NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DRAFT GUIDELINE

Decision-making and mental capacity

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Contents

Introduction

The Department of Health asked NICE to produce this guideline on Decision Making and Mental Capacity for people using health and social services aged 16 and over (see the scope).

What is the purpose of this guideline?

The guideline is intended 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 interests decisions when people lack capacity, and maximise the person's involvement in those decisions.

This may include decisions about where and how people live, their support, care and treatment, their security or safety and financial matters.

The guideline does not cover:

- decision-making activities and support for children under the age of 16
- Deprivation of Liberty Safeguards processes.

Why do we need this guideline?

The Care Quality Commission (CQC) estimates that around 2 million people in England and Wales may lack the capacity to make certain decisions for themselves at some point because of illness, injury or disability. Many of these people will be supported to make those decisions, or if they are assessed as lacking capacity, have best interests decisions made on their behalf, as part of their routine care and support. The Mental Capacity Act 2005 was designed to empower and protect individuals in these circumstances. However the Care Quality Commission identified serious issues with the practical implementation of the Mental Capacity Act. This subject was subsequently reported on by a House of Lords Select Committee in 2014, adding further momentum towards improvement and it is in this context that the Department of Health commissioned this guideline.

What does it cover?

The guideline makes recommendations about practice in relation to people aged 16 years and over who - may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions; may need to have their capacity to make specific decisions about aspects of their care assessed; or may need a best interests decision to be made on their behalf if they have been assessed as lacking capacity.

Who the guideline is for:

- People using health and social care services who may (now or in the future) lack mental capacity, and their families and carers.
- Health practitioners working with people who may lack mental capacity.
- Social care practitioners (including personal assistants) working with people who may lack mental capacity.
- Advocates, including Independent Mental Capacity Advocates, Care Act advocates and Independent Mental Health Advocates.

The guideline is also relevant for:

- Practitioners working in services (including housing, education, employment, police and criminal justice) who may come into contact with people who lack mental capacity.
- Local authorities and clinical commissioning groups.
- Social care and health providers.
- Community and voluntary organisations representing or supporting people who may lack mental capacity, and their families and carers.
- Guardians (under the Mental Health Act), court appointed deputies and those who hold power of attorney.

How has it been developed?

We used the methods and processes in Developing NICE guidelines: the manual (2014).

What is the status of this guideline?

The guideline is not a comprehensive manual for frontline practice; rather, it focuses on areas where practice needs to improve, and where there is a paucity of guidance in existence.

How does it relate to statutory and non-statutory guidance?

Practitioners must comply with the statutory functions of the agencies they work for under the Care Act 2014, the Mental Health Act 2007 and the Mental Capacity Act 2005,

In particular, under the Mental Capacity Act 2005, practice must be underpinned by 5 statutory principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because they make an unwise decision
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Practitioners must also comply with all legislation, codes of practice and guidance relevant to their work. This guideline seeks to complement and build on these existing requirements, to support their implementation and drive improvements in the quality of support. Although it is particularly aligned with the Mental Capacity Act 2005, the guideline is not intended as a step-by-step guide to the implementation of the legislation. Guidance for decisions made under the Mental Capacity Act 2005 is published in the Mental Capacity Act Code of Practice.

1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Overarching principles

1.1.1 Service providers and responsible bodies should ensure that all practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. This includes role appropriate training for new staff, pre-registration, and continuing development and practice supervision for existing staff. Where appropriate, training should be interdisciplinary, involve experts by experience and include:

- the statutory principles of the Mental Capacity Act 2005
- the importance of seeking consent for the process of advance care planning
- how and when to have potentially difficult conversations about loss of autonomy, advance care planning or death
- required communication skills for building trust to supported decision-making
- clarity on roles and responsibilities
- the advantages, disadvantages and ethics of advance care planning, and how to discuss these with the person and their carers, family and friends
- condition-specific knowledge related to advance care planning, where appropriate
- the conduct of decision-specific capacity assessments
- the process of best interests decision-making in the context of section 4 of the Mental Capacity Act and associated guidance

- how to direct people to sources of advice and information.

1.1.2 All health and social care organisations should:

- develop local policy and guidance about which interventions, tools and approaches will be used to support decision-making.

- identify or devise specific tools to help health and social care practitioners to assess the mental capacity of the people they are working with.

1.1.3 Co-develop policies and Mental Capacity Act training programmes with people who have experience of supported decision-making and of having their mental capacity assessed, and their carers, family and friends.

1.1.4 Practitioners should think about decision-making capacity every time a person is asked for consent, or to make a decision, during care and support planning (that is, not only as disagreement resolution).

1.1.5 When giving information about a decision to the person:

- it must be accessible, relevant, and tailored to the specific needs of the individual
- it should be sufficient to allow the person to make an informed choice about the specific decision in question
- it should be supported by tools such as visual materials, visual aids, communication aids and hearing aids, as appropriate.

1.1.6 Record and update information about people’s wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making.

Using independent advocacy to support decision-making and assessment under the Mental Capacity Act

1.1.7 Commissioners should ensure that arrangements for the provision of independent advocacy include support for people to:

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

This could be achieved through expansion of existing statutory independent advocacy roles and/or commissioning and provision of non-statutory independent advocacy.

1.1.8 Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy. Where statutory criteria are met, practitioners must refer to the relevant advocacy service. Otherwise, think about referral to non-statutory advocacy services which will be dependent on local commissioning arrangements.

1.1.9 Consider providing independent advocacy when there is a safeguarding concern.

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

- statutory duties on public bodies to refer to and involve independent advocacy are consistently adhered to and monitored and
- failures in the duty to refer to statutory independent advocacy are addressed.

1.1.11 Commissioners, using their powers, including under the Mental Capacity Act 2005, should work with public bodies and providers to increase investment in training for statutory independent mental capacity and other statutory advocates in key areas. This includes training:

- in communication with people who have minimal or no verbal communication and
- for Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with acquired brain injury.

1.2 Supported decision-making

1.2.1 Ask the person how they want to be supported and who they would like to have involved in decision-making in accordance with Mental Capacity Act Code of Practice, principle 2.

1.2.2 Practitioners supporting a person’s decision-making should build and maintain a trusting relationship with them.

1.2.3 Practitioners should take into account the wide range of factors that can have an impact on a person’s ability to make a decision. These should include:

- the person’s physical and mental condition
- the person’s communication needs
- the person’s previous experience (or lack of experience) in making decisions
- the involvement of others
- situational, social and relational factors
- cultural, ethnic and religious factors
- cognitive and emotional factors, or those related to symptoms.

They should use this knowledge to support the person's decision-making.

Providing information to support decision-making

1.2.4 Practitioners should clearly determine, at the start, what information they need to cover the salient details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself.

1.2.5 Offer accessible information to everyone involved in supporting decision-making. This should be about the process and principles of supported decision-making as well as about the specific decision.

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

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

1.2.7 Record the information that is given to the person during decision-making. Give the person an opportunity to review and comment on what is recorded and write down their views.

1.2.8 Consider tailored training programmes for the person, to provide information for specific decisions – for example sexual education programmes and medication management.

Supporting decision-making

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

1.2.10 Support the person with decision-making even if they wish to make an unwise decision.

1.2.11 Involve significant and trusted people in supporting decision-making, in line with the person's preferences. Have due regard for the principle of confidentiality set out in section 3.15 of the Mental Capacity Act Code of Practice. Ensure that this support is based on the person’s wishes and preferences and is free from coercion or undue influence. If there are no significant trusted people, think about involving an advocate, particularly if the advocate has worked with the person before.

1.2.12 Practitioners should talk to the person and their carer, family and friends, as appropriate, about the potential consequences of supported decision-making. These could include increased autonomy, being better informed, sharing decisions with people interested in their welfare, talking about potentially upsetting issues including declining health or end of life, feeling overwhelmed with having to make a difficult decision at a difficult time and dealing with conflicting opinions.

1.2.13 Give people time during the decision-making process to communicate their needs and feel listened to. Be aware that this may mean meeting with the person for more than 1 session.

1.2.14 Health and social care practitioners should increase the involvement of people and their carers, family and friends in decision-making discussions by using a range of interventions focused on improving shared decision-making and supported decision-making.

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

1.2.16 Health and social care practitioners should refer to other services (for example speech and language therapy and clinical psychology) that could help support decision-making when the person's level of need requires specialist input. This is especially important:

- when the obstacles to decision-making are complex or
- if there is a dispute between those making and supporting decisions or
- if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk).

1.2.17 Practitioners should make a written record of the decision-making process including:

- steps taken to help the person make the decision
- individuals involved in supporting the decision
- information given to the person
- key considerations for the person in making the decision
- the decision reached
- needs identified as a result of the decision
- any further actions arising from the decision.

1.2.18 Organisations should ensure they can demonstrate that they monitor compliance with principle 2, section 1 (3) of the Mental Capacity Act.

1.3 Advance care planning

Advance care planning is one way of discussing and setting out a person's wishes in relation to future care and treatment decisions. Other ways of doing this include appointing a Lasting Power of Attorney or making an advance decision to refuse treatment.

Helping practitioners to undertake advance care planning

1.3.1 Health care commissioners and providers should:

- develop standard protocols and plans for joint working and sharing of information on advance care plans between practitioners, people and families
- commission training on advance care planning
- demonstrate that protocols are in place and training is available by including advance care planning in audits.

Providing information about advance care planning

1.3.2 Offer people verbal and written information about advance care planning, including how it relates to their own circumstances and conditions. All information sharing must fulfil the requirements of the NHS Accessible Information Standard.

1.3.3 If a person has recently been diagnosed with a long-term or life-limiting condition, give them information on:

- their condition
- the process of advance care planning
- how they can change their minds or amend the decisions they make while they retain capacity to make them
- services that will help in advance care planning.

Developing advance care plans collaboratively

1.3.4 All health and social care practitioners who come into contact with the person after diagnosis should help them to make an informed choice about participating in advance care planning. If they wish to do so, practitioners should facilitate this.

1.3.5 Offer the person a discussion about advance care planning:

- at the most suitable time once they receive a diagnosis likely to make advance care planning useful and
- at other times, allowing people to think through and address different issues in their own time.

1.3.6 Practitioners involved in advance care planning should ensure that they have access to information about the person’s medical condition that helps them to support the advance care planning process. It is the practitioner’s responsibility to identify what information they need.

1.3.7 When approaching discussions about advance care planning, health and social care practitioners should:

- be sensitive, recognising that some people may prefer not to talk about this, or prefer not to have an advance care plan
- be prepared to postpone discussions until a later date, if the person wishes
- recognise that people have different needs for knowledge, autonomy and control

- talk about the purpose, advantages and disadvantages of this type of planning
- consider the use of checklists to support discussions.

1.3.8 If the person has given consent for carers, family and friends to be involved in discussions about advance care planning, practitioners should take reasonable steps to include them.

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

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

1.3.10 During advance care planning discussions, practitioners should:

- take into account the person's history, social circumstance, wishes and feelings, values and beliefs (including religious, cultural and ethnic factors), aspirations and any other factors they may consider important to them
- help the person to anticipate how their needs may change in future.

1.3.11 In line with the Mental Capacity Act Code of Practice practitioners should ensure that:

- all notes made on advance care planning are contemporaneous and
- the notes are agreed with the person using services at the time and
- permission is sought to share the information with other people.

1.3.12 Provide the person with an accessible document that records their wishes, beliefs and preferences in relation to advance care planning and which they may take with them to show different services. It may include who the person wants to have involved in decision-making or their preferences for issues such as treatment, support or accommodation.

1.3.13 Practitioners should share the advance care plan in a clear and simple format with everyone involved in the person's care, if the person has given consent.

1.3.14 Practitioners should ensure that information about a person's advance care plan is, with their consent, transferred between services when their care provider changes.

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

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

Joint crisis planning

1.3.17 Offer joint crisis planning to anyone who has a mental disorder with an assessed risk of relapse or deterioration and who is in contact with specialist mental health services. The offer should be documented and, if the person accepts it, the plan should be recorded.

1.4 Assessment of mental capacity

1.4.1 Health and social care organisations should monitor and audit the quality of mental capacity assessments.

1.4.2 Consider including people's views and experiences in data collected for monitoring an organisation's capacity assessment activity.

1.4.3 Organisations should ensure that assessors should be able to seek advice from people with specialist condition-specific knowledge to assist them to assess capacity – for example clinical psychology and speech and language therapists.

1.4.4 Organisations with responsibility for accessible care plans should ensure that they record that the person consents to the care plan and identifies if they are unable to consent.

1.4.5 Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment.

Assessing capacity to make decisions

1.4.6 Assess mental capacity in line with the process set out in section 3 of the Mental Capacity Act. Be aware that the process applies to all decisions, large and small, though the measures adopted and recording will be proportionate to the complexity and significance of that decision.

1.4.7 Assessors should have sufficient knowledge of the person being assessed to be able to:

- provide tailored information, including information about the consequences of making the decision or of not making the decision
- know whether the person would be likely to attach particular importance to any key considerations relating to the decision.

1.4.8 Practitioners should be aware that people may find capacity assessments distressing, particularly if they strongly disagree that they lack capacity.

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

- the person’s options
- what information, knowledge and experience the person needs about their options
- what the person needs to understand, retain, weigh up, use and communicate in relation to this decision, including the use of communication aids
- how to allow enough time for the assessment, giving people with communication needs more time if needed
- how to assess capacity in a way that is respectful and preserves the person’s dignity

- how to make reasonable adjustments including, for example, delaying the assessment until a time when the person feels less anxious or distressed
- how to ensure that the assessment takes place at a location and in an environment and through a means of communication with which the person is comfortable
- whether involving people with whom the person has a trusted relationship would help the assessment decision.

1.4.10 The assessor should take into account the person's decision-making history when preparing for an assessment.

1.4.11 Practitioners must take all reasonable steps to ensure that the process of capacity assessment does not cause a person distress or harm.

1.4.12 Health and social care practitioners should take a structured, person-centred, empowering and proportionate approach to assessing a person's capacity to make decisions, including everyday decisions. The assessment should show where a person has capacity and where they do not. However, they should be aware that for certain areas, such as voting, there is no legal requirement to establish capacity.

1.4.13 As stated in principle 2 of the Mental Capacity Act, health and social care practitioners must take a collaborative approach to assessing capacity, where possible, working with the person to produce a shared understanding of what may help or hinder their communication and decision-making. This may include involving an interpreter, speech and language therapist, someone with sensory or specialist communication skills, clinical psychologists or other professionals to support communication during an assessment of capacity.

1.4.14 Where the individual has identified communication needs the assessor should also think about using communication tools to help with the assessment. Where tools are used, their use should be recorded as recommended by their employer or organisation.

1.4.15 Health and social care practitioners should work with the person where possible and where consent has been provided to identify people they should liaise with about how to carry out the capacity assessment. This could include support workers, carers, family and friends and advocates. They should use the information gathered to help create a complete picture of the person's functional capacity to make a specific decision and act on it.

1.4.16 The assessor should record any differing views on capacity that they are aware of and how the outcome of their assessment addresses or answers those concerns.

1.4.17 Health and social care practitioners should conduct an assessment at a level proportionate to the decision being made.

1.4.18 If a person refuses to engage in a capacity assessment, the assessor should give them a choice about who else could be involved or any other changes that can be made to help them.

1.4.19 Practitioners should use accessible language or an accessible format to tell the person:

- that their capacity is being assessed and
- the outcome of that assessment.

1.4.20 Practitioners should be aware that people with executive dysfunction – for example, people with traumatic brain injury – may be at risk of having their decision-making capacity overestimated. Structured assessments of capacity should be supplemented by real-world observation of the person's functioning and ability.

1.4.21 When assessing capacity, practitioners should take account of principle 3 of the Mental Capacity Act and not assume that the person lacks capacity because they have made a decision that the practitioner perceives as risky or unwise.

1.4.22 Practitioners should understand that the person has to retain the most important points from a discussion only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision.

1.4.23 Practitioners should be aware that if a person is judged to lack insight into their condition, this does not necessarily reflect lack of capacity to make a decision, depending on the nature of the decision being made.

1.4.24 If a practitioner assesses a person as lacking capacity, they must document this, together with the evidence that led to this conclusion.

1.4.25 The person assessing mental capacity should record:

- the practicable steps they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved.
- if the person has capacity but makes an unwise decision
- if the person has capacity and gives valid consent.

1.4.26 All assessments of mental capacity must be recorded at an appropriate level to the complexity of the decision being made, as a stand-alone assessment, in patient notes or in care plans following local policy.

1.4.27 Provide the person with emotional support and information after the assessment, being aware that the assessment process could cause distress, disempowerment and alienation.

1.5 Best interests decision-making

There are some decisions that cannot be made under the provisions of best interests decision-making in the Mental Capacity Act. For example, a person's capacity to vote does not need to be established and best interests decisions cannot be made on the issue. Other examples of excluded decisions include sexual activity and divorce or in circumstances where an advance decision to refuse treatment has been made.

Helping practitioners to deliver best interests decision-making

1.5.1 In line with the Mental Capacity Act 2005, practitioners must not hold a best interests discussion until a capacity assessment has been conducted, and a decision made and recorded that a person lacks capacity to make the decision in question (except in emergency situations).

1.5.2 Ensure that everyone involved in the best interests decision-making process knows who the decision maker is.

1.5.3 Regardless of whether a person has capacity to make a specific decision, practitioners must take all reasonable steps to help them be involved in making decisions.

1.5.4 Health and social care services should ensure that best interests decisions are being made in line with the Mental Capacity Act.

1.5.5 Health and social care services should:

- implement a service-wide process for recording best interests decisions and ensure that staff are aware of this and
- have clear systems in place to support practitioners to identify and locate any relevant written statement made by the person when they had capacity, at the earliest possible time.

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

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

1.5.7 Ensure that knowledge of the Independent Mental Capacity Advocate role in best interests decision-making is embedded in all Mental Capacity Act training, including introductions to health and social care and in preregistration training.

Helping and supporting family members in respect of best interests decision-making

1.5.8 Health and social care practitioners should work with carers, family and friends to find out the wishes and preferences of the person in relation to the specific decision and to understand the person's decision-making history.

1.5.9 If a decision maker is calling a best interests meeting, they should:

- involve the person themselves, unless a decision is made that it would be harmful for them to attend the meeting
- consult carers, family and friends about the meeting in advance, giving them time to ask questions and give their opinions, for example about how to include the person in decision-making
- make it clear that the purpose of the meeting is to make a decision
- provide all information in an accessible format.

1.5.10 Practitioners should access information about the person informally if needed, as well as through any formal meetings.

1.5.11 The decision maker should ensure that all people concerned with the best interests decision are able to be fully involved. This means making sure they have their views encouraged, respected and heard.

Undertaking best interests decision-making

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

- a less formalised approach for day-to-day decisions – that is, recurring decisions being recorded in support or care plans
- formal best interests meetings for significant decisions

- a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments.

1.5.13 Carers and practitioners must wherever possible find out the views and beliefs of the person in the first instance and should be able to demonstrate that they have done so. For example:

- recording in care records what steps have been taken, including reasons why this has not been done
- identifying which steps have been taken to find out the person's wishes.

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

- a clear definition of the decision to be made
- steps that have been taken to help the person make the decision themselves
- a current assessment concluding that the person lacks the capacity to make this decision
- any other decision-making instruments that would prevent best interests decision-making occurring (for example a Lasting Power of Attorney, advance decisions, court orders)
- a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including advanced statements
- a prompt to consult interested parties (for example families, friends and Independent Mental Capacity Advocate and relevant professionals) and a record of who they are
- advice about the degree of formality needed for the decision being made, for example a best interests meeting
- guidance about recording best interests process and decision including a balance sheet of risks and benefits.

1.5.15 Anyone responsible for leading best interests decision-making must consider how best to involve the person in the process and document the steps taken.

1.5.16 Practitioners must think about whether a decision can be delayed until the person has capacity to make a decision and allow all practicable steps to be taken in the interim to help them gain capacity.

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

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

1.5.18 When determining best interests the decision maker must establish whether the decision will deprive the person of their liberty and, if so, ensure that the appropriate legal authority is obtained in a timely manner.

1.5.19 When an Independent Mental Capacity Advocate has been instructed they should be involved in the process until a decision has been made and implemented fully.

1.5.20 Record best interests decisions in a way that is proportionate to its complexity, for example in a best interests toolkit or individual care record. As people’s circumstances change, review the decisions regularly to ensure that they remain in a person’s best interests.

1.5.21 After the outcome has been decided, the decision maker should ensure that it is recorded and communicated to everyone involved and that there is opportunity for all participants to offer feedback or raise objections.

1.5.22 If there is a dispute about a person's best interests, resolve this, where possible, before the decision is implemented – for example through further meetings or mediation. If this cannot be resolved locally, refer to the Court of Protection to determine the person's best interests.

1.5.23 Decision makers should specify a timely review of the implementation of the actions resulting from the best interests decision. If the review establishes that the best interests decision was not successfully actioned, the decision maker should take suitable steps such as:

- convening a multi-agency meeting to resolve issues leading to the best interests decision not being successfully implemented, or
- reassessing and making a new best interests decision that is more achievable, or
- taking steps to refer the decision to the Court of Protection, or
- re-considering whether any further action is appropriate.

Terms used in this guideline

Advance care planning

Advance care planning (ACP) with people who may lack mental capacity now or in the future, is a voluntary process of discussion about future care between the individual and their care providers. If the individual wishes, their family and friends may be included in the discussion. With the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care.

Advance decisions to refuse treatment (living wills)

An advance decision (sometimes known as an advance decision to refuse treatment, an ADRT or a living will) is a decision people can make now to refuse a specific type of treatment at some time in the future. It is legally binding and considered valid if the person is aged 18 or over and had the capacity to make, understand and communicate the decision when it was made.

Advance directive

An advance directive is a way of making a person's views known if he or she should become mentally incapacitous of giving consent to treatment, or making informed choices about treatment, at some future time.

Consent

When a person who may lack mental capacity now or in future gives permission to someone to do something for them.

Duty of care

Duty of Care is defined simply as a legal obligation to: always act in the best interests of people who may lack capacity, not act or fail to act in a way that results in harm and act within your competence and not take on anything you do not believe you can safely do.

Joint crisis planning

A Joint Crisis Plan enables the individual and services to learn from experience and make plans about what to do in the event of another crisis. It is developed by seeking agreement between the person who may lack mental capacity now or in future and their mental health team about what to do if they become unwell in the future.

Lasting Power of Attorney

A Lasting Power of Attorney (LPA) allows the person to give someone they trust the legal power to make decisions on their behalf in case they become unable to make decisions for themselves. The person who makes the LPA is known as the ‘donor’ and the person given the power to make decisions is known as the ‘attorney’.

Mental Capacity Act 2005

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over and covers people in England and Wales who can't make some or all decisions for themselves.

Mental Health Act 1983

The Mental Health Act (MHA) 1983 is a piece of legislation (in England and Wales) which tells people with mental health problems what their rights are regarding: assessment and treatment in hospital, treatment in the community and pathways into hospital, which can be civil or criminal.

Participation

When a person takes part in decisions about things that affect them and other people. This may be about day to day life activities of people who may lack mental capacity such as what to eat or how to spend time.

Practicable steps

'Practicable steps' links to principle 2 of the Mental Capacity Act, which states that 'all practicable steps' should be taken to help a person make a decision before being treated as though they are unfit to make the decision. There are obvious steps one might take, including the use of specific types of communication equipment or types of languages such as Makaton or the use of specialist services, such as a speech and language therapist. Practicable steps could also involve ensuring the best environment in which people are expected to make often significant decisions – for example giving them privacy and peace and quiet or ensuring they have a family member to provide support during decision making, if this is their wish.

Proxy

When authority is given to a person to act for someone else, such as a person authorized to act on behalf of someone who lacks mental capacity to make decisions.

Psychiatric advance directive

Psychiatric advance directives (PAD) are legal instruments that allow competent individuals to appoint proxies and specify how treatment decisions should be made in the event they become incompetent. A PAD describes treatment preferences, or names a person to make treatment decisions, should the person with a mental health condition be unable to make decisions.

Substitute decision-making

Decisions are made on behalf of someone lacking capacity by a person permitted to do so under the law. This 'Substitute Decision Maker' must be willing, available and capable of taking on this responsibility.

Supporter

Supporters are people who support someone who lacks decision making mental capacity in this specific context.

For other social care terms see the Think Local, Act Personal Care and Support Jargon Buster.

2 Research recommendations

The Guideline Committee has made the following recommendations for research.

2.1 Training and support for practitioners

Research question

What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions?

Why this is important

The guideline committee agreed that effective training and support on the Mental Capacity Act and how to apply its principles in practice is essential for practitioners working with people who may lack capacity to make a decision. The evidence the committee reviewed often referred to training and support, but very few studies looked at this area specifically. Some of the evidence suggested that practitioners did not always understand the requirements of the Act and that their practice did not always comply with these. Much of the evidence was of low to moderate quality and there was no good quality evidence evaluating the effectiveness of training and support in relation to the Act.

A better understanding of what training and support increases compliance with the Act could improve outcomes for people who may lack capacity to make a decision. Qualitative studies exploring the current barriers to delivering effective training and support and the challenges that practitioners face in using this learning in practice would help to inform measures for improvement.

Comparative studies are needed to determine the effectiveness and cost effectiveness of different approaches for delivering training and support to practitioners. Evaluating whether these increase compliance with the requirements of the Act would be especially informative.

Criterion	**Explanation**
Population	Health and social care practitioners working with people who may lack mental capacity, now or in the future, to make a specific decision.
Intervention	Training programmes explicitly designed to enable health and social care practitioners to comply with the requirements of the Mental Capacity Act 2005 in relation to support for decision-making, the conduct of capacity assessments and best interests processes.
Comparators	Current standard practice.
Outcomes	Service outcomes Competence and confidence among health and social care practitioners to implement and uphold the principles of the Mental Capacity Act 2005. Compliance with principles of the Mental Capacity Act 2005.
Study design	Comparative studies (ideally randomised controlled trials – RCTs) that include a cost-effectiveness component or provide data suitable for cost-effectiveness analysis, conducted in the UK.
Timeframe	Studies should measure the impact of training programmes in the short and medium term.

2.2 Equalities considerations

Research question

Does a person’s cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions and are these processes acceptable to service users and health and social care practitioners?

Why this is important

We reviewed a small amount of evidence suggesting that people who do not speak English as their first language may sometimes be disadvantaged during assessments of mental capacity. This evidence was drawn from a survey of old age psychiatrists in the UK. Over half of those who responded reported that interpreters were not always involved in cases in which the person being assessed was not fluent in English. The Guideline Committee was particularly concerned about this finding, noting the importance of seeking assistance from interpreters, especially when complex decisions regarding health and social care are being made. The Committee also discussed how other issues of culture, ethnicity or religion might influence both the outcome of an assessment of mental capacity and the outcome of best interests decisions.

As this evidence was drawn from a single study, the Committee agreed that further research into this area was needed. Ensuring that assessments of mental capacity to make a decision do not discriminate against individuals for whom English is not their first language is essential.

Qualitative studies exploring service user and health and social care practitioner views on these issues would help to ensure that assessments of mental capacity are not conducted in a discriminatory manner. Studies exploring the barriers and facilitators to communicating with people for whom English is not their first language during an assessment of mental capacity would be particularly useful, and would help to ensure that services do not discriminate against people from minority groups.

Criterion	**Explanation**
Population	People from a minority ethnic background or whose first language is not English and who have experience of mental capacity assessments and best interests decisions. Health and social care practitioners with experience of mental capacity assessments and best interests decisions.
Intervention	N/A. The focus of the research should be on the views and experiences of service users and health and social care practitioners with regards to current practice.
Comparators	N/A. The focus of the research should be on the views and experiences of service users and health and social care practitioners with regards to current practice.
Outcomes	Service user (and carer) experience and level of satisfaction. Acceptability to service users and carers. Research should also focus on: Service user views and experiences regarding mental capacity assessment and best interests decision processes. Health and social care practitioner views and experiences regarding mental capacity assessment and best interests decisions processes.

Study design	Qualitative studies exploring the views and experiences of service users and health and social care practitioners. Studies should incorporate a quantitative satisfaction measure.
Timeframe	Research should be completed in a sufficiently short timeframe to ensure that findings are relevant to, and illustrate, current practice.

2.3 Targeted interventions to support advance care planning

Research question

What is the effectiveness and cost-effectiveness of targeted advance care planning interventions?

Why this is important

There is a lack of clarity regarding the cost-effectiveness of targeted advance care planning. Although we reviewed some evidence in relation to this issue, this was drawn from a systematic review and much of the data originated from studies conducted outside the UK. The Committee therefore had reservations about the generalisability of this evidence and also expressed concerns about the design of these studies, many of which were non-randomised. They were also concerned that people experiencing executive dysfunction are not well served by existing advance care planning processes and concluded that further research evaluating the effectiveness of interventions targeted towards specific cohorts is needed.

High quality controlled studies are needed to evaluate the effectiveness of targeted interventions and measurement of impact should not be limited to acute health service-related outcomes. Evaluating the impact on service user and carer quality of life is especially important and including some measures related to community health and social care services will provide valuable information that can be drawn from in the commissioning process.

Criterion	**Explanation**
Population	People who may in the future lack mental capacity to make a specific decision.
Intervention	Targeted advance care planning interventions such as people with dementia or those experiencing executive dysfunction. These should be underpinned by comprehensive understanding of the relevant condition.
Comparators	Current standard practice.
Outcomes	Uptake of advance care planning.

	Alignment between content of advance care plans and future health and social decisions/treatment. Involvement in decision-making. Acute care usage. Social care usage. Service user (and carer) health-related quality of life. Service user (and carer) social care-related quality of life. Service user (and carer) experience and level of satisfaction. Acceptability to service users and carers. Service user and carer choice and control. Service user and carer dignity and independence. Acceptability to health and social care practitioners. Health and social care practitioner satisfaction.
Study design	Large, well designed randomised controlled trials (including a cost-effectiveness component or providing data suitable for cost-effectiveness analysis) conducted in the UK evaluating targeted interventions.
Timeframe	Studies would ideally measure outcomes in both the short and medium-term and the long-term in order to ensure that the impact of advance care planning on future care and support can be evaluated.

2.4 Targeted interventions to support and improve decision-making capacity for treatment

Research question

What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups?

Why this is important

Evidence suggests that tailored approaches such as speech and language therapy and psychological and psychosocial interventions can lead to improvements in a person’s capacity to make a decision. However, the studies were limited in number and generally of low quality. The guideline committee agreed that further research in this area would be valuable, particularly in relation to the decision-making capacity for treatment of people with dementia, a learning disability, a head injury or a mental illness. Interventions should be designed to address the needs of these cohorts and underpinned by a comprehensive understanding of the needs associated with each condition.

High-quality comparative studies evaluating the effectiveness of these different types of interventions are needed to help ensure that practitioners refer people to the most appropriate programmes. This would empower people to make their own decisions about their treatment wherever possible.

Criterion	Explanation
Population	People who may lack mental capacity to make a specific decision.
Intervention	Targeted interventions to support and improve treatment decision-making among people who may lack capacity to make a specific decision (on the presumption of capacity), such as people with dementia, a learning disability, a head injury or a mental illness. These should be underpinned by comprehensive understanding of the relevant condition.
Comparators	Current standard practice.
Outcomes	Capacity to make specific treatment decisions. Involvement in decision-making. Alignment of health and social care support to service user wishes and decisions. Service user (and carer) health-related quality of life. Service user (and carer) social care-related quality of life. Service user (and carer) experience and level of satisfaction. Acceptability to service users and carers. Service user and carer choice and control. Service user and carer dignity and independence. Acceptability to health and social care practitioners. Health and social care practitioner satisfaction.
Study design	Large, well designed randomised controlled trials (including a cost-effectiveness component or providing data suitable for cost-effectiveness analysis) conducted in the UK evaluating targeted interventions.
Timeframe	Studies would ideally measure outcomes in the short and medium term.

2.5 Advocacy and support for decision-making on the presumption of capacity

Research question

What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?

Why this is important

The evidence reviewed did not include any studies that evaluated the effectiveness or acceptability of advocacy as a means of supporting people who may lack capacity to make a decision. However, the guideline committee thought that this was an area in which emerging practice shows promise. Expert witness testimony highlighting the Swedish ‘personal Ombuds’ peer support scheme also suggested that further research into the use of advocacy as a means of supporting decision-making might be useful. Although provision for advocacy already exists for people assessed as lacking capacity to make a decision (through an Independent Mental Capacity Advocate), this type of support could also benefit people who, although retaining capacity, may need support to make a decision.

High-quality mixed methods studies with a controlled effectiveness component (preferably randomised) are needed to evaluate the effectiveness and cost effectiveness of advocacy as a tool to support the decision-making of people who may lack capacity to make a decision (on the presumption of capacity). These should include a qualitative component that explores whether advocacy as a means of support to make decisions is acceptable to people using services and valued by practitioners.

Criterion	Explanation
Population	People who may lack mental capacity to make a specific decision. Health and social care practitioners working with people who may lack mental capacity to make a specific decision.
Intervention	Advocacy as a means of support for decision-making (on the presumption of capacity).
Comparators	Current standard practice.
Outcomes	Involvement in decision-making. Alignment of health and social care support to service user wishes and decisions. Service user (and carer) health-related quality of life. Service user (and carer) social care-related quality of life. Service user and carer-related experience. Acceptability to service users and carers. Service user and carer satisfaction. Service user and carer choice and control. Service user and carer dignity and independence. Acceptability to health and social care practitioners. Health and social care practitioner satisfaction.
Study design	Comparative studies (ideally randomised controlled trials) that include a cost-effectiveness component or provide data suitable for cost-effectiveness analysis, conducted in the UK.

	Qualitative studies exploring the views and experiences of service users and health and social care practitioners.
Timeframe	Quantitative studies would require sufficient time to capture impacts on outcomes related to service user wellbeing. Qualitative research should be completed in a sufficiently short timeframe to ensure that findings are relevant to and illustrate current practice.

2.6 Using mental capacity assessment tools to assess capacity

Research question

What is the accuracy and/ or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005?

Why this is important

There is a lack of evidence from the UK on the effectiveness and acceptability of approaches to capacity assessment that are in line with the meaning of mental capacity as outlined in the Mental Capacity Act. Although the guideline committee reviewed some evidence evaluating the accuracy of specific tools, these are not necessarily compatible with the definition of mental capacity.

There is a need for high-quality mixed methods studies that evaluate the accuracy or effectiveness of mental capacity assessment tools that are compliant with the Mental Capacity Act. These should include a qualitative component that explores whether such tools and approaches are acceptable to people using services and valued by practitioners.

Criterion	**Explanation**
Population	People who may lack mental capacity to make a specific decision. Health and social care practitioners working with people who may lack mental capacity to make a specific decision.
Intervention	Tools, aids and approaches designed to support the assessment of mental capacity to make a decision. These should comply with the requirements of the Mental Capacity Act 2005.
Comparators	Gold standard assessment tools, current practice.
Outcomes	Compliance with principles of the Mental Capacity Act 2005. Accuracy of mental capacity assessments.

	Cost of mental capacity assessments. Time taken to conduct mental capacity assessments. Acceptability to service users and carers. Acceptability to health and social care practitioners. Service user and carer-related experience and satisfaction. Service user and carer dignity and independence. Health and social care practitioner experience and satisfaction.
Study design	Diagnostic accuracy studies or comparative studies of a robust design (such as randomised controlled trials) that evaluate tools or approaches to assessment of mental capacity that are clearly aligned with the principles of the Mental Capacity Act 2005.
Timeframe	Studies should measure the impact of specific tools and approaches in the short and medium term.

2.7 Components of a mental capacity assessment

Research question

What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?

Why this is important

There is a lack of clarity about the way in which practitioners conduct assessments of capacity to make a decision and how the process and outcomes of these assessments are being recorded. The guideline committee reviewed the small amount of available evidence suggesting that practice may be improved through the use of standardised forms. However, these studies tended to be poorly designed – for example, relying on audit data.

There is a need for high-quality research that explores in detail how to conduct an effective capacity assessment. This could include studies comparing one-off capacity assessments with multiple assessments, and comparative studies evaluating whether certain approaches or tools are appropriate.

Criterion	**Explanation**
Population	People who may lack mental capacity to make a specific decision. Health and social care practitioners working with people who may lack mental capacity to make a specific decision.
Intervention	Tools, aids and approaches designed to support the assessment of mental capacity to make a decision. These should comply with the requirements of the Mental Capacity Act 2005.

Comparators	Current standard practice.
Outcomes	Compliance with principles of the Mental Capacity Act 2005. Accuracy of mental capacity assessments. Cost of mental capacity assessments. Time taken to conduct mental capacity assessments. Acceptability to service users and carers. Acceptability to health and social care practitioners. Service user and carer-related experience and satisfaction. Service user and carer dignity and independence. Health and social care practitioner experience and satisfaction.
Study design	Comparative studies (ideally randomised controlled trials) that include a cost-effectiveness component or provide data suitable for cost-effectiveness analysis, conducted in the UK.
Timeframe	Studies should measure the impact of specific assessment approaches in both the short and medium term.

2.8 Best interests decision-making processes

Research question

What is the effectiveness and cost-effectiveness of using a checklist to support the best interests decision-making process?

Why this is important

We reviewed evidence that suggested that the use of checklists could improve practice in relation to the best interests decision-making process, particularly with regard to the recording of this process and the outcomes of the best interests decision itself. However, the evidence on this was sparse and was generally of a low methodological quality (for example, audit data). Although some members of the Guideline Committee noted that checklists had been established as an effective means of improving practice in a range of practice fields, there were others who were concerned that checklists often resulted in a ‘tick box’ approach to practice.

Comparative studies evaluating the effectiveness of a standardised approach or checklist based on the principles of the Mental Capacity Act would enable decisions to be made regarding the introduction of these at an organisational level. These studies should ideally be complemented with qualitative studies that explore how they fit into daily practice and whether they can be used as they were originally designed.

Criterion	Explanation
Population	Health and social care practitioners working with people who may lack capacity to make a specific decision.
Intervention	Checklists designed to support the best interests decision-making process.
Comparators	Current standard practice.
Outcomes	Compliance with principles of the Mental Capacity Act 2005. Cost of best interests processes. Time taken to conduct best interests processes. Acceptability to service users and carers. Acceptability to health and social care practitioners Service user and carer-related experience and satisfaction. Service user and carer dignity and independence. Health and social care practitioner experience and satisfaction.
Study design	Comparative studies (ideally randomised controlled trials) that include a cost-effectiveness component or provide data suitable for cost-effectiveness analysis, conducted in the UK.
Timeframe	Studies should measure the impact of tools to support the best interests process in both the short and medium term.

3 Evidence review and recommendations

We used the methods and processes in Developing NICE guidelines: the manual (2014). For more information on how this guideline was developed, including where non-standard methods were used or there were deviations from the manual as agreed with NICE, see Appendix A.

The target group for this guideline was defined as all people aged 16 years and over:

- who may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions
- whose capacity to make specific decisions about aspects of their care may need to be assessed
- when specific best interestsdecisions are being made on their behalf if they are assessed as lacking capacity.

In identifying the population for the review work, it was crucial to note that lack of mental capacity can fluctuate, as described in the Mental Capacity Act Code of Practice. The Code of Practice also provides examples of an impairment or disturbance in the functioning of the mind or brain, which helped to focus the screening of the literature. Examples include:

- conditions associated with some forms of mental illness
- dementia
- significant learning disabilities
- the long-term effects of brain damage
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness
- delirium
- concussion following a head injury
- the symptoms of alcohol or drug use.

Any difficulties in identifying the population during the review process were overcome through close working with the Guideline Committee and examination of the descriptions in the full text of the study.

How the literature was searched

A single search strategy for all the review questions was developed. The questions were translated into a framework of 8 concepts and combined as follows: a) decision and capacity and (supporting people or best interests or safeguarding) or b) decision and capacity and mental health and assessment or c) capacity and advance planning. These reflected the question areas of planning in advance, supporting decision-making, assessment of mental capacity and best-interests decision-making. The search was restricted to material published since 2005. The searches were run between September and October 2016.

An additional search on planning in advance was undertaken in May 2017. The Guideline Committee highlighted additional papers and types of advance planning that had not emerged in the main search. These included areas such as joint crisis planning and ‘do not resuscitate’ (DNR) orders. A broader search on advance planning was conducted and filters were applied where appropriate to capture systematic reviews, clinical trials, economic evaluations and carer and user views.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

The results of the searches were screened on title and abstract and then full text using criteria based on the guideline scope and protocol. The included studies were critically appraised using tools highlighted in the manual and the results tabulated (see Appendix B for tables). Minor amendments were made to some of the checklists to reflect the range of evidence and types of study design considered in the evidence reviews. For more information on how this guideline was developed, including search strategies and review protocols, see Appendix A.

We presented the ‘best available’ evidence, which had implications for the final selection of evidence, for instance in terms of the country in which the study was conducted. The review protocols in Appendix A describe the flexibility we had to look for evidence from comparable international countries, but to prioritise UK evidence over non-UK evidence. This is in line with NICE methods and any flexibilities have been applied systematically. For qualitative data, for all questions, studies were limited to the UK only. This means we focused fully on the experience and views of the people who are the target population of this guideline. For quantitative data, non-UK studies (as defined in the protocol) could be used, based on the assumption that the findings of average effects of specified interventions are likely to be generalisable from countries similar to the UK. However given the volume of evidence, non-UK studies were used only where the UK evidence base was assessed as being not sufficient. The approach to quantitative data taken for each of the review questions is described in sections 3.1–3.5.

In terms of the quality of evidence, studies were rated for internal validity (how convincing the findings of the study are in relation to its methodology and conduct) and external validity (how well the study relates to the review question, particularly its applicability in terms of setting and population) using ++/+/- (meaning good, moderate and low). The internal quality rating is given in the evidence statements with both the internal and external rating reported in the narrative summaries and in the evidence tables in Appendix B.

The critical appraisal of each study takes into account methodological factors to assess internal validity such as:

- whether the method used is suitable to the aims of the study
- whether random allocation (if used), including blinding, was carried out competently
- sample size and method of recruitment
- loss to follow-up
- transparency of reporting and limitations that are acknowledged by the research team.

Critical appraisal also assesses the external validity of each study, judging the extent to which samples are relevant to the population we are interested in and whether the research question matches the guideline review questions.

Evidence rated as of only moderate or low quality was included in evidence statements, and taken into account in recommendations, where the Guideline Committee independently and by consensus supported its conclusions and thought a recommendation was needed.

A further table reports the details (such as aims, samples) and findings. For full critical appraisal and findings tables, arranged alphabetically by author(s), see Appendix B.

3.1 Planning in advance, including for people who experience fluctuating capacity

Introduction to the review question

The purpose of the first review question was to examine evidence on advance planning for people who may lack capacity, including for people who experience fluctuating capacity. Part ‘a’ of the question sought to identify data about the effectiveness and cost-effectiveness of tools and approaches for supporting advance planning for decision-making. Part ‘b’ sought evidence about views and experiences relating to different approaches to advance planning for people who may lack capacity. This included the views of practitioners and those of people who may lack capacity, their families and carers. In particular, question 1b aimed to identify what works and what does not work well and whether people feel advance planning for this population is holistic and person-centred.

Review questions

1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity?

1b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?

Summary of the review protocol

The protocol sought to identify studies that would:

- identify the interventions, tools and approaches that are effective and cost-effective in supporting advance planning for people who need support from health or social care practitioners to make their own decisions
- identify interventions, tools and approaches designed to support advance planning for people who may lack capacity in the future, or experience fluctuating capacity
- describe practitioners' views about advance planning for those who may lack the capacity to make decisions, including what works and what does not work well
- consider specifically whether people who may lack mental capacity, their families and carers think that interventions and tools aimed at supporting future planning are holistic and person-centred
- explore whether interventions, tools and approaches to forward planning acknowledge the fluctuating nature of capacity and support people to make decisions
- consider specifically whether interventions, tools and approaches supporting planning are coordinated across social care, health and other services
- consider whether interventions, tools and approaches to supporting advance planning involve carers and other interested parties.

Population

All people aged 16 years or over who may lack mental capacity and need support from health or social care practitioners to make their own decisions. This group is diverse and according to the Mental Capacity Act Code of Practice may include people suffering from dementia, mental illness, learning disability, brain damage or other conditions that may cause confusion, drowsiness or a loss of consciousness.

Intervention

Review and identification of the needs of adults who may lack mental capacity relating to future decisions about care and support. Supporting people to make decisions in advance, so that their wishes are known should they be assessed as lacking capacity to make those decisions in the future.

Setting

People's own homes, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts.

Outcomes

Person-focused outcomes (empowered and enabled to make decisions about their care and support, afforded access to their human rights and dignity and helped to maintain independence and social inclusion).

Service outcomes (competence and confidence among practitioners to implement and uphold the principles of the Mental Capacity Act, supporting decision-making and conducting best interestsdecision-making, transparency and quality of recording, efficient and effective use of resources). See 1.6 in the scope.

Study design

The study designs which were prioritised for the effectiveness and cost-effectiveness question included: systematic reviews of studies of interventions, tools and approaches related to this topic; randomised controlled trials of interventions, tools and approaches related to this topic; economic evaluations; cohort studies, case control and before and after studies and mixed methods studies.

The study designs which were prioritised for the views and experiences questions included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness and mixed methods studies and observational and cross-sectional survey studies of user experience.

How the literature was searched

A single search strategy for all the review questions was developed. The questions were translated into a framework of 8 concepts and combined as follows: a) decision and capacity and (supporting people or best interests or safeguarding) or b) decision and capacity and mental health and assessment or c) capacity and advance planning. These reflected the question areas of planning in advance, supporting decision making, assessment of mental capacity and best-interests decision-making. The search was restricted to material published since 2005. The searches were run between September and October 2016.

An additional search on this question was undertaken in May 2017. Since they were conducted as separate reviews the results of the additional search are presented separately from the results of the original search and appear in section 3.4.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4, a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- language (must be in English)
- population (must be over 16 years of age who may lack mental capacity, accessing health or social care services, their families or carers)
- intervention (all aspects of assessment, supported decision-making, future planning and best interests decision-making for adults who may lack mental capacity)
- setting (service user’s own home, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and

palliative care settings, educational settings, prisons and other criminal justice settings and family courts)
- country (for qualitative data, must be UK, for quantitative, UK studies are prioritised but non UK would be considered)
- date (must not be published before 2005)
- type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to either ‘a’ or ‘b’ of this review question – or flagged as being relevant to 1 of the other review areas – and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and a random sample of 10%.

See Appendix B for full critical appraisal and findings tables.

Overview of evidence

From the original single search – covering all review areas – our initial screen (on title and abstract) identified 80 studies which appeared relevant to review question 1. We retrieved and then reviewed full texts and included a total of 14 papers: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluation was judged to be moderate quality. As with all the review areas, only UK qualitative evidence was included. Since no UK based quantitative studies were found, we included 5 non-UK quantitative studies (including 3 RCTs) to supplement the evidence base.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements. The approach to synthesising evidence was informed by the PICO within the review protocol.

Studies reporting effectiveness data (n = 4)

Note that due to the heterogeneity of the evidence (the studies delivered different interventions to differing populations for differing lengths of time and used different outcome measures), data from each effectiveness study are presented separately, rather than combining them into a single meta-analysis.

1. Bravo G, Trottier L, Arcand M et al. (2016) Promoting advance care planning among community-based older adults: a randomized controlled trial. Patient Education and Counselling 99: 1785–95

Methods: Quantitative

Data: Effectiveness

Country: Canada

Outline

This moderate quality (+) randomised controlled trial (RCT) compared the impact of a multimodal advance planning intervention to a control intervention. The intervention was given to 118 older adults and their proxies, while 117 received the control. The study had moderate relevance (+) to the current topic area. The study was conducted in Canada, using older adults (mean age 77.6 years) from the community and their designated health proxies (mean age 70.5 years). Participants were of varying health, but with no single specified health problem. Those randomised to receive the multimodal advance planning intervention received 3 monthly sessions:

- session 1: a senior social worker visited their home to explain about decision-making and its difficulties
- session 2: a group session was held where they were taught to use a booklet developed to record preferences

- session 3: the senior social worker assisted them to complete the booklet.

The aim was to show them how difficult decision-making could be and start the process of clarifying and communicating preferences through completing the booklet. By contrast, the control group received 3 monthly sessions of a health intervention programme aimed to promote a healthy lifestyle. The main outcomes variable was the extent to which the older person's preferences were in agreement with the estimation of their preferences by their proxy when presented a series of vignettes about health decisions. Participants were also asked about their health and their feelings about health planning and the future. Outcomes were measured before the intervention, immediately after and again 6 months later.

Findings

At baseline, participants in the 2 groups were similar on all domains. Half rated themselves as being in good health, even though many of these had 1 or more illness. On the whole, proxies tended to predict a higher desire for treatment than subjects themselves did. Initially a third had previously documented their treatment preferences, and 46% had discussed them in some way with their proxy. After 3 sessions, 80% of those in the intervention group had completed one (that is, the booklet).

Overall this study found there were no significant improvements in the proxy's ability to predict the older adult's wishes in the intervention group compared to the control group. The intervention group showed significantly improved agreement compared to baseline on (1) incurable brain cancer specifically and (2) in combined health states overall. However, these domains also equally and significantly improved among controls, suggesting the intervention was not behind this effect. These unilateral improvements may instead have been a result of them all completing the outcome measure.

While not effective, the intervention was highly acceptable. Participants in the experimental group said they were highly satisfied with the intervention. They reported very few adverse side-effects, with just 1 older adult and 2 proxies reporting some upset/anxiety discussing the prospect of having to make difficult decisions for their loved one.

2. Elbogen E, Swanson J, Appelbaum P et al. (2007) Competence to complete psychiatric advance directives: effects of facilitated decision making. Law and Human Behavior 31: 275–89

Methods: Quantitative

Data: Effectiveness

Country: USA

Outline

This moderate quality (+) randomised controlled trial (RCT) was concerned with Psychiatric Advanced Directives (PADs), and compared the effects of a training/support intervention to those of a ‘treatment as usual’ control condition. The intervention was delivered to 213 service users with a mental illness, compared to 206 in the comparison group. This study was assessed as highly relevant (++) our topic area. The study was conducted in the USA, with participants from 2 community mental health programmes that were being treated for some form of psychosis. Those randomised to receive the intervention were offered to meet with a trained facilitator to create a PAD. The session was structured but flexible, giving general orientation as well as direct assistance. By contrast, the control group received written materials, the standard leaflets and information/support usually available (a description of PADs, copies of the standard forms in North Carolina, and contact details for the region’s free helpline). The goal was to improve performance on PAD competence, measured using the Decisional Competence Assessment Tool for PADs (DCAT-PAD), completed at baseline and then and a month later. This tool assesses 2 competencies – ‘competence to write a PAD’ and ‘competence to make treatment decisions’. Each competency had an ‘understanding’ domain (for example, understand the pros and cons of hospital treatment) and a ‘reasoning’ domain (for example, reasoning about how hospital treatment would affect their lives).

Findings

At baseline it was found that a higher DCAT-PAD score was associated with higher IQ, better verbal memory, better abstract thinking and less psychiatric symptoms.

In the area of ‘competence to write a PAD’ the intervention group did not show improvement in the domain of ‘understanding’, but showed significant improvement in the domain of ‘reasoning’ compared to controls. In a multivariate analysis the participants in the intervention group that had below average IQ scores were the ones that showed improvement in reasoning compared to comparable controls, while participants with a higher IQ did not.

Similarly, in the area of ‘competence to make treatment decisions’ those in the intervention group showed no significant improvement within the ‘understanding’ domain compared to controls, but did show significant comparative improvements in the ‘reasoning’ domain. Again, the authors broke this down and found that those with lower IQ had far higher improvement in reasoning compared to controls, while those with an IQ over 100 again had a non-significant difference in improvement.

The authors concluded that the intervention group were more competent to complete a PAD at 1-month follow-up, at least in the domain of ‘reasoning’, but specifically among people whose pre-morbid IQ was estimated below the median score of 100. They concluded that the intervention led to an increased chance of these patients producing a valid as well as complete advance directive.

3. Pearlman R, Starks H, Cain K et al. (2005) Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. Archives of Internal Medicine 165: 667–74

Methods: Quantitative

Data: Effectiveness

Country: USA

Outline

This randomised controlled trial (RCT) was of moderate quality (+) and investigated the impact of an educational and motivational advanced care planning intervention for older veterans compared to the hospital’s usual 8-page advance directives packet. The intervention was delivered to 119 participants, compared to a 129 in the control group. This study was assessed as moderately relevant (+) to our topic area, mostly limited by being a US study of veterans only. Participants were outpatients from 23 health providers. They were 55 years of age or older with chronic conditions although at the time of the study they did not have severe cognitive impairment and were able to participate in advance care planning.. Those randomised to receive the intervention were given a workbook called 'Your Life, Your Choices', and received prompts to complete it, as well as a 30-minute session with a social worker to review their progress, and prompts for their care providers to discuss the preferences with them. By contrast, the control group were posted the hospital’s standard 8-page advance directives packet – including a living will and forms for durable power of attorney for healthcare. The goal of the intervention was to improve rates of completion for advanced care plans, as well as improve awareness and concordance of these preferences between patient and their care provider, and their proxy decision-maker. Patients completed a questionnaire to assess their values, personal beliefs and preferences for treatment, and then family member proxies and care providers were asked about their ‘perceptions of the person’s preferences to assess concordance. Patients were also assessed on quality of life, physical health and mental health. Also monitored were reports of discussions with their service, and number of living wills filed in medical records.

Findings

At follow-up the participants that had received the intervention were more likely to have had a discussion about advance care plans with their care providers. They were also more likely to have an advance care plan filed in their medical record.

Compared to controls, the intervention led to greater concordance between patients and their professional care providers in some domains of the patients’ preferences. Specifically, there was slightly higher agreement found for perceptions of ‘treatment preference’ in some scenarios, and also on perceptions of ‘values’ and ‘personal beliefs’. However, professionals were still quite likely to over- or under-treat in several scenarios. For patients and their proxies, a comparative improvement in concordance was only found in the area of ‘personal beliefs’. The authors concluded that the results had been mixed, with some improvements found but not for many aspects of treatment and not to a high degree.

4. Seal M (2007) Patient advocacy and advance care planning in the acute hospital setting. Australian Journal of Advanced Nursing 24: 29–36

Methods: Quantitative

Data: Effectiveness

Country: Australia

Outline

This mixed methods study was deemed to be of moderate quality for its qualitative component (+), but poor for its quantitative component (-). Overall it was moderately relevant to the current topic area (+).The study was a prospective, quasi-experimental (non-randomised) cluster controlled trial, backed by semi-structured focus groups. A ‘patient advocacy’ intervention was rolled out on 4 wards at a hospital, aiming to promote advanced care planning, improve the systems in place, and improve the nurses’ skills. Nurses on these wards completed a questionnaire before the implementation and again 6 months later. The results were compared to those of nurses on 4 other wards that hadn’t yet received the intervention. Additionally, semi-structured focus groups were conducted with 18 nurses from both the intervention and control wards beforehand, and with 3 nurses from the intervention ward at follow-up.

A 5-point Likert scale was administered to quantitatively assess nurses’ feelings towards 2 service user-related areas and 1 service outcome:

- fostered patient advocacy – how much they felt the environment encouraged patient advocacy
- quality end-of-life assurance – meaning how much they felt patients were getting a ‘good death’
- the nurses’ own ‘associated job satisfaction’.

Findings

The response rate averaged at 55% for the nurses working in the wards. Across all times and conditions 77–87% of nurses agreed that ‘prolonging the dying process with inappropriate measures is nursing’s most disturbing ethical issue’.

Also, 98–100% of nurses across times and conditions stated that ‘respect for patient self-determination at end-of-life was important’ and 94–96% said that delivering quality end-of-life care would give job satisfaction.

The intervention appeared to lead to some significant improvements on all three outcomes:

- fostered patient advocacy: on the question ‘In my work environment I am encouraged to ensure patients understand and can make informed choices about their end of life treatment’, 84% of nurses agreed compared to 49% at baseline, and compared to 42–55% at follow-up in controls
- quality end-of-life assurance: for the question ‘In practice I am able to uphold the end of life wishes of patients’, 73% of nurses agreed compared to 54% at baseline, and compared to 54% at follow-up in controls
- associated job satisfaction: for the question ‘I experience job satisfaction because in practice I can deliver appropriate end-of-life care’, 67% of nurses agreed compared to 47–53% at baseline, and compared to 47–53% at follow-up in controls.

Many nurses (30–49%) initially agreed that they ‘felt powerless to advocate for their patients with respect to the appropriateness of their end-of-life care’, and this reduced to 19% post-intervention for those that received it.

In pre-interviews, nurses stated they currently had no formal pathway for patient advocacy. They were concerned that patients suffered as a result of treatment aimed at restoring health when death was imminent. They also expressed concern about when doctors offered ‘domineering’ family members decision-making powers regarding resuscitation. Finally, they mentioned that patients were willing to talk about dying when it’s brought up, but terminology often made it hard – as did the insistence that curing alone is the goal.

In post-interviews, nurses stated that previously they had felt uncertain about whether initiating end-of-life care discussions was their place. After implementation they felt the culture had changed and patients were appreciative, as it was something they had already thought about. Finding shared terminology made the process clearer. Some had noticed respectful patient care had increased – however they noted an important point: that when it came down to it, doctors did still sometimes completely overlook the patient’s preferences that had been established.

Studies reporting views and experiences data for people who may lack mental capacity, their families and carers, n = 8

5. Ashton S, Roe B, Jack B et al. (2014) End of life care: the experiences of advance care planning amongst family caregivers of people with advanced dementia – a qualitative study. Dementia 15: 958–75

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study was of good methodological quality and relevance to the review question. It aimed to explore the experiences of advance care planning among family caregivers of people with advanced dementia. Qualitative data were collected using semi-structured interviews with family carers (n = 12) in a specialist dementia unit within a nursing home. Participants were recruited via purposive sampling.

Findings

Content analysis of interview data suggests that family carers of people with advanced dementia found advance care planning relevant and welcomed the opportunity to be involved in end-of-life care decisions and discuss the issues of advance care planning openly and honestly with the care staff, though they found it could be an uncomfortable experience. Family carers reported that advance care planning discussion allowed them to confront important and inevitable decisions that had to be made as their loved one’s condition deteriorated. ‘Dying with dignity’, the need to ensure the personal history and personality of the person to be kept to the end were reported to be important in advance care planning discussion, also the issues of complex nursing and medical interventions to relieve suffering or prevent undue distress in the dying person. Family caregivers would need encouragement to ask the right questions during advance care planning to discuss the appropriateness of nursing and medical interventions at the end of life.

6. Bisson J, Hampton V, Rosser A, et al. (2009) Developing a care pathway for advance decisions and powers of attorney: qualitative study. British Journal of Psychiatry 194: 55–61

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This moderate quality (+) qualitative study describes the development of a care pathway for advance decisions. In developing the model for the pathway the study conducted qualitative interviews with 13 practitioners, service users, law practitioners and ethical experts. Only the first part of the study is relevant to the views and experiences question. Despite this, the study had good relevance (++) to the topic area. The study was conducted in the UK and aimed to gather opinions on the use of advance directives with individuals with Huntington's disease. The study used interviews to gather data on when lasting power of attorney should be discussed with the individual and which practitioner was responsible for initiating the lasting power of attorney process and assessing capacity (this study may be relevant to later review questions).

Findings

The findings from the qualitative phase of the study are grouped into 5 themes related to when lasting power of attorney should be discussed, by whom and where. Only findings related to advance decision-making are presented below.

Information and method of delivery

Services users expressed confusion about the nature of advance decision making and powers of attorney: people said that they wanted clear information in either verbal or written format. Interviewees considered information on Huntington's disease to be important, particularly about treatment options and the location of specialist facilities to help with planning. Informants said that a leaflet and a verbal explanation would be useful: 'The Huntington's Disease Association leaflet was actually the best one of all. It gave a lot of information but it’s not too in-depth either’ (service user p60).

Location and individuals

Some interviewees preferred to discuss their conditions at home and others preferred a clinical setting. A good relationship with the practitioner and good communication were important: ‘I think it would be comfortable if it was made less like a hospital appointment. It’s not a hospital appointment. It is something very important to us’ (carer p60); ‘It helped that we know him. I wouldn’t have wanted someone I didn’t know. It made it easier. We have a rapport with him’ (carer p60).

Timing and duration of the process

Practitioners were reluctant to introduce the idea of discussing advance planning because of a concern about causing distress. Service users were much more positive about talking about advance planning early, because of increased autonomy. The duration of the process, it was felt, should be flexible., allowing several sessions to decide and also a 2-week ‘cooling off period’: ‘In order for the individual to have the most control, the discussion should take place earlier. The earlier the better really’ (practitioner p60); ‘I think if I had symptoms, then I’d be panicking to rush this thing through’ (service user p60).

Form of documentation

Interviewees recommended simple decision forms to record advance planning, including personal statements and wishes. Informants reported that the topics that the form should detail were: ‘life saving treatments, percutaneous endoscopic gastrostomy feeding, location of future care, capacity assessment, witness details and a distribution list’ (p56).

Another important elements was: ‘A summary sheet for patient files, and checklists for education, completion and review were considered important’ (p56). ‘I would say it should be a standardised document and additional information could be filled in by speaking to the person. I’d say that was the easiest way to do it’ (practitioner p60).

7. Manthorpe J, Samsi K, Rapaport J (2014) Dementia nurses' experience of the Mental Capacity Act 2005: a follow-up study. Dementia 13: 131–43

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a moderately well conducted (+) qualitative study with a high degree of relevant to the topic area (++). One section has specific relevance to advance planning. This study interviewed 15 specialist dementia nurses about their attitudes to the Mental Capacity Act and their practice experience of its implementation. The study was conducted in the UK and recruited a sample of 15 nurses. The study is the second phase of a previous piece of research into the Act. The paper used qualitative interviews with dementia nurses to gain insight into their practice. The study aimed, specifically, to gather nurses reflections on the Mental Capacity Act process around mental capacity and the challenges associated with it. This paper is likely to be relevant to later review questions as it covers several aspects of the Act.

Findings

The study found that nurses often did not come into contact with patients until they lost capacity, making involvement in advance planning difficult. A key part of their role was advising carers, but some were hesitant to do so. The nurses all reported that they were involved in providing advice to carers about lasting power of attorney provisions in relation to their relatives. Nurses advised carers of the 'practical and financial risks' (p137) of not obtaining lasting power of attorney. Nurses had recruited solicitors to speak to carer groups and at an Alzheimer's cafe. Nurses said that advising on the Act was a key part of their role: 'We always talk about dementia being sort of like a long-term condition and the person would get progressively more unwell and trying to put your house in order before it gets to a stage where they lose capacity' (p137). A total of 30% of respondents said that encouraging end-of-life planning was part of their role. Some nurses felt that carers would be informed of end-of-life planning from their attendance at 'carer education programmes' (p137). This belief was thought to limit their intervention in end-of-life care. Nurses reported that resuscitation was the most common decision discussed along with the move into residential care.

Two nurses said that they had been encouraged to talk to carers about the advance planning part of the Mental Capacity Act. Nurses reported making statements of wishes in nursing notes. GPs were sometimes party to these wishes, but not always. Documents around advance planning were not common and 1 nurse said that statements were usually verbal which led to uncertainty around care wishes later.

8. Poppe M, Burleigh S, and Banerjee S (2013) Qualitative evaluation of advanced care planning in early dementia (ACP-ED). PLoS ONE 8: e60412

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study was considered to be of moderate methodological quality (+) and good relevance to the review question (++). It aimed to explore the experiences and acceptability of discussing advance care plans with people with memory problems and mild dementia shortly after diagnosis. Qualitative data were collected using in-depth interviews with patients (n = 12), family carers (n = 8) and staff members (n = 6) from 2 memory service and community mental health teams. Participants were recruited via purposive sampling.

Findings

Data in this paper suggested that advance care planning in dementia is a positive intervention, perceived by patients with dementia and carers as a positive and helpful experience, though it could also be dispiriting for some. Patients felt relieved and more secure having had their preferences for future care known. Carers found it helpful to know the patient’s wishes in case they had to make a decision on behalf of the patient in the future.

The best time to discuss advance care planning was soon after diagnosis when patients have had time to think about the diagnosis and the future but still have the capacity to make decisions about future care.

The main barriers to advance care planning were patients' non-readiness to accept the diagnosis and discuss advance care planning, and not having detailed information about advance care planning before proceeding to discussion. Disagreement between patients and family members could disrupt the advance care planning process. For staff, the main barrier was a lack of confidence in discussing/facilitating advance care planning which could be addressed by receiving good training and refreshers to improve knowledge about dementia and improve confidence. Staff need to have skills and competence in being open-mined, non-judgemental, ready to listen and able to deal with difficult conversations and manage conflicts. This could help towards building a good relationship with the patient and the patient's family in order to establish trust throughout the advance care planning process.

9. Robinson L, Dickinson C, Bamford C et al. (2013) A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...' Palliative Medicine 25: 401–8

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This good quality (++) qualitative study used focus groups and interviews to explore the views of 95 health and social care practitioners about the implementation of advance care planning. This study has good relevance to the review question (++) and the guideline area more generally. The study sought the views of a wide range of practitioners in North East England, both clinical and non-clinical. The study focused on those working with people with dementia or another life-limiting conditions. The study is non-specific about the life-limiting conditions. The study has an explicit focus on advance planning and used focus groups and qualitative interviews.

Findings

The focus groups and interviews produced thematic findings around advance care planning.

Value and usefulness of advanced care planning

Many participants described advance care planning as positive in theory but difficult to enact. Some said that issues like end-of-life care were difficult to discuss with people but that it was positive to help people resolve fears. Some people questioned the usefulness of advance care planning and the feasibility of reflecting patient choices. They also said that delivering on patient preferences would be challenging. Dementia specialists said that advance care planning duplicated person-centred care measures already in place. There was concern that advance care planning would be a 'tick-box' exercise because it may be seen as a quality indicator of a service.

Delivering patient choice and outcomes

The study described the difficulty for different practitioners to deliver preferences. In some cases appropriate care is not available, and so there are no other options. Ambulance staff found it difficult to adhere to wishes, dealing with DNR (do not resuscitate' orders and balancing patient wishes with family wishes.

Defining advance care planning and legal issues

Some practitioners reported confusion around the legal status of an advance care plan and what was included. Practitioners were most confident around lasting powers of attorney (LPA) and most confused about the content of advance decisions to refuse treatment (ADRT). Generally, practitioners showed a lack of knowledge of the Mental Capacity Act. Practitioners interchanged terms like 'advance directives', 'do not resuscitate orders' and 'living wills'. Health and social care interviewees reported confidence in discussing LPA in relation to property and affairs. They saw signposting to legal advice as part of their role.

Practicalities of implementing advance care plans

Practitioners were uncertain about implementing advance care plans, in relation to the following factors: Who is responsible, supporting documents, when to instigate an advance care plan and the costs of an advance care plan.

Roles and responsibilities

There was debate among practitioners as to who should take overall responsibility for the advance care plan and many participants felt they lacked the skills to implement advance care planning. This was true whether they had received training or not.

Palliative care specialists, solicitors, community nurses and some GPs were more likely to see advance care planning as part of their practitioner responsibilities. Others said that it was either outside of their remit or that they didn't have enough time, training or resources.

Documentation

The variety of documents used for advance care planning caused confusion. Practitioners weren't sure they were transferable to other care settings and different practitioners used different forms for advance care planning. The forms were criticised because they couldn't always capture individual contexts. Some practitioners used their notes, like nurses, which were not available to other practitioners, and others did not formally record advance care planning discussions.

Timing of advance care planning

Interviewees reported delays caused by a lack of clarity about who should complete the advance care plan. Delays led to plans not being in place by the time a person lost capacity. Some practitioners described cues to gauge whether someone was interested in advance care planning. These were talking generally about the future and asking if someone liked to plan ahead. For those with dementia, planning ahead was much harder to gauge, and the right time for advance care planning was not clear. The timing of ADRTs was an issue, and there were problems with knowing if they remained relevant as treatment changed.

Financial costs of lasting power of attorney

Costs were a potential barrier to people using lasting powers of attorney. Practitioners said that families may not want to pay, even though a person had capacity.

10. Samsi K, Manthorpe J, Rapaport P (2011) 'As people get to know it more': experiences and expectations of the Mental Capacity Act 2005 amongst local information, advice and advocacy services. Social Policy and Society 10: 41–54

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This study used qualitative findings to gather the views of 6 Age Concern information and advice workers. The study has a high level of relevance to the guideline (++) in general and to the review question on advance planning. The study is deemed to be of moderate quality (+). The study used hour long interviews to discuss implementation levels of the Mental Capacity Act, particularly around advance planning. It was part of a programme of research related to Mental Capacity Act implementation with specific focus on advice for those with dementia. In particular it looked at planning.

Findings

Findings are organised under 4 themes. Only the findings related to advance planning are extracted below.

Mental Capacity Act understanding

Informants had gained knowledge though Age Concern information network. This included information about changes to enduring power of attorney to lasting power of attorney (LPA), the role of Independent Mental Capacity Advocates (IMCA) and changes to legal definitions of mental capacity. Few know the Act in detail and only 1 had made a referral to IMCA services.

The staff saw the IMCA service as valuable for those who did not have the support of family members. Some staff were critical of the LPA registration system. Staff felt it may discourage people due to complexity and price. The staff said that some attorneys were not clear of their roles which led to problems with advocacy

The role of training

Staff had experienced training in the Mental Capacity Act, which they had found useful. Some commented that it had given them confidence drawing up LPAs, and knowing when to deal with a query themselves or refer to a legal practitioner.

The impact of the MCA on perceived organisational role

Age Concern staff said that they provided information that was valuable to older people. Workers said they signposted people for advance planning and encouraged the drawing up of LPAs. They often sign posted people to solicitors.

Commonly raised areas

Enquires about LPAs were the main query from the public. Callers were signposted to more specialist agencies or told to contact a solicitor. Participants said that social workers had made enquiries about decisions around moving people with dementia to more appropriate care.

Role of Age Concern

Age Concern provided expertise, experience and information to older people. The study indicates that the service was a useful resource to help with planning and that the staff had more time to help other services. The service also offered independent advocacy and had links with other organisations for signposting.

Predictions/expectations of the MCA in relation to older people

Participants said that they hoped that the MCA would encourage people to plan. Staff said that demand for information and advice was likely to rise. Staff said that new LPA and IMCA powers were significant but it was uncertain whether older people with dementia would use the MCA to make future plans. Some people were thought to be unaware of the act, and this was thought to be a barrier to planning.

Age Concern staff felt that older people were reluctant to face the changes ahead and address legal arrangements. Some staff said that they hoped the MCA would encourage people with worries about their future to make plans. The service received lots of enquires about LPAs.

The barriers to future planning were: lack of information, poor legal literacy and limited public awareness. Services were seen as a way to spread information and encourage people to start using the MCA.

11. Sinclair J, Oyebode J, Owens R (2016) Consensus views on advance care planning for dementia: a delphi study. Health and Social Care in the Community 24: 165–74

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This study was considered to be of moderate methodological quality (+) and moderate relevance to the review question (+). It was conducted using the Delphi method to investigate consensus views of how and when advance care planning should be explained and carried out with people with dementia, what should be covered and who should be involved in the process. A 3-round Delphi study used questionnaires assessing levels of agreement from 17 experts (3 policy-makers, 6 old age psychiatrists, 1 person with dementia and 7 family members) on related items above.

Findings

The consensus reached in this study was as follows.

- When? The best time to discuss advance care planning was when the person has come to terms with the diagnosis of dementia and feels ready to engage in the discussion. This respects the person’s personal choice and autonomy and the fact that the person has the right to choose whether to pursue advance care planning or not.

- What? Advance care planning needs to prioritise covering specific points such as financial aspects and also general discussion of values.
- Who? Advance care planning needs to include spouses.
- How? Advance care planning explanation needs to be tailored to the individual concerned, discussing how decisions are better made at an early stage, while the person still maintains control and has ideas of what is important to them. It will also make it easier for families and health practitioners to act in a way the person would have wanted. There was consensus that the process should be couched in terms of 'dealing with certain possibilities', due to the uncertain future relating to the natural progression of the disease of dementia. This softens the notion that what is discussed is necessarily going to happen – advance care planning may not be needed but it would be helpful to discuss it.

There was consensus that practitioners should not be involved in the advance care planning process and they were viewed as carrying some responsibility for low uptake.

12. Wilson E, Seymour J, Perkins P (2010) Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings. Palliative Medicine 24: 396–402

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This study used qualitative methods to investigate staff perspectives on working with Mental Capacity Act guidelines. The study spoke to staff working either in palliative care or specialised neurological centres. The sample is of 26 practitioners and the study is deemed to be of good relevance (++) to the review question and to be of good quality (++). The study focuses on end-of-life care planning. The study used semi-structured interviews to gather views and experiences from practitioners working with individuals affected by multiple sclerosis, Huntington's disease and acquired brain injury in the neurological centre, and advanced cancer. The practitioners were from multidisciplinary teams based at 6 units.

Findings

Participants used a checklist, which was kept in the person's notes, and which signposted any advance care planning decisions and discussions. This was seen as simple and it prompted checking for advance care planning records.

Staff said that they did not agree with the terminology related to the Court Appointed Deputy, which had unfamiliar terminology, and was difficult to convey to families and service users.

Many interviewees said that they did not have confidence explaining the options relating to advance care planning. This lack of confidence stopped staff from discussing it with patients. One team interviewed had solved the issue of unfamiliar terminology by developing a leaflet explaining the key terms.

Staff interviewed said that they had missed training, had not been trained via a useful method, or felt they lacked training. Some staff said that sensitivity was needed to discuss difficult topics.

Staff were unsure who was responsible for initiating the advance care planning process. They were also unsure about how to complete the documents. The staff in the neurological centre had more confidence but those in palliative care did not know whether it was a nursing or medical responsibility.

Knowing when to initiate advance care planning was also a point of uncertainty, as well as when to complete the documentation. Staff reported that advance care planning was meant to start when a person was admitted. Some staff said this was not felt to be appropriate because:

- other issues need to be discussed at admission,
- there was too much paperwork
- and questions from carers and patients about the Mental Capacity Act needed expertise to answer.

Most staff said that the introduction of advance care planning documents had not changed their working practice a great deal because they were already dealing with these types of issues previously. However the MCA did formalise and structure discussions about future care.

Economics

A decision tree model was developed for this review question, which compared the costs and outcomes of Advance Care Planning with standard care for people in their last year of life. The perspective taken was that of NHS and personal social services (PSS) costs. Costs were included in regard to the following service use: cardiopulmonary resuscitation; life-prolonging treatment in the form of assisted ventilation; and place of death. Outcomes were considered in form of quality-adjusted life years (QALYs) as experienced by carers of people dying in the 2 groups. Findings were presented in the form of incremental cost-effectiveness ratios (ICERs). All costs were presented in 2015/16 prices. No discounting was applied as the model referred to a time horizon of 1 year. Probabilistic and 1- and 2-way sensitivity analysis was applied to explore the impact of values from distributions on the incremental cost-effectiveness ratios (ICER). Main data sources included: 1 RCT from Australia (which was used to inform data on uptake, wishes made and followed, and health-related quality of life for carers); 1 cohort study from England (which was a secondary data analysis of a nationally representative sample); and Guideline Committee views (which were gathered in a Delphi-like process to extract information about costs of advance care planning). Unit costs were taken from national sources such as the PSSRU Unit Costs for Health and Social Care 2016.

The mean total cost of advance care planning was £821 with a minimum cost of £214 and a maximum cost of £1,874. Mean costs per person linked to service use in the advance care planning vs standard care groups were as follows: (1) cardiopulmonary resuscitation: £39 (SD 31, 95% CI 30 to 33) vs £41 (SD 34, 95% CI 32 to 36); (2) life-prolonging treatment in the form of assisted ventilation: £436 (SD 225, 95%CI 212 to 238) vs £501 (SD 225, 95% CI 212 to 238); (3) place of death: £2,416 (SD 236, 95% CI 2,414 to 2,444 to 257) vs £2,508 (SD 250, 95% CI 235 to 266). Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572). Mean total costs in the standard care group were £3,072 (SD

354, 95% 332 to 376). The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean QALY was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in QALYs was 0.04 (SD 0.02, 95% CI 0.03 to 0.04).

The mean ICER for the base case was £18,600. Confidence limits on ICER do not give the information needed when there is a (non-negligible) chance that the ICER value could be negative (which was the case for some simulations in this analysis). The uncertainty surrounding the ICER was thus presented differently, in form of cost-effectiveness planes and curves. The probability that advance care planning was cost-effective was above 55% at a willingness-to-pay (WTP) threshold of £20,000 and above 70% at a WTP threshold of £30,000.

One- and 2-way sensitivity analysis was carried out on 2 parameters that had the strongest impact on the ICER: duration of advance care planning and the period over which carers in the standard care group experienced QALY losses. It showed that if the mean duration of advance care planning was 2 hours instead of 4 hours, the ICER decreased to £8,233 and the probability that advance care planning was cost-effective increased to almost 80% at a WTP threshold of £20,000 and just under 90% at a WTP threshold of £30,000. The reduction in mean duration of advance care planning could offset a reduction of QALY gain (if the time that carers in the standard care group experienced reduced health-related quality of life was 0.25 years instead of 0.43 years). The mean ICER was £13,591 and the probability that advance care planning was cost-effective was between 60 and 70%.

Studies reporting cost-effectiveness (n = 6)

There is a large amount of economic evidence that advance care planning for people reaching end of life can reduce the costs of hospital care, but there is a lack of evidence of overall cost impact and cost-effectiveness. Overall, no final conclusions could be drawn about the cost-effectiveness of advance care planning. The quality of evidence is mixed and most studies are from the US. There is a small amount of economic evidence that joint crisis plans (JCP) for people with psychosis or borderline personality disorder can lead to reductions in compulsory treatment under the Mental Health Act 1983 and be cost-effective from a public sector perspective. The quality of studies is high.

Studies concerned with advance care planning (advance care planning) for people reaching end of life

1. Dixon J, Matosevic T, Knapp M (2015) The economic evidence for advance care planning: systematic review of evidence. Palliative Medicine. 29: 869–84

Method: Systematic review

Data: Cost-effectiveness

Country: UK

Outline

This is a systematic review of economic evidence in relation to advance care planning. Studies were included if they were published between 1990 and 2014, reported economic outcomes in relation to advance care planning and in which advance care planning was a stand-alone intervention or formed an important component of a wider palliative care or support programme. While the authors did not define economic outcomes, it was clear from their reporting of study details that this referred to costs (and cost-effectiveness results, although no study was identified which measured this). Studies were excluded if they were solely about medical orders or advance directives in relation to power of attorney and if they were targeting psychiatric patients or children.

Findings

In total n = 18 studies were identified, of which n = 5 used a randomised design, n = 10 natural experiments and n = 3 non-randomised designs. Sample sizes ranged from n = 50 to n = 3000+. N = 7 studies focused on hospital-based samples; n = 3 studies were from nationally representative data from the US Health and Retirement Study of older people. The review found no published cost-effectiveness studies. Included economic studies were costs–savings ones. Different types of costs were evaluated using different methods and data sources but the focus was on costs of hospital care. Cost savings ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer. N = 11 studies reported positive results in regards to cost savings largely due to reductions in hospital admissions or the use of intensive care.

While this systematic review found that most studies did not provide sufficient detail that would have allowed analysis of the source of cost savings, the majority reported reductions in a range of service outcomes that were likely to explain some of the cost savings. This included reductions in: hospital deaths; intensive care unit (ICU) admissions; life-prolonging treatments; hospitalisations; and length of hospital stay. In addition, the systematic review highlighted the following issues of economic studies on advance care planning: of the n = 18 identified studies, n = 8 were not evaluations of advance care planning but retrospective single cohort studies, which used secondary data to measure an association between advance care planning and costs. Another issue was the definition of advance care planning and how it was measured. This ranged from evidence of documented medical decisions to counselling and support services led by nurses or social workers and more complex palliative care interventions, of which advance care planning was only a component. The authors identified a particular challenge in interpreting findings from studies, which analysed secondary data as they provided limited data on the process of advance care planning and the factors known to influence the quality and effectiveness of advance care planning such as when and how it was first initiated, the professionals involved and the frequency of reviews.

2. Klingler C, Schmitten J, Marckmann G (2016) Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative Medicine 30: 42 –33

Study design and type: Systematic review of economic evaluations

Country: US, Canada

Outline

This study was a systematic review of economic evaluations on advance care planning published between 1994 and 2010. The review stated that it included interventions, which contained a communication process facilitated by a professional caregiver involving the patient or legal proxy about the patient's preferences for future medical care. This could include interventions, in which advance care planning was part of a more comprehensive programme to improve end-of-life care.

Findings

The review identified n = 7 studies including 4 RCTs, 1 before and after study and 2 cohort studies. Sample sizes of studies ranged from n = 43 to n = 3000+. Populations were often defined by their medical conditions which included cancer, heart failure, diabetes and chronic obstructive pulmonary disease. Studies collected different types of costs with a focus on costs of hospice and hospital care. Authors conclude that limited data indicate net cost savings may be realised with advance care planning. The review found significant cost reductions ($p < 0.05$) in n = 3 studies; n = 2 studies did not report significance and n = 1 found a non-significant effect. Cost-savings ranged from USD 1,041 to USD 64,827 per patient; relative cost reductions ranged from 5% to 68%. Only n = 3 studies reported the costs of implementing advance care planning; costs were CAD 113, USD 452 and USD 1,968. Other effects reported included improved patient satisfaction in n = 2 studies, but n = 1 found no significant effect on patient or family satisfaction. Studies which evaluated programme costs showed that that these were relatively small, amounting to 6 to 15% of cost savings.

Findings are discussed in the context of previously published findings from studies that investigated advance directives (ADs) – defined as presence of signed legal documents – and which do not find cost reductions; authors conclude that this might suggest that advance care planning is more likely to lead to cost savings if it is implemented comprehensively, because it increased compliance with end-of-life wishes.

3. Abel J, Pring A, Rich A et al, (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive and Palliative Care 3: 168–73

Study design and type: Cost-effectiveness and saving, prospective cohort study

Country: England (UK)

Outline

This is an England-based prospective cohort study (n = 450), which examined the cost-effectiveness of advance care planning for individuals reaching end of life in a hospice in the South West of England. Advance care planning was defined as discussions taking place about place of death using the ‘Planning Ahead’ document, which includes general treatment preferences as well as advance decisions. Both groups received specialist palliative care provided in-hospice, which includes inpatient and outpatient services, visits from specialist palliative care community nurses at home and a day care centre. The primary outcome measure was place of death (including whether person died in their preferred place of death for those who had expressed a preference/were part of the advance care planning group). Costs included those from the hospital only.

Findings

N = 14 (75%) achieved their choice of place of death; for those who chose home, n = 34 (11.3%) died in hospital; for those who chose a care home n = 2 (1.7%) died in hospital; for those who chose a hospice n = 14 (11.2%) died in hospital; for those who chose to die in hospital n = 6 (86%) did so. In the standard care group, n = 112 (26.5%) died in hospital.

Individuals in the intervention group spent a significantly lower mean number of days in hospital in the last year of life (18.1% vs 26.5%, p < 0.001), had a non-significantly (p = 0.3) lower mean number of emergency admissions: 1.61 (95% CI 1.4 to 1.8) vs 1.75 (95% CI 1.6 to 1.9). Mean costs for emergency admissions were non-significantly (p = 0.4) lower in the intervention group: £5,260 (95% CI 4,586 to 5,934) vs CG £5, 691 (95% CI 4,984 to 6,398). The mean cost of hospital treatment during the last year of life for those who died in hospital was significantly higher for those dying in hospital: £11,299 vs £7,730 (MD 3,569; p < 0.001). Authors concluded that those who used advance care plans spent less time in hospital in their last year and that advance care planning was associated with a reduction in the number of days in hospital in the last year of life leading to fewer hospital costs. However, the study had a number of limitations. Findings on costs were not presented for people receiving advance care planning versus those not receiving advance care planning so that not final conclusions could be drawn about the overall cost impact of advance care planning. In addition the cost perspective was limited to hospital costs. The study was a cohort study which only controlled for a very small number of variables so that effects might be explained by other factors, such as whether the person had a carer or not. The study referred to a very specific population, that is, those who were accessing hospice services. This is likely to present a small proportion of the overall population at the end of life (for example, in England only 4% of older people die in a hospice).

Studies concerned with joint crisis plans (JCPs) for people with severe mental illness

4. Flood C, Byford C, Henderson C et al. (2006) Joint crisis plans for people with psychosis: economic evaluation of a randomised controlled trial. BMJ 333: 729

Study design and type: Cost effectiveness, RCT

Country: England (UK)

Outline

This is an England-based, single blinded RCT (n = 160), which examined the cost-effectiveness of JCP versus standardised service information about the Mental Health Act (MHA), complaints procedures, access to case records and treatment options. Joint crisis plans included an introductory meeting at which a facilitator explained the procedure to the person with mental illness and to their care coordinator; contents were discussed and plan completed at a second meeting, which was also attended by a psychiatrist. The study population referred to people of 16 years and above with clinical diagnosis of psychotic illness or non-psychotic bipolar disorder, who were not currently receiving inpatient care, and had experienced an admission in the previous 2 years. Primary outcomes measures included admission to hospital and length of time spent in hospital. Secondary outcome measures included objective coercion (that is, compulsory treatment under the Mental Health Act 1983) and service use over 15 months.

Findings

Findings suggest that, in terms of outcomes, there was a significant reduction in use of MHA (=compulsory admission) in the intervention versus control group (RR 0.48, 95% CI 0.24 to 0.95, p = 0.03) and a non-significant reduction in hospital admissions (RR 0.69, 95% CI 0.45 to 1.04, p = 0.07). In terms of total mean costs at 15 months those were non-significantly lower in the intervention group (£7,264 vs £8,359; MD £1,095; 95% CI−2814 to 5004; p = 0.57).

5. Barrett B, Waheed W, Farrelly S et al. (2013) Randomised controlled trial of joint crisis plans to reduce compulsory treatment for people with psychosis: economic outcomes. PLoS One 8(11)

Study design and type: Cost effectiveness, RCT

Country: England (UK)

Outline

This is an England-based multi-centre RCT (n = 540), which examined the cost-effectiveness of a joint crisis plan (JCP) with standard care. The intervention is the same as described in Flood et al. (2006) as this study sought to substantiate the findings of that study, and was carried out by the same or similar group of researchers. Joint crisis plans included an introductory meeting at which a facilitator explained the procedure to the person with mental illness and to their care coordinator; contents were discussed and plan completed at a second meeting, which was also attended by a psychiatrist. In addition, the person was contacted by the facilitator 9 months later to check if (s)he wanted to update the care JCP. The study population referred to persons of 16 years or above and who had at least 1 psychiatric admission in the previous 2 years and who were registered on the Enhanced Care Programme Approach register. Primary outcomes measures at 18 months were admission to hospital under the Mental Health Act. Secondary outcome measures were not reported in this study but in the main or parent study by Thornicroft et al. (2013).

Findings

In terms of outcomes measured at 18 months, there was no significant reduction compulsory admission (OR 0.90, 95% CI 0.59 to 1.38, p = 0.63) and no significant treatment effects for any other admissions outcomes, although there was evidence for improved therapeutic relationships in the intervention arm, described in detail in the main paper by Thornicroft et al. (2013). In terms of total public sector costs (n = 504), there was no significant reduction in the intervention group: £17,233 (sd 21,013) vs. £19,217 (sd 28,133) with a mean difference (MD) of -£1,994 (95% CI –5,733 to 2,248; p = 0.414). There was also no significant reduction from a societal perspective (which included productivity losses and criminal activity): £22,501 (sd 28,103) vs CG £22,851 (sd 34,532) with a mean difference of -£350 (95% CI –4,727 to 5,404; p = 0.902). Joint crisis plans had 80% probability of cost-effectiveness from public sector perspective (and around 44% from a societal perspective).

In sub-group analyses it was found that for the black and black British population the intervention was achieving higher cost-effectiveness: the primary outcome (=compulsory admissions) was significantly lower in the intervention sub-group (20%, n = 66) compared with the control subgroup (32%, n = 72) with a mean difference (MD 0.553; 95% CI 0.249 to 1.226; p = 0.256). Mean public sector costs in the intervention group were non-significantly lower in the intervention group: £17,628 (sd 25,163) vs £28,377 (sd 36,627) and a mean difference (MD) of £10,749 (95% CI –20,387 to 536; p = 0.079). Mean societal costs were also non-significantly lower in the intervention group: £23,150 (sd 29,588) vs £32,780 (sd 41,170) with a mean difference of £9,630 (95% CI –21,043 to 3,106; p = 0.16).

6. Borschmann R, Barrett B, Hellier JM et al. (2013) Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. British Journal of Psychiatry 202: 357–64

Study design and type: Cost consequences, RCT

Country: England (UK)

Outline

This is an England-based pilot RCT, which examined the cost consequences of Joint crisis plan (JCP) versus standard care for a particular population among people with mental illness – that is, those with borderline personality disorder. The intervention was the same as described before (Barrett et al 2013; Flood et al. 2006) and included: an introductory meeting with facilitator, who explained the procedure to person and care coordinator; contents of the plan discussed and completed by facilitator at second meeting which was attended by the person, care coordinator and psychiatrist. The population referred to persons of 18 years and above with diagnosis of borderline personality disorder, who had self-harmed in past year, were under the ongoing care of a community mental health team and able to give informed consent. Primary outcomes measures included the occurrence of self-harming behaviour at 6 months and secondary outcome measure included depression, anxiety, engagement, satisfaction with services, quality of life, wellbeing and cost-effectiveness.

Results

There were no significant differences between the groups on any of the secondary outcome measures at follow-up. Quality adjusted life years gained (QALYs) were presented in online supplement as they were considered only hypothesis generating: 0.31 (sd 0.11) vs 0.30 (sd 0.15). The mean cost of the intervention was £146 per participant and there were no significant differences in mean total health and social care costs (£5,631 vs £5,308, p = 0.20). In the online supplement, the ICER is reported as -£32,358 suggesting that JCP dominate standard care by being less costly and more effective.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

AP1	There is a good amount of evidence that service users and family carers found advance care planning useful in discussions about future treatment and end-of-life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end-of-life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington’s disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future.
AP2	There is a moderate amount of evidence that practitioners find advance care planning potentially useful and relevant when working with people who may lack mental capacity, although some of the views evidence is

	conflicting. A UK qualitative study of moderate quality (Samsi 2011 +) that gathered views and experience from Age Concern information and advice workers, found that advice related to advance care planning was valuable to assist people to put in place Lasting Power of Attorney (LPA) and encourage advance planning. Samsi (2011 +) found that an information service was valuable to those who did not have family carers. Another qualitative study of good quality (from Australia), (Seal 2007 +) found that 98–100% of nurses on the ward studied said that patients' self-determination at end of life was important and advance care planning helped people made choices. Robinson (2013 ++) found in interviews with 95 practitioners (in the UK) working in dementia and palliative care settings, that advance care planning was considered positive, but difficult to enact and deliver preferences as planned. Practitioners said that advance care planning could be duplicating person centred care measures already in place or risked becoming a 'tick box' exercise.
AP3	There is a good amount of evidence from service users, carers and practitioners that a person's choices and preferences should be represented in advance care planning, but some of the evidence was conflicting. A moderately well conducted qualitative UK study (Ashton 2014 +) a found that family carers, caring for people with dementia, wished to ensure that their relatives personal history and personality be represented in advance care planning. Another moderate quality, qualitative UK study related to dementia (Poppe 2013 +), found that service users felt advance care planning to be a positive experience because it enabled them to express their preferences. The study also found that carers were in favour of allowing service users to express their wishes, to avoid having to make decisions on their behalf later. However, Robinson (2013 ++), a well conducted qualitative UK study of practitioners, found that practitioners working in dementia and end-of-life care services questioned whether advance care planning had the ability to deliver patient preferences. This was on the grounds that preferred care may not be available. Robinson also found that practitioners, such as ambulance staff, were unable to adhere to advance care planning due to conflicting duty of care responsibilities.
AP4	There is a small amount of evidence that service users and family carers need support to understand future treatment options. There is evidence from a moderate quality UK study (Ashton 2014 +) that family carers reported that they needed support and encouragement to ask the right questions during advance care planning, in order to understand treatment options and nursing and medical interventions at end of life. There is also evidence from a moderate quality randomised control trial from the USA (Elbogen 2007) of a training and support intervention that aimed to assist people suffering from mental illness to gain competence in completing a psychiatric advance directive (PAD).The study found a positive effect on the samples ability to 'reason' which treatments were best for them but there was no positive improvement in the ability of the sample's competency to complete a PAD. Overall the intervention was deemed to help a person with a risk of psychosis to complete an advance directive.
AP5	There is a moderate amount of evidence that service users find advance decision-making and lasting powers of attorney process confusing and that clear information is needed. A moderate quality, qualitative UK study (Bisson 2009 +) found that service users were unsure about the nature of advance care planning and LPA and suggested that information in clear formats would be beneficial to inform people about treatment options and

	the location of facilities specific to their condition (in this case Huntington's disease). Another moderate quality UK study corroborates this (Samsi 2011 +). This study of information workers reported that service users seeking advice were confused by the complexity of the LPA process, and this may be a deterrent for completing it. Another good quality qualitative UK study (Wilson 2010 ++) of specialist practitioners found that a leaflet could help decipher unfamiliar terminology for services users.
AP6	There is a small amount of evidence that good relationships with practitioners was beneficial to advance care planning and that interventions can increase the likelihood of advance care planning discussion. A moderate quality UK study (Bisson 2009 +) found that service users valued flexibility about the location of advance care planning sessions and good relationships with practitioners during advance care planning. The study found that service users liked to discuss AP with a practitioners that they knew and in a space where they felt comfortable. A moderate quality RCT based in the USA (Pearlman 2005 +) found that an educational and motivational advanced care planning intervention aimed at older people and based on written information and meetings with a social worker could encourage a sample of older veterans to discuss advanced care planning with their practitioner. The intervention group were found to have a copy of the advance care plan in the information file and a higher level of agreement about treatment options with the practitioner.
AP7	There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end-of-life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end-of-life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning.
AP8	There is a good amount of evidence about the preferred format of documents for advance planning. There is currently great variety in how decisions are recorded and a standardised or summary document was both recommended and seen as a barrier in views-based evidence. A moderate quality UK based views study (Bisson 2009 +) found that practitioners working with people with Huntington's disease liked simple decision-making forms for advance care planning, standardised documents were recommended, documenting treatment preferences and end-of-life wishes. Manthorpe (2014 +) found (in the UK) that dementia nurses made statements of wishes in nursing notes, meaning that other practitioners did not necessarily have access to the plans. Other forms of advance planning documentation were not common and some planning decisions were verbal, which led to later uncertainty. Robinson (2013 ++), a good quality UK study (++), found that the variety of different documentation options was confusing for practitioners, and found that practitioners had doubts

	about transferability between settings and a lack of ability to capture individual contexts. Good quality UK evidence from Wilson (2010 ++) found that checklists were used in patient notes to signpost advance care planning decisions and plans.
AP9	There is a good amount of evidence from moderate quality data that the wishes of service users can conflict with that of carers or practitioners, leading to problems with implementation. Poppe (2013 +) also in interviews with service users and carers in the UK found that a barrier to advance care planning was when patients disagreed with family members or carers. Robinson (2013 ++) reported in relation to dementia care and end of life care in the UK, that delivering patient preferences could be challenging if they conflict with family wishes. There was moderate quality evidence from the USA (Seal 2007 +) that found that nurses perceived that doctors gave end of life decision making responsibility to family members, limiting the involvement of the patient. One Canadian study (Bravo 2016 +) presents effectiveness evidence from a randomised control trial of an intervention designed to improve advance planning via written instructions and social work support. The intervention did not produce improvements in the proxy's abilities to predict the older person's preferences but there were greater levels of agreement following the 3 monthly sessions.
AP10	There was a good amount of qualitative evidence, of moderate quality, that advance planning should be completed early, to avoid the loss of capacity before advance care planning was in place. Manthorpe's UK-based (2014 +) study of dementia nurses found that nurses often only came into contact with people once they had lost capacity, making assistance with advance planning difficult. Another UK qualitative study, Poppe (2013 +) found that the best time to discuss advance care planning was soon after dementia diagnosis, to maximise the persons input before they lost capacity, the study also found that a barrier to advance care planning completion was when a person was unwilling to accept their diagnosis. Sinclair (2016 +) also found that in UK based views evidence, that the best time to discuss advance care planning was when a person has come to terms with their diagnosis but still had capacity. Evidence from the UK about the importance of timing was also found in Robinson (2013 ++). This study found that delays in getting the advance care plans completed meant that they were not in place before the person lost capacity. This was particularly true of dementia. Samsi (2011 +) found that planning was difficult in the case of dementia suffers who did not wish to face their diagnosis.
AP11a	There is a good amount of evidence that a variety of practitioners see providing advice on advance planning as part of their role but a lack of confidence or training could be a barrier. (Relating to evidence statement 11a.) Manthorpe's (2014) moderate quality (+) study on dementia nurses reported that providing advice to carers about advance care planning measures like lasting power of attorney and end-of-life care was part of their role. Another UK based qualitative study, Samsi (2011 +) found that staff were trained in drawing up LPAs and had the confidence to do so. An Australian study of moderate quality (Seal 2007 +) found that nurses saw helping patients make informed choices about end-of-life care as part of their role. Robinson (2013) found that the practitioners most likely to see advance care planning as part of their role were palliative care specialists, community nurses and some GPs, but that some practitioners did not feel they had received adequate training. Similarly Poppe (2013 +) found that UK dementia care staff could lack confidence in discussing advance care planning. This barrier could be combated by training or refresher training to

	increase confidence. Wilson (a UK study) (2010 ++) also found that some staff said they lacked training or had missed training in advance care planning, reducing their confidence or signposting to other agencies. Robinson (2013 ++) found that some practitioners were not clear on the legal status of advance care plans and what needed to be included in LPAs or ADRTs. Practitioners saw signposting to legal advice as part of their role.
AP 11b	These was a moderate amount of moderate and good quality evidence around problems with practitioner understanding of roles and responsibilities in relation to advance care planning (relating to evidence statement 11a.) Some evidence showed a lack of consensus among practitioners about who is responsible for initiating advance care planning. Practitioners were not cohesive in views about who should take overall responsibility for advance care planning. Many practitioners interviewed were not confident in leading the advance care planning process. A good quality UK views study (Wilson 2010 ++) found that staff in palliative care and neurological care settings were unsure about who was responsible for initiating advance care planning. However neurological settings had more confidence than that palliative care. The study also found that staff lacked confidence in advance care planning and this prevented them from initiating planning and delays in advance care planning were caused by a lack of expertise to answer some questions. An Australian study (Seal 2007 +) found that 30–39% of the sample felt unable to advocate for patients about end of life care provision before receiving an advocacy intervention.
EcAP1	There is a large amount of economic evidence that advance care planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies. A systematic review of economic evidence (Dixon et al. 2015 ++) summarised findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use. This ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost-effectiveness. A systematic review of economic evidence (Klingler et al. 2016 +) summarised findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings. A single cost-effective study (Abel et al. 2013 +) found that individuals in a hospice setting who used advance care planning spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, $p < 0.001$); mean cost of hospital treatment during the last year of life for those

	who died in hospital was £11,299, those dying outside of hospital £7,730 (md 3,569; p < 0.001).
EcAP2	There is a small amount of economic evidence that joint crisis plans (JCPs) for people with psychosis or borderline personality disorder can lead to reductions in compulsory treatment under the Mental Health Act and be cost-effective from a public sector perspective. The quality of studies is high; the described intervention is the same between studies, which were carried out by the same group of researchers increasing the homogeneity between studies. A single cost-effectiveness study (Flood et al 2006, ++) found that individuals with psychosis who were currently not in inpatient care had significantly less compulsory admissions under the Mental Health Act (13% vs 27%, p = 0.03); there was a non-significant reduction in hospital admissions and in public sector costs; cost-effectiveness acceptability curves suggested there was a greater than 78% probability that JCP were more cost-effective than standardised service information in reducing the proportion of patients admitted to hospital A multi-centre cost effectiveness study (Barrett et al 2013, ++) found that individuals with psychosis had no significant changes in any of the costs or outcomes (including compulsory admissions); however, JCP had an 80% probability of being cost-effective from a public sector perspective (but only 40% from a societal perspective); results varied noticeably between ethnic groups and JCP was more cost-effective for certain groups of people with psychosis. A small feasibility cost consequences and utility study (Borschmann et al 2013, ++) found that individuals with borderline personality disorder, who self-harmed in the last year and were under ongoing care of a community mental health team, had no significant changes in any of the outcomes (including self-harm and QALY at 6 months); there was no significant difference in mean costs; the incremental cost-effectiveness ratio is -£32,358 suggesting that JCP was less costly and more effective than standard care.
EcAP3	EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the

	ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement.

Included studies for questions 1a and 1b

Abel J, Pring A, Rich A et al. (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive and Palliative Care 3: 168–73

Ashton S, Roe B, Jack B et al. (2014) End of life care: the experiences of advance care planning amongst family caregivers of people with advanced dementia – a qualitative study. Dementia 15: 958–75

Barrett B, Waheed W, Farrelly S et al. (2013), Randomised controlled trial of joint crisis plans to reduce compulsory treatment for people with psychosis: economic outcomes. PLoS One 8(11)

Bisson J, Hampton V, Rosser A et al. (2009) Developing a care pathway for advance decisions and powers of attorney: qualitative study. British Journal of Psychiatry 194: 55–61

Borschmann R, Barrett B, Hellier JM et al. (2013) Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. British Journal of Psychiatry 202: 357–64

Bravo G, Trottier L, Arcand M et al. (2016) Promoting advance care planning among community-based older adults: a randomized controlled trial. Patient Education and Counselling 99: 1785–95

Dixon J, Matosevic T, Knapp M (2015) The economic evidence for advance care planning: systematic review of evidence. Palliative Medicine 29: 869–84

Elbogen E, Swanson J, Appelbaum P et al. (2007) Competence to complete psychiatric advance directives: effects of facilitated decision making. Law and Human Behavior 31: 275–89

Flood C, Byford C, Henderson C et al. (2006) Joint crisis plans for people with psychosis: economic evaluation of a randomised controlled trial, BMJ 333: 729

Klingler C, Schmitten J, Marckmann G (2016) Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative Medicine 30: 423–33

Manthorpe J, Samsi K, Rapaport J (2014) Dementia nurses’ experience of the Mental Capacity Act 2005: a follow-up study. Dementia 13: 131–43

Pearlman R, Starks H, Cain K et al. (2005) Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. Archives of Internal Medicine 165: 667–74

Poppe M, Burleigh S, Banerjee S (2013) Qualitative evaluation of advanced care planning in early dementia (ACP-ED). PLoS ONE 8: e60412

Robinson L, Dickinson C, Bamford C et al. (2013) A qualitative study: professionals’ experiences of advance care planning in dementia and palliative care, ‘a good idea in theory but ...’ Palliative Medicine 25: 401–8

Samsi K, Manthorpe J, Rapaport P (2011) ‘As people get to know it more’: experiences and expectations of the Mental Capacity Act 2005 amongst local information, advice and advocacy services. Social Policy and Society 10: 41–54

Seal M (2007) Patient advocacy and advance care planning in the acute hospital setting. Australian Journal of Advanced Nursing 24: 29–36

Sinclair J, Oyebode J, Owens R (2016) Consensus views on advance care planning for dementia: a delphi study. Health and Social Care in the Community 24: 165–74

Wilson E, Seymour J, Perkins P (2010) Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings. Palliative Medicine 24: 396–402

3.2 Planning in advance, including for people who experience fluctuating capacity – additional search

Introduction to the review question

An additional search on review questions 1a and 1b was conducted because the Guideline Committee believed evidence on certain critical areas of advance care planning had been overlooked by the original search. The review questions and review protocol were the same as those used for the original search, which are described in 3.1. The only difference was in the way the searches were conducted, as described below.

How the literature was searched

The additional search on this question was undertaken in May 2017. The Guideline Committee highlighted additional papers and types of advance planning that had not emerged in the main search. These included areas such as joint crisis planning and ‘do not resuscitate’ orders. A broader search on advance planning was conducted and filters were applied where appropriate to capture systematic reviews, clinical trials, economic evaluations, and carer and user views.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

The search outputs were selected in the same way as for the original search, which is described in section 3.1.

Overview of evidence

From the update search, we included 3 effectiveness studies and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. As with all the review areas, only UK qualitative evidence was included. Since 3 UK-based effectiveness studies were included, it was judged that non-UK effectiveness studies would not add to the evidence base, not least because of the specific contextual issues surrounding advance care planning and the Mental Capacity Act.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements. The approach to synthesising evidence was informed by the PICO within the review protocol.

Studies reporting effectiveness data (n = 3)

Note that due to the heterogeneity of the evidence (the studies delivered different interventions to differing populations for differing lengths of time and used different outcome measures), data from each effectiveness study are presented separately, rather than combining them into a single meta-analysis.

1. Borschmann R, Barrett B, Hellier JM et al. (2013) Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. British Journal of Psychiatry 202: 357–64

Methodology: RCT

Data: Quantitative

Country: UK

Outline

The aim of this study was ‘to examine the feasibility of recruiting and retaining adults with borderline personality disorder to a pilot RCT investigating the potential efficacy and cost-effectiveness of using a joint crisis plan’ (p357). The study was rated as having good external validity (++) and moderate internal validity (+).The study used an RCT design to evaluate ‘joint crisis plans for community dwelling adults with borderline personality disorder’ (BPD) (p357). The study randomised 88 adults with BPD to either receive a joint crisis plan (JCP) as well as usual support from the community mental health team (46 participants, the ‘treatment’ group), or just usual support (42 participants, the ‘control’ group). The JCP is ‘a written document containing a mental health service user’s treatment preferences for the management of future crises. It is drafted a week after the service user is sent a blank template, which has a list of some topics that could be considered for inclusion in the JCP, for example “Positive things I can do in a crisis”, “Specific refusals regarding treatment during a crisis", "Practical help in a crisis" and "Useful telephone numbers"' (p358). 'The service user develops the joint crisis plan in collaboration with their treating clinician at a meeting that is facilitated by an independent mental health practitioner' (p357). After the JCP was agreed with the service user and with other people invited by the service user (for example, family and friends, advocates, key workers), a typed version of the plan was circulated to everybody specified by the service user within 24 hours.

Findings

The 2 groups, who were demographically very similar, were assessed on a number of measures at baseline and at 6-month follow-up. Due to death (1 from each group) and participants lost in other ways to follow-up, the 6-month follow-up comparison was only made for 37 treatment and 36 control participants. There were no significant differences between the treatment and control groups in terms of primary and secondary outcomes.

Primary outcome

For comparisons of the differences in self-harm the data were as follows.

For the TAU group n at baseline was 42 and at 6 month follow-up it was 36. For the JCP+TAU group's self-harm data, n at baseline was 46 and at 6-month follow-up it was 36.

At baseline 42 (100%) of TAU group had self-harmed; at follow-up it was 20 (55.6%).

At baseline 46 (100%) of JCP+TAU group had self-harmed; at follow-up it was 25 (69.4%).

The odds ratio (OR) of self-harming for JCP+TAU v TAU was 1.86 with 95%CI 0.53 to 6.51 and p = 0.33.

At baseline for the TAU group, in terms of self-harm frequency (episodes) the mean was 56.2 with sd 102.2, and median 5.5 with IQR 47. At follow-up mean was 20.3 with sd 67.0, and median was 1 with IQR 3.5.

At baseline for the JCP+TAU group, in terms of self-harm frequency (episodes) the mean was 51.2 with sd 126.4, and median 6 with IQR 37. At follow-up mean was 20.6 with sd 89.7, and median was 2 with IQR 7.0.

The rate ratio (RR) of frequency of self-harm for JCP+TAU v TAU was 0.74 with 95%CI 0.34 to 1.63 and p = 0.46.

Secondary outcomes

Data are provided for TAU vs JCP+TAU at baseline and follow-up, with mean, standard deviation and n, for the following where highest score means best outcome (data to calculate effect sizes not available – definitions provided here are taken from the report).

Working alliance with practitioners

Working Alliance Inventory Client (WAI-C: self-report instrument for measuring the perceived quality of working alliance between client and practitioner, with higher scores indicating a more positive perception of alliance) (range 12–84): for TAU at baseline n = 33, mean 63.36 (sd 17.92); at follow-up n = 30, 60.47 (15.92). For JCP+TAU at baseline n = 38, 58.47 (18.50); at follow-up n = 33, 58.85 (16.75).

Working Alliance Inventory Therapist (WAI-T) (range 12–84): for TAU at baseline n = 37, 61.27 (11.10); at follow-up n = 25, 62.96 (10.74). For JCP+TAU at baseline n = 40, 63.68 (8.72); at follow-up n = 29, 64.66 (10.87).

Satisfaction with services

Client Satisfaction Questionnaire (CSQ: measure of participants' level of satisfaction with treatment received, with higher scores indicating a higher level of satisfaction with services) (range 4–32): for TAU at baseline n = 37, 18.62 (1.53); at follow-up n = 36, 19.64 (1.33). For JCP+TAU at baseline n = 41, 19.85 (1.46); at follow-up n = 37, 19.97 (2.0).

Wellbeing

Warwick–Edinburgh Mental Well-Being Scale (WEMWBS: measure of subjective mental well-being over the preceding 2 weeks and focuses entirely on positive aspects of mental health. Higher scores indicate a higher level of wellbeing) (range 14–70): for TAU at baseline n = 23, 31.74 (10.14); at follow-up n = 35, 35.26 (10.26). For JCP+TAU at baseline n = 26, 29.65 (11.09); at follow-up n = 36, 34.33 (11.40).

Depression and anxiety

Hospital Anxiety and Depression Scale – Depression (HADS-D) (0–21): for TAU at baseline n = 42, 11.76 (4.30); at follow-up n = 34, 10.47 (3.54). For JCP+TAU at baseline n = 46, 11.78 (4.98); at follow-up n = 35, 10.20 (4.96).

Hospital Anxiety and Depression Scale – Anxiety (HADS-A) (0–21): for TAU at baseline n = 42, 14.48 (5.55); at follow-up n = 36, 12.94 (4.55). For JCP+TAU at baseline n = 46, 14.46 (4.07); at follow-up n = 37, 14.57 (3.83).

Data is also provided for TAU vs JCP+TAU at baseline and follow-up, with mean, standard deviation and n, for the following where lowest score means best outcome:

Social functioning

Work and Social Adjustment Scale (WSAS: self-report instrument to assess impaired functioning, with higher scores indicating a higher level of impairment) (0–40): for TAU at baseline n = 42, 26.95 (7.36); at follow-up n = 36, 26.06 (7.98). For JCP+TAU at baseline n = 46, 27.02 (6.46); at follow-up n = 36, 25.81 (8.94).

Perceived coercion

Treatment Experience Scale (TES: assesses the perceived level of coercion experienced by service users during hospital admission) (0–45): for TAU at baseline n = 42, 16.52 (2.75); at follow-up n = 36, 16.0 (3.07). For JCP+TAU at baseline n = 46, 17.04 (2.97); at follow-up n = 37, 17.68 (3.09).

Engagement with services

Service Engagement Scale (SES: self-report scale, completed by the participant’s treating clinician – in this trial typically a care coordinator or key worker – to measure the participant’s level of engagement with community mental health services. Higher scores reflect a greater level of difficulty engaging with services) (range 0–42): for

TAU at baseline n = 34, 10.41 (7.14); at follow-up n = 25, 10.88 (5.62). For JCP+TAU at baseline n = 38, 9.82 (6.04); at follow-up n = 30, 8.63 (6.11).

The study reported, for these secondary clinical outcomes, that ‘Treatment differences were considered in a fully adjusted model. No significant differences ($p < 0.05$) were found between the treatment as usual and joint crisis plans + treatment as usual’ (p362).

The authors nevertheless state that their successful engagement with people who have BPD in advance planning for crises does have clinical implications, as previous research has shown JCPs can ‘promote self-determination and empowerment among service users’ and they may ‘facilitate stronger relationships between service users and providers’ (p363). They also cite the NICE BPD Guideline, that ‘fostering collaborative relationships is essential in the treatment of people with borderline personality disorder’, so that ‘JCPs may provide one approach to ensuring that the values and treatment preferences of such individuals remain central when they experience crises’ (p363).

Resource use

Resource use and cost-effectiveness data have been reviewed by the economist and presented separately in the papers reporting the review of economic evidence.

2. Jones L, Harrington J, Barlow CA et al. (2011) Advance care planning in advanced cancer: Can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. Palliative and Supportive Care 9: 3–13

Methodology: RCT

Data: Effectiveness

Country: UK

Outline

This was a RCT study of advance care planning with advanced cancer patients. The study was judged to have good relevance to the review question (++) and moderate internal validity (+). The design was informed by a qualitative phase, in which focus groups of patients in oncology and palliative care reviewed a draft of the interview topic guide. All participants with advanced cancer in the study had detectable, active, progressive disease and were considered well enough by the referring health professional to complete the advance care planning intervention.

Following baseline interviews, patients were allocated into cohorts. A total of 77 participants were divided into a randomised cohort (22 received advance care planning input + usual treatment, 20 received usual treatment only) and a preference cohort (21 received advance care planning + usual treatment, 14 usual treatment only). The intervention comprised at least 1 and up to 3 discussions with a trained care planning mediator. The primary outcome being measured was ‘the degree to which participants had discussed end-of-life planning with primary and secondary care professionals, and family and friends’ (p6). Secondary outcomes were the ‘patient’s (1) happiness with the level of communication with health professionals and family or friends, (2) satisfaction with healthcare, and (3) HADS anxiety and depression scores’ (p6).

Findings

Participants completed questionnaires at a baseline date and then 8 weeks later.

Eighty-eight per cent completed the study to follow-up. There were insufficient participants to produce findings of statistical significance. Researchers anticipated that this would be a limitation of the study, but it was not a concern for them as the study was a trial, and the data did identify some trends. They noted that ‘asking patients with recurrent progressive cancer to take part in a trial to evaluate the effectiveness of advance care planning does not cause undue anxiety or depression, that attrition is low, and that the majority of participants show interest in and preference for the intervention’ (p11).

Primary outcome

The mean differences (and standard errors) between baseline and follow-up, when patients’ preferences were measured on a visual analogue scale (VAS) scored from –5 (strong preference not to receive the advance care planning intervention) to +5 (strong preference to receive the advance care planning intervention) and 0 no preference either way (standard error), were as follows:

Communication VAS overall:

Randomised cohort (usual care) –2.4 (1.4).

Randomised cohort (advance care planning) –1.4 (1.8).

Preference cohort (usual care) 0.0 (0.8).

Preference cohort advance care planning –0.5 (1.0).

Combined (usual care) –1.3 (0.9).

Combined (advance care planning) –0.9 (1.0).

Communication VAS with professionals:

Randomised cohort (usual care) –0.8 (0.7).

Randomised cohort (advance care planning) –0.1 (0.6).

Preference cohort (usual care) 0.2 (0.5).

Preference cohort advance care planning –0.7 (0.8).

Combined (usual care) –0.4 (0.5).

Combined (advance care planning) –0.4 (0.5).

Communications VAS with family and friends:

Randomised cohort (usual care) –1.5 (0.8).

Randomised cohort (advance care planning) –1.6 (1.1).

Preference cohort (usual care) –0.6 (0.8).

Preference cohort advance care planning 0.3 (0.6).

Combined (usual care) –1.2 (0.6).

Combined (advance care planning) –0.7 (0.6).

Discussion VAS overall:

Randomised cohort (usual care) 2.2 (3.1).

Randomised cohort (advance care planning) 3.7 (2.3).

Preference cohort (usual care) 0.3 (4.2).

Preference cohort advance care planning 1.1 (2.9).

Combined (usual care) 1.5 (2.5).

Combined (advance care planning) 2.4 (1.9).

Discussion VAS with professionals:

Randomised cohort (usual care) 2.2 (2.4).

Randomised cohort (advance care planning) 2.3 (1.1).

Preference cohort (usual care) 0.0 (2.4).

Preference cohort advance care planning 1.2 (1.6).

Combined (usual care) 1.4 (1.7).

Combined (advance care planning) 1.7 (1.0).

Discussion VAS with family and friends:

Randomised cohort (usual care) –0.1 (1.1).

Randomised cohort (advance care planning) 1.5 (1.4).

Preference cohort (usual care) 0.3 (2.3).

Preference cohort advance care planning 0.6 (1.5).

Combined (usual care) 0.1 (1.1).

Combined (advance care planning) 1.1 (1.0).

Data concerning treatment coefficients of ANCOVA models for effect of advance care planning intervention over usual care on VAS domains and HADs scores, adjusting for baseline score and cohort (in the combined models), with 95% confidence intervals and p values:

Communication VAS treatment with professionals:

Randomised cohort coef. 0.3, 95% CI –4.5 to 5.1, p = 0.896.

Preference cohort coef. –1.5, 95% CI –4.7 to 1.8, p = 0.363.

Combined Coef. –0.6, 95% CI –3.5 to 2.3, p = 0.677.

Communication VAS treatment with family and friends:

Randomised cohort coef. 0.3, 95% CI –1.4 to 2.0, p = 0.734.

Preference cohort coef. –1.8, 95% CI –3.9 to 0.3, p = 0.087.

Combined coef. –0.6, 95% CI –1.9 to 0.7, p = 0.351.

Communication VAS treatment:

Randomised cohort coef. –0.3, 95% CI –3.2 to 2.6, p = 0.835.

Preference cohort coef. 0.1, 95% CI –1.9 to 2.2, p = 0.905.

Combined coef. –0.1, 95% CI –1.9 to 1.6, p = 0.872.

Discussion VAS treatment with professionals:

Randomised cohort coef. 1.3, 95% CI –6.4 to 9.0, p = 0.738.

Preference cohort coef. 2.2, 95% CI –4.7 to 9.1, p = 0.520.

Combined coef. 1.3, 95% CI –4.1 to 6.6, p = 0.640.

Discussion VAS treatment with family/friends:

Randomised cohort coef. 0.0, 95% CI –5.0 to 5.1, p = 0.994.

Preference cohort coef. 2.9, 95% CI –1.0 to 6.8, p = 0.132.

Combined coef. 0.9, 95% CI –2.5 to 4.3, p = 0.612.

Discussion with VAS treatment:

Randomised cohort coef. 1.2, 95% CI –2.2 to 4.5, p = 0.482.

Preference cohort coef. 0.0, 95% CI –4.3 to 4.2, p value 0.996.

Combined coef. 0.7, 95% CI –1.9 to 3.2, p value 0.611.

The authors note that in '… the randomized cohort, discussion about the future at follow-up was higher in those randomized to the ACP intervention (coefficient of 1.3, 95% CI from 26.4 to 9.0). This appears to be because of more discussion with friends and family, as there was no difference between treatment arms in discussion with professionals. In the preference cohort, discussion about the future was also higher in those who chose the ACP intervention (coefficient of 2.2, 95% CI from 24.7 to 9.1). In contrast to the randomized cohort, this appears to be because of more discussion with professionals, as there was no difference between treatment arms in discussion with friends and family. Combining the two cohorts showed a trend to discussion about the future being higher in those assigned to the ACP intervention' (p8).

Secondary outcomes

Findings were more mixed for the secondary outcomes: 'happiness with communication was unchanged or worse and satisfaction with services decreased in the ACP versus the usual care groups' (p11). The researchers consider that this may have been due to increased expectations as a result of the advance care planning discussions for the group who took part in these discussions.

Satisfaction with VAS overall:

Randomised cohort (usual care) 1.9 (1.1).

Randomised cohort (advance care planning) 0.6 (1.5).

Preference cohort (usual care) –0.2 (2.8).

Preference cohort advance care planning –2.8 (1.8).

Combined (usual care) 1.1 (1.2).

Combined (advance care planning) –1.0 (1.2).

HADS (anxiety):

Randomised cohort (usual care) –0.3 (0.7).

Randomised cohort (advance care planning) 0.3 (0.5).

Preference cohort (usual care) –0.1 (0.9).

Preference cohort advance care planning –0.6 (0.5).

Combined (usual care) –0.2 (0.6).

Combined (advance care planning) –0.2 (0.3).

HADS (depression):

Randomised cohort (usual care) 1.1 (0.6).

Randomised cohort (advance care planning) –0.4 (0.6).

Preference cohort (usual care) 0.2 (0.9).

Preference cohort advance care planning 0.6 (0.6).

Combined (usual care) 0.7 (0.5).

Combined (advance care planning) 0.1 (0.4).

Satisfaction VAS treatment:

Randomised cohort coef. –2.0, 95% CI –5.8 to 1.7, p = 0.273.

Preference cohort coef. –4.9, 95% CI –12.3 to 2.6, p = 0.190.

Combined coef. –3.1, 95% CI –6.6 to 0.5, p = 0.086.

3. Thornicroft G, Farrelly F, Szmukler G et al. (2013) Clinical outcomes of joint crisis plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. Lancet 381: 1634–41

Methodology: Mixed methods: RCT and qualitative

Data: Effectiveness and views and experiences

Country: UK

Outline

This research evaluated the effectiveness of collaboratively preparing a joint crisis plan (JCP) for people over 16 with a relapsing psychotic illness who had had at least 1 psychiatric hospital admission in the previous 2 years. It was conducted as a randomised controlled trial (RCT) with a qualitative follow-up. It was judged to have good relevance (++) to our review question and to have low internal validity (-). Five hundred and sixty-nine patients from 4 English mental health trusts were randomised into treatment (JCP + usual treatment) and control (usual treatment) groups – 285 in the treatment group, and 284 in the control group. Two meetings were held to prepare the JCPs – a preparatory meeting involving the participant, their care coordinator and a trained JCP facilitator (5 mental health nurses were trained for this role), and then a planning meeting involving the same people plus the participant's psychiatrist, and a friend or relative of the participant if they so choose. After the meeting the JCP was approved by the participant and circulated to those at the meeting plus anybody else the participant nominated, and it was placed electronically on their patient records. The JCP facilitator contacted the participant after 9 months to check whether they wanted the plan to be updated. RCT data for the treatment and control groups was extracted at a baseline date and then after 18 months.

The primary hypothesis being investigated was that the treatment group would have fewer compulsory psychiatric hospital admissions (sections). Secondary outcomes being investigated related to the number of admissions (compulsory or voluntary), the length of stay on psychiatric wards, participants' ratings for coercion, therapeutic relationships as rated by participants and clinicians, and patient engagement as rated by clinicians.

Findings

Effectiveness

The results showed no significant difference for the primary outcome, or for any of the secondary outcomes, other than improved therapeutic relationships in the treatment group (17. 3 [7.6] vs 16.0 [7.1]; adjusted difference –1.28 [95% CI –2.56 to –0.01, p = 0.049]).

Views and experiences

Following the RCT, there were 12 focus groups: 5 with patients only, 5 with care coordinators only, and 2 mixed groups, 1 of which also included a psychiatrist. Thirty-five patients, 22 care coordinators and 1 psychiatrist took part in these group interviews. There were also 37 individual interviews, conducted with 16 psychiatrists, 6 care coordinators and 15 patients.

The qualitative interviews confirmed the improved therapeutic relationship. Patients felt more respected by clinicians, and some clinicians ‘seemed to gain a wider understanding of patients’ views of care and presentation in a crisis’ (pp1638–9).

However a picture emerged from the interviews of JCPs not being used as intended. A number of patients could not recall the JCP meeting as anything distinct from other care planning meetings in which they took part. The report identified 3 particular barriers to implementing JCPs, from the interviews.

1. Clinicians did not perceive the JCP meetings as being very different from usual care planning meetings. However their descriptions of the JCP meetings indicated that they were clinician and not patient led. There was not enough demarcation from usual planning meetings, since 48% of JCP meetings took place in association with a CPA (Care Programme Approach) meeting, the ‘usual treatment’ meeting. Clinicians were also doubtful about routine care planning generally, which they saw as ‘a bureaucratic exercise with limited clinical benefit’ (p1639).

2. Most clinicians ‘failed to recognise that implementing the JCP required a change in the usual clinician–patient relationship on their part, beginning with active discussion of treatment options and supporting patient choice both in the meeting and in implementation’ (p1639).

3. There seems to have been a lack of commitment to implementing the JCPs in practice, as many patients complained about the agreed plans not being honoured, and ‘only five of the 28 care coordinators reported referring to or using the JCP during the follow-up period’ (p1639).

The study reported that these findings were at odds with previous studies of JCPs, and considered possible explanations: the model may not have been adhered to in delivery (considered unlikely as the mean fidelity score was high); there could have been better crisis planning in the control group than at the time of earlier studies (also considered unlikely since assessment of crisis plans for participants considered them to be of poor quality); or clinician engagement at crisis planning meetings and afterwards could have been poor (considered to be supported by the findings that in 48% of cases there was not a specific meeting at which the JCP was formulated).

Studies reporting views and experiences

4. Almack K, Cox K, Moghaddam N et al. (2012) After you: conversations between patients and healthcare professionals in planning for end of life care. BMC Palliative Care 11: 15

Method: Qualitative

Data: Interviews

Country: UK

Outline

This qualitative study from the UK explored the factors influencing if, when and how advance care planning takes place between healthcare professionals, patients and family members from the perspectives of all parties involved and how such preferences are discussed and are recorded. The study was judged to have good relevance to the review area (++) and to be of good methodological quality (++).The study recruited 18 cases made up of patients (n = 18; 10 men; 8 women; median age 75); nominated relatives (n = 11; 7 women; 4 men; median age 65) and healthcare professionals (n = 15) caring for the patient. Data collection included separate, joint and group interviews.

Findings

1. Issues relating to the initiation of discussions around Preferred Place of Care (PPC)

1.1. Open awareness

Of the 18 patients interviewed, 13 were cancer or heart failure patients. Of these 13, 9 had a degree of open awareness. They reported that they had engaged in some level of conversation with both family carers and/or healthcare professionals about end-of-life care, although the depth, process and areas reported to have been addressed in these conversations varied. In a follow-up interview, the care home manager indicated that initiating conversations about residents' preferences for end-of-life care was rarely a priority, particularly when somebody was first admitted (unless admitted as a terminal individual).

1.2. PPC document

Only 2 patients had Preferred Place of Care documents in place that they were able to locate and show to the researcher; 2 patients were uncertain as to whether they may have completed a Preferred Place of Care document; 1 patient knew that her preferences were recorded in her notes but had no PPC document.

Thirteen patients did not have a Preferred Place of Care document nor any recall of preferences being documented elsewhere.

1.3. Engagement in any significant communication about end-of-life care preferences

Four participants appeared not to have engaged in any significant communication about end-of-life care preferences with either family members or healthcare professionals. A key factor appeared to be that at the time of interview these patients reported being at a stage where they didn't want to think too far ahead, 'No, not at this time because I don't see myself as being that far down the road yet, I'm still quite positive, well apart from when I'm feeling really ill' (participant with cancer, p5).

This respondent also acknowledged: '…at the end of the day we know it's serious … It's not going to have a good ending but I just think that you've got to carry on fighting…' (p5).

One patient with heart failure reported some conversations with healthcare professionals during a period when he was seriously ill and required hospitalisation but he had not subsequently followed up on these conversations: 'I've been feeling pretty good now for about 2 or 3 months I suppose.' When asked about whether future plans go to the back of mind when feeling better he said, 'Oh yeah, I don't give them a thought…'.

Another cancer patient responded to the following question: Has anybody talked to you about where you want to be cared for? In terms of staying at home or, has anyone had that sort of conversations with you?

'No, no, not yet. No. I certainly want to stay at home. I'll be quite frank with you. If I'm going to die, I want to die at home; I don't want to die in hospital. And the family, I think, understand that.'

In a follow-up interview with the nominated healthcare professionals involved in the care of this patient (after his death), they recalled difficulties in knowing how and when to initiate conversations with him about his preferences: 'He never really, up until the very end, particularly considered himself to be palliative. Only near the end did he say "I don't think I'm winning this" and that was the first indication I had that he was thinking along the lines of "I'm going to die from this".'

This example illustrates some the complexities involved. The patient gave some indication of his preferences to the researcher about his wishes. However, the healthcare professionals felt he steered them away from such conversations, such that it was perceived to be too difficult and possibly unethical to open up discussions about his preferences for end-of-life care.

2. Healthcare professionals' reports of discussions with patients about preferences for end-of-life care

2.1. Difficulty having conversations about end of life care with patients who do not consider themselves to be in need of palliative care

'If you think they're coming towards end of life, with all the uncertainty around heart failure, you want to discuss that, but at the same time, you don't want to take away all their hope.'

2.2. Waited for patients or family carers to raise the issues themselves

'It's very much led by the patient; if they want to know … how they are doing whatever, and be guided intuitively by them really. There are some patients who will be very open and frank with you and use all the right words but there are others that will say to you or indicate I know where you're going with this and I don't want to hear.'

2.3. Judgments on timing included doing preparatory work and first building up a relationship with the patient and family

'It's important we've built up a rapport with the patient … and that's why we like early referrals so we get to know the person.'

3. Factors that influence if, when and how healthcare professionals initiate discussions about preferences for end-of-life care

3.1. Factors that influence if conversations are initiated

- Barrier of inexperience: the need for training and developing experience in advanced communication skills
- Judgement call on patient's level of awareness/denial
- Unwillingness of relatives to have these conversations
- Uncertainty of trajectory with long-term conditions (heart failure)

3.2. Factors that influence when conversations about PPC take place

- Patients initiate or ask for information

- Judgement on timing don't want to concern patients/relatives too early (nor leave it too late)
- Once preparatory work is carried out (getting to know the patient; planning what to say)
- Because of pressure to follow policy guidelines and find out patient preferences

3.3. Factors that influence how these conversations take place

- Taking a 'drip drip' approach
- Use of trigger questions
- Different choice of language e.g. some healthcare professionals will use the words death and dying; some would not.

5. Barnes K, Jones L, Tookman A et al. (2007) Acceptability of an advance care planning interview schedule: a focus group study. Palliative Medicine 21: 23–8

Methodology: Qualitative

Data: Views and experiences

Country: UK

Outline

The aims of this qualitative study from the UK were twofold: firstly, 'to explore the acceptability of an interview schedule, designed to encourage conversations regarding future care; and secondly, to explore the suitability of such discussions and inquire about their possible timing, nature and impact' (p 23). The study had good relevance to the review question (++) and the methodological quality was rated as good (++).

Focus groups were conducted with a total of 22 participants: 5 (23%) patients from a palliative care day unit at a local hospice; 7 (32%) patients from an oncology outpatient clinic at a London hospital; 7 (32%) members of oncology user groups in the North London Cancer Network (6 patients and 1 person who had cared for someone with cancer); and 3 (13%) relatives of patients at a local hospice. Most of the patients were at different stages of the disease, some were in remission, some with recurrent disease and 4 patients were approaching the end of life. Their ages ranged from 32–80 years and all patients were white.

Findings

Prompting patients to think about issues

Some participants said that the questions in the interview schedule prompted patients to consider issues they may not have thought about before. They acknowledged that these issues worry them, and some may not want to deal with them, while others welcome a discussion and think about a course of action.

‘It’s given me some food for thought ... we do put things to the back of our mind ... I have got some quite firm views about what I would want ... I would like people to do what I want to have done’ (P1) (p25).

Timing of advance care planning

The majority of participants felt the most suitable time to discuss advance care planning would be following a recurrence of disease, or if treatment had not worked and the prognosis is poor. It was better to avoid discussions around the time of diagnosis or during active treatment, ‘Had he asked me about living wills when I was first diagnosed, that would have just flipped me over the edge ... it was hard enough to deal with the diagnosis’ (P7) (p25).

There was recognition that those with a limited life expectancy need time to plan and arrange things and the interview schedule was potentially useful in this respect.

For some patients who had experienced a disease recurrence, it was hard to balance everyday life with the need to consider end-of-life matters. Most participants felt that the opportunity to discuss these issues should be provided more than once to allow patients time to think through and address different issues in their own time, including the need to involve family and friends.

Some participants felt that health professionals should take a more active role in inviting patients to have a discussion if appropriate, following regular assessments in relation to their prognosis and emotional state: ‘I think the problem with it being left up to the individual is that they may put it off and put it off. Because ... everyone wants to hope that it won't be today' (P12) (p26).

Recognising individuality

Participants emphasised the significance of treating patients as individuals. Some may be more willing while others not so in regards to talking through the issues in the schedule and this may be affected by their health condition or prognosis.

Person conducting advance care planning discussion

The participants felt that discussion should be carried out by a trained person with excellent communication skills, who can provide accurate information and allow for discussion in an unhurried atmosphere. Most participants felt that their consultant would not be the right person because of the constraints of time in clinical settings. Some participants felt that advance care planning discussions with their doctor might change the doctor-patient relationship: 'I'm still at the stage where I go to my doctor for him to make me better, not to tell me how to die ... If you're going to go through these kinds of issues with your doctor ... you may lose the hope that you have in your physician...that could be negative'. (P7) (p26).

Losing a sense of hope

Some participants felt that talking about advance care planning may destroy all sense of hope: 'I think it might actually destroy people's hope' (P12) (p27).

'Hope can see people through diseases ... [addressing these issues] might smash that very delicate thing that can keep someone alive for much longer' (P7) (p27).

These comments emphasise that advance care planning discussions must take into account the complex emotions patients may be experiencing.

Maintaining a sense of control

Advance care planning discussions may enhance control by providing individuals with the opportunity to make end of life care choices. One relative pointed out:

‘For patients [at the hospice] ... to feel that they may have a choice, or some input to their environment, rather than those decisions being made for them ... might allow them to feel more empowered and more in control’ (participant, p27).

Advance directives

There was anxiety and confusion about the legalities of advance directives, their connection to euthanasia and how and at what point they should be discussed with patients. Some participants were worried and said that there should be the opportunity to change what is written in an advance directive if a person wishes to change their mind in future.

Effect of taking part in a focus group

For some participants, initiating discussion about end of life matters encouraged them to discuss their wishes for future care with their relatives.

6. Barnes KA, Barlow CA, Harrington J et al. (2011) Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. Palliative and Supportive Care 9: 73–9

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study (n = 40) is considered to have good relevance to the research question (++) and was rated as moderate for internal validity (+). It aimed to explore the views of people with recurrent progressive cancer about the advanced care planning discussions and their use in considering, discussing and planning future care with health professionals. In the context of an exploratory patient preference randomised controlled trial, participants were randomly selected to receive advanced care planning discussion sessions (maximum of 3 sessions) conducted by professional mediators. The discussions involved both health professionals and persons close to the individual, and focused on their feelings about the future and dying, their preferences for place of care, and future healthcare decisions. The researchers used content analysis to identify themes from the data they collected.

Findings

Findings showed that most patients had not spoken extensively to health professionals or their family or friends about the future and their willingness to engage in advance care planning varied widely. There appeared to be tensions between wanting to get on with life as usual and considering end-of-life issues. Participants voiced specific concerns about a potential deterioration in health and expressed a desire for more information. Although they felt it was a doctor's responsibility to initiate such discussions, they believed that their doctors were reluctant to do so. In contrast, some participants felt that it was too soon for these types of conversations.

Many participants were unaware that they could make a choice regarding place of care at the end of life, while others simply wanted to leave important decisions to their doctor, whom they assumed had their best interests at heart. There were also concerns related to distressing symptoms at the end of life and fears that their family members would not be able to cope. These findings suggest that the timing of discussions should be tailored to the needs of each individual, recognising that some patients may wish to postpone advance care planning discussions. Though patients wished for more accurate information, there is a need to recognise their broader values and goals, in particular their interactions with family and others close to them in making healthcare decisions. The authors noted that findings from this study do not fully support the current UK policy of introducing advance care planning in the early stages of a life-threatening illness, as some patients are not yet ready, and may not be even at a later stage in the progression of their disease.

7. Bond CJ, Lowton K (2011) Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study. Age and Ageing 40: 450–6

Methodology: Qualitative.

Data: Views and experiences.

Country: UK – England.

Outline

The aim of this qualitative study from the UK was to ‘ … elicit geriatricians’ views on advance decisions and their use in decision-making in England.’ (p 450). The study had good relevance to the review question (++) and was rated as moderate (+) on methodological quality. The sample was comprised of 6 consultant (and 4 trainee) geriatricians. The researchers used semi-structured face-to-face interviews to gather data.

Findings

Practitioners reportedly supported the use of advance decisions to refuse treatment but made suggestions regarding their use in practice such as the need for advance decisions to refuse treatment to be specify individual treatments that were being declined and at what point; particularly when they involved the refusal of ‘life prolonging treatment’. Practitioners also reportedly suggested that documents needed to provide clarity regarding the use of invasive procedures.

‘To deal with clinical idiots like me, it’s best to be as clear as possible in envisaging the situations in, where the advanced statement should be enacted. Some of them are very vague … so the more detailed somebody can be the better – it helps decision-making. If it’s vague it’s open to interpretation and people might not get what they want’ (p452).

The authors also report that context was important to the decisions that geriatricians made, stating that they would be willing to withhold invasive techniques if the patient were still likely to die, but that in situations in which the outcome was less clear they would use the advance decision to refuse treatment to assist with decision-making. For some participants it was a central factor in the decision-making process while for others it was 1 of several factors to be considered when determining what treatment to provide. If the person was likely to live as a result of treatment, interviewees stated they would be hesitant to follow the advance decision. Others reported that they would follow it if it were written clearly and without ambiguity.

The authors report that the personal attitudes of participants also had a considerable bearing on their views regarding advance decisions, citing 1 practitioner who stated that:

‘It becomes harder for the health professionals, much harder because having an advance directive setting a ceiling of therapy is helpful and is err reassuring to the clinician if it’s in line with what they’re thinking, if in contrast that ceiling of therapy appears suboptimal it would be very difficult, very difficult‘ (p452).

Practitioners also reportedly felt that it would be difficult to draft an advance decision to refuse treatment that could cover the many complex medical decisions that could arise.

‘How can the lay public understand all the intricacies of what we decide? They won’t understand basic science, they don’t understand interventions, they can’t understand lots of issues’ (p452).

Despite these concerns, the authors report that the geriatricians they interviewed acknowledged that while a patient might not have the same knowledge and insight into their condition as a practitioner, the patient’s wishes were central and an advance decision should be used as the basis for treatment.

The researchers found that advance decisions were more likely to be used when they included detailed information and supported the practitioner’s decision-making.

8. Boot M, Wilson C (2014) Clinical nurse specialists’ perspectives on advance care planning conversations: a qualitative study. International Journal of Palliative Nursing 20: 9–14

Method: Qualitative

Data: Interviews

Country: UK

Outline

This qualitative study from the UK explored the challenges experienced by clinical nurse specialists when facilitating advance care planning conversations with terminally ill patients. The study was judged to have good relevance to the review area (++) and to be of good methodological quality (++). Semi-structured interviews were used to collect data from 8 purposively selected palliative care clinical nurse specialists working in 2 different community teams. The interviews were recorded, transcribed, and analysed to identify themes.

Findings

The data revealed that the clinical nurse specialists felt that opening advance care planning conversations entailed taking a risk and required courage. The risks identified were that the patient might be harmed and/or the nurse–patient relationship damaged, but also that the patient might miss the opportunity to be involved in advance care planning.

1. Raising the issue vs missing the opportunity

1.1. Clinical nurse specialists felt the need to ensure that patients have the opportunity to engage with advance care planning but were sensitive to patients' individual wishes, recognising that some patients did not want to undertake the advance care planning process:

'[I] feel there is a moral obligation to do the best you can to be in touch with what people would like so we can plan sensitively for their future. It is that kind of moral dissonance about getting the timing right. Not robbing of the opportunity, but not stepping in insensitively' (p11).

1.2. To introduce advance care planning with individual patients clinical nurse specialists looked for cues from the patients to see if they wished to discuss end-of-life issues:

' … if somebody doesn't want to go back into hospital then I would think that I make sure that they realise that they will be getting good symptom control and good quality of life at home' (p11).

1.3. Clinical nurse specialists described adopting a 'watching and waiting' approach to the timing of advance care planning:

'[I] do tend to pick up on people's cues ... and get the feel if they want to start to talk about end-of-life planning ... and if I do get any cues like that then I will grab the opportunity because they don't really come around very often' (p12).

1.4. Clinical nurse specialists reported times when they had started conversations and found that the patient did not want engage with them:

‘To actually start talking about when their life is coming to an end is something that people push away and we don’t want to face until the end ... some people never get to that point’ (p12).

2. The nurse–patient relationship

2.1. Participants reported that establishing a relationship was an important prerequisite to facilitating the process:

‘She said, “Look I just don’t want to know, I want to go on a day to day basis and that is how I cope” ... but if I am present there is more chance that when she is ready she will share it with me. But I also have to accept that some people are never ready. It is to establish that relationship’ (p12).

2.2. The risk of opening the conversation was weighed against the risk of harming the relationship:

‘ … if people aren’t ready to start talking about end of life I think it can really distance your relationship with them and I have heard of cases where that has happened with health-care professionals’ (p12).

2.3. One participant reported that she was able to press ahead with advance care planning without forming the relationship when she felt that circumstances demanded this:

‘I had to make it a priority, I had to do it the day I met the patient. So sometimes I think you have got [to get] a handle around how quickly you have got to do it’ (p12).

2.4. The clinical nurse specialists reported occasions when they ‘got it wrong’ when trying to introduce an advance care planning discussion

3. Family

3.1. Families were identified as an important factor in advance care planning and should be involved:

‘ … supporting the family is a very strong theme in end-of-life planning ... you need to do it sensitively and pick the right moment otherwise you can distance yourself from the family’ (p13).

3.2. Participants reported ethical challenges when families expressed strong views that they felt were either not in keeping with the patients’ or not in the patients’ best interests:

‘You have occasions when the family views outweighs the patient and so a member of the family’s views are important, [but] it is obviously about the patient ...’ (p13).

9. Brazil K, Carter G, Galway K et al. (2015) General practitioners’ perceptions on advance care planning for patients living with dementia. BMC Palliative Care 14: 14

Methods: Survey

Data: Views (quantitative and qualitative)

Country: UK (Northern Ireland)

Outline

This study used survey methodology to investigate the attitudes and practice preferences of GPs working within the NHS regarding communication and decision-making for patients with dementia and their families. It was judged to be relevant to the review question (++) and was judged to be of moderate methodological quality (+).

The survey was conducted in Northern Ireland using a purposive sampling approach to target GPs with responsibility for people living with dementia. The questionnaire was developed specifically for this study and was based on recommendations proposed by the European Association for Palliative Care on palliative care in dementia. The survey sample was comprised of 340 GPs from 174 practices. A response rate of 40.6% was achieved at the individual level (138 GPs) and 60.9% at the practice level (106 of the surveyed practices).

Findings

The mean age of respondents was 49.3 years and over half were male (57.4%). The average amount of time for which participants had been practicing was 24.7. They had varying levels of experience in terms of caring for people living with dementia. Sixty respondents (46.5%) had cared for 1 to 4 people over the last year and 7 (5.4%) had provided care for 20 or more people living with dementia during the last year.

Physicians were required to indicate to what extent they agreed with a number of statements about advance care planning and future care at the end of life. Numbers responding and percentage agreements are provided:

a. Advance care planning on end of life care should be initiated at the time of diagnosis of dementia n = 133

Strongly disagree 20 [15.0] Moderately disagree 41 [30.8] Neither agree nor disagree 19 [14.3] Moderately agree 41 [30.8] Strongly agree 12 [9.0] Don’t know 0

b. The process of advance care planning should involve revisiting plans with the patient and the family on a highly frequent basis n = 133

Strongly disagree 11 [8.3] Moderately disagree 47 [35.3] Neither agree nor disagree 11 [8.3] Moderately agree 44 [33.1] Strongly agree 20 [15.0] Don’t know 0

c. When a patient cannot participate in treatment decisions an advance directive is essential n = 132

Strongly disagree 9 [6.8] Moderately disagree 21 [15.8] Neither agree nor disagree 34 [25.6] Moderately agree 51 [38.3] Strongly agree 17 [12.8] Don’t know 1 [0.8]

d. The physician should take the initiative to introduce and encourage advance care planning n = 133

Strongly disagree 1 [0.8] Moderately disagree 4 [3.0] Neither agree nor disagree 18 [13.5] Moderately agree 65 [48.9] Strongly agree 45 [33.8] Don’t know 0

e. The advance care planning process requires my making family members agree with the physician on goals of care n = 133

Strongly disagree 25 [18.8] Moderately disagree 45 [33.8] Neither agree nor disagree 26 [19.5] Moderately agree 30 [22.6] Strongly agree 7 [5.3] Don’t know 0

f. When family members have difficulty understanding the limitations and complications of life sustaining therapies, the physician cannot successfully guide the advance care planning process n = 132

Strongly disagree 4 [3.0] Moderately disagree 47 [35.3] Neither agree nor disagree 26 [19.5] Moderately agree 46 [34.6] Strongly agree 9 [6.8] Don’t know 1 [0.8]

g. When the physician cannot make family members accept their loved one’s prognosis, the advance care planning process fails n = 130

Strongly disagree 7 [5.3] Moderately disagree 47 [35.3] Neither agree nor disagree 35 [26.3] Moderately agree 35 [26.3] Strongly agree 6 [4.5] Don’t know 3 [2.3]

h. There should be an agreed format for advance care plans n = 132

Strongly disagree 1 [0.8] Moderately disagree 2 [1.5] Neither agree nor disagree 9 [6.8] Moderately agree 67 [50.4] Strongly agree 53 [39.8] Don’t know 1 [0.8]

i. Physicians need improved knowledge to successfully involve families in caring for dementia patients at the end of life n = 133

Strongly disagree 1 [0.8] Moderately disagree 6 [4.5] Neither agree nor disagree 20 [15.0] Moderately agree 65 [48.9] Strongly agree 41 [30.8] Don’t know 0

j. The pace of advance care planning is primarily determined by patient’s and family’s willingness to face the end of life n = 132

Strongly disagree 1 [0.8] Moderately disagree 11 [8.3] Neither agree nor disagree 19 [14.3] Moderately agree 64 [48.1] Strongly agree 37 [27.8] Don’t know 1 [0.8]

k. Families and patients who are involved in advance care planning should become informed about commonly occurring health problems associated with severe dementia, such as pneumonia and intake problems n = 133

Strongly disagree 0 Moderately disagree 2 [1.5] Neither agree nor disagree 2 [1.5] Moderately agree 62 [46.6] Strongly agree 67 [50.4] Don’t know 0

l. In the case of increasing severity of dementia, the patient’s best interest may be increasingly served with a primary goal of maximising comfort n = 133

Strongly disagree 1 [0.8] Moderately disagree 0 Neither agree nor disagree 1 [0.8] Moderately agree 24 [18.0] Strongly agree 107 [80.5] Don’t know 0

Most respondents thought that discussions in the early stages following a diagnosis would enable decision-making during the advanced stags but a sizeable number felt that these discussions should not happen at the time of diagnosis.

Most felt that timing of advance care planning discussions should accord with the person and their family’s willingness to consider end of life issues. This emphasises the importance of the relationship between the GP and the person and family – so that the GP can judge the optimum time according to the willingness to discuss these issues.

Most participants viewed shared decision-making as a goal of advance care planning but said that a major barrier to achieving this was families’ reluctance to accept the person’s prognosis. Respondents also suggested that families and patients also struggled to understand the ‘limitations of complications of life sustaining therapies’ (p5). The authors conclude that this stresses the importance of education for families (and patients) to help them understand the disease trajectory of dementia and health problems associated with the disease.

10. Farrelly S, Lester H, Rose D et al. (2014) What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 49: 1609–17

Methodology: Qualitative

Data: Views and experiences

Country: UK

Outline

‘This paper describes a sub-study of the CRIMSON trial. The CRIMSON trial was a multi-site randomised controlled trial of joint crisis plans (JCPs) compared with treatment as usual (TAU) for individuals with psychotic disorders' (p1610). The aim of this sub-study were to examine mental health service users' preferences and priorities as a result of a future mental health crisis or relapse. The study had good relevance to the review question (++) and the methodological quality was rated as good (++).

Data collection was carried out by exploring service user preferences for care in the event of a future relapse/crisis through 2 meetings. A joint crisis plan 'menu' was presented to service users in a preliminary meeting with a facilitator. A second meeting chaired by the facilitator was held to finalise the content of the joint crisis plan at which the psychiatrist was also present. The service user's care coordinator, other significant clinicians and family members were also invited. It was the facilitator's role to ensure that service users' views were paramount and that the joint crisis plan could still be finalised regardless of agreement to the content by the clinical team.

The study consisted of a thematic analysis of 221 JCPs.

Findings

The thematic analysis identified two major categories of responses in joint crisis plans: 'delivery of care' and requests (or refusals) of specific treatments/interventions in a crisis situation.

1. Delivery of care

Themes in this category referred to the way in which clinicians interact with service users.

Treat me with respect

The wish to be respected was a central theme in all the joint crisis plans and frequently respect was seen to be absent in the manner in which clinicians communicated.

Respect could also be shown by looking more broadly than just symptom management and illness: '[Other information I would like to be known or taken into account] If I am in hospital for a long period I would like nurses to arrange for me to have a hair cut' (service user, p1612).

Similarly, flexibility in aspects of delivery of care, such as consulting with service users about conveniently timed home visits was another way in which respect could be demonstrated: '[Treatments or other things that have not been helpful in the past] The last time I was unwell, I felt Home Treatment Team messed me about. They came to my flat whenever it suited them. They wanted me to stay in all day. They wanted to visit me twice a day to give me my medication I couldn't do that because I was in the middle of a divorce, I had appointments to see my solicitor, children and other commitments' (service user, p1612).

Understanding what is 'illness' and what is not

Service users described situations in the past where clinicians and the police have misunderstood their behaviour. Other service users stressed the importance of clinicians knowing them as individuals and understanding when it is that they require help: '[Preferred treatment or social care during a crisis or relapse] I have been in and out of hospital because the assessment was done by people who do not know me and didn't pick up that I was becoming unwell so kept discharging me. I would like the Triage ward not to discharge me before speaking to my Consultant' (service user, p1612).

Continuity, consistency and clarity

Most service users said the first contact with services when they started to feel unwell was their usual mental health team. Staff change created stress and usually led to a lack of continuity in treatment.

When unwell, having clear treatment plans helped to reduce the stress of relapse:

'[What I would like to be done when I first start to become unwell] Clarity with my medication – a proper plan of who is giving me my medication and when' (service user, p1613).

Having control/involvement in decisions

The majority of service users wanted to involved in decisions about their care and the need to retain a certain degree of control led to other treatment decisions such as a desire to be treated at home or admitted to hospital on a voluntary basis:

‘[Preferred treatment or social care during a crisis or relapse] I would prefer to be in hospital on an informal basis so I can be involved in decision making around my care’ (service user, p1613).

2. Particular treatments/interventions that service users would/would not like in a crisis situation

Specific treatments/strategies for dealing with crises

Two themes involve non-medical intervention (for example, self-management strategies; talking/support) and the other themes involved intervention from clinical staff. Significantly, the most common first choice for treatment in a crisis was for home treatment team support (35% of the sample), followed by hospitalisation (19%), and medication changes (14%).

Self-management

For many service users, the first step in managing a potential relapse was to take care of their general health/wellbeing, for example, the need to reduce alcohol, or to focus on healthy eating and adequate sleep.

Talking and support

The majority of service users talked about the need for support and to talk to someone to reduce the stress of the relapse, including the importance of clinicians’ understanding the difficult emotions they were experiencing.

‘[Treatments or other things that have not been helpful in the past] Staff who have no respect or empathy for the fact that I am an adult who is suffering’ (service user, p1613).

Staying at home

For many service users, it was essential to be able to remain at home for as long as possible. While 35% of the sample described it as their preferred first line treatment the involvement of home treatment teams was among the preferences of 67% of the sample.

Medication

Fifty six percent of those who made a refusal, made a refusal about medication; 80% of these refusals being about a specific medication and often a substitute was offered. The remaining medication-related refusals referred to injections, high doses and medication changes. A far more common situation was medication review/increase as an initial approach to deal with relapse, which was more favourable than going to hospital for many service users.

Hospital admissions

For the majority of service users, hospital admission was challenging and created further stress to their relapse and could potentially worsen the episode:

‘[Circumstances in which I would wish to be admitted to hospital for treatment] In no circumstances would I agree with coming into hospital – it makes me more paranoid. There’s nothing they have in hospital that I need except for meds and I can take those at home. The only reason you get better in hospital is because you’re back on the meds and not because you’re in hospital’ (service user, p1614).

Most service users were conscious that in some circumstances a hospital admission would be necessary and 77% made a specific statement about when they would like to be admitted, most preferring to go voluntarily to allow them to maintain a certain degree of control.

11. Farrelly S, Lester H, Rose D et al. (2016) Barriers to shared decision making in mental health care: qualitative study of the Joint Crisis Plan for psychosis. Health Expectations 19: 448–58

Methodology: Qualitative

Data: Views and experiences

Country: UK

Outline

A pilot study in London indicated that joint crisis plans were effective in reducing compulsory treatment under the Mental Health Act. However, the definitive trial (CRIMSON) carried out in 4 English mental health trusts did not find this to be the case. Within this context, the aims of this qualitative paper were therefore to understand: how the joint crisis plan was perceived by clinicians and service users and to explore the barriers to shared decision-making identified at the implementation stage. The study had good relevance to the review question (++) and the methodological quality was also rated as good (++). Twelve focus groups were conducted with 35 service users with psychotic disorders, 22 care coordinators and 1 psychiatrist. Thirty-seven semi-structured interviews were also carried out with 15 service users, and (at clinical locations) with 6 care coordinators and 16 psychiatrists. The sample was drawn from the main trial.

Findings

Clinicians identified 4 main barriers to the implementation of supported decision-making in the form of the joint crisis plan, which the authors contrast with positive responses from service users.

The four main barriers for clinicians were as follows.

1. Ambivalence regarding care planning

The majority of care coordinators were frustrated that service users did not value or comply with standard care plans. There was scepticism therefore with introducing a joint crisis plan: ‘One of the reasons I’m so sceptical is that I actually do sit down and do care plans with people, but I go back the next week and say oh can we look at that copy of the care plan again, and they can’t find it. And you think ... you know ... am I really kidding myself that doing it jointly actually does make a difference?’ (nurse, p452).

Others spoke about service users knowing what to do during a crisis anyway and therefore saw the joint crisis plan as presenting an additional care plan of ‘questionable value’: ‘Most of them are aware … a lot of them are fairly basic anyway it's just err, contact your care coordinator who may arrange an emergency appointment, and you know to try and see the consultant or the doctor as soon as possible. And then consider home treatment, go to [accident and emergency centre] if it's outside hours. You know it's very standard and the clients just … they know most of it anyway' (nurse, p452).

2. Already doing shared decision-making

The authors note that clinicians did not appear to be conscious of the power imbalance between them and the service user. Two key problematic areas were firstly, interaction styles and use of language 'When I meet the patients, I explain to them what a consultant is. "I am your consultant and am the person who you consult for expert advice. You are in charge." It is more or less what I tell them ... You come to see me and I am your expert ... I will implore you, at times, to follow my advice' (psychiatrist, p453).

Secondly, clinicians may inadvertently be in control of discussions by withholding information and restricting the options on offer, despite their commitment to shared decision-making: 'And if there is anything that I feel needs to go in, I suggest it, I say "what do you think?" And then I say, "the other thing that needs to go in is this" and we go through it. That's it. I ask them to agree and that's it' (social Worker, p453).

3. Appropriateness of service users' choices

Many clinicians were anxious that service users would make choices that they would not consider to be in the service users' best interest: 'And also, there are things that the service user will want and request and you know it's not really what they need. You have to find a way, to actually communicate that, get them to understand without actually hurting them or without actually sending a message that you don't want them to get that, or you don't want to do it' (nurse, p453).

4. Availability of service users' choices

Concern was expressed about the potential of service users requesting treatments or services that clinicians could not cater for and that the joint crisis plan process was in fact giving false hope. Furthermore, clinicians expressed anxiety that choices made by the service user in their joint crisis plan would not be met as crisis situations would normally be dealt with by a different clinician and not themselves.

The experience of service users

Many service users talked about feeling disempowered with respect to decision-making, not trusting their clinicians, and doubting that they were able to engage in a dialogue with clinicians. For some service users, this was exacerbated by delusional experiences in the past or questioning from clinicians: ‘I have to ask myself whilst [talking to clinicians about treatment decisions] are any of these ideas delusional, are they psychotic? Actually to be honest, once people start talking to you about delusions and psychosis and a lack of insight, you don’t half begin to doubt yourself. So yeah, I think I’m probably okay, but I’m having to ... regain my trust I suppose in my own thinking’ (service user, p454).

The joint crisis plan was therefore valued by many service users because of the perception that having an external person in attendance during the sessions increased their sense of empowerment and ensured that the clinicians were fair. For example: ‘Well it was just like, they didn’t say “no we can’t do that”, they said “we’d try and do x …” They were very helpful, they were saying that as the very last resort you will go into hospital … Whereas before my doctor would say to me, well if you sister thinks you’re going to go to hospital, we’ll put you in’ (service user, p454)

Where clinicians did not engage with the joint crisis plan process, for example by not being at meetings or not taking part in discussions, this had a negative impact on the experience and trust in the process for many service users: ‘I wanted a joint crisis plan cos I thought it might make a difference … with regards to how the psychiatrist would approach things if I got sick. Cos I’ve been sectioned so many times. But I remember, on the day that [the facilitator] came [the psychiatrist] was on the [computer], he was so rude … and he was on his [computer] most of the time when [the facilitator] was talking. He had his back turned’ (service user, p455).

12. Henderson C, Flood C, Leese M et al. (2009) Views of service users and providers on joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 44: 369–76

Methods: Quantitative survey

Data: views and experiences

Country: UK

Outline

This survey (n = 65 and 65 case managers) has good relevance to the research question (++) but was rated low on internal validity (-). It aimed to report on the views of people with mental illness and their case managers on the use and value of joint crisis plans. The research was conducted in the context of a randomised controlled trial examining the effects of joint crisis plans, however the authors do not compare the views of people in the joint crisis plan group with those receiving standard care, but instead report on the views of participants randomised to the intervention group and their case managers regarding joint crisis plans. The study was therefore assessed not as a randomised controlled trial but as a survey of views at 2 points in time, immediately after the intervention and 15 months later.

A joint crisis plan is held by the mental health service user and specifies his or her treatment preferences in anticipation of when he or she is unable to express them. Joint crisis plans include information on contacts, mental and physical illnesses, treatments, relapse indicators and preferences for care during relapse. The participant was asked to provide the name and contact details of a person to be contacted in an emergency, and was encouraged to have a copy of the plan sent to this person as well as other members of their informal support network. The participant was then asked which services they might attend during relapse or in an emergency, and whether they would like a copy sent there. Providers at these services were alerted to the study by the researchers in person as recruitment began (p371)

Findings

Comparison of views data between post-intervention and at 15-month follow-up among participants and their case managers showed that joint crisis plans were valued by most patients and case managers, providing evidence for the feasibility of shared decision-making in psychiatry. The results also suggest that both producing and holding the joint crisis plan promotes self-determination and empowerment among service users. The impact of the joint crisis plan shifted in the direction from positive to no change from the immediate follow-up to 15 months in terms of overall ratings (means 6.1 vs. 8.3, difference 2.2, 95% CI 0.8 to 3.7, p = 0.003; where a higher score indicates less positive views) and for the question on its impact on the likelihood of the holder's continuing with care. The 2 highest endorsements which showed least shift over time were: whether the participant would recommend the joint crisis plan to others (90% initial vs. 82% at 15 months) and whether they felt more in control of their mental health problem as a result (71% at initial vs 56% at 15 months).

Case managers at 15 months were more positive than service users, with total score means of 5 vs 7.8 (difference –2.8, 95% CI –4.5 to –1.2, p = 0.002). The findings suggest that participants felt more in control of their mental health problems and that they felt joint crisis plans can empower patients to obtain their preferred care and treatment in a crisis.

13. Horn R (2014) 'I don't need my patients' opinion to withdraw treatment': patient preferences at the end-of-life and physician attitudes towards advance directives in England and France. Medicine, Health Care, and Philosophy 17: 425–35

Methodology: Qualitative

Data: Views and experience

Country: UK (England) and France

Outline

This study provides a qualitative exploration of the attitudes of British and French doctors on advance directives, placing them in their different cultural, philosophical and legal contexts. The primary concern is responses to patients' wishes around end-of-life treatment, and whether a prior wish that treatment will be withdrawn or extended at a particular point will be respected. The research took the form of 29 semi-structured interviews with 14 French and 14 English doctors who were recruited from 2 English and 3 French university hospitals. The doctors were all specialists whose work meant that they were likely to come into contact with people who faced decisions about end-of life-care (oncologists, palliative care specialists, etc.). The study has moderate relevance to the review question (+) and was judged to be of moderate methodological quality (+).

Findings

Attitudes towards consulting patients

English participants all thought it was important to have a discussion about withdrawing treatment with patients, with 8/14 saying this should be when the patient started to deteriorate but before the prognosis had become very poor. However there could be problems with getting this timing right as some doctors were getting to know their patients at a point when their capacity was already limited. One doctor said that doctors' difficulties in dealing with these situations related to problems with facing their own mortality, which led to doctors making excuses for not having a difficult conversation or communicating a bad prognosis.

In France, doctors made it clear that they did not need their patient's opinion in order to either withdraw treatment or continue to provide it. Doctors described never wanting to stop providing treatment, as to stop seemed to be not valuing patients' lives. Their perception of the doctor–patient relationship was based on active treatment. One doctor described the insistence of continuing to provide treatment beyond any hope of cure as 'the "barbarism of French doctors"' (participant, p429). However, there was recognition that it could be important to limit end-of-life interventions: ' … there are social rules … and we have to avoid that after three months people end up in a vegetative state. … That poses the question of how much will this cost the society. And, then we also have to ask what the emotional and social burden is for the family?' (participant, p429).

Making decisions about treatment

English doctors described the importance of patients making informed decisions, and felt comfortable when treatment decisions were being made if this had happened, even in cases where they disagreed from a medical standpoint. Once the decision has been made it can become part of the doctor–patient relationship. Even where the patient lacks competence, most doctors would take into account previously expressed wishes, the views of family and friends and the opinion of the GP, but would never rely wholly on the family. French doctors also stressed the importance of giving the patient information before asking their opinion. One saw this as presenting '… their clinical opinion to the patient because the final decision remains medical …' (participant, p430). French doctors saw themselves as safeguarding patients' humanity and dignity, and saw decisions about treatment as being a collective decision of society.

Attitude towards advance directives

Both sets of doctors had little experience of advance directives. English doctors raised concerns about whether a snapshot opinion should be taken as representing an authentic wish, and whether they truly covered all eventualities. French doctors questioned the whole concept of the advance directives, 1 seeing them as an attempt to replace a relationship with a signed document to solve the problem. A minority thought they might be accepted in France at some point in the future.

English doctors made suggestions for improving advance directives: better documentation, everyone carrying a card or microchip, including the GP, a standard advance directives on the medical file, more discussion and less bureaucracy.

'The English physicians interviewed allude to the Liverpool Care Pathway, emphasising besides ADs, broader advance-care-planning and doctor-patient communication on end-of-life care. Advance-care-planning can help identifying patients' general and specific preferences. It thus helps assessing the authenticity of a wish … which is important for English doctors when facing the conflict between respect for patient preferences and their concern for patient welfare …' (authors, p433).

French doctors also thought advance directives could be improved, but did not discuss a concrete solution. They felt that doctors needed to accept that medicine couldn't deal with everything, and they should be more empathetic. In expressing views that doctors needed to become better at deciding what would benefit each patient, the views of the patients was not a consideration.

14. Kazmierski M, King N (2015) Role of the community matron in advance care planning and 'do not attempt CPR' decision-making: a qualitative study. British Journal of Community Nursing 20: 19–24

Method: Qualitative

Data: Interviews

Country: UK

Outline

This qualitative study from the UK explored community matrons experience of end-of-life decision-making for individuals with a life-limiting long-term condition, focusing in particular on advance care planning and Do not attempt Cardiopulmonary Resuscitation decision-making. The study was judged to have good relevance to the review area (++) and to be of good methodological quality (++). Qualitative data were generated from 6 community matrons using a broad interpretive phenomenological approach. Face-to-face recorded interviews were analysed using template analysis.

Findings

1. Experiences of training in advance care planning and 'do not attempt cardiopulmonary resuscitation' decisions

Five of the participants had been in post for at least 3 years, yet none of them had received any training in 'do not attempt cardiopulmonary resuscitation' decision-making: 'Being new to the role, it's not something that gets talked about, but you don't get any training in how to approach it, really' (participant, p21).

Another participant attended an advanced communication course but she felt that it did not relate to caring for patients with a long-term condition, especially the difficulty clinicians have when deciding the appropriate time to put in a 'do not attempt cardiopulmonary resuscitation' request. When asked why the community matron had not been included in this training, it was reported that: 'Err, thinking about where I work at the present which is [location of work and area], is that the community matron's role in palliative care hasn't particularly been seen to be, erm, that important. It's been mainly district nurses have very much taken the lead on palliative care, erm, and … advance care planning' (p21).

2. Personal experiences with advance care planning/'do not attempt cardiopulmonary resuscitation'

All participants expressed confidence with the concept of advance care planning and 'do not attempt cardiopulmonary resuscitation' decisions, particularly when they knew the patient/family were in agreement with the decision-making process and/or they knew them well. However, when it came to actually signing the 'do not attempt cardiopulmonary resuscitation' form, many participants were not confident and expressed insecurity: 'I've not actually spoken to a lot of patients and ... their families about do not resuscitate ... To be quite honest I've stayed clear of it really' (p21).

Another participant reported that: 'To be honest, on reflection of that, I think most of my patients should really have some sort of advance care plan from now.'

3. Role in palliative care

All participants felt that the community matron role was a palliative role.

'I think its just like being a palliative care nurse, really; that's what I truly feel' (participant, p22).

Another participant felt that the community matron was in the best position to lead on palliative care for patients with a long-term condition, as their advanced clinical skills, knowledge of long-term conditions and case management were unique among professionals in the community.

Working collaboratively with other professionals around long-term conditions, symptom management and ensuring that they know the patient's journey was seen as 'enhancing the end-of-life care pathway for the patient'.

4. Long-term conditions versus cancer

Participants in the study continued to struggle to get patients on the Gold Standards Framework register in their practice because they were not deemed to be palliative.

'We only think of palliative as cancer. Every one of my COPD patients should be on that Gold Standards Framework, but I can't get them on there – you know I can't –

it's, there's still that thing of trying to get through to the GPs and I think until that's done the only people that are there is the community matrons' (participant, p22).

'I still think GPs struggle to [know] ... when to put [the DNACPR form] in, especially if they're long-term conditions. Cancer patients, they're quite happy, but for long-term conditions there's still that ... they don't know whether we are gonna actually make them better this time' (participant, p22).

5. Relationships: knowing patients well

Participants felt that because they knew their patients well, they were able to recognise clinical deterioration.

'Well, because, I mean, she runs on saturations around 82 most of the time, but if you go in and they're 70 you know something's pretty wrong …' (participant, p22).

'[The] community matron ... [is] often in that unique role, but I also see us being in a position where we are able to care coordinate and be a very valuable ... professional in the end of life care in helping other people understand the journey that they've come on and where they are ... from a disease progression and symptom management and work alongside district nurses, Macmillan nurses, specialist nurses and the wishes of the patient in wherever they wish to end their life' (participant, p22).

6. Communication: transfer of care and lack of discussion

All participants described scenarios, often traumatic, whereby patients had been transferred back into the community with a 'do not attempt cardiopulmonary resuscitation' order in place but with no real discussion with the patient or their family.

One participant described a case where the patient had been very ill and placed on the Liverpool Care Pathway in hospital. He then made a recovery and was discharged home with no review of the 'do not attempt cardiopulmonary resuscitation' status:

‘He was given a DNR form and, when he came home, the form was sent with him, which his son-in-law promptly waved in my face and said “what do you think of this?”’

There appeared to be specific barriers when discussing advance care planning and ‘do not attempt cardiopulmonary resuscitation’ orders, particularly, negative views of these held by the patient and their carers. One participant reported that the recent negative press had had an impact in the sense that while more people were aware of ‘do not attempt cardiopulmonary resuscitation’ order, they were concerned about its use. She felt that if she broached the subject with patients they would think she was trying to ‘euthanize them’.

Another participant, when asked why she had not initiated ‘do not attempt cardiopulmonary resuscitation’ discussions said it was because she went in with ‘a positive outlook in goal setting’, implying that discussing advance care planning would be seen as negative by the patient.

15. MacPherson A, Walshe C, O’Donnell V et al. (2013) The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. Palliative Medicine 27: 265–72

Methodology: Qualitative

Data: Views and experiences

Country: UK

Outline

This was a qualitative study exploring the views of patients with severe chronic obstructive pulmonary disease (COPD) regarding advance care plans. It ‘… aimed to answer whether people with COPD think that advance care planning could be a useful part of their care, and to explore their reasoning behind this view. This included discussion of their knowledge of their diagnosis, as well as their thoughts about their future and any discussions about their future that had taken place …’ (p266). Semi-structured interviews were carried out with 10 patients at their own homes, with a relative present and able to participate if they chose. Data from interviews was analysed using a grounded theory approach. The study was considered to have good external (++) and internal (++) validity.

Findings

Information provision

In terms of information provision, most patients reported that they had not had much discussion with healthcare practitioners about their condition, which angered some, particularly where they felt there was a lack of communication at the time of diagnosis. Although all interviewees were aware their illness was progressive and ultimately fatal, they knew this from observing others with COPD or observing their own condition:

‘Nobody’s ever talked to me about anything really, seriously. I did ... I said to you I didn’t even know I had COPD. That’s how much the doctors have talked to me’ (participant 09, p268).

Discussions about the future

Most of the participants had not had discussions with healthcare professionals about the future. ‘The first had consisted of a district nurse mentioning that he [the participant] was very unwell, and had he thought about the future, which he took to mean had he planned his funeral. He had become very upset by this, and had complained about that nurse’ (p268). The other was initially upset when he was asked to think about what healthcare he might want in the future, but said it no longer bothered him. He had had time to think and prepare for completing a ‘preferred priorities of care’ document with his community matron. ‘He knew that he would prefer to be at home; however, he was uncomfortable documenting this, and felt that this decision could change depending on the circumstances:

‘They kept asking me in the hospital, well what do you want to do? Do you want to be at home, do you want to be in here? Well you don’t know until it happens’ (participant, p268).

The experience of other participants was of discussions with health professionals that focused on the present and on their current problem, with future preferences for treatment never discussed. Most of them did want more information about how their illness would progress, but felt awkward about bringing it up themselves. However, some were not interested in discussing the future, as they felt the discussions would not change anything.

Views about patient involvement

Most wanted to be involved in discussing treatment options and making decisions about treatment, and their relationship with their healthcare provider could be damaged where this didn’t happen, for example, medication being changed without a discussion. Even patients who were generally happy to go along with the doctor’s decisions wanted to be involved in the discussions and included in the decisions.

When it came to planning the future, patients did not see how making plans in advance would be helpful. Their symptoms varied significantly, which they were dealing with already on a day-to-day basis, making routine decisions: ‘I mean, because I don’t know how I would feel until I get there, you know, so ... I don’t make advance decisions, you know’ (participant, p269).

There had been discussion about general preferences for care with participants’ family members, and they did expect that their families would have some input if they lacked capacity themselves: ‘Participants had not discussed these preferences with healthcare professionals, but, as above, all participants stated they would be comfortable with these discussions if asked’ (p269). ‘Some felt that if they were dying, they would be unaware of what was happening and therefore what happened to them was less important. Participants also found it difficult to imagine a scenario in which they wouldn’t be able to make a decision at the time’ (p269). Most stated that more discussion about their illness, its future impact on them, and what their treatment preferences were, would be welcome, but they did not want treatment decisions to be based on preferences stated previously without there being some review of the circumstances and consultation with their families at the time.

Place of care

The most important future consideration for participants was their place of care, which they had considered more than they had considered treatment options such as resuscitation or ventilation. People were influenced by their previous experience, particularly bad experiences in hospital that they wanted to avoid repeating: ‘Last thing at night, nurses had some rubbish and they'd go up with the lid then, let go of the lid and crash! And this is all I remember. That was my main complaint. They were coming round with drugs at two, three o'clock in the morning. You're up again at five. Oh, I just couldn't get no sleep. And nobody could tell me what was wrong with me. Nobody could tell me what was wrong with me. And I swore I would never go back there again' (participant, p269).

Participants' main complaints about hospital were uncaring staff, poor communication with them about management, and the treatment being no different to what they could have had at home. The presence of a social network was a factor in wishes about where to be cared for, with those living alone feeling that their needs for care and support would not be met at home if they became unwell. 'People identified their family as the main source of support at home; they felt that if their family could not support them at home, they would go to hospital …' (p270).

Overall

The study concluded that this group of patients were uncomfortable with the idea of advance care planning as a fixed decision. 'The idea of making binding decisions about future care is not helpful when suffering from a disease following an unpredictable course with wide variability of symptoms …' (p270).

16. Musa I, Seymour J, Narayanasamy MJ et al. (2015) A survey of older peoples' attitudes towards advance care planning. Age and Ageing 44: 371–6

Methodology: Survey

Data: Views and experiences

Country: UK

Outline

This survey of older people's (aged 65 years or over) attitudes towards advance care planning was carried out using a postal survey questionnaire. The questionnaire was designed using a process of consultation with 4 focus groups. A test–retest check of reliability found that the reliability of the questionnaire was moderate. The survey questionnaire was sent out to 5375 patients of 13 general practices who were aged

65 or over and lived in the community. Internal validity (+) and external (+) validity were both judged to be moderate.

Findings

Who had an advance care plan?

A total of 1832 questionnaires were returned, 9 of which were blank. The remaining 1823 were analysed. It was found that 231 respondents (13%) had prepared an advanced care plan, and 77 (4%) an advance decision to refuse treatment (ADRT). However only 84 (4.6%) had been offered the opportunity to have the discussion, and 58 of those (70%) actually had one. ‘Multivariate predictors of ADRT completion included: being offered the opportunity to discuss ACP (OR 10, 95% CI 4.5 to 19.7), older age (OR 1.5, 95% CI 1.0 to 2.2) and male gender (OR 0.5, 95% CI 0.2 to1.0)’ (p374). A total of 219 (12%) of the respondents had approached someone to discuss ACPs ,usually family or friends, less often GPs or other health or social care practitioners.

How respondents felt about advance care plans

Of all respondents 74% felt that they would feel comforted by the knowledge that there was some guidance for their families, but 3% disagreed with this. A total of 60% said that advance care planning discussions would only take place if someone else raised the matter. Almost half (44%) were happy for healthcare decisions to be left to others if they were unable to express themselves. Of those, 76% would trust the doctor or healthcare worker and 94% trust their families to make the right decision for them. Of the whole sample, 85% would trust their families and 61% their doctor to do this. 85% expressed a preference for these decisions to be discussed informally rather than written down.

Around a third (34%) of respondents felt that making an advance care plan would make no difference to what happened anyway, but 47% disagreed. Within the focus groups this particular barrier was mostly expressed by people who were strongly religious or were Asian. There was some pessimism about whether wishes would be carried out: 67% felt there was no point unless there would be help to meet the wishes, and 59% felt it was difficult to know if their advance care planning wishes would be observed. 35% were worried that doctors would stop treatment too early.

There was uncertainty about attending sessions on advance care planning if available: 33% would attend, 38% would not, and 28% were not sure. Maleness and older age were predictors of willingness to engage in such sessions.

17. Preston H, Cohen Fineberg I, Callagher P et al. (2011) The preferred priorities for care document in motor neurone disease: views of bereaved relatives and carers. Palliative Medicine 26: 132–8

Methodology: Qualitative.

Data: Views and experiences

Country: UK – England

Outline

The aim of this qualitative study from the UK was to explore the experiences of the bereaved relatives of people with motor neurone disease. The study focused specifically on their views regarding preferred priorities for care documents and the impact which they felt these had had on the care of their relative at the end of life. The study had good relevance to the review question (++) and it was rated as moderate (+) on methodological quality. The sample was comprised of 11 relatives of people with motor neurone disease. The researchers used semi-structured face-to-face interviews to gather data.

Findings

The majority of participants reported that their relative had completed their preferred priorities for care document with the help of both a carer and a healthcare professional (usually a motor neurone disease nurse or a district nurse). The authors report that all interviewees felt that these professionals were the most appropriate to involve, noting the importance of a pre-established relationship with a professional with whom the patient felt comfortable.

The researchers found that preferred priorities for care documents had been completed between 2 and 17 months prior to the death of the patient, however they note that almost all of the participants recalled that their relatives had begun to discuss their preferences before this point. Participants reportedly emphasised the importance of their relative completing these documents whilst they were still able to sign them or communicate verbally. In cases where a patient had lost the ability to talk; some participants reportedly suggested that the document should have been completed prior to this development. The authors contrast these interviewees with those who had a '… strong sense …' (p133) of their relatives wishes and therefore had less concerns regarding timing.

The authors go on to report that the majority of those interviewed felt that the experience of completing the document had been positive and had provided their relative with peace of mind. However, participants also described the process of completion as emotionally challenging.

The researchers found that the documents were most commonly shared with family/friends, and that this often took place soon after the document had been completed. In contrast, although participants stated that documents had been shared with healthcare professionals, this was less common. Some participants reported that they had shared the document with a paramedic in an attempt to prevent hospitalisation; however the authors note that once their relative had been taken into hospital, only half of the participants stated that they had shared it with hospital staff. The authors also report that participants who had a 'strong' understanding of their relative's wishes were less likely to believe that showing the document to a professional was important.

The authors state that the documents were on the whole seen as a valuable tool, particularly as they helped to provide peace of mind for patients and enabled patients' wishes to be communicated to professionals. However, those participants who 'strongly agreed' with the wishes of their relative did not see the document as particularly useful, although some reportedly acknowledged that it might be found useful by others and had on some occasions prompted discussions regarding issues not previously discussed (for example, resuscitation).

The authors note that while participants viewed the document as important, a number of them felt that its impact on end-of-life care was minimal, and that their own awareness of the patient's wishes had been more influential.

The authors also note that 2 participants felt that the document had had a negative impact, however they do not provide further details in relation to this finding. Despite a small number of negative views regarding the document, the authors report that the majority of participants stated that they would use one themselves or recommend them to others. However, there were also concerns from many regarding the extent to which health care professionals acknowledge preferences expressed in a preferred priorities of care document.

Participants also reportedly identified a lack of awareness among practitioners as a major barrier to the effective use of a preferred priorities of care document, particularly during admission to hospital. The authors state that issues tended to arise when staff did not understand the purpose of the document or appeared to ignore the stated wishes of the patient. The authors go on to suggest that participants believed that work needed to be done to raise awareness of the documents.

18. Seamark D, Blake S, Seamark C et al. (2012) Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study. Primary Care Respiratory Journal 21: 261–6

Methodology: Qualitative

Data: Views and experiences

Country: UK – England

Outline

The aim of this qualitative study was '… to examine whether an admission to hospital for an exacerbation of COPD [chronic obstructive pulmonary disease] is an opportunity for ACP [advance care planning] and to understand, from the patient perspective, the optimum circumstances for ACP' (authors, p261). The study had good relevance to the review question (++) and the methodological quality was also rated as good (++). The sample comprised of 16 patients aged between 58 and 90 years and their carers. Twelve patients were male and 4 were female. The severity of COPD in patients was a mixture of mild, moderate and severe disease, with 1 patient suffering very severe disease.

Findings

1. Was advance care planning discussed in hospital?

None of the patients remembered discussion in hospital about issues of resuscitation, the possibility of being ventilated and planning for future exacerbations. One patient had a directive kept at home asking not to be resuscitated, however, the form was left at home when the patient attended hospital. The authors note that the possible explanations for lack of discussion about advance care planning appeared in the following theme.

2. Hospital admission and discharge: chaotic and too ill to engage

Most patients (14 of 16) were admitted as rushed emergencies with little discussion with the ambulance crew or attending GP: ‘I was seen by a doctor as far as I can remember and pushed into hospital’ (patient 8, p263) and ‘No chance to think, I was whipped in and that was it – “you’re going”’ (patient 3 p263).

Most patients thought admission was chaotic, confusing and lacking in continuity. Extreme illness made decision-making and recall of events exceptionally difficult. For instance, none of the patients remembered end-of-life care discussions with hospital staff during their admission.

3. Attitudes to advance care planning

All patients in the sample agreed to talk about advance care planning and related matters but many found it emotionally difficult and preferred not to make decisions, while for others advance care planning provided an opportunity to focus on the problem. Advance care planning was also considered an area where it could be hard to make firm decisions. With resuscitation, for example, the commonly held view was that patients would only consider this as an option if a successful outcome could be guaranteed, therefore it seemed more rational that this was a medical decision to be made by clinicians.

4. Who to talk to – someone you know or someone who knows?

In response to the question who should discuss advance care planning, there was a desire for a familiar person as well as a person who had expertise in their condition. Most patients favoured their own GP as the person best placed to talk to them about end-of-life issues with the preferred setting being the home or GP surgery in the period after admission. Some patients felt that family involvement in such discussions would be beneficial.

19. Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in homes for older people. Age and Ageing 40: 330–5

Method: Qualitative

Data: Interviews

Country: UK

Outline

This qualitative study was conducted in the UK and aimed to explore the views of care home staff and the families of older residents of advance care planning. The study was judged to have good relevance to the review area (++) and to be of good methodological quality (++). Participants were staff (care managers, nurses and care assistants), community nurses and families. Data were collected using individual semi-structured interviews and analysed using a framework approach in order to develop themes.

Findings

The themes of the qualitative analysis were organised around (i) benefits, (ii) barriers and (iii) facilitators.

Benefits

a) Staff and families spoke positively about advance care planning. However, family and friends failed to qualify why they perceived advance care planning as a good idea.

Quote 1: ‘I think, so much of this stuff can be just tokenism ... my father, when I filled in something for him about his life but then I didn’t hear anything about it after that …’ (son of a recently deceased resident of a nursing home, p332).

b) Staff felt advance care planning promoted respect for residents’ wishes and aided their treatment decisions.

Barriers

a) Staff and families identified residents who lacked cognitive capacity as a common barrier to advance care planning: ‘Yeah if you ask mum where she’d want to be she’d say with me she doesn’t know she’s in a residential home, she thinks she’s in a waiting room from the hospital, waiting to go home’ (family member of a resident).

b) Nurses and managers (the majority of whom were qualified nurses) identified unforeseen medical scenarios as barriers to fulfilling certain advance recommendations.

‘Somebody may tell you, yes I’d be happy to die here but if, during an end-of-life phase they have some terrific bleed there’s no choice other than sending to hospital’ (care manager of a nursing home).

c) Staff and family alike felt that the reluctance of some residents to discuss end-of-life issues was related to fear of thinking about death and not feeling comfortable discussing these issues with care home staff. Care assistants felt it should be the role of the resident’s family to engage in advance care planning discussions and not the role of the staff.

d) Some care home staff had difficulty with advance care planning because of their cultural beliefs: ‘I know there’s other people [staff], some of them they have trouble discussing it’ (nurse working in a nursing home, p332).

Care assistants who reported reluctance were from a similar range of ethnic backgrounds to the nurses and managers, who themselves indicated no reluctance to engage in advance care planning discussions. Staff also perceived that at times family members are reluctant to discuss their relatives’ preferences. This was attributed by staff to their reluctance to accept that their relative was towards the end of life.

e) Conflict between family and staff over advance care planning was identified by care managers and nurses but not by care assistants or family members. A common conflict concerned the nurses’ and managers’ awareness of the resident’s wish to die in the care home, but family insisting on a transfer to hospital. Staff felt that families believed that their relative would receive better care in hospital. In contrast, staff believed the care home could provide a more comfortable setting for end of life care.

‘Relatives they’ve discussed with you and they’ve understood what the relative [wants] but at the last minute they’ve changed their minds, and they think that the hospital will be the best place for their relative’ (care manager of nursing home, p332).

Facilitators

Perceived facilitators of advance care planning were to involve family members to help establish the resident’s preferences and that staff who approach discussions with residents should have a prior familiarity with them and should start discussions early and in gradual stages before the onset of serious health problems.

Advance care planning was also seen to be facilitated by providing guidance to staff on how to approach such discussions. Some considered a direct approach and some felt an indirect approach was better. Family members and care assistants stated it was important to approach the subject sensitively.

20. Stone L, Kinley J, Hockley J (2013) Advance care planning in care homes: the experience of staff, residents, and family members. International Journal of Palliative Nursing 19: 550–7

Methodology: Qualitative

Data: Views and experiences

Country: UK – England

Outline

Through the process of semi-structured interviews, this study aimed to explore the experience of staff, residents, and families having advance care planning discussions within the context of care homes. The study had good relevance to the review question (++) and the methodological quality was also rated as good (++). The sample consisted of 11 residents, 6 family members and 6 staff (5 registered general nurses and 1 healthcare assistant). Residents’ health conditions included cancer of the oesophagus and breast, muscular dystrophy, heart failure and rheumatoid arthritis.

Findings

The findings were divided into 3 main categories.

1. Understanding advance care planning.

2. Undertaking advance care planning discussions.

3. Impact of advance care planning discussions and reactions to these.

1. Understanding advance care planning

When asked to define the term advance care planning, there was no clear idea of what it was. Some staff understood the significance of recording residents' views and thoughts on end-of-life care and other staff thought advance care planning applied to everyday care.

Similarly, residents' and families' understanding of advance care planning also varied, 1 resident relating it to end-of-life care and thinking that if someone was having such a conversation it suggested that they were going to die soon. Other residents thought advance care planning was about general everyday care: 'Well, I'm not quite sure ... Continues all the time, yes, in my care, sort of thing ... And I can ask questions, you know, where I like and I get sensible answers for them' (resident, p552).

2. Undertaking advance care planning discussions

The decision to have an advance care planning conversation was frequently introduced through the monthly Gold Standards Framework in Care Homes meetings, where deterioration of a resident acted as the prompt.

'She was identified as a lady who … might not survive more than a few weeks. She ... she's our most ill person' (staff member, p553).

Decisions around when to undertake an advance care planning discussion varied between different individuals and families. For some, an advance care planning conversation was appropriate soon after admission, but for others it was too overwhelming to handle such discussions at this point.

‘You don’t really want to load too much of the protocol when you’re trying to just get to know the staff, get to know your surroundings ... she sort of left it with me as to when we would fill it out’ (family member, p553).

Many staff simply found it challenging to make time to conduct an advance care planning discussion and some felt that it was not valued by colleagues and management.

‘Where you spend time talking to relatives, then you’re not spending time nursing’ (staff member, p553).

Staff, particularly those with limited experience in palliative care, could be intimidated by approaching the subject of advance care planning. On the other hand, they had more confidence where relationships with the resident or family member were good.

The advance care planning document was typically used to guide advance care planning conversations or given to family members to look at. But this approach could potentially constrain the flow of conversation and consideration of different solutions.

One resident found the approach of the staff member unsettling and felt that advance care planning was just another job that had to be completed.

‘She, she came breezing in and she said she’d got something to fill in and ... “How, where do you want to die?” ... There was, whatever question was at the top, she just read the question out and wanted a tick or a cross ... Well, I felt it was a bit premature: I wasn’t ready for that ... It wasn’t introduced, it was badly, you know, banged into’ (resident, p553).

3. Impact of and reactions to advance care planning discussions

Before the proper implementation of advance care planning, discussions had often been had with residents and/or families about the end of life, but these were usually casual and held during a crisis when a resident’s condition was declining.

In contrast to staff apprehension about advance care planning conversations, the researcher felt that most residents were comfortable talking about end-of-life care.

‘Well it didn’t worry me cos I wa-, I, I thought to myself “Oh well, they wanna know things.” You know ... But er, they asked questions and I er, I just answered them’ (resident, p554).

An advance care planning conversation gave relatives an opportunity to talk about future care and to hear what their loved ones desired. It also provided a chance for them to plan for the future: ‘I thought well at least they know now what we want and all that ... The fact that we’d discussed it and they knew what we wanted’ (family member, p554).

The place of death seemed to be a priority of the advance care planning conversation.

‘It’s her home, this is her home and this is where she wants to be, and this is where she wants to pass away’ (family member, p555).

However, not all residents had indicated a preference and thought that staff and family were better placed to consider the best option.

One occasion was discussed where the Gold Standards Framework in Care Homes facilitator had role-modelled an advance care planning discussion. This process helped a member of staff to learn about advance care planning and supported change in practice.

21. Whitehead B, O’Brien MR, Jack BA (2011) Experiences of dying, death and bereavement in motor neurone disease: a qualitative study. Palliative Medicine 26: 368–78

Methodology: Qualitative

Data: Views and experiences

Country: UK – England

Outline

The authors of this qualitative study from the UK aimed to ‘…to explore the experiences of people with Motor Neurone Disease (MND), current and bereaved carers in the final stages of the disease and bereavement period’ (p369). This included discussion of advance care planning. The study had moderate relevance to the review question (+) and the methodological quality was also rated as moderate (+). The sample comprised 53 people with motor neurone disease and their carers (including those who had recently been bereaved). The authors used narrative face-to-face interviews to collect data.

Findings

In addition to general anxiety regarding the progress of their disease, the authors report that patients also worried that a deterioration in their physical abilities and an inability to communicate would prevent them from participating in decision-making. Some participants also reportedly felt that they needed more information in order to make end-of-life care decisions, and that in some cases relevant information was being withheld.

In contrast to the authors' views regarding the value of advance care planning tools, there were concerns from some participants that patient preferences were not always honoured, and the authors note that 1 participant felt that such tools were unlikely to be of any use. Some participants reported that practitioners had in some cases ignored advance care documents, citing a bereaved carer who reported that her husband's preferences regarding resuscitation (expressed on a preferred priorities for care document) had been disregarded by an accident and emergency practitioner: '… so when I see the A and E doctor …. I said, "look , can I show you?" he said "Well, what is this, what are you talking about?", "Well this is what my husband wants to happen" and I showed him the part where it says in the event of serious collapse, the patient does not want to resuscitated, but the A and E doctor said "well it's not worth the paper it's written on, what are you talking about?" (participant, p372).

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies from the additional search for questions 1a and 1b.

APa 1	There is some evidence that the timing of discussions is an important influence on people's experience of advance care planning. The quality of the evidence is mainly good. Patients and families said that the most suitable time for advance care planning discussions was following the recurrence of a disease or if treatment didn't work and prognosis is poor. Discussions around the time of

	diagnosis should be avoided (Barnes et al. 2007 ++). Participants in the MacPherson study (2012 ++) felt they were being asked to make decisions about future care far too early. Some pointed out that at present they were struggling to cope with the impact of their disease on everyday life, which was as much as they could focus on at present. Both the MacPherson and Barnes studies highlight the importance of offering the opportunity for advance care discussions more than once, allowing patients time to think through and address different issues in their own time. Boot and Wilson (2014 ++) found that when the patient is ready, the advance care planning process is 'easy'. In the case of patients with motor neurone disease, Preston et al. (2011 +) reported that discussions around preferred priorities for care documents were being conducted too late in relation to disease progression. Some relatives said that the conversation was introduced at a point where the patient was no longer able to communicate their preferences or sign relevant documents.
APa 2	There is some evidence that advance care planning depends on the provision of a wide range of information, which is not always made available. The quality of the evidence is mainly good. Respondents in the Barnes et al. study (2007 ++) seemed to lack information about the process of advance planning. They had not realised they could make known their wishes over where to receive end-of-life care and had not had the opportunity for these discussions. Some patients in the MacPherson study (2012 ++) were angered because they had been given little and sometimes no information about the nature of their condition and as a result felt in no position to discuss plans for care in the future. Health professionals in the Almack study (2012 ++) said that the crucial decision about when to initiate discussions about end-of-life planning was triggered partly when patients indicated that they require information about their disease progression or treatment options.
APa 3	There is a moderate amount of evidence that a range of people including families and trained practitioners should be involved in advance planning discussions. The quality of the evidence is good. In Seamark et al. (2012 ++) COPD patients wanted advance planning discussions to involve someone familiar to them, for instance a family member but most importantly, someone with expertise in their condition. Research by Boot and Wilson (2014 ++) and Stewart et al. (2011 ++) highlighted the importance of involving families to facilitate advance care planning discussions. However Stewart et al. also reported difficulties reconciling family views with the resident's known preferences. Almack (2012 ++) found that if relatives were unwilling to engage in conversations about end-of-life care, this represented a key barrier to advance planning. Patients in the Barnes study (2007 ++) were clear that they wanted to have advance planning discussions with a trained person demonstrating excellent communication skills and who could provide accurate information in an unhurried setting. They thought that neither their consultant nor their GP would be appropriate.
APa 4	There is a good amount of evidence that practitioners lack the requisite skills and training to conduct timely and competent discussions about advance care planning. The quality of the evidence is good. Patients in the MacPherson study (2012 ++) described poor communication by health professionals, with some of them failing to discuss the person's condition – let alone future plans – and others attempting to initiate advance planning discussions in such a way which upset the patient and triggered a formal complaint. Almack et al. (2012 ++) identified the need for training and developing experience in advanced communication as a key barrier to conducting advance planning discussions. In Stewart et al. (2011 ++) respondents suggested that work was needed to

	increase staff awareness about and understanding of priorities for care documentation because this lack of understanding was a major barrier to advance care planning. Some of the community matrons in the Kazmierski and King study (2015 ++) said they had not received any training in decision-making relating to 'do not attempt CPR resuscitation'. Although it had been mentioned in the practice context no training was available about how to approach those difficult discussions. Care home staff said they felt intimidated at the prospect of initiating advance care planning discussions and others felt that they did not have a clear understanding of what was involved in advance care planning (Stone 2013 ++).
APa 5	There is a small amount of evidence that staff attitudes to advance care planning can prevent or hinder the conduct of discussions. The quality of the evidence is good. Data from some of the resident interviews suggested that care home staff took a rather unsympathetic approach to advance care discussions, treating it as a 'tick box' exercise (Stone 2013 ++). From the staff perspective, they found it hard to accommodate discussions especially when their colleagues judged it to be a 'waste' of precious nursing time. Stewart (2011 ++) reports that some care home staff felt it was not their job – rather the role of families – to engage with advance care planning discussions.
APa 6	There is a moderate amount of evidence that perceptions of advanced care planning are confused and negative, creating a barrier to discussions. The quality of the evidence is good. Barnes (2007 ++) reported that there was a great deal of anxiety among patients and their families about the legalities of advance directives, their connection with euthanasia and opportunities for changing what is written if a person wishes to do so in future. Similarly, Kazmierski and King (2015 ++) report that community matrons felt that patients and families could be highly suspicious of advanced care planning and 'do not attempt CPR resuscitation' discussions, which they associated with euthanasia, sometimes led by negative press reports. For these reasons, the community matrons were reluctant to initiate discussions. Musa (2015 +) reported uncertainty and scepticism from participants about whether wishes expressed through advance care planning would actually be respected. Similarly, MacPherson (2012 ++) found that some COPD patients failed to see how making plans for future care would be helpful; while others were reluctant to document their wishes in case they changed their minds at a later date. Finally, staff and families shared a view in the Stewart study (2011 ++) that residents would not engage with advance care planning because they were uncomfortable talking about death.
APa 7	There is a small amount of low quality evidence that joint crisis plans positively affect self-determination among people using psychiatric services. In a survey of participants in a controlled trial of joint crisis plans, Henderson et al. (2009 -) found that producing and holding the plans promoted self-determination and empowerment among people using psychiatric services. However it should be noted that there was no change in participants' overall rating of joint crisis plans ($p = 0.003$).
APa 8	There is a small amount of evidence that advanced care planning increases communication with cancer patients, families and health practitioners although other outcomes were unaffected. The quality of the evidence is moderate. In Jones et al. (2011 +) a care planning discussion had a (non-significant) positive effect on communication between advanced cancer patients and their families/friends ($p = 0.612$) and between advanced cancer patients and health professionals ($p = 0.640$), although there was no difference between intervention and control for other outcomes (see evidence tables for detail).

APa 9	There is some evidence that people with borderline personality disorder and psychiatric patients can be successfully engaged with decision-making about future care through joint crisis plans. However, certain outcomes were not affected. The quality of the evidence is mainly low. Borschmann et al. (2013 +) claim that joint crisis plans successfully engaged people with borderline personality disorder in advance planning for crises, although there were no differences between intervention and control groups for primary or secondary outcomes (see evidence tables for detail). The study by Henderson et al. (2009 -) indicates that joint crisis plans were liked by most holders, which the authors suggest provides evidence for the feasibility of shared decision-making in psychiatry. A randomised controlled trial by Thornicroft et al. (2013 -) found that the use of joint crisis plans with people experiencing a relapse in a psychotic illness resulted in significantly improved therapeutic relationships (p = 0.049) although no other outcomes were affected (see evidence tables for detail).

Included for review questions 1a and 1b – additional search

Almack K, Cox K, Moghaddam N et al. (2012) After you: conversations between patients and healthcare professionals in planning for end of life care. BMC Palliative Care 11: 15

Barnes K, Jones L, Tookman A et al. (2007) Acceptability of an advance care planning interview schedule: a focus group study. Palliative Medicine 21: 23–8

Barnes KA, Barlow CA, Harrington J et al. (2011) Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. Palliative and Supportive Care 9: 73–9

Bond CJ, Lowton K (2011) Geriatricians’ views of advance decisions and their use in clinical care in England: qualitative study. Age and Ageing 40: 450–6

Boot M, Wilson C (2014) Clinical nurse specialists’ perspectives on advance care planning conversations: a qualitative study. International Journal of Palliative Nursing 20: 9–14

Borschmann R, Barrett B, Hellier JM et al. (2013) Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. British Journal of Psychiatry 202: 357–64

Brazil K, Carter G, Galway K et al. (2015) General practitioners perceptions on advance care planning for patients living with dementia. BMC Palliative Care 14: 14

Farrelly S, Lester H, Rose D et al. (2014) What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 49: 1609–17

Farrelly S, Lester H, Rose D et al. (2016) Barriers to shared decision making in mental health care: qualitative study of the Joint Crisis Plan for psychosis. Health Expectations 19: 448–58

Henderson C, Flood C, Leese M et al. (2009) Views of service users and providers on joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 44: 369–76

Horn R (2014) ‘I don’t need my patients’ opinion to withdraw treatment’: patient preferences at the end-of-life and physician attitudes towards advance directives in England and France. Medicine, Health Care, and Philosophy 17: 425–35

Jones L, Harrington J, Barlow CA et al. (2011) Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. Palliative and Supportive Care 9: 3–13

Kazmierski M, King N (2015) Role of the community matron in advance care planning and ‘do not attempt CPR’ decision-making: a qualitative study. British Journal of Community Nursing 20: 19–24

MacPherson A, Walshe C, O’Donnell V et al. (2013) The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. Palliative Medicine 27: 265–72

Musa I, Seymour J, Narayanasamy MJ et al. (2015) A survey of older peoples’ attitudes towards advance care planning. Age and Ageing 44: 371–6

Preston H, Cohen Fineberg I, Callagher P et al. (2011) The preferred priorities for care document in motor neurone disease: views of bereaved relatives and carers. Palliative Medicine 26: 132–8

Seamark D, Blake S, Seamark C et al. (2012) Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study. Primary Care Respiratory Journal 21: 261– 6

Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in homes for older people. Age and Ageing 40: 330–5

Stone L, Kinley J, Hockley J (2013) Advance care planning in care homes: the experience of staff, residents, and family members. International Journal of Palliative Nursing 19: 550–7

Thornicroft G, Farrelly F, Szmukler G et al. (2013) Clinical outcomes of joint crisis plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. Lancet 381: 1634–41

Whitehead B, O'Brien MR, Jack BA (2011) Experiences of dying, death and bereavement in motor neurone disease: A qualitative study. Palliative Medicine 26: 368–78

3.3 Supporting decision-making on the presumption of mental capacity

Introduction to the review questions

Review question 2, comprised of parts 'a' and 'b' is reported in this subsection. Part 'a' sought data about the effectiveness and cost-effectiveness of supporting people, on the presumption of capacity, to make decisions. Part 'b' was designed to locate the self-reported views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people. Question 2b also sought to understand whether people making decisions and their families feel involved in decision-making, whether they are empowered through the process and whether issues of safeguarding and risk are considered. Finally, it was designed to locate practitioner views about what works and what does not work well in terms of supporting people to make decisions.

Review questions

2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions?

2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?

Summary of the review protocol

The protocol sought to identify studies that would:

- identify effective interventions, tools and approaches to support people to make decisions about care and support on the presumption of capacity
- consider the cost-effectiveness of interventions, tools and approaches used to assist decision-making on the presumption of capacity
- explore the self-reported views of people who access services, carers and practitioners about interventions, tools and approaches that support people to make decisions on the presumption of capacity, including what works and what does not work well
- identify practitioner views and consider whether they find interventions, tools and approaches to be workable and empowering to support people making decisions
- consider specifically whether interventions, tools and approaches involve families, carers and others with an interest in the person's welfare
- consider specifically whether people accessing services, carers, practitioners and other interested parties believe that support for decision-making adequately considers safeguarding and risk.

Population

All people aged 16 years or over who may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions. Including those whose capacity to make specific decisions about aspects of their care may need to be assessed, and specific best interests decisions made on their behalf if they are assessed as lacking capacity. This group is diverse and according to the Mental Capacity Code of Practice may include people suffering from dementia, mental illness, learning disability, brain damage or other conditions that may cause confusion, drowsiness or a loss of consciousness.

Intervention

Support for decision-making when a person is presumed or assessed as having capacity.

Setting

People's own homes, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts.

Outcomes

Person-focused outcomes (empowered and enabled to make decisions about their care and support, supported where possible to participate in decisions made in their best interests, afforded access to their human rights and dignity and helped to maintain independence and social inclusion).

Service outcomes (competence and confidence among practitioners to implement and uphold the principles of the Mental Capacity Act, including assessment, supporting decision-making and conducting best interests decision-making, transparency and quality of recording, efficient and effective use of resources).

Study design

The study designs which were prioritised for the effectiveness and cost-effectiveness question included: systematic reviews of studies of interventions, tools and approaches related to this topic; randomised controlled trials of interventions, tools and approaches related to this topic; economic evaluations; cohort studies, case control and before and after studies and mixed methods studies.

The study designs which were prioritised for the views and experiences questions included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness and mixed methods studies and observational and cross-sectional survey studies of user experience.

See Appendix A for full protocols.

How the literature was searched

A single search strategy for all the review questions was developed. The questions were translated into a framework of 8 concepts and combined as follows: a) decision and capacity and (supporting people or best interests or safeguarding) or b) decision and capacity and mental health and assessment or c) capacity and advance planning. These reflected the question areas of planning in advance, supporting decision-making, assessment of mental capacity and best interests decision making. The search was restricted to material published since 2005. The searches were run between September and October 2016.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4, a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- language (must be in English)
- population (must be over 16 years of age who may lack mental capacity, accessing health or social care services, their families or carers)
- intervention (all aspects of assessment, supported decision-making, future planning and best interests decision-making for adults who may lack mental capacity)
- setting (service user’s own home, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts
- country (must be UK or other OECD)
- date (must not be published before 2005)
- type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular parts of the review question or flagged as being relevant to 1 of the other review areas and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and a random sample of 10%.

Overview of evidence

In our initial screen (on title and abstract) we found 67 studies which appeared relevant to review question 2. We retrieved and then reviewed full texts and included a total of 8 papers. We then added an additional peer reviewed paper, recently accepted for publication, which has submitted by a Guideline Committee member. A total of 9 papers were therefore included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However, the effectiveness data, although well represented, was mainly low quality and this was considered by the Committee in its discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support Committee decision-making.

Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality. As with all the review areas, only UK qualitative evidence was included.

Narrative summary of the included evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or sub-groups in the form of evidence statements. The approach to synthesising evidence was informed by the PICO within the review protocol.

Studies reporting effectiveness data (n = 6)

1. Dukes E, McGuire BE (2009) Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. Journal of Intellectual Disability Research 53: 727–34

Methods: Quantitative

Data: Effectiveness

Country: Republic of Ireland

Outline

This study was conducted in the Republic of Ireland and although relevant to the review question (+), it was rated with low internal validity (-). The aim was to apply an individualised sexual education programme in order to determine if capacity to make sexuality-related decisions could be improved among adults with a learning disability. The study involved 4 participants – 2 men and 2 women, aged 22–23 years and all resident in a community group home. The participants followed a sexuality education programme, which focused on four target areas: knowledge of sexual safety practices; knowledge of the physical self; knowledge of sexual functioning; and knowledge of choices and consequences in sexual matters. The intervention was offered in the form of twice-weekly one-to-one sessions, lasting 45 minutes for a period of approximately 3 weeks.

Findings

The results indicated, ‘all four participants improved their knowledge in all targeted areas as measured by an increase in the number of SCEA items correctly answered after the intervention’ (p732). Higher SCEA scores are correlated with greater capacity to make sexuality related decisions – so the results show that capacity was improved through sexuality education. At the 6-month follow up, 3 participants maintained their scores (from post-intervention) on the S-Scale (knowledge of safety practices) and some scores dropped at follow-up (from post-intervention) on the K-scale (for example, education on choices and consequences). For all 3 with follow-up scores, the follow-up scores were an improvement on baseline scores. There was no increase from pre to post or at follow up on the inappropriate sexual behaviour scale (see evidence tables for detailed findings).

2. Ferguson L, Murphy GH (2013) The effects of training on the ability of adults with an intellectual disability to give informed consent to medication. Journal of Intellectual Disability Research 58: 864–73

Methods: Quantitative

Data: Effectiveness

Country: UK

Outline

This before and after study aimed '… to investigate the capacity of individuals with intellectual disabilities (ID) to make decisions about their medications, and to evaluate whether the provision of training (information) sessions on medications would increase their capacity' (p864). It had good relevance to the review question (++) but the methodological quality was rated as low (-).

Twenty-eight individuals with a 'mild to moderate' 'intellectual disability' who were over the age of 18, and who were currently taking a specified medication for diabetes (Metformin), epilepsy/convulsions (Epilim), or a condition for which a psychotropic medication was required (Haloperidol) took part.

Individuals were excluded if they were not taking medication, or if they were taking multiple medications. The authors report that after the initial identification of potential participants by practitioners, a number of individuals were excluded due to the severity of their intellectual disability or communication difficulties.

The intervention consisted of 3 information sessions specific to medication type. These focused on the reasons why the medication is prescribed, its risks and side-effects, the benefits of medication, and alternatives to medication.

Knowledge and capacity to give informed consent regarding prescribed medications was measured using the Assessment of Capacity Questionnaire. Note that the authors judged a participant to have capacity to consent to their medication if they scored at least 1 point on each of the questions on the Adapted – Assessment of Capacity Questionnaire relevant to the medication they were taking.

Findings

Outcomes were measured at 3 points – baseline and first reassessment (both pre-intervention), and second r-assessment. First reassessments were conducted in order to explore whether baseline assessments and the intervening period had impacted upon capacity.

Participants in all three groups showed improvements in capacity to give informed consent: mean scores on the Adapted – Assessment of Capacity Questionnaire increased for all medication groups between baseline and second reassessment and analysis showed that there was a significant difference between mean scores at baseline, first, and second re-assessment, with a large effect size (F1.42, 35.55 = 80.60, $p < 0.01$; partial eta squared = 0.88). The interaction effect between occasions (of assessment) and medication group was not significant (F2.84, 35.55 = 4.21, $p > 0.01$); and the between subjects effects (medication group) was also not significant (F2, 25= 0.054, $p > 0.01$).

Post-hoc analysis (using Bonferroni corrections) suggested that the intervention had a positive impact on capacity to give informed consent: the difference between scores on the Adapted – Assessment of Capacity Questionnaire at baseline and first reassessment was not significant (that is, both pre-training, $p > 0.01$), while the difference between scores on this measure at baseline assessment (pre-intervention) and at second reassessment (post-intervention, $p < 0.01$), and between scores at first reassessment (pre-intervention) and second reassessment (post-intervention, $p < 0.01$) were significant (note – no further data reported).

Post-hoc analysis also showed that the number of participants judged able to consent to their medication (determined by achieving a score of at least 1 point on each of the questions on the Adapted – Assessment of Capacity Questionnaire) increased between baseline/first reassessment (pre-intervention) and second reassessment (post-intervention), however this increase was not significant (Fisher's exact test $p = 0.04$).

3. Murphy J, Oliver T (2013) The use of talking mats to support people with dementia and their carers to make decisions together. Health and Social Care in the Community 21: 171–80

Methods: Mixed methods

Data: Effectiveness

Country: UK

Outline

This mixed methods study from the UK evaluated whether '… Talking Mats could help people with dementia and family carers feel more involved in decisions about managing their daily living than using their usual communication methods …' (p173). The study had good relevance to the review question (++) but the methodological quality was rated as low (-). Twenty-two participants living with dementia (specific diagnosis not reported) and their family carers took part in the study. The authors do not provide details on the nature of relationship that is, spouse, cohabiting partner, child, friend, etc.) People with a diagnosis of dementia were eligible if they were: '… aware of their diagnosis and comfortable with the terminology involved … living at home and have a relative or friend (unpaid family carer) who is knowledgeable about how they are managing their daily living activities … a native speaker of English … have sufficient vision to see picture symbols' (p174). One individual originally identified was excluded because they were '… unable to use Talking Mats …' (p176).

Of the people living with dementia who participated, 3 are described as having early stage dementia, 13 as having moderate stage dementia, and 2 as having late stage dementia. Talking mats are described as a low technology augmentative and alternative communication framework designed to support people with communication difficulties to express their views. People do so by placing cards representing a specific activity (using simplistic symbols) below visual scales. Participants and their carers were asked to discuss daily living activities and how the person with dementia was coping with these. Half of the sample was asked to use talking mats at the second visit, while the other half used their usual communication method. This was reversed at the third visit. (First visits were a procedural visit at which consent was sought.) Participants and their carers were asked to complete a questionnaire at the third visit called the Involvement Measure. This measures perception of involvement and feelings of satisfaction with a discussion. Qualitative data appear to have been collected during sessions in which talking mats were used.

Findings

When participants were asked to rate their level of involvement for each discussion type (using the Involvement Measure), the mean score was significantly higher for discussions using talking mats than for discussions using usual methods of communication (Wilcoxon signed-rank test, $z = –3.83$, $p < 0.01$, $r = –0.45$). This was also the case when participants were asked to rate their level of satisfaction for each discussion type (using the Involvement Measure, Wilcoxon signed-rank test, $z = –3.46$, $p < 0.01$, $r = 0.41$).

The authors report that people with dementia found talking mats to be an enjoyable and useful way of communicating with their carer because they enabled them to express their views more clearly, helped them to keep track of the conversation, and helped them to remember words. The mats were also valued because they helped people remember activities in which they were interested and able to participate, and because they prompted them to recognise the help that their carer provided.

The authors also report that family carers valued talking mats because they supported the person they cared for to listen to and understand what they were saying. The tools were also seen as a way of enhancing carer understanding of the person's wishes, for example their choices about food. Carers were also reported to value talking mats as a way for the person they supported to remember what had previously been discussed.

4. Naughton M, Nulty A, Abidin Z et al. (2012) Effects of group metacognitive training (MCT) on mental capacity and functioning in patients with psychosis in a secure forensic psychiatric hospital: a prospective-cohort waiting list controlled study. BMC Research Notes 5: 302

Methods: Quantitative

Data: Effectiveness

Country: Ireland

Outline

This quantitative evaluation (prospective cohort waiting list controlled study) from Ireland aimed to evaluate the effects of group metacognitive training on capacity to consent to treatment, fitness to plead, global functioning and symptoms of schizophrenia in patients in a secure forensic hospital. It had good relevance to the review question (++), while the methodological quality was rated as low (-).

Participants were male patients meeting DSM-IV-TCR criteria for a psychotic disorder who were detained under both forensic and civil mental health legislation in a secure forensic psychiatric hospital. The inclusion/exclusion criteria for the study are not clearly reported, however the authors note that participants had been referred because of incomplete responses to anti-psychotic medication. They go on to state that 2 participants originally referred '… were not deemed suitable; 1 for security issues and the second as the patient was deemed to be highly functioning with good insight' (p4). Four of those originally referred refused to participate. Twenty-nine individuals participated in total, with 11 assigned to the intervention group and 8 to the waitlist control group.

The intervention is described as a manualised group training programme designed to increase awareness of cognitive distortions and to encourage participants to '… critically reflect on, complement and alter their current repertoire of problem solving skills' (p3). Its aim is to reduce symptoms and risk of relapse. Sessions are delivered twice a week for a total of 8 weeks. The programme focuses on the two basic principles of knowledge translation (cognitive biases), and demonstration of the negative consequences of cognitive biases. Outcomes measured included competence to consent to treatment, abnormalities of mental state, fitness to plead and general functional competence. Outcomes were measured pre-treatment and around 3 months after the treatment/waitlist period.

Findings

After the treatment/waitlist period, medium to large effect sizes in favour of the intervention were observed on the MacArthur Competence Assessment Tool-Treatment scale (total scores, d = 1.1419, p = 0.0041), as well as the understanding subscale ($d = 0.7341$, $p = 0.008$) and the reasoning subscale ($d = 1.4164$ $p = 0.023$). These results were significant. A very small effect size was observed on the appreciation subscale. This result was not significant ($d = 0.1333$, $p > 0.7$).

Between baseline and the post-treatment/waitlist period there were no significant differences between groups in change in mean total score on the MacArthur Competence Assessment Tool Treatment ($p > 0.1$), scores on the reasoning subscale ($p > 0.1$) or the appreciation subscale ($p > 0.9$). There was a significant difference between groups in change in mean scores on the understanding subscale, with the intervention group showing a greater change in mean score ($p = 0.009$).

After adjustment for baseline values, analysis showed that change in marginal means (total score) on the MacArthur Competence Assessment Tool Treatment between baseline and follow-up was significantly greater for the intervention group than for the comparison group ($p = 0.019$). This was also the case for change in marginal means on the understanding subscale ($p = 0.011$) and change in marginal means on the reasoning subscale ($p = 0.008$). There were no significant differences between groups in change in marginal means on the appreciation subscale ($p > 0.8$).

When all participants were considered, there were moderate to strong negative correlations between magnitude of total baseline score on the MacArthur Competence Assessment Tool Treatment and magnitude of change in total scores ($r = 0.467$, $p = 0.05$), and magnitude of change in scores on the reasoning subscale ($r = 0.717$, $p < 0.001$). These results were significant. There were very weak to moderate negative correlations between magnitude of total baseline score and magnitude of change in scores on the understanding subscale ($r = 0.185$, $p > 0.4$) and magnitude of change in scores on the appreciation ($r = 0.427$, $p > 0.7$). These results were not significant.

The authors report narratively that when '… only those who had treatment were considered, the correlations between baseline and change were greater …' (p7), however no data are reported to illustrate this finding.

When all participants were considered, there were moderate positive correlations between number of treatment sessions and change in total score on the MacArthur

Competence Assessment Tool Treatment ($r = +0.556$, $p = 0.016$), change in score on the understanding subscale ($r = +0.644$, $p = 0.004$) and change in score on the reasoning subscale ($r = +0.540$, $p = 0.021$). These results were significant. There was a weak positive correlation between number of treatment sessions and change in score on the appreciation subscale. This result was not significant ($r = +0.284$, $p > 0.3$).

After treatment/waitlist period, very small to large effect sizes in favour of the intervention were observed on the MacArthur Competence Assessment Tool Fitness to Plead tool (total scores, $d = 0.5808$, $p > 0.2$) as well as the understanding subscale ($d = 0.0$, $p > 0.3$), the reasoning subscale ($d = 0.8799$, $p > 0.05$) and the appreciation subscale ($d = 0.155$, $p > 0.7$). These results were not significant.

There were also no significant differences in change in mean total score between baseline and post-treatment/waiting list period on the MacArthur Competence Assessment Tool Fitness to Plead ($p > 0.3$). There were also no significant differences between groups in change in mean scores in this period on the understanding subscale of this measure ($p > 0.1$), the reasoning subscale of this measure ($p > 0.05$); and the appreciation subscale ($p > 0.9$).

When all participants were considered, there were weak to moderate positive correlations between number of treatment sessions and: change in total scores on the MacArthur Competence Assessment Tool Fitness to plead ($r = 0.236$, $p > .3$), change in score on the appreciation subscale of this measure ($r =+0.159$, $p > 0.5$) and change in score on the understanding subscale ($r = +0.250$, $p > 0.3$) and change in score on the reasoning subscale of this measure ($r = +0.410$, $p > 0.05$). These results were not significant.

After adjustment for baseline values, there were no significant differences between groups in change in marginal means (total score) on the MacArthur Competence Assessment Tool Fitness to Plead between baseline and post-treatment ($p > 0.2$). There were also no significant differences between groups in change in marginal means on the understanding subscale of this measure ($p > 0.05$); and the appreciation subscale ($p > 0.09$). There was a significant difference between groups in favour of the intervention in change in marginal means on the reasoning subscale (p = 0.049).

After treatment/waitlist period, small to large effect sizes in favour of the intervention were observed on the Positive and Negative Syndrome Scale for Schizophrenia (total scores, d = 0.4393, p > 0.3) and the component scales of this measure – positive schizophrenia symptoms (d = –0.493, p > 0.4), negative schizophrenia symptoms (d = 0.6882, p > 0.1) and general schizophrenia symptoms (d = 0.0994, p > 0.8), however these results were not significant. There were also no significant differences in change in mean scores between baseline and post-treatment/waiting list period on measures of positive schizophrenia symptoms (p > 0.6), negative schizophrenia symptoms (p > 0.1) and general symptoms of schizophrenia (p > 0.1); and total mean scores on the Positive and Negative Syndrome Scale for Schizophrenia (p > 0.2).

The authors report narratively that number of treatment sessions (when all participants were considered) did not correlate with change in scores on any of the component scales of the Positive and Negative Syndrome Scale for Schizophrenia (note, data not reported).

There were no significant differences between groups in change in marginal means on a measure of positive symptoms of schizophrenia between baseline and post-treatment (p > 0.9); negative symptoms of schizophrenia (p > 0.05); general symptoms of schizophrenia (p > 0.2); and total scores on the Positive and Negative Syndrome Scale for Schizophrenia (p > 0.2).

After treatment/waitlist period, a very large effect size in favour of the intervention was observed on the Global Assessment of Functioning Scale. This result was significant (d = 1.0546, p = 0.021). There was also a significant difference between groups in change in score on this measure between baseline and post-treatment/waiting list (p = 0.012).

When all participants were considered, there was a moderate positive correlation between number of treatment sessions and change in score on the Global Assessment of Functioning scale, which was significant (r = +0.592, p = 0.008).

There was a significant difference between groups in change in marginal means on the Global Assessment of Functioning scale (p = 0.024).

At post-treatment/waitlist period there was a significant effect of treatment group on unadjusted mean scores on a measure of global function (ANOVA = 5.1, df = 1, p = 0.035). There was also a significant effect of treatment group on change in score on this measure (ANOVA = 7.0, df = 1, p = 0.017).

(Note: Cohen’s d calculated by NCCSC review team.)

5. Turner D, MacBeth A, Larkin A et al. (2017) The relationship between the ‘jumping to conclusions’ bias and treatment decision-making capacity in psychosis: a participant-blind randomised controlled experiment (not yet published)

Methodology: Quantitative evaluation – randomised controlled trial

Data: Effectiveness

Country: UK – Scotland

Outline

This quantitative evaluation (randomised controlled trial) from Scotland evaluated the effects of a single session of metacognitive training on capacity to consent to treatment, cognitive biases, and anxiety and depression in people with psychosis. It had good relevance to the review question (++) and was rated as moderate (+) with regards to methodological quality.

The authors aimed to test the hypothesis that meta-cognitive therapy would improve treatment related capacity and that outcome would be mediated by changes in the ‘jumping to conclusions’ bias in patients with psychosis.

Participants were inpatients and outpatients with psychosis under the care of 2 NHS health boards in Scotland. Individuals were eligible if they spoke English; were aged between 16 and 65 years; had diagnosed schizophrenia, schizoaffective disorder, delusional disorder, brief psychotic disorder or a psychotic disorder not otherwise specified; and had the capacity to consent to participation in the study.

Individuals were excluded if they had psychotic symptoms resulting from a general medical condition or substance misuse disorder; had a moderate or severe learning disability; had experienced a deterioration in condition suggesting that participation in the study could be harmful; or were involved in ongoing legal proceedings/forensic mental health services.

Thirty-seven individuals participated in total, with 19 assigned to the intervention group and 18 to the control group.

Participants in the intervention group received a single 1-hour session of meta-cognitive training designed to address the 'jumping to conclusions' bias. The session was provides participants with a 'best of' meta-cognitive training that raises awareness of the disadvantages of making decisions based on limited information. The content is derived from a manual on metacognitive training developed by one of the researchers involved in this study (that is, content relevant to the 'jumping to conclusions' bias).

The intervention aimed to '… to repeatedly engage the participant in applying an approach contrary to the JTC bias while reflecting on the pitfalls of JTC ...' (authors, p6). The session is comprised of 11 key components including examples of the 'jumping to conclusions' bias (for example, daily life, politics, medicine, and conspiracy theories), worksheet exercises and tasks focusing on misinterpretations using images, as well as suggested tactics to address this bias.

The control group received a talk on the localisation of brain function and brain processing in different sensory modalities. The control intervention was designed to match the experimental intervention according to modality, duration and non-specific factors not addressing thinking biases (single, 1-hour session, delivered using PowerPoint). Follow-up took place immediately after delivery of the interventions.

Findings

Participants in the intervention group demonstrated better capacity to make treatment decisions at post-treatment (as measured by total scores on the MacArthur Competency Assessment Tool for Treatment) than those in the control group (after controlling for baseline scores on this measure). This result was significant ($F = 7.78$, $p < 0.05$).The effect size was large ($d = 0.96$).

Participants in the intervention group also demonstrated better appreciation at post-treatment in relation to capacity to make treatment decisions (as measured by scores on the MacArthur Competency Assessment Tool for Treatment – appreciation scale) than those in the control group (after controlling for baseline scores on this measure). This result was significant (F = 6.45, $p < 0.05$). The effect size was large (d = 0.87). A sensitivity analysis (to account for negative skew) was conducted and the result was '... consistent with the main ANCOVA in showing a significant effect favouring ...' (p8) the intervention ($\chi 2= 0.11$, $p < .05$).

Participants in the intervention group also demonstrated better understanding and reasoning at post-treatment in relation to capacity to make treatment decisions (as measured by the understanding and reasoning scales of the MacArthur Competency Assessment Tool for Treatment than those in the control group (after controlling for baseline scores on these measures). These results were not significant (understanding F = 2.06, p value not reported; reasoning F = 3.95, p = .055), and the effect sizes were small to large (understanding d = 0.49; reasoning d = 0.68).

Participants in the intervention group had higher levels of distress at post-treatment (as measured by total scores on the Hospital Anxiety and Depression Scale) and anxiety (as measured by scores on the Anxiety subscale of the Hospital Anxiety and Depression Scale) than those in the control group (after controlling for baseline scores on these measures). These results were not significant (distress F = 2.21, p value not reported; anxiety F = 2.21, p value not reported). The effect sizes were very small to medium (distress d = –.51; anxiety d = –.18). Due to significant differences in levels of depression at baseline (as measured by scores on the depression subscale of the Hospital Anxiety and Depression Scale, p = 0.022) the authors conducted an analysis of mean change on this measure as adjusting for this difference with ANCOVA would have violated the assumption of independence of covariate and treatment effect. This analysis demonstrated that the increase in levels of depression for participants in the control group was not significantly greater for those in the intervention group than those in the control group. The effect size was small (p value not reported, d = .30).

Participants in the intervention group demonstrated lower levels of bias and cognitive distortions at post-treatment (as measured by total scores on the Cognitive Biases

Questionnaire for Psychosis) and lower levels of the ‘jumping to conclusions’ bias (as measured by scores on the Cognitive Biases Questionnaire for Psychosis – ‘jumping to conclusions’ subscale) than those in the control group (after controlling for baseline scores on these measures). The results were not significant and effect sizes were small (total scores F = .35, p value not reported, d = .20; ‘jumping to conclusions’ bias (F = .33, p value not reported, d = .20).

Participants in the intervention group also demonstrated lower levels of bias at post-treatment (as measured by the beads task) than those in the control group (after controlling for baseline levels of bias). This result was significant (F = 7.35, p < 0.05). The effect size was large (d = .93)

Mediation analysis (Baron and Kenny method, pre-specified) showed that post-treatment data gathering behaviour (as measured by the beads task) significantly mediated the effect of group allocation on post-treatment capacity to make treatment decisions (as measured by total scores on the MacArthur Competency Assessment Tool for Treatment) at post-treatment, with a medium effect size (d = 0.64, p < .05), and accounted for 38.7% of treatment effects. However the authors note that the second step of the analysis did not meet the requirements described by Baron and Kenny as the result of this was not significant (p < .06) Post-treatment data gathering behaviour also mediated the effect of group allocation (with small to medium effect sizes) on the understanding scale (d = 0.45, 63% mediated); the appreciation scale (d = 0.55, 35.7% mediated); and the reasoning scale (d = 0.59, 28.8% mediated). These results were not significant.

Mediation analysis using the Preacher and Hayes method (post-hoc) showed that post-treatment data gathering behaviour (as measured by the beads task) significantly mediated the effect of group allocation on post-treatment capacity to make treatment decisions (as measured by total scores on the MacArthur Competency Assessment Tool for Treatment), with a medium effect size (d = 0.64, p < .05), and accounted for 38.7% of treatment effects. Post-treatment data gathering behaviour also mediated the effect of group allocation (with small to medium effect sizes) on the understanding scale (d = 0.45, 63% mediated); the appreciation scale (d = 0.55, 35.7% mediated); and the reasoning scale (d = 0.59, 28.8% mediated). These results were significant.

6. Woltmann EM, Wilkniss SM, Teachout A et al. (2011) Trial of an electronic decision support sys-tem to facilitate shared decision making in community mental health. Psychiatric Services 62: 54–60

Methods: Quantitative

Data: Effectiveness

Country: US

Outline

This quantitative evaluation (cluster randomised controlled trial) from the US aimed to examine the feasibility of using an electronic decision support system to improve communication between service users and practitioners in mental health decision-making and to determine the impact of the system on outcomes such as satisfaction and recall of care plans. The study has good relevance (++) to the review question and was judged as moderate in terms of methodological quality (+).

Participants were ‘mental health consumers’ (participants had a primary diagnosis of schizophrenia or schizoaffective disorder, bipolar disorder, major depressive disorder, or post-traumatic stress disorder) and their case managers working at 1 of 3 clinics provided by an agency with a ‘… mission to help mental health clients maintain autonomy over their lives and achieve recovery-oriented goals’ (p55).

Only limited details are provided regarding the clinics and why this agency was selected. Similarly, very few details are provided regarding participants and no inclusion/exclusion criteria are reported.

Case managers were assigned to groups using cluster randomisation and service users were assigned to groups according to the group to which their case manager had been allocated. Twenty case managers (intervention n = 10, control n = 10) and 80 service users (intervention n = 40, control n = 40) took part in total.

The authors describe the electronic decision support system as a 3-step process that ‘… inverts the usual care planning procedures‘ (p55). Service users used a touchscreen computer to identify their top priorities and thoughts about services. This information was then sent to the case manager who did the same. These 2 records were then merged by the programme which produced a graphic to be used in a shared decision-making session. Participants assigned to the control group received care as usual.

The impact of the tool was evaluated by measuring service user and case manager satisfaction (using bespoke questionnaires administered immediately after care planning sessions) and service user recall of care plans (assessed 2 to 4 days later via telephone interviews).

Findings

Multiple linear regression, controlled for case manager age, showed that being in the intervention group significantly predicted a better summary score overall on the case manager satisfaction questionnaire (intercept = 3.29, β = .62, adjusted p = .01).

For the individual items on the case manager satisfaction questionnaire, multiple linear regression showed that being in the intervention group predicted better scores on the communication item ‘My client was able to tell me important information about himself or herself that I did not know before we discussed the care plan‘ (intercept = 2.82, β = 1.01, adjusted p = .001); the organisation of information related item ‘The process of creating a care plan was easy for me to get the right information about what my client needed’ (intercept = 3.40, β = .65, adjusted p = .018); the time-related item ‘Creating the care plan in this way and reviewing it with my client takes up too much time’ (intercept = 2.97, β = –1.04, adjusted p = .026); and the flow-related item ‘I feel that the way I complete the care plan with my client is too cumbersome and hard to use’ (intercept = 2.87, β = –.82, adjusted p = .042). These results were significant.

Being in the intervention group also predicted better scores on the credibility as a clinical tool-related item ‘I think that the care plan my client and I created is realistic’ (intercept = 3.82, β = .43, adjusted p = .130); and the credibility as a clinical tool-related item ‘I am concerned that the care plan does not address something I feel is important for my client to work on’ (intercept = 2.45, β=-.15, adjusted p = .470). These results were not significant.

These models explained 1% to 30% of the variance in summary scores.

For client satisfaction, there was no difference between groups with regard to mean summary scores (measured using the client satisfaction questionnaire; intervention = 3.88 [± .54]; control mean = 3.78 [± .56].

For the individual items on the ‘client’ satisfaction questionnaire, multiple linear regression showed that being in the intervention group predicted a better score on the involvement in decision-making related item ‘I wish I had more of an opportunity to discuss something on my mind with my counsellor before making my care plan’ (intercept = 2.91, β= –.19, p = .001). This result was significant.

Being in the intervention group also predicted better scores on the involvement in decision-making related item ‘I did not feel that my opinion counted for much when decisions were made about my care plan’ (intercept = 1.96, β = –.15, p = .18); the item related to the extent to which service users were informed about decisions made ‘I did not understand why all of the things included in my care plan were there’ (intercept = 2.36, β = –.16, p = .75); the clear management plan-related item ‘I am not exactly sure what I will be working on with my counsellor in the next couple of months’ (intercept = 2.80, β= –.31, p = .40); the communication-related item ‘I feel that my counsellor listened to my opinion’ (intercept = 4.41, β = .11, p = .38); and the involvement in decision-making related item ‘My care plan is about working on areas of my life that are important to me to address’ (intercept = 4.29, β = .23, p = .20); and the communication related item ‘I was able to tell my counsellor important information about me that he or she did not know before we discussed my care plan’ (intercept = 4.20, β = –.10, p = .87). These results were not significant. These models explained up to 7% of the variance in the summary scores.

Recall of care plan goals (assessed 2 to 4 days after care planning sessions by telephone interview) was significantly higher in the intervention group than in the control group (mean proportion of plan goals recalled – intervention = 75% ±28% vs control 57% ±32%; p = .02). There was no significant difference between groups in incorrect recall of care plan goals (mean proportion of plan goals incorrectly recalled intervention 17%±16% vs control 20%±16%). (Note, only 86% of clients were contacted to assess recall of care plans.)

Studies reporting views and experiences data of people who may lack mental capacity, their families and, carers, n = 3

1. Boyle G (2013) Facilitating decision-making by people with dementia: is spousal support gendered? Journal of Social Welfare and Family Law 35: 227–43

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a UK qualitative study, which was judged to be of moderate quality (+) and moderately relevant to the review question (+). The study explored the decision-making interactions of couples living with dementia. It examined the strategies used by spouse carers to support their partner with dementia in making decisions about everyday life and bigger decisions – for instance about day centre attendance or respite arrangements. Twenty-one couples were included in the study, which involved observations by the researcher in the couples' homes and interviews with the couples, either individually or together. The authors analyse the findings in the context of the Mental Capacity Act, judging the extent to which the partners with dementia were enabled to make decisions and whether the spouse carers were taking all practicable steps to ensure their participation in decision-making.

Findings

The study identified key strategies used by carer spouses to support their partner in making decisions. They included the following.

Discussion and consultation

The most common mode of support was for the carer spouse to discuss relevant areas of decision-making with their partner – although barriers to being able to do this included forgetfulness, perceived indecisiveness, lack of understanding and loss of conversational ability. In this context, the carer spouse adapted their approach to take account of their partners' perceived difficulties. For example, adjusting the timing of and time for discussions and consultation. Spouse carers also used repetition and explanation to reinforce or clarify information. They also limited choices in order to simplify decision-making, for example a husband showing his wife 2 different pizza options for dinner using the visual aid of showing her the pizza boxes.

On the other hand, in some cases, there was no discussion at all. For example, husband carers were making decisions on their partners' behalf even when their partner had capacity – according to the researchers, this is because the husband had 'always' made decisions (described as 'habituated decision-making').

Facilitating communication

When the partner living with dementia had limited speech and/or reduced capacity, carer spouses made a particular effort to include them in conversation about decisions. They also looked to non-verbal cues (facial expressions). Some husbands clearly facilitated their wives voices when their wives had difficulty communicating. Others, on the other hand, dominated conversation even when the wives were perfectly capable of communicating.

Supervising, guiding and monitoring

It was clear that some spouse carers imposed their will own will on their partners, directing them towards preferred outcomes. At times, they explained it was in their partners' interest, for example a man insisting his partner accompany him on a daily walk when this clearly was not her preferred choice.

Emotional/loving support

A wife carer emphasised how love and trust are key to managing everyday decision-making – particularly as her husband (with dementia) completely trusts her.

Further findings

Ability to make decisions

Spouse carers tended to say that their partners' ability to make decisions had deteriorated – although the person with dementia felt their decisional abilities were relatively unchanged. For example, ‘Steve said his wife found it difficult to make even basic decisions: “Yes, decisions are not easy for her. Choices are not easy, she’s happy with something laid down, without having to make up her mind about something or decide.” However, as his wife had decided herself that she did not want to go to a day centre and gave a coherent argument why this was not desirable or necessary for her it was evident that she was able to make major decisions’ (p237).

Supporting spousal decision making in the context of the Mental Capacity Act

According to the Mental Capacity Act, ‘all practicable steps’ should be taken to enable individuals to make decisions before they are deemed to lack capacity. Most spouse carers adhered with this in terms of the support provided to make decisions. They often used individualised, perceptive approaches to communicating with their partners so they could be involved in making decisions: ‘The carer-spouses frequently supported their partners to express a choice or view by repeating questions to determine their authentic views and being receptive to indicators of their preferences. For example, they identified their partners’ valid choices if they initially said “yes” when they meant “no” and detected non-verbal signs of their likes and dislikes’ (p237).

However, not all spouse carers enhanced decisional abilities. Some were overly directive, constraining their partners’ scope for ‘authentic decision making’ (p238). They also sometimes made decisions on behalf of their partners, even though they were capable of making the decision themselves, depriving them of autonomy. The carers often explained that this was necessary because their partner had other disabilities, leading to communication problems. However, the researchers observed that these disabilities clearly did not affect their capacity to make or contribute to a decision.

2. Goldsmith L, Woodward V, Jackson L et al. (2013) Informed consent for blood tests in people with a learning disability. Journal of Advanced Nursing 69: 1966–76

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This UK qualitative ethnographic study explored the information needs of people with learning disabilities with respect to consent for blood tests and identified ways of facilitating informed consent. This study was judged to have good relevance to the review area (++) and to be of good quality (++). The study was conducted in 2 phases: phase 1 involved observation of 6 participants with a learning disability having a routine blood test in general practice, followed by semi-structured interviews with 14 participants with a learning disability in phase 2.

Findings

The study identifies 6 main themes: the patient in the healthcare context, information and knowledge, the consent process, behavioural characteristics, strategies and coping mechanisms, and 'the self'.

1. The patient in the healthcare context

Subthemes: attitude to having a blood test, feelings about going to the doctor, knowledge of the healthcare system, relationship and communication with the healthcare professional and the role of supporter.

Consultations involved social chat, explanations of the procedure, the reason for the blood test and often involved humour. Most of the experiences of going to the doctor were routine and held no fear. Some people expressed strong views about their healthcare and appeared unwilling to tolerate a poor level of care. In general, there was a good deal of trust in health professionals. Some participants who attended the surgery independently explained that communication was not always easy.

2. Information and knowledge

Subthemes: presentation of health information, knowledge of blood tests in general, purpose of blood test and procedure.

Information, if any, given during the blood test consultations was verbal, and there were no examples of any alternative presentation such as a leaflet in accessible format. Some participants did not appear to understand why they had had a blood test; some guessed, although others clearly understood.

3. The consent process

Subthemes: seeking consent and expressing content.

Sometimes, both elements (procedure and purpose) were mentioned and the patient indicated understanding using non-verbal communication. In some consultations, there appeared to be little or no explicit attempt to obtain consent from the patient. The responses from participants when expressing consent were fairly minimal, and it was difficult to judge whether they were genuinely giving their informed consent. There were a range of ways the healthcare professionals approached the blood test and there was inconsistency in the level of information-giving and seeking of consent.

4. Behavioural characteristics

Subthemes: anxiety, bravado, fear, pain, relief, resistance.

Participants exhibited behavioural cues as well as verbal expressions, before and after the procedure. Despite anxiety, there was much evidence of bravado prior to and during the procedure. Eventually, participants appeared to resign themselves to having the procedure, despite their apprehension.

5. Strategies and coping mechanisms

Subthemes: distraction tactics, establishing rapport, reassurance, use of humour or teasing.

Throughout the consultations, there were various strategies used by both patients and health staff to deal with apparent nervousness and apprehension. Strategies used by staff were reassurance, involving the patient in the procedure, humour and distraction. Use of humour by both nurse and patient helped to deal with the situation.

6. ‘The self’

Subthemes: self-identity, self-image, ‘how I would like to be treated’, decision-making.

There was a tendency for some participants to try and impress with their reading ability, their level of independence and general capabilities, dismissing others who were less able.

3. Stovell D, Wearden A, Morrison AP et al. (2016) Service users’ experiences of the treatment decision-making process in psychosis: a phenomenological analysis. Psychosis 8: 311–23

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This UK qualitative study used interpretive phenomenological analysis (IPA) to explore service users’ experiences of the treatment decision-making process in psychosis. The study is assessed as having a good level of relevance to the guideline and review question (++) and a good level of methodological quality (++). Seven service users with non-affective psychosis and multiple experiences of treatment for psychosis were included. They were 4 males and 3 females with a mean age 49 and were white, British. Data collection was via in-depth semi-structured interviews from this homogeneous sample, analysed using IPA methodology.

Findings

Four themes and subthemes emerged from the data under the overarching theme of empowerment.

Theme 1: A need to feel listened to

Nearly all participants described experiences of disempowerment arising from feeling that they had not been listened to during treatment decision-making.

Subtheme 1.1: Importance of listening with respect, compassion and empathy.

Participants' experiences of disempowerment included feeling that professionals were not listening, did not believe them, did not take their distress seriously and lacked compassion. A number of participants noted the positive contrast when they did feel heard.

Subtheme 1.2: Disempowerment by system and process.

A number of participants described experiencing the treatment system as disempowering and dehumanising, feeling insignificant.

Subtheme 1.3: Feelings related to power.

Most participants described having experienced feelings of disempowerment within treatment decision-making situations such as tribunals, being turned away from services when feeling suicidal or being sectioned.

Theme 2: Psychotic experiences, treatment and stigma

Experiences of psychosis seemingly affected treatment decision-making situations for participants both directly, via symptoms and medication, and indirectly, with the influence of past treatment experiences, negative beliefs about psychosis, low self-worth and perceptions of being negatively judged by others.

Subtheme 2.1: Reduction in agency and self-efficacy with distressing psychosis.

Psychotic experiences eroded participants' agency and self-efficacy in treatment decision-making directly, through the severity of their distress, the undermining influence of hallucinations and feeling physically unwell.

Subtheme 2.2: Influence of treatment-related experiences and beliefs.

Participants' approaches to treatment decision-making were influenced by their past experiences of, and beliefs about, treatment.

Subtheme 2.3: Power of negative constructions of mental illness.

Participants articulated many taken-for-granted meanings or social constructions around psychosis. They made associations between psychosis and being 'not normal' and these sometimes reduced their confidence to raise concerns about their treatment.

Subtheme 2.4: Stigma, shame and low self-worth.

The effects of self-stigma and low self-worth on treatment decision-making were more immediately apparent for some.

Subtheme 2.5: Feeling negatively judged by others.

Some participants described feeling negatively judged by professionals, in relation to their actions, choices and treatment decision-making capabilities.

Theme 3: Communication and support

Participants described experiences of disempowerment in treatment decision-making where they had not felt adequately informed or supported, or had difficulty communicating their needs within the context of unequal power dynamics.

Subtheme 3.1: Power dynamics, from the implicit to the coercive.

Participants expressed variously the view that psychiatrists hold immutable power, have authority over their patients, are of higher status and are the main drivers of treatment decision-making.

Subtheme 3.2: Power dynamics in sharing and use of knowledge.

Participants felt excluded from the content of multidisciplinary discussions about them; the rationale for decisions; and information about psychosis, medication and other treatment options.

Subtheme 3.3: Importance of self-representation.

Being able to communicate their needs to clinicians during treatment decision-making was very important to most participants, but also frequently challenging because of psychosis-related distress, effects of medication and difficulties with assertiveness or self-expression.

Theme 4: Differing conceptions of recovery

Participants seemed to vary in their degree of recovery orientation, that is, in how far they sought autonomy, considered a range of influences on their wellbeing, prioritised their values and goals and maintained a hopeful outlook.

Subtheme 4.1: Seeking autonomy.

All participants expressed preferences for at least some level of autonomy in their treatment.

Subtheme 4.2: Relationship to the medical model.

A key influence on participants' feelings of empowerment appeared to be their relationship to the medical model.

Subtheme 4.3: Seeking treatment congruent with values and goals.

All participants spoke about their values and goals in relation to treatment decision-making.

Subtheme 4.4: Hope, an influence and an outcome in treatment decision-making.

All participants felt hopeless, at times, in relation to treatment decision-making, due variously to highly restrictive decisions made entirely by others, negative messages imparted by clinicians, limited intervention options and persistently being offered treatment that was antithetical to the participants' understanding of their experience.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

SDM1	There is a moderate amount of evidence that certain approaches and interventions help to facilitate treatment decision-making. The quality of the evidence is mixed. A good quality UK study (Goldsmith 2013 ++) reported that consultations involving social chat and accessible explanations about the proposed medical intervention all helped to make participants with learning disabilities feel involved in giving informed consent. Another good quality study (Stovell et al. 2016 ++) reported that participants needed to be able to communicate their needs and feel listened to during treatment decision-making and, when they were not, this made them feel disempowered. A low quality study (Ferguson and Murphy 2013 -) found that the provision of information about medication through a training programme improved the capacity of people with learning disabilities to give informed consent. A low quality study (Naughton et al.

	2012 -) found that group metacognitive training for patients with psychosis improved participants' competence to consent to treatment and competence increased the more sessions the patient attended. A moderate quality study from the UK (Turner et al. 2017 +) found that a single session of metacognitive training designed to address the 'jumping to conclusions' bias delivered to patients with psychosis significantly improved capacity to make treatment decisions. Analysis suggested that this improvement was mediated by post-treatment data-gathering behaviour. Finally, a moderate quality US study (Woltmann et al. 2011 +) found that an electronic decision support system increased participants' involvement in decision making about their care plan.
SDM2	There is some evidence, based on people's views and experiences, about what prevents them being involved in treatment decision-making. The quality of the evidence is good. A good quality UK study (Goldsmith 2013 ++) reported that in some of the consultations observed by the researcher, there appeared to be little or no explicit attempt to gain informed consent and patients were often given inadequate information about the procedure. Stovell et al. (2016 ++) also reported that patients felt excluded from decision-making when they were given insufficient information about their condition and about treatment options. Being excluded from multidisciplinary team discussions compounded this. Stovell et al. also found that participants' felt they were being excluded because clinicians negatively judged them.
SDM3	There is a small amount of evidence that using different forms of communication and delaying discussions helps to support people living with dementia to make everyday decisions. The quality of the evidence is moderate. A moderate quality UK study (Boyle 2013 +) found that people living with dementia could be supported in everyday decision-making through using different forms of communication, such as visual aids; having decisions delayed until a time when they felt calmer or more able to engage; reducing the length of discussions about decisions and if the person supporting them to make a decision could pick up on non-verbal cues such as facial expressions.
SDM4	There is a small amount of evidence that people with learning disabilities can be supported to make decisions through the provision of information in a more accessible format and structured training to improve capacity. The quality of the evidence is low. A low quality study (Dukes and McGuire 2009 -) found that having followed an individualised sexual education programme, adults with learning disabilities had greater knowledge and better capacity to make informed choices on sexual decisions (p5). Another low quality study (Ferguson and Murphy 2013 -) found that providing information about medication through a training programme improved the capacity of adults with learning disabilities to give informed consent to treatment.
SDM5	There is a small amount of evidence that even when they have capacity, people are excluded from decision-making about their own treatment or everyday activities. The quality of the evidence is moderate to good. A good quality study (Stovell et al. 2016 ++) reported that participants often felt disempowered and excluded from the treatment decision-making process. A moderate quality UK study (Boyle 2013 +) found that some spouses clearly imposed their own will on their partner living with dementia, directing them toward their own preferred outcome during decision-making. This included everyday decision-making but also bigger issues such as day centre or respite attendance.
SDM6	There is some evidence that tailored training programmes increase people's capacity to make a decision. The quality of the evidence is mixed. A low quality study (Dukes and McGuire 2009 -) found that having followed an individualised sexual education programme, adults with learning disabilities had greater

	capacity to make informed choices on sexual decisions. Another low quality study (Ferguson and Murphy 2013 -) found that providing information about medication through a training programme improved the capacity of adults with learning disabilities to give informed consent to treatment. A low quality study (Naughton et al. 2012 -) found that group metacognitive training for patients with psychosis improved participants' competence to consent to treatment. Competence to consent increased the more sessions the patient attended. A moderate quality study (Turner et al. 2017 +) found that a single session of metacognitive training for patients with psychosis (designed to address the 'jumping to conclusions' bias) led to significant improvements in capacity to make treatment decisions.
SDM7	There is some evidence that specific interventions can increase people's involvement in decision-making discussions. The quality of the evidence is low to moderate. A low quality study by Murphy and Oliver (2013 -) found that the use of talking mats helped people living with dementia to feel more involved in decision-making discussions compared with participants using usual methods of communication. A moderate quality US study (Woltmann et al. 2011 +) found that an electronic decision support system for 'mental health consumers' increased participants' involvement in decision-making about their care plan. This reflected that they had adequate opportunity to discuss what was on their mind before agreeing their care plan.
SDM8	There is a small amount of evidence that a specific training programme to increase capacity for decision-making does improve appreciation, understanding and reasoning. The quality of the evidence is mixed. A low quality study (Naughton et al. 2012 -) found that group metacognitive training for patients with psychosis was associated with improved understanding and reasoning about treatment decisions. Understanding and reasoning both increased the more sessions the patient attended. A moderate quality study (Turner et al. 2017 +) found that a single session of metacognitive training designed to address the 'jumping to conclusions' bias improved understanding and reasoning in relation to capacity to make treatment decisions. However, these results were not significant. The intervention did significantly improve appreciation in relation to capacity to make treatment decisions and sensitivity analysis (conducted due to concerns regarding negative skew) showed a similar result in favour of metacognitive training.
SDM9	There is a moderate amount of evidence that a range of interventions is effective in supporting people to make decisions on the presumption of capacity. The quality of the evidence is low to moderate. The evidence is derived from a number of outcome measures. For example, a sexual education programme improved capacity to make sexuality-related decisions among adults with learning disabilities (Dukes and McGuire 2009 -); information and training sessions improved capacity to make informed consent among adults with learning disabilities (Ferguson and Murphy 2013 -); talking mats helped people living with dementia to express their views and keep track of information during decision-making conversations (Murphy and Oliver 2013 -). Group metacognitive training improved participants' competence to consent to treatment (Naughton et al. 2012). An electronic decision support system improved involvement in decision-making about mental health care plans (Woltmann et al. 2011 +)
SDM10	There is some evidence, reporting mixed findings, about people's satisfaction with interventions designed to support people to make decisions. The quality of the evidence is low and moderate. The use of talking mats led to greater satisfaction among participants (Murphy and Oliver 2013) whereas there was no difference in client satisfaction between those using the electronic decision support system compared with people in the control group (Woltmann 2011 +).

SDM11	No evidence was found from studies published since 2005 about the effectiveness of the following interventions and approaches for supporting people to make decisions about care: support and treatment; advocacy; training for professionals; coaching and question prompts; the care programme approach for people with mental disorders; and the single assessment process for older people in England/unified assessment process in Wales.
SDM12	No evidence was found from studies published since 2005 about people's views and experiences of interventions, tools or aids for supporting people to make decisions about care, support and treatment.

Included studies for review questions 2a and 2b

Boyle G (2013) Facilitating decision-making by people with dementia: is spousal support gendered? Journal of Social Welfare and Family Law 35: 227–43

Dukes E, McGuire BE (2009) Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. Journal of Intellectual Disability Research 53: 727–34

Ferguson L, Murphy GH (2013) The effects of training on the ability of adults with an intellectual disability to give informed consent to medication. Journal of Intellectual Disability Research 58: 864–73

Goldsmith L, Woodward V, Jackson L et al. (2013) Informed consent for blood tests in people with a learning disability. Journal of Advanced Nursing 69: 1966–76

Murphy J, Oliver T (2013) The use of talking mats to support people with dementia and their carers to make decisions together. Health and Social Care in the Community 21: 171–80

Naughton M, Nulty A, Abidin Z et al. (2012) Effects of group metacognitive training (MCT) on mental capacity and functioning in patients with psychosis in a secure forensic psychiatric hospital: a prospective-cohort waiting list controlled study. BMC Research Notes 5: 302

Stovell D, Wearden A, Morrison AP et al. (2016) Service users' experiences of the treatment decision-making process in psychosis: a phenomenological analysis. Psychosis 8: 311–23

Turner D, MacBeth A, Larkin A et al. (2017) The relationship between the 'jumping to conclusions' bias and treatment decision-making capacity in psychosis: A participant-blind randomised controlled experiment (not yet published)

Woltmann EM, Wilkniss SM, Teachout A et al. (2011) Trial of an electronic decision support sys-tem to facilitate shared decision making in community mental health. Psychiatric Services 62: 54–60

3.4 Assessment of mental capacity

Introduction to the review questions

Review question 3, comprised of parts 'a' and 'b', is reported in this subsection. Part 'a' sought data about the effectiveness and cost-effectiveness of interventions, tools and approaches to support the assessment of mental capacity for specific decisions. Part 'b' was designed to locate the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity. In particular the question sought to understand whether the nature of decisions is taken into account when assessments are conducted and whether the people involved feel that consideration is given to the possibility that assessments may be refused. Finally, we were looking for data about what works and what does not work well in the assessment of mental capacity for specific decisions.

Review questions

3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity?

3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?

Summary of the review protocol

The protocol sought to identify studies that would:

- identify effective interventions, tools and approaches to assess a person's capacity to make a specific decision

- consider the cost-effectiveness of interventions tools and approaches used to assess a person’s capacity to make a decision
- explore the self-reported views of people who access services, carers and practitioners about approaches, methods and tools for conducting and recording assessments of mental capacity when a decision needs to be made
- consider specifically whether assessment methods and tools adequately consider the timing of assessments
- consider specifically whether the nature of decisions is taken into account by approaches to assessment
- consider specifically whether the people who may lack capacity, carers and practitioners feel that approaches to assessment acknowledge the possibility that the assessment may be refused.

Population

All people aged 16 years or over who may lack mental capacity (now or in the future) and need support from health or social care practitioners to make their own decisions. Including those whose capacity to make specific decisions about aspects of their care may need to be assessed, and specific best interests decisions made on their behalf if they are assessed as lacking capacity. This group is diverse and according to the Mental Capacity Act Code of Practice may include people suffering from dementia, mental illness, learning disability, brain damage, or other conditions that may cause confusion, drowsiness or a loss of consciousness.

Intervention

Assessment of mental capacity, in line with the Mental Capacity Act Code of Practice.

Setting

People’s own homes, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts.

Outcomes

Person-focused outcomes (empowered and enabled to make decisions about their care and support afforded access to their human rights and dignity and helped to maintain independence and social inclusion).

Service outcomes (competence and confidence among practitioners to implement and uphold the principles of the Mental Capacity Act, including assessment, supporting decision-making and conducting best interests decision-making, transparency and quality of recording, efficient and effective use of resources). See 1.6 in the scope.

Study design

The study designs which were prioritised for the effectiveness and cost-effectiveness question included: systematic reviews of studies of interventions, tools and approaches related to this topic; randomised controlled trials of interventions, tools and approaches related to this topic; economic evaluations; cohort studies, case control and before and after studies; mixed methods studies.

The study designs which were prioritised for the views and experiences questions included: systematic reviews of qualitative studies on this topic; qualitative studies of user and carer views of social and integrated care; qualitative components of effectiveness and mixed methods studies and observational and cross-sectional survey studies of user experience.

See Appendix A for full protocols.

How the literature was searched

A single search strategy for all the review questions was developed. The questions were translated into a framework of 8 concepts and combined as follows: a) decision and capacity and (supporting people or best interests or safeguarding) or b) decision and capacity and mental health and assessment or c) capacity and advance planning. These reflected the question areas of planning in advance, supporting decision-making, assessment of mental capacity and best interests decision-making. The search was restricted to material published since 2005. The searches were run between September and October 2016.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4, a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- language (must be in English)
- population (must be over 16 years of age who may lack mental capacity, accessing health or social care services, their families or carers)
- intervention (all aspects of assessment, supported decision making, future planning, and best interests decision making for adults who may lack mental capacity)
- setting (service user's own home, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts)
- country (must be UK or other OECD)
- date (must not be published before 2005)
- type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular parts of the review question or flagged as being relevant to 1 of the other review areas and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and a random sample of 10%.

Overview of evidence

In our initial screen (on title and abstract) we found 27 studies which appeared relevant to review question 3. We retrieved and then reviewed full texts and included a total of 18 papers: 8 effectiveness studies and 10 views and experiences studies. Overall, there was a good amount of evidence although it was of variable quality, particularly in relation evidence in certain areas such as recording of capacity assessments. There was a good amount of evidence in relation to effectiveness (mainly moderate in quality) although the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on Committee discussions about the use of evidence for developing recommendations. Finally, in terms of quantitative evidence, there was only 1 UK study and although it was rated as good quality it was not considered sufficient for Committee decision-making so non-UK studies were used to supplement the evidence.

In terms of qualitative evidence, as with all the review areas, only UK studies were included. There was representation of practitioner views and experiences (mainly low in quality), however no studies reported the views and experiences of people who may lack capacity (or their families/carers). The absence of service user views and experiences data and studies which evaluate tools and approaches to assessment that were aligned with the Mental Capacity Act certainly had implications for the development of recommendations and Committee decisions about the use of expert testimony.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or subgroups in the form of evidence statements. The approach to synthesising evidence was informed by the PICO within the review protocol.

Studies reporting effectiveness data (n = 8)

1. Aydin Er R, Sehiralti M (2014) Comparing assessments of the decision-making competencies of psychiatric inpatients as provided by physicians, nurses, relatives and an assessment tool. Journal of Medical Ethics 40: 453–7

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: Turkey

Outline

This study was judged to have good relevance to the review area (++) and to be of moderate quality (+). The descriptive cross-sectional study compared the evaluations of decision-making capacity of psychiatric inpatients provided by physicians, nurses and family members with the results of the MacArthur Competence Assessment Tool Treatment (MacCAT-T). The study was conducted in 83 patients between 18 and 63 years of age with psychiatric illness, relatives of 65 patients and 8 physicians and 5 nurses responsible for the care of the patients. The study evaluated competence to make treatment decisions of psychiatric patients and the relationships among evaluations made by the physician, nurse, patient's relative and MacCAT-T.

Findings

1. Competence to make treatment decision of psychiatric patients.

1.1. The MacCAT-T scores of the psychiatric patients are presented in Table 1 (page 455). It was found that 73.5% of patients in the study were incompetent.

1.2. Patients living alone demonstrated greater competence in decision making than patients who lived with their families ($\chi 2 = 5888$; $p = 0.028$). There were no statistically significant relationships between demographic variables, such as sex, age, education level and work status and decision-making competence.

1.3. Patients hospitalised for the first time, and those who were hospitalised voluntarily, were more competent in decision-making than patients who had been previously hospitalised or those who had been hospitalised involuntarily ($\chi 2 = 8.310$;

p = 0.016 and χ2 = 8.292; p = 0.002). Other clinical characteristics do not result in a significant difference in decision-making competence.

2. The relationships among evaluations made by the physician, nurse, patient's relative and MacCAT-T.

2.1. The agreement among the evaluations of the physicians, nurses and relatives is shown Table 3 (p456). There was moderate agreement between the evaluations of the physicians and nurses (κ= 0.526, p = 0.000), but poor agreement between the evaluations of either the nurses or physicians and those of the relatives (κ= 0.267, p = 0.003; κ = 0.318, p = 0.000).

2.2. The competence evaluation carried out using MacCAT-T statistically differed from the evaluations of the nurses, physicians and relatives, respectively (χ2 = 9.247, p = 0.010; χ2 = 6.303, p = 0.0043; χ2 = 7.635, p = 0.022) (Table 4, p456).

More than half the patients evaluated by MacCAT-T as incompetent in decision-making were either partially or fully competent. The assessments of the psychiatric nurses were in better agreement with the MacCAT-T results than the assessments of either the physicians or relatives.

2. Carling-Rowland A, Black S, McDonald L et al. (2014) Increasing access to fair capacity evaluation for discharge decision-making for people with aphasia: a randomised controlled trial. Aphasiology 28: 750–65

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: Canada

Outline

This Canadian study used a randomised controlled trial to test the effectiveness of a communicatively accessible capacity evaluation tool with communication training supports, thus allowing healthcare professionals to evaluate more equitably the capacity of people living with aphasia to consent to be admitted to long-term care. This study was judged to have good relevance to the review area (++) and to be of moderate quality (+). The study used an intervention labelled as Communication Aid to Capacity Evaluation (CACE), which is a communicatively accessible version of the 'The Capacity to Make Admissions Decisions' (CMAD). Thirty-two participant pairs (people with aphasia paired with social worker evaluators) completed the study protocol, 17 participant pairs in the experimental group and 15 in the control group. Three speech and language pathologists also participated in the study. All participants with aphasia (PwA) had a diagnosis of stroke apart from 1 with a subdural haematoma. The outcomes measured included capacity determination of people with aphasia, social worker evaluator's communication skills, social worker evaluator's confidence in capacity determination and perspectives of people with aphasia.

Findings

1. Capacity determination of people with aphasia

The results showed that when using the CMAD questionnaire, 1 evaluator found a competent PwA lacking in capacity, and 12 of the evaluators were unable to determine capacity (Table 2). Using the communicatively accessible version of the questionnaire, the CACE, 100% of the evaluators were able to accurately determine capacity.

2. Social worker evaluator's communication skills

The results showed that the social worker evaluators in the experimental group, following the communication training and with the use of the CACE, had significantly better communication skills, revealing competence F(2, 29) = 12.03, p = .002, which in turn increased the PwAs 'abilities to Transfer Information , F(2, 29) = 10.51, p = .003. Three of the 4 constructs in the measure of skill in supported conversation (MSC) and measure of participation in conversation (MPC) showed a large effect size: acknowledging competence, d = .88; revealing competence, d = 1.13; transaction, Cohen's d = .99. The construct of 'interaction' showed a moderate effect size (d = .52).

3. Social worker evaluators' confidence in capacity determination

The group by time result which compared the 2 groups (experimental vs control) across 2 administrations showed that the increase in confidence to determine capacity using CACE with communication training as compared to CMAD was highly significant, F(2, 29) = 13.511, p = .001. Effect size d = 1.3021 (95% confidence Interval – 0.538, 2.0662).

(Note that the effect size was not reported by the authors and has been calculated by the reviewers.)

4. Perspectives of people with aphasia

The results for the 2 questions regarding comprehension were found not to be statistically significant. The question regarding ‘communicating answers’ did reveal a statistically significant difference, t(16) = –5.39, p > 0.000. The paired samples t-test demonstrated a significant difference in the levels of frustration pre- and post-test as a result of the intervention, t(16)= –3.598, p = .002.

5. Post-hoc analysis

The results of the logistical regression analysis showed that neither severity levels of language deficits, nor social worker evaluators’ experience were significant predictors of the evaluators’ ability to determine capacity: expressive language impairments p = .643, receptive aphasia p = .200, social worker evaluator’s experience p = .612. There was a significant difference in communication skills of social worker evaluators contributing to an inability to determine capacity between the two groups, F(2, 29) = 6.17, p = .019.

3. Feng BS, Person C, Phillips-Sabolet J et al. (2014) Comparison between a standardized questionnaire and expert clinicians for capacity assessment in stroke clinical trials. Stroke 45: e229–32

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: US

Outline

This prospective pilot study aimed to compare between a standardised questionnaire (modified, stroke-specific, version of the Aid-to-capacity Evaluation, ACE) and Expert

Clinicians for Capacity Assessment in Stroke Clinical Trials. It was conducted in the US but was nevertheless judged to have good relevance to the review area (++). The study's methodological quality was rated as moderate (+). The 30 participants were diagnosed with stroke and the mean age was 67.8 years. All patients underwent 3 independent capacity assessments: comparison between ACE (aid-to-capacity evaluation) and capacity assessment by psychiatrist and neuropsychologist was done.

Findings

1. Frequency (percentage) of capacity decision by ACE, psychiatrist, and neuropsychologist

The ACE, neuropsychologist and psychiatrist determined many patients lacked medical decision-making capacity: 70% (21/30), 52% (15/29) and 28% (8/29) respectively (Table 2).

2. Sensitivity and specificity of the ACE (Table 3)

The ACE demonstrated high sensitivity: 93.8% (95%CI, 69.8 to 99.8) compared with neuropsychologist and 100% (95% CI, 63.1 to 100) compared with psychiatrist.

ACE demonstrated low specificity: 53.8% (95%CI, 25.1 to 80.8) compared with neuropsychologist and 42.9% (95%CI, 21.8 to 66.0) compared with psychiatrist.

3. Positive predictive value and negative predictive value of the ACE (Table 3)

Positive predictive value is 40% (95%CI, 19.1 to 64) compared with psychiatrist and 71.4% (95%CI, 47.8 to 88.7) compared to neuropsychologists. ACE had a high negative predictive value to detect intact capacity versus clinicians, misclassifying only 1 patient capable when clinicians recorded incapacity (false-negative rate of 6.2%).

4. Gregory R, Roked F, Jones L et al. (2007) Is the degree of cognitive impairment in patients with Alzheimer's disease related to their capacity to appoint an enduring power of attorney? Age and Ageing 36: 527–31

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: UK

Outline

The cross-sectional study conducted in UK investigated whether the capacity to create an EPA (enduring power of attorney) as determined by a clinical assessment is significantly related to a degree of cognitive impairment. It also determined whether the Mini Mental State Examination score is a good predictor of a patient's capacity. Further, it examined whether any sociodemographic factors (age, gender, education and qualifications) are related to a patient's capacity to create an EPA. This study was judged to have good relevance to the review area (++) and to be of good quality (++). The 74 participants had a median age of 80 years and a diagnosis of Alzheimer's disease. The outcomes measured were:

1. Association between capacity and level of cognitive impairment/MMSE score.

2. Association between capacity and sociodemographic factors.

3. Predictors of capacity.

4. Receiver operating characteristic analysis (sensitivity, specificity, positive predictive value, likelihood ratio).

Findings

1. Association between capacity and level of cognitive impairment/ MMSE score

There was a significant association between level of cognitive impairment and capacity to create an EPA ($\chi 2 = 35.15$, $p < 0.0001$). MMSE score was found to be significantly different in patients with capacity and patients without ($U = 103.0$, $p < 0.0001$).

2. Association between capacity and sociodemographic factors

There were no associations between socidemographic factors such as age, gender, qualifications, age of leaving school and capacity to create an EPA.

3. Predictors of capacity

Logistic regression showed that MMSE score was the only variable to significantly predict capacity (odds ratio = 1.6, 95% CI = 1.3 to 2.0). MMSE score correctly classified 83.8% of the patients.

4. Receiver operating characteristic analysis (sensitivity, specificity, positive predictive value, likelihood ratio)

The area under the ROC curve for the MMSE score as a test to identify incapacity to create an EPA was 0.921 (95% CI 0.863 to 0.979).

Optimal sensitivity and specificity were obtained using a cut-off MMSE score of 18: sensitivity 86.2% (95% CI 67.4 to 95.5), specificity 82.2% (95% CI 67.4 to 91.5).

Positive predictive value 75.8% (95% CI 57 - 88%), Negative predictive value 90.2% (95% CI 76 to 97%).

Likelihood ratio for a positive result (LR+ve) = 4.84 (95% CI 2.54 to 9.24) likelihood ratio for a negative result (LR –ve) = 0.16 (95% CI 0.06 to 0.42).

5. Lai JM, Gill TM, Cooney LM, et al. (2008) Everyday decision-making ability in older persons with cognitive impairment. American Journal of Geriatric Psychiatry 16: 693–6

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: US

Outline

This cross-sectional US study demonstrated the reliability and validity of the Assessment of Capacity for Everyday Decision-Making (ACED), an instrument to evaluate everyday decision-making. The 39 study participants had a mean age of 81 years and were treated for cognitive difficulties. Most of them (92%) had a diagnosis of dementia. This study was judged to have good relevance to the review area (++) and to be of moderate quality (+).

Findings

1. Reliability of the ACED

Inter-scorer reliability (n = 15) – intraclass correlation coefficients of 0.72, 0.69, and 0.65, respectively, for understanding, appreciation and reasoning.

Percentage agreement for choice was 93%. For patients and caregivers combined (n = 52), the internal consistency of the ACED abilities was also good, with Cronbach alpha values of 0.92, 0.88 and 0.84, respectively, for understanding, appreciation and reasoning.

2. Distribution of ACED ability scores

Performance of patients (n = 39) and caregivers (n = 13) on measures of everyday decision-making performance were compared. Overall, both groups were equally capable of articulating a choice. They differed in their abilities to understand, appreciate and reason. Higher scores represent better performance on the ability measure.

a) Ability to understand

Only 15 patients (38%) achieved an understanding score above the lowest score observed in the caregiver group. Patients – mean (sd) = 5.2 (3.2) Caregivers – mean (sd) = 9.8 (0.6)

b) Ability to appreciate

Six patients (15%) scored in the highest category (7–8) for appreciation, whereas all caregivers scored within the highest category; 22/39 patients (56%) demonstrated inadequate (score= 0) recognition of proxy reported functional problems. Patients – mean (sd) = 3.5 (2.0) Caregivers - mean (sd) = 7.9 (0.3)

c) Ability to reason

Performance on reasoning ability was similar to appreciation, with only six patients (15%) achieving scores in the highest range (9 or 10). It was also observed total scores above five points in this ability for 30 patients (77%), reflecting the higher scores found from questions testing comparative reasoning and logical consistency. Patients – mean (sd) = 6.3 (2.1) Caregivers – mean (sd) = 10 (0).

d) Ability to express a choice. Patients – mean (sd) = 1.9 (0.3) Caregivers – mean (sd) = 2 (0).

3. Correlates of everyday decision-making performance

No significant correlation between ACED performance and the variables of age, gender or education level. MMSE scores had a moderate to strong correlation with all 3 decision-making abilities (0.48 ≤ rs ≤0.60, all p < 0.002).

Trails B and COFL (Controlled Oral Word Fluency Test) showed a moderate association with ACED understanding and reasoning performance (0.33≤ rs ≤0.59, all p < 0.04).

Three tests (Trails A and B, COFL) demonstrated no correlation with ACED appreciation scores (0.06≤ rs ≤0.25 p > 0.08).

Each ACED ability measure was associated with its corresponding measure on the MacCAT-T: appreciation rs = 0.38 (p = 0.02), reasoning rs = 0.50 (p = 0.001), understanding rs= 0.63 (p < 0.001), and expressing a choice rs= 0.71(p < 0.001).

6. Mills W, Regev T, Kunik M et al. (2014) Making and Executing Decisions for Safe and Independent Living (MED-SAIL): development and validation of a brief screening tool. American Journal of Geriatric Psychiatry 22: 285–93

Outline

This prospective preliminary validation study conducted in the USA describes the development and preliminary validation of Making and Executing Decisions for Safe and Independent Living (MED-SAIL), a brief screening tool for capacity to live safely and independently in the community. This study was judged to have good relevance to the review area (++) and to be of good quality (++). The 49 community-dwelling older adults with a mean age of 76 years had moderate to advanced cognitive impairment, clinically important functional declines, but mild to no depressive symptoms. Outcomes measured were: reliability, criterion-based validity, concurrent validity and accuracy of classification for MED-SAIL.

Findings

Internal consistency

Cronbach's alpha coefficients first scenario, a= 0.77 second scenario, a= 0.78. mean score across the two scenarios a= 0.85.

Concurrent validity

a. Discriminant validity – MED-SAIL did not have a significant relationship with physical function (Activities of Daily Living) and depression (PHQ-9).

b. Convergent validity – Pearson's correlations indicated significant positive correlations for MED-SAIL and Independent Living Scale (ILS) ($r = 0.573$, $p < 0.001$) and Instrumental Activities of Daily Living (IADLs) ($r = 0.440$, $p < 0.01$). The correlation between MED-SAIL and St Louis University Mental Status Examination (SLUMS) was not significant at the p less than or equal to 0.05 level.

Criterion-based validity

A Mann-Whitney test revealed significant differences between the no capacity group ($M = 3.25$, $sd = 1.60$) and partial/full capacity group ($M = 6.11$, $sd = 1.99$) classification using MED-SAIL ($U(48) = 60.5$, $z = 0.38$, $p < 0.0001$).

Accuracy of MED-SAIL as a screening tool by examining sensitivity, specificity, and the AUC.

The receiver operating characteristic analysis revealed an AUC (area under the curve) of 0.864 (95% confidence interval: 0.84–0.99), which indicates good accuracy in distinguishing between no capacity and partial/full capacity.

The authors provided a metrics associated with potential cut points for MED-SAIL scoring (Table 4), including sensitivity, specificity, NPV and PPV across the range of possible MED-SAIL scores.

In the discussion section, the authors state that they chose a mean MED-SAIL cut-off score of 5.0 across 2 scenarios to maximise sensitivity. MED-SAIL cut-off score of 5:

a. Sensitivity – 0.92

b. Specificity – 0.70

c. PPV – 0.50

d. NPV – 0.96

Using Bayesian analysis to examine effect of prevalence on PPV, the authors determined that with the prevalence of no capacity at 25% for the current sample, an older adult with a MED-SAIL score less than 5 has a 79% probability of having no capacity.

7. Moye J, Karel MJ, Edelstein B et al. (2007) Assessment of capacity to consent to treatment. Clinical Gerontologist 31: 37–66

Methodology: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: US

Outline

This cross-sectional study from the US reports on the development of a tool to assess capacity to consent to treatment. The authors also present statistical data in an attempt to determine reliability and validity of the tool. The study had good relevance to the review question (++) but the methodological quality was rated as low (-). The study sample comprised 2 groups – individuals with a clinical diagnosis of dementia or schizophrenia (recruited from an outpatient clinic at a Veterans Affairs centre in Boston) and a '... healthy comparison group ...' (p 46) recruited from primary care clinics at a Salt Lake City Veterans Affairs centre.

To be included in the study, individuals had to be aged 60 years or over, speak English as their first language and be able to participate in a 1-hour interview (ability determined by a clinician with whom the person was familiar). For recruitment to the 'healthy' comparison group, individuals were excluded if they had a clinical diagnosis of dementia or schizophrenia, or if they scored lower than 26 on the Mini Mental State Examination (Folstein et al. 1975). This resulted in a total sample size of n = 59 (dementia group n = 20; schizophrenia group n = 20; comparison group n = 19).

The Assessment of Capacity to Consent to Treatment interview measures ability to consent to medical treatment. The authors report that although the tool was developed for research purposes, it can be adapted for use in clinical settings. While the research version (used in this study) uses hypothetical vignettes, these can be substituted in clinical settings for descriptions of a proposed treatment. The first stage of the Assessment of Capacity to Consent to Treatment interview is described by the authors as a '... values interview to elicit values and preferences relevant to medical decisions' (p 40). The next stage uses hypothetical vignettes (or descriptions of proposed treatment) to assess decision-making ability in relation to appreciation, reasoning, understanding and communication of choice.The Assessment of Capacity to Consent to Treatment interview was evaluated by examining internal consistency, inter-rater reliability, association of scores with cognitive test performance, association of scores with clinician ratings and differences in scores between patients where some degree of impairment is likely (people with dementia and schizophrenia) and a 'healthy' comparison group.

Findings

Note: only data relating to reliability and validity of the tool are reported here (that is, no data on treatment choices made, prevalence of capacity or values identified as most important by participants).

Inter-rater reliability (examined through comparison of 10 protocols)

Inter-rater reliability between scores generated by raters involved in the study and those generated by an independent rater (using 10 patient protocols) demonstrated agreement. For total scores, there was a very strong positive correlation (r =.90). This result was significant (p < .001). For individual subscales, there were also very strong positive correlations (appreciation r =.89 [p < .01]; communicating a choice r =.98 [p < .001]; and understanding r =.90 [p < .001]). For the reasoning subscale there was a strong positive correlation (r =.68 [p < .05]). These results were significant.

Inter-rater reliability examined by vignette also demonstrated agreement. There were strong positive correlations between scores for vignette 1 (r =.95; p < .001) and vignette 2 (r =.83; p <.01). There was a strong positive correlation between scores for vignette 3 (r =.76; p <.05). These results were significant.

Internal consistency

Excellent internal consistency was demonstrated for all decisional ability-related items used in the Assessment of Capacity to Consent to Treatment interview (α=.96). For individual subscales, those on the understanding subscale demonstrated excellent internal consistency (α=.91); while those on the appreciation (α=.88) and reasoning subscales demonstrated good internal consistency. Those on the communicating a choice subscale demonstrated questionable internal consistency (α=.66). Internal consistency was also demonstrated when items were examined by vignette. Excellent internal consistency was demonstrated for vignette 3 (α=.91, 22 items). Good internal consistency was demonstrated for vignette 1 (α=.88, 16 items) and vignette 2 (α=.88, 18 items).

Validity

There was a moderate positive correlation between Assessment of Capacity to Consent to Treatment interview total score and Mini Mental State Examination total score (r = .47). This result was significant (p < .01).

There was a weak positive correlation between Assessment of Capacity to Consent to Treatment interview total score and Brief Symptom Inventory total score (r = .25). This result was not significant (p value not reported).

The authors report narratively that correlations between Assessment of Capacity to Consent to Treatment interview total score and Brief Symptom Inventory subscales (anxiety, depression, paranoia and psychosis) were not significant.

There was moderate agreement between Assessment of Capacity to Consent to Treatment interview capacity ratings and primary care clinician ratings of capacity (κ = .44, n = 20/27, 74%, p < .01); and between Assessment of Capacity to Consent to Treatment interview capacity ratings and ‘experienced clinicians’ ratings of capacity in people with dementia or schizophrenia (κ =.50, n = 9/12, 75%, p < .05). These results were significant.

There was a moderate positive correlation between Assessment of Capacity to Consent to Treatment interview and primary care clinician scores for reasoning (r =.41). This result was significant (p < .05). The authors report narratively that correlations for the appreciation, communicating a choice and understanding subscales were not significant.

There was a very strong positive correlation between Assessment of Capacity to Consent to Treatment interview total score and 'experienced clinician' scores for the reasoning subscale (r =.87, p < .01) and a strong positive correlation between Assessment of Capacity to Consent to Treatment interview and 'experienced clinician' scores for the understanding subscale (r =.73, p < .01). These results were significant. Correlations for the appreciation and communicating a choice subscales are not reported.

Mean group differences on decisional ability subscales for vignette

Three individuals in the dementia and schizophrenia groups showed worse performance than those in the 'healthy' comparison group on the understanding disorder; understanding treatments; appreciation foresight; reasoning rational; and reasoning values subscales. These results were significant (all ps < .05). Post-hoc analysis using Bonferroni correction also showed that individuals in the dementia or schizophrenia groups showed worse performance on these subscales than those in the comparison group. These results were also significant (all ps <.05).

Individuals in the dementia or schizophrenia groups showed worse performance than those in the 'healthy' comparison group on the appreciation distrust subscale. This result was significant (p < .05). Post-hoc analysis using Bonferroni correction also showed that individuals in the schizophrenia group showed worse performance on this measure than those in the comparison group and those in the dementia group. This result was also significant (p < .05).

Individuals in the dementia or schizophrenia groups showed worse performance than those in the 'healthy' comparison group on the naming choices subscale. This result was significant (p < .05). Post-hoc analysis using Bonferroni correction also showed that individuals in the schizophrenia group showed worse performance on this measure than those in the comparison group. This result was also significant (p < .05).

Individuals in the dementia or schizophrenia groups showed worse performance than those in the 'healthy' comparison group on the communicating a choice subscale. This result was significant (p < .05).

8. Sugano K, Okuyama T, Lida S et al. (2015) Medical decision-making incapacity among newly diagnosed older patients with haematological malignancy receiving first line chemotherapy: a cross-sectional study of patients and physicians. PLoS ONE 10: e0136163

Method: Quantitative (diagnostic accuracy data)

Data: Effectiveness

Country: Japan

Outline

This cross-sectional study conducted in Japan aimed to identify the frequency of decision-making incapacity among newly diagnosed older patients with haematological malignancy receiving first-line chemotherapy, to examine factors associated with incapacity and assess physicians' perceptions of patients' decision-making incapacity. This study was judged to have moderate relevance to the review area (+) and to be of moderate quality (+) The 114 participants' mean age was 73.9 years. Seventy-one percent of the subjects had malignant lymphoma and the remaining 28.9% had multiple myeloma. Outcomes measured were frequency of incapacity, factors associated with incompetency and physicians' recognition of patient incompetency.

Findings

1. Frequency of incapacity

Of the 114 patients who completed the SICIATRI-R (Structured Interview for Competency Incompetency Assessment Testing and Ranking Inventory-Revised), 28 (25%, 95% CI: 17%–32%) patients were judged to be incompetent to some extent (Table 1).

2. Factors associated with incompetency: univariate analysis

Compared to participants who were competent, patients judged to be incompetent were more likely to be older, and to have more severe cognitive impairment and lower education level (Table 3). a) Age competent (n = 86) – mean (73.1) sd (5.6); Incompetent (n = 28) – mean 76.6) sd (5.5) p < 0.01 b) Cognitive impairment Competent (n = 86) – mean (26.2) sd (2.7) Incompetent (n = 28) – mean 23.7) sd (4.1) p < 0.01.

Other factors such as performance status, depression, sex, diagnosis, education and household size did not reach statistical significance between competent and incompetent participants.

3. Factors associated with incompetency: logistic regression analysis

Older patients and those with more severe cognitive impairment (that is, lower MMSE score) had higher odds of being classified as incompetent according to the SICIATRI-R (Table 4) a) Age beta (0.92) SE (0.04) p value (0.03) Adjusted OR (1.10) 95% CI 1.01 to 1.19 b) Cognitive impairment beta (–0.18) SE (0.08) p value (0.02) Adjusted OR (0.84) 95% CI 0.73 to 0.97.

4. Physicians' recognition of patient incompetency

Total 3 patients (3%, 95% CI: 0%–6%) were judged to be incompetent by physicians and these three patients were also considered to be incompetent by the SICIATRI-R. Cohen's kappa was –0.54, indicating that agreement was no greater than what would be expected by chance.

Studies reporting views and experiences data of people who may lack mental capacity, their families and carers, n = 10

Note that studies using an audit design have been included to help answer this review question. Audits do not meet the criteria set out in the original review protocol but, given their relevance to the question, the reviewers agreed the studies should be presented to the Guideline Committee as a potential contribution to discussions. Studies using an audit design can legitimately be included in the NICE guideline development process. The quality of the study methods has been appraised using a critical appraisal tool for audits, recommended by NICE. An addendum has been added to the review protocol and agreed with NICE, which reflects the need to include audit studies for this review question and to be able to consider them for question 4.

1. Brown PF, Tulloch AD, Mackenzie C et al. (2013) Assessments of mental capacity in psychiatric inpatients: a retrospective cohort study. BMC Psychiatry 13: 115

Methodology: Audit

Data: Experiences

Country: UK – England

Outline

This audit from the UK aimed to '… evaluate how frequently mental capacity is assessed in psychiatric inpatients, whether the criteria for determining capacity set out in the MCA are used in practice, and whether this has increased with the introduction of the MCA' (p1). The study had good relevance to the review question (++) but the methodological quality was rated as low (-).

The authors extracted data from the South London and Maudsley NHS Foundation Trust Biomedical Research Centre Case Record Interactive Search. The search term 'capacity' was used to identify patient records for admissions to a psychiatric ward between 01 May 2006 and 31 January 2010 (inpatient admissions to an older adult, child or adolescent mental health, forensic psychiatry, rehabilitation service and mental health in learning disability service psychiatric ward, or 1 of the South London and Maudsley NHS Foundation Trusts specialist referral units [for example, affective disorders, eating disorders, psychosis]).

Findings

Data for patients under the age of 16 were excluded due to the scope of the Mental Capacity Act. For patients with multiple admissions during the study period, each admission was counted and considered separately. This resulted in a total sample size of 17,744 admissions.

Instances in which a documented capacity assessment took place

Documented capacity assessments took place for 9.8% of all admissions (1732/17744; 95% CI 9.3 to 10.2%). Mental capacity assessments were suggested by a clinical team member for a further 2.4% of admissions (423/17744); however there is no record to show whether such an assessment took place.

For informal admissions, capacity assessments were documented in only 4% of cases (433/10608); for patients admitted under Sections 4, 5, or 136 of the Mental Health Act, capacity assessments were documented in 9.8% of cases (68/703); for patients admitted under Section 2 of the Mental Health Act, capacity assessments were documented in 14.3% of cases (332/2326); for patients admitted under Section 3 of the Mental Health Act, capacity assessments were documented in 13.6% of cases (507/3740); for patients admitted under Section 3 of the Mental Capacity Act and detained for more than three months, capacity assessments were documented in 16.0% of cases (353/2201); and for patients admitted under a forensic section of the Mental Capacity Act, capacity assessments were documented in 25.1% of cases (92/367).

The authors also report in their discussion section that for those admissions in which a person was detained (for over 3 months) under Section 3, a capacity assessment was documented in only 23% of cases (353/1539). Frequency of capacity assessment by type of admission is not recorded for other statuses.

Frequency of capacity assessments (May 2006 to January 2010)

Change between May 2006 and January 2010 – in May 2006, capacity assessments were conducted for 5% of admissions. By January 2010, this had increased to over 17%.

Time-series regression demonstrated a significant increase of around 0.3 percentage points per month in the proportion of assessments carried out over the course of the study (regression coefficient = 0.294 [95% CI 0.258 to 0.328], p < 0.0001). There was no evidence of autocorrelation (Durbin-Watson statistic = 2.22).

Immediately after the introduction of the Mental Capacity Act (November 2007), there was no step-wise increase in the proportion of inpatients assessed for capacity immediately (regression coefficient = 0.59, [95% CI –1.21 to 2.39], p = 0.5).

Practitioners who conducted capacity assessments

In cases in which a documented capacity assessment was took place, doctors conducted 70.7% of assessments (1227/1732); approved social workers or approved mental health practitioner conducted 17.8% of assessments (308/1732); nurses conducted 6.0% of assessments (103/1732); multidisciplinary team members conducted 2.0% of assessments (34/1732); and 3.5% of assessments were conducted by an ‘unknown’ practitioner (60/1732).

Reason for capacity assessment

In cases in which a documented capacity assessment took place, the prompts for this were: capacity to consent to a psychiatric admission 43.4% (752/1732); psychiatric treatment (including ECT) 25.1% (435/1732); aftercare and accommodation 6.4% (111/1732); physical health interventions 10.1% (174/1732); legal issues 3.4% (59/1732); finances, contracts, Lasting Power of Attorney, Advance Directive 4.4% (75/1732); other 7.3% (126/1732).

In their discussion section, the authors also report that for forensic wards, 87% of capacity assessments related to capacity to consent to treatment.

Instances in which Mental Capacity Act criteria for determining capacity were reported

Mental Capacity Act criteria in relation to determination of capacity were recorded in 14.7% of admissions (254/1732). Before the introduction of the Mental Capacity Act these criteria were recorded in 11.5% of admissions. This increased to 15.5% after the introduction of the Act. This increase was not significant ($\chi 2 = 3.718$, $p = 0.052$).

Time-series analysis also showed an increase of 0.13 percentage points per month, however this increase was not significant (95% CI –0.007 to 0.268, $p = 0.06$)

Use of a form to document mental capacity assessments

A form was used to document capacity assessments in only 0.5% of admissions (8/17744). However, the authors note that they were unable to access documents which were scanned and attached to a patient's record and they note that this figure is likely to be much higher.

Note: findings in relation to prevalence of incapacity are not reported here as the data do not provide information relevant to question 3.

2. Emmett C, Poole, Bond J 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

Methodology: Qualitative

Data: Practitioner views and experiences

Country: UK – England

Outline

This qualitative study from the UK aimed to explore '… how assessments of residents' capacity are actually performed on general hospital wards compared with legal standards for the assessment of capacity set out in the Mental Capacity Act, 2005 (MCA)' (p73). The study had good relevance to the review question (++) but the methodological quality was rated as low (-).

Fieldwork was conducted with elderly patients and their families, and staff working on elderly wards (acute or rehabilitation) in 2 hospitals in the North of England.

The total sample size is unclear and only limited details are provided regarding the sample, however it appears that a wide range of practitioners were involved including a care home manager, junior and senior physicians and psychiatrists, nursing staff (including a psychiatric liaison nurse), an independent mental capacity advocate, occupational therapists, a physiotherapist and social workers.

Findings

The authors report that 3 themes emerged from the data. These related to the 'type' of assessment (use of a functional approach as set out in legislation), the formality of assessments and the extent to which information provided to patients as part of the assessment was 'relevant'.

Approaches to assessment – functional vs outcomes driven

The authors report that while the majority of practitioners understood the requirements for assessment of capacity set out in the Mental Capacity Act, the 'statutory' approach was not always embedded in practice, and they report that some practitioners took an outcomes-based approach rather than a functional one. This was reported to be especially likely if the person had a diagnosis of dementia or a cognitive impairment, and the authors report that practitioners sometimes felt that a 'risky' decision or a failure to show 'insight' was itself indicative of a lack of capacity. The authors report that junior nursing staff in particular appeared to have difficulties and were more likely to be risk-averse. Nursing staff were also identified as a group for whom taking a functional approach was difficult because of the likely longer-term relationship they had developed with the person. The authors conclude that practitioners find it difficult to reconcile the desire to enable service users to make autonomous decisions with the instinct to protect others from the effects of 'risky' discharge decisions – consequently, capacity assessments are often subsumed into wider discussions regarding risk and harm.

Frequency and formality of assessments

The authors report that the assessment of capacity was not routine, particularly when service users did not make their preferences known. The authors also found that practitioners tend to rely on informal assessments which they suggest may be indicative of a failure to understand the requirement for a functional approach as set out in the Mental Capacity Act. Informal assessments were reported to take place on multiple occasions during ward rounds, over an extended period of time, and that these, in combination with other sources of information, 'fed into' an overall assessment of capacity. Practitioners reportedly described this as taking a holistic view of the patient and reported that they often included information gathered from sources such as occupational therapist home visits: '… the result of which would be fed into the assessment process to form a general picture of the patient's capacity' (authors, p78).

The authors report that more 'formal' assessments were usually conducted via '… conversational exchanges between the patient and the assessor with questions about home-life, reasons for the current admission, the patient's feelings and their expectations concerning the future' (authors, p78). They go on to note that practitioners then made judgements of capacity on the basis of whether the person's response was 'reasonable'.

Understanding information relevant to the decision

The researchers found that there was variation in the amount of information provided and its relevance to the capacity assessment, highlighting 'questionable' practice in which practitioners cited a service user's inability to remember previous conversations and general confusion as evidence of a lack of capacity to be able to make a decision on place of residence.

Similarly, the authors suggest that practitioners often failed to identify and provide relevant information to service users, and in some cases focused on irrelevant information. They also expressed concerns that the practitioners they spoke to did not always clearly present information to service users in discussions regarding admission to residential care, and cited 1 practitioner who suggested that there could be a tendency to use euphemisms when discussing long-term placements.

3. Manthorpe J, Samsi K, Rapaport J (2014) Dementia nurses' experience of the Mental Capacity Act 2005: a follow-up study. Dementia 13: 131–43

Methodology: Qualitative

Data: Practitioner views and experiences

Country: UK – England

Outline

This qualitative study from the UK aimed to explore specialist dementia community nurses' understanding and experiences in relation to the Mental Capacity Act. The authors were particularly interested in changes in practice arising as a result of the Act, challenges associated with its incorporation into practice, and whether expectations associated with it had been met. The study had good relevance to the review question (++) and the methodological quality was rated as moderate (+).

Findings

Interviews were conducted with 15 specialist dementia nurses, however only limited details are provided in relation to participants and no sampling criteria are reported. The majority of participants were female (n = 14); however the sample was relatively diverse with respect to age and length of time in post.

The authors report that issues of capacity (and capacity assessments) were beginning to feature much more often in the work of the nurses they interviewed. Participants reported that they were being asked by carers to comment on whether a person with dementia still had capacity and to suggest professionals who could conduct a capacity assessment.

Participants were reported to have concerns regarding the accuracy of some practitioners' assessments; suggesting that these could be '… inaccurate or risk-averse …' (authors p136), particularly in cases where the person's capacity to refuse a service was being queried. Nurses also reportedly suggested that carers did not always understand that capacity was decision-specific.

Nurses also reportedly raised concerns regarding the background of professionals involved in capacity assessments, emphasising that despite guidance provided in the Code of Practice regarding the person who is most appropriate to undertake an assessment, practitioners still deferred to 'professional hierarchy'. Nurses also identified assessments of capacity to appoint a lasting power of attorney as another difficult area of concern, expressing concern that the tendency to involve private medical practitioners was flawed given their lack of knowledge of the service user.

4. McDonald A, Dawson C, Heath B (2008) The impact of the Mental Capacity Act 2005 on social workers' decision making: a report for SCIE. Norwich: University of East Anglia

Methodology: Qualitative

Data: Practitioner views and experiences

Country: UK – England

Outline

This qualitative study from the UK aimed to explore the '... impact of the Mental Capacity Act on assessments of capacity and best interests decision-making and their integration into record keeping and care planning' (p3). The study had good relevance to the review question (++) but the methodological quality was rated as low (-).

Semi-structured interviews were conducted with 13 social workers and 1 social work assistant working with people with dementia. Only limited details are provided in relation to participants and sampling criteria, however interviewees were reported to be based on community teams (and 2 were also members of a hospital-based team). One interviewee was an approved social worker. Length of time qualified varied between 2 months and 15 years.

Findings

Approaches to assessing mental capacity

The authors report that participants accepted the principle of presumption of capacity and understood that it should not be assumed that people with a diagnosis of dementia lack the capacity to make decisions. Similarly, the authors found that participants understood that capacity could fluctuate. Despite this apparent understanding of the functional approach, the authors go on to state that practitioners still seemed to be influenced by an outcomes approach to capacity and have a tendency to focus on risk when discussing individual cases. They suggest that in instances in which the person with dementia did not come to the same conclusion as the social worker about 'risk', interviewees often saw this as evidence of a lack of capacity.

Practitioners were also reported to distinguish between capacity to make 'significant' decisions (for example, financial or place of residence) and 'day to day' decisions, however, the authors suggest that while the majority of assessments related to a single issue (usually admission to residential care) this was sometimes '… combined with financial issues' (authors, p18). Similarly, the authors note that interviewees reported that they tended to 'aggregate' multiple assessments conducted over a period of time to reach a judgement on whether the person had 'capacity or not'.

Providing information and involving the service user in the assessment process

Some interviewees were reported to be concerned that other practitioners did not always provide enough information to service users when assessing capacity, particularly when more significant decisions were being made and/or ‘risk’ was high. The authors also report that they found little evidence of proactive attempts to communicate and involve people in the assessment process, noting that only 1 interviewee stated that they had considered asking a speech therapist to assist them in their assessment of capacity.

Working with other practitioners

The authors report that most interviewees felt that the Mental Capacity Act had increased their confidence, and had empowered them to challenge assumptions made by other practitioners where necessary. Discussions with other professionals, particularly community psychiatric nurses, were seen as helpful in assessing capacity. However, the authors found that collaboration with mental health services was minimal (for example, with consultant psychiatrists), with the exception of those social workers co-located in a hospital based team, and that referrals to obtain a mental health assessment (in order to meet the first requirements of the test of capacity) were often drawn out, and GPs were sometimes reluctant to make referrals. They note that those social workers who were co-located within a mental health team benefited from easier access to mental health practitioners.

Some participants were also reported to express concerns regarding the practice of other professions in relation to assessment of capacity and the authors note that ‘medical opinion’ had sometimes been used to override social workers’ decisions, even when this was not based on a functional approach. For example, a social worker’s suggestion that a person with dementia should enter into a Power of Attorney was overridden because a GP believed that the person lacked capacity ‘because of their dementia’. Some interviewees felt that GPs were especially unlikely to understand the requirements related to assessment set out in the Mental Capacity Act ‘I do think that social workers seem to be the only ones who have any knowledge of the Act – GPs seem to have no concept of it’ (interviewee, p16).

Similarly, the authors note that GPs tended to only be willing to provide '... brief diagnostic letters which unhelpfully "crystallised" situations ...' (authors, p16).

Recording

While participants reportedly suggested that requirements set out in the Mental Capacity Act prompted them to be more careful when recording capacity assessments, the authors state that they were unsure about the most effective and appropriate method of doing so.

5. Murrell A, McCalla L (2016) Assessing decision-making capacity: the interpretation and implementation of the Mental Capacity Act 2005 amongst social care professionals. Practice 28: 21–36

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This small-scale qualitative study aimed to explore how the Mental Capacity Act is understood and interpreted by social care practitioners, with specific reference to assessing decision-making capacity, and it was therefore judged to have good relevance to the review question (++). The researchers purposively sampled 6 practitioners from 1 county council in the South West of England. All 6 were experienced in using the Mental Capacity Act although the frequency with which they assessed capacity to make decisions ranged from fortnightly to every 3 months. Interview questions were based on the Mental Capacity Act and findings from existing research and thematic analysis of the data resulted in the presentation of findings in 8 main areas, with only the most relevant ones reported here. Certain limitations in the survey methodology led to a moderate rating of internal validity (+).

Findings

Knowledge and confidence

All participants were involved in assessing decision-making capacity on a regular basis, ranging from fortnightly to every 3 months. The client group was predominantly people with dementia, with some cases involving people experiencing other forms of mental distress or a learning disability. Decision-making situations were around care needs, accommodation and finance. All participants had received county council delivered training on the Mental Capacity Act. The theoretical knowledge held on the Mental Capacity Act varied, and in some cases was fairly limited.

Participants acknowledged the responsibility that assessing capacity entails and the potential impact on people's lives. Some said they assessed capacity multiple times to make sure the assessment was accurate and others said they would never assess capacity entirely on their own, always consulting other professionals, especially mental health specialists.

Identifying the relevant information

One participant said that when they were assessing capacity they tried to identify how orientated a person is and whether they have insight into their care needs, but as the researchers point out, this is not enough to determine capacity under the Mental Capacity Act (which employs a functional test assessing whether a person can understand, retain and weigh up the relevant information).

Merging capacity and best interests decisions

The responses showed that in complex situations it became difficult to carry out an objective assessment of capacity 'without speculating about the likely outcome of the decision' (p29). The researchers point out that what the assessor perceives to be in the person's best interests should not influence the capacity assessment (because the person has the right to make an unwise decision and because capacity assessment and analysis of best interests are separate processes). There was also often a focus on what the person's wishes were rather than first establishing whether they had capacity, 'Although a person's wishes and preferences are very important, they do not play an express part when assessing capacity' (p29).

Multiple roles and competing demands

One participant highlighted the subjective nature of capacity assessments and said that at times assessing capacity conflicted with their role in assessing eligibility for services: ‘If you are the assessor for say a care plan or the assessor for someone whether they need residential or home-based care and you’re going to someone and saying “Actually, I think in my assessment your needs should be best met within a residential setting” and they actually don’t want that, well then I think that puts you in a difficult position to be the person who carries out a capacity assessment and there is some conflict of interests there’ (participant 6, p30). The researchers point out that the assessor is not the decision-maker – they only take on that role if the person lacks capacity.

The value of the Mental Capacity Act

Most participants said that disagreements and disputes from family members added to the difficulties in assessing capacity – and they said that the Mental Capacity Act helped to counteract these challenges: ‘I went to see the person, I went to see this … the family were very insistent that, you know, their mother required a nursing home and she wasn’t able to stay at home any more – and to sort of explain to the family that, you know, we can’t just go arranging placements for people and capacity comes into it. You know, so then, you know, you’ve got some legal sort of back up really haven’t you? To a process to follow which the family, you know, you need to make them understand that this is what we have to do’ (participant 4, p31). According to the authors, the problem is that participants seemed to value the Mental Capacity Act for the purposes of protecting people’s best interests more than protecting their right to make their own decision.

Implications for practice

The study found that the interplay with other assessments (such as eligibility) affected how decision-making capacity assessments are made, whereas they should be clearly distinguished. The researchers suggest that a key message for this local authority is that the forms for recording decision-making capacity assessments and best interests decisions should be separate (currently they’re on the same form).

Additional training and support

Participants were aware of the responsibility of assessing decision-making capacity and they were mindful of carrying out thorough assessments, often involving other professionals. They also valued being able to observe the practice of other practitioners. In this sense the authors suggest that the findings support the concept of integrating training within the workplace and also of giving practitioners the opportunity to discuss the difficulties they face through reflection, feedback and mutual support.

6. Roy A, Sarus J, Roy A et al. (2011) Improving recording of capacity to consent and explanation of medication side effects in a psychiatric service for people with learning disability: audit findings. Journal of Intellectual Disabilities 15: 85–92

Methodology: Audit

Data: Experiences

Country: UK – England

Outline

This audit from the UK aimed to “examine the practice of psychiatrists in a large learning disability service in recording capacity to consent to treatment and side effect discussion, and the impact of measures aimed at improving this’ (p85). The study had good relevance to the review question (++) but the methodological quality was rated as low (-). The authors analysed the case notes of consultant psychiatrists working as part of a psychiatric service providing support to adults with intellectual disabilities. No details on the individuals to whom the case notes relate or the practitioners who had created them are reported. The authors measured progress against 3 standards and at each cycle (data collected at 3 points) of the audit the authors collected 26 sets of case notes from 1 of 6 teams. It is not clear whether any of these notes related to the same individual or how many practitioners were involved with each case.

Findings

The authors report that the ‘baseline’ stage of the audit (conducted in 2007) prompted the local audit committee to make 3 recommendations aimed at improving recording practice. These were implemented over the following 12 months, at which point the survey was repeated.

The committee recommended that: notes were more abbreviated; that appointments were longer in order to ensure that more accurate notes could be taken in order to better reflect the consultation; that a computer-based information system was used.

Standard 1 – Use of rubber stamp (third cycle of audit – 2009, target = use of rubber stamp in 90% of outpatient encounters).

In 2009, the rubber stamp was used in only 94 sets of case notes in total (60%). Compliance ranged between 4% and 100% for individual teams.

Note: the rubber stamp is stamped onto case notes. The stamp is a visual checklist to record (yes/no) whether a capacity assessment has taken place; whether informed consent had been sought; whether a best interests decision had been taken; and whether side effects of medication had been explained.

Standard 2 – Confirmed discussion about capacity to consent to treatment/assessment of capacity (cycles 1, 2, and 3 of audit (2007–9), target = discussion recorded in more than 90% of outpatient encounters).

2007 – in 2007, discussions about capacity to consent to treatment were confirmed in only 46 sets of case notes in total (30%). Compliance ranged between 12% and 46% for individual teams.

2008 – in 2008, discussions about capacity to consent to treatment were confirmed in only 51 sets of case notes in total (33%). Compliance ranged between 30% and 39% for individual teams.

2009 – in 2009, discussions about capacity to consent to treatment were confirmed in only 81 sets of case notes in total (51%). Compliance ranged between 19% and 96% for individual teams.

Percentage increases between 2008 and 2009 – between 2008 and 2009, there was a total percentage increase of 59% in confirmed discussions about capacity to consent to treatment. Change ranged between –40% and 150% for individual teams.

Change in rates of recording between 2007 and 2009 – overall, the rate of recording improved from a total of 30% in 2007 to a total of 51% in 2009 (p = 0.000006). This result was significant.

Standard 3 – Confirmed discussion about adverse effects of medication (cycles 1, 2, and 3 of audit (2007–2009), target = discussion recorded in more than 90% of outpatient encounters).

2007 – in 2007, discussions about adverse effects of medication were confirmed in 118 sets of case notes in total (76%). Compliance ranged between 69% and 88% for individual teams.

2008 – in 2008, discussions about adverse effects of medication were confirmed in 105 sets of case notes in total (67%). Compliance ranged between 62% and 77% for individual teams.

2009 – in 2009, discussions about adverse effects of medication were confirmed in 110 sets of case notes in total (71%). Compliance ranged between 23% and 88% for individual teams.

Percentage increases between 2008 and 2009 – between 2008 and 2009, there was a total percentage increase of 5% in confirmed discussions about adverse effects of medication. Change ranged between –65% and 44% for individual teams.

Impact of use of rubber stamp on adherence to standards

The authors hypothesised that use of the rubber stamp would lead to greater adherence to standards 2 and 3. Using data for 2009 only, analysis showed that capacity was more likely to be recorded in cases in which the rubber stamp was used (odds ratio 13.5). This result was significant ($p < 0.0001$).

7. Shah A, Banner N, Newbigging K et al. (2009) The early experience of consultant psychiatrists in application of the Mental Capacity Act: issues for black and minority individuals. Ethnicities and Inequalities in Health and Social Care 2: 4–10

Methodology: Quantitative (survey)

Data: Experiences

Country: UK – England and Wales

Outline

This survey from the UK aimed to examine the experiences of consultant psychiatrists with regards to the early implementation of the Mental Capacity Act. The paper reports the results of 2 separate but similar surveys and the findings reported in this paper focus specifically on equalities issues. The study had good relevance to the review question (++) but the methodological quality was rated as low (-). The authors used the Royal College of Psychiatrists' database to identify relevant practitioners. The first survey was sent to 955 consultant psychiatrists working in the fields of general psychiatry, as well as child and adolescent psychiatry, forensic psychiatry, learning disability psychiatry and liaison psychiatry. The second survey was sent to 186 consultants working in old age psychiatry. No further details in relation to the characteristics of respondents are provided.

Findings

The response rate was low – for study 1, only 13% of potential participants responded. For study 2, only 29% responded.

Was consideration given to culture and ethnicity in the assessment of decision-making capacity (consultant responses, study 1 – 'other' specialties)?

Yes – n = 69 (87%).

No – n = 9 (11%).

Did not know – n = 1 (1%).

Total number of respondents – n = 79 (100%).

Was consideration given to culture and ethnicity in the assessment of decision-making capacity (consultant responses, study 2 – old age psychiatry)?

Yes – n = 41 (83%).

No – n = 6 (13%).

Did not know – n = 1 (2%).

Total number of respondents – n = 48 (100%).

Was consideration given to religion in the assessment of decision-making capacity (consultant responses, study 1 – ‘other’ specialties)?

Yes – n = 63 (80%).

No – n = 16 (20%).

Did not know – n = 0 (0%).

Total number of respondents – n = 79 (100%).

Was consideration given to religion in the assessment of decision-making capacity (consultant responses, study 2 – old age psychiatry)?

Yes – n = 38 (79%).

No – n = 9 (19%).

Did not know – n = 1 (2%).

Total number of respondents – n = 48 (100%).

Use of interpreters with patients who lacked fluency in English or where English was not their first language.

‘Nil’ – study 1 n = 28 (40%); study 2 n = 9 (24%).

‘Some’ – study 1 n = 9 (13%); study 2 n = 8 (22%).

‘Half’ – study 1 n = 0 (0%); study 2 n = 0 (0%).

‘Most’ – study 1 n = 4 (6%); study 2 n = 2 (5%).

‘All’ – study 1 n = 17 (24%); study 2 n = 15 (41%).

‘Did not know’ – study 1 n = 12 (17%); study 2 n = 3 (8%).

Total number of respondents – study 1 n = 31 (100%); study 2 n = 70 (100%).

Types of interpreter used.

Professional – study 1 n = 41 (79%); study 2 n = 26 (81%).

Clinical staff – study 1 n = 3 (6%); study 2 n = 1 (3%).

Non-clinical staff – study 1 n = 3 (6%); study 2 n = 3 (9%).

Relatives or friends – study 1 n = 2 (4%); study 2 n = 1 (3%).

Did not know – study 1 n = 3 (6%); study 2 n = 0 (0%).

Total number of respondents – study 1 n = 52 (100%); study 2 n = 31 (100%).

Note: the authors also report on the proportion of patients assessed for decision-making capacity belonging to black and minority ethnic groups, however this has not been reported here in the narrative summary as these data are not considered to be relevant to review question 3.

8. Shah A, Banner, N, Heginbotham C et al. (2010) The early experience of old age psychiatrists in the application of the Mental Capacity Act 2005: a pilot study. International Psychogeriatrics 22: 147 – 157

Method: Quantitative (survey)

Data: Views and experiences

Country: UK – England and Wales

Outline

This is a pilot study conducted in England and Wales in 2008, 6 months after the Mental Capacity Act was fully implemented. It was judged to have good relevance to the review question (++). The methodology, judged to be of moderate quality (+), involved the distribution of a questionnaire to consultants in old age psychiatry who were identified via the Royal College of Psychiatrists' database. The questionnaire was designed to examine several aspects of the implementation of the MCA. The aspects of relevance to this review question are: the availability and utility of local trust (hospital) policy on capacity to consent; the availability and utility of local trust policy on the implementation of the Mental Capacity Act; the availability and utility of local training in the use of the Mental Capacity Act; the documentation of the assessment of decision-making capacity (DMC); the issues for which DMC was routinely assessed; and the criteria used for the assessment of DMC.

Questionnaires were sent to 196 consultants and 52 useable responses were returned, giving a response rate of 27%. Descriptive answers to the open ended questions were coded using thematic analysis and descriptive statistics were used to analyse the categorical responses to the other questionnaire items.

Findings

Note that only findings relating to the assessment of decision-making capacity have been extracted and reported here.

Local training and policy

Over 75% of consultants in old age psychiatry said there was a local trust policy on capacity to consent and this policy was used.

Reported proportions of patients who have a routine assessment of DMC (n = number of consultant responses).

Nil, 1 (2%) Some, 9 (17%) Half, 9 (17%) Most, 13 (25%) All, 10 (19%) DK, 7 (14%)

Reported proportions of patients who have the assessment of capacity to consent documented (n = number of consultant responses).

Nil, 0 (0%) Some, 16 (33%) Half, 9 (19%) Most, 8 (17%) All, 6 (13%) DK, 9 (19%)

Issues for which DMC was assessed

Personal care: Routinely assessed, 19 (43%), Not routinely, 23 (57%), DK, 2 (5%)

Healthcare: Routinely assessed, 39 (80%), Not routinely, 8 (16%), DK, 2 (4%)

Social care: Routinely assessed, 33 (70%), Not routinely, 12 (26%), DK, 2 (4%)

Financial welfare: Routinely assessed, 42 (86%), Not routinely, 5 (10%), DK, 2 (4%)

Also, DMC was assessed separately for each issue and each treatment decision by 67% consultants but 27% said this wasn't the case. Sixty per cent said that for at least half of patients being assessed for DMC, families and other professionals were consulted.

Participants were asked, 'What criteria do you use in assessing capacity?' Descriptive answers were coded into 10 categories:

Understanding information (n = 47; 98%)

Retaining information (n = 47; 98%)

Weighing up information in the balance (n = 47; 98%)

Communicating the decision (n = 45; 96%)

Patient not subject to undue pressure in the assessment (n = 3; 7%)

Assessment of DMC being time-specific (n = 5; 12%)

Assessment of DMC being issue-specific (n = 7; 18%)

Presence of mental impairment (n = 12; 25%)

Dependent upon risk assessment (n = 3; 6%)

The subject may need help in decision-making (n = 3; 6%)

Who conducts DMC assessments?

Over 60% of the consultants reported that more than half of the assessments of DMC were conducted by consultants, but over two-thirds reported that fewer than half ('some'and 'nil') of the assessments of DMC were conducted by junior doctors (71%), nurses (67%), psychologists (75%), social workers (72%), occupational therapists (71%) and others (67%).

Training in the application of the Mental Capacity Act

Less than 50% said it was mandatory which could explain why only 60% said 'half or more' of the staff had received Mental Capacity Act training (p152).

9. Walji I, Fletcher I, Weatherhead S (2014) Clinical psychologists' implementation of the Mental Capacity Act. Social Care and Neurodisability 5: 111–30

Method: Qualitative

Data: Views and experiences

Country: UK

Outline

This is a good quality (++) qualitative study, which explored the experiences of clinical psychologists involved in implementing the Mental Capacity Act. As such, it also had good (++) relevance to the review question. The study was conducted in the North West of England and involved interviews with 7 psychologists who all had experience of conducting assessments of mental capacity as well as participating in best interests meetings and involvement in Deprivation of Liberty Safeguards (DoLS) proceedings. Transcripts of the interviews were subject to thematic analysis and, as a result, 6 themes were identified.

Findings

Note that in line with the review question only the findings relating to participants' experiences of assessing decision-making capacity have been extracted and reported here.

Competence and confidence

Participants had attended training about the MCA but it was largely thought to be too basic. In terms of guidance, they relied on the Code of Practice and the 'easy read guide' (Mental Capacity Implementation Programme 2007). Other guidance was not thought to be very accessible. Training was felt to be too general, not relating to their client groups (for example, based on cases of people with learning disability when their own client group might be people with an acquired brain injury) and also not addressing the complexities of practice. Most knowledge was therefore acquired through their own clinical practice: 'I think it's kind of doing those assessments that focuses you, your attention, and means that you do the reading round and try and, you know, acquire the knowledge that you need. So it was probably through, you know, specific referrals for capacity assessments that kind of led me to getting most, you know, the best knowledge about it' (Hugo, line 69, p118).

This process and confidence development was often facilitated through joint working with colleagues from other disciplines. When learning was shared, knowledge and skills were retained. Availability of appropriate supervision as well as support from peers was really important especially in difficult cases.

Understanding and uncertainty

Psychologists generally felt they had a good understanding of the MCA although there was confusion about the interface between the MCA and Mental Health Act, for example not understanding the difference between them.

Colleagues, collaboration, conflicts and challenges

Joint working was highly valued and participants felt that the MCA facilitated greater collaboration between disciplines. Doing a joint assessment was seen as really positive for developing competence and shared understandings. Incorporating different perspectives was considered best practice. In some teams it wasn't clear whose responsibility it was to take the lead on specific issues such as capacity assessment. In others, responsibility was shared: 'I think the team has developed a really healthy attitude to capacity in that there's no single person who can or can't assess capacity. The people who should be involved are those who perhaps are most relevant to the decision ... there's a real sense of it's a team decision, and that more than 1 opinion is valuable in thinking about capacity. But equally, it doesn't have to be everyone. But anyone can do it' (Juliet, line 161, p121).

Some participants described conflicts arising as a result of different interpretations of the MCA between different professionals – or rather, people in different teams. For example, 'the GP said ... I can't understand why you keep assessing his capacity, he hasn't got capacity ... I was really surprised because I thought a GP would've known time-specific, decision-specific, and he wasn't aware of thatt' (James, line 151, p121).

Working within the law: processes and penalties

Participants emphasised the importance of working with the correct processes and within the law. They tried to keep abreast of ongoing case law to inform their work. Some had clearly adopted defensive practice, ‘You should be able to defend every single piece of work that you do, you should be able to defend it. And I think kind of engaging in MCA assessments, which I think need to be completely defensible ...’ (James, line 317), p121).

As well as being aware of legal consequences of their practice, some participants were concerned about the consequences for the individual: ‘It is that kind of difficult balance within the therapeutic relationship ... you’re asked to provide a capacity assessment and the person doesn’t have capacity and that means that their money’s taken away from them, their children are taken away from them ... you can think of drastic consequences’ (Kate, line 490, p122).

Other findings

Participants emphasised the importance of not being too quick to judge capacity: ‘I’ve been involved with people that the local authority have been involved with ... they look at the kind of three stage test and say, and just make very quick decisions, you know, about communication, about retention, about weighing up, about all those elements ... seemed quite happy just to very quickly and crudely record that somebody doesn’t meet those criteria’ (James, line 100, p123).

They felt that, in contrast, as psychologists they were well placed to treat people in a person-centred way and to conduct capacity assessments in line with the MCA,: ‘I think we should have a clear role which we defend, given our skills in complex assessment, you know, holistic, complex, eclectic assessment’ (Kate, line 649, p122).

Participants discussed the motivations of other professionals and said that on the one hand capacity was sometimes assumed in order to avoid implementing the Mental Capacity Act and on the other hand – for instance in learning disability and older people’s services – a lack of capacity was assumed so that the professional could make a ‘better’ decision for the individual.

10. Williams V, Boyle G, Jepson M et al. (2014) Best interests decisions: professional practices in health and social care. Health and Social Care in the Community 22: 78–86

Methodology: Qualitative

Data: Practitioner views and experiences

Country: UK – England

Outline

This qualitative study from the UK aimed to explore professional practice in relation to best interests decision-making. The study has been included for review question 3 as it also provides information on practice in relation to assessment of mental capacity. The study had good relevance to the review question (++) and the methodological quality was rated as moderate (+).

The sample was comprised of 112 practitioners and relatives or friends of service users, however it is not clear how the latter were involved in the research as the study only provides information in relation to professional practice. Limited details are provided with regards to participants or sampling criteria, however, the roles of the professionals involved are described as: allied health professional, ambulance staff, health clinician, independent mental capacity advocate, legal practitioner, mental health practitioner, psychologist, nurse, residential home staff, social care practitioners, staff in long-stay hospitals or care, and ‘other’.

Findings

Risk

The authors report that practitioner concerns regarding capacity usually arose as a result of an event or change in circumstance (for example, hospitalisation or rapid decline in health), through which it became clear that the service user was ‘at risk’. They go on to suggest that when risk management strategies were no longer thought to be effective, practitioners began to question the capacity of service users and that the concept of risk was sometimes understood to be interchangeable with capacity.

Lack of insight vs lack of capacity

The authors report that practitioners sometimes appeared to understand ‘lack of insight’ to be a proxy for lack of capacity, and they suggest that practitioners were sometimes unaware that an unwise decision is not in itself evidence of a lack of capacity. They report that when asked why they had concluded that an individual lacked capacity, practitioners often cited ‘lack of insight’, which was usually conceptualised as an inability by the service user to understand their condition and the support they needed.

Willingness to assess capacity

Participants were reportedly reluctant to assess capacity, with a number stating that they preferred to consult with other practitioners or to ask a specialist to make the assessment. Interviewees also stated that they preferred to ask someone who knew the service user more closely to conduct the assessment.

The authors report that ‘in general’, practitioners were concerned that capacity assessments were based on instinct, although some were reported to believe that the framework provided by the Mental Capacity Act made this less likely. Practitioners were also reportedly supportive of the decision-specific focus of the Mental Capacity Act.

Overlap with best interests processes

The authors note that the person in charge of the best interests process had assessed capacity in only a minority of cases under discussion. They also suggest that there was an overlap between best interests decisions and capacity assessments, as strategies used to involve a service user in a best interests decision (for example, regular informal meetings in which trust was developed and practitioners were able to explain information in a more useful way to the service user) could ‘feed back’ into capacity assessments ‘… as, if and when they were able to understand and express an opinion, they could then show that they did have capacity after all’.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies.

AMC1	There is a good amount of evidence about the use of specific tools for assessing capacity to make decisions. The quality of the evidence is mixed and the relevance of the data to the context of the Mental Capacity Act is questionable. The competence evaluation by MacCAT-T was found to differ from the evaluations of nurses ($p = 0.010$), physicians ($p = 0.0043$) and relatives ($p = 0.022$) and more than half the patients evaluated by MacCAT-T as incompetent were partially or fully competent (Aydin and Sehiralti 2014 +). The CACE tool was more accurate in determining capacity than the less accessible CMAD. Social workers using CACE also had significantly greater confidence in assessing capacity using CACE than using CMAD (d = 1.3021 (95% CI –0.538 to 2.0662)). Finally, people with aphasia were less frustrated using CACE than CMAD ($p = 0.02$) (Carling-Rowland et al. 2014 +). Feng et al. (2014 +) found out that the ACE questionnaire accurately identified those with capacity to participate in stroke trials, which is shown by the high sensitivity values when assessed by a neuropsychologist (93.8% (95% CI, 69.8–99.8) and a psychiatrist (100% (95% CI, 63.1–100). However, it demonstrated low specificity (53.8% (95%CI, 25.1–80.8) when assessed by a neuropsychologist and 42.9% (95%CI, 21.8–66.0) and when assessed by a psychiatrist. Therefore failing ACE does not adequately determine that a patient lacks decision-making capacity. A good quality UK study found that MMSE score was the only variable that significantly predicted capacity (odds ratio = 1.6, 95% CI = 1.3–2.0) and MMSE scores also correctly classified 83.8% of patients (Gregory et al. 2007 ++). An instrument for assessing capacity to make every day decisions, ACED, was found to be reliable (see Cronbach alpha values for internal consistency for understanding, appreciation, and reasoning) and valid (see association between ACED ability measure and the corresponding measures and the correlation with the MMSE scores) (Lai et al. 2008 +). A good quality US study concluded that MED-SAIL can accurately distinguish between people with and without capacity to make decisions for safe and independent living. An older adult with a MED-SAIL score less than 5 has a 79% probability of having no capacity (Mills et al. 2014 ++). A low quality US study by Moye et al. (2007 -) found that a structured interview for the assessment of capacity to consent to treatment had good inter-rater reliability ($p < 0.001$) and internal consistency (α=.96). There was also moderate agreement between the assessment tool and ratings of capacity given by primary care ($p < 0.01$) and experienced clinicians ($p < 0.05$). Finally, a moderate quality study conducted in Japan (Sugano et al. 2015 +) concluded that 3 cancer patients judged to lack decision-making capacity by physicians were also judged incompetent by the structured interview, SICIATRI-R. However the agreement was no greater than could have been expected to occur by chance. In spite of any positive results synthesised in evidence statement 1, it is important to note the narrow scope of these clinical tools, which do not compare favourably with the approach to decision-making capacity described in the MCA Code of Practice. Careful consideration should therefore be given to lessons that can be drawn from the findings.
AMC2	There is a moderate amount of evidence that certain practitioners are being relied upon to conduct capacity assessments. The quality of the evidence is moderate. Brown et al. (2013 -) found that GPs were conducting capacity assessments among the majority (70%) of psychiatric inpatients. In a UK study, dementia nurses reported that practitioners still defer to a ‘professional hierarchy’ to conduct capacity assessments, despite guidance in the Code of Practice about who should most appropriately complete assessments (Manthorpe et al. 2014 +). In a survey of old age psychiatrists by Shah et al. (2010, +) 60% of consultants reported that more than half of the capacity assessments were conducted by consultants. Williams et al. (2014 +) found that

	practitioners were reluctant to assess decision-making capacity and would instead defer to a specialist to make the assessment.
AMC3	There is some evidence that the extent of collaboration among professional groups in relation to capacity assessment is variable. The quality of the evidence is mixed. A recent study by Murrell and McCalla (2016 +) reported that some social care practitioners always involve other professionals, especially mental health specialists, not least because of the huge responsibility involved in capacity assessment. Similarly, clinical psychologists said that their confidence and abilities in the area of capacity assessment developed through joint working with colleagues from other disciplines. They valued opportunities for sharing knowledge and lessons and considered it best practice to incorporate different perspectives when conducting capacity assessments (Walji et al. 2014 ++). In contrast, only 1 social worker in the McDonald study (-) said they considered asking for other input (in this case a speech therapist).
AMC4	There is a small amount of evidence that some professional groups believe others lack knowledge about the application of the MCA. The quality of the evidence is moderate. In a low quality study by McDonald et al. (2008 -) social workers reported that GPs seem to lack understanding of capacity assessment within the framework of the MCA. In addition, clinical psychologists said that conflicts arose because different professionals seem to have a different interpretation of the MCA. For example, 1 participant described a GP as lacking understanding about the requirement for a functional approach to capacity assessment (Walji et al. 2014 ++).
AMC5	There is a small amount of evidence that practitioners find it hard to reconcile their role in assessing decision-making capacity with other therapeutic roles. The quality of the evidence is mixed. One of the social care practitioners in the Murrell study (+) described feeling conflicted about their role in assessing capacity and their role in deciding how the person's needs would be best met (in fact they should only take on the latter role if it is established that the person lacks capacity). Clinical psychologists said they found it difficult to assess decision-making capacity when they were aware of the potentially devastating effects on an individual if they were judged to lack capacity (Walji et al. 2014 ++).
AMC6	There is a small amount of evidence that there are gaps in training about the conduct of decision-making capacity assessments within the framework of the MCA. The quality of the evidence is mixed. In a recent UK study, theoretical knowledge of the MCA seemed fairly limited among social care practitioners although all of them had received county council training. Findings indicated that practitioners would benefit from workplace training and the opportunity to observe other professionals (Murrell and McCalla 2016 +). Clinical psychologists had attended training about the MCA but felt that it was too basic and not sufficiently specific to their own client groups (for example, focusing on people with learning disabilities rather than people with acquired brain injury) (Walji et al. 2014 ++).
AMC7	There is a good amount of evidence that perceived risk is sometimes conflated with capacity in the context of mental capacity assessments. The quality of the evidence is mixed. Emmett et al. (2013 -) found that practitioners used the likelihood of a risky decision by dementia patients as an indication that they lack capacity. Capacity considerations also appeared to be subsumed into wider discussions around risk and harm. Similarly, dementia nurses felt that some practitioners were risk averse, particularly if a person's capacity to refuse a service was being queried (Manthorpe et al. 2014 +). McDonald et al. (2008 -) reported that social workers seemed to be influenced by an outcomes-focused

	approach to capacity that centred on risk. They report that people with dementia were often judged to lack capacity if they did not appear to agree with the social worker. Clinical psychologists said that, particularly among people living with dementia or learning disabilities, other professionals seemed to assume a lack of capacity so that the professional could make a 'better' decision for the individual (Walji et al. 2014 ++). Finally, Williams et al. (2014 +) found that health and social care practitioners start to question the capacity of service users when risk management strategies begin to fail, and that the concept of risk was sometimes being used interchangeably with capacity.
AMC8	There is some evidence of practitioners reportedly using incorrect or incomplete information to assess capacity to make decisions. The quality of the evidence is mainly moderate. Researchers found variation in the relevance of the information being used by practitioners to make assessments of capacity – for example, citing a service user's inability to remember previous conversations (Emmett et al. 2013 -). A social care practitioner in the 2016 study by Murrell and McCalla (+) said that they take account of whether the person has insight into their condition and whether they are orientated, which the authors observe is not enough to assess decision-making capacity. Williams et al. (2014 +) reported that practitioners were using inappropriate information to inform capacity assessments, for example whether they anticipated the person would make an unwise decision or whether they lacked insight into their condition.
AMC9	There is a small amount of evidence that practitioners do not always assess capacity to make specific decisions at specific points in time. The quality of the evidence is low. Emmett et al. (2013 -) reported that a range of practitioners took an outcomes approach to assessment rather than a functional approach, especially in people with a dementia diagnosis. There was a reliance on informal assessments, which the authors suggest indicates a failure to understand the requirements of the MCA relating to functional approaches to assessment. McDonald et al. (-) found that social workers tended to consider a multiple number of assessments conducted over a long period in an 'overall' assessment, rather than focus on each decision separately and at the specific time point.
AMC10	There is a small amount of evidence that the assessment of decision-making capacity is sometimes being merged with best interests discussions, although this is not always perceived to be negative. The quality of the evidence is moderate. Murrell and McCalla (2016 +) reported that social care practitioners found it difficult to conduct an objective assessment without speculating about the likely outcome and potentially unwise decision if they judge the person to have capacity to decide. On the other hand, Williams et al. (2014, +) identified an overlap between best interests decision-making and capacity assessment, because strategies used to involve a person in best interests decisions (e.g. regular informal meetings) could result in finding that with this level of input, the person has capacity after all.
AMC11	There is a moderate amount of evidence that decision-making capacity assessments are poorly recorded. The quality of the evidence is low. An audit conducted in 1 NHS foundation trust showed that documented capacity assessments took place for just 9.8% of admissions – and a specific form was used to document capacity assessments in only 0.5% of psychiatric admissions (Brown et al. 2013 -). Social workers in the McDonald study (2008 -) said that although they knew the requirements for recording assessments, they were unsure about the most effective and appropriate way of doing so. Despite a specific focus on improving recording practice among psychiatrists in a learning disability setting, discussions about capacity to consent to treatment were

	confirmed in 30% of cases and this rose to 51% 3 years later, falling short of the 90% target (Roy et al. 2011 -). In the survey by Shah et al. (2010, +) just over a third of old age psychiatrists said that they documented capacity to consent assessments in less than half of patients.
AMC12	There is a small amount of evidence that in the context of capacity assessments, people are not given adequate or clearly presented information. The quality of the evidence is low. Emmett et al. (2013 -) reported that dementia patients were not always given clearly presented information, particularly during discussions about admission to residential care. Similarly, McDonald (2008 -) reported that social workers did not always provide enough information to service users when assessing capacity.
AMC13	There is a small amount of evidence about issues relating to the assessment of capacity among black and minority ethnic individuals. A survey by Shah et al. (++/+) found that over half of old age psychiatrists said interpreters were used in less than half of assessments when people lacked fluency in English.
AMC14	No evidence was located about the effectiveness and cost-effectiveness of the assessment of decision-making capacity as described in the Mental Capacity Act Code of Practice.
AMC15	No evidence was located about the views and experiences of people who may lack capacity, their families or carers in relation to the assessment of decision-making capacity.

Included studies for review questions 3a and 3b

Aydin Er R, Sehiralti M (2014) Comparing assessments of the decision-making competencies of psychiatric inpatients as provided by physicians, nurses, relatives and an assessment tool. Journal of Medical Ethics 40: 453–7

Carling-Rowland A, Black S, McDonald L et al. (2014) Increasing access to fair capacity evaluation for discharge decision-making for people with aphasia: a randomised controlled trial. Aphasiology 28: 750–65

Feng BS, Person C, Phillips-Sabolet J et al. (2014) Comparison between a standardized questionnaire and expert clinicians for capacity assessment in stroke clinical trials. Stroke 45: e229–32

Gregory R, Roked F, Jones L et al. (2007) Is the degree of cognitive impairment in patients with Alzheimer’s disease related to their capacity to appoint an enduring power of attorney? Age and Ageing 36: 527–31

Lai JM, Gill TM, Cooney LM et al. (2008) Everyday decision-making ability in older persons with cognitive impairment. American Journal of Geriatric Psychiatry 16: 693–6

Mills W, Regev T, Kunik M et al. (2014) Making and Executing Decisions for Safe and Independent Living (MED-SAIL): development and validation of a brief screening tool. American Journal of Geriatric Psychiatry 22: 285–93

Moye J, Karel MJ, Edelstein B et al. (2007) Assessment of capacity to consent to treatment. Clinical Gerontologist 31: 37–66

Sugano K, Okuyama T, Lida S et al. (2015) Medical decision-making incapacity among newly diagnosed older patients with haematological malignancy receiving first line chemotherapy: a cross-sectional study of patients and physicians. PLoS ONE 10: e0136163

Brown PF, Tulloch AD, Mackenzie C et al. (2013) Assessments of mental capacity in psychiatric inpatients: a retrospective cohort study. BMC Psychiatry 13: 115

Emmett C, Poole, Bond J 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

Manthorpe J, Samsi K, Rapaport J (2014) Dementia nurses’ experience of the Mental Capacity Act 2005: a follow-up study. Dementia 13: 131–43

McDonald A, Dawson C, Heath B (2008) The impact of the Mental Capacity Act 2005 on social workers’ decision making: a report for SCIE. Norwich: University of East Anglia

Murrell A, McCalla L (2016) Assessing decision-making capacity: the interpretation and implementation of the Mental Capacity Act 2005 amongst social care professionals. Practice 28: 21–36

Roy A, Sarus J, Roy A et al. (2011) Improving recording of capacity to consent and explanation of medication side effects in a psychiatric service for people with learning disability: audit findings. Journal of Intellectual Disabilities 15: 85–92

Shah A, Banner N, Newbigging K et al. (2009) The early experience of consultant psychiatrists in application of the Mental Capacity Act: issues for black and minority individuals. Ethnicities and Inequalities in Health and Social Care 2: 410

Shah A, Banner, N, Heginbotham C et al. (2010) The early experience of old age psychiatrists in the application of the Mental Capacity Act 2005: a pilot study. International Psychogeriatrics 22: 147–57

Walji I, Fletcher I, Weatherhead S (2014) Clinical psychologists’ implementation of the Mental Capacity Act. Social Care and Neurodisability 5: 111–30

Williams V, Boyle G, Jepson M et al. (2014) Best interests decisions: professional practices in health and social care. Health and Social Care in the Community 22: 78–86

3.5 Best interests decision-making for those who have been assessed as lacking the mental capacity to make a specific decision

Introduction to the review questions

Review question 4, comprised of parts ‘a’ and ‘b’, is reported in this subsection. Part ‘a’ sought data about the effectiveness and cost-effectiveness of interventions, tools and approaches for supporting best interests decision-making. Part ‘b’ was designed to locate the self-reported views and experiences of people who lack mental capacity, their families and carers and others interested in their welfare on the acceptability of tools and approaches for best interests decision-making. This included views on what works and what does not work well, for example, whether people feel involved in decisions made in their best interests and whether carers are families are involved in the process. Question 4b also sought specific information about the contribution of safeguarding and risk management in best interests decision-making and about deprivation of liberty safeguards guidance and applications to the Court of Protection.

Review questions

4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making?

4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?

Summary of the review protocol

The protocol sought to identify studies that would:

- identify effective approaches to involve people as far as possible in decisions made in their best interests
- assess the effectiveness and cost-effectiveness of interventions, tools and approaches designed to support best interests decision-making
- explore the self-reported views of people who access services, their carers and practitioners about methods and tools for conducting and recording assessments of mental capacity when a decision needs to be made
- consider specifically whether people accessing services feel involved in decisions made on their behalf
- consider specifically whether practitioners feel that people – and carers – are involved adequately in best interests decision-making
- consider specifically the integration of safeguarding and risk management into interventions, tools and approaches to support best interests decision-making
- specifically consider approaches that provide independent advocacy for a person who is subject to best interests decision-making.

Population

All people aged 16 years who have been assessed as lacking capacity to make a particular decision. This group is diverse and according to the Mental Capacity Act Code of Practice may include people suffering from dementia, mental illness, learning disability, brain damage or other conditions that may cause confusion, drowsiness or a loss of consciousness.

In addition, the Equalities Impact Assessment sets out protected characteristics and other specific groups of the population which it is understood often face particular difficulties. The review process will both include and seek evidence of any considerations specific to these groups of people.

Intervention

Best interests decision-making by practitioners.

Setting

People's own homes, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts.

Outcomes

Person-focused outcomes (supported, where possible, to participate in decisions made in their best interests, afforded access to their human rights and dignity and helped to maintain independence and social inclusion).

Service outcomes (competence and confidence among practitioners to implement and uphold the principles of the Mental Capacity Act, including assessment, supporting decision-making and conducting best interests decision-making, transparency and quality of recording, efficient and effective use of resources). See 1.6 in the scope.

Study design

The study designs which were prioritised for the effectiveness and cost-effectiveness question included: systematic reviews of studies of interventions, tools and approaches for best interests decision-making; randomised controlled trials of interventions, tools and approaches related to best interests decision-making; economic evaluations; cohort studies, case control and before and after studies.

The study designs which were prioritised for the views and experiences questions included: systematic reviews of qualitative studies on best interests decision making;

qualitative studies of user and carer views about best interests decision-making; qualitative components of effectiveness and mixed methods studies, and observational and cross-sectional survey studies of user experience.

See Appendix A for full protocols.

How the literature was searched

A single search strategy for all the review questions was developed. The questions were translated into a framework of 8 concepts and combined as follows: a) decision and capacity and (supporting people or best interests or safeguarding) or b) decision and capacity and mental health and assessment or c) capacity and advance planning. These reflected the question areas of planning in advance, supporting decision-making, assessment of mental capacity and best interests decision-making. The search was restricted to material published since 2005. The searches were run between September and October 2016.

See Appendix A for full details of the search including the rationale for the date limit.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4, a software program developed for systematic review of large search outputs. Coding tools were applied and all papers were screened on title and abstract. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- language (must be in English)
- population (must be over 16 years of age who may lack mental capacity, accessing health or social care services, their families or carers)
- intervention (all aspects of assessment, supported decision-making, future planning, and best interests decision-making for adults who may lack mental capacity)
- setting (service user’s own home, family homes, extra care settings, supported housing, shared lives schemes, care homes, inpatient healthcare settings, inpatient mental healthcare settings, outpatient and day hospitals, hospices and palliative care settings, educational settings, prisons and other criminal justice settings and family courts)

- country (must be UK or other OECD)
- date (must not be published before 2005)
- type of evidence (must be research).

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular parts of the review question – or flagged as being relevant to 1 of the other review areas – and retrieved as full texts.

Full texts were again reviewed for relevance and research design. A list of studies excluded on full text can be found in Appendix A, organised by exclusion criteria.

If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and a random sample of 10%.

Overview of evidence

In our initial screen (on title and abstract) we found 22 studies which appeared relevant to review question 4. We retrieved and then reviewed full texts and included a total of 9 papers. No UK quantitative studies were found and for this question at all, and the non-UK studies that were available included best interests decision-making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and which is in line with the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population.

The 9 studies that were included all provided data about views and experiences, which ranged in quality. The studies, all from the UK, provided a good insight into professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends.

Narrative summary of the evidence

In this section, a narrative summary of each included study is provided, followed by a synthesis of the evidence, according to the key outcomes, themes or subgroups in the form of evidence statements. The approach to synthesising evidence was informed by the PICO within the review protocol.

Studies reporting views and experiences data of people who may lack mental capacity, their families and carers (n = 9)

1. Dunn MC, Clare ICH, Holland AJ (2010) Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. Journal of Intellectual Disability Research 54: 144–60

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

The authors of this qualitative study from the UK aimed to gain an understanding of the process of substitute decision-making in the day-to-day care of people with intellectual disabilities in residential settings. The study had moderate relevance to the review question (+) and the methodological quality was rated as low (-). The sample was comprised of 21 support workers of people with intellectual disabilities. The 3 homes at which these participants worked were selected because they operated on a non-statutory basis (including for profit services and charities). Residents of these homes were deemed to have high support needs and be unable to live independently. The authors note that at the time of the study none of the participants had received training in the Mental Capacity Act. No further details are provided in relation to participants or the people they cared for. The authors interviewed participants and made observations of practice in order to gather data on the substitute decision-making process.

Findings

Note: it should be noted that the authors do not clearly frame their findings in the specific context of the best interests principle of the Mental Capacity Act and they do not clearly indicate whether any of the people who were being supported had been determined to lack capacity with regards to these 'substitute decisions'. However, in their discussion of their findings they suggest that their data indicate that the substitute decisions that support workers were making were not preceded by concerns about the person's decision-making capacity and that these substitute decisions do '… not appear to be used in practice to solve the "non-autonomy" problem highlighted by the MCA, but rather as a way of addressing a very different kind of problem: how to support residents to lead a good life' (authors, p155).

The authors report that support workers' approaches to substitute decision-making were shaped by their hopes of providing 'a life like ours' to the people they supported and that they attempted to do so in two ways.

Enabling residents to have 'ordinary' life experiences

Support workers are reported to have provided a 'moral account' (authors, p150) of their role and the way in which they made substitute decisions, which they saw as mitigation against the repetitive nature of life in a residential home. By drawing on their own experiences and preferences they felt that they were able to enhance the lives of the people they supported.

Using care plans in the substitute decision process is reported to have been a concern for some participants, who felt that these could in some cases exacerbate the uniformity of residential care, despite the intention that plans should be person-centred.

Thinking about what they would want in a similar situation is described as a common method by which support workers made substitute decisions and the authors cite 1 interviewee who stated that they often needed to: '... stand back and think, "what would I like to do? Would I really want to do that again when I did it the same time last week, the same time the week before?" Cause that's what it's all about you know, asking them kind of questions, thinking about what might be best, if they're ever going to live a life like ours' (participant, p151).

New experiences for residents

Support workers also described their attempts to enable the person they supported to have new experiences. These were similarly shaped by the support workers' own beliefs and thoughts about a meaningful life. Making substitute decisions on this basis was again reportedly described as a ‘positive’ means of counteracting the ‘negative’ characteristics of institutional life.

In particular, spontaneous decisions, and those decisions which involved a degree of risk, were reportedly viewed positively by support workers as they provided an opportunity to challenge established routines. They cite a participant who they argue decided to take a spontaneous decision on something that they saw as an integral part of the day’s activities even though it was not allowed, ‘… regardless of the fact that there was no attempt to imagine how the resident himself would recognise this experience in the same way as the support worker did’ (authors, p152). The authors go on to report that similar ideas about risk and its centrality to everyday life were raised by a number of interviewees.

The authors also state that interviewees saw substitute decisions as an opportunity for them to enrich people’s lives and enable them to take part in ‘extraordinary’ experiences (usually an activity or a holiday). They argue that because these experiences were compatible with their own ideas about interesting activities they were valued by support workers and seen as the right decision despite ‘limited evidence’ that they were something that the service user themselves would have chosen to do.

2. Emmett C, Poole M, Bond J et al. (2014) A relative safeguard? The informal roles that families and carers play when patients with dementia are discharged from hospital into care in England and Wales. International Journal of Law, Policy and the Family 28: 302–20

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

The authors of this qualitative study aimed to explore the informal role of relatives of people with dementia in best interests decisions made regarding discharge from hospital and to determine whether they ‘… fulfil an effective safeguarding role when decisions are made to discharge older patients with dementia from hospital either back home or into long-term care' (p304). The study had good relevance to the review question (++) but the methodological quality was rated as low (-). Interviews, focus groups and observations of practice were used to gain an understanding of the role that relatives play. The sample was comprised of 29 people with dementia who had been admitted to an elderly or ortho-geriatric ward, their carers/relatives, and a range of health and social care practitioners such as nursing staff, physicians, psychiatrists and social workers. Note: the authors only report on the 16 individuals who had been determined to lack the capacity to make a decision in relation to place of discharge in this paper and the number of practitioners and relatives/carers included in the sample is unclear.

Findings

The informal roles that relatives of people with dementia take on during the discharge process

The authors report that relatives often took on roles as advocates, caretakers or information-gatherers, noting that they often facilitated communication between patients and practitioners, or advocated for relatives who were unable to convey their preferences as a result of their illness and/or confusion. The authors also highlight the role that relatives played in questioning practitioners and soliciting information. They suggest that this mirrors the 'inquisitorial' role which an independent mental capacity advocate can take in such circumstances. However, some relatives reportedly found it difficult to ask for more information or challenge professional opinions, which the authors contrast with the independent mental capacity advocate's statutory right to access health and social care records.

Potential barriers that can prevent relatives from effectively fulfilling a safeguarding role during the discharge process

The authors identify a number of barriers which hindered relatives' attempts to ask for more information or challenge professional opinion. The provision of information to relatives was seen as key and the authors report that relatives were sometimes unaware of the purpose of discharge planning meetings or in some cases had not been told that the meeting had any link to the discharge process whatsoever. The authors go on to note that a number of relatives felt that they had not been given enough information in advance to enable them to prepare for such meetings. Relatives reportedly felt they were not sufficiently informed to make a judgement about place of discharge or challenge practitioner views when they felt this was mistaken.

The authors report that relatives who were older or less assertive could also find it difficult to play a safeguarding role despite their belief that they should do so. They suggest that many were ‘ill-equipped’ to take on this role as a result of their deference to professionals and hospital processes, inability to access clinical information, or a tendency to cede to the views of more ‘coercive’ family members. Relatives also reportedly found that taking on a safeguarding role could be emotionally demanding.

Positive factors helping relatives to provide an effective safeguard during the discharge process

The authors suggest that social class and level of education can play a role in relatives’ ability to take on a safeguarding role. They cite the case of 1 patient who was able to be discharged to her own home (a preference which she had expressed despite her having been assessed as lacking capacity in this regard), noting her families understanding of hospital processes (her daughter worked in the same hospital), and their ‘… tenacity and persistent questioning of hospital professionals ...’ (authors, p314).

The authors also suggest that family dynamics can play a role and that when relatives believe that the person retains the capacity to make a decision they are more likely to advocate for them, even when they have been assessed as lacking capacity.

3. Harris D, Fineberg IC (2011) Multidisciplinary palliative care teams’ understanding of Mental Capacity Act 2005 ‘best interest’ determinations. International Journal of Palliative Nursing 17: 20–5

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This UK study explored multidisciplinary palliative care teams' implementation of the concept of 'best interests' as outlined in the Mental Capacity Act. The study was judged to have good relevance to the review area (++) and to be of moderate quality (+). Participants were 11 health and social care professionals who provide palliative care services to terminally ill patients.

Findings

Understanding of the Mental Capacity Act

Participants' understanding of the Mental Capacity Act varied, with some demonstrating clarity but almost half demonstrating a lack of clarity about the Act, the best interests principle, and the best interests checklist.

'The only things I would say I have picked up, I couldn't really tell you where from, is just that we should be making sure we go as far as we can in making sure we enable somebody to make their own choice before we look at other ways of getting things done. I couldn't really say I know much more than that' (participant, p22).

Perspectives on best interests

Participants clearly attempted to establish patients' past and present wishes as far as reasonably practicable given the time frame. Members of both teams placed high importance on providing assessments, care, and treatments in the patients' best interests, although not specifically in relation to the Mental Capacity Act definition of best interests.

'Best interests, very much you are looking to see what would be in their best interests. What do you do with patients who do not have capacity? It is very much a question of speaking to the family, speaking to the GP, speaking to whoever is involved in their care and what you can do for the best for them and that is not easy to decide always' (participant, p22).

Diagnosis and presumption of capacity

Patients with a diagnosis of Alzheimer's disease or other types of dementia were sometimes automatically considered to lack intellectual capacity.

'I think we manage it really well, it happens a lot, and that people do not have capacity especially when they have got end-stage dementia as well' (participant, p23).

Documented patient preferences

One experienced palliative care professional commented that most patients have not written down their preferences for the types of care or treatment that they may desire in the future.

'Well, my understanding is that you have to take into account – well, you have to ask the person in the first place what they think their best interests are. Beyond that obviously from what they have done in the past, how they have been. You can get that either from them or from their family, so it is really about finding out how they would have wanted you to act even when they have not written it down' (participant, p23).

'Well we haven't introduced this documentation yet because for the simple reason we need to do the training and communication skills training so that hasn't happened yet' (participant, p23).

Timing and consultation in decision-making

Specialist teams are making best interests decisions in the patient's home rather than in the multidisciplinary team context.

'You can't leave it a week to get round and sit down and make a decision, particularly in the community. But someone in their own home you have to decide there and then. You can't fiddle about and wait for the GP and the family and whoever else to get together. So often it is done very informally' (participant, p23).

Conversely, participants working in the community hospital described best interests decisions being made in the multidisciplinary team context.

‘This has to be a multidisciplinary decision involving family and carers and the team who are involved in the care. You have to work towards what is deemed to be in the best interests of the patient. There might be completely differing views from members of the team and it can be a difficult decision and if a decision is not reached then of course it will go to the court …’ (participant, p23).

4. Manthorpe J, Samsi K, Rapaport J (2012) When the profession becomes personal: dementia care practitioners as family caregivers. International Psychogeriatrics 24: 902–10

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This UK-based study explored dementia care professionals with family experiences of dementia and their reflections on decision-making frameworks. The study was judged to have good relevance to the review area (+) and to be of good quality (++). Interviews were conducted with 123 dementia care practitioners regarding their role as a family caregiver.

Findings

Informing the professional role

Participants reported feeling greater empathy with carers, in which the potential to share some of their own experiences of distress or feelings of helplessness, at times bewilderment and uncertainty, emerged as illustrations of this.

Two nurses (specialist nurses 1 and 2) and a social worker explained that they would cross professional boundaries to share some of their personal experiences with carers if this helped to explain a specific Mental Capacity Act provision (such as the benefits of making financial arrangements in advance of loss of decision-making capacity).

Participants confessed bewilderment when arranging care for their relative with dementia and expressed that lay people would be even more likely to find the system baffling.

‘I don’t know what it’s like for carers who don’t know the system . . . it was a nightmare’ (specialist nurse 4) (p905).

‘The MCA has affected both myself and my partner … it’s been an enormous help’ (safeguarding adults coordinator 1) (p905).

Insight into services

Participants considered themselves more focused, with better understanding of services, and to be more confident. Reflecting on the provisions of the Mental Capacity Act, they felt that they would have been more assertive about their relatives’ care: ‘Both my parents had advanced dementia, my mother was in residential care, and looking back, if I knew what I know now and there had been an Act in place, then I would certainly have dealt with some issues that she encountered in residential care differently, very much so’ (safeguarding adults coordinator 2) (p905).

Some professionals had chosen to work in dementia care because of their personal experiences, and they were motivated to try to create changes for other people with dementia: ‘I know I can’t change the whole thing but I’d like to make someone have a better quality of life than they had in a home. [Grandparent] was strapped to a chair … covered in mess … sat in a room told to sit there and stay there’ (care home manager 5) (p906).

Professional influences on caring

Several participants viewed the Mental Capacity Act as something they would have wanted to be in place when they were carers negotiating or communicating with other professionals involved in their relative’s care: ‘It [MCA] certainly informed my job and my job informed how I coped with it, it’s circular really. I’m sure because I was a social worker I was in a good position to argue to get him [relative] some personal care that took into account his background and personal choices to stay at home for as long as possible until he became a bit muddled and he went into a home' (safeguarding adult coordinator 5, p906).

Participants across all professions were noticing possible early signs of dementia in some close relatives, the occasional 'out of character' forgetfulness and repetitive speech patterns being seen as worrying.

Bridging the personal and professional worlds

Some participants reported often being consulted by anxious family members, being used as a bridge across the family and outside professionals and respected for their knowledge about dementia and how best to respond.

Various examples were provided of the Mental Capacity Act's actual or potential influence to assertively persuade relatives and friends to respect the seemingly 'unwise' wishes of a person near the end of life and to challenge medical opinion on the same grounds: 'The doctors go on at him to stop drinking [alcohol] but he said, I'm 77 years old, I've drunk all my life. If it's going to kill me it's going to kill me … He smokes about 10 cigarettes a day … at the end of the day he's 77. Why should he stop because they tell him to stop?' (care home manager 5) (p906).

Planning

There was no difference between professions with respect to making arrangements or plans in anticipation of their own loss of decision-making capacity, such as a lasting power of attorney, an advance decision, or a statement of wishes. Few had actually done this, but most were thinking of doing so, either for older relatives and/or themselves as a result of their combined professional and personal experiences and, for some, their Mental Capacity Act training: 'Yes, I'm thinking I will probably move next year … And my mother has no intention whatsoever of giving any of us lasting power of attorney … it's impossible … it's going nowhere' (specialist nurse 10).

Several care home staff mentioned that a prime objective of their own plan was (or would be) to avoid being a burden on their children, if and when dementia or something similar struck; these concerns did not feature elsewhere: 'Yes, as a matter of fact I said to my kids I am going to do my own care plan . . .and then one day if ever they need it they can have it' (care home manager 2) (p907).

Several participants had relatives who had drawn up lasting power of attorney. However, family resistance due to emotional and sometimes cultural issues had hampered this, for example, registration of the lasting power of attorney (local Alzheimer's Society 3).

No apparent effect of the Mental Capacity Act

There were a small number of individual examples where, in spite of personal experiences, participants claimed that the Mental Capacity Act had not impacted upon their professional role or decision-making, or giving advice on, planning, or stating personal wishes if the legislation had been in place at that time.

5. Ramasubramanian L, Ranasinghe N, Ellison J (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

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This audit from the UK was conducted to ' … explore the quality, thoroughness and practice of how mental capacity and issues around consent, best interests and final care plan decisions were assessed and documented in a specialist learning disabilities unit and to develop and evaluate a structured assessment framework to act as a guideline to help adhere to the requirements of the Mental Capacity Act' (authors, p316). The study had good relevance to the review question (++) but the methodological quality was rated as low (-).

The authors carried out a review of patient notes (including the minutes of best interests group meetings) for 20 people admitted to a specialist inpatient unit for people with learning disabilities. The patients are described as having mild, moderate or severe learning disabilities (note: the authors do not report how level of disability was determined). Many patients also had an additional ICD-10 diagnosis. No details are provided in relation to the practitioners involved in the case of each patient.

The audit was conducted in two stages – prior to the introduction of a checklist (6 cases) and after the introduction of the checklist (14 cases) to enable comparison. The checklist is described as a ' … 20-point structured assessment framework … developed to act as a guideline for assessment and documentation of capacity, consent and best interests …' (authors, p317).

Findings

Note: all participants had been assessed as lacking capacity to make a specific decision. For each standard measured, the authors targeted a 100% adherence rate.

The least restrictive option was explored in 16% (1/6) of those cases examined before introduction of the checklist and 71% (10/14) of those cases examined after its introduction. This increase was not significant ($p = 0.180$).

The possibility that the person may have capacity to make the decision at a different time was considered in 33% (2/6) of those cases examined before introduction of the checklist and 100% (14/14) of those cases examined after its introduction. This increase was significant ($p < 0.001$).

Practitioners explored whether the decision could be delayed until a point at which the person was likely to have capacity in 33% (2/6) of those cases examined before introduction of the checklist and 100% (14/14) of those cases examined after its introduction. This increase was significant ($p < 0.001$).

Practitioners checked whether the person had an advance statement, lasting power of attorney, court-appointed deputy, etc. in 0% (0/6) examined before introduction of the checklist and 86% (12/14) of those cases examined after its introduction. This increase was significant ($p < 0.05$).

Families, carers and other relevant parties were involved in decision-making in 67% (4/6) of those cases examined before introduction of the checklist and 100% (14/14) of those cases examined after its introduction. This increase was significant ($p < 0.001$).

An independent mental capacity advocate was considered in 33% (2/6) of those cases examined introduction of the checklist and 86% (12/14) of those cases examined after its introduction. This increase was not significant (p = 0.180).

A finalised care plan was documented in 33% (2/6) of those cases examined before introduction of the checklist and 100% (14/14) of those cases examined after its introduction. This increase was significant (p < 0.001).

Note: this study also provided data relating to question 3 (assessment of capacity). This will be presented at a future Guideline Committee meeting.

6. Redley M, Clare ICH, Luke L et al. (2009) Mental Capacity Act (England and Wales) 2005: the emergent independent mental capacity advocate (IMCA) service. British Journal of Social Work 40: 1812–28

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

The aim of this study conducted in the UK was to ascertain whether an independent mental capacity advocate service could protect the interests of adults who lack capacity, are without family or friends and are faced with a potentially life-changing decision. In addition, the researchers also aimed to identify and understand any practical difficulties that independent mental capacity advocates might face following the introduction of the statutory service. The study was judged to have good relevance to the review area (++) and to be of good quality (++). Quantitative data describing the number and types of referrals to the pilot independent mental capacity advocate service, and qualitative interview data capturing key stakeholders' experiences and perceptions of independent mental capacity advocate casework were collected. The participants included 231 clients with compromised capacity, 7 managers of independent mental capacity advocate provider organisations, 7 independent mental capacity advocate case workers, 8 members of staff from advocacy provider organisations, 16 decision-makers in health and social care and 35 healthcare practitioners.

Findings

Quantitative findings

Number of referrals for each type of decision (n = 249).

a. Serious medical treatment – 37 (15%).

b. Change of accommodation

Prior to discharge from hospital – 98 (39%)

Other change of accommodation – 114 (46%).

Consultation with family and friends

Total 63% of the 231 clients had family or friends who could, in principle, have been consulted, but this step was judged by decision-makers not to be practical or appropriate.

Barriers – practical

a. Family or friends had not been in contact for a long time (30%).

b. Mentally or physically too frail (16%).

c. Lived far away or were simply reluctant to be involved (8% for both).

Reasons family and friends not considered appropriate

a. Conflicts of interest where it was felt they stood to gain or lose some material benefit as a result of a particular outcome (17%).

b. Suspicions that they had abused the person lacking capacity (11%).

c. Disagreements among different family members (3%).

d. Disputes with the decision-maker (3%).

Other findings

a. Men and women referred for a change of accommodation prior to discharge from hospital were significantly older than those referred for the 2 other decisions.

b. Majority (60%) of referrals for decisions of this kind related to people with a diagnosis of dementia.

c. Among the older group, 67% were moving from 1 residential placement to another.

d. The majority (60%) of referrals relating to serious medical treatment related to people with a diagnosed learning disability.

Communication

a. Three-quarters (74%) of the 231 clients used English or another spoken language.

b. One in 5 (17%) used an alternative means of communication (sign language, pictures or non-standard vocalisations).

c. Only 6% were described as having no obvious means of expressing themselves to others.

d. Importantly, it was reported by the independent mental capacity advocates that more than half (54%) of the 109 clients whose referrals were completed at the end of the evaluation were able to communicate some indication of their wishes that could be passed on to a decision-maker.

Dealing with referrals

a. Overall, independent mental capacity advocates spent just over 9 hours on each referral.

b. Independent mental capacity advocates revealed considerable uncertainty around the ending of their involvement with clients, particularly in relation to change of accommodation decisions. There was a consensus among the independent mental capacity advocates that their involvement should end only when a decision had been made and implemented fully. Independent mental capacity advocates reported that they often felt ‘out of the loop’ and that it was rare for them to receive any response to, or even acknowledgement of, their written reports.

c. In 16 (15%) of 149 referrals, independent mental capacity advocates challenged the decision that had been made.

Qualitative findings

The independent mental capacity advocate role

a. Over the course of the pilot, there were changes in the views of both those independent mental capacity advocates who were strongly committed to a person-centred approach and those independent mental capacity advocates who were more comfortable with decision-specific advocacy.

b. Decision-makers in both health and social care expressed positive views of involving advocates in substitute decisions about a change of accommodation.

c. The decision-makers in social care were impressed with the independent mental capacity advocates’ knowledge, feeling that they shared a common language.

d. The 7 healthcare decision-makers who had worked with independent mental capacity advocates in change of accommodation decisions for inpatients reported that they had been impressed with the service they had received, though some concern was expressed over the possibility that advocates had contributed to slight delays in the process of discharging a patient from hospital.

e. Two of the healthcare decision-makers who had worked with independent mental capacity advocates reported that their initial scepticism had been challenged by the experience and that statutory advocacy had made a useful contribution to the decision-making process.

f. Healthcare decision-makers who had not worked with an independent mental capacity advocate expressed 4 main concerns. First, doubts about the contribution that could be made by anyone without medical training; secondly, scepticism about the professional ability of advocates to represent clients’ views; thirdly, that advocacy was unnecessary, since, as healthcare practitioners, they themselves already acted in the best interests of their patients; and, finally, that a service available only within office hours was unhelpful.

g. In striking contrast, the same respondents were enthusiastic about the involvement of an independent mental capacity advocate in change of accommodation decisions arising in the context of patients being discharged from hospital. These decisions were not seen as entirely medical and, therefore, the involvement of an advocate, offering a lay person's perspective, was considered to be both appropriate and possibly of considerable value.

h. It was apparent, however, from our interviews with these healthcare decision-makers that many of them did not fully understand the Mental Capacity Act's decision-specific approach to capacity.

7. Samsi K, Manthorpe J (2013) Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. International Psychogeriatrics 25: 949–61

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This qualitative study from the UK was conducted to explore the experiences of people with dementia and their family carers with regards to everyday decision-making, how decisions are negotiated and how experiences changed over time. The study had moderate relevance to the review question (+) and the methodological quality was rated as moderate (+).

The sample was comprised of 15 people with dementia and their family carers (n = 15). The authors describe the participants as having 'mild to moderate dementia' on the basis that they had been diagnosed 3 to 11 months before the first stage of the study. The researchers conducted face-to-face interviews with participants every 3 to 4 months over a 1-year period. Note: people with dementia who were unable to consent to interview were excluded.

Findings

Carers reported a number of strategies to involve the person they cared for in decision-making, including asking for the person's opinion at the 'right' time, and making smaller everyday decisions on their behalf in order to 'save' their relative's decision-making capacities for bigger and more significant decisions.

The authors report that the concept of 'best interests' underpinned many carers' intentions when making decisions with or on behalf of the person they supported, however they note that many carers found it difficult to 'weigh up' best interests as they had a tendency to connect their own best interests with those of the person they supported. However, spousal carers reportedly used their in-depth knowledge of the person to 'retrospectively' think about their beliefs and preferences in order to come to a decision about what they 'would have wanted'.

There were concerns from some carers regarding the level of responsibility that they had to take when making substitute decisions, and some reportedly found this to be a strain. The authors report that only 'a few' carers had received support and cite the case of 1 carer who reported feeling isolated when making decisions on behalf of her husband, adding that while she had received some support from the local carers centre, everyday decision-making tended to be seen as a private matter. The authors go on to report that most carers felt that they would benefit from support with decision-making, however this was reportedly not widely available.

8. Sorinmade O, Strathdee G, Wilson C et al. (2011) Audit of fidelity of clinicians to the Mental Capacity Act in the process of capacity assessment and arriving at best interests decisions. Quality in Ageing and Older Adults 12: 174–9

Methods: Qualitative

Data: Views and experiences

Country: UK

Outline

This audit from the UK was designed to '… evaluate health professionals' fidelity to the Mental Capacity Act (MCA) principles on determining mental capacity and arriving at best interests decisions in the care of individuals found to lack the relevant decision-making capacity' (p174). The study had good relevance to the review question (++) but the methodological quality was rated as low (-).

The authors analysed the records of 68 patients who had been found to lack capacity to make a decision. Records were provided by community mental health teams/psychiatrists (working age psychiatry, older adult's psychiatry and learning disability psychiatry) for patients who were over the age of 18 and had (in the last 2 years) been determined to lack capacity to make a decision regarding their place of residence, their finances or their treatment. The authors also requested records from geriatricians working at a local hospital, however it is not clear for which type of decisions these patients had been found to lack capacity. Note: no further details on the individuals to whom the case notes relate or the practitioners who had created them are reported.

The audit measured fidelity to the Mental Capacity Act in relation to reasons for capacity assessment; the legal tests used to assess capacity; the best interests process followed after it had been determined that the patient lacked capacity; and documentation of capacity issues.

Findings

Enquiries regarding the existence of a court appointed deputy with powers relating to the issue for which capacity had been questioned were made in 9% of cases. The authors report that ' … in none of those cases was the existence of a court appointed deputy ascertained' (p176).

The authors report narratively that '… the majority of clinicians … consulted with the family and friends of patients when making a best interests decision but that in … only a very small proportion of the entire sample … did records indicate that an Independent Mental Capacity Advocate had been involved'.

Note: this study also provided data relating to question 3 (assessment of capacity). This will be presented at a future Guideline Committee meeting.

9. Williams V, Boyle G, Jepson M et al. (2012) Making best interests decisions: people and processes. London: Mental Health Foundation

Williams V, Boyle G, Jepson M et al. (2012) Making best interests decisions: people and processes. Appendices A– F. London: Mental Health Foundation

Note: the findings of the above 2 reports were combined and presented as a single narrative summary.

Outline

The central goal of this study was to provide a picture of practice according to the main contexts and types of decisions being made (health are, personal welfare and property and affairs), and the different groups for whom these decisions were made. The study was judged to have good relevance to the review area (++) and to be of moderate quality (+). The multi-stage, mixed methods project included an online survey of 385 individuals; a telephone survey with 68 participants; and face-to-face interviews with 25 participants. Participants were drawn from the health and social care sector and the legal professions. Only the findings relating to RQ4 are presented here. Other findings, relevant to RQ1–3 will be reported in the update searches.

Findings

The 2 largest client groups represented in this survey were people with dementia (154; 40%), followed by those with a learning disability (131; 34%). Other groups represented included people with mental illness (n = 107, 28%) and people with a neurodisability (n = 75, 19.5%).

Respondents were drawn from 4 areas of England – Bradford (34%), Surrey (26%), Dorset (21%) and Sandwell (19%).

Combined findings (online survey, telephone interview and face-face interview)

When and why are best interests decisions made?

Of the 385 valid responses to online the survey, almost half (48%) of all decisions were reported to be made regarding healthcare. A quarter (24%) were about personal welfare or social matters and a slightly smaller percentage (20%) were about more than 1 matter (n = 78, 20%), property and finance (n = 28, 7%).

A total of 184 people needed a decision made regarding a health matter; 40% of the decisions were regarding consent to serious physical healthcare treatment and a further 33% were regarding other physical healthcare treatment.

The role of respondents in making the best interests decisions: almost half (n = 170; 43%) of respondents were part of a multidisciplinary team that made the best interests decision. A third (n = 126, 32%) were joint decision-makers, and a small number (n = 26; 7%) said that they were the sole decision-maker.

The role of respondents and the type of decision being made: respondents involved in healthcare decisions were almost exclusively healthcare professionals (87.5%). The number of respondents describing themselves as joint decision-makers was 46, and most (87%) were healthcare professionals – 99 respondents were part of a multidisciplinary team, and again almost all of these (91%) were healthcare professionals.

Findings from telephone and face-to-face interviews

Physical healthcare

Serious deterioration in physical health was often cited as the start of a best interests process. Other causes for best interests processes included a refusal to be treated, or the need to balance treatment against the psychological wellbeing or quality of life of the individual.

Discharge from hospital and change of accommodation was the second largest context for making a best interests decision.

Personal welfare or social matters – 93 decisions reported by participants related to a personal welfare or social matter. The majority (41%) involved a change in the person's accommodation involving a move into or out of a care home (p36). People with dementia were more likely than others to have decisions made for them regarding a change in their accommodation involving a move into or out of a care home than were people without dementia ($p < .01$).

Safeguarding triggers and deprivation of liberty safeguards – risk was a very common trigger for a best interests process, and best interests decisions were taken to protect people from harm. Fifteen (16%) of the social care decisions in the online survey were reported to be about adult safeguarding (p43). Ten (15%) of the 68 telephone interviewees described a situation in which there was a safeguarding concern, and for an additional 2 the concern was about safeguarding financial interests. Safeguarding was of course also a concern in those cases which had involved an application for 'deprivation of liberty safeguards', of which 4 were mentioned in telephone interviews.

Matters primarily triggered by social care needs – a specific change in social care needs could also give rise to a best interests decision. For instance, that accounted for 35 of the 93 (38%) social care cases in the online survey. Most typical in this group were those cases where a breakdown of existing care arrangements was foreseen: 'The difficulty arose was because her husband really didn't think he could cope. He didn't think she had capacity to weigh up the implications of her going home; she couldn't manage stairs, and the house had steps up to it' (T12) (p13).

It was interesting, however, that many of these 'breakdown of care' situations arose particularly at the point when the person lacking capacity had had a health intervention or a stay in hospital. Several of those instances involved a person who was living in a supported situation, but was refusing to accept care or support in particular ways.

Property (including a person's tenancy) or financial affairs matters – 29 people (7%) had a best interests decision made regarding property (including a person's tenancy) or financial affairs. Two thirds (68%) of decisions were regarding the person's financial affairs. Concerns about financial capacity, or about possible financial abuse, also led to best interests decisions in a few cases in this research.

Health deteriorates past a critical point – medical practitioners tended to identify only the medical need itself, while care home staff then had the task of considering the issues and effectively bringing a medical decision into the arena of 'best interests'.

Decisions precipitated by pressure from a third party – there were a few cases that appeared to have been precipitated not just by the person's own escalating needs, but by a particular crisis that was initiated by another party. These cases particularly highlighted the need for joint working.

Decision-making because the person was making a decision thought to be unwise – 23 (6%) respondents stated that the main reason for deciding what was in the person's best interests was because the person was making a decision thought to be unwise. Eight of the 23 decisions (35%) were made because the person was making a decision thought to be unwise with respect to healthcare decisions. Nine of the 23 decisions (39%) were made because the person was making a decision thought to be unwise with respect to personal welfare or social matters.

Decision-making because of the person's age, their appearance or their behaviour – 13 (3%) respondents stated that the main reason for deciding what was in the person's best interests was because of the person's age, their appearance or their behaviour. Six of these decisions were made with respect to personal welfare or social care matters; 4 were made regarding a healthcare matter and 1 was made with regard to a property or financial affairs matter.

Time taken to assess the person's best interests before the decision had to be made or action taken – over a third (126; 32.5%) of assessments were made within 24 hours of the decision having to be made. Almost a third (118; 30.5%) of assessments were made up to a couple of weeks before action had to be taken, and just over a third (141; 37%) were made over several weeks. Decisions regarding healthcare and personal welfare or social matters were more likely to be made within 24 hours, whereas decisions about property or financial affairs matters were more likely to be made over the course of several weeks. However, there is no statistically significant difference when considering time in which it took to make the decision and the type of decision (Chi-square value = 6.83; p = .337).

Delays in best interests decision-making – for almost half of the cases (167; 43.5%) it was not thought possible to delay the best interests decision. A greater proportion of healthcare decisions (47%), and personal welfare or social decisions (45%) were thought not able to be delayed. A quarter of property or financial affairs decisions (25%) or those involving more than 1 issue (23%) were delayed so that the person could regain capacity or be helped to make the decision (p60).

The process of best interests decision-making – although not statistically significant, it seems that urgent decisions were more likely to fall into the healthcare category (38% up to 24 hours), and lengthier decisions were more likely to be about property and affairs (50%, several weeks) or about more than 1 matter. Unsurprisingly, further analysis showed that urgent decisions were most likely to be associated with people who were unconscious or who were under the influence of drink or drugs (p60). From this sample of interviews, the most urgent decisions involved ambulance crews deciding to transport someone to hospital in their best interest. None of the best interests cases involving ambulance crews took more than 2 hours to complete. Quick decision-making processes are more likely to be associated with healthcare.

The online survey revealed that almost half of respondents were part of a multidisciplinary team making a best interests decision, and a third were joint decision-makers; only a small proportion (7%, 26) claimed to be the sole decision-maker. The greatest trend towards multidisciplinary decision-making appeared to be reported by nurses, of whom 56% were part of a multidisciplinary team, and by professions allied to medicine, of whom 61% were part of a team (p63).

‘All the ones I’ve been involved with are very much a team effort. It’s not one person making a decision’ (mental health professional, p64).

A mental health service manager described a decision about financial appointeeship for someone with dementia, who was giving away his money without full understanding of others’ motives. ‘it’s not a single person’s decision. I think what makes it easier is because we look at it from a totally multi-disciplinary angle’ (T05) (p27).

There was a distinction between leading a best interests process and actually being the decision-maker. On occasions, these 2 functions were carried out by different people.

Those in multidisciplinary teams often held regular meetings, where best interests decisions were incorporated as part of the standing agenda. Best interests were also considered in some cases as part of other processes, such as safeguarding. Over half of the respondents in the online survey identified that they were part of a multidisciplinary team making a decision. There was a highly significant difference regarding the process of decision-making when considering the types of decisions made (Chi-square value = 33.92; p < .001). People with learning disabilities were more likely to have decisions made for them at 1 or more meetings that did not involve them compared to those without learning disabilities (p = .001). There were also significant differences between people with dementia and people without dementia (p < .05), and between people who were intoxicated and those who were not intoxicated (p < .05) (p67).

A special best interests meeting for a patient or client could take many different shapes. In some cases, an ‘executive’ meeting fed into a larger more formal meeting; at other times a single best interests meeting pulled together relevant parties, and the outcome was then fed into a regular multidisciplinary process. However, approximately 1 in 10 of the decisions did not involve the person lacking capacity.

‘There was a build up of getting to the point where we were going to the consultant with everybody having built up information about pros and cons and everything. And then when we got to that final one with everybody together, it was sort of, right, on this date a decision will be made, with the consultant having the overriding, “we’ll do it, or we won’t”’ (participant, p74).

Over half of all decisions regarding personal welfare or social matters, property or financial matters, and more than 1 matter, involved a series of meetings between the decision-maker, the person and usually others who knew the person. However, this was the case for only 31% of healthcare decisions. Healthcare decisions were more frequently than other types of decisions made at a single meeting, or at meeting(s) that did not involve the person lacking capacity (p65).

Disagreement about the person’s best interests – most respondents (303; 79%) said that there has been no disagreement about the person’s best interests. However, 65 respondents (17%) said that there had been disagreement. The remaining 17 respondents (4%) were not sure.

The 65 respondents who thought there had been disagreement about the person’s best interests were examined in more depth. The majority (35; 57%) reported that the decision had been made over a series of meetings, which was a greater proportion than the 48% overall. Respondents reporting that there had been disagreement also more frequently reported that they were consulted in the best interests decision-making process but that they were not the decision-maker (21%, compared with 13% overall). Together, these findings were statistically significant (Chi-Square value = 10.63; p = .005) (p92).

Where there was disagreement, the decision was less likely to have been made within 24 hours (20% compared with 33% overall) and more likely to have been made over several weeks (43% compared with 36%). This was of borderline statistical significance (Chi-square value = 6.17; p = .046).

The more people involved in any best interests process, the more likely it was that a conflict of opinion could arise. As noted in the telephone survey, these conflicts could be between professionals, as well as between family members and professionals. As we have explored in this report, the basic conflict in some of the social care cases was between the person lacking capacity and his or her care staff. These were the cases in which a person was refusing to accept advice with regard to safety or to other matters relating to their own best interests.

The real frustrations in conflicting situations were expressed by those professionals who felt that they were disempowered to speak up for the client or patient they knew. That was so, for instance, with the appointees. In one example, they felt they knew the client better than the social worker who overturned their decision to protect a young woman from a potentially harmful decision to purchase a car, where her money would be likely to run out and she would also put herself at risk on the roads. There was also a strong sense of disempowerment among the care home staff dealing with GP decisions in end-of-life cases. Further, there seemed to be almost a professional antagonism between solicitors and social services: ‘I haven’t spoken to anybody from social services about this, but I get the impression that if a client comes to you and instructs a solicitor, they’re immediately on their guard, and they feel as if you’re criticising them’ (p34).

Best interests decisions were not always made via meetings; sometimes they were made through informal processes, such as conversations around a bedside: ‘I mean there are times obviously you’ve got to maintain safety, you’ve got to make a decision quite quickly and there might not be time to consult people earlier. In other decisions you've got time to speak to the family, the individual, the people that know him' (nursing home manager, p78).

Although most people said they had taken into account the wishes and values of the person lacking capacity, there were only a few clear examples where wishes and values were influential in the best interests decision, or where past values had been explored. The vast majority of respondents in the online survey said that the person's past and present wishes and feelings had been taken into account (90%) and/or that the person's beliefs and values (for example, religious, cultural or moral) had been taken into account (76%) (p85). Few people (32; 8%) had any written statement about their wishes and feelings, and all but 2 of these people were felt to have had their statement considered. Further, of the 270 respondents who answered the question about how the final decision was reached, 80% (215) said that all the information from the process of deciding the person's best interests was used to make a decision.

Cases where the person's wishes and feelings, or beliefs and values, were not always considered in the best interests decision-making process – when considering the type of decision made, in half of the cases (26; 54%), the decision that was being made was in relation to healthcare. Almost a quarter (10; 21%) were having more than 1 decision made; 7 (15%) were having a decision made about a personal welfare or social matter; 5 (10%) were having a decision made about property or financial affairs, and 1 person was having another type of decision made. Overall, there was no statistically significant difference when considering cases where the person's views, wishes or feelings were not considered and the type of decision being made (Chi-square value 3.46; p = .326) (p70).

Communication with a person lacking capacity was sometimes more successfully accomplished outside meetings, and with accessible information strategies or real-life experiences, or observation.

'A man with autism and some complex communication and learning disabilities had been living in an NHS residential facility that was due to close as a result of local policy. He had been assessed as not needing continuing health care, and so was due to move into a flat on a “supported living” basis. However, the interviewee felt that time needed to be taken to consider the man’s needs carefully, before he moved. He therefore raised this matter with the social worker, and fought hard to get things in place so that the man would have a well-managed move into a situation where his needs could best be met. An accessible information picture book was made with the man, who was taken to see the new house which was proposed. Photos were taken, and the interviewee had continued conversations with the man about the place’ (p85).

Involving the person lacking capacity and those close to him/her – 47% of people lacking capacity were involved in best interests meetings with multiple participants. People with learning disabilities were significantly less likely to be invited to a formal meeting, and those with dementia were more likely. The online survey results showed that best interests processes were most likely to involve the person lacking capacity, either in a series of meetings (36%, 140 cases) or in a single meeting (21%, 80 cases). Only 12% of cases (46) definitely did not involve the person lacking capacity in any meetings, while a further 9.5% (37) respondents were unsure or marked as ‘other’ (p83).

‘In another case concerning a woman with learning disabilities in a decision about her personal care, the woman herself disagreed with the decision about receiving more support. She went to the meeting to discuss this, and, as our interviewee (a nurse) said: “We ... yeah; I mean it went sort of spectacularly wrong, though, which was quite interesting: from the capacity, that went really well, but what the young lady doesn’t like is lots of people, she doesn’t particularly like to be challenged about her views and choices, so she actually disengaged from the process.”’ (p40).

Best interests decision-making meetings that did not involve the person at any meetings – there were 46 cases for whom best interests decision-making meetings did not involve them. 70% (n = 32) of these cases involved a healthcare decision, 15% (n = 7) involved a personal welfare or social matter; 1 involved a property or financial affairs matter; and 13% (n = 6) involved more than 1 type of decision. Over half of the 46 cases (27, 59%) had learning disabilities. Others had dementia (12, 26%); mental illness (10, 22%), neuro-disability (9, 20%) or were unconscious (3, 6.5%).Although they may not have been involved in the best interests meetings, over half of the cases (27, 59%) were thought to have been as fully involved as possible in the decision-making process, and over three-quarters (37; 80%) were said to have had their past and present wishes and feelings taken into account. Most respondents (41, 89%) thought that overall, the person's best interests had been decided upon quite well or extremely well. A small number (5, 11%) felt that the decision-making process for these people had been quite poor.

88% of respondents in the online survey felt that people close to the person lacking capacity had been consulted, and 86% felt that their views had been taken into account. The majority of the 68 telephone interviews concerned a decision, which could be discussed in relatively informal and repeated ways with the person lacking capacity, particularly if there were people who knew the person well.

Independent mental capacity advocates – independent mental capacity advocates were involved in 47 (25.5%) of the 184 best interests decisions regarding personal welfare or social matters, and with 22 (24%) of the 74 best interests decisions regarding serious medical treatment. Statistically, there were no significant differences between those in a particular impairment group and others when considering whether or not an independent mental capacity advocate was involved.

One of the themes that emerged in the telephone survey was that there was a mixed level of awareness of the independent mental capacity advocate role among professionals. This finding was echoed in the face-to-face interviews with independent mental capacity advocates themselves. In a positive example from a medical setting, an independent mental capacity advocate was invited to attend a multidisciplinary team meeting to discuss a proposed intervention for a man with dementia. The meeting chair was a cardiologist, and he clearly described the role of the independent mental capacity advocate: 'He explained that I was there to support the gentleman and speak up for him, and also, from the Mental Capacity Act point of view, making sure that we were making good best interests decisions for this gentleman. He had a really good understanding' (p43).

Where an independent mental capacity advocate was instructed, they were generally involved in best interests meetings, and 4 of the 7 who filled in the online survey said they were involved in making the decision. There was often a tension in cases where an independent mental capacity advocate was instructed, between the need to delay processes against the clinical need for immediate action. A consultant involved in making a decision about a move from a hospital setting appeared to appreciate this role of the independent mental capacity advocate in seeking out information: ‘And then if you’re still not sure about whether you’ve got all the information, then think about who else could be usefully involved in helping you make that decision. So I mean using the IMCA was useful’ (p45).

Independent mental capacity advocates were sometimes appointed when there was a conflict with family members or suspicion about their motives. Their commitment to the person lacking capacity, however, sometimes reinforced disputes.

Recording of best interests decisions and assessment of capacity – most best interests processes were recorded formally, with about a third of the online respondents using formal note-keeping (35.5%) and a further third using standardised pro-forma (34%, more common among social care practitioners). Decisions about healthcare matters were more frequently recorded in a detailed note about the process and outcome, whereas decisions regarding property or financial affairs, or about personal welfare or social matters, were more frequently recorded on standardised forms or pro-forma. These differences were statistically significant (Chi-square value = 18.68; p = .005) (p94).

Standardised forms or pro-forma was more likely to be used for people with dementia than with people without dementia. Best interests decision was recorded was significantly different for people with dementia than for people without dementia (p = .001).

People often felt frustrated by how inadequately records were shared, even though their concerns sometimes hinged on a lack of understanding of the confidentiality of an independent mental capacity advocate report. In some of the more complex and time-consuming cases described, minutes and notes were clearly shared among the many professionals involved. Best interests decisions for everyday matters were sometimes recorded informally on daily staff logs, or as ‘balance sheets’ attached to a care plan.

The basis of the decision – both medical and social care decisions were often based on an assessment of risk. In social care decisions, protection and safety were key drivers, but respondents did sometimes mention having considered less restrictive options. A strong guide in making a best interests decision was a consideration of what a person did actually want, or would have wanted, if they had capacity to decide for themselves.

Best interests decisions often had to balance the needs of 1 person against another – there were dilemmas for staff who were driven primarily by the need to respect autonomy in clients or patients, and felt concerned about overriding that autonomy.

Person-centred practice – in some cases, this entailed going beyond the obvious ‘clinical’ decision, as this nurse explained, in relation to an older patient being discharged into a nursing home: ‘I think everybody has to understand it can’t be a clinical decision. Because it’s an emotional one, and clinical makes it too easy. And I think if you’re trying to do what’s right – like this gentleman – the clinical, easy decision was to put him into a nursing home, but it wasn’t what he wanted, or what his wife wanted. And I think these decisions shouldn’t just be clinical’ (participant, p47).

The success of a best interests decision could only be known if there was a system for keeping in touch, or reviewing, how things were for the person lacking capacity. Family members, for instance, were well aware of the detail in their relative’s life.

Medical decisions – successful decisions about medical interventions were sometimes made through a multi-stage process, where consultation was carried out with those who knew the person, and the result was passed up to the senior medical practitioner, who had to take the final decision. In some of the successful practice the social and personal interests of the patient were weighed up well. Strictly medical best interests did not always predominate, although they always did play a role in reaching the end decision.

Social care matters

Despite possible research sampling effects, it would seem that the Mental Capacity Act was most often being used in social care in relation to change of accommodation and safeguarding in a broad sense. By contrast, it appeared to be under-used in relation to care reviews, direct payments and care planning, and also in everyday, routine best interests decisions.

Best interests decisions in social care were most frequently carried out through a series of multidisciplinary team meetings.

Pro-forma for recording best interests decisions were more often used, and found to be useful, in social care cases. However, in everyday decisions it was more difficult to find appropriate ways to keep accurate records.

Social care decision-makers in general were strong in involving and persuading family members in sensitive ways.

Property and affairs decisions

A much smaller proportion (9, 13%) of our 68 telephone interviews concerned a decision relating to property and affairs. One of these was with a solicitor, but others were with people who had been involved in best interests decisions, and included a community psychiatric nurse who had referred a client to appointees in the local council. These corporate deputies (or appointees) were also involved in making best interests decisions (p72).

People with dementia and best interests decisions – people with dementia accounted for 40% (154) of the cases discussed in the online survey. Most of the social care decisions about people with dementia related to a change of accommodation and only a minority related to safeguarding. They were less likely to have health or medical treatment decisions made for them.

People with learning disabilities and best interests decisions – people with learning disabilities accounted for 131 (34%) in the online survey. Healthcare decisions were common, and the pattern emerged where a health deterioration or sudden need for treatment could reveal a raft of other issues, primarily relating to social care and/or accommodation. People with learning disabilities were less likely than other groups to be invited to best interests meetings, but they often had their views taken into account in other ways, including through: a) one-to-one communication; b) real life experiences and observation; c) accessible information. Family members and others were more likely to be consulted in decisions made in the best interests of people with learning disabilities than for other groups.

People with mental health problems and best interests decisions – people with mental health problems accounted for 107 (28%) in the online survey. Typically, their best interests were considered in relation to their mental health needs, rather than in relation to physical health care needs. Successful processes for best interests decisions for people with mental health problems were often characterised by informality, quiet or calm contexts, and by the involvement of trusted and familiar people.

People with neuro-disabilities and best interests decisions – people with neuro-disability and those with brain injuries were under-represented in our research (75 or 19.5% in the online survey). This summary is therefore more speculative than that for other groups. Best interests decisions and the issues involved in capacity are likely to be distinct for the 2 groups, those with neuro-disability and those with brain injury. Family members were regularly involved, and had strong and important roles to play in best interests processes.

Models of best interests decision-making – urgent decisions – some decisions simply have to be actioned almost immediately, and in those cases, the assessment of capacity was indistinguishable from the actual decision, and then the action.

Multidisciplinary meetings – a typical model for many of the decisions, both health and social care, was the best interests meeting, preceded by a series of more informal discussions and fact-finding with those concerned with the case.

Regular meetings – some of the decisions described took place in the course of routine staff meetings, which teams would have on a weekly or monthly basis, to discuss patients in a hospital or residents in a home. Where a best interests matter came up, this would then just be a part of the meeting.

Informal meetings – informal meetings often led into a more formal best interests meeting. However, in other cases, the best interests decision was made entirely through a series of informal meetings between professionals, the person lacking capacity and others who may have information.

Good information and preparation to inform a decision – a 'best interests process' is not a homogenous entity. However, there is a sense that all those coming to the meeting needed to be well informed, and to have already been in prior discussion about some of the most complex cases. In Derek's story, for example, the clinical psychologist explained how there had been a string of meetings and information which all parties had taken part in before the actual face-to-face meeting. She said: 'Where it works badly is you just get an invitation to attend a safeguarding meeting. And you don't know what it's about, not being involved. That to me would work very badly. In fact I would express strong reservations about in what way could I be useful in such a situation.'

Leading a best interests decision – interviewees were sometimes reluctant to call themselves a 'best interests decision-maker'. That lack of clarity was reiterated in the interviews, however, it is clearly important that someone takes on the responsibility of both leading the process, and ensuring that a decision is made.

Evidence statements

The evidence statements listed in this section synthesise the key themes across included studies. Note that the following evidence statements refer to both questions 1 and 2 because they report the views of service users or carers and practitioners.

BIA1	There is some evidence that practitioners and family carers sometimes draw on their own experiences or preferences when making a decision on behalf of someone who lacks capacity. The quality of the evidence is mixed, low to moderate. Dunn et al. (2010 -) reported that the substitute decisions that support workers were making on behalf of their clients were not prompted by concerns regarding decision-making capacity as outlined in the Mental Capacity Act but were instead driven by their own beliefs about how to provide residents with 'meaningful' life experiences. Samsi and Manthorpe (2013 +) report that while the concept of 'best interests' underpinned many family carers intentions when making decisions on behalf of their relative, many had a tendency to connect their own best interests with those of the person they supported.
BIA 2	There is some evidence to suggest that relatives of people who have been determined to lack capacity can find involvement in best interests processes to be stressful and feel that they should be supported in this role and provided with more information. The quality of the evidence is mixed, moderate to good. Emmett et al. (2014 ++) report that some relatives find participation in best interests meetings regarding place of discharge to be emotionally demanding.

	The same study found that carers are sometimes unable to access information far enough in advance to enable them to participate fully in decision-making processes. Samsi and Manthorpe (2013 +) found that some family carers had concerns regarding the level of responsibility associated with substitute decision-making, a role which some found to be a strain. The authors report that most carers felt that they would benefit from support with decision-making, however this was reportedly not widely available.
BIA 3	There is a small amount of evidence to suggest that relatives of people who have been determined to lack capacity may find it difficult to be involved in best interests decisions because they feel unable to or are unwilling to challenge the opinions of professionals. The quality of the evidence is good. Emmett et al. (2014 ++) found that some relatives felt uncomfortable asking for clinical information or challenging professional opinion regarding in the context of best interests decisions regarding place of discharge.
BIA 4	There is a small amount of evidence that family carers are able to support ongoing involvement of people who lack capacity in everyday decision-making. The quality of the evidence is moderate. Samsi and Manthorpe (2013 +) found that carers used a number of strategies to ensure that the person they cared for could still be included in everyday decision-making. These included asking for the person's opinion at the 'right' time, and making smaller everyday decisions on their behalf in order to conserve their relative's decision-making abilities for more significant issues.
BIA 5	There is some evidence that practitioners are unclear about how to determine the best interests of a person who lacks capacity to make a particular decision. The quality of the evidence is low. Ramasubramanian et al. (2011 ++) found in their audit of practice in a specialist learning disabilities unit that before the introduction of a checklist practitioners had not always checked whether the person had an advance statement, lasting power of attorney, court-appointed deputy, etc; had not always involved families, carers and other relevant parties in the decision-making process; and had not always considered involving an independent mental capacity advocate in cases where this would have been appropriate. Sorinmade et al. (2011 ++) found that while the majority of mental health practitioners did consult with family and friends when making a best interests decision, this was not always the case. Enquiries regarding the existence of a court appointed deputy or the involvement of an independent mental capacity advocate were only recoded in a small minority of cases.
BIA 6	There is a small amount of evidence that practitioners are unclear about the requirements to consider whether a person may have capacity to make the decision at a point in the future and to consider whether the decision can be delayed until that time; and to explore the least restrictive options. The quality of the evidence is low. Ramasubramanian et al. (2011 ++) found that before the introduction of a checklist the possibility that the person may have capacity to make the decision at a different time and that the decision could be delayed until that time was only considered in just over a third of cases they examined. They also report that in only a very small minority of these cases was the least restrictive option explored.
BIA 7	There is a small amount of evidence that indicates that a checklist can improve practitioners' adherence to requirements relating to best interests processes as outlined in the Mental Capacity Act. The quality of the evidence is low. Ramasubramanian et al. (2011 ++) found that after the introduction of a checklist there was greater adherence to Mental Capacity Act principles such as the need to check whether the person had stated their wishes in advance, the possibility of delaying the decision until a time at which the person may

	have capacity to make the decision, involving families and carers in the decision, involvement of an independent mental capacity advocate, and the exploration of the least restrictive option.
BIA 8	There is a small amount of evidence that some practitioners are unfamiliar with the principle of best interests decisions. The quality of the evidence is good. Harris and Fineberg (2011 ++) report that almost half of the health and social care professionals working for the palliative care teams they sampled demonstrated a lack of understanding of the best interests principle and checklist as outlined in the Mental Capacity Act.
BIA 9	There is a small amount of evidence that the level of formality of best interests decisions may be shaped by the timescale in which the decision needs to be made. The quality of the evidence is good. Harris and Fineberg (2011 ++) found that the practitioners they spoke to were clearly attempting to establish patients' past and present wishes as far as reasonably practicable, however best interests decisions were sometimes being made on an informal basis, particularly when the person was being cared for at home where it may be difficult to convene a meeting that all relevant parties can attend.
BIA 10	There is a small amount of evidence that independent mental capacity advocates tend to be involved in cases in which there were disagreements. The quality of the evidence is moderate. Williams et al. (2012 +) report that independent mental capacity advocates were sometimes appointed when there was a conflict with family members or suspicion about their motives and that there was a trend towards the involvement of independent mental capacity advocates in cases where there was disagreement.
BIA 11	There is a small amount of evidence that independent mental capacity advocates believe there can be a lack of clarity regarding how long they should work with someone who lacks capacity. The quality of the evidence is good. Redley et al. (2009 ++) report that advocates were sometimes unclear regarding the point at which their involvement should cease, particularly in relation to cases where a change in accommodation was the key issue. Advocates reportedly believed that they should be involved in a case until a decision had been made and fully implemented. They also expressed concern that they rarely received responses to or even an acknowledgement of their report.
BIA 12	There is small amount of evidence that some practitioners are not aware of the independent mental capacity advocate role. The quality of the evidence is good. Williams et al. (2012 +) found that there was a mixed level of awareness of the role among professionals. Advocates themselves also reported that the role was not well understood.
BIA 13	There is a small amount of evidence that health and social care practitioners have mixed views about and experiences of the role of independent mental capacity advocates. The quality of the evidence is good. Redley et al. (2009 ++) found that health care practitioners had concerns regarding the ability of independent mental capacity advocates to contribute to decisions regarding healthcare when they did not have medical training. They also questioned the ability of advocates to accurately represent the views of their clients and the need for IMCAs when, as healthcare practitioners, they already acted in their patients' best interests. On the other hand, Redley et al. also found that health and social care practitioners who had worked with independent mental capacity advocates on proposals for a change of accommodation for inpatients reported that they had been impressed with the service, albeit that their involvement may have caused slight delays in the transfer from hospital.

BIA 14	There is a small amount of evidence that best interests decisions are not always preceded by an assessment of capacity. The quality of the evidence is good. Williams et al. (2012 +) found that 1 in 10 of those best interests decisions reported by respondents had not been preceded by an assessment of capacity.
BIA 15	There is a small amount of evidence that practitioners take a mixed approach to best interests meetings. The quality of the evidence is good. Williams et al. (2012 +) report that while some decisions were made informally as part of routine meetings (or a series of meetings) between practitioners, patients and other relevant parties, decisions were just as likely to be taken in a more formal meeting arranged specifically to make a best interests decision.
BIA 16	There is a small amount of evidence that the timescales over which best interests decisions take place vary according to the type of decision that is being made. The quality of the evidence is good. Williams et al. (2012 +) report that best interests decisions regarding health care were more likely to be made rapidly (e.g. all decisions cited by ambulance crew members were made within 2 hours), whereas other decisions (e.g. relating to property and financial affairs) could take several weeks.
BIA 17	There is a small amount of evidence that best interests decisions are sometimes being made because practitioners believe that a person is likely to make an 'unwise' decision. The quality of the evidence is good. Williams et al. (2012 +) found that a small minority of respondents reported that the main reason for deciding what was in the person's best interests was because the person was thought to have made an unwise decision.
BIA 18	There is a small amount of evidence that people who have been determined to lack capacity are not always involved in best interests meetings regarding their care. The quality of the evidence is good. Williams et al. (2012 +) report that in a small number of cases the person determined to lack capacity was not involved in best interests meetings. The authors report that people with learning disabilities were less likely to be invited to a formal meeting, whilst those with dementia were more likely.
BIA 19	There is a small amount of evidence that the involvement of people is not always achieved by ensuring they attend a formal best interests meeting. The quality of the evidence is good. Williams et al. (2012 +) report that communication with a person lacking capacity was sometimes more successfully accomplished outside meetings, and with accessible information strategies such as picture books, photos, etc. In some cases, it was thought inappropriate to involve the person in these meetings if there was a risk that they might become distressed or withdraw from the process.
BIA 20	There is a small amount of evidence that some practitioners feel disempowered by professional hierarchies. The quality of the evidence is good. Williams et al. (2012 +) found that care home staff felt disempowered by GPs' decisions regarding end-of-life care for residents whom they felt they had a better knowledge of.
BIA 21	There is a small amount of evidence that the majority of best interests decisions are recorded. The quality of the evidence is good. In an online survey, Williams et al. (2012 +) found that around a third of practitioners used formal note-keeping methods while a further third used standardised pro-formas. Best interests decisions for everyday matters were sometimes recorded informally using staff logs, or 'balance sheets' attached to a care plan. However, practitioners reportedly found it more difficult to find an appropriate means to record everyday decisions.

Included studies for review questions 4a and 4b

Dunn MC, Clare ICH, Holland AJ (2010) Living 'a life like ours': support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. Journal of Intellectual Disability Research 54: 144–60

Emmett C, Poole M, Bond J et al. (2014) A relative safeguard? The informal roles that families and carers play when patients with dementia are discharged from hospital into care in England and Wales. International Journal of Law, Policy and the Family 28: 302–20

Harris D, Fineberg IC (2011) Multidisciplinary palliative care teams' understanding of Mental Capacity Act 2005 'best interest' determinations. International Journal of Palliative Nursing 17: 20–5

Manthorpe J, Samsi K, Rapaport J (2012) When the profession becomes personal: dementia care practitioners as family caregivers. International Psychogeriatrics 24: 902–10

Ramasubramanian L, Ranasinghe N, Ellison J (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

Redley M, Clare ICH, Luke L et al. (2009) Mental Capacity Act (England and Wales) 2005: the emergent independent mental capacity advocate (IMCA) service. British Journal of Social Work 40: 1812–28

Samsi K, Manthorpe J (2013) Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. International Psychogeriatrics 25: 949–61

Sorinmade O, Strathdee G, Wilson C et al. (2011) Audit of fidelity of clinicians to the Mental Capacity Act in the process of capacity assessment and arriving at best interests decisions. Quality in Ageing and Older Adults 12: 174–79

Williams V, Boyle G, Jepson M et al. (2012) Making best interests decisions: people and processes. London: Mental Health Foundation

3.6 Evidence to recommendations

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the Guideline Committee discussions. Section 3.6 provides a summary of the evidence sources for each recommendation. Section 3.7 provides substantive detail on the evidence for each recommendation, presented in a series of linking evidence to recommendations (LETR tables).

Summary map of recommendations to sources of evidence

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.1 Overarching principles	
1.1.1 Service providers and responsible bodies should ensure that all practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. This includes role appropriate training for new staff, pre-registration, and continuing development and practice supervision for existing staff. Where appropriate, training should be interdisciplinary, involve experts by experience and include: • the statutory principles of the Mental Capacity Act 2005 • the importance of seeking consent for the process of advance care planning • how and when to have potentially difficult conversations about loss of autonomy, advance care planning or death • required communication skills for building trust to supported decision-making • clarity on roles and responsibilities • the advantages, disadvantages and ethics of advance care planning, and how to discuss these with the person and their carers, family and friends • condition-specific knowledge related to advance care planning, where appropriate • the conduct of decision-specific capacity assessments • the process of best interests decision-making in the context of section 4 of the Mental Capacity Act and associated	APa4, AP11a, EW LS

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
guidance - how to direct people to sources of advice and information.	
1.1.2 All health and social care organisations should: - develop local policy and guidance about which interventions, tools and approaches will be used to support decision-making. - identify or devise specific tools to help health and social care practitioners to assess the mental capacity of the people they are working with.	AMC7
1.1.3 Co-develop policies and Mental Capacity Act training programmes with people who have experience of supported decision-making and of having their mental capacity assessed, and their carers, family and friends.	AMC7
1.1.4 Practitioners should think about decision-making capacity every time a person is asked for consent, or to make a decision, during care and support planning (that is, not only as disagreement resolution).	AMC7
1.1.5 When giving information about a decision to the person: - it must be accessible, relevant, and tailored to the specific needs of the individual - it should be sufficient to allow the person to make an informed choice about the specific decision in question - it should be supported by tools such as visual materials, visual aids, communication aids and hearing aids, as appropriate.	AMC12
1.1.6 Record and update information about people's wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making.	AP3
Using independent advocacy to support decision making and assessment under the Mental Capacity Act.	
1.1.7 Commissioners should ensure that arrangements for the provision of independent advocacy include support for people to: - Enable them to make their own key	SDM3, SDM4

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
decisions, for example, about their personal welfare, medical treatment, property or affairs - Facilitate their involvement in decisions that may be made, or are being made under the Mental Capacity Act. This could be achieved through expansion of existing statutory independent advocacy roles and/or commissioning and provision of non-statutory independent advocacy.	
1.1.8 Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy. Where statutory criteria are met, practitioners must refer to the relevant advocacy service. Otherwise, think about referral to non-statutory advocacy services which will be dependent on local commissioning arrangements.	SDM3, SDM4
1.1.9 Consider providing independent advocacy when there is a safeguarding concern.	GC consensus
1.1.10 Commissioners, public bodies and providers of independent advocacy services should work closely to ensure that: - statutory duties on public bodies to refer to and involve independent advocacy are consistently adhered to and monitored and - failures in the duty to refer to statutory independent advocacy are addressed.	GC consensus
1.1.11 Commissioners, using their powers, including under the Mental Capacity Act 2005, should work with public bodies and providers to increase investment in training for statutory independent mental capacity and other statutory advocates in key areas. This includes training: - in communication with people who have minimal or no verbal communication and - for Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with acquired brain injury.	GC consensus
1.2 Supported decision making	
1.2.1 Ask the person how they want to be supported and who they would like to have	EW LS

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
involved in decision-making in accordance with Mental Capacity Act Code of Practice, principle 2.	
1.2.2 Practitioners supporting a person's decision-making should build and maintain a trusting relationship with them.	SDM2, SDM3, SDM4, EW LS
1.2.3 Practitioners should take into account the wide range of factors that can have an impact on a person's ability to make a decision. These should include: • the person's physical and mental condition • the person's communication needs • the person's previous experience (or lack of experience) in making decisions • the involvement of others • situational, social and relational factors • cultural, ethnic and religious factors • cognitive and emotional factors, or those related to symptoms. They should use this knowledge to support the person's decision-making.	SDM2, SDM3, SDM5
Providing information to support decision making	
1.2.4 Practitioners should clearly determine, at the start, what information they need to cover the salient details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself.	EW LS
1.2.5 Offer accessible information to everyone involved in supporting decision-making. This should be about the process and principles of supported decision-making as well as about the specific decision.	SDM1
1.2.6 When providing the person with information to support a particular decision: • do so in line with the NHS Accessible Information Standard • support them to identify, express and document their own communication needs • ensure options are presented in a balanced and non-leading way.	SDM1
1.2.7 Record the information that is given to the person during decision-making. Give the person an opportunity to review and comment on what is recorded and write down their views.	SDM1
1.2.8 Consider tailored training programmes for the	SDM6

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
person, to provide information for specific decisions – for example sexual education programmes and medication management.	
Supporting decision making	
1.2.9 Support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with sections 3.10 and 3.11 of the Mental Capacity Act Code of Practice.	SDM3, SDM4, SDM7, EW LS
1.2.10 Support the person with decision-making even if they wish to make an unwise decision.	BIA17
1.2.11 Involve significant and trusted people in supporting decision-making, in line with the person's preferences. Have due regard for the principle of confidentiality set out in section 3.15 of the Mental Capacity Act Code of Practice. Ensure that this support is based on the person’s wishes and preferences and is free from coercion or undue influence. If there are no significant trusted people, think about involving an advocate, particularly if the advocate has worked with the person before.	SDM1
1.2.12 Practitioners should talk to the person and their carer, family and friends, as appropriate, about the potential consequences of supported decision-making. These could include increased autonomy, being better informed, sharing decisions with people interested in their welfare, talking about potentially upsetting issues including declining health or end of life, feeling overwhelmed with having to make a difficult decision at a difficult time and dealing with conflicting opinions.	GC consensus
1.2.13 Give people time during the decision-making process to communicate their needs and feel listened to. Be aware that this may mean meeting with the person for more than 1 session.	SDM1, EW LS
1.2.14 Health and social care practitioners should increase the involvement of people and their carers, family and friends in decision-making discussions by using a range of interventions focused on improving shared decision-making and supported decision-making.	SDM7
1.2.15 Where possible, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time.	SDM1, EW LS
1.2.16 Health and social care practitioners should	EW LS

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
refer to other services (for example speech and language therapy and clinical psychology) that could help support decision-making when the person's level of need requires specialist input. This is especially important: • when the obstacles to decision-making are complex or • if there is a dispute between those making and supporting decisions or if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk) or • if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk).	
1.2.17 Practitioners should make a written record of the decision-making process including: • steps taken to help the person make the decision • individuals involved in supporting the decision • information given to the person • key considerations for the person in making the decision • the decision reached • needs identified as a result of the decision • any further actions arising from the decision.	GC consensus
1.2.18 Organisations should ensure they can demonstrate that they monitor compliance with principle 2, section 1 (3) of the Mental Capacity Act.	GC consensus
1.3 Advance care planning	
Helping practitioners to undertake advance care planning	
1.3.1 Health care commissioners and providers should: • develop standard protocols and plans for joint working and sharing of information on advance care plans between practitioners, people and families • commission training on advance care planning	AP2

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
• demonstrate that protocols are in place and training is available by including advance care planning in audits.	
Providing information about advance care planning	
1.3.2 Offer people verbal and written information about advance care planning, including how it relates to their own circumstances and conditions. All information sharing must fulfil the requirements of the NHS Accessible Information Standard.	AP1
1.3.3 If a person has recently been diagnosed with a long-term or life-limiting condition, give them information on: • their condition • the process of advance care planning • how they can change their minds or amend the decisions they make while they retain capacity to make them • services that will help in advance care planning.	AP7, AP10, APa2
Developing advance care plans collaboratively	
1.3.4 All health and social care practitioners who come into contact with the person after diagnosis should help them to make an informed choice about participating in advance care planning. If they wish to do so, practitioners should facilitate this.	AP12a
1.3.5 Offer the person a discussion about advance care planning: • at the most suitable time once they receive a diagnosis likely to make advance care planning useful and • at other times, allowing people to think through and address different issues in their own time.	AP12a
1.3.6 Practitioners involved in advance care planning should ensure that they have access to information about the person's medical condition that helps them to support the advance care planning process. It is the practitioner's responsibility to identify what information they need.	AP7, APa2
1.3.7 When approaching discussions about advance care planning, health and social care practitioners should: • be sensitive, recognising that some people	AP1, AP7

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
may prefer not to talk about this, or prefer not to have an advance care plan - be prepared to postpone discussions until a later date, if the person wishes - recognise that people have different needs for knowledge, autonomy and control - talk about the purpose, advantages and disadvantages of this type of planning - consider the use of checklists to support discussions.	
1.3.8 If the person has given consent for carers, family and friends to be involved in discussions about advance care planning, practitioners should take reasonable steps to include them.	AP1
1.3.9 Health and social care practitioners should help everyone to take part in advance care planning and co-produce their advance care plan if they choose to have one (including people with fluctuating or progressive conditions). They should: - work with the person to identify any barriers to their involvement, and investigate how to overcome these - help them to communicate by providing communication support appropriate to their needs (for example, communication aids, advocacy support, interpreters, specialist speech and language therapy support, involvement of family members or friends).	AP1, AP2, AP7
1.3.10 During advance care planning discussions, practitioners should: - take into account the person's history, social circumstance, wishes and feelings, values and beliefs (including religious, cultural and ethnic factors), aspirations and any other factors they may consider important to them - help the person to anticipate how their needs may change in future.	AP3
1.3.11 In line with the Mental Capacity Act Code of Practice practitioners must ensure that: - all notes made on advance care planning are contemporaneous and - the notes are agreed with the person using services at the time and - permission is sought to share the	AP12a

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
information with other people.	
1.3.12 Provide the person with an accessible document that records their wishes, beliefs and preferences in relation to advance care planning and which they may take with them to show different services. It may include who the person wants to have involved in decision-making or their preferences for issues such as treatment, support or accommodation.	APa7, EcAPa1, EcAPa3
1.3.13 Practitioners should share the advance care plan in a clear and simple format with everyone involved in the person's care, if the person has given consent.	APa7, EcAPa1, EcAPa3
1.3.14 Practitioners should ensure that information about a person's advance care plan is, with their consent, transferred between services when their care provider changes.	AP1, AP2, AP7, EcAPa1, EcAPa3
1.3.15 Review advance care plans at reviews of treatment or support, while the person has capacity, and amend as necessary, if the person wishes.	AP7
1.3.16 When people are reaching the end of life, give them the opportunity to review or develop an advance care plan if they haven't already done so.	EcAPa1, EcAPa2
Joint crisis planning	
1.3.17 Offer joint crisis planning to anyone who has a mental disorder with an assessed risk of relapse or deterioration and who is in contact with specialist mental health services. The offer should be documented and, if the person accepts it, the plan should be recorded.	EcAPa1, EcAPa2
1.4 Assessment of mental capacity	
1.4.1 Health and social care organisations should monitor and audit the quality of mental capacity assessments.	AMC2
1.4.2 Consider including people's views and experiences in data collected for monitoring an organisation's capacity assessment activity.	AMC2
1.4.3 Organisations should ensure that assessors should be able to seek advice from people with specialist condition-specific knowledge to assist them to assess capacity – for example clinical psychology and speech and language therapists.	AMC3
1.4.4 Organisations with responsibility for accessible care plans should ensure that they record that the person consents to the care plan	GC consensus

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
and identifies if they are unable to consent.	
1.4.5 Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment.	GC consensus
Assessing capacity to make decisions	
1.4.6 Assess mental capacity in line with the process set out in section 3 of the Mental Capacity Act. Be aware that the process applies to all decisions, large and small, though the measures adopted and recording will be proportionate to the complexity and significance of that decision.	GC consensus
1.4.7 Assessors should have sufficient knowledge of the person being assessed to be able to: • provide tailored information, including information about the consequences of making the decision or of not making the decision. • know whether the person would be likely to attach particular importance to any key considerations relating to the decision.	GC consensus
1.4.8 Practitioners should be aware that people may find capacity assessments distressing, particularly if they strongly disagree that they lack capacity.	EW LS
1.4.9 In preparing for an assessment, the assessor should be clear about: • the person's options • what information, knowledge and experience the person needs about their options • what the person needs to understand, retain, weigh up, use and communicate in relation to this decision, including the use of communication aids • how to allow enough time for the assessment, giving people with communication needs more time if needed • how to assess capacity in a way that is respectful and preserves the person's dignity • how to make reasonable adjustments including, for example, delaying the assessment until a time when the person feels less anxious or distressed • how to ensure that the assessment takes	EW LS, EW IS

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
place at a location and in an environment and through a means of communication with which the person is comfortable - whether involving people with whom the person has a trusted relationship would help the assessment decision.	
1.4.10 The assessor should take into account the person's decision-making history when preparing for an assessment.	EW LS
1.4.11 Practitioners must take all reasonable steps to ensure that the process of capacity assessment does not cause a person distress or harm.	EW LS
1.4.12 Health and social care practitioners should take a structured, person-centred, empowering and proportionate approach to assessing a person's capacity to make decisions, including everyday decisions. The assessment should show where a person has capacity and where they do not. However, they should be aware that for certain areas, such as voting, there is no legal requirement to establish capacity.	AMC1, EW LS
1.4.13 As stated in principle 2 of the Mental Capacity Act, health and social care practitioners must take a collaborative approach to assessing capacity, where possible, working with the person to produce a shared understanding of what may help or hinder their communication and decision-making. This may include involving an interpreter, speech and language therapist, someone with sensory or specialist communication skills, clinical psychologists or other professionals to support communication during an assessment of capacity.	AMC13
1.4.14 Where the individual has identified communication needs the assessor should also think about using communication tools to help with the assessment. Where tools are used, their use should be recorded as recommended by their employer or organisation.	AMC1
1.4.15 Health and social care practitioners should work with the person where possible and where consent has been provided to identify people they should liaise with about how to carry out the capacity assessment. This could include support workers, carers, family and friends and advocates. They should use the information gathered to help create a complete picture of the person's functional capacity to make a specific decision and act on it.	EW HJ

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
1.4.16 The assessor should record any differing views on capacity that they are aware of and how the outcome of their assessment addresses or answers those concerns.	EW HJ
1.4.17 Health and social care practitioners should conduct an assessment at a level proportionate to the decision being made.	AMC9
1.4.18 If a person refuses to engage in a capacity assessment, the assessor should give them a choice about who else could be involved or any other changes that can be made to help them.	EW LS
1.4.19 Practitioners should use accessible language or an accessible format to tell the person: • that their capacity is being assessed and • the outcome of that assessment.	EW LS
1.4.20 Practitioners should be aware that people with executive dysfunction – for example, people with traumatic brain injury – may be at risk of having their decision-making capacity overestimated. Structured assessments of capacity should be supplemented by real-world observation of the person's functioning and ability.	EW HJ
1.4.21 When assessing capacity, practitioners should take account of principle 3 of the Mental Capacity Act and not assume that the person lacks capacity because they have made a decision that the practitioner perceives as risky or unwise.	AMC7
1.4.22 Practitioners should understand that the person has to retain the most important points from a discussion only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision.	AMC8
1.4.23 Practitioners should be aware that if a person is judged to lack insight into their condition, this does not necessarily reflect lack of capacity to make a decision, depending on the nature of the decision being made.	AMC8
1.4.24 If a practitioner assesses a person as lacking capacity, they must document this, together with the evidence that led to this conclusion.	EW HJ
1.4.25 The person assessing mental capacity should record: • the practicable steps they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved.	EW HJ

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
- if the person has capacity but makes an unwise decision - if the person has capacity and gives valid consent.	
1.4.26 All assessments of mental capacity must be recorded at an appropriate level to the complexity of the decision being made, as a stand-alone assessment, in patient notes or in care plans following local policy.	AMC11
1.4.27 Provide the person with emotional support and information after the assessment, being aware that the assessment process could cause distress, disempowerment and alienation.	EW LS
1.5 Best interests decision making	
Helping practitioners to deliver best interests decision making	
1.5.1 In line with the Mental Capacity Act 2005, practitioners must not hold a best interests discussion until a capacity assessment has been conducted, and a decision made and recorded that a person lacks capacity to make the decision in question (except in emergency situations).	AMC10
1.5.2 Ensure that everyone involved in the best interests decision-making process knows who the decision maker is.	BIA19, GC consensus
1.5.3 Regardless of whether a person has capacity to make a specific decision, practitioners must take all reasonable steps to help them be involved in making decisions.	SDM5
1.5.4 Health and social care services should ensure that best interests decisions are being made in line with the Mental Capacity Act.	BIA9
1.5.5 Health and social care services should: - implement a service-wide process for recording best interests decisions and ensure that staff are aware of this and - have clear systems in place to support practitioners to identify and locate any relevant written statement made by the person when they had capacity, at the earliest possible time.	BIA9
1.5.6 Health and social care services should have clear systems in place to obtain and record the person’s wishes and feelings in relation to a relevant decision, as well as their values and beliefs, or any other factor that would be likely to	AP3

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
influence such a decision. Services should: - have mechanisms in place to make these available in a timely way - ensure that the person's personal history and personality is represented in the above.	
1.5.7 Ensure that knowledge of the Independent Mental Capacity Advocate role in best interests decision-making is embedded in all Mental Capacity Act training, including introductions to health and social care and in preregistration training.	BIA12
Helping and supporting family members in respect of best interests decision making	
1.5.8 Health and social care practitioners should work with carers, family and friends to find out the wishes and preferences of the person in relation to the specific decision and to understand the person's decision-making history.	BIA1, EW LS
1.5.9 If a decision maker is calling a best interests meeting, they should: - involve the person themselves, unless a decision is made that it would be harmful for them to attend the meeting - consult carers, family and friends about the meeting in advance, giving them time to ask questions and give their opinions, for example about how to include the person in decision-making - make it clear that the purpose of the meeting is to make a decision - provide all information in an accessible format.	BIA3
1.5.10 Practitioners should access information about the person informally if needed, as well as through any formal meetings.	BIA19
1.5.11 The decision maker should ensure that all people concerned with the best interests decision are able to be fully involved. This means making sure they have their views encouraged, respected and heard.	BIA18, BIA20
1.5.12 When making a decision on behalf of the person who lacks capacity, practitioners should use a range of approaches, as needed, to ensure that people's best interests are met, if they lack capacity. This might include:	BIA15

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
• a less formalised approach for day-to-day decisions – that is, recurring decisions being recorded in support or care plans • formal best interests meetings for significant decisions • a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments.	
1.5.13 Carers and practitioners must wherever possible find out the views and beliefs of the person in the first instance and should be able to demonstrate that they have done so. For example: • recording in care records what steps have been taken, including reasons why this has not been done • identifying which steps have been taken to find out the person's wishes.	BIA1
1.5.14 Health and social care organisations should provide toolkits to support staff to carry out and record best interests decisions. These toolkits should include: • a clear definition of the decision to be made • steps that have been taken to help the person make the decision themselves • a current assessment concluding that the person lacks the capacity to make this decision • any other decision-making instruments that would prevent best interests decision-making occurring (for example a Lasting Power of Attorney, advance decisions, court orders) • a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including advanced statements • a prompt to consult interested parties (for example families, friends and Independent Mental Capacity Advocate and relevant professionals) and a record of who they are • advice about the degree of formality needed for the decision being made, for example a best interests meeting • guidance about recording best interests process and decision including a balance	BIA5

Recommendation	Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)
sheet of risks and benefits.	
Undertaking best interests decision making	
1.5.15 Anyone responsible for leading best interests decision-making must consider how best to involve the person in the process and document the steps taken.	BIA18
1.5.16 Practitioners must think about whether a decision can be delayed until the person has capacity to make a decision and allow all practicable steps to be taken in the interim to help them gain capacity.	BIA6
1.5.17 When making best interests decisions, explore whether there are less restrictive options that will meet the person's needs. Take into account: • what the person would prefer, including their wishes and feelings, based on past conversations, actions, choices, values or known beliefs • what decision the person who lacks capacity would have made if they were able to do so • all the different options • the restrictions and freedoms associated with each option • the likely risks associated with each option (including the potential negative effects on the person who lacks capacity to make a decision – for example trauma or disempowerment).	BIA6
1.5.18 When determining best interests the decision maker must establish whether the decision will deprive the person of their liberty and, if so, ensure that the appropriate legal authority is obtained in a timely manner.	BIA6
1.5.19 When an Independent Mental Capacity Advocate has been instructed they should be involved in the process until a decision has been made and implemented fully.	BIA11
1.5.20 Record best interests decisions in a way that is proportionate to its complexity, for example in a best interests toolkit or individual care record. As people’s circumstances change, review the decisions regularly to ensure that they remain in a person’s best interests.	BIA21

Recommendation	**Evidence statements and other supporting evidence (expert witness testimony Guideline Committee consensus)**
1.5.21 After the outcome has been decided, the decision maker should ensure that it is recorded and communicated to everyone involved and that there is opportunity for all participants to offer feedback or raise objections.	BIA18
1.5.22 If there is a dispute about a person's best interests, resolve this, where possible, before the decision is implemented – for example through further meetings or mediation. If this cannot be resolved locally, refer to the Court of Protection to determine the person's best interests.	GC consensus
1.5.23 Decision makers should specify a timely review of the implementation of the actions resulting from the best interests decision. If the review establishes that the best interests decision was not successfully actioned, the decision maker should take suitable steps such as: • convening a multi-agency meeting to resolve issues leading to the best interests decision not being successfully implemented, or • reassessing and making a new best interests decision that is more achievable, or • taking steps to refer the decision to the Court of Protection, or • re-considering whether any further action is appropriate.	GC consensus

3.7 Evidence to recommendations

Topic/section heading	Overarching principles
Recommendations	1.1.1 Service providers and responsible bodies should ensure that all practitioners undergo training to help them to apply the Mental Capacity Act 2005 and its Code of Practice. This includes role appropriate training for new staff, pre-registration, and continuing development and practice supervision for existing staff. Where appropriate, training should be interdisciplinary, involve experts by experience and include: • the statutory principles of the Mental Capacity Act 2005 • the importance of seeking consent for the process of advance care planning • how and when to have potentially difficult conversations about loss of autonomy, advance care planning or death • required communication skills for building trust to supported decision-making • clarity on roles and responsibilities • the advantages, disadvantages and ethics of advance care planning, and how to discuss these with the person and their carers, family and friends • condition-specific knowledge related to advance care planning, where appropriate • the conduct of decision-specific capacity assessments • the process of best interests decision-making in the context of section 4 of the Mental Capacity Act and associated guidance • how to direct people to sources of advice and information. 1.1.2 All health and social care organisations should: • develop local policy and guidance about which interventions, tools and approaches will be used to support decision-making. • identify or devise specific tools to help health and social care practitioners to assess the mental capacity of the people they are working with. 1.1.3 Co-develop policies and Mental Capacity Act training programmes with people who have experience of supported decision-making and of having their mental capacity assessed, and their carers, family and friends. 1.1.4 Practitioners should think about decision-making capacity every time a person is asked for consent, or to make a decision, during care and support planning (that is, not only as disagreement resolution).

	1.1.5 When giving information about a decision to the person: • it must be accessible, relevant, and tailored to the specific needs of the individual • it should be sufficient to allow the person to make an informed choice about the specific decision in question • it should be supported by tools such as visual materials, visual aids, communication aids and hearing aids, as appropriate. 1.1.6 Record and update information about people's wishes, beliefs and preferences in a way that practitioners from multiple areas (for example care staff, paramedics) can access and update. This information should be used to inform advance planning, supported decision-making and best interests decision-making.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	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 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? 3.2 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?
Quality of evidence	Recommendations 1.1.1 and 1.1.6 are based on evidence from review question 1 about advance planning. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. Recommendations 1.1.2, 1.1.3, 1.1.4 and 1.1.5 are based on evidence from review question 3 about assessment of mental capacity. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. In particular, no information were identified that would have allowed to compare the costs and outcomes of different training programmes. In addition, the evidence on effectiveness of tools was judged by the Guideline committee as not relevant and the Guideline committee felt thus unable to recommend a particular tool for assessing mental capacity. In terms of costs of training, the Committee referred to the ‘National Mental Capacity Act Competency Framework’. As highlighted in the Framework, localities could employ different

	strategies of how to help professionals and volunteers develop Mental Capacity Act skills: “This can be done by participating in formal training and development opportunities. However, there are also many opportunities for staff to learn and develop within the workplace, for example, discussions in team meetings, shadowing with more experienced staff, and mentoring opportunities.” More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial ‘end loading’ of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	APa4 There is a good amount of evidence that practitioners lack the requisite skills and training to conduct timely and competent discussions about advance care planning. The quality of the evidence is good. • Patients in the MacPherson (2012, ++) study described poor communication by health professionals, with some of them failing to discuss the person’s condition – let alone future plans – and others attempting to initiate advance planning discussions in such a way which upset the patient and triggered a formal complaint. • Almack et al (2012, ++) identified the need for training and

	developing experience in advanced communication as a key barrier to conducting advance planning discussions. - In Stewart et al (2011, ++) respondents suggested that work was needed to increase staff awareness about and understanding of Priorities for Care documentation because this lack of understanding was a major barrier to advance care planning. - Some of the community matrons in the Kazmierski study (2015, ++) said they had not received any training in decision making relating to ‘Do Not Attempt CPR resuscitation’. Although it had been mentioned in the practice context no training was available about how to approach those difficult discussions. - Care home staff said they felt intimidated at the prospect of initiating advance care planning discussions and others felt that they did not have a clear understanding of what was involved in advance care planning (Stone 2013, ++). (Recommendation 1.1.1) AP11a There was a good amount of qualitative evidence, of moderate quality, that advance planning should be completed early, to avoid the loss of capacity before advance care planning was in place. Manthorpe’s UK based (2014 +), study of dementia nurses, found that nurses often only came into contact with people once they had lost capacity, making assistance with advance planning difficult. Another UK qualitative study, Poppe (2013 +) found that the best time to discuss advance care planning was soon after dementia diagnosis, to maximise the persons input before they lost capacity, the study also found that a barrier to advance care planning completion was when a person was unwilling to accept their diagnosis. Sinclair (2016 +) also found that in UK based views evidence, that the best time to discuss advance care planning was when a person has come to terms with their diagnosis but still had capacity. Evidence from the UK about the importance of timing was also found in Robinson (2013 ++). This study found that delays in getting the advance care plan completed meant that they were not in place before the person lost capacity. This was particularly true of dementia. Samsi (2011 +) found that planning was difficult in the case of dementia suffers who did not wish to face their diagnosis. (Recommendation 1.1.1) AMC7 There is a good amount of evidence that perceived risk is sometimes conflated with capacity in the context of mental capacity assessments. The quality of the evidence is mixed. - Emmett et al (2013, -) found that practitioners used the likelihood of a risky decision by dementia patients as an indication that they lack capacity. Capacity considerations also appeared to be subsumed into wider discussions around risk and harm. (p22) - Similarly, dementia nurses felt that some practitioners were risk averse, particularly if a person’s capacity to

	- refuse a service was being queried (Manthorpe et al, 2014 +). (p24) - McDonald et al (2008, -) reported that social workers seemed to be influenced by an outcomes focussed approach to capacity that centred on risk. They report that people with dementia were often judged to lack capacity if they did not appear to agree with the social worker. (p25) - Clinical psychologists said that particularly among people living with dementia or learning disabilities, other professionals seemed to assume a lack of capacity so that the professional could make a "better" decision for the individual. (Walji et al, 2014 ++) (p36) - Finally, (Williams et al, 2014 +) found that health and social care practitioners start to question the capacity of service users when risk management strategies begin to fail, and that the concept of risk was sometimes being used interchangeably with capacity (Williams et al, 2014 +). (p38) (Recommendations 1.1.2, 1.1.3 and 1.1.4) AMC12 There is a small amount of evidence that in the context of capacity assessments, people are not given adequate or clearly presented information. The quality of the evidence is low. Emmett et al (2013, -) reported that dementia patients were not always given clearly presented information, particularly during discussions about admission to residential care. (p22) Similarly, McDonald (2008, -) reported that social workers did not always provide enough information to service users when assessing capacity. (p25) (Recommendation 1.1.5) AP3 There is a good amount of evidence from service users, carers and practitioners, that a person's choices and preferences should be represented in advance care planning, but some of the evidence was conflicting. A moderately well conducted qualitative UK study (Ashton 2014 +) a found that family carers, caring for people with dementia, wished to ensure that their relatives personal history and personality be represented in advance care plan. Another moderate quality, qualitative UK study related to dementia (Poppe 2013 +), found that service users felt advance care planning to be a positive experience because it enabled them to express their preferences. The study also found that carers were in favour of allowing service users to express their wishes, to avoid having to make decisions on their behalf later. However, Robinson (2013 ++), a well conducted qualitative UK study of practitioners found that practitioners working in dementia and end of life care services questioned whether advance care planning had the ability to deliver patient preferences. This was on the grounds that preferred care may not be available. Robinson also found that practitioners, such as ambulance staff, were unable to adhere to advance care plans due to conflicting duty of care responsibilities. (Recommendation 1.1.6)
Other considerations	Recommendation 1.1.1 is based on evidence synthesised in APa4 and AP11a and supported by expert testimony (EW LS).

	APa4 reported a good amount of evidence that practitioners lack the requisite skills and training to conduct timely and competent discussions about advance care planning. AP11 reported evidence from qualitative studies about the importance of the timing of advance care planning discussions. Evidence from expert testimony (EW LS) emphasised the crucial importance of communication as a means of building trust, which is essential to successfully supporting decision making. Drawing on this evidence and on their own practice experiences, the committee had long discussions about drafting recommendations for training on various separate aspects of decision making, for instance on supported decision making or on advance care planning. They eventually agreed to draft an overall training recommendation to appear in the overarching principles of the guideline, which would cover all aspects of practice under the Mental Capacity Act. The committee discussed whether the training recommendation should focus on particular staff groups but there was some concern that the evidence to do this is not strong enough. Ultimately the committee agreed that training to apply the Mental Capacity Act and Code of Practice is in any case important for all staff so the recommendation should apply generally. Finally, committee members were aware that it is not within the scope of the guideline to mandate a particular exam, assessment, or qualification but that they should instead focus on skills and competencies required to successfully enable people to participate in decision making. They agreed that mentoring, supervision and continuing professional development are all crucial for ensuring skills are learned, reviewed and consistently applied in practice. Recommendation 1.1.2 is based on a good amount of evidence in AMC7 that perceived risk is sometimes conflated with capacity in the context of mental capacity assessments. During discussions it was noted that whilst the quality of the evidence included in this statement was mixed, committee members were aware that this was an issue in practice and had been highlighted by recent legal reviews. It was suggested that a recommendation to ensure that capacity assessments are conducted within the terms of the Mental Capacity Act and Code of Practice could be a relatively straight-forward statement that assessments are recorded using standardised tools. However the group discussed whether standardised forms could help to improve recording and there were concerns regarding whether this was appropriate for all decisions. It was suggested that this might only be suitable for complex decisions rather than low level decisions made on a daily basis e.g. about clothes or food in a care home context. Since the evidence did not provide the basis to recommend a specific tool, the committee ultimately agreed to recommend that local policies and guidance should be developed and that specific tools, which meet the requirements of the Act and are appropriate to different decisions are devised and made available to practitioners. Recommendation 1.1.3 is based on the same discussions as those surrounding 1.1.2 and therefore also based on AMC7. The recommendation was finalised after expert witness testimony about the importance of involving experts by experience in

	training and in the development of the policies cited in 1.1.2 Recommendation 1.1.4 is also based on discussions about AMC7. Although the evidence was mixed, the expertise of the group supports the evidence statement. The committee focused on the point that assessments should not simply be conducted at the point when people disagree with a professional's decision. They also raised the point that practitioners need to be more aware of the need to obtain a person's consent around a decision and this may then flag the need for capacity assessment. However even if the person provides their consent and in doing so agrees with the practitioner, committee members were keen to point out that it should not be assumed that they have capacity or understand. These complexities led to the committee's decision to draft the recommendation that practitioners should always think about capacity in the context of obtaining consent. Recommendation 1.1.5 is based on AMC12 which reports a small amount of evidence that in the context of capacity assessments, people are not given adequate or clearly presented information. Although the quality of the evidence was low the findings resonated with the committee's expertise, especially the experts by experience. The group agreed that the provision if information in this context is fundamentally important. They felt strongly that the information provided as part of mental capacity assessments should be appropriate to the needs of the person and the decision that needed to be made and must not be overly complicated and it was noted that this reflected case law and judgements stating that the level of understanding should be similar to that expected from the general population. The group also agreed that the recommendation should include details regarding the use of images or visual aids to support those who may not be able to communicate verbally. Recommendation 1.1.6 is based on AP3 which reports that a person's choices and preferences should be represented in advance care planning although evidence that this happens is conflicting. The research findings were supported by the committee's own practice experiences which suggest that even if a person's wishes are known, they have not been recorded and even if they have been recorded are not accessible to practitioners who may be vital within the pathway of care and support. Paramedics and care staff were cited as practitioners who had particular difficulty in accessing records and this had implications for the care and support being delivered, sometimes compromising the person's expressed wishes. As a result of discussions the committee agreed to include this recommendation as an overarching principle because of the importance of recording and making available people's wishes for use in all aspects of decision making within the context of the Mental Capacity Act.

Topic/section heading	Using independent advocacy to support decision-making and assessment under the Mental Capacity Act

Recommendations	1.1.7 Commissioners should ensure that arrangements for the provision of independent advocacy include support for people to: • Enable them to make their own key decisions, for example, about their personal welfare, medical treatment, property or affairs • Facilitate their involvement in decisions that may be made, or are being made under the Mental Capacity Act. This could be achieved through expansion of existing statutory independent advocacy roles and/or commissioning and provision of non-statutory independent advocacy. 1.1.8 Practitioners should tell people about advocacy services as a potential source of support for decision-making, and for those who lack capacity, a referral should be made to an independent mental capacity advocacy. Where statutory criteria are met, practitioners must refer to the relevant advocacy service. Otherwise, think about referral to non-statutory advocacy services which will be dependent on local commissioning arrangements. 1.1.9 Consider providing independent advocacy when there is a safeguarding concern. 1.1.10 Commissioners, public bodies and providers of independent advocacy services should work closely to ensure that: • statutory duties on public bodies to refer to and involve independent advocacy are consistently adhered to and monitored and • failures in the duty to refer to statutory independent advocacy are addressed. 1.1.11 Commissioners, using their powers, including under the Mental Capacity Act 2005, should work with public bodies and providers to increase investment in training for statutory independent mental capacity and other statutory advocates in key areas. This includes training: • in communication with people who have minimal or no verbal communication **and** for Independent Mental Capacity Advocates to have expertise in specific areas that require additional skills and knowledge – for example working with people with acquired brain injury.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial

	interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendations 1.1.7 and 1.1.8 were both derived from expert witness testimony and the review of evidence for question 2, supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK.
Economic considerations	No economic evidence was identified to support the recommendations. The Guideline committee discussed if there were cases where involvement of an Independent Mental Capacity Advocate would make things more effective and it was suggested by some that there had been a definite improvement in change of accommodation decisions. It was noted that whilst the quality of decision making might improve it could lead to higher care costs; however there were also substantial improvement in quality of life. It was suggested that the involvement of Independent Mental Capacity Advocates leads to better decision-making, and ensures that decision makers have a better understanding of benefits and burdens, and enhances compliance with the best interests process. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels.

	In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there was likely to be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	SDM3 There is a small amount of evidence that using different forms of communication and delaying discussions helps to support people living with dementia to make every day decisions. The quality of the evidence is moderate. • A moderate quality UK study (Boyle, 2013 +) found that people living with dementia could be supported in every day decision making through; using different forms of communication, such as visual aids; having decisions delayed until a time when they felt calmer or more able to engage; reducing the length of discussions about decisions and if the person supporting them to make a decision could pick up on non-verbal cues such as facial expressions (p16). (Recommendations 1.1.7 and 1.1.8) SDM4 There is a small amount of evidence that people with learning disabilities can be supported to make decisions through the provision of information in a more accessible format and structured training to improve capacity. The quality of the evidence is low. • A low quality study (Dukes and McGuire, 2009 -) found that having followed an individualised sexual education programme, adults with learning disabilities had greater knowledge and better capacity to make informed choices on sexual decisions (p5).

	- Another low quality study (Ferguson and Murphy, 2013 -) found that providing information about medication through a training programme improved the capacity of adults with learning disabilities to give informed consent to treatment (p6). Recommendations 1.1.7 and 1.1.8 were also supported by expert witness testimony linked with the review of evidence for question 2, supported decision-making. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E.
Other considerations	Recommendations 1.1.7 and 1.1.8 are based on discussions about the evidence in SDM3 and SDM4 describing ways in which people can be successfully supported to participate in decision making. On the basis of the evidence the committee noted that there are principles and tools (e.g. talking mats and signing) which could be applicable to people living with dementia or with a learning disability. The committee acknowledged that there are ways of enabling people to participate in decision making, even where they are experiencing substantial difficulty and that this would not be limited to learning disabilities and dementia. They discussed other means of support (beyond those cited in the research) and agreed, on the basis of their expertise and then supported by expert testimony (EW LS) that it is appropriate to recommend independent advocacy as a means of providing the kind of support which is valued by people engaged in decision making. The committee agreed that in the context of the Act, local authorities have responsibility to provide independent advocacy and that 1.1.7 would therefore be a 'must' recommendation. With recommendation 1.1.8 the committee then highlighted the role of practitioners in telling people about their right to advocacy as a source of support during decision making – whether this be statutory or non-statutory services. During discussions, it became clear that given the practice and evolving policy and legal context there was a need to say more about the role of independent advocacy, particularly in terms of the responsibilities of commissioners and public bodies. However, the evidence reviewed and presented to the committee did not provide a sound basis for making such recommendations. Recommendations 1.1.9, 1.1.10 and 1.1.11 were therefore drafted on the basis of lengthy committee discussions, drawing on members' expertise and knowledge of consistent findings in a number of reports by the Department of Health, the Care Quality Commission and the House of Lords. The consistent message from this body of work, as it was interpreted by the committee, was that practitioners and people using services lack understanding of the critical role that Independent Advocacy can play in upholding rights and ultimately providing a safeguard from abuse in the context of decision making. Experts on the committee particularly focused on one of the key recommendations for the expansion of the role of Independent Mental Capacity Advocates in the House of Lords report on

	Mental Capacity Act implementation. However due to the lack of statutory instrument to enforce the recommendations, together with financial constraints, the committee pointed out that this has not resulted in any substantial change in capacity in England and Wales to allow for an expanded role. In addition one member pointed out that The UN Committee for the Convention on the Rights of Disabled Persons (CRPD) has been calling for nine years for countries to adopt regimes of supported decision making that provide access to individualised support which fully respects the autonomy, will and preferences of persons with disabilities. This is the space within which Independent Advocacy sits and the committee wished to 'strengthen' its resources through these three recommendations. They firmly believed that Independent Advocacy services require funding to expand both their statutory roles and non-statutory roles and the purpose of these recommendations is to draw attention to the need for this increased funding in England and Wales in order to increase capacity and reach as well as more effective monitoring of outcomes and increased specialised training. Finally, the committee recognised that Independent Advocacy is a relatively new discipline for Commissioners to fully understand in a crowded list of professions and services and aimed to therefore support commissioners through these recommendations.

Topic/section heading	Supported decision-making
Recommendations	1.2.1 Ask the person how they want to be supported and who they would like to have involved in decision-making in accordance with Mental Capacity Act Code of Practice, principle 2. 1.2.2 Practitioners supporting a person's decision-making should build and maintain a trusting relationship with them. 1.2.3 Practitioners should take into account the wide range of factors that can have an impact on a person's ability to make a decision. These should include: • the person's physical and mental condition • the person's communication needs • the person's previous experience (or lack of experience) in making decisions • the involvement of others • situational, social and relational factors • cultural, ethnic and religious factors • cognitive and emotional factors, or those related to symptoms. They should use this knowledge to support the person's decision-making.
Research	Research recommendation 1: What is the effectiveness and cost

recommendations	effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendation 1.2.1 was derived from expert witness testimony (EW LS) connected with the review on supported decision making. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E. Recommendations 1.2.2 and 1.2.3 were based on evidence reviewed for question 2, supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve

	while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	SDM2 There is some evidence, based on people's views and experiences, about what prevents them being involved in treatment decision-making. The quality of the evidence is good. • A good quality UK study (Goldsmith, 2013 ++) reported that in some of the consultations observed by the researcher, there appeared to be little or no explicit attempt to gain informed consent and patients were often given inadequate information about the procedure (p18). • Stovell et al (2016 ++) also reported that patients felt excluded from decision-making when they were given insufficient information about their condition and about treatment options. Being excluded from multi-disciplinary team discussions compounded this. Stovell et al also found that participants' felt they were being excluded because clinicians negatively judged them (p20). (Recommendations 1.2.2 and 1.2.3) SDM3 There is a small amount of evidence that using different forms of communication and delaying discussions helps to support people living with dementia to make every day decisions. The quality of the evidence is moderate. • A moderate quality UK study (Boyle, 2013 +) found that people living with dementia could be supported in every

	day decision making through; using different forms of communication, such as visual aids; having decisions delayed until a time when they felt calmer or more able to engage; reducing the length of discussions about decisions and if the person supporting them to make a decision could pick up on non-verbal cues such as facial expressions (p16). (Recommendations 1.2.2 and 1.2.3) SDM5 There is a small amount of evidence that even when they have capacity, people are excluded from decision-making about their own treatment or every day activities. The quality of the evidence is moderate to good. • A good quality study (Stovell et al, 2016 ++) reported that participants often felt disempowered and excluded from the treatment decision-making process (p20). • A moderate quality UK study (Boyle, 2013 +) found that some spouses clearly imposed their own will on their partner living with dementia, directing them toward their own preferred outcome during decision making. This included every day decision making but also bigger issues such as day centre or respite attendance (p16). (Recommendations 1.2.2 and 1.2.3)
Other considerations	Recommendation 1.2.1 is based on expert witness testimony (EW LS) which describes evidence that there are cultural variations in the way that people wish to be supported in decision making. The expert witness also endorsed asking people who they wished to involve in supporting their decision-making and given that this is also enshrined in principle 2 of the Mental Capacity Act the committee agreed the recommendation. Recommendation 1.2.2 is based on evidence synthesised in SDM2, SDM3 and SDM5 about what helps and what hinders people's involvement in decision-making. The committee felt that the research evidence highlighted the importance of human relationships in the context of supported decision making as well as the need for an understanding of how the person's condition affects their ability to communicate. The group felt that this evidence was later supported by expert witness testimony (EW LS) so they finalised the recommendation, emphasising the importance of building a trusting relationship. Recommendation 1.2.3 is also based on evidence in SDM2, SDM3, SDM5 about what helps and what hinders people's involvement in decision-making. They used the evidence, which was moderate to good in quality, combined with their own experiences of supported decision-making to identify a range of factors that could affect people's ability to participate in decision-making. They felt the onus should be on practitioners should to take account of these factors, address them and use them to support decision-making.

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Topic/section heading	Providing information to support decision-making

Recommendations	1.2.4 Practitioners should clearly determine, at the start, what information they need to cover the salient details of the decision they are supporting the person to make. This will depend on the nature and complexity of the decision itself. 1.2.5 Offer accessible information to everyone involved in supporting decision-making. This should be about the process and principles of supported decision-making as well as about the specific decision. 1.2.6 When providing the person with information to support a particular decision: • do so in line with the NHS Accessible Information Standard • support them to identify, express and document their own communication needs • ensure options are presented in a balanced and non-leading way. 1.2.7 Record the information that is given to the person during decision-making. Give the person an opportunity to review and comment on what is recorded and write down their views. 1.2.8 Consider tailored training programmes for the person, to provide information for specific decisions – for example sexual education programmes and medication management.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and

	approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendations 1.2.5 – 1.2.8 are based on evidence reviewed for question 2 about supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented in terms of volume was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK. Recommendation 1.2.4 was derived from expert witness testimony (EW LS) connected with the same review. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The

	Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial ‘end loading’ of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	SDM1 There is a moderate amount of evidence that certain approaches and interventions help to facilitate treatment decision-making. The quality of the evidence is mixed. • A good quality UK study (Goldsmith, 2013 ++) reported that consultations involving social chat and accessible explanations about the proposed medical intervention all helped to make participants with learning disabilities feel involved in giving informed consent (p18). • Another good quality study (Stovell et al, 2016 ++) reported that participants needed to be able to communicate their needs and feel listened to during treatment decision-making and when they were not, this made them feel disempowered (p20). • A low quality study (Ferguson and Murphy, 2013 -) found that the provision of information about medication through a training programme improved the capacity of people with learning disabilities to give informed consent (p6). • A low quality study (Naughton et al, 2012 -) found that group metacognitive training for patients with psychosis improved participants’ competence to consent to treatment and competence increased the more sessions the patient attended (p9). • Finally, a moderate quality US study (Woltmann et al, 2011 +) found that an electronic decision support system increased participants’ involvement in decision making about their care plan (p13). (Recommendations 1.2.5, 1.2.6, and 1.2.7) SDM6 There is some evidence that tailored training programmes increase people’s capacity to make a decision. The quality of the evidence is low. • A low quality study (Dukes and McGuire, 2009 -) found that having followed an individualised sexual education programme, adults with learning disabilities had greater capacity to make informed choices on sexual decisions (p5). • Another low quality study (Ferguson and Murphy, 2013 -) found that providing information about medication through a training programme improved the capacity of adults with learning disabilities to give informed consent to treatment (p6). • A low quality study (Naughton et al, 2012 -) found that group metacognitive training for patients with psychosis improved participants’ competence to consent to treatment. Competence to consent increased the more sessions the patient attended (p9) (Recommendation 1.2.8)

Other considerations	Recommendation 1.2.4 was derived from expert witness testimony, which placed the onus on practitioners to determine what information they need themselves and which they will then share with the person so they can make a fully informed decision. Recommendations 1.2.5, 1.2.6 and 1.2.7 are based on SDM1, which presents evidence about the effectiveness of a range of approaches to supported decision making. The committee did not feel the evidence provided a basis for recommending specific interventions but instead, the studies provided key messages for how supported decision-making should be approached. One of the key issues was ensuring clear explanations about supported decision-making and about the decision in question, including through the provision of accessible information, which is why the Accessible Information Standard is referenced in 1.2.6. The committee did discuss whether the provision of information and record keeping about the information provided ought to be replaced by an overarching recommendation but they felt strongly that it is crucial to stipulate the provision of accessible information in relation to supported decision making in order to maximise the chances that it is successfully carried out. Recommendation 1.2.8 is based on SDM6, which reported evidence about the effectiveness of tailored training programmes to increase capacity to make a decision. The evidence and the drafting of the recommendation were subject to much debate in the committee. Some members thought a recommendation was warranted on the basis of the evidence of improved capacity following the training programmes but this was challenged on the basis of study design, quality and sample size. In addition, one member noted that, almost universally, when a capacity issue is identified this type of intervention is already being suggested and it is difficult for legal professionals to keep up to date with the evidence for their effectiveness. The committee agreed they wished to make a recommendation on the basis of this evidence but were concerned about how to make it useful, considering the shortcomings of the studies. Eventually they agreed to develop a weaker ‘consider’ recommendation in favour of training programmes to support decision making. They provided two examples, sexual education and medication, which are derived from the evidence but are not intended to be an exhaustive list of recommended options.

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Topic/section heading	Supporting decision-making
Recommendations	1.2.9 Support people to communicate so that they can take part in decision-making. Use strategies to support the person's understanding and ability to express themselves in accordance with sections 3.10 and 3.11 of the Mental Capacity Act Code of Practice. 1.2.10 Support the person with decision-making even if they wish to make an unwise decision.

	1.2.11 Involve significant and trusted people in supporting decision-making, in line with the person's preferences. Have due regard for the principle of confidentiality set out in section 3.15 of the Mental Capacity Act Code of Practice. Ensure that this support is based on the person's wishes and preferences and is free from coercion or undue influence. If there are no significant trusted people, think about involving an advocate, particularly if the advocate has worked with the person before. 1.2.12 Practitioners should talk to the person and their carer, family and friends, as appropriate, about the potential consequences of supported decision-making. These could include increased autonomy, being better informed, sharing decisions with people interested in their welfare, talking about potentially upsetting issues including declining health or end of life, feeling overwhelmed with having to make a difficult decision at a difficult time and dealing with conflicting opinions.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendations 1.2.9, 1.2.11 and 1.2.12 were based on discussions around and the evidence from review area 2, supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in

	their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK. Recommendation 1.2.10 was based on evidence reviewed for question 4, best interests decision making. A total of 9 papers were included for this review, which provided data about views and experiences, ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal

	with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	SDM1 There is a moderate amount of evidence that certain approaches and interventions help to facilitate treatment decision-making. The quality of the evidence is mixed. • A good quality UK study (Goldsmith, 2013 ++) reported that consultations involving social chat and accessible explanations about the proposed medical intervention all helped to make participants with learning disabilities feel involved in giving informed consent (p18). • Another good quality study (Stovell et al, 2016 ++) reported that participants needed to be able to communicate their needs and feel listened to during treatment decision-making and when they were not, this made them feel disempowered (p20). • A low quality study (Ferguson and Murphy, 2013 -) found that the provision of information about medication through a training programme improved the capacity of people with learning disabilities to give informed consent (p6). • A low quality study (Naughton et al, 2012 -) found that group metacognitive training for patients with psychosis improved participants' competence to consent to treatment and competence increased the more sessions the patient attended (p9). • Finally, a moderate quality US study (Woltmann et al, 2011 +) found that an electronic decision support system increased participants' involvement in decision making about their care plan (p13). (Recommendation 1.2.11) BIA17 There is a small amount of evidence that best interests decisions are sometimes being made because practitioners believe that a person is likely to make an 'unwise' decision. The quality of the evidence is good. • Williams V et al (2012, +) found that a small minority of respondents reported that the main reason for deciding what was in the person's best interests was because the person was thought to have made an unwise decision. (Recommendation 1.2.10) SDM3 There is a small amount of evidence that using different forms of communication and delaying discussions helps to support people living with dementia to make every day decisions. The quality of the evidence is moderate. A moderate quality UK study (Boyle, 2013 +) found that people living with dementia could be supported in every day decision making through; using different forms of communication, such as visual aids; having decisions delayed until a time when they felt calmer or more able

	to engage; reducing the length of discussions about decisions and if the person supporting them to make a decision could pick up on non-verbal cues such as facial expressions (p16). (Recommendation 1.2.9) SDM7 There is some evidence that specific interventions can increase people's involvement in decision-making discussions. The quality of the evidence is low to moderate. • A low quality study by Murphy and Oliver (2013, -) found that the use of Talking Mats helped people living with dementia to feel more involved in decision-making discussions compared with participants using usual methods of communication (p8). • A moderate quality US study (Woltmann et al, 2011 +) found that an electronic decision support system for 'mental health consumers' increased participants' involvement in decision making about their care plan. This reflected that they had adequate opportunity to discuss what was on their mind before agreeing their care plan (p13). (Recommendation 1.2.9)
Other considerations	Recommendation 1.2.9 is based on evidence reported in SDM3 SDM7 and SDM4. The committee took the combined evidence to demonstrate that there are various principles and tools (such as talking mats and signing), which could support communication and enable the person to be involved in decision-making. Although some of the evidence related to people living with dementia the group felt that the recommendation should be made more broadly applicable to anyone with communication difficulties. The committee also cited expert testimony (EW LS), which emphasised that the efficacy of decision making is dependent on the way people are listened to and the way they have choices and information presented to them. Recommendation 1.2.10 is based on BIA17, which reported a small amount of evidence that best interests decisions are sometimes being made because practitioners believe that a person is likely to make an 'unwise' decision. This evidence strongly resonated with the experience of the group who agreed that sometimes the fact that someone is making an unwise decision actually triggers the assessment process. They reported that this is generally the case when others (practitioners and the family) don't agree with person's decision. The group therefore agreed to reiterate section 1.4 of the Act and state explicitly that the person should be supported with decision making regardless of whether their anticipated decision is judged by others to be unwise. Recommendation 1.2.11 is based on SDM1, which reports findings from a range of studies describing how various approaches helped people feel positively involved in supported decision making. The committee did not feel the evidence provided the basis for recommending specific interventions to support decision making (such as meta cognitive training or an electronic decision support system) but they did feel that combined with their own expertise some of the principles

	identified by the data should be recommended. It was particularly important that people should be enabled to express their preferences and although one way of doing this is to involve families the committee was in strong agreement that this involvement should be free from undue influence. Recommendation 1.2.12 is based on committee consensus following discussions about the evidence base for supported decision making. The committee did not feel that the evidence had provided a basis for a recommendation about alerting people to the potential consequences of supported decision-making. They nevertheless agreed it was important for practitioners to discuss the issues with the person, their carer and family before decision-making took place and this included both the positive and sometimes difficult consequences.

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Topic/section heading	Supporting decision-making (continued)
Recommendations	1.2.13 Give people time during the decision-making process to communicate their needs and feel listened to. Be aware that this may mean meeting with the person for more than 1 session. 1.2.14 Health and social care practitioners should increase the involvement of people and their carers, family and friends in decision-making discussions by using a range of interventions focused on improving shared decision-making and supported decision-making. 1.2.15 Where possible, ensure that the same practitioner provides continuous support to the person as they make different decisions at different points in time. 1.2.16 Health and social care practitioners should refer to other services (for example speech and language therapy and clinical psychology) that could help support decision-making when the person's level of need requires specialist input. This is especially important: • when the obstacles to decision-making are complex or • if there is a dispute between those making and supporting decisions or if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk). or • if the consequences of the decision would be significant (for example a decision about a highly complex treatment which carries significant risk).
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language

	therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendations 1.2.13, 1.2.14, and 1.2.15were based on evidence reviewed for question 2, supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK. Recommendation 1.2.16 was derived from expert witness testimony (EW LS) connected with the same review. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be

	less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	SDM1 There is a moderate amount of evidence that certain approaches and interventions help to facilitate treatment decision-making. The quality of the evidence is mixed. • A good quality UK study (Goldsmith, 2013 ++) reported that consultations involving social chat and accessible explanations about the proposed medical intervention all helped to make participants with learning disabilities feel involved in giving informed consent (p18). • Another good quality study (Stovell et al, 2016 ++) reported that participants needed to be able to communicate their needs and feel listened to during treatment decision-making and when they were not, this made them feel disempowered (p20). • A low quality study (Ferguson and Murphy, 2013 -) found that the provision of information about medication through a training programme improved the capacity of people with learning disabilities to give informed consent (p6). • A low quality study (Naughton et al, 2012 -) found that group metacognitive training for patients with psychosis improved participants' competence to consent to treatment and competence increased the more sessions the patient attended (p9). • Finally, a moderate quality US study (Woltmann et al, 2011 +) found that an electronic decision support system increased participants' involvement in decision making about their care plan (p13). (Recommendations 1.2.13 and 1.2.15) SDM7 There is some evidence that specific interventions can increase people's involvement in decision-making discussions. The quality of the evidence is low to moderate. • A low quality study by Murphy and Oliver (2013, -) found that the use of Talking Mats helped people living with dementia to feel more involved in decision-making discussions compared with participants using usual methods of communication (p 8). • A moderate quality US study (Woltmann et al, 2011 +) found that an electronic decision support system for 'mental health consumers' increased participants' involvement in decision

	making about their care plan. This reflected that they had adequate opportunity to discuss what was on their mind before agreeing their care plan (p 13). (Recommendation 1.2.14)
Other considerations	Recommendation 1.2.13 is based on evidence in SDM1, which reports findings from a range of studies describing how various approaches helped people feel positively involved in supported decision making. This was supported by EW (LS) who highlighted that the efficacy of decision making is dependent on the extent to which people are listened to and the way they have choices and information presented to them. Recommendation 1.2.14 is based on SDM7, which reports findings from 2 studies about the effectiveness of different interventions for supporting decision-making. The findings were mixed and the committee did not feel the evidence provided a basis for recommending a specific intervention. However some members felt it might be possible to make a recommendation regarding the importance of involvement and empowerment. Although they did not recommend a specific intervention they did recommend that practitioners use a range of interventions, which have the aim of improving supported decision-making. Recommendation 1.2.15 is based on SDM1, which reports findings from a range of studies describing how various approaches helped people feel positively involved in supported decision making. The committee agreed with the importance of people being able to communicate their needs and feeling listened. They felt that for this to be achieved, human relationships between the practitioner, the person and their families are incredibly important, as is an understanding of how the person's condition affects their ability to communicate. The committee agreed that trust is a part of this and very important for facilitating communication. In this context and supported by expert testimony (EW LS) the group agreed to recommend that there is continuity in terms of the practitioner supporting decision making in order to build up trust and understanding. Recommendation 1.2.16 Derived from expert witness testimony (EW LS) about the importance of involving other specialist services to enable the person's full participating in decision-making. The committee agreed with this and felt it was particularly important in complex cases or where there are likely to be disputes.

Topic/section heading	Supporting decision-making (continued)
Recommendations	1.2.17 Practitioners should make a written record of the decision-making process including: • steps taken to help the person make the decision • individuals involved in supporting the decision • information given to the person • key considerations for the person in making the decision • the decision reached • needs identified as a result of the decision

	- any further actions arising from the decision. 1.2.18 Organisations should ensure they can demonstrate that they monitor compliance with principle 2, section 1 (3) of the Mental Capacity Act.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	2a) What interventions, tools and approaches are effective and cost-effective in supporting people, on the presumption of capacity, to make decisions? 2b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support people, on the presumption of capacity, to make decisions?
Quality of evidence	Recommendations 1.2.17 and 1.2.18 are based on committee consensus and discussions about evidence reviewed for question 2, supported decision-making. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision-making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality and were all conducted in the UK.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already

	being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	Recommendations 1.2.17 and 1.2.18 were not derived from any specific evidence statements but from committee discussions about evidence from review question 2.
Other considerations	Following from this and in the context of the same discussions, recommendation 1.2.17 was also agreed on the basis of group consensus. The committee agreed that practitioners needed clear guidance about all the information they should record in the context of supported decision making, not least to ensure that all the important elements of this process are carried out. Recommendation 1.2.18 was suggested by a committee member after all the evidence about supported decision making had been reviewed and recommendations had been drafted. The committee member argued that although no specific research evidence provided the basis for this recommendation, practice experience would strongly suggest the need to monitor compliance with principle 2 of the Act. The suggestion was made for this

	recommendation during group work and then ratified by the full committee in plenary.

Topic/section heading	Advance care planning
Recommendations	Helping practitioners to undertake advance care planning 1.3.1 Health care commissioners and providers should: • develop standard protocols and plans for joint working and sharing of information on advance care plans between practitioners, people and families • commission training on advance care planning • demonstrate that protocols are in place and training is available by including advance care planning in audits. Providing information about advance care planning 1.3.2 Offer people verbal and written information about advance care planning, including how it relates to their own circumstances and conditions. All information sharing must fulfil the requirements of the NHS Accessible Information Standard. 1.3.3 If a person has recently been diagnosed with a long-term or life-limiting condition, give them information on: • their condition • the process of advance care planning • how they can change their minds or amend the decisions they make while they retain capacity to make them • services that will help in advance care planning.
Research recommendations	Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions?
Review questions	1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity? 1b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
Quality of evidence	Recommendations 1.3.1 to 1.3.3 are based on evidence from review question 1 on advanced planning. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were

	mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. 3 economic studies of Advance care planning for people reaching end of life were identified. The quality of studies was moderate to good and included 2 systematic reviews and 1 single cost-effectiveness study
Economic considerations	Recommendations 1.3.1 to 1.3.3 were supported by economic evidence on EcAPa1 and findings from the additional economic analysis, which was carried out for this guideline on advance care planning for older people reaching end of life (EcAPa3). 1.3.1 to 1.3.3 Economic evidence from published studies showed that advance care planning can reduce hospital costs at end of life by not providing unwanted life-sustaining treatment. However, studies had a limited cost perspective, were mainly from the US and referred to different interventions. Thus, additional economic analysis was carried out for this guideline. Findings from the additional economic analysis showed that advance care planning for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of the 4 hours assumed for the base case, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. However, the guideline committee thought that ensuring advance care planning was offered to individuals reaching end of life was the appropriate thing to do and was likely to save money. The Committee was convinced of the benefits of advance care planning from practice expertise and evidence: They thought that advance care planning could lead to important benefits for carers and families; it helped to reduce the huge pressure on carers and families that came from having to guess the end of life wishes of the person (e.g. Mum would have wanted x, y, z treatment). The committee also thought it had wider benefits by making sure that practitioners were engaging with and adhering to person's prior wishes and feelings. They thought that this also supported best interests. The committee thought that o order to achieve the benefits of advance care planning it was important to review/revisit the advance care plan when there was a change in treatment or a change in circumstances (rather than specifying a date).
Evidence statements – numbered	AP2 There is a moderate amount of evidence that practitioners find advance care planning potentially useful and relevant when working with people who may lack mental capacity, although

evidence statements from which the recommendations were developed	some of the views evidence is conflicting. A UK qualitative study of moderate quality (Samsi 2011 +) that gathered views and experience from Age Concern information and advice workers, found that advice related to advance care planning was valuable to assist people to put in place Lasting Power of Attorney (LPA) and encourage advance planning. Samsi (2011 +) found that an information service was valuable to those who did not have family carers. Another qualitative study of good quality (from Australia), (Seal 2007 +) found that 98-100% of nurses on the ward studied said that patients' self-determination at end of life was important and advance care planning helped people make choices. Robinson (2013 ++) found in interviews with 95 practitioners (in the UK) working in dementia and palliative care settings, that advance care planning was considered positive, but difficult to enact and deliver preferences as planned. Practitioners said that advance care planning could be duplicating person centred care measures already in place or risked becoming a tick box exercise. (Recommendation 1.3.1) AP1 There is some evidence that service users and family carers found advance care planning useful in discussions about future treatment and end of life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end of life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington's disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future. (Recommendation 1.3.2) AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end

	of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.3) AP10 There is a good amount of evidence from moderate quality data that the wishes of service users can conflict with that of carers or practitioners, leading to problems with implementation. Poppe (2013) also in interviews with service users and carers in the UK found that a barrier to advance care planning was when patients disagreed with family members or carers. Robinson (2013) reported in relation to dementia care and end of life care in the UK, that delivering patient preferences could be challenging if they conflict with family wishes. There was moderate quality evidence from the USA (Seal 2007 +) that found that nurses perceived that doctors gave end of life decision making responsibility to family members, limiting the involvement of the patient. One Canadian study (Bravo (2016 +) presents effectiveness evidence from a randomised control trial of an intervention designed to improve advance planning via written instructions and social work support. The intervention did not produce improvements in the proxy's abilities to predict the older person's preferences but there were greater levels of agreement following the three monthly sessions. (Recommendation 1.3.3) APA2 There is some evidence that advance care planning depends on the provision of a wide range of information, which is not always made available. The quality of the evidence is mainly good. • Respondents in the Barnes et al study (2007, ++) seemed to lack information about the process of advance planning. They had not realised they could make known their wishes over where to receive end of life care and had not had the opportunity for these discussions. • Some patients in the MacPherson study (2012, ++) were angered because they had been given little and sometimes no information about the nature of their condition and as a result felt in no position to discuss plans for care in the future. • Health professionals in the Almack study (2012, ++) said that the crucial decision about when to initiate discussions about end of life planning was triggered partly when patients indicated that they require information about their disease progression or treatment options. (Recommendation 1.3.3) EcAPa1 There is a large amount of economic evidence that Advance Care Planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies.

	• A systematic review of economic evidence (Dixon et al, 2015 +) summarized findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use; this ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost effectiveness. • A systematic review of economic evidence (Klingler et al, 2016 +) summarized findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings. • A single cost-effective study (Abel et al 2013, +) found that individuals in a hospice setting who used advance care plans spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, p<0.001); mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730; MD 3,569; p<0.001. (Recommendations 1.3.1 to 1.3.2) EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the ICER decreased

	to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. (Recommendations 1.3.1 to 1.3.2)
Other considerations	Recommendation 1.3.1 is based on evidence synthesised in AP2, which describes how beneficial advance care planning discussions appear to be but at the same time how practitioners often find them difficult to facilitate. Practitioners in 1 UK study also pointed out that advance planning discussions can sometimes appear to be a “box ticking” exercise. The committee were in agreement about the importance of therefore supporting practitioners to lead advance care planning discussions. They felt the responsibility for providing this support lay with health care commissioners and providers in the form of training, the development of protocols and audit. Recommendation 1.3.2 is based on evidence reported in AP1 that people and their families found advance planning discussions particularly useful for discussing future treatment and end of life care. It made them feel involved and empowered to express their preferences. In discussing the evidence the committee identified that in order for people to be able to express their preferences and fully engage in discussions they would need accessible verbal and written information about advance care planning. Although the evidence in AP1 referred to people with dementia and people with Huntingdon’s disease the committee agreed that on the basis of their own experiences of people benefitting from advance care planning, the recommendation should apply more broadly. Recommendation 1.3.3 is based on AP7, AP10 and APa2, which reported that practitioners were worried about causing distress through initiating advance planning discussions, that there are sometimes conflicts between people’s wishes and those of carers or practitioners and that information on advance care planning is not always readily available. The committee therefore agreed this recommendation to provide practitioners with guidance about the point at which to provide people with information about advance planning. In addition, to try and address uncertainties reported in Barnes et al (2007, ++) the committee wanted to ensure practitioners told people not only that they can express their preferences but also that they can later amend decisions while they retain capacity to do so.

Topic/section heading	Developing advance care plans collaboratively
Recommendations	1.3.4 All health and social care practitioners who come into contact with the person after diagnosis should help them to make an informed choice about participating in advance care planning. If they wish to do so, practitioners should facilitate this. 1.3.5 Offer the person a discussion about advance care planning:

	- at the most suitable time once they receive a diagnosis likely to make advance care planning useful and - at other times, allowing people to think through and address different issues in their own time. 1.3.6 Practitioners involved in advance care planning should ensure that they have access to information about the person's medical condition that helps them to support the advance care planning process. It is the practitioner's responsibility to identify what information they need. 1.3.7 When approaching discussions about advance care planning, health and social care practitioners should: - be sensitive, recognising that some people may prefer not to talk about this, or prefer not to have an advance care plan - be prepared to postpone discussions until a later date, if the person wishes - recognise that people have different needs for knowledge, autonomy and control - talk about the purpose, advantages and disadvantages of this type of planning - consider the use of checklists to support discussions.
Research recommendations	Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions?
Review questions	1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity? 1b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
Quality of evidence	Recommendations 1.3.4 to 1.3.7 are based on evidence from review question 1 on advanced planning. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. 3 economic studies of advance care planning for people reaching end of life were identified. The quality of studies was moderate to good and included 2 systematic reviews and 1 single cost-effectiveness study.
Economic	Recommendation 1.3.4 is based on EcAPa1 as well as on the

considerations	additional economic analysis, which was carried out on advance care planning for older people reaching end of life. Economic evidence from published studies showed that advance care planning can reduce hospital costs at end of life by not providing unwanted life-sustaining treatment. However, studies had a limited cost perspective, were mainly from the US and referred to different interventions. Thus, additional economic analysis was carried out for this guideline. Findings from the additional economic analysis showed that advance care planning for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of the 4 hours assumed for the base case, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. However, the guideline committee thought that ensuring advance care planning was offered to individuals reaching end of life was the appropriate thing to do and was likely to save money. The committee was convinced of the benefits of advance care planning from practice expertise and evidence: They thought that advance care planning could lead to important benefits for carers and families; it helped to reduce the huge pressure on carers and families that came from having to guess the end of life wishes of the person (e.g. Mum would have wanted x, y, z treatment). The committee also thought it had wider benefits by making sure that practitioners were engaging with and adhering to person's prior wishes and feelings. They thought that this also supported best interests. The committee thought that in order to achieve the benefits of advance care planning it was important to review/revisit the advance care plan when there was a change in treatment or a change in circumstances (rather than specifying a date).
Evidence statements – numbered evidence statements from which the recommendations were developed	AP12a There is a good amount of evidence that a variety of practitioners see providing advice on advance planning as part of their role but a lack of confidence or training could be a barrier. (Relating to evidence statement 12a). Manthorpe's (2014) moderate quality (+) study on dementia nurses reported that providing advice to carers about advance care planning measures like 'Lasting Power of Attorney' and end of life care was part of their role. Another UK based qualitative study, Samsi (2011 +) found that staff were trained in drawing up LPAs and had the confidence to do so. An Australian study of moderate quality Seal (2007 +) found that nurses saw helping patients make informed choices about end of life care as part of their role. Robinson (2013) found that the practitioners most likely to see advance care planning as part of their role were: Palliative care specialists, community nurses and some GPs but that some practitioners did not feel they had received adequate training. Similarly Poppe (2013 +) found that UK dementia care staff could lack confidence

	in discussing advance care planning. This barrier could be combatted by training or refresher training to increase confidence. Wilson (a UK study) (2010 ++) also found that some staff said they lacked training or had missed training in advance care planning, reducing their confidence or signposting to other agencies. Robinson (2013 ++) found that some practitioners were not clear on the legal status of advance care planning and what needed to be included in LPAs or ADRTs. Practitioners saw signposting to legal advice as part of their role. (Recommendations 1.3.4 and 1.3.5) AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.6) APa2 There is some evidence that advance care planning depends on the provision of a wide range of information, which is not always made available. The quality of the evidence is mainly good. • Respondents in the Barnes et al study (2007, ++) seemed to lack information about the process of advance planning. They had not realised they could make known their wishes over where to receive end of life care and had not had the opportunity for these discussions. • Some patients in the MacPherson study (2012, ++) were angered because they had been given little and sometimes no information about the nature of their condition and as a result felt in no position to discuss plans for care in the future. • Health professionals in the Almack study (2012, ++) said that the crucial decision about when to initiate discussions about end of life planning was triggered partly when patients indicated that they require information about their disease progression or treatment options. (Recommendation 1.3.6)

	AP1 There is some evidence that service users and family carers found advance care planning useful in discussions about future treatment and end of life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end of life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington's disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future. (Recommendation 1.3.7) AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.7) EcAPa1 There is a large amount of economic evidence that Advance Care Planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies. • A systematic review of economic evidence (Dixon et al, 2015 +) summarized findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use; this ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with

	dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost effectiveness. • A systematic review of economic evidence (Klingler et al, 2016 +) summarized findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings. • A single cost-effective study (Abel et al 2013, +) found that individuals in a hospice setting who used advance care plans spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, $p<0.001$); mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730; MD 3,569; $p<0.001$. (Recommendation 1.3.4) EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. (Recommendation 1.3.4)
Other considerations	Recommendation 1.3.4 is based on evidence in AP12a, which reported that a variety of practitioners saw advance care planning as an important part of their role but sometimes lacked

	confidence and expertise in this area. The committee's experience supported the evidence that there is sometimes a lack of clarity about who should be conducting advance care planning discussions. They therefore agreed this recommendation to provide guidance and emphasise that all health and social care practitioners who have contact with a person after diagnosis should enable advance care planning. After the initial drafting there was some concern among the committee that the recommendation would lead to lots of different practitioners encouraging a person to do something they may not want to do. They therefore altered the wording to reflect that practitioners should help them make a choice about whether to conduct advance planning – as opposed to saying that all practitioners should conduct advanced planning. Recommendation 1.3.5 is based on the same discussions about AP12a with the committee aiming to provide guidance about when advance care planning discussions should be offered. They felt that timing was crucial and ought to be tailored to the person in the context of their diagnosis. They also agreed with the evidence that advance planning is a process and not a one off conversation at a specific point in time. Recommendation 1.3.6 is based on evidence in AP7 and APa2. AP7 reported findings that families and practitioners were worried about causing distress through initiating advance care planning discussions. APa2 reported good quality evidence that advance care planning is sometimes compromised when people are given inadequate information as a part of the process or if practitioners themselves lack information about the person they are attempting to support through planning discussions. The committee agreed that having clinical information about the person's condition is crucial to advance care planning. There was a strong feeling among the group that the onus should be on the practitioner to obtain and provide information rather than being the responsibility of the person to ask for the information during advance planning. Recommendation 1.3.7 is based on evidence in AP1 and AP7. AP1 reported that people and families found advance planning discussions were useful, particularly in terms of decisions about future treatment and end of life care. The committee accepted this is one perspective but they were also aware that in practice not everyone will want to talk about future preferences or will want an advance care plan, and tact should be used in how practitioners approach them. This need for sensitivity and flexibility is supported by research findings in AP7 and led the committee to agree a recommendation that would provide guidance about how to take a sensitive approach to advance planning discussions.

Topic/section heading	Developing advance care plans collaboratively (continued)
Recommendations	1.3.8 If the person has given consent for carers, family and friends to be involved in discussions about advance care planning, practitioners should take reasonable steps to include

	them. 1.3.9 Health and social care practitioners should help everyone to take part in advance care planning and co-produce their advance care plan if they choose to have one (including people with fluctuating or progressive conditions). They should: • work with the person to identify any barriers to their involvement, and investigate how to overcome these • help them to communicate by providing communication support appropriate to their needs (for example, communication aids, advocacy support, interpreters, specialist speech and language therapy support, involvement of family members or friends). 1.3.10 During advance care planning discussions, practitioners should: • take into account the person's history, social circumstance, wishes and feelings, values and beliefs (including religious, cultural and ethnic factors), aspirations and any other factors they may consider important to them • help the person to anticipate how their needs may change in future. 1.3.11 In line with the Mental Capacity Act Code of Practice practitioners must ensure that: • all notes made on advance care planning are contemporaneous and • the notes are agreed with the person using services at the time and • permission is sought to share the information with other people.
Research recommendations	Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions?
Review questions	1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity? 1b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
Quality of evidence	Recommendations 1.3.8 to 1.3.11 are based on evidence from review question 1 on advanced planning and expert witness testimony (EW LS) linked with that review. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were

	included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. Three economic studies of advance care planning for people reaching end of life were identified. The quality of studies was moderate to good and included 2 systematic reviews and 1 single cost-effectiveness study.
Economic considerations	Recommendation 1.3.9 was supported by EcAPa1 as well as finding from the additional economic analysis, which was carried out for this Guideline on advance care planning for older people reaching end of life (EcAPa3). Economic evidence from published studies showed that advance care planning can reduce hospital costs at end of life by not providing unwanted life-sustaining treatment. However, studies had a limited cost perspective, were mainly from the US and referred to different interventions. Thus, additional economic analysis was carried out for this guideline. Findings from the additional economic analysis showed that advance care planning for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of the 4 hours assumed for the base case, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. However, the guideline committee thought that ensuring advance care planning was offered to individuals reaching end of life was the appropriate thing to do and was likely to save money. The committee was convinced of the benefits of advance care planning from practice expertise and evidence: They thought that advance care planning could lead to important benefits for carers and families; it helped to reduce the huge pressure on carers and families that came from having to guess the end of life wishes of the person (e.g. Mum would have wanted x, y, z treatment). The committee also thought it had wider benefits by making sure that practitioners were engaging with and adhering to person's prior wishes and feelings. They thought that this also supported best interests. The committee thought that o order to achieve the benefits of advance care planning it was important to review/revisit the advance care plan when there was a change in treatment or a change in circumstances (rather than specifying a date).
Evidence statements – numbered evidence statements from	AP1 There is some evidence that service users and family carers found advance care planning useful in discussions about future treatment and end of life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family

which the recommendations were developed	carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end of life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington's disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future. (Recommendation 1.3.8) AP1 There is some evidence that service users and family carers found advance care planning useful in discussions about future treatment and end of life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end of life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington's disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future. (Recommendation 1.3.9) AP2 There is a moderate amount of evidence that practitioners find advance care planning potentially useful and relevant when working with people who may lack mental capacity, although some of the views evidence is conflicting. A UK qualitative study of moderate quality (Samsi 2011 +) that gathered views and experience from Age Concern information and advice workers, found that advice related to advance care planning was valuable to assist people to put in place Lasting Power of Attorney (LPA) and encourage advance planning. Samsi (2011 +) found that an information service was valuable to those who did not have family carers. Another qualitative study of good quality (from Australia), (Seal 2007 +) found that 98-100% of nurses on the ward studied said that patients self-determination at end of life was important and advance care planning helped people made choices. Robinson (2013 ++) found in interviews with 95 practitioners (in the UK) working in dementia and palliative care settings, that advance care planning was considered positive, but difficult to enact and deliver preferences as planned. Practitioners said that advance care planning could be duplicating person centred care measures already in place or risked becoming a tick box exercise. (Recommendation 1.3.9)

	AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.9) AP3 There is a good amount of evidence from service users, carers and practitioners, that a person's choices and preferences should be represented in advance care planning, but some of the evidence was conflicting. A moderately well conducted qualitative UK study (Ashton 2014 +) a found that family carers, caring for people with dementia, wished to ensure that their relatives personal history and personality be represented in advance care planning. Another moderate quality, qualitative UK study related to dementia (Poppe 2013 +), found that service users felt advance care planning to be a positive experience because it enabled them to express their preferences. The study also found that carers were in favour of allowing service users to express their wishes, to avoid having to make decisions on their behalf later. However, Robinson (2013 ++), a well conducted qualitative UK study of practitioners found that practitioners working in dementia and end of life care services questioned whether advance care planning had the ability to deliver patient preferences. This was on the grounds that preferred care may not be available. Robinson also found that practitioners, such as ambulance staff, were unable to adhere to advance care plans due to conflicting duty of care responsibilities. (Recommendation 1.3.10, partly informed by expert witness testimony EW LS) AP12a There is a good amount of evidence that a variety of practitioners see providing advice on advance planning as part of their role but a lack of confidence or training could be a barrier. (Relating to evidence statement 12a). Manthorpe's (2014) moderate quality (+) study on dementia nurses reported that providing advice to carers about advance care planning measures like 'Lasting Power of Attorney' and end of life care was part of their role. Another UK based qualitative study, Samsi (2011 +) found that staff were trained in drawing up LPAs and had the confidence to do so. An Australian study of moderate quality Seal

	(2007 +) found that nurses saw helping patients make informed choices about end of life care as part of their role. Robinson (2013) found that the practitioners most likely to see advance care planning as part of their role were: Palliative care specialists, community nurses and some GPs but that some practitioners did not feel they had received adequate training. Similarly Poppe (2013 +) found that UK dementia care staff could lack confidence in discussing advance care planning. This barrier could be combatted by training or refresher training to increase confidence. Wilson (a UK study) (2010 ++) also found that some staff said they lacked training or had missed training in advance care planning, reducing their confidence or signposting to other agencies. Robinson (2013 ++) found that some practitioners were not clear on the legal status of advance care plans and what needed to be included in LPAs or ADRTs. Practitioners saw signposting to legal advice as part of their role. (Recommendation 1.3.11) EcAPa1 There is a large amount of economic evidence that Advance Care Planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies. • A systematic review of economic evidence (Dixon et al, 2015 +) summarized findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use; this ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost effectiveness. • A systematic review of economic evidence (Klingler et al, 2016 +) summarized findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings. • A single cost-effective study (Abel et al 2013, +) found that individuals in a hospice setting who used advance care plans spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, p<0.001); mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730; MD 3,569; p<0.001.

	(Recommendation 1.3.9) EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. (Recommendation 1.3.9)
Other considerations	Recommendation 1.3.8 is based on evidence reported in AP1 that people and their families found it beneficial to have advance care planning discussions about future treatment and end of life care. Although the committee agreed about the importance of involving families in advance planning discussions they though it was more relevant to recommend the involvement of a wider group of people, hence carers, family and friends. They agreed that practitioners had responsibility to take all reasonable steps to facilitate their involvement, assuming the person has provided consent for them to do so. Recommendation 1.3.9 is based on AP1, AP2 and AP7. The evidence in AP1 suggested that people and families found advance care planning discussions useful, especially about future treatment and end of life care. AP2 reported that practitioners also find it useful to carry out advance care planning discussions although there is a risk it can become a ‘tick box’ exercise. AP7 supported this although data highlighted how difficult practitioners can find it to initiate these discussions. This prompted the committee to acknowledge that in practice it can be difficult to carry out advance care planning discussions, fully involving the person and their friends and family and that there may be reasons for this beyond the sensitivity of the subject. They therefore agreed about the importance of taking every reasonable step to enable people to engage in advance planning so they drafted the recommendation to make practitioners aware of the different

	ways this can be done and help with communication was seen as particularly crucial. Recommendation 1.3.10 is based on AP3 and supported by expert testimony about the range of details seen as crucial to discuss and record during advance care planning. The evidence in AP3 gave the committee the basis to state that advance care plans should include a person’s history as well as their preferences and wishes. To address equalities issues the committee also agreed to include religious, cultural and ethnic factors which may have a bearing on people’s choices and preferences. In addition the expert testimony led the committee to highlight the importance of practitioners helping people to think about how their needs may change in future and to incorporate this in decisions and planning. Recommendation 1.3.11 is based on AP12a, derived from evidence identified in the additional search on advance care planning. The evidence statement identified how practitioners saw advance care planning as an important part of their role but sometimes lacked confidence and expertise in this area. The committee’s experience supported the evidence that there is a lack of understanding about advance decisions and planning and they therefore agreed this recommendation to provide guidance about recording decisions and seeking permission to share the information with others. Finally the committee agreed this would be a ‘must’ recommendation because the main messages are enshrined in the Act.

Topic/section heading	Developing advance care plans collaboratively (continued)
Recommendations	1.3.12 Provide the person with an accessible document that records their wishes, beliefs and preferences in relation to advance care planning and which they may take with them to show different services. It may include who the person wants to have involved in decision-making or their preferences for issues such as treatment, support or accommodation. 1.3.13 Practitioners should share the advance care plan in a clear and simple format with everyone involved in the person’s care, if the person has given consent. 1.3.14 Practitioners should ensure that information about a person’s advance care plan is, with their consent, transferred between services when their care provider changes.
Research recommendations	Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions?
Review questions	1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity? 1b) What are the views and experiences of people who may lack

	mental capacity, their families and carers and others interested in their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
Quality of evidence	Recommendations 1.3.12 to 1.3.14 are based on evidence from review question 1 on advanced planning. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. 3 economic studies of advance care planning for people reaching end of life were identified. The quality of studies was moderate to good and included 2 systematic reviews and 1 single cost-effectiveness study.
Economic considerations	Recommendations 1.3.12 and 1.3.14 were supported by EcAPa1 as well as by findings from the additional economic analysis, which was carried out for this guideline on advance care planning for older people reaching end of life (EcAPa3). 1.3.12 to 1.3.14 Economic evidence from published studies showed that advance care planning can reduce hospital costs at end of life by not providing unwanted life-sustaining treatment. However, studies had a limited cost perspective, were mainly from the US and referred to different interventions. Thus, additional economic analysis was carried out for this guideline. Findings from the additional economic analysis showed that advance care planning for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of the 4 hours assumed for the base case, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. However, the guideline committee thought that ensuring advance care planning was offered to individuals reaching end of life was the appropriate thing to do and was likely to save money. The Committee was convinced of the benefits of advance care planning from practice expertise and evidence: They thought that advance care planning could lead to important benefits for carers and families; it helped to reduce the huge pressure on carers and families that came from having to guess the end of life wishes of the person (e.g. “Mum would have wanted x, y, z treatment”). The

	committee also thought it had wider benefits by making sure that practitioners were engaging with and adhering to person’s prior wishes and feelings. They thought that this also supported best interests. The committee thought that in order to achieve the benefits of advance care planning it was important to review/revisit the advance care plan when there was a change in treatment or a change in circumstances (rather than specifying a date).
Evidence statements – numbered evidence statements from which the recommendations were developed	APa7 There is a small amount of low quality evidence that Joint Crisis Plans positively affect self-determination among people using psychiatric services. In a survey of participants in a controlled trial of joint crisis plans, Henderson et al (2009, -) found that producing and holding the plans promoted self-determination and empowerment among people using psychiatric services. However it should be noted that there was no change in participants’ overall rating of joint crisis plans (p = 0.003). (Recommendations 1.3.12 and 1.3.13) AP1 There is some evidence that service users and family carers found advance care planning useful in discussions about future treatment and end of life care. This statement is evidenced by UK based qualitative studies related to dementia sufferers. A moderate quality qualitative study (Ashton 2014 +) of family carers to those with dementia, found advance care planning relevant to them and welcomed the opportunity to be involved, particularly in end of life care. Another moderate quality study (Poppe 2013 +) reported that advance care planning was seen by most service users as positive and helpful as an experience, because they felt they had had the opportunity to express preferences. There is also evidence from another UK based moderate quality study (Bisson 2009) that people with a diagnosis of Huntington’s disease were positive about discussing advance care planning because it increased feeling of autonomy and allowed them to make decisions about the future. (Recommendation 1.3.14) AP2 There is a moderate amount of evidence that practitioners find advance care planning potentially useful and relevant when working with people who may lack mental capacity, although some of the views evidence is conflicting. A UK qualitative study of moderate quality (Samsi 2011 +) that gathered views and experience from Age Concern information and advice workers, found that advice related to advance care planning was valuable to assist people to put in place Lasting Power of Attorney (LPA) and encourage advance planning. Samsi (2011 +) found that an information service was valuable to those who did not have family carers. Another qualitative study of good quality (from Australia), (Seal 2007 +) found that 98-100% of nurses on the ward studied said that patients self-determination at end of life was important and advance care planning helped people made choices. Robinson (2013 ++) found in interviews with 95 practitioners (in the UK) working in dementia and palliative care settings, that advance care planning was considered positive, but difficult to enact and deliver preferences as planned. Practitioners said that advance care planning could be duplicating person centred care

	measures already in place or risked becoming a tick box exercise. (Recommendation 1.3.14) AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington's disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.14) EcAPa1 There is a large amount of economic evidence that Advance Care Planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies. • A systematic review of economic evidence (Dixon et al, 2015 +) summarized findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use; this ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost effectiveness. • A systematic review of economic evidence (Klingler et al, 2016 +) summarized findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings. • A single cost-effective study (Abel et al 2013, +) found that

	individuals in a hospice setting who used advance care planning spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, p<0.001); mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730; MD 3,569; p<0.001. (Recommendation 1.3.12 to 1.3.14) EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. (Recommendation 1.3.12 to 1.3.14)
Other considerations	1.3.12 and 1.3.13 are based on APa7, which reports evidence that holding joint crisis plans improves self-determination and empowerment among people using psychiatric services. The committee noted that the evidence statement was derived from just one low quality study, which was specifically about Joint Crisis Plans for people with particular needs. They therefore discussed whether it would be appropriate to make recommendations on the basis of the evidence statement. The group felt that it would be acceptable to extrapolate from the evidence statement and draft a recommendation in which it was outlined that advance care plans should be made accessible, available, discussed appropriately, as an option, at point of diagnosis.) It was also suggested that practitioners should ask patients who they wanted to share copies of the plan with. One member added that the Mental Health Act was clear on this issue, and required that practitioners should always share plans with patients. The committee also discussed what the Mental Capacity Act required in relation to advance planning and it was noted that the focus tended to be on written advance decisions, with the language suggesting that the individual 'owns' the document. The

	committee therefore agreed that the recommendations should reinforce current thinking regarding ownership of medical records. On the basis of these considerations, it was agreed that the recommendations should be ‘strong’ despite the evidence underpinning APa7. Recommendation 1.3.14 is based on AP1, AP2 and AP7. The evidence in AP1 suggested that people and families found advance care planning discussions useful, especially about treatment and end of life care. AP2 reported that practitioners also find it useful to carry out advance care planning discussions although there is a risk it can become a ‘tick box’ exercise. AP7 supported this although data highlighted how difficult practitioners can find it to initiate these discussions. In discussing the evidence the committee agreed about the importance of advance care planning discussions but some of them raised the point that having had these sensitive discussions, plans often get lost when people move between services and these are not conversations that people should be expected to engage in every time they come in contact with another service or practitioner. The committee therefore agreed that on the basis that discussions should take place and with the outcome having been recorded (as in recommendations 1.3.12) then with the person’s consent, the advance plan should be transferred whenever there are changes in care provider.

Topic/section heading	Developing advance care plans collaboratively (continued)
Recommendations	1.3.15 Review advance care plans at reviews of treatment or support, while the person has capacity, and amend as necessary, if the person wishes. 1.3.16 When people are reaching the end of life, give them the opportunity to review or develop an advance care plan if they haven't already done so. Joint crisis planning 1.3.17 Offer joint crisis planning to anyone who has a mental disorder with an assessed risk of relapse or deterioration and who is in contact with specialist mental health services. The offer should be documented and, if the person accepts it, the plan should be recorded.
Research recommendations	Research recommendation 3: What is the effectiveness and cost effectiveness of targeted advance care planning interventions?
Review questions	1a) What interventions, tools and approaches are effective and cost-effective in supporting advance planning for decision-making for people who may lack mental capacity? 1b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in

	their welfare, on the acceptability of interventions, tools and approaches to support planning in advance for decision-making?
Quality of evidence	Recommendations 1.3.15, 1.3.16 and 1.3.17 are all based on evidence reviewed for question 1 on advance planning. From the original search on advance planning a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. 3 economic studies of advance care planning for people reaching end of life were identified. The quality of studies was moderate to good and included 2 systematic reviews and 1 single cost-effectiveness study. 3 cost-effectiveness studies were identified that evaluated Joint crisis planning for people with severe mental health problems and in contact with mental health services. All 3 studies were of high quality and used randomised controlled designs. 2 referred to people living with psychosis and 1 feasibility trial referred to people living with borderline personality disorder.
Economic considerations	Recommendations 1.3.16 and 1.3.17 are based on EcAPa1 and EcAPa2 as well as by the additional economic analysis, which was carried out on advance care planning for this Guideline (EcAPa3). 1.3.16 Economic evidence from published studies showed that advance care planning can reduce hospital costs at end of life by not providing unwanted life-sustaining treatment. However, studies had a limited cost perspective, were mainly from the US and referred to different interventions. Thus, additional economic analysis was carried out for this guideline. Findings from the additional economic analysis showed that advance care planning for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of the 4 hours assumed for the base case, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. However, the guideline committee thought that ensuring Advance care planning was offered to individuals reaching end of life was the appropriate thing to do and was likely to save money. The

	committee was convinced of the benefits of advance care planning from practice expertise and evidence: They thought that advance care planning could lead to important benefits for carers and families; it helped to reduce the huge pressure on carers and families that came from having to guess the end of life wishes of the person (e.g. “Mum would have wanted x, y, z treatment”). The committee also thought it had wider benefits by making sure that practitioners were engaging with and adhering to person’s prior wishes and feelings. They thought that this also supported best interests. The committee thought that o order to achieve the benefits of advance care planning it was important to review/revisit the advance care plan when there was a change in treatment or a change in circumstances (rather than specifying a date). 1.3.17 The guideline committee thought it was important to emphasise that the Code of Practice 1.7 to 1.12 in the Mental Health Act set out that joint crisis planning was required for people who were in the care of specialist mental health services. The committee also thought that it reflected good practice and that evidence suggested that it was good value for money. The committee highlighted important gaps in (cost-) effectiveness evidence in regards to people who were not in specialist mental health treatment.
Evidence statements – numbered evidence statements from which the recommendations were developed	AP7 There is a good amount of evidence that practitioners and carers saw advance care planning as a necessary but sensitive topic and had concerns about causing distress. A moderate quality, qualitative UK study (Ashton 2014 +) found that family carers found discussing end of life care uncomfortable, but saw it as a necessary to approach inevitable decisions. Another qualitative study of moderate quality from the UK (Bisson 2009 +) also found that practitioners working with people with Huntington’s disease were reluctant to raise the topic of advance care planning because they were concerned about causing distress. A good quality mixed methods study conducted in the UK (Robinson 2013 ++) found that practitioners felt that end of life care and advance treatment were difficult to discuss topics, but could help people resolve fears. Wilson 2010 had good quality evidence from the UK (++) and reported that practitioners felt that sensitivity was necessary when discussing difficult topics like end of life care and the prospect of diminished capacity. Poppe 2013 (+), also found that staff in the UK needed to feel competent in having difficult conversations about advance care planning. (Recommendation 1.3.15) EcAPa1 There is a large amount of economic evidence that Advance Care Planning for people reaching end of life can reduce the costs of hospital care. The quality of evidence is mixed and refer to a wide range of different settings; most studies were from the US. No conclusions can be drawn about total costs or outcomes from those studies. • A systematic review of economic evidence (Dixon et al,

2015 +) summarized findings on identified cost savings in the majority of economic evaluations of advance care planning; they found that those primarily referred to reductions in hospital use; this ranged from USD 64,827 for the terminal hospital stay to USD 56,700 for total healthcare costs over the past 6 months for people with dementia and USD 1,041 in hospital costs over the last week of life for those with cancer; however, neither individual health and wellbeing outcomes nor other costs – including those of community health and social care and those from a societal perspective (unpaid care, out-of-pocket expenditure) – were not captured so that no final conclusions could be drawn about cost effectiveness.

- A systematic review of economic evidence (Klingler et al, 2016 +) summarized findings on cost savings identified in the majority of economic evaluations; most individual studies measured hospital costs but did not include a comprehensive cost perspective; cost savings ranged from USD 1,041 to USD 64,830; studies which evaluated programme costs were relatively small amounting to 6 to 15% of cost savings.
- A single cost-effective study (Abel et al 2013, +) found that individuals in a hospice setting who used advance care planning spent considerable less time in hospital in their last year of life (IG 18.1 vs. CG 26.5 days, p<0.001); mean cost of hospital treatment during the last year of life for those who died in hospital was £11,299, those dying outside of hospital £7,730; MD 3,569; p<0.001. (Recommendation 1.3.16)

EcAPa2 There is a small amount of economic evidence that joint crisis plans (JCP) for people with psychosis or borderline personality disorder can lead to reductions in compulsory treatment under the Mental Health Act and be cost-effective from a public-sector perspective. The quality of studies is high; the described intervention is the same between studies, which were carried out by the same group of researchers increasing the homogeneity between studies.

- A single cost-effectiveness study (Flood et al 2006, ++) found that individuals with psychosis who were currently not in inpatient care had significantly less compulsory admissions under the Mental Health Act (13% vs. 27%, P=0.03); there was a non-significant reduction in hospital admissions and in public sector costs; cost effectiveness acceptability curves suggested there was a greater than 78% probability that JCP was more cost effective than standardised service information in reducing the proportion of patients admitted to hospital.
- A multi-centre cost effectiveness study (Barrett et al 2013, ++) found that individuals with psychosis had no significant changes in any of the costs or outcomes (including compulsory admissions); however, JCP had 80% probability of being cost-effective from a public-sector

	perspective (but only 40% from a societal perspective); results varied noticeably between ethnic groups and JCP was more cost-effective for Black for certain groups of people with psychosis. - A small feasibility cost consequences and utility study (Borschmann et al 2013, ++) found that individuals with borderline personality disorder, who self-harmed in the last year and were under ongoing care of a community mental health team, had no significant changes in any of the outcomes (including self-harm and QALY at 6 month); there was no significant difference in mean costs; the incremental cost-effectiveness ratio is -£32,358 suggesting that JCP was less costly and more effective than standard care. (Recommendation 1.3.17) EcAPa3 Economic evidence from additional economic analysis carried out for this Guideline showed that advance care planning carried out for older people towards the end of life had a 55% to 70% probability to be cost-effective when compared with standard care. This was based on willingness-to-pay (WTP) thresholds of between £20,000 and £30,000. The mean incremental cost-effectiveness ratio (ICER) for the base case was £18,600. Costs included those to the NHS as well as Personal Social Services (PSS). Outcomes referred to quality-adjusted life years gained from the perspective of the person caring for the person dying. The mean cost of advance care planning was £821; costs ranged between £214 and £1,874. Mean total costs in the advance care planning group were £3,748 (SD 539, 95% CI 502 to 572) and £3,072 (SD 354, 95% 332 to 376) in the standard care group. The mean difference in total costs between the 2 groups was £677 (SD 430, 95% CI 403 to 457). Mean quality-adjusted life years was 0.83 in the advance care planning group (SD 0.07, 95% CI 0.83 to 0.84) and 0.8 in the standard care group (SD 0.06, 95% CI 0.79 to 0.8). The mean difference in quality-adjusted life years was 0.04 (SD 0.02, 95% CI 0.03 to 0.04). In sensitivity analysis it showed that if the mean duration of advance care planning discussions was 2 hours instead of 4 hours, the ICER decreased to £8,233 and the probabilities that advance care planning was cost-effective increased to between 80% and 90%. The Guideline committee discussed whether this shorter duration could be recommended as good practice but did not come to an agreement. (Recommendation 1.3.16)
Other considerations	Recommendation 1.3.15 is based on evidence statement AP7, which describes how practitioners see advance planning as a very important component of care, support and treatment. Having developed advance plans the committee therefore agreed it was important to ensure that they are reviewed – and amended if necessary - at important points, for instance during treatment reviews. Recommendations 1.3.16 and 1.3.17 are based on economic evidence (EcAPa1 and EcAPa2). Committee discussions, which led from the evidence to the recommendations are described above in ‘economic considerations’.

Topic/section heading	Assessment of mental capacity
Recommendations	1.4.1 Health and social care organisations should monitor and audit the quality of mental capacity assessments. 1.4.2 Consider including people's views and experiences in data collected for monitoring an organisation's capacity assessment activity. 1.4.3 Organisations should ensure that assessors should be able to seek advice from people with specialist condition-specific knowledge to assist them to assess capacity – for example clinical psychology and speech and language therapists. 1.4.4 Organisations with responsibility for accessible care plans should ensure that they record that the person consents to the care plan and identifies if they are unable to consent. 1.4.5 Organisations should have clear policies or guidance on how to resolve disputes about the outcome of the capacity assessment.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack

	mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendation 1.4.1, 1.4.2 and 1.4.3 are all based on evidence reviewed and discussions about question 3, assessment of mental capacity. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts (as for recommendation 1.4.2), including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve

	such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	AMC2 There is a moderate amount of evidence that certain practitioners are being relied upon to conduct capacity assessments. The quality of the evidence is moderate. • Brown et al (2013, -) found that GPs were conducting capacity assessments among the majority (70%) of psychiatric inpatients. (p20) • In a UK study, dementia nurses reported that practitioners still defer to a 'professional hierarchy' to conduct capacity assessments, despite guidance in the code of practice about who should most appropriately complete assessments. (Manthorpe et al, 2014 +) (p24) • In a survey of old age psychiatrists by Shah et al (2010, +) 60 per cent of consultants reported that more than half of the capacity assessments were conducted by consultants. (p34) • Williams at al (2014, +) found that practitioners were reluctant to assess decision-making capacity and would instead defer to a specialist to make the assessment. (p38) (Recommendations 1.4.1 and 1.4.2) AMC3 There is some evidence that the extent of collaboration among professional groups in relation to capacity assessment is variable. The quality of the evidence is mixed. • A recent study by Murrell and McCalla (2016, +) reported that some social care practitioners always involve other professionals, especially mental health specialists, not least because of the huge responsibility involved in capacity assessment. (p27) • Similarly clinical psychologists said that their confidence and abilities in the area of capacity assessment developed through joint working with colleagues from other disciplines. They valued opportunities for sharing knowledge and lessons and considered it best practice to incorporate different perspectives when conducting capacity assessments (Walji et al, 2014 ++) (p36) • In contrast, only one social worker in the McDonald study (-) said they considered asking for other input (in this case a speech therapist). (p25) (Recommendation 1.4.3) AMC2 There is a moderate amount of evidence that certain practitioners are being relied upon to conduct capacity assessments. The quality of the evidence is moderate. • Brown et al (2013, -) found that GPs were conducting capacity assessments among the majority (70%) of psychiatric inpatients. (p20)

	- In a UK study, dementia nurses reported that practitioners still defer to a 'professional hierarchy' to conduct capacity assessments, despite guidance in the code of practice about who should most appropriately complete assessments. (Manthorpe et al, 2014 +) (p24) - In a survey of old age psychiatrists by Shah et al (2010, +) 60 per cent of consultants reported that more than half of the capacity assessments were conducted by consultants. (p34) - Williams at al (2014, +) found that practitioners were reluctant to assess decision-making capacity and would instead defer to a specialist to make the assessment. (p38) (Recommendation 1.4.2) Recommendation 1.4.3 was also supported from expert testimony (EM LS and EW HJ). No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E.
Other considerations	Recommendation 1.4.1 is based on evidence synthesised in AMC2, which reported that the most appropriate practitioner, in accordance with the Act, is not necessarily conducting capacity assessments. There was a committee discussion about what training is needed and how local audits could be used to monitor staff doing this work. The committee agreed on a training recommendation about the conduct of assessments for all health and social care practitioners but on reflection they decided this should be included in a broader training recommendation under 'overarching principles'. For the purposes of this section of the guideline, they decided that responsibility should be given to health and social care organisations to monitor and audit the conduct and quality of capacity assessments. Recommendation 1.4.2 is based on evidence in AMC2, which suggests that certain practitioners are always relied upon to conduct assessments although they are not necessarily the most appropriate to the decision or to the person whose capacity is being assessed. This led to the discussion described above, culminating in recommendation 1.4.1 about auditing the quality of assessments. Within this discussion, the experts by experience were keen to emphasise the important role that user views and experiences should have in monitoring and audit and the rest of the committee concurred. Recommendation 1.4.3 is based on evidence in AMC3, which suggests that the extent of collaboration between professionals in the context of capacity assessments is variable. This was supported by the expert testimony and the committee therefore agreed a recommendation that good practice involves a multi-disciplinary approach to assessment. They discussed the merits of listing practitioners who should be involved in assessments but felt the emphasis should be on tailoring assessments, involving practitioners with expertise in the person's condition. They finally decided to simply provide two examples (clinical psychologists and speech and language therapists) although they were clear this should not be interpreted as an exhaustive list of those who

	should be involved in assessments. Recommendation 1.4.4 is based on committee consensus in the context of discussions about capacity assessment. The committee had a discussion about assessing capacity to make decisions about care plans (as opposed, for example, to decisions about treatment plans). A committee member suggested that for the avoidance of doubt, the organisation responsible for the accessible plan should ensure that it is clear whether the person has given consent for the plan or if they are unable to consent. This suggestion was made during small group work and taken back to the plenary, where it received support from the whole committee. Recommendation 1.4.5 is also based on committee consensus in the context of discussions about capacity assessment. In recognition that the outcome of capacity assessments are often contended, for example by the person, their family and friends or other practitioners, it was suggested that organisations should have clear policies and guidance on how to resolve disputes. This suggestion was made during small group work and taken back to the plenary, where it received support from the whole committee.

Topic/section heading	Assessing capacity to make decisions
Recommendations	1.4.6 Assess mental capacity in line with the process set out in section 3 of the Mental Capacity Act. Be aware that the process applies to all decisions, large and small, though the measures adopted and recording will be proportionate to the complexity and significance of that decision. 1.4.7 Assessors should have sufficient knowledge of the person being assessed to be able to: • provide tailored information, including information about the consequences of making the decision or of not making the decision. • know whether the person would be likely to attach particular importance to any key considerations relating to the decision. 1.4.8 Practitioners should be aware that people may find capacity assessments distressing, particularly if they strongly disagree that they lack capacity. 1.4.9 In preparing for an assessment, the assessor should be clear about: • the person's options • what information, knowledge and experience the person needs about their options • what the person needs to understand, retain, weigh up, use and communicate in relation to this decision, including

	the use of communication aids - how to allow enough time for the assessment, giving people with communication needs more time if needed - how to assess capacity in a way that is respectful and preserves the person's dignity - how to make reasonable adjustments including, for example, delaying the assessment until a time when the person feels less anxious or distressed - how to ensure that the assessment takes place at a location and in an environment and through a means of communication with which the person is comfortable - whether involving people with whom the person has a trusted relationship would help the assessment decision. 1.4.10 The assessor should take into account the person's decision-making history when preparing for an assessment.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendations 1.4.6 to 1.4.10 are based on evidence reviewed and discussions about question 3, assessment of mental capacity. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as

	recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial ‘end loading’ of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered	AMC1 There is a good amount of evidence about the use of specific tools for assessing capacity to make decisions. The quality of the evidence is mixed and the relevance of the data to

evidence statements from which the recommendations were developed	the context of the Mental Capacity Act is questionable. • The competence evaluation by MacCAT-T was found to differ from the evaluations of nurses (p=0.010), physicians (p=0.0043) and relatives (p=0.022) and more than half the patients evaluated by MacCAT-T as incompetent were partially or fully competent (Aydin and Milne, 2014 +). (p6) • The CACE tool was more accurate in determining capacity than the less accessible CMAD. Social workers using CACE also had significantly greater confidence in assessing capacity using CACE than using CMAD (d = 1.3021 (95% Confidence Interval – 0.538, 2.0662)). Finally, people with aphasia were less frustrated using CACE than CMAD (p=0.02) (Carling-Rowland et al, 2014 +). (p7) • Feng et al (2014, +) found out that the ACE questionnaire accurately identified those with capacity to participate in stroke trials, which is shown by the high sensitivity values when assessed by a neuropsychologist (93.8% (95%CI, 69.8 -99.8) and a psychiatrist (100% (95% CI, 63.1-100). However, it demonstrated low specificity (53.8% (95%CI, 25.1 -80.8) when assessed by a neuropsychologist and 42.9% (95%CI, 21.8-66.0) and when assessed by a psychiatrist. Therefore failing ACE does not adequately determine that a patient lacks decision-making capacity. (p9) • A good quality UK study found that MMSE score was the only variable that significantly predicted capacity (odds ratio=1.6, 95% CI = 1.3 - 2.0) and MMSE scores also correctly classified 83.8% of patients (Gregory et al (2007, ++). (p10) • An instrument for assessing capacity to make every day decisions, ACED, was found to be reliable (see Cronbach alpha values for internal consistency for understanding, appreciation, and reasoning) and valid (see association between ACED ability measure and the corresponding measures and the correlation with the MMSE scores) (Lai et al, 2008 +). (p12) • A good quality US study concluded that MED-SAIL can accurately distinguish between people with and without capacity to make decisions for safe and independent living. An older adult with a MED-SAIL score less than 5 has a 79% probability of having no capacity (Mills et al, 2014 ++). (p13) • A low quality US study by Moye et al (2007, -) found that a structured interview for the assessment of capacity to consent to treatment had good inter-rater reliability (p<0.001) and internal consistency (α = .96). There was also moderate agreement between the assessment tool and ratings of capacity given by primary care (p<0.01) and experienced clinicians (p<0.05). (p15) • Finally, a moderate quality study conducted in Japan (Sugano et al, 2015 +) concluded that 3 cancer patients

	judged to lack decision-making capacity by physicians were also judged incompetent by the structured interview, SICIATRI-R. However the agreement was no greater than could have been expected to occur by chance. (p18) In spite of any positive results synthesised in evidence statement 1, it is important to note the narrow scope of these clinical tools, which do not compare favourably with the approach to decision-making capacity described in the MCA code of practice. Careful consideration should therefore be given about lessons that can be drawn from the findings. Recommendation 1.4.10 Recommendations 1.4.8 and 1.4.9 and were based on expert witness testimony (EW LS) and 1.4.10 was also supported by this evidence. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E.
Other considerations	Recommendation 1.4.6 was developed on the basis of committee consensus during discussions about assessing mental capacity. The group agreed about the importance of making a definitive statement recommending that mental capacity be assessed in line with section 3 of the Act and they agreed to emphasise the importance of taking a proportionate approach to assessment, relative to the size of the decision. Recommendation 1.4.7 was also developed on the basis of committee consensus during discussions about assessing mental capacity. Given that the committee had already agreed recommendations about providing accessible information surrounding assessment and the decision in question, members agreed that the responsibility for ensuring this happens lies with the assessor. They felt that the assessor should undertake to have enough knowledge of the individual so they can ensure information is specifically tailored to their needs and preferences. Recommendation 1.4.8 was based on expert witness testimony (EW LS) about the potential negative emotional and psychological effects of capacity assessments. The committee felt that practitioners should be fully cognisant of this so they agreed a recommendation to 'be aware' of the potential distress caused by a capacity assessment. Recommendation 1.4.9 is based on testimony from two expert witnesses about the importance of preparing people for capacity assessments, ensuring they fully understand the process and the decision for which their capacity is being assessed. Also, that the person has all the support they require to participate in the assessment, including making all reasonable adjustments. The committee agreed the specific detailed wording of the recommendation in order to emphasise the application of principles 2 and 3 and to reference the Montgomery judgement. Recommendation 1.4.10 is also derived from expert witness testimony (EW LS) about the importance of comprehensive preparation for the conduct of the capacity assessment. The testimony emphasized the importance of taking a person centred approach to preparing for assessment, finding out about the

	person's decision making history in advance.

Topic/section heading	Assessing capacity to make decisions (continued)
Recommendations	1.4.11 Practitioners must take all reasonable steps to ensure that the process of capacity assessment does not cause a person distress or harm. 1.4.12 Health and social care practitioners should take a structured, person-centred, empowering and proportionate approach to assessing a person's capacity to make decisions, including everyday decisions. The assessment should show where a person has capacity and where they do not. However, they should be aware that for certain areas, such as voting, there is no legal requirement to establish capacity. 1.4.13 As stated in principle 2 of the Mental Capacity Act, health and social care practitioners must take a collaborative approach to assessing capacity, where possible, working with the person to produce a shared understanding of what may help or hinder their communication and decision-making. This may include involving an interpreter, speech and language therapist, someone with sensory or specialist communication skills, clinical psychologists or other professionals to support communication during an assessment of capacity. 1.4.14 Where the individual has identified communication needs the assessor should also think about using communication tools to help with the assessment. Where tools are used, their use should be recorded as recommended by their employer or organisation. 1.4.15 Health and social care practitioners should work with the person where possible and where consent has been provided to identify people they should liaise with about how to carry out the capacity assessment. This could include support workers, carers, family and friends and advocates. They should use the information gathered to help create a complete picture of the person's functional capacity to make a specific decision and act on it.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions?

	and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendations 1.4.11 – 1.4.15 were based on evidence reviewed question 3, about assessment of mental capacity as well as from expert testimony connected with that review area. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. In particular, no information were identified that would have allowed to compare the costs and outcomes of different training programmes. In addition, the evidence on effectiveness of tools was judged by the Guideline committee as not relevant and the Guideline committee felt thus unable to recommend a particular tool for assessing mental capacity. In terms of costs of training, the Committee referred to the 'National Mental Capacity Act Competency Framework'. As highlighted in the Framework, localities could employ different strategies of how to help professionals and volunteers develop Mental Capacity Act skills: "This can be done by participating in formal training and development opportunities. However, there

	are also many opportunities for staff to learn and develop within the workplace, for example, discussions in team meetings, shadowing with more experienced staff, and mentoring opportunities." More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	AMC1 There is a good amount of evidence about the use of specific tools for assessing capacity to make decisions. The quality of the evidence is mixed and the relevance of the data to the context of the Mental Capacity Act is questionable. • The competence evaluation by MacCAT-T was found to differ from the evaluations of nurses (p=0.010), physicians (p=0.0043) and relatives (p=0.022) and more than half the patients evaluated by MacCAT-T as incompetent were partially or fully competent (Aydin and Milne, 2014 +). (p6) • The CACE tool was more accurate in determining capacity than the less accessible CMAD. Social workers using CACE also had significantly greater confidence in assessing capacity using CACE than using CMAD (d = 1.3021 (95% Confidence Interval – 0.538, 2.0662)).

	Finally, people with aphasia were less frustrated using CACE than CMAD ($p=0.02$) (Carling-Rowland et al, 2014 +). (p7) • Feng et al (2014, +) found out that the ACE questionnaire accurately identified those with capacity to participate in stroke trials, which is shown by the high sensitivity values when assessed by a neuropsychologist (93.8% (95%CI, 69.8 -99.8) and a psychiatrist (100% (95% CI, 63.1-100). However, it demonstrated low specificity (53.8% (95%CI, 25.1 -80.8) when assessed by a neuropsychologist and 42.9% (95%CI, 21.8-66.0) and when assessed by a psychiatrist. Therefore failing ACE does not adequately determine that a patient lacks decision-making capacity. (p9) • A good quality UK study found that MMSE score was the only variable that significantly predicted capacity (odds ratio=1.6, 95% CI = 1.3 - 2.0) and MMSE scores also correctly classified 83.8% of patients (Gregory et al (2007, ++). (p10) • An instrument for assessing capacity to make every day decisions, ACED, was found to be reliable (see Cronbach alpha values for internal consistency for understanding, appreciation, and reasoning) and valid (see association between ACED ability measure and the corresponding measures and the correlation with the MMSE scores) (Lai et al, 2008 +). (p12) • A good quality US study concluded that MED-SAIL can accurately distinguish between people with and without capacity to make decisions for safe and independent living. An older adult with a MED-SAIL score less than 5 has a 79% probability of having no capacity (Mills et al, 2014 ++). (p13) • A low quality US study by Moye et al (2007, -) found that a structured interview for the assessment of capacity to consent to treatment had good inter-rater reliability ($p<0.001$) and internal consistency ($\alpha = .96$). There was also moderate agreement between the assessment tool and ratings of capacity given by primary care ($p<0.01$) and experienced clinicians ($p<0.05$). (p15) • Finally, a moderate quality study conducted in Japan (Sugano et al, 2015 +) concluded that 3 cancer patients judged to lack decision-making capacity by physicians were also judged incompetent by the structured interview, SICIATRI-R. However the agreement was no greater than could have been expected to occur by chance. (p18) In spite of any positive results synthesised in evidence statement 1, it is important to note the narrow scope of these clinical tools, which do not compare favourably with the approach to decision-making capacity described in the MCA code of practice. Careful consideration should therefore be given about lessons that can be drawn from the findings. (Recommendation 1.4.12)

	AMC13 There is a small amount of evidence about issues relating to the assessment of capacity among black and minority ethnic individuals. • A survey by Shah et al (++/+) found that over half of old age psychiatrists said interpreters were used in less than half of assessments when people lacked fluency in English. (p32) (Recommendations 1.4.13 and 1.4.14)
Other considerations	Recommendation 1.4.11 was based on expert witness testimony (EW LS) about the potential negative emotional and psychological effects of capacity assessments. The committee felt that practitioners should be fully cognisant of this so they agreed a recommendation to 'be aware' of the potential distress caused by a capacity assessment. Some GC members felt they should go a step further and state that practitioners must (because it is enshrined in the Act) take all reasonable steps to prevent distress during capacity assessment. Other committee felt it may be unnecessary to state this but ultimately there was an overall agreement in favour of making the recommendation. Recommendation 1.4.12 was based on evidence reported in AMC1 and supported by expert witness testimony (EW LS). The studies cited in AMC1 provided extensive data about the accuracy of a range of tools being used to establish capacity. However the committee realised that an important weakness in the evidence was that the tools did not conform to the Mental Capacity Act and Code of Practice. In particular the pointed out the medical nature of most of the tests in the studies. They felt there was not enough evidence to support use of the specific tools, largely because they are not compliant with the Act and because there is no evidence they are used in England. The committee did however feel they could take lessons from the evidence about the use of formalised approached to capacity assessment, which is what they did in this recommendation. However on the basis of their own expertise and supported by the expert witness testimony (LS) they also felt it was important to emphasise that no one size fits all and there should be a person-centred approach taken that builds on the person's history. Finally, on the basis of the expert testimony, which highlighted that it is common practice for people to be assessed before they can vote the committee agreed to specifically highlight this need or should not be done. Recommendation 1.4.13 is based on data reported in AMC13. The group agreed that the evidence regarding the failure to use interpreters was a disgrace. There were some concerns that it would not be possible to recommend that assessments should always be conducted in the first language of the person however the group were clear that this was vital in situations where complex decisions needed to be made. The group therefore agreed a recommendation to ensure that assessors should work with the person and other practitioners to identify what may help or hinder communication and decision-making. This might include the use of interpreters but the committee also wished to broaden this out to other means of improving communication and decision-

	making, for instance involving a speech and language therapist. Recommendation 1.4.14 is based on evidence synthesised in AMC1 about the effectiveness of a range of tools intended to assess mental capacity. Given the communication difficulties often experienced by people whose capacity is being assessed, the committee agreed that any tools being used to support assessment should include communication tools. However the committee did not feel the evidence provided a sound basis for recommending a particular communication tool so agreed that assessors should use tools clearly recommended by their employer. Recommendation 1.4.15 is based on expert witness testimony (EW HJ) about the importance of taking a collaborative approach to capacity assessment, identifying people who can contribute to create a complete picture of the person and their functional capacity. In discussing the testimony, committee members were however keen to ensure that other people were not involved by default but only with the consent of the person being assessed.

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Topic/section heading	Assessing capacity to make decisions (continued)
Recommendations	1.4.16 The assessor should record any differing views on capacity that they are aware of and how the outcome of their assessment addresses or answers those concerns. 1.4.17 Health and social care practitioners should conduct an assessment at a level proportionate to the decision being made. 1.4.18 If a person refuses to engage in a capacity assessment, the assessor should give them a choice about who else could be involved or any other changes that can be made to help them. 1.4.19 Practitioners should use accessible language or an accessible format to tell the person: • that their capacity is being assessed and • the outcome of that assessment.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of

	cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendations 1.4.16 – 1.4.19 are all based on evidence and from expert witnesses relating to the review on capacity assessment. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff

	Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	Recommendations 1.4.16, 1.4.18 and 1.4.19 were all developed on the basis of expert witness testimony connected with the review on capacity assessments. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E. AMC9 There is a small amount of evidence that practitioners do not always assess capacity to make specific decisions at specific points in time. The quality of the evidence is low. Emmett et al. (2013 -) reported that a range of practitioners took an outcomes approach to assessment rather than a functional approach, especially in people with a dementia diagnosis. There was a reliance on informal assessments, which the authors suggest indicates a failure to understand the requirements of the MCA relating to functional approaches to assessment. McDonald et al. (-) found that social workers tended to consider a multiple number of assessments conducted over a long period in an 'overall' assessment, rather than focus on each decision separately and at the specific time point. (Recommendation 1.4.17)
Other considerations	Recommendation 1.4.16 is also based on expert witness testimony (EW HJ) about disagreements relating to the outcome of capacity assessments. Committee members were not clear that the Code of Practice sufficiently addresses this issue and were therefore keen to develop a recommendation about trying to address and also recording disagreements. One of the members suggested that a 'balance sheet of views' could be included in the recommendation but there was insufficient support for this from others who felt it was too prescriptive. Recommendation 1.4.17 is based on evidence synthesised in AMC9 that practitioners did not necessarily understand the requirements of the Mental Capacity Act to take a functional

	approach to assessment and there were others who judged overall capacity rather than capacity in relation to specific decisions at specific time points. Although the quality of the evidence was low, members felt that the findings resonated with their own experiences and therefore agreed to develop a recommendation combining the evidence with the own expertise. Instead of specifying exactly how different assessments of capacity should be made for different types of decisions, the committee agreed it was better to emphasise that different decisions and situations will call for varying levels of structure or depth of assessment, hence the wording, 'proportionate to the decision'. Recommendation 1.4.18 was developed on the basis of expert testimony (EW LS). The guideline committee initially felt that the testimony pointed to the need for people to have an influence over who should conduct their assessment. However, through discussions they concluded that in fact this would be incompatible with the Mental Capacity Act and Code of Practice. They agreed about the importance of drawing a clear distinction between the person who needs to determine if the person lacks capacity (which is determined by the nature of the decision) and the parties who can be invited/chosen to assist. Ultimately the committee agreed it is the latter which should be the focus of this recommendation – that it would help to reduce anxiety if the person being assessed could identify others they would like to be involved in the process (for example, family members, friends or other practitioners who may know them well). Recommendation 1.4.19 is also based on expert witness testimony (EW LS) about steps that should be considered in order to reduce anxiety around capacity assessments. The committee agreed that it is important to ensure people know their capacity is being assessed and at the end of the assessment, what the outcome is. Given that people have a range of communication needs, committee members were keen to emphasise the importance of communicating the information in an accessible format.

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Topic/section heading	Assessing capacity to make decisions (continued)
Recommendations	1.4.20 Practitioners should be aware that people with executive dysfunction – for example, people with traumatic brain injury – may be at risk of having their decision-making capacity overestimated. Structured assessments of capacity should be supplemented by real-world observation of the person's functioning and ability. 1.4.21 When assessing capacity, practitioners should take account of principle 3 of the Mental Capacity Act and not assume that the person lacks capacity because they have made a decision that the practitioner perceives as risky or unwise.

	1.4.22 Practitioners should understand that the person has to retain the most important points from a discussion only for the purposes of making the specific decision in question, and for the period of time necessary to make the decision. 1.4.23 Practitioners should be aware that if a person is judged to lack insight into their condition, this does not necessarily reflect lack of capacity to make a decision, depending on the nature of the decision being made.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendations 1.4.20 – 1.4.23 were based on evidence reviewed for question 3, about assessment of mental capacity as well as from expert testimony connected with that review area. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant

	and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	Recommendation 1.4.20 was derived from expert witness testimony (EW HJ) connected with the review on capacity assessments. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E. AMC7 There is a good amount of evidence that perceived risk is sometimes conflated with capacity in the context of mental capacity assessments. The quality of the evidence is mixed.

	- Emmett et al (2013, -) found that practitioners used the likelihood of a risky decision by dementia patients as an indication that they lack capacity. Capacity considerations also appeared to be subsumed into wider discussions around risk and harm. (p22) - Similarly, dementia nurses felt that some practitioners were risk averse, particularly if a person's capacity to refuse a service was being queried (Manthorpe et al, 2014 +). (p24) - McDonald et al (2008, -) reported that social workers seemed to be influenced by an outcomes focussed approach to capacity that centred on risk. They report that people with dementia were often judged to lack capacity if they did not appear to agree with the social worker. (p25) - Clinical psychologists said that particularly among people living with dementia or learning disabilities, other professionals seemed to assume a lack of capacity so that the professional could make a "better" decision for the individual. (Walji et al, 2014 ++) (p36) - Finally, (Williams et al, 2014 +) found that health and social care practitioners start to question the capacity of service users when risk management strategies begin to fail, and that the concept of risk was sometimes being used interchangeably with capacity (Williams et al, 2014 +). (p38) (Recommendation 1.4.21) AMC8 There is some evidence of practitioners reportedly using incorrect or incomplete information to assess capacity to make decisions. The quality of the evidence is mainly moderate. - Researchers found variation in the relevance of the information being used by practitioners to make assessments of capacity, for example citing service user's inability to remember previous conversations. (Emmett et al, 2013 -) (p22) - A social care practitioner in the 2016 study by Murrell et al (+) said that they take account of whether the person has insight into their condition and whether they are orientated, which the authors observe is not enough to assess decision-making capacity. (p27) - Williams et al (2014, +) reported that practitioners were using inappropriate information to inform capacity assessments, for example whether they anticipated the person would make an unwise decision or whether they lacked insight into their condition. (p38) (Recommendations 1.4.22 and 1.4.23)
Other considerations	Recommendation 1.4.20 is based on expert witness testimony (EW HJ) which described how people with executive dysfunction can appear to be capacitous because of responses they can give in a structured assessment when in fact they do not have capacity to make the specific decision in question, in the terms set out in the Mental Capacity Act. The expert witness explained how this can be overcome by making observations of the person's

	functioning during real-life situations. The committee supported this evidence – especially members with expertise in brain injury – and therefore agreed this recommendation. Recommendation 1.4.21 is based on evidence from AMC7 that the assessor's perception of risk is often conflated with capacity. In other words, if the assessor perceives that the decision the person wants to make is unwise or unsafe they may conclude that the person lacks capacity to take that decision. Although the evidence was mixed in terms of quality, the findings resonated with the group's experience. They felt strongly that the Mental Capacity Act cannot be used to prevent people from taking risks. By the same token, some members pointed out that one should not assume that just because a person agrees or is compliant means they have capacity or understand. The committee agreed to focus practitioners on principle 3 of the Mental Capacity Act and to reinforce the importance of separating out considerations of risk from the assessment of capacity. Recommendation 1.4.22 is based on evidence synthesised in AMC8, which reported practitioners using incorrect information in capacity assessments. This included information about whether the person had insight into their condition or whether they could remember past conversations. The quality of the evidence was mainly moderate and resonated with the group's experiences. They pointed out that someone's insight into their own condition may not be relevant to the specific decision being made and a lack of insight should not automatically infer lack of capacity. They also agreed that the person actually only has to remember relevant information about the decision while they are engaged in making the decision, which is why they developed this recommendation. Recommendation 1.4.23 is also based on evidence reported in AMC8 and was developed from discussions described above about the way that someone's lack of insight into their own condition should be treated.

Topic/section heading	Assessing capacity to make decisions (continued)
Recommendations	1.4.24 If a practitioner assesses a person as lacking capacity, they must document this, together with the evidence that led to this conclusion. 1.4.25 The person assessing mental capacity should record: • the practicable steps they have taken to help the person make the relevant decision for themselves and any steps taken by other parties involved. • if the person has capacity but makes an unwise decision • if the person has capacity and gives valid consent. 1.4.26 All assessments of mental capacity must be recorded at an appropriate level to the complexity of the decision being made, as

	a stand-alone assessment, in patient notes or in care plans following local policy. 1.4.27 Provide the person with emotional support and information after the assessment, being aware that the assessment process could cause distress, disempowerment and alienation.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 6: What is the accuracy and/or effectiveness, cost effectiveness and acceptability of mental capacity assessment tools that are compliant with the Mental Capacity Act 2005? Research recommendation 7: What are the components of an effective assessment of mental capacity to make a decision (for example checklists, memory aids or standardised documentation)?
Review questions	3a. What interventions, tools and approaches are effective and cost-effective in supporting the assessment of mental capacity? 3b. What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support the assessment of mental capacity?
Quality of evidence	Recommendations 1.4.24 – 1.4.27 were based on evidence reviewed for question 3, about assessment of mental capacity as well as from expert testimony connected with that review area. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of

	people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial ‘end loading’ of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	Recommendations 1.4.24, 1.4.25 and 1.4.27 were all derived from expert witness testimony connected with the review on capacity assessments. No specific evidence statements were derived from the expert testimony but the full submissions from the expert witnesses can be found in appendix E. AMC11 There is a moderate amount of evidence that decision-making capacity assessments are poorly recorded. The quality of the evidence is low. • An audit conducted in one NHS Foundation showed that documented capacity assessments took place for just 9.8% of admissions – and a specific form was used to

	document capacity assessments in only 0.5% of psychiatric admissions (Brown et al, 2013 -). (p20) - Social workers in the McDonald study (2008, -) said that although they knew the requirements for recording assessments, they were unsure about the most effective and appropriate way of doing so. (p25) - Despite a specific focus on improving recording practice among psychiatrists in a learning disability setting, discussions about capacity to consent to treatment were confirmed in 30% of cases and this rose to 51% 3 years later, falling short of the 90% target (Roy et al (2011, -). (p29) - In the survey by Shah et al (2010, +) just over a third of old age psychiatrists said that they documented capacity to consent assessments in less than half of patients. (p34) (Recommendation 1.4.26)
Other considerations	Recommendation 1.4.24 is based on expert witness testimony about the importance of documenting capacity assessments and their outcomes. Committee members pointed out that this is a requirement of the Mental Capacity Act. As such this had to be a 'must' recommendation requiring that the process of assessment be clearly documented, in particular the evidence used to judge that the person lacks capacity. Recommendation 1.4.25 was based on the same discussions of the expert witness testimony, described above. The committee felt it was important to provide a detailed recommendation for assessors about specific information and evidence that should be recorded. Recommendation 1.4.26 is based on evidence in AMC11. Although the quality of the evidence was low, the committee were aware from their own experience that poor recording of assessments is evident in practice and had been highlighted by recent legal reviews. It was suggested that the recommendation could be a relatively straightforward statement that decision-making capacity assessments are recorded and that this could be accompanied by a research recommendation regarding the use of standardised forms. The group agreed that because the code of practice requires that capacity assessments are recorded, this could be a 'must' recommendation. Recommendation 1.4.27 is based on expert witness testimony (EW LS) about the potential negative emotional and psychological effects of capacity assessments. In response to the testimony, the committee felt it should be a requirement to ensure appropriate support is available post assessment. This could take the form of emotional support or the provision of information however they the committee did not meant to imply the assessor would be responsible for delivering the support, just ensuring it is offered and provided should the person need it.

Topic/section heading	Best interests decision making -

	Helping practitioners to deliver best interests decision making
Recommendations	1.5.1 In line with the Mental Capacity Act 2005, practitioners must not hold a best interests discussion until a capacity assessment has been conducted, and a decision made and recorded that a person lacks capacity to make the decision in question (except in emergency situations). 1.5.2 Ensure that everyone involved in the best interests decision-making process knows who the decision maker is. 1.5.3 Regardless of whether a person has capacity to make a specific decision, practitioners must take all reasonable steps to help them be involved in making decisions. 1.5.4 Health and social care services should ensure that best interests decisions are being made in line with the Mental Capacity Act.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendation 1.5.1 was based on evidence reviewed for question 3, about assessment of mental capacity as well as from expert testimony connected with that review area. Overall, a good amount of evidence was included for this review although it was of variable quality, particularly in relation to evidence in certain areas such as recording of capacity assessments. The effectiveness evidence was mainly moderate in quality and although there were a good amount of data, the tools evaluated in the studies do not align well with the approach to assessment

	stipulated by the Mental Capacity Act and Code of Practice. This had a strong bearing on committee discussions about the use of evidence for developing recommendations and led to the decision to invite expert witnesses to provide relevant and up to date testimony. In terms of qualitative data, there was representation of practitioner views and experiences (mainly low in quality) but no studies reported the views and experiences of people who may lack capacity (or their families/carers). This absence of service user views and experiences data also led the committee to elicit testimony from experts, including from a user perspective. Recommendation 1.5.2 and 1.5.4 were based on evidence reviewed for question 4, about best interests decision-making. A total of 9 papers were included, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise. Recommendation 1.5.3 was based on evidence reviewed for question 2, about supported decision-making on the assumption of capacity. A total of 9 papers were included for RQ2: 6 effectiveness studies and 3 views and experiences studies. Overall, the quality of the evidence was moderate. However the effectiveness data, although well represented was mainly low quality and this was considered by the committee in their discussions. Combined with the fact that only 2 of the quantitative studies were from the UK, non-UK quantitative studies were used to supplement the evidence to support committee decision making. Studies providing views and experiences of people who may lack capacity, their families and practitioners were good to moderate in terms of quality.
Economic considerations	No economic evidence was identified to support the recommendations. However, the guideline committee thought that most recommendations were required by law and thus monies were already spent in localities. The committee thought that by suggesting what they consider good practice, this would help to increase (cost-) effectiveness as recommendations would lead to increase in effectiveness at similar levels of costs. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve

	while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	AMC10 There is a small amount of evidence that the assessment of decision-making capacity is sometimes being merged with best interests discussions although this is not always perceived to be negative. The quality of the evidence is moderate. • Murrell et al (2016, +) reported that social care practitioners found it difficult to conduct an objective assessment without speculating about the likely outcome and potentially unwise decision if they judge the person to have capacity to decide. (p27) • On the other hand, Williams at al (2014, +) identified an overlap between best interests decision making and capacity assessment, because strategies used to involve a person in best interests decisions (e.g. regular informal meetings) could result in finding that with this level of input, the person has capacity after all. (p38) (Recommendation 1.5.1) BIA19 There is a small amount of evidence that the involvement of people is not always achieved by ensuring they attend a formal best interests meeting. The quality of the evidence is good. • Williams V et al (2012, +) report that communication with a person lacking capacity was sometimes more successfully accomplished outside meetings, and with accessible

	information strategies such as picture books, photos, etc. In some cases, it was thought inappropriate to involve the person in these meetings if there was a risk that they might become distressed or withdraw from the process. (Recommendation 1.5.2) SDM5 There is a small amount of evidence that even when they have capacity, people are excluded from decision-making about their own treatment or every day activities. The quality of the evidence is moderate to good. • A good quality study (Stovell et al, 2016 ++) reported that participants often felt disempowered and excluded from the treatment decision-making process (p20). • A moderate quality UK study (Boyle, 2013 +) found that some spouses clearly imposed their own will on their partner living with dementia, directing them toward their own preferred outcome during decision making. This included every day decision making but also bigger issues such as day centre or respite attendance (p16). (Recommendation 1.5.3) BIA9 There is a small amount of evidence that the level of formality of best interests decisions may be shaped by the timescale in which the decision needs to be made. The quality of the evidence is good. • Harris D et al (2011, ++) found that the practitioners they spoke to were clearly attempting to establish patients' past and present wishes as far as reasonably practicable however best interests decisions were sometimes being made on an informal basis, particularly when the person was being cared for at home where it may be difficult to convene a meeting that all relevant parties can attend. (Recommendation 1.5.4)
Other considerations	Recommendation 1.5.1 is based on evidence synthesised in AMC10, indicating that capacity assessments and best interests decision-making are sometimes being merged in practice. The committee was divided about whether or not this should be considered to be negative. They felt that there may be a natural tendency for some practitioners to combine assessments of capacity with best interests processes. The committee thought that this should be discouraged such that capacity assessment always precedes and is distinguished from best interests decision making. They also recognised, however, that the two processes should fit closely together, given the importance of ensuring assessment and decision-making takes place in a timely manner. They also acknowledged that in emergency situations it may not be possible to complete the assessment and record the outcome in a way that is separate and distinct from the best interests process, which is why 'except in emergency situations' was added. Recommendation 1.5.2 was derived from discussions about

	BIA19 which highlighted that having the person attend a formal best interests meeting is not always the best way to maximise their involvement in the process. In discussing this evidence the committee considered who should have responsibility for ensuring the person can contribute in the most suitable way. Although they agreed this should be the responsibility of the decision maker they felt that it may not always be clear who should make those arrangements because the identity of the decision maker is not always clear to people. Therefore although it is not directly derived from the evidence statement, the committees' discussion about the evidence led them to develop a consensus recommendation that it is fundamentally important for everyone involved to know who they decision maker is. Recommendation 1.5.3 is based on evidence from SDM5, which suggests that even when people have capacity, they feel excluded from decision-making. The committee felt very strongly that if people have capacity to make decisions, they cannot be excluded from decision making. However in reflecting on this, the group wished to emphasise that, in fact, regardless of the person's capacity all reasonable steps should be taken to help involve them in decision-making. Given that this principle is enshrined in the Act, this is a 'must' recommendation. Recommendation 1.5.4 is based on BIA9, which reported data that practitioners sometimes made best interests decisions on an informal basis, especially where the person is being cared for at home. The committee therefore agreed to reiterate the need to comply with the best interests process set out in the Act and the Code of Practice.

Topic/section heading	Helping practitioners to deliver best interests decision making (continued)
Recommendations	1.5.5 Health and social care services should: • implement a service-wide process for recording best interests decisions and ensure that staff are aware of this and • have clear systems in place to support practitioners to identify and locate any relevant written statement made by the person when they had capacity, at the earliest possible time. 1.5.6 Health and social care services should have clear systems in place to obtain and record the person's wishes and feelings in relation to a relevant decision, as well as their values and beliefs, or any other factor that would be likely to influence such a decision. Services should: • have mechanisms in place to make these available in a timely way • ensure that the person's personal history and personality is represented in the above.

	1.5.7 Ensure that knowledge of the Independent Mental Capacity Advocate role in best interests decision-making is embedded in all Mental Capacity Act training, including introductions to health and social care and in preregistration training.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 4: What is the effectiveness and cost effectiveness of different targeted interventions (speech and language therapy and psychological and psychosocial interventions) to support and improve decision-making capacity for treatment in specific groups? Research recommendation 5: What is the effectiveness, cost effectiveness and acceptability of advocacy as a means of supporting people who may lack capacity to make a decision (on the presumption of capacity)?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendation 1.5.6 was based on evidence reviewed for question 1 about advance planning. From the original search a total of 14 papers were included: 5 effectiveness studies and 9 views and experiences studies. The quality of the studies was moderate to good and the systematic review of economic evaluations was judged to be moderate quality. From the update search 3 effectiveness studies were included and 18 views and experiences studies, which were mainly good quality. The main focus of the studies was on advance planning in relation to mental health and palliative care decisions. Recommendation 1.5.7 was based on evidence reviewed for question 4, about best interests decision-making. A total of 9 papers were included, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as

	lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. In particular, no information was identified that would have allowed the comparison of costs and outcomes of different training programmes. In addition, the evidence on effectiveness of tools was judged by the guideline committee as not relevant and the guideline committee felt thus unable to recommend a particular tool for assessing mental capacity. In terms of costs of training, the committee referred to the 'National Mental Capacity Act Competency Framework'. As highlighted in the Framework, localities could employ different strategies of how to help professionals and volunteers develop Mental Capacity Act skills: "This can be done by participating in formal training and development opportunities. However, there are also many opportunities for staff to learn and develop within the workplace, for example, discussions in team meetings, shadowing with more experienced staff, and mentoring opportunities." More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The

	Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	AP3 There is a good amount of evidence from service users, carers and practitioners, that a person's choices and preferences should be represented in advance care planning, but some of the evidence was conflicting. A moderately well conducted qualitative UK study (Ashton 2014 +) a found that family carers, caring for people with dementia, wished to ensure that their relatives personal history and personality be represented in advance care plans. Another moderate quality, qualitative UK study related to dementia (Poppe 2013 +), found that service users felt advance care planning to be a positive experience because it enabled them to express their preferences. The study also found that carers were in favour of allowing service users to express their wishes, to avoid having to make decisions on their behalf later. However, Robinson (2013 ++), a well conducted qualitative UK study of practitioners found that practitioners working in dementia and end of life care services questioned whether advance care planning had the ability to deliver patient preferences. This was on the grounds that preferred care may not be available. Robinson also found that practitioners, such as ambulance staff, were unable to adhere to advance care plans due to conflicting duty of care responsibilities. (Recommendation 1.5.6) BIA12 There is small amount of evidence that some practitioners are not aware of the Independent Mental Capacity Advocate role. The quality of the evidence is good. • Williams V et al (2012, +) found that there was a mixed level of awareness of the role amongst professionals. Advocates themselves also reported that the role was not well understood. (Recommendation 1.5.7)
Other considerations	Recommendation 1.5.5 is based on BIA9, which reported data that practitioners sometimes made best interests decisions on an informal basis, especially where the person is being cared for at home. The committee agreed that it was appropriate for less formal practice to be used in more urgent situations, particularly those of a life and death matter and it was noted that the research referenced in the evidence statement was not of great use in this regard. However members felt that the research did provide enough detail to conclude that some practitioners are not taking a thorough approach to the conduct and recording of best interests decisions and this resonated with their own practice experience. It was suggested that a tool could be devised to record best interests and that services should provide a tool for practitioners to record all best interests processes not just formal best interests meetings. It was informed by committee expertise that the person's own wishes were not routinely fed into the best interests process. They therefore reached a recommendation to address this. They thought services needed to establish systems that support practitioners to locate any written statements made by the person while they had capacity.

	Recommendation 1.5.6 is based on evidence from AP3, which suggests that the extent to which people's wishes are included in advance planning varies in practice. The committee felt strongly that obtaining and recording people's wishes and feelings as well as values and beliefs should be routine and that health and social care services should facilitate this by establishing relevant systems. Recommendation 1.5.7 is based on evidence in BIA12, which reported a lack of awareness among some practitioners about the Independent Mental Capacity Advocate role. The group discussed whether it would be appropriate to draft a recommendation stating that awareness of the Independent Mental Capacity Advocate role should be included in inductions and formal training for example for nurses and social work practitioners. It was also suggested that this should cover care workers. Having drafted the recommendation the group discussed what was meant by the term 'embedded' and it was suggested that this should ensure that the role is covered as part of the degree curriculum, however other members of the group also suggested that it should also be covered in introduction to health and social care services, which explains the final wording.

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Topic/section heading	Helping and supporting family members in respect of best interests decision making
Recommendations	1.5.8 Health and social care practitioners should work with carers, family and friends to find out the wishes and preferences of the person in relation to the specific decision and to understand the person's decision-making history. 1.5.9 If a decision maker is calling a best interests meeting, they should: • involve the person themselves, unless a decision is made that it would be harmful for them to attend the meeting • consult carers, family and friends about the meeting in advance, giving them time to ask questions and give their opinions, for example about how to include the person in decision-making • make it clear that the purpose of the meeting is to make a decision • provide all information in an accessible format. 1.5.10 Practitioners should access information about the person informally if needed, as well as through any formal meetings. 1.5.11 The decision maker should ensure that all people concerned with the best interests decision are able to be fully involved. This means making sure they have their views encouraged, respected and heard.
Research	Research recommendation 1: What is the effectiveness and cost

recommendations	effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendations 1.5.8 to 1.5.11 were all based on the evidence reviewed for question 4 about best interests decision-making as well as expert witness testimony connected with that review area. A total of 9 papers were included, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty

	Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	BIA1 There is some evidence that practitioners and family carers sometimes draw on their own experiences or preferences when making a decision on behalf of someone who lacks capacity. The quality of the evidence is mixed, low to moderate. • Dunn MC et al (2010, −) reported that the substitute decisions that support workers were making on behalf of their clients were not prompted by concerns regarding decision-making capacity as outlined in the Mental Capacity Act but were instead driven by their own beliefs about how to provide residents with 'meaningful' life experiences. • Samsi K et al (2013, +) report that whilst the concept of 'best interests' underpinned many family carers intentions when making decisions on behalf of their relative, many had a tendency to connect their own best interests with those of the person they supported. (Recommendation 1.5.8 – also partially derived from expert witness testimony EW LS) (Recommendation 1.5.8) BIA3 There is a small amount of evidence to suggest that relatives of people who have been determined to lack capacity may find it difficult to be involved in best interests decisions because they feel unable to or are unwilling to challenge the opinions of professionals. The quality of the evidence is good. • Emmett C et al (2014, ++) found that some relatives felt uncomfortable asking for clinical information or challenging professional opinion regarding place of

	discharge in the context of best interests decisions. (Recommendation 1.5.9) BIA19 There is a small amount of evidence that the involvement of people is not always achieved by ensuring they attend a formal best interests meeting. The quality of the evidence is good. • Williams V et al (2012, +) report that communication with a person lacking capacity was sometimes more successfully accomplished outside meetings, and with accessible information strategies such as picture books, photos, etc. In some cases, it was thought inappropriate to involve the person in these meetings if there was a risk that they might become distressed or withdraw from the process. (Recommendation 1.5.10) BIA18 There is a small amount of evidence that people who have been determined to lack capacity are not always involved in best interests meetings regarding their care. The quality of the evidence is good. • Williams V et al (2012, +) report that in a small number of cases the person determined to lack capacity was not involved in best interests meetings. The authors report that people with learning disabilities were less likely to be invited to a formal meeting, whilst those with dementia were more likely. (Recommendation 1.5.11) BIA20 There is a small amount of evidence that some practitioners feel disempowered by professional hierarchies. The quality of the evidence is good. • Williams V et al (2012, +) found that care home staff felt disempowered by GPs decisions regarding end-of-life care for residents whom they felt they had a better knowledge of. (Recommendation 1.5.11)
Other considerations	Recommendation 1.5.8 is based on evidence in BIA1, which reported that families and carers often draw on their own preferences when they are contributing to best interests decision making for someone assessed as lacking capacity. In discussing this evidence, the committee did not believe this was necessarily a negative finding so long as decisions were not contrary to the person's own previously expressed and recorded wishes. The committee felt that in fact families and carers should be encouraged to be actively involved in giving insight to practitioners about the person's wishes and preferences and they felt this was also supported by the testimony provided from one of the expert witnesses (EW LS). Recommendation 1.5.9 is based on discussions around BIA3 which reported a small amount of good quality evidence that relatives find it difficult to be involved in best interests meetings because they are uncomfortable and unwilling to challenge the opinions of professionals. The committee agreed that in practice this can be problematic and felt the responsibility was on the decision maker to facilitate relatives' meaningful involvement

	including through clear communication about the purpose of any formal meetings, the provision of accessible information and giving families time and space to ask questions and give their opinions. Recommendation 1.5.10 is based on evidence reported in BIA19 that ensuring people attend formal best interests meetings is not always the most successful way of including their preferences and views in the process. The committee concurred with this finding and agreed to draft a recommendation alerting decision makers to the need to access people's views informally as well as formally via meetings. Recommendation 1.5.11 is based on BIA18, which reported that people who have been determined to lack capacity are not always involved in best interests meetings and BIA20 which reported evidence that care home staff felt disempowered by decisions made by apparently more 'senior' professionals. The committee agreed the recommendation to ensure that everyone concerned – whether the person themselves, families or practitioners working closely with them – is fully involved and truly has their views listened to and respected.

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Topic/section heading	Helping and supporting family members in respect of best interests decision making (continued)
Recommendations	1.5.12 When making a decision on behalf of the person who lacks capacity, practitioners should use a range of approaches, as needed, to ensure that people's best interests are met, if they lack capacity. This might include: • a less formalised approach for day-to-day decisions – that is, recurring decisions being recorded in support or care plans • formal best interests meetings for significant decisions • a decision-making approach appropriate to the circumstances and personalised to the individual, making all reasonable adjustments. 1.5.13 Carers and practitioners must wherever possible find out the views and beliefs of the person in the first instance and should be able to demonstrate that they have done so. For example: • recording in care records what steps have been taken, including reasons why this has not been done • identifying which steps have been taken to find out the person's wishes. 1.5.14 Health and social care organisations should provide toolkits to support staff to carry out and record best interests decisions. These toolkits should include: • a clear definition of the decision to be made • steps that have been taken to help the person make the decision themselves

	• a current assessment concluding that the person lacks the capacity to make this decision • any other decision-making instruments that would prevent best interests decision-making occurring (for example a Lasting Power of Attorney, advance decisions, court orders) • a clear record of the person's wishes, feelings, cultural preferences, values and beliefs, including advanced statements • a prompt to consult interested parties (for example families, friends and Independent Mental Capacity Advocate and relevant professionals) and a record of who they are • advice about the degree of formality needed for the decision being made, for example a best interests meeting • guidance about recording best interests process and decision including a balance sheet of risks and benefits.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendations 1.5.12, 1.5.13 and 1.5.14 were based on evidence from review question 4 about best interests decision-making and recommendation 1.5.13 was based on committee consensus linked with that review area. A total of 9 papers were included, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was

	effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations	BIA15 There is a small amount of evidence that practitioners take a mixed approach to best interests meetings. The quality of the evidence is good. Williams et al. (2012 +) report that while some decisions were made informally as part of routine meetings (or a series of meetings) between practitioners, patients and other relevant parties, decisions were just as likely to be taken in a more formal meeting arranged specifically to make a best

were developed	interests decision. (Recommendation 1.5.12) BIA1 There is some evidence that practitioners and family carers sometimes draw on their own experiences or preferences when making a decision on behalf of someone who lacks capacity. The quality of the evidence is mixed, low to moderate. Dunn et al. (2010 -) reported that the substitute decisions that support workers were making on behalf of their clients were not prompted by concerns regarding decision-making capacity as outlined in the Mental Capacity Act but were instead driven by their own beliefs about how to provide residents with ‘meaningful’ life experiences. Samsi and Manthorpe (2013 +) report that while the concept of ‘best interests’ underpinned many family carers intentions when making decisions on behalf of their relative, many had a tendency to connect their own best interests with those of the person they supported. (Recommendation 1.5.13) BIA5 There is some evidence that practitioners are unclear about how to determine the best interests of a person who lacks capacity to make a particular decision. The quality of the evidence is low. Ramasubramanian et al. (2011 ++) found in their audit of practice in a specialist learning disabilities unit that before the introduction of a checklist practitioners had not always checked whether the person had an advance statement, lasting power of attorney, court-appointed deputy, etc; had not always involved families, carers and other relevant parties in the decision-making process; and had not always considered involving an independent mental capacity advocate in cases where this would have been appropriate. Sorinmade et al. (2011 ++) found that while the majority of mental health practitioners did consult with family and friends when making a best interests decision, this was not always the case. Enquiries regarding the existence of a court appointed deputy or the involvement of an independent mental capacity advocate were only recoded in a small minority of cases. (Recommendation 1.5.14)
Other considerations	Recommendation 1.5.12 is based on evidence from BIA15 which suggests that practitioners take mixed approaches to best interests decision making, sometimes taking a far less formalised approach for day to day decisions. The committee did not feel this was negative and in fact demonstrated that practitioners were applying appropriate proportionality. They agreed that taking a best interests decision did not necessarily have to involve a formal meeting and that this should depend on the nature of the decision and the circumstances of the individual. Recommendation 1.5.13 is based on BIA1 which reports evidence that families and practitioners draw on their own preferences when making a decision on behalf of someone who lacks capacity. Although the committee acknowledged that families and practitioners make a valuable contribution to the best interests decision making process, they felt it was important to emphasise the key role that the person’s own beliefs and preferences should play. Members pointed out that in line with the Mental Capacity Act, practitioners must find out the person’s views and record the steps that they have taken to do this. Recommendation 1.5.14 is based on evidence in BIA5 which

	suggests that practitioners are unclear about how to determine someone's best interests. In discussing the evidence the committee highlighted that the findings may to some extent be explained by the research having been conducted several years ago, since when practitioners are likely to have become more proficient in determining best interests. Rather than developing a training recommendation on this issue they therefore felt it would be a better reflection of current practice to recommend that organisations provide toolkits for best interests decision making in order to support practitioners in this process. The committee agreed that guidance on recording best interests decision making processes is as vital as guidance on how to conduct the process and this was confirmed in expert witness testimony.

Topic/section heading	Undertaking best interests decision making
Recommendations	1.5.15 Anyone responsible for leading best interests decision-making must consider how best to involve the person in the process and document the steps taken. 1.5.16 Practitioners must think about whether a decision can be delayed until the person has capacity to make a decision and allow all practicable steps to be taken in the interim to help them gain capacity. 1.5.17 When making best interests decisions, explore whether there are less restrictive options that will meet the person's needs. Take into account: • what the person would prefer, including their wishes and feelings, based on past conversations, actions, choices, values or known beliefs • what decision the person who lacks capacity would have made if they were able to do so • all the different options • the restrictions and freedoms associated with each option • the likely risks associated with each option (including the potential negative effects on the person who lacks capacity to make a decision – for example trauma or disempowerment).
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural

	background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendations 1.5.15, 1.5.16 and 1.5.17 were based on evidence from review question 4 about best interests decision-making. A total of 9 papers were included in this review, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was

	likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	BIA There is a small amount of evidence that people who have been determined to lack capacity are not always involved in best interests meetings regarding their care. The quality of the evidence is good. Williams et al. (2012 +) report that in a small number of cases the person determined to lack capacity was not involved in best interests meetings. The authors report that people with learning disabilities were less likely to be invited to a formal meeting, whilst those with dementia were more likely. (Recommendation 1.5.15) BIA 6 There is a small amount of evidence that practitioners are unclear about the requirements to consider whether a person may have capacity to make the decision at a point in the future and to consider whether the decision can be delayed until that time; and to explore the least restrictive options. The quality of the evidence is low. Ramasubramanian et al. (2011 ++) found that before the introduction of a checklist the possibility that the person may have capacity to make the decision at a different time and that the decision could be delayed until that time was only considered in just over a third of cases they examined. They also report that in only a very small minority of these cases was the least restrictive option explored. (Recommendations 1.5.16 and 1.5.17)
Other considerations	Recommendation 1.5.15 is based on BIA18 which reported that people who have been assessed as lacking capacity are not always involved in best interests meetings about their care. This was echoed by the testimony of one of the expert witnesses so the committee agreed about the importance of thinking through how best to involve the person in the process, acknowledging that this may not necessarily be in the context of a formal meeting. The committee also wanted to emphasise the importance of making a record of the steps taken to involve the person. Recommendation 1.5.16 is based on BIA6 which reported a small amount of evidence that practitioners are unaware about requirements around best interests decision making, for example considering whether a decision can be delayed until a point at which the person may have capacity to make the decision.

	Although the quality of this evidence was low it resonated with committee experiences so they agreed to simply recommend that practitioners think about whether a decision can be delayed and take all practicable steps to help the person gain capacity. Since this approach is enshrined in the Act, this is a 'must' recommendation. Recommendation 1.5.17 is also based on BIA6 with the committee focussing on the finding that in only a very small number of cases the least restrictive option was explored. The committee agreed that in their experience practitioners do tend to lack understanding about the importance of exploring least restrictive options, which includes a judgement about associated risks and developing an understanding about the person's likely wishes. Recommendation 1.5.17 was therefore developed in order to provide guidance about how to explore less restrictive options.

Topic/section heading	Undertaking best interests decision making (continued)
Recommendations	1.5.18 When determining best interests the decision maker must establish whether the decision will deprive the person of their liberty and, if so, ensure that the appropriate legal authority is obtained in a timely manner. 1.5.19 When an Independent Mental Capacity Advocate has been instructed they should be involved in the process until a decision has been made and implemented fully. 1.5.20 Record best interests decisions in a way that is proportionate to its complexity, for example in a best interests toolkit or individual care record. As people's circumstances change, review the decisions regularly to ensure that they remain in a person's best interests.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person's cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost

	effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Recommendations 1.5.18, 1.5.19 and 1.5.20 were based on evidence from review question 4 about best interests decision-making. A total of 9 papers were included in this review, which provided data about views and experiences and ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic considerations	No economic evidence was identified to support the recommendations. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the

	Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial 'end loading' of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the recommendations were developed	BIA6 There is a small amount of evidence that practitioners are unclear about the requirements to consider whether a person may have capacity to make the decision at a point in the future and to consider whether the decision can be delayed until that time; and to explore the least restrictive options. The quality of the evidence is low. • Ramasubramanian et al (2011, -) found that before the introduction of a checklist the possibility that the person may have capacity to make the decision at a different time and that the decision could be delayed until that time was only considered in just over a third of cases they examined. They also report that in only a very small minority of these cases was the least restrictive option explored. (Recommendation 1.5.18) BIA 11 There is a small amount of evidence that independent mental capacity advocates believe there can be a lack of clarity regarding how long they should work with someone who lacks capacity. The quality of the evidence is good. Redley et al. (2009 ++) report that advocates were sometimes unclear regarding the point at which their involvement should cease, particularly in relation to cases where a change in accommodation was the key issue. Advocates reportedly believed that they should be involved in a case until a decision had been made and fully implemented. They also expressed concern that they rarely received responses to or even an acknowledgement of their report. (Recommendation 1.5.19) There is a small amount of evidence that the majority of best interests decisions are recorded. The quality of the evidence is good. In an online survey, Williams et al. (2012 +) found that around a third of practitioners used formal note-keeping methods while a further third used standardised pro-formas. Best interests decisions for everyday matters were sometimes recorded informally using staff logs, or 'balance sheets' attached to a care plan. However, practitioners reportedly found it more difficult to find an appropriate means to record everyday decisions. (Recommendation 1.5.20)
Other considerations	Recommendation 1.5.18 is also based on BIA6 with the committee focussing on the finding that in only a very small number of cases the least restrictive option was explored. The committee agreed that in their experience practitioners do tend to lack understanding about the importance of exploring least restrictive options, which includes a judgement about associated

	risks and developing an understanding about the person's likely wishes. Recommendation 1.5.18 was therefore developed in order to provide guidance about how to explore less restrictive options. Recommendation 1.5.19 was based on BIA11 which reported that Independent Mental Capacity Advocates believe there is some lack of clarity about their role, including the length of time for which they should be involved in a case. The committee noted that Independent Mental Capacity Advocates are contracted for a set number of hours regardless of the complexity of the decision or the needs of the individual. They discussed whether the evidence showed that there was a problem with time-limited involvement of Independent Mental Capacity Advocates. Some members felt that arbitrary cut-offs to the involvement of Independent Mental Capacity Advocates can limit their effectiveness so the group agreed this recommendation based on the view that the IMCA role should be expanded. The committee wished to emphasise the point an Independent Mental Capacity Advocate has to remain involved in a case until a decision is made as full involvement allows them to check whether the decision has been implemented. Recommendation 1.5.20 is based on BIA21 which described a small amount of evidence that practice varies in terms of recording best interests decisions. Practitioners found it particularly difficult to know how to record best interests decisions about day to day matters. This resonated with members' experience and in fact they were rather surprised that as many as two thirds of practitioners claimed to record decisions at all. They therefore agreed to develop this recommendation that a toolkit be made available.

Topic/section heading	Undertaking best interests decision making (continued)
Recommendations	1.5.21 After the outcome has been decided, the decision maker should ensure that it is recorded and communicated to everyone involved and that there is opportunity for all participants to offer feedback or raise objections. 1.5.22 If there is a dispute about a person's best interests, resolve this, where possible, before the decision is implemented – for example through further meetings or mediation. If this cannot be resolved locally, refer to the Court of Protection to determine the person's best interests. 1.5.23 Decision makers should specify a timely review of the implementation of the actions resulting from the best interests decision. If the review establishes that the best interests decision was not successfully actioned, the decision maker should take suitable steps such as: • convening a multi-agency meeting to resolve issues

	leading to the best interests decision not being successfully implemented, or - reassessing and making a new best interests decision that is more achievable, or - taking steps to refer the decision to the Court of Protection, or - re-considering whether any further action is appropriate.
Research recommendations	Research recommendation 1: What is the effectiveness and cost effectiveness of different training programmes on the Mental Capacity Act for practitioners involved in supporting decision-making, conducting capacity assessments and making best interests decisions? Research recommendation 2: Does a person’s cultural background, ethnicity or religion influence the outcome of mental capacity assessments or best interests decisions? and What are the views of services users, their carers and families, and health and social care practitioners on the influence of cultural background, ethnicity, or religion on the outcome of mental capacity assessments or best interests decisions? Research recommendation 8: What is the effectiveness and cost effectiveness of using a checklist to support the best interests decision-making process?
Review questions	4a) What interventions, tools and approaches are effective and cost-effective in supporting best interests decision-making? 4b) What are the views and experiences of people who may lack mental capacity, their families and carers and others interested in their welfare on the acceptability of interventions, tools and approaches to support best interests decision-making?
Quality of evidence	Research recommendations 1.5.21, 1.5.22 and 1.5.23 are based on evidence and committee consensus relating to review question 4 about best interests decision making A total of 9 papers were included in the review, which provided data about views and experiences ranging in quality from low to good in terms of internal validity. The studies, all from the UK, provided a good insight in to professional practice with a mixture of perspectives from practitioners, people who may lack capacity and their families or friends. The main gap within this review question was effectiveness data. No UK quantitative studies were found and the non UK studies that were available included best interests decision making for people who had not been assessed as lacking capacity, which was at odds with the population stipulated in the review protocol and the Mental Capacity Act. Those non-UK studies were therefore excluded on the basis of population and this lack of effectiveness data had implications for the development of recommendations and the use of other evidence, including committee expertise.
Economic	No economic evidence was identified to support the

considerations	recommendations. The guideline committee discussed if there were cases where involvement of an Independent Mental Capacity Advocate would make things more effective and it was suggested by some that there had been a definite improvement in change of accommodation decisions. It was noted that whilst the quality of decision making might improve it could lead to higher care costs; however there were also substantial improvement in quality of life. It was suggested that the involvement of Independent Mental Capacity Advocates leads to better decision-making, and ensures that decision makers have a better understanding of benefits and burdens, and enhances compliance with the best interests process. More generally, the Guideline committee thought that since most recommendations were required by law, monies were already being spent. However by recommending what they consider good practice, the Committee thought this would this might help to increase cost-effectiveness as outcomes were likely to improve while costs potentially remain at similar levels. In particular they thought by getting it right at every stage of the process (from Decision making, Independent advocacy, Assessing capacity, Best interest decisions, Deprivation of Liberty Safeguards and the Court of Protection), this would ensure that practice adhered to the law and that unlawful actions were prevented. This could prevent costly scrutiny by the Court of Protection if that case would otherwise have been brought to them. The Committee referred to evidence from the Cardiff Report of Welfare Cases that showed that the average cost of a personal welfare case was £13,000 and that this estimate was likely to reflect the lower end. The Committee thought that if the recommendations in the Guideline were used correctly, there would be less reason for complaints processes or legal hearings as a result of disputes and other objections. However, the Committee thought that it was important to emphasise that this must not discourage court applications to determine complex and significant decisions i.e. those with impact on Article 8 rights or those on end of life issues that required judicial decisions. Those were part of good practice and could not be prevented. However, the Committee thought by following the recommendations in the Guideline there would be a reduction in unnecessary and avoidable applications thus creating capacity for the courts to deal with matters that warrant their attention. The best way to achieve such increases in capacity was to ensure that professionals were legally literate and apply the Mental Capacity Act lawfully. The Committee thought that improved practice as a result of practice that followed the recommendations reduced the need for financial ‘end loading’ of expensive complaints and legal processes and led to better health and social care outcomes of people.
Evidence statements – numbered evidence statements from which the	BIA18 There is a small amount of evidence that people who have been determined to lack capacity are not always involved in best interests meetings regarding their care. The quality of the evidence is good. Williams et al. (2012 +) report that in a small number of cases the person determined to lack capacity was not involved in best interests meetings. The authors report that

recommendations were developed	people with learning disabilities were less likely to be invited to a formal meeting, whilst those with dementia were more likely. (Recommendation 1.5.21)
Other considerations	Recommendation 1.5.21 is based on discussions about BIA18 and BIA20 and is linked with the importance of ensuring people are heard and respected. The committee agreed that an important way of ensuring this happens is to ensure that the outcome of the best interests process is recorded and communicated to everyone, including the person themselves, even if they were unable to attend formal meetings. The committee agreed this was the responsibility of the decision maker. Recommendation 1.5.22 is based on committee consensus following discussions about the evidence on best interests decision-making. One committee member proposed the recommendation as a means of clarifying the steps to take in the event of a disagreement over the person's best interests. Having made the suggestion during small group work the whole committee then debated the suggestion and concluded that it would be an important addition to the guideline. In particular committee members were keen to emphasise that other options such as meetings and mediation should be explored locally before making referrals to the Court of Protection. Recommendation 1.5.23 was based on committee consensus from discussions about the review on best interests decision making. Having drafted recommendations based on the evidence presented, the committee identified an important gap regarding review of the implementation of best interests decisions, to ensure intended actions are carried out and the involvement of a multi agency approach in these reviews. They also identified that the study by Williams (2014, +) concluded that the success of a best interests decision could only be known if there was a system for keeping in touch or reviewing. In this sense they considered that the Williams study supported the need for a recommendation on this issue and the committee was satisfied that this would also address the gap they had been concerned about.

4 Implementation: getting started

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during the development of this guideline. They are:

- Ensuring a greater focus on supported decision making. Underpinned by Principles 1 and 2 of the MCA, supported decision making is fundamental to effective implementation of the legislation and to empowering individuals who have difficulties making their own decisions independently. Organisations need local policies and local training, and to ensure that their policies, procedures and forms for capacity assessment and best interests are congruent with an emphasis on supported decision making.

- Ensuring a workforce that is well-trained and well-developed in supporting decision making and in implementing the MCA, with an awareness of the nature and functional impact of the impairments that give cause to question whether the MCA applies and how it should be assessed. Practitioners need to understand the nature of the person's condition; how that impairment/condition affects decision making; how their decision making can be supported; and what help to seek and from where. Training must be delivered with input from people who use services. It should start at pre-registration level and continue throughout an individual's employment, particularly whenever legislation is updated. Ensuring training is delivered to all health and social care practitioners to a minimum standard will be difficult.
- Access to independent advocacy. There is consistent evidence of a lack of understanding amongst commissioners, public bodies, practitioners and people who use services of the critical role independent advocacy can play in upholding rights and providing an ultimate safeguard from abuse. Consequently, ensuring the recommendations relating to independent advocacy are acted upon will be a challenge of communication and persuasion beyond statutory requirements, and they will require a concerted effort to implement effectively.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. Raise awareness through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. Identify a lead with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. Carry out a baseline assessment against the recommendations to find out whether there are gaps in current service provision.

4. Think about what data you need to measure improvement and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. Develop an action plan, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. For very big changes include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. Implement the action plan with oversight from the lead and the project group. Big projects may also need project management support.

8. Review and monitor how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

5 References

Abel J, Pring A, Rich A, et al. (2013) The impact of advance care planning of place of death, a hospice retrospective cohort study. BMJ Supportive and Palliative Care 3: 168–73

Almack K, Cox K, Moghaddam N et al. (2012) After you: conversations between patients and healthcare professionals in planning for end of life care. BMC Palliative Care 11: 15

Ashton S, Roe B, Jack B, et al. (2014) End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – a qualitative study. Dementia 15: 958–75

Aydin Er R, Sehiralti M (2014) Comparing assessments of the decision-making competencies of psychiatric inpatients as provided by physicians, nurses, relatives and an assessment tool. Journal of Medical Ethics 40: 453–7

Barnes KA, Barlow CA, Harrington J et al. (2011) Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. Palliative and Supportive Care 9: 73–9

Barnes K, Jones L, Tookman A et al. (2007) Acceptability of an advance care planning interview schedule: a focus group study. Palliative Medicine 21: 23–8

Barrett B, Waheed W, Farrelly S et al. (2013), Randomised controlled trial of joint crisis plans to reduce compulsory treatment for people with psychosis: economic outcomes. PLoS One 8(11)

Bisson J, Hampton V, Rosser A et al. (2009) Developing a care pathway for advance decisions and powers of attorney: qualitative study. British Journal of Psychiatry 194: 55–61

Bond CJ, Lowton K (2011) Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study. Age and Ageing 40: 450–6

Boot M, Wilson C (2014) Clinical nurse specialists' perspectives on advance care planning conversations: a qualitative study. International Journal of Palliative Nursing 20: 9–14

Borschmann R, Barrett B, Hellier JM et al. (2013) Joint crisis plans for people with borderline personality disorder: feasibility and outcomes in a randomised controlled trial. British Journal of Psychiatry 202: 357–64

Boyle G (2013) Facilitating decision-making by people with dementia: is spousal support gendered? Journal of Social Welfare and Family Law 35: 227–43

Bravo G, Trottier L, Arcand M et al. (2016) Promoting advance care planning among community-based older adults: A randomized controlled trial. Patient Education and Counseling 99: 1785–95

Brazil K, Carter G, Galway K et al. (2015) General practitioners perceptions on advance care planning for patients living with dementia. BMC Palliative Care 14: 14

Brown PF, Tulloch AD, Mackenzie C, et al., (2013) Assessments of mental capacity in psychiatric inpatients: a retrospective cohort study. BMC Psychiatry 13: 115

Care Quality Commission (2013) Monitoring the Deprivation of Liberty Safeguards in 2012/13. Newcastle upon Tyne: Care Quality Comission

Carling-Rowland A, Black S, McDonald L et al. (2014) Increasing access to fair capacity evaluation for discharge decision-making for people with aphasia: a randomised controlled trial. Aphasiology 28: 750–65

Dixon J, Matosevic T, Knapp M (2015) The economic evidence for advance care planning: systematic review of evidence. Palliative Medicine. 29: 869–84

Dukes E, McGuire BE (2009) Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. Journal of Intellectual Disability Research 53: 727–34

Dunn MC, Clare ICH, Holland AJ (2010) Living ‘a life like ours’: support workers’ accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. Journal of Intellectual Disability Research 54: 144–160

Elbogen E, Swanson J, Appelbaum P et al. (2007) Competence to complete psychiatric advance directives: effects of facilitated decision making. Law and Human Behavior 275–89

Emmett C, Poole, Bond J 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

Emmett C, Poole M, Bond J et al. (2014) A relative safeguard? The informal roles that families and carers play when patients with dementia are discharged from hospital into care in England and Wales. International Journal of Law, Policy and the Family 28: 302–20

Farrelly S, Lester H, Rose D, et al. (2014) What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 49: 1609–17

Farrelly S, Lester H, Rose D, et al. (2016) Barriers to shared decision making in mental health care: qualitative study of the Joint Crisis Plan for psychosis. Health Expectations 19: 448–58

Feng BS, Person C, Phillips-Sabolet J et al. (2014) Comparison between a standardized questionnaire and expert clinicians for capacity assessment in stroke clinical trials. Stroke 45: e229–32

Ferguson L, Murphy GH (2013) The effects of training on the ability of adults with an intellectual disability to give informed consent to medication. Journal of Intellectual Disability Research 58: 864–73

Flood C, Byford C, Henderson C et al. (2006) Joint crisis plans for people with psychosis: economic evaluation of a randomised controlled trial, BMJ 333: 729

Goldsmith L, Woodward V, Jackson L, et al. (2013) Informed consent for blood tests in people with a learning disability. Journal of Advanced Nursing 69: 1966–76

Gregory R, Roked F, Jones L et al. (2007) Is the degree of cognitive impairment in patients with Alzheimer's disease related to their capacity to appoint an enduring power of attorney? Age and Ageing 36: 527–31

Harris D, Fineberg IC (2011) Multidisciplinary palliative care teams' understanding of Mental Capacity Act 2005 'best interest' determinations. International Journal of Palliative Nursing 17: 20–5

Henderson C, Flood C, Leese M et al. (2009) Views of service users and providers on joint crisis plans. Social Psychiatry and Psychiatric Epidemiology 44: 369–76

Horn R (2014) 'I don't need my patients' opinion to withdraw treatment': patient preferences at the end-of-life and physician attitudes towards advance directives in England and France. Medicine, Health Care, and Philosophy 17: 425–35

Jones L, Harrington J, Barlow CA et al. (2011) Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. Palliative and Supportive Care 9: 3–13

Kazmierski M, King N (2015) Role of the community matron in advance care planning and 'do not attempt CPR' decision-making: a qualitative study. British Journal of Community Nursing 20: 19–24

Klingler C, Schmitten J, Marckmann G (2016) Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations. Palliative Medicine. 30: 423–33

Lai JM, Gill TM, Cooney LM et al. (2008) Everyday decision-making ability in older persons with cognitive impairment. American Journal of Geriatric Psychiatry 16: 693–6

MacPherson A, Walshe C, O'Donnell V et al. (2013) The views of patients with severe chronic obstructive pulmonary disease on advance care planning: a qualitative study. Palliative Medicine 27: 265–72

Manthorpe J, Samsi K, Rapaport J (2012) When the profession becomes personal: dementia care practitioners as family caregivers. International Psychogeriatrics 24: 902–10

Manthorpe J, Samsi K Rapaport J (2014) Dementia nurses' experience of the Mental Capacity Act 2005: a follow-up study. Dementia 13: 131–43

McDonald A, Dawson C, Heath B (2008) The impact of the Mental Capacity Act 2005 on social workers' decision making: a report for SCIE. Norwich: University of East Anglia

Mental Capacity Act Committee, Mental Capacity Act (2005) Post-legislative scrutiny, 13 March 2014, HL 139 2013–14

Mills W, Regev T, Kunik M, et al. (2014) Making and Executing Decisions for Safe and Independent Living (MED-SAIL): development and validation of a brief screening tool. American Journal of Geriatric Psychiatry 22: 285–93

Moye J, Karel MJ, Edelstein B et al. (2007) Assessment of capacity to consent to treatment. Clinical Gerontologist 31: 37–66

Murphy J, Oliver T (2013) The use of talking mats to support people with dementia and their carers to make decisions together. Health and Social Care in the Community 21: 171–80

Murrell A, McCalla L (2016) Assessing decision-making capacity: the interpretation and implementation of the Mental Capacity Act 2005 amongst social care professionals. Practice 28: 21–36

Musa I, Seymour J, Narayanasamy MJ et al. (2015) A survey of older peoples' attitudes towards advance care planning. Age and Ageing 44: 371–6

Naughton M, Nulty A, Abidin Z et al. (2012) Effects of group metacognitive training (MCT) on mental capacity and functioning in patients with psychosis in a secure forensic psychiatric hospital: a prospective-cohort waiting list controlled study. BMC Research Notes 5: 302

Pearlman R, Starks H, Cain K et al. (2005) Improvements in advance care planning in the Veterans Affairs System: results of a multifaceted intervention. Archives of Internal Medicine 165: 667–74

Poppe M, Burleigh S, Banerjee S (2013) Qualitative evaluation of advanced care planning in early dementia (ACP-ED). PLoS ONE 8: e60412

Preston H, Cohen Fineberg I, Callagher P et al. (2011) The preferred priorities for care document in motor neurone disease: views of bereaved relatives and carers. Palliative Medicine 26: 132–8

Ramasubramanian L, Ranasinghe N, Ellison J (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

Redley M, Clare ICH, Luke L et al. (2009) Mental Capacity Act (England and Wales) 2005: the emergent independent mental capacity advocate (IMCA) service. British Journal of Social Work 40: 1812–28

Robinson L, Dickinson C, Bamford C et al. (2013) A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...' Palliative Medicine 25: 401–8

Roy A, Sarus J, Roy A et al. (2011) Improving recording of capacity to consent and explanation of medication side effects in a psychiatric service for people with learning disability: audit findings. Journal of Intellectual Disabilities 15: 85–92

Samsi K, Manthorpe J (2013) Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. International Psychogeriatrics 25: 949–61

Samsi K, Manthorpe J, Rapaport P (2011) 'As people get to know it more': experiences and expectations of the Mental Capacity Act 2005 amongst local information, advice and advocacy services. Social Policy and Society 10: 41–54

Seal M (2007) Patient advocacy and advance care planning in the acute hospital setting. Australian Journal of Advanced Nursing 24: 29–36

Seamark D, Blake S, Seamark C et al. (2012) Is hospitalisation for COPD an opportunity for advance care planning? A qualitative study. Primary Care Respiratory Journal 21: 261–6

Shah, A, Banner, N, Heginbotham C et al. (2010) The early experience of old age psychiatrists in the application of the Mental Capacity Act 2005: a pilot study. International Psychogeriatrics 22: 147–57

Shah A, Banner N, Newbigging K et al. (2009) The early experience of consultant psychiatrists in application of the Mental Capacity Act: issues for black and minority individuals. Ethnicities and Inequalities in Health and Social Care 2: 4–10

Sinclair J, Oyebode J, Owens R (2016) Consensus views on advance care planning for dementia: a delphi study. Health and Social Care in the Community 24: 165–74

Sorinmade O, Strathdee G, Wilson C, et al. (2011) Audit of fidelity of clinicians to the Mental Capacity Act in the process of capacity assessment and arriving at best interests decisions. Quality in Ageing and Older Adults 12: 174–9

Stewart F, Goddard C, Schiff R et al. (2011) Advanced care planning in homes for older people. Age and Ageing 40: 330–5

Stone L, Kinley J, Hockley J (2013) Advance care planning in care homes: the experience of staff, residents, and family members. International Journal of Palliative Nursing 19: 550–57

Stovell D, Wearden A, Morrison AP et al. (2016) Service users' experiences of the treatment decision-making process in psychosis: a phenomenological analysis. Psychosis 8: 311–23

Sugano K, Okuyama T, Lida S et al. (2015) Medical decision-making incapacity among newly diagnosed older patients with haematological malignancy receiving first line chemotherapy: a cross-sectional study of patients and physicians. PLoS ONE 10: e0136163

Thornicroft G, Farrelly F, Szmukler G et al. (2013) Clinical outcomes of joint crisis plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. Lancet 381: 1634–41

Turner D, MacBeth A, Larkin A et al. (2017) The relationship between the ‘jumping to conclusions’ bias and treatment decision-making capacity in psychosis: A participant-blind randomised controlled experiment (not yet published)

Walji I, Fletcher I, Weatherhead S (2014) Clinical psychologists’ implementation of the Mental Capacity Act. Social Care and Neurodisability 5: 111–30

Whitehead B, O’Brien MR, Jack BA (2011) Experiences of dying, death and bereavement in motor neurone disease: A qualitative study. Palliative Medicine 26: 368–78

Williams V, Boyle G, Jepson M et al. (2012) Making Best Interests Decisions: People and processes. London: Mental Health Foundation

Williams V, Boyle G, Jepson M et al. (2014) Best interests decisions: professional practices in health and social care. Health and Social Care in the Community 22: 78–86

Wilson E, Seymour J, Perkins P (2010) Working with the Mental Capacity Act: findings from specialist palliative and neurological care settings. Palliative Medicine 24 396–402

Woltmann EM, Wilkniss SM, Teachout A et al. (2011) Trial of an electronic decision support system to facilitate shared decision making in community mental health. Psychiatric Services 62: 54–60

6 Related NICE guidance

To find out what NICE has said on topics related to this guideline, see our web pages on:

Patient experience in adult NHS services (2012) NICE guideline CG138

Service user experience in adult mental health (2011) NICE guideline CG136

Medicines adherence (2009) NICE guideline CG76

Transition between inpatient mental health settings and community and care home settings (2016) NICE guideline NG53

Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015) NICE guideline NG5

Care of dying adults in the last days of life (2015) NICE guideline NG31

Developing and updating local formularies (2014) NICE guideline MPG1

Managing medicines in care homes (2014) NICE guideline SC1

Service user experience in adult mental health; improving the experience of care for people using adult NHS mental health services (2011) NICE guideline CG136

Dementia: supporting people with dementia and their carers in health and social care (2006) NICE guideline CG42

Mental health problems in people with learning disabilities (2016) NICE guideline NG54

Managing medicines for adults receiving social care in the community (2017) NICE guideline NG67

Dementia: assessment, management and support for people living with dementia and their carers (update) NICE guideline. Publication expected June 2018

Care and support of older people with learning disabilities NICE guideline. Publication expected May 2018

End of life care for adults in the last year of life: service delivery (update) NICE guideline. Publication expected July 2018

People's experience in adult social care services: improving the experience of care for people using adult social care services NICE guideline. Publication expected February 2018

7 Contributors and declarations of interests

Members of the Committee and other contributors to the guideline declared any relevant interests. [Add guideline number to hyperlink] in line with the conflicts of interest policy.

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A technical team at the NICE Collaborating Centre for Social Care was responsible for this guideline throughout its development. It prepared information for the Guideline Development Group, drafted the guideline and responded to consultation comments.

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Declarations of interests

The following members of the Guideline Development Group made declarations of interest. All other members of the Group stated that they had no interests to declare.

Committee member	Interest declared	Type of interest	Decision taken
Caroline Bennett	15/10/2016 Paid work to develop a training programme with a local theatre organisation.	Personal financial (non-specific)	No action needed
Caroline Bennett	15/10/2016 We do occasional key note training presentations and workshops in local authority areas.	Non-personal financial (non-specific)	No action needed
Caroline Bennett	15/10/2016 Co-author of paper on MCA for Preparing for Adulthood programme.	Personal non-financial (specific)	Declare and participate
Caroline Bennett	08/05/2017 Authoring strategic briefing on Deprivation of Liberty, decision making and Mental Capacity Act to be published end of 2017.	Personal non-financial (specific)	Declare and participate
Peter Carpenter	25/04/2017 Special visitor for the Office of Public Guardian.	Personal financial (specific)	Declare and participate

Peter Carpenter	25/04/2017 Instructed as independent expert for court of protection cases.	Personal financial (specific)	Declare and participate
Peter Carpenter	25/04/2017 Teach on Capacity (unpaid).	Personal non-financial (specific)	Declare and participate
Peter Carpenter	25/04/2017 Occasionally chair meetings for Section 12/ AC training for RCpsych SouthWest Division.	Personal non-financial (specific)	Declare and participate
Julie Carr	14/06/2016 I practise as an Independent Best Interests Assessor. Updated 27/06/2017: Role no longer active from Jan 2017	Personal financial (specific)	Declare and participate
Julie Carr	05/10/2016 Co-authoring a chapter on best interests assessments for occupational therapists, which is due to launch this year.	Personal non-financial (specific)	Declare and participate
Julie Carr	05/10/2016 Teaching MCA on Huddersfield University under-graduate nursing course. Teaching on Leeds Beckett University undergraduate and Post graduate OT courses. Teaching on York St John university undergraduate and post-graduate OT courses. These roles are unpaid (expenses only).	Personal non-financial (specific)	Declare and participate

Julie Carr	02/10/2017 Received an approach to be involved in writing a chapter in a text book for Health care professionals on assessing capacity	Personal non-financial (specific)	Declare and participate.
Mark Holloway	06/06/2016 Independent brain injury case manager, expert witness and designated LLP member for Head First, a small case management company. I can perceive no direct financial or business related benefit that would accrue by taking this role on as per the Conflicts of Interest Policy.	Personal financial (specific)	Declare and participate
Mark Holloway	06/06/2016 I am a part-time academic researcher. Recently awarded a small grant by the NIHR to support research in the field of adult social care. The grant is paid to my employer and I am not financially benefitting from it. It is my intention to utilise this award to investigate and research supported decision making for people with acquired brain injuries.	Non-personal financial (specific)	Declare and participate
Mark Holloway	05/10/2016 3 speaking engagements: poor decision making, brain injury and decision making.	Personal non-financial (specific)	Declare and participate
Mark Holloway	05/10/2016 Author of a number	Personal non-financial (specific)	Declare and participate

	of papers relating to decision-making and mental capacity (no studies included in guideline evidence review)		
Mark Holloway	23/01/2017 Baroness Finlay invited me to speak at the National Mental Capacity Act Forum on 27/02/17 (unpaid)	Personal non-financial (specific)	Declare and participate
Mark Holloway	08/05/2017 Member of Association of Brain Injury Case Managers' sub-committee	Personal non-financial (specific)	Declare and participate
Paul Hutton	Declared at recruitment Author/Co-author of academic studies relevant to decision making and mental capacity. 14/3/2017: Co-author of study included for evidence review, presented at GC4 - Stovell D, Wearden A, Morrison AP, Hutton P (2016) Service users' experiences of the treatment decision-making process in psychosis: a phenomenolog-ical analysis. Psychosis 8: 311 – 323	Personal non-financial (specific)	Asked to withdraw from discussion of evidence that included paper in question
Paul Hutton	14/06/2016 I have received research grant funding from the National Institute of Health Research to evaluate the efficacy of cognitive therapy for people with psychosis who are	Personal financial (non-specific)	No action needed

	not taking antipsychotic medication.		
Paul Hutton	14/06/2016 I have received small grant funding from the University of Edinburgh to engage in knowledge exchange, consultation and network development events in relation to the development of a research programme on treatment decision-making capacity in psychosis	Personal financial (specific)	Declare and participate
Paul Hutton	14/06/2016 I have applied for research grant funding to the Chief Scientist Office and MQ to investigate the effects of existing and new interventions for treatment decision-making capacity in psychosis.	Personal financial (specific)	Declare and participate
Paul Hutton	14/06/2016 I have co-written a British Journal of Psychiatry Editorial calling for greater patient choice in relation to the use of antipsychotic medication for schizophrenia.	Personal non-financial (non-specific)	No action needed
Paul Hutton	14/06/2016 I am senior author on a systematic review and meta-analysis of shared treatment decision-making interventions for people with psychosis. This examined the effect	Personal non-financial (specific)	Declare and participate

	of these interventions on decisional capacity (paper not included in evidence review)		
Paul Hutton	14/06/2016 I am senior author on a systematic review and meta-analysis of correlates of treatment decision-making capacity in psychosis, currently under review. (paper not included for evidence review)	Personal non-financial (specific)	Declare and participate
Paul Hutton	14/06/2016 I am currently preparing a paper on our proposed cognitive model of impaired treatment decision-making capacity in psychosis. (paper not included for evidence review)	Personal non-financial (specific)	Declare and participate
Paul Hutton	14/06/2016 I am collaborating with two CG178 guideline development group members on a systematic review and meta-analysis of cognitive therapy for psychosis project.	Personal non-financial (non-specific)	No action needed
Paul Hutton	14/03/2017: I have supervised one of the co-authors of an RCT reviewed & discussed at GC5.	Personal non-financial (specific)	Asked to withdraw from discussion of evidence that included paper in question
Paul Hutton	19/9/2017 Co-author of study included for evidence review, presented at GC10: Turner D, MacBeth A, Larkin A, et al, Moritz S, Livingstone	Personal non-financial (specific)	Asked to withdraw from discussion of evidence that included paper in question

	K, Campbell A, Hutton P (2017) The relationship between the 'jumping to conclusions' bias and treatment decision-making capacity in psychosis: A participant-blind randomised controlled experiment (NYP)		
Paul Hutton	03/11/2017 Appointed as Lead for an Edinburgh Napier University course which trains practitioners on the assessment of mental capacity, and issues Section 47 certificates to allow practitioners to perform capacity assessments under the Adults with Incapacity (Scotland) Act 2000.	Personal non-financial (specific)	Declare and participate
Paul Hutton	03/11/2017 Appointed as Associate Director of the Edinburgh Research and Innovation Centre for Complex and Acute mental health problems, a joint Edinburgh Napier University and NHS Lothian research centre.	Personal financial (non-specific)	No action needed
Paul Hutton	03/11/2017 On the Expert Steering Group of Professor Jill Stavert's Centre for Mental Health and Incapacity Law Rights and Policy at Edinburgh Napier University.	Personal non-financial (specific)	Declare and participate
Nageena Khalique	08/06/2016	Personal non-	No action needed

	Co-director of FaceFacts Charity (supporting patients who have undergone maxillofacial surgery) - unpaid	financial (non-specific)	
Nageena Khalique	08/06/2016 Regional Chair of CoPPA (Court of Protection Practitioners' Association) - unpaid	Personal non-financial (specific)	Declare and participate
Nageena Khalique	08/06/2016 Former Board Member of Ashram Housing Association - unpaid	Personal non-financial (non-specific)	No action needed
Nageena Khalique	05/10/2016 Lecturing and writing health care law with focus on mental health.	Personal non-financial (non-specific)	No action needed
Nageena Khalique	05/10/2016 Author of chapter in a book to be published next year - children and young adult mental health and mental capacity.	Personal non-financial (specific)	Declare and participate
Nageena Khalique	05/10/2016 Writing joint guidance for Scottish government on DOLS cross border issues.	Personal financial (specific)	Declare and participate
Nageena Khalique	05/10/2016 LEXISNEXIS expert panel dealing with questions re the court of protection – paid work	Personal financial (specific)	Declare and participate
Nageena Khalique	05/10/2016 Director of No 5 Chambers Ltd since 2015 (not related to mental capacity)	Personal financial (non-specific)	No action needed
Nageena Khalique	05/10/2016 Honorary lecturer at	Personal non-financial (non-	No action needed

	Birmingham University.	specific)	
Chris Lucas	04/01/2016 I undertake work as an independent Best Interests Assessor (DOLS) for several local authorities.	Personal financial (specific)	Declare and participate
Chris Lucas	05/10/2016 Teaching and training sessions relating to DOLS and implementing the MCA and some consultancy work. Involved in developing tools for assessing.	Personal financial (specific)	Declare and participate
Chris Lucas	02/10/2017 I mark students' assignments for Bournemouth University's Best Interests Assessor award. I am paid for this on a sessional basis.	Personal financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Access Medical Services Limited, Non-Executive Director. 0/11/2016 No longer active in this role.	Personal non-financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 SELDOC Ltd Non-Executive Director. 01/11/2016 No longer active in this role.	Personal non-financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Member of Service User and Carer Steering Group, Social Work and Social Care Education, Kingston University. 01/03/2017:	Personal non-financial (non-specific)	No action needed

	Acting Chair of above group.		
Phil Ruthen	15/06/2016 Specialist Advisor, Care Quality Commission.	Personal financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Temporary Projects' Manager, National Charity Survivors' Poetry. 01/10/2016 No longer active in this role.	Personal non-financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Volunteer editorial team ISSN registered Survivors' Poetry e-magazine Poetry Express.	Personal non-financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Book publishing grant from The Gane Trust (Arts).	Personal financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Sole trader author and researcher, including royalties from Waterloo Press poetry publications.	Personal financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Monograph commission, Eleusinian Press, UK mental health system. Ad hoc review and policy work national MIND.	Personal financial (non-specific)	No action needed
Phil Ruthen	15/06/2016 Joint Attorney, holding LPA's for Finance & Property, and Health & Welfare for a friend. LPA's ended December 2016.	Personal non-financial (specific)	Declare and participate
Phil Ruthen	05/10/2016 Research grant	Personal financial (non-specific)	No action needed

	application – St. George's, University of London.		
Phil Ruthen	01/04/2017 Employed as full time Care Assistant, Sentry Care Ltd. 23/06/2017 No longer active in this role.	Personal financial (non-specific)	No action needed
Phil Ruthen	01/04/2017 Grant from John Masefield Memorial Fund via The Society of Authors (Arts).	Personal financial (non-specific)	No action needed
Phil Ruthen	23/06/2017: Public contributor, NIHR Dissemination Centre Themed Review Steering Group on care of frail older people in acute hospital settings.	Personal non-financial (non-specific)	No action needed
Phil Ruthen	19/09/2017 Strategic Peer Consultant, National Survivor User Network (NSUN), Real-Insight project.	Personal non-financial (specific	Declare and participate
James Shutt	15/06/2016 I am an employee (service manager) of POhWER, a charity that provides information, advocacy and advice services.	Personal financial (specific)	Declare and participate
James Shutt	15/06/2016 Member of the Critical Values Based Practice Network (unremunerated).	Personal non-financial (specific)	Declare and participate
James Shutt	15/10/2016 Writing a paper with members of Critical Values Based Practice Network re supporting decision	Personal financial (specific)	Declare and participate

	making.		
James Shutt	15/10/2016 Involved in training local authority and CCGs.	Personal financial (non-specific)	No action needed
Marie Soros	12/06/2016 Director of a small social care company (less than 50 staff) – Avon Support Limited – which provides support to disabled adults in South Warwickshire. My sole income comes from this position, and is taken partly as a monthly salary, and partly as a Dividend.	Personal financial (non-specific)	No action needed
Marie Soros	12/06/2016 Company has been commissioned by Warwickshire County Council, and South Warwickshire NHS Trust to provide services. Some people use a Direct Payment to purchase our services.	Personal financial (non-specific)	No action needed
Anna Volkmer	02/08/2016 I have published two books which contain information related to the area of mental capacity: Volkmer, A. (2013) Assessment and Therapy for Language and Cognitive Communication Difficulties in Dementia and Other Progressive Diseases. J& R Press, UK. (Book). Volkmer, A. (2016) Dealing with Capacity and Other Legal Issue with	Personal financial (specific)	Declare and participate

	Adults with Acquired Neurological Conditions: A Resource for SLTs. J&R Press, UK.		
Anna Volkmer	02/08/2016 Co-author of a recent magazine article on the topic: Devereux, C., Jackson, J., Marjoribanks, J., Harris, C. & Volkmer, A. (2016) Let's talk about capacity. Bulletin magazine, Royal College of Speech and Language Therapists. Issue 771 p12-14.	Personal non-financial (specific)	Declare and participate
Anna Volkmer	02/08/2016 Grants: Oct 2015-Sept 2019; National Institute for Health Research (NIHR) Doctoral Research Fellowship award (£312,956), "Better Conversations with Primary Progressive Aphasia (BCPPA): Communication training to keep families together"	Personal financial (non-specific)	No action needed
Anna Volkmer	02/08/2016 Awards: June 2016 UCL Alzheimer's Research UK Network, £500 Travel Award to attend the Interdem summer school "Multidisciplinary approaches in dementia" in Nottingham, 4/7/2016-8/7/2016	Personal financial (non-specific)	No action needed
Anna Volkmer	23/01/2017 I am jointly leading	Personal non-financial (specific)	Declare and participate

	the development of a position paper on the role of the speech and language therapist in mental capacity for the Royal College of Speech and Language Therapists (RCSLT)		
Anna Volkmer	02/10/2017 I am second author on the forthcoming Royal College of Speech and Language Therapy position statement and resources around the MCA 2005.	Personal non-financial (specific)	Declare and participate
Anna Volkmer	02/10/2017 I am jointly present a paid training session with Mark Jayes (Expert witness at GC9) in Northern Ireland on 9th December 2017 on the role of the SLT in Mental Capacity.	Personal financial (specific)	Declare and participate
Robert Walker	20/05/2016 I am Co-Founder of a company called CHANGES PLUS Ltd, a Well-Being consultancy company.	Personal financial (non-specific)	No action needed
Robert Walker	05/10/2016 Deputy lead governor for MH trust	Personal non-financial (non-specific)	No action needed
Robert Walker	05/10/2016 Honorary lecturer at John Moores University	Personal non-financial (non-specific)	No action needed
Robert Walker	05/10/2016 Associate Fellow of Academy	Personal non-financial (non-specific)	No action needed

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8 Glossary and abbreviations

Glossary

Abuse

Harm that is caused by anyone who has power over another person, which may include family members, friends, unpaid carers and health or social care practitioners. It can take various forms, including physical harm or neglect, and verbal, emotional or sexual abuse. In the context of this guideline, the victims of abuse could be people over 16 years or over who may lack mental capacity now or in the future.

Advance decision

A decision made by a person about what medical treatment they would or would not want in the future, if they were unable to make decisions because of illness or because they lacked capacity to consent.

Advance statement

A written document recording a person's wishes, feelings and preferences about future care and support, in case the person lacks mental capacity in future to express themselves.

Advocacy

Help to enable the person who lacks mental capacity to get the care and support they need that is independent of their local council.

Advocate

An advocate can help people express needs and wishes, and weigh up and take decisions about available options. They can help find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.

Autonomy

When a person as control and choice over their life and the freedom to decide what happens to them. Even when people need a lot of care and support, they should still be able to make their own choices and should be treated with dignity.

Best interests

If a person is unable to make a particular decision for them self (for example, about health or finances), others should act in their ‘best interests’. The law does not define what ‘best interests’ might be, but gives a list of things that those around the individual must consider when they are deciding what is best for the person. These include the person’s wishes, feelings and beliefs, the views of their close family and friends on what the person would want, and all their personal circumstances.

Capacity

The ability of a person to make their own choices and decisions. In order to do this, a person needs to be able to understand and remember information, and communicate clearly – whether verbally or non-verbally – what they have decided. A person may lack capacity because of a mental health problem, dementia or learning disabilities.

Care plan

A written plan following an assessment setting out a person’s care and support needs, how they will be met (including the role of family or friends) and what services will be received. People should have the opportunity to be fully involved in the plan and to express their own priorities. In care homes or day services, the plan for daily care may also be called a care plan.

Court of Protection

An English court that makes decisions about the property, finances, health and welfare of people who lack mental capacity to make decisions for themselves. The court can appoint a ‘deputy’ to make ongoing decisions on behalf of someone who lacks capacity. It is also able to grant power of attorney.

Deprivation of liberty safeguards

Legal protection for people in hospitals or care homes who are unable to make decisions about their own care and support, property or finances. People with mental health conditions, including dementia, may not be allowed to make decisions for themselves, if this is deemed to be in their best interests. The safeguards exist to make sure that people do not lose the right to make their own decisions for the wrong reasons.

Independent mental capacity advocate (IMCA)

An independent person who is knowledgeable about the Mental Capacity Act and people's rights. An IMCA represents someone who does not have capacity to consent to specific decisions, such as whether they should move to a new home or agree to medical treatment. The law says that people over the age of 16 have the right to receive support from an IMCA, if they lack capacity and have no one else to support or represent them.

Independent mental health advocacy (IMHA)

A service that should be offered to someone being treated in hospital or somewhere else under the Mental Health Act. Independent mental health advocates are there to help people understand their legal rights, and to help make the person's views heard. This is not the same as independent mental capacity advocacy (IMCA), which is for people who are unable to make certain decisions and have no one to support or represent them. But there may be times when someone needs both an IMHA and an IMCA.

Informed consent

When the person has received the right information to enable them to decide whether to allow someone to do something to them or for them. Individuals should only give consent if they understand what they are being asked to agree to, what the benefits and risks might be, and what the alternatives are if they do not agree.

Neglect

When someone is mistreated by not being given the care and support they need, if they are unable to care for themself. It may include not being given enough food, or the right kind of food, being left without help to wash or change clothes, or not being helped to see a doctor when they need to.

Nominated person

When someone receives direct payments from the council to arrange their own care and support, they can choose someone they trust to receive these payments on their behalf. This person is called the ‘nominated person’ and is different to a ‘suitable person’, who receives direct payments on behalf of someone who does not have mental capacity to make decisions for themselves.

Power of attorney

A legal decision a person makes to allow a specific individual to act on their behalf, or to make decisions on their behalf, if they are unable to do so.

Rights

What individuals are entitled to receive, and how they should be treated, as a citizen.

Risk assessment

An assessment of a person’s health, safety, wellbeing and ability to manage essential daily routines.

Risk enablement

When a person is able to make their own choices and do things that other people might consider ‘risky’, as part of self-directed support.

Risk management

The process of working out what situations might be risky for someone’s health or wellbeing, and taking steps to help reduce or prevent the risk of harm.

Safeguarding

The process of ensuring that adults at risk are not being abused, neglected or exploited, and ensuring that people who are deemed ‘unsuitable’ do not work with them.

Supported decision-making

Ensuring people get the support they need to make decisions for themself, or to express their wishes or preferences if someone is making a decision on their behalf.

Please see the NICE glossary for an explanation of terms not described above.

Abbreviations

Abbreviation	Term
ACP	advance care planning
ADRT	advance decision to refuse treatment
IMCA	independent mental capacity advocate
IMHA	independent mental health advocacy
LPA	lasting power of attorney
MCA	Mental Capacity Act
MHA	Mental Health Act
PAD	psychiatric advance directive

About this guideline

What does this guideline cover?

The Department of Health (DH) asked the National Institute for Health and Care Excellence (NICE) to produce this guideline on Decision-making and mental capacity (see the scope). [update hyperlink with guideline number]

The recommendations are based on the best available evidence. They were developed by the Guideline Committee – for membership see section 7.

For information on how NICE social care guidelines are developed, see Developing NICE guidelines: the manual

Other information

For consultation document: We will develop a pathway and information for the public and tools to help organisations put this guideline into practice. Details will be available on our website after the guideline has been issued.

For final document: We have developed a pathway and information for the public and tools to help organisations put this guideline into practice. They are available on our website [update hyperlink when guideline number is assigned].

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