more than a quarter of people who have a stroke develop vascular dementia within three months, and this may further impair their ability to communicate.[8] We are pleased to see that the scope will cover people who do not have support from family members. According to latest Sentinel Stroke National Audit Programme data, 26% of patients who are discharged home following a stroke are living alone.[9] These people are particularly vulnerable, and it is important that they are supported in the event that they may lack mental capacity in the absence of family or friends to assist them.	
Stroke Association	3	65	We would welcome the inclusion of lack of mental capacity due to Transient Ischaemic Attack (TIA). TIA can cause confusion and sudden memory loss, which may have an impact on mental capacity in some patients.[10]	Thank you for your comment and for the information about this condition. Unfortunately we cannot include an exhaustive list of conditions in the scoping document, due to a risk of omissions. The 'who is the focus' section borrows wording from the Mental Capacity Act Code of Practice which refers to physical or medical conditions that cause confusion, drowsiness or loss of consciousness'
Stroke Association	4	86	We are pleased to see that this guideline will apply to acute healthcare settings. Stroke is a sudden onset condition and, due to its effects on the brain, it can be very difficult for medical professionals to judge the capacity of those who have suffered a stroke. Methods need to be developed for estimating the capacity of patients with	Thank you for your comment and for the information specific to stroke survivors. Other NICE guidelines and information in the pathway may have relevant

---

[8] Stroke Association, 'Dementia after Stroke' April 2012, http://www.stroke.org.uk/sites/default/files/Dementia%20after%20stroke_0.pdf

[9] Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx

[10] Stroke Association, 'Transient Ischaemic Attack', April 2014, https://www.stroke.org.uk/sites/default/files/transient_ischaemic_attack.pdf

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			acute stroke, and there should be the development of a procedure for capacity assessment which is specific for stroke.[11] One particular issue we would like to highlight is the patient need to consent to thrombolysis following a stroke.[12] Both assessing and achieving capacity to consent for treatments when a patient is suffering from acute stroke can be extremely difficult. In this context, the chance of a patient understanding a complex medical issue is very low, and assessing capacity is extremely complicated for the doctor involved. In order to make a decision on thrombolysis, a patient would need the capacity to understand the nature and seriousness of stroke, the risks and benefits of treatment and how the benefit of thrombolysis falls rapidly with time. It is imperative that, where thrombolysis is an appropriate treatment, it is administered as quickly as possible to achieve optimal outcomes. 1.9 million neurons are lost with every minute that a stroke goes untreated. For every 1,000 patients treated with thrombolysis within three hours, about 100 more will be alive and live independently than 1,000 patients not treated with thrombolysis.[13] There is a clear need to make a quick decision on this course of action where the patient is eligible. Under the terms of the Mental Capacity Act, in order to have capacity to make a decision, a person needs to understand information given to them, retain that information long enough to make a decision, weigh up the information available, and communicate the decision. It seems quite unlikely that, during or in the immediate aftermath of stroke, a patient would fully understand the risks and benefits associated with thrombolysis, and have the capacity to make an informed decision. The same issues also apply to thrombectomy (mechanical clot retrieval). Healthcare professionals need to be fully aware of this in order to manage this difficult situation where it arises, and make the right decision regarding someone's mental capacity (or lack of it). This is particularly important in order to ensure treatment, where appropriate, is delivered as quickly as possible where a patient	information to stroke survivors.

---

[11] White-Bateman SR, Schumacher HC, Sacco RL, Appelbaum PS, 'Consent for intravenous thrombolysis in acute stroke: review and future directions', *Arch Neurol.*, June 2007, Vol 64, No 6: 785-92

[12] Jonathan Akinsanya, Paul Diggory, Elizabeth Heitz and Valerie Jones, 'Assessing capacity and obtaining consent for thrombolysis for acute stroke', *Clinical Medicine*, 2009, Vol 9, No 3: 239–41

[13] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			lacks capacity to make a decision, but the treatment it is in their best interest.	
Stroke Association	4	88	Particular importance needs to be attributed to making sure that the needs of stroke survivors are being met in a palliative care setting where they are unable to communicate their decision. Palliative care is an extremely important issue for stroke patients. Stroke is the fourth single leading cause of mortality in the UK, causing 7% of all deaths and take a life every 13 minutes.[14] According to the most recent SSNAP statistics about 5% of patients who have a stroke experience a stroke of such severity that a decision is made to palliate within 72 hours.[15] 30% of those who have a stroke die within 28 days, but little is known about the palliative needs of stroke patients.[16] Recent SSNAP data suggests that palliative care needs to improve for stroke patients, as the evidence suggests that a majority of patients prefer to die at home, but in reality, this only happens in a minority of cases.[17] Safeguards need to be put in place to ensure that the wishes of stroke survivors are being taken into account, and that they are allowed to die at home where this is something they would have wanted.	Thank you for your comment and for the information specific to stroke survivors. All recommendations related to stroke in other guidelines can be accessed via the pathways page. Found here.
Stroke Association	4	99	We are pleased to see that the scope contains some consideration of decisions around "where they live" but would welcome a more in-depth consideration of issues surrounding discharge for those that lack mental capacity. Research has shown that multi-disciplinary teams are often unsure about the capacity of people to make decisions about their discharge destination following a stroke.[18] Cognitive test scores, age and dysphasia are not good predictors of capacity to decide about discharge destination in stroke patients receiving rehabilitation. Staff need clear guidance on how to handle uncertainty around mental capacity in stroke patients when it comes to making a decision about discharge.	Thank you for highlighting this. The scope is designed to introduce the parameters of the project. The review process will search for and hopefully generate evidence on particular issues associated with the broader topic area. You may also find it helpful to know that the NICE guideline on Transition between general hospital settings and community or care home settings does address

---

[14] Stroke Association, 'State of the Nation', January 2016, https://www.stroke.org.uk/resources/state-nation-stroke-statistics

[15] Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx

[16] Christopher R. Burton, Sheila Payne, Julia Addington-Hall and Amanda Jones, 'The palliative care needs of acute stroke patients: a prospective study of hospital admissions**'**, *Age and Ageing*, 2010, Vol 39, No 5, 554-559.

[17] 5 Royal College of Physicians, 'SSNAP Clinical Audit October-December 2015 Public Report', March 2016, https://www.strokeaudit.org/Documents/Results/National/OctDec2015/OctDec2015-PublicReport.aspx

[18] Mackenzie J, Lincoln N, Newby G, 'Capacity to make a decision about discharge destination after stroke: a pilot study', *Clinical Rehabilitation*, December 2008, Vol 22, No 12:1116-26

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				discharge from hospital of people who have had a stroke and makes reference to the MCA..
Stroke Association	4	112	Information provision for those who have communication difficulties (aphasia) needs to be carefully tailored to those with the difficulty. The Stroke Association publishes guidance on 'aphasia-friendly' communications[19] – any information for stroke survivors following a stroke should be clear to follow these guidelines. Our guidance advises using a short message, clear sentences, easy words, a good layout, and making a set of messages.	Thank you for your comment and this information related to stroke survivors. The guideline will consider good quality evidence about interventions, tools and approaches to maximise involvement.
Stroke Association	6	153	Tools such as communication aids can be extremely important for facilitating stroke survivors to communicate decisions. For example, we suggest using tools such as a small card explaining that a communication difficulty is present and word and picture charts to help stroke survivors communicate. These tools are cost-effective ways of helping stroke survivors to get their message across when suffering from aphasia.[20]	Thank you for your comment and this information related to stroke survivors. The review questions include information related to tools and interventions aimed at assisting decision making for those who may lack mental capacity. The EIA documents also makes specific mention of those with communication difficulties.
The Royal College of Midwives	General	general	The RCM agrees with the draft guideline scope on Supporting decision making for people who may lack capacity, and has no further comment at this stage .	Thank you for your comment and your support for this guideline
VoiceAbility Advocacy	1	25	Include Care Act advocates within the list	Thank you for your comment. Advocates are included in the list of primary audiences for this guideline. The specific inclusion of independent mental capacity advocates and independent mental health advocates is illustrative. Independent advocates commissioned by local authorities under the Care Act are also included within the scope of this guideline.
VoiceAbility Advocacy	1	18	Include paid carers as an identifiable group in their own right under who the guideline is for	Thank you for your comment. Paid carers are included under the umbrella for social care practitioners.

---

[19] Stroke Association, July 2012, 'Accessible Information Guidelines', https://www.stroke.org.uk/sites/default/files/Accessible%20Information%20Guidelines.pdf(1).pdf

[20] Stroke Association, 'Communication Aids' accessed 11 June 2016, https://www.stroke.org.uk/professionals/resources-professionals/communication-aids

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
VoiceAbility Advocacy	2	52	Include people who don't speak English at all	Thank you for your comment. People who do not speak English are given consideration in the Equality Impact Assessment (EIA) that accompanies this guideline.
VoiceAbility Advocacy	3	65-72	It should be made clear that this is not an exhaustive list of impairments that may contribute to a lack of mental capacity or fluctuation of mental capacity	Thank you for your comment. The scoping group discussed this issue and it was felt that that the current wording conveys that this list is not exhaustive. The 'who is the focus' section borrows wording from the Mental Capacity Act Code of Practice.
VoiceAbility Advocacy	3	79	As the list is not exhaustive, insert the word 'including' followed by the list ie any settings where health and social care practitioners support decision making by people who may lack mental capacity, including:	Thank you for your comment. The scoping group discussed this issue and it was felt that that the current wording conveys that this list is not exhaustive.
VoiceAbility Advocacy	4	101	Day to day decisions about daily living - would this include leisure /recreation? Should this be made more explicit/a separate heading?	Thank you for highlighting this. Decisions about daily living may include leisure and recreation, but the focus of the guideline will be on decisions related to health and social care.
VoiceAbility Advocacy	5	116 & 117	Include when assessment MUST be considered as well as those that should	Thank you for your comment. We realise that assessment of capacity is an important key area with many aspects to it. In key area 4 we have added some further points about approaches to assessment, including this, that we will search for evidence on but this is illustrative only.
VoiceAbility Advocacy	5	115-118	Include what to do if a person refuses to be part of a capacity assessment	Thank you for your comment. We recognise that there are many aspects of this guideline that will touch upon areas covered by the Mental Capacity Act Code of Practice, of which this is one. Key area 5 illustrates some of the aspects of assessment likely to be covered by the guideline, including the possibility that assessment may be refused, but is not an exhaustive list.

Stakeholder	Page no.	Line no.	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
VoiceAbility Advocacy	5	131	Some reference here to the Care Act and advocacy under the Care Act to support people with their decisions during a safeguarding enquiry	Thank you for your comment. We do have specific reference to Care Act advocates here. However, taking account of a range of views, the scoping group decided that safeguarding should be reflected as a separate bullet point in each of key areas 4 and 6.
VoiceAbility Advocacy	7	180-187	As a person centred outcome - insert that the wishes, thoughts and feelings of the person are heard and prioritised	Thank you for your comment and this suggestion. The scoping group agreed to add a point under person centred outcomes about the participation of people in decision making.
VoiceAbility Advocacy	7	188-192	As a service outcome - insert that, a person who is entitled to an advocate, gets an independent advocate, enabling the person to receive the support they need to make decisions about their care/support. This outcome should be included because for the MCA, MHA and Care Act evidence shows that many people who are entitled to an independent advocate are not getting one as health & social care professionals are either unware of their statutory responsibility or fail to refer.	Thank you for your comment. The outcomes found in the scope are intended to be a general guide. Prior to the review process, specific outcomes cannot be detailed in this section.
VoiceAbility Advocacy	10	251	Flow chart: The flow chart starts off with the presumption that the person many not have capacity before the information is provided. However it should be that the information is provided to everyone in a way that is appropriate for them. It is then only when the person appears to be struggling that you consider their capacity and what else can be done to support them to understand, retain, weigh up and communicate their decision. It is only if you are not able to overcome this that someone is judged to lack capacity. The flow chart therefore needs to start from a different position.	Thank you for your comment. A decision has been taken, in collaboration with colleagues at NICE, to remove this diagram. An updated version of the pathway will be developed at a later stage in the development process.
VoiceAbility Advocacy	general	general	We appreciate the rational of having the scope of this document for people aged 16 and over (ie that the MCA applies to people aged 16 and over). However we would recommend further consideration being given to including young people who are transitioning to adult services who may well need support earlier than this (ie from age 14 onwards) to help them prepare and make decisions about the next stage in their life. Care Act statutory guidance says: *For young people with special educational needs who have an education, health and care plan under the children and families act,*	Thank you for your comment. Unfortunately the remit for this guidance is on decision making and mental capacity for adults and young people cannot be included in the scope. The focus on adults is also in line with the focus of the Mental Capacity Act. However, NICE guideline on Transition

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			preparation for adulthood must begin from year 9 (ie 14 years). The transition assessment should be undertaken as part of one of the annual statutory reviews of the EHC plan, and should inform a plan for the transition from children's to adult care and support.(Guidance 16.11). A number of these young people may well lack capacity (or have fluctuating capacity) and need support to help them make decisions about where they want to live, personal choices about how they live and who they live with, about their care and support etc.	from children's to adults' services NG 43 Publ. 24 February 2016 does recommend that young person's capacity should be taken into account, following the principles of the Mental Capacity Act and other relevant legislation, as necessary (Recommendation 1.2.20).
VoiceAbility Advocacy	11	273-278	These Statistics from the HSCIC on DoLS seem quite dated. HSCIC annual report figures of 2014-15 give a better indication as to the number of DoLS applications post Cheshire West ruling and the impact this is having on LAs, services and independent advocacy.	Thank you for highlighting this. These statistics have now been updated using the 2014-2015 report.
Westcountry Case Management Ltd	2	50	The scope identifies specific groups who are vulnerable to inequalities. Some are specific ie mental health. We believe that people with acquired brain injury should be specified as a group vulnerable to inequality due to the very specific nature of their difficulties in comparison to other people who may fall into the complex needs and long term condition group. They are vulnerable to inequality particularly if they are assessed by professionals without the specific experience and skills required to understand capacity issues for people with ABI in particular, and the reasons their capacity can be difficult to assess and can fluctuate from formal assessment to real life situations.	Thank you for your comment. A more detailed account of equalities issues can be found in the equalities impact assessment (EIA), which includes details of specifically vulnerable groups including people with acquired brain injuries.
Westcountry Case Management Ltd	4	109	It would be useful to add some guidance relating to supporting decision making indirectly, for example a person with executive difficulties (possibly as a result of an ABI, but also other conditions) can struggle to make decisions because they are overwhelmed with information and a high volume of day to day decisions to make. This can render them apparently unable to make some decisions for themselves. When well supported in terms of managing their cognitive difficulties; reducing overload, support to reduce executive load by introducing structure and routine, their capacity to attend to and process information related to decision making can be enhanced. In essence, someone with sufficient background support can be in a better position to be involved with and make decisions for themselves. Their support requirements in terms of decision making are not simply at the time of making the decision itself.	Thank you for your comment. The final guideline will include recommendations about supporting people, when they have capacity to make decisions. These recommendations may relate to a variety of contexts and to people with various needs. The specific needs of those with cognitive issues are also dealt with in the EIA.
Westcountry Case	5	115	We believe it would be useful to address the issue of discrepancy in capacity when undertaking formal assessments; the person who, in a structured environment ie a	Thank you for your comment. The guideline will present recommendations

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Management Ltd			1:1 appointment with a professional assessing their capacity, can function quite differently than when they are in a busy real life situation, with multiple demands on their cognition, which is when they will need to actually make the decision in question. This may come down to an assessment being undertaken by someone with specific experience of the condition, for example ABI.	on decision making in a variety of contexts and for people with various levels of need. The needs for people with specific conditions are dealt with in the EIA (if their conditions presents an equalities issue). Assessment is one of the key areas that the guideline will focus on.
Westcountry Case Management Ltd	5	130	We believe it would be useful to have some guidelines about DOL in the community in particular, where DOLs do not apply. Particularly following the judgement from the CoP on 24 May 2016 on Staffordshire County Council V SRK.	Thank you for your comment. The guideline on decision making and mental capacity will look at decision making around a variety of topics and for people with various levels of need. DoLs and best interest's decision making are within the scope of the guideline and one of the key areas to focus on (key area 6).

Registered stakeholders