Appendix D Expert testimony papers

Section A: Developer to complete	
Name:	Dr Lucy Series
Role:	Dr Lucy Series, Cardiff University https://www.cardiff.ac.uk/people/view/478911-series-lucy
Institution/Organisation (where applicable):	School of Law and Politics Cardiff University Cardiff Wales CF10 3AT
Contact information:	SeriesL@cardiff.ac.uk
Guideline title:	Decision making and mental capacity
Guideline Committee:	Meeting 8, 16th August 2017
Subject of expert testimony:	Best practice in supported decision-making under the Mental Capacity Act 2005
Evidence gaps or uncertainties:	We have searched for evidence in relation to the effectiveness and cost-effectiveness of interventions, tools, aids and approaches to: - support advance planning for people who may lack mental capacity in the future - support people (on the presumption of capacity) to make decisions - support the assessment of mental capacity - support best interests decision-making for those who have been assessed as lacking capacity. The Guideline Committee (GC) have identified gaps in the literature in this regard, particularly in terms of good practice implementation of legal duties, and views and experiences of people using services and those who support them (family, carers, practitioners and others). More detail is provided below. We would therefore like you to speak on the basis of your expertise and understanding of best practice in the assessment of mental capacity. The GC is interested in learning about best practice in implementation of the

MCA and in respect of best interest decision-making for people who have been assessed as lacking capacity.

The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 or over.[1] The guideline aims to help health and social care practitioners to:

- Support people to make their own decisions as far as possible
- Assess people's capacity to make specific health and social care decisions
- Make specific best interest decisions when people lack capacity, and maximise the person's involvement in those decisions.

This guideline seeks to build on, rather than replicate what is already in legislation and guidance. We are therefore particularly interested in effective practice in implementing existing legislative duties.

Where the research evidence is lacking, or inconclusive, Guideline Committee members can invite expert witnesses to the group to provide expert testimony, and recommendations can be drawn from this expert witness testimony and Guideline Committee consensus.

As priority, for this Guideline Committee meeting, the Committee would like to ask you the following questions about best interest decision-making.[2]

4.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting best interests decision-making?

4.2 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support best interests decision-making?

For your information, the other review questions being addressed by the Committee are listed below.

1.1. What interventions, tools, aids and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity in the future?

1.2. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people planning in advance for decision-making?

[1] The definition of adults includes young people aged 16 or 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

[2] Please note the numbering reflects our review protocol

2.1. What interventions, tools, aids and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2.2. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people, on the presumption of capacity, to make decisions?

3.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting the assessment of mental capacity?

3.2 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support the assessment of mental capacity?

The GC noted in particular the lack of evidence from the research on the effectiveness and cost-effectiveness of the following on people who may lack capacity and those who support them:

- Advocacy
- Training of professionals
- Specific technologies

They also need to ensure that the guideline reflects the current legal and practice context, and would welcome expert witness advice on this. Specifically, they have noted a particular gap in terms of effective implementation of the MCA and the practice of making best practice decisions.

For all questions, the GC are interested in impact on:

- *Person-focused outcomes* e.g. choice, control, dignity, respect, ability to express preference etc.
- *Service-focused outcomes* e.g. practitioner competence and confidence in respect of Mental Capacity Act principles, service efficiency and effectiveness etc.

The potential benefits and harms of interventions should be considered and safety prioritised as an outcome. Services should protect people from abuse and avoidable harm, whilst recognising the right of individuals to take risks and make unwise decisions.

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Expert testimony by Lucy Series

Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires states to ensure disabled people can exercise legal capacity on an equal basis with others, have access to supports for exercising legal capacity, and safeguards to ensure supports are free from exploitation and abuse, and respect the 'rights, will and preferences of the person'.

The CRPD Committee (2014) has called for regimes of 'supported decision making' to replace 'substitute decision making'. Their terminology is confusing: on the Committee's view, supported decision making encompasses a wide range of measures to enable an individual to exercise legal capacity in accordance with their 'will and preferences'. It would even encompass decisions made by third parties, based on a 'best interpretation' of the person's will and preferences if they were unable to communicate their decision. Substitute decisions, are decisions that are not based on the person's 'will and preferences' but instead on their 'objective best interests'. The Committee states these are prohibited by the CRPD. Although the Committee's view is not binding, it is authoritative.

The Mental Capacity Act 2005 (MCA) is increasingly considered incompatible with the CRPD (e.g. Martin et al, 2016). The Law Commission (2017) has proposed amendments placing a greater emphasis on the 'wishes, feelings, values and beliefs' of the person when making best interests decisions, and a power allowing the government to introduce regulations for formal recognition of an individual's chosen supporters. Many jurisdictions around the world have adopted, or are considering, similar changes prompted by the CRPD (Dinerstein, 2016; Series, 2018).

There are important differences in the CRPD approach to support and the MCA's requirement that a person is not to be considered unable to make a decision until all practicable steps have been taken to help them make it for themselves. Under the MCA, the goal of support is simply to help a person perform better in a functional test of mental capacity. Under the CRPD, it is to ensure the exercise of legal capacity by, or on behalf of, that person is in accordance with their 'will and preferences'. Under the MCA, the duty to provide support is fragmented across whoever is assessing mental capacity, and the individual has no entitlement to specify who they want to support them, or how. Under the CRPD, states should facilitate and recognise long-term relationships of support based on trust and the person's own will and preferences. Many states have frameworks allowing a person to nominate a chosen support person, often a friend or family member, whose role is to help them obtain and understand information, make and communicate decisions, and see that they are enforced (Dinserstein, 2016; Series, 2015).

There are some promising signs that supported decision making can enhance decision making ability, confidence, wellbeing, and offer a potential alternative to substitute decision making, but we still know very little about who uses support, and the process of supporting decisions. There appear to be cultural differences in how

far people want supported decision making. There are some concerns about possible risks of undue influence or abuse of support (Pathare and Shields, 2012; Kohn and Blumenthal, 2013; Davidson et al, 2016). Domestic research involving younger people emphasised the importance of opportunities to make decisions (Shaw et al, 2012). Cultures of risk aversion and blame are considered detrimental to good supported decision making, whilst building trust – including through narrative approaches – is conducive to good decision making (Broome et al, 2012). Longitudinal research is taking place in the USA to develop the evidence base for supported decision-making (Dinerstein, 2016).

A pilot project from South Australia, which asked people with brain injuries or learning disabilities to choose supporters and draw up written agreements specifying how they wanted to be supported, is a useful example of the kind of framework that could be developed in England (Wallace, 2012). The Swedish 'personal ombuds' service, set up by mental health service users to provide a professional support service for people who are reluctant to engage with traditional health and welfare services, has also proved successful and is of growing interest (Engman et al, 2008). This project also appeared to deliver savings through reduced reliance on crisis services.

The MCA will never be completely compatible with the CRPD, but professionals practising under the MCA can take the following steps to enhance CRPD compliance:

1. Supports include 'accessibility' measures: how accessible is the information provided by your organisation, and any forms of communication you use, for the service users you work with? Do you need to invest in further training in communication, or commission accessible materials to support people's decision making in your field?
2. If a person's decision making is impeded by communication problems, psychological problems or wider issues, such as interpersonal relationships, could you offer a referral to other services to help the person (e.g. speech and language therapy, psychotherapy, CBT or family therapy?)
3. Building and recognising relationships of trust will facilitate supported decision making. This may take time, and relies strongly on continuity of care and good working relationships between practitioners and the friends and family of the person.
4. Good support is based on what the person wants. Start by simply asking the person who they want to help them and how they want to be helped to make decisions.
5. Understanding and communication is a two-way street. Are the skills of the assessor sufficient to help the individual make decisions?
6. Is there a sufficient relationship of trusts between the capacity assessor and the individual to help them express choices and explain their decisions?
7. If a 'best interests' decision is unavoidable, how far can you go to ensuring it meets with the person's wishes, feelings, values and beliefs? If these are unclear, what evidence can you gather to arrive at a 'best interpretation' of what they would have wanted?
8. Support includes advance planning. How can you help the person to express their wishes, feelings, values and beliefs in a way that can form the basis of decision making in the future? Can you help them make an advance decision refusing treatment, an advance statement or support making an LPA?

References to other work or publications to support your testimony' (if applicable):

Broome, S, et al. 'Improving decision-making in the care and support of older people' (Joseph Rowntree Foundation 2012)

CRPD Committee, 'General comment No 1 (2014) Article 12: Equal recognition before the law' UN Doc CRPD/C/GC/1 (19 May 2014).

Davidson, G. et al, 'An international comparison of legal frameworks for supported and substitute decision-making in mental health services' (2016) 44 (January–February) *International Journal of Law and Psychiatry* 30 – 40

Dinerstein, R. 'Emerging international trends for practices in guardianship laws for people with disabilities' (2016) 22(2) *ILSA Journal of International and Comparative Law* 435-460.

Engman, T., et al. *A New Profession is Born – Personligt ombud, PO* (Socialstyrelsen, Fhebe Hjälm, 2008)

Kohn, N. A. and Blumenthal, J. A. 'A critical assessment of supported decision-making for persons aging with intellectual disabilities' (2013) 7 *Disability & Health Journal* S40–S43.

Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 372 2017)

Martin, M., et al. 'The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK' (University of Essex 2016)

Pathare, S. and Shields, L. 'Supported Decision-Making for Persons with Mental Illness: A Review', (2001) 34(2) *Public Health Reviews* 1-40.

Series, L. 'Relationships, autonomy and legal capacity: Mental capacity and support paradigms' (2015) 40 *International Journal of Law and Psychiatry* 80-91.

Series, L. 'Article 12: Equal Recognition Before the Law' *Commentary on UN Convention on the Rights of Persons with Disablities,* Bantekas, Stein and Anastasiou (Eds) (Oxford University Press, forthcoming 2018)

Shaw, C., et al. 'The VIPER project: what we found' (2012).

Wallace, M. 'Evaluation of the Supported Decision Making Project' (Office of the Public Advocate, South Australia 2012)

Section A: Developer to complete	
Name:	**Dr. Howard Jackson** B.Sc., M.Clin.Psychol., Ph.D, C.Psychol., C.Psychol., A.F.B.P.S.
Role:	Clinical Director (T.R.U.) Chartered Clinical Psychologist (No 33419) Consultant Clinical Neuropsychologist Honorary Lecturer (Doctor of Clinical Psychology Course), University of Liverpool External Examiner University of Swansea
Institution/Organisation (where applicable): **Contact information:**	Transitional Rehabilitation Unit Margaret House 342 Haydock Lane St. Helens Merseyside WA11 9UY
Guideline title:	Decision making and mental capacity
Guideline Committee:	Meeting 8, Wed 16th August 2017
Subject of expert testimony:	Supported decision making, including any specific data on supported decision making in respect of people with acquired brain injury
Evidence gaps or uncertainties:	We have searched for evidence in relation to the effectiveness and cost-effectiveness of interventions, tools, aids and approaches to: - support advance planning for people who may lack mental capacity in the future - support people (on the presumption of capacity) to make decisions - support the assessment of mental capacity - support best interests decision-making for those who have been assessed as lacking capacity. The GC have identified gaps in the literature in this regard, particularly in terms of good practice implementation of legal duties, and views and experiences of people using services and those who support them (family, carers, practitioners and others). More detail is provided below. We would therefore like you to speak on the basis of your expertise of supported decision making, including supported decision making in respect of people with acquired brain injury.

The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 or over.[3] The guideline aims to help health and social care practitioners to:

- Support people to make their own decisions as far as possible
- Assess people's capacity to make specific health and social care decisions
- Make specific best interest decisions when people lack capacity, and maximise the person's involvement in those decisions.

This guideline seeks to build on, rather than replicate what is already in legislation and guidance. We are therefore particularly interested in effective practice in implementing existing legislative duties.

Where the research evidence is lacking, or inconclusive, Guideline Committee members can invite expert witnesses to the group to provide expert testimony, and recommendations can be drawn from this expert witness testimony and Guideline Committee consensus.

As priority, for this Guideline Committee meeting, the Committee would like to ask you to address the following questions about supporting decision-making.[4]

2.3. What interventions, tools, aids and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2.4. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people, on the presumption of capacity, to make decisions?

For your information, the other review questions being considered by the Committee are also listed below.

1.3. What interventions, tools, aids and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity in the future?

1.4. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people planning in advance for decision-making?

3.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting the assessment of mental capacity?

3.3 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support

[3] The definition of adults includes young people aged 16 or 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

[4] Please note the numbering reflects our review protocol

the assessment of mental capacity?

4.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting best interests decision-making?

4.2 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support best interests decision-making?

The GC noted in particular the lack of evidence from the research on the effectiveness and cost-effectiveness of the following on people who may lack capacity and those who support them:

- Advocacy
- Training of professionals
- Specific technologies

They also need to ensure that the guideline reflects the current legal and practice context, and would welcome expert witness advice on this. Specifically, they have noted a particular gap in terms of effective implementation of the MCA and the practice of making best practice decisions.

For all questions, the GC are interested in impact on:

- *Person-focused outcomes* e.g. choice, control, dignity, respect, ability to express preference etc.
- *Service-focused outcomes* e.g. practitioner competence and confidence in respect of Mental Capacity Act principles, service efficiency and effectiveness etc.

The potential benefits and harms of interventions should be considered and safety prioritised as an outcome. Services should protect people from abuse and avoidable harm, whilst recognising the right of individuals to take risks and make unwise decisions.

Section B: Expert to complete

Summary testimony: [Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Expert testimony by Dr Howard F Jackson

Some Unique Issues in Decision Making in cases of Acquired Brain Injury

It is argued that the nature of the neuropsychological consequences of acquired brain injury present unique challenges for the assessment of Mental Capacity and endeavours to raise such capacity.

1. Certain abilities are resilient to traumatic brain injury

Premorbid knowledge, concepts and skills

Language

Reading

Memory/attention span

Production of social skills

Procedural learning

As a result, assessment by interview may be misleading in that the brain injured individual may appear mentally competent.

2. Others are very vulnerable

Speed and depth of information processing

Memory for new information

Executive functions (cognitive)

Logico-deduction

Planning and organising

Control of attention so as to be able to compare and contrast,

Abstract thinking

To estimate (eg. consider probable/possible consequences/risks)

Executive functions (behavioural)

Over-responsiveness to immediate circumstances/cues

Suggestibility

Impulsivity

Amotivation

<u>Executive Functioning in ABI Affecting Mental Capacity</u>

It is now generally accepted in neuropsychology that there is a marked difference between what is said and what is done by individuals with impaired executive functioning. Barkley (2012)[5] makes the distinction between Executive Cognition (EC) and Executive Action (EA) and points out that "*Conveying more knowledge does not prove as helpful as altering the parameters associated with performing that behavior at its appropriate point of performance. Coupled with this is the realization that such changes in behavior are likely to be maintained only as long as those environmental adjustments or accommodations are as well. To expect otherwise would seem to approach the treatment of EF deficits with outdated or misguided assumptions about the essential nature of EF and its impairments.*" (pp.200-201).

[5] Barkley R A (2012) Executive Functions. Guilford Press, London.

The orthogonality of the cognitive and behavioural elements of executive functioning is also reflected in assessment of executive functioning. For example, the Behavioral Rating Inventory of Executive Functioning (BRIEF) [6] divides executive functioning into Metacognition and Behavioural Self-Regulation. Currently the assessment of mental capacity and indeed the definitions explicit in the Mental Capacity Act are almost exclusively related to executive cognition (EC) with a neglect of executive action (EA). Furthermore, standardised neuropsychometric assessments have been severely criticised as being insensitive in the literature including that from myself and colleagues[7], since there is apparently little correlation between performance on these executive tests and everyday executive performance.

Decision Specific Capacity -

There is often a lack of clarity with regard to the actual decision to be considered when assessing mental capacity. The usual ones are:-

1. The ability to manage finances

The problem often is the definition is ambiguous. For example does this mean mental capacity for managing a simple weekly, monthly or yearly budget? Or making investments, expensive purchases, drugs, alcohol? Or agreeing to enter into financially binding contracts (eg. loans, hire purchase, etc).

2. To instruct a solicitor

This involves by definition the mental capacity to follow the proceedings of the court as well as instruct the solicitor. The factors involved are complex but include, memory, attention, executive problems, which are tempered by the expert legal support and also often by ABI clinicians involved in the litigation process. Again the main issues involved in terms of the standards of 'comprehending' and 'weighing' up involve executive functions; abstract thinking, ability to estimate, insight and awareness, and consequential/sequential thinking. Memory is also a potential problem but this is relatively easily managed in mild/moderate cases albeit less so in more severe cases.

Static vs Fluid Decisions

The Mental Capacity Act is clear in that evaluation of mental capacity should be decision-specific. I contend that whilst each decision has its own unique issues relating to mental capacity, the neuropsychological processes involved in *static* decisions are fundamentally different from those involved in *fluid* decisions. *Static* decisions are those which involve a single point of decision making, where the decision is a 'one-off', usually where there is little or no time pressure, are more easily managed and structured, and are accessible to external support for the cognitive processes involved in decision making. Examples of more *static* decisions would be testamentary capacity, making a specific gift, buying a house, etc. These decisions can often be made at a leisurely pace, allowing supporters to help simplify

[6] Gioia, G. A., Isquith, P.K., Guy, S.C., and Kenworthy, L. (2000). BRIEF: Behavioral Rating Inventory of Executive Function - professional manual. Odessa, FL: Psychological Assessment Resources.

[7] Manchester, D. Priestly, N and JACKSON, H.F. (2004) The assessment of executive functioning: coming out of the office. Brain Injury, 18, 1067-1081.

(literalise), make clear pertinent from irrelevant issues, help define the desired goal or outcome, and establish a structured process for decision making. Such *static* decisions are made at the end of this process and do not require repeated decision making.

In contrast, *fluid* decisions are those on-the-hoof decisions that are made frequently, often in un-structured situations, where there is usually a degree of time pressure, where there are many potential distracters, where benevolent guidance and advice is limited or not available, where there is less reflective cognitive processing and where the decision may be more automatic. Examples of such *fluid* decisions would be whether to buy from a door-to-door salesman, whether to initiate or continue drinking alcohol, whether to pay for an item from a shop, etc. Such decisions are more vulnerable to the immediate influences of the environment, especially in those cases where executive functions are impaired or poor.

In cases of acquired brain injury, whilst *static* and *fluid* decisions may both be affected, especially in cases where the frontal lobes have been damaged, *fluid* decisions are clearly more vulnerable and require a different rehabilitative model involving procedural learning, neurobehavioural interventions and integrated use of decision making aids and strategies.

Supporting decision making in People with Acquired Brain Injury

Protective Mechanisms : - Personal

Insight, help-seeking, self-monitoring, risk awareness, self-structuring, training in structured problem solving, antecedent planning, goal/decision maintenance.

Protective Mechanisms :- Environmental

Structure, personal relationships, trained support/rehabilitation staff

Barkley (2012) emphasises the importance of providing help and support at the 'point of need' in individuals with impaired executive functioning as opposed to remote advice or information. Therefore it is important for clinical interventions to radically change from classroom or periodic therapy sessions to more integrated and systemic approaches 'at the point of performance'. Such approaches therefore require specialised education and training for front-line staff and supporters[8]. For the past 25 years myself and my colleagues at TRU have been developing methods for helping our brain injured clients make decisions, choices and maintaining these choices in everyday life. We have pointed to the importance of structure in reducing the handicaps caused by such executive disabilities but more importantly the procedures and interventions that permit our clients to self-structure[9]. I have appended a copy of our recent paper addressing these issues.

[8] JACKSON H F and Manchester D Towards the Development of Brain Injury Specialists, Neurorehabilitation, 2001,16, 27-40.

[9] JACKSON, H.F., Hague, G., Daniels, L., Aguilar, R., Carr, D. & Kenyon, W. Structure to Self-Structuring: Infrastructures and Processes in Neurobehavioural Rehabilitation. **Neurorehabilitation,** 2014, 34, 681–694.

Section A: Developer to complete	
Name:	Isaac Samuels
Role:	Peer advocate
Institution/Organisation (where applicable): **Contact information:**	Newham People First 27 Romford Rd, London E15 4LJ 020 8519 9001
Guideline title:	Decision making and mental capacity
Guideline Committee:	Meeting 8, 16th August 2017
Subject of expert testimony:	Best practice in the assessment of mental capacity, with a particular focus on the views and experiences of people who use services in this regard
Evidence gaps or uncertainties:	We have searched for evidence in relation to the effectiveness and cost-effectiveness of interventions, tools, aids and approaches to: - support advance planning for people who may lack mental capacity in the future - support people (on the presumption of capacity) to make decisions - support the assessment of mental capacity - support best interests decision-making for those who have been assessed as lacking capacity. The Guideline Committee (GC) have identified gaps in the literature in this regard, particularly in terms of good practice implementation of legal duties, and views and experiences of people using services and those who support them (family, carers, practitioners and others). More detail is provided below. We would therefore like you to speak on the basis of your expertise and understanding of best practice in the assessment of mental capacity. The GC is interested in learning about what is effective in terms of coproduction, care planning and assessment, informed by the best available evidence on the views and experiences of people who use services.

The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 or over.[10] The guideline aims to help health and social care practitioners to:

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3.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting the assessment of mental capacity?

3.4 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support the assessment of mental capacity?

For your information, the other review questions being addressed by the Committee are listed below.

1.5. What interventions, tools, aids and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity in the future?

1.6. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people planning in advance for decision-making?

2.5. What interventions, tools, aids and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2.6. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the

[10] The definition of adults includes young people aged 16 or 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

[11] Please note the numbering reflects our review protocol

acceptability of interventions, tools, aids and approaches to support people, on the presumption of capacity, to make decisions?

4.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting best interests decision-making?

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- Advocacy
- Training of professionals
- Specific technologies

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- *Service-focused outcomes* e.g. practitioner competence and confidence in respect of Mental Capacity Act principles, service efficiency and effectiveness etc.

The potential benefits and harms of interventions should be considered and safety prioritised as an outcome. Services should protect people from abuse and avoidable harm, whilst recognising the right of individuals to take risks and make unwise decisions.

Section B: Expert to complete

Summary testimony: [Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Importance of independent support and awareness that independent support is available.

Understanding context of family and culture – not applying western values.

Experience has left many people disengaged from social services.

Knowing the person and their context – understanding how someone communicates.

Importance of having informal or formal support for person during assessment process – examples of family being excluded.

Capacity isn't fixed. How do we support practitioners to conduct capacity assessments?

- Ensure family members are fully involved in process.
- Accessible information available.
- Accessible communication.
- Allocating sufficient time for assessment.
- Supporting person and family to access information at all stages of assessment process.
- Creating right environment – people should be able to choose where assessment takes place. If person not able to communicate choice/preference, getting input from people who know the person.
- Ensuring assessments are done in a proportionate way.
- Deal with other factors that could impact on assessment e.g. deal with acute psychotic episode before conducting assessment.
- Work across organisations to have clear info accessible at all times. Revisit.
- Have clear support plan to be shared with people the individual wants to share it with.

Sharing the personal narrative of people with a lived experience of assessments of mental capacity, highlighting some of the challenges that people face in relation to getting adequate support to manage the assessment process in a way that makes them stronger and is not detrimental to psychological and mental health.

Highlighting the challenges around assessment and the ongoing need for support and understanding for families and people who are assessed that is based on people's contacts and is in an accessible format so people can make informed decisions.

Ensuring coproduction is at the heart of all assessments and where possible ensuring that a wide range of people come together to wrap around the individual that is being assessed in the way that supports the individual to make informed choices and receive the appropriate support.

Planning for the future of future assessments and highlighting any challenges that may need to be considered in the future.

Draw on a multidisciplinary team approach to ensuring that people that have assessments share their stories once and that the assessment process is based on the needs of the individual not the system.

Fair access to all different groups that have access needs in relation to assessment process e.g. LGBT and BME

The utilisation of personal narratives to ensure that people understand that coproduction is at the heart of all the work that we do - Huma and Jay's narrative.

References to other work or publications to support your testimony' (if applicable):
N/A

Section A: Developer to complete	
Name:	**Dr Mark Jayes** PhD Health Services Research: Mental Capacity Assessment (awarded subject to minor amendments) (2017). MSc Clinical Research (2011). MMedSci Clinical Communication Studies (2003). Conversion Diploma in Psychology for Graduates (1999). BA (Hons) French (1993).
Role:	Highly Specialist Speech and Language Therapist. Health Education England / National Institute for Health Research Clinical Doctoral Research Fellow (2014-17). Mental Capacity Lead for NHS Trust Speech and Language Therapy service. Royal College of Speech and Language Therapists (RCSLT) Clinical Adviser: Mental capacity assessment. Lead Author: RCSLT Mental capacity assessment and supported decision-making clinical web pages and position statement project. Member of Department of Health / Ministry of Justice National Mental Capacity Forum.
Institution/Organisation (where applicable): **Contact information:**	Sheffield Teaching Hospitals NHS Foundation Trust / University of Sheffield. Mark Jayes Speech and Language Therapy Vickers Main Hall Northern General Hospital Herries Road Sheffield S5 7AU. 07967 604750 mark.jayes@sheffield.ac.uk

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Guideline title:	Decision making and mental capacity
Guideline Committee:	Meeting 9, 18th September 2017
Subject of expert testimony:	Best practice in supporting assessment
Evidence gaps or uncertainties:	We have searched for evidence in relation to the effectiveness and cost-effectiveness of interventions, tools, aids and approaches to: - support advance planning for people who may lack mental capacity in the future - support people (on the presumption of capacity) to make decisions - support the assessment of mental capacity - support best interests decision-making for those who have been assessed as lacking capacity. The GC have identified gaps in the literature in this regard, particularly in terms of good practice implementation of legal duties, and views and experiences of people using services and those who support them (family, carers, practitioners and others). More detail is provided below. We would therefore like you to speak on the basis of your expertise of supporting assessment, in particular enabling professionals to demonstrate best practice in this regard.
The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 or over.[12] The guideline aims to help health and social care practitioners to: - Support people to make their own decisions as far as possible - Assess people's capacity to make specific health and social care decisions - Make specific best interest decisions when people lack capacity, and maximise the person's involvement in those decisions.	

[12] The definition of adults includes young people aged 16 or 17 years because they are covered by most aspects of the Mental Capacity Act (2005).

This guideline seeks to build on, rather than replicate what is already in legislation and guidance. We are therefore particularly interested in effective practice in implementing existing legislative duties.

Where the research evidence is lacking, or inconclusive, Guideline Committee members can invite expert witnesses to the group to provide expert testimony, and recommendations can be drawn from this expert witness testimony and Guideline Committee consensus.

As priority, for this Guideline Committee meeting, the Committee would like to ask you to address the following questions about supporting assessment.[13]

3.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting the assessment of mental capacity?

3.5 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support the assessment of mental capacity?

For your information, the other review questions being considered by the Committee are also listed below.

1.7. What interventions, tools, aids and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity in the future?

1.8. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people planning in advance for decision-making?

2.7. What interventions, tools, aids and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2.8. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people, on the presumption of capacity, to make decisions?

4.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting best interests decision-making?

4.2 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support best interests decision-making?

[13] Please note the numbering reflects our review protocol

The GC noted in particular the lack of evidence from the research on the effectiveness and cost-effectiveness of the following on people who may lack capacity and those who support them:

- Advocacy
- Training of professionals
- Specific technologies

They also need to ensure that the guideline reflects the current legal and practice context, and would welcome expert witness advice on this. Specifically, they have noted a particular gap in terms of effective implementation of the MCA and the practice of making best practice decisions.

For all questions, the GC are interested in impact on:

- *Person-focused outcomes* e.g. choice, control, dignity, respect, ability to express preference etc.
- *Service-focused outcomes* e.g. practitioner competence and confidence in respect of Mental Capacity Act principles, service efficiency and effectiveness etc.

The potential benefits and harms of interventions should be considered and safety prioritised as an outcome. Services should protect people from abuse and avoidable harm, whilst recognising the right of individuals to take risks and make unwise decisions.

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Expert testimony by Mark Jayes

This testimony is based in part on my own doctoral research, which focused on mental capacity assessment practice within acute hospital and intermediate care settings. My testimony is also based on my clinical experience as a Speech and Language Therapist involved in multidisciplinary mental capacity assessment in acute hospital and specialist rehabilitation settings.

My research identified a lack of high quality evidence relating to the effectiveness and acceptability of interventions, tools, aids and approaches designed to support mental capacity assessment. I am not aware of any published evidence relating to the cost-effectiveness of any interventions.

I summarise below tools, aids and approaches which may be effective in supporting capacity assessment and which may be acceptable to people who may lack capacity, their families and carers, practitioners and others interested in their welfare.

Mental capacity assessment tools / aids:

Standardised tools have been developed to support assessment of capacity to consent to treatment and research participation (see two published reviews: 1, 2). Most tools provide semi-structured interview formats that can be used to structure and document capacity assessments. There is published evidence of variable quality relating to the reliability and

validity of these tools. None of the tools was designed specifically to be used within the Mental Capacity Act (MCA) framework or provide methods for assessors to identify and support people's cognitive and communication needs to ensure their decision-making capacity is maximised. I am not aware that any are used routinely to support mental capacity assessments in England and Wales.

The Communication Aid to Capacity Evaluation (CACE) (3) was designed to enable Canadian social worker staff to complete capacity assessments for people with the language disorder aphasia to make decisions about future residence and care. The CACE was not designed to be used within the MCA framework. The CACE involves a training package and assessment tool. Use of the CACE was associated with improvements in assessors' accuracy in determining capacity and their ability to support the communication needs of the people being assessed. Assessors reported increased confidence in their ability to assess capacity when they used the CACE. People with aphasia reported increased ability to express themselves during the capacity assessment and decreased levels of frustration related to communication support when the CACE was used. The cost-effectiveness and acceptability of the CACE have not been reported.

Practical resources (4) were developed in the UK to enable assessors to prepare, complete and document mental capacity assessments for people with communication disorders. The resources include documentation proformas and strategies and photographic materials that can be used to make information more accessible to people with communication difficulties. However, the effectiveness, cost-effectiveness and acceptability of these resources have not been reported.

The Mental Capacity Assessment Support Toolkit (MCAST) (5) was developed in the UK to support multidisciplinary assessors to prepare, complete and document capacity assessments and to identify and support the needs of people with communication disorders during the assessment process. Unpublished evidence indicates that assessors reported increased confidence in their ability to assess capacity and that the quality of their documented assessments increased when they used the MCAST. The cost-effectiveness of the MCAST has not been investigated. Unpublished evidence suggests that assessors, people being assessed and their family carers found the MCAST materials and processes acceptable.

Clinical initiatives and approaches:

Studies have reported clinical initiatives designed to facilitate or improve mental capacity assessment. These initiatives involve methods to support different aspects of the capacity assessment process:

i. Preparation for the assessment: the use of communication histories, cognitive and communication screening tests to identify people's cognitive and communication needs prior to assessments of their capacity (6-9);
ii. Completion of the assessment: the use of assessment checklists or algorithms to structure the assessment and ensure it is thorough (8-10);
iii. Documentation of the assessment: use of assessment proformas to aid comprehensive documentation (7, 10-12).

The authors of these studies identified positive changes in practice following the introduction of these initiatives. However, the study designs mean that the effectiveness, cost-effectiveness and acceptability of these initiatives are not established.

Published evidence and my own research indicate approaches to assessment which may facilitate and/or improve the quality of capacity assessments. The effectiveness, cost-effectiveness and acceptability of these approaches have not been demonstrated empirically. These approaches are summarised below:

- Using an assessor who understands the background and support needs of the person being assessed and the decision options available to her/him;
- Involving family carers / people who know the person during the assessment;
- Gathering information about the person's abilities and support needs before the assessment (e.g., by taking a case history; by referral to a specialist in cognitive or communication disorders or mental health conditions; by using cognitive or communication or mental health screening tests);
- Using strategies to support the person's individual cognitive needs (e.g., by referral to an occupational therapist, psychologist or speech and language therapist);
- Using strategies to support the person's communication needs (e.g., by referral to a speech and language therapist);
- Using strategies to support the person's mental health needs (e.g., by referral to a mental health professional).

Approaches to supporting communication needs during capacity assessments

Different approaches can be used to support people with communication disorders to understand and express information during capacity assessments. A common approach is to supplement spoken language with other communication methods, including written information and the use of images (e.g., drawings, diagrams, photographs), physical objects and actions (including facial expression, gesture, pointing at objects). I am not aware of high quality evidence that demonstrates the effectiveness, cost-effectiveness and acceptability of these methods.

Guidelines can be used by assessors to adapt written information to make it more accessible to specific clinical populations during capacity assessments (e.g., 13-15). There is limited, low-medium quality evidence to demonstrate the effectiveness of these guidelines in making information easier to understand. The evidence indicates that people with aphasia and people with learning disabilities find the methods promoted by the guidelines generally acceptable. However, information should always be adapted to meet individual needs and preferences.

References to other work or publications to support your testimony' (if applicable):

1. Lamont, S. *et al*. (2013) Assessing patient capacity to consent to treatment: an integrative review of instruments and tools. *Journal of Clinical Nursing,* 22(17-18), 2387-2403.
2. Sturman (2005) The Capacity to consent to treatment and research: A review of standardized assessment tools. *Clinical Psychology Review*, 25, 954-974.

3. Carling-Rowland, A. *et al.* (2014) Increasing access to fair capacity evaluation for discharge decision-making for people with aphasia: A randomised controlled trial. *Aphasiology*, 28(6), 750-765.
4. Allen, J. and Bryer, H. (2014) Supporting Adults with Communication Impairment to Make Decisions. Keighley, Black Sheep Press. Available from: http://www.blacksheeppress.co.uk/products/adults/MCA#
5. Jayes, M**.** *et al.* (2015) Development of a mental capacity assessment support tool: A user-centred design process. *International Journal of Stroke*, 10 (s5), 65.
6. Biswas, A. B. and Hiremath, A. (2010) Mental capacity assessment and 'best interests' decision-making in clinical practice: a case illustration. *Advances in Psychiatric Treatment,* 16**,** 440-447.
7. Jayes, M*. et al.* (2016 online) An exploration of mental capacity assessment within acute hospital and intermediate care settings in England: a focus group study. *Disability & Rehabilitation.* Available from: http://dx.doi.org/10.1080/09638288.2016.1224275
8. Oldreive, W. and Waight, M. (2011) Assessment of capacity: reflections from practice. *Learning Disability Practice*, 14, 31-6.
9. Skinner, R. *et al*. (2011) Demystifying the process? A multidisciplinary approach to assessing capacity for adults with a learning disability. *British Journal of Learning Disabilities*, 39, 92-7.
10. Ramasubramanian, L. *et al*. (2011) Evaluation of a structured assessment framework to enable adherence to the requirements of Mental Capacity Act 2005. *British Journal of Learning Disabilities,* 39**,** 314-20.
11. Emmett, C. *et al*. (2013) Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: Comparing practice with legal standards. *International Journal of Law and Psychiatry,* 36**,** 73-82.
12. Guyver, P. *et al*. (2010) The Mental Capacity Act 2005: Review of mental capacity assessment in people with proximal femoral fracture. *The Psychiatrist,* 34**,** 284-286.
13. Dementia Engagement and Empowerment Project (DEEP) (2013) Guidance for dementia-friendly information. Available from: http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf
14. Department of Health (2010) Making written information easier to understand for people with intellectual disabilities. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215923/dh_121927.pdf
15. Stroke Association (2012) *Accessible information Guidelines.* Available from: http://www.stroke.org.uk/sites/default/files/Accessible%20Information%20Guidelines.pdf.pdf

Section A: Developer to complete	
Name:	Tim Spencer-Lane
Role:	Lawyer
Institution/Organisation (where applicable):	Law Commission
Guideline title:	Decision making and mental capacity
Guideline Committee:	Meeting 9, Monday 18th September 2017
Subject of expert testimony:	Best practice in supported decision making
Evidence gaps or uncertainties:	We have searched for evidence in relation to the effectiveness and cost-effectiveness of interventions, tools, aids and approaches to: - support advance planning for people who may lack mental capacity in the future - support people (on the presumption of capacity) to make decisions - support the assessment of mental capacity - support best interests decision-making for those who have been assessed as lacking capacity. The GC have identified gaps in the literature in this regard, particularly in terms of good practice implementation of legal duties, and views and experiences of people using services and those who support them (family, carers, practitioners and others). More detail is provided below. We would therefore like you to speak on the basis of your expertise of supporting decision making, with a particular focus on enabling professionals to implement legislative requirements and relevant case law.
The Department of Health in England has asked NICE to develop a guideline about decision-making and mental capacity for people using health and social services aged 16 or over.[14] The guideline aims to help health and social care practitioners to: - Support people to make their own decisions as far as possible - Assess people's capacity to make specific health and social care decisions	

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- Make specific best interest decisions when people lack capacity, and maximise the person's involvement in those decisions.

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Where the research evidence is lacking, or inconclusive, Guideline Committee members can invite expert witnesses to the group to provide expert testimony, and recommendations can be drawn from this expert witness testimony and Guideline Committee consensus.

As priority, for this Guideline Committee meeting, the Committee would like to ask you to address the following questions about supporting decision-making.[15]

2.9. What interventions, tools, aids and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2.10. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people, on the presumption of capacity, to make decisions?

For your information, the other review questions being considered by the Committee are also listed below.

1.9. What interventions, tools, aids and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity in the future?

1.10. What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support people planning in advance for decision-making?

3.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting the assessment of mental capacity?

3.6 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare on the acceptability of interventions, tools, aids and approaches to support the assessment of mental capacity?

4.1 What interventions, tools, aids and approaches (including practitioner understanding, knowledge and expertise) are effective and cost-effective in supporting best interests decision-making?

4.2 What are the views and experiences of people who may lack mental capacity, their families and carers, practitioners and others interested in their welfare

[15] Please note the numbering reflects our review protocol

on the acceptability of interventions, tools, aids and approaches to support best interests decision-making?

The GC noted in particular the lack of evidence from the research on the effectiveness and cost-effectiveness of the following on people who may lack capacity and those who support them:

- Advocacy
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They also need to ensure that the guideline reflects the current legal and practice context, and would welcome expert witness advice on this. Specifically, they have noted a particular gap in terms of effective implementation of the MCA and the practice of making best practice decisions.

For all questions, the GC are interested in impact on:

- *Person-focused outcomes* e.g. choice, control, dignity, respect, ability to express preference etc.
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The potential benefits and harms of interventions should be considered and safety prioritised as an outcome. Services should protect people from abuse and avoidable harm, whilst recognising the right of individuals to take risks and make unwise decisions.

Section B: Expert to complete

Summary testimony:	[Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Expert testimony by Tim Spencer-Lane

Between 2014 and 2017, the Law Commission undertook a review of the Deprivation of Liberty Safeguards which operate in England and Wales under the Mental Capacity Act 2005. The final report (which included a draft Bill) was published in March 2017.

The purpose of the review was to develop an effective replacement scheme for the Deprivation of Liberty Safeguards which was capable of delivering positive outcomes to the large numbers of individuals now considered deprived of their liberty following the Supreme Court's decision known as *Cheshire West*. But the review was not limited to Article 5 ECHR matters. We also explored ways in which law reform could place the person at the heart of decision-making, particularly through greater use of supported decision making.

The Law Commission was concerned that, whilst supported decision making is enshrined in law (most notably through the second principle of the Mental Capacity Act), in practice it is rarely implemented. This view was confirmed by our public consultation exercise; many consultees gave examples of cases where supported decision making had not been implemented due to its time and cost implications, and

there was too much focus on protection and safeguarding. In addition, there have been a small number of domestic cases which have reached the courts which have looked at the notion of supported decision making. However, the relevance of the jurisprudence is broadly speaking limited to cases relating to capacity to consent to sexual relations, and has limited general applicability.

One of the key drivers for supported decision making has been the Convention on the Rights on the Rights of Persons with Disabilities. In particular Article 12 (the right of disabled people to enjoy legal capacity on an equal basis with others) has been interpreted as indicating that national laws should provide support to disabled people to ensure that their wishes and preferences are respected, rather than overruled by action that is considered to be in the person's objective best interests.

As a result of our consultation we concluded that:

1. The law could be used to ensure greater acknowledgement of supported decision making by health and social care professionals. Therefore we drafted amendments to section 5 of the Mental Capacity Act to provide that professionals would not be give protection from civil and criminal liability for decisions taken on behalf of a person lacking capacity to consent, unless the professional had documented that they had attempted (without success) to implement a supported decision. This would apply to certain "key" decisions under the Act such as placing the person into long term accommodation and the provision of serious medical treatment.

2. A formal supported decision making scheme should be introduced to make it easier for a person with borderline capacity to consent to a health or welfare decision, to appoint a supporter in order to assist them in decision making. We reviewed a number of common law and other jurisdictions where such systems have been introduced (including Australia, Saskatchewan, and Ireland). We concluded that a formal system would give greater certainty and transparency for individuals, families, carers, professionals and service providers, and would help to ensure that the Mental Capacity Act works as intended. The draft bill therefore gives the Government powers to issue regulations setting out a detailed supported decision making scheme. The content of the scheme would be left for Government to develop and following public consultation. The key questions that would need to be addressed before such a scheme is implemented include the following:

    - Who should be eligible to appoint and receive assistance from an appointed supporter?
    - Who should be eligible to act as a supporter (and indeed should there be any prohibitions in this respect)?
    - How should supporters be appointed?
    - What functions should a supporter have?
    - What powers should a supporter have?
    - What kinds of decisions should be included in the scheme and should there be any limits on the range of decisions that are potentially included?
    - How should a supporter relationship be amended or terminated?
    - What duties should a supporter have?
    - Should there be an independent monitor role of the appointment of supporters?

- Should there be administrative or judicial oversight of individual supports and of the supported decision making scheme in general?

We await the formal response from Government to our final report and an announcement about the likely next steps for our draft Bill.

References to other work or publications to support your testimony' (if applicable):

N/A