Improving mental capacity assessment: iterative, user-centred design of a toolkit and examination of its use in clinical practice.

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Abbreviations used in this thesis

ACE-R: Addenbrooke's Cognitive Examination – Revised
ASSIA: Applied Social Sciences Index and Abstracts
CEBM: Centre for Evidence-Based Medicine
CINAHL: Cumulative Index to Nursing and Allied Health Literature
COP: Mental Capacity Act Code of Practice (2007)
CST: Consent Support Tool
DoLS: Mental Capacity Act (2005) Deprivation of Liberty Safeguards
EMBASE: Excerpta Medica database
FAST: Frenchay Aphasia Screening Test
GP: General practitioner
ICW: Information carrying word
MCA: Mental Capacity Act (2005)
MCAST: Mental Capacity Assessment Support Toolkit
MDT: Multidisciplinary team
MEDLINE: Medical Literature Analysis and Retrieval System Online
MeSH: Medical subject headings
MMSE: Mini-Mental State Examination
NA: Not applicable
NHS: National Health Service
NR: No response
OT: Occupational therapist
PCPI: Patient, Carer and Public Involvement
PEG: Percutaneous endoscopic gastrostomy
PICOS: Population, Intervention, Comparator, Outcome, Study design
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
ScHARR: School of Health and Related Research, University of Sheffield
SLT: Speech and language therapist
SSTALD: Sheffield Screening Test for Acquired Language Disorders
STHFT: Sheffield Teaching Hospitals NHS Foundation Trust

Abstract

Introduction: The Mental Capacity Act (MCA, 2005) requires health and social care professionals to complete a mental capacity assessment if a patient appears to have difficulty making decisions. This thesis explores current practice variations and professionals' support needs and describes the development and testing of the Mental Capacity Assessment Support Toolkit (MCAST).

Aims: To develop a toolkit to facilitate and improve mental capacity assessment and test the feasibility of its use in healthcare settings.

Method: A sequential, mixed methods design was employed. Published research evidence and case law were reviewed. Multidisciplinary healthcare professionals were interviewed about their practice in focus groups. This evidence informed a design specification for the MCAST. User-centred design methods were employed to develop the prototype MCAST. Design modifications were identified from survey, interview and ethnographic data collected during professional, service user and topic expert reviews of prototype iterations. Professionals piloted using the MCAST to assess hospital and intermediate care patients. Document analysis, professional surveys and patient and family carer interviews were used to investigate the MCAST's usability, acceptability and its effects on compliance with the MCA and professionals' confidence levels.

Results: The reviews and focus group data identified barriers and facilitators to good practice and suggested that current practice varies and professionals require support to improve their assessments, especially for patients with communication disorders. The MCAST was designed to enable professionals to: i) prepare, complete and document capacity assessments; ii) identify and support patients with communication disorders during capacity assessments. Most professional participants reported that the MCAST was easy to use and helped them to assess capacity. The MCAST was considered acceptable and potentially beneficial by all patients and family carers interviewed. Use of the MCAST was associated with improved assessment documentation and increased professional confidence.

Conclusion: This study provides new knowledge about capacity assessment, especially in relation to people with communication disorders. The MCAST appears feasible to use in healthcare settings. Further research to refine the prototype and test its effectiveness is warranted.

Chapter One: Background

This chapter introduces this research study. It presents the background to and rationale for the topic of research: mental capacity assessment. The chapter reports the research aims and objectives and outlines a structure for this thesis.

1.1 Mental capacity and the Mental Capacity Act (2005)

With its implementation in 2007, the Mental Capacity Act (MCA, 2005) introduced the term mental capacity to the health and social care systems in England and Wales to denote the ability of adults to make a specific decision at the time it needs to be made (Department for Constitutional Affairs, 2007). In England and Wales, the MCA provides the legislative framework for assessing mental capacity for people over the age of 16 years. The MCA and its Code of Practice (COP) describe in what circumstances a mental capacity assessment should be carried out, who is responsible for completing the assessment, and how capacity or incapacity should be determined.

The MCA is based on five statutory principles (MCA, paragraph 1(2)). These principles are presented in figure 1.1.

1. A person must be assumed to have capacity unless it can be established he lacks capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes 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 his best interests.
5. Before the act is done, or the decision made, regard must be had to whether the purpose for which it is needed can be effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Figure 1.1: The five statutory principles of the Mental Capacity Act (2005)

The first statutory principle of the MCA is the assumption of intact capacity, unless it can be established through a process of assessment that an individual lacks capacity. The MCA defines a two-stage process of capacity assessment to be followed in situations when there is reason to believe an individual may lack capacity to make a decision for her/himself. The capacity assessment can be carried out by anyone "directly concerned" with the individual at the time the decision needs to be made (COP, paragraph 4.38). This often means that health and social care professionals are directly involved in capacity assessment. The Code of Practice explicitly states that a capacity assessment should only be used to determine an individual's ability to make a particular decision at the specific time it needs to be made and should not be used to make judgements about a person's general decision-making ability (COP, paragraph 4.4).

The first stage of the MCA assessment process described by the MCA states that an individual may lack capacity if it can be established that they have an impairment or disturbance of their mind or brain which may affect their ability to make decisions (MCA, paragraph 2(1)). The Code of Practice lists conditions that might cause such impairment or disturbance and affect mental capacity. These include temporary disturbances due to a delirium or alcohol use, and longer-term conditions due to neurological change, mental illness or learning disability. If no such impairment or disturbance is present, it should be concluded that the individual has intact capacity to make a decision and further assessment is not indicated.

If an impairment or disturbance is present, the MCA states that a functional assessment of the individual's decision-making ability should be conducted. The MCA defines the abilities the individual needs to demonstrate, in order for it to be concluded that s/he has capacity: i) the ability to understand information related to the decision to be made; ii) the ability to retain that information; iii) the ability to weigh the information; iv) the ability to communicate a decision using any means (MCA, paragraph 3(1)). If the assessment finds that the person cannot demonstrate one or more of these abilities, then the individual is deemed to lack capacity to make that decision and the MCA outlines a process whereby the decision can be made on the person's behalf by others acting in her/his "best interests" (MCA, paragraph 1(5)).

The implementation of MCA in 2007 represented an important change in the way that the law considered that people who may lack mental capacity should be treated. Previous legal approaches to mental capacity in England and Wales were based on provisions of existing mental health law (e.g., the Mental Health Act, 1959; Ministry of

Health, 1959) or principles drawn from existing case law (sometimes referred to as "common law") (Volkmer, 2016). These approaches to decision-making capacity tended to assume that individuals with some type of mental disorder were incapable of making any decision autonomously and would require others to act on their behalf. Thus, people with conditions such as dementia or learning disability were often presumed to lack capacity and were not involved in decisions that directly impacted on their lives (Boyle, 2011). Within health and social care, this resulted in professionals making decisions on behalf of people with these conditions, on the basis of their own perceptions of what would contribute to an individual's well-being; this meant that professionals could make decisions about an individual's care, treatment or residential arrangements without consulting that person or engaging her/him in a process of informed consent. This type of practice has been described as "paternalistic" (Graham & Crowley, 2015). The new approach promoted within the MCA was in part motivated by a number of important legal cases in which this paternalistic practice was challenged.

The MCA's five statutory principles (figure 1.1) clearly laid out a new approach to considering mental capacity and an intention to provide legal rights to individuals who might lack capacity (House of Lords, 2014). The MCA placed a new emphasis on placing each individual at the heart of decision-making, by assuming intact capacity unless this could be demonstrated not to be the case through a process of assessment using a defined two-stage test of capacity. Previous legal approaches to substituted decision-making were not based on a defined test of capacity. The MCA also provided a legal framework that could be applied to any decision an individual might be asked to make, whereas previous approaches to mental capacity tended to focus on decisions relating to financial arrangements and medical treatment.

Furthermore, the MCA proposed a novel approach to substituted decision-making by defining more clearly the concept of "best interests". Prior to the implementation of the MCA, doctors making medical decisions on behalf of patients deemed to lack capacity based their judgements about those patients' best interests on medical evidence or expert opinion. Thus, the concept of best interests emphasised medical benefits and risks rather than other, more holistic aspects of an individual's welfare (e.g., their emotional needs). The MCA challenges professionals to consider all aspects of individuals' well-being when making decisions in their best interests.

1.2 Mental capacity assessment in hospital and intermediate care settings

Patients in acute hospital and intermediate care[1] settings are often asked to make important decisions about their medical treatment and arrangements for their care following discharge (Herbert, 2013). The involvement of patients in decision-making is considered to be fundamental to the provision of ethical, high quality, patient-centred care within the National Health Service (e.g., Department of Health, 2010a). "Shared decision making", which involves the joint participation of professionals and patients in healthcare decision-making, is recognised internationally for its potential to engage patients in the management of their healthcare conditions (Hoffman *et al*., 2014). It has been argued that the MCA has made an important contribution to the facilitation of shared decision making in England and Wales (Ryan *et al*., 2012), because it reinforces the importance of supporting patient decision making and makes this a legal requirement.

Patients may lack capacity to make decisions due to cognitive or communication difficulties that make it difficult for them to understand, retain, weigh up information and express their decisions. These cognitive and communicative difficulties may arise from acquired neurological condition including stroke and brain injury and progressive conditions such as dementia. A recent review of 23 studies estimated that 34% of medical inpatients were found to lack capacity to make decisions about their treatment (Lepping *et al*., 2015). Demographic changes mean that increasing numbers of patients in England and Wales are likely to require mental capacity assessment in future (Moye and Marson, 2007). This is because health conditions such as stroke and dementia tend to affect older people more than younger people and the population of older people in the UK is increasing.

Mental capacity assessment findings impact directly on patients' ability to retain independent control over many aspects of their lives (Lamont *et al*., 2013). Consequently, it is important that assessments are compliant with the requirements of the MCA and provide accurate evaluations of patients' decision-making ability. However, health and social care professionals lack awareness of how to assess capacity and of the requirements of the MCA (Myron *et al*., 2008; Guyver *et al*., 2010; Willner *et al*., 2010). Many professionals find mental capacity assessment difficult and

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[1] Intermediate care refers to healthcare services, including rehabilitation, that are delivered in community settings and are designed to prevent admission to, or facilitate early discharge from, hospital (Ariss *et al*., 2015).

their practice is not always rigorous (Williams *et al*., 2012; Care Quality Commission, 2013). In 2014, a House of Lords committee published a report summarising the findings of a Post-Legislative Scrutiny of the MCA (House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005, 2014). The committee considered oral and written evidence submitted by professionals, non-professional carers and service-users relating to their experience of the MCA and its implementation. The report concluded that whilst the legal framework provided by the MCA was sound, its implementation had been poor, the quality of mental capacity assessments carried out by health and social care professionals was low and future practice needed to be improved. Mental capacity assessment is challenging because the MCA and its Code of Practice do not provide detailed instructions about how capacity should be assessed in practice. In addition, there is no established gold standard mental capacity assessment tool available for professionals to use. Consequently, capacity assessment is “subjective and can be complex” (Ripley *et al*., 2008, p56).

1.3 Patients with communication disorders

Patients with conditions such as stroke, brain injury and dementia are more likely to lack capacity due to the communicative deficits associated with these conditions (Mujic *et al*., 2009; Carling-Rowland and Wahl, 2010). These patients all require mental capacity assessments before it can be established that they lack capacity and need decisions in their “best interests” to be made by others.

The functional assessment of decision making outlined by the MCA requires an assessment of the ability to understand information about a decision and the ability to express a decision. The MCA and its Code of Practice do not provide guidance on how to carry out these assessments. These assessments become more complicated when a patient has communication difficulties, for example the language disorder aphasia, which can affect the patient’s ability to understand and express spoken and written language (Brady *et al*., 2013). Health and social care professionals without specialist knowledge of such communication disorders find it difficult to assess these abilities accurately (Ferguson *et al*., 2010). Inaccurate identification of a patient’s comprehension ability might lead professionals to conclude incorrectly that the person has capacity to make an informed decision (Savage, 2006). There is also a risk that professionals may conclude that a patient who has an expressive language or speech deficit may not be able to make a decision, because they cannot understand the patient or because they assume the patient cannot understand them (Stein and Brady Wagner, 2006).

As shown in figure 1.1 (p3), the second statutory principle of the MCA requires professionals to provide practical support to maximise patients' capacity to make decisions, before it can be established that they lack capacity. For patients who have difficulty understanding language, there is a requirement for professionals to provide information "in a way that is appropriate to (the patient's) circumstances" (MCA, paragraph 3(2)). This recognises that such patients will have individual support needs, based on the specific nature of their language difficulties and residual abilities. The Code of Practice describes ways that information can be adapted to make it more accessible[2], but does not provide guidance on how to identify the format that is most accessible for each individual. For patients with difficulties using language to express their thoughts or choices, the COP recommends that provision is made to enable them to use alternative communication methods to express themselves. However, the COP does not explain how to identify the alternative communication method that will be most effective for each individual.

Due to these complications, professionals report that they find it difficult to assess capacity for patients with communication difficulties (Carling-Rowland and Wahl, 2010). Inaccurate assessment places this population at risk, either of being excluded from decision-making when it is wrongly assumed they lack capacity, or of making uninformed decisions when it is incorrectly assumed their capacity is intact (Ferguson *et al.*, 2010).

1.4 Rationale for this research study

Mental capacity assessment is an increasingly frequent aspect of clinical practice in acute hospital and intermediate care settings and is a legal requirement. Capacity assessment is complex and involves subjective judgements, which health and social care professionals find challenging. The quality of capacity assessments is low. Some professionals lack awareness of the law whilst others find it difficult to operationalise it when assessing capacity. The MCA and the COP do not provide a structured framework to facilitate assessment; nor do they enable professionals to meet the needs of patients with communication disorders, who are likely to require additional support to

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[2] 'Accessible' information can be defined as information that is presented in such a way that it can be understood and used easily by its target audience (Litherland, 2007).

make decisions. Therefore, there is a need for interventions to facilitate and improve the quality of mental capacity assessment and increase the inclusion and engagement of people with communication difficulties in decision-making (Boyle, 2011).

This doctoral research was motivated by this clinical need. The research was carried out by a practising speech and language therapist (SLT) with a special clinical interest in and professional experience of mental capacity assessment in NHS settings. Throughout this thesis, the doctoral student and author of the thesis is referred to as “the researcher”. The researcher had identified during his own work in an acute hospital setting that mental capacity assessment is a complex clinical activity; he found assessing capacity challenging and observed from discussions with multidisciplinary colleagues that other health and social care professionals shared this view. The researcher was aware of aspects of local practice that were not consistent with guidance contained within the MCA COP (2007). This motivated him to carry out research in order to understand and attempt to facilitate and improve mental capacity assessment practice.

The researcher engaged in Patient, Carer and Public Involvement (PCPI) activity to investigate whether this proposed research topic was important to health care users. He consulted members of the Sheffield Brain Injury Rehabilitation Research Partnership (BIRRP), the NIHR Stroke Research Network’s Clinical Studies Group on Patient, Carer and Public Involvement, and visitors to the Stroke Association's "TalkStroke" online forum. The members of these groups are representative of the types of patients that may require mental capacity assessment and their carers. Ten people reviewed a lay summary of the research study. All reviewers recognised the need for a tool to facilitate mental capacity assessment and the importance of the proposed research.

The focus of this study was to examine how health and social care professionals assess mental capacity for patients within acute hospital and intermediate care settings, in order to identify ways to facilitate and improve practice. These settings were selected because a significant number of patients receiving acute and intermediate care are likely to require mental capacity assessments (Lepping *et al*., 2015). The study involved the iterative development and evaluation of a toolkit to support multidisciplinary professionals to carry out mental capacity assessments and support the needs of patients with communication disorders during mental capacity assessments in acute hospital and intermediate care settings. These patients had diagnoses of stroke or acute or chronic cognitive impairment and the majority were older people. The thesis describes the methods used to develop the toolkit and test the feasibility of using it in clinical practice.

1.5 Terminology

The terms “mental capacity” and “capacity” are used in the thesis to refer to the definition of mental capacity provided by the MCA. The terms “competence” and “capacity” are both used within English language healthcare literature to refer to the ability to make informed decisions. Authors have differentiated competence as a global judgment of decision-making ability that is usually made in legal contexts and capacity as a determination of the ability to make a specific decision that is usually made in clinical settings (e.g., Applebaum, 2007; Lamont *et al*., 2013).

The term “professional” is used in this thesis to describe a health and social care professional who is involved in mental capacity assessment. The term “professional participant” is used to describe health and social care professionals involved in mental capacity assessment who were recruited to this study. The term “patient” is used in the thesis to refer to healthcare patients who might require a mental capacity assessment. The term “patient participant” is used to refer to healthcare patients requiring a mental capacity assessment who were recruited to the study. The term “service user” is used to denote an individual in receipt of health or social care services. The term “carer” is used in this thesis to describe an individual who is involved in providing care to an individual. A “family carer” refers to a carer who is related to the patient whilst a “paid carer” refers to a carer who is employed to provide care.

1.6 Study aims

1. To develop a tool to support assessment of mental capacity for patients in hospital and intermediate care settings.
2. To evaluate the feasibility of using the tool in clinical practice.

1.7 Study objectives

1. Case law and literature relating to current mental capacity assessment practice in England and Wales will be reviewed and synthesised.

2. Professionals' views about and experiences of mental capacity assessment practice within acute hospital and intermediate care settings will be explored.

3. Literature relating to methods that can be used to make information more accessible to people with communication disorders during capacity assessments will be reviewed and synthesised.

4. A support tool will be developed using evidence from the literature and case law reviews that is responsive to user needs.

5. The support tool will be tested to investigate its usability and acceptability in clinical settings and the validity and reliability of its outcomes.

1.8 Research questions

1. How do professionals currently assess adults' ability or mental capacity to make informed decisions in England and Wales?

2. What are professionals' experiences of assessing mental capacity within acute hospital and intermediate care settings?

3. How can information be adapted to make it more accessible to people with communication disorders?

4. What are professionals' opinions of resources designed to support mental capacity assessments?

5. Can professionals use a support tool to assess mental capacity and support patients with communication disorders during mental capacity assessments?

6. Do professionals and patients find the support tool materials and processes acceptable?

7. Does the support tool provide valid and reliable outcomes?

1.9 Thesis structure

The thesis structure is illustrated in figure 1.2. This figure includes descriptions of the methods used during the study. These methods are discussed more fully in chapter 2.

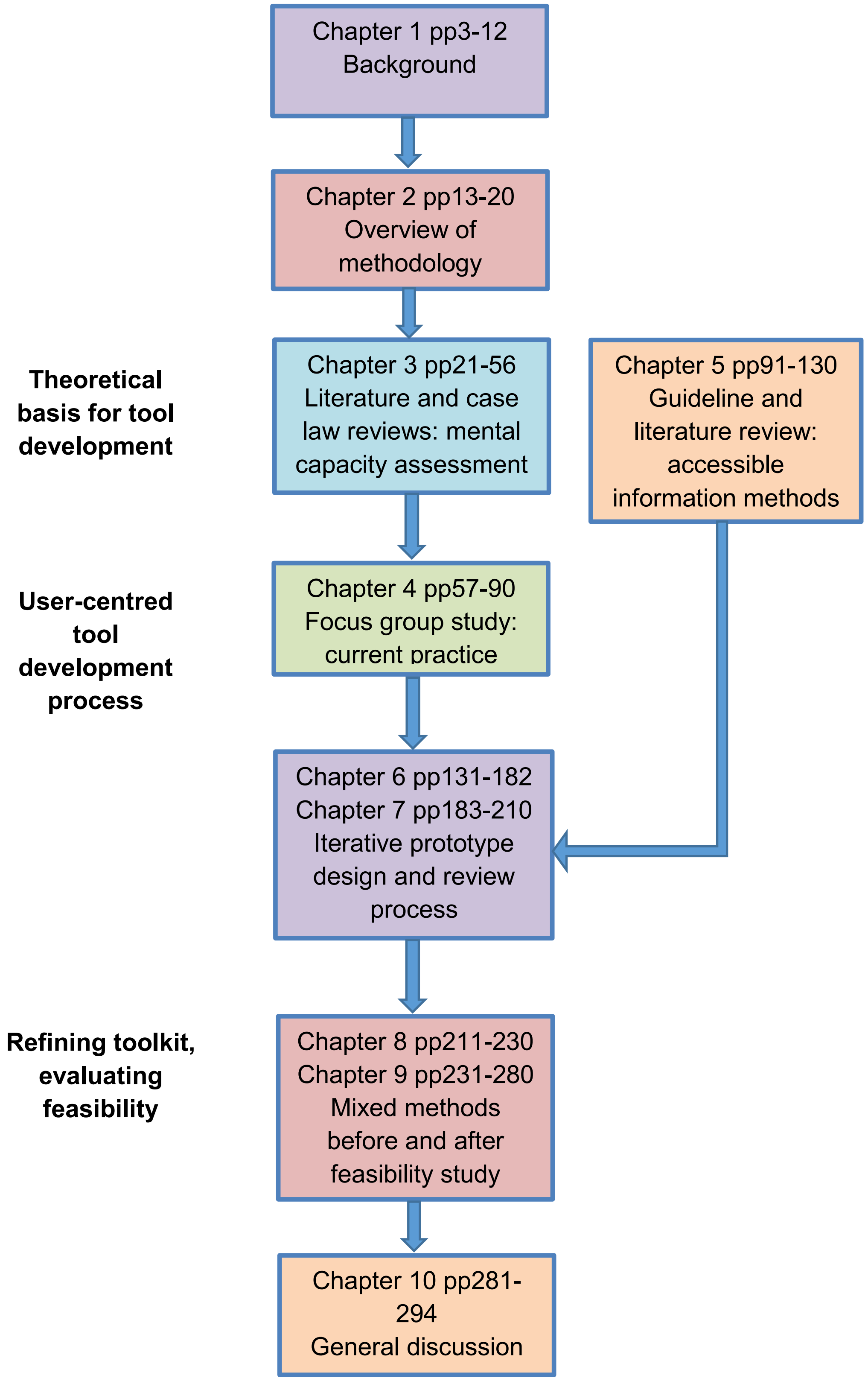


Figure 1.2 Summary of thesis structure

Chapter Two: Overview of Methodology

This chapter introduces the research design, identifies the researcher's ontological and epistemological perspectives and summarises the methods used during the study.

2.1 Research design

The study design was informed by the Medical Research Council (MRC)'s initial framework for developing and evaluating randomised controlled trials of complex interventions (MRC, 2000) and its revised guidance for developing and evaluating complex interventions (Craig *et al*., 2008). These frameworks were used because the tool that this research aimed to develop can be considered to be a complex intervention. The 2008 MRC guidance defines a complex intervention in healthcare as any intervention that involves a number of interacting components which require its users to carry out different tasks. The tool designed in this study needed to incorporate different elements that would enable its users to complete the different tasks required to complete the MCA two-stage assessment process (as described on p4). The 2008 guidance also suggests that an intervention can be considered complex if is designed to be used by several different groups of people. The tool developed as part of this research needed to be used by diverse professional and patient groups. Complex interventions are also defined as those which can provide several different outcomes. It was important that the intervention developed in this study enabled professional users to identify different outcomes relating to a patient's ability to make a decision and their decision-making support needs. Finally, the tool could be considered to be a complex intervention (as defined by the 2008 MRC guidance) because it was designed to be used flexibly, according to the needs and abilities of individual patients.

As illustrated in figure 2.1, the 2008 MRC framework for developing and evaluating complex interventions identifies different phases of intervention development, feasibility and piloting, evaluation and implementation. These phases may not be linear or cyclical.

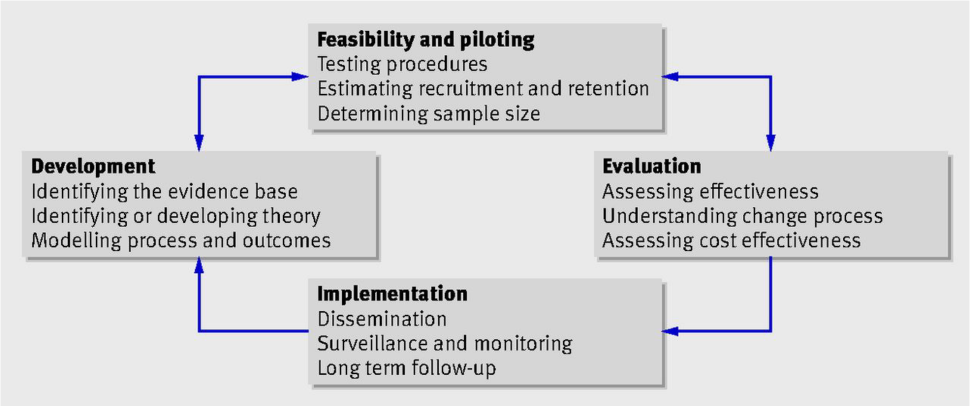


Figure 2.1: MRC Complex intervention development and evaluation framework (reproduced with permission from Craig *et al*., 2008)

This study involved the development and initial feasibility testing of the tool. Drawing on the 2008 MRC framework (figure 2.1), the development phase involved an exploration of the evidence base relating to mental capacity assessment and the design of a prototype tool that was informed by this evidence. The MRC guidance emphasises the need to assess the feasibility of complex interventions before proceeding to full evaluations, for ethical and cost-efficiency reasons. The feasibility testing phase involved an exploration of the prototype's use in clinical practice and the feasibility of methods used to recruit professionals and patients and collect data in order to test the prototype. The methods used during these development and feasibility testing phases are summarised in section 2.3.

The study used a mixed methods design. Mixed methods designs involve the combination of qualitative and quantitative data collection and analysis methods within the same study (Creswell, 2003). This type of design was appropriate for this study because it provided a comprehensive way of answering the different research questions (Teddlie and Tashakkori, 2009). This was an exploratory, complex study that aimed to develop a tool to support health and social care professionals to assess mental capacity and evaluate the feasibility of using it in clinical practice. It was important to review the available published evidence relating to mental capacity assessment and to understand professionals' experiences of capacity assessment and the types of support they perceive they need to help them assess capacity, in order to ensure the tool was clinically useful. It was equally important to find out if the tool that was developed could be used by professionals within clinical practice and whether its use and its materials would be acceptable to professionals and to the patients being assessed. A qualitative methodology was the optimum approach to generate data to answer these questions. At the same time, the tool would need to provide consistent, appropriate support to professionals when conducting their capacity assessments. Therefore, it would be beneficial to investigate how valid and reliable its outcomes were when used by professionals. A quantitative methodology was appropriate to enable an evaluation of these psychometric properties. These quantitative and qualitative data would be integrated to determine whether the tool was useable, acceptable, valid and reliable.

2.2 Ontological and epistemological perspectives

Ontology refers to a theory of what can be considered to be a source of data (Bryman, 2012). During this study, different types of data were collected to answer the research questions. Quantitative data included the outcomes that different people obtained when using the support tool during its feasibility evaluation and participants' responses to surveys during the development and evaluation stages. Qualitative data that included participants' reported experiences, beliefs and opinions were collected in order to understand the reality of how mental capacity assessment is carried out within a healthcare context. Because of this, the researcher adopted a constructionist ontological perspective, which considers that data are constructed through social interactions and consequently are subjective. Epistemology refers to the study of what constitutes knowledge (Bryman, 2012). The researcher adopted a subtle realist epistemology (Mays and Pope, 2000). This position recognises that an underlying reality exists, which can be investigated and described, but acknowledges that any research process is subjective and research data are socially constructed and do not reproduce any underlying reality (Murphy *et al*., 1998). The subtle realist approach is consistent with a mixed methods design (O'Cathain *et al*., 2010).

2.3 Summary of methods

2.3.1 User-centred design methodology

This study adopted a user-centred design methodology. The user-centred approach directly involves target users in the design process, to ensure that novel services, products and tools are designed in response to users' needs (Rekha Devi *et al*., 2012). This methodological approach, sometimes referred to using the terms "participatory design" or "cooperative design", originated in the field of software design but is becoming increasingly utilised in healthcare research (e.g., Mountain *et al*., 2006). The ultimate aim of a user-centred design approach is to make products that are usable and understandable (Norman, 2002). The international standard for human-centred design for interactive systems design defined usability as “the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use” (ISO 52075, 2010). Rubin (1994) has associated usability with the concepts “usefulness”, “effectiveness” or ease of use, “learnability” and “attitude” or likeability. The usability of a product can be conceptually linked to its face validity, a psychometric property that is often evaluated during the design of novel assessment tools. Face validity is based on the subjective judgement of people using the tool that it appears to contain items that will enable users to achieve the tool’s stated aims (Ivanova and Hallowell, 2013).

The international standard for human-centred design for interactive systems design (ISO-standard 52075, 2010) set out six key principles characterising user-centred design. The first is that products should be designed on the basis of a clear understanding of their users, the tasks they need to achieve and the environment in which this takes place. Next, users need to be involved at all stages of the design process. Third, the design process should be directed and refined by user-centred evaluation. The next principle is that design should be an iterative process. Fifth, the product should be designed to address all aspects of the user’s experience. Finally, the design process should involve multidisciplinary perspectives and skills.

Kravetz (2005) identified three phases to the user-centred design process. The first involves the development of an understanding of potential users, the second is the product design phase and the third is an evaluation phase. The first two of these phases are broadly consistent with the intervention development phase as defined by their 2008 complex intervention framework (Craig *et al*., 2008); the third is consistent with the feasibility and piloting phase. The ISO-standard 52075 (2010) describes various methods that can be used to collect data to guide the design process through these three stages. These include inquiry methods, which can be used in the initial phase to collect data about user requirements and needs. Inquiry methods include focus groups and surveys. Participatory design methods are adopted to involve users directly in the product development phase by asking them to review design iterations. Usability testing can be used during the evaluation phase; this method involves asking users to trial the product whilst an observer records the users’ behaviour and responses. Inspection methods can also be utilised to evaluate usability; these methods include inviting experts to review a prototype to identify usability problems. Expert review also can be carried out to establish a novel tool's content validity. Content validity refers to the extent to which a tool contains items necessary to measure outcomes accurately (Franzen, 1989).

The user-centred design approach was adopted in this study in order to maximise the support tool's usability. Professionals who carry out mental capacity assessments were identified as the primary users of the tool or toolkit. Therefore, health and social care professionals were recruited to contribute directly to the design process. Another aim was to ensure the acceptability of the tool or toolkit both to professionals and patients who might require mental capacity assessments. Acceptability has been described as the perception amongst stakeholders that an innovation, intervention or service is "agreeable, palatable, or satisfactory" (Proctor *et al.*, 2011). Both usability and acceptability factors are likely to impact significantly on how successfully the tool or toolkit is implemented within clinical practice in future.

In order to increase acceptability, people with communication disorders secondary to stroke and dementia, who were recruited to a Patient, Carer and Public Involvement (PCPI) advisory group for this study, were invited to participate in the design process. The involvement of service users in the design of health and social care services has been described as "co-production" (Needham and Carr, 2009). In a similar way to user-centred design, co-production aims to increase the likelihood that new products will be responsive to user needs, will function effectively, and will be acceptable to service users.

The specific methods employed during the product development and feasibility testing phases are described below and summarised in figure 2.2. This methodology was informed through consultation with local experts in user-centred design, including health researchers and design engineers.

2.3.2 Product development phase methods

First, inquiry methods were used at the initial design phase to understand users' needs. Case law and published evidence relating to mental capacity assessment in practice were reviewed (chapter 3, pp21-30). Next, healthcare professionals were interviewed about their experiences of assessing mental capacity in a focus group study (chapter 4, pp57-90). A review of guidance and published evidence relating to the use of accessible information was completed, in order to identify potential methods for supporting people with impaired communication skills during capacity assessments (chapter 5, pp91-130). The researcher examined and integrated data from the different reviews and the focus group study in order to determine an initial design specification for a support tool (chapter 6, pp140-142). The researcher used an online survey method and a practical workshop to enable health and social care professionals and topic experts to review the design specification and iterative versions of prototype tool materials that were developed in collaboration with topic and design experts and members of the project's PCPI group (chapters 6-7, pp131-210).

2.3.3 Feasibility testing phase

The MRC guidance emphasises the need to assess the feasibility of complex interventions before proceeding to full evaluations, for ethical and cost-efficiency reasons. Therefore, this study was designed primarily to assess the feasibility of the MCAST's processes and materials, in terms of their usability and acceptability to professionals and patients, before proceeding to a full evaluation of its effectiveness. The study was also designed to test the practicability of the planned recruitment processes and data collection methods.

The tool's usability, acceptability, and aspects of its validity and reliability were investigated by inviting health care professionals to use it during their capacity assessments for patients as part of a feasibility study (chapters 8-9, pp211-280).

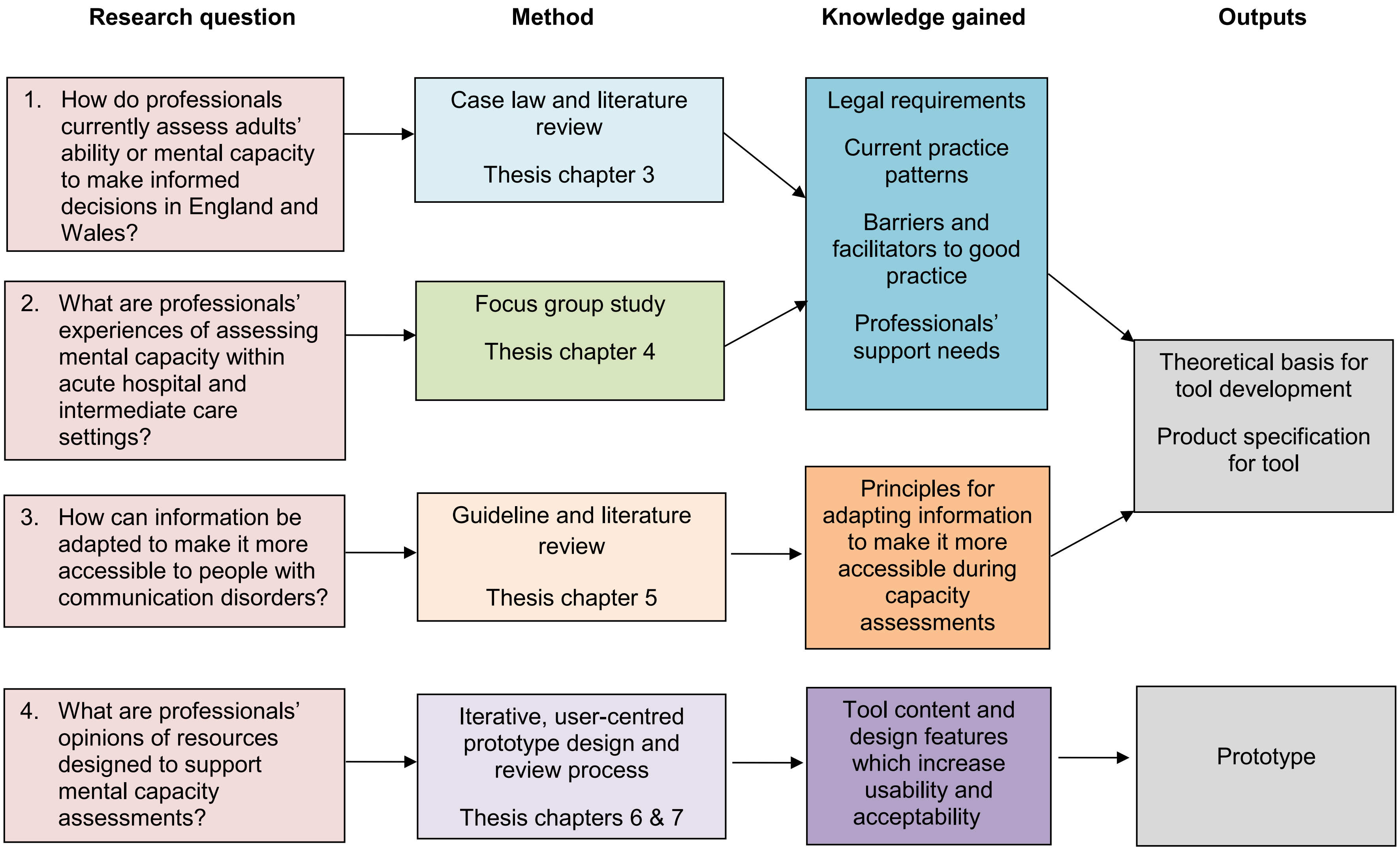
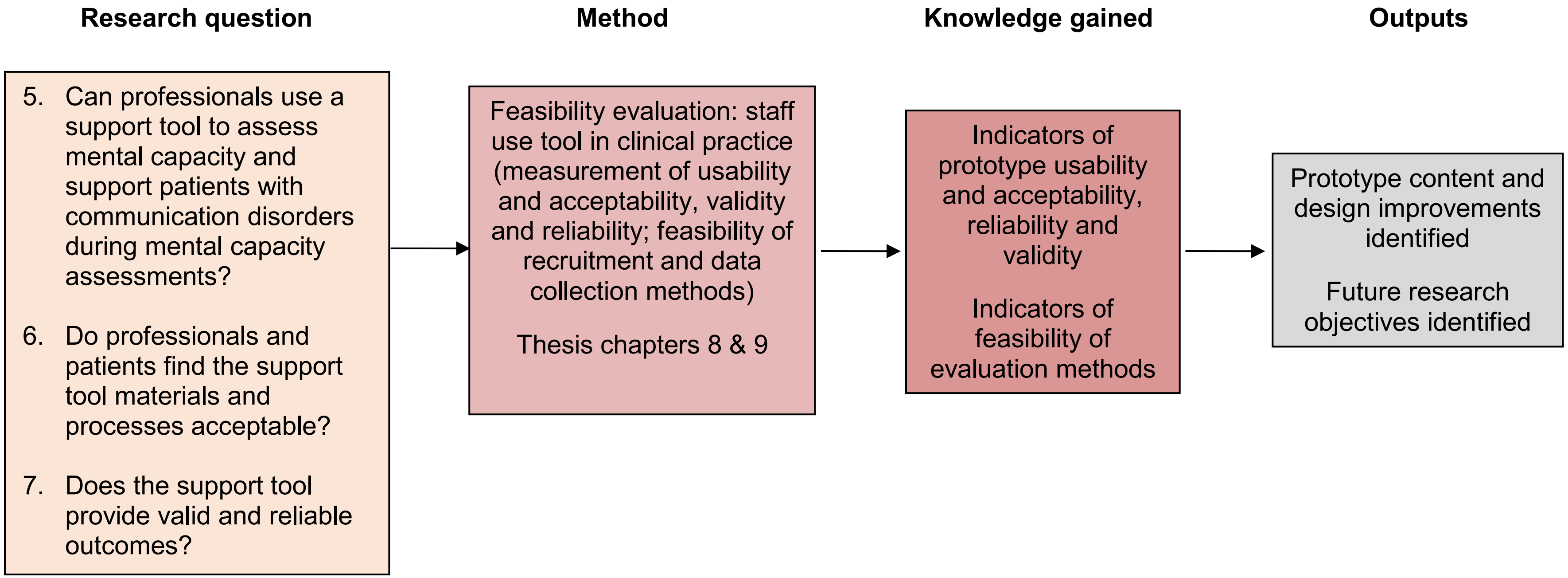


Figure 2.2 Summary of research design (continued overleaf)


Research question
Method
Knowledge gained
Outputs
5. Can professionals use a support tool to assess mental capacity and support patients with communication disorders during mental capacity assessments?
6. Do professionals and patients find the support tool materials and processes acceptable?
7. Does the support tool provide valid and reliable outcomes?
Feasibility evaluation: staff use tool in clinical practice (measurement of usability and acceptability, validity and reliability; feasibility of recruitment and data collection methods)
Thesis chapters 8 & 9
Indicators of prototype usability and acceptability, reliability and validity
Indicators of feasibility of evaluation methods
Prototype content and design improvements identified
Future research objectives identified

Chapter Three: Mental Capacity Assessment in Practice

This chapter examines how health and social care professionals assess mental capacity in England and Wales, in relation to the legal framework provided by the MCA. Case law and published research evidence are reviewed and synthesized, in order to understand how practice might be improved. These reviews were carried out in order to meet the first objective for this doctoral study (see p10).

3.1 Introduction

The chapter starts with a review of case law that has focused on mental capacity assessment processes. This review was designed to explore the legal standards that professionals need to maintain when assessing capacity. This was achieved by examining a number of cases in which capacity assessments have been subject to legal scrutiny. The chapter then presents a separate review of literature relating to mental capacity assessment practice in England and Wales since the implementation of the MCA. The review was designed to provide a broad overview of mental capacity assessment, in order to contextualise this research study both clinically and within the current literature. The chapter critically appraises the studies included in the review, in order to establish the validity, reliability and generalizability of their findings. The evidence presented in this chapter will be used, in conjunction with the findings of the focus group investigation of local practice presented in chapter four, to identify ways in which mental capacity practice might be improved.

3.2 Review of case law: legal implications of mental capacity assessment

Relevant case law was reviewed to identify instances when assessment practice has been examined using the legal framework provided by the MCA. As described in chapter 1 (p4), the MCA Code of Practice (COP, 2007) outlines a clear two-stage functional process for mental capacity assessment. The first stage involves an assessment of whether the person has “an impairment of, or a disturbance in the functioning of, their mind or brain” (COP, p44). If an assessor finds that such an impairment or disturbance is present, s/he should proceed to the second stage of the MCA functional test, which involves an assessment of the person’s decision-making ability. The MCA requires assessors to ascertain whether a person is able to understand, retain and weigh up information that is relevant to the decision in question and then communicate a decision. If the person is able to do all of these tasks, with whatever support or communication adaptations they require, the assessor should conclude they have intact capacity to make a decision. If the person is unable to do any of the four tasks, the assessor should conclude that the person lacks capacity to make the decision and a process of best interests decision-making should be initiated.

3.2.1 Methods

The following search strategy was developed in collaboration with a librarian specialising in legal documents and a legal expert specialising in mental capacity law. As this was a search for case law reports, a review question was not indicated. The Westlaw UK, Lexis Library and Balliol electronic databases of UK legal research were searched for case law relating to mental capacity assessment (last search December 2016). These databases can be searched for case reports relating to specific legislation or using a free text “key word” search facility. Cases were eligible for inclusion in the review if they included descriptions of mental capacity assessment processes and/or judges’ commentaries on the quality of assessments.

An initial scoping search was carried out by searching for all cases relating to the MCA. This generated over 100 records from each database. Examination of the first 30 records suggested that many were ineligible for inclusion because they did not relate to the process of mental capacity assessment but to other aspects of the MCA (for example, best interests decision-making processes). Therefore, a more focused search strategy was used, which involved using the search term “mental capacity assessment” to search case reports in all databases. This generated 75 case reports, including 27 duplicates. The researcher assessed the 48 remaining records for eligibility for inclusion in this review. Seven case reports were found to be eligible. Two of these made reference to two further cases which also met the eligibility criteria. This resulted in nine case reports being reviewed. The legal expert indicated that this search strategy appeared to be effective in terms of the number of records identified, based on his own experience of reviewing case law on this topic.

3.2.2 Results

Summary information relating to each case is presented in table 3.1. The nine cases are discussed initially in terms of why they were initiated and by whom, the characteristics of the patients or service users involved and the nature of the decisions for which mental capacity assessment was required. Following this, the discussion will focus on the judges’ observations of the process of mental capacity assessment. Each case is referred to using its numerical identifier (shown in table 3.1). The patients or service users are referred to by their initials.

Table 3.1: Summary of case law relating to mental capacity

Case identifier	Case name	Person being assessed	Issue relating to assessment	Judge's reflections on mental capacity assessment
1	L v J [2010] EWHC 2665 (Fam)	R, female, 18 years. Diagnosis: Learning disability, epilepsy, communication impairment.	• Local authority applied for declaration that R lacked capacity to make decisions about care, residence, contact, property, finances. • An interim order was in place, based on local authority's previous assessment which found patient lacked capacity to make these decisions.	• Capacity needed to be assessed separately for specific decisions as they arose. • Local authority had not paid adequate attention to effects of R's "typical teenage behaviour" on the consistency of her answers during the capacity assessment. • Judge found that R had capacity to make decisions about care, contact and residence.
2	PH and a local authority and Z limited and R [2011] EWCOP 1704	PH, male, 49 years. Diagnosis: Huntingdon's Disease.	• PH had been admitted to live in a specialist care unit under an MCA Deprivation of Liberty (DoLS) standard authorisation[3], as he was found to lack capacity to decide where to live. • PH wished to appeal against this.	• One capacity assessor (consultant neuro-psychiatrist) did not make a complete assessment as he was unaware of all PH's care needs. • Judge satisfied with four other assessments and agreed PH lacked capacity.
3	SC v BS, A Local Authority [2011] MHLO 78 COP	BS, female, 17 years. Diagnosis: Asperger syndrome and post-traumatic stress disorder.	• BS's mother applied to Court of Protection for a declaration that BS lacked capacity to make any decisions about her life. • Local authority argued that BS had capacity whilst her mother asserted that she did not.	• Expert witness' capacity assessment criticised. • Judge noted the witness (a psychiatrist) had never had formal training in the MCA and lacked experience in applying the functional test of capacity. • Judge decided to appoint a new expert.

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[3] The MCA Deprivation of Liberty Safeguards (DoLS) provide a legal framework relating to the deprivation of liberty of people who lack mental capacity. A person is deemed to be deprived of their liberty if they are under constant supervision or control and not free to leave a care setting. Care providers may apply to a local authority for a standard authorisation that it is in a person's best interests to be deprived of their liberty.

Case identifier	Case name	Person being assessed	Issue relating to assessment	Judge's reflections on mental capacity assessment
4	CC v KK [2012] EWCOP 2136	K: female, 82 years. Diagnosis: Parkinson's disease, vascular dementia, physical disability.	• K disputed local authority's finding that she lacked capacity to decide where to live; this had resulted in her being placed in a nursing home. • K wished to return to own home.	• Risk of capacity assessors conflating best interests decisions with capacity assessment. • Original capacity assessor had not presented detailed information to K about her care options to enable full assessment of her capacity to weigh information. • Local authority had failed to prove K lacked capacity to decide where she lived.
5	EM v SC [2012] EWHC 1518 COP	EM, male, 92 years. Diagnosis: Cognitive impairment (case report suggests undiagnosed dementia).	• EM, a Nursing Home resident, wished to go to live in his own home. • Local Authority did not think this would be in his best interests. • A social worker had assessed EM's capacity to make this decision and found he lacked capacity.	• Psychiatrist instructed by court to assess capacity needed prompting to use the MCA rather than the Mental Health Act 1983. • Judge agreed with social worker and 2nd psychiatrist that EM lacked capacity and was satisfied all practicable steps had been taken to support EM's decision-making.
6	A Local Authority v SY [2013] EWHC 3485 (COP)	SY, female, 19 years. Diagnosis: Learning disability.	• Local authority wished court to approve an order declaring SY lacked capacity to litigate and make decisions about her residence; contact with others; care package; whether to marry. • Capacity assessments relating the above decisions had been carried out by SY's social worker.	• Judge satisfied with social worker's capacity assessments. • Counsel commented that capacity assessments would usually be completed by physicians or psychiatrists. The judge responded that it was entirely appropriate for a qualified social worker to complete capacity assessments.

Case identifier	Case name	Person being assessed	Issue relating to assessment	Judge's reflections on mental capacity assessment
7	RB v Brighton and Hove City Council [2014] EWCA Civ 561	RB, male, 37 years. Diagnosis: Traumatic brain injury, excessive alcohol use.	• RB sought to overturn an MCA DoLS authorisation which had led to him being detained in residential rehabilitation facility. • RB had been found to lack capacity to decide where to live in two previous court cases.	• Judge satisfied all steps had been taken to support RB's decision-making and agreed with previous two rulings that he lacked capacity to decide where to live.
8	Norfolk County Council v PB [2014] EWCOP 14	PB, female, 79 years. Diagnosis: Schizophrenia.	• PB's contact with her husband was restricted by her care team, due to concerns about her safety and well-being. • Local authority requested court make declaration that PB lacked capacity to decide whether to live with or have contact with her husband and what her care arrangements should be.	• Capacity assessment completed by an old age psychiatrist (the expert instructed by court) criticised. • Psychiatrist did not take account of other professionals' reports about PB's cognitive and mental health function. • Psychiatrist's assessment was not holistic and his evidence was "speculative". • Judge found PB lacked capacity.
9	P v Kent County Council [2015] EWCP 89	P, male, age unknown. Diagnosis: Learning disability and personality disorder.	• P sought to overturn an MCA DoLS authorisation which enabled the local authority to detain him in a residential care facility. • Court asked to establish if P had the mental capacity to decide where to live and how to access support and care.	• Expert witness did not follow the first principle of the MCA. • Both assessors influenced by the potential outcomes of the decision rather than a functional test of P's decision-making ability. • Two experts instructed by the court failed to establish causality between P's impairment of the brain and his inability to make a decision. • Judge overturned previous finding of incapacity and MCA DoLS authorisation.

Nature of reviewed cases

Table 3.1 shows that three of the nine cases (1,6,8) were brought by local authorities seeking legal declarations that individuals were unable to make decisions about different aspects of their lives. Another case (3) was brought by a woman who disputed the local authority's view that her 17 year old daughter, BS, had capacity to make decisions about different aspects of her life; the woman requested that the court re-investigate BS's mental capacity. The five remaining cases (2,4,5,7,9) were initiated by individuals who wished to contest a previous finding that they lacked capacity to make a decision about where they should live.

In four cases (1,4,6,8) the judges examined the process of capacity assessment that had taken place prior to the legal case, in order to make a judgement about whether the assessment was carried out appropriately and whether its findings were valid. In case 7, the Court of Appeal[4] judge examined the process of capacity assessment that had taken place during two previous legal cases. In five cases (2,3,5,8,9), the courts instructed expert witnesses to carry out new mental capacity assessments for individuals. In case 2, the court actually called six witnesses to provide evidence about PH's capacity to decide where he lived. These witnesses included a consultant neuro-psychiatrist, a general practitioner (GP), PH's consultant in old age psychiatry, his GP and his social worker. The judge also asked PH's former partner whether he thought PH had the capacity to decide where to live.

None of the case reports provide detailed descriptions of how mental capacity assessments were carried out. When reports do include some description of a capacity assessment, the assessments appeared to follow the structure of the MCA's two-stage functional test. In most cases, the judge, health or social care professionals determined whether the individual being assessed had an impairment or disturbance of the mind or brain that may affect her/his decision-making ability.

In two cases, this assessment involved the use of formal testing. In case 5, the second psychiatrist used “a standard memory test for frontal lobe functioning“ (para 28) to establish that EM's loss of frontal lobe function might impair his ability to weigh up information. In case 2, the consultant in old age psychiatry used the Mini Mental State

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[4] The Court of Appeal is the second most senior court in England and Wales and hears appeals against judgements based in other courts.

Examination (MMSE) (Folstein *et al*., 1975) to determine that PH was cognitively impaired and the Addenbrooke's Cognitive Examination (ACE-R) (Mathuranath *et al*., 2000) to examine more specifically his frontal lobe function. The reviewed case reports do not provide detailed information about how specific decision-making abilities[5] were assessed. In most cases, the assessment appeared to take place within a single interview or over multiple interviews, using a conversation format to check people's ability to understand and process information relating to the decision.

Judges' reflections on capacity assessments

The judge was satisfied with the process of capacity assessment in only two cases (6, 7). In case 7, the Court of Appeal judge concluded that all steps had been taken to support RB's decision-making ability during the previous capacity assessment and agreed with two previous legal rulings that RB lacked capacity to decide where to live. In case 6, the judge praised the comprehensive and detailed assessment by a social worker and commented to counsel that such assessments by professionals other than physicians or psychiatrists were to be commended.

A number of case reports include comments made by judges on the quality of mental capacity assessments. Significantly, in three cases (3,5,9), judges criticised the instructed assessors' apparent lack of knowledge about how to assess capacity in line with the requirements of the MCA. In case 3, the judge noted a professor of psychiatry had never received formal training in the MCA and had used inaccurate legal terminology in his assessment report, demonstrating poor understanding of the law. In case 9, the judge identified that the consultant in old age psychiatry did not appear to apply the MCA's first principle (assumption of capacity) when completing his capacity assessment.

In case 5, the Official Solicitor[6] had to write to the initial assessor, a consultant in old age psychiatry, to remind him about the MCA two-stage test, because the consultant appeared to be confusing the MCA with aspects of the Mental Health Act (1983). However, the judge in this case was satisfied with two subsequent capacity assessments carried out by a psychiatrist and social worker respectively, and agreed with their finding that EM lacked capacity. The judge observed that all practicable steps had been taken to support EM's decision-making during the assessments; the judge

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[5] As part of the MCA functional test of decision-making.

[6] The Office of the Official Solicitor (part of the Ministry of Justice) acts for people who lack mental capacity to manage their affairs or to make use of the judicial system and who do not have any other person to support them in these ways.

particularly praised EM's social worker and the local authority's representative for arranging for EM to be taken on home visits with sympathetic chaperones to help him understand more about what living at home would entail.

Judges made a number of more specific criticisms of mental capacity assessment practice. In case 1, the judge observed that the local authority was wrong to seek a declaration that R lacked capacity to make decisions about daily living. The judge reminded the court that the second stage of the MCA two-part test requires capacity assessments to be carried out for individual decisions, as and when they needed to be taken. This judge also criticised the local authority for not considering how aspects of R's behaviour might impact on her responses to questions during a capacity assessment. The judge overturned the interim ruling that R did not have capacity to make decisions about daily living herself.

In case 4, the judge suggested there was a risk that previous mental capacity assessments of K were invalid, because they had been based in part on the fact that K wanted to make what professionals perceived to be an unwise decision about her living arrangements. The judge warned that a person should not be judged to lack capacity because s/he wished to make a decision that did not appear to the assessor to be in her/his best interests. Similarly, the judge in case 9 stated that two experts' conclusions about P's capacity to decide where to live appeared to be influenced by the potential outcomes of the decision, rather than based on a functional assessment of P's decision-making ability. The judge disagreed with the experts' conclusions that P lacked capacity to decide where to live and overturned the local authority's standard authorisation.

In case 4, the judge also criticised the capacity assessment because K had not been given detailed information about the range of care options available to her. Therefore, the judge argued, the assessment did not adequately assess whether K was able to weigh up information relevant to the decision about where to live. The judge decided that the capacity assessment was invalidated and found that K did in fact have capacity to decide for herself where she should live.

The judge in case 8 criticised the old age psychiatrist instructed to assess PB's capacity for not considering other professionals' reports about PB's cognitive and mental health function when carrying out his capacity assessment. The judge indicated that this meant the psychiatrist's assessment was "speculative" (para 79) and lacking in holism. The judge in case 2 criticised the initial capacity assessment made by the consultant neuro-psychiatrist. The judge identified that the neuro-psychiatrist did not make a complete assessment of PH’s ability to understand, retain and weigh up information about his care needs because the assessor himself was unaware of some of this information. The judge also criticised the fact that the assessment had been made during a single 90 minute meeting, which may have resulted in the assessment being somewhat superficial.

Finally, in case 9, the judge was critical of two expert capacity assessors for not establishing a causal link between P’s impairment or disturbance in the functioning of the mind or brain (learning disability and personality disorder) and his perceived inability to make a decision about residence and care. Capacity assessors need to demonstrate a causal association, or “causative nexus”, between the outcomes of the diagnostic and functional tests of decision-making, in order to be able to conclude that a person lacks mental capacity (Bogg and Chamberlain, 2015).

Summary of case law

The reviewed cases provide examples of practice that has been judged to be compliant with the requirements of the MCA and examples of practice that does not meet these requirements. In three cases, the judges found that a previous capacity assessment was not consistent with the MCA and, as a result, had failed to demonstrate that a patient lacked capacity; this resulted in earlier rulings being overturned. This review has identified specific aspects of practice that judges have criticised. These include basing capacity assessments on the outcomes of patient/service user decisions rather than on a functional assessment, and carrying out generic assessments rather than separate assessments for specific decisions. Judges have also criticised assessors for not using comprehensive, holistic information about patients and for not providing adequate information to patients about decisions during capacity assessments. Finally, one case highlights the need for assessors to identify a causative nexus between diagnostic and functional evidence, in order to demonstrate that a person lacks capacity.

3.3 Literature review: mental capacity assessment in practice

3.3.1 Methods

Review question and search strategy

A systematised[7] literature review was carried out to address the following review question:

> "How do professionals assess adults' ability or mental capacity to make informed decisions in England and Wales?".

This broad review question was selected because a previous scoping review in 2012 by the researcher (unpublished) found that a limited number of studies relating to mental capacity assessment in England and Wales had been published since the implementation of the MCA. The scoping review identified few studies that had investigated how the standards of the MCA were being applied to capacity assessment, or how assessment practice could be improved to meet these standards. This review, therefore, was designed to provide a general overview of current mental capacity assessment practice.

Selection criteria for included studies were developed using the PICOS[8] structure (NHS Centre for Reviews and Dissemination, 2009); these criteria are shown in table 3.2.

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[7] The review was "systematised" because it used systematic review approaches but only involved one reviewer (Grant and Booth, 2009).

[8] The PICOS structure for developing review questions and search strategies stands for: Population, Intervention, Comparator, Outcome, Study design.

<table>
<tr><th colspan="3">Review question: How do professionals assess adults’ ability or mental capacity to make informed decisions in England and Wales?</th></tr>
<tr><th>Parameter</th><th>Inclusion criteria</th><th>Exclusion criteria</th></tr>
<tr><td>Population</td><td>• Adults (people aged 16 years or above) in England and Wales;
• All medical conditions.</td><td>• Children, due to differences in legal framework;
• Adults in other countries with different legislative frameworks.</td></tr>
<tr><td>Intervention</td><td>Mental capacity assessment</td><td>Other interventions not including Mental Capacity assessment.</td></tr>
<tr><td>Comparator</td><td>Possibly, comparison of one method of assessment against another.</td><td>Other types of comparator</td></tr>
<tr><td>Outcome</td><td>• Assessment findings: judgement of capacity or incapacity;
• Validity or reliability of assessment findings;
• Acceptability to patient / service user / carer / professional.</td><td>Other outcomes not relating to Mental Capacity assessment.</td></tr>
<tr><td>Study design</td><td>• Must include description of assessment method;
• All design types except expert opinion.</td><td>Expert opinion</td></tr>
<tr><td>Publication language</td><td>English</td><td>Non-English languages</td></tr>
</table>

Table 3.2: Selection criteria for included studies

A search strategy was developed in collaboration with local information specialists. Search terms related to key concepts were identified using the PICOS structure: “adults”, “mental capacity”, “decision making”, “informed decisions”, “assess”, “England”, “Wales”. Database thesauri, including Medical Subject Heading (MeSH) terms, truncation and wildcards were used to generate synonyms and alternative forms and spellings for each search term. Boolean operators were used to combine the results of free text searches for each term. As the search was designed to be broad, all study designs were included. The search was limited to English language records published from 2007 onwards (the year the MCA was implemented). An example of the strategy is shown in appendix 1.

The following electronic databases of published medical, health and social care research were searched: ASSIA[9], Campbell Library, CINAHL[10], Cochrane Library, EMBASE[11], MEDLINE[12], PsycINFO, Social Services Abstracts and Web of Science (last search November 2016). In order to broaden the search beyond published research articles, relevant grey literature was identified through searches using Google Scholar and through contact with national experts involved in mental capacity assessment practice and research.

Study selection

The electronic database search generated 575 records and a further 35 records were identified within the grey literature. Removal of duplicate records resulted in a total of 459 records. The study selection process is reported in a PRISMA[13] flow diagram (Moher *et al*., 2009) below (figure 3.1). Each record was reviewed against the selection criteria (table 3.2) to check its eligibility for inclusion in the review. A three-stage sifting process was used to review each record first by title, then by abstract, and finally by the full text report. The researcher reviewed all records and rejected any studies not meeting all selection criteria at each stage. The researcher consulted his primary academic supervisor in cases when it was unclear whether a record should be included; the supervisor applied the selection criteria independently before discussing with the researcher whether to include the record.

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[9] Applied Social Sciences Index and Abstracts

[10] Cumulative Index to Nursing and Allied Health Literature

[11] Excerpta Medica database

[12] Medical Literature Analysis and Retrieval System Online

[13] Preferred Reporting Items for Systematic Reviews and Meta-Analyses

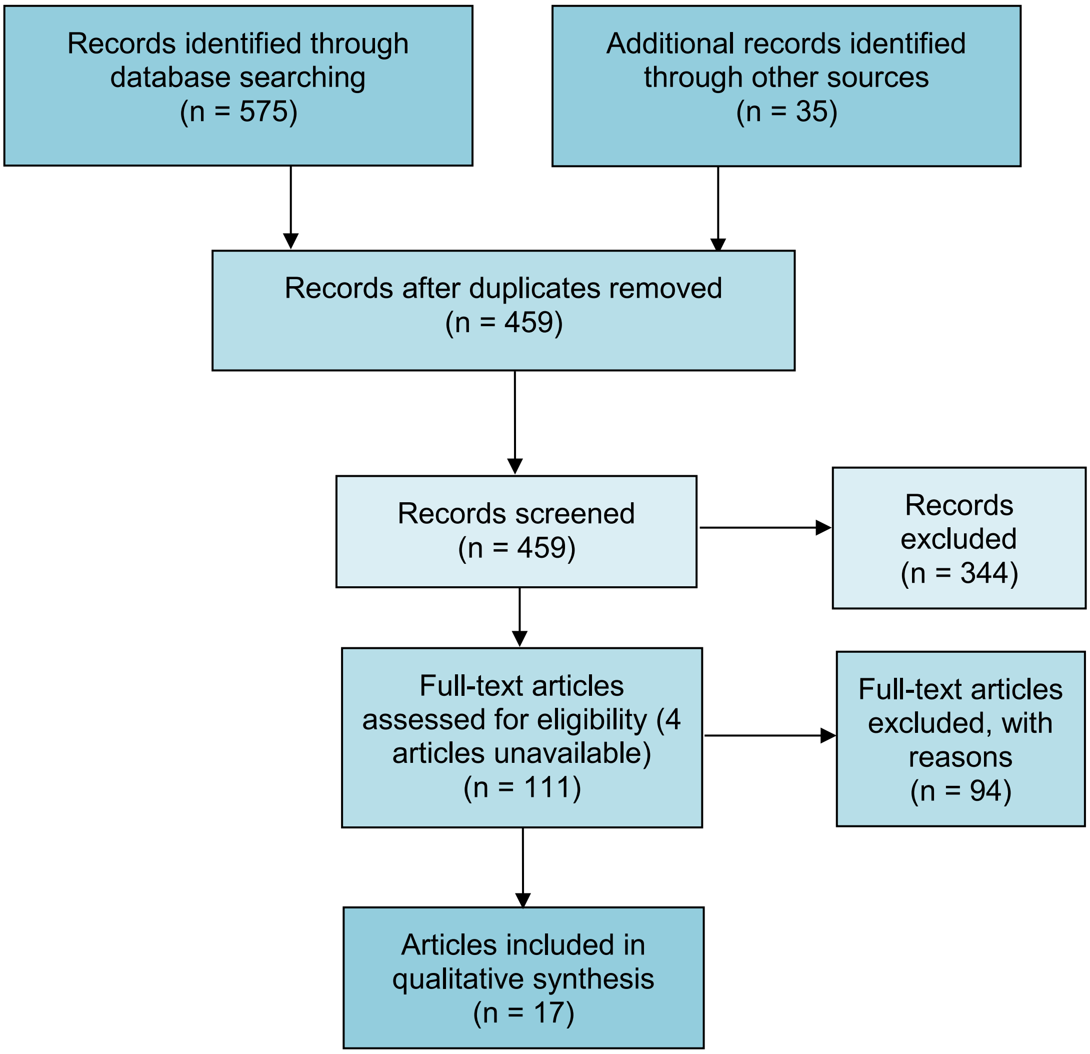

Figure 3.1: PRISMA flow diagram documenting study selection process

Data extraction

An electronic data extraction form was used to enable efficient and comprehensive extraction of data relevant to the review question (blank form shown in appendix 2). The form was piloted with one study initially, in order to identify ways in which it could be refined; minor adjustments were made as a result. Only data extraction by the researcher was possible.

Quality assessment

The researcher assessed the quality of identified studies following the data extraction process. Due to the diverse methodologies employed in the studies, several critical appraisal tools were used to assist this process. The Critical Appraisal Skills Programme checklist for qualitative research (CASP, 2013) was used to assess qualitative designs. Crombie's (2002) checklist for appraising survey studies was used to assess survey and also case note audit/review studies. The Centre for Evidence-Based Management's Critical Appraisal of a Case Study checklist (CEBM, 2014) was used to appraise case study and case series designs.

3.3.2 Results

Research study characteristics

The review identified 17 eligible records describing mental capacity assessment practice. The 17 records report the findings of 15 studies, as four records present different data derived from two studies. A number of records reporting studies designed to measure professionals' knowledge of mental capacity issues were excluded following full-text review; this was because these studies provided information about how professionals approach mental capacity assessment, but did not include descriptions of assessment in practice.

Individual study characteristics are summarised in table 3.3. This table presents data at study rather than publication level. In the rest of this chapter, each study is referred to using its record number (shown in table 3.3). All records were published after 2009, two years after the implementation of the MCA. As table 3.3 shows, 12 records were published in peer-reviewed scientific journals; eight of these journals specialise in research related to either psychiatric or learning disabled populations. Two records (10,15) were research reports published by national charities and one (4) was a report published by the House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act. The content of the studies/records varied in terms of their aims, designs and findings. Commonalities between the included studies/records are discussed below.

Table 3.3: Characteristics of included studies

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to mental capacity assessment	Threats to study quality
1	Biswas and Hiremath (2010)	Single case study	Adults with learning disability in specialist inpatient unit (n=1).	To describe capacity assessment practice and good practice in best interests decision-making.	• Practice consistent with requirements of stage 2 of MCA • Strategies used to facilitate communication with service-user.	• Lack of reflexivity; • Data collection methods unclear; • Limited generalizability, due to design.
2	Emmett *et al.* (2013)	Qualitative: ethnography, interviews, focus groups.	Hospital patients with dementia (n=28); carers (n=28); health and social care professionals (n=35).	To describe capacity assessment practice in relation to legal standards derived from MCA.	• Only 50% patients formally assessed; • Practice variable but generally not consistent with requirements of MCA.	• Lack of reflexivity; • Data analysis not fully described; • No discussion of deviant cases or credibility of findings.
3	Guyver *et al.* (2010)	Case note audit	Hospital orthopaedic patients (n=50).	To compare practice against standards derived from MCA, before and after intervention (written guidance and training).	• Improvement in documented practice following intervention.	• Sampling unclear; • Limited generalizability, as limited description of patients and assessors; • Unable to establish causal link between intervention and results, due to design.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	• Key findings relating to mental capacity assessment	• Threats to study quality
4	House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005 (2014)	Committee considered oral (n=61) and written evidence (n=206) submitted.	Anyone having involvement with the MCA and its implementation (e.g., practitioners, service users).	To scrutinise the MCA and its implementation in practice.	• Capacity assessments generally are not completed / recorded or are of poor quality; • Professionals not clear when assessments should be triggered; • Professionals may refer to specialists to assess due to low confidence; • Superior assessments completed by professionals who know patients well; • Assessors make assumptions about capacity based on diagnosis / impairment; • Judgments of incapacity may be influenced by resource-management implications; • Supported decision-making is not used effectively.	• Limited information about any methods used (not a research study).

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to mental capacity assessment	Threats to study quality
5	Jepson *et al.* (2016)	Qualitative interviews	Social work professionals (n=67); adults managing "direct payments"[14] on behalf of people lacking capacity (n=18).	To explore how social care professionals manage social care direct payments system for people who lack capacity to consent to them.	• Most practitioners appeared to understand and comply with MCA; • Practitioners confused capacity to consent to payments with capacity to manage payments;	• Data collection and analysis methods lack full description; • Lack of reflexivity.
6	Linn *et al.* (2013)	Case studies	Patients with mental health conditions on general medical hospital wards (n=2).	To describe influence of mental disorders on mental capacity, role of specialist assessors.	• Assessment content and outcome differed between two professional groups (non-specialist vs specialist).	• Lack of reflexivity; • Data collection methods unclear; • Limited generalizability, due to design.
7	Murrell and McCalla (2016)	Qualitative interviews	Social care professionals: social workers (n=5); field work assessor (n=1).	To explore how social care professionals interpret the MCA and assess capacity.	• Participants had variable knowledge of MCA; • Occasional conflation of capacity and best interests assessments • Different methods used to maximise capacity / increase quality of assessments.	• Recruitment strategy unclear; • Data collection and analysis methods unclear; • Relationship between researcher and participants unclear.

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[14] "Direct payments" refers to social care payments made to individuals who hold personal care budgets. Third parties may manage personal care budgets on behalf of adults who lack mental capacity to make a decision about receiving the payments themselves (so called "indirect payments").

Record number	Study authors / publication date	Design / method	Population studied	Study aim	• Key findings relating to mental capacity assessment	• Threats to study quality
8	Oldreive and Waight (2011)	Case series	Adults with learning disability (n=18).	To describe use of and outcomes from structured assessment pathway.	• Pathway enabled assessment to be adapted to cognitive and communication needs;	• Lack of reflexivity; • Data collection methods unclear.
9	Ramasubramanian *et al.* (2011)	Case note audit	Adults with learning disability in specialist inpatient unit (n=20).	To compare practice before and after intervention (structured assessment framework).	• Significant improvement in practice following intervention.	• Incomplete data set; • Unclear who collected audit data; • Unable to establish causal link between intervention and results.
10	Scope (2009)	Qualitative: ethnography, interviews, completion of “work books”.	Disabled adults with complex needs in residential settings (n=6); family members and professionals (n not stated).	To explore the impact of the MCA on disabled people.	• No evidence of formal capacity assessment for 4/6 service-users; • Practice not consistent with MCA; • Some professionals did not understand legal responsibilities of MCA.	• Lack of reflexivity; • Data collection and analysis methods unclear; • Authors say results unlikely to be generalizable.
11	Shah *et al.* (2009a)	Case note review	Patients of old age psychiatrists (n=37).	To investigate old age psychiatrists’ experience of implementing the MCA.	• Doctors carried out most capacity assessments. • Stage 2 of MCA test satisfied in 89% cases. • Consideration of culture/ethnicity, religion, language variable.	• Possible selection bias: psychiatrists who responded selected notes for inclusion themselves.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	• Key findings relating to mental capacity assessment	• Threats to study quality
12	Shah *et al.* (2009b) (additional data reported in Shah *et al.* (2010)	Survey	Consultants in old age psychiatry (n=52); consultants in other psychiatric specialities (n=113).	To explore psychiatrists' experience of implementing the MCA with black and ethnic minority groups.	• Over 80% participants reported they consider culture, ethnicity and religion; • 30-40% have used interpreters to support patients with language needs; • Assessments not routinely documented; • 67% participants assess capacity separately for different decisions; • 96% participants appear to consider 4 criteria in stage 2 of MCA test.	• Low response rate; • No description of sample, therefore unclear if results generalizable; • Data analysis flawed.
13	Skinner *et al.* (2010)	Case series with 2 case studies	Adults with learning disability referred to ophthalmology (n=17).	To describe new structured assessment system and outcomes from use of system.	• New system enables assessment to be adapted to patient's communication and cognitive needs; • System involves carers in assessment process.	• Lack of reflexivity; • Limited generalizability, due to design.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to mental capacity assessment	Threats to study quality
14	Sorinmade *et al*. (2011)	Case note review	Patients under care of Community Mental Health Teams or acute hospital geriatricians (n=68).	To investigate health care professionals' compliance with MCA principles when assessing capacity and making best interests decisions.	• 4 criteria in Stage 2 of MCA test considered in assessments; • 53% case notes included detailed documentation of assessment process.	• Possible selection bias: clinicians selected notes for audit themselves; • Incomplete sample: did not audit notes for patients with capacity; • Relationship between audit professionals and clinicians unclear.
15	Williams *et al*. (2012) (on behalf of Mental Health Foundation). Additional data reported in Williams *et al*., (2014)	Survey and qualitative interviews	Health and social care, legal professionals involved in MCA implementation (online survey n=385; telephone interviews n=68; face-to-face interviews n=44).	To describe current practice in best interests decision-making.	• Professionals report capacity assessment most difficult part of MCA; • Capacity assessment not done in 10% cases; • Assessment practice not consistent with MCA; • Joint capacity assessment common; • Assessors have difficulty reconciling unwise decisions with intact capacity; • Professionals concerned assessment largely based on "gut feeling".	• Lack of reflexivity; • Unclear if sampling strategy representative; • Possible selection bias: professionals with most positive practice may have volunteered to take part; • Data analysis methods not fully described.

Study aims

All studies/records aimed to provide descriptions of how mental capacity assessment and best interests decision-making are carried out in clinical practice. Eight records (1,4,6-7,11,12,15) presented data relating to the types of patients or service users requiring mental capacity assessments, the categories of decisions these people are being asked to make, and the professional groups involved in carrying out mental capacity assessment. Twelve records (1-5,7,9-12,14-15) included comparisons of practice with standards derived from the MCA and thus provide some evidence relating to the quality of mental capacity assessment. Three studies (2,10,15) specifically investigated professionals' and some patients' and carers' experiences and perceptions of mental capacity assessment. One study (6) also compared assessment processes and outcomes across two professional groups. Of most interest to this review are four studies (3,8,9,13) describing the effects on practice of a new tool or procedure designed to facilitate or improve assessment; in two of these studies (3, 9), the authors compared practice directly before and after the interventions (see pp51-54).

Study designs

The studies included in this review varied in terms of their design and methods. All were descriptive studies, involving surveys, qualitative designs, case studies or case series. Two studies (2,10) collected data relating to assessment practice directly using ethnographic observations, but the majority used more indirect methods; these included single and group interviews with professionals, service-users and carers, surveys of professionals, and audits or reviews of clinical case notes. Most studies directly involving groups of service-users, carers or professionals had relatively modest sample sizes, with less than 100 participants. In contrast, a survey study (15) and the House of Lords Post-Legislative Scrutiny (4) each included over 200 respondents.

Study quality

The House of Lords Post-Legislative Scrutiny (4) was not a research report and did not provide description of any methods used to sample respondents or collect and analyse data. Therefore, it was not included in the quality analysis. Many of the study reports did not include sufficient information to enable the researcher to assess methodological quality fully. However, all studies had methodological weaknesses associated with their designs which challenge the validity, reliability and generalizability of their findings. Important themes relating to study quality are discussed below, in relation to each type of study design.

Case studies / case series (records 1, 6, 8, 13)

These records did not address the issue of researcher reflexivity or clarify the nature of the relationship between researchers and participants. This makes it difficult to establish how valid and reliable the studies' findings are. Due to the nature of their design, all studies involved very small sample sizes; this clearly limits the generalizability of their findings.

Qualitative studies (records 2, 5, 10, 15)

None of the records provided detailed descriptions of data analysis methods; this makes it difficult to assess how rigorous data analysis was. They did not include detailed consideration of researcher reflexivity; it is possible that the role of the researcher in the research process introduced bias. Despite these weaknesses, two studies (2,15) do appear to provide valuable contributions to our understanding of this under-researched area of clinical practice.

Survey (record 12)

There are errors in the results reported, which suggests the data may not have been analysed rigorously. The response rate was relatively low (below 30%) and the authors did not provide any demographic information about participants to enable a judgement to be made about how representative the sample was. The psychiatrists who chose to participate in the survey may have had a special interest in the MCA or their practice may have differed from that of those who did not respond.

Case note reviews/audits (records 3, 9, 11, 14)

None of these records reported robust sampling strategies. The sampling strategies used in two studies (11,14) may have introduced selection bias. It is not possible to know whether the improvements in practice observed in studies 3 and 9 were causally related to the capacity assessments interventions introduced by the researchers, due to limitations in the study designs.

Populations studied

As shown in table 3.3, most studies investigated mental capacity assessment issues relating to a particular clinical population. Seven studies focused on two main clinical groups: adults with learning disabilities and adults with mental health conditions. Two studies (2,15) examined how mental capacity is assessed for people with dementia, and two studies (3,15) investigated practice relating to hospital patients with orthopaedic injuries or people with neurological disability. The study by the Scope charity (10) described assessment practice in relation to disabled people with complex needs. All studies and the House of Lords committee report described assessments taking place in hospital and community settings.

Which patient / service-user decisions are commonly associated with mental capacity assessments?

The records reported a range of patient or service-user decisions associated with mental capacity assessments. The most common type of decision related to providing consent to some kind of medical treatment or healthcare intervention (e.g., surgery, medication, occupational or physiotherapy). Other common decisions related to living arrangements (often choice of discharge destination following inpatient stay), financial affairs, personal or social care.

Which professional groups carry out mental capacity assessments?

Chapter four of the MCA Code of Practice states in very general terms that the person responsible for assessing an individual's mental capacity should be the person who is directly involved with that person when a decision needs to be made; thus different people might assess an individual's ability to make different decisions (COP, 2007, p

53). Study records described assessments being carried out by health and social care professionals belonging to community or hospital multidisciplinary teams; the specific professional groups involved included physicians, nurses, occupational therapists (OTs), physiotherapists, psychiatrists, psychologists, social care practitioners (including social workers) and SLTs. One study (1) also reported the role of care home managers in assessment.

Two studies (11,12) reported data suggesting that assessments tended to be carried out by doctors, and particularly more senior doctors, on behalf of the multidisciplinary team. For example, a case note review (11) found that 83% of assessments for psychiatric patients in the study sample were carried out by doctors, the majority of which were consultant old age psychiatrists. In a later survey study (12), 64% respondents stated a majority of assessments were conducted by consultant psychiatrists. It is unclear from the data reported in these two studies whether it would have been appropriate for other professional groups to have assessed capacity, rather than doctors.

A survey and interview study (15) reported similar findings relating to the role of professional hierarchies in patterns of assessment practice. More junior professionals working in residential settings tended to defer to more senior colleagues working outside the settings to complete mental capacity assessments. However, there was also a trend reported in this and another study (7) for joint assessment or for professionals to favour carrying out assessments “by consensus” rather than one person taking responsibility for making a judgement about capacity.

The House of Lords committee report (4) suggested that professionals sometimes referred to mental health specialists when they lacked confidence in their own ability to assess capacity. Another record (6) described the benefits of involving professionals with specialist knowledge in capacity assessments for patients with mental health conditions. They reported two case studies in which input by psychiatrists changed the outcome of the assessment for two patients with mental health disorders on general medical hospital wards. The authors suggested that the psychiatrists’ greater understanding of mental health presentations enabled the team to carry out more accurate assessments of the patients’ functional decision-making abilities.

The process of assessment

The researcher identified common themes arising in the descriptions of assessment processes reported in the records. These themes are discussed below.

Formal and informal assessment processes

A study by Emmett *et al*. (2) suggested assessment can involve both formal and informal processes. These authors used ethnographic observations and interviews with professionals, patients and their families to investigate how assessments were carried out on care of the elderly hospital wards. They specifically examined assessments for patients with dementia and cognitive difficulties who needed to make decisions about where to live following discharge from hospital.

The authors were able to identify formal processes of assessment, which tended to involve investigations of patients' understanding of their situations and their wishes for the future. Professionals collected this information in conversation-format interviews with patients. It is unclear to what extent these formal assessments were consistent with the standards of the MCA functional test. Informal assessment processes tended to involve capacity judgements being made on the basis of less objective observations carried out over a longer period of time. For example, the team might gather information during a number of conversations with a patient over the course of several ward rounds, and use this information to build up an impression about her/his capacity. Alternatively, a capacity judgement might be based wholly, or at least in part, on professionals' observations of a patient's functional abilities (including the ability to weigh up information) during a home visit.

Emmett *et al*. (2) observed that these informal assessment processes might take place in conjunction with, or instead of, more formal processes. In fact, they noted that formal assessments only took place in approximately half the 29 patient cases in their sample. It also appeared that formal assessments tended to be completed only in situations when patients disagreed with professionals' recommendations about discharge destination and were able to communicate this to professionals.

This finding that formal capacity assessments are not always completed is supported by evidence from other studies included in the review and was a common theme in testimony submitted to the House of Lords Post-Legislative Scrutiny (7). Williams *et al*. (15) carried out a large survey (n = 385) and interview (n = 68) study to investigate current practice in best interests decision-making amongst health and social care and legal professionals in England. They found that formal capacity assessments for patients with dementia were apparently not completed in 10% of the cases they studied, and that assessments were often only carried out if patients appeared reluctant to accept a professional's recommendation that they should enter a care home.

Similarly, a smaller qualitative study by the Scope charity (10), exploring the impact of the MCA on six disabled people, reported a lack of documented evidence of a capacity assessment having taken place for four of the six people. On the basis of her contact with these people, the study investigator argued that assessments were indicated in all four cases. A case note audit by Guyver *et al*. (3) found that eight of a group of 50 orthopaedic patients did not appear to have received a capacity assessment, despite having a documented medical condition that may affect their decision-making ability. In another case note audit study, Ramasubramanian *et al*. (9) found clear documentation of capacity assessments in only two of six cases where assessment was indicated (a process of best interests decision-making had been initiated in all six cases, therefore a lack of capacity had apparently been established). It is possible that these assessments did take place in practice but were simply not documented. However, this in itself would not be consistent with the requirements of the MCA Code of Practice.

Diagnosis or impairment-based assessments

Four studies and the House of Lords report (4) indicated that judgements about mental capacity were sometimes based on people's characteristics, such as their medical diagnosis, cognitive ability or communication skills, rather than an assessment of their ability to make an informed decision. These practices are inconsistent with the first statutory principle of the MCA, which states that people must be presumed to have intact capacity to make a decision unless it has been demonstrated (i.e., through assessment) that they do not.

Williams *et al.* (15) noted that some professionals appeared to make assumptions about people's decision-making capacity on the basis of their dementia or learning disability diagnosis or level of cognitive impairment, especially in the case of care home residents. The same authors also found that professionals sometimes believed erroneously that diagnostic dementia assessments could be used to make judgements about mental capacity instead of specific capacity assessments. Similarly, Murrell and McCalla (7) noted that some social work practitioners working with people with dementia, learning disability or mental illness described using information about patients' orientation to person, time and place to help determine their capacity. Furthermore, researchers carrying out the Scope study (10) found professionals' perceptions of disabled service-users' mental capacity appeared to be heavily influenced by their impressions of these people's ability to communicate.

Two studies provide evidence that professionals may confuse decision-making capacity with executional capacity (the ability to carry out the outcome of a decision). In one study (15), professionals reported that they might base capacity assessments for people with dementia on their ability to carry out a functional task related to living independently at home, rather than their ability to make an informed decision about where to live. Similarly, an interview study (5) investigating the experience of social work practitioners involved in managing direct payments to people with personal social care budgets found that practitioners commonly confused incapacity to manage a personal budget with incapacity to make a decision about receiving such payments (which could be managed by a third party on the individual's behalf).

Generic assessments and longstanding judgements

Although the MCA states clearly that capacity assessments should be time and decision-specific, it appears some professionals make judgements about people's capacity that are then applied to different decisions across time. Shah *et al*. (12) surveyed 52 old age psychiatrists to ask about their experiences of implementing the MCA. Over a quarter of respondents stated that they did not routinely carry out separate capacity assessments for different decisions. Similarly, Williams *et al*. (15) noted that patients with either dementia or learning disability diagnoses were sometimes subject to a single, generic capacity assessment. It was apparent that some people with profound or severe learning disabilities might be assumed to lack capacity for all decision-making, on the basis of a single initial assessment.

Outcome-based assessments

Three studies (2, 7,15) noted cases where assessors appeared to base their judgements about capacity on the outcome of the decision selected by the patient or service-user, rather than an application of the MCA's two-stage functional test. In their ethnographic and interview study, Emmett *et al*. (2) observed that some capacity assessments for hospital patients with dementia or cognitive deficits appeared to be influenced by whether or not professionals felt patients were making unwise decisions. The authors reported a trend for certain professional groups to associate what they perceived to be unwise or risky decisions, which might jeopardise a patient's safety, with reduced insight on the patient's part; this led professionals to conclude that patients making apparently unwise or high risk decisions did so because they lacked capacity. This practice appeared to be most prevalent amongst junior nurses or nurses who had formed strong relationships with patients. Williams *et al.* (15) noted that professionals commonly reported that patients were found to lack capacity because they wanted to make decisions with which professionals did not agree; this was particularly the case in situations where patients were being asked to make decisions about where they wanted to live.

Emmett *et al.* (7) noted that most professionals they observed or interviewed did appear to understand the legal standards for functional assessment outlined by the MCA. However, the practice they observed was clearly inconsistent with the MCA's third statutory principle, which states that people should not be considered to lack capacity if they make unwise decisions. Murrell and McCalla (7) reported a similar trend for social care professionals to conflate capacity assessment with best interests decision-making, and suggested this was due to a perceived "duty to protect" amongst social care practitioners (7, p29). The House of Lords committee report (4) reported witness statements describing similar risk-aversive and paternalistic approaches to decision-making amongst both social and health care professionals.

Assessing decision-making ability using the MCA's four criteria

This review suggests that practice can vary considerably in terms of whether and how professionals fulfil the requirements of the MCA's functional test of decision-making ability. Only four of the seventeen records (1,11,12,14) provided evidence that professionals incorporated the four criteria of the MCA's functional test within their assessments (the ability to understand, retain, weigh up information and communicate a decision). Shah *et al*. (11) audited case notes for 37 patients who had undergone capacity assessments. They found that the assessor had considered each of the four criteria in 89% of the documented assessments. The same authors later surveyed 52 consultant old age psychiatrists to investigate their experience of implementing the MCA (12). They found that 96% respondents described assessments that satisfied the four criteria. Sorinmade *et al*. (14) audited case notes for 68 patients under the care of community mental health teams or acute hospital geriatricians. These authors found that all the assessments they examined appeared to include consideration of the four criteria. However, as in most studies in this review, the documentation reviewed by Sorinmade *et al*. (14) did not detail the methods used to achieve this.

Consideration of cultural, ethnic and religious factors during assessments

Chapter three of the MCA Code of Practice (2007) advises those assessing mental capacity to consider “cultural, ethnic or religious factors that shape a person’s way of thinking, behaviour or communication” (p 33). Two studies (11,12) provided mixed evidence about whether professionals took account of such factors during capacity assessments. Shah *et al*. (11) noted that assessors appeared to consider these factors in less than half of the patient cases they examined; assessors were more likely to consider cultural, ethnic, religious and also linguistic factors for patients from black and minority ethnic groups. A subsequent survey study by the same authors (12) found more positive results. Over 80% consultants in old age psychiatry responding to the survey reported considering cultural, ethnic and religious factors during capacity assessments.

Supported decision-making

The second statutory principle of the MCA states that professionals should take all practicable steps to support a person to make a decision before it can be concluded that s/he lacks capacity. The findings of four studies (2,11,12,15) suggest that the way that professionals provide information to patients during capacity assessments may not always be consistent with the second principle.

Emmett *et al*. (2) identified that professionals did not always provide clear, explicit information to support patients’ decision-making. For example, the authors reported that professionals describing discharge destination options to patients sometimes used the euphemistic expression “somewhere where you can get a bit more help” rather than “a residential nursing home” (p79). The same authors also observed that some professionals appeared to test patients’ ability to understand information that appeared irrelevant to the decision in question, during their capacity assessments.

Williams *et al*. (15) identified that at times professionals did not appear to take steps to support the communication needs of people with learning disabilities during the assessment process. Conversely, they noted that some professionals used accessible information and other communication strategies to enable these people to be included in best interests meetings[15] once a judgement had been made that they lacked capacity. For example, professionals used a real size body map to help a woman understand about a planned surgical procedure. Interestingly, these methods sometimes enabled people to understand more information about a decision and demonstrate that they did in fact have intact capacity to make the decision.

Shah *et al*.'s (11) case note review examined assessment practice in relation to patients from black and minority ethnic groups who might not be native English speakers. They found that clinicians only considered patients' language needs in approximately half the assessments audited; this did not appear to depend on the level of fluency in English of the patients being assessed. In a subsequent survey of 52 consultant old age psychiatrists (12), the authors found that only 30-40% respondents had used interpreters to support patients with language needs during capacity assessments.

These findings are supported by witness statements included in the House of Lords report (4). These statements indicate a trend for decisions to be taken in people's best interests in the absence of efforts to support people to make their own decisions, for example through communication support. The report suggests that this may be related to resource availability in the current economic climate.

Use of methods to improve or facilitate assessment

Several studies described clinical initiatives that were introduced to facilitate or improve mental capacity assessment practice. These initiatives appear to have been motivated by recognition that mental capacity assessment is a complex clinical activity and that implementation of the MCA within clinical practice has challenged health and social care professionals.

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[15] A best interests meeting involves a discussion between relevant professionals, family carers and patient advocates in order to make a decision in the best interests of somebody who has been judged to lack capacity to make that decision for her/himself.

Shah *et al.*’s (11) case note audit for patients under the care of old age psychiatrists identified a number of strategies used by clinicians to facilitate assessments; these strategies included allowing adequate time to complete assessments, carrying out serial assessments if necessary, using a calm environment to assess patients, and choosing assessors who were familiar with the patients.

Three studies (1,8,13) from the learning disability literature described methods to gather pre-assessment information to guide the assessment process and support the person being assessed. Biswas and Hiremath (1) reported a case study in which a mental capacity assessment was completed for a woman with mild learning disability and psychosis. The multidisciplinary team gathered information relating to the woman’s cognitive, communication and decision-making skills, her mental health condition, her previous experience of medical treatment and her understanding of her medical condition and a proposed treatment. An SLT and a psychologist used information about the woman’s communication skills to develop a communication strategy to support communication with her about her condition and treatment choices. This involved using simple spoken language and pictures, photographs and drawing to supplement language. This practice is clearly consistent with the MCA’s second statutory principle, which states that all “practicable steps” must be taken to support a person to make a decision (COP, p22).

Similarly, Oldreive and Waight (8) described the use of screening assessments to collect information about the cognitive, communication and money skills of people with learning disability referred for mental capacity assessment. These screening assessments formed part of a novel “structured pathway” for mental capacity assessment and appeared to serve two purposes. First, the findings of language and literacy screens were used to adapt the way that information might be presented during mental capacity assessments, to tailor it to individual needs. Second, the findings of communication, reasoning and money skills could contribute directly to a judgement about an individual’s ability to make an informed decision about signing a tenancy agreement. If a person was found to lack adequate money skills, a judgement of incapacity might be made. It is important to note that the use of information about a person’s ability to manage money in order to make a judgement about mental capacity appears to confuse decision-making with executional capacity and does not take into account the four criteria of the MCA functional test.

Skinner *et al*. (13) described the implementation of a new structured system to guide mental capacity assessments for people with learning disability being asked to make decisions about whether to have eye surgery. The system involved a two-phase assessment process and incorporated documentation support, including an assessment process flowchart. The initial screening phase used an interview format to collect information about a person's expressive and receptive communication skills, ability to process and remember information and her/his mental health status. This screening phase enabled assessors to determine, in a time-efficient way, whether/how to proceed to a more detailed capacity assessment, in which an individual's ability to understand and process more complex information could be tested. For example, the screen outcomes could indicate that: i) the person lacked capacity and further assessment was not indicated; ii) a referral should be made to an SLT for more detailed communication assessment; iii) a full capacity assessment should be carried out using ready-made accessible information materials and involving people who knew the person and could provide additional support (e.g., family carers). The study report (13) included two case studies describing how the system was used during capacity assessments for two women with learning disabilities. One woman reported that she appreciated the use of pictures in the accessible information materials, as they helped her to remember the information.

Three other studies (2,3,9) reported the implementation of documentation designed to facilitate or improve the assessment process for different clinical groups. Ramasubramanian *et al*. (9) report the introduction and evaluation of a structured assessment framework designed to support professionals working with people with learning disabilities to comply with the requirements of the MCA. This framework comprised a 20 point checklist covering key aspects of the MCA which professionals could use as a prompt when assessing capacity and making best interests decisions. Only four of the 20 points related to aspects of capacity assessment, and these appeared somewhat loosely defined at times: i) was a single clear test used to assess capacity; ii) were assumptions about someone's capacity not based on their age / appearance / condition / behaviour; iii) was information relevant to the decision given adequately and support with decision-making offered; iv) was the person's right to make an unwise decision considered.

Ramasubramian *et al*. (9) audited case notes for patients on a specialist inpatient unit before and after introduction of the framework. They found that practice improved in relation to each of the four points listed above after the checklist was introduced. However, the design of the study makes it difficult to draw any firm conclusions about the effectiveness of the checklist. The study involved small samples (the initial audit only included 6 sets of case notes) and the investigators only audited notes for patients who needed best interests meetings, i.e., those who were assessed as lacking capacity; it is therefore unclear if the checklist was beneficial in the cases of patients who were judged to have capacity. In addition, it should be noted that both audits took place within six months of the MCA's implementation. It could be argued that professionals' knowledge and practice relating to mental capacity assessment was still developing at this time.

In a similar study, Guyver *et al*. (3) described the introduction of an MCA assessment guidance and documentation resource and accompanying training package for professionals working with hospital patients with proximal femoral fractures. The authors audited patient case notes before and after the intervention, in order to measure its impact. Like Ramasubramian *et al*. (9), these authors found that practice improved following the introduction of the intervention: professionals completed documentation for more patients and their capacity assessments were more consistent with the MCA Code of Practice. Unfortunately, the authors did not describe any aspects of this intervention, or the standards they used in their audit. Emmett *et al*. (2) also noted that documentation of mental capacity assessment appeared superior when professionals used a new documentation proforma with a patient with dementia; they observed that descriptions of the assessment were detailed and consistent with the requirements of the MCA. Unfortunately the authors did not provide any information about the content of the proforma.

Summary of reviewed literature

The literature review was designed to answer the question: "How do professionals assess adults' ability or mental capacity to make informed decisions in England and Wales?" The findings suggest that there is limited published evidence relating to how mental capacity is assessed in England and Wales.

The review identified a small number of low to moderate quality studies. Most studies described assessments for people with learning disabilities or mental health conditions. These studies did not provide very detailed information about the methods used by professionals to carry out capacity assessments. The studies and the report by the House of Lords Post-Legislative Scrutiny of the Mental Capacity Act 2005 (4) suggest that currently, professionals find mental capacity assessment challenging and that their practice varies. Table 3.4 summarises examples of reported practice that appears consistent with the requirements of the MCA and also practice that does not appear to comply with the MCA two-stage functional test. A number of studies described measures developed to facilitate and improve assessment. These measures are also summarised in table 3.4.

Practice that appears consistent with the MCA
• Following four criteria of MCA functional assessment • Providing individualised support to understand information and communicate • Involving carers in assessments • Documenting assessments fully
Practice that appears inconsistent with the MCA
• Not formally assessing decision-making ability • Basing judgements about capacity on diagnosis / impairment, not decision-making ability • Basing judgements about capacity on perceptions of how wise people’s decisions are • Basing judgements about decision-making capacity on perceptions of executional capacity • Not completing decision or time-specific assessments of capacity • Not considering cultural/ethic/religious factors that may affect decision-making • Not providing support with decision-making (i.e., explicit, accessible information and support to understand it) • Not assessing understanding of information accurately during functional assessment of decision-making
Practice that appears to facilitate / improve assessment
• Assessing in a calm environment • Devoting extra time for assessments or carrying out serial assessments • Carrying out joint assessments with colleagues • Using an assessor who is familiar with person being assessed • Involving carers in assessment • Gathering information about abilities and needs pre-assessment, e.g., using communication screens • Developing communication strategies to support individual needs • Using some kind of structure (a flowchart / prompt sheet / checklist) • Using some kind of documentation aid (e.g., a proforma)

Table 3.4: Summary of literature review findings relating to current practice

3.4 Discussion

This chapter reports reviews of case law and literature relating to current mental capacity assessment practice in England and Wales that were carried out to satisfy the first objective of this doctoral study (see p10). The reviews of case law, the published literature and the House of Lords Scrutiny of the MCA and its implementation (4) suggest that mental capacity assessment practice is of mixed quality, in terms of how it complies with the MCA's legal requirements. A number of specific examples of inadequate practice identified in the literature review and in the House of Lords' report have also been the subject of judges' criticisms in legal cases. First, it appears that professionals sometimes base their capacity assessments on patients' diagnoses or impairments, or the outcomes of their decisions, rather than on their ability to make informed decisions. Second, some professionals carry out generic capacity assessments, rather than individual assessments for specific decisions. Thirdly, professionals do not always assess decision-making abilities or support people to make decisions adequately. This is often because professionals do not provide appropriate information or support to people who have difficulty understanding information.

Although the reviews do not provide detailed information about capacity assessment processes generally, and particularly for people with communication disorders, they do indicate ways in which capacity assessments can be facilitated and improved. They identify methods that have been developed to help professionals to structure and document their assessments and also initiatives designed to support people with communication needs. These initiatives involve the use of screening tools to identify people's communication needs prior to the capacity assessment. The results of these screens can then be used to make information about decisions more accessible to them during the capacity assessment. Although the researchers in these studies clearly believed these methods improved capacity assessments for people with communication difficulties, the study designs they used did not enable them to demonstrate this empirically.

The case law and research studies reviewed in this chapter provide confirmatory evidence that health and social care professionals need support to improve the quality of their mental capacity assessments. The literature review provides indications of how this might be achieved. These data will be used to inform a design specification for a mental capacity support tool in chapter 6 (see table 6.4, page 142). The next chapter reports a qualitative study in which healthcare professionals were interviewed about their experiences of mental capacity assessment, particularly in relation to patients with communication disorders. This study was designed to collect more detailed data about practice and professionals' support needs, to further inform the design specification for a mental capacity support tool.

Chapter Four: Professionals' Experience of Mental Capacity Assessment - a Focus Group Study

This chapter reports the methods and results of a focus group study that was carried out in a large NHS healthcare trust. Professionals were interviewed about their views about and experiences of assessing mental capacity and their support needs. The data were collected to complement the published evidence relating to current practice in mental capacity assessment that was reviewed in chapter 3. This study was carried out in order to meet the second objective for this doctoral study (see p11) The study has been reported previously in Jayes *et al*. (2016).

4.1 Introduction

This chapter describes a qualitative study that used a focus group method to collect data from professionals working in acute hospital and intermediate care settings, relating to their views about and experiences of assessing mental capacity. These settings were chosen because capacity assessment in a common clinical activity in these clinical environments. Data collected from thirteen professionals are discussed in relation to the findings of the previous literature review (chapter 3) to provide a greater understanding of how mental capacity is assessed in clinical practice and to identify the types of support that professionals report they need to improve and facilitate their assessments. The study was designed particularly to ask professionals about their experiences of conducting capacity assessments for patients with communication disorders. As noted in chapter one (p8), people with impaired communication need individualised support to demonstrate abilities that are key indicators of mental capacity, which makes assessment of their capacity more complex (Penn *et al*., 2009). Existing evidence indicates that professionals find assessing this clinical group challenging and are likely to need additional assistance to do this well (Carling-Rowland and Wahl, 2010).

A range of data collection methods were originally considered, including ethnographic and survey methods. Ethnographic or observational methods also provide opportunities to collect rich, contextualised data. However, focus group interviews provide a more efficient means of generating data from a range of participants than ethnographic methods (Morgan, 1997).

Using a paper or electronic survey can facilitate the efficient collection of responses from a large sample of participants, potentially across different geographical regions. An additional advantage of the survey method is that respondents may provide more honest answers than they would in individual or group interviews, particularly if a survey is designed to collect data anonymously.

However, focus groups have the potential to generate richer, more complex and potentially unexpected data than surveys due to the nature of interactions between participants and group dynamics (Kitzinger, 2006).This is especially pertinent to this study, because the composition of the focus groups with a range of different professional roles could resemble the social context in which mental capacity assessments are planned and discussed; this should enable an exploration of common practices and beliefs as well as divergent views and understandings within the group (Morgan, 1997). Data collected in interviews may be more valid and reliable than those collected in surveys; this is because interviews provide an opportunity for researchers to probe individual responses, request additional information and clarify respondents' intended meanings.

4.2 Research aim and objectives

The aim of this research was to explore the views, practices and experiences of health and social care professionals[16] who assess mental capacity in acute hospital and intermediate care settings. The following research objectives were identified:

1. To identify the main decisions that professionals need to support patients to make
2. To identify the types of patients that have particular difficulty making these decisions
3. To identify the types of professionals involved in mental capacity assessment
4. To explore how professionals currently assess patients' decision-making capacity, particularly for patients with communication difficulties
5. To explore perceived barriers and facilitators to mental capacity assessment

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[16] For example social workers, who may carry out capacity assessments relating to decisions that patients need to make about where they will live on discharge from hospital.

6. To investigate whether professionals think a support tool might be beneficial to their practice and what it should incorporate.

4.3 Method

The previous literature review (chapter 3) suggested that in order to meet the above research aim, this study should be designed to collect data relating to people's experiences, behaviours, understandings and opinions. A qualitative methodology and a focus group method were selected in order to generate these types of rich, complex data. Focus groups are qualitative, semi-structured interviews involving groups of participants; they are commonly used as an inquiry method in the initial stages of user-centred design processes (see chapter 2, p16).

4.3.1 Ethical approval / governance

Ethical approval was obtained from the University of Sheffield School of Health and Related Research (ScHARR) Ethics Committee on 17/06/14 (see appendix 3). The focus group study was registered with Sheffield Teaching Hospitals NHS Foundation Trust as a Service Evaluation project on 31/07/14 (see appendix 4).

4.3.2 Participant identification and eligibility

The study aimed to sample the experiences and views of professionals working in a range of professional roles across different clinical settings. It was possible to access these settings within a single large healthcare trust, Sheffield Teaching Hospitals NHS Foundation Trust (STHFT). STHFT is a teaching hospital trust providing acute medical care and rehabilitation for adult patients across two main hospital sites and has approximately 2000 beds. STHFT also provides intermediate care in a range of community settings. The trust employs over 16000 staff. All professionals involved in mental capacity assessment were eligible for inclusion in the focus group study. There were no identified exclusion criteria. The findings of the previous literature review (chapter 3) were used to identify the most relevant professional groups to recruit to the focus groups; these groups were physicians, physiotherapists, liaison psychiatrists, nurses, OTs, psychologists, SLTs and social workers.

The researcher sent information about the study's aims and methods via email to the managers of these professional groups, requesting that they cascade this information to their colleagues. He also sent the same email to existing contacts in each professional group and posted the same information on an electronic newsletter sent to all STHFT employees. Due to a relatively low response rate, the researcher re-sent the email to managers and requested they cascade the information to their colleagues a second time. An electronic participant information sheet (appendix 5) was sent to those interested on request. The researcher emailed these individuals at least 48 hours later to ask if they wished to take part in the study. Staff wishing to participate were invited to attend a focus group.

4.3.3 Sampling strategy for constituting focus group membership

The researcher planned to use a purposive sampling strategy, in order to ensure each focus group included representation from every professional group and from a range of clinical settings. A sampling frame was developed to facilitate participant selection (see appendix 6). The target sample size was up to 10 participants per group. This number was identified on the basis of recommendations by Morgan (1997) that the optimum size for focus groups is between six and ten people and that researchers should aim to over-recruit by 20%, in order to compensate for participant attrition. A convenience sampling strategy was actually used, due to a relatively low response rate to the electronic advertisements and because not all members of staff who expressed interest in participating were able to attend one of the scheduled groups, due to work commitments. All staff who expressed an interest in taking part in the study and were able to attend one of the groups were included. The researcher attempted to ensure that each group included professionals from different disciplines and clinical settings.

4.3.4 Materials

A topic guide (appendix 7) was developed based on the findings of the previous literature review (chapter 3) and the study objectives (section 4.2, pp58-9). A digital recording device was used to make audio recordings for each group.

4.3.5 Procedure

4.3.5.1 Setting

A focus group was held at each hospital site. Each group took place in an easily accessible, quiet seminar room that was amenable to group discussion and audio recording. These rooms were not associated with any of the participants' clinical work locations and therefore represented "neutral" spaces. Participants were invited to sit around a meeting table for the focus group session. Refreshments were provided at the start of each session.

4.3.5.2 Consent

Written informed consent was taken at the start of each focus group, using a consent form (appendix 8). Participants were reminded that they were free to withdraw from the session at any point.

4.3.5.3 Data collection

The researcher facilitated each focus group whilst his primary academic supervisor acted as assistant facilitator and was responsible for taking field notes relating to the general nature of the discussion. At the start of each group interview, the researcher welcomed the participants, provided an overview of the topic for discussion and established ground rules[17].

Participants were asked to introduce themselves by providing their name, job role and clinical base. These questions were designed as "ice- breakers" (Morgan, 1997, p49) and to aid participant identification during subsequent transcription of the audio data. Following this, the researcher asked questions using the topic guide (appendix 7) but allowed discussions to develop freely, in order to generate rich data (Mason, 2002).

At the end of each session, the assistant facilitator read back the field notes. Participants were given opportunities to comment on the field notes and correct any misunderstandings / misinterpretations.

4.3.5.4 Data analysis approach

Data were analysed thematically, using a Framework approach (Ritchie and Spencer, 1994). Framework analysis enables large amounts of raw data to be reduced through a transparent, systematic process of summarisation and synthesis (Gale *et al*., 2013). It involves five iterative stages of thematic analysis; these analytic stages are described

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[17] These ground rules included the importance of participants demonstrating respect for other participants' opinions and maintaining group confidentiality.

in relation to this study in table 4.1. The Framework approach was chosen because it allowed themes and subthemes to be generated both deductively from the research objectives and the findings of the evidence review (chapter 3) and inductively, from open data coding. Framework analysis has been demonstrated to enable rigorous, timely data analysis within health services research (Pope *et al*., 2006).

4.3.5.5 Analysis method

The researcher transcribed the digital recording for each session verbatim into a Microsoft Word file. Any unintelligible utterances were transcribed as “(unintelligible)”. Each Word file was imported into QSR NVivo 10 software, to facilitate rapid data analysis; NVivo is compatible with the Framework approach. A summary of the analytic process is shown in table 4.1; this is based on Pope *et al*.’s (2000) description of Framework.

Analytic stage	Aim	Description of researcher activity
Familiarisation	• To immerse researcher in raw data; • To identify initial themes.	• Digital recordings transcribed; • Transcriptions and field notes read; • Initial notes made in margins of transcriptions on potential themes.
Identification of thematic framework	• To create initial analytic framework.	• Study aims and objectives, topic guide, literature review findings (chapter 3) used to identify potential themes; • Transcriptions read within context of these themes to check validity of themes and to identify new themes inductively from raw data; • Themes added as codes[18] in NVivo 10.
Indexing	• To systematically apply codes from thematic framework to all data.	• Transcriptions coded according to thematic framework using NVivo 10.
Charting	• To summarise and synthesise data for each theme within Framework Matrix.	• Data summarised across participants for each theme within Framework Matrix using NVivo 10 software.
Mapping and interpretation	• To describe and interpret findings in relation to study aims.	• Framework Matrix reviewed to identify relationships between themes and sub-themes; • Themes and relationships described and interpreted in thesis chapter.

Table 4.1: Application of Framework Analysis approach to data analysis

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[18] Codes are labels that are used to represent sections of the data that are related or have the same meaning.

4.3.5.6 Rigour

Different techniques were used to increase the credibility, dependability and confirmability of the research findings (Lincoln and Guba, 1985). Firstly, respondent validation was used at the end of each focus group to establish the credibility of initial data interpretation in the field notes (Donovan and Sanders, 2005). Second, the researcher used a research journal to document how coding decisions were made and record reflections about how he may have influenced the data collection and analytic processes; this provided an audit trail for the analytic process. Third, an experienced qualitative researcher was invited to review the Framework Matrix and the transcriptions. This peer scrutiny process did not identify any changes to the matrix, which provides indicative evidence of the credibility of the analytic method (Shenton, 2004). Finally, the researcher used strategies to ensure the study was reported rigorously; these included providing “thick description” (Murphy *et al*., 1998) of the participants, study context and methods and comparing the study findings with those reported in existing published evidence (Silverman, 2005).

4.4 Results

4.4.1 Participants

Thirteen participants were recruited to two focus groups. Most participants (n=11) were female. Participants were from the following professional groups: nurses (n=1), OTs (n=2), physicians (n=3), physiotherapists (n=1), psychiatrists (n=1), psychologists (n=2) and SLTs (n=3). No social workers were recruited. Participants worked in diverse clinical locations: acute care of the elderly wards (n=3); acute medical wards (n=2); acute stroke wards (n=4); acute surgical wards (n=1); acute infectious diseases and endocrinology wards (n=1); intermediate care stroke services (n=1); general intermediate care services (n=1); outpatients services (n=2). Participants had varying levels of professional experience, having worked in their professional role for between six and 38 years. They had received either general healthcare trust training[19] about the MCA or more specialist, profession-specific training. These participant data are displayed in table 4.2

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[19] General training refers to training in the MCA provided by the healthcare trust as part of its staff training programme.

Participant identifier[20]	Professional role	Clinical setting	Type of training received in MCA
Focus group 1			
001	OT	Acute hospital	General and self-directed learning
002	SLT	Acute hospital	General
003	Clinical psychologist	Acute hospital and outpatients services	General and specialist
004	Consultant geriatrician	Acute hospital	General and specialist
005	Consultant geriatrician	Acute hospital	General and specialist
007	Consultant psychiatrist	Acute hospital	Data not provided
Focus group 2			
006	Physiotherapist	Intermediate care	General
008	Clinical psychologist	Acute hospital	General and specialist
009	SLT	Acute hospital and intermediate care	General
010	OT	Acute hospital	General
011	SLT	Acute hospital	General
012	Consultant neurologist	Acute hospital and outpatients services	General and specialist
013	Mental health nurse assessor	Acute hospital	Data not provided

Table 4.2: Participant characteristics

4.4.2 Findings

The findings are presented in terms of four major themes that were developed deductively from the focus group topic guide (appendix 7). These themes are:

i) the process of assessing mental capacity;

ii) how professionals find mental capacity assessment;

iii) working with patients with communication difficulties;

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[20] Participant identification numbers were allocated when participants were allocated to each group rather than in order of recruitment. This explains why they do not appear in numerical order in table 4.2.

iv) how a support tool might help professionals work with these patients.

Sub-themes associated with each of these themes are summarised in table 4.3.

Themes	Sub-themes
The assessment process	• Patients who require capacity assessment • Types of patient decision involved • Who assesses capacity • Activities involved in assessment
Professionals' experience of capacity assessment	• Time pressures • Having the right knowledge and skills • Other people's practice
Working with patients with communication difficulties	• Identifying communication difficulties • Supporting people's communication needs • Challenges associated with working with this group
How a support tool could help	• Providing structure • Increasing professionals' confidence • Raising awareness of patients with communication difficulties • Providing support to identify and support communication needs

Table 4.3: Themes and sub-themes identified within data

These themes and sub-themes are discussed below and illustrated with sections of original data.

4.4.2.1 The mental capacity assessment process

Participants' responses suggest a number of variables within the assessment process. These are described below.

Types of patient who require mental capacity assessment

Participants identified two main groups of patients who require mental capacity assessments: those who had cognitive and communication difficulties following stroke and those with cognitive difficulties due to dementia or delirium. Four participants (003, 006, 007, 013) reported that they had been asked to assess capacity for people with learning disabilities; however, this appeared to be a relatively infrequent event. Three participants (007, 008, 013) who work with patients with mental health conditions also reported that patients with diagnoses such as depression, psychosis, schizophrenia and personality disorder may require assessment. Three participants (002, 003, 008) also identified patients with acquired brain injury (both traumatic and non-traumatic) as another group that might need assessment.

Types of patient decision involved in capacity assessments

Most participants reported that in their experience, most mental capacity assessments tend to involve patients needing to make decisions about discharge arrangements or treatment options. Decisions about discharge arrangements often include patients choosing between going back to their usual residence with or without support from paid carers or moving to a care home setting. A patient may be asked to make a decision about the type of rehabilitation setting to which s/he is discharged. The capacity assessment for these types of decisions requires professionals to establish if patients can understand and weigh up the risks and benefits of each option:

> *I think in intermediate care very often the capacity question is…do they understand the risk to go home or do they have the capacity to make the decision about discharge destination* (006)

Decisions about treatment options might include choosing to take a type of medication or undergo a therapeutic or surgical procedure. However, it appears that assessing capacity to consent to surgical procedures is not common practice in all clinical settings; participant 004, a consultant geriatrician commented:

> *Yeah I mean in the sort of the surgical role that I'm doing at the minute you know I'm often consulted about discharge destination or future care but no one ever talks to (me) about whether or not these patients can consent to their operations* (004)

Three participants (002, 011, 013) reported being involved in capacity assessments related to decisions about whether to eat and drink orally or receive nutrition or hydration alternatively, for example via Percutaneous Endoscopic Gastrostomy (PEG) tube. Participant 002, an SLT working on acute hospital wards commented:

> *another decision often that we might get involved in is around alternative feeding…long term that decision about do I have a PEG or not, what the implications are…* (002)

Three participants working with patients with mental health conditions (007, 008, 013) described also being asked by teams to assess patients' capacity to make informed decisions about refusing medications or treatment. Participant 008, a clinical psychologist, reported she is often asked to assess whether patients have mental capacity to consent to sexual relationships. Finally, participant 007, a consultant liaison psychiatrist, discussed being asked to assist with a capacity assessment relating to a patient who needed to make decisions about his finances.

Professionals involved in assessing mental capacity

Participants suggested a range of professionals carry out mental capacity assessments within hospital and intermediate care settings, as shown in table 4.4:

Professionals who assess mental capacity
• Clinical psychologists
• Physicians
• Nurses: transfer of care nurses, mental health nurse assessors
• OTs
• Physiotherapists
• Psychiatrists
• SLTs

Table 4.4: Professionals involved in assessing mental capacity

Three participants (005, 007, 010) commented that the choice of assessor would depend on the nature of the specific patient decision. This appeared to be because participants felt it important that the assessor have access to specific information that may impact on the decision. This might include information about the patient (e.g., their medical status, home situation, pre-admission and current functional abilities) or treatment options (e.g., a surgical procedure). Therefore, doctors would usually be involved in assessing capacity for decisions about treatment and an OT, whose role involves collecting information about a patient's home life and ability to manage activities of daily living, would tend to be involved in assessments about discharge arrangements. Participant 001, an OT working in an acute hospital commented:

> *it makes sense for the people who are getting that information to begin with to actually then use that…rather than it being passed to somebody else* (001)

Participants described a number of situations where particular members of the multidisciplinary team might be asked to be involved in an assessment because of their specific skills and knowledge. For example, SLTs might be asked to facilitate communication between professionals and patients during assessments for patients with communication disorders. Similarly, mental health professionals might be asked to assess patients with mental health conditions.

At times, this may be challenging for the professionals involved. Participant 007, a liaison psychiatrist, reported that he prefers a member of the treating team to be present when he assesses capacity, because he recognises that he does not always have the specific knowledge that is relevant to the decision in question:

> *for example if they are planning some sort of fancy treatment or investigation which I wouldn't have a clue about then it's very difficult to assess capacity unless there's expert knowledge within the room* (007)

It appears that the involvement of professionals outside the treating team in mental capacity assessment can sometimes cause resentment between professionals. Two participants (006, 010) stated that it should always be the professional who knows a patient best who assesses capacity. Participant 006, a physiotherapist in intermediate care, suggested that it might cause dissatisfaction within a team if an external professional were asked to carry out a capacity assessment:

> *I personally would feel quite insulted if somebody that didn't know that person came in and did the capacity assessment when you know we've potentially been working with that person for 5 to 6 weeks, know all the ins and outs we've done the assessments* (006)

Participant 013, a mental health nurse assessor, complained that he is often asked to assess capacity on a particular unit because of his specific training in mental health conditions and that this causes an excessive workload; however, he believes that professionals working on that unit should carry out the assessments instead:

> *Well they've been told… they can't do it…because they haven't had sufficient training…they've had the same training as we've had and they're more than capable…nurses, therapists…they're more than capable of doing it* (013)

Similarly, participant 007 commented that teams may refer to her to carry out an assessment for a patient with a mental health condition when they do not feel able to manage that patient's behaviour:

> *Yes, and also you know it's about owning the decision making isn't it? I've seen many teams who feel that if somebody is being difficult it's not their problem with the patient…it's call the psychiatrist* (007)

Participant 003, a clinical psychologist, reported that she sometimes receives referrals from transfer of care nurses[21] to assess capacity in situations when it is very hard to judge if a patient has capacity or when members of the multidisciplinary team disagree on whether or not the patient has capacity; she suggested this was because of her knowledge and experience of the MCA. Participant 003 stressed the importance of such assessments being carried out jointly by the team that knows the patient well and the external professional who brings specialist knowledge:

> *I think it needs to be a team thing with all that information there and yes you might need somebody with a bit of knowledge and experience of the mental capacity act to know where you draw the line but you know you're not necessarily the expert in whatever the situation is* (003)

Two participants (006, 010), who work as part of a multidisciplinary team, reported that they had experience of joint assessment and found it beneficial. Participant 010, an OT, reported that it was standard practice in her team to conduct capacity assessments in pairs. Participant 006 reported that being able to discuss an assessment afterwards with a colleague who had been present provided opportunities for reflective practice and learning.

Participants' responses also suggested that professional hierarchies may impact on who is responsible for assessing capacity in certain settings. Participant 004, a consultant geriatrician, commented that in her experience, the most senior members of medical teams tend to carry out capacity assessments. She added that this is what usually happens in her team and this may be because junior doctors assume it is the

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[21] Nursing staff who primarily organise patient discharges from hospital and transfers to other care settings.

consultant's role to assess or because she may be shielding junior members of her team from the responsibility involved in assessing capacity:

> *I tend to own it I think it's a huge responsibility I wouldn't really want to give that to someone who didn't feel they wanted it* (004)

Another consultant geriatrician (005) commented that when the MCA was implemented, it seemed appropriate for senior doctors to assess capacity, because this represented a novel aspect of clinical practice. However, he argued, it has become apparent that other professionals may be more qualified to carry out assessments, provided they have enough opportunities to gain experience and build confidence as assessors. He was surprised to observe that within certain teams, senior doctors do not appear happy for other professions to carry out assessments:

> *I would assume that a consultant surgeon would be happy for somebody else to do the capacity assessment so that they could be busy you know chopping bits of people's body up…that may relate to their working relationship with people on those wards* (005)

Activities involved in mental capacity assessment

Participants described several distinct activities involved in mental capacity assessment. These are discussed below.

Gathering information

Participants reported gathering information from a number of sources in order to prepare for capacity assessments. Often this involved collecting information about the patient's pre-admission functional abilities from family and paid carers and other professionals. For patients with cognitive difficulties, this information was sometimes available on the ward within a document called "All About Me"; this booklet enables family and carers to record personalised information about a patient's functional abilities, preferences and care needs. Participant 008, a clinical psychologist working with patients with mental health conditions, described often spending long periods of time reading patients' medical notes at their GP surgery and interviewing their families and friends prior to a mental capacity assessment. Participant 001, an OT, described liaising with a variety of people to gain a collateral history about a patient's life at home prior to admission:

> *sometimes we get input, feedback from other services involved…maybe they've had therapy input at home before or you know we try and get as broad information that we can or speaking to wardens or social workers or whoever's appropriate* (001)

Participants described using both formal and informal assessment findings to obtain information about patients' current abilities; this type of information enabled participants to identify factors that may affect a patient's decision-making ability. For example, participant 002, an SLT, described carrying out an informal language assessment with patients prior to a capacity assessment, in order to gain baseline information about their abilities and how the assessment should be adapted to meet their individual needs:

> *I probably do an informal language assessment and then from the findings from that, then go away, make the appropriate resources if needed to then hopefully support the decision that you're trying to assess* (002)

Similarly, participants 006 and 013 reported using information from cognitive screening assessments such as the Mini Mental State Examination (MMSE) (Folstein *et al*., 1975) to gain an understanding of a patient's cognitive ability. Again, this information might be used to help professionals prepare an assessment of decision-making ability for that patient. However, it might also be used to provide evidence that a patient has an impairment of the mind or brain that may affect decision-making, in order to satisfy stage one of the two-part functional test of capacity[22]. This type of information gathering appears to be especially pertinent for patients who are referred for capacity assessment but lack a formal diagnosis of cognitive impairment.

Participants reported using information from functional assessments to ascertain how well patients might manage particular activities related to a decision (e.g., a decision about discharge destination). For example, participants 003 and 004 reported asking other professionals about patients' abilities to do certain tasks that they would need to do in order to live safely in their own home (e.g., the ability to prepare a meal). Participants also described gathering information about treatments or interventions that might need to be discussed with patients during capacity assessments.

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[22] As described in the Mental Capacity Act Code of Practice (2007).

Informal and formal assessments of decision-making ability

Participants did not provide detailed descriptions about how they assess decision-making. They tended to describe both informal and formal processes of how they carry out assessments. Several participants described having initial conversations with patients prior to an assessment of decision-making ability. A clinical psychologist (003) reported tending to ask patients general questions about their home life and hospital admission:

> *I don't launch straight in with it…I try and sort of talk a little bit about you know are they aware that they're in hospital…are they aware of how long they've been in hospital for, why they came into hospital* (003)

Two consultant geriatricians (004, 005), an OT (001) and SLT (011) all reported having similar conversations with patients. Their comments suggest that this type of conversation appears to serve several purposes; it can provide information about a patient's cognitive function (their orientation and insight) and it may provide an informal assessment of capacity:

> *I certainly start those same questions you know, do you know where you are, do you know why, do you know how long you've been here…but you know sometimes really I don't get much further than that 'cos if they really haven't got a clue about any of those things…* (004)

These conversations also appear to be useful in helping to establish rapport with patients. Participant 005 suggested that immediately starting the assessment by testing a patient's decision-making ability can appear challenging to patients and can cause them to be argumentative, which can disrupt the assessment process.

A clinical psychologist (003) described a general process of using conversations with patients to explore their ability to understand, retain and weigh information relevant to a decision and then communicate their decision; this appeared to be consistent with the requirements of the MCA functional test of decision-making. This participant reported that her first conversation with a patient enabled her to take an initial "gut pass" at capacity assessment, using a "mental proforma" to work through the stages of her assessment:

> *on the first sort of pass at it I might sort of think well you know from their responses they do seem to be understanding what I'm saying, clearly able to communicate a decision* (003)

She added she might reflect on this assessment and assess the patient again to explore any issues she felt she had missed initially or to explore specific aspects of the MCA functional test of decision-making:

> *are they weighing up and judging and you know that might take a whole sort of assessment in itself* (003)

Four participants described more formalised ways of assessing decision-making. An OT (001) and two SLTs (009, 011) working in different teams reported structuring their assessments using a proforma developed within the healthcare trust; this proforma provides information about the requirements of the functional test and can be used to document the assessment process. Professionals using the proforma found it very helpful.

Participant 010, an OT, reported using a standardised assessment process within her multidisciplinary team, although stressed that capacity assessments are still patient and decision-specific; her team uses an approach that involves preparing patients for the capacity assessment, by providing opportunities for them to learn information relevant to decision-making:

> *we've got our own paperwork that we use, we use questions that can be repeated, we give them time to relearn that information so we actually prepare them for the assessment itself and then we come to a conclusion* (010)

Participant 003 reported that this type of approach to supporting patients' decision-making ability was also being used by professionals working in a different inpatient rehabilitation unit within the trust, for patients with executive dysfunction[23] secondary to acquired brain injury. Other participants commented that they might consider applying this approach to their own practice.

Two OTs (001, 010) both described asking patients questions about risks associated with discharge decisions to explore how well they can understand and weigh up information when making decisions:

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[23] Executive dysfunction refers to cognitive, behavioural and emotional processing deficits that arise due to impaired "executive functions", such as planning, abstract thinking, problem-solving, decision-making and inhibition. It often results from brain injury.

> *how many falls have you had then and how have you kind of managed to deal with that…have you been able to get help?* (001)

> *I'll say ok then so you say you'll be fine but what would you do if there was a fire?* (010)

Similarly, a clinical psychologist (008) and a physiotherapist (006) both emphasised the importance of assessing whether patients can understand and weigh up information about the long-term consequences of decisions:

> *And understanding the significance of that decision as well, so 99.9% of people might say they want to go home, but do they understand then what their life's going to be like at home that they might have to sit in a wet pad for eight hours overnight* (006)

Documenting assessments

Several participants reported that they felt it was important to produce detailed and transparent documentation for their assessments. Participant 001 reflected that she found it very challenging to give second opinions on capacity when other professionals had not documented their own capacity assessments clearly and this led her to want to "overcompensate" by writing more detail about her own assessments. As described above, three participants (001, 009, 011) described using proformas to help them document their assessments. Participant 001 reported using the proforma enabled her to produce more succinct and transparent documentation:

> *it's clear for people to see that you've followed the process and they can see what evidence has made you come to that conclusion* (001)

Repeat assessment

Participant 013, a mental health nurse assessor, commented that due to the high number of referrals he received for mental capacity assessments, he and his colleagues are only usually able to carry out single assessments and have to limit the amount of time they can spend on each assessment to 45 minutes. This contrasted with several other participants, who reported they might assess some patients' decision-making on repeat occasions.

As described above, participants 003 and 010 said they might use several sessions to assess a patient; a potential reason for doing this would be to assess whether the patient was able to retain information relevant to decision-making over time. Participant 004, a consultant geriatrician, reported that she might also use a repeat assessment to reassure herself that a previous assessment was accurate. She added that she sometimes reassessed capacity for patients whose capacity might be expected to fluctuate, for example due to a temporary condition such as delirium. A clinical psychologist (008) also emphasised the importance of capacity assessment being a repeating process, especially for the patient groups she works with who may have fluctuating capacity due to their mental health conditions.

4.4.2.2 Professionals' experience of capacity assessment

Most participants, irrespective of their professional role or level of seniority, reported finding mental capacity assessment challenging. A consultant geriatrician (004) commented "I find it all really quite difficult…makes me quite stressed". Participants in both groups described a range of sources of challenge. These are discussed below.

Time pressures

Several participants commented that mental capacity assessment is time consuming and that they sometimes feel under pressure from other professionals to provide a rapid judgement about a patient's capacity. As reported above, participant 013 described needing to complete four or five assessments a day and only being able to spend 45 minutes on an assessment. Other participants were clearly surprised by this and expressed sympathy towards participant 013 because of what they felt was a difficult workload. A consultant psychiatrist (007) and consultant geriatrician (004) both reported that they sometimes have to be assertive with professionals about needing extra time to complete assessments:

> *having that confidence to say actually I don't think I can make a decision based on what I've got today…I need more time…because there is a pressure…you know you have to produce the answers today* (007)
>
> *I just can't do it today, I can't do it properly…if we're gone do this properly you're just gonna have to wait until I can come back* (004)

Having the right knowledge and skills

Participants identified situations where they felt they lacked the knowledge or skills needed to carry out effective mental capacity assessments. These situations sometimes involved not having detailed knowledge about a particular treatment related to decision-making. For example, a consultant geriatrician (004) reported being asked to assess patients' capacity to consent to certain surgical procedures but being unable to do this because she lacked sufficient knowledge of these procedures.

Other challenging situations involve being asked to assess unfamiliar patient groups or patients with special characteristics. A consultant geriatrician (005) reported that whilst he felt experienced and confident when working with patients with dementia or delirium, he found it difficult to assess patients with other diagnoses:

> *I find it really hard with conditions that aren't related to dementia and delirium…so I find depression really, really hard* (005)

Participants reported that they find it challenging to assess patients with communication difficulties. The particular challenges associated with this group are discussed fully in section 4.4.2.3 (pp80-81).

Colleagues' practice that is not consistent with the MCA

Participants talked frequently about aspects of other professionals' practice that they find challenging. An OT (010) voiced concerns that there may be variations in practice across the healthcare trust. Participant 008, a clinical psychologist, had general concerns that many professionals lacked awareness about the MCA and commented that in her experience, some professionals failed to recognise when patients may require an assessment:

> *They don't identify that there's a capacity issue…they refer their patients to me for other things and I go have you not noticed then that they haven't got the capacity to boil an egg let alone make a decision about treatment* (008)

Other participants identified that even if professionals can recognise that a patient needs a capacity assessment, they may not understand that this assessment should be decision and time-specific. Related to this, some participants expressed concern that patients who may have fluctuating capacity are sometimes not reassessed. Participant 006 described a situation where a patient with delirium was judged by hospital professionals not to have capacity to decide where to live on discharge from hospital and was not reassessed at a later date when the delirium had resolved.

Other participants described situations where professionals do not appear to complete or document the two stages of the functional test of capacity in ways that are consistent with the MCA. A consultant geriatrician (004) reported that she sometimes receives referrals to assess capacity for patients without any formal diagnosis or clear evidence of any impairment of the mind or brain that may cause a problem with decision-making (in order to fulfil stage one of the functional test). Another consultant geriatrician (005) commented that some professionals make statements about patients' capacity based on informal impressions and do not use the two-stage test:

> *…people can often make mental shortcuts about whether someone will have capacity, you know things like well I saw them today and they seemed a bit muddled so they can't have capacity* (005)

A number of participants warned that professionals may exclude certain patients from the capacity assessment process or from general discussions about future plans on the basis of these subjective impressions:

> *the doctor that I sat in with didn't talk to her once and there was nothing to suggest she didn't have capacity to understand, nothing to suggest that at all…(*008)

The influence of others

Participants reported that they can find it difficult not to be influenced by other people when carrying out capacity assessments. Participants 001 and 005 described how other professionals' opinions about a patient's capacity can be very influential:

> *sometimes you hear around sort of the MDT*[24] *oh I don't think this person's got capacity and it's not having a pre-judged view before you do the assessment* (001)
>
> *it can sometimes skew your thinking…it's very hard to keep that clarity of thinking and don't go into the room with a pre-conceived idea* (005)

Three participants (002, 003, 007) described how different groups of people's views on what is in a patient's best interests can also impinge on the assessment process. A consultant psychiatrist (007) commented:

> *often what makes it challenging is the medical team have a certain opinion, the family has a contrary opinion, the patient's caught in the middle…it's easy for you to get caught into one camp or the other you need to make sure that you're as neutral as possible and focus on the patient* (007)

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[24] Multidisciplinary team

4.4.2.3 Assessing capacity for patients with communication difficulties

Participants described different methods they use to identify communication difficulties and support patients' needs. These are summarised in table 4.5 and discussed below.

Identifying difficulties	Supporting people's needs
• Using assessments • Asking other people • Using existing information	• Maximising people's abilities • Changing own communication style • Using alternative communication methods • Accessing support from others

Table 4.5: Methods used when working with patients with communication difficulties

Identifying difficulties

Participants described several types of communication difficulty patients might present with during capacity assessments. Most participants identified difficulties with understanding and expressing language associated with aphasia post-stroke or with dementia. Two mental health professionals (007, 008) also described patients having problems using speech and language due to conditions such as autism and more subtle communication problems such as impaired emotional processing due to personality disorder. Participants reported that hearing or visual impairments could cause communication problems directly or may impact on other conditions (e.g., aphasia).

Four participants reported using informal assessments to identify communication difficulties. An SLT (002) uses an informal language assessment, whilst an OT (001) uses a screening assessment that forms part of her routine patient assessment. A clinical psychologist (003) reported making judgements about spoken language during conversations with patients, based on techniques she had learned from SLTs. A consultant neurologist (012) described observing non-verbal behaviours to gain information about patients with dementia:

> *I'm actually reliant quite a lot on their eye contact, their facial expressions, their gestures when I'm talking about certain things to see whether there's any distress* (012)

Two participants reported that they found it useful to ask other professionals about patients, to find out about communication difficulties. Participant 001 described talking to nursing and other ward professionals who may know a patient better than she does. A physiotherapist (006) and consultant psychiatrist (007) also reported liaising with paid carers and families to gain information. Other participants described looking for entries by other professionals about a patient's communication abilities in their medical notes, or using information that accompanies the patient into hospital. Three participants (001, 012, 013) mentioned consulting the "All About Me" booklet that families and carers complete for patients with cognitive impairment (described on p67).

Supporting people's communication needs

Two participants (001, 003) reported that they would take steps to support patients with impaired hearing during their assessments; this might involve checking whether a patient needed hearing aids and had working aids or taking a patient into a quiet environment to facilitate communication. Four participants (002, 004, 007, 013) described making adjustments to their own communication to support people with communication difficulties to engage in decision-making. This might include trying to use simplified language and gesture to facilitate a patient's understanding:

> *a long sentence perhaps wouldn't be understood but you know perhaps something as simple as can you hear or can you hear (gesture to ear*) (013)

Most participants were able to describe alternative methods of communication they might use to support a patient with receptive or expressive communication difficulties. These different methods are listed below in table 4.6. Participant 011, an SLT, emphasised the importance of practising these alternative communication methods with patients prior to using them within capacity assessments, to ensure they are effective.

Alternative communication method
• Writing information down (e.g., on paper or a whiteboard) • Drawing pictures to explain concepts • Using symbols / pictures / photographs / diagrams to explain concepts (this might include the Talking Mats © [25] communication system) • Using gesture / pointing in addition to or instead of words • Using printed alphabet charts[26] or other communication aids to support a patient to express themselves

Table 4.6: Alternative communication methods used by participants during capacity assessments

Amongst the participants who were not SLTs, some appeared confident about using alternative methods, whilst others reported they would be more likely to refer the patient to speech and language therapy for specialist support. An SLT (002) reflected that her service did not receive many referrals for communication support for patients during mental capacity assessments. Other participants discussed the fact that professionals may be unaware that this type of support is available. Participants suggested that this might be in part because SLTs are often not based on wards with the rest of the multidisciplinary team. A consultant geriatrician (004) reflected that it might also be because professionals assume that SLTs are primarily involved in assessing and managing swallowing difficulties:

> *…we as clinicians feel that referrals for language are not a priority you know because you've got to get these people who are nil by mouth they've got to be assessed* (004)

Challenges experienced when working with patients with communication difficulties

In order to collect data that might be used to assess the need for and inform the design of a support tool, participants were asked whether working with these patients caused

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[25] Talking Mats© is a low technology communication aid which involves simple picture symbols that can be placed along visual scales, to support people to understand information and express their feelings, preferences, needs and choices in relation to different topics. More information can be found at www.talkingmats.com.

[26] An alphabet chart is a visual alphabet display. A person with reduced speech intelligibility could point to individual letters on an alphabet chart to spell out words. The aim of this would be to assist the listener to understand the person's message better, by supplementing speech with written language.

any difficulties. They identified a number of challenges which are listed in table 4.7 and illustrated by sections of original data.

Challenges	Supporting data
Identifying communication difficulties and needs	*I suspect I don't pick up a lot of language you know communication issues* (004) *I think with people with dementia…differentiating between the short-term memory and the communication as to what's the barrier* (003)
Communicating effectively: • Expressing complex information in different ways • Adjusting own communication style	*for someone with a communication difficulty it's very hard to try and explain…if it's around a decision around complex treatment that's got quite a lot of information to get across* (002) *it's extremely difficult because you're more used to a certain way of working and you have to be very aware that you can't use the usual way* (007)
Demonstrating whether a patient can or cannot understand information	*trying to find exactly the right question to elicit the fact that they don't understand it so that I can show that as evidence when I write this all down later* (004) *have I done enough to demonstrate they can understand me?* (007)
Time required	*if we know that people have got communication impairment it should be flagged up beforehand and additional time should be allocated, because you can't do it in 20 minutes* (008)

Table 4.7: Challenges experienced by participants when working with patients with communication difficulties

4.4.2.4 How a support tool could help

Participants were asked general and focused questions about if and how they thought some type of support tool might help them to assess capacity and what it might include. All participants responded favourably to the idea of a support tool and identified three potential benefits it could bring to their and others' practice: more structure to assessments generally, increased professional confidence and increased awareness amongst professionals about the needs of people with communication difficulties. One participant (006) suggested that she felt she and her team were able to assess capacity for patients with communication difficulties and had access to appropriate resources already. She suggested the tool would be more beneficial for professionals with less experience of assessment.

Proposed purpose of a support tool

Participants suggested a number of potential purposes for a support tool. Some felt it would be important for a tool to help professionals to identify communication difficulties. This might include prompts to remind professionals to check patients' hearing needs and simple ways to check their level of understanding:

> *I'd like some steps you know a simple test that you can do to see are they following simple commands* (002)

An SLT (011) suggested that the tool should make professionals aware that they need to assess patients' ability to understand information that is relevant to the decision they need to make. A physiotherapist (006) suggested the tool would be really useful if it enabled professionals to check that patients understood this information as part of the second stage of the functional test of capacity:

> *If you think you can develop something that would tell us if somebody understands…that would be amazing* (006)

Participants also identified a need to flag patients with communication difficulties to ensure that they receive support with general communication and decision-making during hospital admissions. They suggested a support tool might be used for this purpose too:

> *there should be something so that you think I have to have a communication strategy I have to you know look at this person's ability to communicate whether that's capacity or whatever it is* (008)

Several participants proposed that a tool could be used to identify ways to support patients' communication needs during capacity assessments. A consultant geriatrician (004) advised this should include simple guidance about maximising patients' vision and hearing as some professionals may not automatically consider this. Participants also suggested the tool could provide guidance about simplifying language and even give examples of simple sentences and questions that professionals could use during assessments. Similarly, it could propose alternative communication methods to trial with patients who needed them, for example using written language or accessible visual analogue scales[27].

There was general agreement amongst participants that a tool should incorporate a range of resources to make information more accessible (e.g., pictures). However, participants recognised that creating a tool and resources to support patients from different clinical populations with individual communication abilities and for a range of specific decisions might be too challenging. Participants suggested the tool could focus on supporting the most frequent groups of patients with communication disorders; it could include a limited range of resources to support the most common patient decisions (e.g., discharge decisions) but also promote the use of personalised images:

> *maybe around certain decisions like discharge planning you could have a bank of resources* (002)

> *when you go on a home visit or to a nursing home…actually a picture of that nursing home, so you've got something to look at that's relevant* (011)

Three participants suggested the tool should also include a reminder to prompt users to refer to speech and language therapy for specialist support. A clinical psychologist (003) reflected that the tool should incorporate certain tasks that non-specialist professionals could attempt independently but also identify when specialist support is required:

> *it's almost like having a pathway there isn't it these are the things that we think people should be able to do with the right sort of knowledge and this is when you need to call in an expert* (003)

Design considerations

Participants suggested specific ways the tool could be designed to make it useable within clinical practice. Several professionals argued the tool needed to be quick and

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[27] A visual analogue scale is a line with two end points used to measure subjective judgements (e.g., degree of satisfaction, perceived ability to do something, pain sensation). A person can indicate a position on the line to represent her/his response to a specific question. For people with communication difficulties, such scales are potentially useful because they can be explained and used without words.

simple to use, potentially portable and easy to find, in order for professionals to incorporate it within their capacity assessments:

> *I think if the tool's brief and compact it's probably more useable compared to a very lengthy one* (007)
>
> *something that you could either…carry round with you easily… or something that you could download easily (004)*
>
> *it would need to be simple to understand...simple to fill in and quick (013)*

4.5 Discussion

This study was designed to explore health and social care professionals' views about and experiences of mental capacity assessment practice within acute hospital and intermediate care settings, in order to meet the second objective for this doctoral study.

Participants in this study suggested the two most important groups of patients requiring capacity assessment in this setting were patients who have a diagnosis of stroke or who have cognitive impairment due to dementia or delirium. Most previous studies have focused on assessments for two different groups: people with learning disabilities and those with mental health conditions (e.g., Ramasubramanian *et al*., 2011; Linn *et al*., 2013). In the current study, most participants indicated that they did not carry out assessments for these groups of patients very often. This difference reflects the professional roles of the majority of participants recruited to this study and the acute hospital and intermediate care context.

Participants identified the main patient decisions implicated in capacity assessments as those relating to discharge arrangements and treatment planning. This is consistent with data reported by previous studies reviewed in chapter three (e.g., Williams *et al*., 2012; Shah *et al*. 2009b). One participant in the current study expressed concern that sometimes professionals may not assess patients' capacity to consent to surgery. Other studies have identified situations in which capacity assessments are not completed but are indicated (e.g., Scope, 2009). Failure to complete a capacity assessment in these situations means that patients may be denied the right to make important decisions about their treatment, care and living arrangements, or instead may be asked to make uninformed decisions, because they are not given support to understand different decision options and their consequences.

Participants in this study identified that different multidisciplinary professionals tend to be involved in capacity assessment. They did not describe the direct involvement of social workers, which is surprising as other studies have emphasised this group's role within capacity assessment in the acute hospital setting (e.g., Emmett *et al.*, 2013). The choice of which professional assesses capacity appears to be related to perceptions of professional hierarchy and responsibility in certain settings. This trend has been reported in earlier studies (e.g., Shah *et al.*, 2009a). Participants suggested that the choice of assessor should depend on which professional has access to information about the decision and the patient and can best support the patient's needs. This view is consistent with guidance provided by the MCA Code of Practice (COP, 2007). Participants identified that joint assessment by professionals with complementary knowledge and skills can be beneficial; however, this practice did not appear to be widespread throughout the healthcare trust, perhaps due to differences in staffing resources across settings.

Participants provided novel data about the methods professionals use to assess mental capacity in acute hospital and intermediate care settings. Their responses suggest that the assessment process includes potentially overlapping phases of information gathering and both formal and informal assessments of patients' decision-making abilities. Professionals appear to use informal approaches to collect information to help them plan more formalised assessments. A number of participants described using a local proforma to structure their assessments and their documentation and finding this helpful. Previous studies have described similar initiatives that have facilitated assessments (e.g., Guyver *et al.*, 2010; Oldreive and Waight, 2011). This finding suggests that professionals identify a need for support with assessment of capacity and are keen to use tools and resources to facilitate specific aspects of their practice. Participants also described local initiatives to support patients with neurological diagnoses to learn information relevant to decision-making as part of their rehabilitation, to enhance their capacity. This approach does not appear to have been reported in previous published studies.

The majority of the participants in this study had received some level of training in the legal requirements of the MCA and some had received further specialist, profession-specific training. However, most participants reported that they find capacity assessment to be challenging. Perhaps unsurprisingly within the context of a busy healthcare environment, professionals identified pressure of time as an important source of challenge.

As described in the literature and case law reviews reported in chapter 3, the assessment of cognitive and communication skills associated with decision-making is complex and can take a long time. The MCA requires assessors to provide support for patients with cognitive and communication difficulties, to enable them to maximise and demonstrate their decision-making capacity. Support can include using specific skills and practical resources to provide information and ask questions and often involves allocating additional time to an assessment, as noted by participant 008 in this study (see p81).

These types of activities are particularly challenging in modern healthcare settings, where clinical service delivery is resource limited. This means that there is an increasing focus on reducing patients' length of admission to hospital and intermediate care settings. As a result, health and social care professionals find that they have to respond promptly to requests for assessments and complete those assessments rapidly. Furthermore, capacity assessments usually need to take place in busy, noisy clinical environments which may not facilitate communication with cognitively and communicatively-impaired patients and are not conducive to calm discussions about important issues such as treatment options or living and care arrangements.

Several participants also expressed concern that they might lack specific knowledge and skills required to carry out capacity assessments in certain situations. This often related to working with particular patient groups, for example those with mental health conditions or those with communication needs. Participants in previous studies have expressed similar concerns, and like certain participants in the present study, have reported preferring to assess capacity jointly or to refer patients to more specialist or senior colleagues for assessment, instead of attempting to assess them themselves (Williams *et al*, 2012).

When participants described aspects of their assessment, their practice appeared to be generally consistent with the requirements of the MCA. However, they spoke at length about their concerns about other professionals' practice and provided examples of practice that would not be consistent with the MCA. Many studies reviewed in chapter three reported similar concerns expressed by professionals and also evidence from case note reviews and ethnographic studies that assessments may not be compliant with legal requirements (e.g., Scope, 2009; Sorinmade *et al*, 2011). The review of case law in chapter three provides additional evidence to support the views expressed by participants in the current study that professionals engaged in mental capacity assessment may lack awareness of their responsibilities under the MCA and that their practice may be inadequate. These findings all indicate that assessment practice is variable and add support to the conclusions of the House of Lords' post-legislative scrutiny of the MCA and its implementation (House of Lords Mental Capacity Act Post-Legislative Scrutiny, 2014) that capacity assessment practice needs to be improved and that professionals need to have access to a range of practical resources and tools to assist them to carry out assessments more easily and rigorously.

Participants provided important data relating to how professionals with and without specialist training in communication disorders assess capacity for patients with these types of difficulties. Very few published studies have investigated how professionals identify and support this patient group during capacity assessments. Patients with impaired communication skills are especially vulnerable during the assessment process because they are likely to require additional, individualised support to understand, use and express information about decisions (Zuscak *et al*., 2016). Professionals without specialist training or experience of working with this patient group may find it difficult to identify patients with communication difficulties or know how to support such difficulties (Emmett *et al*., 2013). Participants in this study confirmed that they find it challenging to work with this patient group and require additional support. They also indicated that patients who require communication support may not always be referred to speech and language therapy, due to a misperception amongst professionals that SLTs may not provide this type of support or may need to prioritise patients with swallowing disorders instead. These are important findings that indicate a need to develop novel capacity assessment training or other practical resources for a broad range of professionals.

Participants appeared receptive to the researcher's proposal to develop a tool to support professionals to assess capacity for patients with communication disorders. Several participants suggested it might take the format of a more generic prompt list or flowchart to guide professionals through a structured assessment for all patients (i.e., not just those with communication difficulties). Four studies reviewed in chapter three describe the implementation of initiatives with similar flowchart or checklist designs (Emmett *et al*., 2013; Guyver *et al*., 2010; Oldreive and Waight, 2011; Ramasubramanian *et al*., 2011). These interventions have been associated with positive outcomes on assessment practice. Participants in this study also made specific suggestions regarding which professional groups might benefit most from using a support tool and which aspects of the assessment process the tool should aim to support.

4.5.1 Limitations

It was not possible to employ a purposive sampling strategy due to the reduced number of participants who were available to attend a focus group. Although the sample included participants with different professional roles from a range of clinical settings and with varying amounts of professional experience, the use of convenience sampling may have introduced selection bias.

The composition of the sample may have influenced the credibility of the study findings in a number of ways. Firstly, each different professional group was represented by a small number of participants. These participants' responses may not have been representative of the opinions and experiences of other members of their professional group. Secondly, social workers were not represented in the sample, as they have been in previous studies. This professional group may have provided unique insight into the process of capacity assessment and should be included in future studies related to this topic. Thirdly, professionals may have volunteered to participate in the study because they have a special interest in mental capacity assessment. Their knowledge about the MCA and their practice may be different to those of other professionals working in the healthcare trust.

Another potential limitation is that data collection took place within a single healthcare trust and the majority of participants worked in two types of clinical setting: care of the elderly wards and within stroke services. This means that it is unclear how transferable the findings are to other settings in England and Wales. The fact that many of the findings are broadly consistent with evidence provided in previous studies, however, suggests commonalities between the experiences and practices described by participants in this study and those observed elsewhere.

It is possible that the primary author's professional role as an SLT working in the healthcare trust may have influenced data collection and analysis. This represents a potential limitation to the confirmability of the study findings. Participants may have perceived an expectation to provide particular responses, despite reassurances that the study was not designed to test their knowledge or identify inadequate practice and that data would be used confidentially. It is interesting that participants were sometimes critical of other professionals' practice but did not tend to criticise their own practice or describe aspects of their own practice that were inconsistent with the MCA.

Furthermore, the primary author may have made assumptions about the meaning of certain participant responses based on contextual knowledge gained from assessing mental capacity in the same healthcare trust. However, peer scrutiny of the thematic framework by an independent researcher with no experience of mental capacity assessment provided confirmatory evidence of the credibility of the analytic process.

4.5.2 Implications for doctoral study

Data from this study indicate that a mental capacity support tool should be designed to prompt and aid professionals to carry out structured assessments that are consistent with the requirements of the MCA and that the tool should support professionals to identify patients with communication difficulties and propose ways to support these needs. Participants thought the tool could usefully include a limited range of practical resources to support patients' needs, for example a range of pictorial resources to support the most common patient groups to understand information relating to the most common decisions. In order to identify useful resources to include in a support tool, guidelines and evidence relating to accessible information were reviewed. These reviews are reported in the next chapter.

Chapter Five: Making Information Accessible to People with Communication Disorders

This chapter provides a review and synthesis of literature relating to methods that can used to make information more accessible to different groups of people with communication disorders during mental capacity assessments. Guidelines and research evidence relating to accessible information were reviewed, in order to identify methods that could inform the design of a mental capacity support tool. These reviews were completed in order to meet the third objective of this doctoral study (see p11).

5.1 Introduction

The evidence reviewed in chapter 3 suggests that currently, professionals do not always provide information that is easy for patients with communication difficulties to understand during mental capacity assessments or sufficient support to help them understand this information better (p51). Participants in the focus group study (chapter 4) suggested that they were not confident about their ability to support patients with communication difficulties to understand information about decisions and would like to do this better (p80). These findings indicated that this research project should aim to support professionals to improve the way they provide information during mental capacity assessments.

The Mental Capacity Act Code of Practice (COP, 2007) provides only very broad guidance to assessors about how they might support people to understand information relating to a particular decision. Chapter 3 of the COP states that:

> *"Information must be tailored to an individual's needs and abilities. It must also be in the easiest and most appropriate form of communication for the person concerned."*
>
> (COP, 2007, p 31)

The COP suggests that assessors should consult people who know the person being assessed, in order to identify optimum communication methods. It recommends that information be explained to people in simple language, using images or objects to demonstrate the meanings of words. Complex information should be broken into small amounts and may need to be repeated to help people understand it. The COP also states that people with communication difficulties should be given time to process and understand information.

Speech and language therapists (SLTs) commonly support people with impaired comprehension by simplifying spoken language and by supplementing it with non-verbal communication methods; these might include written information and the use of images (e.g., drawings, diagrams, photographs), physical objects and actions (including facial expression, gesture, pointing at objects). The use of both verbal and non-verbal communication methods to support an individual to maximise her/his communicative ability has been described as “total communication” (Jones *et al*., 1992; Rautakoski, 2011). The use of different communication modalities to supplement spoken information is thought to increase access to semantic knowledge, which may facilitate understanding (Kerr *et al*., 2010). Combining written and spoken information is also thought to aid information recall (Short *et al*., 2014).

Focus group participants suggested a mental capacity support tool would need to quick and easy to use, for it to be useful (pp83-4). The researcher identified that a potential way to enable professionals to support patients with communication disorders during capacity assessments would be to provide simple accessible information[28] resources that professionals could use to supplement their spoken explanations. Therefore, it was important to investigate evidence-based ways in which to present or adapt information to make it accessible to people with impaired communication.

This chapter provides a review and synthesis of literature relating to methods that can used to make information more accessible to different groups of people with communication disorders. The chapter starts with a review of existing accessible information guidelines before reporting a systematised review[29] and critical appraisal of published evidence relating to the use of accessible information with specific clinical populations. These reviews were completed to generate knowledge about accessible information that would inform the design of an evidence-based mental capacity support tool.

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[28] Accessible information can be defined as information that is presented in such a way that it can be understood and used easily by its target audience (Litherland, 2007).

[29] The review was systematised because it used systematic review approaches but only involved one reviewer (Grant and Booth, 2009).

5.2 Accessible information guideline review

5.2.1 Methods

Initially, the researcher reviewed the NHS written information guidance (Department of Health, 2010b). This guidance, summarised in table 5.1, was written in collaboration with the Royal National Institute for the Blind, the Patient Information Forum and the Plain English Campaign. All three organisations are engaged in the production and promotion of accessible information. It is unclear if NHS patients were involved in the creation of the guidance or if it was produced using expert opinion.

The guidance provides detailed recommendations for adapting the content and design of information materials to increase their accessibility. Content recommendations include ways to adapt language to make it simpler to understand, including changes to lexis, syntax and grammar. It is suggested that pictures and diagrams are added to support the understanding of textual information. The guidance identifies specific type fonts and sizes to use to aid reading and recommends the use of bold font to highlight key information. It also describes ways to reduce the amount of information presented to make documents easier to view. Finally, specific recommendations are made regarding the type of paper that should be used when producing patient information materials.

It should be noted that this NHS guidance is designed to be used with the general patient population and not specifically with patients with communication disorders. This latter group of patients may present with different information needs associated with their specific patterns of communication impairment.

In 2015, NHS England launched the Accessible Information Standard (NHS England, 2015), which aims to provide a common framework for “identifying, recording, flagging, sharing and meeting individuals’ information and communication support needs” (p15). In July 2016, it became a statutory requirement for all health and adult social care providers to comply with the standard. It was not within the scope of the standard to define best practice methods for making information more accessible or for supporting communication with people with disordered communication.

Therefore, the researcher identified more specific accessible information guidance by searching the websites of national charities supporting people with health conditions that may cause communication disorders and impaired decision-making capacity. The participants in the focus group study (chapter 4) indicated that they primarily needed support to provide information to patients with stroke or cognitive difficulties secondary to stroke, dementia or delirium. However, the researcher decided to seek guidance that related to people with a wider range of health conditions to ensure the search was comprehensive. The health conditions selected were brain injury, dementia, stroke and learning disability. The researcher identified these as the main conditions affecting patients requiring mental capacity assessments in hospital and intermediate care settings, based on the findings of the literature review (chapter 3) and his clinical experience as an SLT. Further sources of guidance were identified within records included in the accessible information literature review (section 5.3). The researcher also consulted a colleague who had completed a review of accessible information resources for people with aphasia.

5.2.2 Results

The guidance identified during this search is summarised in table 5.1. Specific guidelines will be referred to using the reference numbers shown in table 5.1. Most of the guidelines (2-7) relate to two clinical populations: people with aphasia post-stroke and people with learning disability. Very limited guidance (8-9) was found for making information accessible to people with dementia or people with brain injury. Most of the guidelines (2-3,5-7,9) were created by experts working in collaboration with people with communication difficulties; these guidelines emphasise the importance of working in partnership with the target audience for the information when creating accessible information, to ensure it meets their needs.

Although they relate to four different clinical populations, all the guidelines provide relatively consistent content and design recommendations; furthermore, these recommendations are often similar to those contained in the generic NHS written information guidance. As shown in table 5.1, the guidelines all suggest similar methods for simplifying language. They recommend using simple, everyday words and many guidelines warn against using childish or patronising language. Different guidelines for people with aphasia (2,3), learning disability (5,6) and dementia (9) recommend that short sentences should be used and that each sentence should only contain one main idea or concept. A common recommendation across guidelines is to use the active voice to simplify sentence syntax.

Some guidelines make specific recommendations regarding sentence length and content. For example, the Easy Read (5) and Easyinfo guidance (6) suggest that sentences should be a maximum of 15 words long to make them easier for people with learning disability to read. In contrast, the Stroke Association guidance (3) recommends that sentences need to contain five words or less for them to be accessible to people with aphasia. The latter guidance also recommends that information producers should calculate the Flesch-Kincaid Grade Level (Kincaid *et al.*, 1975) for new documents; the Grade Level provides a measure of how difficult information is to read. The Stroke Association guidance (3) suggests that documents designed for people with aphasia should have Grade Levels equal to or less than five. The Connect guidelines (2) specify that each sentence should contain no more than three key words[30].

All the guidelines recommend including different kinds of visual image (e.g., drawings, pictures or photographs) to support text. In general, the guidelines all suggest that images should be unambiguous and placed carefully in relation to text, in order to assist recognition and understanding. The guidance (9) for making information accessible to people with dementia warns against including too many images, as this can make documents confusing. The Mencap guidelines (7) suggest people with learning disability prefer photographs to other types of image. Both the Mencap (7) and Easyinfo guidelines (6) state that communication symbols should only be included if people are already familiar with the symbol systems. In addition to pictures, the Headway guidance (8) promotes the use of other non-verbal communication methods (e.g., gesture and pointing) to supplement verbal information when working with people with brain injury who have comprehension difficulties.

All the guidelines recommend that text should be printed in standard fonts of at least size 12 point; most guidelines specify that sans serif fonts (e.g., Arial) of size 14 point or more should be used. The majority of guidelines for people with aphasia or learning disabilities also specify that dark text on a light background should be used to maximise contrast, which should facilitate reading. The guidelines for different populations suggest similar methods for highlighting important information, including

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[30] A key word is a word in a sentence that provides salient information about the sentence's meaning. A key word is also sometimes known as an information carrying word (ICW) (Knowles and Masidlover, 1982).

the use of bold font, headings and text boxes. They also recommend using plenty of white space and bullet points to break up text and limit the amount of information presented on each page.

The guidelines for people with learning disabilities (5-7) specify that good quality, non-shiny paper should be used to make documents easier to handle and to reduce glare and ease reading. Two of these guidelines (6,7) also suggest making information available to people with learning disabilities in alternative formats, for example using audio or video recordings.

Table 5.1: Summary of existing guidelines for making information accessible

Guideline reference	Organisation	Summary of guidance	Evidence base
Target population: General population			
1	NHS	**Written information: general guidance (Department of Health, 2010b)** • Make information relevant to individual patients • Give information about risks and benefits to support people to make decisions • Use plain, everyday (but not childish) language, avoiding jargon and acronyms • Use short sentences (maximum 15-20 words long) • Use present tenses and active voice • Use labelled pictures and diagrams to support text. Do not use "ClipArt". • Use at least 12 point font size (14 point for an older target audience) • Use Frutiger Roman font (if unavailable, use Arial) • Use bold font to emphasise key information (avoid italics, capitals or underlining) • Use bullet or numbered points to break up complex information • Use small blocks of text and plenty of white space • Use dark text on light background for best contrast • Use matte paper of 130-150 gsm weight • Involve information users in information design	Guidelines developed in collaboration with the Patient Information Forum, the Royal National Institute for the Blind and the Plain English Campaign. Unclear if based on expert opinion or if people with communication disorders involved in guideline development.
Target population: People with aphasia			
2	Connect – The Communication Disability Network.	**Including people with communication disability in stroke research and consultation: A guide for researchers and service providers (Connect, 2007).** • Use short sentences containing simple language • Each sentence to contain one key concept • Use no more than three key words per sentence • Place key words in bold • Use unambiguous pictures to illustrate concepts	Collaboration with people with aphasia (methods unclear).

Guideline reference	Organisation	Summary of guidance	Evidence base
		• Use bullet points and spacing to reduce amount of text on page • Use 14 point Arial font	
3	Stroke Association	**Accessible information Guidelines (Stroke Association, 2012).** • Use a short message • Use simple, everyday words • Use short sentences (about five words long) • Put one main idea in a sentence • Use active voice • Aim for a Flesch-Kincaid reading level of 5 or under • Use 14-18 point font sans serif font • Use plenty of white space (recommends specific A5 layout) • Use bold, larger font size for key words • Use bold, coloured headings • Use clear photos or line drawings under text to illustrate single concepts • Use dark text on white background	Literature review completed. Asked people with aphasia in focus groups what helps them to understand information.
4	University of Queensland	**Four key aphasia-friendly principles for adapting written information (described by Brennan *et al*., 2005, p 695).** • Use simple words and short sentences • Use large and standard fonts • Use increased white space • Use relevant pictures	Expert opinion

Guideline reference	Organisation	Summary of guidance	Evidence base
Target population: People with intellectual or learning disability			
5	Department of Health	**Making written information easier to understand for people with intellectual disabilities: guidance for people who commission or produce Easy Read information (Department of Health, 2010c).** • Use simple, consistent language (avoiding jargon) • Explain difficult words • Use short sentences (ideally less than 15 words) • Use bullet points, text boxes, bold text and extra space to break up information • Use at least size 16 point sans serif font • Use large clear pictures or photographs to illustrate each main idea • Ensure text clearly visible against background and reduce glare • Involve people with learning disability in information production	Guidance produced in collaboration with people with intellectual disabilities (methods unclear).
6	Easyinfo	**Information for All team guidance on how to make information easy for people with Learning Disabilities (Rodgers *et al.*, 2004).** • Use consistent, easy words • Use short, simple sentences of 15 words or less • Include one main idea per sentence • Use active voice and literal language • Use large clear pictures to left of words, preferably photographs • Only use symbols if people understand them • Break information into clear chunks, space out information • Use headings to highlight key points • Use at least size 14 sans serif font • Use dark text on heavy, non-shiny, white paper • Offer alternative formats (audio, video)	Researchers interviewed and surveyed people with learning disabilities to produce and evaluate guidance (Rodgers and Namaganda, 2005: included in literature review, section 5.3).

Guideline reference	Organisation	Summary of guidance	Evidence base
		• Consider cultural differences • Collaborate with target audience when making information	
7	Mencap	**Am I making myself clear? (Mencap, 2000).** • Use simple, consistent language in short, simple sentences • Use active voice, personal language • Place drawings, photos, symbols next to text to support understanding • Only use symbols if people understand them • Use a clear font (e.g., Arial) in at least size 12 point • Use bullet points or boxes to highlight key information • Use plenty of white space, break information into chunks • Ensure good contrast between text and background • Use good quality matte paper • Provide alternative formats (audio, video) • Collaborate with target audience when making information	Collaborative project between Mencap and people with learning disabilities (methods unclear).
Target population: People who have had a brain injury			
8	Headway	**Coping with communication problems after brain injury (Headway, 2014).** • Use simple words and sentences but do not patronise • Use non-verbal communication methods to support understanding • Use larger, clear fonts • Use a line guide to support people to look at a full line of text • Use increased context between print and paper (e.g., black text on yellow background)	Expert opinion

Target population: People living with dementia			
9	Dementia Engagement and Empowerment Project (DEEP)	**Writing dementia-friendly information (DEEP, 2013).** • Present one piece of information at a time, in a logical order • Use simple but not patronising language; avoid jargon. • Present one topic per sentence • Do not carry over topics between paragraphs • Contextualise information by including quotes or examples • Use relevant clear pictures, diagrams and photographs • Avoid illustrations, which may be ambiguous or patronising • Do not use too many images, as this can be confusing • Separate text from images for clarity • Use a sans serif font in at least point 12 size (ideally 14); avoid italics. • Use plenty of white space, bullets and bold headings to break up text • Use text boxes to highlight important information • Use colour to separate sections and attract interest	Researchers facilitated four discussion groups with people with dementia across England; they asked participants how to present information so that it was relevant and useful to them (see Litherland, 2007).

Many of the guidelines were created in partnership with people with communication disorders and therefore reflect their views on what makes information more accessible. However, it was important to establish whether the various methods for making information accessible described in the guidelines are actually effective in increasing people's ability to understand information. This was the rationale for undertaking a review of the literature relating to accessible information for people with communication disorders.

5.3 Literature review

5.3.1 Methods

5.3.1.1 Review question and search strategy

The aim of the literature review was to appraise evidence relating to the effectiveness of different methods used to make information accessible to a range of patients. The review question selected was:

> *"How can information be adapted to make it more accessible to people with communication disorders?".*

The review question was deliberately broad. This was so that in addition to identifying evidence relating to effectiveness, the search strategy might also identify sources of evidence describing additional methods for making information accessible (i.e. other than those described in the guideline review in section 5.2.2).

A systematised literature review[31] was carried out. The researcher developed a search strategy in collaboration with local information specialists. The PICOS structure (NHS Centre for Reviews and Dissemination, 2009) was used to identify search terms relating to key concepts: "adults", "communication disorders" and "information". MeSH terms and synonyms for each search term were selected using database thesauri; alternative forms were identified using truncation and wildcards. The results of searches for each term were combined using boolean operators. The search was

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[31] The review was "systematised" because it used systematic review approaches but only involved one reviewer (Grant & Booth, 2009).

limited to English language records. An example of the strategy is shown in appendix 9.

The following electronic databases of published medical and health research were searched: CINAHL, Cochrane Library, PsycINFO (last search November 2016). The Cochrane Library was selected in order to search for systematic reviews of research on accessible information. CINAHL and PsycINFO were selected because these databases specialise in research relating to the behavioural sciences, mental health, nursing and allied health. An initial search of these databases produced a large proportion of records relating to accessible information for people with aphasia post-stroke. In order to identify evidence relating to other populations, three additional searches were carried out of each database using the search terms “brain injury”, “dementia” and “learning disability” as substitutes for “communication disorder”. These clinical populations were identified as the major groups of patients requiring mental capacity assessments in the acute setting (see rationale on p94). These subsequent searches produced a higher number of records relating to these clinical groups. The reference lists of included papers were checked for further sources of evidence and new records referencing the included studies were searched using the Google Scholar citation checking facility.

The researcher also searched for relevant grey literature, in order to broaden the search beyond published research articles. This was achieved by contacting local and national colleagues with a specific interest in accessible information and by searching the websites of national organisations providing support to people with communication disorders (e.g., Stroke Association, Headway, Alzheimer’s Society, Mencap).

Studies were selected for inclusion in the review using criteria developed using the PICOS structure The selection criteria used are shown below in table 5.2.

<table>
<tr><th colspan="3">Review question: How can information be adapted to make it more accessible to people with communication disorders?</th></tr>
<tr><th>Parameter</th><th>Inclusion criteria</th><th>Exclusion criteria</th></tr>
<tr><td>Population</td><td>Adults (people aged 16 years or above) with communication disorders.
All medical conditions</td><td>Children, due to differences in legal framework.
Adults without communication disorders.</td></tr>
<tr><td>Intervention</td><td>Any intervention to adapt information to make it more accessible to people with communication disorders.</td><td>Other interventions not involving accessible information.</td></tr>
<tr><td>Comparator</td><td>Another accessible information intervention / standard information.</td><td>Other types of comparator</td></tr>
<tr><td>Outcome</td><td>Any outcome to people with communication disorders’ experience of adapted information.</td><td>Other outcomes not relating to people with communication disorders’ experience of adapted information.</td></tr>
<tr><td>Study design</td><td>Any experimental or observational designs, literature reviews or discussion papers.</td><td>None</td></tr>
<tr><td>Publication language</td><td>English</td><td>Non-English languages</td></tr>
</table>

Table 5.2: Selection criteria for included studies5.3.1.2 Study selection

The study selection process is reported in a PRISMA flow diagram (Moher *et al*., 2009) below (figure 5.1). The electronic database searches generated 3181 records and a further 50 records were identified from within the grey literature or through reference and citation checking. Following removal of duplicate records, the researcher reviewed 3176 records against the selection criteria (table 5.2) in order to verify their eligibility for inclusion in the review. This review involved a three-stage sifting process, whereby each record was reviewed by title, abstract and finally by the full text report. Studies that did not fully meet the selection criteria were rejected at each stage.

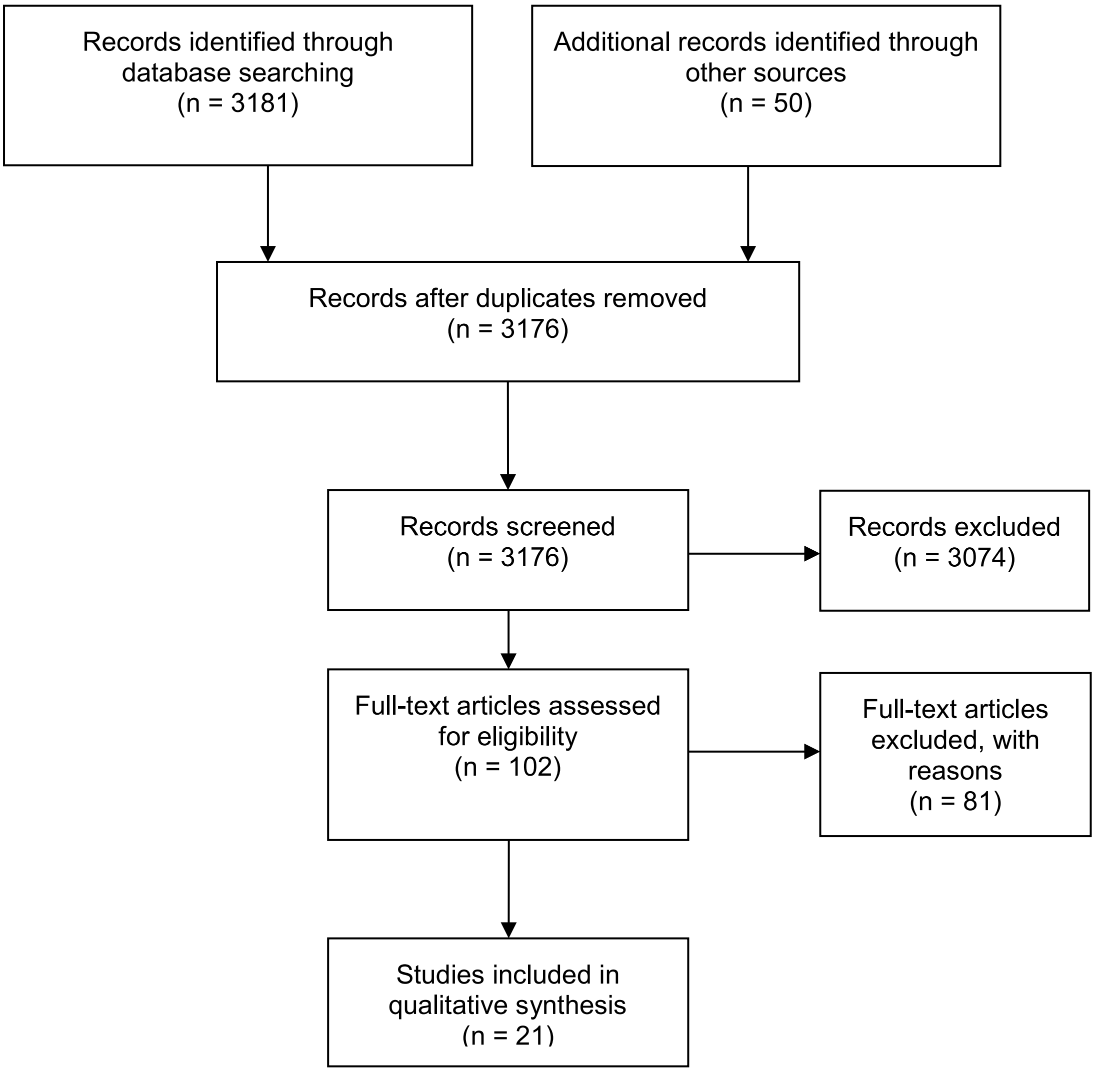

Figure 5.1: PRISMA flow diagram documenting study selection process

5.3.1.3 Data extraction and quality assessment

The researcher extracted data relevant to the review question using an electronic data extraction form. This form was piloted with one record initially, in order to refine its content.

Quality assessment took place in parallel with the data extraction process. A number of critical appraisal tools were used, due to the different designs involved in the included studies. Case study and case series designs were appraised using the Centre for Evidence-Based Management's Critical Appraisal of a Case Study checklist (CEBM, 2014). Qualitative studies were appraised using the Critical Appraisal Skills Programme checklist for qualitative research (CASP, 2013). Survey studies were assessed with Crombie's (2002) checklist for appraising survey studies.

5.3.2 Results

5.3.2.1 Research study characteristics

Twenty-one published studies describing processes of creating or appraising accessible information were selected for inclusion in this review. Table 5.3 summarises the characteristics of each study. The records were published in national and international peer-reviewed journals between 1995 and 2015. The 21 studies differ in terms of their aims, designs, the populations studied and their findings. Common themes emerging from the studies are discussed below.

Table 5.3: Characteristics of included studies

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
1	Brennan *et al*. (2005)	Case series	Adults with mild-to-moderately severe aphasia of different types (n=9)	To investigate individual / combined effects of four "aphasia-friendly" principles on comprehension of written paragraphs.	Participants understood significantly more aphasia-friendly paragraphs than control paragraphs. Simplified vocab/syntax, use of large print, increased white space each associated with significantly increased comprehension; use of pictures or four aphasia-friendly features combined not associated with significantly increased comprehension. Trend for participants with mild-to-moderate aphasia to benefit most from aphasia-friendly features.	Limited generalizability, due to small sample and sample characteristics (did not include people with severe aphasia). Ecological validity unclear due to nature of reading materials used.
2	Codling and Macdonald (2008)	Qualitative: focus groups	Adults with learning disability (n=65)	To review the literature on accessible information. To explore the use of	Participants commonly reported not understanding symbols (e.g., ticks and crosses) used alongside pictures. Participants had different understandings of meanings	Lack of reflexivity. Sample selection may have introduced bias.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
				user-friendly information with people with learning disability.	conveyed by pictures. Too much text or too many pictures increased complexity of information.	
3	Dalemans *et al*. (2009)	Qualitative: interviews using adapted questionnaire	Adults with different severities of aphasia (n=128)	To investigate acceptability of adapted social participation measurement instruments to people with aphasia.	Participants reported use of pictograms and key concepts printed in bold supported their understanding.	Lack of reflexivity. Questionable generalizability, as no information about participant characteristics. Data collection and analysis methods not fully described.
4	Dietz *et al*. (2009)	Case series	Adults with chronic aphasia (different severities, Broca's type) (n=7)	To investigate effect of visuographic supports (photographs) on reading comprehension.	Significantly increased comprehension when photographs used, especially for high context photographs; however, gains in functional reading ability "modest". Majority of participants found use of photographs helpful and made comprehension tasks easier.	Limited generalizability, due to small sample and lack of clarity about sample selection methods. Outcome measurement not blinded.
5	Eames *et al*. (2003)	Qualitative: interviews	Stroke survivors (n=20), including	To investigate the perceptions of stroke	People with aphasia wanted information to contain simpler	Lack of reflexivity.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
			those with aphasia (n=10); carers of stroke survivors (n=14).	survivors and carers of written stroke education materials.	language, more instructional diagrams, figures and pictures. Technical words, small font size, poor information organization, information overload, absence of simple visual aids identified as barriers to understanding.	Limited generalizability, due to relatively small sample; sample may not be representative of population.
6	Hemsley *et al*. (2013)	Qualitative: interviews	Adults with chronic aphasia post-CVA (n=9) and primary progressive aphasia (n=1) and their spouses (n=10)	To collect the views of people and their spouses about adverse events experienced in hospital.	People with aphasia and spouses suggested strategies to improve communication in hospital: giving time to communicate; using simple, clear explanations; using models and pictures as communication aids; involving spouses to support communication.	Lack of reflexivity. Questionable generalizability: only 6/10 people with aphasia were main informants.
7	Hurtado *et al*. (2014)	Uncontrolled, repeated measures	Adults with mild and moderate intellectual disability (n=44)	To investigate effect on comprehension of two Easy Read information formats (text and pictures vs pictures only).	Easy Read formats associated with significant increase in scores on comprehension questionnaire. No significant differences in scores obtained on text and picture and picture-only versions.	Limited generalizability due to small sample. Sample selection unclear. Did not include a standard information format or oral explanation condition, to isolate effects of Easy Read formatting.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
8	Jayes and Palmer (2014)	Case series (mixed methods)	Adults with different severities of aphasia (n=13)	To investigate effect of different information formats on comprehension accuracy. To investigate acceptability of information formats to people with aphasia.	Aphasia-friendly formatting associated with significantly increased comprehension accuracy compared with standard format. Increased support not associated with increased comprehension. People with mild comprehension difficulties benefitted most from aphasia-friendly formats. 9/10 participants preferred an aphasia-friendly format to the standard one. Majority liked use of pictures, reduced text, total communication strategies.	Limited generalizability due to small sample. Outcome measurement not blinded. Single investigator.
9	Jones *et al*. (2007)	Non-randomised controlled, repeated measures	Adults with aphasia (n=11) / adults without brain damage (n=11)	To investigate the effect of familiar content compared with neutral content on spoken paragraph comprehension.	Higher comprehension scores for familiar paragraphs for both groups. No effect of age/education/time post-onset/standardised comprehension and naming scores on scores for people with aphasia.	Limited generalizability due to small sample; sample selection unclear.
10	Kagan &	Quantitative:	Adults with	To investigate	76% participants preferred	Lack of detailed information

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
	Kimmelman (1995)	survey	different severities of aphasia (n=50)	participants' preference between a standard and an aphasia-friendly consent form.	adapted consent form; 8% wished to be offered both versions.	about sample selection / participants / data collection methods.
11	McKelvey *et al*. (2010)	Uncontrolled, repeated measures	Adults with severe aphasia (n=8)	To investigate effects of personal relevance and contextualisation of images on participants' preferences and word-picture matching accuracy.	Participants tended to prefer personally relevant, contextualised photos. Participants significantly more accurate when matching personally relevant, contextualised photos.	Limited generalizability, due to small sample size and inclusion of only people with severe aphasia. Questionable transferability of findings due to decontextualised experimental paradigm.
12	Owens (2006)	Qualitative: focus group and individual interviews	Adults with complex communication needs (n=20) and "significant others" (n=15)	To investigate participants' opinions of different information materials targeting people with communication needs.	Participants recommended: Simple vocabulary; short, simple sentences; precise, direct language; avoidance of acronyms; highlighted key points; use of headings and bullet points; adequate spacing; use of colour contrasts; larger fonts (14-16 point, non-serif); text to be supported with visual information,	Lack of reflexivity. Data collection method flawed. Data analysis methods not fully described. Questionable generalizability due to relatively small sample containing people with

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
					preferably photographs; provision of audio/video alternatives.	mixed diagnoses.
13	Poncelas & Murphy (2007)	Randomised, controlled (matched groups)	Adults with intellectual disabilities (n=34)	To investigate the effect of inclusion of symbols on participants' comprehension of written information.	No significant difference between comprehension scores for information with and without symbols.	Questionable generalizability as sample included participants who were all able to communicate verbally.
14	Rodgers & Namaganda (2005)	Qualitative: evidence review, interviews.	Adults with learning disability, researchers, expert advisors	To create guidance about how to make information easier to understand for people with learning disabilities.	Evidence review found very few RCTs / high quality evidence. More evidence available regarding use of language than use of video. Guidance recommends use of: simple language; chunked information; relevant, interesting, timely information; clear and bold font; pictures / photos / symbols to supplement key words; adequate spacing; video / audio / computerised formats.	Lack of reflexivity. Questionable generalizability as sample selection / participants not clearly described. Data collection methods not fully described.
15	Rose *et al*. (2011a)	Qualitative: interviews	Adults with different severities of aphasia (n=40)	To investigate participants' opinions on which formatting characteristics are	Reported barriers: too much text / information; small font size. Reported facilitators: simple, straight to the point language;	Lack of reflexivity.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
				barriers and facilitators to reading printed education materials (PEMs). To investigate participants' preferences for PEM formats.	short sentences; relevant content; spaced out information; use of distinctive headings; key information highlighted; use of graphics (e.g., black and white line drawings); use of colour. Most participants preferred aphasia-friendly PEMs. Some people with severe aphasia and significant reading difficulties disliked aphasia-friendly PEMs.	
16	Rose *et al*. (2011b)	Case series and survey	Adults with different severities and types of aphasia (n=25) and "significant others" (n=15)	To investigate effect of black and white line drawings and colour photographs on reading comprehension of people with and without aphasia. To investigate participants' opinions on use of illustrations in PEMs.	Inclusion of either drawings or photographs did not significantly affect comprehension, although comprehension scores higher in the photograph condition. Most people with aphasia reported pictures, line drawings and photographs helped understanding, made reading easier and quicker. All participants with aphasia preferred inclusion of illustrations. Most did not have a preference	Questionable generalizability, as participants with severe aphasia / reading impairment could not complete tasks. Ecological validity unclear due to nature of reading materials used. Assessment not blinded.

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
					between drawings or photos.	
17	Rose *et al*. (2012)	Quantitative: survey administered face-to-face	Adults with aphasia (n=40)	To investigate participants' preferences for specific design characteristics of PEMs.	Preferences of majority of participants: • Numbers to be written as figures (people with severe aphasia tended to prefer numbers in writing). • Point 14 or 30 font sizes easiest to read. • Verdana and Arial fonts easier to read. • 1.5 spacing easiest to read. • Inclusion of graphics viewed positively: helpful, appealing. Some found use of graphics childish and embarrassing. Photographs most often reported as helpful graphic / graphic that best depicted target word.	None noted
18	Rose *et al*. (2003)	Matched-pairs, repeated	Adults with different types/severities	To investigate if use of aphasia-friendly principles aids	Participants understood significantly more from aphasia-friendly PEMs.	Questionable generalizability, due to small sample which

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
		measures	of aphasia (n=12)	participants to understand PEMs. To investigate participants' preferences regarding aphasia-friendly and standard materials.	Trend for people with moderate-to-mild aphasia to benefit most. Participants significantly more confident in their knowledge after reading aphasia-friendly PEMs. Participants did not report a clear preference for aphasia-friendly materials, even when they benefitted from them. Some participants did not appreciate use of pictures, found aphasia-friendly PEMs too long.	included only people with mild-to-moderate aphasia.
19	Skorpen *et al.* (2010)	Qualitative interviews (individual and group)	Adults with moderate intellectual disability (n=12) and their mothers (n=2); health care professionals (n=10).	To explore user preferences and experiences in relation to adapted information formats.	All participants preferred the inclusion of photographs compared with drawings, which some perceived to be childish.	Lack of reflexivity. Generalizability unclear as sample selection methods not clearly described. Data collection methods not fully described.
20	Wallace *et al.* (2012)	Uncontrolled, repeated measures	Adults with different types/severities of chronic	To investigate effects of high-context photos vs low-context drawings/no context	Inclusion of any type of visual aid did not significantly affect comprehension accuracy.	Questionable generalizability, as all participants had relatively strong sentence level

Record number	Study authors / publication date	Design / method	Population studied	Study aim	Key findings relating to accessible information	Threats to study quality
			aphasia (n=21)	photos vs no context photos on participants' auditory comprehension.		spoken comprehension. Ecological validity unclear due to mature of experimental tasks.
21	Wilson and Read (2015)	Uncontrolled, repeated measures	People with mild-to-moderate aphasia (n=9)	To investigate effects of aphasia-friendly design formatting on paragraph reading comprehension.	Sans serif fonts and lower case letters associated with significant increases in paragraph comprehension. Inclusion of single image (photograph or ClipArt) in each paragraph had no significant effect on comprehension.	Generalizability unclear due to small sample which included only people with mild-to-moderate aphasia. Ecological validity unclear due to nature of reading materials used. Single image used to support paragraph vs key words (as recommended in guidelines).

5.3.2.2 Populations studied

As shown in table 5.3, 15 of the 21 studies involved participants with different severities and types of aphasia post-stroke. One of these studies (6) also included a participant with a diagnosis of primary progressive aphasia. Four of the 15 studies included family members or carers of people with aphasia within their samples (5,6,12,16). Five studies (2,7,13,14,19) investigated the provision of accessible information to people with learning or intellectual disabilities. The remaining study (12) included a sample of adults with “complex communication needs” secondary to a number of conditions, including cerebral palsy and learning disability. No studies involving participants with dementia or brain injury met the selection criteria.

5.3.2.3 Study aims

Table 5.3 shows that 11 studies (1,4,7-9,11,13,16,18,20-21) aimed to investigate the effects of adaptations to information design and content to participants’ understanding of that information. Most studies examined effects on comprehension of written language but one study (9) investigated effects of information content on participants’ understanding of spoken language. Twelve studies aimed to investigate what content and design features people with communication disorders consider to be facilitators and barriers to understanding information; ten of these studies also explored participants’ preferences for specific information content and design adaptations compared with standard information formats.

5.3.2.4 Study designs

One study (13) involved a randomised, controlled design. The majority of the other studies used non-randomised, uncontrolled designs. Ten studies (1,4,7-9,11,16,18,20-21) employed a case series design, involving either quantitative or mixed methods. Study 9 involved comparison of outcomes between matched groups of participants with and without aphasia. Eight studies (2-3,5-6,12,14-15,19) used a qualitative design, involving interview methods. The remaining two studies (10, 17) involved a quantitative survey design.

5.3.2.5 Study quality

In a number of cases, the researcher was unable to assess methodological quality fully because the study reports lacked detailed information. As shown in table 5.3, the majority of studies included methodological weaknesses which limit the validity, reliability and particularly the generalizability of their findings. Important themes relating to study quality are discussed below, in relation to each type of study design.

Case series and randomised controlled designs (records 1,4,7-9,11,16,18,20-21)

Many of these studies involved small sample sizes and/or included participants with particular communication skill profiles; this means that the generalizability of their findings to a wider clinical population is limited. The ecological validity of the findings of four studies (1,7,16,20) is limited due to the methods used. Major limitations in the experimental design of study 7 means the validity of its findings is questionable. A lack of blinded outcome measurement could mean that the results of three studies (4,8,16) were subject to bias.

Qualitative studies (records 2-3,5-6,12,14,15,19)

None of the records for qualitative studies reported any consideration of the role of the researcher in the research process, which may have introduced bias during the recruitment, data collection and analysis stages. Moreover, four records (3,12,14,19) do not provide adequate information about data collection and data analysis methods; this makes it difficult to assess the validity and reliability of these studies' findings.

Surveys (records 10,17)

The study by Kagan and Kimmelman (10) represents one of the first published studies in which people with aphasia were asked about their preferences regarding adapted information. However, the record lacks any description of the sampling process, participant characteristics or data collection methods. Therefore, it is difficult to judge the validity reliability or generalizability of its findings. The survey by Rose *et al*. (17) was judged to be of good methodological quality and its findings support the conclusions in Kagan and Kimmelman's study (10).

5.3.2.6 Study findings

The findings of the included studies are reported below in terms of two main themes. Firstly, evidence is described that relates to the effects of making changes to information content and design on people's understanding of that information. This is followed by a discussion of evidence relating to people's preferences for different adapted or accessible information formats. Within these themes, evidence is described that refers to the two main clinical groups investigated: people with aphasia and people with learning or intellectual disabilities.

Effects of changes to information content and design on comprehension

People with aphasia

Three small experimental studies (1,8,18) investigated the effects of using "aphasia-friendly" principles to adapt written information to make it more accessible to people with mixed severities and types of aphasia. Each study found that people with aphasia were able to understand significantly more when presented with an aphasia-friendly version of the same information. An interesting common finding across these three studies is that each reported a non-significant trend for people with milder comprehension difficulties to benefit most from the aphasia-friendly information.

In one of these studies (18), printed health education materials (PEMs) were adapted using four aphasia-friendly principles: i) use of simple words and short sentences; ii) use of a large standard font; iii) additional white space; iv) inclusion of relevant pictures to support text. The original and adapted versions were shown to 12 people with aphasia. The adapted versions were associated with significant increases in participants' understanding of health information and in their reported levels of confidence about their knowledge. However, the matched-pairs design means that this effect could have been influenced by selection bias or confounding variables.

In a later study (1) researchers examined the effects of applying the same four aphasia-friendly principles both singularly and in combination to written information. Interestingly, the use of simplified language or a large font or increased white space were each associated with significant increases in understanding for the nine study participants, but the inclusion of pictures was not. Furthermore, in contrast to study 18, the application of all four aphasia-friendly principles in combination was not associated with any statistically significant gain in understanding, although this may be linked to the small sample size (n=9). The authors proposed that the combination of four principles might have caused the information to be excessively long and imposed increased demands on participants' working memory. It is not clear from the study report whether the experimental materials included health-related information, as in Rose *et al*.'s (2003) study.

In a more recent study (8), information relating to participating in a fictional research study in unadapted and two different aphasia-friendly formats was presented to 13 people with aphasia. One aphasia-friendly version used the Connect (2007) content and design principles (see guideline 2, section 5.2). The second format was designed to offer increased support to assist understanding. It incorporated the same Connect aphasia-friendly principles with a staged presentation of the information in small chunks via Microsoft Powerpoint; this presentation was facilitated by the experimenter, who maximised and verified participants' understanding using speech, writing, gesture, mime and drawing, according to a "total communication" approach (Jones *et al*., 1992). Overall, participants in study 8 understood significantly more information when they were presented with either of the two aphasia-friendly versions of the information; however, contrary to the authors' expectations, participants did not understand significantly more information when given the additional support provided by the second aphasia-friendly version.

Six other experimental studies (4,9,11,16,20-21) examined the effects of adapting more specific aspects of information content and design on participants' understanding. In study 9, researchers manipulated the extent to which spoken information contained personally-relevant information to investigate whether familiarity with information content affected participants' ability to understand that information. The authors found that participants with and without aphasia did comprehend significantly more information when it included personally familiar content.

The four other studies provide conflicting findings regarding the effects of different types of visual support on the ability of people with aphasia to understand written and spoken language. Dietz *et al*. (4) compared the reading comprehension abilities of seven people with chronic aphasia when they were given either no additional visual support or photographs that contained either low or high levels of contextual information. The authors observed that participants understood significantly more information contained within narrative passages when the text was supplemented by photographs, and especially when the photographs provided high levels of contextual information. Dietz *et al*. (4) claimed that this finding contradicted the results of an earlier study (1) which indicated that the addition of picture support did not lead to increased understanding; however, the authors did concede that they observed only modest functional gains in reading ability associated with the addition of photographs.

In a small study (11) which only included eight people with severe aphasia, McKelvey *et al*. compared participants' ability to match written words with different types of visual stimuli (photographs and iconic images). The authors found that participants were more accurate on the matching task when the visual stimulus was a photograph that was personally relevant to the participant and contained high levels of contextual information.

Rose *et al*. (16) also investigated the effects of different types of visual support on reading comprehension. They observed that the addition of black and white line drawings did not significantly affect the ability of 25 people with aphasia or 15 people without aphasia to understand paragraphs containing information unrelated to health. In contrast, the authors found that including colour photographs appeared to enable both groups to understand more information in the paragraphs, although this result was not significant.

Wallace *et al*. (20) compared the effects of different types of visual image (photographs and drawings) presented in parallel with spoken narratives on the auditory comprehension abilities of 21 people with chronic aphasia. Like Dietz *et al*. (4), the authors included images with different levels of contextual information. However, like Rose *et al*. (16), Wallace *et al.* (20) found that participants' understanding was not significantly affected by the addition of any of the visual supports they tested.

Wilson and Read (21) investigated whether nine people with mild-to-moderate aphasia understood more information in written paragraphs when they manipulated specific design aspects: font, letter case and use of images. This study used similar methods to Brennan *et al*. (1). The study found that increased comprehension was associated with the use of sans serif fonts (compared with serif fonts) and with lower case letters (compared with upper case). The inclusion of a single photographic or ClipArt image did not significantly improve comprehension; this finding is similar to those reported in earlier studies (1,18). However, as in study 16, Wilson and Read (21) observed a non-significant trend for participants to understand more information in paragraphs containing a colour photograph.

People with learning disabilities / complex communication needs

One study (7) compared the amount of information people with mild and moderate intellectual disability understood when they were shown information in two “Easy Read” formats (see guideline 5, section 5.2). These authors found that providing information in either a text and picture format or a picture only format appeared effective in increasing participants’ understanding. However, important flaws in the study design undermine the validity of this finding.

Two studies (2,13) investigated the effects of incorporating symbols or pictures on the written language comprehension of people with intellectual or learning disabilities. Neither study found convincing evidence for the use of visual supports to increase this population’s access to information.

Study 13 used a randomised, controlled design to compare how much information people with intellectual disability understood when information was presented using simple, clear language and when the same format also incorporated Makaton symbols. The authors found that participants who received the simple, clear language with symbols did not understand significantly more information than the control group who received the information solely in written form. Some participants in the symbols group who reported having seen the symbols before did understand more information when those symbols were included in the materials. The authors concluded that people with intellectual disability need to be familiar with symbols to derive benefit from their use in adapted information materials.

Codling and MacDonald (2) presented published “user-friendly” information materials that had been adapted using symbols and other images to 65 participants in eight focus groups. The authors reported that participants commonly reported not understanding the use of symbols presented in combination with pictures (for example, a tick or a cross next to an image of an item of food). The authors also observed that participants across all focus groups reported different interpretations of the meanings of pictures used in the user-friendly materials.

What features of accessible information formats do people prefer?

People with aphasia

Four studies (8,10,15,18) showed people with aphasia both standard and aphasia-friendly versions of the same information and asked them which they preferred. These studies report mixed results. In study 18, 12 people with aphasia were shown standard and aphasia-friendly versions of health-related printed education materials (PEMs). Overall, participants did not show a clear preference between the standard and adapted versions and, interestingly, did not always prefer the version that had been observed to help them understand the most information. Participants appeared to have mixed feelings about the inclusion of pictures in the aphasia-friendly PEMs; one participant considered them to be disrespectful. Participants also frequently commented that they found the aphasia-friendly versions too long.

The three other studies reported that most respondents preferred aphasia-friendly information. In their survey study, Kagen and Kimmelman (10) found that 76% of their 50 respondents preferred the aphasia-friendly version of a research consent form, whilst 8% stated that they wished to be offered both versions. Jayes and Palmer (8) found that 9/10 participants interviewed stated they preferred the aphasia-friendly version of research information they were shown, especially when it was combined with a staged presentation using total communication methods. The exception was a participant who reported that although he found the adapted version helpful to his understanding, he thought the pictures used were childish and preferred the standard information.

In the third study (15), 40 people with aphasia were shown both standard and aphasia-friendly versions of PEMs providing information on stroke and aphasia. 56.4% of participants preferred the aphasia-friendly stroke PEMs and 87.2% preferred the aphasia-friendly aphasia PEMs. Participants reported that they preferred the adapted materials because they were simple, they could read them easily and quickly and could understand them. Interestingly, participants who reported they did not prefer the standard PEMs tended to have more severe aphasia and reading comprehension difficulties. Three participants commented that the aphasia-friendly information appeared childish and they would not want to read it in public. This is similar finding to those reported in studies 8 and 18.

Content / language characteristics

Eleven studies involved researchers asking people with aphasia which aspects of information content and design they preferred and found helpful to their understanding. Four studies (5,6,8,15) provide evidence that people with aphasia prefer to receive smaller amounts of information and language that is simplified and avoids jargon. Hemsley *et al*. (6) interviewed ten people with chronic aphasia and their spouses about adverse events they had experienced during hospital admissions. In their responses, participants described ways in which communication between patients and professionals could be facilitated in hospital settings. Participants stressed the importance of hospital professionals giving simple, clear explanations and using patients' spouses to support communication in interactions with patients with aphasia.

Eames *et al*. (5) interviewed people with and without aphasia and carers about their experiences of receiving stroke information and asked them to review and rank three examples of current stroke information materials. Seven of ten participants with aphasia reported wanting materials to incorporate simpler language. Similarly, Rose *et al*. (15) interviewed 40 people with aphasia and found that participants reported that simple language that went "…straight to the point without the jargon" (p340) facilitated understanding. Participants reported that information in stroke education materials is easier to read and understand if it is relevant, interesting and also familiar; they reported that too much information in a document can be a barrier to reading the materials. In the remaining study (8), eight of ten participants with aphasia interviewed reported that they preferred the aphasia-friendly information formats because they contained less written information than the standard version.

Design characteristics

Ten studies explored participants' opinions of particular design features of adapted information. The findings are discussed below in relation to these specific design characteristics.

Text font and size

Participants in four studies (5,8,15,17) expressed a preference for large font sizes to be used to present written information. Rose *et al*. (17) presented written paragraphs containing educational information about stroke in different fonts to 40 people with aphasia. The majority of respondents identified size 14 as the optimum font size. In the same study, most participants preferred a sans serif font type (Verdana and Arial were chosen most frequently by participants).

Highlighted key information

All 128 participants in Dalemans *et al*.'s interview study (3) reported that placing key concepts in bold print helped them to understand questionnaire items more. Similarly, an emergent theme in Rose *et al*.'s interview study (15) was that participants found it helpful if important information in texts could be highlighted; participants suggested various methods to achieve this, including using bold print and distinctive headings.

Use of white space

Participants in two studies by Rose *et al*. (15,17) identified that using white space to limit the amount of information presented on each page facilitated reading and understanding and made documents more appealing to look at. In the other study (17), most participants reported that 1.5 line spacing was optimal, because they found that text was too close together or too spread out was difficult to read.

Inclusion of images

Nine studies investigated participants' views about the use of different types of images (for example, line drawings, pictographs, Microsoft ClipArt images, photographs) in adapted information materials (3-5,8,11,15-18). In all studies, the majority of participants favoured the use of images to support their understanding of text. However, as noted previously, a minority of participants in certain studies (11, 15-18) expressed the view that they disliked the use of graphics or found them unhelpful. In Rose *et al*.'s two studies (16-17), people with milder reading difficulties reported that pictures, drawings and photographs were not beneficial to their reading. In three studies (8, 17-18) a minority of participants found the use of graphics childish or embarrassing; there was a trend for participants with more severe reading deficits in study 17 to find the use of graphics offensive.

Evidence from the reviewed studies suggests people with aphasia have mixed views on the types of images that should be used in adapted information. Most participants in Rose *et al*.'s study (16) reported pictures, line drawings and photographs facilitated reading and understanding; they expressed no clear preference between drawings and photos. In a later study (17), Rose *et al*. observed that photographs were the type of graphic that was most often reported to be helpful to reading or that best depicted target words.

Other methods to make information more accessible

Participants in a study by Hemsley *et al.* (7) study suggested that using models and pictures during spoken explanations helps people with aphasia to understand information more easily. Similarly, most participants in study 8 reported preferring written information to be supported by spoken explanations using different total communication strategies (for example, drawing and gesture).

People with intellectual or learning disabilities / complex communication needs

Content / language characteristics

Owens (12) interviewed 20 people with complex communication needs (including people with learning disability) and their relatives, advocates, therapists and other professionals. Owens showed these participants different information materials and asked them to discuss their information preferences in focus groups and individual interviews. The study collected very detailed data about participants' preferences. Most respondents reported preferring information materials to include simple vocabulary and short, simple sentences containing plain language; they specified that acronyms should be avoided and sentences should contain a single concept. Participants also emphasised the need for information to appear relevant to readers to increase its accessibility; they suggested this could be achieved through the inclusion of personal stories or by using a question and answer approach to information provision.

Study 14 described the "Information for All" project, in which researchers collaborated with people with learning disability to produce and evaluate easy information guidance. The detailed guideline (6) is discussed in section 5.2. The guidance suggests that people with learning disability prefer information to be relevant, timely and interesting and, consistent with findings in study 12, should be expressed in simple words and sentences with a single sentence being used to express each concept. Participants in the project recommended that sentences ideally should contain 15 words or less.

Participants preferred consistent vocabulary to be used throughout documents and language to be literal rather than figurative. They reported preferring the use of the active rather than the passive voice and made specific recommendations about the order in which information should be presented: information should be presented in a logical order throughout a document, but familiar information should appear first in each sentence, in order to contextualise the remaining information.

Design characteristics

Respondents in Owens' study (12) reported that highlighting key information and headings (for example in colour) and breaking up information using dot (bullet) points made information easier to read. Participants in the Information for All project (14) recommended using headings to make important information stand out; they also suggested key points could be highlighted using text boxes or bubbles sparingly (so that information did not become crowded with graphics and text).

Participants in study 12 stated a preference for larger font sizes (14-16 point) and non-serif fonts. They recommended using dark fonts against light backgrounds to make text stand out. Similarly, the Information for All project (14) found that people with visual impairment prefer a 14 point font size, as this was easiest to read. Arial font was recommended as the best font to use for everyday documents. In both studies, participants reported that providing space between sentences, lines and sections of text facilitated reading.

Participants in all groups in Owens' study (12) reported that the inclusion of different kinds of visual aid such as photographs, pictures, diagrams, communication symbols and video helped them to understand information. Most participants stated a preference for photographs over other types of visual aid. Participants with complex communication needs recommended that if communication symbols were used to adapt information, they should be used for single key concepts only and look like the concepts they represent. They recognised that symbols needed to be understood by readers, in order for them to increase a document's accessibility. Participants warned that including too many symbols in a document made it difficult to read. This finding was echoed by participants with learning disability in a focus group study (2). These participants frequently reported that adding too many pictures to information materials increased the complexity of the information and therefore did not facilitate its comprehension.

The Information for All project (study 14) reported very similar findings to study 12. The project found that people with learning disability found the inclusion of graphic information helpful, and that most people preferred photographs to be used. Participants in the project emphasised that large, clear images should be used and that a single graphic should be used for a single concept. As in study 12, participants stressed that symbols should only be used if information users are familiar with them. Similarly, in Skorpen *et al.*'s study (19), all participants reported a preference for photographs over drawings, because they perceived the former to be “more realistic” than the latter, which can be “childish” (19, p204). Interestingly, some participants with aphasia made similar comments about illustrations appearing childish or embarrassing (see studies 8,17-18).

Studies 12 and 14 suggest that people with complex communication needs and people with visual impairments prefer information to be printed on heavier, non-glossy paper, to make it easier to handle and also to look at.

Alternative formats

Participants in studies 12 and 14 highlighted the need to ensure that information should be made available in different languages and be culturally appropriate, in order for it to be accessible. Many participants in both studies also promoted the use of audio and video formats as methods for increasing the accessibility of information to people with communication needs.

5.3.2.7 Summary of reviewed literature

This review was designed to identify evidence to answer the question: “How can information be adapted to make it more accessible to people with communication disorders?”. The review identified relatively few studies investigating the use of accessible information with people with communication difficulties. Most studies involved one main clinical population: people with aphasia. The remaining studies examined use of accessible information with people with learning or intellectual disabilities. It should be noted that the studies included in this review were judged to be largely of low to medium quality and the generalizability of their individual findings was often questioned. The review's findings suggest that currently there is only limited, conflicting published evidence to support the use of specific methods for making accessible information for people with aphasia and learning disabilities.

The reviewed evidence indicates that general aphasia-friendly content and design principles such as simplified language and use of clear large fonts, highlighted key information and extra spacing may facilitate reading and comprehension and are appreciated by most people with aphasia. People with milder comprehension difficulties may benefit most from aphasia-friendly information. The evidence relating to the use of different types of image to support people's understanding of text is less convincing. In addition, a minority of people with aphasia may prefer pictures not to be used because they find them disrespectful.

The review identified no strong evidence to suggest that using accessible information supports people with learning disabilities to understand more information. However, evidence does suggest that many people with learning disabilities appreciate the use of the same general content and design adaptations that are used in aphasia-friendly information. This clinical group also appreciate the addition of different visual supports to text-based information, especially photographs.

5.4 Discussion and implications for study

In order to meet the third objective for this doctoral study, this chapter reviewed guidelines and research evidence relating to how information can be made more accessible to people with communication disorders. The purpose of these reviews was to identify acceptable and effective methods to use within a mental capacity support tool. These reviews demonstrated that although a number of guidelines for making information accessible to specific clinical populations exist, there is very limited published evidence to demonstrate their effectiveness and the evidence is of low to medium quality. However, the available evidence does suggest that people with aphasia and learning disability generally approve of the adaptations to information content and design proposed in guidelines for making information accessible to these groups.

Different adaptations appear to be beneficial to some but not to others, indicating the need for adaptations to be made in response to an individual's specific requirements. However, there are some general principles which appear to assist improving accessibility for all. The guidelines propose similar content and design adaptations to make information easier to read and understand. Content adaptations involve the use of simplified language and methods to reduce the amount of information presented. Design adaptations include the use of fonts that are easy to read and visual aids that support understanding of text; they also include the use of different ways to draw the reader's attention to the most important information. These common content and design principles are summarised in figure 5.2.

1. Use simple, everyday words and sentence structures.
2. Use short sentences with one main idea per sentence.
3. Use clear photographs to illustrate important single concepts.
4. Use communication symbols if the reader is familiar with them.
5. Use a sans serif font of at least size 14 point.
6. Highlight important information using bold, headings and text boxes.
7. Break up text using line spacing, bullet points, headings and white space.
8. Involve target audience in creation of adapted information.

Figure 5.2: Identified content and design principles for making information accessible to people with communication disorders

These general principles could be applied when developing accessible information resources for inclusion in a mental capacity support tool. However, it would be important for a support tool to incorporate some mechanism for prompting and enabling professionals to verify that any accessible information they provide during a capacity assessment is helpful to the patient being assessed. As it cannot be assumed that accessible information materials will be effective for every patient in every context, professionals will need to check whether patients receiving such information have understood it sufficiently, in order to make an informed decision. In addition, a support tool will need to provide a means of prompting professionals to check whether patients want to receive information in an accessible format, as not all may appreciate adaptations to content and design. These issues will be discussed further in chapters 6 and 7, which describe the development of a mental capacity support tool.

Chapter Six: Initial Development of a Mental Capacity Support Tool

This chapter describes the initial process of developing a support tool, using the iterative, user-centred design methodology introduced in chapter 2 (p15). The support tool was developed using evidence from the literature and case law reviews and was designed to be responsive to user needs. The support tool development process was completed in order to meet the fourth objective of this doctoral study (see p11).

6.1 Introduction

This chapter describes how the evidence relating to current mental capacity assessment practice and user needs identified during the literature and case law reviews (chapter 3) and focus group study (chapter 4) was integrated with evidence relating to methods for making information more accessible to people with communication disorders (chapter 5), in order to identify a design specification for a mental capacity support tool. The chapter reports two sub-studies in which participatory and co-production methods were used to develop prototype versions of support tool materials, in collaboration with health and social care professionals, service users and topic experts.

Chapter 7 describes subsequent work to refine the toolkit's usability and create additional materials with the support of a team of professional designers. During this process of development, the researcher retitled the support tool as "the Mental Capacity Assessment Support Toolkit" or "MCAST". Throughout chapters 6 and 7, therefore, the support tool is referred to as either "the toolkit", "the Mental Capacity Assessment Support Toolkit (MCAST)" or "the product".

6.2 Research aims for iterative design process (chapters 6 and 7)

1. To determine the optimum composite features of a mental capacity support tool
2. To identify existing resources that include these features to inform the design of an initial prototype for a support tool
3. To refine prototypes of a support tool, using an iterative process of participatory design.

6.3 Methods

6.3.1 Research objectives and methods used in chapters 6 and 7

The research objectives and methods identified to achieve them are summarised in table 6.1.

Table 6.1: Summary of research objectives and methods

Objective		Methods used
1	A design specification will be created.	The optimum composite features of a support tool were determined using data from the literature review (chapter 3) and focus group study (chapter 4).
2	Resources that could be used to support mental capacity assessment will be identified.	a. Mental capacity assessment resources were identified from the findings of the literature review (chapter 3). b. Existing communication screening tools were identified from a new database search and by consulting experts. c. These resources were compared against the design specification to establish if they met user needs. d. Novel prototype materials were developed if existing resources did not appear to meet user needs.
3	Health and social care professionals' opinions about whether the design specification accurately reflects their needs and existing resources meet their needs will be elicited.	Materials for review were sent electronically to participants. A survey method was used to collect participant responses.
4	A prototype product will be developed if the survey data indicate that existing resources do not include the required features.	The researcher created prototype materials in collaboration with a team of design experts.

Objective		Methods used
5	The product's content validity will be assessed.	Experts in mental capacity assessment and communication disorders were invited to review prototype materials. Surveys and interviews were used to collect data. Data were analysed using frequency counts and thematic analysis.
6	The product's face validity will be assessed.	Health and social care professionals were invited to review the required iterations of the prototype materials. A survey was used to collect data. Data were analysed using frequency counts and thematic analysis.
7	The product's usability and acceptability will be assessed.	a. Health and social care professionals were asked to review the required iterations of the prototype materials. A survey was used to collect data. Data were analysed using frequency counts and thematic analysis. b. People with communication disorders and carers from the study's PCPI group[32] were invited to review prototype materials. An interview method was used to collect data. Data were analysed using frequency counts and thematic analysis. c. Health and social care professionals, people with communication disorders and carers were invited to use the prototype product in a workshop. Data were collected using survey and observation methods. Data were analysed using frequency counts and thematic analysis.

6.3.2 Overview of design process

The iterative design process used is summarised in figure 6.1. As noted in chapter 2 (p16), participatory design methods were used, whereby users reviewed design iterations during the product development phase. The process involved five iterative phases of prototype material identification/design and participant review. For clarity, these phases are reported in chapters 6 and 7 as separate but related sub-studies in sections 6.4.1-6.4.2 and 7.1-7.3. Each section describes the specific methods employed in each sub-study and the results obtained. In order to help the reader to understand the way that these sub-studies are linked and contribute to the overall iterative prototype design process, the process flow chart (figure 6.1) is repeated at the start of each sub-study section. The sections of the flow chart that are relevant to the specific sub-study are shaded for clarity.

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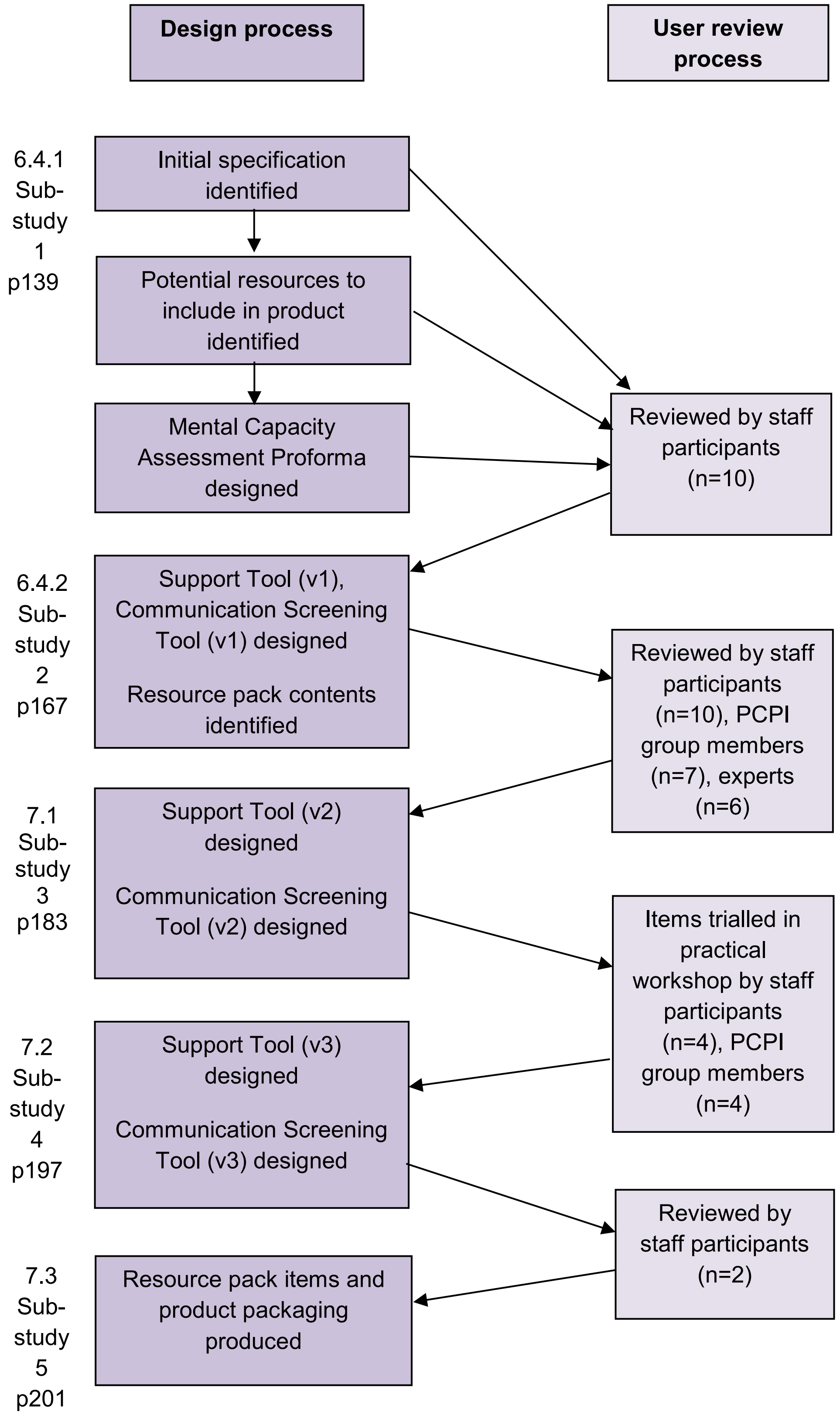
[32] PCPI group refers to the research project's Patient, Carer and Public Involvement advisory group.

Figure 6.1: Iterative design process summary



6.3.3 Ethical approval / governance

Ethical approval for this new study was obtained from the University of Sheffield School of Health and Related Research (ScHARR) Ethics Committee on 02/02/15 (see appendix 10). NHS governance permissions were obtained on 20/04/15 (see appendix 11).

6.3.4 Participants

Professional participant identification and recruitment

The 13 healthcare professionals who participated in the focus group study (chapter 4, p64) were invited to take part in the iterative design study. These individuals were selected because their data were used to identify the initial design specification for the product. Despite encouragement to participate, not all 13 professionals consented to take part in the design study. Therefore, additional professionals were invited to take part in sub-studies 2 to 4, in order to create a larger, purposive sample.

For recruitment to sub-study 1, an email was sent directly to professionals who had participated in the focus group study. For subsequent sub-studies, the email was also sent to the managers contacted previously to publicise the focus group study. Managers were requested to forward the email to their professional groups. The email summarised the study aims and methods and included an electronic participant information sheet as an attachment (appendix 12). The researcher also sent the email to professionals who had shown interest in participating in the focus group study but had been unable to attend a group and had asked to be informed of further participation opportunities. He posted the same information on an electronic newsletter sent to all STHFT employees. Professionals were asked to send an email to the researcher if they wished to participate; this email was considered as evidence of consent to participate in sub-studies 1 to 4.

The researcher communicated with participants regularly via email throughout the data collection process, in order to increase participant retention. The researcher sent professionals clear information about what their participation involved and gentle reminders to return data collection forms when required. Participant withdrawal from sub-studies did occur; several professionals reported this was due to not having enough time to be involved in the study due to increased clinical workload. In order to recruit new participants when dropouts occurred, the researcher re-sent the advertisement email to the managers for the professional groups and re-posted the advertisement on the electronic staff newsletter.

Participant characteristics are presented in table 6.2 for professionals who took part in each sub-study. As table 6.2 shows, different numbers of professionals were recruited to participate in each sub-study. Ideally, the researcher aimed to use a purposive sampling strategy to recruit at least eight participants to each sub-study: this number was selected to ensure representation from all the disciplines identified as target users for the MCAST (see p45) and from different clinical settings. However, this was not possible, due to a low response rate and limited professional availability (e.g., when trying to arrange attendance at the workshop in sub-study 3). Therefore, a convenience sampling strategy was used.

As shown in table 6.2, 14 professionals overall were recruited to take part in the iterative design sub-studies. Participants DEV001-DEV011 had all participated in the focus group study (see p64). Participants DEV012, DEV013 and DEV015 were additional participants recruited to the user-centred design study.

Thirteen of the fourteen participants were female. Participants were recruited from the following professional groups: nurses (n=1), OTs (n=3), physicians (n=3), physiotherapists (n=1), psychiatrists (n=1), psychologists (n=1), SLTs (n=3) and social workers (n=1). Table 6.2 shows the different representation of these groups in each sub-study. Participants worked in diverse clinical locations: acute care of the elderly wards (n=3); acute medical wards (n=2); acute stroke wards (n=4); acute surgical wards (n=1); intermediate care stroke services (n=3); general intermediate care services (n=1); outpatients services (n=2). Participants had varying levels of professional experience, having worked in their professional role for between six and 38 years. They had received either general training[33] about the MCA or more specialist, profession-specific training.

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[33] General training refers to training in the MCA provided by the healthcare trust or the local authority as part of its staff training programme.

Identifier	Professional role	Clinical setting	Study participation			
			Sub-study 1	Sub-study 2	Sub-study 3	Sub-study 4
DEV001	Physiotherapist	Intermediate care	✓	✓		
DEV002	OT	Acute hospital			✓	✓
DEV003	SLT	Intermediate care	✓	✓		
DEV004	Clinical psychologist	Acute hospital and outpatients services	✓	✓	✓	✓
DEV005	SLT	Acute hospital	✓	✓		
DEV006	Consultant psychiatrist	Acute hospital	✓			
DEV007	Consultant geriatrician	Acute hospital surgery	✓	✓		
DEV008	OT	Acute hospital	✓	✓		
DEV009	Consultant neurologist	Acute hospital and outpatient services	✓	✓		
DEV010	Mental health nurse assessor	Acute hospital	✓			
DEV011	SLT	Acute hospital	✓	✓		
DEV012	OT	Intermediate care		✓	✓	
DEV013	SLT	Acute hospital and intermediate care		✓		
DEV015	Social worker	Acute hospital			✓	

Table 6.2: Professional participant characteristics

Expert reviewer identification and recruitment

Six experts were identified and invited to review the product prototype materials. These participants' individual characteristics are shown in table 6.3. The researcher's two academic supervisors, who are academic SLTs, were identified as experts in communication disorders and communication assessment because of their significant clinical and academic experience and because they have designed and published communication screening tools. Four individuals were identified as experts in mental capacity assessment. One of these (DEV014) was selected as an expert because she is the Practice Development Lead for the MCA and Deprivation of Liberty Safeguards (DoLS) for an NHS healthcare trust and has developed training and best practice guidance for capacity assessment. Two individuals (DEV018, DEV019) are academic researchers and have acted as project advisors to the researcher; they were chosen as experts because they have conducted research on topics related to mental capacity assessment in England and Wales. Another expert (DEV020) was selected because he has a national reputation as a barrister and honorary research lecturer who specialises in mental capacity law.

The experts were all known to the researcher at the time of the study. Summary information about the project's aims and methods and an electronic participant information sheet were emailed to the experts (appendix 13). They were asked to send an email to the researcher if they wished to participate. This email was considered as evidence that they consented to take part in the study.

Participant identifier	Gender	Professional role	Nature of expertise
DEV014	Female	MCA/DoLS practice development lead	MCA legal framework and mental capacity assessment practice
DEV016	Female	Academic SLT	Communication disorders and assessment
DEV017	Female	Academic SLT	Communication disorders and assessment
DEV018	Female	Researcher	Mental capacity assessment practice
DEV019	Male	Clinical psychologist / researcher	Mental capacity assessment practice
DEV020	Male	Barrister / honorary research lecturer	Mental capacity law and practice

Table 6.3: Expert reviewer characteristics

Patient, Carer and Public Involvement (PCPI) advisory group reviewers

The research project PCPI advisory group were also asked to review prototype materials. The group included four women and two men with post-stroke aphasia, one woman with communication difficulties secondary to dementia and a male family carer.

6.4 Sub-studies

6.4.1 Sub-study 1: Identification of initial product design specification and potential resources to include in product

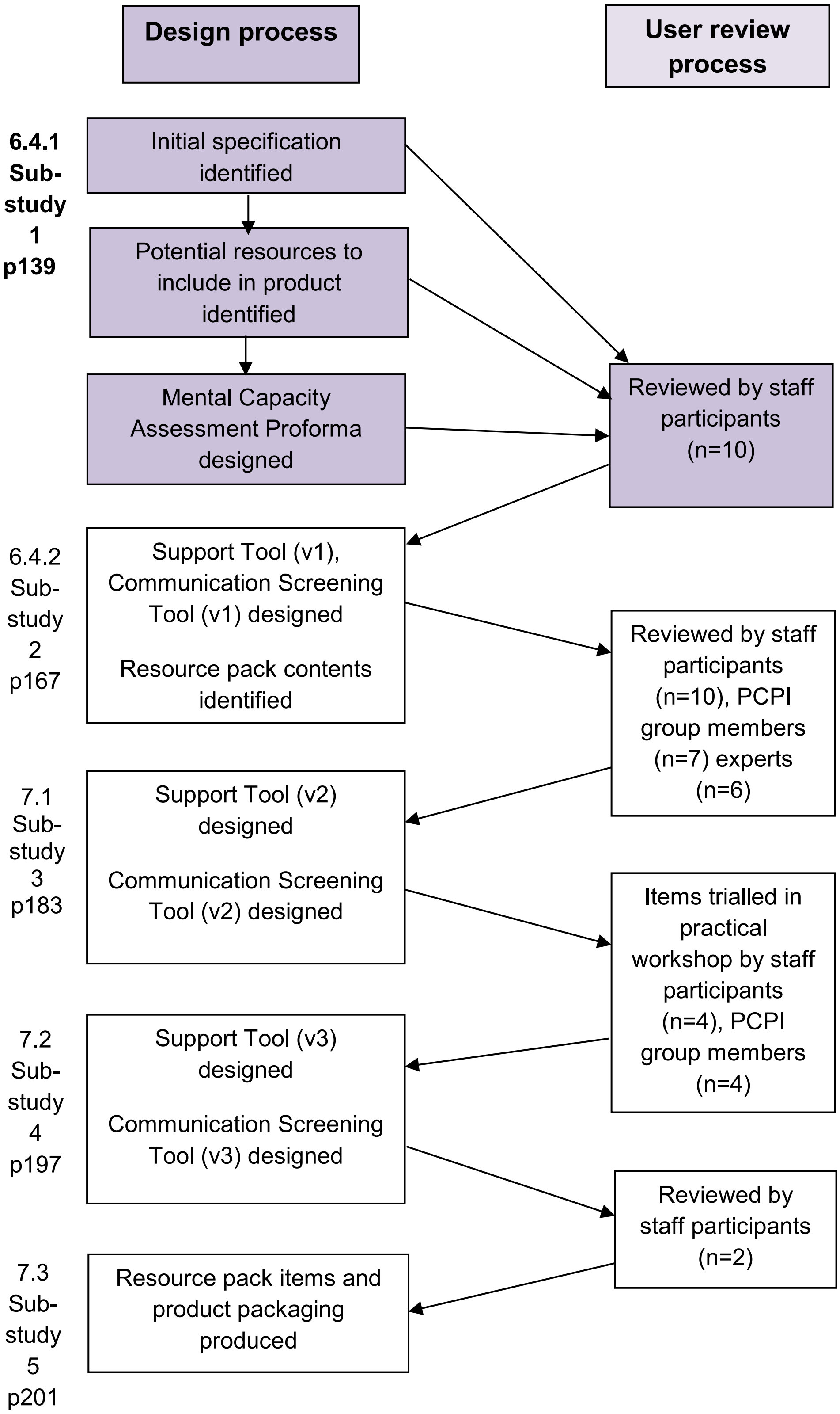

Figure 6.2: Iterative design process summary

6.4.1.1 Identification of design specification

The findings of the literature review relating to mental capacity assessment practice (chapter 3) and the focus group data (chapter 4) were re-examined. The aim of this was to identify factors thought to facilitate or improve capacity assessment and ways that the product might be designed to support identified professional needs. This information would be used to develop an initial specification for the product.

Summary of literature review evidence: factors that may aid practice

The literature review findings (pp31-55) suggested that having sufficient time to assess mental capacity and being able to assess across different points in time is beneficial. Carrying out the assessment in a calm environment and using an assessor who is familiar with the patient are also reported to be facilitative. The involvement of family carers in the assessment process has been identified as potentially beneficial. Assessors report they find it helpful to collect information about patients' abilities and support needs (for example, in relation to communication) before commencing the capacity assessment. The use of an assessment structure (e.g., a flowchart or checklist) and documentation aid is reported to be valued by professionals who assess mental capacity. The literature review findings emphasise the importance of assessors being able to support patients' visual, hearing and communication needs during assessments. This involves being able to support patients with communication disorders to understand information relevant to decisions, by providing information that is accessible.

Summary of findings from focus group study: nature of support required from product

Focus group participants suggested they assessed capacity for two main patient groups: patients with communication disorders secondary to stroke and those with communication disorders associated with dementia and delirium (p66). Professionals also identified that they frequently have to assess patients' capacity to make two main types of decisions: those relating to treatment options and those linked to discharge arrangements (p66). Therefore, in order for it to be useful, a product should be designed primarily for use with these patient populations and for capacity assessments involving these types of decisions.

Focus group participants suggested a number of factors that appear to facilitate capacity assessment. Several of these are consistent with findings from the literature review, for example having enough time and an assessor who knows the patient being assessed (p68). They reported that being able to gather information before the assessment about the patient's individual abilities and needs is helpful (pp70-71). Some participants reported that they found it beneficial to use a proforma to document assessments (p74).

Participants indicated that a support tool would need to be quick and easy to use, portable or easily accessible and should provide a number of components in order for it to be helpful to professionals (p82-84). It should include prompts to help professionals to comply with the requirements of the MCA. Consistent with the results of the literature review, participants reported the product should provide methods to enable professionals to identify patients with communication difficulties and support these patients to understand information during capacity assessments, for example by increasing the accessibility of information provided about decisions. However, participants indicated that they thought professionals should still refer to speech and language therapy for specialist support when assessing capacity for patients with more complex communication needs; they suggested the product should be designed to help them to determine when to do this. They also suggested it would be helpful if the product included a method for flagging patients with communication difficulties to other professionals. In addition, it should provide methods to enable professionals to check whether patients understand information given to them during capacity assessments.

These data were used to create an initial product design specification. The design specification is shown in table 6.4. Because the data indicated that the product should provide a means of structuring and documenting capacity assessments, the researcher decided to base the product around an assessment flowchart and documentation aid. The flowchart should incorporate the specific design features identified as beneficial by the focus group participants and include methods to promote the facilitative factors identified in the literature.

The specification included the need for a communication screening tool. Screening tools are designed to provide a rapid test of specific abilities, in order to identify the presence or absence of a disorder; they are usually used to identify the need for further assessment or referral to a specialist (e.g. in the case of communication, an SLT). The specification also included the provision of methods for making information more accessible. The researcher proposed including accessible information resources that professionals could use to explain important information during capacity assessments.

Product requirement and source of evidence*	**Proposed design feature to meet requirement and source of evidence***
Assessment structure[1,2]	• Create a flowchart for assessment[1] • Include prompts to ensure assessor addresses all aspects of MCA two-stage test[1,2] • Provide prompt to devote extra time for assessments or to carry out assessment over different points in time[1,2] • Provide prompt to assess capacity in a calm environment[1,2] • Provide prompt to ensure assessor is familiar with patient[1,2] • Provide prompt to involve carers in assessment[1]
Documentation aid[1,2]	• Incorporate documentation space within flowchart[4]
Methods to gather information about a patient's abilities and needs pre-assessment[1,2]	• Provide prompts to check sensory needs[2] • Include communication screening tool for use with patients with aphasia and people with dementia/delirium[2] • Include method to check if a patient can recognise images for use in accessible information resources[4]
Methods to support a patient's visual, hearing and communication needs during an assessment[1,2]	• Provide prompts to check if a patient can/wants to use accessible information formats[3] • Create guidance for professionals about using communication strategies (e.g. video training resource) [4] • Create guidance for professionals about how to make information more accessible[3] • Create range of accessible information materials for discharge destination and treatment decisions (simplified language and images)[3] • Create guidance for professionals about producing further images[3] • Provide a prompt for assessors to refer to SLT for specialist communication support when needed[2]
Method to check if a patient can understand information provided during capacity assessment[2]	• Include sample questions in different formats for professionals to use for most common decisions[2,4] • Provide guidance about establishing reliability of responses[4]
Method to flag people with communication difficulties to other professionals[2]	• Create a document for professionals to use to summarise a patient's communication skills that can be attached to the patient's clinical notes[4]

***Sources of evidence:** 1. Mental capacity assessment literature review data (chapter 3); 2. Focus group data (chapter 4); 3. Accessible information guideline/literature review data (chapter 5); 4. Researcher's own proposal.

Table 6.4: Proposed product design specification

6.4.1.2 Identification of existing resources for use within product

The researcher surveyed existing mental capacity assessment and communication screening tools, in order to identify any resources that might meet the product design specification and could be reviewed by professional participants.

Search strategy used to identify mental capacity assessment resources

A search was conducted to answer the following question:

> “What tools exist to enable professionals to assess mental capacity according to the MCA framework?”.

A search strategy was developed, which involved re-examining records from the mental capacity assessment practice literature review (chapter 3, p31), to check the content of records and their reference lists for assessment tools. The primary selection criteria were that resources needed to be compatible with the legal requirements of the MCA and meet over 50% of the design requirements specified in table 6.4. In addition, resources were only selected if they could be used by multidisciplinary professionals, who represent the target users of the product. These criteria are shown in table 6.5

<table>
<tr><th colspan="3">Review question: Which tools exist to enable professionals to assess mental capacity according to the MCA framework?</th></tr>
<tr><th>Parameter</th><th>Inclusion criteria</th><th>Exclusion criteria</th></tr>
<tr><td>Population</td><td>• Adults (people aged 16 years or above) in England and Wales;
• All medical conditions.</td><td>• Children, due to differences in legal framework;
• Adults in other countries with different legislative frameworks.</td></tr>
<tr><td>Intervention</td><td>Mental capacity assessment tools suitable for use in England and Wales;
Tools satisfying at least 50% specified design requirements (table 6.5);
Tools designed to be used by multidisciplinary professionals.</td><td>• Other interventions not involving mental capacity assessment;
• Tools designed for use in other jurisdictions;
• Tools designed for use by specific professionals.</td></tr>
<tr><td>Comparator</td><td>Possibly, comparison of one capacity assessment tool against another.</td><td>Other types of comparator</td></tr>
<tr><td>Outcome</td><td>• Assessment findings: judgement of capacity or incapacity;
• Validity or reliability of assessment tools;</td><td>Other outcomes not relating to mental capacity</td></tr>
<tr><td>Study design</td><td>• Must include description of assessment tool;
• All design types.</td><td>None</td></tr>
<tr><td>Publication language</td><td>English</td><td>Non-English languages</td></tr>
</table>

Table 6.5: Selection criteria for included studies

Tool selection process

The process used to select tools for inclusion in the review is summarised in figure 6.3. The researcher re-examined 111 records that had been selected for full text review during the original literature review (see chapter 3, p34). Each of these records was examined to identify if it referred to, or described, a mental capacity assessment tool. Six records were selected for review through this process. Next, the researcher reviewed the reference lists of the 17 records that had been selected for inclusion in the original review; the purpose of this review was to identify other articles describing mental capacity assessment tools. Two further records describing mental capacity assessment tools were identified from this reference list review. Finally, the researcher reviewed the descriptions of the mental capacity assessment tools included in the five selected records against the selection criteria (table 6.5); the purpose of this was to check whether any of these tools was eligible for inclusion in the review.

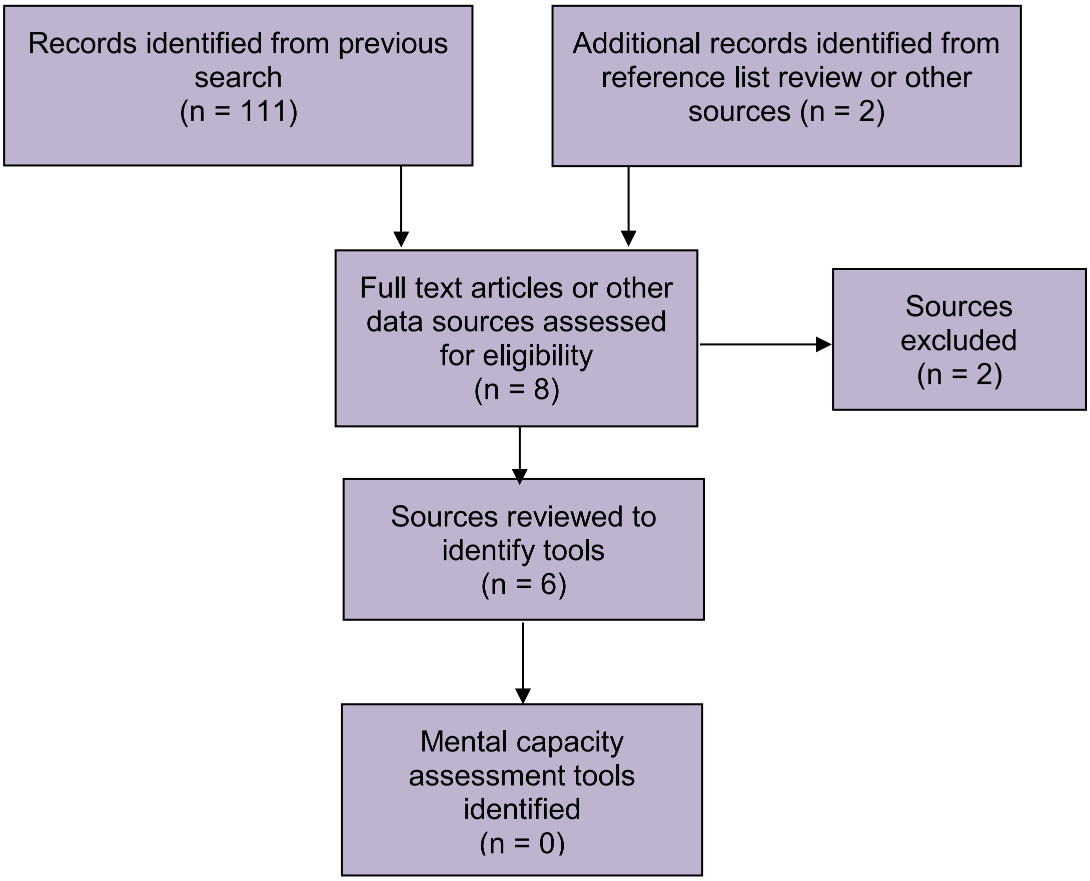

Figure 6.3: PRISMA flow diagram documenting data source selection process

Search results

The search did not identify any mental capacity assessment tools that were compatible with the requirements of the MCA jurisdiction or met at least 50% of the specified design requirements (see table 6.4). The initial literature search (chapter 3) identified two published reviews of mental capacity assessment tools. These records were not included in the initial review because they did not provide descriptions of assessment practice (see search strategy inclusion criteria, p32). The first review by Sturman (2005) included 13 standardized tools for assessing people’s capacity to consent to treatment and research. The second review by Lamont *et al.* (2013) included 19 tools which were designed to assess patients' capacity to consent to treatment. The majority of the tools included in both reviews propose semi-structured interview formats that can be used by assessors to structure capacity assessments and document their observations. The MacArthur Competence Assessment Tool-Treatment (MacCAT-T, Grisso *et al.*, 1997) is identified as the "gold standard" measure by Sturman (2005) and judged to be well tested across different clinical populations by Lamont *et al.* (2013). Unfortunately, none of these tools were designed to be used by professionals working within the MCA legal framework or provide a means for assessors to identify and support people's communication needs to ensure their decision-making capacity is maximised. Therefore, these tools were excluded.

Similarly, the search strategy identified a capacity assessment resource developed in Canada called the Communication Aid to Capacity Evaluation (CACE, Carling-Rowland, 2012). The CACE was specifically designed for assessments involving people who need to make decisions about whether to move from their own homes to a nursing or residential home. The CACE was not designed to be used within the MCA legal framework and its content appears quite specific to the context in which it was developed. Therefore, the researcher concluded that it did not meet the design specification.

Five other records identified from the original literature review (chapter 3) described interventions that had been designed to facilitate mental capacity assessment within the MCA legal framework. These interventions included two structured clinical pathways developed to support capacity assessments for people with learning disabilities (Oldreive and Waight, 2011; Skinner *et al.*, 2011). The three other interventions involved novel documentation resources (Emmett *et al.*, 2013; Guyver *et al.*, 2010; Ramasubramanian *et al.*, 2011). These interventions were excluded from further review, either because they did not include or specify methods for assessing and supporting communication or were designed to be used with a different clinical population.

A set of online resources (Allen and Bryer, 2014) were identified that were specifically designed by SLTs to support professionals to assess mental capacity for people with communication difficulties in England and Wales. The resources include general guidance about capacity assessment and information about supporting the needs of people with communication disorders. There are also practical resources such as documentation proformas and strategies and photographic materials that can be used to make information more accessible to people with comprehension difficulties. However, these resources do not provide a means of structuring a capacity assessment or identifying communication difficulties. Therefore, they were not selected for inclusion in the review by professional participants.

Search strategy used to identify communication screening resources

A literature review was carried out to address the following review question:

> "What screening tools exist to enable professionals without specialist training to identify patients with communication disorders?".

Selection criteria were used to enable the identification of screening tools that could be considered for inclusion in the product and could be sent to professional participants to review. These criteria were developed using information contained in the product design specification (see table 6.4) and are shown in table 6.6.

Review question: What screening tools exist to enable professionals without specialist training to identify patients with communication disorders?		
Parameter	**Inclusion criteria**	**Exclusion criteria**
Population	• People being screened: adults with diagnoses of stroke, delirium or dementia; • People using screening tool: professionals without specialist training in communication disorders.	• Adults with other conditions; • Children.
Intervention	Communication screening tools for use with English speakers	Other interventions not including communication screening
Comparator	Possibly, comparison of one screening method against another.	Other types of comparator
Outcome	• Screening outcomes: presence or absence of communication disorder, nature/severity of disorder, potential management of disorder; • Validity or reliability of screening outcomes; • Acceptability to patient / service user / carer / professional.	Other outcomes not relating to communication disorders
Study design	• Must include description of screening tool; • All design types.	None
Publication language	English	Non-English languages

Table 6.6: Selection criteria for included studies

The following search terms were used: “communication disorders”, “measurement”, “screening” and “screening tests”. Database thesauri, including Medical Subject Heading (MeSH) terms, truncation and wildcards were used to generate synonyms and alternative forms and spellings for each search term. Boolean operators were used to combine the results of free text searches for each term. As the search was designed to be broad, all study designs were included. The search was limited to English language records as it was designed to identify English language screening tools. An example of the strategy is shown in appendix 14.

The following MEDLINE, PsycINFO and Cochrane Library electronic databases were searched in May 2015. In order to broaden the search beyond published research articles, relevant grey literature was identified through searches using Google Scholar and through contact with national experts involved in communication disorders and their assessment.

Study selection

The electronic database search generated 137 records. Removal of duplicate records resulted in a total of 132 records. The study selection process is reported in a PRISMA[34] flow diagram (Moher *et al*., 2009) in figure 6.4. Each record was reviewed first to identify if it described a communication screening tool; if this was the case, the record was the reviewed against the selection criteria (table 6.6) to check its eligibility for inclusion in the review. A three-stage sifting process was used to review each record first by title, then by abstract, and finally by the full text report. The researcher reviewed all records and rejected any studies not meeting all selection criteria at each stage. The researcher consulted his primary academic supervisor in cases when it was unclear whether a record should be included.

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[34] Preferred Reporting Items for Systematic Reviews and Meta-Analyses

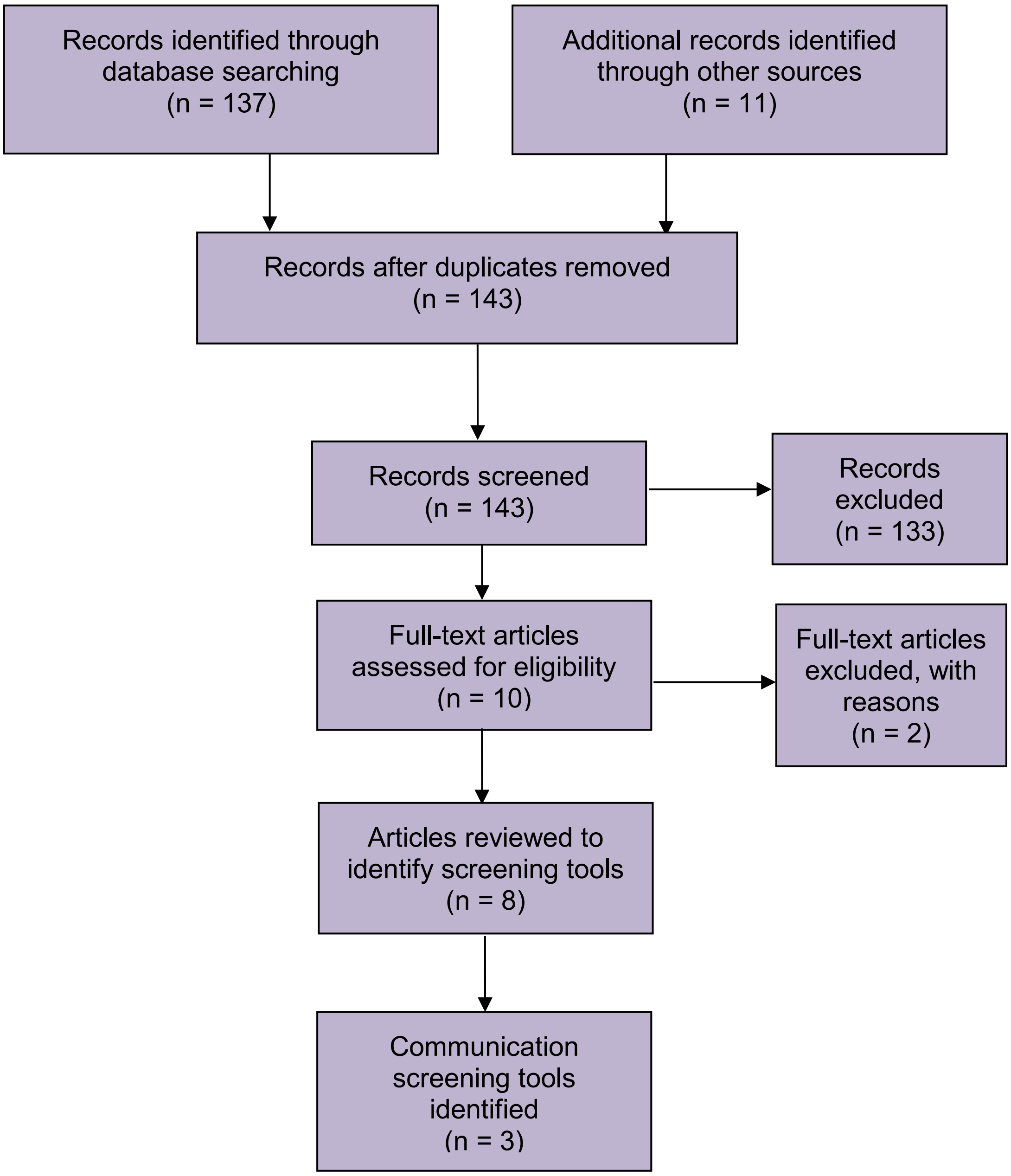

Figure 6.4: PRISMA flow diagram documenting data source selection process

Data extraction / quality assessment

The researcher used an electronic data extraction form to record data from the eight included articles that related to the content of each screening tool and its psychometric properties. The researcher did not assess the quality of identified studies.

Search results

The search strategy did not identify a large number of screening tools for use with people with diagnoses of stroke, delirium or dementia. It identified two tools designed for the purpose of screening stroke survivors for communication disorders: the Frenchay Aphasia Screening Test (FAST, Enderby *et al*., 2012) and the Consent Support Tool (CST, as described in Jayes and Palmer, 2014). The search also identified the Sheffield Screening Test for Acquired Language Disorders (SSTALD, Syder *et al*., 1993), which was designed to be used to screen language disorders secondary to a range of neurological conditions, including stroke and dementia. The review did not identify any communication screening tools specifically designed for non-specialists to use to screen people with diagnoses of dementia or delirium.

The FAST is a standardised, validated and reliable screening tool which has been used widely to identify individuals with disordered language in both clinical and research contexts (e.g., Enderby and Crow, 1996; Blake *et al*., 2002). The FAST contains scored subtests that examine understanding and expression of spoken and written language. It provides a summary score and age-related cut-off scores based on normative data, which enable the user to determine the presence or absence of aphasia and whether referral to an SLT is indicated.

The SSTALD includes scored subtests that examine spoken language comprehension and expression and verbal reasoning. Like the FAST, the SSTALD provides a summary score and normative data, which enable the assessor to identify if the person being assessed has a language disorder requiring referral to speech and language therapy. The development of the SSTALD involved standardization and investigations of the test's validity and reliability, but reports of these studies did not undergo peer-review for the purposes of publication.

The CST was designed to enable research professionals to identify potential research participants with speech and language deficits during the informed consent process. Like the FAST, the CST examines receptive and expressive spoken and written language ability. It does not provide any scoring or normative data. However, this tool suggests compensatory strategies that can be used by researchers to make research study information and the consent process more accessible to people with communication difficulties, based on their individual language profiles (as identified by their performance on the CST). The CST has undergone initial validation (Jayes and Palmer, 2014).

Other tools were identified but excluded from the review because they did not meet the eligibility criteria. For example, the Language Screening Test for the Elderly (LeST, Delia *et al.,* 2012) was excluded because the tool is designed to be used to assess the language skills of Maltese speakers.

It is important to acknowledge that the search strategy failed to identify at least two other communication screening tools that would have met the inclusion criteria: the Language Screening Tool (LAST) (Flamand-Roze *et al*., 2011) and the Mississippi Aphasia Screening Test (MAST) (Nakase-Thompson *et al*., 2005). These tools could have been included in the review by professional participants. Although broad search terms were used in the search strategy in an attempt to identify a large number of tools for review, it appears the strategy was not entirely effective in identifying relevant records. This may be because a relatively small number of electronic databases were selected for searching.

6.4.1.3 Creation of new mental capacity assessment resource

Three communication screening tools but no mental capacity assessment tools were identified for review by participants. Therefore, the researcher designed a novel Mental Capacity Assessment Process Proforma (shown in appendix 15). This four-sided A4 MS Word document was designed specifically to meet the design requirements listed in the design specification (table 6.4, p142). This specification had not yet been reviewed by professionals but the researcher decided to create the proforma and ask professionals to review it at the same time as the specification and the three communication screening tools, for reasons of efficiency.

The proforma was designed primarily to provide a structured approach to capacity assessment and a means for professionals to document their findings. The proforma included prompts and questions designed to assist assessors to consider and document important aspects of the MCA two-stage functional test of decision-making. In addition, the proforma incorporated guidance to help professionals to identify and support patients' communication skills during capacity assessments; it included written instructions to prompt professionals to use different methods to identify patients' communication needs (for example, by using a published screening tool or by liaising with an SLT). The proforma listed total communication strategies (see p92) and low-tech communication aids (e.g., an alphabet chart) that could be used to support patients who have difficulties speaking or understanding spoken or written language. Finally, the proforma described methods that could be used to investigate the four decision-making abilities specified in stage two of the MCA functional test (for example, the ability to weigh or use information).

6.4.1.4 Professional review of product design specification, mental capacity assessment proforma, existing communication screening resources

Overview of methods

Health and social care professionals were invited to review the specification, the three communication screening tools and the Mental Capacity Assessment Proforma using an online survey method. This method was selected because it was identified as an efficient participatory design method (Rekha Devi *et al*., 2012). As noted previously, participants were asked to review all items at the same time for reasons of efficiency. Participant responses were used to verify the content of the design specification and to determine the extent to which the Mental Capacity Assessment Proforma and communication screening tools could be used within the product or whether any novel resources would need to be created to meet user needs.

Materials

Items for review

Participants were sent the following items to review: the toolkit design specification (table 6.4, p144), the novel Mental Capacity Assessment Proforma (appendix 15), the FAST (Enderby *et al*., 2012), the SSTALD (Syder *et al*., 1993) and the CST (as described in Jayes and Palmer, 2014).

Data collection forms

A document (appendix 16) was prepared in order to collect participants' views on the design specification. The document summarised the information presented in table 6.4 and asked questions to verify whether participants felt the individual factors / design features were needed and realistic[35] and whether there was any information contained in the document that participants did not understand. These questions were designed to verify that the design specification accurately reflected information provided by participants in the focus groups.

A separate document was prepared (appendix 17) in order to collect participants' opinions about the Mental Capacity Assessment Process Proforma. This data collection tool was designed to investigate whether the proforma fulfilled the requirements of the design specification or whether further resources would need to be developed. The data collection document asked the following closed and open questions:

- Do you think you understand how to use the proforma? If no, which sections are difficult to understand?
- Does the proforma include any sections that you think are unnecessary? If yes, which ones and why?
- Do you think there is anything missing from the proforma? If yes, please specify what is missing.
- How could the proforma be improved?

Respondents were also invited to add any other comments or suggestions. Another data collection tool (appendix 18) was designed to ask respondents questions about their opinions of the three communication screening tools. This data collection form was designed to enable the identification of resources that might fulfil the design specification and could be used as part of the product, or useful components that could inform the design of new resources. The form asked participants to judge whether they thought each resource would help them during capacity assessments and provided three response categories: i) yes, very much; ii) yes, partially; iii) not at all. If participants judged a resource to be only partially helpful, they were asked to identify the components of the resource that were most helpful. If they did not judge the resource to be at all helpful, they were asked to specify why. Two researchers were asked to review all the data collection tools before data collection commenced, to ensure they were easy to understand and use. Feedback from these professionals was used to identify amendments to the forms.

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[35] The term "realistic" was used in this context to signify feasible or usable.

Data collection

The resources and data collection forms were sent to participants via email. Participants were informed that they could complete the forms electronically or in paper format or discuss their comments with the researcher by telephone, if they preferred not to complete the form.

Data analysis

Individual participant responses to the design specification, Mental Capacity Assessment Proforma and the three communication screening tests were transferred from each data collection form and collated within five separate MS Word documents to enable analysis. Quantitative data were analysed using frequency counts. Qualitative data were analysed using a thematic analysis approach (Braun and Clarke, 2006).

The thematic analysis approach involved several iterative analytical stages. First, the researcher read the entire set of participant responses for each review item several times, to become familiar with the data and to identify initial codes. Coding was carried out manually. Next, the researcher developed a coding framework iteratively, by re-examining the data against the initial codes and by identifying new codes. Following this, the codes were organised into meaningful conceptual groups, in order to identify themes, corresponding to important patterns within participants' responses, and sub-themes. Finally, the researcher reviewed the data again to revise and refine these themes and sub-themes and organise them within a thematic map for each data set.

The thematic analytical approach selected was "theoretical" or deductive (Braun and Clarke, 2006, p12). This means that analysis was driven by the specific questions the researcher asked participants on the data collection forms. The aim of initial coding, therefore, was to identify pre-defined features or themes within the data set. In addition, themes were identified from the surface or explicit meanings of the data, at a purely semantic level, rather than at a deeper, interpretative level (Boyatzis, 1998). For example, qualitative responses to the design specification were coded in terms of data that supported each design feature, data that did not support it, and data that contained suggestions for different features. Responses to the Mental Capacity Assessment Proforma were coded to identify data corresponding to respondents' comments about the resource's ease of use and content. Responses to the communication screening tools were coded to identify data relating to any aspects of each tool participants perceived to be helpful and unhelpful.

6.4.1.5 Results

Participants

Ten participants were recruited. Participant characteristics are presented in table 6.2 (p137). These participants were from a range of professions and acute hospital and intermediate care settings. The following professional groups were represented: nurses (n=1), OTs (n=1), physicians (n=2), physiotherapists (n=1), psychiatrists (n=1), psychologists (n=1), speech and language therapists (n=3). Participant responses to each resource are reported below. All respondents chose to complete the data collection forms electronically.

Participant responses to proposed design specification

Participants' responses to the survey are summarised in table 6.7, which shows the number of respondents who reported that each proposed design feature would be beneficial and any themes arising from respondents' comments. 100% respondents stated that 13 of the 14 proposed design features would be beneficial. Most respondents stated that the proposal to include a prompt to encourage professionals to include family carers in the capacity assessment may not be beneficial, because family carers may influence the assessment process adversely.

Table 6.7: Participant responses to design specification survey

Proposed design feature	Participant responses[36]
Provide prompt to devote extra time for assessments or to carry out assessment over different points in time.	8/8 respondents stated this would be beneficial. Participants commented that in some settings it might not be realistic to assess capacity over different points in time.
Provide prompt to assess capacity in a calm environment.	8/8 respondents stated this would be beneficial. DEV008 commented that it may not always be possible to move a bedbound patient to a quieter area, but that prompts could be included to reduce distractions or to assess at a quieter time.

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[36] Not every participant responded to each section of the data collection tool. Therefore, the total number of responses quoted in the frequency counts varies.

Proposed design feature	Participant responses[36]
Provide prompt to ensure assessor is familiar with patient.	9/9 respondents stated this would be beneficial. Participants identified that it might not always be possible for the assessor to know the patient but prompts could be used to encourage the assessor to gather comprehensive information about the patient.
Provide prompt to involve family carers in assessment.	2/7 respondents stated this would be beneficial, especially for patients with communication difficulties or those with high levels of anxiety. Other participants disagreed because they were concerned that carers may have a conflict of interest or might intervene during the assessment, which could influence the outcome. Participants suggested that it might be more helpful for assessors to involve carers when gathering information before the assessment.
Provide an assessment structure (a flowchart / prompt sheet / checklist).	9/9 respondents stated this would be beneficial. Responses indicated that providing a structure could help assessments to become more consistent and could be particularly beneficial to less experienced capacity assessors.
Provide a documentation aid (e.g., a proforma).	10/10 respondents stated this would be beneficial. Several participants reported finding the current healthcare trust proforma helpful, however, DEV001 stated that sections were “vague and open to interpretation”. It was suggested that it would be helpful to be able to document assessments electronically.
Provide methods to gather information about a patient’s abilities and needs pre-assessment:	9/9 respondents stated these features would be beneficial. Participants suggested that it would be important for professionals to be able to use these features quickly and easily.
Prompts to check sensory needs;	Participants described this feature as “essential”. DEV003 suggested a “quick pre-assessment checklist” would be beneficial.
Communication screening tool for use with patients with aphasia and people with dementia / delirium; Method to check if a patient can recognise images for use in accessible information resources.	Participants suggested specific prompts could be included to encourage assessors to i) check a patient’s first / preferred language; ii) gather information about a patient’s pre-admission communication style from family; iii) involve speech and language therapy early in the assessment process.

Proposed design feature	Participant responses[36]
Provide methods to support a patient's visual, hearing and communication needs during an assessment: Prompts to check if a patient can/wants to use accessible information; Guidance about using communication strategies (e.g. video training resource); Guidance about accessible information principles; Range of accessible information materials (simplified language and images).	10/10 respondents stated that these features would be beneficial. DEV008 commented: "These resources could help professionals to obtain the depth of detail required during a capacity assessment". Participants expressed concerns that incorporating all these features in the tool could cause it to become "unwieldy" (DEV003). They suggested that the guidance and accessible information materials could form part of a separate resource pack. Respondents expressed mixed views about including a training video. Several reported a video would be useful. Others stated it was unnecessary or that it might take professionals too much time to read guidance and watch a video. Instead, respondents suggested a training on working with patients with communication difficulties could be included within the trust MCA training or in an electronic learning package.
Provide methods to check if a patient can understand information provided during capacity assessment.	10/10 respondents stated this would be beneficial. DEV004 commented "I think this is essential and often missed in capacity assessments I suspect".
Provide a method to flag people with communication difficulties to other professionals.	7/7 respondents stated this would be beneficial.
Provide prompt for assessors to refer to SLT for specialist support when needed.	10/10 respondents stated this would be beneficial. DEV004 suggested this "might highlight previously unmet needs" for patients with communication difficulties.
Ensure tool is quick to use	9/9 respondents stated this would be beneficial. Several respondents suggested that different versions of the tool could be developed for different situations (e.g., different versions for patients with and without communication difficulties).
Ensure tool is simple to use	9/9 respondents stated this would be beneficial.
Ensure tool is portable or easily accessible (e.g. online).	8/8 respondents stated this would be beneficial. DEV005 suggested an online version could be developed for use in settings where professionals document assessments electronically, or the tool could be developed as an application for use on a tablet device.

Participant responses to Mental Capacity Assessment Process Proforma

Responses to each of the closed survey questions are presented in table 6.8. Themes arising from respondents' additional comments are summarised below.

Survey question	Response		
	Yes	No	NR*
Do you think you understand how to use the proforma?	9	0	0
Does the proforma include any sections that are unnecessary?	3	6	0
Do you think there is anything missing from the proforma?	4	5	0

Table 6.8: Participant responses to the Mental Capacity Assessment Process Proforma survey

*NR: No response

Important themes arising in the qualitative data related to respondents' opinions about the proforma's layout, content, the approach to capacity assessment it provided and how it might support them to work with patients with communication difficulties.

Layout

Respondents considered the proforma to appear clear and easy to use. Participant DEV008 commented: "(the) layout is clear and user friendly…it may help to create a more standardised approach". However, one participant (DEV007) found the layout of pages 3 and 4 difficult to understand. Two respondents also suggested that they would prefer the proforma to be shorter.

Content

Participants reported that the content of the proforma was comprehensive. DEV010 commented: "I would feel I had all the prompts and information necessary to conduct an in-depth capacity assessment". Respondents identified that the prompts in section 2 to gather information about the decision and the patient's support needs were useful reminders for experienced assessors and would benefit new assessors. It was suggested that tick boxes could be incorporated in this section to ensure assessors provided documented evidence that they had considered these issues. Participants also appreciated the inclusion of different methods to test decision-making abilities.

In response to survey question 2, respondents suggested a number of features that could be helpfully added to the proforma. These included a box for assessors to document reasons for carrying out a capacity assessment and that they had gained consent from the patient to proceed with assessment. Respondents also suggested that a box could be added for assessors to document identified risks associated with certain decision options and that contact details for speech and language therapy should be included on the proforma. Participants requested additional documentation space be included, to enable assessors to record evidence to support their judgements about capacity and any future actions to be taken. Respondents also indicated that it might be beneficial to include examples of completed, documented assessments to model ways to carry out assessments and record evidence.

Approach to capacity assessment

During the functional test of decision-making, the proforma prompts the assessor to conclude that a patient lacks capacity to make the decision as soon as the patient appears unable to either understand, retain or weigh information, or communicate a decision. This means that the assessor may not investigate other decision-making abilities if it becomes apparent early in the assessment that the patient has difficulty with one aspect of decision-making. The proforma was designed this way to reduce the amount of time taken to complete a capacity assessment and is consistent with the requirements of the MCA. Participants had mixed views on this stepped approach to capacity assessment. Some participants appreciated this feature, whilst one participant (DEV003) working in a rehabilitation setting suggested it might be beneficial to consider all four steps or abilities, in order to identify whether a specific ability could be supported further, in order to enhance capacity.

Support for working with patients with communication difficulties

Respondents appreciated this section of the proforma and indicated that its content was comprehensive. They suggested that the communication strategies section could be developed to enable professionals to identify when they need to use specific strategies with a patient. They also suggested that rather than provide a list of communication screening tools, the proforma should have a screening tool attached to it, to increase the likelihood of professionals using one.

Participant responses to communication screening resources

Participants' responses to the survey question are summarised in table 6.9. Themes arising from respondents' additional comments are summarised below.

Resource	Responses to question: Do you think this resource would help you during your capacity assessments?			
	Yes, very much	Yes, partially	Not at all	No response
Consent Support Tool (CST)	5	4	0	1
Frenchay Aphasia Screening Test (FAST)	2	6	1	1
Sheffield Screening Test for Acquired Language Disorders (SSTALD)	3	6	0	1

Table 6.9: Participant responses to communication screening tool survey

Important themes that emerged from the qualitative data relate to the screening tools' apparent ease of use, their content and purpose, and how the tools might be used in the context of capacity assessment.

Ease of use

Participants' perceptions of each tool's ease and speed of use appeared to influence their responses to the survey question "Do you think this resource would help you during capacity assessments?". DEV001 stated that the CST appeared "quick and straightforward". DEV004 appreciated the "simplicity, brevity and user friendliness" of the SSTALD. The fact that the CST could be used without the need to carry extra resources or read interpretation instructions was perceived as beneficial.

In contrast, other participants reported that they found the tools too long. DEV006 stated that he would rather refer to an SLT for specialist support than use any of the tools. DEV004 indicated that some of the communication strategies promoted by the

CST (e.g., using a Powerpoint presentation) might place unrealistic demands on assessors' time.

Other participants were concerned that professionals without specialist training or with less experience of working with people with communication difficulties might find the CST and SSTALD difficult to use.

Content and purpose

Participants welcomed the inclusion of prompts to check patients' sensory needs in the CST and FAST. Respondents appreciated the inclusion of items in all the tools to test patients' understanding of spoken language, because they commented that capacity assessments tend to take place within a spoken conversation format. They also reported that the inclusion of tests of reading ability was useful, as these could be used to identify a communication strategy for use with patients with hearing difficulties. Respondents identified that the SSTALD does not include any written language tests. Some respondents expressed concern that the FAST might be difficult to use with patients with visual or cognitive difficulties, due to its visual materials.

Link to capacity assessment

Several respondents made comments about whether the screening tools would enable assessors to support patients better during capacity assessments. DEV003 appreciated that the CST "makes explicit" the impact of a person's language profile on her/his ability to provide informed consent. DEV005 identified that use of the FAST would not enable assessors to know how to make information more accessible during capacity assessments. Other respondents expressed concerns that some subtests of the SSTALD (for example, those assessing metalinguistic skills) might not provide information that would be relevant or useful to capacity assessors.

Summary and implications of results of sub-study 1

Participants' responses to the surveys provided important information about how different product content and design features could be modified or added, in order to increase the product's face validity and usability. Responses to the design specification indicated general consensus amongst professionals about its contents. The researcher used the data relating to the Mental Capacity Assessment Proforma and the three communication screening tools to identify potential content and design solutions for each of the requested modifications and additions. These changes and proposed solutions are listed in table 6.10.

Table 6.10: Suggested content and design modifications and proposed solutions

Aspect of assessment process	Modifications or additions suggested by participants	Proposed solution
Assessment environment	Prompt professionals to reduce distractions / choose a quiet time to assess.	Add written prompts to assessment flowchart.
Ensuring assessor is familiar with patient	Prompt the assessor to gather information about the patient before the assessment. Use tick box format to ensure assessor addresses prompts.	Add written prompts relating to patient support needs (cognitive, communicative, mental health) to assessment flowchart with tick boxes.
Involvement of family carers	Prompt to gather information from family carers rather than involve directly in assessment.	Add written prompt to assessment flowchart.
Identification of communication needs	Add SLT contact details	This information is trust specific and could change over time, therefore not added.
	Include communication screening tool as part of product. Tool should: - Include spoken comprehension and reading tests. - be useable with patients with visual impairments. - be useable without extra resources/ an instruction manual.	Create new screening tool including these content and design requirements, as existing resources do not meet all user requirements.

Aspect of assessment process	Modifications or additions suggested by participants	Proposed solution
Support for communication needs	Provide guidance about realistic communication strategies to use to meet patients' individual needs.	Incorporate guidance about communication strategies within communication screening tool.
	Create separate electronic training resource or provide training on communication strategies as part of trust training programme.	Ensure communication resources can be used without the need for additional training. Consider developing training resources in future if indicated.
Documentation	Provide more space to write.	Create separate documentation form within product to enable this information to be recorded.
	Add space to record why capacity assessment initiated.	
	Add space to document consent obtained to assess.	
	Add space to record risks linked to decision options.	
Format	Ensure all documents are as short as possible.	Create a **toolkit** comprising **three main components**, to reduce size of individual documents: i) a **generic tool** to support capacity assessment with a separate proforma to facilitate documentation; ii) a **communication screening tool** which identifies communication strategies to use with patients; iii) a **pack of communication resources** to support assessments for people with communication difficulties secondary to stroke / delirium / dementia.
	Create one version of product for use with patients with and one for use with patients without communication needs.	
	Create an electronic version (e.g. for use on a tablet to enable data to be uploaded to electronic patient records).	Current healthcare trust information technology and governance systems would not support an electronic version, therefore paper version retained.

The researcher used the proposed content and design solutions listed in table 6.10 to redesign the mental capacity assessment proforma and to create a communication screening tool and resource pack. This process is described in sub-study 2.

6.4.2 Sub-study 2: Creation of Mental Capacity Assessment Support Toolkit (MCAST) materials (v1) and review by professionals, PCPI group and experts

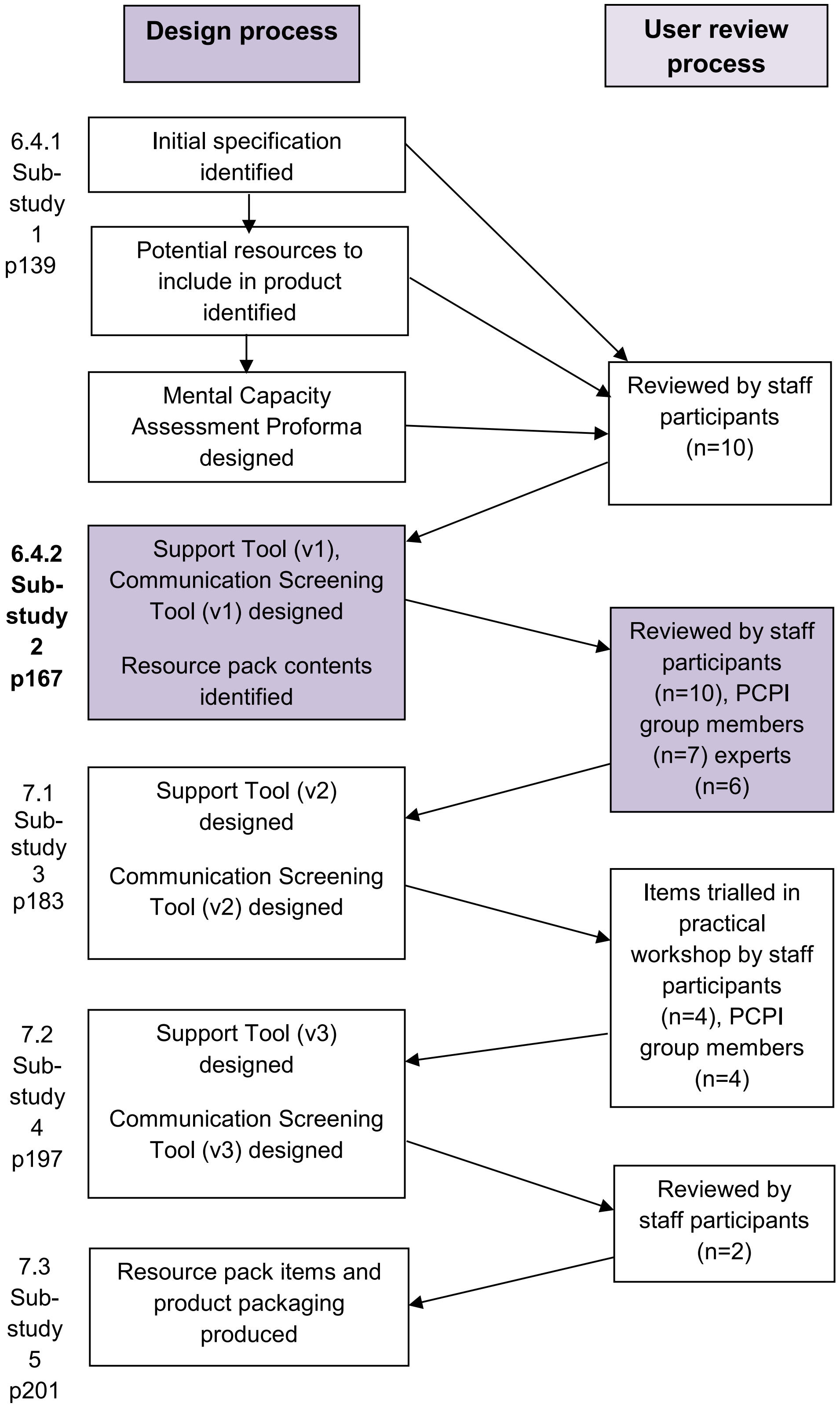

Figure 6.5: Iterative design process summary

6.4.2.1 Overview of methods

The data collected in sub-study 1 indicated that the product should include different components or tools to support different aspects of capacity assessment (see table 6.10, pp164-5). Therefore, it was decided that the product could be described as a toolkit and would be named the Mental Capacity Assessment Support Toolkit (MCAST). In sub-study 2, the prototypes for individual components of the toolkit were developed. Different groups of participants were invited to review these prototype materials, in order to identify potential usability challenges and to maximise their face and content validity. Professional participants were asked to respond to an electronic survey about the materials, whilst experts in communication disorders and mental capacity were invited to review the materials using survey and interview methods. Members of the study's Patient, Carer and Public Involvement (PCPI) advisory group were invited to review the materials during a face-to-face meeting, in order to investigate the prototype's acceptability.

6.4.2.2 Creation of prototype materials

Support Tool (v1)

The researcher modified the previous Mental Capacity Assessment Proforma (appendix 15) using the content and design solutions proposed in table 6.10 (pp165-5). The revised proforma, entitled the Support Tool, is shown in appendix 19. Unlike the original four-page proforma, the Support Tool (v1) was a two-sided A4 MS Word document. It was designed to provide the same structured approach to capacity assessment but contained additional prompts to encourage professionals to gather more comprehensive information about a patient's abilities and support needs prior to commencing the assessment. The Support Tool also contained prompts to remind assessors to take various actions to support the patient's participation in the capacity assessment (e.g., inviting various professionals to provide specialist support to the patient during the assessment). To reduce the length of the Support Tool, the amount of documentation space was reduced. A separate Evidence Form (shown in appendix 20) was designed to enable professionals to record comprehensive information about the capacity assessment.

Communication Screening Tool (v1)

The researcher designed a novel Communication Screening Tool as participants' responses in sub-study 1 suggested that no existing resources met their requirements. The Communication Screening Tool (v1) (appendix 21) was specifically created to meet the design requirements identified by professional participants in sub-study 1 (see table 6.10, pp164-5).

This tool was designed to enable multidisciplinary professionals to identify a patient's communication deficits and potential strategies that they could use to support the patient to overcome these deficits during the capacity assessment. In order to assist professionals to identify communication deficits, the tool included methods to test the specific communicative abilities that patients would need to use during a capacity assessment, to demonstrate intact decision-making ability: the ability to provide a reliable "yes/no" response, the ability to understand spoken language and the ability to use spoken language to express opinions and choices.

The ability to provide a reliable "yes/no" response has been described as fundamental to the demonstration of decision-making capacity (Ferguson *et al.*, 2010). Patients with language and cognitive deficits may not be able to communicate "yes" or "no" reliably due to perseverative responding[37]. However, perseveration may not be obvious to non-specialist professionals, who may erroneously interpret a patient's perseverative responses as representing her/his intended meaning. The ability to understand and express spoken language can also be considered fundamental, as capacity assessments tend to be conducted using a conversational format, in which assessors provide information about decisions using spoken language and test decision-making abilities by asking spoken questions (Emmett *et al.*, 2013).

Specific tasks were developed to enable professionals to test each of these abilities. These tasks were based on similar tasks used in the CST (as described in Jayes and Palmer, 2014) and those used in informal screening tools by SLTs. The "yes/no" response reliability sub-test required the assessor to ask the patient questions that contained either accurate or false information, in order to prompt them to respond either "yes" or "no". Because the assessor should already know the correct response to

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[37] Perseverative responding when speaking refers to the uncontrolled / undesired repetition of a particular verbal response (Stark, 2011). This could mean that a person might say "yes" when s/he meant to say "no". The person may or may not be aware that their response is perseverative.

each question, any unreliable responses should be easily identified. This sub-test is shown in figure 6.6.

Ask the following questions. If the person is unable to say “yes” and “no”, write down “yes” and “no” clearly in large print on a piece of paper and ask the person to point to the word they want to use to respond to each question.	**✓ / X**
1. Is your surname (use their correct name)?	
2. Is your first name (use an incorrect name)?	
3. Do you live in London?	
4. Is your first name (use their correct name)?	
5. Do you live in (use the correct place)?	
6. Is this your house? (point around the room)?	
If person scores less than 6/6, STOP this screen and refer to Speech and Language Therapy	

Figure 6.6: Yes/No response reliability subtest from Communication Screening Tool (v1)

The spoken language comprehension subtest required the assessor to give spoken instructions to the patient which required a behavioural response (e.g., “touch your left knee”). These instructions could be manipulated to involve different levels of linguistic complexity, by changing the number of information carrying words (ICWs)[38] they contained. This sub-test is shown in figure 6.7.

<table>
<tr><th colspan="2">Say the following to the person and only mark as correct (✓) if they get the task completely right. Do not look at the objects as you say the words.</th><th>✓ / X</th></tr>
<tr><td colspan="2">1. Show me the door, window and the light</td><td></td></tr>
<tr><td colspan="2">2. Touch your left knee</td><td></td></tr>
<tr><td colspan="2">3. Shake your head and touch your chin</td><td></td></tr>
<tr><td>If person did not score 3/3, STOP this screen and refer to SLT for support with capacity assessment.</td><td colspan="2">If person scored 3/3, say the following to the person and only mark as correct if they get the task completely right.</td></tr>
<tr><td colspan="2">Touch each shoulder twice with two fingers whilst keeping your eyes closed</td><td></td></tr>
<tr><td>If person able to do this, talk to the person using lay language during the capacity assessment</td><td colspan="2">If person not able to do this, use simple language and other supportive strategies – see below</td></tr>
</table>

Figure 6.7: Spoken language comprehension sub-test from Communication Screening Tool (v1)

The spoken language expression subtest required the assessor to engage in a short conversation with the patient about a familiar topic (e.g., their family or hobbies). The subtest then guided the assessor to consider whether the patient’s speech and language appeared normal or instead showed broad patterns of impairment that should

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[38] An information carrying word (ICW) is any word in the instruction that the patient would need to understood in order to complete the instruction accurately (Knowles and Masidlover, 1982).

be easily observable to a non-specialist (e.g., “the person’s speech is slurred or sounds different but you can understand most of the words”).

Based on participants’ responses to the communication screening tool survey in sub-study 1, the researcher designed these tasks to be simple and quick to administer, without the need for additional materials or training. For example, each task or sub-test contained a low number of test items; the researcher judged this number on the basis of his clinical experience as an SLT and by reviewing the other screening tools identified in sub-study 1. In addition, tasks were designed to require professionals to use only materials easily found within the immediate environment; for example, in the spoken language comprehension sub-test, the assessor was instructed to ask the patient to indicate objects such as their own body parts or those found in any room (e.g., the ceiling, a light).

Professional participants in the focus group study (chapter 4, p83) who were not SLTs reported that they wanted to be able to distinguish instances when they could support patients with milder communication difficulties during capacity assessments from instances when they should refer patients with more moderate or severe difficulties to speech and language therapy for specialist support. Therefore, the researcher designed the screening tool sub-tests to provide this information to assessors.

The researcher decided that if a patient was unable to complete all six questions designed to test “yes/no” reliability with 100% accuracy, the assessor should be instructed to refer the patient to speech and language therapy, as specialist support would be required to attempt to establish a reliable system of signalling “yes” and “no” (e.g., using gesture or by pointing to written words or symbols) (see figure 6.6). For the spoken language comprehension sub-test, the researcher decided that any patient unable to demonstrate understanding of spoken instructions containing three ICWs should be referred to speech and language therapy for specialist support (see figure 6.7).

The researcher made this decision based on very limited published evidence relating to the relationship between levels of spoken understanding and use of compensatory communication strategies. It has been proposed that people require this level of understanding to benefit from supportive communication strategies that use symbolic representations of concepts (e.g., pictorial images) (Murphy and Cameron, 2008; Oldreive and Waight, 2013). Furthermore, studies indicate that people with this level of understanding and greater understanding benefit most from accessible information approaches (Brennan *et al*., 2005; Rose *et al*., 2003; Jayes and Palmer, 2014). The researcher also chose this threshold level of understanding because it could be argued that people who can follow spoken commands with three ICWs are likely to be able to understand simple sentences that include a basic subject-verb-object structure (one of the compensatory strategies proposed by the Screening Tool).

The researcher did not incorporate any specific instructions within the screening tool about whether assessors should refer a patient to an SLT based on her/his performance on the spoken language expression sub-test. Instead, the subtest provided guidance that professionals should refer to an SLT if they felt they needed more support.

The Communication Screening Tool also included methods for professionals to use to test whether patients were able to use simple communication strategies to compensate for any identified communication deficits. For example, if a patient could understand instructions containing three ICWs on the spoken language comprehension sub-test but not the more complex instruction, the Screening Tool indicated that the patient would need support to understand information during the capacity assessment. The tool guided the assessor to support the patient to understand by using simplified language during the capacity assessment (see figure 6.7).

The assessor was also guided to use other screening tool sub-tests to investigate whether s/he could support the patient's comprehension deficit using written language or photographic images representing important information relating to decision options. The researcher selected photographic images because the review of accessible information guidelines and research evidence (chapter 5, pp126-7) suggested that some people with communication disorders find this type of image easier to recognise and more appealing than graphic images such as illustrations and symbols. Separate sub-tests could be used to establish a patient's ability to read single words or sentences or to understand the meaning of photographic images (see figure 6.8). Similarly, the spoken language expression subtest provided guidance for professionals about ways they could support a patient to compensate for any identified expressive speech or language deficits during the capacity assessment (e.g., by slowing their rate of speech in the case of slurred speech).

Do the following:	
Show the person the three photos below, one at a time. Ask the person to show you the same thing in the room. Do not say the name of the object shown in the photo or look at the objects in the room. Note how many objects the person is able to find.	**/3**
If person did not score 3/3, you cannot reply on using photos to help them understand information during the capacity assessment. Just speak using simple language and write down single words or simple sentences, depending on the results of the reading check.	**If person did score 3/3, you can use clear photos to explain key pieces of information during the assessment to help the person to understand you as you speak. See Resource pack for sample photos.**

Figure 6.8: Photograph comprehension sub-test from Communication Screening Tool (v1)

Finally, the Communication Screening Tool contained a chart for professionals to use, on completion of the sub-tests, in order to record a summary of the patient's communication support needs. This summary could be used to flag the patient's communication needs to other professionals, as suggested by participants in sub-study 1 (table 6.10, pp164-5). This chart is shown in figure 6.9.

Tick all the boxes that apply. Write in other effective strategies suggested by family / friends / carers / Speech and Language Therapist etc..			
Strategies to help person to understand you better	**✓ / X**	**Strategies to help person to express themselves better**	**✓ / X**
Use simple language: use everyday words in short, simple sentences.	✓	Ask closed questions requiring one word or yes/no answers	
Speak slowly and clearly. Repeat important information.	✓	Write useful words down for person to point to	
Check regularly that the person understands what you are saying and recap if they do not	✓	Offer photos corresponding to important concepts for person to point to	
Write down single words corresponding to important concepts and encourage person to read them		Encourage the person to write down their answers	
Write down short, simple sentences and encourage person to read them		Encourage person to use a slow rate of speech, say one word at a time and break longer words into chunks	
Use clear images representing important concepts and encourage person to look at them		Encourage the person to mouth words slowly, one at a time	
		Ask closed questions requiring one word or yes/no answers	
See Resource Pack for further information about strategies and practical examples. If you feel that you need more support, refer to Speech and Language Therapy			

Figure 6.9: Patient communication support needs summary chart from Communication Screening Tool (v1)

6.4.2.3 Participant review

Materials

Resources for review

Professional participants, topic experts and members of the PCPI group were invited to review the Mental Capacity Assessment Support Tool (v1) and the Communication Screening Tool (v1) documents. Professional participants were also asked to review suggestions for categories or topics for items to include in a resource pack of accessible information materials (photographs and simplified language materials) to form part of the toolkit. These topics are listed in table 6.15 (page 180) and relate to information that professionals might discuss with patients when assessing their capacity to make decisions about treatment options and discharge destination. Topics were identified by the researcher after examining the themes arising from the literature review (chapter 3) and focus group study (chapter 4) and based on his clinical experience of mental capacity assessment involving these types of decisions.

Data collection forms

A document was prepared (appendix 22) to collect participants' opinions about the Mental Capacity Assessment Support Tool (v1) and the Communication Screening Tool (v1). This data collection form asked the same closed and open questions as the form used to collect data about the initial Mental Capacity Assessment Proforma (see p116). The form also invited respondents to add any other comments or suggestions.

Another data collection tool (appendix 23) was designed to ask respondents for their opinions about the topics proposed for inclusion in the Resource Pack. Respondents were asked to state if the proposed topics were useful and to suggest additional topics and specific items or photographs that could be included within each topic. Two researchers were asked to review the data collection tools, to ensure they were easy to use. The forms were amended on the basis of their feedback.

Data collection

The resources and data collection forms were sent to professionals and expert participants via email. The same method was used to collect data from professional participants as in sub-study 1 (p155). Experts were invited to provide their responses via email using the data collection form or verbally, in person or via Skype conversation.

The PCPI advisory group were shown the Mental Capacity Assessment Support Tool (v1) and Communication Screening Tool (v1) during a group meeting held on university premises. The researcher explained the purpose of each form and answered any questions. Group members were encouraged to provide feedback on the forms, particularly the Communication Screening Tool, in order to investigate whether the tool would be acceptable to people with communication disorders. The researcher made written notes based on the group's feedback.

Data analysis

The same analysis methods were used as for sub-study 1 (see p155).

6.4.2.4 Results

Participants

Ten professionals, six experts and seven members of the PCPI advisory group provided reviews. Professional participant characteristics are presented in table 6.2 (p137) and expert participant characteristics are displayed in table 6.3 (p138). Eight professional participants were from the original group of professionals who took part in study 1. DEV006 and DEV010 did not respond to the survey. Two additional participants consented to take part: DEV012 and DEV013. The participant sample represented a range of professional groups and clinical settings across hospital and intermediate care sites. The following professional groups were represented: OTs (n=2), physicians (n=2), physiotherapists (n=1), psychologists (n=1), speech and language therapists (n=4).

Participant responses

The eight professionals who had participated previously provided their responses via email, using the electronic data collection forms. Participants DEV012 and DEV013 preferred to provide their responses verbally in person at the researcher's office. The researcher took written notes to record their responses. Four of the six experts provided their responses verbally in person or via Skype conversation. The researcher made written notes to record these responses. DEV014 and DEV020 provided their responses via email. DEV020 also made annotations to an electronic version of the MCAST resource. The PCPI group members provided their responses verbally.

Responses to the Support Tool (v1): quantitative data

Professional participant responses to the survey closed questions are summarised in table 6.11.

Survey question	Response		
	Yes	No	NR*
Do you think you understand how to use the proforma?	10	0	0
Does the proforma include any sections that are unnecessary?	1	8	1
Do you think there is anything missing from the proforma?	3	5	2

Table 6.11: Participant responses to the Support Tool (v1) survey

*NR: No response

Comparison of the scores in table 6.11 with those recorded in table 6.8 (p159) for sub-study 1 suggests that overall, professional participants appeared more satisfied with the Support Tool (v1) than they were with the Mental Capacity Assessment Proforma. All participants found the Support Tool easy to understand. Compared with responses to the previous proforma, fewer respondents indicated that the Support Tool either contained unnecessary sections or lacked some specific component.

Responses to the Support Tool (v1): qualitative data

Analysis of qualitative data collected from professional and expert participants and PCPI group members identified two main themes. These themes were similar to those identified in sub-study 1 and related to the tool's apparent ease of use, its length, content and design.

Ease of use / length

Respondents commented that the Support Tool appeared to be user-friendly, clear and easy to follow. Participant DEV009 appreciated the Support Tool proforma's "clear, step-wise flow". Expert reviewer DEV018 reported that the proforma appeared "comprehensive" but also "pragmatic". Certain participants suggested that the proforma's length and layout might deter some professionals from using it, despite it being designed to be shorter than the earlier Mental Capacity Assessment Proforma (on the basis of participants' previous concerns). Participants DEV007 and DEV009 commented that physicians working in surgical settings might be less inclined to use the tool than physicians working on medical wards because of its length and the time it might take to use. Members of the project PCPI group also expressed concern that professionals might not have time to complete the proforma.

Content

Respondents suggested specific amendments to aspects of the proforma, to make it more comprehensive. These amendments are shown in table 6.12.

Participant	Suggested amendment
DEV016, DEV017	Prompt professionals to consider if a formal capacity assessment is indicated.
DEV014	Prompt assessor to ascertain and document a patient's expressed wish or preference in relation to available decision options.
DEV013	Include examples of types of communication difficulty to help non-specialist professionals understand prompt about communication needs.
DEV020	Prompt professionals to consider a patient's emotional needs during the capacity assessment.
DEV020	Reword prompt questions for the functional test of decision-making ability on page 2, to make them consistent with the MCA.
DEV020	Prompt assessors to consider the "causative nexus": whether a patient's apparent inability to make an informed decision is due to the impairment or disturbance of the functioning of their mind or brain.

Table 6.12: Changes to Support tool (v1) content identified by participants

Design

Professional participants suggested that parts of the Support Tool might be reformatted to make them easier to use and appear less repetitive. For example, DEV003 suggested that the "Preparation for mental capacity assessment" section on page 1 could be condensed by removing some of the text. Respondents suggested the tool should include sufficient space for professionals to record their findings directly on the document, rather than use the separate Evidence Form, as this may improve the quality of record-keeping.

Responses to Communication Screening Tool (v1): quantitative data

Table 6.13 summarises professional participant responses to the closed survey questions. These data suggest that most participants thought that the Screening Tool appeared easy to use and were satisfied with its content.

Survey question	Response		
	Yes	No	NR*
Do you think you understand how to use the Communication Screening Tool?	9	1	0
Does the tool include any sections that are unnecessary?	0	7	3
Do you think there is anything missing from the tool?	0	7	3

Table 6.13: Participant responses to the Communication Screening Tool (v1) survey

*NR: No Response

Responses to Communication Screening Tool (v1): qualitative data

Four main themes merged from analysis of the qualitative data collected from professional and expert participants and the PCPI group members. These themes related to respondents' perceptions of the Screening Tool's ease of use and length, its usefulness, content and acceptability.

Ease of use

Participants expressed different views about how easy to use they perceived the Screening Tool to be. Several participants suggested that some of the prompts designed to help professionals interpret subtest findings and navigate between sections could be made more explicit. An SLT (DEV003) expressed concern that some non-specialist professionals might find it difficult to use the tool without some introductory training. Respondents commented that the tool appeared long, but felt that this was necessary, in order for it to be comprehensive.

Usefulness

The majority of respondents described the Screening Tool as potentially useful and helpful. DEV013, an SLT, commented that the tool could help other disciplines to learn to use communication strategies, which would be beneficial. Only one participant, DEV006, stated that the tool appeared too complex and he would prefer to ask an SLT for specialist support. This participant had made a similar comment about the communication screening tools he reviewed in sub-study 1.

Content

Respondents indicated that some amendments to the content of the Communication Screening Tool could make it more comprehensive and easy to use. These modifications are shown in table 6.14.

Participant	Suggested amendment
DEV001	Provide checklist at the beginning of the tool to inform professionals what materials they will require to administer it.
DEV016 DEV017	Add written alternatives to spoken questions in yes/no response reliability subtest to meet needs of patients with hearing difficulties.
DEV013	Amend specific text to make it easier to understand for all professionals, e.g., “lay language” and “important concepts” (p2).
DEV018	Including case vignettes to illustrate how the tool might be used with patients with different types of communication difficulty.

Table 6.14: Changes to Communication Screening Tool (v1) content identified by participants

Acceptability

The researcher demonstrated to the PCPI group how the tool might be administered. The members reported that all items in the tool were acceptable.

Responses to items to include in Resource Pack

Seven professional participants provided responses to the Resource Pack survey. Their responses are presented in table 6.15. The majority of participants responded that items for all 15 topics would be useful and were able to suggest different items for each topic. They also proposed five new topics for inclusion: “transfers” (e.g., getting in and out of bed), “equipment” (e.g., commode), “places” (e.g., bank), “transport” (e.g., ambulance) and “communication aids/equipment” (e.g., hearing aid). Respondents suggested 201 items in total to be included in the Resource Pack (shown in Appendix 24).

Survey question: would this topic be useful?	Response			
	Yes	No	Unsure	NR
Activities of daily living (e.g., washing, dressing)	7	0	0	0
Body parts	4	3	0	0
Eating and drinking	7	0	0	0
Family members / friends	6	0	0	1
Feelings	4	1	2	0
Managing finances	5	0	2	0
Medical conditions (e.g., stroke)	7	0	0	0
Medical procedures (e.g., X ray)	6	0	0	1
Mobility	6	0	1	0
Places (e.g., house, residential home, hospital)	7	0	0	0
Professional roles or services (e.g., doctor, nurse, Police, Ambulance)	5	0	2	0
Risks (e.g., falls, fire, injury, infection)	6	0	0	1
Symptoms (e.g., pain, feeling hot, hungry)	4	0	3	0
Time (e.g., day of week, months of year)	6	0	0	1
Types of treatment (e.g., tablets, operation, feeding tube)	7	0	0	0

Table 6.15: Participant responses to Resource Pack survey

*NR: No Response

The researcher discussed the composition of the Resource Pack with the expert advisor DEV018, who has experience of providing pictorial resources for use by people with dementia. She agreed that providing photographic images for use with this group would be beneficial, but that other types of image (diagrams and pictures) could also be useful.

6.4.2.5 Summary and implications of results of sub-study 2

These data suggest that Support Tool (v1) has increased face validity than the earlier Mental Capacity Assessment Proforma and that the Communication Screening Tool (v1) appears to have strong face validity. The expert reviewer data indicate ways in which both tools' content validity can be increased. Professional participants' perceptions that they would be able to use the two tools provide indications of both tools' usability. The PCPI group's responses suggest that both tools appear acceptable to service users. The researcher used the data to identify potential content and design solutions for each of the requested modifications. These changes and proposed solutions are shown in table 6.16 for the Support Tool and table 6.17 for the Communication Screening Tool.

Support Tool feature	Modifications or additions suggested by participants	Proposed solution
Support to prepare for assessment	Prompt user to consider if formal capacity assessment required.	Add written prompt.
	Prompt user to consider patients' emotional needs.	Add written prompt.
	Provide examples of specific communication needs.	Add examples to existing prompt.
	Reduce repetition in this section.	Reformat with design expert.
Support to conduct assessment	Modify wording in prompts for functional test of decision-making to make it consistent with MCA.	Change wording, using suggestions from expert reviewer.
	Prompt user to record if decision-making deficit is caused by impairment / disturbance of mind or brain.	Work with design expert to create new prompt.
Support to record assessment	Provide space on tool to record assessment process, instead of on separate Evidence Form.	Work with design expert to add documentation space to all sections.
Format	Make tool shorter / less time consuming to use.	Reformat with design expert. Investigate how long tool would take to use.

Table 6.16: Suggested content and design modifications to Support Tool (v1) and proposed solutions

Communication Screening Tool feature	Modifications or additions suggested by participants	Proposed solution
Support to prepare to use tool	Tool should inform users what materials needed to use tool.	Add checklist at beginning of tool.
Yes/no response reliability sub-test	Add method to use with patients who have hearing difficulties.	Add instructions to check if patient able to read. If patient able to read, add instruction to write questions.
Spoken language expression sub-test	Move sub-test to beginning of tool.	Modify subtest position within tool.
Ease of use	Make tool easier to use with clearer navigation prompts and instructions.	Reformat with design expert. Simplify test administration by removing "understanding written sentences" subtest.
	Ensure instructions are written in language that users will understand.	Modify instructions using reviewers' suggestions. Check users understand instructions when testing future versions of tool.
	Provide examples of how patients with different types of communication difficulty might present.	Consider for inclusion as part of Resource Pack.

Table 6.17: Suggested content and design modifications to Communication Screening Tool (v1) and proposed solutions

The researcher collaborated with a team of design experts to redesign the Support Tool and Communication Screening Tool, using the proposed content and design solutions listed in tables 6.16 and 6.17. This process is described in sub-study 3 in chapter 7. Participants' responses to the Resource Pack survey indicated that a set of specific photographic resources should be developed to support conversations with patients about decisions relating to discharge arrangements and treatment options. The researcher worked with a professional photographer and design experts to create the Resource Pack; this process is described in sub-study 5 (chapter 7, pp202-4).

This chapter reported the initial stages involved in developing the Mental Capacity Assessment Support Toolkit (MCAST). Healthcare staff, service users and topic experts reviewed and helped to refine an initial iteration of prototype toolkit materials. Chapter 7 describes sub-studies 3-5, in which two further iterations of materials were developed using participatory and co-production methods.

Chapter Seven: Further development of the Mental Capacity Assessment Support Toolkit (MCAST)

7.1 Sub-study 3: Creation of Mental Capacity Assessment Support Toolkit (MCAST) materials (v2) and review by professionals and PCPI group

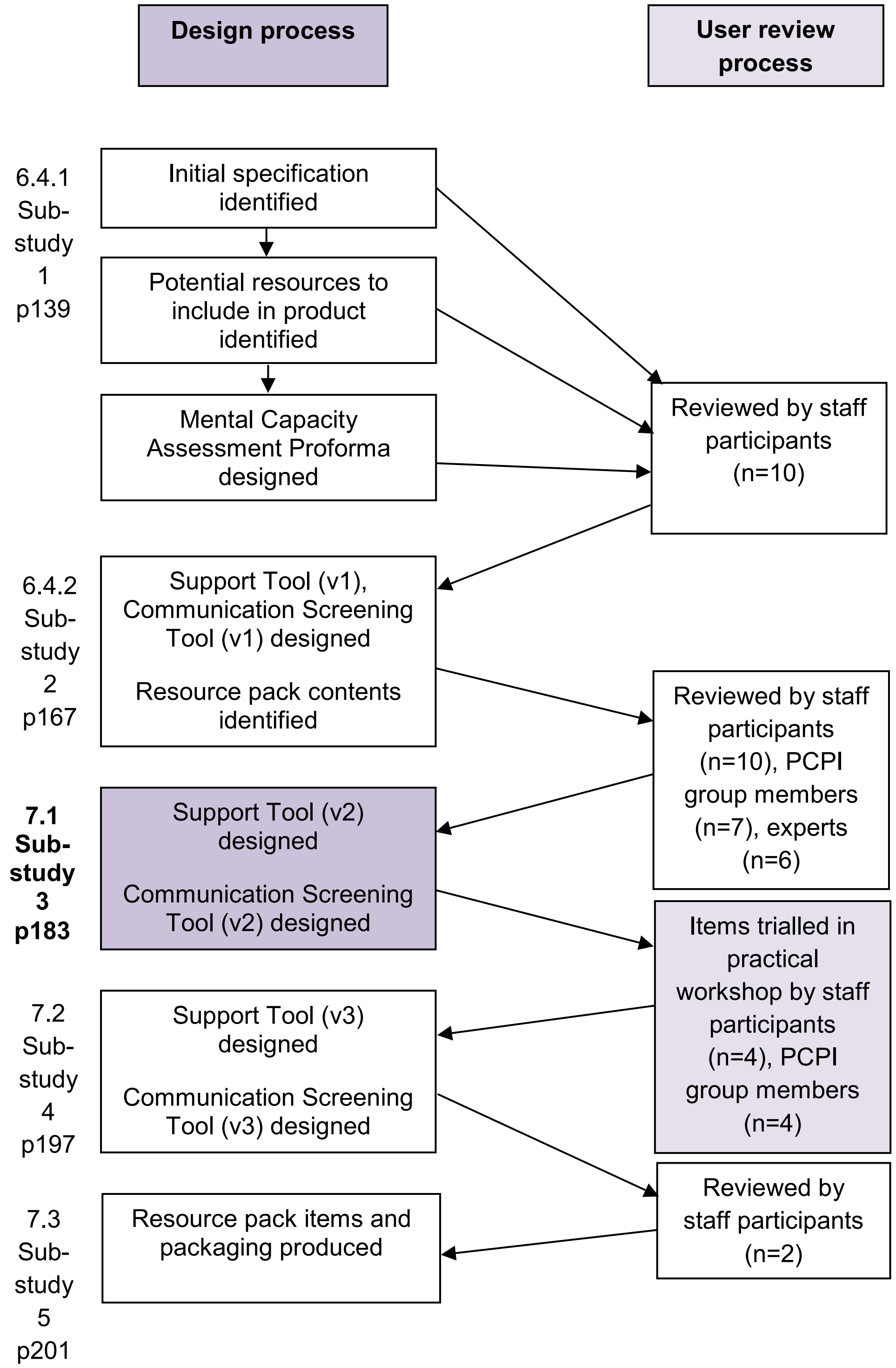

Figure 7.1: Iterative design process summary

7.1.1 Overview of methods

In sub-study 3, the Support Tool (v2) and Communication Screening Tool (v2) were developed, in collaboration with design experts. Professional participants and members of the project PCPI group were asked to try using these prototype materials in a practical workshop, in order to investigate their face validity, usability and acceptability. Data were collected using ethnographic, interview and survey methods.

7.1.2 Creation of prototype materials

The researcher worked with a team of designers at the Design Futures Consultancy Group[39] based at Sheffield Hallam University. The Design Futures team specializes in product and packaging design and have contributed to a range of commercial product design and research-based projects. This team was selected because its members have experience of contributing to user-centred product design projects in healthcare settings. The researcher worked closely with a graphic designer to revise the prototype materials. This involved the researcher reviewing different versions of the materials produced by the graphic designer and providing feedback on their content and design features. This iterative process continued until a version was created that incorporated all the content and design solutions proposed in table 6.16 (for the Support Tool) and table 6.17 (for the Communication Screening Tool). The researcher also collaborated with the graphic designer and a design engineer specialising in user-centred design projects to plan the data collection methods employed in this sub-study.

Support Tool (v2)

The revised Support Tool is shown in appendix 25. Unlike the one page, two-sided format used for the first version of the Support Tool (appendix 19), version two included four sides within a two-page A4 folded booklet. The additional pages enabled the content to be presented more clearly and provided increased documentation space as well as areas for the assessor to write notes about the assessment. The graphic designer used a greater amount of colour and different visual icons in version two, in order to differentiate specific sections and aid the user's navigation though the document. For example, the designer included a system of arrows and "pointing finger"

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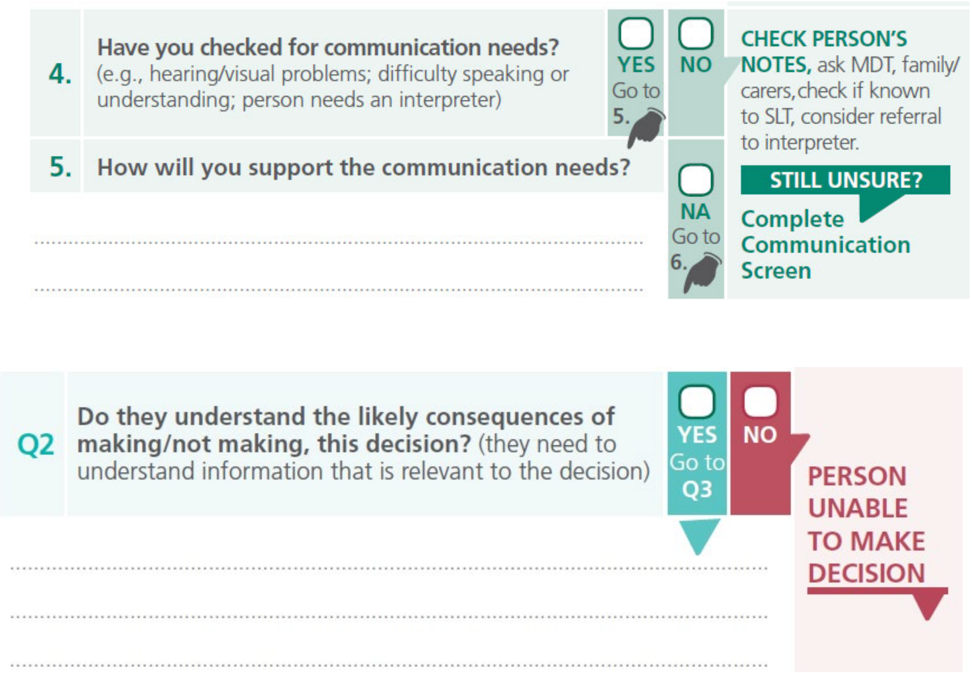
[39] For more information, visit www.shu.ac.uk/research/specialisms/cultural-communication-and-computing-research-institute/what-we-do/commercial-services/design-futures

icons to signpost the user between specific questions and prompts. The colour red was used to signal when important actions were required on the part of the person carrying out the assessment. Examples of these design features are shown in figure 7.2.



4. **Have you checked for communication needs?** (e.g., hearing/visual problems; difficulty speaking or understanding; person needs an interpreter) ☐ YES Go to 5. ☐ NO **CHECK PERSON'S NOTES,** ask MDT, family/carers, check if known to SLT, consider referral to interpreter.

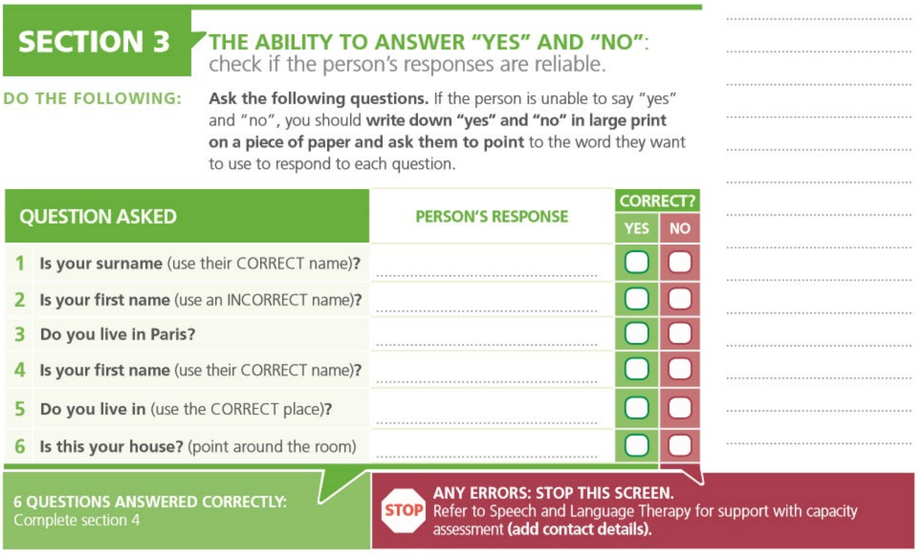
5. **How will you support the communication needs?** ☐ NA Go to 6. **STILL UNSURE?** **Complete Communication Screen**

Q2 **Do they understand the likely consequences of making/not making, this decision?** (they need to understand information that is relevant to the decision) ☐ YES Go to Q3 ☐ NO **PERSON UNABLE TO MAKE DECISION**

Figure 7.2: Examples of graphic design used in Support Tool (v2)

Communication Screening Tool (v2)

The revised Communication Screening Tool is shown in appendix 26. The designer reformatted the tool as a four-page A4 folded booklet with a similar basic layout to the Support Tool (v2), but with a different colour scheme. This approach was used to enable users to identify both tools as recognisable but separate components within the same toolkit. The designer used a similar system of visual icons and colour variations to that used for the Support Tool (v2), in order to make the Communication Screening Tool layout clearer and easier to navigate. Screening subtests were reorganised as separate sections with explicit instructions to signpost the user from one section to the next. The researcher revised subtest prompts and instructions initially proposed by the graphic designer to ensure they were written in clear, simple language. An example of these revisions is shown in figure 7.3 for the yes/no response reliability subtest (compare with the original version of this subtest, shown in figure 6.4, p132).



SECTION 3 **THE ABILITY TO ANSWER "YES" AND "NO":**
check if the person's responses are reliable.

DO THE FOLLOWING: **Ask the following questions.** If the person is unable to say "yes" and "no", you should **write down "yes" and "no" in large print on a piece of paper and ask them to point** to the word they want to use to respond to each question.

QUESTION ASKED	PERSON'S RESPONSE	CORRECT? YES	CORRECT? NO
1 **Is your surname** (use their CORRECT name)**?**	....	☐	☐
2 **Is your first name** (use an INCORRECT name)**?**	....	☐	☐
3 **Do you live in Paris?**	....	☐	☐
4 **Is your first name** (use their CORRECT name)**?**	....	☐	☐
5 **Do you live in** (use the CORRECT place)**?**	....	☐	☐
6 **Is this your house?** (point around the room)	....	☐	☐

6 QUESTIONS ANSWERED CORRECTLY:
Complete section 4

STOP **ANY ERRORS: STOP THIS SCREEN.**
Refer to Speech and Language Therapy for support with capacity assessment **(add contact details).**

Figure 7.3: Example of graphic design used in Communication Screening Tool (v2)

The content was changed in several ways to incorporate modifications and additions suggested by reviewers. A checklist was added to the beginning of the communication screening tool to prompt users to consider what materials they would need to complete the screening test and different ways in which they could prepare each patient for the test. This included providing methods for checking for visual or hearing needs and recommendations for actions to take to support any identified needs. The order of subtests was changed in order to make the screening subtests easier to administer and the tool layout easier to navigate and more compact, as requested in sub-study 2. For example, the spoken language expression subtest was moved to an earlier position within the tool.

7.1.3 Participant review

The experiential workshop was planned by the researcher in collaboration with the graphic designer and design engineer from Design Futures, who have experience of running similar workshops with groups of target users for new products.

7.1.3.1 Materials

Items for review

Paper copies of the Support Tool (v2) and Communication Screening Tool (v2) prototypes were prepared for participants to review during the workshop. The original design specification for the product (table 6.4, p142) was written out on flipchart paper for use during the workshop. Three different clinical vignettes or scenarios were created (appendix 27), to enable professionals to trial using the Support Tool within a realistic clinical context. Each vignette was presented on an A4 MS Word document and provided a short description of an individual patient requiring a mental capacity assessment. This description was designed to give the type of information about a patient that might be provided to a professional when a patient is referred for a capacity assessment. Each description included information about the reason for the patient's hospital admission, their diagnosis and symptoms, the decision they were being asked to make and the reasons the capacity assessment was initiated.

Data collection forms

A general observation record form (shown in appendix 28) was created for the co-facilitators to record their observations and reflections during each section of the workshop. Participants provided verbal feedback to the researcher on their opinions about the Support Tool (v2) and this was recorded on a flipchart. Therefore, no data collection form was required.

Two observation record forms were designed for use during the Communication Screening Tool session. One form (shown in appendix 29) was designed to be used by professional participants and co-facilitators observing a professional participant using the tool to carry out a screening test for a member of the PCPI group. This form provided a structure to prompt observers to record what they perceived to be positive and problematic aspects of the session and suggest changes or improvements to the communication screening tool.

The other form (shown in appendix 30) was designed to be completed by professional participants after they had used the Screening Tool. This form asked participants to record their reflections about the tool's ease of use, any problems they experienced, how easy the tool might be to use in a clinical context and how the PCPI group member appeared to respond to being tested. The co-facilitators provided guidance on how these forms should be designed and reviewed them before the workshop. Slight amendments were made to the content of the forms, on the basis of the co-facilitators' suggestions.

7.1.3.2 Data collection

The workshop took place on university premises. The workshop was recorded using a video camera (with prior consent from all participants) in order to aid data collection and analysis. The researcher welcomed all participants and provided a brief overview of the workshop purpose and content before taking written consent. Next, professional participants were asked to review the original design specification for the toolkit. This was displayed on a flipchart and the researcher read aloud each item and invited comments from participants. The researcher recorded these comments on a separate flipchart sheet.

Next, professional participants were asked to review the Support Tool (v2). Participants were given a copy of the tool and asked to inspect and comment on the visual aspects of its design. The researcher asked probe questions about the layout, font size, spacing and use of colour. Participants' responses were recorded on a flipchart sheet. After this, each professional participant was given a clinical vignette and asked to complete the first two pages of the Support Tool using this information. These two pages are designed to enable professionals to prepare for a capacity assessment, by ensuring they have all relevant information they need about the patient and decision. The researcher then asked participants to provide feedback on their experience of using these pages of the Support Tool. Probe questions were used to elicit responses about whether these sections of the Support Tool met the original design specification, their ease of use, whether it would be practical to use them within a clinical environment and whether participants could identify any ways to improve these sections of the Support Tool. Participants' responses were recorded on flipchart paper.

In the next part of the workshop, professional participants were asked to review the Communication Screening Tool. First, they were asked to read through the tool. They were then invited to try using the tool with a member of the PCPI advisory group. Observer participants were asked to complete the observation record forms during these sessions. The researcher moved between groups observing the screening sessions and making field notes. After this, the researcher elicited feedback from all participants about their experience of taking part in or observing a screening session. Probe questions were used to elicit specific information about the tool's ease of use, the feasibility of using it in a clinical environment, how long it took to use and how it might be changed or improved. Feedback was recorded on a flipchart sheet.

In the final section of the workshop, professional participants were invited to examine pages 3 and 4 of the Support Tool, which were designed to enable professionals to conduct and document a capacity assessment. They were asked to provide feedback on its content. The researcher asked the same probe questions used to elicit feedback about pages 1 and 2 of this tool. Participants' comments were noted on a flipchart sheet.

At the end of the workshop, participants were asked if they had any further comments to make about the toolkit materials.

7.1.3.3 Data analysis

Written data, including notes the researcher made on flipchart paper, the researcher's field notes, notes made by participants on the MCAST prototype documents and all the completed observation record forms, were collated on MS word documents. The researcher watched the video recording of the workshop and made written notes using the same data collection forms observers completed during the workshop. These notes were then added to the other written data and analysed using the same thematic analysis approach used in previous reviews (see p155).

7.1.4 Results

7.1.4.1 Participants

Four professionals participated. Three of these had taken part in previous review stages. The fourth, DEV015, was recruited uniquely to participate in the workshop. Participant characteristics are shown in table 6.2 (p137). Participants represented three different professional groups: OTs (n=2), psychologists (n=1) and social workers (n=1); the latter group had not been represented previously. Participants worked in care of the elderly and stroke services across hospital and intermediate care settings.

Four members of the PCPI advisory group attended the workshop. Two women were stroke survivors living with aphasia and one woman had communication difficulties associated with dementia. These three individuals all took part in the practical workshop session to trial the Communication Screening Tool. The fourth individual, the partner of the woman with dementia, observed professional participants use the Screening Tool with his partner and provided verbal feedback about his impressions of the tool.

7.1.4.2 Participant responses to product design specification

There was general consensus among the professional participants that the content of the design specification included necessary elements and that nothing needed to be amended.

7.1.4.3 Participant responses to Support Tool (v2) and observations relating to its use

Analysis of the qualitative data identified main themes in participants' responses. These related to the Support Tool's ease of use, its content and design. These themes are discussed below.

Ease of use

Participants were observed to work through pages 1-2 of the Support Tool when completing the clinical vignette task. They took different amounts of time (between 5 and 10 minutes) to complete the task. Participants did not ask any questions. After the task, one respondent, DEV015, reported that she found the tool "difficult to follow", because she already used specific paperwork provided by social services to record her capacity assessments and the paperwork was formatted differently.

Content

Participants suggested amendments to some of the text in the Support Tool, to improve the tool's comprehensiveness and clarity. For example, DEV002 suggested additional text could be used to clarify the phrase "cognitive needs" on page 2. Respondents also suggested that the prompt questions about different support needs on page 2 could be amended to encourage assessors to clarify exactly what the needs were and how they would be supported during the capacity assessment.

Design

Participant DEV012 commented that the tool contained “a good balance of space and text”. In contrast, DEV015 suggested that more space was needed for professionals to record their response to one of the questions. Some participants reported using the “notes” area on the right-hand margin of each page to record their thoughts during the assessment, whilst others did not use this space.

Participants suggested that some navigation prompts in the documents could be reordered or redesigned. For example, DEV002 suggested that the coloured prompts on pages 3 and 4 should be modified to ensure that assessors always document evidence to justify their decisions about a patient’s different decision-making abilities and are required to answer question 6 on page 4, which asks about the patient’s decision or preferred decision option, before moving onto the next section of the Support Tool.

Participants commented on the use of colour and suggested coloured fonts might be expensive to print. They also questioned whether professionals would find it easy to photocopy or scan the tool document for clinical use because of its booklet format. They identified that the tool would need to be compatible with the healthcare trust’s different electronic notes systems (i.e., that professionals would need to be able to scan a paper version onto an electronic database).

7.1.4.4 Participant responses to the Communication Screening Tool (v2) and observations relating to its use

Due to the numbers of professionals and advisory group members who attended, three professional participants each used the Screening Tool with a different member of the advisory group. The other professional participant and the two design experts each observed one of these screening sessions. Participants took between 5 and 10 minutes to use the tool. The themes that emerged from analysis of qualitative data related to the screening tool’s ease of use, its design and its acceptability. Each theme is discussed below.

Ease of use

Participants were observed to have, and reported that they experienced, different levels of difficulty when they used the Screening Tool. One participant, DEV002 reported that she found the tool “easy to administer” and believed it would be easy to use in a clinical context. She was observed by the researcher and the graphic designer to work quickly through the tool with apparent ease. In contrast, DEV004, who observed participant DEV015 use the tool, expressed concern that DEV015 appeared to find it difficult to use the tool. DEV004 suggested that professionals might benefit from training before they use the tool. When the researcher reviewed the video recording of participant DEV015 using the tool, it appeared that she may not have understood the administration instructions for the subtests in sections 1 to 4, because she tended to simplify spoken instructions and questions and attempt to help the PCPI group member to provide the correct responses. This may be because participant DEV015 had less experience than the other participants of administering screening tests or assessments of functional ability as part of her professional role as a social worker.

Participants identified specific sections in the tool that appeared more difficult to complete. For example, one of the expert observers indicated that the professional participant he observed found section 7, the summary of communication strategies, challenging. Participants also identified tasks that might benefit from having additional or more explicit administration instructions to make it easier for professionals to complete them and interpret the results. Participants suggested amendments to the instructions for the tasks in sections 4, 5 and 6.

Design

Participants suggested that the tool appeared dense and would benefit from a modified layout, in order to separate out the different sections more. One suggestion was to remove the notes section on the right-hand margin of each page. Not all participants were observed to make use of this section during the workshop. Another suggestion was to remove section 7 and include this as a separate summary sheet.

Participants who observed the Screening Tool being used with members of the PCPI group suggested that the task order could be changed to facilitate use of the tool. One of the design experts, DEV004 and the member of the PCPI group who is a family carer suggested that the task in section 2, designed to test the patient's ability to speak, should be completed before the photograph recognition task in section 1. They argued that this would make it easier for professionals to administer the rest of the tool and might also improve the experience for patients; they suggested an opening conversation could be used to establish rapport and put the patient at ease and provide some initial information about the patient's communication skills.

Acceptability

Some professional participants expressed concern that patients might feel uncomfortable if they found tasks difficult to complete. Members of the PCPI group indicated that the screening tool content and the way it was administered felt acceptable to them.

7.1.5 Summary and implications of results of sub-study 3

Data collected during the workshop provide an indication that the Support Tool (v2) has face validity and is generally usable and acceptable. Three of the four professional participants found the Support Tool easy to use. DEV015 reported habitually using different paperwork to assess capacity, which made it harder for her to use pages 1 and 2 of the Support Tool. Participants suggested minimal content changes and minor design changes to the Support Tool and raised no objections to using it in clinical practice. The data also suggest that the Communication Screening Tool (v2) is also usable and acceptable to some professionals. DEV015, the only social care professional in the group, appeared to have more difficulty using the Communication Screening Tool than the other professionals; this may reflect differences between participants in how experienced they were in using clinical assessment tools. The data indicated that minor changes needed to be made to the design of the Screening Tool to improve its ease of use. None of the PCPI group members objected to being tested using the Screening Tool.

Participants' responses and observations suggested specific changes that could be made to both tools, to further increase the MCAST's face validity, usability and acceptability. The researcher and design experts collaborated to identify potential content and design solutions for each of the requested modifications. These changes and proposed solutions are shown in table 7.1 for the Support Tool (v2) and table 7.2 for the Communication Screening Tool (v2).

Support Tool feature	Modifications or additions suggested by participants	Proposed solution
Page 1: Support to prepare for capacity assessment	Provide more space to record details about the decision the patient needs to make.	Extend documentation space across entire page by removing “Notes” section from right margin.
	Make prompt and decision options relating to temporary impairments / disturbances of mind or brain clearer.	Create new options to i) continue assessment, or ii) set review date and discontinue assessment.
Page 2: Support to Prepare for capacity assessment	Prompt user to check patient’s notes earlier in the process of gathering information about support needs.	Move prompt to top of page and highlight in bold font.
	Change wording of prompts to check for cognitive / mental health / emotional needs to make these clearer.	- Add examples of specific needs - Prompt user to identify needs; and ways to support needs; - Prompt to refer to specific professionals.
Pages 3-4: Support to conduct capacity assessment	Change wording in preparation prompts section to “consider making changes *where practicable*”.	Change wording as suggested.
	Prompt user to record evidence under each assessment question.	Add “EVIDENCE” prompt to documentation space for each question.
	Change navigation system between assessment questions: if assessor records “no” for any of questions 1-5, they should be prompted to record evidence and move to question 6.	Add “GO TO Q6” prompt after “NO” option for each question
	Prompt user to answer question 6 even if s/he has completed the assessment.	- Add “GO TO Q6” prompts; - Highlight question 6 by placing bold border around text.
	Change layout to make it clearer to user how to make a judgement about the patient’s capacity and record this.	Reconfigure decision options and navigation prompts.
General format	Add space on each page to record more patient identifiable information (e.g., Date of Birth).	Provide space to place patient identifier sticker on each page.
	Add social care logo as some professional users may not be employed by NHS.	Do not include any corporate logos, to ensure product can be used across organisations.
	Add page numbers to all pages to improve navigation.	Add page numbers.
	Consider expense of colour printing and scan / fax capability.	Keep current format as final product is not designed to be printed or scanned locally.
	Consider compatibility with electronic record keeping systems.	

Table 7.1: Suggested content and design modifications to Support Tool (v2) and proposed solutions

Communication Screening Tool feature	Modifications or additions suggested by participants	Proposed solution
Page 1 Section 1 Preparation prompts	Provide sample wording to use to explain rationale to patients for doing screening test.	Add to product instruction booklet, to conserve space on tool.
	Differentiate section 1 preparation prompts from rest of tool, as not part of screening test.	Add PREPARATION heading in bold font and use section borders to differentiate this section.
	Add “Not Applicable” response option to denture prompt.	Add NA tick box option.
Page 1 Section 1 Photograph recognition subtest	Isolate photographs from rest of the page as other page content is distracting to patient.	- Move subtest to page 4; - Reduce content on page 4; - Make individual images larger.
	Add referral information to cognitive / vision assessment prompt.	Keep as generic information as specific referral information will differ between locations.
Page 2 Section 2 Ability to speak subtest	Move this subtest to the beginning of the screening test.	Move subtest to beginning.
Page 3 Section 4 Ability to understand speech subtest	Make administration instructions for all subtest items clearer.	Make instructions comprehensive but language simpler.
	Revise layout and use of prompts to facilitate navigation through items.	- Use arrow icons to aid navigation; - Differentiate sub-sections using spacing / shading.
Page 3 Section 5 Ability to read subtest	Make administration instructions for all subtest items clearer.	Make language simpler.
Page 4 Section 6 Ability to write subtest	Make administration instructions for all subtest items clearer.	Make language simpler.
	Change instruction to “Show the person *three objects in the room*” as difficult to move from page 4 instructions to page 1 photo stimuli.	Move photo recognition subtest to page 4.
Page 4 Section 7 Summary of Strategies	Consider moving to separate page / making optional.	Create separate, optional page.
General format	Add page numbers to all pages to aid navigation.	Add page numbers
	Reduce density of text on pages to make easier to read.	- Create space by removing “Notes” section from margin; - Remove Section 7.

Table 7.2: Suggested content and design modifications to Communication Screening Tool (v2) and proposed solutions

The researcher collaborated with the graphic designer to redesign the Support Tool and Communication Screening Tool, using the proposed content and design solutions listed in tables 7.1 and 7.2. This process is described in sub-study 4.

7.2 Sub-study 4: Creation of Mental Capacity Assessment Support Toolkit (MCAST) materials (v3) and review by professional participants

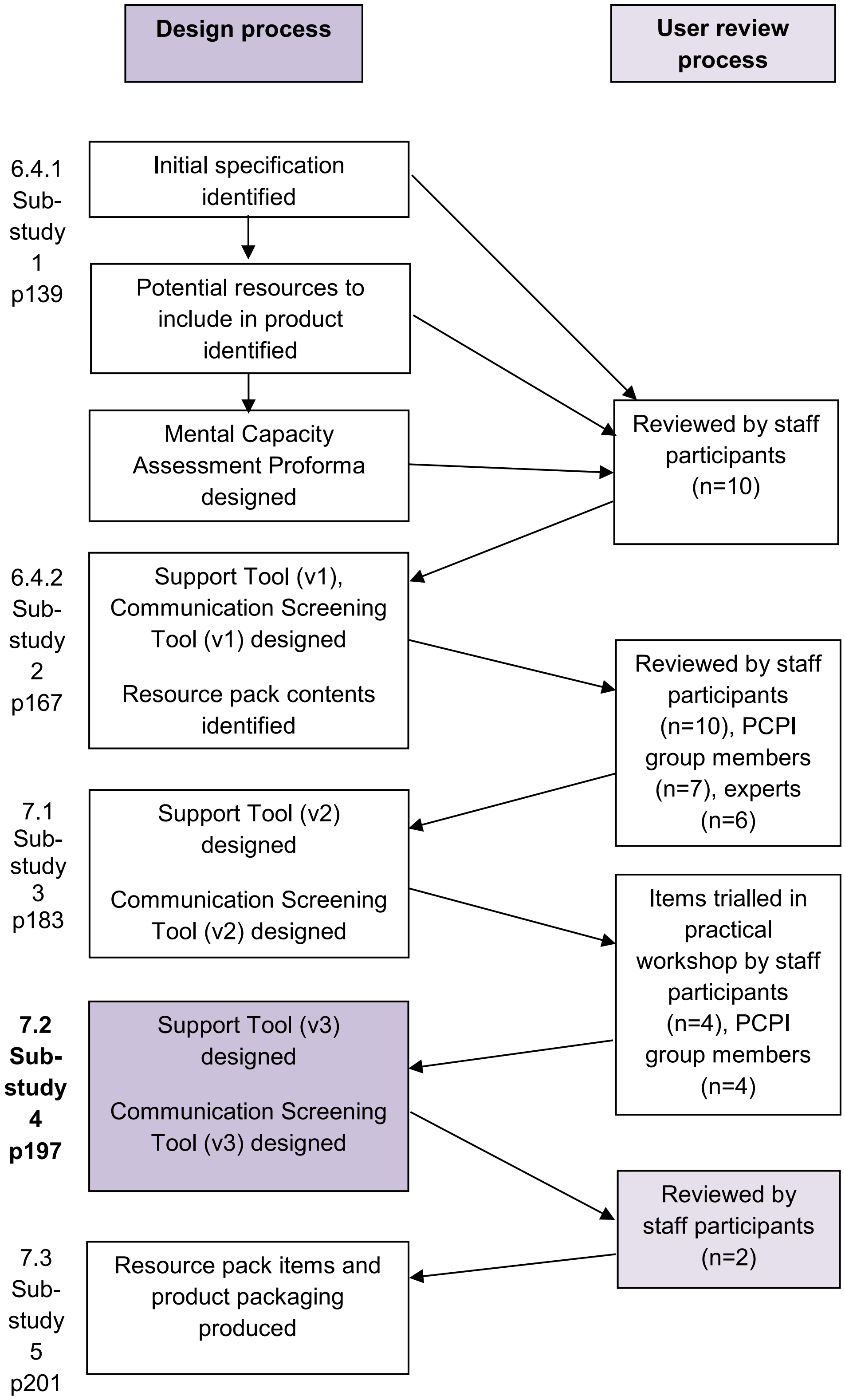


Figure 7.4: Iterative design process summary

7.2.1 Overview of methods

In sub-study 4, the Support Tool (v2) and Communication Screening Tool (v2) were revised using the content and design modifications shown in tables 7.1 and 7.2 (pp194-5). All professionals who participated in the practical workshop were invited to review the third iterations of these documents and provide feedback on whether the changes were consistent with suggestions they had made during the workshop.

7.2.2 Creation of prototype materials

Support Tool (v3)

The revised form is shown in appendix 31. It had the same four-page A4 booklet format as version 2. The graphic designer was able to incorporate all the content and design modifications proposed in table 7.1.

Communication Screening Tool (v3)

The graphic designer revised the Screening Tool using the changes suggested in table 7.2. The Screening Tool (shown in appendix 32) included a four-page colour printed A4 booklet comprising the main screening test and a separate one-page document for recording communication strategies that could be used to support individual patients during the capacity assessment. The latter document was created to replace Section 7 in the previous version of the Screening Tool (shown in appendix 33).

7.2.3 Participant review

7.2.3.1 Materials: resources for review

Participants were asked to review the Support Tool (v3) and the Communication Screening Tool (v3) via email.

7.2.3.2 Data collection method

The researcher emailed electronic copies of the revised tool documents to participants. The researcher requested that participants review the documents and provide feedback via email about whether they thought the revisions responded to the amendments suggested by participants in the workshop.

7.2.3.3 Data analysis

Participant responses were collated in an MS word document and analysed for themes using the method adopted in sub-study 1 (see p155).

7.2.4 Results

7.2.4.1 Participants

Two participants, DEV002 and DEV004, provided responses (see table 6.2, p137). These individuals work in different roles and with different clinical populations. DEV002 is an OT working in acute stroke care and DEV004 is a clinical psychologist working in care of the elderly services and neuropsychology outpatient services.

7.2.4.2 Participant responses

Neither participant provided detailed feedback on the resources. Both reported that the revised tools appeared easier to use. It is unclear if participants trialled using the tools or merely examined them. Their responses suggest that generally, they agreed with the revisions made to the content and design of each tool.

Responses relating to Support Tool (v3)

Participant DEV004 commented that the Support Tool layout made “better use of space” and the instructions appeared “easier to follow”. Participant DEV002 appreciated the revisions made to the tool but reported that she still found certain navigation prompts on pages 3 and 4 unclear.

Responses to Communication Screening Tool (v3)

DEV002 reported that the Communication Screening Tool appeared “really easy to follow” and that she was “looking forward to using it”. She suggested that it might be beneficial to add examples of phrases that professionals could use to explain to patients why they needed to use the Screening Tool, in order to reassure patients. The researcher responded via email that this would be included in a separate instruction booklet. DEV004 commented that the “reorganised” Screening Tool appeared more “straightforward”.

7.2.5 Summary and implications of results of sub-study 4

Only two participants reviewed the revised toolkit materials. In general, their responses indicated that they thought the new versions were superior to the previous ones. Although DEV002 suggested slight additional modifications to both tools, the researcher decided not to make any further amendments to the prototypes. This was because the data collected in this sub-study might not be representative of the views of the wider population of potential users of the toolkit. Further refinement of the two tools would be carried out if indicated by usability data collected from a larger group of participants in the feasibility study (chapters 8 and 9).

7.3 Sub-study 5: Creation of MCAST Resource Pack, Instruction Booklet and product packaging

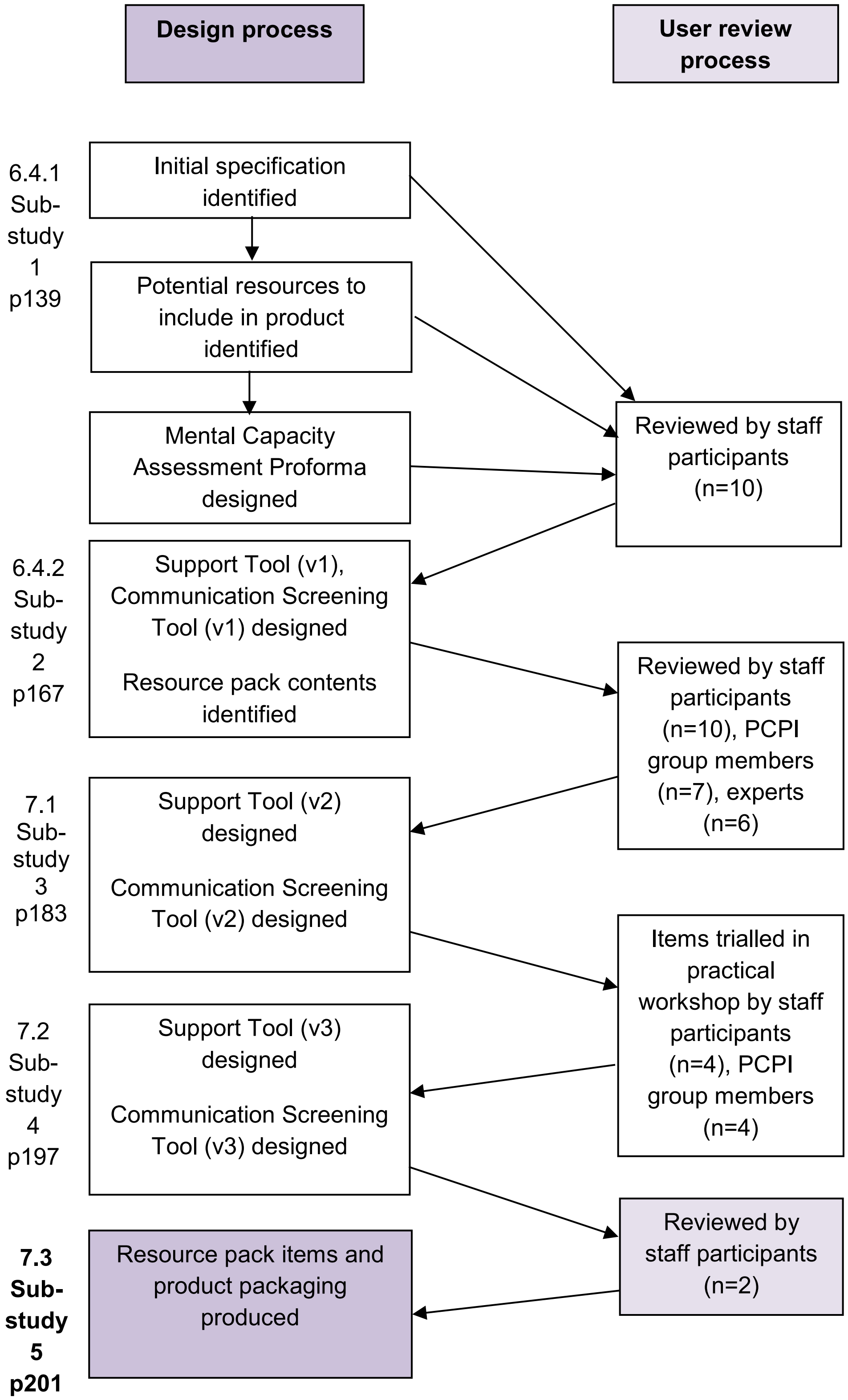


Figure 7.5: Iterative design process summary

7.3.1 Overview of methods

The researcher collaborated with design professionals, a photographer and members of the project PCPI group to produce photographic and simplified language resources to include in the MCAST Resource Pack. The researcher sought to involve people with communication disorders and carers in this co-production process, in order to increase these resources' acceptability to patients. It has been suggested that people with disabilities find photographic materials more attractive when they include genuine images of other people with disabilities (Skorpen *et al*. (2010). The toolkit packaging and Instruction booklet were designed by the researcher and graphic design experts at Design Futures, in order to make the toolkit portable and usable during the feasibility study (chapters 8 and 9).

7.3.2 Creation of prototype materials

7.3.2.1 Resource Pack

Photographic resources

Participants' suggestions for topic themes and individual items to include in the Resource Pack were reviewed. The researcher was able to identify themes and items that could be combined or reclassified in order to avoid duplication and to make the Resource Pack easier to use. For example, the themes "Family/friends" and "Professional Roles" were combined and relabelled "People". Similarly, "Mobility" and "Transfers" were combined under the new theme "Moving".

The researcher worked with a professional photographer to create the individual photographs. The photographer had previous experience of collaborating on health-related research projects with health professionals and service users. The item list (appendix 24) was reviewed to identify subjects (people, places, objects) that could be photographed locally and items that would require images to be taken from existing photograph libraries, due to the nature of their specialist content.

Novel photographic images

Ninety photographic images were created in collaboration with six members of the research project's PCPI group. These individuals consented to appear in the photographs (consent form shown in appendix 34) and were photographed in different locations on University of Sheffield and Sheffield Teaching Hospitals NHS Foundation Trust premises. The PCPI group members were photographed engaging in different activities (e.g., walking, getting in and out of bed or a chair for the "Moving" theme). The researcher and photographer also appeared in certain photographs. Members of the PCPI group were encouraged to be actively involved in the planning and execution of these images. For example, they were asked whether they thought individual images represented the target concept.

Photographic images taken from existing resources

103 photographic images were taken with full permission and with no infringement of copyright from the Shutterstock online photograph library (www.shutterstock.com) and eight images were kindly provided by the specialist mobility and access equipment provider Clark and Partners Ltd., from their website (www.clarkshop.co.uk).

Creation of photograph cards

The researcher then collaborated with the design team at Design Futures to create an A5 card for each image (see figure 7.6 for an example). This size was chosen because it enabled the image to be shown clearly and appeared easy to hold and could be stored within the toolkit more easily than larger sizes. Each card showed the photograph with a text label displayed underneath it for the concept represented by the photograph. The text was written in simplified language using the accessible information content and design principles summarised in table 5.1 (chapter 5, p130). Written language labels were used in combination with the images to provide additional support to patients with comprehension difficulties; the use of different communication modalities to express information may increase access to semantic knowledge, which may enhance understanding (Kerr *et al.*, 2010).

Figure 7.6: Example of photograph card used in Resource Pack

The cards were laminated in order for them to comply with NHS infection control policies. Information was added to the rear of each card to identify the item and its overarching theme. This information was presented using a colour-coding system for each theme. The same colour coding system was used on an A4 laminated card that was created to show all the themes and their constituent photograph cards, in order to act as a “resource menu” for toolkit users.

Review by PCPI group members

The PCPI group were asked to review each image and text label during two group meetings held on university premises. The researcher and photographer presented the photographs on a laptop computer and also provided a “mock up” of an individual card prepared by the design team. Group members were invited to provide feedback on the photographs and the text labels. The researcher initially asked the group what they thought each photographic image represented, to check how closely this corresponded to the target concept for each image. The researcher then asked the group to give specific feedback on whether the images were recognisable and appeared to represent the concepts they were designed to represent. For some photographs, the photographer provided a number of alternative images and asked the group to select the image that corresponded most closely to the concept being represented. For each text label, group members were asked to comment on whether the language used was accessible to them and appeared to correspond to the concept(s) suggested by the photographic image. Decisions were made based on consensus during the meetings about which version of alternative photographs to use and whether/how to replace specific text labels. The researcher kept a written record of these decisions.

Simple language guidance

Information was prepared to provide guidance to professionals about strategies they could use to make their language simpler to patients with communication difficulties. The use of simplified language was identified as a strategy that non-specialist professionals could use to make information more accessible to patients with milder comprehension difficulties during capacity assessments (see chapter 5, p129, and sub-study 2, p171). Guidance about using simple language was created using the accessible information guidelines that were reviewed in chapter 5 (see table 5.1, p97). The guidance was presented on a laminated A4 card (shown in appendix 31).

Methods to use to check decision-making abilities

The researcher also prepared guidance relating to methods that professionals could use to assess the four different decision-making abilities identified within the MCA's functional test of decision-making ability: the ability to understand information relevant to a decision, retain it, weigh or use it, and then communicate a preferred decision option (MCA, 2005). The need for this guidance was identified in the design specification (table 6.4, p142) from the focus group data (chapter 4, p82). Professional participants in sub-study 1 identified this type of guidance as an "essential" component of the toolkit (see p158). These methods to check decision-making abilities could be used as part of capacity assessments for patients with and without communication difficulties. The guidance is based on information provided within the MCA Code of Practice (2007) and methods commonly used and promoted by SLTs to support conversation with people with communication disorders. For example, the guidance lists simple ways to ask questions to support people with impaired language comprehension and/or expressive communication difficulties to demonstrate what they understand; these questions might involve asking the person to choose between a limited number of alternative response options or to answer a question that only requires a "yes" or "no" response. This guidance is shown in appendix 36.

Instruction Booklet

The researcher wrote a set of instructions to provide guidance about using the toolkit. It described each component of the toolkit and the procedures for using each element. It was not designed to provide training in how to assess mental capacity. These instructions were presented in a colour printed A4 booklet. The booklet was designed by the graphic designers at Design Futures.

Packaging and branding

Packaging experts at Design Futures designed a cardboard carrying case for the toolkit (see figure 7.7). The graphic designer created a branding logo for the MCAST that was used on the carrying case and all the components stored inside it: the Instruction Booklet, Support Tool, Communication Screening Tool and Resource Pack.

Figure 7.7: Toolkit carrying case design

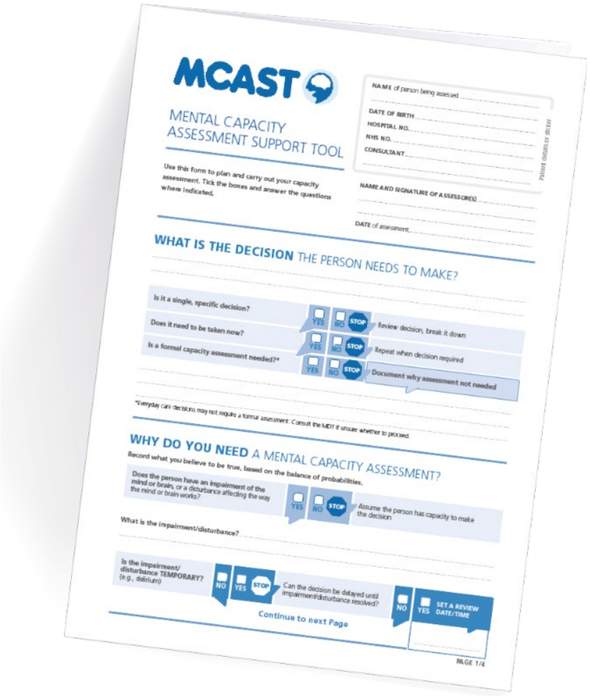
7.4 Summary of iterative design process and discussion for chapters 6 and 7

Chapters six and seven have presented the participatory and co-production design methods employed to create the MCAST. Consistent with the fourth objective for this doctoral study, the MCAST was developed using evidence from literature and case law reviews (reported in chapter three) and in response to user needs that were identified from the literature and case law reviews and from the focus group study data (reported in chapter 4). A user-centred design approach was chosen in order to maximise the product's face and content validity, its usability and acceptability. The approach involved five iterative phases of prototype material design and review by potential professional users of the product; these participants' responses to prototype materials were used to develop the materials, to ensure the product has strong face validity and is usable. Topic experts were invited to review the first iteration of the Support Tool and Communication Screening Tool, in order to increase their content validity (sub-study 2). This sub-study included review by experts in mental capacity assessment practice and law. Professionals were asked to trial aspects of the product in a practical workshop with people with communication difficulties (sub-study 3). The data collected in this workshop was used to identify changes that could be made to the materials, to increase their usability and acceptability. People with communication disorders and a family carer reviewed prototype materials (sub-study 2) and co-produced communication resources (sub-study 5), in order to strengthen these materials' acceptability to other patients who may experience mental capacity assessments conducted by professionals using the toolkit. The design process was supported by a professional design team which was able to contribute expertise in user-centred design and research methods.

This design process was used to produce the prototype Mental Capacity Assessment Support Toolkit (MCAST). The MCAST includes the following components, which are housed within a branded, portable, lightweight carrying case:

i) An instruction booklet

ii) A Support Tool (shown on right), that can be used to prepare, complete and record a capacity assessment in ways that are consistent with the requirements of the MCA.


MCAST

MENTAL CAPACITY
ASSESSMENT SUPPORT TOOL

Use this form to plan and carry out your capacity assessment. Tick the boxes and answer the questions where indicated.

NAME of person being assessed
DATE OF BIRTH
HOSPITAL NO.
NHS NO.
CONSULTANT
Patient details or sticker

NAME AND SIGNATURE OF ASSESSOR(S)
DATE of assessment

WHAT IS THE DECISION THE PERSON NEEDS TO MAKE?

Is it a single, specific decision? ☐ YES ☐ NO STOP Review decision, break it down
Does it need to be taken now? ☐ YES ☐ NO STOP Repeat when decision required
Is a formal capacity assessment needed?* ☐ YES ☐ NO STOP Document why assessment not needed

*Everyday care decisions may not require a formal assessment. Consult the MDT if unsure whether to proceed.

WHY DO YOU NEED A MENTAL CAPACITY ASSESSMENT?
Record what you believe to be true, based on the balance of probabilities.

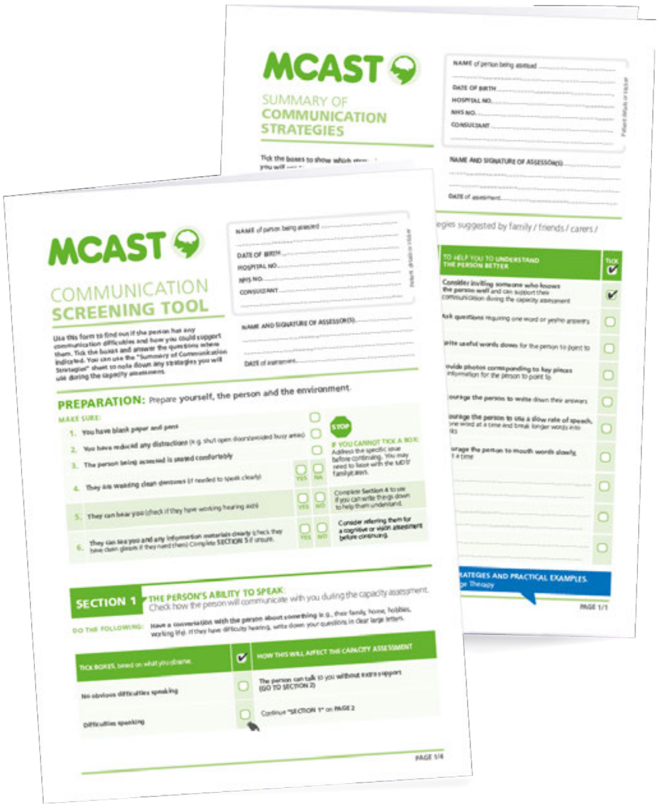
Does the person have an impairment of the mind or brain, or a disturbance affecting the way the mind or brain works? ☐ YES ☐ NO STOP Assume the person has capacity to make the decision

What is the impairment/disturbance?

Is the impairment/disturbance TEMPORARY? (e.g., delirium) ☐ NO ☐ YES STOP Can the decision be delayed until impairment/disturbance resolved? ☐ NO ☐ YES SET A REVIEW DATE/TIME

Continue to next Page

PAGE 1/4



MCAST

SUMMARY OF COMMUNICATION STRATEGIES

MCAST

COMMUNICATION SCREENING TOOL

PREPARATION:

SECTION 1

iii) A Communication Screening Tool (shown on right), that can be used to identify patients with communication difficulties and methods to support their needs during a capacity assessment.

iv) A Summary of Communication Strategies form (also shown on right), to record strategies that can be used to support an individual’s communication, based on the results of a screening test using the tool.

v) A Resource Pack, which includes simple language and photographic materials that can be used to support conversations with communication-impaired patients about topics relating to decisions about discharge arrangements and treatment options (see figure 7.6 for an example).

There are a number of limitations to the methods used during the design process. Firstly, the number of professional participants recruited to the study was initially relatively small and it decreased over successive sub-studies; very few participants were recruited to sub-studies 3 and 4. Although the initial sample included a range of professional groups working in different clinical settings, each professional group was represented by a small number of participants. Furthermore, the number of different professional groups and clinical settings represented in the sample diminished as the sample size decreased. In some sub-studies, certain professional groups were not represented at all. This means that the data collected may not be representative of the wider population of professionals who assess mental capacity in acute hospital and intermediate care settings within this particular healthcare trust or in other locations.

Another potential limitation is the principle data collection method used was an electronic survey. Whilst this provided an efficient means to collect data from busy professionals working in different locations, other methods may have provided different types of data. For example, the practical workshop provided rich interview and ethnographic data about the usability of the prototype materials. Additional practical review sessions could have been used to test out different aspects of the product more comprehensively (e.g., the Resource Pack items). In addition, it may have been possible to conduct some prototype testing in a clinical context, in order to increase the ecological validity of the data. The practical workshop provided an opportunity for professionals to discuss the prototype materials, whereas this was not possible using the survey method. As described in chapter 4 (p58) group data collection methods can enable the exploration of rich, complex and sometimes unanticipated data, due to interactions and dynamics between participants.

The results of the iterative development and review process suggest that the prototype MCAST meets the initial design specification (table 6.4, p142) and has strong face and content validity. Its usability and acceptability, as well as other aspects of its validity and also reliability, will require further testing before it can be evaluated fully in a clinical context. The next two chapters (chapters 8 and 9) describe a feasibility study carried out in acute hospital and intermediate care settings. This study was designed to investigate the product’s validity, reliability, usability and acceptability further. It was also designed to assess the feasibility of methods that could be used to evaluate the MCAST more comprehensively within a healthcare setting.

Chapter Eight: MCAST Feasibility Evaluation Methods

This chapter describes the methods employed to test the feasibility of using the Mental Capacity Assessment Support Toolkit (MCAST) in clinical practice. In this feasibility study, staff were recruited to use the prototype toolkit during capacity assessments for inpatients in acute and intermediate care settings at Sheffield Teaching Hospitals NHS Foundation Trust (STHFT). In order to test feasibility, the MCAST's usability and acceptability and the validity and reliability of its outcomes were investigated, in line with the fifth objective for this doctoral study.

8.1 Introduction

As described in chapter 2 (p13), the MRC framework for developing and evaluating complex interventions (Craig *et al*., 2008; see figure 8.1) was used to guide the methodological design of this doctoral study.

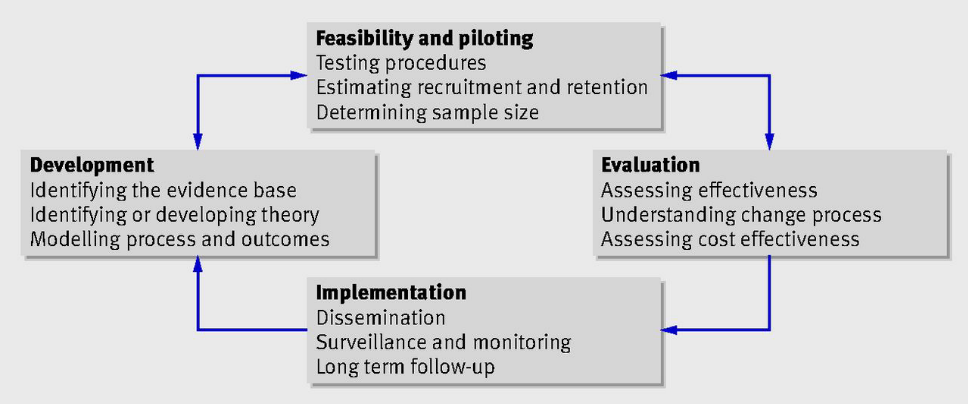


Figure 8.1: MRC Complex intervention development and evaluation framework (reproduced with permission from Craig *et al*., 2008)

The MRC guidance recommends that the feasibility of a novel complex intervention should be established before a full evaluation of its effectiveness is undertaken, for ethical and cost-efficiency reasons. Therefore, the study reported in this chapter was designed primarily to assess the feasibility of the MCAST's processes and materials, in terms of their usability and acceptability to professionals and patients. The study was also designed to test the practicability of the planned recruitment processes and data collection methods.

The toolkit was designed in response to a specification (table 6.4, p142) identified from the literature and case law review (chapter 3) and focus group study (chapter 4). This specification included a number of functions identified by professionals. These functions included prompts to enable professionals to carry out assessments that are consistent with the requirements of the MCA and to identify and support the needs of patients with communication difficulties. Therefore, the feasibility evaluation was also designed to investigate whether use of the MCAST enabled professionals to carry out these functions and was associated with changes in practice. This included testing of the Communication Screening Tool's validity and reliability, to investigate whether its use enabled professionals to identify and support patients with communication disorders accurately and reliably.

8.2 Research questions

1. Does use of the MCAST increase compliance with the Mental Capacity Act (2005)?
2. Does use of the MCAST increase professionals' confidence levels when assessing mental capacity?
3. Can professionals use the MCAST to identify communication difficulties in patients with stroke and/or cognitive difficulties and how to support patients with these difficulties accurately and reliably during mental capacity assessments?
4. Do professionals and patients find the MCAST useable and acceptable?
5. Are the recruitment and data collection methods used in this study feasible within NHS settings?

8.3 Method

8.3.1 Summary of study design

The study involved a mixed methods, case series design. A combination of quantitative and qualitative data collection and analysis methods were required to generate evidence relating to assessment practice, the toolkit's usability and acceptability and the communication screen's validity and reliability. A non-randomised design was used since this study was designed to investigate the toolkit's feasibility and to provide an indication in changes in practice associated with its use; the study was not designed to measure the toolkit’s effectiveness in comparison with another intervention or usual practice.

8.3.2 Summary of methods

The study aimed to recruit 20 professionals of different disciplines to use the MCAST during mental capacity assessments for 20 consecutive patients (i.e., each professional participant was asked to use the MCAST to assess at least one patient). The different methods used to collect data are described below.

Compliance with the Mental Capacity Act (2005)

A case note review was used to investigate the extent to which capacity assessment practice and compliance with the MCA changed following introduction of the MCAST. Case note records for 20 capacity assessments carried out before professional participants had used the MCAST were reviewed against standards contained in the British Psychological Society’s (2010) audit tool for mental capacity assessments. Twenty capacity assessments completed after professional participants had used the MCAST were reviewed against the same standards. Outcomes were compared across the two audits in order to measure changes in practice and compliance.

Professionals’ confidence in their ability to assess mental capacity

A questionnaire method was used to investigate whether professional participants’ levels of confidence in their ability to assess capacity changed after they had used the MCAST. Participants were asked to complete the questionnaire prior to using the MCAST and again when they had used the MCAST. Data from the two sets of questionnaires were compared in order to measure any change in reported confidence levels. The questionnaire method was chosen as it provided an efficient data collection method and could be completed confidentially by participants in their own time.

MCAST Communication Screening Tool validity and reliability

Data were collected in order to investigate the Communication Screening Tool’s validity, the extent to which it enabled professionals to accurately identify patients with communication difficulties and the type of communication support these patients needed during a capacity assessment. The communication screen is a novel instrument because it identifies people's communication difficulties and proposes strategies that can be used to compensate for these individual difficulties. Because there is no existing gold standard measure that provides the same outcomes, assessment of the Screening Tool's validity was methodologically challenging. Different types of validity were considered when designing the evaluation.

Face validity is based on the subjective judgement of people using a tool that it appears to contain items that will enable users to achieve the tool's stated aims (Ivanova and Hallowell, 2013). As described in chapters 6 and 7, data collected from professional participants who reviewed iterations of the Screening Tool during its development were used to establish its face validity. Further data relating to the toolkit's face validity were collected using a usability and acceptability questionnaire created for this study (see pp218-9).

Content validity refers to the extent to which a tool contains items necessary to measure outcomes accurately; content validity can be established on the basis of expert judgement (Franzen, 1989). As described in chapter 6, data collected from experts in communication assessment who reviewed the screen were used to establish its content validity.

A tool is said to have construct validity if it can be demonstrated that it measures the theoretical constructs that it purports to measure (Ivanova and Hallowell, 2013). Construct validity can be investigated by comparing outcomes from a new tool with outcomes from an established tool designed to measure the same constructs. As described in chapter 5, a literature review did not identify any existing standardised tools that enable an assessor to identify whether somebody has a communication disorder and how to support that person's needs. Therefore, it was not possible to investigate the screen's construct validity.

Criterion validity refers to the extent to which an outcome from one tool agrees with an external criterion variable, for example an observed behaviour or an outcome from another validated measure (Franzen, 1989). As described above, no existing tools measure the same outcomes as the Communication Screening Tool. In clinical practice, the approach commonly used to identify a patient's communication abilities and needs and the methods that can be used to support those needs would be to ask a speech and language therapist (SLT) to complete a specialist communication assessment and use her/his expertise to identify support methods to meet an individual's communication needs. Therefore, an SLT's communication assessment was identified as the criterion variable for the Screening Tool. Criterion validity was therefore investigated by comparing outcomes on the Communication Screening Tool obtained by professional participants with outcomes the researcher obtained in his capacity as a trained SLT when he completed a specialist communication assessment.

Data were also collected to investigate the communication screen's reliability. A tool is considered to be reliable if it provides stable outcomes when used by different people at the same time (inter-rater reliability) or by the same person at different times (intra-rater reliability) (Franzen, 1989). It was not appropriate to measure intra-rater reliability, because mental capacity can fluctuate and its assessment is considered to be relevant only to a specific point in time (MCA, 2005). Instead, inter-rater reliability was investigated by comparing the outcomes of screening assessments carried out by two different professional participants.

MCAST usability and acceptability

The researcher carried out a documentary analysis of Support Tool and Communication Screening Tool proformas completed by professional participants during the study, to identify evidence relating to the proformas' feasibility and usability. Quantitative and qualitative data were collected from professional participants after they had used the MCAST using an electronic survey method, in order to investigate whether they found the MCAST usable, useful and its materials and procedures acceptable. This method was chosen because it enabled participants to provide anonymous feedback about the MCAST; this should have reduced the likelihood of response bias and increased the validity of the data.

Patient perceptions of MCAST acceptability

A semi-structured interview method was used to investigate whether patient participants found the MCAST's materials and procedures acceptable and helpful. The interview method was selected because it provided opportunities for patients' individual communication needs to be supported, to maximise their ability to participate. Patients were able to invite family members, carers or friends to support them during the interviews if they wished.

8.3.3 Ethical approval / governance

Ethical approval was obtained from the Bradford Leeds NHS Research Ethics Committee on 12/11/15 (see appendix 37). NHS governance permissions were obtained on 16/02/16 (see appendix 38).

8.3.4 Sampling strategy

Three participant samples were recruited: 1) Sheffield Teaching Hospitals Foundation Trust (STHFT) professionals, 2) STHFT patients and 3) patients' family members, carers or friends (if patients wished these people to participate in the interviews).

Patient participants

A purposive strategy was used to ensure the patient sample included individuals with diagnoses of stroke and cognitive impairment and people with a range of severities of communication difficulty. Patients were included if they had a diagnosis of stroke or cognitive impairment and required a mental capacity assessment relating to a decision about treatment options or discharge arrangements (as identified by the treating multidisciplinary team). The MCAST was designed for use with these groups of patients and for these types of decisions in response to requests from professional participants in the focus group study (chapter 4). Patients were excluded if they had visual difficulties that meant they could not see the toolkit's visual materials or if they required written or spoken information to be made available in a language other than English during the capacity assessment (as this edition of the toolkit was developed using English language materials). Finally, patients were excluded if they required a mental capacity assessment urgently, as the research process might delay this.

Professional participants

A purposive sampling strategy was used, in order to recruit a range of professional groups working across different clinical locations. The professional groups targeted were: liaison psychiatrists, nurses, OTs, physicians, physiotherapists, psychologists, SLTs and social workers. Professionals were eligible for inclusion if they were involved in assessing mental capacity for patients with diagnoses of stroke or cognitive impairment. There were no exclusion criteria.

Patient participants’ family members, carers or friends

A sampling strategy was not used, as these participants were identified by the patient participants. Family members, carers and friends were included if they were willing to support the patient during the interviews. They were not included if they were unable or unwilling to consent to take part in the interviews.

8.3.5 Sample size

Patient participants

As this study was designed primarily to assess the feasibility of the MCAST and the study’s data collection methods, a sample size calculation was not required (NIHR, 2014). Julious (2005) suggests that in this type of situation, a sample size of 12 should be used for reasons of feasibility and because this size provides sufficiently precise estimates for effect sizes and variances that can be used to plan a larger, more definitive investigation. In this study, a sample size of 20 patients was selected to ensure that at least 12 patients with communication difficulties received a communication screen. Over-recruitment by 15% was planned, in order to compensate for participant attrition.

Professional participants

A sample size of 20 health and social care professionals was identified. It was anticipated that each professional would be asked to use the MCAST with one or two patients.

8.3.6 Materials

The Mental Capacity Assessment Support Toolkit (MCAST)

The MCAST Support Tool, Communication Screening Tool and Resource Pack (as described in chapter 7) were used in this evaluation.

The British Psychological Society (2010) Audit Tool for Mental Capacity Assessments

This tool (shown in appendix 39) was selected to measure compliance and identify changes in practice. The audit tool contains standards relating to preparation of the capacity assessment, its conduct, measures taken to support the patient's individual communication needs and documentation.

Self-rated confidence questionnaire for professionals

A paper questionnaire (appendix 40) was developed specifically for this study. The questionnaire asked professional participants to rate on a four option multi-choice scale how confident they felt about assessing mental capacity. It also asked them to explain why they chose to rate themselves as they did. The questionnaire was piloted with three research professionals who have experience of assessing capacity, to ensure it was easy to understand and complete and generated data that answered the questions it posed. No modifications were identified.

Usability and acceptability questionnaire for professionals

An electronic questionnaire was developed specifically for the study, using SurveyMonkey® software. The questionnaire was designed to investigate whether the MCAST met the aims and requirements identified by professionals during the previous focus group study (chapter 4) and whether they found its contents acceptable. The questionnaire content was informed by data collected in the previous focus group study and by user-centred and usability research methods. The survey design was informed by a review of survey methodology literature (e.g., Gehlbach, 2015). The survey content and design were reviewed by an expert in usability testing based at Design Futures (see p184). Minor amendments were made to the survey as a result of this review. The questionnaire included different question formats, including rating scales, multiple choice questions and open questions. It asked professional participants to respond to questions relating to:

- the MCAST's ease of use and usefulness;
- whether any components of the MCAST needed to be modified / removed / added;
- whether and in what ways the MCAST helped professional participants to assess capacity;

- whether and in what ways use of the MCAST benefited patients during capacity assessments;
- the length of time it took to use the MCAST to assess capacity, in comparison with usual practice;
- whether using the MCAST helped professional participants to feel more confident about assessing capacity (responses to this question were compared with responses to the separate confidence questionnaire, in order to investigate whether the questionnaires generated reliable confidence data).

The survey questions are shown in appendix 41. Three researchers were asked to trial completing the questionnaire to ensure it was easy to understand and complete. The software collected data anonymously.

Patient interview materials

A topic guide (appendix 42) was developed to use in the semi-structured interviews with patient participants. The guide was designed to collect data about patients' experience of being assessed using the MCAST communication screen and being supported by professionals using the Resource Pack materials. Questions were identified using information from the accessible information literature review (chapter 5), relating to how people with communication disorders respond to accessible information, and using Proctor *et al.*'s (2011) conceptualisation of acceptability.

A set of resources (example shown in appendix 43) were created to facilitate patient understanding and expression during the interviews. These resources included examples of the MCAST materials and photographs of professional participants which could be shown to patients, to support their memory skills. Accessible rating scales were designed to enable patients to indicate their responses non-verbally to a range of questions (e.g., whether they were happy to be shown Resource Pack materials and whether they felt the materials helped them to participate in the capacity assessment). The study Patient, Carer and Public Involvement (PCPI) advisory group reviewed these materials and commented on their acceptability and usability.

8.3.7 Procedure

Setting

The study took place within STHFT's two acute hospitals and four nursing homes providing STHFT intermediate care services.

Participant identification

Professional participants

An email advertising the study's aims and methods was sent to managers within the following professional groups: liaison psychiatrists, nurses, OTs, physicians, physiotherapists, psychologists, SLTs and social workers. Managers were asked to cascade this information to each professional group. The same email was sent to professionals who had previously participated in the focus group study (chapter 4) and MCAST user-centred design sub-studies (chapters 6 and 7). The study was also advertised via the STHFT electronic staff newsletter. Professionals were invited to email or telephone the researcher if they wished to receive more information about the study or wished to participate.

The researcher emailed and telephoned participants regularly throughout the data collection process, in order to increase participant retention and encourage data collection. Participant withdrawal did occur due to illness or a change in clinical role. In order to recruit new participants when dropouts occurred, the researcher re-sent the advertisement email to the managers for the professional groups and re-posted the advertisement on the electronic staff newsletter.

Patient participants

Patients with diagnoses of stroke or confirmed/suspected cognitive impairment were identified by professionals who had consented to take part in the study. Professionals were given guidance to help them identify patients meeting the eligibility criteria. Professionals asked identified patients if they agreed for the researcher to visit them to discuss participation in the study.

Patients' family members, carers or friends

These participants were identified by patient or professional participants. Contact details for these people were provided with consent by the patient or professional participants.

Participant recruitment

Professional participants

A participant information sheet (appendix 44) was sent electronically to all interested individuals. These individuals were contacted at least 24 hours later to ask if they wished to participate in the study. Written consent was taken using a consent form (appendix 45).

Patient participants

The researcher visited patients to talk to them about participating in the study. As many of these patients had communication difficulties due to their neurological conditions, all patients were given an accessible participant information sheet (appendix 46) to support them to understand what their participation in the study would involve. Supportive communication strategies were used to help each participant to understand the content of the information sheet. The researcher revisited each patient at least 24 hours after the first visit to ask if s/he wished to take part in the study. When a patient agreed to participate, the researcher reviewed the content of the accessible participant information sheet with her/him and asked questions relating to the study and the role of participants, in order to assess the patient's capacity to consent to take part. These questions required only "yes/no" answers and were asked using simplified language.

If a patient demonstrated capacity to consent, written informed consent was taken using an accessible consent form (appendix 47). If a patient demonstrated an inability to understand, retain or weigh the information, but appeared satisfied with the general idea of participating, the researcher asked the patient's family member, friend or carer to complete a "consultee declaration" (appendix 48) to confirm that they were satisfied that the patient wanted to and should participate. This recruitment method has been used in other studies recruiting people with communication difficulties (e.g., Penn *et al.*,

2009) and is consistent with the MCA. It was not possible to recruit patients if they did not demonstrate capacity to consent to participate in the study and did not have family members, friends or carers to complete this declaration.

During the validity and reliability data collection period, patient participants were identified to take part in the acceptability interviews. The sampling frame was used to ensure that participants with diagnoses of stroke and suspected/confirmed cognitive impairment and a range of severities of communication difficulty were represented amongst the interview sample.

Patient family member, friend or carer participants

An information sheet (appendix 49) was sent by post to family members, friends or carers or given to them in person. If these individuals wished to participate, the researcher took written informed consent from them using a consent form (appendix 50) at the start of the patient interview sessions.

Data collection

Measurement of compliance with the MCA

Following recruitment, each professional participant was asked to identify three patients for whom s/he had completed a capacity assessment previously. Each patient was assigned a number and one patient was selected at random by the researcher. The patient's medical notes were located in the clinical setting or requested from the medical records service for the purposes of auditing the capacity assessment documentation within the notes. The assessment documentation was reviewed on hospital premises using the British Psychological Society (2010) audit tool. After professional participants had used the MCAST during the evaluation data collection period, they were encouraged to use the toolkit during their usual clinical practice for a period of up to two months. Professionals were asked to identify patients for whom they had completed capacity assessments during this period. One of these patients was selected at random for each professional participant. The patient's medical notes were audited using the same BPS tool.

Measurement of professionals' self-rated confidence

After each professional participant was recruited, s/he was sent a paper copy of the confidence questionnaire by post. Participants were asked to complete the questionnaire before they used the MCAST and return it in a stamped addressed envelope. When they had completed the evaluation study, participants were sent and asked to complete a second copy of the questionnaire and return this by post. These questionnaires were labelled with anonymised numeric participant identification codes by a member of the PhD supervisory team. This was done to reassure participants that their responses would be anonymous. Participants were also advised not to include identifiable data in their responses to the questionnaires. The use of a unique code per participant enabled both questionnaires to be compared for each participant during data analysis.

Use of the MCAST during capacity assessments

Following recruitment, professional participants were invited to attend a training session, in which the MCAST materials were demonstrated and the patient identification and recruitment and data collection procedures were explained. Written guidance was also provided for participants to refer to during the data collection period. Professionals were instructed that they should use the toolkit to plan and carry out a capacity assessment for at least one patient, in order to collect data for the evaluation study, but could continue to use the MCAST for a period of two months following this, as part of their clinical practice. Professionals were encouraged to be vigilant at all times for signs that patient participants were becoming fatigued or distressed and to pause or terminate a data collection session if they felt this was in the patient's best interests. Each training session lasted approximately 45 minutes.

Before data collection commenced, each professional participant was paired with another participant working in the same clinical locality (e.g., on the same or neighbouring wards or in the same nursing home) to facilitate inter-rater reliability data collection. Professional participants used the MCAST to plan and carry out mental capacity assessments for patient participants identified and recruited within their clinical locality. For each patient, the professional participant completed the MCAST Support Tool and Communication Screening Tool documents (when the latter tool was used).

Professionals were instructed to send completed Support Tool and Communication Screening Tool documents to the researcher. The researcher examined these documents and recorded observations relating to how participants had completed them, in order to identify evidence about the documents' feasibility and usability.

Measurement of Communication Screening Tool inter-rater reliability

The following procedure was used to collect data to measure inter-rater reliability. After a professional participant used the Communication Screening Tool to assess a patient, the paired professional participant was asked to use the tool to screen the same patient within a 48-hour period, to ensure the patient's communication skills were assessed contemporaneously but to enable the patient to rest between assessments. If a patient had a new medical event that might affect her/his communication or cognitive skills (e.g., a urinary tract infection or neurological event) between the two communication screening tests, the second professional participant was asked to record the nature of the medical event. Professionals were instructed not to discuss the screening test outcomes with each other, as this might bias data collection.

Within the same 48-hour period, the researcher visited each patient in the sample to assess her/his spoken and written communication skills. This assessment was used to collect data as part of the procedure for measuring criterion validity (as described on p224). The researcher used the FAST (Enderby *et al*., 2012, see p151 for description) to provide a framework for this communication assessment, in order to ensure that each patient received the same type of assessment. The researcher supplemented the FAST test items with a “yes/no” reliability subtest and a photograph recognition subtest. These subtests contained the same number of test items as the corresponding MCAST Communication Screening Tool subtests and represented a similar level of difficulty (as judged by the researcher’s academic supervisors and members of the project’s PCPI group who had communication disorders).

The researcher’s communication assessment was also used to investigate the validity of professional participants’ decisions about when to use the Communication Screening Tool. If a patient had experienced a new medical event that may have affected her/his communication or cognitive skills between the initial use of the Communication Screening Tool and the researcher’s assessment, these data were recorded. The researcher was blinded to professional participants’ screening test outcome data for patients, to reduce the likelihood of measurement bias.

Measurement of professionals’ perceptions of MCAST usability and acceptability

At the end of the data collection period, participants were sent an electronic link to the SurveyMonkey® questionnaire. They were asked to complete the questionnaire within two weeks. Data were collected automatically by the survey software. Data on the SurveyMonkey® website were accessed by the researcher using a secure password.

Measurement of patient perceptions of MCAST acceptability

The researcher carried out semi-structured interviews with patients after they had been assessed by a professional participant using the MCAST Communication Screening Tool. The researcher aimed to interview patients within 48 hours of their screening test, but this was not always possible. Patients were interviewed in a healthcare setting, unless they had already been discharged from hospital and agreed to be interviewed in their home. Patients’ family members, friends and carers were present during the interviews, if patients invited them to attend. Interviews were recorded with consent, using a digital audio recording device.

The researcher used the communication resources (appendix 43) and different strategies to maximise the participation of patients with communication and cognitive difficulties in the interviews. These strategies were based on the researcher’s clinical experience as an SLT and the work of Luck and Rose (2007). For example, he gave participants additional time to respond and clarified the meaning of individual responses by summarising and paraphrasing answers. To facilitate the participation of individuals with word-finding or memory difficulties, the researcher sometimes offered words or provided a choice of potential response options. He also asked a higher number of closed questions than might usually be used in qualitative interviews, to support participants to generate answers more easily.

8.3.8 Data analysis

Quantitative data from the case note review, professional confidence rating and usability and acceptability questionnaires were inputted to separate Microsoft Excel files and analysed using frequency counts and descriptive statistics, including mean and median values and ranges. Case note review and confidence rating data were also inputted to SPSS files for statistical analysis. Tests for differences were used to investigate whether data collected before and after use of the MCAST were different. A Wilcoxon signed-rank test for non-parametric data was used, as it could not be assumed that population data for these samples would be normally distributed.

Communication Screening Tool data were also inputted to SPSS files for statistical analysis. In order to evaluate the Screening Tool's inter-rater reliability, a Fleiss's Kappa statistic (Fleiss, 1971) was calculated to measure the strength of agreement between nominal data relating to patient participants' performance on the yes/no response reliability and spoken comprehension sub-tests. These data were used because it is on the basis of this type of information that professionals using the Screening Tool are guided to make decisions about how they should support patients' communication difficulties during a mental capacity assessment (see p172 for more details). The same analytic approach was used to investigate the Communication Screening Tool's criterion validity. A Fleiss's Kappa statistic was calculated to measure the strength of agreement between the yes/no response reliability and spoken comprehension data obtained for each patient by the professional participant and the data obtained by the researcher.

When a professional participant did not use the MCAST Communication Screening Tool to screen a patient, the researcher examined quantitative and qualitative data from his own communication assessment of the patient to establish if the patient did or did not demonstrate any communication deficits. A frequency count was used to describe how often professional participants decided not to use the Screening Tool when its use was, in fact, indicated.

Qualitative data from the professional confidence rating and usability and acceptability questionnaires and the patient interviews were transcribed verbatim into separate Microsoft Word files. Each Word file was imported into QSR NVivo 9 software to aid analysis of the qualitative data. The data were analysed thematically, using a Framework approach. This analytic approach was described in chapter 4 (p61).

8.3.9 Data integration

Each data collection method was predominantly designed to generate data to answer an individual research question (see section 8.3.2, p213). However, collection methods generated data that contributed to the answers to multiple questions. Table 8.1 (p228) shows the types of data collected using different methods that are relevant to individual research questions.

The entire dataset was integrated, in order to provide richer, more complete answers to the research questions. Integration of quantitative and qualitative data represents an important stage of analysis within mixed methods studies because it can increase the knowledge yield of individual data collection methods (O'Cathain *et al*., 2010).

Data collection source / Research Question	Document Analysis	Communication Screening Tool Reliability and Validity data	Case note audit	Confidence Survey	Usability Survey	Patient / carer interviews	Researchers reflective journal / field notes
Does use of the MCAST increase compliance with the MCA?	Qual	------	Quant	Qual	Qual	------	Qual
Does use of the MCAST increase professionals' confidence levels when assessing mental capacity?	------	------	------	Quant & Qual	Quant & Qual	------	Qual
Can professionals use the MCAST to identify communication difficulties in patients with stroke and/or cognitive difficulties and how to support patients with these difficulties accurately and reliably during mental capacity assessments?	Qual	Quant	------	------	Quant & Qual	------	Qual
Is the MCAST useable by and acceptable to professionals and patients?	Qual	------	------	Qual	Quant & Qual	Qual	Qual

Table 8.1: Types of data collected by each method in relation to research questions (Qual: qualitative; Quant: quantitative)

Data were integrated using methodological and data triangulation. Methodological triangulation involves the integration of data collected using different methods, whilst data triangulation refers to the integration of data from more than one source (Tonkin-Crine *et al*., 2016). Due to the nature of the research project, investigator triangulation (use of multiple researchers to triangulate) was not possible, although the researcher did discuss the triangulation process and results with his supervisors.

A triangulation protocol (Farmer *et al*, 2006) was used to facilitate integration. This approach provided a structured approach to combining, examining and interpreting data across all collection methods and sources and is compatible with a subtle realist epistemology (O'Cathain *et al*., 2010). Use of a triangulation protocol can increase the validity of findings (Tonkin-Crine *et al*., 2016). Data from the researcher's reflective diary and field notes were also included in the triangulation process.

First, the researcher sorted the quantitative and qualitative data into meaningful categories that related to each research question. For example, for research question 1 "Does use of the MCAST increase compliance with the MCA?", qualitative data collected using the confidence surveys, usability survey and document analysis methods were sorted, in order to identify themes relating to compliance. These categories were examined to identify "key findings", which the researcher expressed as statements, using the approach described by Onwuegbuzie and Teddlie (2003). For example, for research question 1, the key finding was "use of the MCAST appeared to improve the content and recording of capacity assessments". Identification of these statements facilitated comparison of key findings across the different data methods and sources.

Key findings were organised within a separate table or "convergent coding matrix" for each research question (see appendix 51). This organisation enabled the researcher to identify examples of convergence (agreement), complementarity and dissonance (disagreement) between findings and instances of "silence", where findings present in some data sources were not present in others (Farmer *et al*., 2006).

This chapter has reported the data collection and analysis methods that were employed to evaluate the feasibility of using the MCAST in clinical practice. The results of this feasibility evaluation are presented in chapter 9.

Chapter Nine: MCAST Feasibility Evaluation Results

9.1 Introduction

This chapter presents the results of the feasibility study in which the MCAST was tested in clinical practice. First, the results of each of the data collection methods described in chapter 8 are presented. Next, data from all these data collection methods are integrated, in order to identify evidence to answer the first four study research questions (see figure 9.1 below). Data relating to the feasibility of the methods used in this study are then reported (research question 5). Finally, the results are discussed in relation to the research project aims and limitations to this study are identified.

1. Does use of the MCAST increase compliance with the Mental Capacity Act (2005)?
2. Does use of the MCAST increase professionals' confidence levels when assessing mental capacity?
3. Can professionals use the MCAST to identify communication difficulties in patients with stroke and/or cognitive difficulties and how to support patients with these difficulties accurately and reliably during mental capacity assessments?
4. Do professionals and patients find the MCAST useable and acceptable?
5. Are the recruitment and data collection methods used in this study feasible within NHS settings?

Figure 9.1: Feasibility study research questions

9.2 Results

9.2.1 Participants

Professional participants

Twenty-four professional participants were recruited purposively to take part in the study (see sampling strategy, pp216-7). Three of these participants withdrew from the study before data collection commenced. One participant withdrew due to long-term illness and two withdrew because participation in the study was no longer compatible with their professional role. Participant characteristics for the remaining 21 participants are shown in table 9.1. Two of the participants, E005 and E007, had taken part in the focus group study (chapter 4) and the toolkit development sub-studies (chapters 6 and 7).

Twenty participants were female and one was male. Five different professional groups were represented in the sample: physicians (n=3), nurses (n=1), OTs (n=10), physiotherapists (n=2) and SLTs (n=5). Eleven participants worked in acute hospital settings, including neurosciences (n=2), neurorehabilitation (n=3), stroke and geriatric medicine (n=5). The remaining participant, an SLT (E009), worked in a peripatetic capacity across diverse acute medical and rehabilitation settings. Nine participants worked in multidisciplinary intermediate care teams providing either general rehabilitation (n=7) or specialist stroke rehabilitation (n=2). One participant, a neurologist (E007), worked in acute stroke and geriatric medicine and cognitive neurology services across acute and community settings.

Participants’ length of experience in their professional role ranged from three to twenty-four years. The majority of participants (n=17) had received general training in mental capacity assessment from the healthcare trust or a previous employing trust, as part of its staff training programme. Five participants had received additional training within their multidisciplinary team, two had learned about capacity assessment by shadowing colleagues and three had received training at professional conferences or as part of a taught course. One participant (E011) had received no formal training.

Staff participant identifier	Professional role	Clinical setting	Type of training received in MCA[40]
E001	OT	Acute hospital	General and setting-specific
E003	SLT	Acute hospital	General and setting-specific
E004	SLT	Acute hospital	General and setting-specific
E005	OT	Acute hospital	General
E006	OT	Acute hospital	General and shadowing colleagues
E007	Consultant neurologist	Acute hospital and community services	General and discipline-specific
E008	Discharge planning Sister	Acute hospital	General and setting-specific
E009	SLT	Acute hospital	General
E010	OT	Acute hospital	"1 hour in previous trust"
E011	OT	Acute hospital	No formal training
E013	SLT	Intermediate care	General
E014	Physiotherapist	Intermediate care	General
E015	OT	Intermediate care	Data not provided
E016	OT	Intermediate care	General and setting-specific
E017	OT	Intermediate care	General
E018	Physio-therapist	Intermediate care	Data not provided
E020	OT	Intermediate care	General
E021	Consultant Physician	Acute hospital	Academic study
E022	Specialist Registrar	Acute hospital	General, shadowing colleague
E023	SLT	Intermediate care	General
E024	OT	Intermediate care	General

Table 9.1: Professional participant characteristics

Patient participants

Seventeen patients were recruited to the study: nine males and eight females. Participant characteristics are presented in table 9.2. Participants' ages ranged from 48 to 93 years at the time of recruitment. Six individuals had a diagnosis of acute stroke whilst one participant had had a stroke prior to this episode of care. Four stroke survivors had comorbidities (subdural haematoma, schizophrenia, space occupying lesion, chronic memory impairment). Ten participants presented with cognitive

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[40] General training refers to training in the MCA provided by the healthcare trust as part of its staff training programme.

difficulties, due to sub-arachnoid haemorrhage (n=3), a diagnosed or suspected dementia process (n=6) or a history of memory impairment (n=1). Patients were recruited from a range of clinical settings, including acute and intermediate care stroke services (n=6), a sub-acute neuro-rehabilitation unit (n=3) and an acute hospital dementia unit (n=2). Six participants were able to provide informed consent whilst a Consultee Declaration was obtained for the remaining 11 participants.

Nature of capacity assessments

The majority of mental capacity assessments conducted using the MCAST related to decisions about choice of residence or care arrangements on discharge from hospital (n=15). For one participant (P02), the assessment related to whether the patient could provide informed consent for ongoing inpatient rehabilitation. For the other participant (P12), the capacity assessment concerned the decision to accept or decline a Percutaneous Endoscopic Gastrostomy (PEG). Twelve participants were found to lack mental capacity to make the specified decision, whilst three were found to demonstrate capacity. Capacity assessment outcome data were not available for two participants (P11, P13) because the professional participant did not complete the planned assessment.

Table 9.2: Patient participant characteristics and nature of capacity assessments

Patient participant identifier	Age	Diagnosis	Clinical setting	Consent or Consultee Declaration obtained	Decision patient asked to make during capacity assessment	Outcome of capacity assessment
P01	91	Stroke	Acute hospital	Consultee declaration	To accept / decline care at home on discharge	Lacked capacity to make decision
P02	73	Sub-arachnoid haemorrhage	Acute hospital	Consent	To consent to ongoing inpatient rehabilitation	Lacked capacity to make decision
P03	82	Delirium, ? existing dementia	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home on discharge	Demonstrated capacity to make decision
P04	52	Sub-arachnoid haemorrhage	Acute hospital	Consent	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P05	86	Delirium, ? existing dementia	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home with care on discharge	Lacked capacity to make decision
P06	48	Sub-arachnoid haemorrhage	Acute hospital	Consent	To return to own home or live near family on discharge	Lacked capacity to make decision
P07	92	Chronic memory impairment	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P08	82	Subdural haematoma, previous stroke	Intermediate care	Consent	To enter 24-hour care or return to own home with care on discharge	Lacked capacity to make decision
P09	93	Dementia	Acute hospital	Consultee declaration	To enter 24-hour care or return to own home with care on discharge	Lacked capacity to make decision
P10	88	Dementia	Acute hospital	Consultee declaration	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P11	55	Stroke / Schizophrenia	Acute hospital	Consent	To enter 24-hour care or return to own home on discharge	Data not available: patient not assessed by E005

Patient participant identifier	Age	Diagnosis	Clinical setting	Consent or Consultee Declaration obtained	Decision patient asked to make during capacity assessment	Outcome of capacity assessment
P12	76	Stroke	Acute hospital	Consent	To consent to PEG placement	Demonstrated capacity to make decision
P13	70	Stroke / space occupying lesion	Acute hospital	Consultee declaration	To enter 24-hour care or return to own home on discharge	Data not available: patient not assessed by E006
P14	67	Stroke	Acute hospital	Consultee declaration	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P15	73	Dementia	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P16	92	Stroke, chronic memory impairment	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home on discharge	Lacked capacity to make decision
P17	73	Dementia	Intermediate care	Consultee declaration	To enter 24-hour care or return to own home on discharge	Demonstrated capacity to make decision

Family carer participants

Two family carers were recruited to take part in interviews about the use of the MCAST with their relative: see table 9.3. The family carers were recruited because the researcher and family carer judged that the patient participant would be unable to participate in an interview due to their communicative and cognitive impairments.

Participant identifier	Gender	Family carer for patient participant
C01	Male	P14
C02	Male	P15

Table 9.3: Family carers recruited to participate in interviews

9.2.2 Case note audit

A case note audit was carried out before and after introduction of the MCAST to investigate whether capacity assessment practice and compliance with the MCA changed following the introduction of the MCAST. Participants were asked to identify up to three capacity assessments they had carried out in the twelve-month period before the feasibility study (T1) and three assessments carried out during/after the study (T2). The researcher randomly selected one assessment at T1 and one at T2 for each participant and audited the assessments using the British Psychological Society (2010) audit tool (appendix 39).

The audit scores for each participant’s capacity assessment at T1 and T2 are shown in table 9.4. A higher score indicates an assessment was more compliant with the MCA. It was only possible to audit assessments at both T1 and T2 for 10 professional participants, for the reasons shown in table 9.4. Most audited assessments had been documented in patients’ paper or electronic records, either in the body of the notes or using proformas provided by the hospital trust or the local authority (LA). One participant (E008) inserted the MCAST proforma within patient records as evidence of a capacity assessment at T2.

Professional participant identifier	Audit score T1 (min = 0, max = 86)	Method of documentation	Audit score T2 (min = 0, max = 86)	Method of documentation
E001	46	Trust proforma	59	Trust proforma
E003	43	Trust proforma	72	Trust proforma
E004	44	Electronic patient record	67	Trust proforma
E005	55	LA proforma	No data provided	
E006	68	LA proforma	83	LA proforma
E007	42	Patient record	Unable to locate data	
E008	47	LA proforma	66	MCAST
E009	Unable to locate data		51	Electronic patient record
E010	Unable to locate data		No assessments completed	
E011	49	Trust proforma	No assessments completed	
E013	68	Trust proforma	60	Electronic patient record
E014	55	Trust proforma	75	Trust proforma
E015	60	Trust proforma	No data provided	
E016	46	Trust proforma	No data provided	
E017	45	Trust proforma	61	Electronic patient record
E018	Unable to locate data		No data provided	
E020	51	Trust proforma	71	Trust proforma
E021	Unable to locate data		57	Patient record
E022	57	LA proforma	Unable to locate	
E023	57	Trust proforma	No assessments completed	
E024	43	Electronic patient record	70	Electronic patient record

Table 9.4: Audit scores and nature of documentation for capacity assessments completed before (T1) and after (T2) the introduction of the MCAST.

The audit score for assessments carried out after the introduction of the MCAST (T2) were observed to be higher than those carried out before its introduction (T1) for nine participants. The audit score was lower at T2 for one participant (E013). The T1 and T2 audit scores were compared statistically using a Wilcoxon Signed Ranks Test for non-parametric data. This statistical analysis was based on data for the ten participants for whom the researcher was able to audit capacity assessments at both T1 and T2. Incomplete data for the other eleven participants were excluded from the statistical testing because it is not possible to account for missing data using the Wilcoxon Signed Ranks Test. Scores for assessments recorded after introduction of the MCAST were significantly higher than those for earlier assessments (Z = -2.703, p=0.007) for the ten participants. This suggests that these participants' capacity assessments were more compliant with the MCA after they had experienced using the MCAST.

9.2.3 Professional confidence questionnaire

Professional participants were asked to complete two copies of the confidence questionnaire (appendix 36), one at the start (T1) and one at the end (T2) of the feasibility study. This measure was used to investigate whether participants' levels of confidence in their ability to assess capacity changed after they had used the MCAST. The questionnaire asked respondents to tick a box corresponding to a written statement that best described how confident they felt at that moment about assessing mental capacity. These statements are shown in table 9.5. The researcher attached a numerical score (1-4) to each statement as shown in table 9.5, to enable comparisons to be made between data collected at T1 and T2.

Questionnaire statement	Score for purposes of T1/T2 comparison
Not confident at all	1
Not too confident	2
Fairly confident	3
Very confident	4

Table 9.5: Statements used in confidence questionnaire and associated numerical score

The questionnaire also included a free text question which asked respondents to explain why they had selected a particular statement to describe how confident they felt. Complete data were obtained for 17 participants.

Quantitative data

Quantitative data collected from professional participants using the confidence questionnaire at the start (T1) and end (T2) of the study are shown in table 9.6. The confidence scores collected at T2 were higher than those at T1 for seven participants, indicating greater confidence, whilst they remained unchanged for 10 participants. Confidence scores at T1 and T2 for the 17 participants who provided complete data were compared statistically using The Wilcoxon signed Ranks Test for non-parametric data. Incomplete data for the other four participants were excluded from the statistical testing because it is not possible to account for missing data using the Wilcoxon Signed Ranks Test. This statistical testing demonstrated that, for these 17 participants, confidence scores were found to be significantly higher at T2, i.e., following introduction of the MCAST (Z = -2.646, p=0.008).

Professional participant identifier	Confidence score T1	Confidence score T2
E001	3	3
E003	3	4
E004	3	3
E005	4	4
E006	3	4
E007	3	No data provided
E008	3	No data provided
E009	3	3
E010	3	4
E011	3	3
E013	3	4
E014	3	3
E015	3	3
E016	3	No data provided
E017	2	3
E018	2	No data provided
E020	3	3
E021	3	4
E022	3	3
E023	3	3
E024	2	3

Table 9.6: Quantitative confidence survey data

Qualitative data

Analysis of professional participants' responses to the free text question in the questionnaire identified major themes relating to factors that may have positive and/or negative effects on how confident professionals feel about assessing mental capacity. These themes included how participants learned about and experienced capacity assessment, and factors relating to individual practice, the wider organisation and the nature of individual patients' situations. The analytic process enabled the identification of a number of subthemes within these themes. The identified themes and subthemes are presented in table 9.7 with illustrative sections of raw data.

Many of the same themes were present in participants' responses both before (T1) and after (T2) the introduction of the MCAST, indicating that similar factors affected participants' confidence at both times. At T2, several participants directly referred to being involved in the feasibility study and using the MCAST to complete capacity assessments; they indicated the positive effect that this had had on their confidence. They described specific ways in which using the MCAST had influenced their confidence. These included being better able to structure and prepare assessments and to identify and support patients' communication needs. Interestingly, at T2, participants did not refer to the organisational or individual practice factors that they had identified as having a negative effect on their confidence at T1.

Table 9.7: Themes and subthemes in qualitative confidence survey data

Themes and subthemes relating to factors that appear to affect confidence positively	
T1 data	**T2 data**
Theme: Education	**Theme: Education**
Subtheme: Training / private study "I think the MCA training was really good at explaining what capacity is…" (E023) **Subtheme: Learning from observing others** "I have gained in confidence to carry out assessments by carrying them out, often with patients with complex cognitive and communication impairments, with experienced colleagues" (E005)	**Subtheme: Training / private study** "…attended numerous talks / courses on MCA." (E021)
Theme: Experience of assessment	**Theme: Experience of assessment**
Subtheme: Assessing capacity frequently "…it depends on the frequency with which we do them as to how confident I feel…" (E001)	**Subtheme: Assessing capacity frequently** "Have had lots of prior experience, including experience in using assistive

Subtheme: Assessing jointly with colleagues “Assessments are usually done in pairs so it helps to have the support of a colleague.” (E015)	technologies.” (E021) **Subtheme: Assessing jointly with colleagues** “I usually carry out assessments with a colleague and find discussions with them very useful for this.” (E004)
Themes and subthemes relating to factors that appear to affect confidence positively	
Theme: Individual practice	**Theme: Individual practice**
Subtheme: Having specialist knowledge of patient group “I only complete (the assessment) if I feel I know the patient / situation well and their skills / abilities are within my remit.” (E006) **Subtheme: Preparing thoroughly for assessments** “We usually gather a lot of information before a capacity assessment so we get to know patients fairly well beforehand.” (E015) **Subtheme: Reflecting on own practice** “I find it helpful to reflect on capacity assessments I have carried out, with colleagues and have become more confident in my practice through applying their advice in subsequent assessments.” (E013)	**Subtheme: Having specialist knowledge of patient group** “I feel I know my patient group well to be able to prepare.” (E006)
	Theme: Study participation
	Subtheme: Using the MCAST “Using the MCAST helped me feel much better prepared and made the assessment easier. The communication tool prompted me to use tools/resources I wouldn’t have before which again made the assessment process easier.” (E015) **Subtheme: Participating in study brings increased awareness of mental capacity issues** “being involved in the study I now have increased awareness of issues of communication and capacity.” (E020)

Themes and subthemes relating to factors that appear to affect confidence negatively	
T1 data	**T2 data**
Theme: Organisational factors	
Subtheme: Uncertainty about best practice “…as a team there is still uncertainty around best practice…” (E003) **Subtheme: Inconsistent practice** “…different team members do carry out assessments in varying levels of detail” (E003)	
Themes and subthemes relating to factors that appear to affect confidence negatively	
Theme: Patient factors	**Theme: Patient factors**
Subtheme: Complex patient presentation “…I feel confident when the capacity assessment is straightforward but I struggle with the complex ones particularly when it is a question between unwise decision and lack of capacity” (E016)	**Subtheme: Complex patient presentation** “Where a patient presents as intellectual or gives expected / stock answers it can be very difficult to tease apart the answers to identify how much depth there is to their understanding.” (E014)
Theme: Individual practice	
Subtheme: Lack of preparation for assessments “Sometimes I don’t feel very well prepared – for example not knowing all the risks and benefits of the decision I am supposed to be discussing with the patient.” (E009)	

9.2.4 Document analysis

Support Tool

Fifteen completed Support Tool proformas were received from professional participants. Proformas were not returned for patient participants P11 and P13. These individuals were identified by professional participants in the study who planned to complete mental capacity assessments for them; however, their capacity assessments were actually completed by other professionals who were not study participants. The Support Tool proformas had been completed by 11 participants, i.e., four participants each returned completed proformas for two different patients.

Table 9.8 presents a summary of the researcher's observations and the frequency with which specific participant behaviours were observed across the 15 completed Support Tool proformas. The Support Tool proforma can be viewed in appendix 31.

Table 9.8: Document analysis of completed Support Tool proformas

Page	Section of the Support Tool proforma	Researcher's observations	Is observed behaviour consistent with MCA?	Number of instances
1	What is the decision the person needs to make?	All items completed	Yes	4/15
		Decision recorded not single or specific	No	8/15
		Decision recorded for *assessor* to make, not patient	No	1/15
		No patient decision recorded	No	2/15
1	Why do you need a mental capacity assessment?	All items completed	Yes	14/15
		Review date option used even when capacity assessment could not be delayed	NA	1/15
2	**Preparation for mental capacity assessment**			
	Q1	Complete relevant information provided	Yes	4/15
		Only summary information recorded	No	7/15
		Incomplete information recorded (e.g., incomplete decision options; risks but not benefits of options)	No	4/15
	Q2	Specific examples of individual characteristics that may affect decision-making recorded	Yes	3/15
		"Nil known / not known" recorded	No	3/15
		"Nothing identified" recorded	Yes	2/15
		"NA" recorded	No	4/15
		No response recorded	No	3/15
	Q3-10	All items completed	Yes	6/15
		"Yes / no / NA" decision boxes not completed	No	6/15
		Evidence about support methods incomplete / missing	No	5/15
		More documentation space needed	NA	3/15
3	Preparing the person and environment	All items completed	Yes	9/15
		Extra information recorded about changes made	Yes	2/15

Page	Section of the Support Tool proforma	Researcher's observations	Is observed behaviour consistent with MCA?	Number of instances
3-4	**Document below what your assessment indicates, based on the balance of probabilities**			
	Q1-6	All questions completed when indicated	Yes	7/15
		"Yes/ no" decision boxes not completed	No	4/15
		Evidence to support decisions incomplete / missing	No	6/15
		More documentation space required	NA	3/15
		Q1-6 completed in full even if not required	NA	7/15
	Q7	Decision about mental capacity recorded	Yes	15/15
	Q8	Causative nexus question completed *3/15 patients were found to have capacity therefore Q8 irrelevant	Yes	12/12*
		Relevant evidence provided	Yes	3/12*

Communication Screening Tool

Eighteen completed Communication Screening Tool proformas were received from professional participants. The 18 proformas were used for screening assessments of nine patient participants, as two professionals independently screened the same patient participant, to collect data to inform the measurement of the tool's validity and reliability. The Screening Tool was used by 12 different professional participants. Table 9.9 presents observations made by the researcher relating to how these participants had completed the tool proforma. The proforma can be viewed in appendix 32.

Page	Section of Communication Screening Tool	Observations	Number of instances
1	Preparation	All items completed	15/18
		Additional documentation space needed	4/18
1-2	Section 1: The person's ability to speak	All items completed	17/18
		"Yes/no" decision boxes not completed	1/18
2	Section 2: The person's ability to answer "yes / no"	All items completed	18/18
		Additional documentation space needed	2/18
3	Section 3: The person's ability to understand speech	All items completed when indicated	14/14*
		Section completed when not indicated	3/4*
3	Section 4: The person's ability to read	All items completed when indicated	4/4*
		Section completed when not indicated	8/14
		Assessor wrote targets on form	3/12
4	Section 5: The person's ability to recognise photographs	All items completed when indicated	4/4*
		Section completed when not indicated	6/14
		Additional documentation space needed	2/10
		E004 noted P04 unable to generalise from specific photograph to objects	N/A
4	Section 6: The person's ability to write	All items completed when indicated	4/4*
		Section completed when not indicated	6/14
		Additional documentation space needed	1/10

*The professional participant did not have to complete all sections for all patients; the sections to be completed depended on patients' performance on earlier sections.

Table 9.9: Document analysis of Communication Screening Tool proformas

9.2.5 Communication Screening Tool criterion validity and inter-rater reliability

Criterion validity and inter-rater reliability were investigated by comparing findings obtained by professional participants using the Communication Screening Tool with those obtained by the researcher completing a separate communication assessment (method on p224). Data relating to the professional and patient participants involved in the communication screening tests are shown in table 9.10. A range of professionals working in different acute and intermediate care settings used the Screening Tool. Most professionals who used the tool were OTs; this trend is consistent with the relatively high representation of OTs in the complete professional participant sample (table 9.1, p233). Professionals used the Screening Tool with patients with primary diagnoses of stroke, brain injury, delirium and dementia.

As shown in table 9.10, most participants were assessed by the researcher (R) and then received a screening test administered by the professional participant leading the capacity assessment for the patient (A), followed by a screening test by the paired professional participant (B) (i.e., order RAB). As noted in chapter 8 (p186), the study protocol recommended that the researcher and professional participant A complete their assessment / screening test within the same 48-hour period; similarly, the protocol recommended that professional participants A and B complete their tests within the same 48-hour period. Table 9.10 shows that this was achieved for most patients. However, some patients were tested over longer periods of time, due to professional participants not being available to complete data collection promptly.

Table 9.11 presents the results of the communication assessment carried out by the researcher for each patient participant and the results obtained by professional participants A and B using the MCAST Communication Screening Tool.

Patient participant			Professional participant A		Professional participant B		Order of testing*	Testing time period*
Identifier	**Diagnosis**	**Clinical setting**	**Participant identifier**	**Professional role**	**Participant identifier**	**Professional role**		
P01	Stroke	Acute hospital	E006	OT	E005	OT	RAB	RA >48h AB <48h
P03	Delirium, ? existing dementia	Intermediate care	E014	Physio	E016	OT	RAB	RA >48h AB <48h
P04	Sub-arachnoid haemorrhage	Acute hospital	E004	SLT	E003	SLT	RBA	RA <48h BA <48h
P05	Delirium, ? existing cognitive impairment	Intermediate care	E020	OT	E016	OT	RAB	RA <48h AB <48h
P08	Subdural haematoma, previous stroke	Intermediate care	E015	OT	E017	OT	RAB	RA >48h AB <48h
P11	Stroke / Schizophrenia	Acute hospital	E005	OT	E001	OT	RAB	RA <48h AB <48h
P14	Stroke	Acute hospital	E021	Physician	E006	OT	ARB	AR <48h AB >48h
P15	Dementia	Intermediate care	E020	OT	E014	Physio	BAR	AR <48h BA >48h
P17	Dementia	Intermediate care	E014	Physio	E020	OT	RBA	RA >48h BA >48h

Table 9.10: Communication Screening Tool validity and reliability testing: patient and participant characteristics, testing order and timing data

* R: Researcher, A: Professional participant A; B: Professional participant B.

Patient participant identifier	Yes / No response accuracy (Screening Tool Section 2)			Spoken comprehension ability (Screening Tool section 3)			R screen outcome *	A screen outcome *	B screen outcome *	Researcher observations
	R	A	B	R	A	B				
P01	6/6	6/6	6/6	< 3 ICW**	Complex command	Complex command	3	1	1	• Visual difficulties may have affected performance on R's assessment. • Patient already assessed by ward SLT; SLT not involved in capacity assessment.
P03	6/6	6/6	6/6	< 3 ICW	Complex command	3 ICW	3	1	2	Nil
P04	6/6	6/6	6/6	Complex command	< 3 ICW	3 ICW	1	3	2	• Patient developed signs of urinary tract infection between A and B screens. • Professional participant A was an SLT.
P05	6/6	6/6	6/6	< 3 ICW	Complex command	Complex command	3	1	1	Nil
P08	6/6	6/6	6/6	< 3 ICW	3 ICW	Complex command	3	2	1	Professional participant A reported using results of screening test to aid capacity assessment.
P11	6/6	6/6	6/6	3 ICW	Complex command	Complex command	2	1	1	Impulsive responding evident in Section 3 responses during R's assessment.
P14	<6/6	< 6/6	<6/6	< 3 ICW	< 3 ICW	Not tested***	3	3	3	Patient already assessed by ward SLT; SLT was not involved in capacity assessment.
P15	<6/6	< 6/6	<6/6	< 3 ICW	< 3 ICW	< 3 ICW	3	3	3	Following screen, professional participant A referred to SLT who contributed to capacity assessment.
P17	6/6	6/6	6/6	< 3 ICW	Complex command	Complex command	3	1	1	Patient's hearing difficulties evident during R's assessment.

Table 9.11: Communication Screening Tool data collected during validity and reliability testing

Legend for table 9.11:
* Outcome corresponds to the approach the MCAST Screening Tool indicates staff should adopt during the capacity assessment, based on the patient's performance on the yes/no response reliability and spoken comprehension sub-tests:

1: Staff should avoid using any specialist language to explain information during the capacity assessment;
2: Staff should use specified communication strategies during the capacity assessment;
3: Staff should refer to an SLT for specialist communication assessment prior to the capacity assessment.

** Number of information carrying words (ICW): the words in a sentence that need to be understood in order for its meaning to be derived (see p89).

*** The spoken comprehension tasks (Screening Tool section 3) do not need to be completed if the patient scores <6/6 on the yes/no response accuracy task (Screening Tool section 2).

Criterion validity

The criterion validity of the MCAST Communication Screening Tool was investigated by comparing outcomes obtained by the researcher using his own communication assessment (used as the criterion variable; see pp214-5) and outcomes obtained by professional participants (those with the participant A role). Table 9.11 shows that the researcher obtained outcome 3 (referral to an SLT) for the majority of patients. There was greater variability in the outcomes obtained by professional participants using the Screening Tool, although most participants obtained outcome 1 (use of non-specialist language). The researcher and professional participants obtained the same outcome for two of the nine patient participants. These two patients presented with severe communication difficulties; one was globally aphasic[41] following a stroke (P014) and the other had severe cognitive-communication difficulties secondary to dementia (P015). Statistical analysis using a Fleiss kappa statistic (k=-0.370, 95% CI [-0.882, 0.144]) suggests that there was "poor" agreement[42] between outcomes obtained using the Screening Tool and those obtained by the researcher (Landis and Koch, 1977).

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[41] Global aphasia refers to severe impairments in the abilities to understand and express spoken and written language.

[42] Landis and Koch (1977) provided the following benchmarks for interpreting the value of the kappa statistic in terms of the strength of agreement between variables: <0.00: poor agreement; 0.00-0.20: slight agreement; 0.21-0.40: fair agreement; 0.41-0.60: moderate agreement; 0.61-0.80: substantial agreement; 0.81-1.00: almost prefect agreement.

However, the wide confidence interval suggests the estimate for kappa was not precise; this is likely to be due to the sample size.

However, table 9.11 shows that the yes/no response accuracy outcomes obtained for patient participants by the researcher and by professional participants were 100% consistent. Statistical analysis using a Fleiss kappa statistic (k=1, 95% CI [0.347, 1.653]) suggests that there was “near perfect” agreement between outcomes from this Screening Tool subtest and those obtained by the researcher (Landis and Koch, 1977); this provides indicative evidence of this subtest’s criterion validity. However, the wide confidence interval suggests the estimate for kappa was not precise; again, this is likely to be due to the sample size.

Consistent outcomes on the spoken comprehension tasks were obtained for only two participants (P14, P15). The kappa statistic calculated for these data indicated “poor” agreement between outcomes from the Screening Tool spoken comprehension subtest and those obtained by the researcher (k=-0.370, 95% CI [-0.882, 0.144]). Several patient-related factors may have contributed to the differences in outcomes observed between the researcher’s and professional participant A’s tests of spoken comprehension. Participant P01 experienced difficulty seeing the visual materials used in the FAST subtests used by the researcher due to changes in her eyesight caused by her stroke; this may have affected her performance during the researcher’s assessment (for subsequent patient participants with visual difficulties, the researcher adjusted the procedure by substituting the spoken comprehension items with tasks that could be completed without the patient needing to view the FAST materials). Participant P11 responded impulsively to a spoken comprehension test item during the researcher’s screening test, which affected his overall outcome, as the FAST requires the test assessor to score only the participant’s first response. Participant P11 was able to self-correct his response independently, suggesting that his comprehension was intact. Finally, participant P04 developed a urinary tract infection (UTI) at the time that professional participants A and B completed their screening tests; this may have affected his performance on the MCAST Screening Tool.

Inter-rater reliability

Inter-rater reliability was investigated by comparing outcomes obtained by professional participants A and B when they both used the Screening Tool with the same patient. Table 9.11 shows that participants A and B obtained the same outcomes for six of the nine patient participants. The kappa statistic calculated for these data indicated "moderate" agreement between outcomes obtained by participants A and B using the Screening Tool (k=0.432, 95% CI [-0.053, 0.917]). The very wide confidence interval suggests the kappa estimate was not precise; this is likely to be related to the small sample size.

The yes/no response accuracy outcomes obtained by the pairs of professional participants were 100% consistent. Statistical analysis using a Fleiss kappa statistic (k=1, 95% CI [0.347, 1.653]) indicated that there was "near perfect" agreement between outcomes on this subtest when it was used by different assessors, which suggests the subtest has excellent inter-rater reliability. However, the confidence interval for kappa was wide, which suggests the estimate for the statistic was not precise. Professional participants obtained consistent outcomes on the spoken comprehension subtest for five of eight patients (data for participant P14 were not included in this analysis because professional participant B discontinued the screening test before the spoken comprehension subtest). The kappa statistic calculated for these data (k=0.304, 95% CI [-0.208, 0.144]) indicated "fair" agreement between outcomes obtained by different participants using this subtest on the Screening Tool. Again, the confidence interval suggests the estimate for kappa is likely to be imprecise, due to size of the sample.

Sequelae of communication screening

Professionals in the participant A role were instructed to use the results of her/his screening test to decide how to support the patient's communication during the capacity assessment. As shown in table 9,11, the results of four of the nine screening tests indicated that the professional participant should take specific action to support the patient. This either involved use of communication strategies (P08) or referral to an SLT (P04, P14, P15). Based on their documentation of the capacity assessment on the Support Tool proforma, professional participants appeared to provide the support indicated by the communication screen in three of four cases. E015 used strategies to support P08 during the capacity assessment. E004, herself an SLT, provided specialist support to P04 during the capacity assessment, whilst E020 referred to an SLT for communication assessment and practical support during the capacity assessment for P15. In contrast, E021 did not involve an SLT in P14's capacity assessment, despite her evident significant communication difficulties caused by global aphasia.

Patients for whom professional participants did not use the Communication Screening Tool

The second page of the MCAST Support Tool prompts professionals to consider using the Communication Screening Tool to screen a patient's communication skills if they are unsure if this person has any communication support needs and cannot obtain this information from the patient's medical record or from their family or friends or from professionals.

Data relating to the eight patient participants who did not receive a communication screening test are shown in table 9.12. These participants had a range of diagnoses and were being treated in different clinical settings. The professional participants completing their capacity assessments were from a range of professional roles. Three of the patients had previously been assessed by an SLT prior to being recruited to the feasibility study. This is likely to explain why professional participants chose not to use the Screening Tool. For two of these patients (P13, P06), the SLT contributed to the capacity assessment that took place during the feasibility study. For the other participant (P12), professional participant A completed the capacity assessment without involving an SLT. Participant P12 had been assessed by the ward SLT but was not found to have a communication disorder; this was confirmed by the researcher's communication assessment, which indicated that the patient did not require any additional communication support during a capacity assessment (outcome 1). Of the five patients whom professional participants decided not to screen, the researcher found that one (P02) did not present with any significant communication difficulties (outcome 1). However, the researcher's assessment indicated that the remaining four patients had significant communication support needs that warranted referral to an SLT (outcome 3).

Patient participant			Researcher screening test			Professional participant A professional role	Researcher Observations
Identifier	Diagnosis	Clinical setting	Yes / No response accuracy	Spoken comprehension ability	Screen Outcome*		
P02	Sub-arachnoid haemorrhage	Acute hospital	6/6 correct	Complex command	1	OT	Nil
P06	Sub-arachnoid haemorrhage	Acute hospital	6/6 correct	< 3 ICW	3	OT	Patient already assessed by ward SLT, who contributed to capacity assessment.
P07	Chronic memory impairment	Intermediate care	6/6 correct	< 3 ICW	3	OT	Nil
P09	Dementia	Acute hospital	6/6 correct	< 3 ICW	3	Nurse	Nil
P10	Dementia	Acute hospital	6/6 correct	< 3 ICW	3	Physician	Nil
P12	Stroke	Acute hospital	6/6 correct	Complex command	1	Physician	Visual difficulties affected R's assessment: procedure adjusted. • Patient already assessed by ward SLT who was not involved in capacity assessment.
P13	Stroke / space occupying lesion	Acute hospital	<6/6 correct	< 3 ICW	3	OT	• Reduced attention during R's assessment. • Patient already assessed by ward SLT who contributed to capacity assessment.
P16	Stroke, chronic memory impairment	Intermediate care	6/6 correct	< 3 ICW	3	OT	Patient's hearing difficulties evident during R screen

Table 9.12: Data relating to patient participants with whom professionals did not administer Communication Screening Tool

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Legend for table 9.12:
* Approach that MCAST indicates staff should adopt with the patient based on the results of researcher’s communication screening test:
1: Staff should proceed to capacity assessment but avoid use of specialist language;
2: Staff should proceed to capacity assessment using specified communication strategies;
3: Staff should refer to an SLT for specialist communication support

9.2.6 Usability survey

An online survey was used to collect anonymous quantitative and qualitative data from professional participants after they had used the MCAST, in order to investigate whether they found the MCAST to be usable and its materials and procedures acceptable.

Respondents

Nineteen participants completed the survey, which represents a 90% response rate. Respondents were representative of the complete professional participant sample, because they worked in a range of professional roles and clinical settings and with different groups of patients. The survey sample included one nurse, eight OTs. three physicians, two physiotherapists and five SLTs. Eleven respondents worked in hospital settings, seven in intermediate care and one participant worked across both clinical contexts. Twelve professionals reported they worked with stroke survivors, 15 worked with people living with dementia and 15 reported working with people with other types of cognitive difficulties.

Use of the MCAST

Eighteen respondents reported that they had used the toolkit at least once. Nine participants had used it two or three times. The participant who had not used the toolkit reported that this was because s/he had had “limited opportunities to complete mental capacity assessments during the time frame” of the study (April to September 2016).

Professional participants’ views of the Support Tool

Ease of use

All respondents reported that the Support Tool was easy to use. Eleven respondents stated that they found it “quite easy” to use, whilst six found it “very easy”. Analysis of the qualitative survey data indicates that participants found the Support Tool easy to use due to the clarity of its content and layout. One respondent commented that the tool contained “very clear instructions and (an) obvious flow of information”. Four participants indicated that they needed some time to familiarise themselves with the instructions for using the Support Tool or that they found it easier to use with increased practice.

Usefulness

Figure 9.2 presents respondents’ responses to the survey question: “To what extent, if at all, was the Support Tool useful?”. Figure 9.2 shows that 17/18 respondents reported that they found the Support Tool useful to some extent.

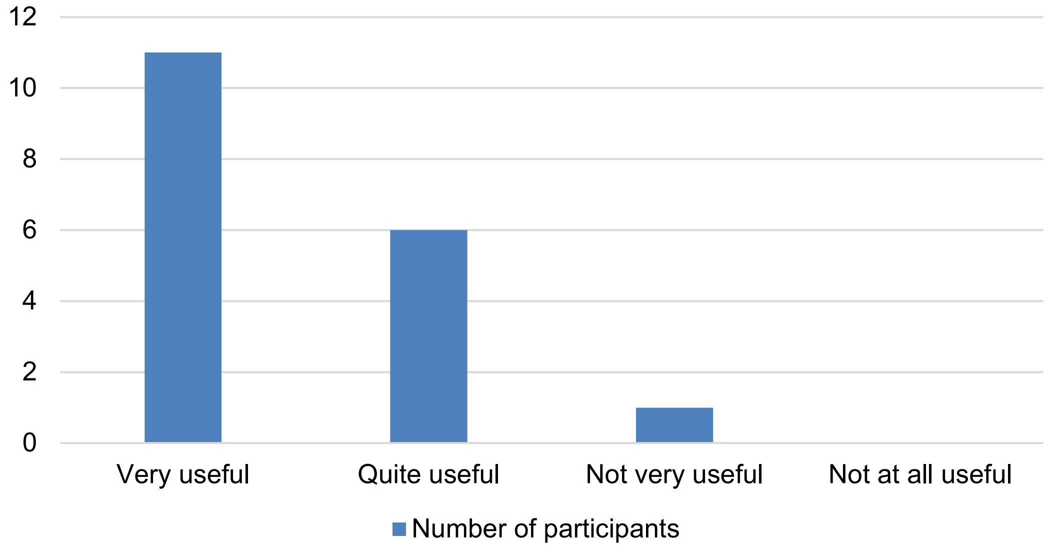

Figure 9.2: Respondents’ views about the Support Tool’s usefulness

Analysis of the themes arising within participants’ qualitative responses suggests a number of ways in which they found the Support Tool to be useful during capacity assessments. These are summarised in table 9.13.

Way in which Support Tool was useful	Illustrative quotations taken from participants' responses
Promoted a focused and reflective approach to assessment	"It keeps the process focused and succinct…" "It helped me to have a clearer idea of what I was trying to achieve and why." "It forces us to think before we act!"
Provided a structure for the assessment	"Logical layout that helped structure the process of a capacity assessment." "It provided a structured approach ensuring capacity is thoroughly assessed"
Aided preparation for the assessment	"It helped me prepare which made the actual assessment easier." "I feel that before using the MCAST I rushed into a capacity assessment without doing the necessary preparation…"
Helped make the assessment thorough	"It made me think about my practice, whether I am being thorough enough…" Provided a systematic, thorough approach to assessing mental capacity."
Increased the focus on communication	"(It) created a discussion about communication and how consideration of this might be strengthened in future practice." "It allowed me to think again about Speech and Language Therapy and calling upon them for skilled support more than I think I have done in the past."

Table 9.13: Ways in which professionals perceived the Support Tool to be useful

Potential improvements to the Support Tool

Eight respondents were able to identify changes to the Support Tool that might improve its usability. Most of these participants suggested that it would be beneficial to provide additional space for professionals to record evidence on the proforma. One participant suggested that the graphic navigation prompts and instructions could be made clearer. Another participant thought that it would help her/him to feel more confident about using the proforma if s/he could observe an experienced user complete it first.

Communication Screening Tool

Frequency of use

Fifteen respondents reported that they had used the Communication Screening Tool at least once during the feasibility study. Eight participants had used it more than twice. Three participants reported they did not need to use the Screening Tool, either because their patient did not appear to have any communication difficulties (n=1) or because they were already aware of their patient's communication difficulties and knew how to support them (n=2).

Ease of use

All respondents who used the Screening Tool reported that they found it easy to use. Ten participants stated that they found it "very easy" to use, whilst five found it "quite easy". Analysis of participants' qualitative responses indicates that the Screening Tool's instructions and layout contributed to its ease of use. One participant described the tool as a "Logical, step by step, clearly explained sequence of assessments". Another reported it was "Clearly set out for people without a background in speech/language". As was the case for the Support Tool, some respondents reported that they had needed time to familiarise themselves with the tool or would need further experience of using it to feel fully at ease.

Usefulness

All respondents who used the Screening Tool reported that it was useful. Eight participants stated that they found it "very useful", whilst seven found it "quite useful". Participants' qualitative responses suggest that they thought the Screening Tool was useful because it helped them to complete a thorough capacity assessment and tailor the assessment to the patient's individual communication needs. One participant commented:

> *It prompted us to check we had covered all the vital elements of communication required to support a patient during the assessment process.*

The qualitative data also indicate that using the Screening Tool enabled professionals to gain new skills and knowledge about communication:

> *it made me think of strategies that I wouldn't have considered such as using the photographs to explain key pieces of information.*

Professionals confidence in the results of Communication Screening Tool

Most respondents reported that they had some degree of confidence in the results they obtained when they used the Screening Tool. Seven reported they felt "very confident", seven reported feeling "quite confident", whilst one reported that they felt "not very confident". Analysis of the qualitative data indicates that participants felt confident when the results they obtained using the Screening Tool appeared to provide accurate information about the patient's communication needs:

> *The strategies suggested seemed to work well during the assessment…*

> *from what I could glean about the patient from the notes the results (of the Screening Tool) appeared to be consistent with how he was presenting.*

> *(the Screening Tool results) matched my expectations as a specialist in this area.*

One participant reported that she would have felt more confident about the results she obtained if she had had the opportunity to observe an SLT using the tool first.

Potential improvements to the Communication Screening Tool

Four participants identified changes that could be made to the tool's content and design to improve its usability. One participant suggested making the navigation instructions in section 3 clearer. Another proposed that the instructions in Section 5 could be reworded to make them clearer for patients. Two participants questioned the inclusion of two of the photographs in section 5, which they said had confused patients who were not able to find identical items in the local environment for this matching task. However, these items were purposefully selected because the aim of this task was to investigate patients' ability to generalise from one image to an object from the same category (in order to ascertain if patients would be able to derive meaning from the photographs in the Resource Pack).

Resource Pack

Frequency of use

Twelve of eighteen participants who responded to this section of the survey indicated that they had used the Resource Pack at least once. Four respondents had used it at least twice. Five participants reported they did not need to use the Resource Pack, either because their patient did not appear to need any communication support (n=4) or because they were able to support their patient's communication in a different way (n=1). One participant reported that they did not use the pack because they thought this would take too much time.

Ease of use of the Resource Pack

All respondents reported that they thought the Resource Pack was easy to use, with four of twelve respondents stating it was "very easy" to use and the remaining eight stating it was "quite easy". Most respondents commented that the photograph cards were clearly labelled and organised and easy to find. Others suggested that because there were a high number of cards, it took them some time to select relevant cards for their assessment; one participant also commented that the cards became disorganised through use and would be easier to use if they were stored differently.

Usefulness of the Resource Pack

Ten of the twelve respondents indicated that they had found the Resource Pack useful to some extent, with 50% reporting they found it very useful. Respondents' qualitative comments suggest that they thought the Resource Pack was useful because they valued the support the photograph cards provided for patients with communication needs during capacity assessments. One participant commented "it was useful as I felt I could communicate better with the patient".

Professionals confidence in using the Resource Pack

The majority of respondents reported they had felt some degree of confidence when they used the Resource Pack. Seven reported they had felt "very confident", three reported feeling "quite confident" but two reported that they had felt "not very confident”. In their qualitative responses, several participants linked their feelings of confidence to the ease with which they were able to use the resources and the fact that they considered the photographs to be “clear and comprehensive”. Others indicated that they thought they would feel more confident using the resources with increased experience / practice.

Potential improvements to the Resource Pack

Five participants suggested practical changes that could be made to increase the Resource Pack’s usability. These included reducing the number of photograph cards or improving their organization (for example in a separate folder). Respondents also suggested that additional items could be provided, such as a dry wipe pen, a board with “yes” and “no” printed on it for patients to point at, and examples of key words that could be used in discussions about particular decisions. One participant suggested that some of the photographs needed to be clearer.

Impact of using the MCAST on practice

Perceived effects on patients of using the MCAST

Ten of eighteen respondents reported that using the MCAST during a capacity assessment appeared to have a positive effect on patients. Five respondents reported that they did not know what sort of effect their use of the MCAST had had on patients, whilst three stated that they did not think it had had any effect. No respondents reported that they thought using the MCAST had a negative effect on patients.

Analysis of participants’ qualitative responses suggests that professionals who used the MCAST thought that it enabled them to do better mental capacity assessments, which was beneficial to patients. Participants commented that the toolkit helped them to be more focused and prepared in their approach, which enabled them to complete more thorough, patient-centred assessments. Participants identified the focus on communication within the MCAST as beneficial to patients, because it ensured that those with communication difficulties had an increased chance of understanding information and being able to demonstrate mental capacity. Several participants appeared to link these benefits for patients to their own feelings of increased confidence during capacity assessments.

Perceived effects on professionals of using the MCAST

Benefits for capacity assessments

Most respondents indicated that using the MCAST helped them to assess capacity; the majority (n=13) reported it helped them "to some extent", whilst four reported that it helped them "a great deal". One participant indicated that the toolkit did not help her/him much, explaining that s/he had not had many opportunities to use the MCAST during the feasibility study.

Respondents indicated which aspects of a mental capacity assessment the MCAST helped them to complete. Their responses are summarised in figure 9.3. The data indicate that using the MCAST assisted participants to complete all aspects of mental capacity assessment.

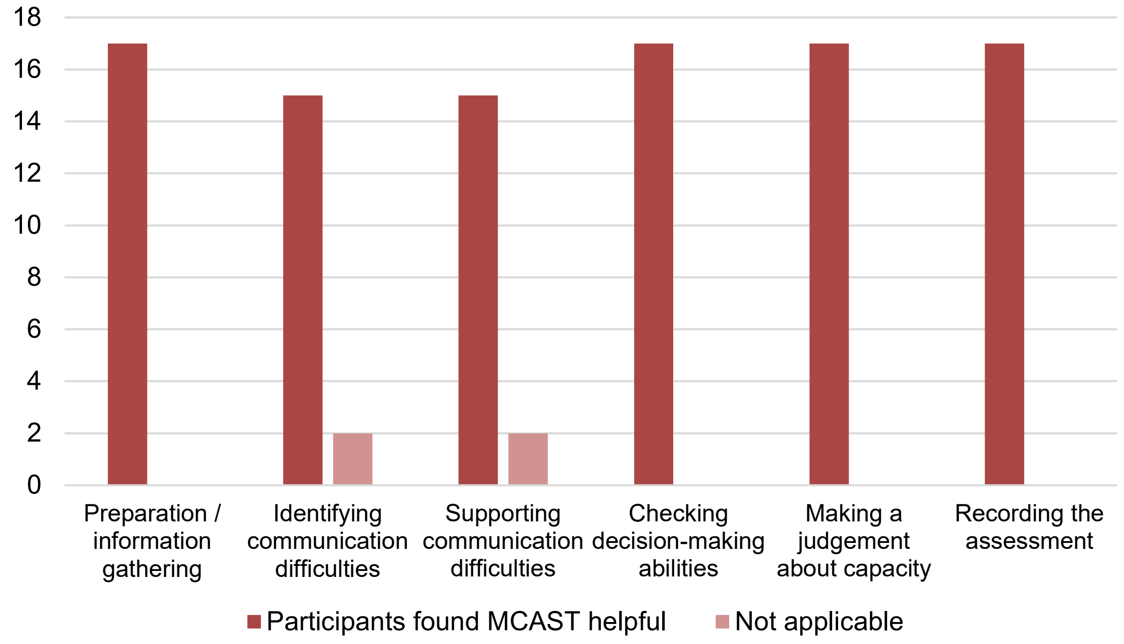

Figure 9.3: How using the MCAST helped professionals to complete different aspects of capacity assessment

Effects on professionals' confidence levels

Twelve of eighteen respondents reported that using the MCAST made them feel more confident about assessing capacity. The remaining participants indicated that using the toolkit had no effect on their level of confidence. Analysis of participants' qualitative responses suggests that professionals who reported feeling more confident associated this confidence with improvements they observed in their capacity assessments when they used the MCAST. Again, participants suggested that the structure provided by the toolkit enabled them to prepare their assessments better, which meant that the assessments were more thorough. One participant commented that this made her/him feel more confident about her/his overall judgement about the patient's capacity. Several participants linked their increased feelings of confidence to improved skills in working with patients with communication disorders. Two respondents also identified that using the MCAST helped them to provide clear documentation of their assessment, which made them feel more confident. One commented:

> *you know…that it is documented clearly so that anyone can pick it up and make sense of it.*

Effects on time taken to complete capacity assessments

Seven of eighteen respondents reported that using the MCAST had no effect on the time they took to complete their capacity assessments. Four participants reported that assessments appeared to be quicker using the MCAST. Seven respondents reported that they thought assessments were longer when they used the MCAST. However, these individuals tended to comment that the additional time required was either because they were not familiar with the toolkit paperwork or because using the MCAST encouraged them to spend longer preparing their assessments, which they indicated was a positive thing:

> *I think it's taking longer because I'm doing a better and more thorough assessment.*

Future use of the MCAST

All eighteen respondents stated that they thought they would use the MCAST during capacity assessments after the feasibility study had finished. Ten participants stated they thought they would use it often and eight thought they would use it sometimes. This difference appeared to relate in part to individual participants' job roles. Two physicians commented that they would use the MCAST less often in hyper-acute settings or emergency situations, where capacity assessments need to be completed very quickly, because using the MCAST may be a barrier to rapid assessment.

All respondents indicated they thought it would be helpful to be able to place the Support Tool in a patients' record, as evidence of their capacity assessment. Similarly, all suggested they thought it would be useful to have an electronic version of the toolkit that could be used on a portable device (e.g., a tablet computer). Two respondents commented that they would like the toolkit to be implemented in practice within the hospital trust. Several participants suggested that the toolkit would be especially beneficial to more junior professionals with less experience of capacity assessment.

9.2.7 Interviews with patients and carers

Participants

Four interviews took place with patient participants (P01, P04, P08, P17). These patients' characteristics are presented in table 9.2 (see pp235-6). These individuals were representative of the wider patient sample in terms of their diagnoses and the clinical settings in which they received a capacity assessment. Two participants were interviewed in a clinical setting and two in residential settings following discharge from hospital. Two family carers were also interviewed (C01, C02). These individuals were included as advocates for two patient participants (P14, P15), who were unable to participate due to the nature of their cognitive and communication difficulties.

Results

Patient and carer participants indicated that they had no objections to any of the patient tasks or visual materials involved in the Communication Screening Tool. Participant P08, a man being treated in intermediate care following a subdural haematoma, recalled being screened by professional participant E015 and commented "it didn't upset me". Participant P17, a man living with dementia being treated in intermediate care following a fall, was unable to remember the screening test but commented "I've no problem with it" when the researcher explained the processes and demonstrated some of the materials involved.

Participant C01, the husband of a woman with global aphasia being treated in hospital following a stroke commented that he thought that it was "a good idea" to have a Screening Tool that could be used by all professionals to identify communication difficulties and ways to support patients' needs. Participant C02, the husband of participant P14, a woman with severe dementia being treated in an intermediate care setting, commented that he thought it was acceptable to use the Screening Tool with people like his wife and did not think that she would find it "distressing" in any way; however, he recognised that she might not be able to complete many of its tasks:

> *there's no objection to me with trying but I can't see as if she'll realise what you're doing or understand.*

Similarly, participants reported that they did not object to professionals using communication strategies suggested on the Screening Tool or items from the Resource Pack to support patients' communication during capacity assessments. Participant P04, a man living in a residential home after being treated for sub-arachnoid haemorrhage in hospital, remembered the strategy of writing key information down that professional participant E004 had used to support his communication during his capacity assessment. He commented that he had found this helpful and that he thought it was "alright". He indicated that he would not find the use of photographs to explain information childish or patronizing. Similarly, participant P17 said that he would not be offended by professionals using the photograph cards to communicate with him. Participant P08 recalled that professional participant E015 had used photograph cards and had written words and sentences down to explain important information about his decision options. He commented "it didn't bother me that" and said, "it's ok to show me (photograph cards)".

Most participants found the photographic images clear. However, participant P01, a woman who experienced visual changes following an acute stroke, reported that she had difficulty seeing some of the details in certain photographs (e.g., "scanner") and felt that other patients might experience similar difficulties. The researcher asked participants whether they thought some photographs in the Resource Pack might be distressing for patients to see (for example, images representing medical conditions such as stroke or heart attack). All participants commented that whilst they did not find any of the items shown to them by the researcher distressing or offensive, some patients might become upset. They suggested that professionals should be sensitive to this possibility. Participant P01 commented:

> *Well it probably might be (upsetting) if you showed (the "stroke" photograph card) to somebody who's just had one (a stroke) but it's not bothering me and I've had quite a few…*

9.2.8 Integration of findings to answer research questions

The results of the methodological and data triangulation integration process are presented below for each research question.

Research question 1: Does use of the MCAST increase compliance with the MCA?

Compliance with the MCA requires professionals to complete capacity assessments that include elements specified in the MCA and its Code of Practice (2007) and to record these elements of the assessments comprehensively, using unambiguous language.

A key finding identified within the integration process was that use of the MCAST appeared to improve the content and recording of capacity assessments, in line with the requirements of the MCA. The quantitative case note audit data, which demonstrated a significant increase in audit scores following introduction of the MCAST, indicated that professional participants' documented assessments were more consistent with the requirements of the Mental Capacity Act (2005) when they used the MCAST. This finding was complemented by themes arising in the qualitative data collected using the professional confidence and usability surveys. A convergent finding across both surveys was that respondents perceived that their assessments were more thorough and robust when they used the MCAST. Respondents in the usability survey reported that using the MCAST enabled them to document their assessments clearly and reliably.

The researcher's analysis of the completed Support Tool and Communication Screening Tool proformas and the results of the Communication Screening Tool validity and reliability testing provided complementary findings. Professional participants did not always use the proformas as they were designed to be used. Furthermore, the Communication Screening Tool may not have provided valid and reliable outcomes, which may have diminished the overall quality of capacity assessments. This suggests that capacity assessments could be improved further in future if the MCAST is refined and professionals are incentivised to use it as it is designed. There were no instances of dissonance between data collection methods and sources in relation to this key finding. There was silence[43] in the patient and carer

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[43] "Silence" occurs when findings noted in other data sources are absent in the data being examined (Farmer *et al*., 2006).

interview data in relation to the key finding about assessment quality; this is not surprising as this method was not designed to collect these data and these participants may not be aware of the requirements of the MCA.

Research Question 2: Does use of the MCAST increase professionals' confidence levels when assessing mental capacity?

The integration process identified the key finding that professionals appeared to feel more confident about assessing capacity when they used the MCAST. The professional confidence and usability surveys provided convergent findings relating to professionals' perceptions of confidence. Quantitative data collected in the confidence survey indicated that professionals felt significantly more confident when they had used the MCAST. The majority of respondents to the usability survey reported that using the MCAST helped them to feel more confident. The qualitative data from both surveys provide convergent findings that complement the quantitative data. Across both surveys, professionals identified the same reasons why they perceived their confidence had been affected positively by using the MCAST: having an additional structure, an improved ability to prepare, carry out and record assessments and increased skills in working with patients with communication difficulties. There were no instances of dissonance between data collection methods or sources in relation to this key finding, but many instances of silence. This is likely to be because the other methods were not designed to investigate professionals' perceptions of confidence.

Research question 3: Can professionals use the MCAST to identify communication difficulties in patients with stroke and/or cognitive difficulties and how to support patients with these difficulties accurately and reliably during mental capacity assessments?

Two key findings emerged from the integration process that indicate that professionals may not be able to use the MCAST to identify and support communication difficulties for these patients during capacity assessments. First, some professional participants did not use the Screening Tool as it was designed to be used. This was evident in the results of the researcher's analysis of the proformas completed by participants. Convergent evidence of this was provided by the validity and reliability testing data, which indicated that in four cases, professionals did not use the tool to screen patients with communication difficulties, which meant that they did not identify these difficulties before completing a capacity assessment. The researcher's field notes contained the same finding; a professional participant reported to the researcher during the study that she had chosen not to use the Screening Tool because a patient appeared “able to verbalise”; it was unclear if the professional participant knew whether the patient had intact comprehension. There was silence in the results of the other data sources and collection methods in relation to this key finding.

The second key finding was that the Screening Tool may not provide valid and reliable outcomes, which would affect the way professionals identify and support patients with communication difficulties during capacity assessments. The validity and reliability data indicated that the Spoken Comprehension subtest’s criterion validity was poor whilst its inter-rater reliability was fair, but that these results may not be precise, due to the small sample size. Most other data collection methods and sources were silent on this finding. However, data from the usability survey appeared to disagree with this key finding. Quantitative survey data indicated that the majority of professionals felt confident about the tool’s outcomes; their qualitative responses suggest that this was because the outcomes obtained in relation to a patient’s communication appeared consistent with how the patient’s communication appeared at other times (e.g., when observed by other professionals or during the capacity assessment) or consistent with the professional participant’s own expectations (for a participant who was an SLT).

Research question 4: Is the MCAST useable and acceptable to professionals and patients?

Usability

As described in chapter 2 (p16), the usability of an object has been described as being related to users’ perceptions of its usefulness, ease of use, learnability and likeability (Rubin, 1994). Four key findings relating to the MCAST’s usability emerged from the integration process.

First, professionals appear to find the toolkit useful. There was convergence between the confidence and usability survey results in relation to this finding. Most respondents in the usability survey reported they found the toolkit useful and that it helped them to assess capacity. Qualitative data in both surveys confirmed this result. In both surveys, respondents described ways in which the MCAST helped them to assess capacity: it helped them to prepare, structure and document assessments and work with patients with communication difficulties. Respondents in both surveys reported that using the toolkit made assessment easier. There were no instances of dissonance but there was silence in the results of the other data collection methods and sources in relation to this key finding.

The second key finding was that the MCAST appears easy to use. In the usability survey, all respondents indicated they found the toolkit easy to use. There was convergence between this result and qualitative data collected by the survey, which indicated professionals found the toolkit easy to use due to the clarity of its instructions and layout. There were instances of partial disagreement with this key finding in the results of the usability survey, patient and carer interviews and the researcher's analysis of completed MCAST proformas. Across these results, minor changes were identified to the content and design of toolkit materials which would make them easier to use by professionals and patients (e.g., changes to the layout of proformas or the content of photographic images in the Resource Pack to make them clearer). The Communication Screen validity and reliability testing, case note audit and confidence survey results were silent about the toolkit's ease of use.

The third key finding in relation to usability was that the MCAST may take some time to learn how to use. Qualitative data from the usability survey indicate that some professionals perceived that they needed to take time to familiarise themselves with the MCAST, in order to use it effectively or confidently. The results of other data collection method and sources were silent in relation to the MCAST's learnability.

The final key finding was that professionals appeared to want to use the MCAST. All respondents reported that they would like to continue using the MCAST in future capacity assessments (i.e., after the feasibility study) and use the Support Tool to document their assessments in patient records. The results of the confidence survey were largely silent in relation to this finding, except for a comment by one participant who stated she was "really enjoying using the MCAST" (E024). There was silence in the findings of the other data collection methods and sources.

Acceptability

Three key findings emerged in relation to the MCAST's acceptability to professionals and patients. First, professionals perceived that using the MCAST appeared to be beneficial to patients. Most respondents reported in the usability survey that their use of the MCAST was beneficial to patients during capacity assessments and none reported it was detrimental. Professional participants' qualitative responses provide convergent evidence that they perceived the MCAST to be beneficial to patients. For example, professionals commented that using the toolkit helped them to complete patient-centred assessments and enabled patients to better demonstrate their mental capacity. Data from the patient and carer interviews provided convergent evidence to support this finding. Patients and carers suggested that the MCAST Screening Tool and Resource Pack materials had the potential to help patients with communication difficulties to understand more about their situations and the decisions they were asked to make.

The second key finding in relation to acceptability was that the MCAST processes and materials appeared generally acceptable to patients and carers. The patient and carer interview data indicated that these participants had no personal objections to the items used in the Communication Screening Tool or Resource Pack, although they acknowledged that some patients might find certain photographic images upsetting.

The third key finding was that most professionals appeared to find that the time taken to use the MCAST was acceptable. The quantitative data collected in the usability study suggested that most professionals took the same or less time to complete their capacity assessments when they used the MCAST whereas a minority took more time than they would normally. Qualitative data collected in the usability survey indicated that most professionals who took longer felt the additional time was beneficial because the assessments were better prepared and more thorough. There was partial disagreement in the qualitative data, because a minority of participants felt that the additional time required to use the toolkit could not be justified, due to the busy nature of environment in which they worked. There was silence in the results of other data collection methods and sources in relation to acceptability.

9.2.9 Feasibility of conducting research into mental capacity assessment within the NHS context

Recruitment

The researcher kept field notes and a reflective journal during the recruitment period to record issues related to professional and patient participant recruitment.

Professional participants

The target professional sample size was 20. It was possible to recruit 24 professionals from five disciplines across a range of clinical settings using the purposive sampling strategy over a six-month period within one hospital trust. Three participants withdrew prior to data collection; one due to long-term absence from work due to illness and two because of changes in their professional role. Additional professionals expressed interest in participating in the study but were not recruited because the quota of professionals with their characteristics (i.e., from their discipline or clinical setting) had already been met. It was not possible to recruit three important professional groups: psychiatrists, psychologists and social workers. The researcher advertised the study to all groups by contacting managers as well as personal contacts within each discipline via email and by placing a recruitment advertisement on a weekly trust email newsletter. This recruitment method was clearly not successful for these particular professional groups.

Patient participants

Professionals were invited to identify at least one patient for potential recruitment to the study over a two-month period. Only 17 of 21 professional participants were able to do this. Two of the four remaining professionals were unable to identify patients due to factors related to their job role (e.g., being absent due to illness or changing jobs), whilst the third reported she was unable to identify any patients requiring capacity assessments. It is unclear why the fourth member of professional was unable to identify a patient. In total, 28 patients were identified by professionals. However, it was possible to recruit only 17 to the study. The reasons for this are summarised in table 9.14.

Reason unable to recruit	Number of instances
Patient declined / did not appear to be interested in participating	6
Consultee declined to sign declaration	2
Change in professional doing assessment	1
Assessment delayed or no longer required	1
Insufficient time to take consent / see Consultee, due to urgency of assessment	1

Table 9.14: Identified barriers to patient recruitment

As table 9.14 shows, the most frequent reason for non-recruitment was that the patient communicated verbally or non-verbally that s/he did not wish to participate. In some cases, the patient indicated this during an initial discussion with a professional participant (i.e., the researcher did not actually speak to the patient about participation). It was often not possible to ascertain patients' reasons for not wishing to participate, due to the nature of their cognitive and/or communication impairments. On two occasions, family members were reluctant to sign a Consultee Declaration. In one instance, this was because different family members disagreed about whether participation was in their relative's best interests; in the other instance, a patient's husband felt that she needed more time to recover from her stroke, in order to participate fully in the study. Aspects of the research process appeared to impede recruitment on only one occasion; this was when there was insufficient time to obtain consent or a Consultee Declaration due to the urgent nature of the capacity assessment.

No patient participants withdrew from the study. The researcher attempted to invite six patients recruited to the study to take part in the interviews and recruit two family carers of patients with significant communication difficulties. Both carers consented to take part. Four patients agreed to take part whilst one declined because he was no longer interested in the research. Unfortunately, one patient had died after leaving hospital.

Data collection processes

Ability to collect data

Each data collection method generated a data set. However, none of the data sets were complete. Table 9.15 presents target and achieved data set sizes for different data collection methods and identified reasons for not reaching each target. The data are presented at participant level, i.e., the total number of participants for whom data were required and the number and percentage of these for whom complete data were collected. As the data in table 9.15 show, response rates were above 70% for all data collection methods except for the case note audit carried out at T2. When completing the case note audit, the researcher was unable to locate the capacity assessment in the paper or electronic patient record on six occasions. It is unclear whether this was due to a professional participant making a recording error or not remembering the details of a previous capacity assessment accurately or due to a hospital trust data storage error.

Data collection method	Target data set size	Actual data set size	Percentage of participants providing data	Reasons for not achieving target
Case note audit T1	21	17	81%	Researcher unable to locate specific record (n=4)
Case note audit T2	21	12	57%	Researcher unable to locate specific record (n=2) No data provided by participant (n=4) No capacity assessments completed to provide data (n=3)
Confidence survey T1	21	21	100%	NA
Confidence survey T2	21	17	81%	No data provided by participant (n=4)
Document analysis: Support Tool	21	15	71%	Only 17 professional participants identified patients for recruitment to study. For two of these patients, the capacity assessment was completed by professionals not involved in the study.
Document analysis: Communication Screening Tool	12	9	75%	Professional participants only used the Communication Screening Tool with 9 patients.
Communication Screening Tool validity and reliability testing	12 (2 x 9 proformas)	9	75%	Professional participants only used the Communication Screening Tool with 9 patients.
Usability survey	21	19	90%	Unknown

Table 9.15: Target and actual data sets

Feasibility of measures / data collection methods

It was possible to measure a significant change in response between T1 and T2 using the case note audit and confidence questionnaire data collection tools, which suggests they are sensitive measures of change. The usability survey and confidence survey free text questions generated a large amount of rich data. The nature of individual responses and their relevance to each question suggests the survey questions were specific and clear. Convergent evidence across both surveys in relation to key findings strengthens their validity as data collection tools. The researcher's analysis of completed proformas using a structured data collection form generated a large amount of data, suggesting it was a comprehensive, sensitive data collection tool. The patient and carer interviews did not generate a large amount of data. This may reflect the topic guide used by the researcher or it could indicate that patients and carers may not have varied opinions on the types of support that patients are offered to communicate or make decisions.

The methods used to measure the validity and reliability of the Communication Screening Tool generated mixed results. It is difficult to establish if these results are an accurate reflection of the psychometric properties of the Communication Screening Tool or an artefact of the methods used to measure validity and reliability. This is discussed further below.

9.3 Discussion

This study was designed to test the feasibility of the MCAST materials and processes and also the recruitment and data collection methods. Specifically, it was designed to investigate: i) whether professionals demonstrated greater compliance with the MCA when they used the MCAST; ii) whether they reported increased confidence in their ability to assess capacity when they used the toolkit; iii) whether professionals could use the MCAST to identify and support the needs of people with communication difficulties accurately and reliably; iv) the toolkit's usability and acceptability to professionals and patients.

The case note audit and survey results indicate that use of the MCAST was associated with increased compliance with the MCA. This is an important finding because one of the primary motivations to develop the MCAST was the reported (and observed) need to develop a resource to improve practice (see pp8-9). It is notable that a significant increase in audit scores was observed following introduction of the toolkit, even though most capacity assessments audited were not documented in patient records using the Support Tool proforma (due to local information governance restrictions). This suggests that the case note audit method used was sensitive and strengthens the finding that using the MCAST has the potential to improve the content and recording of capacity assessment methods. The audit tool used provided a summary score to represent the overall quality of an assessment but included scored subsections examining specific aspects of the assessment process (e.g., what was done to enhance capacity). It would be useful to investigate whether the MCAST provides particular benefits for certain aspects of the assessment process rather than others in a future study, in order to identify further refinements to the toolkit.

The confidence and usability survey results suggest that, overall, professionals felt more confident about assessing mental capacity when they used the MCAST. This is a positive outcome, because professionals had reported in the focus group study (see p76) that they and other professionals lacked confidence in their ability to assess capacity, particularly for certain patient groups (e.g., people with communication difficulties); this trend has been reported elsewhere in the literature (e.g., Williams *et al*., 2012). The qualitative data collected in the surveys indicates that the MCAST helped professionals to feel more confident in a number of ways, including by enabling them to work better with communication-impaired patients.

The study results indicate that currently, professionals may not be able to use the MCAST to accurately and reliably identify patients with communication difficulties and know how to support their needs during capacity assessments. This is because the data collected suggest that the Communication Screening Tool spoken comprehension subtest's criterion validity and inter-rater reliability are weak; this affects the validity and reliability of the tool's overall outcomes and the clinical decisions that professionals would make on the basis of these outcomes, in relation to a patient's communication skills. However, it is difficult to establish if this finding was caused by the psychometric properties of the tool itself or the methods used to measure them. It is interesting to note that the inter-rater reliability of the Screening Tool appears stronger than its criterion validity. It is possible that the researcher's screening test did not provide a fair comparator to use as the gold standard measure. The researcher needed to adapt some test items on the Frenchay Aphasia Screening Test (FAST, Enderby *et al*., 2012) used in his screening assessment, as the items were difficult to use with patients with visual difficulties. This may have affected the validity and reliability of the researcher's screening test results, which in turn may have affected comparisons with outcomes obtained by professionals.

Similarly, the results obtained by professionals may have been affected by the way they administered the MCAST Screening Tool. It is uncertain whether professionals used the tool as it was designed to be used. For example, some professionals may have provided coaching to support patients to complete subtest tasks, for example by repeating spoken instructions. Future investigations of the tool's validity and reliability could use ethnographic methods to investigate how professionals use the tool and to identify how this may affect outcomes. It appears from the researcher's documentary analysis and field notes that some professionals chose not to use the Screening Tool in cases where the patient did not appear to have communication difficulties through initial conversation. For example, this occurred for a number of patients with a dementia diagnosis. Professionals who are not SLTs may not be aware that people with dementia can present with communication impairments, or that SLTs can support these types of patients. The prompt about screening communication on page 2 of the Support Tool (appendix 31) deliberately encourages professionals to *consider* using the Screening Tool, but does not imply this is recommended for all patients. It will be important to review the wording of this prompt in future revisions of the Support Tool, to ensure that professionals are more likely to screen patients who need screening.

The study results indicate that the MCAST was usable and acceptable to most professionals, patients and carers. Participants' responses to the surveys and during the interviews, in addition to the results of the researcher's documentary analysis, identified a small number of content and design changes that could be made to improve the usability of the toolkit materials. For example, patients and carers suggested that some photographic images in the Resource Pack could be made clearer. All items in the toolkit were reviewed and approved by people with communication difficulties secondary to stroke or dementia and a carer from the project's Patient, Carer and Public Involvement (PCPI) group. However, it is evident that this group of seven people cannot be representative of the target population for the Resource Pack. Further refinement of the toolkit materials would need to involve wider consultation with this population, to increase their usability. A minority of professional participants reported in the usability survey that they would be less likely to use the MCAST in future because they worked in very busy environments and they perceived that it would be quicker for them to complete capacity assessments without the toolkit. This suggests that the toolkit may not be used in practice by all professionals across all clinical environments. As other professionals indicated in the survey, it may be most beneficial to professionals with less experience of assessments or to professionals working in non-emergency or less busy settings.

The recruitment processes and data collection methods employed in the study appeared generally to be feasible. Changes to recruitment methods need to be identified to increase the range of professional disciplines represented in future investigations. In this study, it is possible that some patients may have been interested in participating if they had received information about the study directly from the researcher rather than a professional, because the researcher might have been able to provide more comprehensive information about the study in a format to suit the patient's communication needs. Recruitment methods could be adapted to promote this practice in a future evaluation. Retention of professionals and patient participants was high. Response rates were above 70% for all data collection methods except for one of the case note audits. If this method is to be used in a future study, it would be beneficial to consult with clinical information managers to identify more reliable ways to collect / locate records of capacity assessments.

It is interesting to note that four patient participants who were able to provide informed consent to participate in the study were not later found to demonstrate mental capacity to make a specific decision about care or discharge arrangements. The opposite trend was observed for two patients. This important finding provides evidence that mental capacity should be assessed on a decision and time-specific basis, as prescribed in the MCA. The observed difference in mental capacity is likely to be due to differences in the nature of the decision the patient was asked to make. However, it could also reflect differences in the capacity assessment processes used by the researcher and the professional participant for each patient and indicative of the subjective nature of capacity assessment.

9.3.1 Study limitations

Study design and methods

The uncontrolled study design does not enable causality to be established between variables, only association. The data collection methods employed may have introduced bias. Professionals' responses to the surveys may have been influenced by social desirability bias (King and Bruner, 2000). Respondents may have felt a need to present themselves favourably in terms of their behaviour and the opinions they expressed about the MCAST. In the usability survey, social desirability bias should have been reduced because the survey was designed to enable anonymous responding. It is possible that for the case note audit, professionals identified patient cases that they perceived to be the best examples of their practice. The researcher tried to control for this by asking professionals to identify up to three cases in order for him to sample one at random; however, a number of professionals were unable to identify more than one case. Furthermore, the researcher was not blind to the temporal order of assessments he audited, which may have affected the scores he allocated.

It is possible that professionals using the Communication Screening Test became unblinded to information about patients' communication skills during the data collection process. This may have influenced their use of the tool and the outcomes they obtained using it, particularly if they were influenced by social desirability bias. Furthermore, it was not possible to counterbalance the order in which participants were screened by the researcher or professional participants A and B, to control for learning effects that may have confounded outcomes. This was due to practical constraints related to researcher and professional availability. Similarly, it was not possible to ensure that patients received the three screening tests within a 48 hour period. This could mean that patients' communication skills varied between screening assessments, for example due to changes in their general health condition.

Certain professional participants' responses may also have been subject to a type of confirmation bias caused by the "Halo effect" (Nisbett and Wilson, 1977). Their responses to the surveys may have been affected by global judgements about the researcher based on their pre-existing professional relationship with him. Social desirability and confirmation bias should have been weaker in the patient and carer interviews, because the respondents did not have a pre-existing relationship with the researcher.

Sample

The composition of the sample limits the transferability of the study findings. Although a range of professions were represented in the sample, most participants were either OTs or speech and language therapists. Only three physicians, two physiotherapists and one nurse were recruited. These participants' responses may not have been representative of the opinions and experiences of other members of their professional group. Social workers, psychologists and psychiatrists were not represented in the sample at all. These professionals are usually involved in mental capacity assessments (see chapter 3, p45). It would be important to recruit these disciplines to any future evaluation study, in order to collect data relating to their experience of using the MCAST. The sample size for the Communication Screening Tool validity and reliability testing (n=9) was relatively small, which is likely to have affected the precision of the statistics calculated and therefore the validity of the results.

This study investigated the feasibility of the MCAST processes and materials and the recruitment and data collection methods used. The results have provided opportunities to identify changes that could be made to the MCAST prototype to improve the toolkit's general usability and the reliability and validity of its Communication Screening Tool. The results could also be used to guide the design of a future study to investigate the MCAST's effectiveness. These issues are discussed further in the next chapter.

Chapter Ten: General Discussion

This study aimed to develop a tool to support the assessment of mental capacity for patients in hospital and intermediate care settings and to evaluate the feasibility of using this tool in clinical practice. The study was motivated by an identified need to facilitate and improve mental capacity assessment within the legal framework provided by the Mental Capacity Act (MCA, 2005). The Mental Capacity Assessment Support Toolkit (MCAST) was designed in response to this clinical need.

Five objectives were identified for this doctoral study (see section 1.7, pp10-11). These objectives were partly achieved. The first objective was to review and synthesise case law and literature relating to current mental capacity assessment practice in England and Wales. This review was completed and was reported in chapter 3. The second objective was to explore health and social care professionals’ views about and experiences of mental capacity assessment within acute hospital and intermediate care settings. The focus group study reported in chapter 4 explored healthcare professionals’ views and experiences but unfortunately no social care professionals were recruited to the study.

The third objective for this doctoral study was to review and synthesize the literature relating to methods that can be used to make information more accessible to people with communication disorders during capacity assessments. This review was completed and was reported in chapter 5. The fourth objective was to develop a support tool using evidence from the literature and case law reviews that was responsive to user needs. The MCAST was developed using the evidence relating to current practice and user needs reported in chapters 3 and 4. The process of the MCAST’s user-centred development was reported in chapters 6 and 7. The final objective for this doctoral study was to test the support tool, in order to investigate its usability and acceptability in clinical settings and the validity and reliability of its outcomes. An evaluation of the feasibility of using the MCAST in clinical practice was carried out in order to meet this fifth objective and was reported in chapters 8 and 9. The main findings of this doctoral study and new knowledge gained are discussed below.

10.1 Summary of study findings / identification of new knowledge

10.1.1 Mental capacity assessment practice

This doctoral study increases our understanding of how healthcare professionals assess mental capacity within the MCA legal framework and the types of support they need to do this well. The review of research evidence relating to mental capacity assessment within the MCA legal framework (chapter 3) suggested that research examining this area of clinical practice has been limited and has focused on two main clinical populations: people with learning disabilities and people with mental health conditions. The focus group and feasibility studies (chapters 4 and 9 respectively) provide complementary evidence about mental capacity assessment in the acute hospital and intermediate care setting, in relation to two different clinical populations: stroke survivors and people with acute and chronic cognitive impairment. These two groups of patients were composed mainly, but not exclusively, of older people. This doctoral study also provides novel evidence relating to how specialist and non-specialist professionals address the specific needs of people with communication disorders during capacity assessments. The review of case law (chapter 3) indicated that a small number of legal cases have involved judicial scrutiny of the ways that professionals have assessed mental capacity. Nevertheless, analysis of these cases provides important information about aspects of current practice.

A common theme emerging from these different sources of evidence is that health and social care professionals find mental capacity assessment challenging and lack confidence in their ability to do it effectively. Another important finding is that current practice is variable and may not always comply with the MCA. This is consistent with the findings of the House of Lords' Post-Legislative Scrutiny (House of Lords Select Committee on the Mental Capacity Act 2005, 2014).

This research study has identified specific examples of practice that are inconsistent with the aims and spirit of the MCA. First, the reviews in chapter 3 highlighted instances where assessments have not taken place but were indicated or where assessors have sought to make judgements about people's global decision-making ability rather than examine mental capacity for single, time-specific decisions. Similarly, the focus group study findings indicate that professionals may not always assess patients' capacity to make significant decisions (e.g., whether to consent to surgery) or may not understand that capacity assessments should relate to individual decisions.

Second, evidence reported in chapters 3 and 4 indicates that some capacity assessors do not base their judgements about capacity on the MCA functional two-stage test of capacity but on their subjective perceptions of a person's diagnosis, the severity of her/his communication or cognitive impairment, or whether the outcome of the decision the individual wishes to make appears to be in her/his best interests. Third, another important finding from chapters 3 and 4 is that capacity assessors do not always provide relevant information to people to enable them to consider decision options fully or do not adequately support people to understand information about decisions. This observation is particularly relevant to capacity assessments involving people with communication disorders, who are likely to require additional, individualised assistance to understand and use information and express their choices.

This study confirms previous findings that healthcare professionals find mental capacity assessment challenging, lack confidence in their ability to do it effectively and welcome resources designed to help them to improve their practice. Importantly, participant responses suggest that this trend is common across professional disciplines and is not related to level of seniority, amount of clinical experience or previous training in the MCA. This research has explored the causes for this lack of confidence in assessing capacity and what may constitute barriers to good practice. Some professionals may not understand aspects of the MCA or their responsibilities as assessors. The case law review (chapter 3) demonstrated that even expert assessors instructed by the courts may lack basic knowledge of the MCA or how it should be implemented. Additionally, professionals can feel under pressure to complete assessments rapidly in busy healthcare environments, which can be a barrier to assessing capacity in a way that fulfils the requirements of the MCA. Furthermore, professionals may not understand aspects of the patient decisions involved in capacity assessments, which makes it difficult for them to provide accurate and comprehensive information to patients about available decision options. Lastly, professionals may feel they do not possess the necessary skills to support particular patient groups to think and communicate about decisions.

This is particularly the case for patients with communication disorders. This study provides important new evidence relating to how both specialist and non-specialist professionals carry out capacity assessments for this clinical group. Participants indicated that they find assessing capacity for these types of patients especially challenging and would welcome support from SLTs and opportunities to learn new skills in working with this population. However, the focus group results in chapter four indicated that some professionals may not refer to speech and language therapy due to a perception that support for patients with communication needs during capacity assessments may not be available. It is unclear if this perception is unique to the hospital trust in which the study took place or shared by professionals in other settings. Nonetheless, this finding has important clinical implications. It suggests SLTs may need to consider how they publicise the contribution they can make to this area of practice or how they can deliver this type of clinical work more frequently.

This study has identified potential ways in which practice can be facilitated and improved. External supports such as proformas and flowcharts may enable professionals to prepare, structure and document their assessments more easily and effectively. Collecting comprehensive information about the different decision options available to a person, and the types of support s/he may need to understand and use that information to make a decision, can help assessors to feel prepared for assessments and more confident that their assessments are thorough. Access to usable and acceptable screening tools and communication strategies can enable assessors to feel more confident about identifying people with communication needs during capacity assessments and supporting these individuals to maximise and demonstrate their decision-making ability.

10.1.2 The MCAST

A key output from this research is the MCAST, a novel toolkit to support multidisciplinary professionals to complete better assessments more easily. This innovation responds directly to the conclusion by the House of Lords Post-Legislative Scrutiny committee that additional resources should be made available to professionals to drive forward improvements in practice. The MCAST is a unique resource because it supports professionals to assess capacity in accordance with the legal requirements of the MCA and to meet the needs of people with communication disorders during the assessment process. Existing mental capacity tools were designed to support mental capacity assessment in different jurisdictions and their use is therefore limited. Currently available communication screening tests do not enable professionals to identify both communication needs and compensatory strategies to use to meet these needs in the context of supporting mental capacity assessment.

The feasibility study demonstrated that the MCAST is a usable and acceptable resource that has the potential to make an important contribution to mental capacity assessment practice in England and Wales. The case note audit findings indicated that professionals completed assessments that were more compliant with the MCA when they used the MCAST. The confidence survey results indicated that professionals felt more confident about their ability to assess capacity when they used the toolkit. The majority of professionals who used the toolkit reported that they would like to use the MCAST as part of their future practice. Individual participant responses indicated that the toolkit might be most useful to particular professional groups: those with less experience of assessing capacity or those working in non-emergency or less busy settings. It will be useful to plan to collect data relating to levels of professional experience and training and type and amount of clinical activity in different settings when designing a larger-scale evaluation of the MCAST. This contextual information could be used to inform the interpretation of the evaluation findings and to determine whether the toolkit could be used by different professional groups and in different settings with or without modification. This type of consideration is key to successful implementation in clinical practice (Brady *et al*., 2011).

To the researcher's knowledge, it is the first time that a resource to facilitate mental capacity assessment has been developed using a synthesis of research evidence and case law and by adopting a user-centred design approach. The iterative development process reported in this thesis increases our understanding of how this methodology can be used to develop novel products in collaboration with professionals and service users in healthcare settings. This study contributes to a growing evidence base for such methodologies and for the active role that people with communication disorders can play in healthcare design (Cooke *et al*., 2016; Wilson *et al*., 2015). The active involvement of healthcare professionals and service users during the development of the MCAST made an important contribution to the toolkit's current usability and acceptability and to the feasibility of the research methods used to test it in clinical practice.

The prototype toolkit developed during this study requires further development work before it can be used more widely. The feasibility study data identified further content and design modifications that could be made to the toolkit to increase its usability. The Communication Screening Tool requires further psychometric testing and adaptations to increase user adherence. Several participants reported that they chose not to use the Screening Tool because they believed the patient's communication skills to be intact, despite the fact that this was found not to be the case. This finding confirms previous evidence that non-specialist professionals do not always recognise when patients need communication support (Hemsley and Balandin, 2014).

The majority of professionals who used the Communication Screening Tool reported they understood how to use it and found it easy to use. However, it was evident from documentary analysis of completed tool proformas that some professionals did not appear to understand how to use the tool. This observation is supported by data collected during the toolkit development phase; although three professional participants appeared to be able to use the Screening Tool easily and competently, one individual experienced significant difficulties (see p193). This may have been because the individual (a social worker) had less experience of using this type of skills-based assessment than the other participants.

Together, these findings suggest that professionals will need additional support to use this aspect of the toolkit effectively and different professional groups may require different levels of support. Modifying aspects of the toolkit's design may facilitate use of the Communication Screening Tool. For example, the Support Tool could be adapted to include an explicit prompt to use the Screening Tool with every patient, although this would not guarantee user compliance or accurate use of the tool. Specific training could be developed to support professionals to use the Screening Tool. However, some professional participants indicated during the MCAST development phase that the toolkit should be used easily without the need for training. Any additional training requirement might mean that professionals would be less inclined to use the MCAST.

A potential solution, suggested by professional participants during the toolkit development phase, would be to integrate training in use of the MCAST as part of existing general MCA training provided by healthcare trusts. It is noteworthy that although most participants in this study had received this general training, they still reported lacking confidence in their ability to assess capacity. Perhaps the focus in existing training could move from increasing knowledge about the MCA to provision of more skills-based learning relating to practical aspects of capacity assessment, including opportunities to practise using the MCAST. Certain participants in this study reported they would appreciate opportunities to observe an SLT use the Screening Tool to help them understand how to use it and gain confidence in using it. This possibility is being discussed with the MCA Practice Development Lead at Sheffield Teaching Hospitals NHS Foundation Trust, which could serve as a pilot site for any new integrated training programme.

An important consideration arising from the feasibility study findings is whether non-specialist professionals should be expected / required to assess and support communication skills during mental capacity assessments. The involvement of non-specialists could mean that people with communication disorders might not always receive the type of support they require during capacity assessments. This could place these individuals at risk of being judged to lack capacity to make a decision or of being asked to make an uninformed decision. However, SLTs have argued for some time that other professional groups should develop knowledge and skills to be able to support the needs of people with impaired communication, in order to be able to work more effectively with this population (e.g., Kagan *et al*., 2001). In the UK, SLTs increasingly work in a consultative way with other professionals and family carers, by providing guidance and training in issues relating to disordered communication; this consultative role promotes the notion that everybody should take responsibility for supporting a person with communication difficulties, not just SLTs, because “communication is everybody’s business” (Jensen *et al*., 2015).

A potential way to manage the possible risks inherent in non-specialists identifying and supporting communication difficulties might be to introduce an inter-professional competency framework identifying the specific knowledge and skills required to work with people with communication disorders. This type of framework is currently used to help different disciplines to develop and maintain competencies in the management of dysphagia (swallowing disorders) (Boaden *et al*., 2006). An inter-professional framework for communication assessment and management could define different professionals’ roles and responsibilities in working with this clinical group and might be used to identify associated training needs. The ultimate goal of such a framework could be to harmonise learning and practice in this area.

10.1.3 Accessible information

Finally, this study contributes to our understanding of how information can be made more accessible to people with communication disorders. The reviews of guidelines and research evidence identified a set of general content and design principles that can be used to guide the development of accessible information materials, but highlighted that information provision should be tailored to people’s individual needs and preferences. An important finding was that currently there is limited evidence to demonstrate that the application of existing guidelines can support people with impaired comprehension to understand more information. This indicates that more research is needed to identify effective methods for producing accessible information, in order to support health and social care professionals to meet the requirements of frameworks such as the Accessible Information Standard (NHS England, 2015).

10.2 Study limitations

As this was a doctoral study, a single researcher was primarily responsible for all data collection, analysis and reporting activities. This may have introduced bias in a number of ways. For example, the case law and literature reviews may have been affected by confirmation bias: the researcher's expectations (based on prior experience) or his perceptions of what would constitute a desirable outcome may have influenced the processes of study / case selection, data extraction, synthesis and reporting. The nature of the researcher's clinical role and his existing relationship with participants may have introduced different types of bias during the data collection and analysis stages in the focus group, toolkit development and feasibility studies. Participants' responses may have been subject to social desirability bias or the halo effect. Confirmation bias may have affected the researcher's decisions when he interpreted and analysed participant responses.

The researcher employed a number of strategies to ensure that all data collection and analysis processes were rigorous and to minimise these potential sources of bias. For example, he consulted his supervisors, local information specialists and national experts in mental capacity law and accessible information during his reviews of evidence and case law, to raise queries about the search strategies he employed and the results he obtained. He used respondent validation and peer scrutiny techniques to increase the credibility and dependability of the focus group data. A triangulation approach was used to integrate data from different sources and collection methods during the feasibility study, in order to increase the credibility and confirmability of the data. The researcher kept a research journal to promote reflexivity and to provide an audit trail for data collection and analysis processes; these strategies also enhanced the credibility, dependability and confirmability of the findings. Finally, the researcher endeavoured to use thick description when reporting study methods and results. This should help readers of this thesis to judge the credibility of its findings and how transferable they are to other settings.

The sampling strategies employed throughout the study may have introduced bias. Data collection took place at a single, albeit large, healthcare trust. The professional sample size was small for some sub-studies during the toolkit development phase.

Similarly, the patient sample used to generate data to investigate the Communication Screening Tool reliability and validity was small, which affected the precision of the statistical analysis. Individuals with a range of diagnoses and communication impairments were successfully recruited to the patient sample. However, there were too few participants in each diagnosis sub-group to enable conclusions to be drawn about how the toolkit could be used with particular groups of patients, for example people living with dementia.

Although care was taken to ensure representation from different professional groups working in a range of clinical settings in each professional sample, the use of convenience sampling in some studies may have introduced selection bias. Certain disciplines associated with mental capacity assessment were under-represented or not present in the samples. This was particularly true for social workers. This group is frequently involved in capacity assessment in healthcare settings and may approach the process of capacity assessment differently to healthcare professionals, due to the nature of their professional training and practices. This possibility was suggested by the social worker who attended the workshop during the toolkit development phase (see p152). It will be important to identify effective ways to recruit social workers when planning future studies to evaluate the MCAST.

The professional, patient and carer samples were not culturally diverse. The professional samples were predominantly composed of white British participants, whilst the patient and carer sample was entirely made up of white British participants. Similarly, the Patient, Carer and Public Involvement (PCPI) group, which made an important contribution to the toolkit design process, only included white British people. This represents an important limitation to the MCAST's potential usability and acceptability. Professionals and patients with different cultural, ethnic and religious backgrounds may have responded differently to the toolkit materials and processes. Different cultural groups vary in terms of their approach to decision-making. For example, people from "collectivist" cultures, which are more common in Asia and Eastern Europe, may prefer to make decisions as a family or with other community members, rather than on an individual basis, which is a predominantly western cultural norm (Hawley and Morris, 2017). Furthermore, different cultural groups are likely to have different needs and preferences in terms of the content and style of delivery of information about decisions that they receive from professionals (Yates and de Oliveira, 2016). Further evaluation of the MCAST should involve professionals and patients or carers from more diverse cultural groups, to ensure the toolkit is "culturally safe" (Papadopoulos and Lees, 2002).

The study did not establish the robustness of the Communication Screening Tool's psychometric properties. It is unclear to what extent the validity and reliability outcomes obtained provide a true representation of the tool's psychometric properties, or were caused by methodological artefacts such as differences in the way that professional participants administered the tool. It is possible that the method used to provide a criterion variable (the researcher's communication assessment) did not provide valid and reliable outcomes. These methodological challenges need to be addressed in future investigations.

10.3 Implications for practice

The study findings relating to best practice barriers and facilitators could be used to inform mental capacity assessment guidelines and training programme specifications for a range of professionals. The researcher has already used the findings to inform training on mental capacity assessment delivered to different multidisciplinary groups. An important finding in the focus group study (chapter 4) was that other disciplines may lack awareness of the role that SLTs can play in supporting people with communication disorders during capacity assessments. This suggests that SLTs in England and Wales may need to consider how they publicise the contribution they can make to this area of practice or how they can deliver this type of clinical work more frequently. The researcher is currently supporting the Royal College of Speech and Language Therapists (RCSLT) to develop a position paper on mental capacity assessment to clarify the role of SLTs in capacity assessments and to promote best practice in supporting people with communication disorders to make decisions.

10.4 Implications for future research

The researcher has identified three distinct themes for future research work involving the MCAST. First, the prototype toolkit developed during this study requires further development work to increase its usability and acceptability before it can be used more widely. Once this has been achieved, the toolkit's effectiveness can be investigated. Finally, further iterations of the toolkit can be developed, for use with different groups of patients. Each of these research "work packages" is described in more detail below.

Work package 1: Refinement of the prototype

The feasibility study data provide indications of ways in which the toolkit should be modified to improve its usability further. First, minor content and design changes need to be made to the Support Tool, on the basis of professional participants' responses to the usability survey and observations made by the researcher during his analysis of completed Support Tool proformas.

Second, further research is required to establish the validity and reliability of the Communication Screening Tool and aspects of its usability. This can be achieved partly by making changes to the screening tool's content and design, on the basis of data collected from the usability survey and documentary analysis during the feasibility study. As already noted, the methods used to measure validity and reliability may have involved methodological artefacts relating to the way in which professionals used the screening tool or the method used to establish a criterion variable. A future investigation could involve the use of ethnographic methods to examine whether participants adhere to the tool's administration instructions; this investigation might generate data relating to how professionals could be supported to adhere more closely to the instructions. Future research could also use evidence from more than one SLT to establish the criterion variable.

After the Communication Screening Tool's psychometric properties have been established, it will be important to investigate whether professionals are able to use the results of the tool to accurately identify and implement strategies to support an individual's communication needs during a capacity assessment; it will also be necessary to establish whether these strategies are actually effective. These considerations were beyond the scope of the present study. Ethnographic methods could be used to collect data relating to how communication strategies are identified and used by professionals.

Any examination of the effectiveness of the communication strategies suggested by the toolkit, should include a more thorough investigation of whether professional and patient users consider the photographic items included in the Resource Pack to be useful and usable and whether any important items are missing from the pack. The current study only provides limited data about this aspect of the toolkit. A future study could be planned to seek the opinions of larger numbers of professionals and patients about the content and design of the photographic items.

Work package 2: Effectiveness of the MCAST

Once the prototype has been refined, the toolkit's effectiveness will need to be measured before it can be implemented with confidence. This study could be planned using the MRC framework for evaluating complex interventions (see figure 2.1, p14). Effectiveness in the context of mental capacity assessment will need to be carefully defined, in order to identify the optimum evaluation study design and which outcomes to measure. The evaluation of this area of practice is challenging due to the current lack of any gold standard instrument to serve as an external criterion variable (Ripley *et al*., 2008). The measures used in this study provide indications of how mental capacity assessment practice could be evaluated in future research studies. The data collection methods used to measure compliance with the MCA and professional confidence were found to be feasible and sensitive.

Effectiveness for this type of tool could be considered to mean that it enables professionals to make accurate and reliable judgements about people's mental capacity. This is an approach that has been taken when mental capacity tools have been developed for use in other countries. For example, tools such as the MacArthur Competence Assessment tool-Treatment (MacCAT-T, Grisso, Applebaum & Hill-Fotouhi, 1997, see p146) have been validated by comparing outcomes relating to judgement of capacity or incapacity obtained using the tool with those obtained by an expert assessor (usually a psychiatrist); their inter-rater reliability has been investigated by comparing the outcomes obtained by two or more assessors. These methods are similar to those employed in the feasibility study to investigate the Communication Screening Tool's validity and reliability. As discussed above, the use of these types of methods is likely to present different challenges, especially the use of an expert assessor to provide a criterion variable. It is unclear how one might identify an expert mental capacity assessor. The case law review (chapter 3) indicated that even experts instructed by the Court of Protection may lack basic knowledge of the MCA or how it should be implemented.

It would be important to consider measuring the MCAST's cost-effectiveness, as successful commissioning and implementation within clinical settings would require persuasive arguments of the toolkit's value for money. Cost-effectiveness might be investigated by comparing the costs of producing or purchasing the toolkit and the time taken for professionals to learn how to use it (if a training element was incorporated in a future version) with any cost savings achieved through its use (for example, in terms of reductions in professional time taken to complete assessments or patient length of stay).

Work package 3: Future iterations of the toolkit

In future, it would be beneficial to test the feasibility of using the MCAST with different groups of patients. The MCAST was designed specifically to facilitate and improve mental capacity assessment for stroke survivors and people with acute or chronic acquired cognitive impairments. It is possible that it also could be used during capacity assessments for people with different diagnoses (e.g., learning disability). The resources designed to enable professionals to identify and support people with communication difficulties were created using evidence that related to a range of populations and might be able to be used with other clinical groups.

The Support Tool includes prompts to guide assessors to consider people's other support needs, relating to cognition, mental health and emotional processing. Future development of the toolkit could include the inclusion of methods that would enable non-specialist professionals to identify and support people's cognitive, mental health and emotional needs. For example, strategies have been identified to support people with attention, information processing and memory impairments to understand and use information more easily when making decisions (Suleman and Kim, 2015). It could be argued that it is unhelpful to consider communicative and cognitive impairments and associated compensatory strategies in isolation. Many people who have communication disorders have concomitant cognitive difficulties that can affect their decision-making abilities, for example their verbal reasoning skills. Stroke survivors may experience different cognitive changes following a stroke, depending on the location of brain lesions (Penn *et al*., 2009). People with dementia are likely to experience "cognitive-communication" difficulties during the course of the disease, due to the impact of changes in cognitive functioning on communication skills (Bayles and Tomoeda, 2014). It will be important to consider how to include strategies that address such cognitive-communication difficulties in future versions of the MCAST.

10.4 Conclusion

This study explored mental capacity assessment practice since the implementation of the Mental Capacity Act (2005). Mental capacity assessment is complex and challenging, especially when it involves people with communication disorders. Currently, practice is variable and health and social care professionals need support to facilitate and improve their capacity assessments. The Mental Capacity Assessment Support Toolkit (MCAST) was developed in response to this clinical need. Results of initial testing indicate revisions required to the prototype before final evaluation of its effectiveness. However, this thesis has demonstrated that the MCAST appears to be feasible to use in healthcare settings and improves professionals' confidence and reporting of their mental capacity assessments.

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Appendix 1: Example of literature review search strategy (chapter 3)

1. Mental Competency/
2. mental capacity.mp.
3. mental ability.mp.
4. 1 or 2 or 3
5. Informed Consent/ or Decision Making/
6. informed decision$.mp.
7. decision making.mp.
8. 5 or 6 or 7
9. 4 and 8
10. assess$.mp.
11. tool$.mp.
12. measur$.mp.
13. scale$.mp.
14. Questionnaires/
15. questionnaire$.mp.
16. survey$.mp.
17. instrument$.mp.
18. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. 9 and 18
20. Young Adult/ or Adult/
21. adult$.mp.
22. limit 19 to ("all adult (19 plus years)" or "adolescent (13 to 18 years)")
23. 20 or 21
24. 19 and 23
25. 22 or 24
26. limit 25 to (english language and humans)
27. limit 26 to yr="2007 -Current"
28. (Britain or british or wales or welsh or Scottish or scots or Scotland or England or English or Birmingham or leeds or London or Liverpool or Manchester or Glasgow or Edinburgh or Cardiff or Belfast or UK or GB or aberdeen or united kingdom).ti,ab,in,hw.
29. exp Great Britain/
30. 28 or 29
31. 27 and 30

Appendix 2: Literature search data extraction form (chapter 3)

Study/ data extraction Study identification Reviewer Review date	**Study design** a. Design b. Data collection period c. Method of randomisation d. Allocation concealment e. Blinding	**Population** a. Target population b. Number (N) c. Age d. Gender e. Location / setting f. Diagnosis g. Inclusion criteria h. Exclusion criteria	**Intervention (I) / Comparator (C)**	**Outcomes** a. Outcomes measured b. Measurement method/tool c. Who measured outcome d. Measurement reliability e. Measurement validity f. Acceptability of measurement to service user / carer / professional	**Results** Outcomes directly relating to how mental capacity was assessed or comparison of >1 method Analysis method used	**Quality** Risk of bias **References** Studies in reference list to be checked for potential inclusion in review

Appendix 3: Focus group study ethical approval letter (chapter 4)

The
University
Of
Sheffield.

Kirsty Woodhead
Ethics Committee Administrator

Regent Court
30 Regent Street
Sheffield S1 4DA
Telephone: +44 (0) 114 2225453
Fax: +44 (0) 114 272 4095 (non confidential)
Email: k.woodhead@sheffield.ac.uk

Our ref: 0753/KW

12 May 2014

Mark Jayes
ScHARR

Dear Mark

Exploration of mental capacity assessment in the acute hospital.

Thank you for submitting the above research project for approval by the ScHARR Research Ethics Committee. On behalf of the University Chair of Ethics who reviewed your project, I am pleased to inform you that on 17 June 2014 the project was approved on ethics grounds, on the basis that you will adhere to the documents that you submitted for ethics review.

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken. You are also required to ensure that you meet any research ethics and governance requirements in the country in which you are researching. It is your responsibility to find out what these are.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

Yours sincerely

[redacted]

Kirsty Woodhead
Ethics Committee Administrator

Appendix 4: Focus group study research governance permission email (chapter 4)

RE: PS-SR-039 Evaluation of mental capacity assessment in acute hospital

Bradley, Erica (Speech & Language Therapy)

To:
Jayes, Mark (Speech & Language Therapy)
13 February 2017 15:15

Dear Mark,
I can confirm that, following the Service Review Panel on 14th August 2014, your project 'RE: PS-SR-039 Evaluation of mental capacity assessment in acute hospital' was approved.

Best wishes,
Erica

Erica Bradley

Audit Lead Therapeutics & Palliative Care

(Working days Monday pm & Wednesday pm)

Appendix 5: Focus group study participant information sheet (chapter 4)

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

The University Of Sheffield.

Participant Information Sheet (12/05/14 Version 1.1)

1. **Project Title:** Exploration of mental capacity assessment in the acute hospital.

2. **Invitation**

You are being invited to take part in a project to explore staff's experiences of mental capacity assessment in hospitals. Before you decide it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information. Please ask if there is anything you do not understand or if you would like more information. Take time to decide if you wish to take part.

3. **What is the purpose of the project?**

This project aims to find out how mental capacity assessments are carried out for hospital patients. This will involve asking staff who carry out mental capacity assessments questions about what they do, what they find easy about the process, and what they find more challenging. The project will use focus group interviews to collect this information from staff. The project lead will use the findings to develop a tool to support staff when they carry out mental capacity assessments.

4. **Why have I been chosen?**

You have been chosen because you are likely to have experience of assessing patients' mental capacity as part of your job.

5. **Do I have to take part?**

You do not have to take part in the project - it is your decision. If you do decide to take part, you will be given this information sheet to keep. You will also be asked to sign a consent form.

If you do decide to take part, you can still change your mind and leave the project either before or during the focus group interview. You do not need to give a reason for not taking part or leaving. If you decide not to take part, or you want to leave the project, this will not affect your job. If you decide to leave the project during the interview, any answers you have already provided will still be part of the project's results.

6. What will happen to me if I take part?

You will be asked to attend a focus group interview held on Sheffield Teaching Hospitals NHS Foundation Trust premises. Each focus group will include up to ten members of staff. The project lead, Mark Jayes, will ask the group questions about their experiences of mental capacity assessment. He will record the interview with a digital recorder and take notes during the session.

7. How much time will it take?

You will be asked to attend one focus group. The focus group should take between 60 and 90 minutes.

8. What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks to you taking part.

9. What are the possible benefits of taking part?

There are no immediate benefits to you if you decide to take part. However, we hope the project will contribute to our understanding of the mental capacity assessment process and may lead to improvements in practice in the future.

11. What if something goes wrong?

This project does not involve any special risks. If you want to make a complaint about how people have approached you or treated you during the project, please contact Mark's supervisor, Dr Rebecca Palmer, at University of Sheffield on 0114 222 0863.

If you are still not satisfied with the way your complaint has been handled, please contact the University's 'Registrar and Secretary', Philip Harvey on 0114 222 1100.

12. Will my taking part in this project be kept confidential?

All information we collect about you during the project will be kept confidentially and securely. Only Mark Jayes and Rebecca Palmer will be able to see your personal information. Your name will not be shown in any reports or publications.

Everything you say during the focus group interview will remain confidential to Mark Jayes, Rebecca Palmer and other people taking part in the interview. All staff taking part in the interviews will be asked not to discuss the content of the interviews or reveal the identities of other attendees to people outside the focus group.

13. What will happen to the results of the project?

The results will be used to help Mark Jayes design a tool to support staff to carry out mental capacity assessments, as part of his PhD studies. The results of the project will be published in Mark Jayes' PhD thesis. Your name will not appear in the thesis. The results may be used in articles written later for scientific journals or in presentations at conferences. Again, this information will be kept confidential and your name will not be shown. Your personal information and any information you provide during the focus group will be stored securely at the University of Sheffield until one year after the end of Mark Jayes' PhD studies (approximately February 2018), when it will be destroyed.

14. Who is organising and funding the project?

The project is being organised by Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. It is being funded by the National Institute for Health Research.

15. Who has ethically reviewed the project?

This project has been ethically approved by the University of Sheffield's School of Health and Related Research's ethics review procedure.

16. Contact for further information:

If you have any questions about the project, please contact Mark Jayes via telephone on 0114 222 5427, or via email at mark.jayes@sheffield.ac.uk.

Thank you very much for taking part in this project.

You will be given a copy of this information sheet and a signed consent form to keep.

Appendix 6: Focus group study sampling frame (chapter 4)

Professional group	Work setting	
	Acute hospital	Intermediate care
Physicians		
Nurses		
OTs		
Physiotherapists		
Psychiatrists		
Psychologists		
SLTs		
Social Workers		

Appendix 7: Focus group study topic guide (chapter 4)

Introductions: Please tell us your name, your job role, where you work and how you are involved in mental capacity assessment.

Ground rules: mutual respect, turn taking, confidentiality.

General questions:

1. Which types of patient decisions are involved in mental capacity assessments?
2. Which types of patients have particular difficulty with these decisions?
3. Which types of staff are involved in mental capacity assessments?
4. How do you assess mental capacity?
5. What's different about assessing patients with communication difficulties?
6. How do you support patients with communication difficulties during an assessment?
7. How do you find mental capacity assessment?
8. What makes it difficult?
9. What can make it easier?
10. Would some type of support tool help you to assess capacity? How? What should it incorporate?

Optional probes:

1. What information about a patient do you consider when assessing capacity?
2. Do you include patients' families in the assessments?
3. How do you document your assessments?
4. How often do you need to assess capacity?
5. What happens if staff disagree about whether a patient has capacity?
6. What makes it hard for patients to make decisions?
7. What types of communication difficulties do patients tend to have?
8. How confident do you feel about assessing capacity?

Appendix 8: Focus group study participant consent form (chapter 4)

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

The
University
Of
Sheffield.

Participant Consent Form (22/05/14 Version 1.3)

Project title: **Exploration of mental capacity assessment in the acute hospital.**

Name of project lead: **Mark Jayes**

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understood the information sheet dated 12/05/14 explaining the above project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I agree for the focus group interview I take part in to be audio recorded. ☐
4. I agree not to discuss the content of the focus group interview or reveal the identities of other participants outside the group. ☐
5. I give permission for members of the project team to have access to my anonymised responses. I understand that my name will not be linked with the project materials, and I will not be identified or identifiable in the report or reports that result from the project. ☐
6. I agree to take part in the above project. ☐
7. I agree for Mark Jayes to contact me about future, related projects. ☐

Name of Participant (*or legal representative*)	Date	Signature
Project Lead	Date	Signature

To be signed and dated in presence of the participant

Copies:
Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix 9: Example of literature review search strategy (chapter 5)

Database: PsycINFO <1806 to July Week 1 2014>

Search Strategy:

----

1 exp Communication Disorders/ (45194)

2 communication disabilit$.mp. (208)

3 exp Communication Barriers/ (377)

4 communication disorder$.mp. (2636)

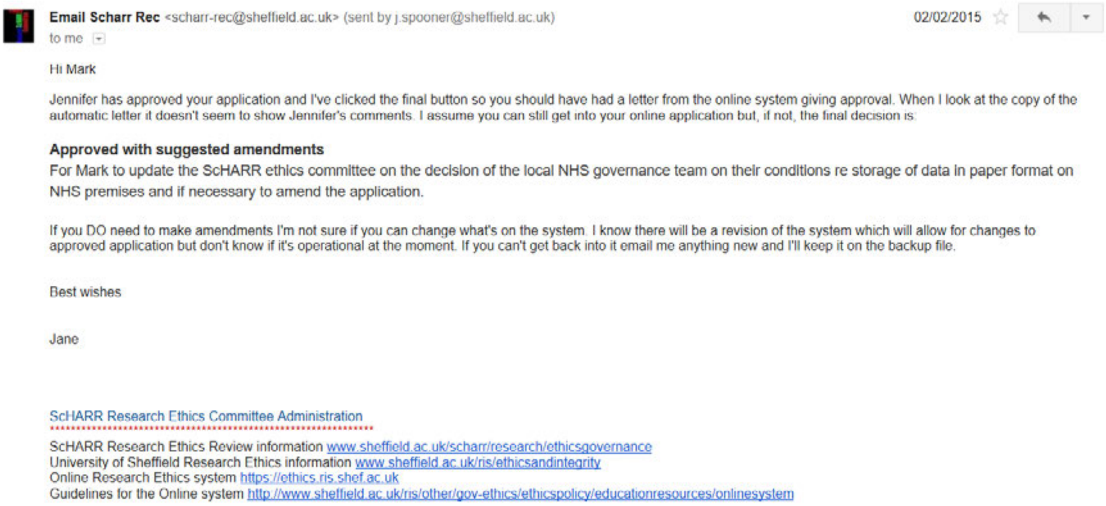
5 communication barrier$.mp. (683)

6 exp Information/ (10784)

7 1 or 2 or 3 or 4 or 5 (46396)

8 6 and 7 (72)

Appendix 10: MCAST development study ethical approval letter (chapter 6)



Email Scharr Rec <scharr-rec@sheffield.ac.uk> (sent by j.spooner@sheffield.ac.uk) 02/02/2015

to me

Hi Mark

Jennifer has approved your application and I've clicked the final button so you should have had a letter from the online system giving approval. When I look at the copy of the automatic letter it doesn't seem to show Jennifer's comments. I assume you can still get into your online application but, if not, the final decision is:

Approved with suggested amendments

For Mark to update the ScHARR ethics committee on the decision of the local NHS governance team on their conditions re storage of data in paper format on NHS premises and if necessary to amend the application.

If you DO need to make amendments I'm not sure if you can change what's on the system. I know there will be a revision of the system which will allow for changes to approved application but don't know if it's operational at the moment. If you can't get back into it email me anything new and I'll keep it on the backup file.

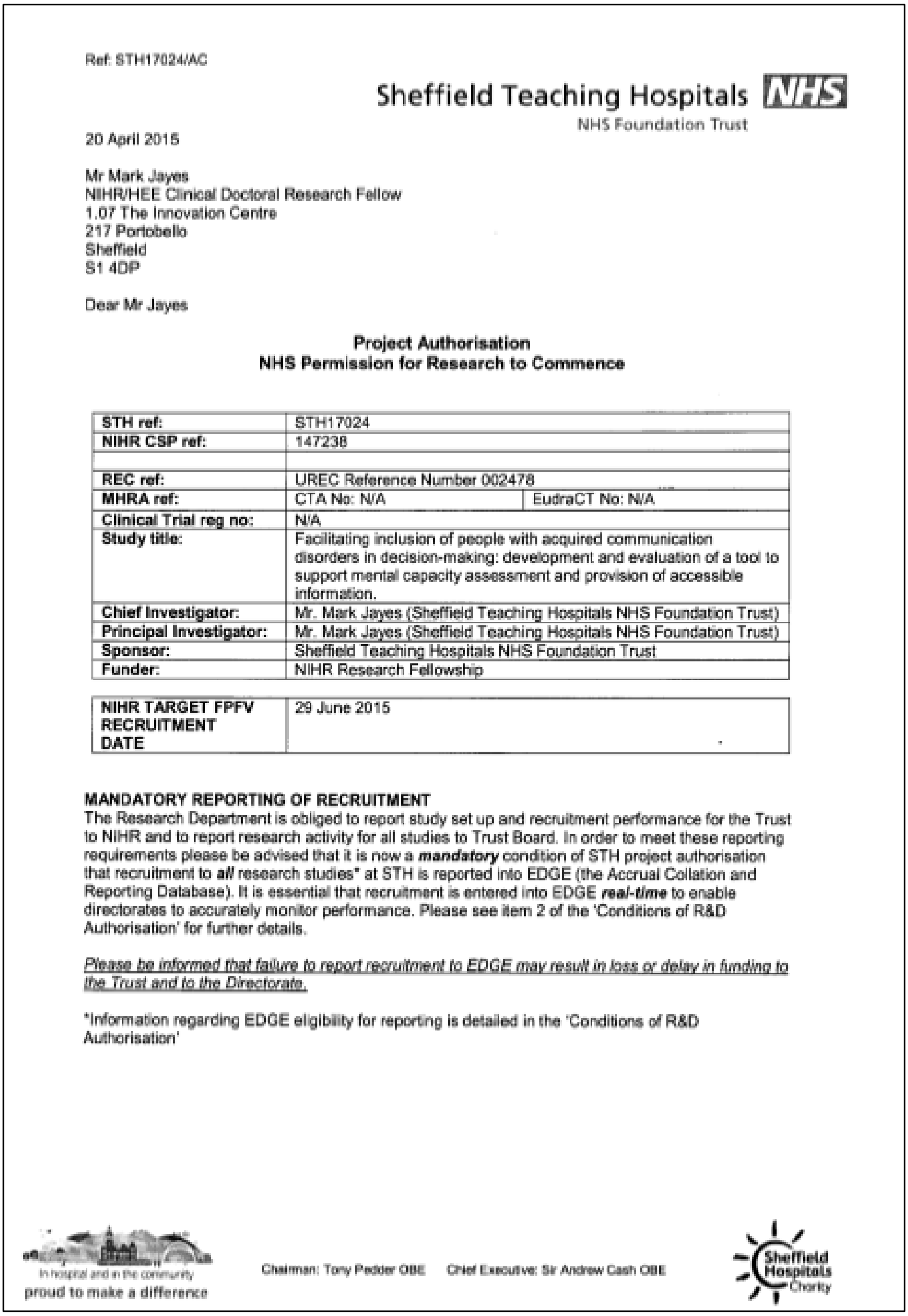
Best wishes

Jane

ScHARR Research Ethics Committee Administration

ScHARR Research Ethics Review information www.sheffield.ac.uk/scharr/research/ethicsgovernance
University of Sheffield Research Ethics information www.sheffield.ac.uk/ris/ethicsandintegrity
Online Research Ethics system https://ethics.ris.shef.ac.uk
Guidelines for the Online system http://www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy/educationresources/onlinesystem

Appendix 11: MCAST development study research governance permission letter (chpater 6)



Ref: STH17024/AC

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

20 April 2015

Mr Mark Jayes
NIHR/HEE Clinical Doctoral Research Fellow
1.07 The Innovation Centre
217 Portobello
Sheffield
S1 4DP

Dear Mr Jayes

Project Authorisation
NHS Permission for Research to Commence

STH ref:	STH17024	
NIHR CSP ref:	147238	
REC ref:	UREC Reference Number 002478	
MHRA ref:	CTA No: N/A	EudraCT No: N/A
Clinical Trial reg no:	N/A	
Study title:	Facilitating inclusion of people with acquired communication disorders in decision-making: development and evaluation of a tool to support mental capacity assessment and provision of accessible information.	
Chief Investigator:	Mr. Mark Jayes (Sheffield Teaching Hospitals NHS Foundation Trust)	
Principal Investigator:	Mr. Mark Jayes (Sheffield Teaching Hospitals NHS Foundation Trust)	
Sponsor:	Sheffield Teaching Hospitals NHS Foundation Trust	
Funder:	NIHR Research Fellowship	

NIHR TARGET FPFV RECRUITMENT DATE	29 June 2015

MANDATORY REPORTING OF RECRUITMENT
The Research Department is obliged to report study set up and recruitment performance for the Trust to NIHR and to report research activity for all studies to Trust Board. In order to meet these reporting requirements please be advised that it is now a ***mandatory*** condition of STH project authorisation that recruitment to ***all*** research studies* at STH is reported into EDGE (the Accrual Collation and Reporting Database). It is essential that recruitment is entered into EDGE ***real-time*** to enable directorates to accurately monitor performance. Please see item 2 of the 'Conditions of R&D Authorisation' for further details.

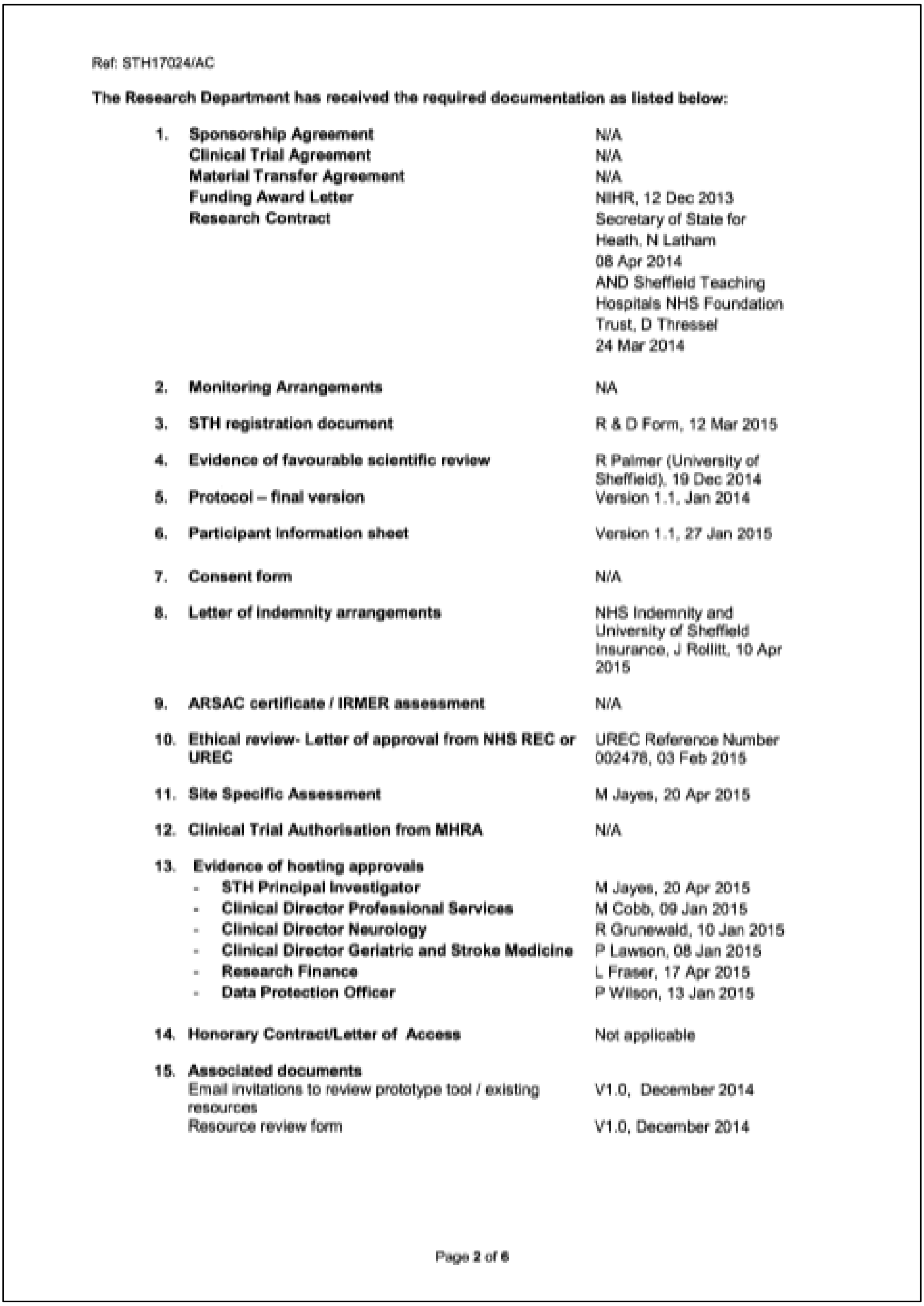
Please be informed that failure to report recruitment to EDGE may result in loss or delay in funding to the Trust and to the Directorate.

*Information regarding EDGE eligibility for reporting is detailed in the 'Conditions of R&D Authorisation'

In hospital and in the community
proud to make a difference

Chairman: Tony Pedder OBE Chief Executive: Sir Andrew Cash OBE

Sheffield Hospitals Charity

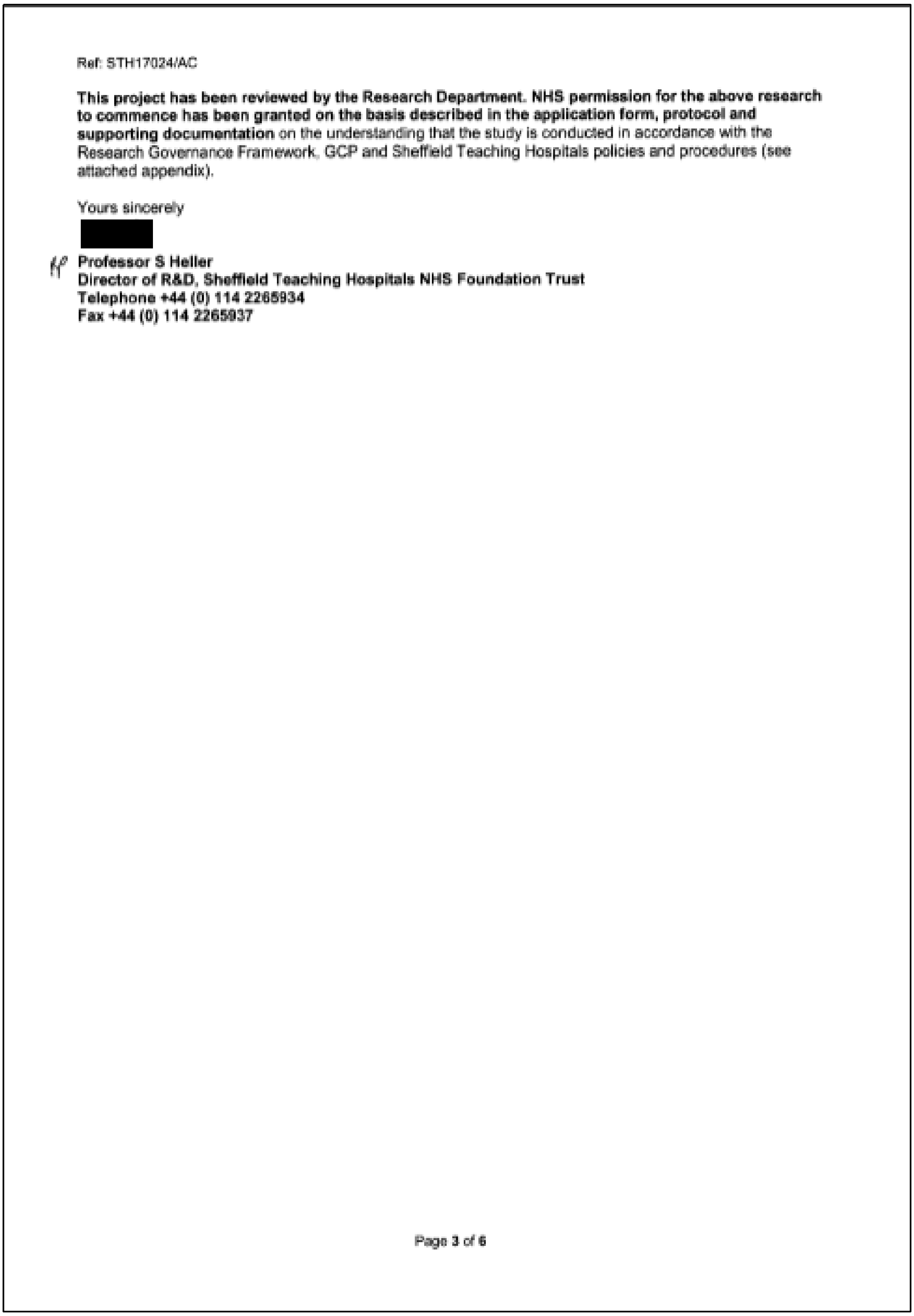


Ref: STH17024/AC

The Research Department has received the required documentation as listed below:

1.	**Sponsorship Agreement**	N/A
	Clinical Trial Agreement	N/A
	Material Transfer Agreement	N/A
	Funding Award Letter	NIHR, 12 Dec 2013
	Research Contract	Secretary of State for Heath, N Latham 08 Apr 2014 AND Sheffield Teaching Hospitals NHS Foundation Trust, D Thressel 24 Mar 2014
2.	**Monitoring Arrangements**	NA
3.	**STH registration document**	R & D Form, 12 Mar 2015
4.	**Evidence of favourable scientific review**	R Palmer (University of Sheffield), 19 Dec 2014
5.	**Protocol – final version**	Version 1.1, Jan 2014
6.	**Participant information sheet**	Version 1.1, 27 Jan 2015
7.	**Consent form**	N/A
8.	**Letter of indemnity arrangements**	NHS Indemnity and University of Sheffield Insurance, J Rollitt, 10 Apr 2015
9.	**ARSAC certificate / IRMER assessment**	N/A
10.	**Ethical review- Letter of approval from NHS REC or UREC**	UREC Reference Number 002478, 03 Feb 2015
11.	**Site Specific Assessment**	M Jayes, 20 Apr 2015
12.	**Clinical Trial Authorisation from MHRA**	N/A
13.	**Evidence of hosting approvals**	
	- **STH Principal Investigator**	M Jayes, 20 Apr 2015
	- **Clinical Director Professional Services**	M Cobb, 09 Jan 2015
	- **Clinical Director Neurology**	R Grunewald, 10 Jan 2015
	- **Clinical Director Geriatric and Stroke Medicine**	P Lawson, 08 Jan 2015
	- **Research Finance**	L Fraser, 17 Apr 2015
	- **Data Protection Officer**	P Wilson, 13 Jan 2015
14.	**Honorary Contract/Letter of Access**	Not applicable
15.	**Associated documents**	
	Email invitations to review prototype tool / existing resources	V1.0, December 2014
	Resource review form	V1.0, December 2014

Page **2** of **6**



Ref: STH17024/AC

This project has been reviewed by the Research Department. NHS permission for the above research to commence has been granted on the basis described in the application form, protocol and supporting documentation on the understanding that the study is conducted in accordance with the Research Governance Framework, GCP and Sheffield Teaching Hospitals policies and procedures (see attached appendix).

Yours sincerely

[redacted]

Professor S Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 2265934
Fax +44 (0) 114 2265937

Appendix 12: MCAST development study staff participant information sheet (chapter 6)

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

The University Of Sheffield.

Participant Information Sheet (Version 1.2 03.07.15)

1. Project Title: **Survey and workshop** to inform design of a tool to support mental capacity assessment.

2. Invitation

You are being invited to take part in the next stage of a project to design a tool to support mental capacity assessment. You may have taken part in an earlier study which asked staff about their experiences of assessing mental capacity. Before you decide, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information. Please ask if there is anything you do not understand or if you would like more information. Take time to decide if you wish to take part.

3. What is the purpose of the project?

This project aims to develop a support tool to help hospital staff to carry out mental capacity assessments. The project will involve asking staff to review a prototype tool and other resources that could be used to make mental capacity assessment easier. Staff's comments on these resources will be used to make improvements to the support tool. **Staff will also be asked to try using the support tool during a practical workshop, to check it is easy to use**.

4. Why have I been chosen?

You have been chosen because you are likely to have experience of assessing patients' mental capacity as part of your job. You may have taken part in an earlier study which asked staff about their experiences of assessing mental capacity. The information participants provided in this earlier study has been used to design the prototype tool and identify the other resources.

5. Do I have to take part?

You do not have to take part in the project - it is your decision. If you do decide to take part, you can still change your mind and leave the project at any point. You do not need to give a reason for not taking part or leaving. If you decide not to take part, or you want to leave the project, this will not affect your job. If you decide to leave the project, any answers you have already provided will still be part of the project's results.

6. What will happen to me if I take part?

Mark Jayes (the investigator) will send you some electronic documents (e.g., a prototype support tool, a communication assessment form) via email. You will be asked to look at these documents and then use an electronic form to record your opinions of them and make suggestions about how they could be improved. You will be asked to send this form back to Mark Jayes via email. Alternatively, you can receive the documents in paper format and record your comments on a paper form. You can also discuss your comments with Mark Jayes by telephone if you prefer. You may be asked to review two or three versions of the prototype tool using this procedure.

You will be invited to try using the support tool during a practical workshop. This will involve you using the tool during role-played capacity assessments with people with communication difficulties. These people are voluntary members of Mark Jayes' PhD project lay advisory group. Mark Jayes will ask you what you think of the tool and how easy it is to use. The workshop may be video-recorded if you consent to this.

7. How much time will it take?

We expect it to take you approximately 15 minutes to review each resource and record your opinions. You may be asked to review two or three resources up to three times. We expect the workshop to take 60-90 minutes.

8. What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks to you taking part.

9. What are the possible benefits of taking part?

There are no immediate benefits to you if you decide to take part. However, we hope the project may lead to improvements in mental capacity assessment practice in the future.

10. What if something goes wrong?

This project does not involve any special risks. If you want to make a complaint about how people have approached you or treated you during the project, please contact Mark's supervisor, Dr Rebecca Palmer, at University of Sheffield on 0114 222 0863.

If you are still not satisfied with the way your complaint has been handled, please contact Professor Jon Nicholl, Dean of the School of Health & Related Research on 0114 222 5453.

11. Will my taking part in this project be kept confidential?

All information we collect about you during the project will be kept confidentially and securely. **Participants in the workshop will be asked to keep issues discussed during the workshop confidential.** Only Mark Jayes and Rebecca Palmer will be able to see your personal information. Your name will not be shown in any reports or publications.

12. What will happen to the results of the project?

The results will be used to help Mark Jayes design a tool to support staff to carry out mental capacity assessments, as part of his PhD studies. The results of the project will be published in Mark Jayes' PhD thesis. Your name will not appear in the thesis. The results may be used in articles written later for scientific journals or in presentations at conferences. Again, this information will be kept confidential and your name will not be shown. Your personal information and any information you provide during the **review process or workshop** will be stored securely at the University of Sheffield until one year after the end of Mark Jayes' PhD studies (approximately February 2018), when it will be destroyed.

13. Who is organising and funding the project?

The project is being organised by Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. It is being funded by the National Institute for Health Research and Health Education England.

14. Who has ethically reviewed the project?

This project has been ethically approved by the University of Sheffield's School of Health and Related Research's Ethics Committee.

15. Contact for further information:

If you have any questions about the project, please contact Mark Jayes via telephone on 0114 222 5427, or via email at mark.jayes@sth.nhs.uk.

Thank you very much for taking the time to consider taking part in this project.

Appendix 13: MCAST development study expert participant information sheet (chapter 6)

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

The University Of Sheffield.

Participant Information Sheet (Version 1.0 03.07.15)

1. **Project Title: Interviews to inform design of a tool to support mental capacity assessment.**

2. **Invitation**

You are being invited to take part in a project to design a tool to support mental capacity assessment. Before you decide, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information. Please ask if there is anything you do not understand or if you would like more information. Take time to decide if you wish to take part.

3. **What is the purpose of the project?**

This project aims to develop a support tool to help hospital staff to carry out mental capacity assessments. The project will involve asking hospital staff and experts in mental capacity assessment to review a prototype tool that could be used to make mental capacity assessment easier. These people’s comments about the prototype will be used to make improvements to the support tool.

4. **Why have I been chosen?**

You have been chosen because you have extensive knowledge of mental capacity assessment.

5. **Do I have to take part?**

You do not have to take part in the project - it is your decision. If you do decide to take part, you can still change your mind and leave the project at any point. You do not need to give a reason for not taking part or leaving. If you decide to leave the project, any answers you have already provided will still be part of the project’s results.

6. What will happen to me if I take part?

Mark Jayes (the investigator) will send you electronic version of the support tool to look at. Mark Jayes will arrange to visit you to ask you what you think of the tool and whether any parts need to be changed. With your consent, Mark Jayes will make an audio recording of the conversation.

7. How much time will it take?

We expect the meeting to last between 1 and 2 hours.

8. What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks to you taking part.

9. What are the possible benefits of taking part?

There are no immediate benefits to you if you decide to take part. However, we hope the project may lead to improvements in mental capacity assessment practice in the future.

10. What if something goes wrong?

This project does not involve any special risks. If you want to make a complaint about how people have approached you or treated you during the project, please contact Mark's supervisor, Dr Rebecca Palmer, at University of Sheffield on 0114 222 0863.

If you are still not satisfied with the way your complaint has been handled, please contact Professor Jon Nicholl, Dean of the School of Health & Related Research on 0114 222 5453.

11. Will my taking part in this project be kept confidential?

All information we collect about you during the project will be kept confidentially and securely. Only Mark Jayes and Rebecca Palmer will be able to see your personal information. Your name will not be shown in any reports or publications.

12. What will happen to the results of the project?

The results will be used to help Mark Jayes design a tool to support staff to carry out mental capacity assessments, as part of his PhD studies. The results of the project will be published in Mark Jayes' PhD thesis. Your name will not appear in the thesis. The results may be used in articles written later for scientific journals or in presentations at conferences. Again, this information will be kept confidential and your name will not be shown. Your personal information and any information you provide during the meeting will be stored securely at the University of Sheffield until one year after the end of Mark Jayes' PhD studies (approximately February 2018), when it will be destroyed.

13. Who is organising and funding the project?

The project is being organised by Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. It is being funded by the National Institute for Health Research and Health Education England.

15. Who has ethically reviewed the project?

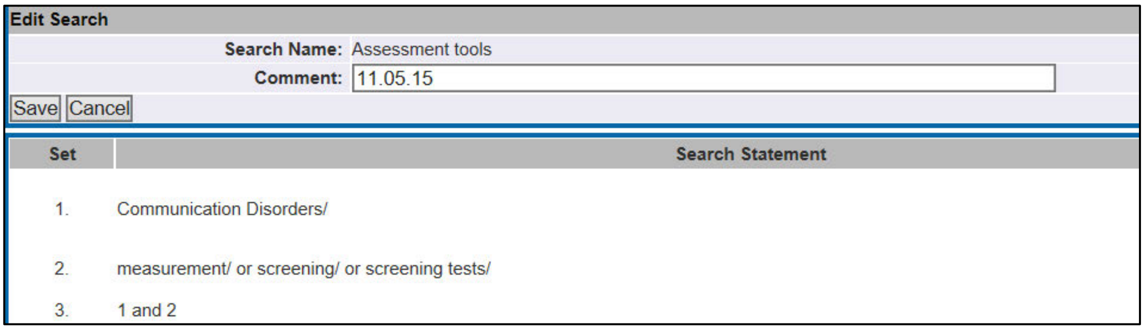
This project has been ethically approved by the University of Sheffield's School of Health and Related Research's Ethics Committee.

16. Contact for further information:

If you have any questions about the project, please contact Mark Jayes via telephone on 0114 222 5427, or via email at mark.jayes@sheffield.ac.uk.

Thank you very much for taking the time to consider taking part in this project.

Appendix 14: Example of literature review search strategy (chapter 6)

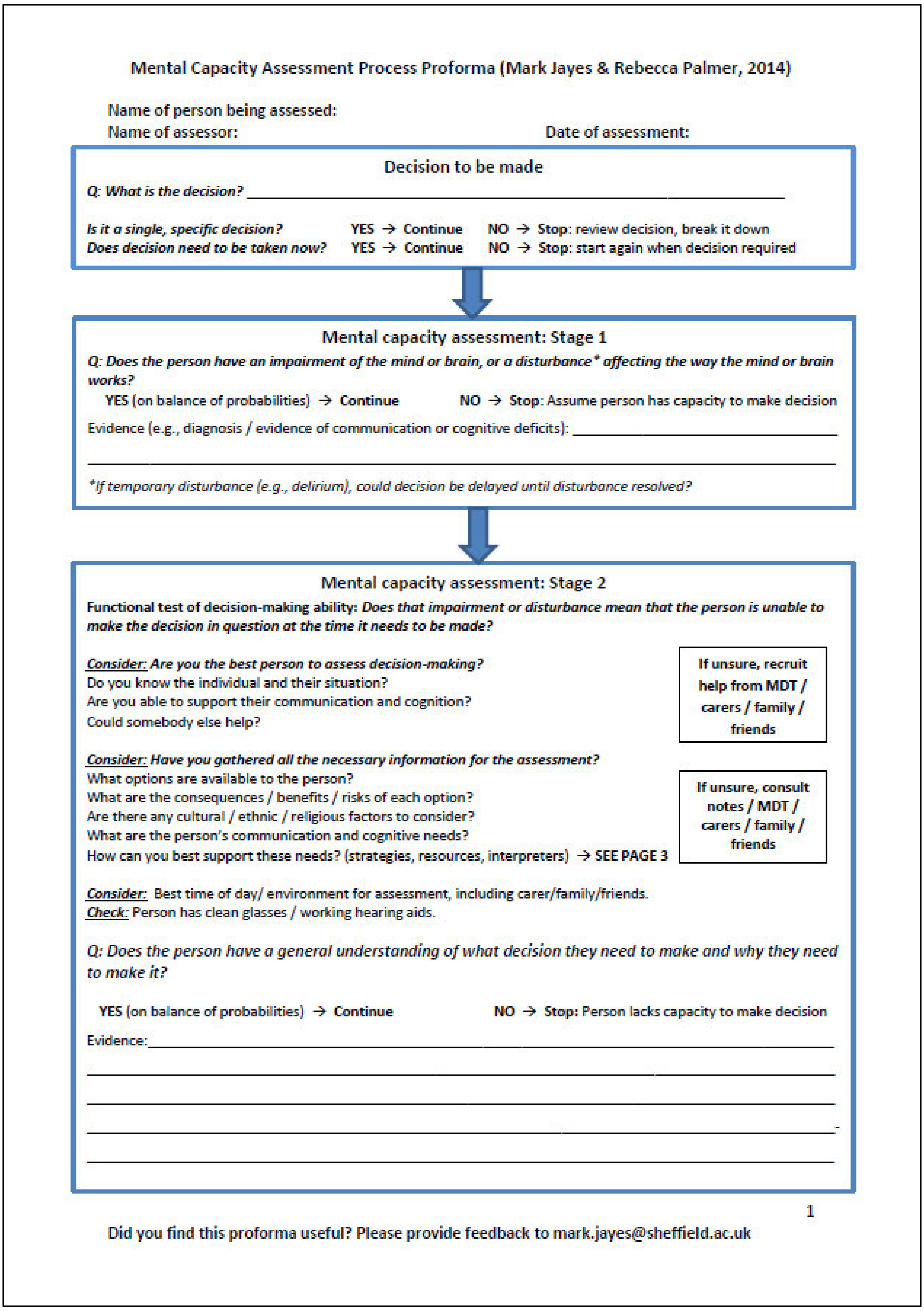


Search Name: Assessment tools

Comment: 11.05.15

Set	Search Statement
1.	Communication Disorders/
2.	measurement/ or screening/ or screening tests/
3.	1 and 2

Appendix 15: Mental Capacity Assessment Process Proforma (chapter 6)



Mental Capacity Assessment Process Proforma (Mark Jayes & Rebecca Palmer, 2014)

Name of person being assessed:
Name of assessor: Date of assessment:

Decision to be made

Q: What is the decision? ______________________________

Is it a single, specific decision? **YES → Continue** **NO → Stop**: review decision, break it down
Does decision need to be taken now? **YES → Continue** **NO → Stop**: start again when decision required

Mental capacity assessment: Stage 1

Q: Does the person have an impairment of the mind or brain, or a disturbance* affecting the way the mind or brain works?

YES (on balance of probabilities) → **Continue** **NO → Stop:** Assume person has capacity to make decision

Evidence (e.g., diagnosis / evidence of communication or cognitive deficits): ______________________________

____

**If temporary disturbance (e.g., delirium), could decision be delayed until disturbance resolved?*

Mental capacity assessment: Stage 2

Functional test of decision-making ability: *Does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?*

Consider: ***Are you the best person to assess decision-making?***
Do you know the individual and their situation?
Are you able to support their communication and cognition?
Could somebody else help?

If unsure, recruit help from MDT / carers / family / friends

Consider: ***Have you gathered all the necessary information for the assessment?***
What options are available to the person?
What are the consequences / benefits / risks of each option?
Are there any cultural / ethnic / religious factors to consider?
What are the person's communication and cognitive needs?
How can you best support these needs? (strategies, resources, interpreters) → **SEE PAGE 3**

If unsure, consult notes / MDT / carers / family / friends

Consider: Best time of day/ environment for assessment, including carer/family/friends.
Check: Person has clean glasses / working hearing aids.

Q: Does the person have a general understanding of what decision they need to make and why they need to make it?

YES (on balance of probabilities) → **Continue** **NO → Stop:** Person lacks capacity to make decision

Evidence:______________________________

____

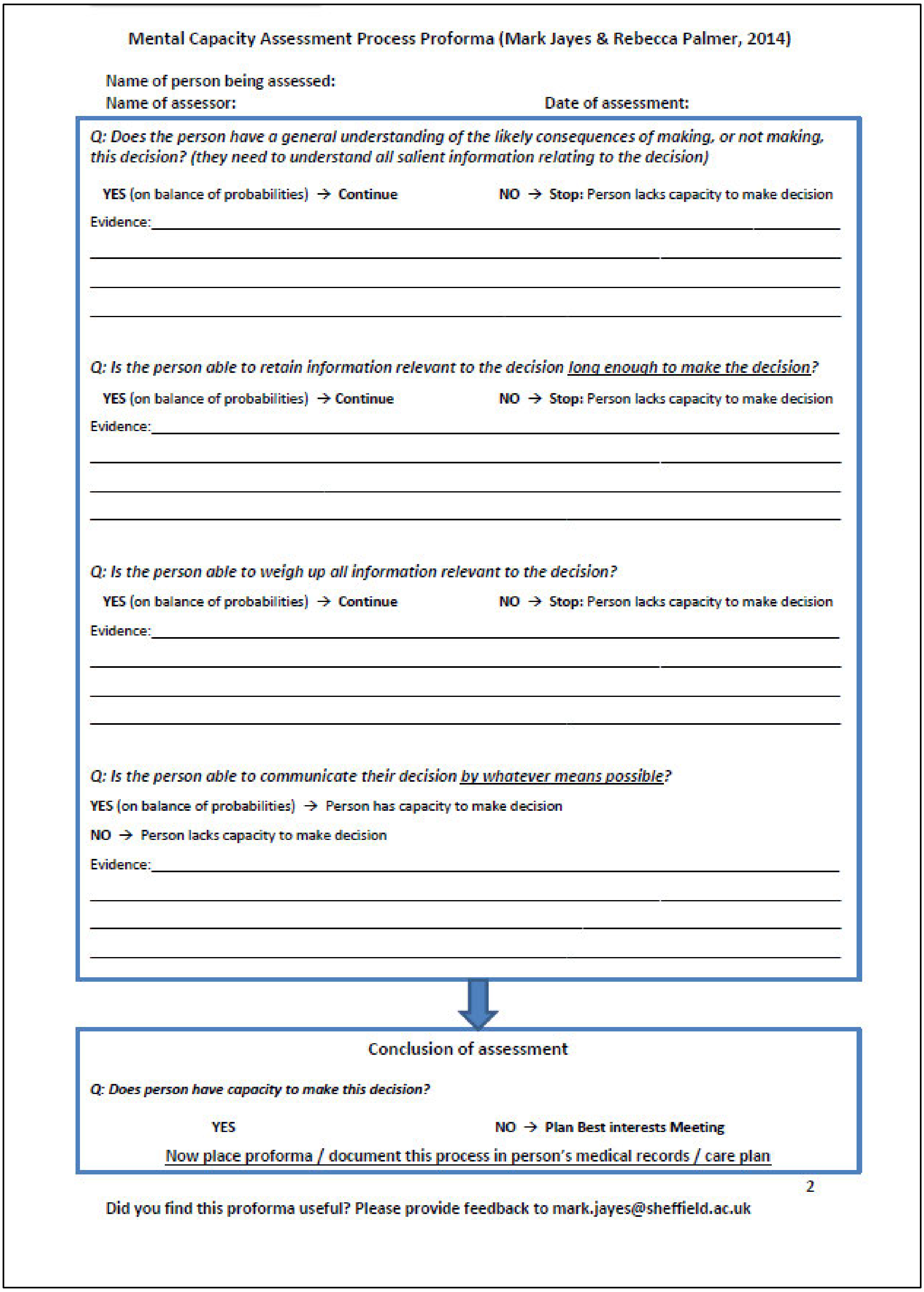
____

____

____

1

Did you find this proforma useful? Please provide feedback to mark.jayes@sheffield.ac.uk



Mental Capacity Assessment Process Proforma (Mark Jayes & Rebecca Palmer, 2014)

Name of person being assessed:
Name of assessor: Date of assessment:

Q: Does the person have a general understanding of the likely consequences of making, or not making, this decision? (they need to understand all salient information relating to the decision)

YES (on balance of probabilities) → **Continue** **NO** → **Stop:** Person lacks capacity to make decision

Evidence:________

Q: Is the person able to retain information relevant to the decision <u>long enough to make the decision</u>?

YES (on balance of probabilities) → **Continue** **NO** → **Stop:** Person lacks capacity to make decision

Evidence:________

Q: Is the person able to weigh up all information relevant to the decision?

YES (on balance of probabilities) → **Continue** **NO** → **Stop:** Person lacks capacity to make decision

Evidence:________

Q: Is the person able to communicate their decision <u>by whatever means possible</u>?

YES (on balance of probabilities) → Person has capacity to make decision

NO → Person lacks capacity to make decision

Evidence:________

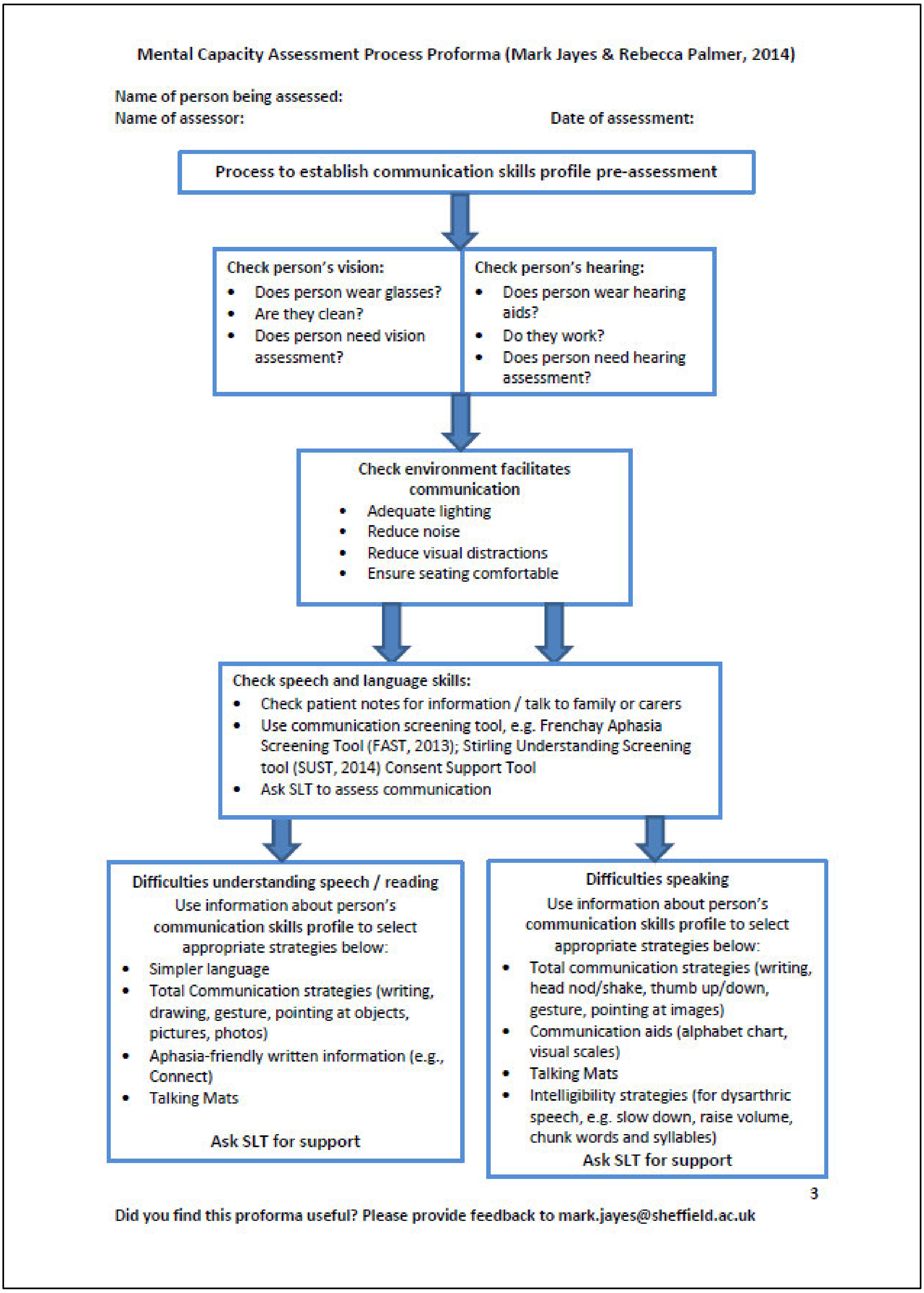
Conclusion of assessment

Q: Does person have capacity to make this decision?

YES **NO** → **Plan Best interests Meeting**

<u>Now place proforma / document this process in person's medical records / care plan</u>

Did you find this proforma useful? Please provide feedback to mark.jayes@sheffield.ac.uk



Mental Capacity Assessment Process Proforma (Mark Jayes & Rebecca Palmer, 2014)

Name of person being assessed:
Name of assessor: Date of assessment:

Process to establish communication skills profile pre-assessment

Check person's vision:

- Does person wear glasses?
- Are they clean?
- Does person need vision assessment?

Check person's hearing:

- Does person wear hearing aids?
- Do they work?
- Does person need hearing assessment?

Check environment facilitates communication

- Adequate lighting
- Reduce noise
- Reduce visual distractions
- Ensure seating comfortable

Check speech and language skills:

- Check patient notes for information / talk to family or carers
- Use communication screening tool, e.g. Frenchay Aphasia Screening Tool (FAST, 2013); Stirling Understanding Screening tool (SUST, 2014) Consent Support Tool
- Ask SLT to assess communication

Difficulties understanding speech / reading

Use information about person's communication skills profile to select appropriate strategies below:

- Simpler language
- Total Communication strategies (writing, drawing, gesture, pointing at objects, pictures, photos)
- Aphasia-friendly written information (e.g., Connect)
- Talking Mats

Ask SLT for support

Difficulties speaking

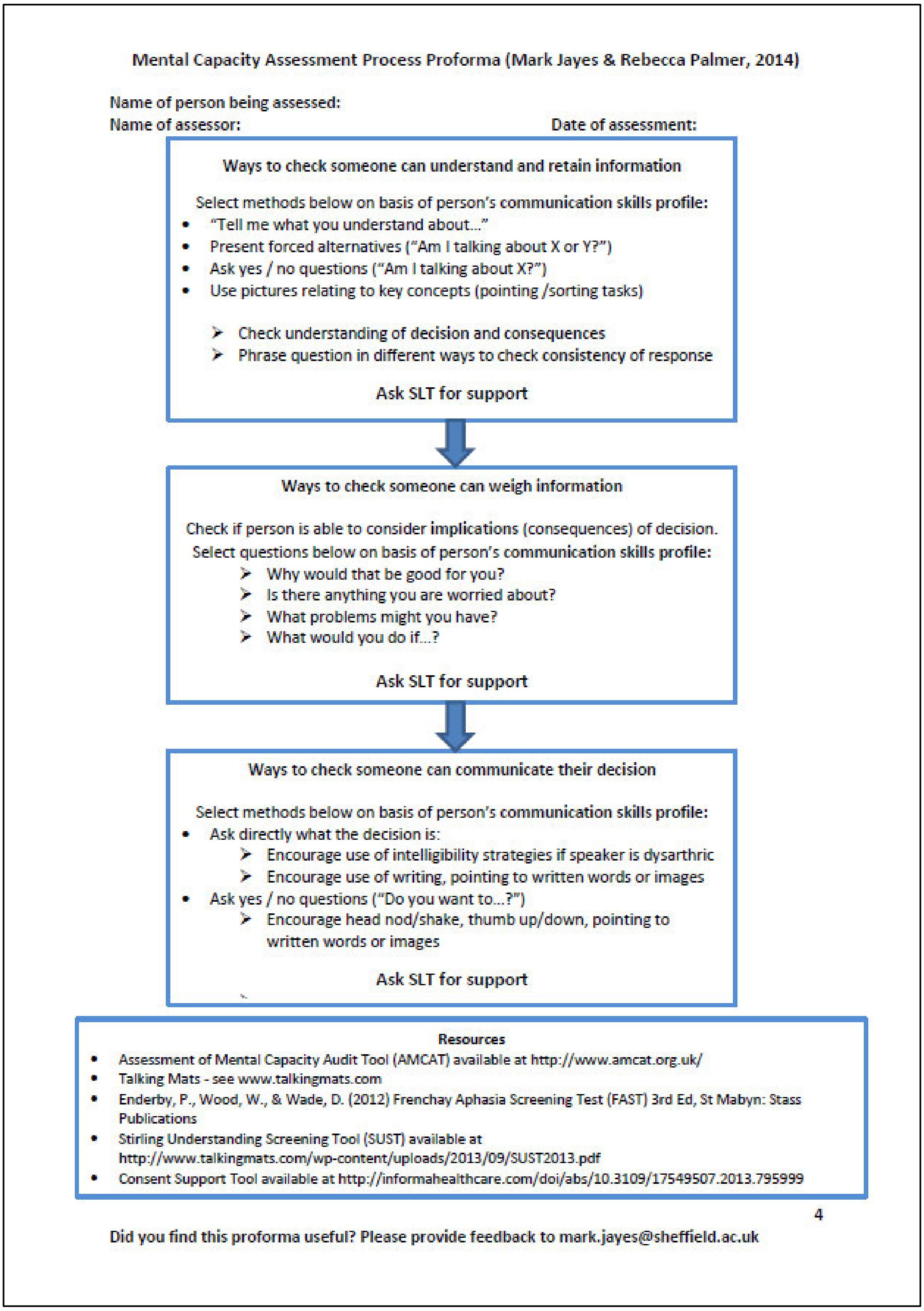
Use information about person's communication skills profile to select appropriate strategies below:

- Total communication strategies (writing, head nod/shake, thumb up/down, gesture, pointing at images)
- Communication aids (alphabet chart, visual scales)
- Talking Mats
- Intelligibility strategies (for dysarthric speech, e.g. slow down, raise volume, chunk words and syllables)

Ask SLT for support

3

Did you find this proforma useful? Please provide feedback to mark.jayes@sheffield.ac.uk



Mental Capacity Assessment Process Proforma (Mark Jayes & Rebecca Palmer, 2014)

Name of person being assessed:
Name of assessor: **Date of assessment:**

Ways to check someone can understand and retain information

Select methods below on basis of person's communication skills profile:
- "Tell me what you understand about..."
- Present forced alternatives ("Am I talking about X or Y?")
- Ask yes / no questions ("Am I talking about X?")
- Use pictures relating to key concepts (pointing /sorting tasks)

  - ➢ Check understanding of decision and consequences
  - ➢ Phrase question in different ways to check consistency of response

Ask SLT for support

Ways to check someone can weigh information

Check if person is able to consider implications (consequences) of decision.
Select questions below on basis of person's communication skills profile:
- ➢ Why would that be good for you?
- ➢ Is there anything you are worried about?
- ➢ What problems might you have?
- ➢ What would you do if...?

Ask SLT for support

Ways to check someone can communicate their decision

Select methods below on basis of person's communication skills profile:
- Ask directly what the decision is:
  - ➢ Encourage use of intelligibility strategies if speaker is dysarthric
  - ➢ Encourage use of writing, pointing to written words or images
- Ask yes / no questions ("Do you want to...?")
  - ➢ Encourage head nod/shake, thumb up/down, pointing to written words or images

Ask SLT for support

Resources
- Assessment of Mental Capacity Audit Tool (AMCAT) available at http://www.amcat.org.uk/
- Talking Mats - see www.talkingmats.com
- Enderby, P., Wood, W., & Wade, D. (2012) Frenchay Aphasia Screening Test (FAST) 3rd Ed, St Mabyn: Stass Publications
- Stirling Understanding Screening Tool (SUST) available at http://www.talkingmats.com/wp-content/uploads/2013/09/SUST2013.pdf
- Consent Support Tool available at http://informahealthcare.com/doi/abs/10.3109/17549507.2013.795999

4

Did you find this proforma useful? Please provide feedback to mark.jayes@sheffield.ac.uk

Appendix 16: MCAST development study data collection form (design specification) (chapter 6)

Factors / components you said appear to facilitate / improve capacity assessment	**How I think I could design a tool to incorporate these components**	**Your comments:** • **Do you agree that this is what is needed?** • **Do you think this is realistic?** • **Is there anything you don't understand?** • **Any other comments?**
Devoting extra time for assessments or carrying out serial assessments	• Include written prompts for assessor	
Assessing in a calm environment	• Include written prompts for assessor	
Using an assessor who is familiar with person being assessed	• Include written prompts for assessor	
Involving carers in assessment	• Include written prompts for assessor	
Using a structure (an algorithm / prompt sheet / checklist)	• Provide structure for assessment within tool	
Using a documentation aid (e.g., a proforma)	• Include documentation prompts / space to record assessment findings	
Gathering information about patient's abilities and needs pre-assessment (e.g., communication skills)	• Include written prompts to check sensory needs • Include communication screening tool for use with people with aphasia and people with dementia (most important groups identified by focus group participants) • Include method to check patient can identify / recognise images to be used in accessible information resources (see below)	

Supporting patient's visual, hearing and communication needs, e.g. how to simplify language, use alternative formats (accessible information, images to support text, drawing)	• Include written prompts for professionals to check patients want accessible formats and can understand accessible information • Provide guidance about communication strategies, ? include video training resource • Provide guidance about accessible information principles • Provide sample information materials for most *common decisions* (focus group data suggest these are decisions about discharge and treatment options) • Include sample statements and questions in simplified language for use in capacity assessments for common decisions • Include limited range of images (photos/pictures) to support staff to explain information relating to most common decisions during assessments (physical resource / online) • Provide recommendations for producing further images to use for other decisions	
Method to check if patient can understand information provided during capacity assessment	• Include sample questions in different formats for staff to use for most common decisions • Provide guidance about establishing reliability of response	
Method to flag patients with communication difficulties	• Include blank summary table of patient's communication skills profile to attach to patient notes /scan into electronic notes	
Prompt to refer to SLT for specialist support when needed	• Include written prompt as part of communication screening tool	
Design features that may make tool easier to use	**How I think I could design a tool to include these features**	**Your comments**
Quick to use	• Needs to be short	
Simple to use	• Needs to be easy to administer	
Portable or easily accessible	• Needs to be small or available online	

Appendix 17: MCAST development study data collection form (Communication screening assessment resources) (chapter 6)

Thank you for agreeing to review these resources. These are existing resources that have been developed to screen for communication difficulties. The Consent Support Tool (CST) also suggests strategies that could be used to support identified difficulties. Please have a look at each resource and consider whether it would help you during your capacity assessments. Then please answer the questions in the table.

Please get in touch if you have any questions about this document.

Resource reviewed	**Question: Do you think this resource would help you during your capacity assessments?**		
Consent Support Tool (CST):	**Please tick one answer:**		**If “Yes, partially”, which sections would help? If “Not at all”, why not?**
	Yes, very much		
	Yes, partially		
	Not at all		
Frenchay Aphasia Screening Test (FAST)	**Please tick one answer:**		**If “Yes, partially”, which sections would help? If “Not at all”, why not?**
	Yes, very much		
	Yes, partially		
	Not at all		

(Continued on next page)

Sheffield Screening Test for Acquired Language Disorders (SSTALD)	**Please tick one answer:**		**If “Yes, partially”, which sections would help? If “Not at all”, why not?**
	Yes, very much		
	Yes, partially		
	Not at all		

Do you think a new resource needs to be developed to help you identify and support patients with communication difficulties? Yes / No

Please add any other general comments or suggestions below:

Appendix 18: MCAST development study data collection form (screening tools) (chapter 6)
Resource review form (Version 1.0 December 2014)

Thank you for agreeing to review these resources. Please look at the resources listed in column 1 and consider the questions in columns 2-5. Please record your response in the relevant cell. Please get in touch if you have any questions about this document.

Resource reviewed	Do you think you understand how to use this resource? (Y/N) *If No, which sections are difficult to understand?*	Does the resource include any sections that you think are unnecessary? (Y/N) If Yes, which ones and why?	Do you think there is anything missing from the resource? If Yes, please specify what is missing.	How could the resource be improved?	Any other comments
Communication screening tools					
Consent Support Tool (CST):					
Frenchay Aphasia Screening tool (FAST)					
Sheffield Screening Test for Acquired Language Disorders (SSTALD)					

Please add any other general comments or suggestions below:

Appendix 19: MCAST Support Tool v1 (chapter 6)

Decision to be made

Q: What is the decision? ____

Tick the boxes

Is it a single, specific decision? Yes ☐ **Continue** No ☐ **Stop**: review decision, break it down
Does decision need to be taken now? Yes ☐ **Continue** No ☐ **Stop**: start again when decision required

Mental capacity assessment: stage 1

Q: Does the person have an impairment of the mind or brain, or a disturbance* affecting the way the mind or brain works?

Tick the boxes to record what you believe to be true, based on the balance of probabilities. Use Evidence Form 1 to document this information (optional):

Yes ☐ **Continue** No ☐ **Stop**: Assume person has capacity to make decision

**If temporary disturbance (e.g., delirium), could decision be delayed until disturbance resolved?*

Preparation for mental capacity assessment stage 2:

<u>Consider:</u> Have you gathered all the information you need to do the assessment?
Tick the boxes and use Evidence Form 1 to document this information (optional):

1. You know what decision options are available to the person ☐
2. You know what the consequences / benefits /risks are for each option ☐
3. You have considered any cultural / ethnic / religious factors ☐
4. You have considered any Power of Attorneys ☐

If you cannot tick a box: check the person's notes or ask MDT/ family / carers for help

5. You know if the person has any communication needs	Yes ☐ No/unsure ☐	**Go to question 6** **Check person's notes, ask MDT, check if known to SLT, ask family/carers. If still unsure, <u>complete Communication Screen form</u>**
6. You know how to support the person's communication needs	Yes ☐ No/unsure ☐	**Go to question 7** **Complete Communication Screen Form**
7. You know if the person has any cognitive needs	Yes ☐ No/unsure ☐	**Go to question 8** **Check person's notes, ask MDT, ask family /carers. Ask OT / Psychologist for help.**
8. You know how to support the person's cognitive needs	Yes ☐ No/unsure ☐	**Go to question 9** **Check person's notes, ask MDT, ask family /carers. Ask OT / Psychologist for help.**
9. You know if the person has any mental health needs	Yes ☐ No/unsure ☐	**Go to question 10** **Check person's notes, ask MDT, ask family /carers. Ask Liaison Psychiatry for help.**
10. You know how to support the person's mental health needs	Yes ☐ No/unsure ☐	**Go to page 2** **Check person's notes, ask MDT, ask family /carers. Ask Liaison Psychiatry for help.**

Mental capacity assessment: Stage 2

Functional test of decision-making ability: ***does the impairment or disturbance mean the person is unable to make the decision at the time it needs to be made?***

<u>Consider:</u> ***Have you done everything to prepare the person and the environment for the assessment?***
Tick the boxes

1. You have chosen a time of day when the person is more alert and less distracted Yes ☐
2. You have chosen a place for the assessment that is quieter with less distractions Yes ☐
3. You have invited any professionals who can support the person's specific needs Yes ☐
4. You have invited family / friends, if you think they can offer support /reassurance Yes ☐
5. The person has the right glasses /working hearing aids (if they need them) Yes ☐

If you cannot tick a box, consider making changes before continuing

<u>You need to provide evidence to demonstrate that you have considered each of these questions during your assessment. Use Evidence Form 1 to document this evidence (optional)</u>
Tick the boxes to record what you believe to be true, based on the balance of probabilities:

Q1: Does the person have a general understanding of what decision they need to make and why they need to make it?

YES ☐**Go to Q2** **NO** ☐ **Stop:** Person lacks capacity to make decision

Q2: Does the person have a general understanding of the likely consequences of making, or not making, this decision? (they need to understand all salient information relating to the decision)

YES ☐**Go to Q3** **NO** ☐ **Stop:** Person lacks capacity to make decision

Q3: Is the person able to retain information relevant to the decision <u>long enough to make the decision</u>?

YES ☐**Go to Q4** **NO** ☐ **Stop:** Person lacks capacity to make decision

Q4: Is the person able to weigh up all information relevant to the decision?

YES ☐**Go to Q5** **NO** ☐ **Stop:** Person lacks capacity to make decision

Q5: Is the person able to communicate their decision <u>by whatever means possible (i.e., using strategies)</u>?

YES ☐ **Person has capacity** to make decision **NO** ☐ **Person lacks capacity** to make decision

Conclusion of assessment

Q: Does person have capacity to make this decision?

YES ☐ **NO** ☐ **Plan Best interests Meeting**

<u>Now place Evidence Form 2 / document your assessment in person's medical records / care plan</u>

Appendix 20: MCAST Support Tool Evidence Form (chapter 6)

Use this form to record additional evidence relating to the mental capacity assessment you have completed with the Support Tool. This form could be placed directly in the patient's medical notes or care record.
Patient name: **Patient identifier:** **Decision patient needs to make:**
Mental Capacity Assessment Stage 1: Impairment of or disturbance in the functioning of the mind or brain:
Mental Capacity Assessment Stage 2: Functional test of decision-making:
Your conclusion about patient's mental capacity to make this decision:
Planned actions as a result of the capacity assessment:
Signed: **PRINT NAME:** **Date:**

Appendix 21: MCAST Communication screening tool v1 (chapter 6)

Collect information from medical notes, talk to family / carers / MDT about person's communication:

- Vision: do they wear glasses, what for, are they available?
- Hearing: do they use a hearing aid, are they available, do they work?
- Do they have a communication difficulty? If so, what sort of strategies help?
- Do they use any aids (communication book / alphabet chart / electronic aid).

Check person can see:

- Are they wearing the right glasses?
- Are they clean?
- Do you need to refer for vision assessment?

Check person's hearing:

- Are they wearing hearing aids that work?
- Do you need to refer for hearing assessment?

Check environment makes communication easier

- Adequate lighting (you both need to be see each other's faces any information materials clearly)
- Reduce noise
- Reduce visual distractions (e.g. close open doors / avoid busy areas on ward)
- Ensure seating is comfortable

Check person is able to say "yes" and "no" reliably in response to questions:

Ask the following questions. If the person is unable to say "yes" and "no", write down "yes" and "no" clearly in large print on a piece of paper and ask the person to point to the word they want to use to respond to each question.	**✓ / X**
1. Is your surname (use their correct name)?	
2. Is your first name (use an incorrect name)?	
3. Do you live in London?	
4. Is your first name (use their correct name)?	
5. Do you live in (use the correct place)?	
6. Is this your house? (point around the room)?	
If person scores less than 6/6, STOP this screen and refer to Speech and Language Therapy	

Check person’s ability to understand speech:

Say the following to the person and only mark as correct (✓) if they get the task completely right. Do not look at the objects as you say the words.	**✓ / X**
1. Show me the door, window and the light	
2. Touch your left knee	
3. Shake your head and touch your chin	
If person did not score 3/3, STOP this screen and refer to SLT for support with capacity assessment.	**If person scored 3/3, say the following to the person and only mark as correct if they get the task completely right.**
Touch each shoulder twice with two fingers whilst keeping your eyes closed	
If person able to do this, talk to the person using lay language during the capacity assessment	**If person not able to do this, use simple language and other supportive strategies – see below**

SUPPORTIVE STRATEGIES SECTION

Check person’s ability to <u>read</u>, to see if you can write things down to help them understand:

Do the following:	**Score**
Write down the names of three objects in the room (e.g., “table”, “pen”, “cup”) on a piece of paper. Write clearly, using large print. Point to each word one at a time and ask the person to show you the object in the room. Do not say the word as you point to it. Do not look at the object. Note how many objects the person is able to find.	**/3**
If person did not score 3/3, you cannot reply on writing things down to help the person understand during the capacity assessment. Check to see if you could use photographs instead (see below)	**If person scored 3/3, continue with task below:**
Write out the sentences below on a piece of paper. Write clearly, using large print. Point to each sentence in turn and ask the person to do what it says. Do not read the sentences aloud as you point to them. Do not look at the objects as you say the words. Only mark as correct (✓) if they get the task completely right.	**✓ / X**
1. Show me the ceiling, table and door	
2. Touch your left shoulder three times	
3. Look at the ceiling and shake your head	
If person did not score 3/3, you cannot rely on them being able to read whole sentences. But you can write down single words to explain key pieces of information during the capacity assessment to help them understand you.	**If person did score 3/3, you can write down short, simple sentences to explain key pieces of information during the assessment to help the person to understand you as you speak. See Resource Pack for sample sentences.**

Check person’s ability to recognise photos, to see if you can use photos to help them understand:

Do the following:	
Show the person the three photos below, one at a time. Ask the person to show you the same thing in the room. Do not say the name of the object shown in the photo or look at the objects in the room. Note how many objects the person is able to find.	**/3**
ADD IMAGES: Light, Chair, Ear	
If person did not score 3/3, you cannot reply on using photos to help them understand information during the capacity assessment. Just speak using simple language and write down single words or simple sentences, depending on the results of the reading check.	**If person did score 3/3, you can use clear photos to explain key pieces of information during the assessment to help the person to understand you as you speak. See Resource pack for sample photos.**

Check person’s ability to speak, to determine how they will communicate they can understand, weigh, retain information and then tell you their decision:

Do the following:		
Have a conversation with the person about something (e.g., their family, home, hobbies, working life).		
Based on how they respond, tick all the boxes that apply:	✓	**If you tick a box, this means:**
Person has no obvious difficulties speaking		The person can talk to you and answer your questions without extra support
Person’s speech is slurred or sounds different, but you can understand most of the words		You should encourage the person to use a slow rate of speech, say one word at a time and break longer words into chunks
The person can mouth words but you cannot hear their voice		You should use strategies to help the person express themselves: • Encourage the person to mouth words slowly, one at a time • Check if the person can write (see below). If they can, encourage the person to write down their answers • Ask closed questions requiring one word or yes/no answers (see Resource pack)
Person only uses single words to tell you what they mean,		You should use strategies to help the person express themselves: • Ask closed questions requiring one word or yes/no answers (see Resource pack) • If the person can read: write useful words down for them to point to (see Resource Pack) • If the person can recognise photos: offer photos corresponding to important concepts for them to point to (see Resource pack) • Check if the person can write (see below). If they can, encourage the person to write down their answers
The person has difficulty finding words or uses the wrong words		
You cannot understand the person’s speech		
If you feel that you need more support, refer to Speech and Language Therapy		

Check person's ability to write, to see if they can write things down to help them communicate:

Do the following:	
Show the person the photos you showed them earlier (see above). Ask them to write down the names of the three objects. Note how many of the names you are able to recognise as being correct.	**/3**
If the person scored 3/3, you can encourage them to write information down when they are answering your questions.	**If the person did not score 3/3, writing may not be an effective strategy for them.**

Summary of strategies to use during mental capacity assessment:

Tick all the boxes that apply. Write in other effective strategies suggested by family / friends / carers / Speech and Language Therapist etc..

Strategies to help person to understand you better	**✓ / X**	**Strategies to help person to express themselves better**	**✓ / X**
Use simple language: use everyday words in short, simple sentences.	✓	Ask closed questions requiring one word or yes/no answers	
Speak slowly and clearly. Repeat important information.	✓	Write useful words down for person to point to	
Check regularly that the person understands what you saying and recap if they do not	✓	Offer photos corresponding to important concepts for person to point to	
Write down single words corresponding to important concepts and encourage person to read them		Encourage the person to write down their answers	
Write down short, simple sentences and encourage person to read them		Encourage person to use a slow rate of speech, say one word at a time and break longer words into chunks	
Use clear images representing important concepts and encourage person to look at them		Encourage the person to mouth words slowly, one at a time	
		Ask closed questions requiring one word or yes/no answers	

See Resource Pack for further information about strategies and practical examples. If you feel that you need more support, refer to Speech and Language Therapy

Appendix 22: Support Tool v1 and Communication Screening Tool v1 data collection form (chapter 6)

Question	**Your Response**	
	Support Tool	**Communication Screening Tool**
Do you think you understand how to use the proforma? (Y/N) ***If No, which sections are difficult to understand?***		
Does the proforma include any sections that you think are unnecessary? (Y/N) ***If Yes, which ones and why?***		
Do you think there is anything missing from the proforma? ***If Yes, please specify what is missing.***		
How could the proforma be improved?		

Appendix 23: Resource Pack topic review form (chapter 6)

Suggested topic area	**Would this topic be useful? (Yes/No)**	**Please add any suggestions for specific items / photographs to include**
Activities of daily living (e.g., washing, dressing)		
Body parts		
Eating and drinking		
Family members / friends		
Feelings		
Managing finances		
Medical conditions (e.g., stroke, dementia)		
Medical procedures (e.g., X ray)		
Mobility		
Places (e.g., house, residential home, hospital, Sheffield)		
Professional roles or services (e.g., doctor, nurse, Police, Ambulance)		
Risks (e.g., falls, fire, injury, infection)		
Symptoms (e.g., pain, feeling hot, hungry)		
Time (e.g., day of week, months of year)		
Types of treatment (e.g., tablets, operation, feeding tube)		
Please feel free to add more here…..		

Appendix 24: Suggested items to include in Resource Pack (chapter 6)

Theme	Items (A5 photos with text labels below unless otherwise specified)
People	Family Friends Carer SLT Social worker OT Physio Solicitor Nurse District Nurse GP Warden Solicitor Priest / chaplain
Places	Bungalow House Flat Lift Stairs Care home Sheltered accommodation Hospital Hospice Rehab setting Bank Post office Pub Shops Park Chemist Day centre “Work” setting
Time	A clock with moveable hands Simple timetable eg morning afternoon and night Morning / waking up Bedtime
Daily activities	Having a wash independently Having a wash with help Getting dressed independently Getting dressed with help Putting shoes on Using the toilet Making food Cooking Making a drink Cleaning Eating Drinking Taking medication Using phone *Objects:* Toilet Bath

	Sink Shower
Moving	Getting out of bed Getting into bed Getting out of a chair Getting into a chair Getting out of a chair with assistance Getting on/off the toilet Walking independently inside Walking independently outside Walking independently with stick inside Walking independently with stick outside Walking with stick and assistance Walking without stick and assistance Walking with a frame Climbing stairs Falling Someone in a wheelchair Driving
Equipment / adaptations	Dentures Glasses Hearing aids Communication aid Commode Stick Frame Wheelchair Hoist x 2 Bed downstairs Hospital bed Stair lift Toilet frame Bath board Meals on wheels Citywide care alarm Telephone Rotunda Slide board Toilet frame/raise Stair rails Kitchen trolley Bathing equipment
Transport	Bus Taxi Car Ambulance
Body parts	Head Eyes Ears Mouth Neck Shoulder Chest Arms Elbow Hand Abdomen Bottom Hip Legs

	Knees Feet
Feelings	Happy Sad Worried Angry Lonely Depressed Embarrassed Psychological support
Eating and drinking	Food you like Food you don't like Eating Not eating (eating with cross through it) Drinking Not drinking (drinking with a cross through it) Breakfast Lunch Tea Snack Pureed diet Fork-mashable diet Thickened drink Sandwich Cold drink (water) Hot drink (tea) PEG tube NG tube
Finances	Cash Bank cards Cheque Bills Pension Bank Post office Cash machine Shopping online Power of Attorney
Medical conditions	Stroke (Bleed in brain) Stroke (Infarct) Aphasia Hypertension / blood pressure measuring Heart attack Fractured limb Arthritis Diabetes Brain injury Learning Difficulty Huntington's Disease Multiple Sclerosis Brain tumour
Symptoms	Feeling hot Losing weight Chest infection Coughing Very poorly Diarrhoea Bleeding Choking Difficulty swallowing.

Medical procedures	CT scan MRI PET Scan Xray Echo Dopplers Angiography Carotid stenting PEG Catheterisation Do not attempt resuscitate/Do not resuscitate Barium swallow OGD Videofluoroscopy FEES Trache Nomad Ventilation Non-invasive ventilation
Risks	Using telephone Opening front door Security chain on door City Wide Alarm Self-discharge Choking Death Managing at night

Appendix 25: Support Tool v2 (chapter 7)

MCAST

NHS

MENTAL CAPACITY ASSESSMENT SUPPORT TOOL

Use this form to plan and carry out your capacity assessment.
Tick the boxes and answer the questions where indicated.
You can add any supporting comments/observations
to the notes section on your right.

NAME/UNIQUE IDENTIFIER of person being assessed:

NAME/ROLE of assessor(s):

DATE of assessment:

SIGNATURE(S):

Use this area for **NOTES:**

WHAT IS THE DECISION THE PERSON NEEDS TO MAKE?

Is it a single, specific decision?	☐ YES	☐ NO STOP	Review decision, break it down
Does it need to be taken now?	☐ YES	☐ NO STOP	Repeat when decision required
Is a formal capacity assessment needed?*	☐ YES	☐ NO STOP	**Document why assessment not needed**

*Everyday care decisions may not require a formal assessment. Consult the MDT if unsure whether to proceed.

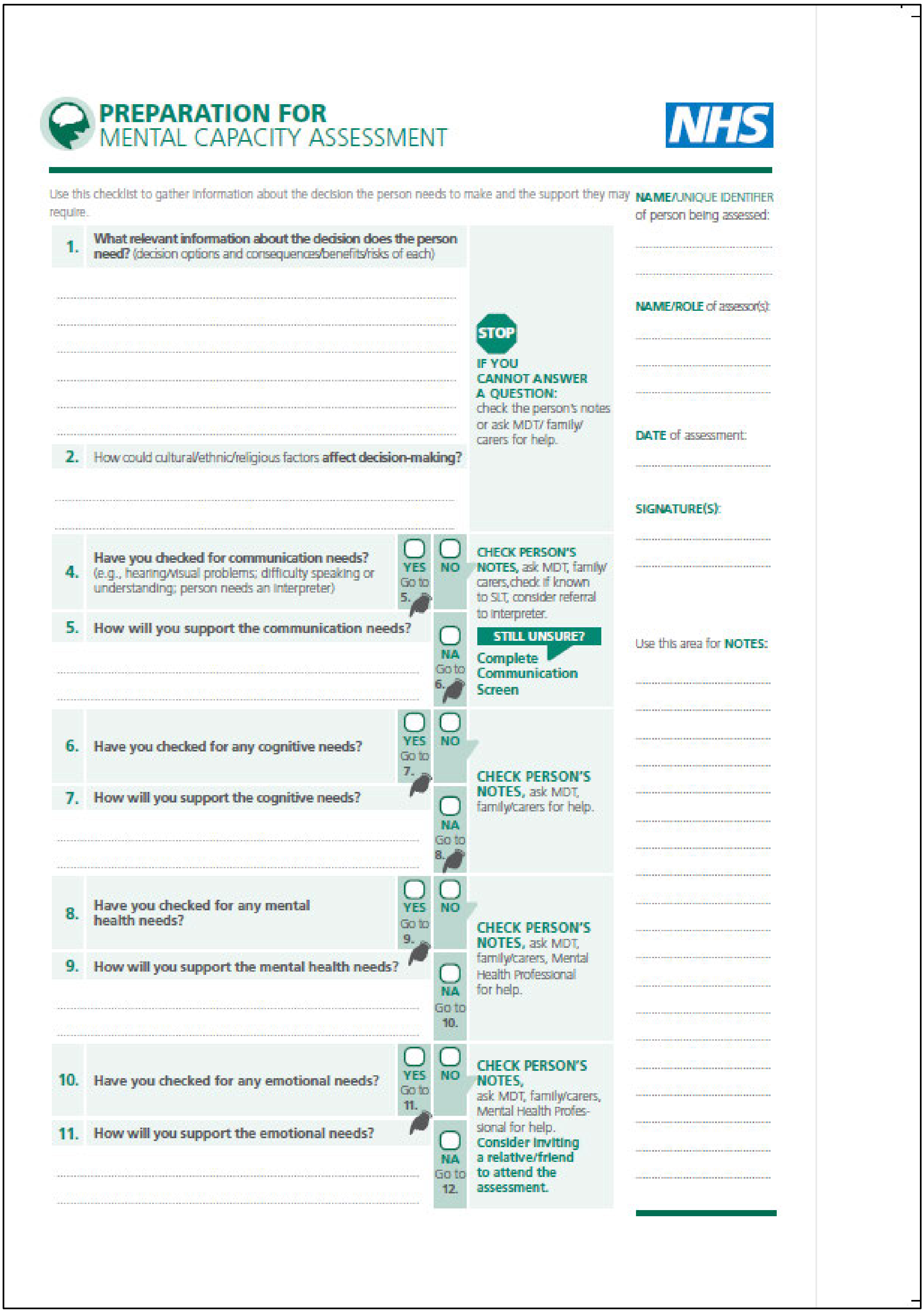
WHY DO YOU NEED A MENTAL CAPACITY ASSESSMENT?

Record what you believe to be true, based on the balance of probabilities.

Does the person have an impairment of the mind or brain, or a disturbance affecting the way the mind or brain works?	☐ YES	☐ NO STOP	Assume the person has capacity to make the decision

What is the impairment/disturbance?

Is the impairment/disturbance TEMPORARY? (e.g., delirium)	☐ NO	☐ YES STOP	Consider delaying the decision until impairment/disturbance resolved. **SET A REVIEW DATE.**



PREPARATION FOR MENTAL CAPACITY ASSESSMENT

NHS

Use this checklist to gather information about the decision the person needs to make and the support they may require.

1. What relevant information about the decision does the person need? (decision options and consequences/benefits/risks of each)

2. How could cultural/ethnic/religious factors **affect decision-making?**

STOP
IF YOU CANNOT ANSWER A QUESTION:
check the person's notes or ask MDT/ family/ carers for help.

4. Have you checked for communication needs? (e.g., hearing/visual problems; difficulty speaking or understanding; person needs an interpreter)
☐ **YES** Go to **5.** ☐ **NO**

CHECK PERSON'S NOTES, ask MDT, family/ carers,check if known to SLT, consider referral to interpreter.

5. How will you support the communication needs?
☐ **NA** Go to **6.**

STILL UNSURE?
Complete Communication Screen

6. Have you checked for any cognitive needs?
☐ **YES** Go to **7.** ☐ **NO**

7. How will you support the cognitive needs?
☐ **NA** Go to **8.**

CHECK PERSON'S NOTES, ask MDT, family/carers for help.

8. Have you checked for any mental health needs?
☐ **YES** Go to **9.** ☐ **NO**

9. How will you support the mental health needs?
☐ **NA** Go to **10.**

CHECK PERSON'S NOTES, ask MDT, family/carers, Mental Health Professional for help.

10. Have you checked for any emotional needs?
☐ **YES** Go to **11.** ☐ **NO**

11. How will you support the emotional needs?
☐ **NA** Go to **12.**

CHECK PERSON'S NOTES,
ask MDT, family/carers, Mental Health Professional for help.
Consider inviting a relative/friend to attend the assessment.

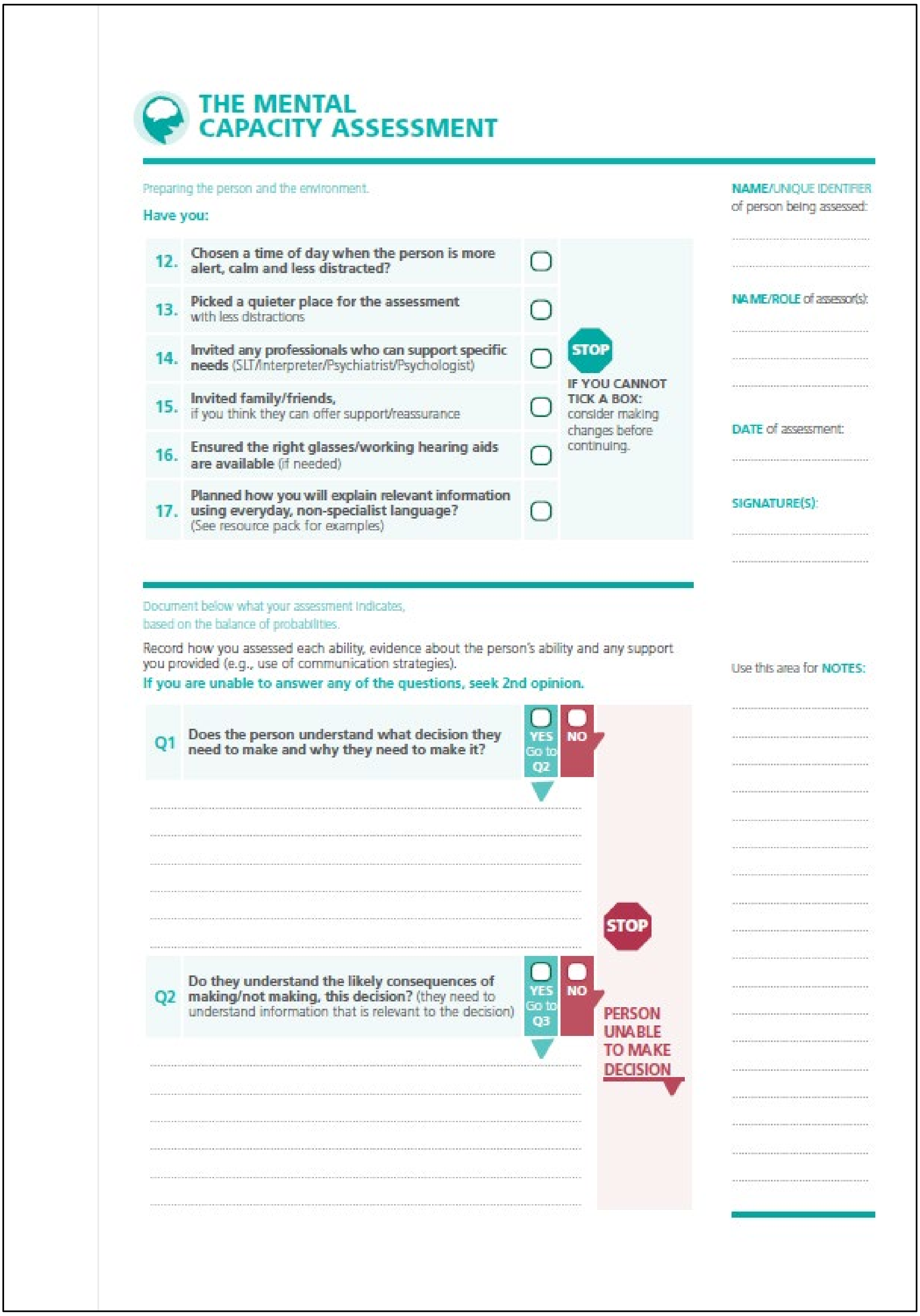
NAME/UNIQUE IDENTIFIER of person being assessed:

NAME/ROLE of assessor(s):

DATE of assessment:

SIGNATURE(S):

Use this area for **NOTES:**



THE MENTAL CAPACITY ASSESSMENT

Preparing the person and the environment.

Have you:

12.	**Chosen a time of day when the person is more alert, calm and less distracted?**	☐	**STOP** **IF YOU CANNOT TICK A BOX:** consider making changes before continuing.
13.	**Picked a quieter place for the assessment** with less distractions	☐	
14.	**Invited any professionals who can support specific needs** (SLT/Interpreter/Psychiatrist/Psychologist)	☐	
15.	**Invited family/friends,** if you think they can offer support/reassurance	☐	
16.	**Ensured the right glasses/working hearing aids are available** (if needed)	☐	
17.	**Planned how you will explain relevant information using everyday, non-specialist language?** (See resource pack for examples)	☐	

NAME/UNIQUE IDENTIFIER of person being assessed:

NAME/ROLE of assessor(s):

DATE of assessment:

SIGNATURE(S):

Document below what your assessment indicates, based on the balance of probabilities.

Record how you assessed each ability, evidence about the person's ability and any support you provided (e.g., use of communication strategies).

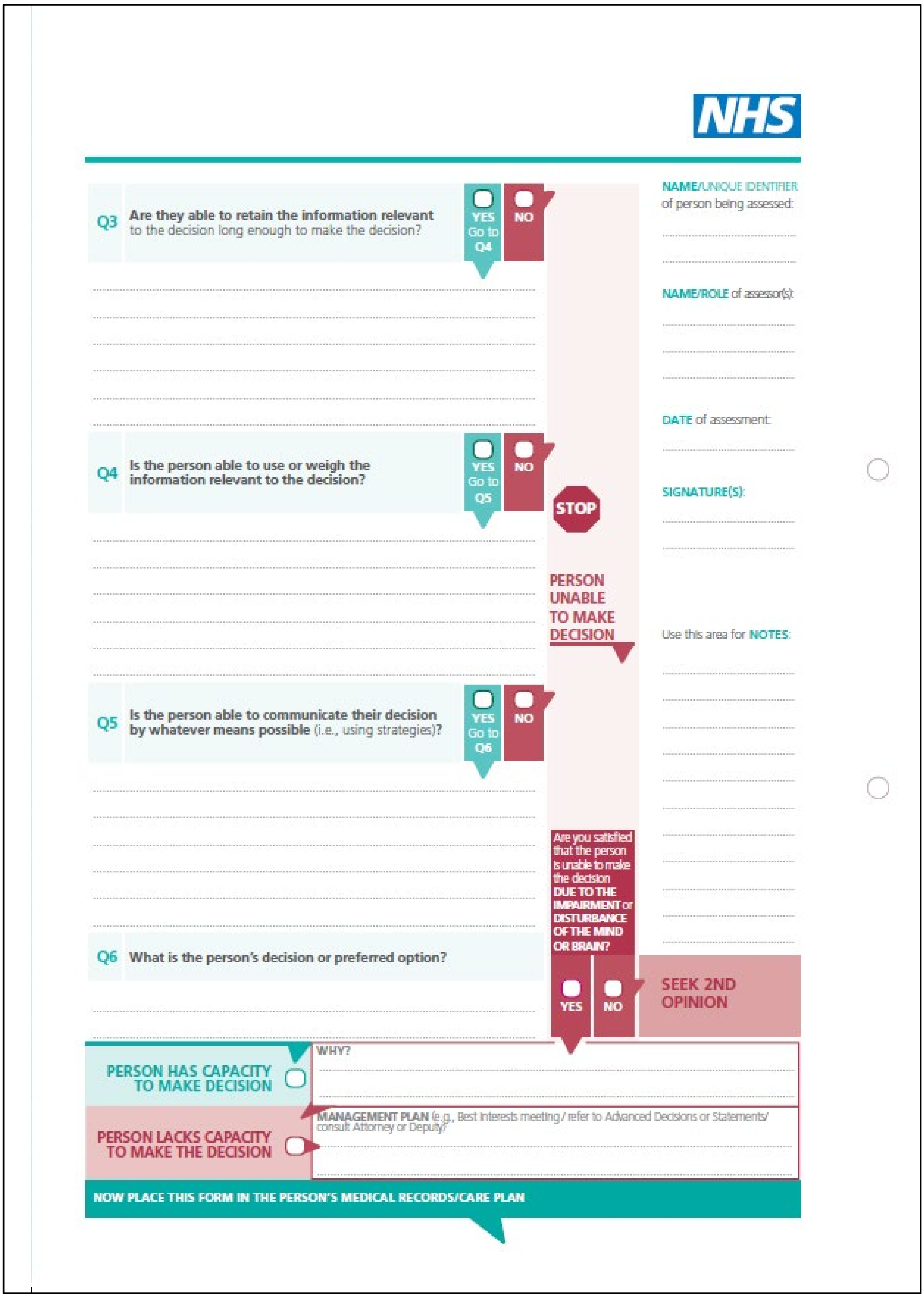
If you are unable to answer any of the questions, seek 2nd opinion.

Q1	**Does the person understand what decision they need to make and why they need to make it?**	☐ **YES** Go to Q2	☐ **NO**
Q2	**Do they understand the likely consequences of making/not making, this decision?** (they need to understand information that is relevant to the decision)	☐ **YES** Go to Q3	☐ **NO**

STOP

PERSON UNABLE TO MAKE DECISION

Use this area for **NOTES:**



NHS

Q3 **Are they able to retain the information relevant** to the decision long enough to make the decision?

☐ YES Go to Q4 ☐ NO

Q4 **Is the person able to use or weigh the information relevant to the decision?**

☐ YES Go to Q5 ☐ NO

STOP

PERSON UNABLE TO MAKE DECISION

Q5 **Is the person able to communicate their decision by whatever means possible** (i.e., using strategies)?

☐ YES Go to Q6 ☐ NO

Are you satisfied that the person is unable to make the decision **DUE TO THE IMPAIRMENT** or **DISTURBANCE OF THE MIND OR BRAIN?**

☐ YES ☐ NO

SEEK 2ND OPINION

Q6 **What is the person's decision or preferred option?**

PERSON HAS CAPACITY TO MAKE DECISION ☐

WHY?

PERSON LACKS CAPACITY TO MAKE THE DECISION ☐

MANAGEMENT PLAN (e.g., Best Interests meeting / refer to Advanced Decisions or Statements/ consult Attorney or Deputy)

NOW PLACE THIS FORM IN THE PERSON'S MEDICAL RECORDS/CARE PLAN

NAME/UNIQUE IDENTIFIER of person being assessed:

NAME/ROLE of assessor(s):

DATE of assessment:

SIGNATURE(S):

Use this area for **NOTES:**

Appendix 26: Communication Screening Tool v2 (chapter 7)

MCAST

COMMUNICATION SCREEN

NHS

Complete sections 1-4 below.
Sections 5-6 can be completed if indicated. Section 7 is optional.
Tick the boxes and answer the questions where indicated. Any supporting comments/ observation you can add to the notes section on your right.

SECTION 1 PREPARE

yourself, the person and the environment.

MAKE SURE:

1.	**You have blank paper and pens**		☐	STOP **IF YOU CANNOT TICK A BOX:** Address the specific issue before continuing. You may need to liaise with the MDT/family/ carers.
2.	**You have reduced any distractions** (e.g. shut open doors/avoided busy areas)		☐	
3.	**The person being assessed is seated comfortably**		☐	
4.	**They are wearing clean dentures** (if needed to speak clearly)		☐	
5.	**They can hear you** (check if they have working hearing aids)	☐ YES	☐ NO	Complete **Section 5** to see if you can write things down to help them understand.
6.	**They can see you and any information materials clearly** (check they have clean glasses if they need them)		☐	**Before you continue, check this using the photo recognition task below.**

DO THE FOLLOWING: **Show the person the three photos below, one at a time.** Ask them to show you the same thing in the room. **DO NOT SAY** the name of the object **OR LOOK AT THE OBJECTS** in the room.

FOUND ☐ FOUND ☐ FOUND ☐

STOP **IF THE PERSON COULD NOT FIND ALL 3 OBJECTS** consider referring them for a cognitive or vision assessment before continuing.

NAME/UNIQUE IDENTIFIER of person being assessed:

....

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NAME/ROLE of assessor(s):

....

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....

DATE of assessment:

....

SIGNATURE(S):

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Use this area for **NOTES:**

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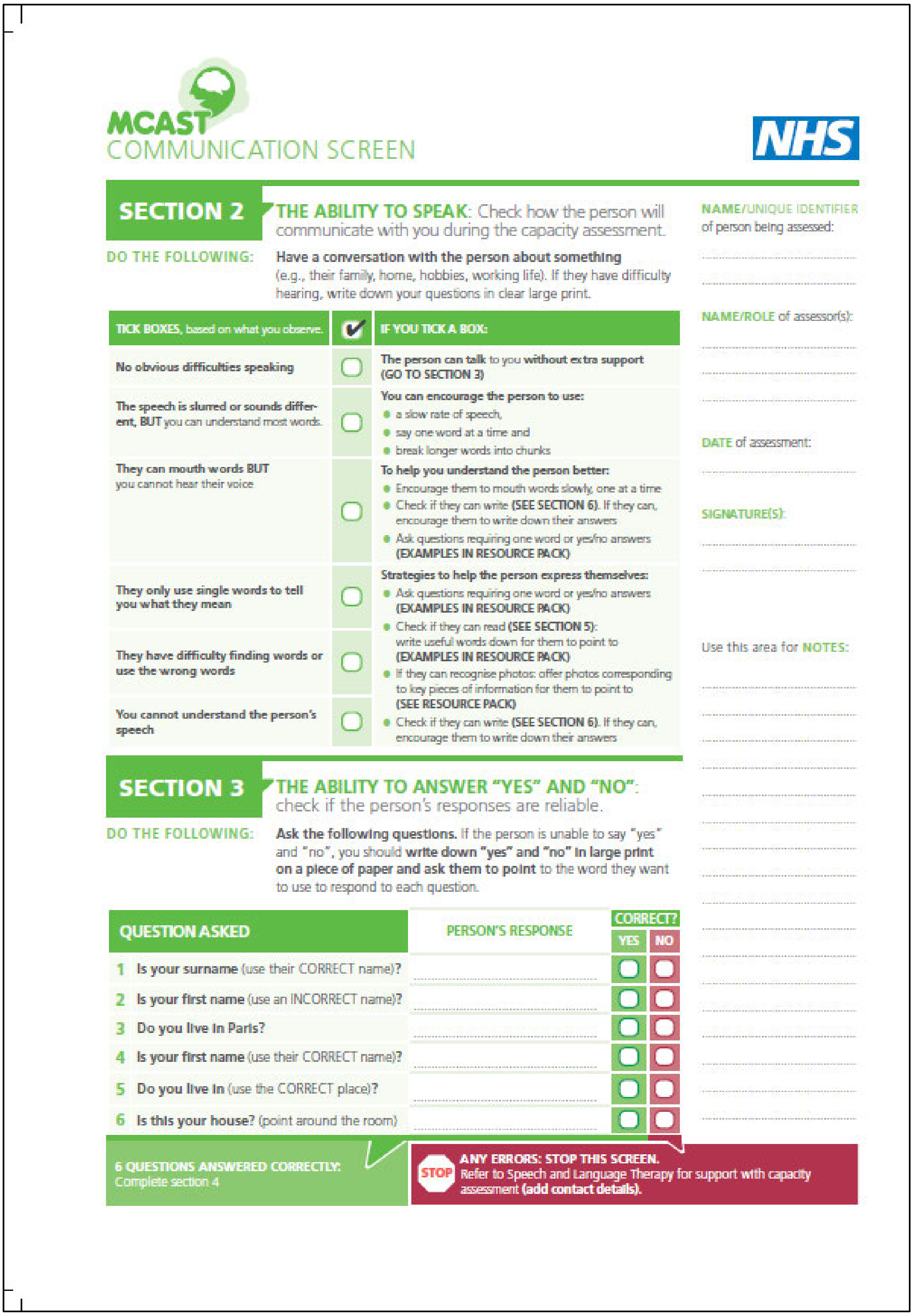


MCAST

COMMUNICATION SCREEN

NHS

NAME/UNIQUE IDENTIFIER of person being assessed:

NAME/ROLE of assessor(s):

DATE of assessment:

SIGNATURE(S):

Use this area for NOTES:

SECTION 2

THE ABILITY TO SPEAK: Check how the person will communicate with you during the capacity assessment.

DO THE FOLLOWING: **Have a conversation with the person about something** (e.g., their family, home, hobbies, working life). If they have difficulty hearing, write down your questions in clear large print.

TICK BOXES, based on what you observe.	✓	**IF YOU TICK A BOX:**
No obvious difficulties speaking	☐	**The person can talk** to you **without extra support (GO TO SECTION 3)**
The speech is slurred or sounds different, BUT you can understand most words.	☐	**You can encourage the person to use:** ● a slow rate of speech, ● say one word at a time and ● break longer words into chunks
They can mouth words BUT you cannot hear their voice	☐	**To help you understand the person better:** ● Encourage them to mouth words slowly, one at a time ● Check if they can write **(SEE SECTION 6)**. If they can, encourage them to write down their answers ● Ask questions requiring one word or yes/no answers **(EXAMPLES IN RESOURCE PACK)**
They only use single words to tell you what they mean	☐	**Strategies to help the person express themselves:** ● Ask questions requiring one word or yes/no answers **(EXAMPLES IN RESOURCE PACK)** ● Check if they can read **(SEE SECTION 5)**: write useful words down for them to point to **(EXAMPLES IN RESOURCE PACK)** ● If they can recognise photos: offer photos corresponding to key pieces of information for them to point to **(SEE RESOURCE PACK)** ● Check if they can write **(SEE SECTION 6)**. If they can, encourage them to write down their answers
They have difficulty finding words or use the wrong words	☐	
You cannot understand the person's speech	☐	

SECTION 3

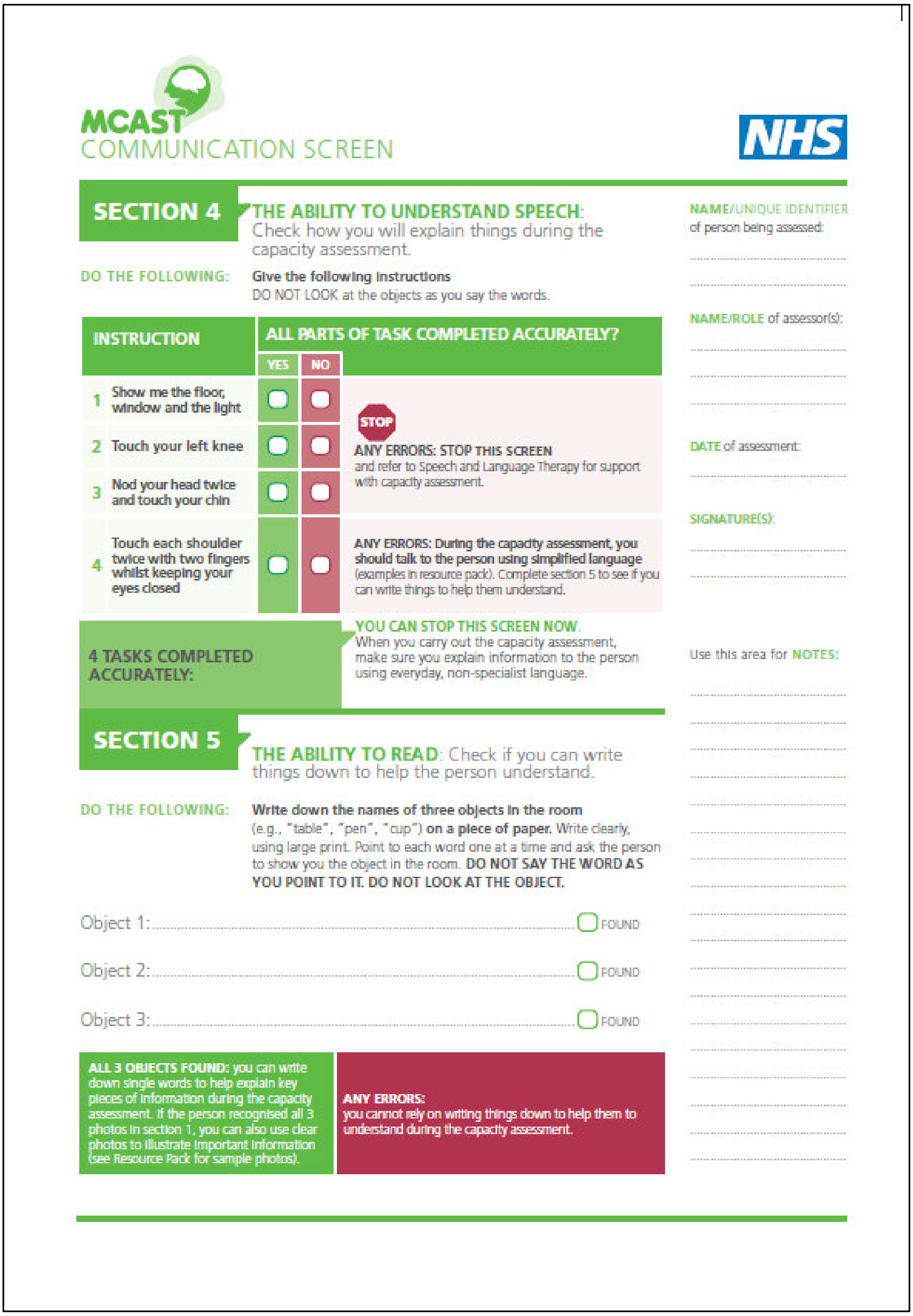
THE ABILITY TO ANSWER "YES" AND "NO": check if the person's responses are reliable.

DO THE FOLLOWING: **Ask the following questions.** If the person is unable to say "yes" and "no", you should **write down "yes" and "no" in large print on a piece of paper and ask them to point** to the word they want to use to respond to each question.

QUESTION ASKED		PERSON'S RESPONSE	CORRECT?	
			YES	NO
1	**Is your surname** (use their CORRECT name)?		○	○
2	**Is your first name** (use an INCORRECT name)?		○	○
3	**Do you live in Paris?**		○	○
4	**Is your first name** (use their CORRECT name)?		○	○
5	**Do you live in** (use the CORRECT place)?		○	○
6	**Is this your house?** (point around the room)		○	○

6 QUESTIONS ANSWERED CORRECTLY:
Complete section 4

STOP **ANY ERRORS: STOP THIS SCREEN.**
Refer to Speech and Language Therapy for support with capacity assessment **(add contact details).**



MCAST

COMMUNICATION SCREEN

NHS

SECTION 4

THE ABILITY TO UNDERSTAND SPEECH: Check how you will explain things during the capacity assessment.

DO THE FOLLOWING: **Give the following instructions**
DO NOT LOOK at the objects as you say the words.

INSTRUCTION		ALL PARTS OF TASK COMPLETED ACCURATELY? YES	NO	
1	Show me the floor, window and the light	☐	☐	STOP **ANY ERRORS: STOP THIS SCREEN** and refer to Speech and Language Therapy for support with capacity assessment.
2	Touch your left knee	☐	☐	
3	Nod your head twice and touch your chin	☐	☐	
4	Touch each shoulder twice with two fingers whilst keeping your eyes closed	☐	☐	**ANY ERRORS: During the capacity assessment, you should talk to the person using simplified language** (examples in resource pack). Complete section 5 to see if you can write things to help them understand.

4 TASKS COMPLETED ACCURATELY: **YOU CAN STOP THIS SCREEN NOW.** When you carry out the capacity assessment, make sure you explain information to the person using everyday, non-specialist language.

SECTION 5

THE ABILITY TO READ: Check if you can write things down to help the person understand.

DO THE FOLLOWING: **Write down the names of three objects in the room** (e.g., "table", "pen", "cup") **on a piece of paper.** Write clearly, using large print. Point to each word one at a time and ask the person to show you the object in the room. **DO NOT SAY THE WORD AS YOU POINT TO IT. DO NOT LOOK AT THE OBJECT.**

Object 1:.. ☐ FOUND

Object 2:.. ☐ FOUND

Object 3:.. ☐ FOUND

ALL 3 OBJECTS FOUND: you can write down single words to help explain key pieces of information during the capacity assessment. If the person recognised all 3 photos in section 1, you can also use clear photos to illustrate important information (see Resource Pack for sample photos).

ANY ERRORS: you cannot rely on writing things down to help them to understand during the capacity assessment.

NAME/UNIQUE IDENTIFIER of person being assessed:
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NAME/ROLE of assessor(s):
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DATE of assessment:
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SIGNATURE(S):
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Use this area for **NOTES:**
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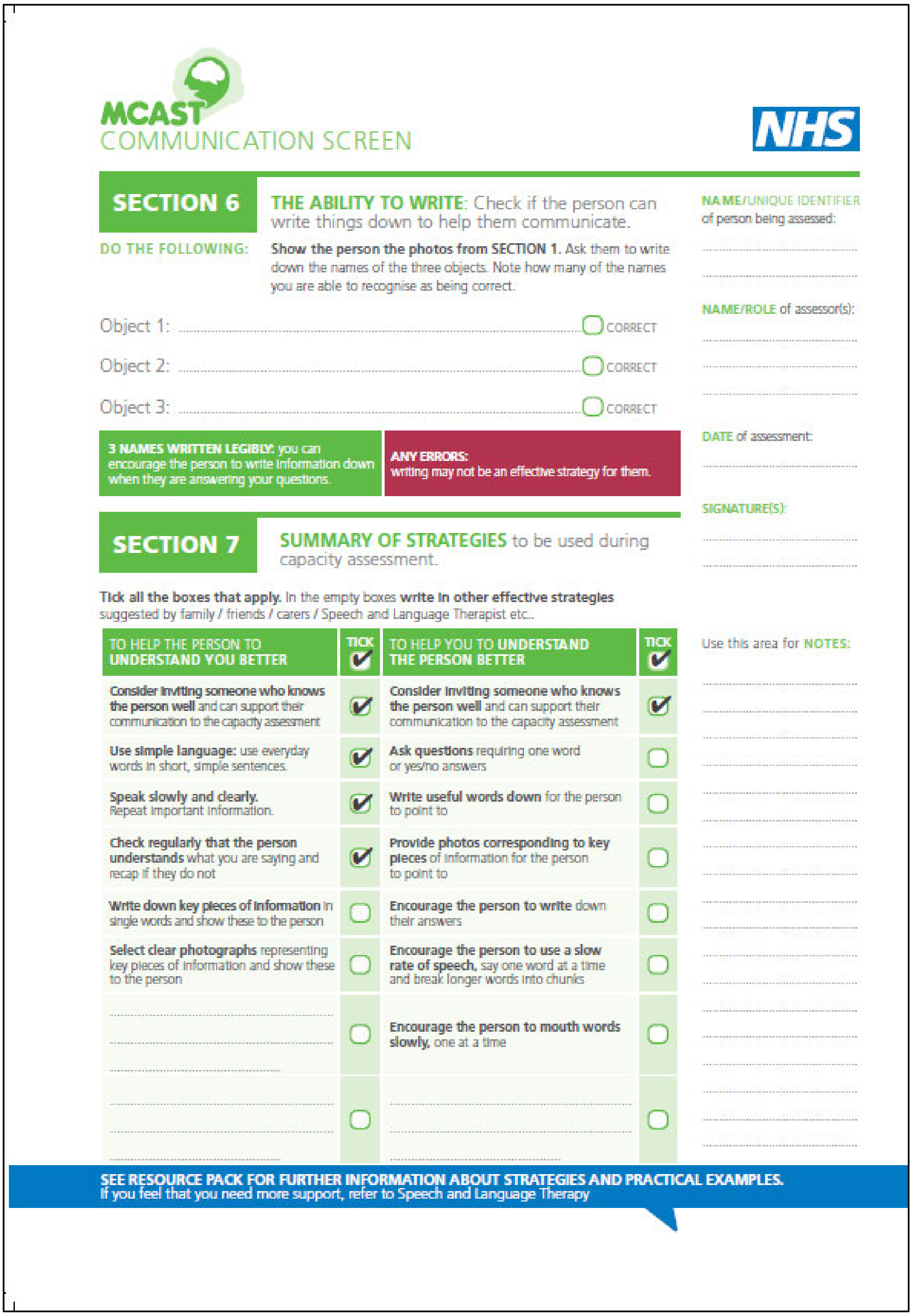

MCAST
COMMUNICATION SCREEN

NHS

SECTION 6

THE ABILITY TO WRITE: Check if the person can write things down to help them communicate.

DO THE FOLLOWING: **Show the person the photos from SECTION 1.** Ask them to write down the names of the three objects. Note how many of the names you are able to recognise as being correct.

Object 1: .... ☐ CORRECT

Object 2: .... ☐ CORRECT

Object 3: .... ☐ CORRECT

3 NAMES WRITTEN LEGIBLY: you can encourage the person to write information down when they are answering your questions.

ANY ERRORS: writing may not be an effective strategy for them.

NAME/UNIQUE IDENTIFIER of person being assessed:
....
....

NAME/ROLE of assessor(s):
....
....
....

DATE of assessment:
....

SIGNATURE(S):
....
....

SECTION 7

SUMMARY OF STRATEGIES to be used during capacity assessment.

Tick all the boxes that apply. In the empty boxes **write in other effective strategies** suggested by family / friends / carers / Speech and Language Therapist etc..

TO HELP THE PERSON TO **UNDERSTAND YOU BETTER**	TICK ✔	TO HELP YOU TO **UNDERSTAND THE PERSON BETTER**	TICK ✔
Consider inviting someone who knows the person well and can support their communication to the capacity assessment	☑	**Consider inviting someone who knows the person well** and can support their communication to the capacity assessment	☑
Use simple language: use everyday words in short, simple sentences.	☑	**Ask questions** requiring one word or yes/no answers	☐
Speak slowly and clearly. Repeat important information.	☑	**Write useful words down** for the person to point to	☐
Check regularly that the person understands what you are saying and recap if they do not	☑	**Provide photos corresponding to key pieces** of information for the person to point to	☐
Write down key pieces of information in single words and show these to the person	☐	**Encourage the person to write** down their answers	☐
Select clear photographs representing key pieces of information and show these to the person	☐	**Encourage the person to use a slow rate of speech,** say one word at a time and break longer words into chunks	☐
....	☐	**Encourage the person to mouth words slowly,** one at a time	☐
....	☐	....	☐

Use this area for **NOTES:**
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SEE RESOURCE PACK FOR FURTHER INFORMATION ABOUT STRATEGIES AND PRACTICAL EXAMPLES.
If you feel that you need more support, refer to Speech and Language Therapy

Appendix 27: Clinical vignettes used in workshop (chapter 7)

Betty

75 years old

Admitted with broken neck of femur from own home.

Diagnosed with post-surgical infection.

Concerns raised by family and MDT about Betty's ability to cope at home on discharge.

Betty is being asked to consider entering 24 hour care.

Betty appears confused on the ward and disorientated at times. She can follow conversations with staff and other patients but her family report she doesn't seem herself and says some "odd things".

The MDT have asked you to assess Betty's capacity.

Mohammed

86 years old.

History of mild vascular dementia.

Admitted with left sided limb weakness. Family have not noticed any changes in Mohammed's ability to communicate with them.

SLT has diagnosed severe dysphagia and recommended NGT.

Ward staff note Mohammed pulled out NGTs on a previous admission.

Mohammed's family feel he should have an NGT again to help him recover.

The MDT have asked you to assess Mohammed's capacity.

Sam

48 years old. Previously fit and well, living at home with partner and 2 children.

Admitted with severe stomach pain, hx of vomiting and diarrhoea.

Scan shows mass in colon.

Sam becomes acutely confused on ward, is agitated and can be aggressive towards staff.

Sam wishes to self-discharge. MDT staff and family members feel this would be detrimental to Sam.

The MDT have asked you to assess Sam's capacity.

Appendix 28: Workshop observation record (co-facilitators)

Form for research staff to note observations

Specification
Support tool
Communication screen
Other

Appendix 29: Workshop observation record (Screening Tool observers)

Form for staff observing use of communication screen

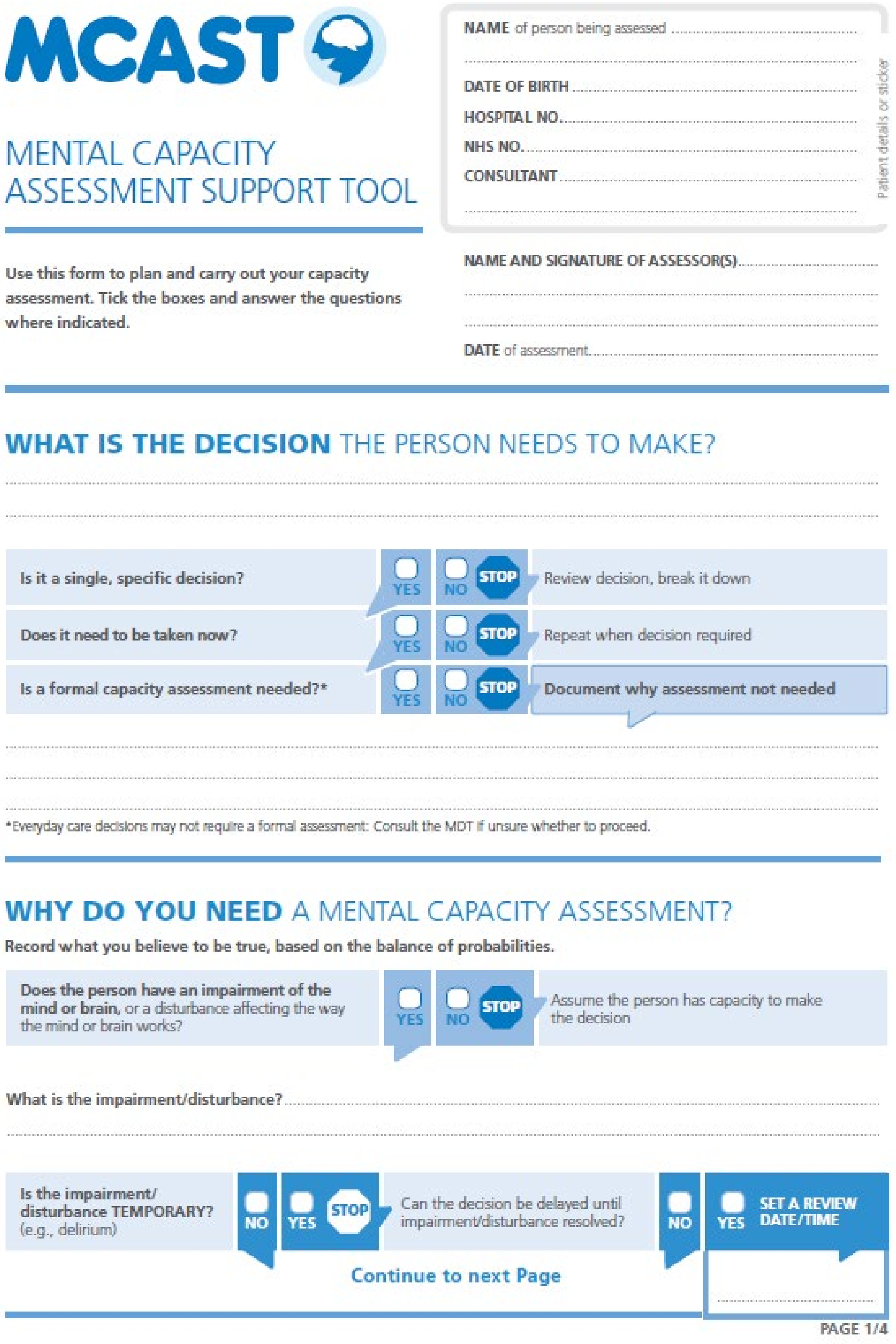
Does the session seem to flow easily?
Have you noticed any obvious problems?
How do you think the service user is coping? **(e.g., any signs of frustration or fatigue?)**
How easy would it be to use the screen in a clinical context?
Any other observations? **(e.g., how could it be improved?)**

Appendix 30: Workshop observation record (Screening Tool users)

Form for staff observing use of communication screen

How easy was it to use the screen? **(e.g., was it easy to follow? easy to document information?)**
Please list any problems you experienced
How easy would it be to use the screen in a clinical environment?
How do you think the service user coped with the screen? **(e.g., did they appear to get frustrated or tired?)**
Any other observations? **(e.g., how could it be improved?)**

Appendix 31: Support Tool v3 (chapter 7)



MCAST

MENTAL CAPACITY ASSESSMENT SUPPORT TOOL

Use this form to plan and carry out your capacity assessment. Tick the boxes and answer the questions where indicated.

NAME of person being assessed ……………………………

……………………………

DATE OF BIRTH ……………………………

HOSPITAL NO. ……………………………

NHS NO. ……………………………

CONSULTANT ……………………………

……………………………

Patient details or sticker

NAME AND SIGNATURE OF ASSESSOR(S) ……………………………

……………………………

……………………………

DATE of assessment ……………………………

WHAT IS THE DECISION THE PERSON NEEDS TO MAKE?

……………………………

……………………………

Is it a single, specific decision?	☐ YES	☐ NO STOP	Review decision, break it down
Does it need to be taken now?	☐ YES	☐ NO STOP	Repeat when decision required
Is a formal capacity assessment needed?*	☐ YES	☐ NO STOP	**Document why assessment not needed**

……………………………

……………………………

……………………………

*Everyday care decisions may not require a formal assessment: Consult the MDT if unsure whether to proceed.

WHY DO YOU NEED A MENTAL CAPACITY ASSESSMENT?

Record what you believe to be true, based on the balance of probabilities.

Does the person have an impairment of the mind or brain, or a disturbance affecting the way the mind or brain works?	☐ YES	☐ NO STOP	Assume the person has capacity to make the decision

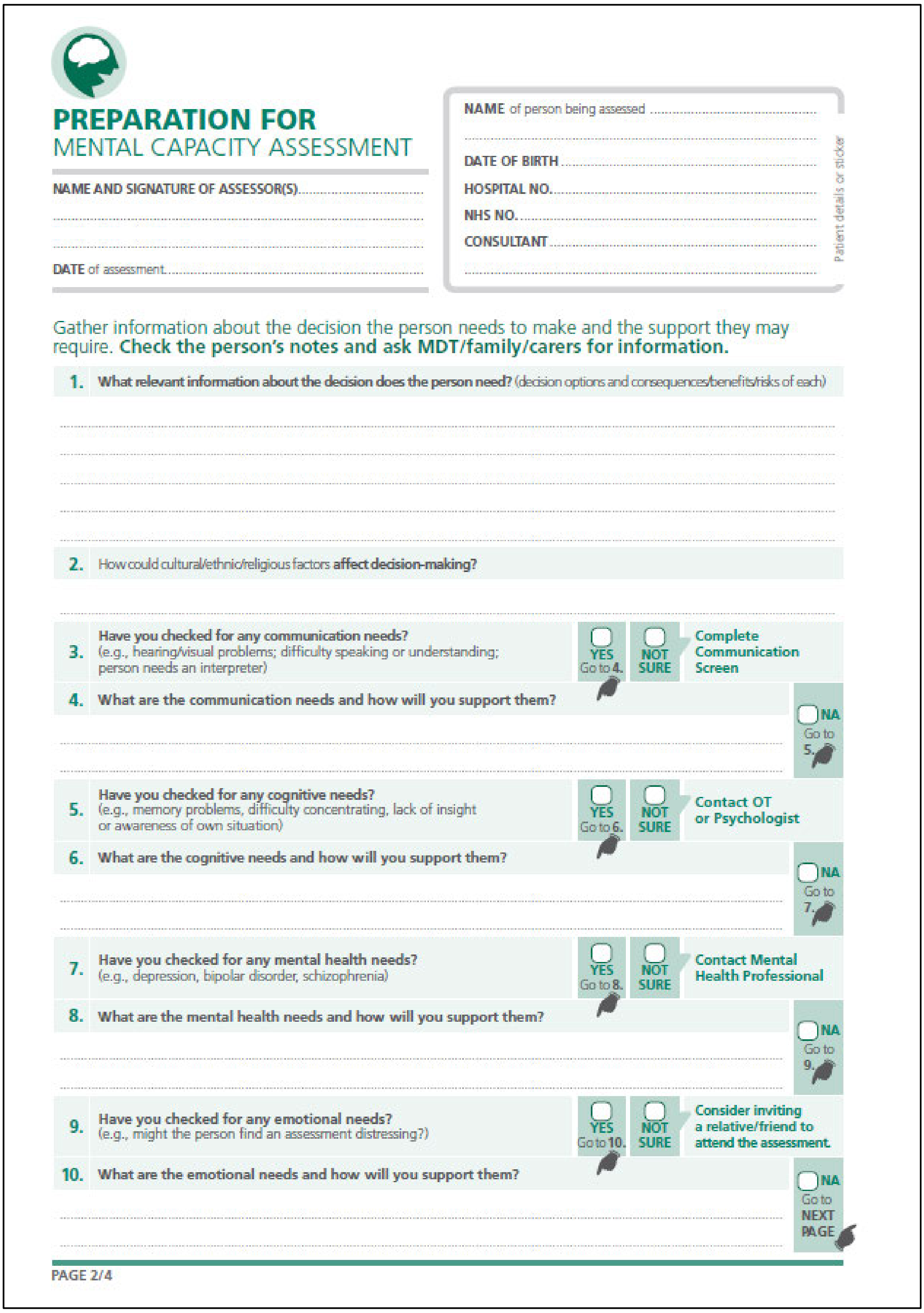
What is the impairment/disturbance? ……………………………

……………………………

Is the impairment/ disturbance TEMPORARY? (e.g., delirium)	☐ NO	☐ YES STOP	Can the decision be delayed until impairment/disturbance resolved?	☐ NO	☐ YES **SET A REVIEW DATE/TIME** ……………

Continue to next Page

PAGE 1/4



PREPARATION FOR
MENTAL CAPACITY ASSESSMENT

NAME AND SIGNATURE OF ASSESSOR(S)……………………

DATE of assessment……………………

NAME of person being assessed ……………………

DATE OF BIRTH ……………………

HOSPITAL NO. ……………………

NHS NO. ……………………

CONSULTANT ……………………

Patient details or sticker

Gather information about the decision the person needs to make and the support they may require. **Check the person's notes and ask MDT/family/carers for information.**

1. **What relevant information about the decision does the person need?** (decision options and consequences/benefits/risks of each)

2. How could cultural/ethnic/religious factors **affect decision-making?**

3. **Have you checked for any communication needs?** (e.g., hearing/visual problems; difficulty speaking or understanding; person needs an interpreter)
☐ YES Go to 4. ☐ NOT SURE **Complete Communication Screen**

4. **What are the communication needs and how will you support them?**
☐ NA Go to 5.

5. **Have you checked for any cognitive needs?** (e.g., memory problems, difficulty concentrating, lack of insight or awareness of own situation)
☐ YES Go to 6. ☐ NOT SURE **Contact OT or Psychologist**

6. **What are the cognitive needs and how will you support them?**
☐ NA Go to 7.

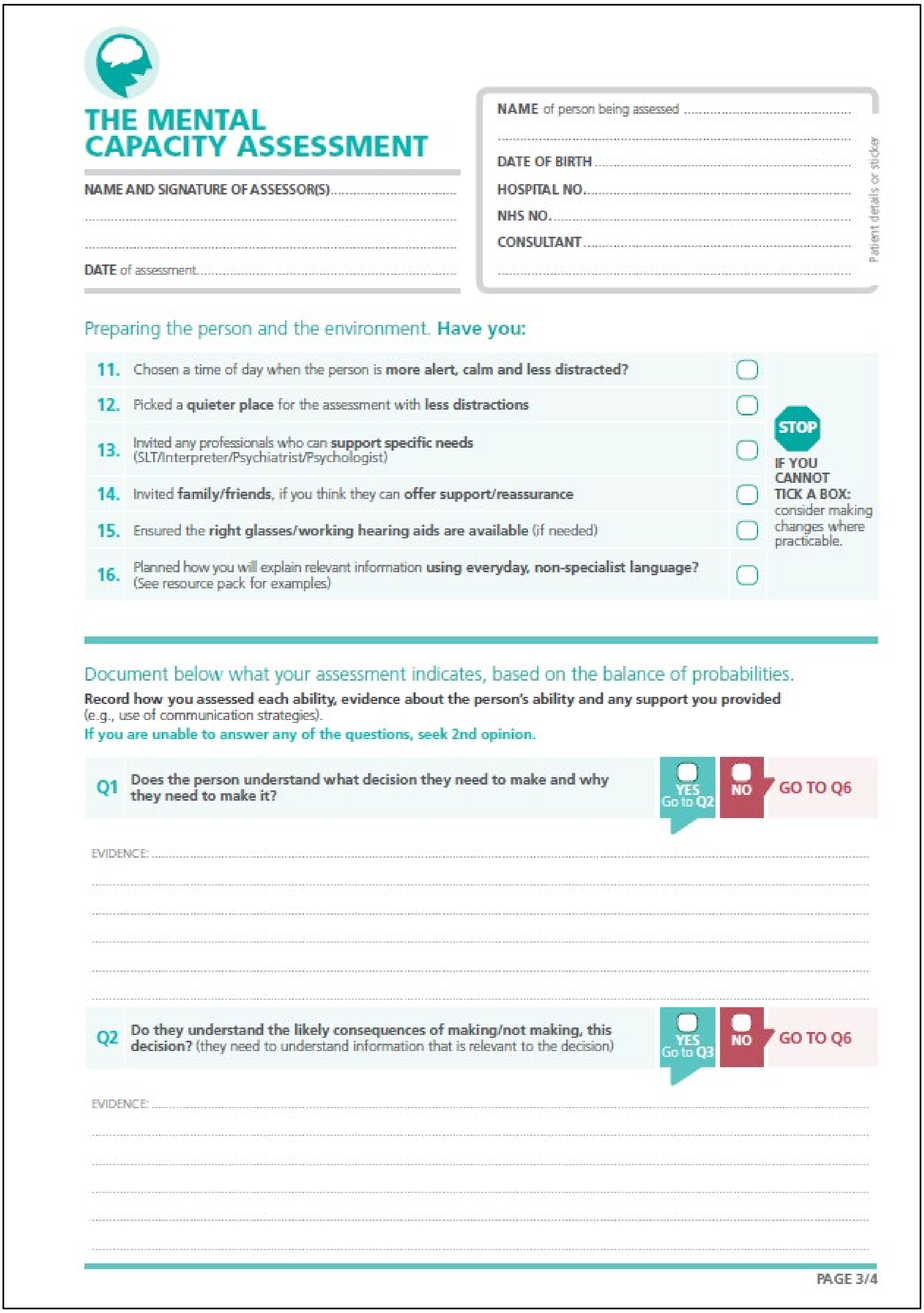
7. **Have you checked for any mental health needs?** (e.g., depression, bipolar disorder, schizophrenia)
☐ YES Go to 8. ☐ NOT SURE **Contact Mental Health Professional**

8. **What are the mental health needs and how will you support them?**
☐ NA Go to 9.

9. **Have you checked for any emotional needs?** (e.g., might the person find an assessment distressing?)
☐ YES Go to 10. ☐ NOT SURE **Consider inviting a relative/friend to attend the assessment.**

10. **What are the emotional needs and how will you support them?**
☐ NA Go to NEXT PAGE

PAGE 2/4



THE MENTAL CAPACITY ASSESSMENT

NAME AND SIGNATURE OF ASSESSOR(S)..

....

DATE of assessment..

NAME of person being assessed ....

....

DATE OF BIRTH ....

HOSPITAL NO. ....

NHS NO. ....

CONSULTANT ....

....

Patient details or sticker

Preparing the person and the environment. **Have you:**

11.	Chosen a time of day when the person is **more alert, calm and less distracted?**	☐	**STOP** **IF YOU CANNOT TICK A BOX:** consider making changes where practicable.
12.	Picked a **quieter place** for the assessment with **less distractions**	☐	
13.	Invited any professionals who can **support specific needs** (SLT/Interpreter/Psychiatrist/Psychologist)	☐	
14.	Invited **family/friends**, if you think they can **offer support/reassurance**	☐	
15.	Ensured the **right glasses/working hearing aids are available** (if needed)	☐	
16.	Planned how you will explain relevant information **using everyday, non-specialist language?** (See resource pack for examples)	☐	

Document below what your assessment indicates, based on the balance of probabilities.

Record how you assessed each ability, evidence about the person's ability and any support you provided (e.g., use of communication strategies).

If you are unable to answer any of the questions, seek 2nd opinion.

Q1 **Does the person understand what decision they need to make and why they need to make it?** ☐ YES Go to Q2 ☐ NO GO TO Q6

EVIDENCE: ....

....

....

....

....

Q2 **Do they understand the likely consequences of making/not making, this decision?** (they need to understand information that is relevant to the decision) ☐ YES Go to Q3 ☐ NO GO TO Q6

EVIDENCE: ....

....

....

....

....

....

PAGE 3/4

THE MENTAL CAPACITY ASSESSMENT

NAME AND SIGNATURE OF ASSESSOR(S)..

....

DATE of assessment..

NAME of person being assessed ....

....

DATE OF BIRTH ....

HOSPITAL NO. ....

NHS NO. ....

CONSULTANT ....

....

Patient details or sticker

Q3 **Are they able to retain the information relevant** to the decision long enough to make the decision?

☐ YES Go to **Q4** ☐ NO GO TO Q6

EVIDENCE: ....

....

....

....

Q4 **Is the person able to use or weigh the information relevant to the decision?**

☐ YES Go to **Q5** ☐ NO GO TO Q6

EVIDENCE: ....

....

....

....

Q5 **Is the person able to communicate their decision by whatever means possible** (i.e., using strategies)?

☐ YES Go to **Q6** ☐ NO GO TO Q6

EVIDENCE: ....

....

....

....

Q6 **What is the person's decision or preferred option?** ....

....

....

Q7 **Did you tick yes to all Questions Q1-Q5**

☐ NO Go to **Q8** ☐ YES **THIS PERSON HAS CAPACITY,** now place this form in the person's medical records/care plan

Q8 Are you satisfied that the person is unable to make the decision due to the **impairment or disturbance of the mind or brain?**

☐ YES DOCUMENT **WHY** ☐ NO **SEEK 2ND OPINION**

WHY?: ....

....

MANAGEMENT PLAN: (e.g., Best Interests meeting / refer to Advanced Decisions or Statements/ consult Attorney or Deputy)

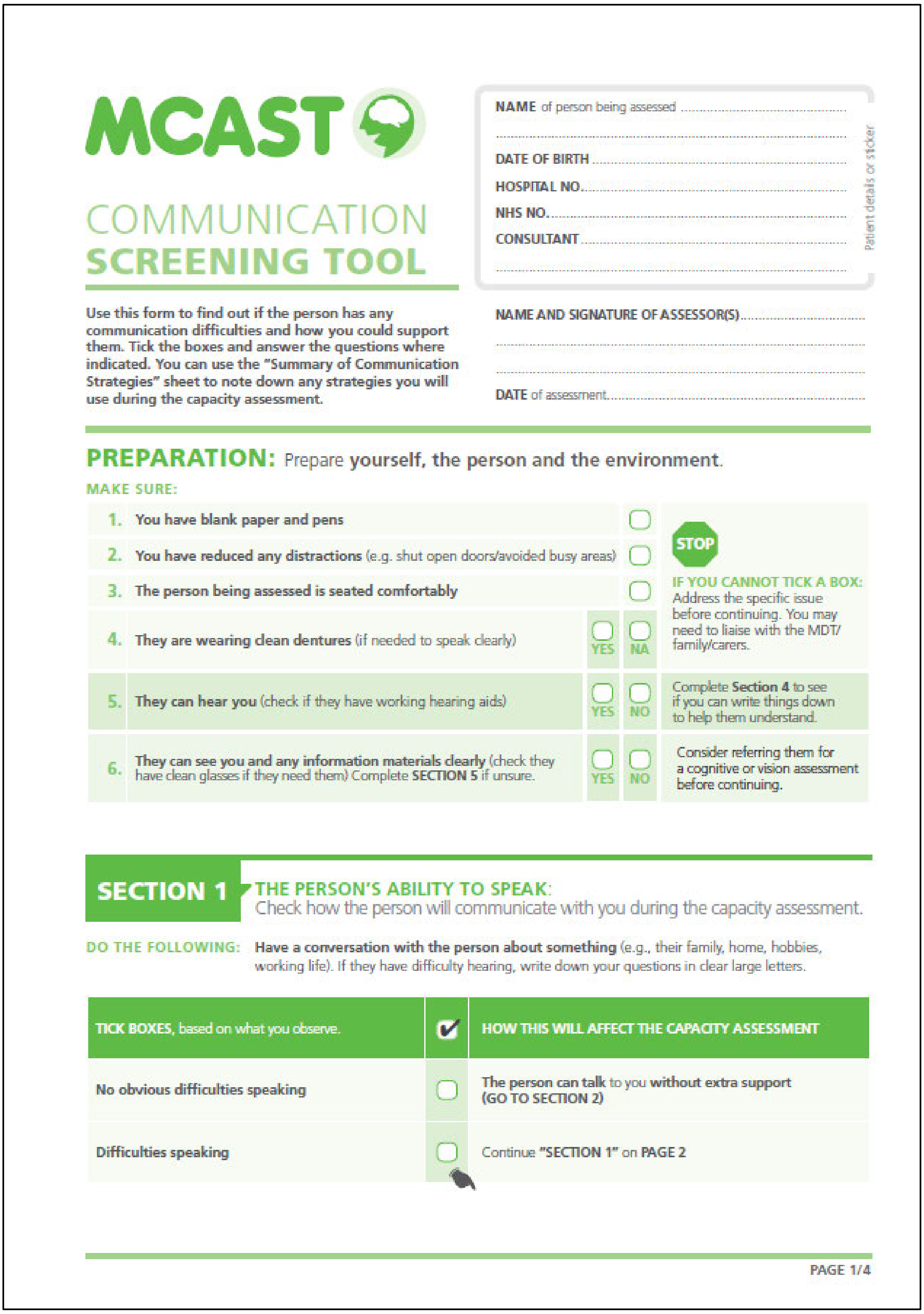
....

....

NOW PLACE THIS FORM IN THE PERSON'S MEDICAL RECORDS/CARE PLAN

PAGE 4/4

Appendix 32: Communication Screening Tool v3 (chapter 7)



MCAST

COMMUNICATION
SCREENING TOOL

NAME of person being assessed ....

....

DATE OF BIRTH ....

HOSPITAL NO. ....

NHS NO. ....

CONSULTANT ....

....

Patient details or sticker

Use this form to find out if the person has any communication difficulties and how you could support them. Tick the boxes and answer the questions where indicated. You can use the "Summary of Communication Strategies" sheet to note down any strategies you will use during the capacity assessment.

NAME AND SIGNATURE OF ASSESSOR(S) ....

....

....

DATE of assessment ....

PREPARATION: Prepare **yourself, the person and the environment.**

MAKE SURE:

1.	**You have blank paper and pens**		☐	**STOP** **IF YOU CANNOT TICK A BOX:** Address the specific issue before continuing. You may need to liaise with the MDT/ family/carers.
2.	**You have reduced any distractions** (e.g. shut open doors/avoided busy areas)		☐	
3.	**The person being assessed is seated comfortably**		☐	
4.	**They are wearing clean dentures** (if needed to speak clearly)	☐ YES	☐ NA	
5.	**They can hear you** (check if they have working hearing aids)	☐ YES	☐ NO	Complete **Section 4** to see if you can write things down to help them understand.
6.	**They can see you and any information materials clearly** (check they have clean glasses if they need them) Complete **SECTION 5** if unsure.	☐ YES	☐ NO	Consider referring them for a cognitive or vision assessment before continuing.

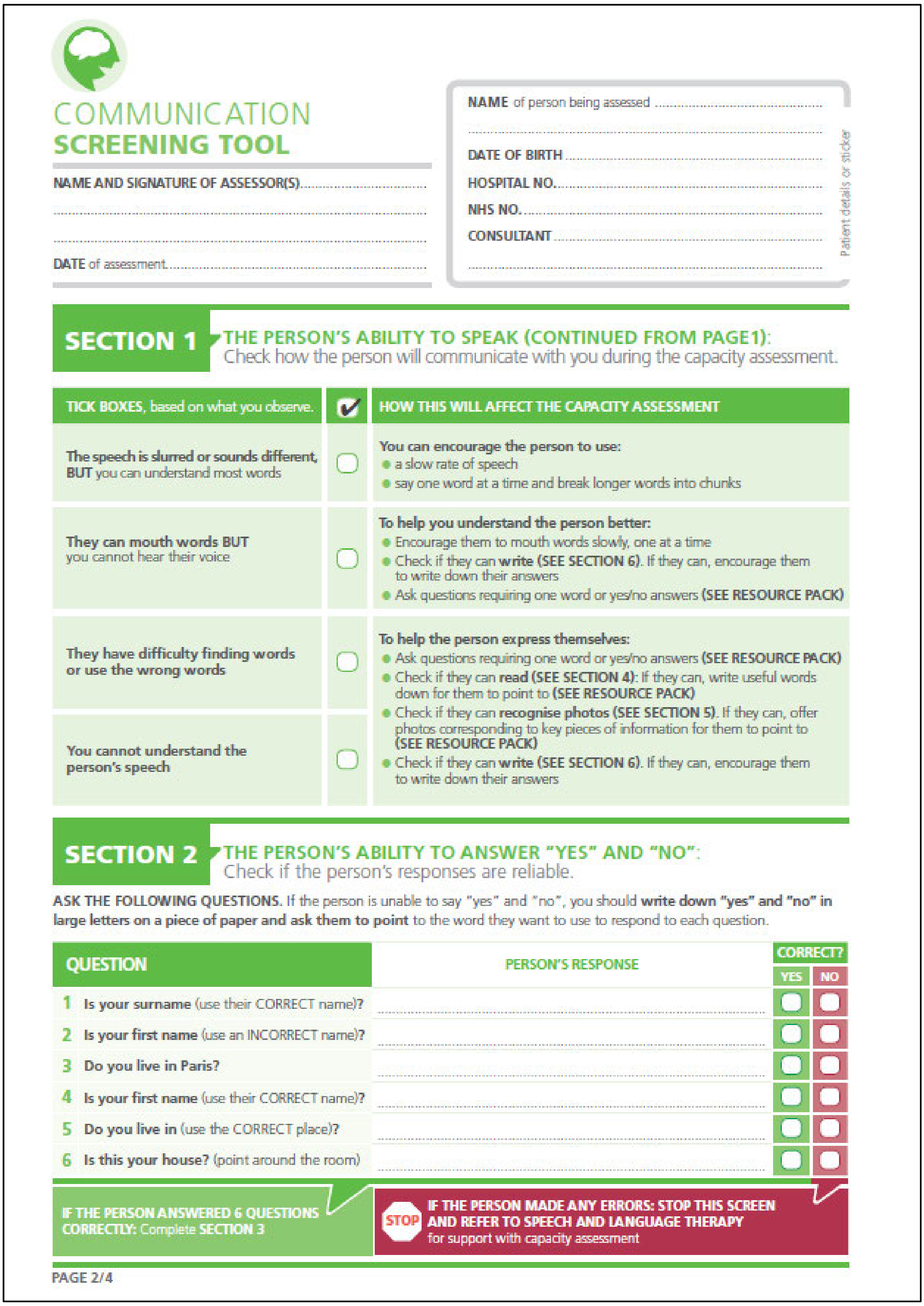
SECTION 1 THE PERSON'S ABILITY TO SPEAK:

Check how the person will communicate with you during the capacity assessment.

DO THE FOLLOWING: **Have a conversation with the person about something** (e.g., their family, home, hobbies, working life). If they have difficulty hearing, write down your questions in clear large letters.

TICK BOXES, based on what you observe.	✔	**HOW THIS WILL AFFECT THE CAPACITY ASSESSMENT**
No obvious difficulties speaking	☐	**The person can talk** to you **without extra support (GO TO SECTION 2)**
Difficulties speaking	☐	Continue **"SECTION 1"** on **PAGE 2**

PAGE 1/4



COMMUNICATION
SCREENING TOOL

NAME AND SIGNATURE OF ASSESSOR(S)..

....

....

DATE of assessment...

NAME of person being assessed ....

....

DATE OF BIRTH ....

HOSPITAL NO....

NHS NO...

CONSULTANT ....

....

Patient details or sticker

SECTION 1 THE PERSON'S ABILITY TO SPEAK (CONTINUED FROM PAGE1):

Check how the person will communicate with you during the capacity assessment.

TICK BOXES, based on what you observe.	✓	**HOW THIS WILL AFFECT THE CAPACITY ASSESSMENT**
The speech is slurred or sounds different, BUT you can understand most words	☐	**You can encourage the person to use:** ● a slow rate of speech ● say one word at a time and break longer words into chunks
They can mouth words BUT you cannot hear their voice	☐	**To help you understand the person better:** ● Encourage them to mouth words slowly, one at a time ● Check if they can **write (SEE SECTION 6)**. If they can, encourage them to write down their answers ● Ask questions requiring one word or yes/no answers **(SEE RESOURCE PACK)**
They have difficulty finding words or use the wrong words	☐	**To help the person express themselves:** ● Ask questions requiring one word or yes/no answers **(SEE RESOURCE PACK)** ● Check if they can **read (SEE SECTION 4)**: If they can, write useful words down for them to point to **(SEE RESOURCE PACK)** ● Check if they can **recognise photos (SEE SECTION 5)**. If they can, offer photos corresponding to key pieces of information for them to point to **(SEE RESOURCE PACK)** ● Check if they can **write (SEE SECTION 6)**. If they can, encourage them to write down their answers
You cannot understand the person's speech	☐	

SECTION 2 THE PERSON'S ABILITY TO ANSWER "YES" AND "NO":

Check if the person's responses are reliable.

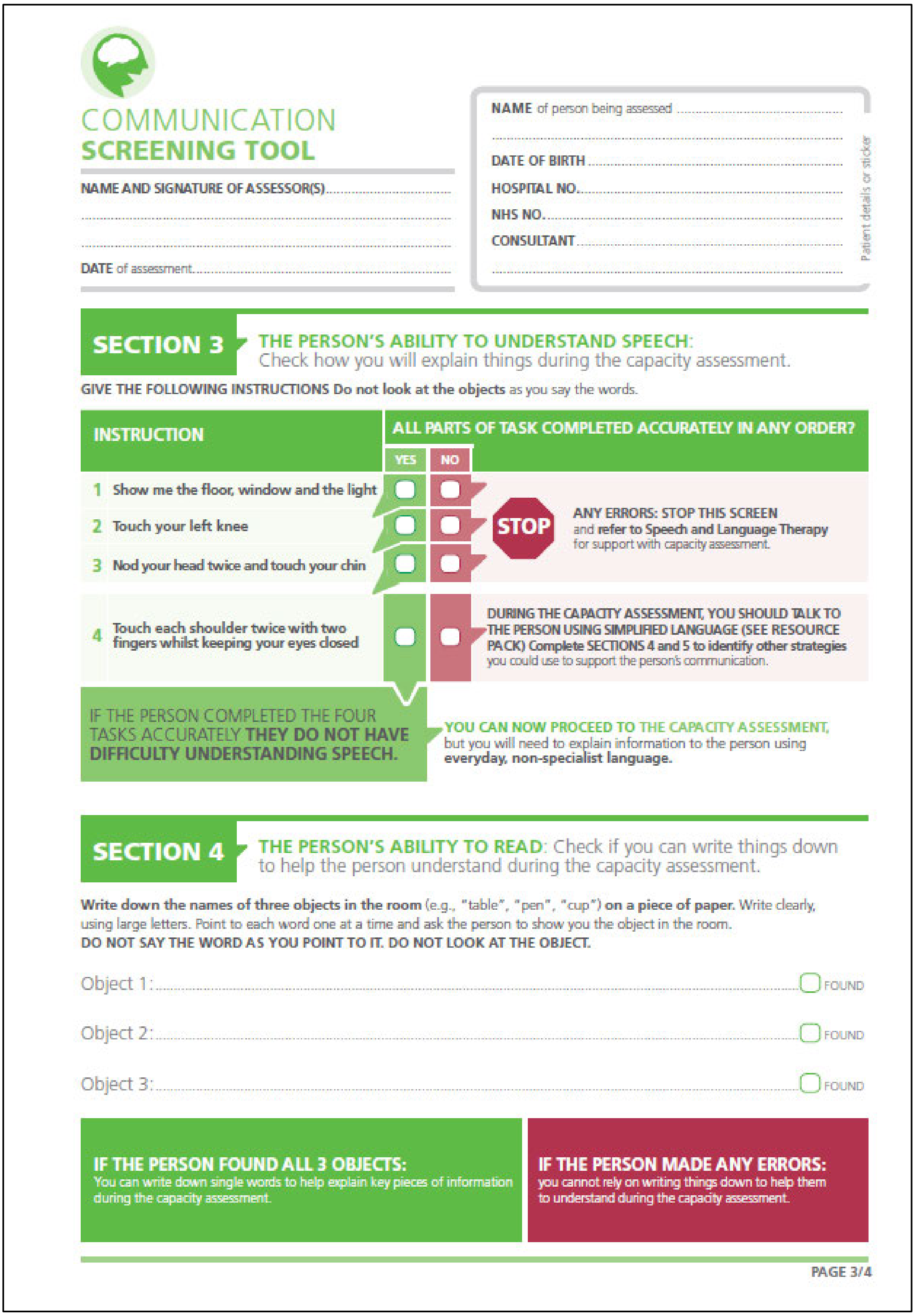
ASK THE FOLLOWING QUESTIONS. If the person is unable to say "yes" and "no", you should **write down "yes" and "no" in large letters on a piece of paper and ask them to point** to the word they want to use to respond to each question.

QUESTION	**PERSON'S RESPONSE**	**CORRECT?**	
		YES	**NO**
1 **Is your surname** (use their CORRECT name)?	....	☐	☐
2 **Is your first name** (use an INCORRECT name)?	....	☐	☐
3 **Do you live in Paris?**	....	☐	☐
4 **Is your first name** (use their CORRECT name)?	....	☐	☐
5 **Do you live in** (use the CORRECT place)?	....	☐	☐
6 **Is this your house?** (point around the room)	....	☐	☐

IF THE PERSON ANSWERED 6 QUESTIONS CORRECTLY: Complete **SECTION 3**

STOP **IF THE PERSON MADE ANY ERRORS: STOP THIS SCREEN AND REFER TO SPEECH AND LANGUAGE THERAPY** for support with capacity assessment

PAGE 2/4



COMMUNICATION SCREENING TOOL

NAME AND SIGNATURE OF ASSESSOR(S).................................

....

....

DATE of assessment..

NAME of person being assessed ....

....

DATE OF BIRTH ....

HOSPITAL NO....

NHS NO....

CONSULTANT..

....

Patient details or sticker

SECTION 3

THE PERSON'S ABILITY TO UNDERSTAND SPEECH: Check how you will explain things during the capacity assessment.

GIVE THE FOLLOWING INSTRUCTIONS Do not look at the objects as you say the words.

INSTRUCTION	ALL PARTS OF TASK COMPLETED ACCURATELY IN ANY ORDER? YES	NO
1 Show me the floor, window and the light	☐	☐
2 Touch your left knee	☐	☐
3 Nod your head twice and touch your chin	☐	☐
4 Touch each shoulder twice with two fingers whilst keeping your eyes closed	☐	☐

STOP **ANY ERRORS: STOP THIS SCREEN** and **refer to Speech and Language Therapy** for support with capacity assessment.

DURING THE CAPACITY ASSESSMENT, YOU SHOULD TALK TO THE PERSON USING SIMPLIFIED LANGUAGE (SEE RESOURCE PACK) Complete SECTIONS 4 and 5 to identify other strategies you could use to support the person's communication.

IF THE PERSON COMPLETED THE FOUR TASKS ACCURATELY **THEY DO NOT HAVE DIFFICULTY UNDERSTANDING SPEECH.**

YOU CAN NOW PROCEED TO THE CAPACITY ASSESSMENT, but you will need to explain information to the person using **everyday, non-specialist language.**

SECTION 4

THE PERSON'S ABILITY TO READ: Check if you can write things down to help the person understand during the capacity assessment.

Write down the names of three objects in the room (e.g., "table", "pen", "cup") **on a piece of paper.** Write clearly, using large letters. Point to each word one at a time and ask the person to show you the object in the room.
DO NOT SAY THE WORD AS YOU POINT TO IT. DO NOT LOOK AT THE OBJECT.

Object 1:.. ☐ FOUND

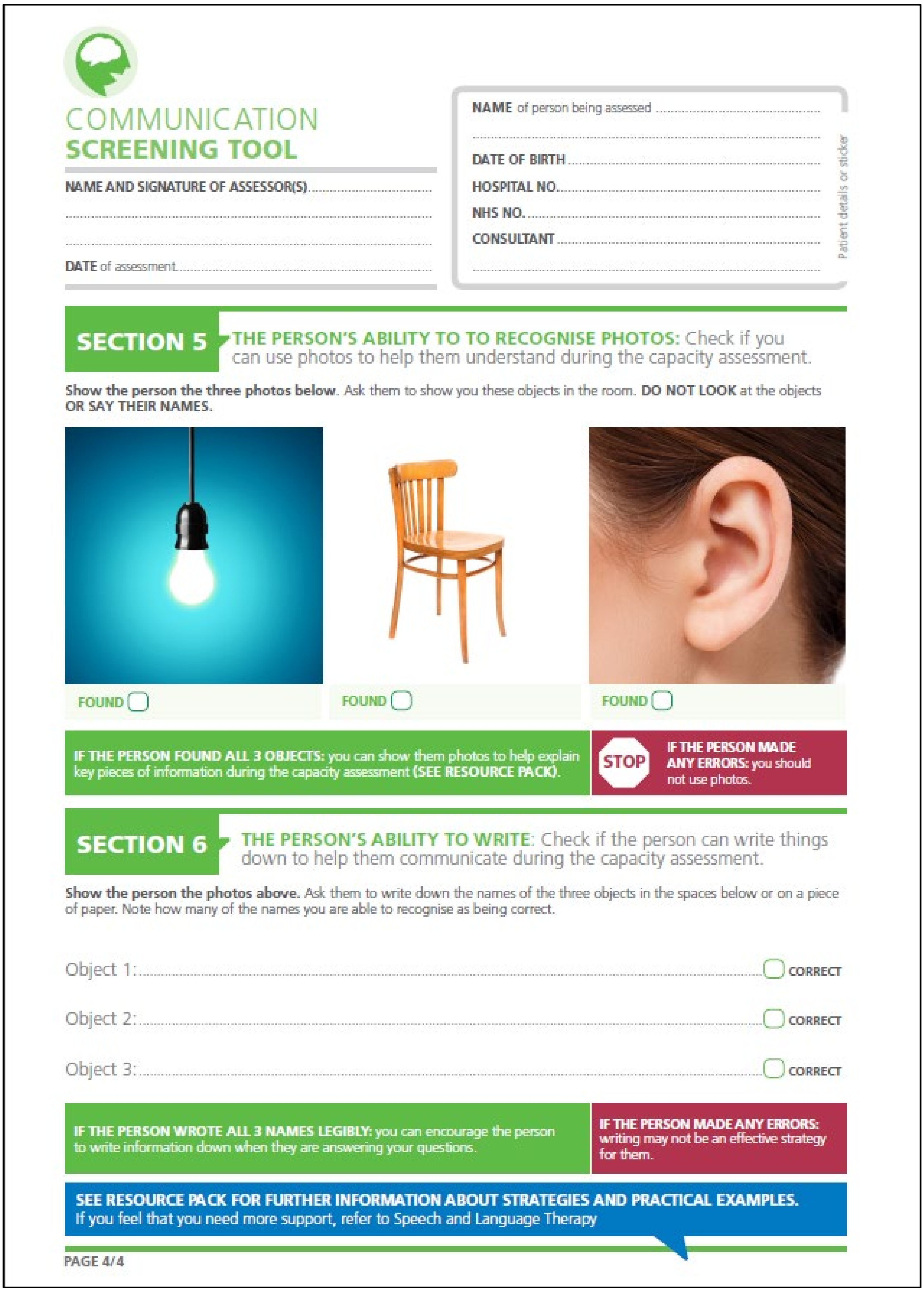
Object 2:.. ☐ FOUND

Object 3:.. ☐ FOUND

IF THE PERSON FOUND ALL 3 OBJECTS:
You can write down single words to help explain key pieces of information during the capacity assessment.

IF THE PERSON MADE ANY ERRORS:
you cannot rely on writing things down to help them to understand during the capacity assessment.

PAGE 3/4



COMMUNICATION SCREENING TOOL

NAME AND SIGNATURE OF ASSESSOR(S)……………………………

……………………………………………………

……………………………………………………

DATE of assessment……………………………………

NAME of person being assessed ……………………………

……………………………………………………

DATE OF BIRTH……………………………………

HOSPITAL NO.……………………………………

NHS NO.……………………………………

CONSULTANT……………………………………

……………………………………………………

Patient details or sticker

SECTION 5

THE PERSON'S ABILITY TO TO RECOGNISE PHOTOS: Check if you can use photos to help them understand during the capacity assessment.

Show the person the three photos below. Ask them to show you these objects in the room. **DO NOT LOOK** at the objects **OR SAY THEIR NAMES.**

FOUND ☐ FOUND ☐ FOUND ☐

IF THE PERSON FOUND ALL 3 OBJECTS: you can show them photos to help explain key pieces of information during the capacity assessment **(SEE RESOURCE PACK).**

STOP **IF THE PERSON MADE ANY ERRORS:** you should not use photos.

SECTION 6

THE PERSON'S ABILITY TO WRITE: Check if the person can write things down to help them communicate during the capacity assessment.

Show the person the photos above. Ask them to write down the names of the three objects in the spaces below or on a piece of paper. Note how many of the names you are able to recognise as being correct.

Object 1:…………………………………………… ☐ CORRECT

Object 2:…………………………………………… ☐ CORRECT

Object 3:…………………………………………… ☐ CORRECT

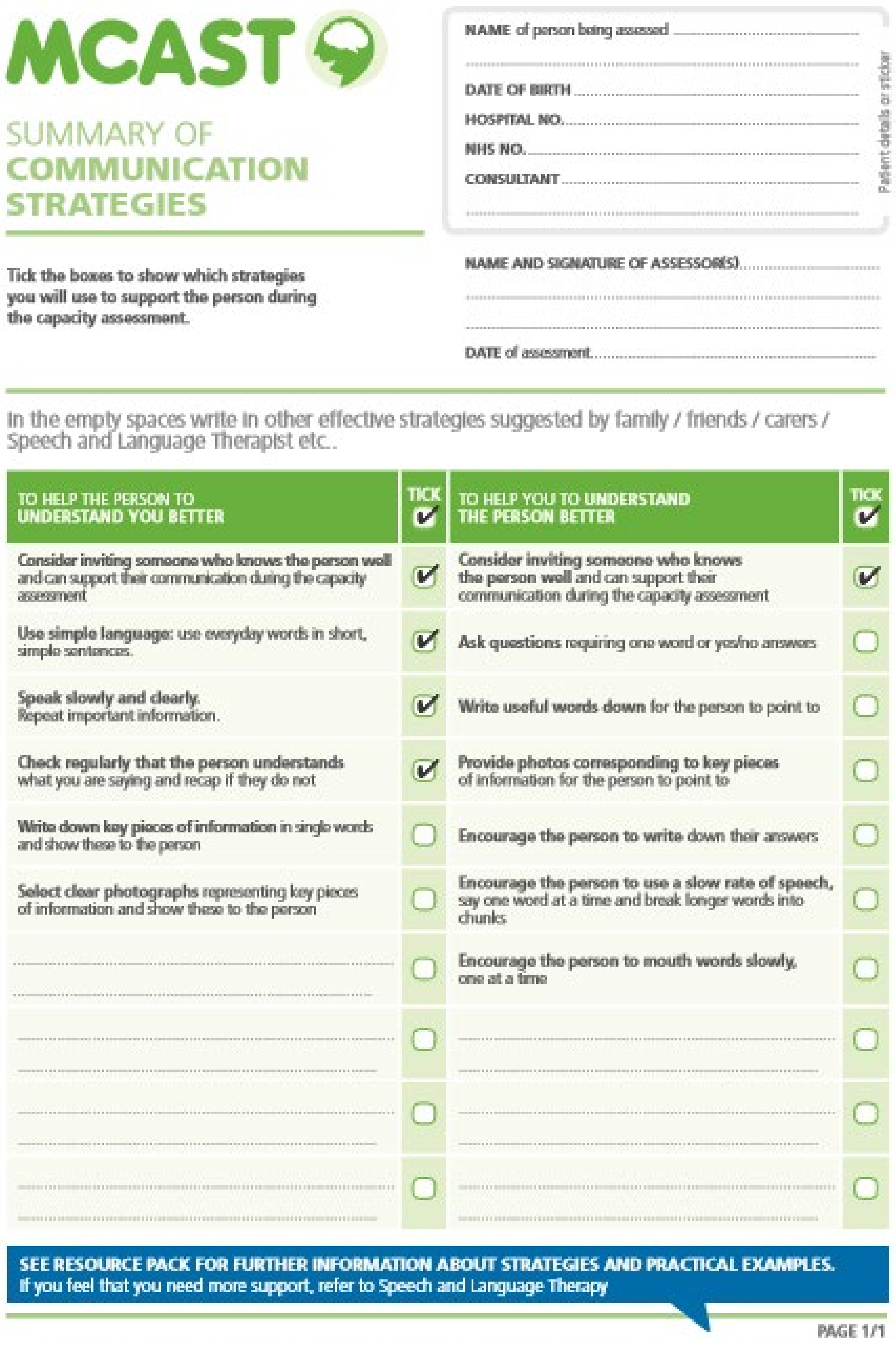
IF THE PERSON WROTE ALL 3 NAMES LEGIBLY: you can encourage the person to write information down when they are answering your questions.

IF THE PERSON MADE ANY ERRORS: writing may not be an effective strategy for them.

SEE RESOURCE PACK FOR FURTHER INFORMATION ABOUT STRATEGIES AND PRACTICAL EXAMPLES.
If you feel that you need more support, refer to Speech and Language Therapy

PAGE 4/4

Appendix 33: MCAST Communication strategies summary sheet (chapter 7)



MCAST

SUMMARY OF COMMUNICATION STRATEGIES

NAME of person being assessed ……………………………

……………………………………………………

DATE OF BIRTH ……………………………

HOSPITAL NO. ……………………………

NHS NO. ……………………………

CONSULTANT ……………………………

……………………………………………………

Patient details or sticker

Tick the boxes to show which strategies you will use to support the person during the capacity assessment.

NAME AND SIGNATURE OF ASSESSOR(S) ……………………………

……………………………………………………

……………………………………………………

DATE of assessment ……………………………

In the empty spaces write in other effective strategies suggested by family / friends / carers / Speech and Language Therapist etc..

TO HELP THE PERSON TO **UNDERSTAND YOU BETTER**	TICK ✓	TO HELP YOU TO **UNDERSTAND THE PERSON BETTER**	TICK ✓
Consider inviting someone who knows the person well and can support their communication during the capacity assessment	☑	**Consider inviting someone who knows the person well** and can support their communication during the capacity assessment	☑
Use simple language: use everyday words in short, simple sentences.	☑	**Ask questions** requiring one word or yes/no answers	☐
Speak slowly and clearly. Repeat important information.	☑	**Write useful words down** for the person to point to	☐
Check regularly that the person understands what you are saying and recap if they do not	☑	**Provide photos corresponding to key pieces** of information for the person to point to	☐
Write down key pieces of information in single words and show these to the person	☐	**Encourage the person to write down** their answers	☐
Select clear photographs representing key pieces of information and show these to the person	☐	**Encourage the person to use a slow rate of speech,** say one word at a time and break longer words into chunks	☐
…………………………… ……………………………	☐	**Encourage the person to mouth words slowly,** one at a time	☐
…………………………… ……………………………	☐	…………………………… ……………………………	☐
…………………………… ……………………………	☐	…………………………… ……………………………	☐
…………………………… ……………………………	☐	…………………………… ……………………………	☐

SEE RESOURCE PACK FOR FURTHER INFORMATION ABOUT STRATEGIES AND PRACTICAL EXAMPLES.
If you feel that you need more support, refer to Speech and Language Therapy

PAGE 1/1

Appendix 34: PCPI group consent form for photography work (chapter 7)

Consent Form for taking part in photography for the Mental Capacity Assessment Support Toolkit (MCAST) project.

Mark Jayes has organised the photography project as part of his research at the University of Sheffield. Optical Jukebox are taking the photographs (website: www.opticaljukebox.org).

This form is for you to sign so that there is an agreement between us all about how these photographs will be used.

I agree for the photographs taken of me to be used as part of the Mental Capacity Assessment Support Toolkit (MCAST).

I can withdraw my consent to be photographed, or for my photographs to be used in the toolkit, at any time until the final edited version is approved.

I give my consent for the reproduction, exhibition and use of the photographs. The photographs will be used in the toolkit but may be shown on websites, in journal articles or at conferences.

This consent has no time limits (the photographs can be shown forever), or geographical limits (which means the photos may be shown abroad). It relates to any kind of media (existing formats or new ones in the future).

Signed: ____ Date: __________________________

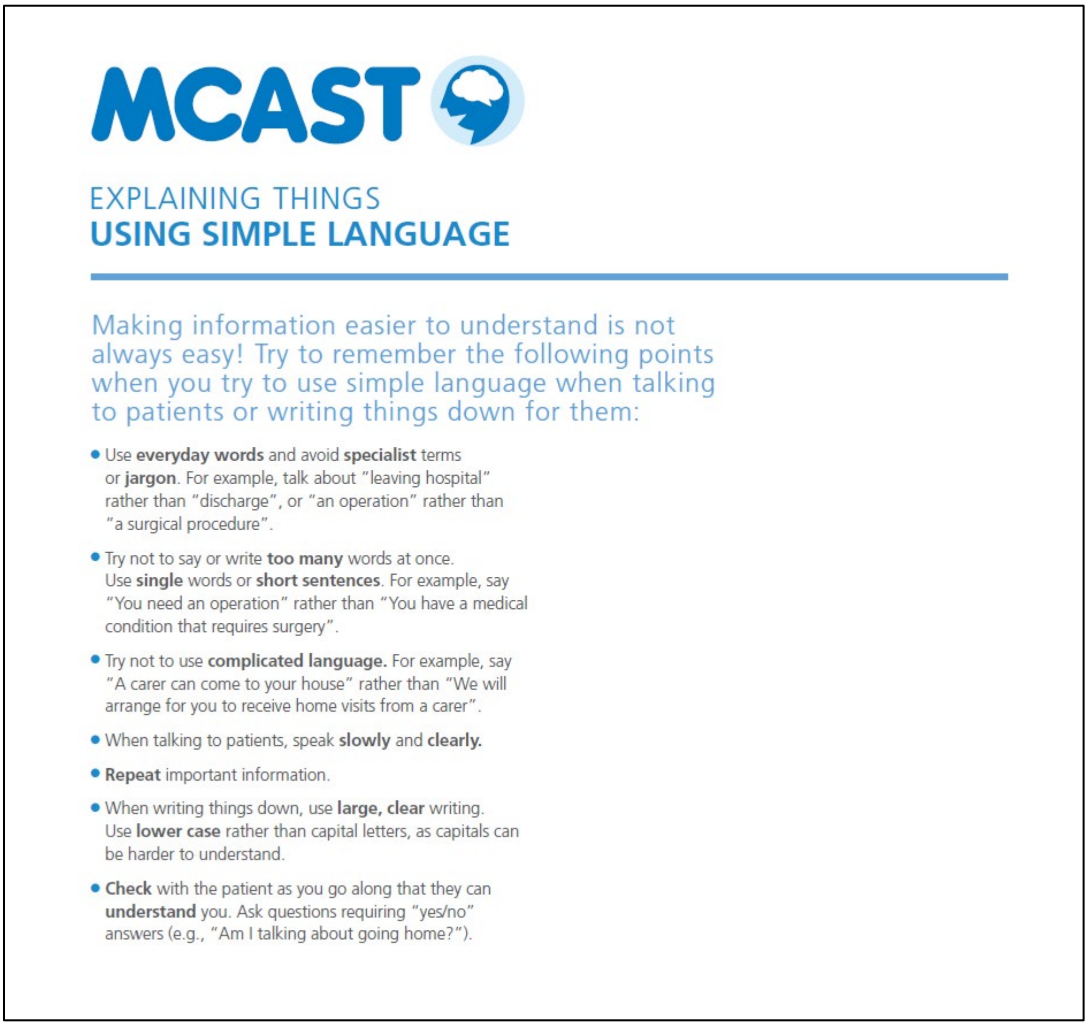
Name: ____

Witnessed by: ____ (signature)

Name: ____ Role: __________________________

Contacts:
Mark Jayes, Researcher, Sheffield Teaching Hospitals NHS Foundation Trust / University of Sheffield, mark.jayes@sheffield.ac.uk
Cathy Soreny, Photographer, Optical Jukebox, cathy@opticaljukebox.org

Appendix 35: MCAST simple language guidance (chapter 7)



MCAST

EXPLAINING THINGS
USING SIMPLE LANGUAGE

Making information easier to understand is not always easy! Try to remember the following points when you try to use simple language when talking to patients or writing things down for them:

- Use **everyday words** and avoid **specialist** terms or **jargon**. For example, talk about "leaving hospital" rather than "discharge", or "an operation" rather than "a surgical procedure".
- Try not to say or write **too many** words at once. Use **single** words or **short sentences**. For example, say "You need an operation" rather than "You have a medical condition that requires surgery".
- Try not to use **complicated language.** For example, say "A carer can come to your house" rather than "We will arrange for you to receive home visits from a carer".
- When talking to patients, speak **slowly** and **clearly.**
- **Repeat** important information.
- When writing things down, use **large, clear** writing. Use **lower case** rather than capital letters, as capitals can be harder to understand.
- **Check** with the patient as you go along that they can **understand** you. Ask questions requiring "yes/no" answers (e.g., "Am I talking about going home?").

Appendix 36: MCAST guidance about methods to use to test decision-making abilities (chapter 7)

During the capacity assessment, you will need to check whether the patient is able to demonstrate the following decision-making abilities:

- **understand** information that is relevant to the decision
- **retain** this information long enough to make a decision
- **use** or **weigh** this information
- **communicate** their decision

We have listed below some methods that you could use to **test** each of these abilities when assessing capacity for patients, including those with a **communication difficulty**.

Understanding the information

- Ask the patient to **say** / **write down** what they have understood about the decision, the need for a decision, the options available and potential consequences of these.
- Encourage them to use **gestures** or **drawing** to communicate what they have understood.
- Ask them to **choose** between two **alternatives** relating to the decision information (e.g., “Am I talking about an operation or a tablet?”).
- Ask them **“yes / no” questions** about the decision information (e.g., “Am I talking about an operation?”).
- **Write down** some words that are related to the decision information and some that are unrelated. Ask the patient to **point** to the words that are related to the decision.
- Select some **photographs** or **diagrams** that are related to the decision information and some that are unrelated from the **Resource Pack**. Ask the patient to **point** to the images that are related to the decision.
- Ask the same question using **different methods** or ensure your questions are **phrased in different ways**, in order to check the patient’s response are consistent (e.g., “Is the decision about [correct answer]?”, “So you need to make a decision about [incorrect answer]?”).

Retaining the information

- Use the same methods as for understanding (above).
- Check the **consistency** of the patient’s responses throughout the assessment.

Using or weighing the information

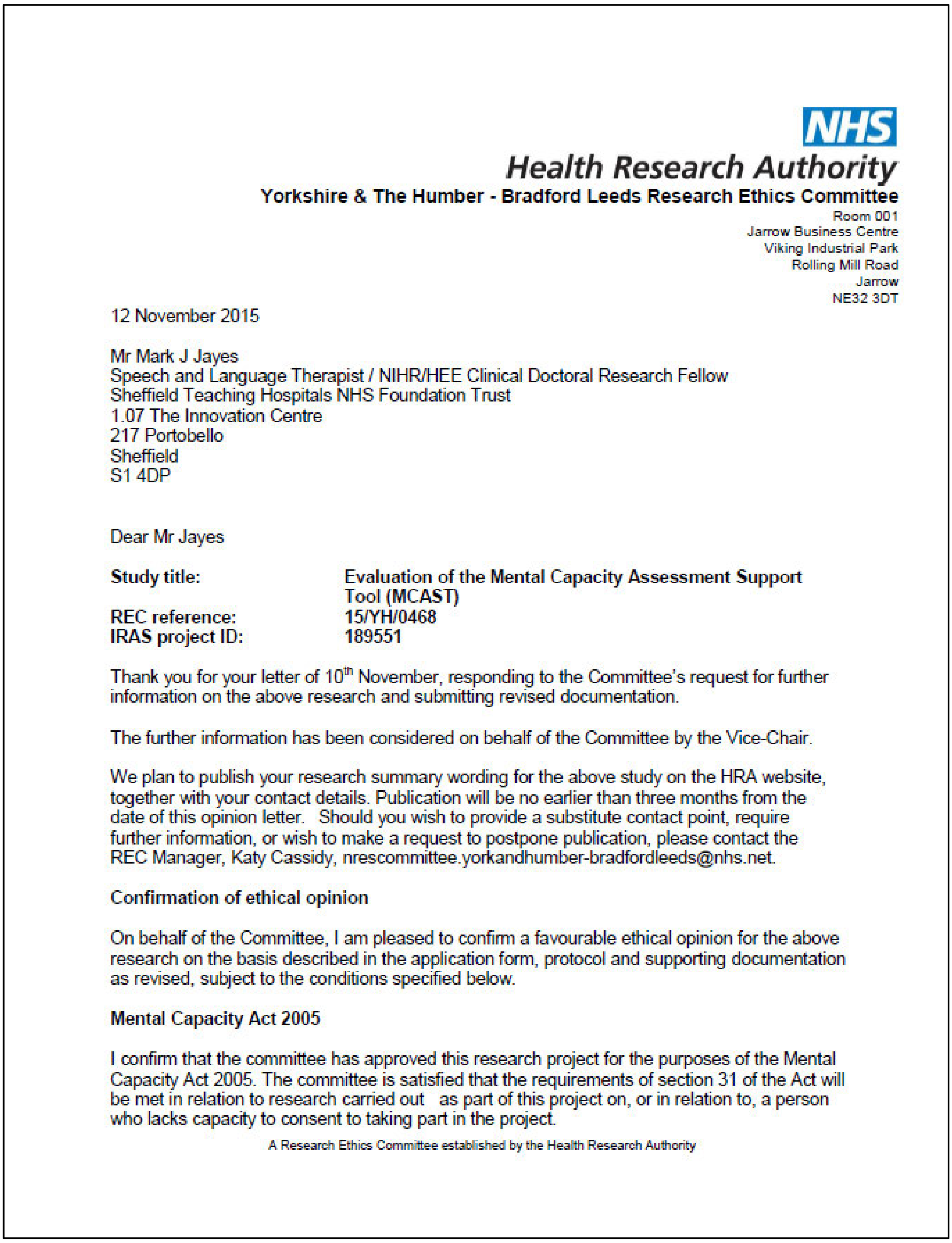
- Ask the patient to **say** / **write down** why they have chosen a particular option.
- Encourage them to use **gestures, mime** or **drawing** to communicate why they have chosen a particular option.
- Ask the patient to **say** / **write down** the **pros and cons** of different options.

- Ask them to **choose** between two **alternatives** relating to different decision options (e.g., “Which is safer, going home or staying here?”).
- Ask them **“yes / no” questions** about the pros / cons, risks and benefits of decision options (e.g., “Could drinking water make you ill?”).
- **Write down** some words corresponding to the pros / cons, risks and benefits of decision options and words that do not correspond to these. Ask the patient to **point** to the words that correspond to the pros / cons etc..
- Select some **photographs** or **diagrams** corresponding to the pros / cons, risks and benefits of the decision options and some that are unrelated from the **Resource Pack**. Ask the patient to **point** to the images that correspond to the pros / cons etc...
- Encourage the patient to use **gestures, mime** or **drawing** person to communicate what they would do in hypothetical situations (e.g., if they fell over at home; if there was a fire in the house).
- Check the **consistency** of the patient’s responses throughout the assessment.

Communicating a decision

- If the patient’s speech is not easy to understand, encourage them to **slow down** and say **one word at a time**.
- If the patient’s speech is very difficult to understand, ask them **“yes / no” questions** to clarify which decision option they wish to choose (e.g., “Do you want to…?”).

Appendix 37: Feasibility study ethical approval letter (chapter 8)



NHS
Health Research Authority
Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
Room 001
Jarrow Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

12 November 2015

Mr Mark J Jayes
Speech and Language Therapist / NIHR/HEE Clinical Doctoral Research Fellow
Sheffield Teaching Hospitals NHS Foundation Trust
1.07 The Innovation Centre
217 Portobello
Sheffield
S1 4DP

Dear Mr Jayes

Study title:	**Evaluation of the Mental Capacity Assessment Support Tool (MCAST)**
REC reference:	**15/YH/0468**
IRAS project ID:	**189551**

Thank you for your letter of 10th November, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Katy Cassidy, nrescommittee.yorkandhumber-bradfordleeds@nhs.net.

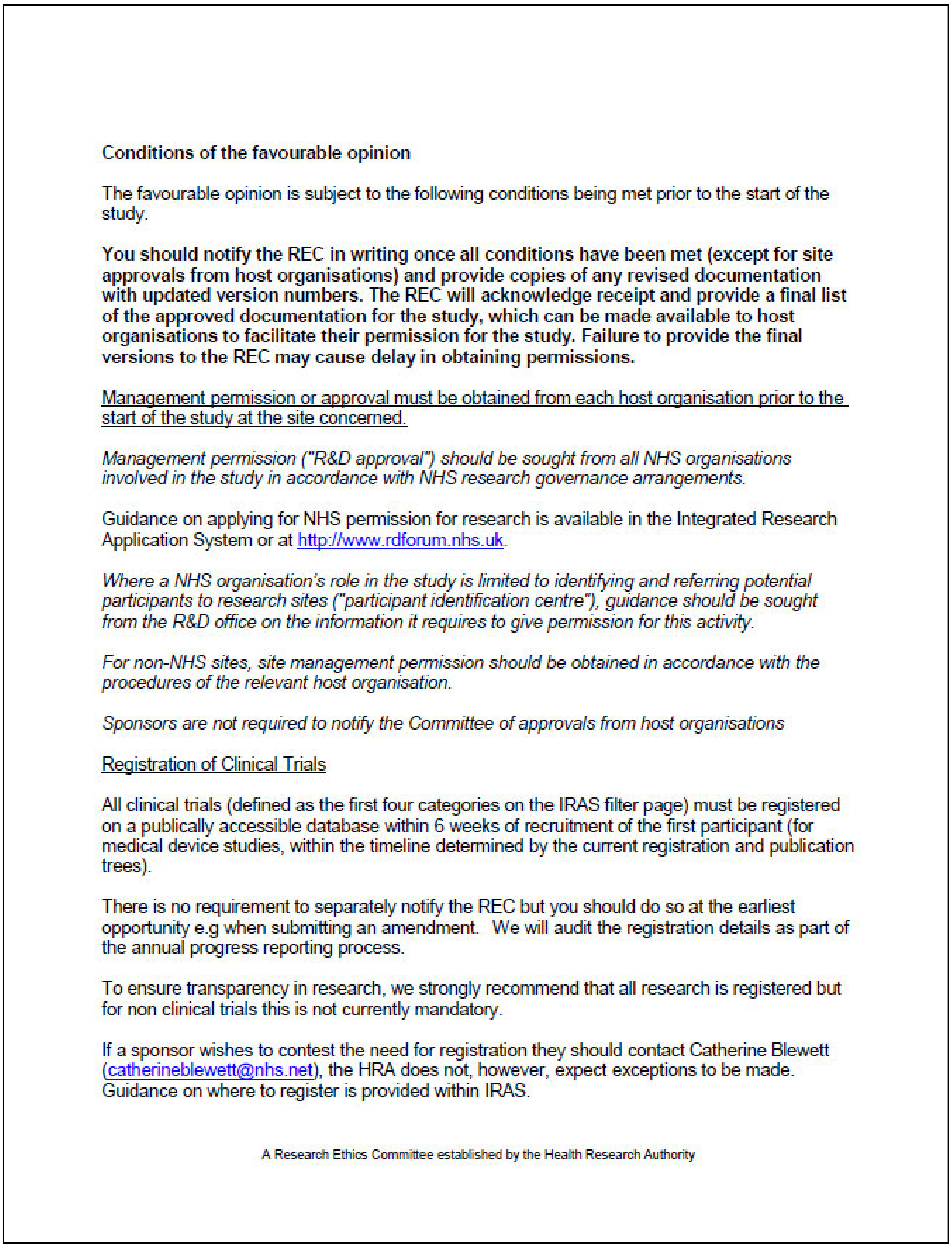
Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

A Research Ethics Committee established by the Health Research Authority



Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

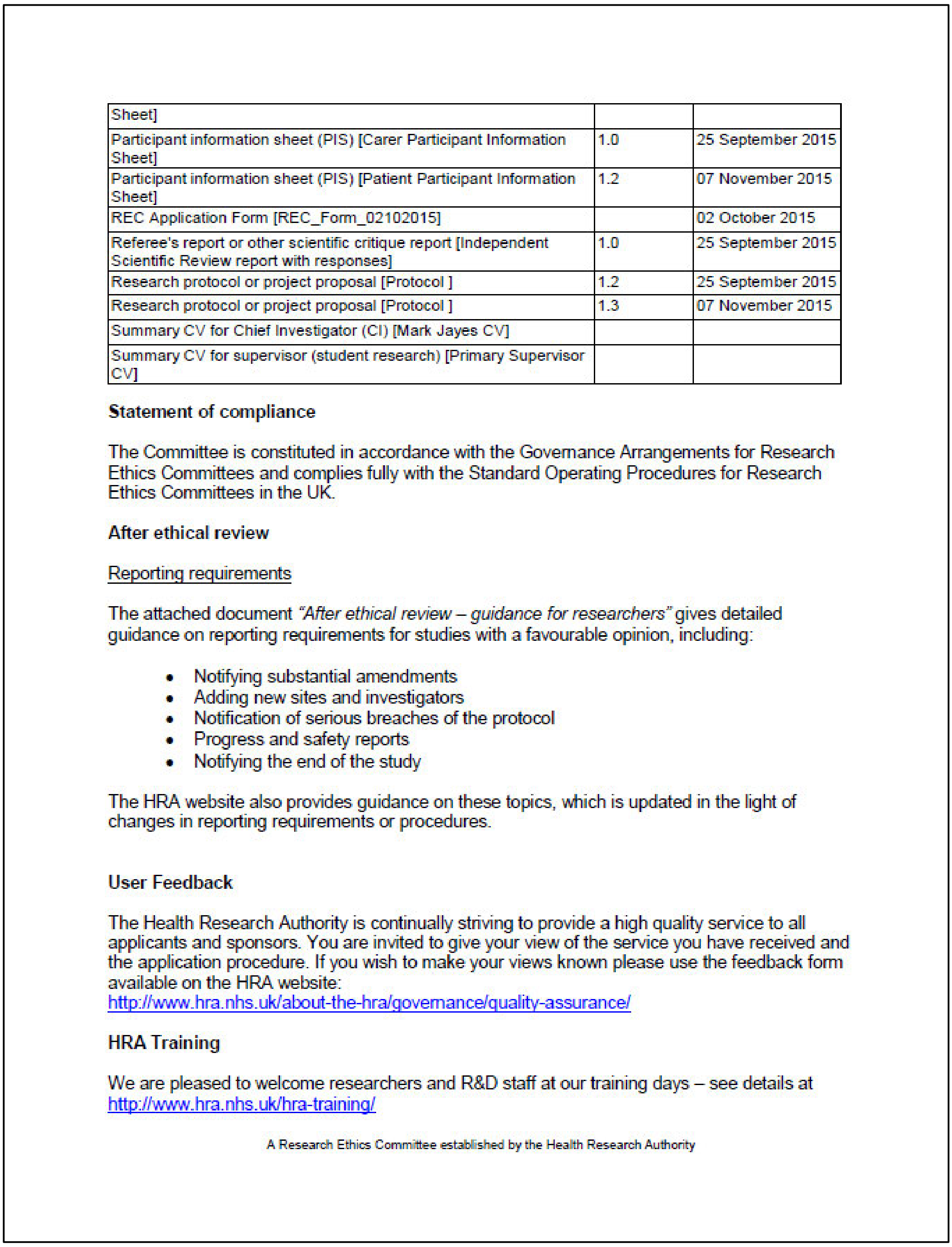
Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.



Sheet]		
Participant information sheet (PIS) [Carer Participant Information Sheet]	1.0	25 September 2015
Participant information sheet (PIS) [Patient Participant Information Sheet]	1.2	07 November 2015
REC Application Form [REC_Form_02102015]		02 October 2015
Referee's report or other scientific critique report [Independent Scientific Review report with responses]	1.0	25 September 2015
Research protocol or project proposal [Protocol]	1.2	25 September 2015
Research protocol or project proposal [Protocol]	1.3	07 November 2015
Summary CV for Chief Investigator (CI) [Mark Jayes CV]		
Summary CV for supervisor (student research) [Primary Supervisor CV]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

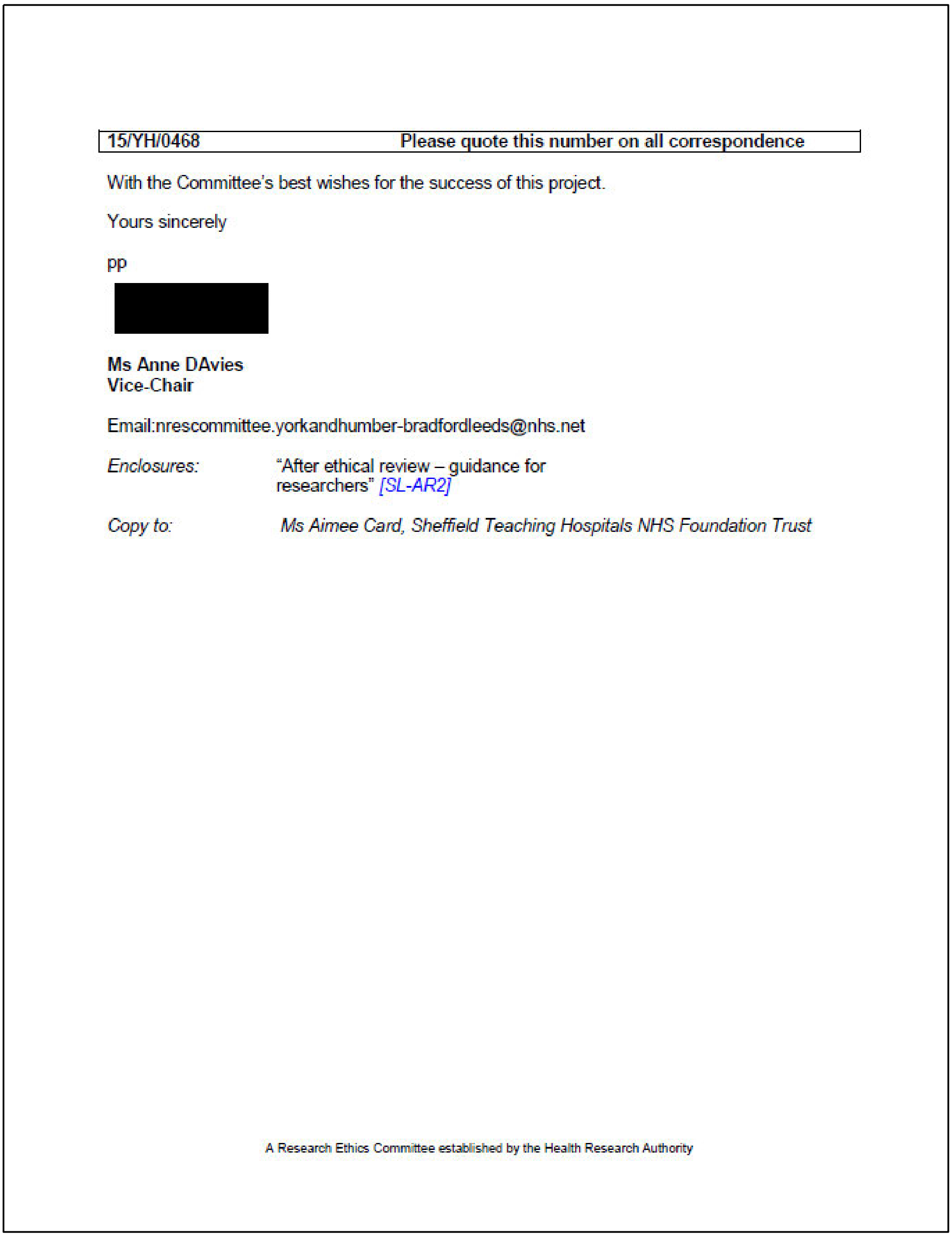
The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/



15/YH/0468 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp

[redacted]

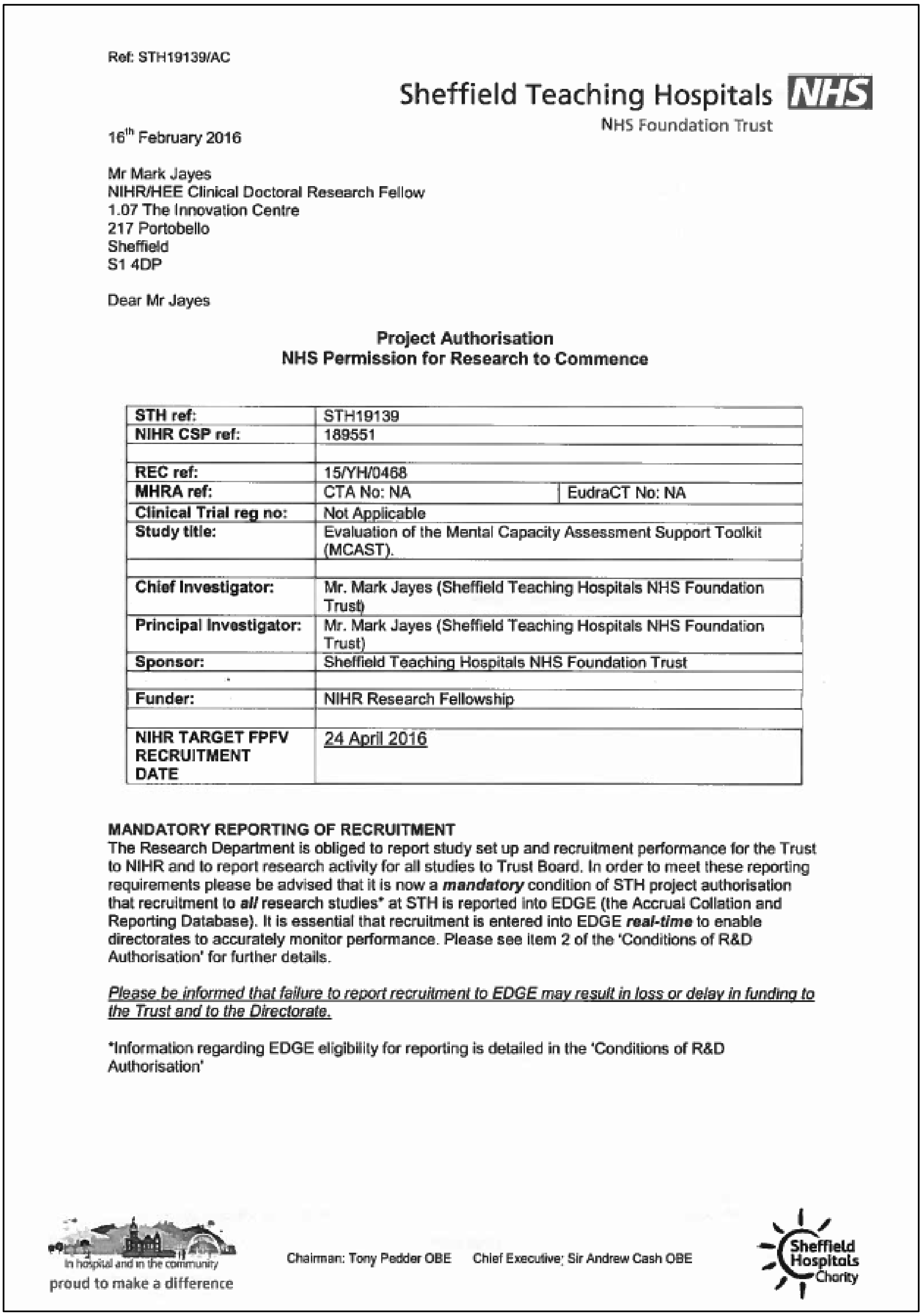
Ms Anne DAvies
Vice-Chair

Email:nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures:	"After ethical review – guidance for researchers" *[SL-AR2]*
Copy to:	*Ms Aimee Card, Sheffield Teaching Hospitals NHS Foundation Trust*

A Research Ethics Committee established by the Health Research Authority

Appendix 38: Feasibility study NHS governance approval letter (Chapter 7)



Ref: STH19139/AC

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

16th February 2016

Mr Mark Jayes
NIHR/HEE Clinical Doctoral Research Fellow
1.07 The Innovation Centre
217 Portobello
Sheffield
S1 4DP

Dear Mr Jayes

Project Authorisation
NHS Permission for Research to Commence

STH ref:	STH19139	
NIHR CSP ref:	189551	
REC ref:	15/YH/0468	
MHRA ref:	CTA No: NA	EudraCT No: NA
Clinical Trial reg no:	Not Applicable	
Study title:	Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST).	
Chief Investigator:	Mr. Mark Jayes (Sheffield Teaching Hospitals NHS Foundation Trust)	
Principal Investigator:	Mr. Mark Jayes (Sheffield Teaching Hospitals NHS Foundation Trust)	
Sponsor:	Sheffield Teaching Hospitals NHS Foundation Trust	
Funder:	NIHR Research Fellowship	
NIHR TARGET FPFV RECRUITMENT DATE	24 April 2016	

MANDATORY REPORTING OF RECRUITMENT
The Research Department is obliged to report study set up and recruitment performance for the Trust to NIHR and to report research activity for all studies to Trust Board. In order to meet these reporting requirements please be advised that it is now a ***mandatory*** condition of STH project authorisation that recruitment to ***all*** research studies* at STH is reported into EDGE (the Accrual Collation and Reporting Database). It is essential that recruitment is entered into EDGE ***real-time*** to enable directorates to accurately monitor performance. Please see item 2 of the 'Conditions of R&D Authorisation' for further details.

Please be informed that failure to report recruitment to EDGE may result in loss or delay in funding to the Trust and to the Directorate.

*Information regarding EDGE eligibility for reporting is detailed in the 'Conditions of R&D Authorisation'

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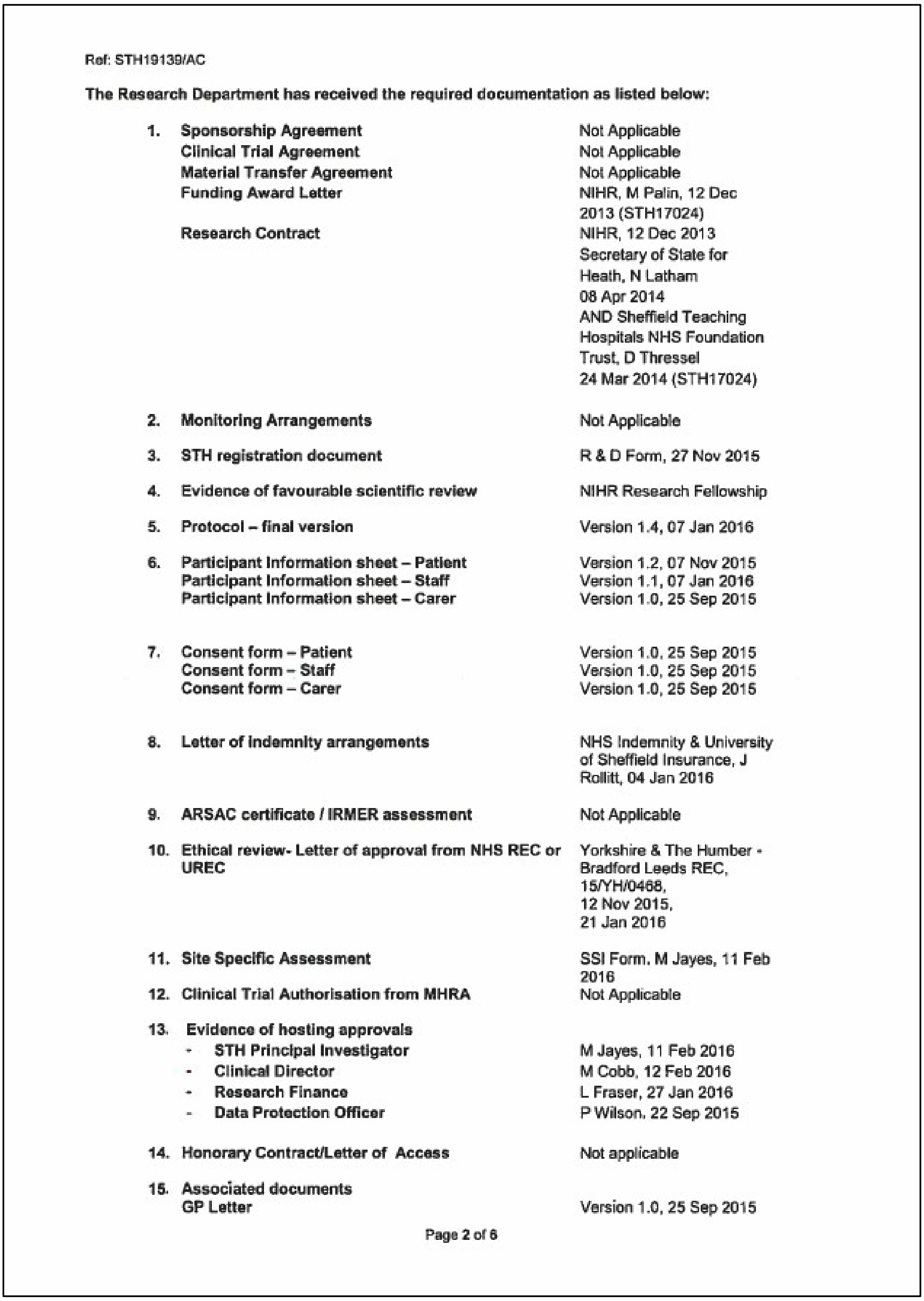
proud to make a difference

Chairman: Tony Pedder OBE Chief Executive: Sir Andrew Cash OBE

Sheffield Hospitals Charity



Ref: STH19139/AC

The Research Department has received the required documentation as listed below:

1.	**Sponsorship Agreement**	Not Applicable
	Clinical Trial Agreement	Not Applicable
	Material Transfer Agreement	Not Applicable
	Funding Award Letter	NIHR, M Palin, 12 Dec 2013 (STH17024)
	Research Contract	NIHR, 12 Dec 2013 Secretary of State for Heath, N Latham 08 Apr 2014 AND Sheffield Teaching Hospitals NHS Foundation Trust, D Thressel 24 Mar 2014 (STH17024)
2.	**Monitoring Arrangements**	Not Applicable
3.	**STH registration document**	R & D Form, 27 Nov 2015
4.	**Evidence of favourable scientific review**	NIHR Research Fellowship
5.	**Protocol – final version**	Version 1.4, 07 Jan 2016
6.	**Participant Information sheet – Patient**	Version 1.2, 07 Nov 2015
	Participant Information sheet – Staff	Version 1.1, 07 Jan 2016
	Participant Information sheet – Carer	Version 1.0, 25 Sep 2015
7.	**Consent form – Patient**	Version 1.0, 25 Sep 2015
	Consent form – Staff	Version 1.0, 25 Sep 2015
	Consent form – Carer	Version 1.0, 25 Sep 2015
8.	**Letter of indemnity arrangements**	NHS Indemnity & University of Sheffield Insurance, J Rollitt, 04 Jan 2016
9.	**ARSAC certificate / IRMER assessment**	Not Applicable
10.	**Ethical review- Letter of approval from NHS REC or UREC**	Yorkshire & The Humber - Bradford Leeds REC, 15/YH/0468, 12 Nov 2015, 21 Jan 2016
11.	**Site Specific Assessment**	SSI Form, M Jayes, 11 Feb 2016
12.	**Clinical Trial Authorisation from MHRA**	Not Applicable
13.	**Evidence of hosting approvals**	
	- **STH Principal Investigator**	M Jayes, 11 Feb 2016
	- **Clinical Director**	M Cobb, 12 Feb 2016
	- **Research Finance**	L Fraser, 27 Jan 2016
	- **Data Protection Officer**	P Wilson, 22 Sep 2015
14.	**Honorary Contract/Letter of Access**	Not applicable
15.	**Associated documents**	
	GP Letter	Version 1.0, 25 Sep 2015

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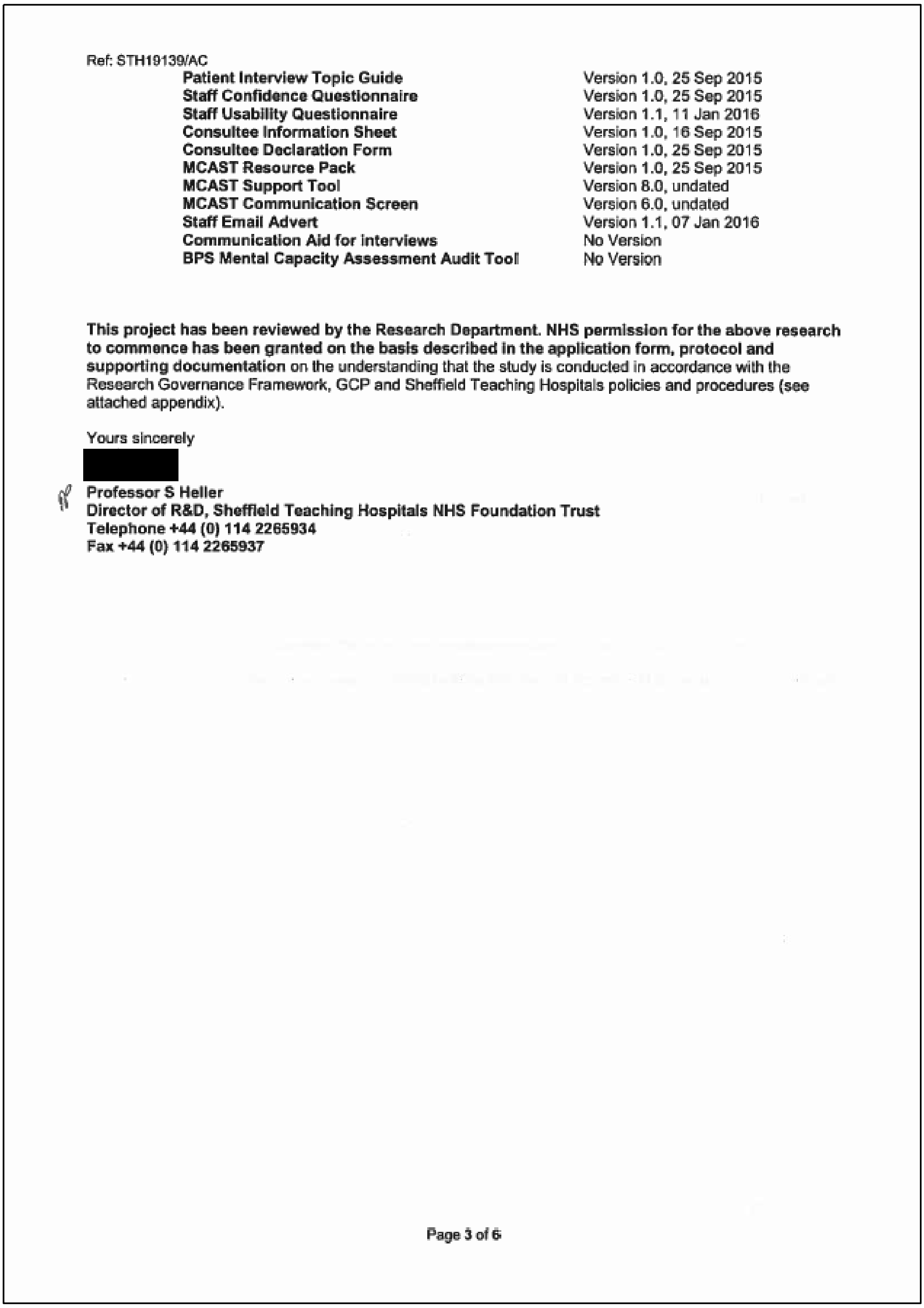


Ref: STH19139/AC

Patient Interview Topic Guide	Version 1.0, 25 Sep 2015
Staff Confidence Questionnaire	Version 1.0, 25 Sep 2015
Staff Usability Questionnaire	Version 1.1, 11 Jan 2016
Consultee Information Sheet	Version 1.0, 16 Sep 2015
Consultee Declaration Form	Version 1.0, 25 Sep 2015
MCAST Resource Pack	Version 1.0, 25 Sep 2015
MCAST Support Tool	Version 8.0, undated
MCAST Communication Screen	Version 6.0, undated
Staff Email Advert	Version 1.1, 07 Jan 2016
Communication Aid for interviews	No Version
BPS Mental Capacity Assessment Audit Tool	No Version

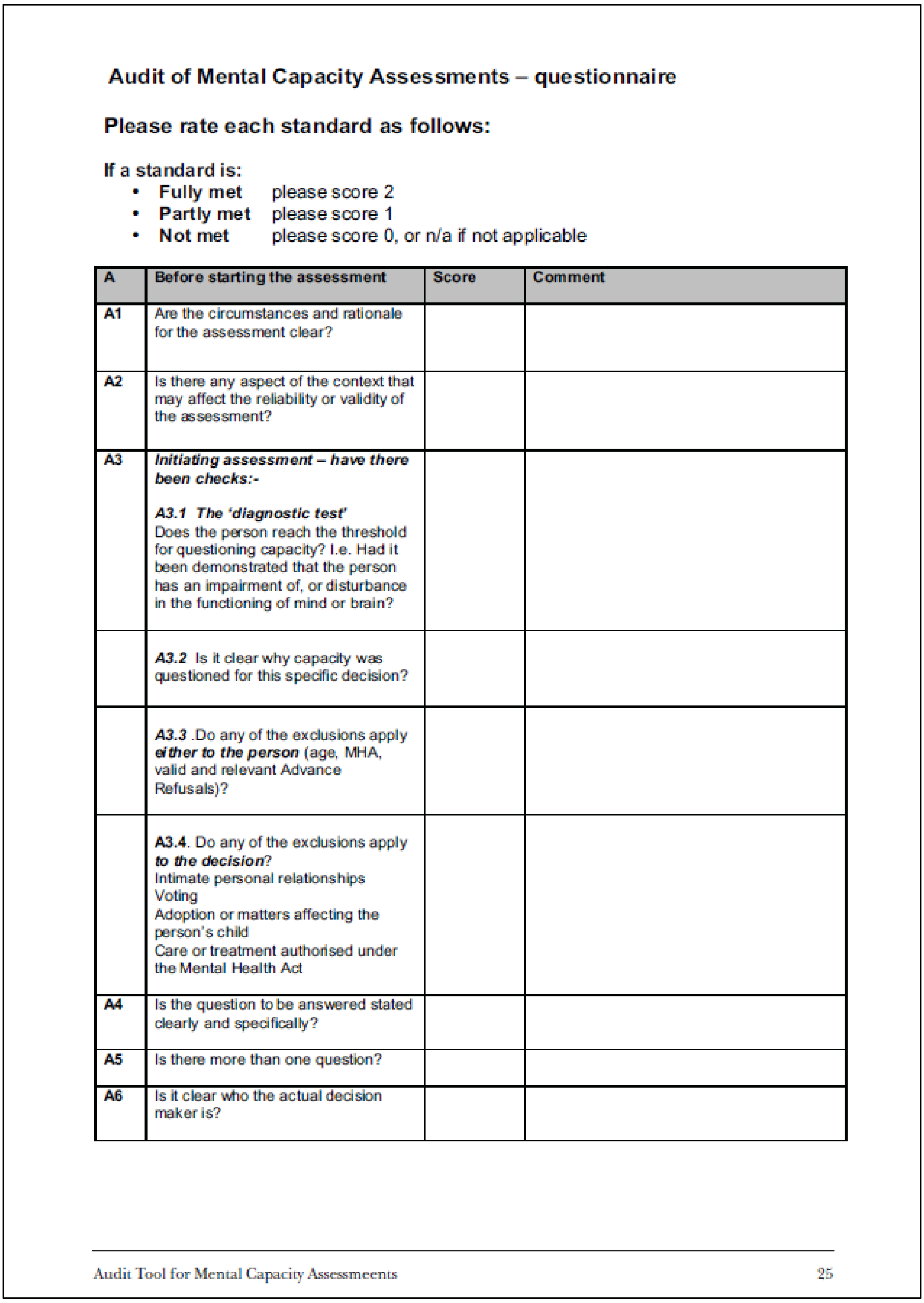
This project has been reviewed by the Research Department. NHS permission for the above research to commence has been granted on the basis described in the application form, protocol and supporting documentation on the understanding that the study is conducted in accordance with the Research Governance Framework, GCP and Sheffield Teaching Hospitals policies and procedures (see attached appendix).

Yours sincerely

[redacted]

Professor S Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 2265934
Fax +44 (0) 114 2265937

Appendix 39: British Psychological Society (2010) Audit Tool for Mental Capacity Assessment (chapter 8)



Audit of Mental Capacity Assessments – questionnaire

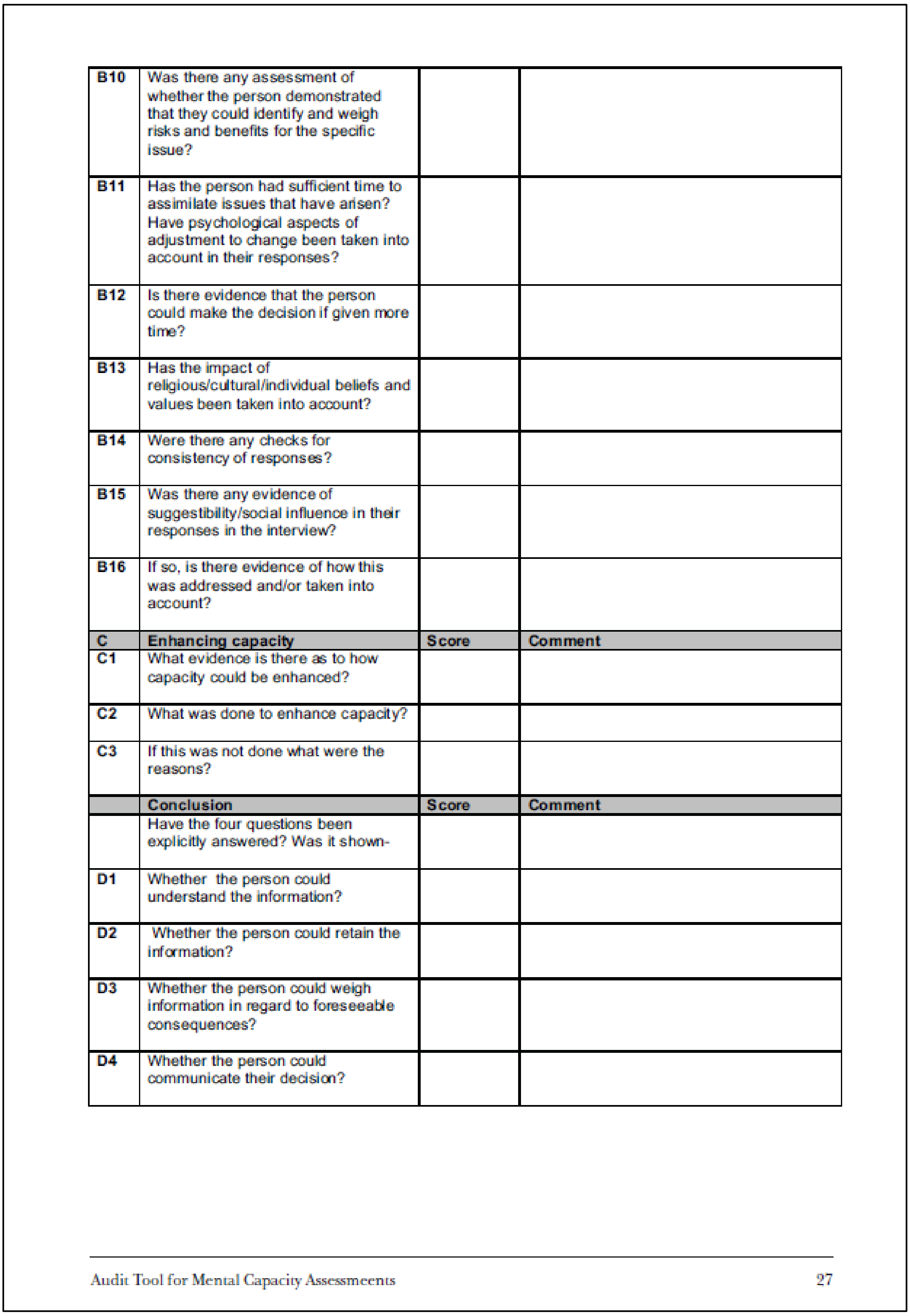
Please rate each standard as follows:

If a standard is:

- **Fully met** please score 2
- **Partly met** please score 1
- **Not met** please score 0, or n/a if not applicable

A	Before starting the assessment	Score	Comment
A1	Are the circumstances and rationale for the assessment clear?		
A2	Is there any aspect of the context that may affect the reliability or validity of the assessment?		
A3	***Initiating assessment – have there been checks:-*** ***A3.1 The 'diagnostic test'*** Does the person reach the threshold for questioning capacity? I.e. Had it been demonstrated that the person has an impairment of, or disturbance in the functioning of mind or brain?		
	A3.2 Is it clear why capacity was questioned for this specific decision?		
	A3.3 .Do any of the exclusions apply ***either to the person*** (age, MHA, valid and relevant Advance Refusals)?		
	A3.4. Do any of the exclusions apply ***to the decision***? Intimate personal relationships Voting Adoption or matters affecting the person's child Care or treatment authorised under the Mental Health Act		
A4	Is the question to be answered stated clearly and specifically?		
A5	Is there more than one question?		
A6	Is it clear who the actual decision maker is?		

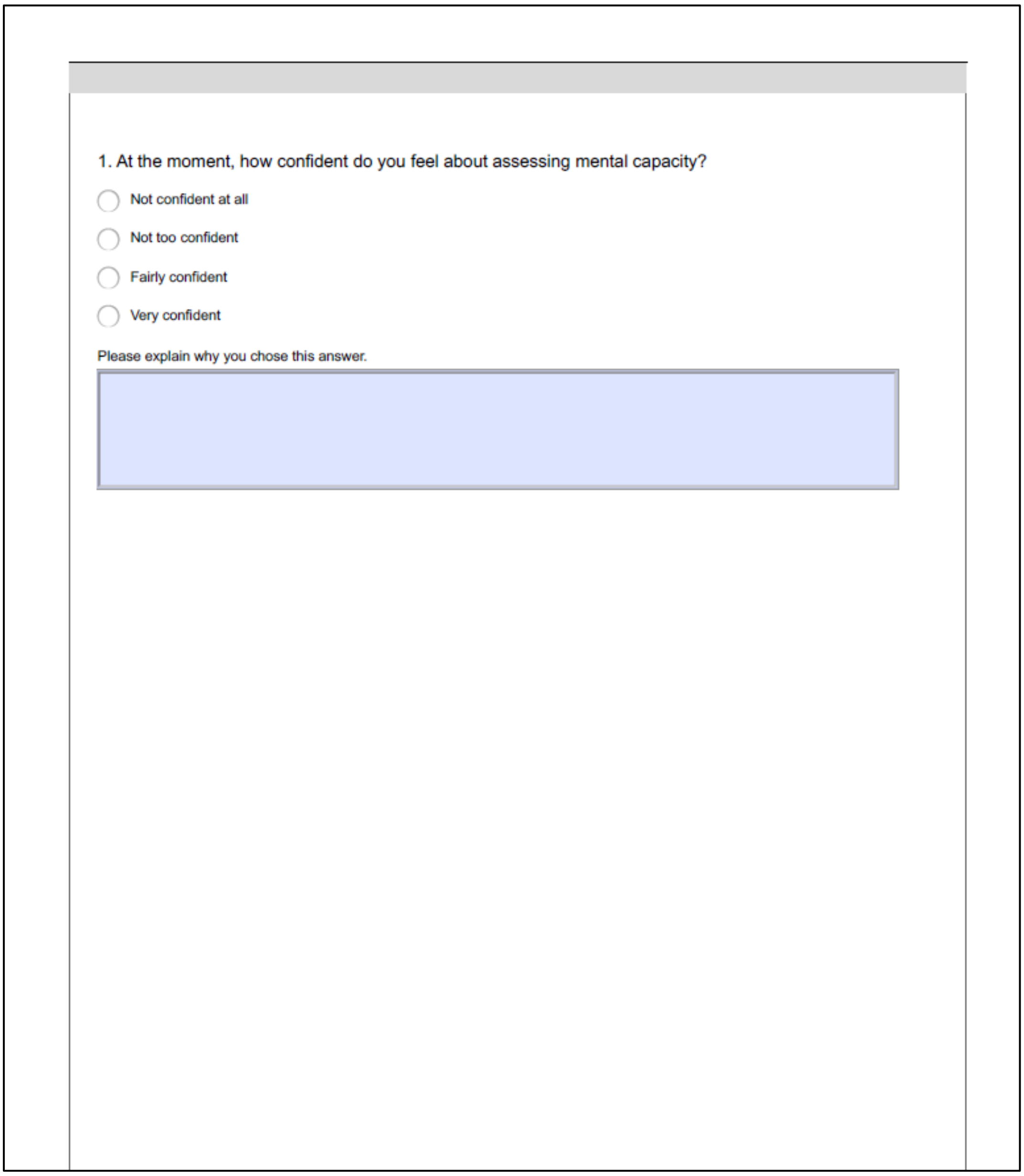
A7	The assessment should be made against clear criteria for the expected level of knowledge/decision making required to demonstrate the required capacity. Has this been stipulated in advance?		
B	**The assessment**	**Score**	**Comment**
B1	Is there evidence that the assessment was carried out at the right time?		
B2.	Was appropriate and relevant information included? This might include the following:		
B2.1	Adequate background information/from people or records		
B2.2	Information from/Interviews with relevant parties Have these been listed in the report?		
B3	Was there a check on/assessment of the person's neurological, cognitive and communication ability?		
B4	What evidence is there of attempts to compensate for cognitive/communication/emotional disabilities or use support tools?		
B5	Were formal assessments used that were relevant to the functional capacity question?		
B6	Were the formal assessments listed and/or described?		
B7	Was there identification of any emotional factors/mental illness that might affect responses: including • anxiety • depression • psychosis		
B8	Does insight impact on the person's ability to understand the information relevant to the decision and of foreseeable consequences of the decision?		
B9	Was there any assessment of whether the person demonstrated that they could retain the information relevant to the decision?		



B10	Was there any assessment of whether the person demonstrated that they could identify and weigh risks and benefits for the specific issue?		
B11	Has the person had sufficient time to assimilate issues that have arisen? Have psychological aspects of adjustment to change been taken into account in their responses?		
B12	Is there evidence that the person could make the decision if given more time?		
B13	Has the impact of religious/cultural/individual beliefs and values been taken into account?		
B14	Were there any checks for consistency of responses?		
B15	Was there any evidence of suggestibility/social influence in their responses in the interview?		
B16	If so, is there evidence of how this was addressed and/or taken into account?		
C	**Enhancing capacity**	**Score**	**Comment**
C1	What evidence is there as to how capacity could be enhanced?		
C2	What was done to enhance capacity?		
C3	If this was not done what were the reasons?		
	Conclusion	**Score**	**Comment**
	Have the four questions been explicitly answered? Was it shown-		
D1	Whether the person could understand the information?		
D2	Whether the person could retain the information?		
D3	Whether the person could weigh information in regard to foreseeable consequences?		
D4	Whether the person could communicate their decision?		

E	The Outcome	Score	Comment
E1	Was information about the assessment process and content clearly stated?		
E2	Were issues of reliability and validity that might have affected the assessment acknowledged as part of the opinion/judgement?		
E3	Did the assessment include sufficient explanation of capacity findings?		
E4	Was the decision making process well structured?		
E5	Was factual evidence clearly distinguished from opinion?		
E6	Has the assessment duly considered and balanced different factors, ethical principles and value judgements, (such as autonomy versus protection)?		
E8	Was the opinion/judgement of the assessor clearly expressed?		
F	**Recommendations**	**Score**	**Comment**
F1	If the person is judged to lack capacity are their recommendations for actions to empower and protect the person?		
F2	If the person is judged to have capacity are there recommendations for actions to provide support to empower and protect the person? e.g. Safeguarding/Advocacy		
F3	Is there a recommendation as to whether the assessment should be repeated?		

Appendix 40: Confidence questionnaire (chapter 8)



1. At the moment, how confident do you feel about assessing mental capacity?

○ Not confident at all

○ Not too confident

○ Fairly confident

○ Very confident

Please explain why you chose this answer.

Appendix 41: Professionals' usability and acceptability survey (chapter 8)

Multi option and free text questions included in electronic SurveyMonkey© survey:

1. Please tell us your job role
2. Where do you work?
3. Who do you work with?
4. How many times have you used the MCAST during a capacity assessment?
5. How difficult or easy to use was the Support Tool?
6. To what extent, if at all, was the Support Tool useful?
7. What changes, if any, could be made to the Support Tool?
8. How many times did you use the Communication Screening Tool?
9. How easy or difficult to use was the Communication Screening Tool?
10. To what extent, if at all, was the Communication Screening Tool useful?
11. To what extent, if at all, did you feel confident about the results you obtained using the Communication Screening Tool (e.g., whether the patient had any communication difficulties / what you should do to support the patient's communication during the assessment)?
12. What changes, if any, could be made to the Communication Screening Tool?
13. You said you did not use the Communication Screening Tool. Please tell us why.
14. How many times did you use the Resource Pack?
15. How difficult or easy to use was the Resource Pack?
16. To what extent, if at all, was the Resource Pack useful?
17. To what extent, if at all, did you feel confident using the items in the Resource Pack?
18. What changes, if any, could be made to the Resource Pack?
19. You said you did not use the Resource Pack. Please tell us why.
20. What effect, if any, did using the MCAST have on patients during capacity assessments?
21. Please tell us why you chose this answer (to question 20).
22. To what extent, if at all, did using the MCAST help you to assess capacity?
23. Please tell us why you chose this answer (to question 22).
24. Which of the following aspects of capacity assessment did it help you with?
25. What effect, if any, did using the MCAST have on how confident you felt about assessing capacity?
26. Please explain why you chose this answer (to question 25).

27. Think about how long you spent using the MCAST to carry out a capacity assessment. How does this length of time compare with the time you would normally spend on a capacity assessment (i.e., when you're not using the MCAST)?
28. How do you feel about it taking longer? (for respondents who responded to question 27 that it took longer using the MCAST).
29. How often do you think you would use the MCAST in future during capacity assessments?
30. To what extent do you think it would be helpful if staff could place the MCAST forms directly in patients' notes, as a record of their capacity assessments?
31. How useful, if at all, would it be to have an electronic version of the MCAST that staff could use on a portable device, such as a tablet computer?
32. Please tell us any further feedback you have about the MCAST here.
33. Could you tell us why you haven't used the MCAST? Please give as much detail as you can (for respondents who responded to question 4 that they had not used the MCAST).

Appendix 42: Patient and family carer topic guide (chapter 8)

Patient interview topic guide Version 1.0 25.09.15

General questions about toolkit:

- What was it like when the member of staff talked to you about the decision? (Prompt: show photo of staff participant who did capacity assessment)
- What was difficult? (Probe: why?)
- What helped? (Probe: why?)
- Did the member of staff help you make the decision?

Specific questions about Communication Screening Tool:

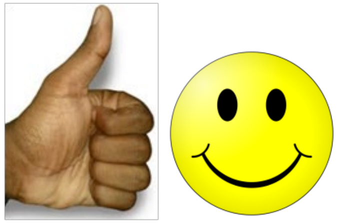
- What was it like when the member of staff checked your communication skills? (Prompt: show communication screening tool materials / demonstrate some of questions)
- What was difficult? (Probe: why?)
- What helped?(Probe: why)

Specific questions about Resource pack:

- Did the member of staff show you photos? (Prompt: show sample photos from Resource pack)
- Did that help? (Probe: why/why not?)
- Did you like the photos? (Probe: why/why not?)
- Did the member of staff write things down? (Prompt: demonstrate writing things down for patient)
- Did that help? (Probe: why/why not?)
- Did you like it when they wrote things down? (Probe: why/why not?)

Appendix 43: Example of accessible information resource for use in patient interviews (chapter 8)

Did [   ] help you?



No, it did not help me

Yes, it helped me

0--- 0--- --0--- ----0---0

Appendix 44: Feasibility study staff participant information sheet (chapter 8)

The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Participant Information Sheet for staff (Version 1.1 07.01.16)

1. Study Title: Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST).

2. Invitation

You are being invited to take part in the next stage of a study to design a toolkit to support mental capacity assessment. You may have taken part in two earlier studies which asked staff: firstly what they thought should be included in the toolkit and secondly to review different designs for the toolkit. Before you decide, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information. Please ask if there is anything you do not understand or if you would like more information. Take time to decide if you wish to take part.

3. What is the purpose of the study?

This study aims to evaluate a toolkit called the MCAST. The toolkit has been designed to help hospital staff to carry out mental capacity assessments. It includes three main components: i) a support tool to help staff plan and carry out a capacity assessment; ii) a communication screening assessment to help staff identify if a patient has communication needs and what to do to support these needs; iii) a pack of practical resources for staff to use during the capacity assessment to explain information to patients with communication needs and check their decision-making abilities.

The study will involve asking staff to use the toolkit during mental capacity assessments they need to carry out for hospital patients with a stroke diagnosis or confirmed / suspected cognitive difficulties. The study will collect information to find out if the toolkit provides reliable and accurate information about patients' communication needs and whether it helps staff to feel more confident about capacity assessment and to carry out assessments that are more consistent with the Mental Capacity Act (2005). Staff will be asked if they find the toolkit useful and easy to use. Patients will be asked if they find the toolkit processes and materials acceptable and helpful.

4. **Why have I been chosen?**

You have been chosen because you work with patients with a stroke diagnosis or confirmed / suspected cognitive difficulties and you are likely to carry out mental capacity assessments as part of your job.

5. **Do I have to take part?**

You do not have to take part in the study - it is your decision. If you do decide to take part, you can still change your mind and leave the study at any point. You do not need to give a reason for not taking part or leaving. If you decide not to take part, or you want to leave the study, this will not affect your job. If you decide to leave the study, any answers you have already provided will still be part of the study's results.

6. **What will happen to me if I take part?**

Firstly, Mark Jayes (the investigator) will ask you to complete an anonymous questionnaire asking you how confident you feel about assessing mental capacity. Next, Mark will talk to you about the study and demonstrate how the toolkit works. Mark will ask you to identify some capacity assessments you have completed in the past. Mark will pick one of these assessments and will look at the documented assessment in the patient's case notes and audit it against standards contained in the Mental Capacity Act (2005). Mark will ask you to let him know when you need to complete a mental capacity assessment for a patient in your clinical location. Mark will ask you to use the toolkit to prepare and carry out for the assessment. You will be asked to complete some paperwork when you use the toolkit. After you have used the toolkit, you will be asked to complete the confidence questionnaire again and another anonymous questionnaire about what you thought about the toolkit. Mark will also ask you to identify some capacity assessments you have completed using the toolkit and will pick one of these to audit, using the same standards.

.

How much time will it take?

We expect it to take you approximately 2 hours to take part in the study, in addition to the time you would normally spend carrying out a capacity assessment.

8. What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks to you taking part.

9. What are the possible benefits of taking part?

There are no immediate benefits to you if you decide to take part. However, we hope the study may lead to improvements in mental capacity assessment practice in the future.

11. What if something goes wrong?

This study does not involve any special risks. If you want to make a complaint about how people have approached you or treated you during the study, please contact Mark's supervisor, Dr Rebecca Palmer, at University of Sheffield on 0114 222 0863.

If you are still not satisfied with the way your complaint has been handled, please contact Professor Jon Nicholl, Dean of the School of Health & Related Research on 0114 222 5453.

12. Will my taking part in this study be kept confidential?

All information we collect about you during the study will be kept confidentially and securely. Only Mark Jayes will be able to see your personal information. Your name will not be shown in any reports or publications.

13. What will happen to the results of the study?

The results will help Mark Jayes to decide whether the toolkit requires further testing or if parts of it need to be redesigned, as part of his PhD studies. The results will be published in Mark Jayes' PhD thesis. Your name will not appear in the thesis. The results may be used in articles written later for scientific journals or in presentations at conferences. Again, this information will be kept confidential and your name will not be shown. Your personal information and any information you provide during the review process or workshop will be stored securely at the University of Sheffield until one year after the end of Mark Jayes' PhD studies (approximately March 2018), when it will be destroyed.

14. **Who is organising and funding the study?**

The study is being organised by Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. It is being funded by the National Institute for Health Research and Health Education England Clinical Doctoral Research Fellowship scheme.

15. **Who has ethically reviewed the study?**

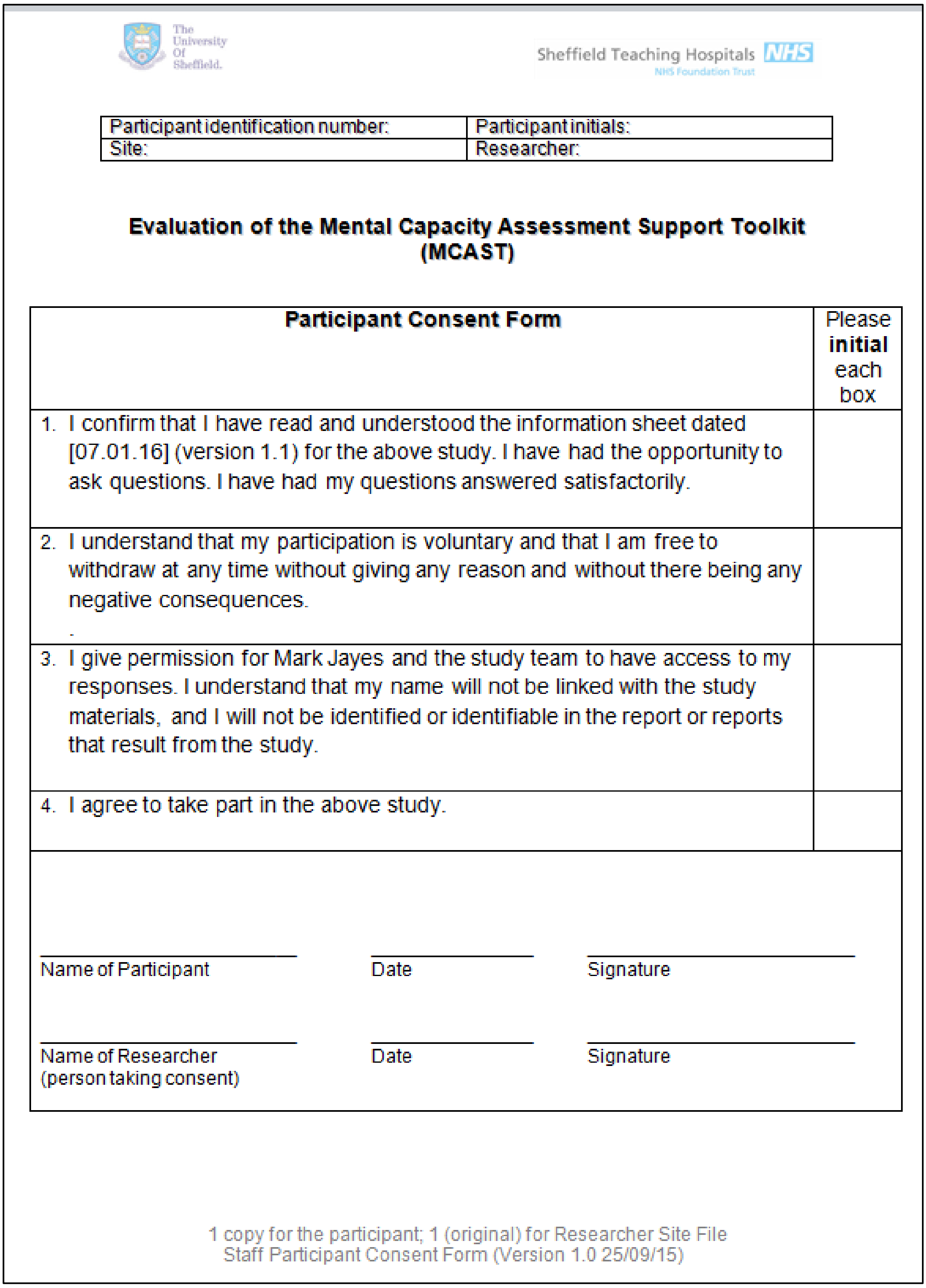
This study has been ethically approved by the Bradford Leeds Research Ethics Committee.

16. **Contact for further information:**

If you have any questions about the study, please contact Mark Jayes via telephone on 0114 222 5427, or via email at mark.jayes@sth.nhs.uk.

Thank you very much for taking the time to consider taking part in this study.

Appendix 45: Feasibility study staff participant consent form (chapter 8)



Participant identification number:	Participant initials:
Site:	Researcher:

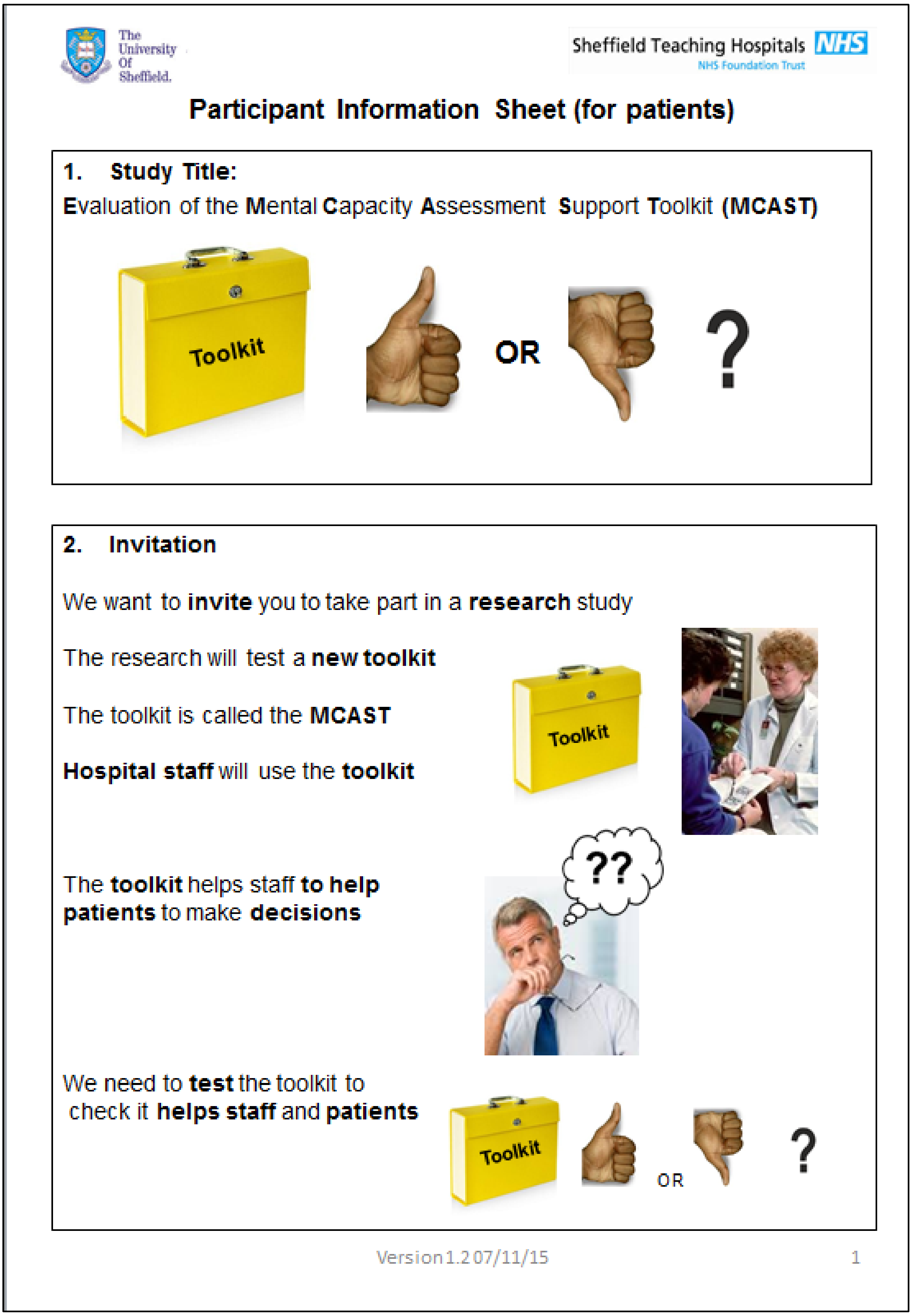
Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST)

Participant Consent Form	Please **initial** each box
1. I confirm that I have read and understood the information sheet dated [07.01.16] (version 1.1) for the above study. I have had the opportunity to ask questions. I have had my questions answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. .	
3. I give permission for Mark Jayes and the study team to have access to my responses. I understand that my name will not be linked with the study materials, and I will not be identified or identifiable in the report or reports that result from the study.	
4. I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Researcher (person taking consent)	Date	Signature

1 copy for the participant; 1 (original) for Researcher Site File
Staff Participant Consent Form (Version 1.0 25/09/15)

Appendix 46: Feasibility study patient participant information sheet (chapter 8)



The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Participant Information Sheet (for patients)

1. Study Title:

Evaluation of the **M**ental **C**apacity **A**ssessment **S**upport **T**oolkit **(MCAST)**

2. Invitation

We want to **invite** you to take part in a **research** study

The research will test a **new toolkit**

The toolkit is called the **MCAST**

Hospital staff will use the **toolkit**

The **toolkit** helps staff **to help patients** to make **decisions**

We need to **test** the toolkit to check it **helps staff** and **patients**

Version 1.2 07/11/15 1

Before you decide it is **important** for you to **understand**

- **why** we are doing the research
- **what happens** during the research

Please **take time** to **read** this **information**

Talk to **friends** and **family** about the **research** if you wish

Ask if you **do not understand**

Ask if you would like **more information**

Take **time** to **decide** if you wish to **take part**

3. What is the purpose of the study?

Hospital patients often need to make important **decisions**

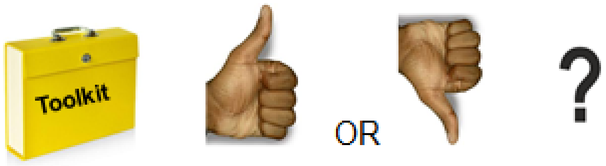
Staff need to give patients **information** to **help** them make these **decisions**

You need to have this operation because….
The **benefits** are….
The **risks** are….

Patients may find it difficult to **understand** information about decisions

We have made a **toolkit** to help **staff** to help **patients** make **decisions**

We need to **test** the **toolkit** to check if it **works**



The **toolkit** is a **box** of different things for **staff** to use

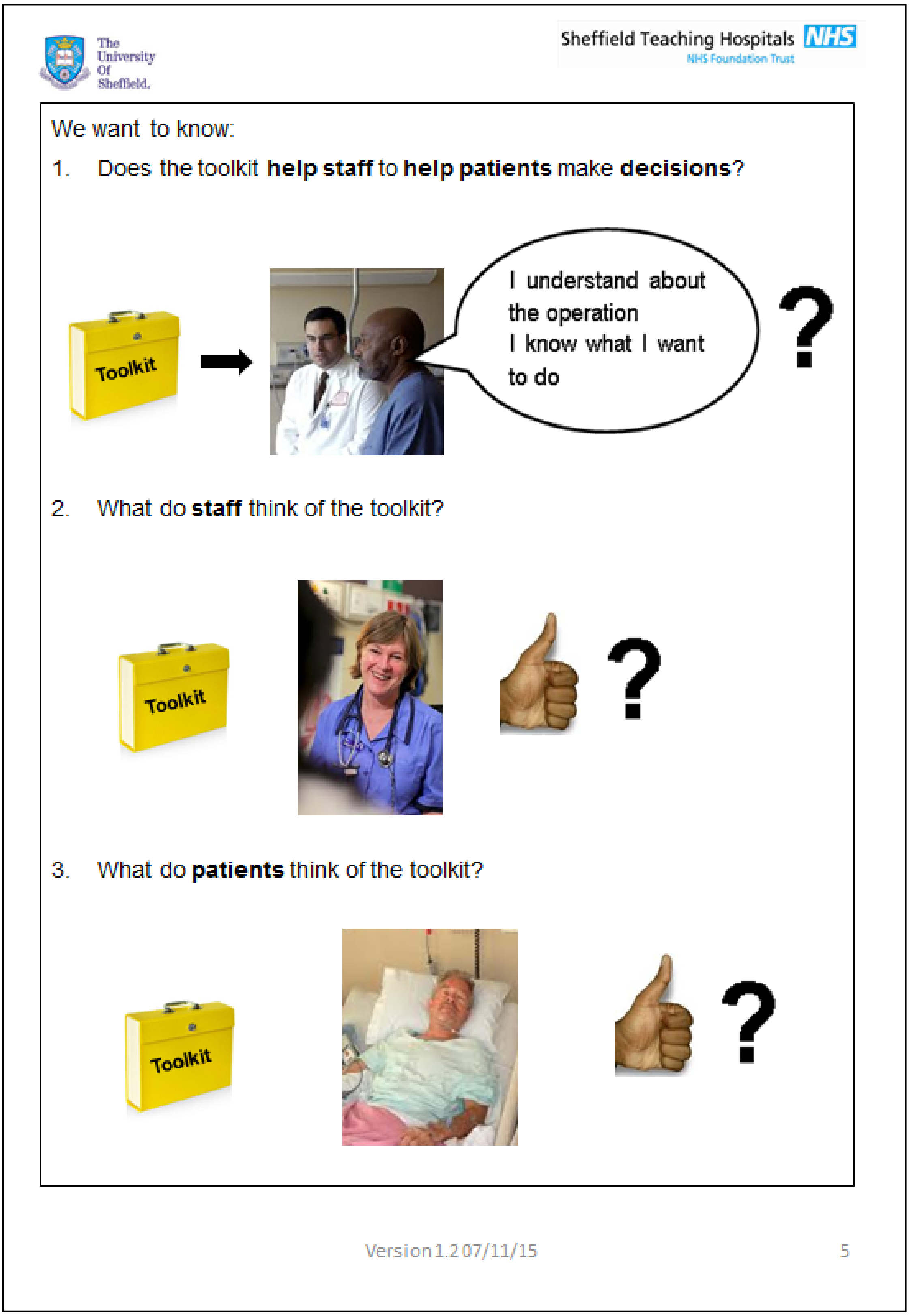
Staff will use the box when they talk to you about **decisions**

The box **contains**:

- **Forms** to help staff **check** if you can **make a decision**

- **Questions** for staff to ask you to check your **communication skills**

- **Photographs** and **words** to help staff **explain** things to you



We want to know:

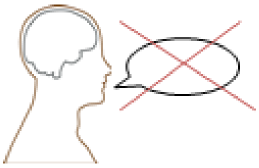
1. Does the toolkit **help staff** to **help patients** make **decisions**?

2. What do **staff** think of the toolkit?

3. What do **patients** think of the toolkit?

4. Why have I been chosen?

You **need** to make a **decision**



You may have **communication difficulties**

5. Do I have to take part?

No - it is **your choice**

If you choose to **take part**…

- we will give you **this information sheet** to keep
- we will ask you to sign a **consent form**
- you can still **leave** the study at **any time**
- if you leave, you **do not** need to give a **reason**

If you choose **not to take part**
or you want to **leave** the study…

- this will **not affect** your **rights** to any **health** or **voluntary services**
- if you leave **during** the study, we will still **use** any **information** you have already given us

6. **What will happen to me if I take part?**

We will tell your **doctor** that you are taking part

A member of the **hospital staff** will **talk** to you about a **decision** you need to make

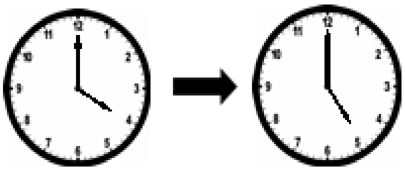
They will use the **toolkit** to help them do this

They may check your **communication skills** by asking you **questions**

They may **write** things down

They may show you **photographs** to **explain** things

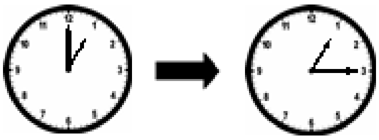
This should take up to **one hour**



Another member of **staff** may also visit you

They will check your **communication skills again** by asking you **questions**

This may take up to **15 minutes**



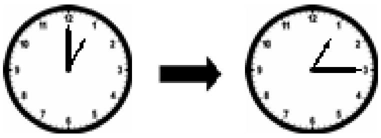
A **Research Speech and Language Therapist** will visit you in hospital

He is called **Mark Jayes**

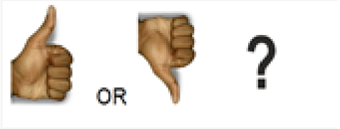
Mark will look in your **hospital notes**

Mark will check your **communication skills again** by asking you **questions**

This will take up to **15 minutes**

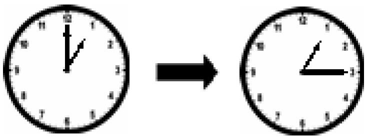


Mark may want to **ask you** about your **opinions** of the **toolkit**



You can choose to talk to **Mark** with someone from your **family** or a **friend**

This will take up to **15 minutes**

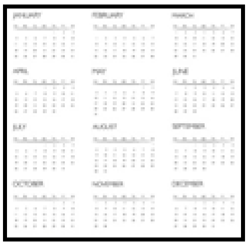


If you **agree** to talk to **Mark**, he will **record** your words on a **voice recorder**

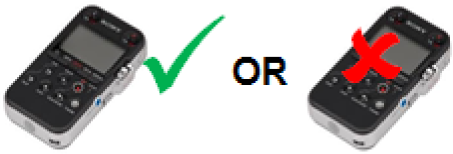
This is to help Mark **remember** what you say

Mark will keep the recording for **12 months**

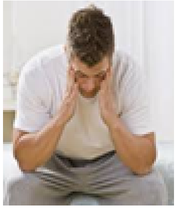
After this, Mark will **destroy** the **recording**



You **can choose not** to be **recorded**

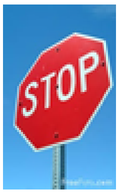


7. What are the possible disadvantages and risks of taking part?



You may find the **assessments** are **difficult**

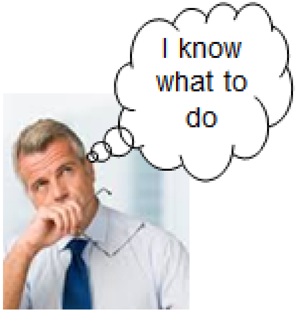
This might make you feel **tired** and **frustrated**



You can have **regular breaks** if you feel tired

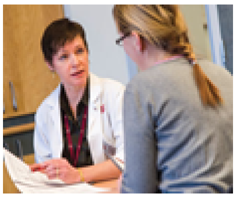
You can **stop** at any time if you want

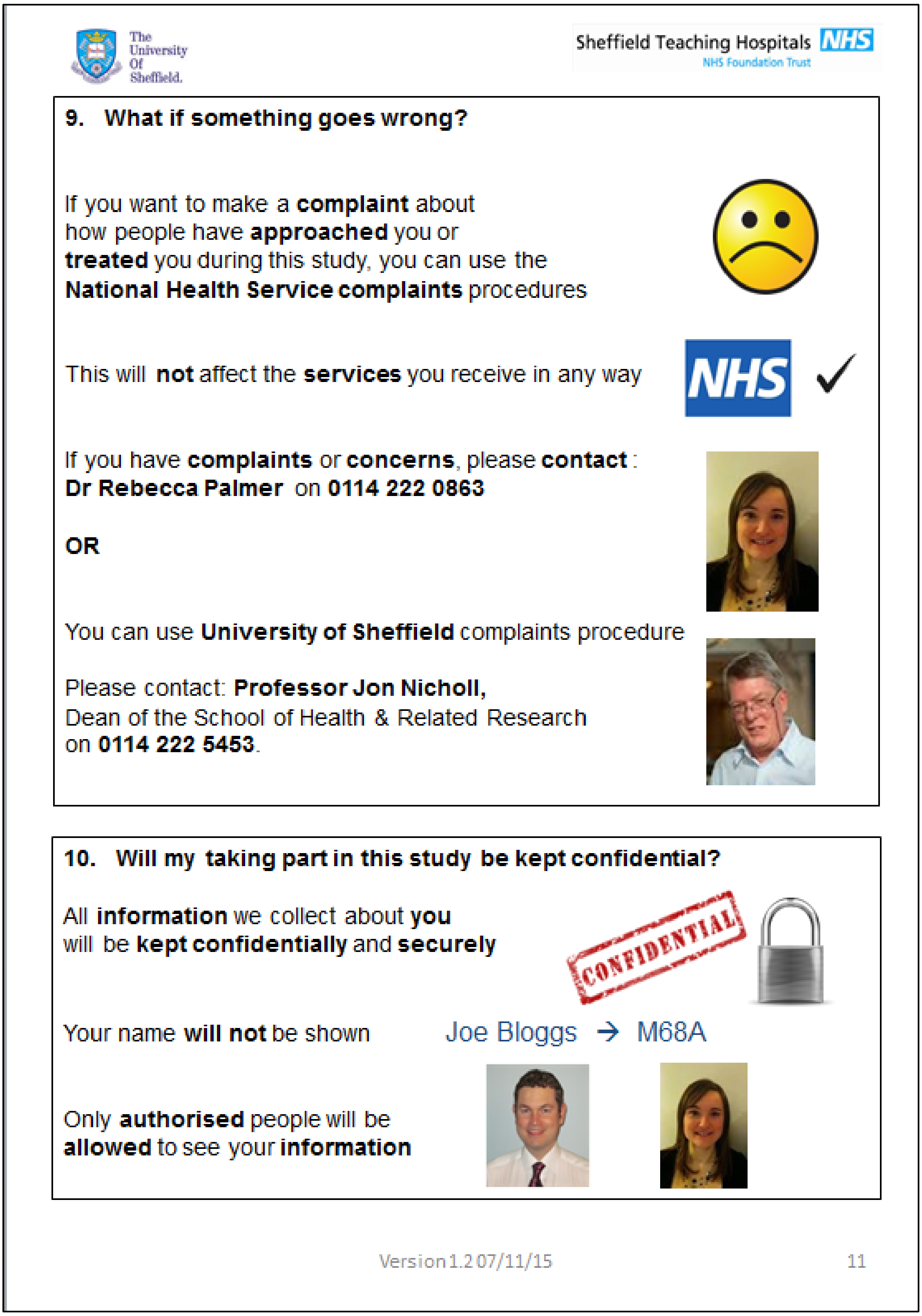
8. What are the possible benefits of taking part?



You may find it **easier** to make the **decision** you need to make at the moment

Hospital staff may be able to help **more patients** make **decisions**





9. What if something goes wrong?

If you want to make a **complaint** about
how people have **approached** you or
treated you during this study, you can use the
National Health Service complaints procedures

This will **not** affect the **services** you receive in any way

If you have **complaints** or **concerns**, please **contact** :
Dr Rebecca Palmer on **0114 222 0863**

OR

You can use **University of Sheffield** complaints procedure

Please contact: **Professor Jon Nicholl,**
Dean of the School of Health & Related Research
on **0114 222 5453**.

10. Will my taking part in this study be kept confidential?

All **information** we collect about **you**
will be **kept confidentially** and **securely**

Your name **will not** be shown

Joe Bloggs → M68A

Only **authorised** people will be
allowed to see your **information**

11. What will happen to the results of the research study?

The researchers will **publish** the **results** in **scientific journals**

The researchers will talk to **patients**, **NHS staff** and **researchers** about the **results**.

12. Who is organising and funding the research?

Sheffield Teaching Hospitals NHS Foundation Trust

and the **University of Sheffield**

are **organising** the research.

The **Department of Health** is **funding** the research (The National Institute for Health Research and Health Education England Clinical Doctoral Fellowship scheme).

13. Who has reviewed the study?

An **independent** group of people looks at **research** in the NHS

This is called a **Research Ethics Committee**

Bradford Leeds Research Ethics Committee has **reviewed** and **approved** this research study.

14. Who can I contact for further information?

If you have any **questions** regarding this study, please contact the **researcher**.

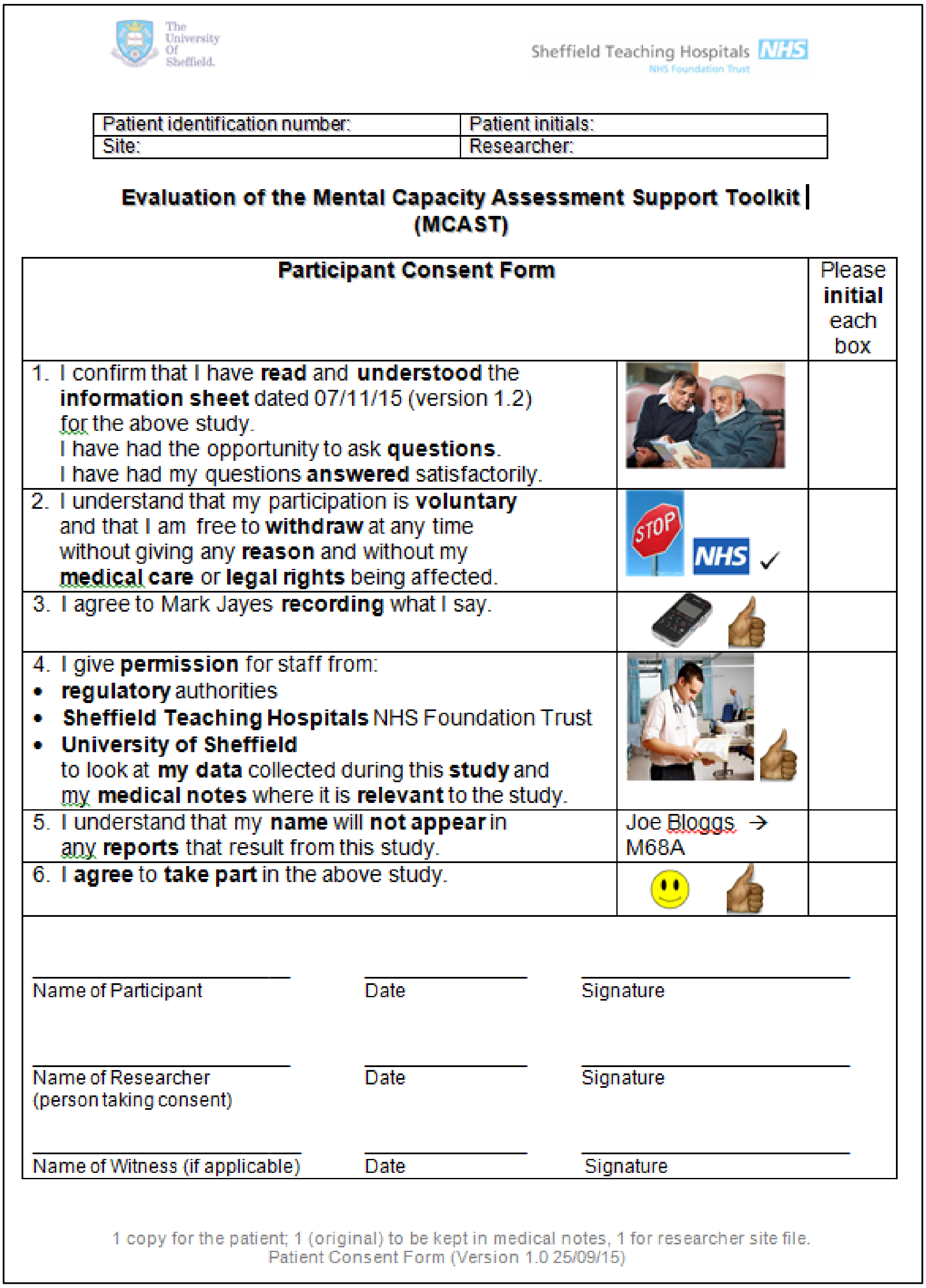
Mark Jayes

0114 222 5427

mark.jayes@sheffield.ac.uk

Thank you for reading about this study

Appendix 47: Feasibility study patient participant consent form (chapter 8)



The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Patient identification number:	Patient initials:
Site:	Researcher:

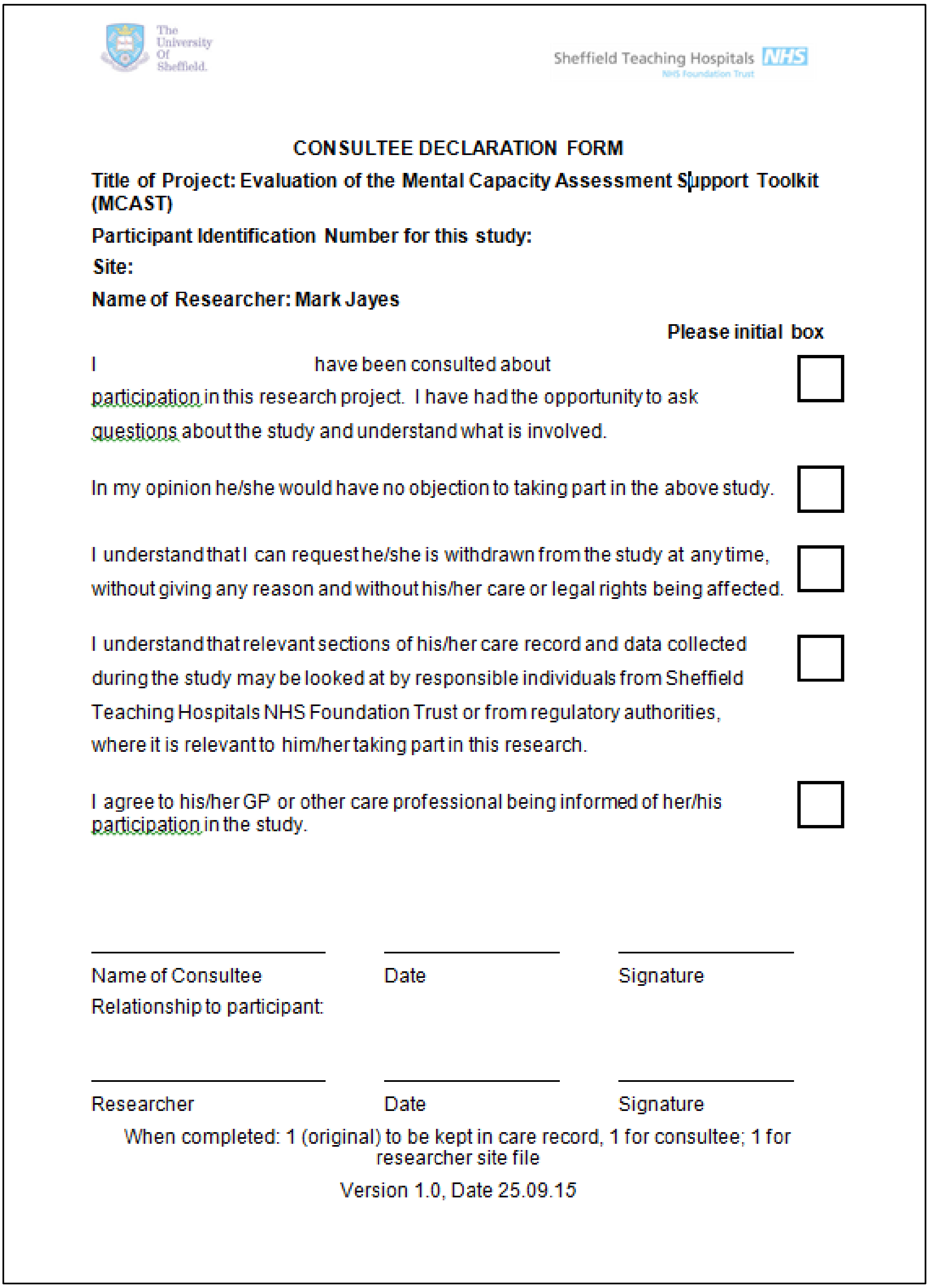
Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST)

Participant Consent Form		Please **initial** each box
1. I confirm that I have **read** and **understood** the **information sheet** dated 07/11/15 (version 1.2) for the above study. I have had the opportunity to ask **questions**. I have had my questions **answered** satisfactorily.		
2. I understand that my participation is **voluntary** and that I am free to **withdraw** at any time without giving any **reason** and without my **medical care** or **legal rights** being affected.		
3. I agree to Mark Jayes **recording** what I say.		
4. I give **permission** for staff from: • **regulatory** authorities • **Sheffield Teaching Hospitals** NHS Foundation Trust • **University of Sheffield** to look at **my data** collected during this **study** and my **medical notes** where it is **relevant** to the study.		
5. I understand that my **name** will **not appear** in any **reports** that result from this study.	Joe Bloggs → M68A	
6. I **agree** to **take part** in the above study.		

Name of Participant	Date	Signature
Name of Researcher (person taking consent)	Date	Signature
Name of Witness (if applicable)	Date	Signature

1 copy for the patient; 1 (original) to be kept in medical notes, 1 for researcher site file.
Patient Consent Form (Version 1.0 25/09/15)

Appendix 48: Feasibility study consultee declaration (chapter 8)



The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

CONSULTEE DECLARATION FORM

Title of Project: Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST)

Participant Identification Number for this study:

Site:

Name of Researcher: Mark Jayes

Please initial box

I have been consulted about participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved. ☐

In my opinion he/she would have no objection to taking part in the above study. ☐

I understand that I can request he/she is withdrawn from the study at any time, without giving any reason and without his/her care or legal rights being affected. ☐

I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from Sheffield Teaching Hospitals NHS Foundation Trust or from regulatory authorities, where it is relevant to him/her taking part in this research. ☐

I agree to his/her GP or other care professional being informed of her/his participation in the study. ☐

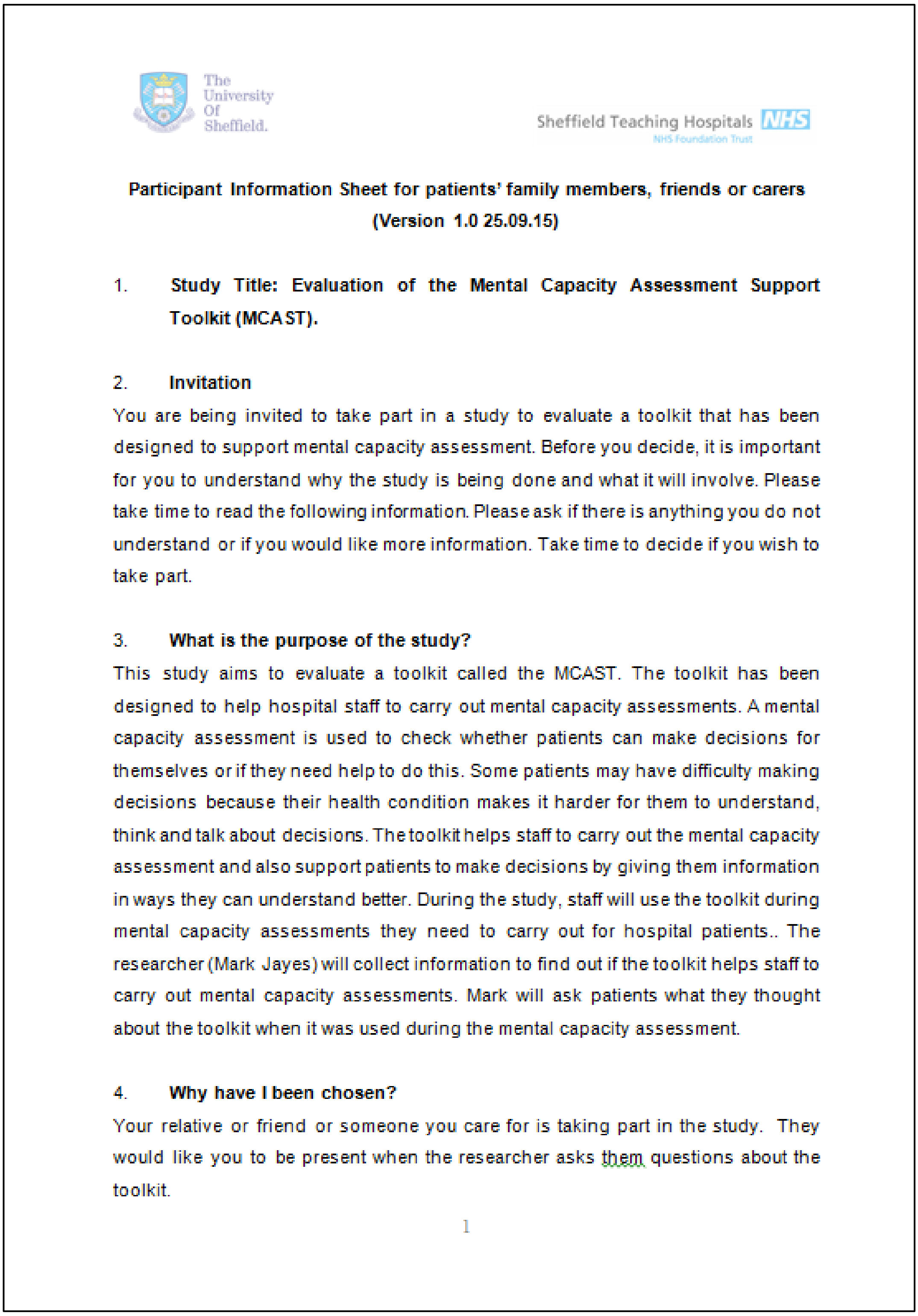
Name of Consultee Relationship to participant:	Date	Signature
Researcher	Date	Signature

When completed: 1 (original) to be kept in care record, 1 for consultee; 1 for researcher site file

Version 1.0, Date 25.09.15

Appendix 49: Feasibility study family carer participant information sheet

(chapter 8)



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Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Participant Information Sheet for patients' family members, friends or carers
(Version 1.0 25.09.15)

1. Study Title: Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST).

2. Invitation

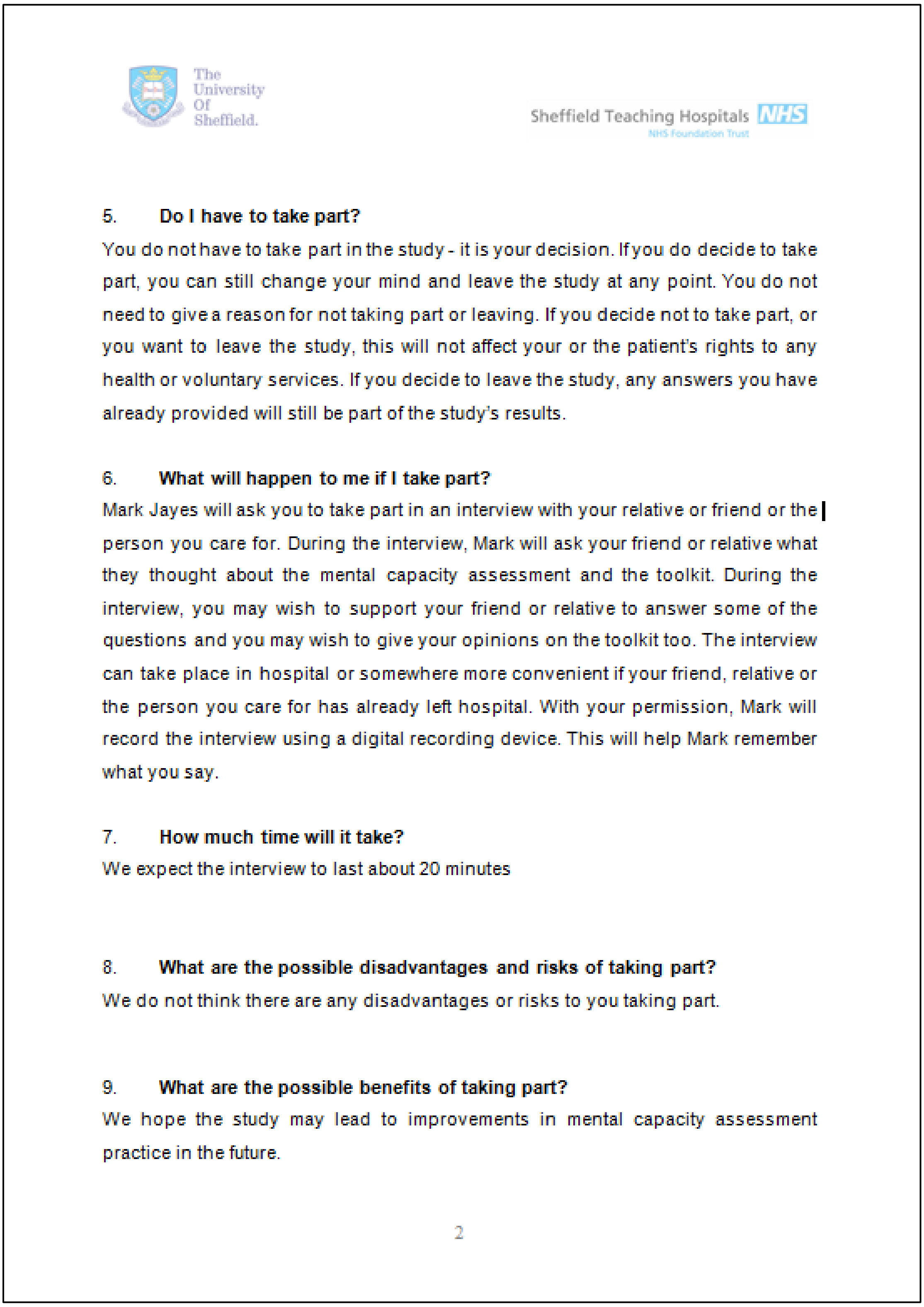
You are being invited to take part in a study to evaluate a toolkit that has been designed to support mental capacity assessment. Before you decide, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information. Please ask if there is anything you do not understand or if you would like more information. Take time to decide if you wish to take part.

3. What is the purpose of the study?

This study aims to evaluate a toolkit called the MCAST. The toolkit has been designed to help hospital staff to carry out mental capacity assessments. A mental capacity assessment is used to check whether patients can make decisions for themselves or if they need help to do this. Some patients may have difficulty making decisions because their health condition makes it harder for them to understand, think and talk about decisions. The toolkit helps staff to carry out the mental capacity assessment and also support patients to make decisions by giving them information in ways they can understand better. During the study, staff will use the toolkit during mental capacity assessments they need to carry out for hospital patients.. The researcher (Mark Jayes) will collect information to find out if the toolkit helps staff to carry out mental capacity assessments. Mark will ask patients what they thought about the toolkit when it was used during the mental capacity assessment.

4. Why have I been chosen?

Your relative or friend or someone you care for is taking part in the study. They would like you to be present when the researcher asks them questions about the toolkit.



5. Do I have to take part?

You do not have to take part in the study - it is your decision. If you do decide to take part, you can still change your mind and leave the study at any point. You do not need to give a reason for not taking part or leaving. If you decide not to take part, or you want to leave the study, this will not affect your or the patient's rights to any health or voluntary services. If you decide to leave the study, any answers you have already provided will still be part of the study's results.

6. What will happen to me if I take part?

Mark Jayes will ask you to take part in an interview with your relative or friend or the person you care for. During the interview, Mark will ask your friend or relative what they thought about the mental capacity assessment and the toolkit. During the interview, you may wish to support your friend or relative to answer some of the questions and you may wish to give your opinions on the toolkit too. The interview can take place in hospital or somewhere more convenient if your friend, relative or the person you care for has already left hospital. With your permission, Mark will record the interview using a digital recording device. This will help Mark remember what you say.

7. How much time will it take?

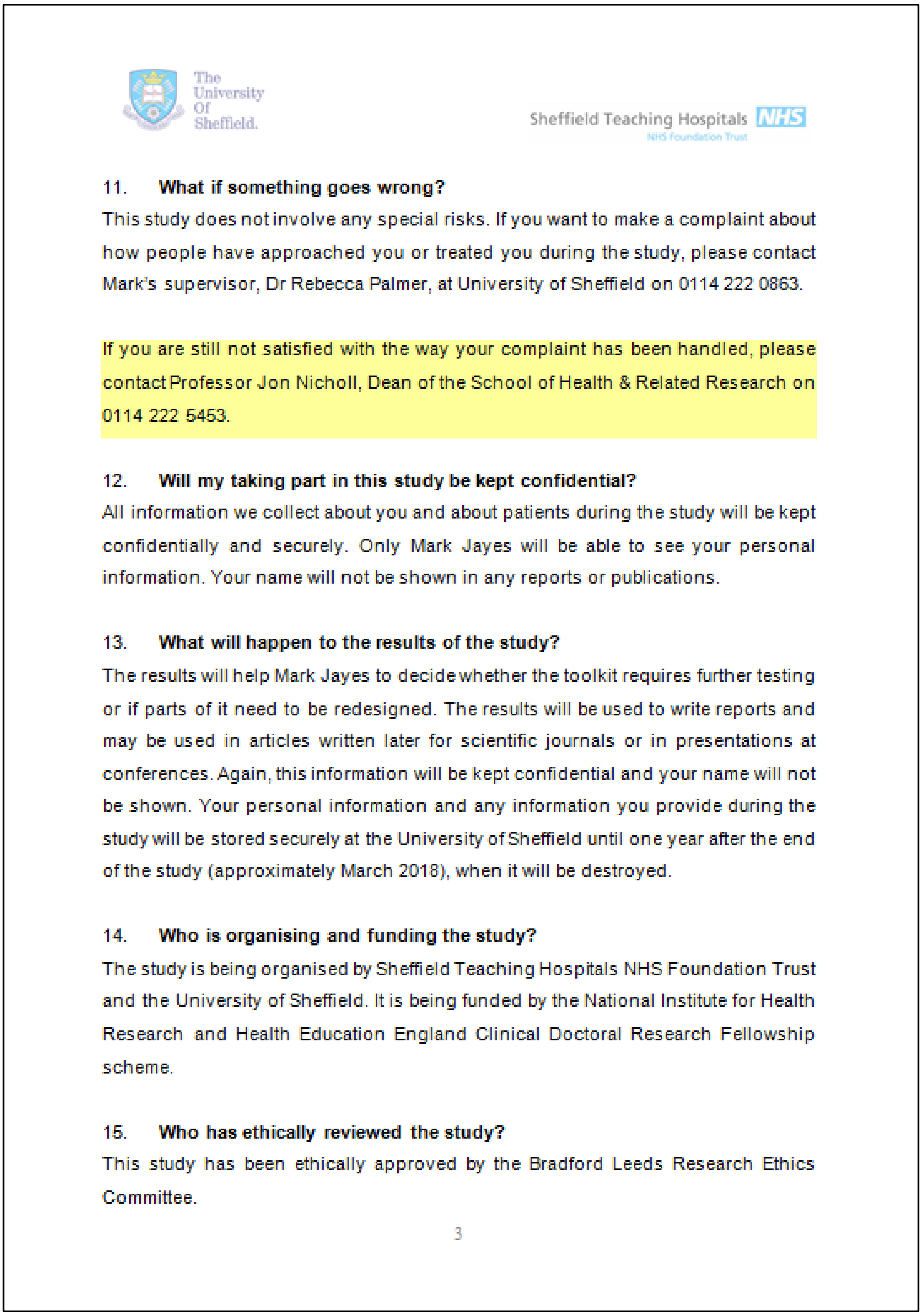
We expect the interview to last about 20 minutes

8. What are the possible disadvantages and risks of taking part?

We do not think there are any disadvantages or risks to you taking part.

9. What are the possible benefits of taking part?

We hope the study may lead to improvements in mental capacity assessment practice in the future.



11. What if something goes wrong?

This study does not involve any special risks. If you want to make a complaint about how people have approached you or treated you during the study, please contact Mark's supervisor, Dr Rebecca Palmer, at University of Sheffield on 0114 222 0863.

If you are still not satisfied with the way your complaint has been handled, please contact Professor Jon Nicholl, Dean of the School of Health & Related Research on 0114 222 5453.

12. Will my taking part in this study be kept confidential?

All information we collect about you and about patients during the study will be kept confidentially and securely. Only Mark Jayes will be able to see your personal information. Your name will not be shown in any reports or publications.

13. What will happen to the results of the study?

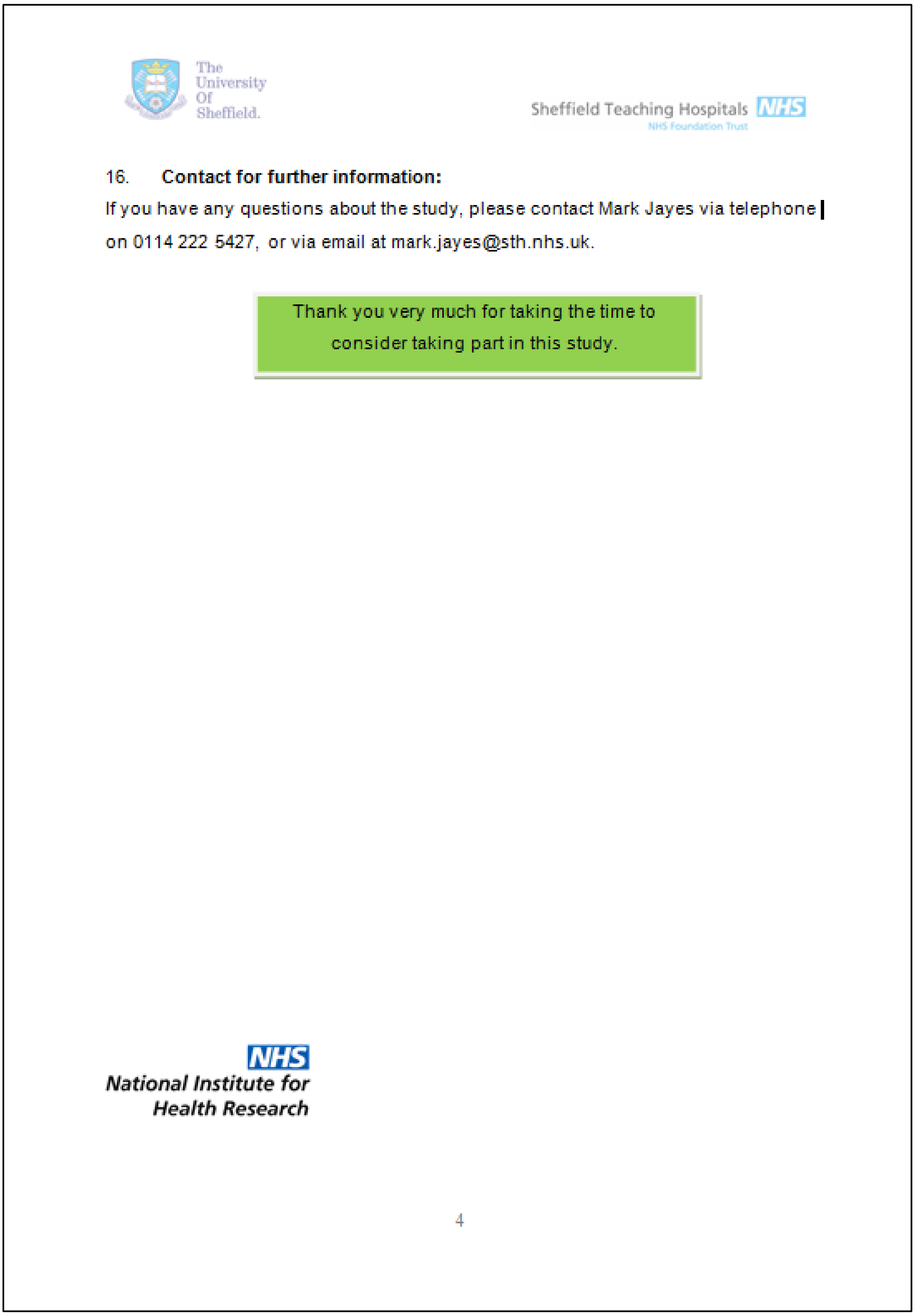
The results will help Mark Jayes to decide whether the toolkit requires further testing or if parts of it need to be redesigned. The results will be used to write reports and may be used in articles written later for scientific journals or in presentations at conferences. Again, this information will be kept confidential and your name will not be shown. Your personal information and any information you provide during the study will be stored securely at the University of Sheffield until one year after the end of the study (approximately March 2018), when it will be destroyed.

14. Who is organising and funding the study?

The study is being organised by Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. It is being funded by the National Institute for Health Research and Health Education England Clinical Doctoral Research Fellowship scheme.

15. Who has ethically reviewed the study?

This study has been ethically approved by the Bradford Leeds Research Ethics Committee.



The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

16. **Contact for further information:**

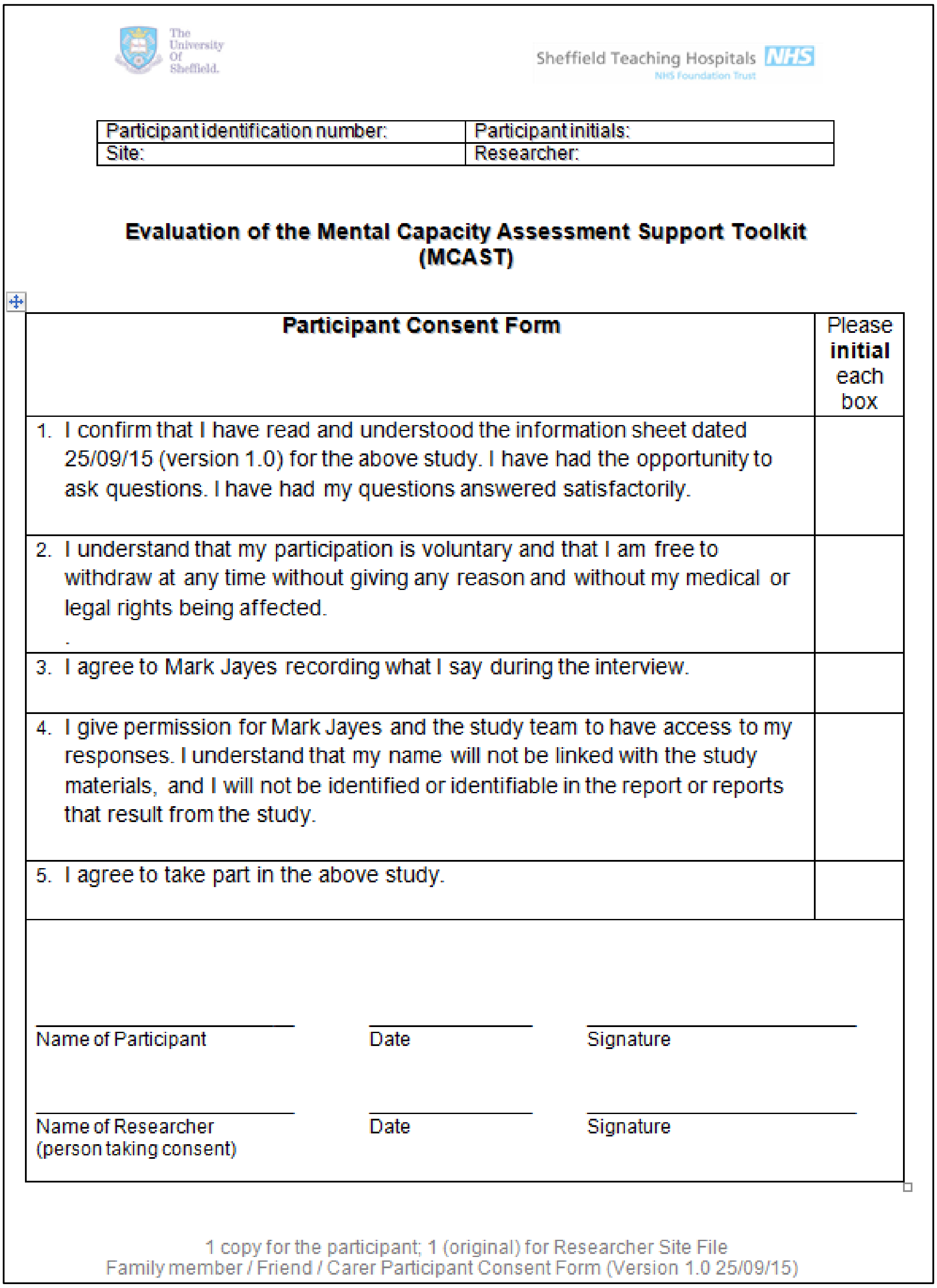
If you have any questions about the study, please contact Mark Jayes via telephone on 0114 222 5427, or via email at mark.jayes@sth.nhs.uk.

Thank you very much for taking the time to consider taking part in this study.

NHS
National Institute for Health Research

4

Appendix 50: Feasibility study family carer participant consent form (chapter 8)



The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Participant identification number:	Participant initials:
Site:	Researcher:

Evaluation of the Mental Capacity Assessment Support Toolkit (MCAST)

Participant Consent Form	Please **initial** each box
1. I confirm that I have read and understood the information sheet dated 25/09/15 (version 1.0) for the above study. I have had the opportunity to ask questions. I have had my questions answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical or legal rights being affected. .	
3. I agree to Mark Jayes recording what I say during the interview.	
4. I give permission for Mark Jayes and the study team to have access to my responses. I understand that my name will not be linked with the study materials, and I will not be identified or identifiable in the report or reports that result from the study.	
5. I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of Researcher (person taking consent)	Date	Signature

1 copy for the participant; 1 (original) for Researcher Site File
Family member / Friend / Carer Participant Consent Form (Version 1.0 25/09/15)

Appendix 51: Example of convergent coding matrix (chapter 8)

Data collection source **Key finding**	**Document analysis**	**Communication Screening Tool Reliability and Validity data**	**Case note Audit**	**Confidence survey**	**Usability Survey**	**Patient / carer interviews**	**Researchers reflective journal / field notes**
Improved content of Assessment	Staff did not always use Support Tool or Screening Tool as intended	Staff did not use the tool to screen 4/13 patients who had a communication disorder. Spoken Comprehension subtest criterion validity was poor, inter-rater reliability was fair.	Significant improvement in audit scores after using MCAST	Staff reported their assessments were more thorough and robust	Staff reported their assessments were more thorough and robust	Silent	Silent
Improved documentation	Staff did not always complete Support Tool fully	Silent	Significant improvement in audit scores after using MCAST	Silent	Staff reported that using the MCAST enabled them to document clearly and reliably.	Silent	Silent