From Policy to Practice: Exploring Health and Social Care Practitioners' Experiences of Mental Capacity Legislation

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Contents

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Chapter 1 (including references): 6,209

Chapter 2 (including references): 7,929

Appendices: 7,245

Total: 22,016

Introductory Chapter

Thesis Overview

The overall aim of this thesis was to better understand the clinical utility of mental capacity legislation in health and social care practice. It has been estimated that approximately two million people living in England and Wales will at some point lack the mental capacity to make specific decisions about their care and treatment because of injury, disability, or illness (NICE, 2018). The Mental Capacity Act (MCA; 2005) provides a legal decision-making framework to protect and empower individuals in such circumstances. In 2007, the Deprivation of Liberty Safeguards (DoLS) were introduced as an amendment to the MCA. The aim of DoLS was to protect vulnerable individuals who lack capacity to make decisions about their care and residence whilst also preventing any decisions that may inappropriately restrict their freedom (Lennard, 2015). Since the implementation of the MCA there have been concerns highlighted in its post-legislative scrutiny report (House of Lords, 2014) that it has not been sufficiently embedded into the heart of health and social care practice as was originally intended. DoLS, particularly, have received many criticisms regarding their application and complexity (Blamires et al, 2017). Exploring the use of MCA and DoLS in health and social care practice is an important avenue of research to inform policy, practice and more importantly ensure the protection of peoples' rights and safety.

The first chapter of this thesis is a systematic review. The review aimed to explore qualitative research on practitioners' knowledge and experiences of the MCA in health and social care settings. This was the first known systematic review conducted in this area. Findings offer insight into the positive aspects and challenges of implementing the MCA in practice, enhancing current understandings, and offering recommendations for practice improvements. This review has been accepted for publication in 'The Journal of Adult Protection' (appendix A). The journal was selected for its niche focus on the development of safeguarding across all adult service-user groups.

The second chapter in this thesis is an empirical grounded theory study. There has been no previous research exploring the use of DoLS when applied to individuals with an Acquired Brain Injury (ABI). Given that research and policy have emphasised concerns around the use of DoLS (House of Lords, 2014; Blamires et al, 2017) and given the complexity of difficulties that individuals with a brain injury can present with e.g. physical, cognitive, and emotional difficulties (Fleminger and Ponsford, 2005), it is important that this gap in research is addressed. As such, this study aimed to develop a model to enhance understanding of the DoLS decision-making process from the perspective of health and social care practitioners when applied to brain injury survivors. Findings offer insight into the use of DoLS in those with an ABI and raise concerns about the reliability of the decision-making process for this client group. This study was submitted to the journal of 'Ethics and Social Welfare'. The journal was selected for its focus on critical and reflective articles surrounding ethical issues in social welfare practice and policy (appendix B).

References

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Chapter 1

Practitioners’ Experiences and Knowledge of the Mental Capacity Act (MCA)

Abstract

Purpose – The Mental Capacity Act (MCA, 2005) provided a new legal framework for decision making practice in England and Wales. This systematic review explored qualitative research on practitioners’ knowledge and experiences of the MCA in health and social care settings to inform practice and policy.

Design/methodology/approach – Four electronic databases and Google Scholar were searched in November 2019 for peer-reviewed, qualitative, English language studies exploring practitioners’ experiences and knowledge of the MCA in health and social care settings. Nine studies were included and appraised for methodological quality. Data was analysed using thematic synthesis.

Findings – Data revealed both positive aspects and challenges of applying the MCA in practice within five main themes: travelling the ‘grey line’, the empowering nature of the MCA, doing the assessment justice, behaviours and emotional impact, and, knowledge gaps and confidence.

Practical Implications – The fundamental principles of the MCA appear to be adhered to and embedded in practice. However, practitioners find mental capacity work remains challenging in its uncertainties. Whilst calling for more training, practitioners may also benefit from further MCA skills development and support to increase confidence and reduce apprehension.

Originality/value – This is the first systematic review to synthesise qualitative literature on practitioners' experiences and knowledge of the MCA. Findings offer insight into practice experiences of the MCA and provide a basis for the development of training and supervisory support.

Introduction

The Mental Capacity Act (MCA; 2005), fully implemented in England and Wales in 2007, provides a legal framework to support individuals (age 16 and over) when their capacity to make specific decisions is impaired. The Act defines procedures that must be followed when supporting people to make decisions and when making decisions on their behalf. The fundamental principle of the Act is to empower individuals to make their own decisions wherever possible, whilst also protecting those who lack decision-making capacity (Jones, 2010). The latter is achieved by keeping the individuals' past and present beliefs/values at the centre of the decision-making process, and, where necessary, to make 'best interest' decisions on their behalf. It also makes provision for the criminalisation of abuse and mistreatment of service users (Department for Constitutional Affairs, 2007). The Act covers a broad range of social, welfare, financial and healthcare decisions, and arrangements. It spans everyday decisions (e.g. managing finances) as well as major decisions (e.g. moving home and end-of-life care [Chapman and Makin, 2011]) and sets out the framework for proxy appointments and advance decisions.

Prior to the MCA, decisions made on behalf of individuals lacking capacity were often inconsistent, paternalistic, subjective, and risk-averse (Jenkins and Williamson, 2012), and thus failed to support the rights of vulnerable individuals (Nazarko, 2004). The MCA was celebrated as ‘a visionary piece of legislation for its time, which marked a turning point in the statutory rights of people who may lack capacity’ (House of Lords, 2014, pg. 6).

The MCA is relevant to many health and social care practitioners (Johnstone and Liddle, 2007). Although it was welcomed, research has subsequently highlighted some challenges with interpretation and application in practice. In its post-legislative scrutiny report of the MCA, the House of Lords (2014) concluded that the MCA was not working as envisioned and that numerous barriers prevented the Act from being delivered as intended. These barriers included: lack of understanding and awareness about the Act and the MCA being used as an ‘add on’ rather than being central to practice. It concluded that the empowering ethos and rights conferred by the Act were not being realised and suggested that a ‘lack of central ownership’ of the Act may account for such failures.

Several studies explored a range of practitioners’ knowledge and experiences of the MCA prior to and just following implementation (mostly in 2007). Common observations include lack of training and knowledge of the MCA. For instance, quantitative research in emergency healthcare, found that a third of survey respondents gave incorrect answers to questions about capacity even after undertaking MCA training (Evans et al, 2007). In the area of learning disability services, Skinner et al, (2011) reported case study complexities in decision making and capacity assessment. Others, commenting on early implementation, found variable knowledge of what should trigger an assessment of capacity and some misuse of the Act in its very early days (Myron et al, 2007). Other potential difficulties of implementation, such as heavy workloads and lack of resources, were noted by Jones (2005), and in a commentary by Shickle (2006). More recent quantitative research utilising questionnaire data has reported variable knowledge of MCA assessment within a learning disability population (Chapman et al, 2019).

Understanding of MCA related practice may be informed by systematic qualitative synthesis of the evidence. Whilst quantitative findings are important, a synthesis of qualitative research has the potential to offer an in-depth understanding of practice experiences and thus contribute to the development of continuing professional development (CPD), practice education, policy, and practice. This is pivotal to ensure the protection of individuals' rights and safety.

Aims

This review aimed to systematically identify research that explored health and social care practitioners' knowledge and experiences of the MCA. The review addressed the question, 'what are health and social care professionals' experiences and knowledge of the MCA in an adult clinical population?'

Method

Protocol and registration

This review followed the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) guidelines (Tong and Flemming, 2012). The review protocol was pre-registered with the PROSPERO database for systematic reviews (CRD42019124738).

Search strategy

Systematic literature searches took place in November 2019. Searches were updated in March 2020 and an additional Google Scholar search was conducted to ensure that any eligible, recent articles were identified.

Specialist library services helped with searching: PSYCHINFO, EMBASE, CINAHL and EMCARE. The following search terms were applied to each database: (“mental capacity” OR “mental capacity act” OR “mental capacity assessment”) AND (knowledge OR experience* OR understand* OR view* OR perspective* OR apply* OR application* OR implement*). Date limits (in line with the full implementation of the MCA in 2007) were applied from 2007-2020. See appendix C for an example search strategy.

Experts in the field were contacted (see appendix D) and citation chaining (forwards and backwards) was utilised to identify additional eligible publications. The Cochrane library and PROSPERO database were searched to identify existing or anticipated relevant reviews. Endnote software was used to organise the articles, remove duplicates, and support the screening process.

Inclusion and exclusion criteria

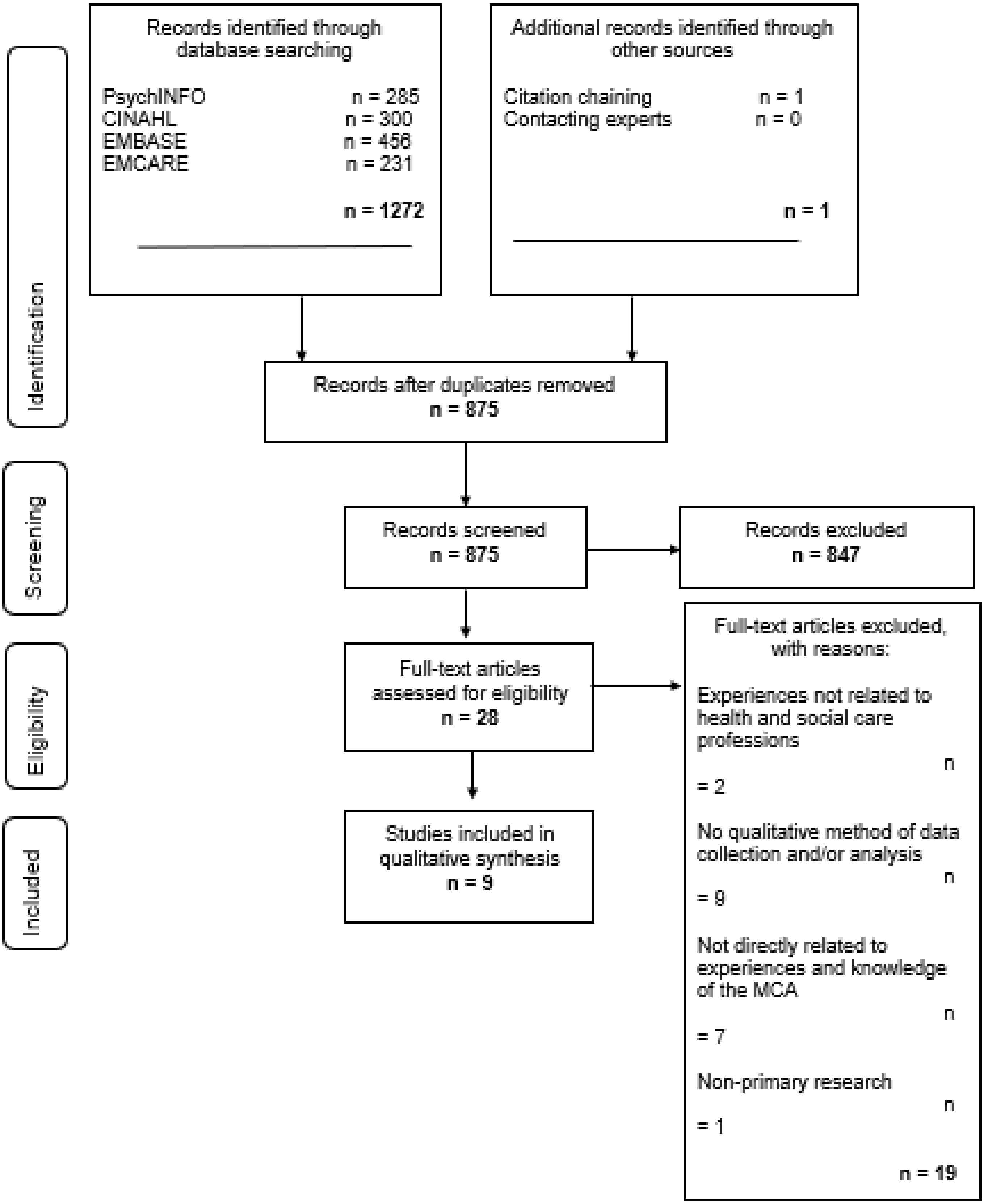
The following inclusion criteria were applied: (a) research published in peer-reviewed journals; (b) research published from 2007 when the majority of the MCA came into force; (c) English language papers; (d) qualitative methods of data collection and analysis (may include a discrete part of a larger-mixed method study) and (e) research relating to experiences and/or knowledge of the MCA in practice.

Articles were excluded that were: (a) quantitative research only; (b) mixed-method studies with limited qualitative data; (b) studies which investigate experiences/knowledge of non-health and social care practitioners, e.g. carer perspectives; (c) studies focusing on specific elements of the MCA only, e.g. Deprivation of Liberty Safeguards; and (d) non-peer reviewed articles.

Study Selection

The search yielded 1,272 articles (PsychINFO, 285; CINAHL, 300; EMBASE, 456; EMCARE, 231). Following the removal of duplicates, 875 papers remained. To ensure trustworthiness of the review findings, two researchers (JS; MM) independently screened both abstracts/ titles (n = 875) and full papers (n = 28) against the inclusion/exclusion criteria. Disagreements were discussed (e.g. around the inclusion of an audit) and where necessary the opinion of the wider team was sought. Thus, nine papers were included in this review (see figure 1).

Figure 1. Flow Diagram showing identification of papers [Adapted from: Moher et al, (2009).]



Quality assessment

The Critical Appraisal Skills Programme (CASP, 2014) tool for qualitative research (See appendix E) was used to appraise study quality. This 10-question protocol was selected as it is commonly used in health and social care research and aims to capture the main principles of research: credibility, rigour, and relevance (Spencer and Ritchie, 2012). Although no formal scoring system is included in the CASP, the following frequently used scoring system was applied (as with, e.g. Butler et al, 2016); item not met= 0 (no), item partially met= 1 (unsure), item fully met= 2 (yes). The use of this scoring system supported critical reflection.

No papers were excluded on quality grounds as we did not want to limit the development of potential new insights. Instead, use of the CASP provided an overview of strengths and limitations of insights. Nonetheless, studies with lower scores were reviewed to see if they altered the synthesis outcome – they did not, as similar themes emerged across both low- and high-quality studies. All studies included in the review constitute valuable research. Table 1 provides an overview of the scores of each individual study. Quality is reflected upon further in the results section of this article.

Table 1: Quality appraisal-based on the CASP tool

Authors	*Aims*	*Methodology*	*Design*	*Recruitment*	*Data collection*	*Researcher bias*	*Ethical Issues*	*Data analysis*	*Findings*	*Valuable*	*Score /20*
Samsi et al, (2011)	Yes	Yes	Yes	Unsure	Yes	No	Yes	Unsure	Yes	Yes	16
Walji et al, (2014)	Yes	Yes	Yes	Unsure	Unsure	Yes	Unsure	Yes	Yes	Yes	17
Ratcliff and Chapman, (2016)	Yes	Yes	Unsure	Unsure	Yes	No	Unsure	Unsure	Yes	Yes	14
Jayers et al., (2017)	Yes	Yes	Yes	Yes	Yes	Unsure	Unsure	Unsure	Yes	Yes	17
Cliff and McGraw, (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	17
Marshall and Sprung, (2016)	Yes	Yes	Yes	Yes	Yes	No	Unsure	Unsure	Yes	Yes	16
Wilson et al, (2010)	Yes	Yes	Unsure	Unsure	Unsure	No	Unsure	Unsure	Yes	Yes	13
Murrell and McCalla, (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	20
Manthorpe et al, (2011)	Yes	Yes	Unsure	Unsure	Yes	No	Unsure	Unsure	Yes	Yes	14

Data extraction and synthesis

To ensure consistency among reviewers and researchers, descriptive data were extracted based on the Joanna Briggs Institute Qualitative Data Extraction Tool (Table 2). Thomas and Harden (2008) regard thematic synthesis as a method of conducting "*systematic reviews that address questions about peoples' perspectives and experiences*" (pg. 46). This technique was selected as it is slightly more integrative than other approaches; an output based on an approach that is more integrative (rather than interpretative) was felt relevant to policy makers and clinicians, particularly given that more interpretative synthesis methods e.g. meta-ethnography produce more complex and conceptual outputs that require a level of interpretation (Boland et al, 2017).

Thematic Synthesis draw on methods from both grounded theory and meta-ethnography to develop descriptive and analytic themes that 'go beyond' original findings and generate new constructs. In line with this technique, data labelled as 'findings' and 'results' were extracted for analysis (including both primary data and author interpretations). The synthesis consisted of three stages. The first stage involved line-by-line coding with the aim of capturing the "meaning and content of each sentence" (Thomas and Harden, 2008, pg. 49). Following this, similarities and differences between the codes were examined, enabling the identification of *descriptive themes* both within and across studies. Finally, these themes were grouped and discussed with the supervisory team to develop overarching *analytical themes* (see appendix F for an example of how the theme of 'The Empowering

Nature of MCA' was developed). The first author completed all stages of the analysis, facilitated by discussions with the wider team.

Table 2: Data extraction for included studies

Author(s) Year	*Method*	*Phenomena*	*Setting*	*Geography*	*Participant characteristics*	*Sampling method*	*Analysis*	*Conclusions*
Samsi et al, (2011)	Qualitative semi-structured interviews	Community nurses' experiences of the MCA with people with dementia.	Clinical: Community dementia services	North London, England	N=15, diversity: White British=7; Black British=3; Chinese=3; Asian=2	Convenience sampling	Thematic analysis (Braun & Clarke, 2006)	Not all 'participants felt confident using the MCA & would benefit from further practice & training. MCA was empowering and supports safeguarding.
Walji et al, (2014)	Qualitative interviews	Clinical Psychologists experiences of implementing the MCA.	Clinical: ABI & older adult	North West England	N=7, diversity: not reported	Not reported	Thematic analysis (Braun & Clarke, 2006)	Psychological training & values support MCA implementation despite difficulties around uncertainty, lack of confidence, challenges & conflicts.
Ratcliff and Chapman, (2016)	Qualitative semi-structured interviews.	Health & Social Practitioners experiences of undertaking MCA assessments with people with learning disabilities.	Clinical: community learning disability team	Not reported	N=8, diversity: not reported	Not reported	Thematic network analysis	Organisational, systemic and person-specific factors impacted on the quality of and on the confidence of participants MCA assessments.
Jayes et al, (2017)	Qualitative focus group interviews.	MDT staff experiences of MCA assessment in acute hospital and intermediate care settings.	Clinical: acute hospital & intermediate care (neurology, stroke, older adult)]	North of England	N=13, diversity: not reported	Purposive sampling	Thematic analysis using framework approach	Participants found MCA assessments complex & challenging.

Cliff and McGraw, (2016)	Qualitative, semi-structured interviews.	Non-medical health care practitioners' experiences of MCA assessments in home health care settings.	Clinical: home health care settings	One NHS Trust in London	N=14, diversity: not reported	Purposive sampling	Thematic analysis (Braun & Clarke, 2006)	Family members, practitioner-patient relationships and distance from co-workers increase the complexity of MCA assessments.
Marshall and Sprung, (2016)	Mixed-methods including focus group and paired-interviews.	Community nurses' experiences of using the MCA in clinical practice.	Clinical: community	Not reported	N=7 for focus group, N=2 for paired interviews, diversity: not reported	Snowball & volunteer sample	Content analysis	Study identified examples of self-appraised confidence & excellent patient care, but there was scope for developing knowledge and utilisation of MCA in practice.
Wilson et al, (2010)	Qualitative Interviews & focus groups	Staff knowledge of MCA, capacity and documentation processes.	Clinical: six specialised units (three neurological, 2 palliative care).	Not reported	N=26, diversity: not reported	Purposive sample	Framework analysis	Participants had a good understanding of capacity issues but were unclear about some aspects of the MCA impacting on their confidence levels.
Murrell and McCalla, (2015)	Qualitative, semi-structured interviews.	Exploring how capacity assessments are being carried out in practice.	Clinical: Health & Social care teams (specifics not reported)	South West England	N=6, diversity: not reported	Purposive sample	Theoretical thematic analysis	The interpretation of the MCA and MCA assessments vary. Assessing capacity is complex.
Manthorpe et al, (2011)	Qualitative, semi-structured interviews.	Staff challenges with MCA in practice with people with dementia and professional expectations regarding using the MCA.	Clinical: five dementia care homes.	Southern England	N=32, diversity: White British, African Caribbean, Mainland Europe	Not reported	Thematic analysis (Braun & Clarke, 2006)	Regardless of lack of knowledge around the MCA, the daily working ethos of staff appeared to be within the remit of the MCA.

Results

Five over-arching themes and 14 sub-themes regarding participants' knowledge and experience of the MCA were identified: 1) Travelling the 'grey line' (complexity of the MCA legislation, subjective nature of the MCA, person-specific challenges), 2) The empowering nature of the MCA (upholding human rights, magnifying person-centred care), 3) Doing the assessment justice (finding the appropriate practitioner with the relevant skills, enhancing capacity, importance of information gathering), 4) Behaviours and emotional impact (practitioners' feelings, avoidance and shifting responsibility, collaboration and consultation), 5) Knowledge gaps and confidence in practice (lack of knowledge, training dissatisfaction, variable confidence levels). These themes are displayed in table 3 and the distribution of these themes across all nine studies are displayed in Table 4. Illustrative quotes (both participant quotes and author interpretations) are displayed in Table 5. Please note that reference to 'papers' or 'participants' in the results section refers to the results of papers with author references.

Evaluation of quality

It is important to consider the quality of papers and their contributions to the evidence base when interpreting study findings. The CASP tool was used to assess the quality of included articles. CASP scores varied, ranging from 13-20/20 (see Table 1). All articles stated clear research aims which were assessed as appropriate for the use of qualitative methodology. Findings were clearly presented and were thought to constitute valuable research.

The most common methodological limitation was the lack of adequate consideration of the possible influence of the relationship between the researcher and participants and the absence of acknowledging the researchers' position (Samsi et al, (2011); Ratcliff and Chapman, (2016); Jayers et al, (2017); Cliff and McGraw, (2016); Marshall and Sprung, (2016); Wilson et al, (2010); Manthorpe et al, (2011)). Researcher bias e.g. assumptions and prejudices, may have therefore impacted on the process of data collection and subsequent findings of these articles. This may have affected the validity of the findings. Moreover, although all papers reported that approval had been sought from an ethics committee, six papers failed to expand further on the maintenance of ethical standards (Walji et al, (2014); Ratcliff and Chapman, (2016); Jayers et al, (2017); Marshall and Sprung, (2016); Wilson et al, (2010); Manthorpe et al, (2011)). For instance, there were no discussions around managing confidentiality and informed consent.

The variation in sample sizes across the studies may impact on the transferability of the findings. For instance, Manthorpe et al's (2011) study of 32 participants is likely to be more transferable than Murrell and McCalla's (2016) study of six participants. Subsequently, the impact of these articles may vary, which must be considered when interpreting the findings. Furthermore, CASP results are inevitably influenced by journal criteria. For instance, the lowest scoring paper (Wilson et al, 2010) was published in a journal with a 3,000-word limit, whereas the highest scoring paper (Murrell and McCalla, 2016) was published in a journal with a 7,000-word limit. CASP scores must therefore be considered with caution.

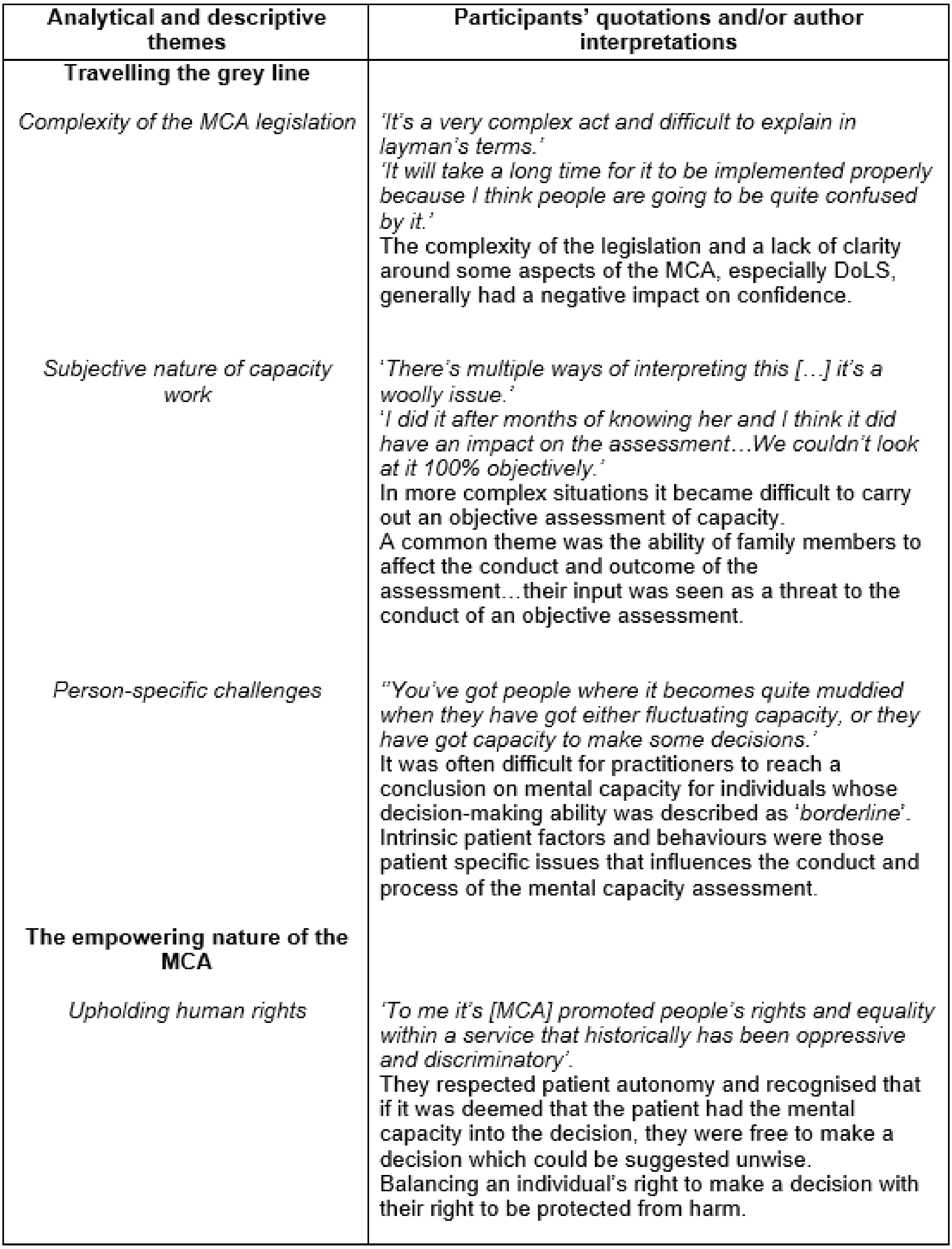
Table 3: Summary of analytical and descriptive themes

Analytical themes	Descriptive themes
Travelling the grey line	Complexity of the MCA Subjective nature of capacity work Person-specific challenges
The empowering nature of the MCA	Upholding human rights Magnifying person-centred care
Doing the assessment justice	Appropriate practitioner with relevant skills Enhancing decision-making capacity Importance of information gathering
Behaviours & emotional impact	Practitioner feelings Avoidance & shifting responsibility Collaboration & consultation
Knowledge gaps and confidence in practice	Lack of knowledge Training dissatisfaction Variable confidence levels

Table 4: Distribution of analytical and descriptive themes

	References								
Analytical and descriptive themes	Samsi et al, (2011)	Walji et al, (2014)	Ratcliff and Chapman, (2016)	Jayes et al, (2017)	Cliff and McGraw, (2016)	Marshall and Sprung, (2016)	Wilson et al, (2010)	Murrell and McCalla, (2015)	Manthorpe et al, (2011)
Travelling the grey line									
Complexity of the MCA	x	x	x		x			x	
Subjective nature of capacity work	x		x	x	x			x	
Person-specific challenges	x		x	x	x	x			
The empowering nature of the MCA									
Upholding human rights	x	x	x			x		x	x
Magnifying person-centred care	x	x			x	x	x	x	x
Doing the assessment justice									
Appropriate practitioner with relevant skills		x		x	x		x	x	
Enhancing decision-making capacity		x	x	x	x	x		x	
Importance of information gathering	x	x	x	x		x	x	x	
Behaviours & emotional impact									
Practitioner feelings	x	x	x	x		x	x	x	
Avoidance & shifting responsibility	x	x	x	x	x		x		
Collaboration & consultation	x	x	x	x	x	x	x	x	x
Knowledge gaps & confidence in practice									
Lack of knowledge	x	x		x		x	x	x	x
Training dissatisfaction	x	x			x		x	x	
Variable confidence levels	x	x	x	x	x	x	x	x	x

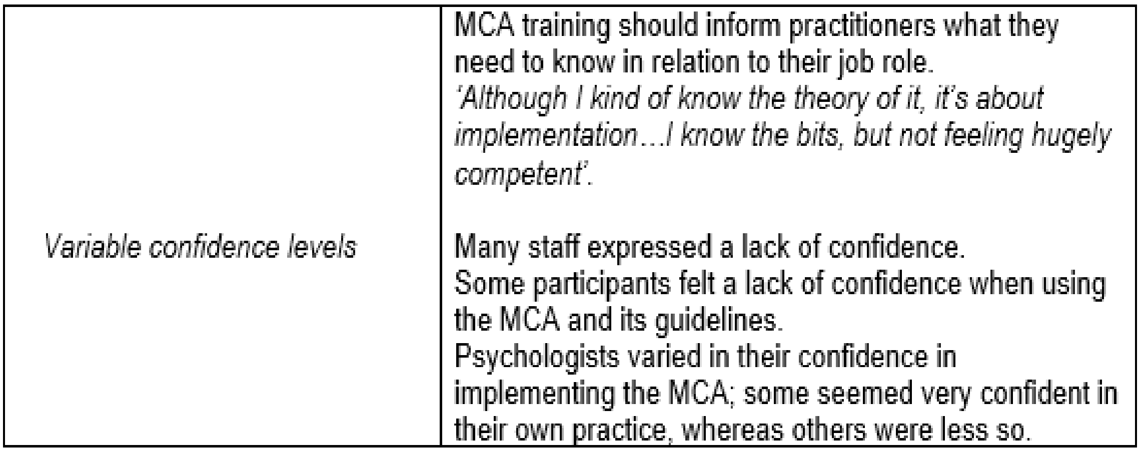
Tab*le 5: Quotes reflecting descriptive themes*



Analytical and descriptive themes	Participants' quotations and/or author interpretations
Travelling the grey line	
Complexity of the MCA legislation	*'It's a very complex act and difficult to explain in layman's terms.'* *'It will take a long time for it to be implemented properly because I think people are going to be quite confused by it.'* The complexity of the legislation and a lack of clarity around some aspects of the MCA, especially DoLS, generally had a negative impact on confidence.
Subjective nature of capacity work	*'There's multiple ways of interpreting this […] it's a woolly issue.'* *'I did it after months of knowing her and I think it did have an impact on the assessment…We couldn't look at it 100% objectively.'* In more complex situations it became difficult to carry out an objective assessment of capacity. A common theme was the ability of family members to affect the conduct and outcome of the assessment…their input was seen as a threat to the conduct of an objective assessment.
Person-specific challenges	*"You've got people where it becomes quite muddied when they have got either fluctuating capacity, or they have got capacity to make some decisions.'* It was often difficult for practitioners to reach a conclusion on mental capacity for individuals whose decision-making ability was described as '*borderline*'. Intrinsic patient factors and behaviours were those patient specific issues that influences the conduct and process of the mental capacity assessment.
The empowering nature of the MCA	
Upholding human rights	*'To me it's [MCA] promoted people's rights and equality within a service that historically has been oppressive and discriminatory'.* They respected patient autonomy and recognised that if it was deemed that the patient had the mental capacity into the decision, they were free to make a decision which could be suggested unwise. Balancing an individual's right to make a decision with their right to be protected from harm.

Magnifying person-centred care	*'We think in that very person-centred way'* Participants identified person-centred care as a central principle of the MCA…and tried to ensure individual choices and wishes were always considered. Participants endeavoured to keep patients at the centre of the assessment and sought to interview patients and family members separately.
Doing the assessment justice	
Finding the appropriate practitioner with the relevant skills	*'It's about saying who is the best person to actually assess for capacity.'* Particular staff groups might be asked to carry out or facilitate assessments because of their specific skills and knowledge. Doctors would usually be involved in making decisions about treatment, whilst occupational therapists would tend to be involved in assessments about discharge arrangements.
Enhancing capacity	*'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).'* Most participants were able to describe alternative methods of communication they might use to support a patient with receptive or expressive language difficulties. Participants indicated that additional support most commonly involved the provision of extra time or delaying the assessment to an occasion when the patient might be more willing or better able to engage.
Importance of information gathering	Other participants reported that they find it useful to talk to hospital and community staff who know the patient well. Liaising with the GP regarding previous care and the patient's family and friends to gain insight into the individuals wishes. *"I think you miss out a huge part if you don't engage the family how can you find out them prior wishes."*
Behaviours and emotional impact	
Practitioners' feelings	*'I think people are quite nervous about work and I think by default when people are a bit anxious and they are under a lot of pressure in their own work they sometimes think well surely someone else is better placed for this.'* *'You do feel a bit cruel because really you are demonstrating to them that they don't know'.*

	'The fear factor comes around the whole sort of decision-making.' *"The volume of the work is the number one [pressure]"*
Avoidance and shifting responsibility	*'I think people often think, let's get the geriatric psychiatrist to do the capacity assessment. When actually it doesn't need to be a psychiatrist to do a capacity assessment'.* *'sometimes they didn't get done because the doctors didn't do them, but latterly the doctors have said that they feel…that the nurses should do it.'* *'[referring to other professionals] they tend to look to us as mental health practitioners to make the decisions'* Psychologists frequently took the lead in implementing the MCA; however, some wanted to avoid being in this position.
Collaboration and consultation	*"I think with complex decision making, you feel there is a greater responsibility…I have knowledge of that by getting advice, and other workers viewing over the work that I have done and the decisions that I have reached."* A strong theme was the importance of joint working, and less formal support was viewed as essential to working practice. Participants frequently sought out other colleagues to discuss cases with and to 'sound out' thoughts or ideas. *'I have gone to nursing colleagues and also psychology and I have found it useful because I think it clarifies your own thought processes.'* Participants who had experience of joint assessment found this beneficial, as it afforded opportunities for joint reflective practice and learning.
Knowledge gaps and confidence in practice	
Lack of knowledge	Theoretical knowledge on the MCA varied, and in some cases was fairly limited. One nurse said she rarely worked with people who lack capacity, yet went on to give an example of someone who was unable to make a decision about treatment. *'I think that is something that is something that I wouldn't have the knowledge to explain.'*
Training dissatisfaction	*'There is not enough training on it. We need more training.'* The training should be delivered more frequently than every three years as '*people forget.*'



Variable confidence levels	MCA training should inform practitioners what they need to know in relation to their job role. *'Although I kind of know the theory of it, it's about implementation…I know the bits, but not feeling hugely competent'.* Many staff expressed a lack of confidence. Some participants felt a lack of confidence when using the MCA and its guidelines. Psychologists varied in their confidence in implementing the MCA; some seemed very confident in their own practice, whereas others were less so.

Theme 1: Travelling the grey line

The first analytical theme reflected participants' views of the MCA and the difficulties they experienced with it in practice.

Complexity of MCA legislation

Some participants felt that the legislation itself was difficult to understand particularly commenting on the lack of clarity around specific sections of the MCA such as the Deprivation of Liberty Safeguards (DoLS [introduced as an amendment to the MCA through the Mental Health Act 2007]). Some felt that the legislation was too broad and therefore sometimes difficult to apply on an individual level.

Subjective nature of capacity work

In five of the papers, participants spoke about how the MCA could be open to multiple interpretations thus increasing the struggle to maintain objectivity (particularly when cases were perceived as complex). Prior to an assessment of capacity, some participants had encountered strong opinions from other professionals and/or family members about the outcome of the assessment. Some participants reported how this could, at times, threaten the objectivity of their assessment due to the pressure and anxiety they felt when disagreeing with others.

Some participants felt that their pre-existing relationship with their patients/service users, their individual biases, values, and beliefs, could impact upon the outcome of the capacity assessment, particularly when mindful of the impact that the assessment outcome could have on an individuals' quality of life. One paper expanded on this notion further by describing the difficulty of remaining objective when allowing an individual to make an unwise decision that may be incongruent with their previous beliefs.

Person-specific challenges

In five papers participants described person-specific factors that seemed to challenge the decision-making abilities of the individual being assessed. Many participants felt that an individuals' level of cognitive ability affected the ease of a mental capacity assessment. They perceived that, individuals with more severe cognitive impairment (e.g. those with severe working memory difficulties who were unable to retain information) were easier to assess than those with milder cognitive impairments. Another common challenge in relation to the individual being assessed was whether they had communication difficulties. Participants from a non-speech and language therapy background reported finding it difficult to adapt and assess communication difficulties effectively. One paper also mentioned language barriers and the challenge of involving an interpreter when English was not an individuals' first language. Participants described how, in their experience, interpreters' might sometimes speak for the person being assessed thus making it difficult to conduct an effective assessment.

Theme 2: The empowering nature of the MCA

Although participants struggled with the MCA, they valued its underlying principles and felt that it had a positive impact on practice.

Upholding human rights

Most participants described how the MCA had intensified their focus on an individuals' human rights and allowed them to embed such principles into their daily practice. There was a strong focus upon balancing the right to autonomy with the right to be protected from harm. Overall, participants felt that the MCA promoted equality and inclusivity.

Magnifying person-centred care

Over half of the participants reported that the principles of the MCA complemented the notion of person-centred care. Participants said they endeavoured to ensure that the individual being assessed was always at the heart of each decision. There was a sense that participants strove to hear and consider individual wishes and preferences. Participants said they were aware of the significant impact that the outcome of an MCA assessment could have on an individuals' life and appeared to put much thought and effort into every aspect of decision-making.

Theme 3: Doing the assessment justice

This theme reflected participants' experiences and opinions on how to conduct an effective and fair mental capacity assessment.

Finding the appropriate practitioner with the relevant skills

Although an MCA assessment is not specific to any one profession, participants felt it was important to find a professional with relevant skills to the decision being made and/or with the relevant knowledge of the decision options to complete (or be part of) the capacity assessment. For instance, some participants discussed how decisions around medication would be most appropriately assessed by a medical practitioner, whereas decisions around hospital discharge destinations may be more suited to occupational therapists.

Enhancing decision-making capacity

In over half of the papers, participants spoke about adapting mental capacity assessments to capture the individual at their best and magnify decision-making capacity. Participants reported that they employed a range of methods to do this, these involved; providing extra time, delaying an assessment to a time when an individual might be better able to engage, repeating assessments if there are elements of uncertainty, spending time to build rapport to ease anxiety, and adapting the assessment to meet an individuals' communication needs, e.g. through use of non-verbal communication aids.

The importance of information gathering

Several papers discussed how participants felt that gathering information about an individual from multiple sources was important when assessing their mental capacity. Speaking to others to gain further information allowed participants to gain insight into an individuals' cognitive, communication and functional abilities. In turn, this supported participants to prepare for the capacity assessment and plan any required adaptations. The views about the value of gathering information from family members varied across the different papers. In some studies, participants felt it was useful, particularly when obtaining information about an individuals' previous wishes and/or behaviours which participants felt would support 'best interests' decisions and the assessment of capacity to undertake what may seem an unwise decision. However, other participants felt that gathering information from family members could hinder capacity assessment. Participants felt this was due to some family members not understanding the individuals' difficulties and having strong opinions (which may involve their own views about the assessment outcome). Here participants commented on the difficulty of managing such family dynamics and high emotions. One paper referred to the MCA as a useful resource for helping to gently address such dynamics.

Theme 4: Behaviours and emotional impact

This theme referred to participants' feelings about capacity work and behaviours in response to such feelings. Many seemed fearful about capacity work and some participants appeared to avoid or shift responsibility for assessments to others. However, others appeared to ease their anxiety through collaborating and consulting with other practitioners.

Practitioners' feelings

Some participants expressed fears about capacity assessments and feelings of being pressured by the responsibility of the decision-making. These appeared to be compounded by organisational factors such as having to balance multiple responsibilities and having little time to complete assessments and the associated paperwork.

Avoidance and shifting responsibility

In response to the fear and anxiety around capacity work, some participants appeared to avoid and/or shift the responsibility of assessment to others. This usually involved referrals to their seniors, such as psychiatrists and other doctors.

Collaboration and consultation

A prominent theme, present in all papers, was the value of working with others. There appeared to be numerous motivations for this; one of which seemed to be reduction of fear and increased reassurance. Another reason seemed to be the consequent greater clarity of complicated or uncertain areas, to aid learning and development. Participants said they greatly valued the opportunity to work collaboratively and felt their practice improved as a result.

Theme 5: Knowledge gaps and confidence in practice

The final theme refers to participants' reported knowledge gaps in mental capacity work and their perceived levels of confidence in applying the MCA in practice.

Lack of knowledge

Participants reported gaps in their knowledge. Some of these involved the absence of detailed specific knowledge and difficulties with recording and documentation processes. A prominent theme across most papers was the reported difficulty of linking mental capacity theory to practice. However, despite this, some papers reported that participants still held on to the MCA principles in practice when talking about case examples. This perhaps suggests that knowledge may have been assimilated.

Training dissatisfaction

Although some participants valued MCA training opportunities, most participants were dissatisfied with both the frequency and quality of the training on offer. One participant felt their training had been a "*tick box exercise".* Generally, the consensus was that learning was not optimised by the training offered but was instead enhanced through practice and collaboration with others.

Variable confidence levels

Reported confidence levels throughout the papers varied. Knowledge and confidence appeared to be linked, participants commented that as their knowledge and expertise increased so did their confidence. Initially, lack of confidence prevented participants from challenging decisions with which they did not agree. Supportive and accessible literature alongside joint working were both identified as factors that improve confidence levels.

Discussion

This review synthesised qualitative data from nine empirical research studies (with a total of 130 participants) exploring experiences and knowledge of the MCA. The original studies included in the synthesis were published between 2011-2017 and, as such, the results represent a snapshot of the use of the MCA within this specific time frame. Participants' experiences highlighted both the positive aspects and challenges of utilising the MCA in practice within five analytical themes: 1) Travelling the 'grey line', 2) The empowering nature of the MCA, 3) Doing the assessment justice, 4) Behaviours and emotional impact, and 5) Knowledge gaps and confidence in practice.

The qualitative literature reviewed here supports and is supported by quantitative literature about knowledge gaps and questions about the possible adequacy of early MCA training (e.g. Todd et al, 2008; McDonald, 2010; Sawhney et al, 2009). By examining the qualitive literature we begin to understand more about what these knowledge gaps entail. The synthesis highlighted themes around infrequent and possibly poor-quality training (although this data was not systematically collected). Among many, training was thought to be too general and therefore difficult to apply to specific individual cases. Some papers referred to participants reporting a lack of knowledge but nonetheless answering questions in a knowledgeable manner. Burch’s (1970) conscious competence model suggests that there are four stages involved in the process of moving from ‘incompetence’ to ‘competence’. The final stage of the model suggests that individuals reach a state of ‘unconscious competence’, here people tend to be unaware of a skill they have acquired. In line with Burch’s (1970) conscious competence learning model, the findings presented in the current synthesis would suggest that participants have perhaps reached the ‘competence’ stage through acquiring MCA knowledge effectively but without conscious contemplation of this knowledge.

The current synthesis offered insights into participants’ struggles with the complex and subjective nature of the MCA. In the current synthesis, the notion of complexity resided in three key areas. Firstly, the lack of clarity within the legislation was regarded as a challenge, particularly specific elements of the MCA such as DoLS. This is consistent with others’ observations. For instance, the Care Quality Commission (CQC, 2015) reported limited understanding and awareness of how to implement DoLS effectively. Secondly, managing subjectivity was apparent, with participants describing how the MCA is open to multiple interpretations so that decisions may be influenced by external factors such as the opinion of other stakeholders. The acknowledgement of subjectivity is provided in the MCA itself (Department of Constitutional Affairs, 2007) which suggests that the evidence required for decision-making about capacity needs to be made only with “reasonable belief.” However, commenting on best interests’ decisions, Taylor (2016) suggested that the process is ‘too complex’ and that the subjective nature of it can prohibit professionals from fully appreciating and taking an individuals’ past and present beliefs into consideration. Finally, individual characteristics of the person being assessed were regarded as a challenge, particularly when a person presented with ‘borderline’ cognitive abilities. Difficulties in assessing people with milder cognitive difficulties have been recognised (e.g. Brown et al, 2013), with a specific focus upon the problem of assessing an individuals’ ability to weigh up information (Willner et al, 2010).

This synthesis exposes the presence of professional fear and anxiety surrounding capacity work. In response to this, some participants seemed to avoid or shift the responsibility of capacity assessments to their seniors. This is supported by other studies. For instance, Newby (2011) found that ‘unsafe uncertainty’ leads to avoidance. Moreover, a trend of delegating to those perceived higher in the professional hierarchy is consistent with previous research (e.g. Shah et al, 2009; Williams et al, 2014). Mason (1993) suggests that as humans we often seek certainty, but that this can lead to a lack of creativity and paralysis. Mason (1993) believes that the key position for people to be in when faced with situations of certainty/uncertainty is ‘safe uncertainty’. This encapsulates a position of ‘authoritative doubt’ which encompasses both expertise and uncertainty. This idea could be fostered to encourage practitioners to reflect upon their position when making risk decisions in line with the MCA and encourage them to think about what needs to happen to move towards a position of safe uncertainty and to feel comfortable in this position.

The synthesis identified that the ability to collaborate and consult with other professionals appeared to be a strong protective factor in minimising some of this anxiety through supporting new learning and the development of confidence. Indeed, Cranley et al, (2011) have shown that clinical uncertainty raises anxiety and that "getting everyone on the same page" (p155) helped practitioners to manage these difficult feelings. However, other research also suggests that group decision making can lead to more errors than individual decision making, due the powerful influences people can have on one another (Kahneman, 2012). Thus, although collaboration seems to reduce professional fear, it may potentially increase the likelihood of inaccuracy.

Despite some limitations, the present synthesis offers new insights into how participants appeared to work within the ethos of the MCA – keeping individuals at the heart of the decision-making and striving to complete thorough and flexible capacity assessments. This is high on the national agenda (HM Government 2014) but in contrast to the House of Lords' post-legislative scrutiny report (2014) which pinpointed concerns that the empowering ethos and rights conferred by the Act were not being realised in practice.

Moreover, one of the fundamental principles of the MCA is that all practicable steps must be taken to support an individual to make a decision for themselves, before any decision is made that they lack capacity (MCA 2005, section 1[3]). The studies within this review consistently found that participants said they utilised a range of methods to maximise an individuals' decision-making capacity, such as providing extra time and delaying assessments to a time when individuals are better able to engage.

Participants also knew that capacity assessments should be done by those who are close to the subject of the decision and based on knowledge of the individual. Such practice is in line with the MCA Code of Practice (Department of Constitutional Affairs, 2007). Overall, the detailed accounts from health and social care practitioners in the present synthesis suggest that good practice is followed in the main and that the fundamental principles of the MCA are successfully becoming embedded in practice.

Clinical implications

The findings from this review suggest the MCA has magnified health and social care practitioners' focus on human rights and complemented the notion of person-centred care. As such, the fundamental principles of the MCA appear to be adhered to and successfully embedded within practice. However, the review suggests that professionals feel they are at times 'travelling the grey line' in regards to capacity work and would benefit from regular training opportunities that have a particular focus on the specific elements of the Act, and that support the link between MCA theory and practice. Perhaps the use of more case studies within training or MCA peer groups or communities of practice to discuss complex cases would assist with this.

Moreover, as the MCA or its Code of Practice does not provide information on 'how' to assess capacity, practitioners may benefit from further training/guidelines on how to conduct capacity assessments particularly for individuals with milder cognitive impairments or for those with communication difficulties. Shared training and collaboration could potentially enhance confidence and reduce professional fear around capacity work. In turn, this may reduce the avoidance and shifting of MCA work. The use of Masons (1993) theory of 'safe uncertainty' could also be fostered here to encourage practitioners to reflect upon the position they are in when making risk decisions, with the aim of encouraging them to move towards a state of 'safe uncertainty'.

Finally, professionals may benefit from regular reflective practice groups to reflect on their own potential biases and external influences that may threaten the likelihood of the conduct of a fair capacity assessment. Reflective practice may support staff to reflect upon whether they categorise individuals' as having 'mild' vs 'severe' cognitive impairment and to think about the influence this may have on their capacity assessment. Reflective practice could aim to support staff to consider the importance of a thorough cognitive and behavioural assessment to understand the individuals' unique profile as opposed to using categories to understand and make decisions about an individuals' capacity status.

Strengths and limitations

This is the first systematic review to synthesise existing qualitative evidence regarding health and social care practitioners' knowledge and experiences of the MCA. It elucidates the main benefits and challenges of applying the MCA in practice, providing greater insight into this area. The review adhered to ENTREQ guidelines (Tong and Flemming, 2012) and followed robust and transparent methodology (Thomas and Harden, 2008) and processes, e.g. the use of two independent reviewers to screen and quality assess all articles. A key strength of the synthesis consisted of the quality of the included studies - the majority of which were considered high quality, thus increasing the rigour of the systematic review findings. Only nine studies were eligible for inclusion in this review - this is a key limitation which may affect the transferability of findings. As such, the conclusions must be considered within this context and remain as tentative hypotheses for further exploration. Moreover, limiting the inclusion criteria to peer reviewed literature may have missed additional insights from grey literature. However, this decision was made due to quality considerations regarding the rigours peer-review process that published research encounters.

Future research

Following this review, several areas warrant further investigation. Qualitative research could further explore where apprehension around mental capacity work remains. It could explore the roots of any remaining fear and if this can be reduced at personal or organisation level. Researchers' may wish to investigate the relationship between perceived and actual knowledge of the MCA to determine if there is a difference between the two. It is also important for future research to replicate this review, including more recent papers as they emerge to identify whether the challenges raised in the current synthesis persist. Finally, it is important to explore the impact of the MCA on those making use of it or subject to it/affected by it, e.g. members of the public, patients/service users, and family members/carers. Such research could offer valuable insights and more holistic understandings of the experiences of the MCA.

Summary and conclusions

This review of nine research papers describing 130 participants’ experiences and knowledge of the MCA in health and social care practice has identified five overarching themes highlighting both positive and challenging aspects of utilising the MCA. Overall, although the Act was held in high regard and believed to have positively impacted on person-centred care and the safeguarding of human rights, findings suggest a need for effective interventions to improve confidence and knowledge in practitioners, and to reduce apprehensions around capacity assessment in practice.

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Chapter 2

Operationalising the Deprivation of Liberty Safeguards (DoLS) in Support of Brain Injury Survivors – Views from Practice

Abstract

Deprivation of Liberty Safeguards (DoLS;2007) provide a legal framework for safeguarding adults who lack capacity to make decisions in relation to care and residence in England and Wales. The purpose of this study was to understand the DoLS decision-making process from the perspective of health and social care practitioners when applied to individuals with an Acquired Brain Injury (ABI). It is hoped that this will inform practice and policy. 12 health and social care practitioners were interviewed in 2019/2020 about their experiences of using and making or supporting decisions in the DoLS framework with brain injury survivors. A constructivist grounded theory model was used for analysis. Three distinct approaches emerged capturing different decision-making styles (risk-averse, risk-balancing, and risk-simplifying) which influenced the outcome of DoLS assessments. A range of mediating factors accounted for the variability in these styles. The model also illustrated the wider contextual challenges that impact upon practitioners' overall experience and use of DoLS processes. The findings highlight a need for changes in practice and policy in relation to how DoLS or similar processes are used in practice with brain injury survivors and may be relevant to proposed reforms of the DoLS system and their implementation.

Introduction

Incidence and Impact of Acquired Brain Injury (ABI)

Acquired Brain Injury (ABI) is an umbrella term used to describe an injury caused to the brain since birth (Headway, 2018). The most common causes include, traumatic brain injury (TBI) and Ischaemic stroke (Feigin et al, 2010). ABI is a rapidly growing public health concern, in 2016-2017 it was estimated that it resulted in 348,543 hospital admissions in the UK alone (Headway, 2018). Moreover, with an estimated 1.4 million people sustaining a TBI per year, TBI is classified now as one of the leading causes of disability in young adults (Yates et al, 2006).

Survivors of an ABI can suffer from a cascade of lasting challenges including physical, cognitive, behavioural, sexual, mood, personality, and communication difficulties (Fleminger and Ponsford, 2005). These can complicate any potential return to pre-injury life, with high rates of unemployment (Van Velzen et al, 2009) and marital instability evidenced post-ABI (Kreutzer et al, 2016). There is also growing awareness of high incidence of psychological difficulties, including depression, anxiety, and substance misuse (Kreutzer et al, 2016). Furthermore, cognitive difficulties are especially associated with injury to the frontal and temporal lobes (regions often implicated in ABI), including problems with memory, attention, executive function, emotional regulation, and behavioural control (Fleminger and Ponsford, 2005). Given the lack of physical indication of impairment, such difficulties have been described as a “silent epidemic” (Langlois et al, 2006) and are linked to numerous problems such as, increased risk-taking behaviours (Weil et al, 2016), suicidality (Homaifar et al, 2012) and involvement with the criminal justice system (Holloway, 2014).

Given the complexity of problems that individuals with a brain injury may encounter, their decision-making abilities may be impaired (Douglas, 2013). As such, some may lack capacity to make a specific decision regarding their care and residence and may need to be protected in their best interests for their own safety, which may result in them being legally deprived of their liberty.

Deprivation of Liberty Safeguards (DoLS)

DoLS were introduced as an amendment to the Mental Capacity Act (MCA; 2005) in 2007 (implemented 2009), to safeguard vulnerable individuals deemed to lack capacity to consent to a decision about their treatment or care (Lennard, 2015). They provide for the legal deprivation of liberty if it is in the best interests of an adult who lacks capacity. DoLS provide legal authorisation for individuals' care (in care homes, hospitals, supported accommodation and in the community) in the least restrictive manner whilst preventing arbitrary decisions that may entail a deprivation of liberty (Lennard, 2016). Operationally, following a mental capacity assessment, if it is believed that it is in a person's best interest to be deprived of their liberty, the managing authorities (e.g. a care home/hospital in which the individual resides) must apply to the supervisory body (local authorities) to authorise the DoLS. A best interest assessor (BIA) and mental health assessor will then be allocated to complete a series of assessments (e.g. age assessment, a capacity assessment and an assessment of best interests [Blamires et al, 2016]).

The operation of DoLS has received substantial criticism. In its post-legislative scrutiny report, The House of Lords (2014) viewed DoLS as “overly complex”, “poorly implemented” and “not well understood” (pg.7). It recommended a new system. The Care Quality Commission (CQC, 2015), reported; low numbers of applications, regional variations, and limited knowledge and awareness of DoLS. Subsequent research highlighted uncertainty and concerns about practitioners’ implementation of DoLS (e.g. Blamires et al, 2017). In a vignette-based study, Cairns et al, (2011) explored DoLS decision-making. They found inconsistencies in practice as the level of agreement between professionals was only ‘slight’.

In response to the UK Supreme Court Case known as ‘Cheshire West’, the notion of what constituted a deprivation of liberty was clarified and broadened to include anyone who met the ‘acid test’: whether the individual is ‘under continuous supervision and…not free to leave’ (Penny and Exworthy, 2015). In effect, this lowered the threshold for when a DoLS application was needed, leading to substantial increases and an overstretched system (McNicoll, 2015). In response, DoLS’ replacement (Mental Capacity (Amendment) Act 2019), the ‘Liberty Protection Safeguards’ are due to be implemented in 2021. Some of the key changes include: being able to renew authorisations for up to three years; LPS will apply to people from the age of 16 (in comparison to 18) and in any setting/more than one setting; unlike DoLS extra powers will be given to managers of care homes e.g. ability to arrange reviews and renew authorisations (Griffith, 2020).

The current study

A literature search conducted in February 2020 found no research relating specifically to the use of DoLS with people with brain injuries and the views of practitioners involved in the process. Given that research and policy have highlighted concerns around DoLS decision-making and given the complexity of the multitude of difficulties that brain injury survivors can present with, it is pivotal that this area of research is investigated.

Research Aims

The current study aimed to contribute to this gap in evidence using a grounded theory approach to address the question of: ‘How are DoLS decisions made, in brain injury services, from a sample of different practitioners involved?’

The main objectives were to:

- Explore DoLS decision-making from the perspectives of a sample of health and social care practitioners.
- To develop a framework to capture how DoLS policy is applied in practice.
- To examine factors that may account for variation in DoLS decision-making.
- To develop an explanatory theoretical model to capture any variation of the DoLS decision-making processes.

Method

Design

A qualitative design was used to gain an in-depth exploration of participants' experiences of the decision-making process in relation to the use of DoLS with brain injury survivors. A modified version of grounded theory (Charmaz, 2014) was felt appropriate to meet the study aims as this approach aims to go beyond the meaning of lived experiences of phenomena, and instead develop a theoretical understanding of the social processes reported by participants (Starks et al, 2007). Grounded theory can help develop understandings, because it may enable the generation of a model detailing information on how the DoLS decision-making process is seen from the perspectives of different practitioners. The approach adopts a constructivist epistemological position, which understands emerging theory as a socially constructed meaning of experience, processed through the interaction and shared meaning/understanding of the researcher and participants. Thus, rather than representing an objective truth, the research is thought to represent a 'co-construction' (Charmaz, 2014).

Ethics

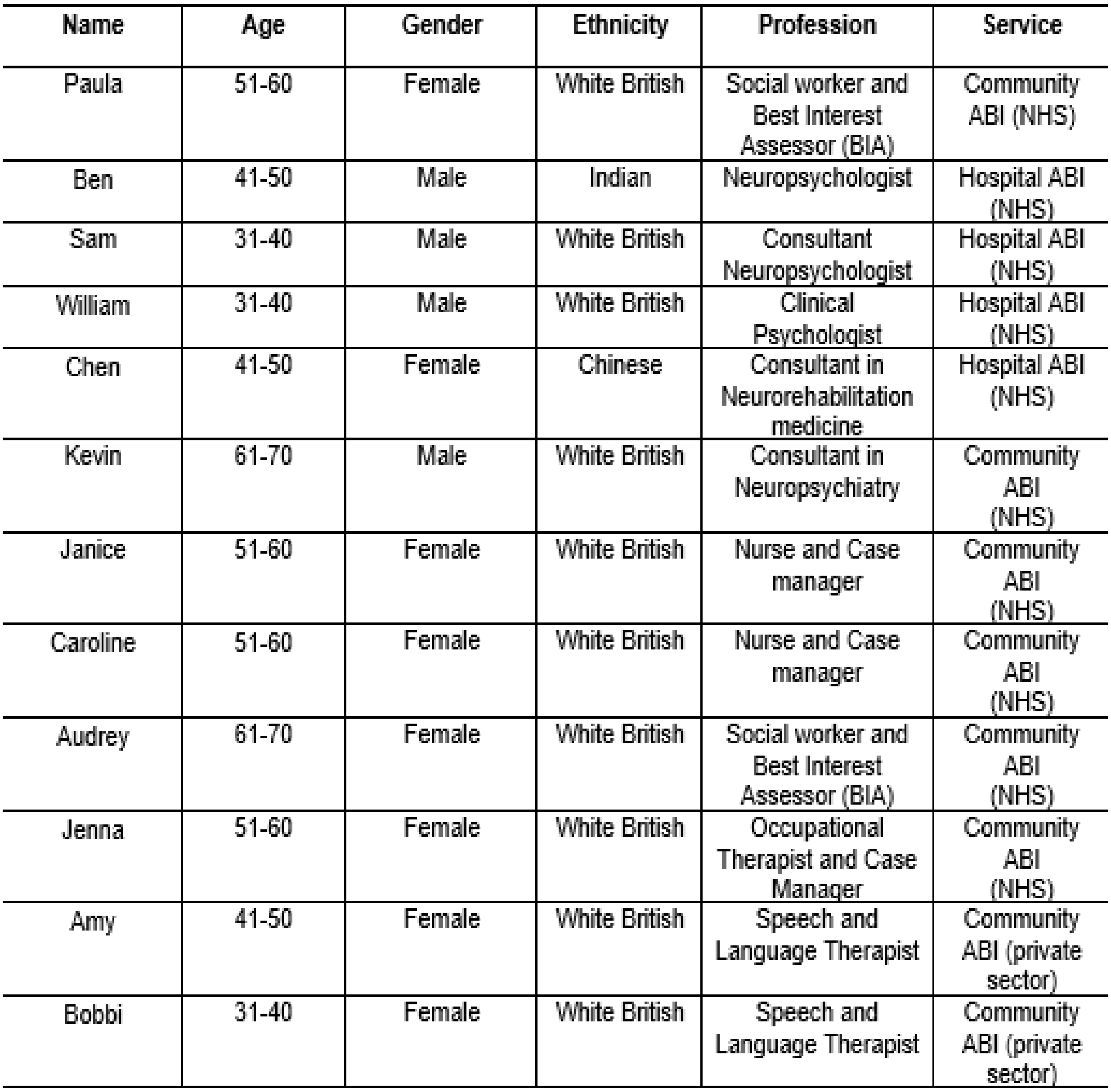
This study was sponsored by the University of Liverpool (appendix G). Ethical approval was granted by both The University of Liverpool Health and Life Sciences Research Ethics Committee (appendix H) and the Health Research Authority (HRA) (appendix I).

All participants gave informed consent to participate. Any personally identifiable information was anonymised during the transcription process and the primary researcher assigned pseudonyms to each participant to preserve anonymity. Participants were told they could terminate the interview at any point and withdraw their data within one week after participation. All were debriefed and given the opportunity to ask questions.

Participants

A total of 12 participants were interviewed between May 2019 – February 2020. Participants were all professionally qualified health or social care practitioners currently working with service-users with an ABI. Each had been involved in DoLS decision-making processes in the past 12 months to reflect the current/recent context (see Table 5). A potential additional two participants were excluded on the basis that they worked in dementia rather than ABI services. All names are pseudonyms.

Table 6. *Participant demographic information – n=12*



Name	Age	Gender	Ethnicity	Profession	Service
Paula	51-60	Female	White British	Social worker and Best Interest Assessor (BIA)	Community ABI (NHS)
Ben	41-50	Male	Indian	Neuropsychologist	Hospital ABI (NHS)
Sam	31-40	Male	White British	Consultant Neuropsychologist	Hospital ABI (NHS)
William	31-40	Male	White British	Clinical Psychologist	Hospital ABI (NHS)
Chen	41-50	Female	Chinese	Consultant in Neurorehabilitation medicine	Hospital ABI (NHS)
Kevin	61-70	Male	White British	Consultant in Neuropsychiatry	Community ABI (NHS)
Janice	51-60	Female	White British	Nurse and Case manager	Community ABI (NHS)
Caroline	51-60	Female	White British	Nurse and Case manager	Community ABI (NHS)
Audrey	61-70	Female	White British	Social worker and Best Interest Assessor (BIA)	Community ABI (NHS)
Jenna	51-60	Female	White British	Occupational Therapist and Case Manager	Community ABI (NHS)
Amy	41-50	Female	White British	Speech and Language Therapist	Community ABI (private sector)
Bobbi	31-40	Female	White British	Speech and Language Therapist	Community ABI (private sector)

Recruitment and sampling

Participants were recruited from one large NHS Trust, across multiple ABI services/sites in North West England (n = 4) and via the social media platform ‘Twitter’ (n = 8). The study advertisement (appendix J) and information sheet (appendix K) were emailed to ABI services within the NHS Trust and to any participants that expressed an interest via social media. Participants were then selected for the study based on those who wished to take part and met the inclusion criteria. Participants were given the opportunity to re-read the information sheet and ask any questions prior to signing a consent form (appendix L). Following completion of the study all participants were debriefed (appendix M).

The first four participants were selected using a convenience sampling strategy. Subsequent participants were recruited using theoretical sampling to facilitate the exploration of emerging relationships between participants' narratives and their job role and work setting (see figure 2).

Figure 2. Theoretical sampling process

Stage 1: Convenience sampling – four participants

Stage 2: Consistent similarities and differences noted between narratives of different practitioners (e.g. social workers and medics) continue recruitment from a range of professional backgrounds – five participants

Stage 3: Curious if type of work setting would provide a different narrative – recruit from a range of settings e.g. private sector, NHS hospital and community settings – three participants

Interview Procedures

Interviews were held at participants' workplaces for convenience. Each participant was interviewed once, using a semi-structured topic guide. This was based on guidance from Charmaz (2014) in line with the principles of grounded theory methodology. The topic guide was adapted over the course of the interviews to explore emerging themes/hypotheses (appendix N). The researcher adopted a curious stance which facilitated flexibility within the interviews, allowing them to adapt to participant responses and to probe areas of interest. Interviews lasted between 28-77 minutes and were audio recorded. The first recording was listened to by a second researcher and subsequent transcripts were read to inform the researchers' interviewing techniques.

Reflexivity

Given the researchers background, values, and relationship with the research topic and in line with constructivist grounded theory (Charmaz, 2017) it was deemed important to adopt a reflexive stance. As such, prior to the commencement of recruitment, the researcher wrote a reflexive statement (appendix O) regarding their initial thoughts and expectations to encourage awareness of any impact this may have on data collection or analysis. Reflexivity was also documented in a reflective journal (appendix P), discussed regularly in research meetings and supported through detailed memo writing (appendix Q).

Analysis

A systematic approach to analysis was undertaken using an electronic software package (Excel [see appendix R]). Transcripts were firstly read and re-read so that the researcher could fully immerse herself in the data. Following this, in line with

Charmaz’s (2014) approach to grounded theory, each transcript was analysed using line-by-line, focused and theoretical coding. The primary researcher transcribed the first four audio interviews. Subsequent interviews were transcribed by an approved university transcription service. Initial coding involved the technique of utilising ‘gerunds’, (recommended by Charmaz, 2014) i.e. verbs ending in *-ing* as codes to capture ‘actions’ and ‘processes.’ Next, the most significant and frequent codes were integrated and synthesised to form focused codes. From focused coding, ‘conceptual categories’ were developed, incorporating common themes and patterns across codes. In line with Charmaz (2014), the researcher strove for categories to have abstract power and analytical direction to explain processes and ideas within the data. Emerging findings were used to adapt the interview guide and to identify directions for theoretical sampling.

Constant comparative methods were utilised at each stage of the analysis to inform analytical direction (e.g. comparing data with data, codes with data and codes with codes) and were supported through; memo writing, reflective diary writing, diagramming and use of supervision to refine analytical thinking. As no new focused codes emerged following interview nine, the final three interviews were used to check and refine theoretical thinking. Data saturation was reached after interview 12 (as no new codes were constructed) and recruitment ceased. Multiple validation procedures were completed to ensure credibility of the grounded theory model, codes, and theoretical categories (Yardley, 2017). For instance, as multiple coding is recommended to ensure rigour of qualitative research (Barbour, 2001), two researchers independently coded segments of research transcripts (appendix S) to cross-check coding techniques. Validation checks were supported through a second researcher reviewing coding and emergent frameworks.

Results

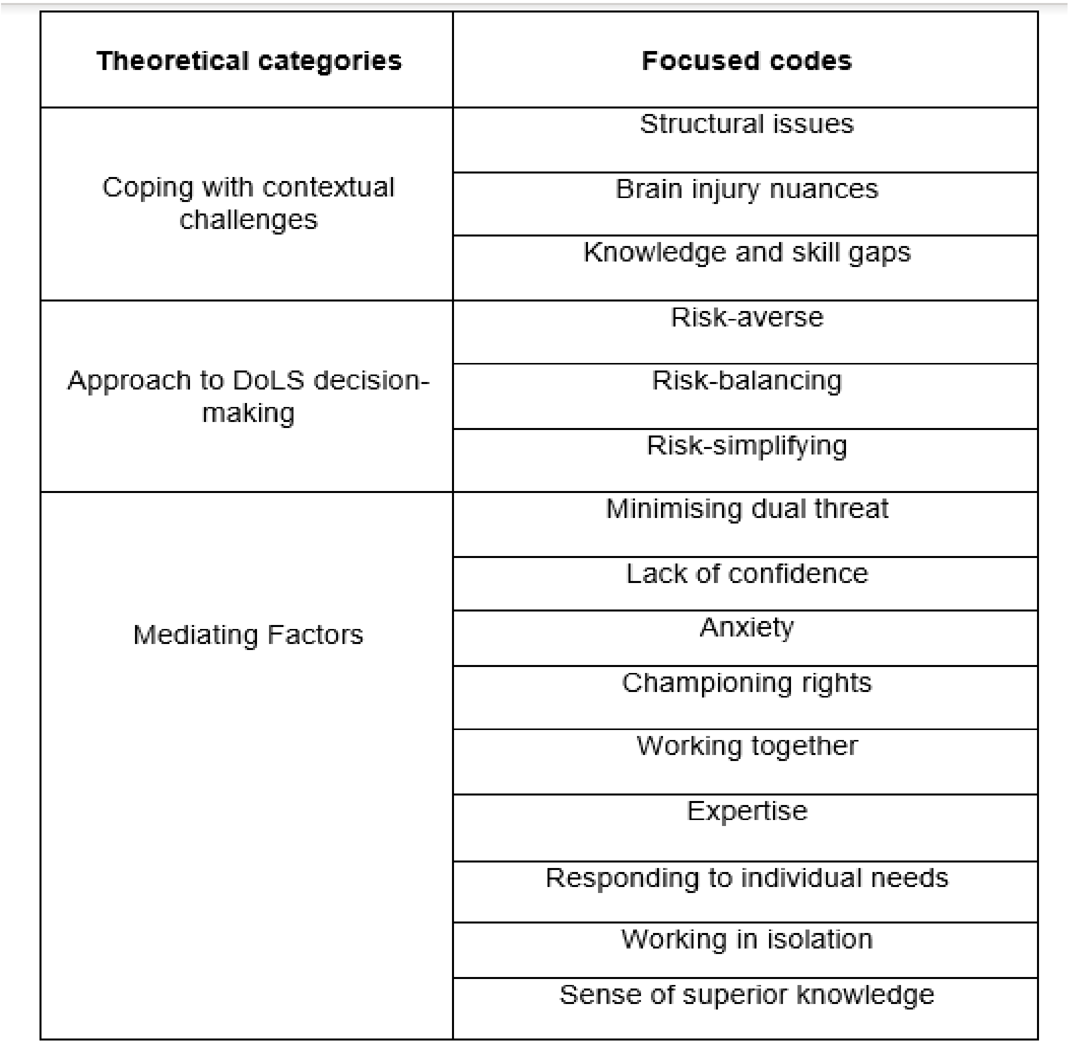
Figure 3 illustrates the explanatory theoretical model of findings, highlighting a variety of approaches that capture how DoLS is used in practice. Theoretical categories and associated focused codes are presented in Table 6. The process of DoLS decision-making with clients with brain injuries is described through the interplay of categories and associated focused codes. Each element of the model and the interconnections between categories is described below along with a visual representation of the theoretical framework (figure 3).

Summary of the model

Figure 1 is a theoretical representation of the process and variation in which DoLS decisions are made in practice for people with a brain injury. It reveals three distinct decision-making approaches, all of which seemed directly influenced by different mediating factors. The risk-averse approach represents practitioners who were more restrictive in their decision-making and were therefore more likely to apply DoLS. This approach was directly influenced by the mediating factors of ‘minimising dual threat’ (encapsulating threat to both patient safety and professional safety), ‘lack of confidence’ and ‘anxiety’. At the opposite end of the decision-making spectrum was the ‘risk-simplifying’ approach. This decision-making style captured practitioners who made more generalised and apparently rash decisions, usually based on assumptions without following through with a thorough capacity assessment. Here a practitioners’ decision around DoLS is likely to go either way. Risk simplifying decision-makers were directly influenced by the mediating factors of ‘sense of superior knowledge’ and ‘working in isolation’. Finally, the risk-balancing approach represented practitioners who seemed more likely to make decisions in line with MCA legislation, i.e. based on a balance of probabilities rather than possibilities. Here practitioners seemed able to tolerate risk and make balanced decisions that considered quality of life as well as patient safety. This style of decision-making seemed driven by the mediating factors of ‘expertise’, ‘championing rights’, ‘working together’ and ‘responding to individual needs.’

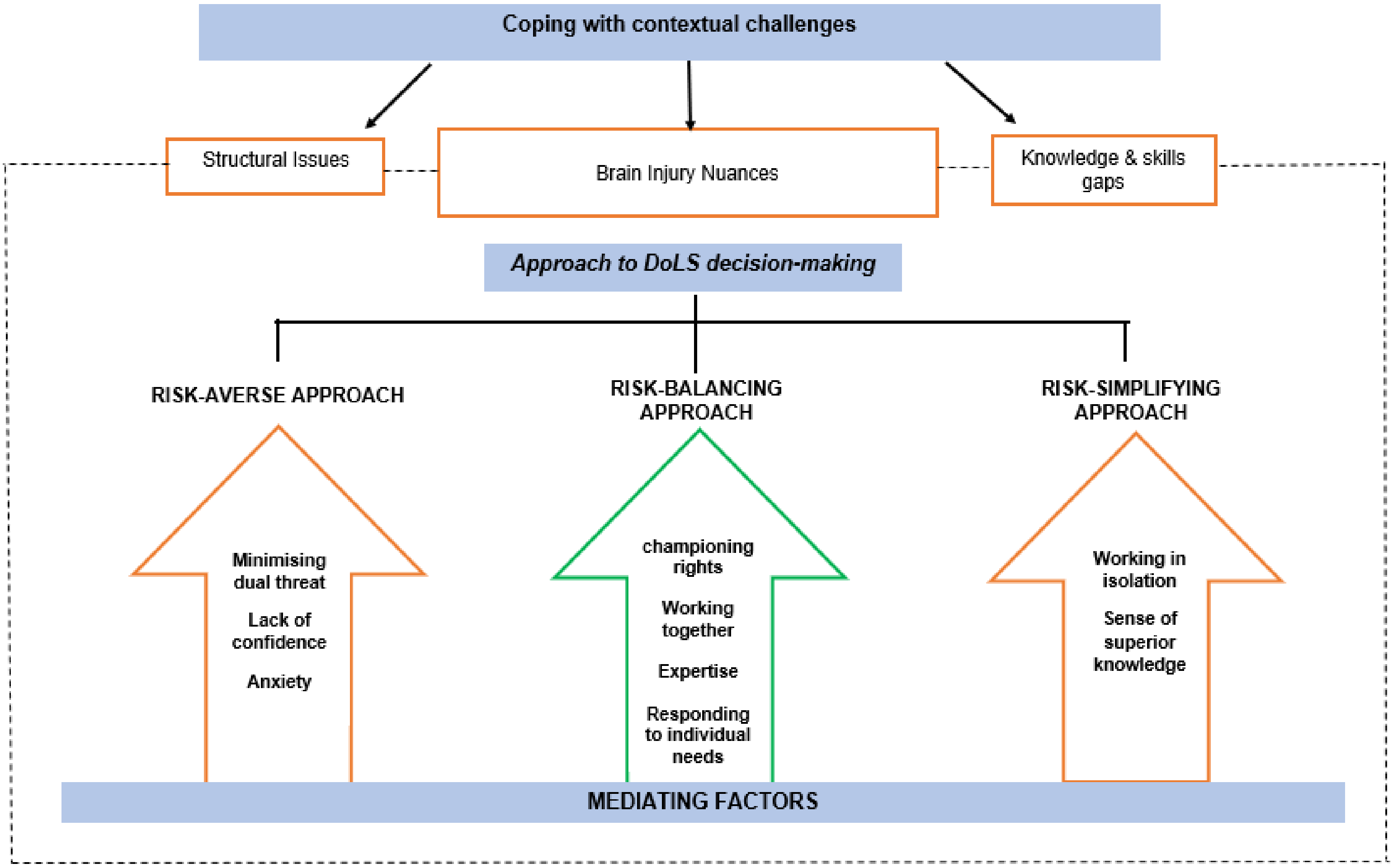
The peripheral category ‘coping with contextual challenges’ represents the challenges decision-makers face when considering/completing DoLS assessments for people with brain injuries. Challenges involved: structural issues (e.g. backlog of assessments to complete and disjoint in communication with Best Interest Assessors); brain injury nuances (i.e. the complexity of assessing someone with executive dysfunction difficulties) and knowledge and skill gaps (i.e. lack of understanding and subsequent misuse of DoLS legislation). These factors surround the decision-making process and appear to indirectly influence practitioners to adopt either a ‘risk-averse’ or a ‘risk-simplifying’ approach (colour coded in orange). Despite ‘risk-balancers’ working within the same context and being faced with the same contextual challenges, the mediating factors, ‘expertise’, ‘championing rights’, ‘working together’ and ‘responding to individual need’ (colour coded in green) act as protective factors - preventing contextual challenges from influencing how practitioners make balanced person-centred decisions. Each element of model is described below and supported with participant quotes.

Table 7: Theoretical categories and focused codes



Theoretical categories	**Focused codes**
Coping with contextual challenges	Structural issues
	Brain injury nuances
	Knowledge and skill gaps
Approach to DoLS decision-making	Risk-averse
	Risk-balancing
	Risk-simplifying
Mediating Factors	Minimising dual threat
	Lack of confidence
	Anxiety
	Championing rights
	Working together
	Expertise
	Responding to individual needs
	Working in isolation
	Sense of superior knowledge

Figure 3. Grounded theory model capturing the variation in which DoLS decisions are made.



1. Approach to DoLS decision-making

All practitioners described observing different decision-making approaches in practice or illustrated a specific style of decision-making, as below:

Risk-averse approach

Some participants described being reluctant to take any risk due to a strong desire to keep patients safe. As such, they seemed overly restrictive in their approach to DoLS decision-making:

> …if it's somebody's erm, health, wellbeing or life, that's at risk, it's better to be over-cautious, put too many restrictions in place, and miss having a slapped wrist for it, saying well 'you went a bit OTT (over the top) there', well that's ok, because they are safe and they're still here (Caroline).

Practitioners utilising this approach seemed aware that they were restricting individuals by limiting their autonomy and freedom but were able to justify the level of restriction through doing so in their 'best interest'; "We are doing it in their best interest, we are trying to keep them safe" (Paula). Here practitioners seemed to rationalise overly restrictive decisions through their belief that it would always be a priority and in someone's' best interest for them to be kept physically safe e.g. in 24-hour nursing care. However, some participants recalled patients expressing strong desires to stay in their own home, thus insinuating that physical safety (e.g. 24-hour care) may not always be in their overall best interest:

> The person is so distressed, you know, that whole point about it being a gilded cage, why keep someone physically safe if they are so miserable and trying to escape, what is the point? (Paula, referencing a

> much-cited judicial decision that a person may be safe but unhappy in a ‘gilded cage’)

Moreover, one practitioner described how working within a hospital setting could almost positively reinforce risk averse DoLS decision making, due to the strong hospital ethos of keeping patients safe:

> From a hospital setting we are rated as outstanding by CQC (Care Quality Commission) because safety is a priority, but does that make us risk averse? (Sam)

When checking the idea of risk-averse decision-making with (Jenna [after this category had emerged from the data]) she explained that she had witnessed other practitioners utilising this approach:

> I do personally think that a lot of case managers can be quite risk averse and can be clouded in that concept of being paternalistic.

Risk-balancing approach

This subcategory describes practitioners who weighed up “physical safety” with the impact a DoLS restriction can have on quality of life and “emotional safety” (Paula). Jenna demonstrates the use of this approach:

> My experience has been that some care providers will use DoLS as a way to just keep somebody safe…and I take that very seriously, you know what restrictions have they got in place, are they necessary, could they do it in a different way, you know to enhance the quality of the person's life.

Here practitioners conveyed a sense of expertise in both brain injury and DoLS and seemed more likely to make decisions in accordance with legislation by considering the "probabilities rather than possibilities" (Ben) of risk. As Ben summarises "What does the law require…you have got to work within the law." Risk-balancing decision-makers seemed to strive to provide patients with the best possible chance of proving that they had capacity, prior to making any decisions that could restrict them. This was often illustrated through practitioners talking about the use of adaptations in capacity assessments, for example, Bobbi said she would always use "communication software" to support patients with communication difficulties. Moreover, risk-balancers indicated the ability to tolerate risk, e.g. through respecting patients' rights to make unwise decisions, even when this was perceived as illogical and potentially harmful to the person's health:

> …we are not trying to take unacceptable risks; we knew this lady had capacity, so we had to allow her to make unwise decisions…if it was my child, God, of course I wouldn't let them do that… but that's why it's not the family that make these decisions…(Janice)

Risk Simplifying decision-makers

This approach captured practitioners who would simplify DoLS decisions through using mental short-cuts, e.g. if a person had a diagnosis and looked physically disabled then they were more likely to “slap them on a DoLS” (Paula). This type of decision-making was discussed by Audrey:

> One of the doctors did seven assessments in one care home, in one afternoon...it was almost as if he was going around going ‘oh hello, yeah I’m a doctor, what’s your name, oh yeah, you have got a brain injury, so you haven’t got capacity’

Some practitioners were also reported to make rash decisions when they perceived patients as looking ‘OK’ on the outside, despite having underlying cognitive difficulties; “staff will come in and do quick capacity assessment and say ‘yeah they look fine, they have capacity’” (Chen). Paula described how “you don’t often see capacity assessments…you’ll just see a lot of tick boxes” (Paula), indicating a lack of thorough, well documented capacity assessments.

2. Mediating factors

Mediating factors capture the variety of influencers that directly contribute to the different styles of decision-making.

Minimising dual threat, anxiety, and lack of confidence

Minimising dual threat encapsulates how some practitioners prioritise threat to patient safety “they see themselves as having a role of keeping that person safe” (Jenna) and threat to professional safety “this is my pin number (registration) on the line” (Paula) when making DoLS decisions. If decisions compromised patient safety they feared for their professional reputation and integrity, “we will be challenged in court if we make the wrong judgment” (Chen). Minimising dual threat was about practitioners wanting to ensure their actions were justifiable against a backdrop of both professional and patient safety risk. Despite the MCA, their desires to keep people physically safe and protect themselves seemed a powerful motivation to seemingly make risk averse and subsequently restrictive DoLS decisions:

> We can’t let people leave at risk so we would have to demonstrate to the Court of Protection that we have done everything we can to keep the person safe (William)

Interestingly, none of the practitioners utilising or witnessing a risk-averse approach demonstrated or observed any actual professional challenges or threat to patient safety within their work, but nonetheless they all saw such threats as a possibility. As such, it appears that anxiety and lack of confidence were underlying processes involved in the decision-making. Jenna described:

> …you get that pull, that pull between professional responsibility and fear. I think from the professional’s perspective, we worry about getting it wrong and something bad happening…

Championing rights, working together, expertise and responding to individual need

Championing rights, working together, expertise and responding to individual need represent the personal values, skills, and ways of working that directly contribute to practitioners adopting a risk-balancing approach in DoLS decision-making. These practitioners' shared narrative of ensuring that decisions were tailored to the individual included "I want to make sure that we are doing what is right for that particular person" (Paula) and that unnecessary restriction was avoided, "It's not a case of putting a DoLS on them…it's about doing an assessment and working out the least restrictive option" (Sam). Some seemingly understood the ramifications a restriction could have; "it's life changing" (Caroline) and thus adopted a thorough approach to decision-making, including working together with people who knew the individual well and drawing on other practitioners' expertise:

> We will involve speech and language therapy if there are language problems that we feel are above and beyond our scope (Sam)

Working together through multi-disciplinary team (MDT) involvement, consulting with family members and drawing upon others' expertise facilitated shared responsibilities and increased confidence. Practitioners believed they were championing individuals' rights, with freedom and quality of life prioritised: "it's someone's freedom isn't it, it's a massive decision to make" (Audrey).

Sense of superior knowledge and working in isolation

Having a sense of superior knowledge but working in isolation appeared to contribute to adoption of a risk simplifying approach, e.g. “you only have to look at people to know if they lack mental capacity” (Chen). Practitioners seemed fixed in their beliefs “I did feed back to the staff there and then…this man clearly had capacity” (Amy) and appeared less open to others’ opinions when there were disagreements regarding DoLS decisions. For example, Audrey explained how she had refused to shift her thinking when challenged by another practitioner:

> I said to them, ‘I don’t feel I need to go out to revisit my capacity assessment…I can’t see me coming to any different conclusion.

3. Coping with contextual challenges

Coping with contextual challenges describe the wider difficulties of completing capacity assessments of people with brain injuries. These influenced participants experience of DoLS and indirectly impacted on decision-making styles. Three subcategories emerged relating to this category. These were: ‘structural issues’, ‘brain injury nuances’ and ‘knowledge and skill gaps.’

Structural issues

All participants described difficulties with the structure and process of DoLS. Moreover, the increase in DoLS assessments since the Cheshire West Ruling, had left them feeling unable to meet demand, particularly since DoLS work was not perceived as a practice priority.

> …when there were changes within in it, that made it nearly an impossible job to do…a sort of industry grew up overnight, and nobody had capacity and waits were horrendously long and continue to be horrendously long (Janice)

All participants mentioned the legal implications of this backlog, “once those 14 days have gone, the person then is probably being unlawfully deprived” (Paula) and of the potential impact on the individual, “I’ve had patients who have been discharged before they get assessed by the DoLS assessors” (Chen).

Another commonly mentioned problem was disjointed communication between practitioners making the application for DoLS and the independent assessors that have the final say in the outcome of the DoLS assessment. This problem was felt to be structural, for example resulting from difficulties assessing documentation:

> The number of people coming to do the assessment will do it as an add on to their job…they might do them of a weekend or of an evening they can’t document on our electronic healthcare records so we don’t know what they have done, how they have done it, equally we don’t know what they have seen from us, they don’t have access to the patients electronic healthcare records …so I think there is massive disconnect between us and them… (Sam)

Frustration with structural problems was expressed by all participants, as William summarised:

> …the process doesn’t always work the way we want it to because of the system and environment we find ourselves in

Brain injury nuances

Participants felt many other practitioners did not always understand the complexities of brain injury, particularly the ‘frontal lobe paradox’, which can subsequently lead to individuals being deemed, wrongly in their view, to have capacity and subsequently not ‘placed’ on DoLS. This lack of understanding was thought to indirectly contribute to practitioners adopting a risk-simplifying approach when making DoLS decisions. As one participant summarised:

> …people don’t understand executive dysfunction… you know the frontal lobe paradox comes into play, which creates a lot of differences in opinion, some professionals think they should be able to go home because they look OK on the outside, they don’t understand what is happening on the inside (Sam)

More specifically, participants considered that structuring a capacity interview helps someone with executive functioning difficulties to appear as though they have capacity even when they do not:

> The very act of structuring an interview enables them, but they don’t have that in real life, and that’s a major issue (Jenna)

Participants felt that the two-stage MCA capacity test was not robust enough to detect some of the "hidden disabilities" (Amy) of individuals with brain injury:

> I don't always think it's easy when the tests of capacity are around taking in information, retaining it, telling it back, I don't always think it is subtle enough for brain injury (Bobbi)

Knowledge and skill gaps

All participants commented on either their own knowledge gaps: "I have not had any training in DoLS…but I have been doing it for several years" (Chen) or of witnessing other practitioners using/applying DoLS incorrectly, "they were using DoLS to stop her going out, well that's not correct what so ever" (Audrey). Many felt that they were insufficiently prepared for the responsibility of undertaking DoLS assessments.

> …we have professionals doing capacity assessments who don't have much training. Like as a psychologist, I got some, but I think from what I remember we got half a day on capacity which you know, is not sufficient to walk into a job and be able to capacity assess (William)

In such circumstances, participants explained that they had to "deliberately up-skill" (William) themselves through seeking out courses, reading materials or training. Most felt knowledge and skill gaps contributed to misuse of DoLS:

> …you will see a lot of incredibly restrictive practices that the staff were just not challenging…you will see stuff on Panorama (TV programme) that is absolutely horrific but the majority of abuse is not happening like that, it's not that violence really, it's the small things, like restricting people's lives (Paula)

Discussion

The aim of this study was to develop a theoretical framework to describe the variations in how DoLS is applied in brain injury settings. Further objectives were to:

- Explore DoLS decision-making from the perspectives of a sample of health and social care practitioners.
- To develop a framework to capture how DoLS policy is applied in practice.
- To examine factors that may account for variation in DoLS decision-making.
- To develop an explanatory theoretical model to capture any variation of the DoLS decision-making processes.

Twelve Health and Social Care Practitioners were interviewed about their experiences of the use of DoLS in brain injury survivors. Data were collected and analysed in accordance with grounded theory methodology (Charmaz, 2014); an explanatory theoretical framework was developed, describing variations in the decision-making process. Thus, study objectives were met. Regarding results, three distinct approaches emerged encapsulating different decision-making styles when managing risk (risk-averse, risk-balancing, and risk-simplifying). Different mediating factors seemed to account for the variability in practice models. These encapsulated the wider contextual challenges of practice.

The theoretical model highlighted different decision-making styles that seemed to influence the outcome of DoLS assessments for people with brain injuries. As such, the findings emphasise that the decision-making process may not always be equitable or standard. This supports previous concerns that DoLS processes are open to wide interpretations (Shah et al, 2010) and that capacity assessments are complex and ultimately based on judgments (Banner and Szmukler, 2013). The findings suggest that people with brain injuries are perhaps receiving different levels of safeguarding and thus different levels of care depending on the decision-making style practitioners take when managing risk. Taking a ‘risk averse’ approach leaves people unnecessarily restricted, taking away their autonomy. Alternatively, not applying DoLS by adopting a ‘risk-simplifying’ approach or through misunderstanding brain injury nuances and DoLS can leave incapacitated individuals at risk of harm.

Practitioners who were risk-averse in their approach to DoLS decisions appeared to think it would always be in an individuals’ best interest to keep them ‘physically’ safe and some perceived a dual benefit of protecting themselves professionally. This reflects The House of Lords (2014) observation of a prevailing culture of risk-aversion and paternalism which was preventing the MCA from being used as Parliament intended. The present study highlights that a paternalistic culture may remain in relation to the use of DoLS with people with brain injuries. It offers further insight into the motivations behind paternalistic practice. Participants seemed driven to make-risk averse decisions through lack of confidence and feelings of anxiety around managing risk to patient safety and risk to the professional self. This reflects research that has shown that feelings can directly influence decision-making. For instance, Loewenstein et al, (2001) noted that at times of uncertainty it is the possibility rather than probability of risk that drives affect. This supports the present study which suggests that risk-averse decision-makers place disproportionate weight on minimising risk as much as possible. In such circumstances, these participants may be experiencing the possibility of risk as anxiety provoking and may be driven to make decisions primarily focusing on reducing their anxiety. Alternatively, behavioural decision-making theory in relation to law suggests that biases are more difficult to shift when there is a strong underlying motivation (Cunliffe, 2014). Participants in the current study were perhaps driven by the underlying motivation of patient and professional safety, which in turn may have increased cognitive biases and increased the likelihood of risk-adverse decision-making.

The risk-simplifying approach driven by a sense of superior knowledge and working in isolation was a particularly novel finding, which seems not to have been highlighted in previous MCA research. The MCA Code of Practice encourages joint assessments with professionals who know the client well (George and Gilbert, 2018), however, participants indicated that this is not consistently practiced. Interestingly, most spoke about witnessing a ‘risk-simplifying approach’ in practice rather than demonstrating this in their narrative. This perhaps represents a recruitment bias, in that those who expressed an interest to participate in the study were perhaps more experienced in DoLS work who wanted to share their frustration regarding others’ practice and the system. Although the risk-simplifying approach was a novel finding in relation to MCA research, there are perhaps some parallels with judicial decision-making research. For example, Cunliffe (2014) suggests that once decision-makers have formed a coherent narrative, they may overlook further facts that could aid decision-making and become overly confident in their own conclusions.

The findings also highlighted positive aspects of the use of DoLS. Many participants said they adopted a risk-balancing approach to DoLS decision-making. They embraced the legislation, utilising it as a tool to champion their patients' rights, promote their individual needs and strive to enhance their quality of life whilst simultaneously safeguarding them against harm. This approach was closely aligned with the MCA principles of balancing rights and protection (Bingham, 2012). Practitioners utilising this approach valued working together to draw upon expertise and to involve others who knew the person well. Such practice is in line with National Institute for Clinical Excellence (NICE, 2018) MCA guidelines which recommend involving others in the assessment process to gain a "complete picture of the person's capacity."

Unlike previous research, this study focused on the use of DoLS in people with brain injuries, rather than the wider population for whom DoLS may apply. It revealed concerns about other practitioners' knowledge of brain injury and concerns regarding the use of a 'risk-simplifying' approach to DoLS assessments for this population. Practitioners in the present study consistently reported concern about other professionals' assumptions of capacity in individuals with ABI. In support of findings by Moore et al, (2019) practitioners in the present study felt other professionals did not always understand the complexity of brain injury and its presentations. They noted the hidden effects of executive dysfunction difficulties, which might be masked well and contribute to practitioners wrongly judging someone as capacitous. This reflects other research which suggests that individuals with an ABI can mask their executive functioning difficulties due to their intact intellect (Acquired Brain Injury and Mental Capacity Act Interest Group, 2014) and intact language abilities (McCrea and Sharma, 2008). It may be that professionals without brain injury expertise and those who may utilise short-cuts and not conduct a thorough capacity assessment may judge individuals as more capable than they are. Other research supports this finding, suggesting that the decisions professionals make are complex and multifaceted, which the MCA assessment process might overlook (Brown and Marchant, 2013).

In addition to managing the complexity of brain injury nuances, the present study highlighted additional contextual challenges which influence use of DoLS in brain injury settings. One involved structural factor in relation to DoLS processes. The backlog of DoLS cases added further pressure on an already over-stretched system. Since the Cheshire West decision in 2014, a 10-fold increase was reported of DoLS cases (McNicoll, 2015) leading the Law Commission (2017) to describe the system as in crisis, reflecting participants' experiences in the present study. Other structural factors involved a disjoint in communication between Best Interest Assessor's (BIA's) and staff completing initial DoLS/capacity assessments. Frustration was expressed from both sides.

Finally, the present study confirmed long-standing concerns about the complexity of DoLS and subsequent misunderstandings (House of Commons Health Committee, 2013; Law Commission, 2017). Participants reported a lack of training and that their knowledge of DoLS was mainly self-taught. Some had witnessed misuse of the MCA. They noticed DoLS were often used for decisions other than care and residence and that people were at times unlawfully restricted. Others have remarked some professionals struggle to differentiate between deprivation and restriction, reflecting previous research (e.g. Szerlectics and O'Shea, 2011).

Taken together, the findings overall raise serious concerns regarding the complexity of DoLS and the practical difficulties of making reliable judgements of capacity for people with brain injuries. Arising from this is the possibility of unequal levels of safeguarding and subsequent care for people with brain injuries in England. Practitioners utilising DoLS appear to be working in an overstretched system, with a lack of training, confidence and understanding of the legislation. As such, the current research supports the DoLS reforms but draws attention to the need for implementation of the new law to address training and awareness raising about the liberty protection safeguards and responsibilities. Other considerations include potentially adapting capacity assessments for individuals with a brain injury to capture executive functioning difficulties which may be easily missed in a structured capacity assessment.

Implications

It may be useful for the theoretical model to be discussed within brain injury services to raise awareness of the ways in which DoLS has been used and ways in which new systems can build on this experience. The model could be used as a reflective tool to encourage practitioners to think about their own decision-making style and the processes that are driving this. The ‘risk-balancer’ approach seemed to reflect the intended ethos of the MCA/DoLS and may be fostered. This will help ensure decisions are made in the best interest of the patient rather than staff, especially if the outcome presents risks. The mediating factors associated with a risk-balancing approach may safeguard against risk-averse and risk-simplifying practices.

There is a need for good quality training about the new Liberty Protection Safeguards to ensure they are embedded in practice and that good knowledge and understanding can boost practitioners’ confidence and reduce anxiety and uncertainty. Given the importance of such legislation and the impact it can have on people’s lives, this training should be given priority.

Finally, the findings suggest the benefits of practitioners completing DoLS assessments to have brain injury expertise when relevant, and to perhaps utilise functional assessments to mitigate risks of overlooking executive functioning difficulties and subsequent care needs.

Strengths

To the best of our knowledge this is the first study to explore DoLS decision making processes for people with brain injuries. The findings reflect other views of DoLS and MCA legislation, such as knowledge gaps (House of Commons Health Committee, 2013), systemic problems (Law Commission, 2017) and complexities of assessing people with executive dysfunction difficulties (Moore et al, 2019). However, there were new findings, particularly in relation to styles of decision-making and factors that influence such styles. A constructivist grounded theory methodological approach supported the researcher to explore and capture rich participant narratives. This led to the emergence of a new model for understanding the processes underlying DoLS decision-making for those with an ABI.

The study contributes to developing research on mental capacity legislation. The implications provide an opportunity to implement change prior to the launch of the new Liberty Protection Safeguards. The importance and timeliness of the topic were noted by many of the research participants. A key strength of study included the recruitment strategy; theoretical sampling of participants allowed for the exploration of a range of narratives across services and professional job roles. Moreover, the study adhered to guidelines proposed by Elliot et al, (1999) on ensuring quality in qualitative research (see appendix U).

Limitations

A key limitation of the study concerns the data itself. All participants volunteered to participate. Given the complexity of DoLS, practitioners' motivations for wanting to participate must be considered. Perhaps they felt they had something particularly positive or negative to contribute. This is an inherent difficulty with self-report data (Edwards, 1990) and it is therefore possible that some experiences have not been represented, thus the theoretical model must be interpreted with caution.

In addition, although multiple validation checks were completed, the researcher could have enhanced this process through returning to original participants to gain feedback on the model. However, given that the appropriateness of this has been debated in the literature due to issues such as ‘collusion’ and the potential for discrepant accounts (e.g. researchers aim to provide an overview, whereas some participants want to highlight individual concerns [Barbour, 2001]), the researcher decided not to gain feedback from original participants.

Future Research

Future research could look to explore the decision-making process from the view of the person subject to DoLS and the carers/family members involved in the process. This would help build on the current model to show how practitioners’ decision-making impacts on them all.

The decision-making styles and mediating factors contributing to these styles should be explored in other populations to whom DoLS’ successor applies (e.g. to individuals with dementia or learning disabilities) to test whether the same underlying processes and challenges apply. This could further our understanding of the use of such legislation in certain populations and inform the focus of training and supervision/support for practitioners.

Finally, it would be interesting for this research to be replicated to gain insight into any changes, improvements, or remaining challenges with the new legislation.

Summary

This study aimed to understand the DoLS decision-making process in an ABI population. 12 health and social care practitioners were interviewed about their experiences of the process and practice of DoLS with individuals with a brain injury. A grounded theory approach to data collection and analysis was used, and a decision-making model was developed. The model demonstrated a variety of decision-making styles. Each style was influenced by an array of mediating factors. The model emphasised the importance of the mediating factors which contributed to the risk-balancing style: working together, championing rights, expertise and responding to individual need. These factors contributed to an approach which mirrored best practice guidelines and protected practitioners from implementing risk averse or risk-simplifying practice; both of which can result in DoLS being used incorrectly. The model also highlighted the shared contextual challenges that all practitioners experience when utilising DoLS for this client group. Again, the mediating factors contributing to a risk-balancing approach protected against the impact of these.

Despite highlighting some good practice, the model developed from the interviews demonstrated the complexities and challenges practitioners face with the use of DoLS in those with ABI. The variety of decision-making styles and reported contextual challenges raise concerns about the reliability of DoLS decisions for this client group. Taken together, the findings overall support the need for reform to ensure the protection of people's rights and safety.

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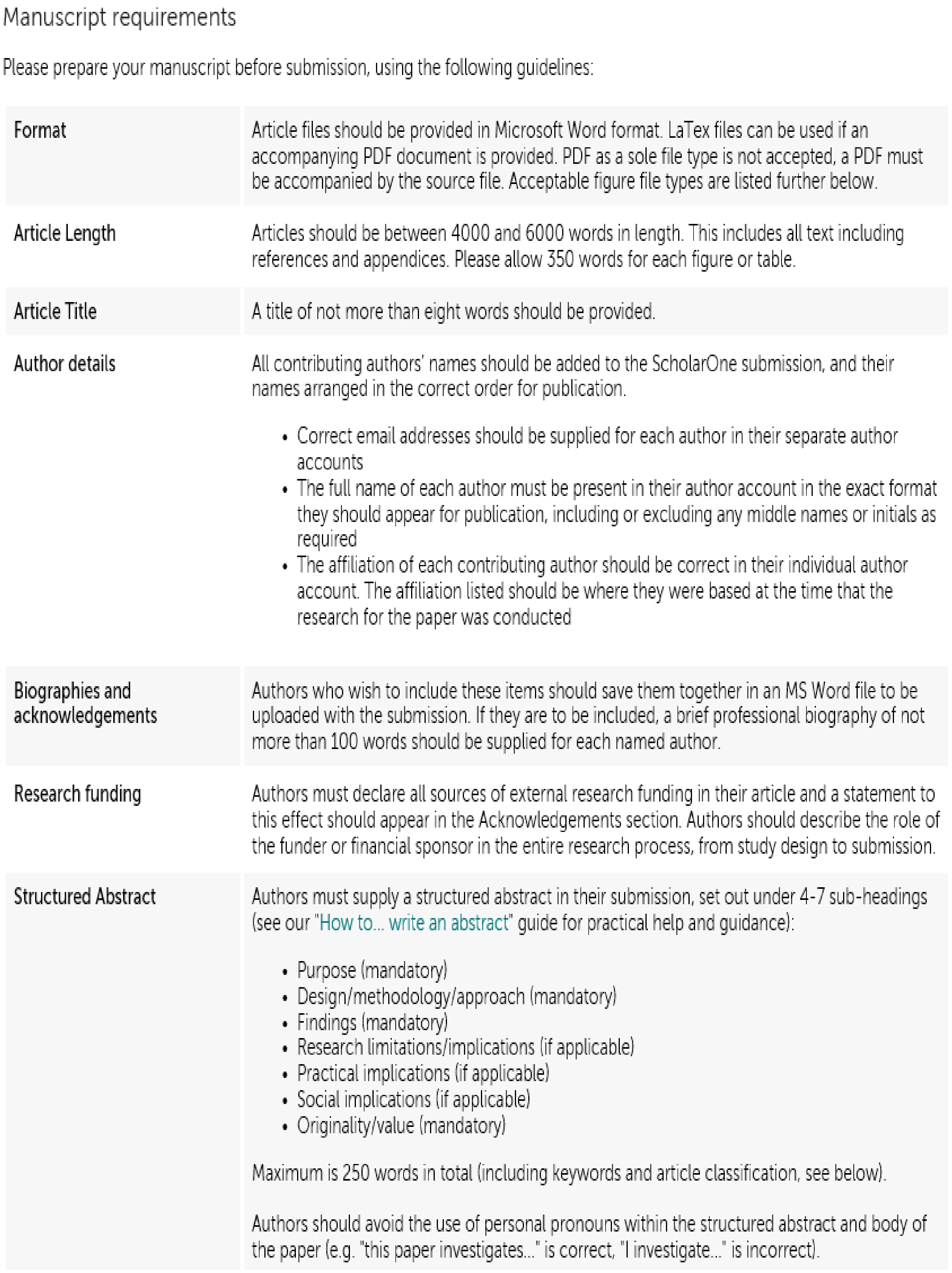
Appendix A – Author Guidelines for The Journal of Adult Protection



Manuscript requirements

Please prepare your manuscript before submission, using the following guidelines:

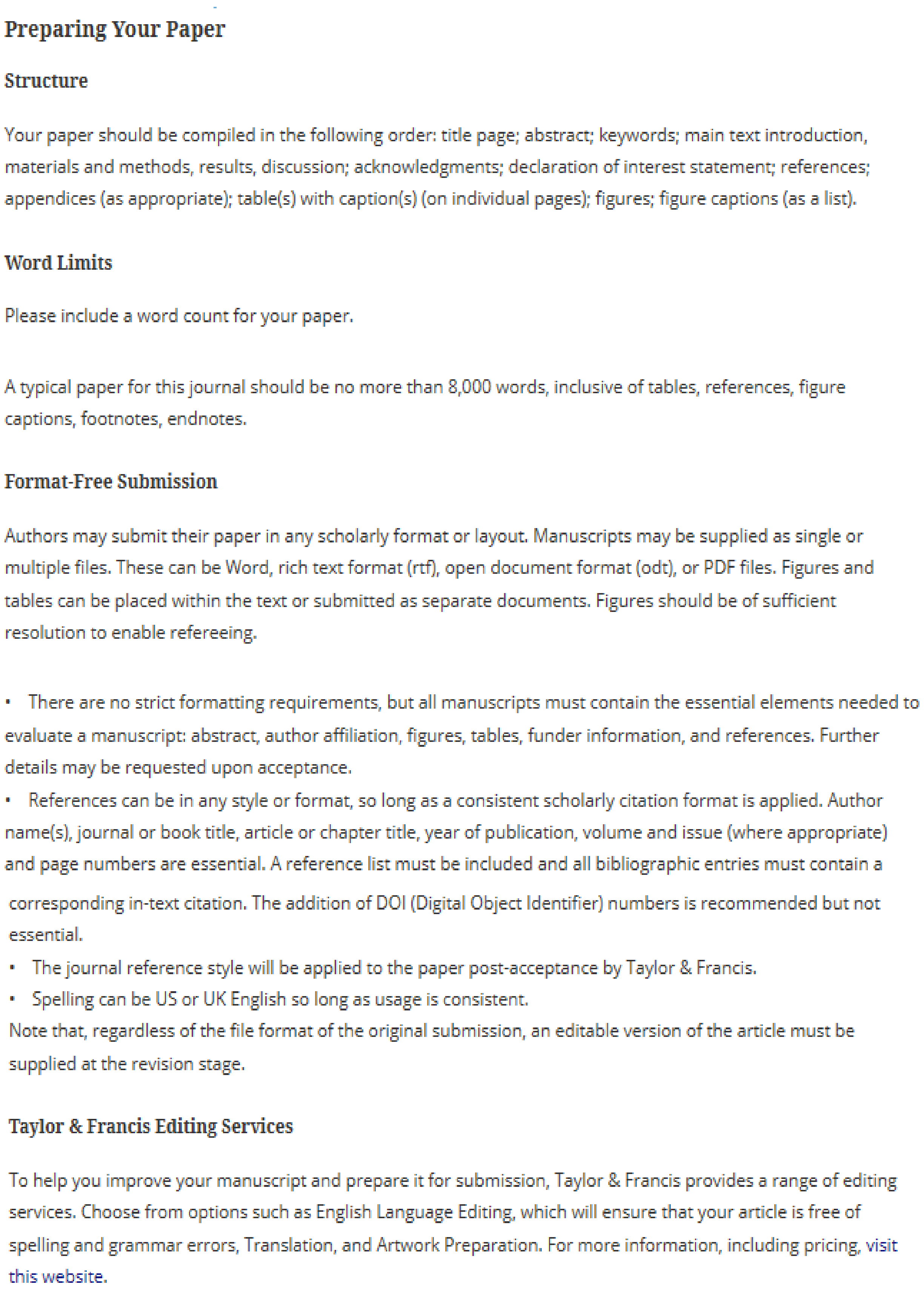
Format	Article files should be provided in Microsoft Word format. LaTex files can be used if an accompanying PDF document is provided. PDF as a sole file type is not accepted, a PDF must be accompanied by the source file. Acceptable figure file types are listed further below.
Article Length	Articles should be between 4000 and 6000 words in length. This includes all text including references and appendices. Please allow 350 words for each figure or table.
Article Title	A title of not more than eight words should be provided.
Author details	All contributing authors' names should be added to the ScholarOne submission, and their names arranged in the correct order for publication. • Correct email addresses should be supplied for each author in their separate author accounts • The full name of each author must be present in their author account in the exact format they should appear for publication, including or excluding any middle names or initials as required • The affiliation of each contributing author should be correct in their individual author account. The affiliation listed should be where they were based at the time that the research for the paper was conducted
Biographies and acknowledgements	Authors who wish to include these items should save them together in an MS Word file to be uploaded with the submission. If they are to be included, a brief professional biography of not more than 100 words should be supplied for each named author.
Research funding	Authors must declare all sources of external research funding in their article and a statement to this effect should appear in the Acknowledgements section. Authors should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
Structured Abstract	Authors must supply a structured abstract in their submission, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance): • Purpose (mandatory) • Design/methodology/approach (mandatory) • Findings (mandatory) • Research limitations/implications (if applicable) • Practical implications (if applicable) • Social implications (if applicable) • Originality/value (mandatory) Maximum is 250 words in total (including keywords and article classification, see below). Authors should avoid the use of personal pronouns within the structured abstract and body of the paper (e.g. "this paper investigates..." is correct, "I investigate..." is incorrect).

Keywords	Authors should provide appropriate and short keywords in the ScholarOne submission that encapsulate the principal topics of the paper (see the How to... ensure your article is highly downloaded guide for practical help and guidance on choosing search-engine friendly keywords). The maximum number of keywords is 12. Whilst Emerald will endeavour to use submitted keywords in the published version, all keywords are subject to approval by Emerald's in house editorial team and may be replaced by a matching term to ensure consistency.
Article Classification	Authors must categorize their paper as part of the ScholarOne submission process. The category which most closely describes their paper should be selected from the list below. **Research paper.** This category covers papers which report on any type of research undertaken by the author(s). The research may involve the construction or testing of a model or framework, action research, testing of data, market research or surveys, empirical, scientific or clinical research. **Viewpoint.** Any paper, where content is dependent on the author's opinion and interpretation, should be included in this category; this also includes journalistic pieces. **Technical paper.** Describes and evaluates technical products, processes or services. **Conceptual paper.** These papers will not be based on research but will develop hypotheses. The papers are likely to be discursive and will cover philosophical discussions and comparative studies of others' work and thinking. **Case study.** Case studies describe actual interventions or experiences within organizations. They may well be subjective and will not generally report on research. A description of a legal case or a hypothetical case study used as a teaching exercise would also fit into this category. **Literature review.** It is expected that all types of paper cite any relevant literature so this category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular subject area. It may be a selective bibliography providing advice on information sources or it may be comprehensive in that the paper's aim is to cover the main contributors to the development of a topic and explore their different views. **General review.** This category covers those papers which provide an overview or historical examination of some concept, technique or phenomenon. The papers are likely to be more descriptive or instructional ("how to" papers) than discursive.
Headings	Headings must be concise, with a clear indication of the distinction between the hierarchy of headings. The preferred format is for first level headings to be presented in bold format and subsequent sub-headings to be presented in medium italics.
Notes/Endnotes	Notes or Endnotes should be used only if absolutely necessary and must be identified in the text by consecutive numbers, enclosed in square brackets and listed at the end of the article.

Figures	All Figures (charts, diagrams, line drawings, web pages/screenshots, and photographic images) should be submitted in electronic form. All Figures should be of high quality, legible and numbered consecutively with arabic numerals. Graphics may be supplied in colour to facilitate their appearance on the online database. • Figures created in MS Word, MS PowerPoint, MS Excel, Illustrator should be supplied in their native formats. Electronic figures created in other applications should be copied from the origination software and pasted into a blank MS Word document or saved and imported into an MS Word document or alternatively create a .pdf file from the origination software. • Figures which cannot be supplied as above are acceptable in the standard image formats which are: .pdf, .ai, and .eps. If you are unable to supply graphics in these formats then please ensure they are .tif, .jpeg, or .bmp at a resolution of at least 300dpi and at least 10cm wide. • To prepare web pages/screenshots simultaneously press the "Alt" and "Print screen" keys on the keyboard, open a blank Microsoft Word document and simultaneously press "Ctrl" and "V" to paste the image. (Capture all the contents/windows on the computer screen to paste into MS Word, by simultaneously pressing "Ctrl" and "Print screen".) • Photographic images should be submitted electronically and of high quality. They should be saved as .tif or .jpeg files at a resolution of at least 300dpi and at least 10cm wide. Digital camera settings should be set at the highest resolution/quality possible.
Tables	Tables should be typed and included in a separate file to the main body of the article. The position of each table should be clearly labelled in the body text of article with corresponding labels being clearly shown in the separate file. Ensure that any superscripts or asterisks are shown next to the relevant items and have corresponding explanations displayed as footnotes to the table, figure or plate.
References	References to other publications must be in **Harvard** style and carefully checked for completeness, accuracy and consistency. This is very important in an electronic environment because it enables your readers to exploit the Reference Linking facility on the database and link back to the works you have cited through CrossRef. You should cite publications in the text: (Adams, 2006) using the first named author's name or (Adams and Brown, 2006) citing both names of two, or (Adams *et al.*, 2006), when there are three or more authors. At the end of the paper a reference list in alphabetical order should be supplied:
For books	Surname, Initials (year), *Title of Book*, Publisher, Place of publication. e.g. Harrow, R. (2005), *No Place to Hide*, Simon & Schuster, New York, NY.
For book chapters	Surname, Initials (year), "Chapter title", Editor's Surname, Initials, *Title of Book*, Publisher, Place of publication, pages. e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", in Stankosky, M. (Ed.), *Creating the Discipline of Knowledge Management*, Elsevier, New York, NY, pp. 15-20.
For journals	Surname, Initials (year), "Title of article", *Journal Name*, volume issue, pages. e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", *Journal of Consumer Marketing*, Vol. 22 No. 2, pp. 72-80.

For published conference proceedings	Surname, Initials (year of publication), "Title of paper", in Surname, Initials (Ed.), *Title of published proceeding which may include place and date(s) held*, Publisher, Place of publication, Page numbers. e.g. Jakkilinki, R., Georgievski, M. and Sharda, N. (2007), "Connecting destinations with an ontology-based e-tourism planner", in *Information and communication technologies in tourism 2007 proceedings of the international conference in Ljubljana, Slovenia, 2007*, Springer-Verlag, Vienna, pp. 12-32.
For unpublished conference proceedings	Surname, Initials (year), "Title of paper", paper presented at Name of Conference, date of conference, place of conference, available at: URL if freely available on the internet (accessed date). e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).
For working papers	Surname, Initials (year), "Title of article", working paper [number if available], Institution or organization, Place of organization, date. e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.
For encyclopedia entries (with no author or editor)	*Title of Encyclopedia* (year) "Title of entry", volume, edition, Title of Encyclopedia, Publisher, Place of publication, pages. e.g. *Encyclopaedia Britannica* (1926) "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp. 765-71. (For authored entries please refer to book chapter guidelines above)
For newspaper articles (authored)	Surname, Initials (year), "Article title", *Newspaper*, date, pages. e.g. Smith, A. (2008), "Money for old rope", *Daily News*, 21 January, pp. 1, 3-4.
For newspaper articles (non-authored)	*Newspaper* (year), "Article title", date, pages. e.g. *Daily News* (2008), "Small change", 2 February, p. 7.
For archival or other unpublished sources	Surname, Initials, (year), "Title of document", Unpublished Manuscript, collection name, inventory record, name of archive, location of archive. e.g. Litman, S. (1902), "Mechanism & Technique of Commerce", Unpublished Manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.
For electronic sources	If available online, the full URL should be supplied at the end of the reference, as well as a date that the resource was accessed. e.g. Castle, B. (2005), "Introduction to web services for remote portlets", available at: http://www-128.ibm.com/developerworks/library/ws-wsrp/ (accessed 12 November 2007). Standalone URLs, i.e. without an author or date, should be included either within parentheses within the main text, or preferably set as a note (roman numeral within square brackets within text followed by the full URL address at the end of the paper).
For data	Surname, Initials (year), *Title of Data Set*, Name of data repository, available at: Persistent URL e.g. Campbell, A. and Kahn, R.L. (1999), *American National Election Study, 1948*, ICPSR07218-v3, Inter-university Consortium for Political and Social Research (distributor), Ann Arbor, MI, available at: http://doi.org/10.3886/ICPSR07218.v3

Appendix B – Author Guidelines for Journal of Ethics and Social Welfare



Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper.

A typical paper for this journal should be no more than 8,000 words, inclusive of tables, references, figure captions, footnotes, endnotes.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. A reference list must be included and all bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

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Checklist: What to Include

1. **Author details.** All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain an unstructured abstract of 200 words.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 3 and 10 **keywords.** Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].
6. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.
7. **Biographical note.** Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).
8. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
9. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
13. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

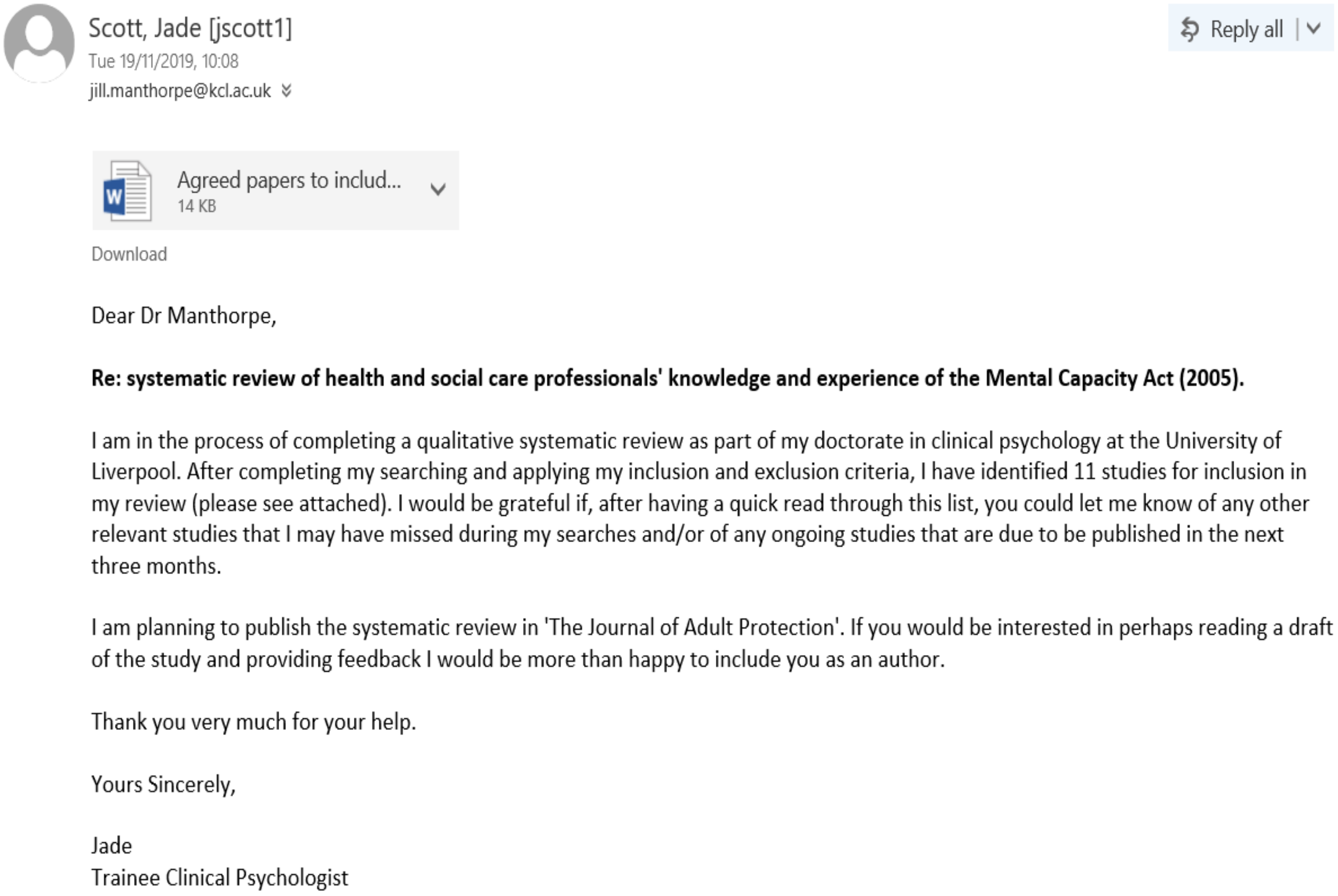
Appendix C - Example Search Strategy

PsychINFO

1. “mental capacity”
2. “mental capacity act”
3. “mental capacity assessment”
4. 1 OR 2 OR 3
5. Knowledge
6. experience*
7. understand*
8. view*
9. perspective*
10. apply*
11. application*
12. implement*
13. 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12
14. 13 AND 4
15. 13 AND 4 [DT 2007 – 2019]

Total papers found **285**

Appendix D – Email to Author of Some Included Papers and Expert in Field of MCA Research



Scott, Jade [jscott1]
Tue 19/11/2019, 10:08
jill.manthorpe@kcl.ac.uk

Dear Dr Manthorpe,

Re: systematic review of health and social care professionals' knowledge and experience of the Mental Capacity Act (2005).

I am in the process of completing a qualitative systematic review as part of my doctorate in clinical psychology at the University of Liverpool. After completing my searching and applying my inclusion and exclusion criteria, I have identified 11 studies for inclusion in my review (please see attached). I would be grateful if, after having a quick read through this list, you could let me know of any other relevant studies that I may have missed during my searches and/or of any ongoing studies that are due to be published in the next three months.

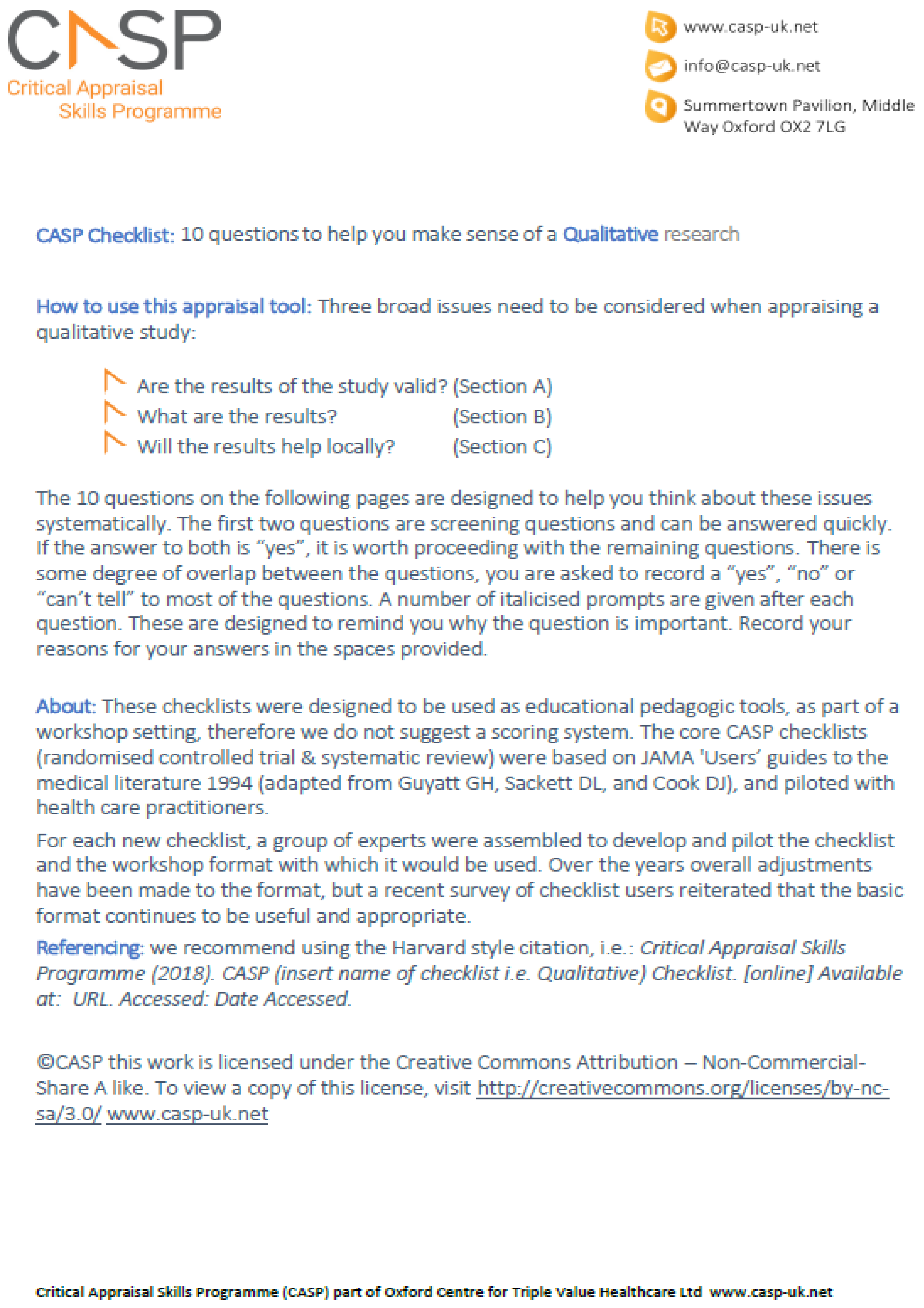
I am planning to publish the systematic review in 'The Journal of Adult Protection'. If you would be interested in perhaps reading a draft of the study and providing feedback I would be more than happy to include you as an author.

Thank you very much for your help.

Yours Sincerely,

Jade
Trainee Clinical Psychologist

Appendix E – CASP Quality Assessment Tool



CASP
Critical Appraisal
Skills Programme

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Summertown Pavilion, Middle
Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare Ltd www.casp-uk.net

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?	Yes ☐ Can't Tell ☐ No ☐	HINT: Consider • If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

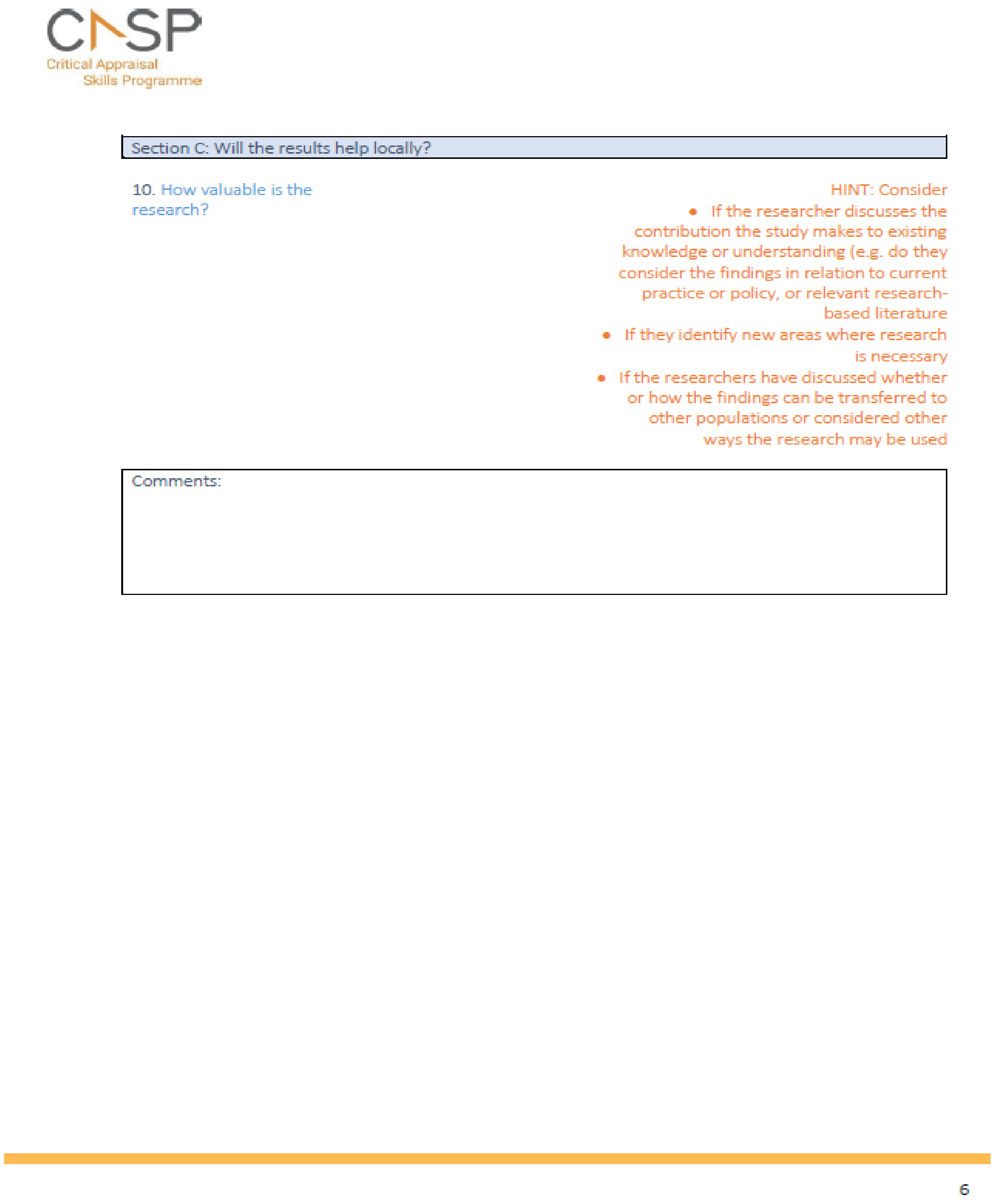
Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:



Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

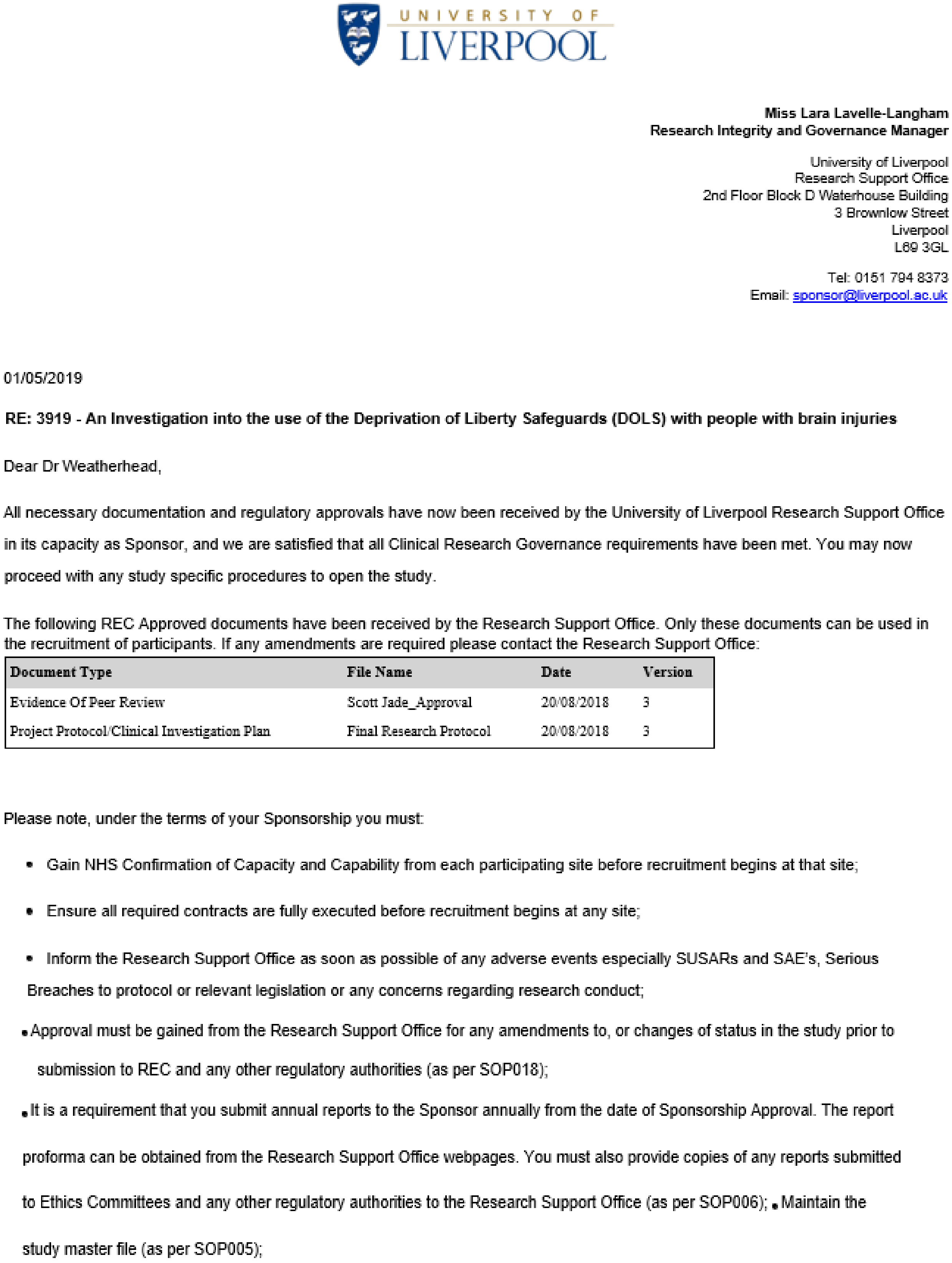
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix F – Example of how the Theme of ‘The Empowering Nature of the MCA’ was Developed

Line by line codes	Descriptive themes	Analytical Theme
Promoting rights	Upholding Human rights	‘The empowering nature of the MCA’
Balancing rights		
Protects best interests		
Provides a ‘fair chance’		
Embeds thoughts about rights		
Balancing autonomy vs protection		
Balancing risk		
MCA = Increases focus on human rights		
Considering rights		
Increases patient involvement	Magnifying person-centred care	
Protects choice		
Increases patient control		
Empowering individuals		
Respecting autonomy		
Improved access to information		
Optimising shared decision-making		
Keeping patients central		
Dispels myths of incapacity		
Advocating for patients		
Offers clarity		
Encourages participation		
Offering concrete information		

Appendix G – Sponsorship Approval



Miss Lara Lavelle-Langham
Research Integrity and Governance Manager

University of Liverpool
Research Support Office
2nd Floor Block D Waterhouse Building
3 Brownlow Street
Liverpool
L69 3GL

Tel: 0151 794 8373
Email: sponsor@liverpool.ac.uk

01/05/2019

RE: 3919 - An Investigation into the use of the Deprivation of Liberty Safeguards (DOLS) with people with brain injuries

Dear Dr Weatherhead,

All necessary documentation and regulatory approvals have now been received by the University of Liverpool Research Support Office in its capacity as Sponsor, and we are satisfied that all Clinical Research Governance requirements have been met. You may now proceed with any study specific procedures to open the study.

The following REC Approved documents have been received by the Research Support Office. Only these documents can be used in the recruitment of participants. If any amendments are required please contact the Research Support Office:

Document Type	File Name	Date	Version
Evidence Of Peer Review	Scott Jade_Approval	20/08/2018	3
Project Protocol/Clinical Investigation Plan	Final Research Protocol	20/08/2018	3

Please note, under the terms of your Sponsorship you must:

- Gain NHS Confirmation of Capacity and Capability from each participating site before recruitment begins at that site;
- Ensure all required contracts are fully executed before recruitment begins at any site;
- Inform the Research Support Office as soon as possible of any adverse events especially SUSARs and SAE's, Serious Breaches to protocol or relevant legislation or any concerns regarding research conduct;
- Approval must be gained from the Research Support Office for any amendments to, or changes of status in the study prior to submission to REC and any other regulatory authorities (as per SOP018);
- It is a requirement that you submit annual reports to the Sponsor annually from the date of Sponsorship Approval. The report proforma can be obtained from the Research Support Office webpages. You must also provide copies of any reports submitted to Ethics Committees and any other regulatory authorities to the Research Support Office (as per SOP006);
- Maintain the study master file (as per SOP005);

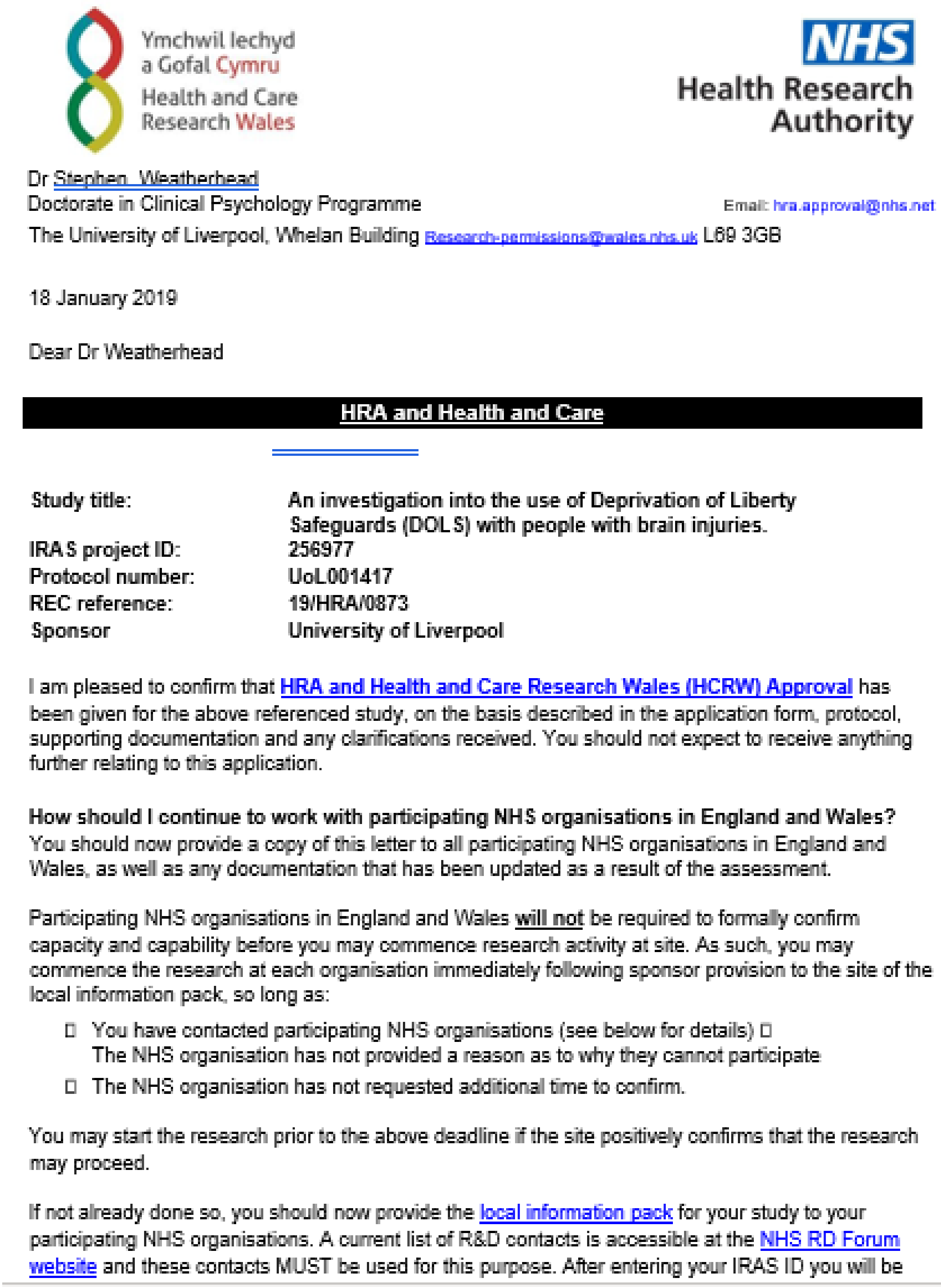
- Make available for review any study documentation when requested by the sponsors and regulatory authorities for the purposes of audit or inspection;
- Upon the completion of the study it is a requirement that you submit an End of Study Declaration (within 90 days of the end of the study) and End of Study Report (within 12 months of the end of the study) to the Sponsor. The End of Study Declaration proforma can be obtained from the Research Support Office webpages. You must also provide copies of any reports submitted to Ethics Committees and any other regulatory authorities to the Research Support Office (as per SOP021);
- Ensure you and your study team are up to date with the current RSO SOPs throughout the duration of the study.

If you have any queries regarding the sponsorship of the study, please do not hesitate to contact the Clinical Research Governance Team on 0151 794 8373 (email sponsor@liverpool.ac.uk).

Yours sincerely,

Miss Lara Lavelle-Langham
Research Integrity and Governance Manager
Research Support Office

Appendix H – Health Research Authority (HRA) Approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Stephen Weatherhead
Doctorate in Clinical Psychology Programme
The University of Liverpool, Whelan Building Research-permissions@wales.nhs.uk L69 3GB

Email: hra.approval@nhs.net

18 January 2019

Dear Dr Weatherhead

HRA and Health and Care

Study title:	**An investigation into the use of Deprivation of Liberty Safeguards (DOLS) with people with brain injuries.**
IRAS project ID:	**256977**
Protocol number:	**UoL001417**
REC reference:	**19/HRA/0873**
Sponsor	**University of Liverpool**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

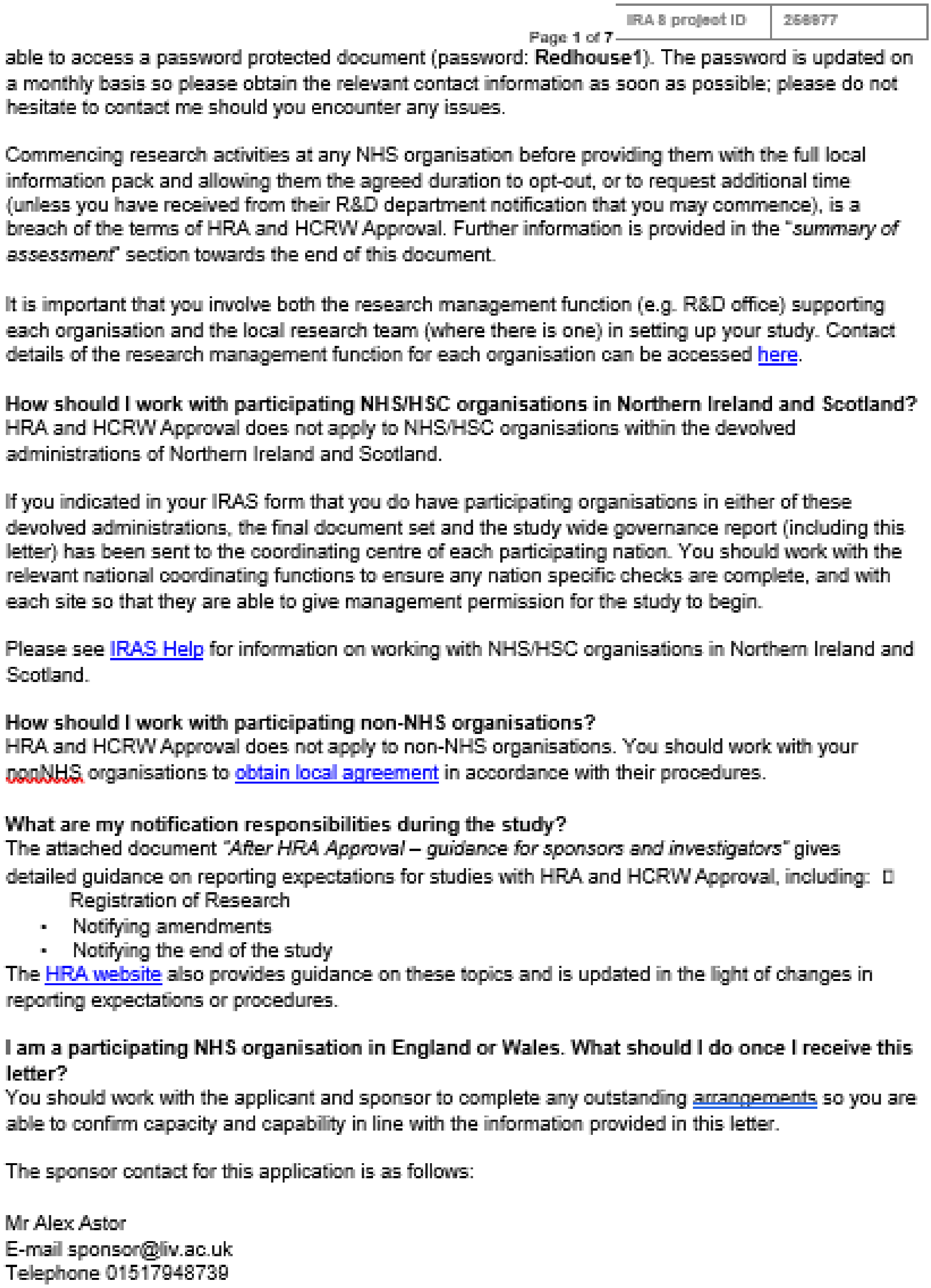
How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales will not be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation immediately following sponsor provision to the site of the local information pack, so long as:

☐ You have contacted participating NHS organisations (see below for details) ☐
The NHS organisation has not provided a reason as to why they cannot participate
☐ The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. After entering your IRAS ID you will be



IRAS project ID	258877

Page 1 of 7

able to access a password protected document (password: **Redhouse1**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your nonNHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

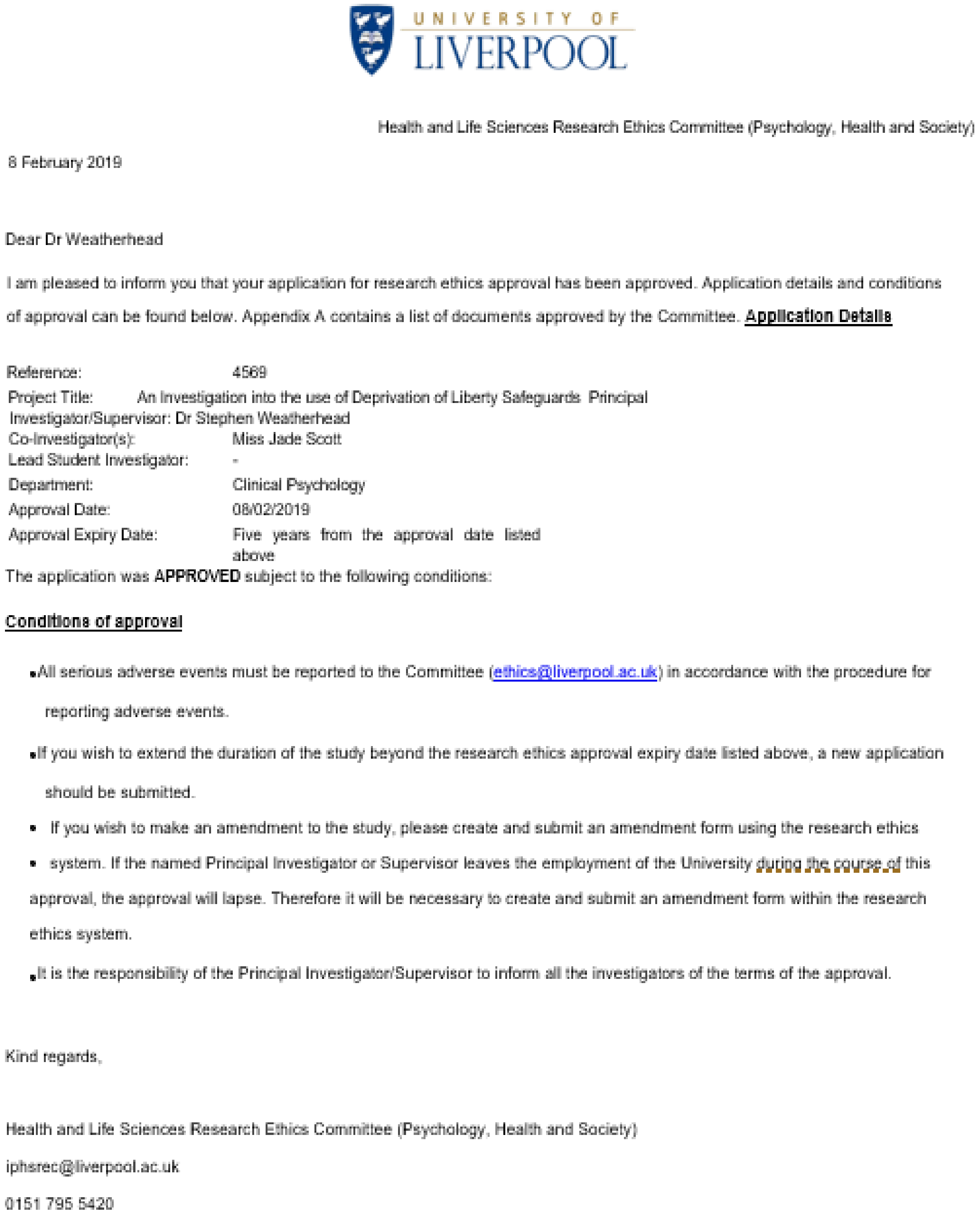
The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Mr Alex Astor
E-mail sponsor@liv.ac.uk
Telephone 01517948739

Appendix I – University of Liverpool Ethical Approval



UNIVERSITY OF LIVERPOOL

Health and Life Sciences Research Ethics Committee (Psychology, Health and Society)

8 February 2019

Dear Dr Weatherhead

I am pleased to inform you that your application for research ethics approval has been approved. Application details and conditions of approval can be found below. Appendix A contains a list of documents approved by the Committee. **Application Details**

Reference: 4569
Project Title: An Investigation into the use of Deprivation of Liberty Safeguards Principal Investigator/Supervisor: Dr Stephen Weatherhead
Co-Investigator(s): Miss Jade Scott
Lead Student Investigator: -
Department: Clinical Psychology
Approval Date: 08/02/2019
Approval Expiry Date: Five years from the approval date listed above

The application was **APPROVED** subject to the following conditions:

Conditions of approval

- All serious adverse events must be reported to the Committee (ethics@liverpool.ac.uk) in accordance with the procedure for reporting adverse events.
- If you wish to extend the duration of the study beyond the research ethics approval expiry date listed above, a new application should be submitted.
- If you wish to make an amendment to the study, please create and submit an amendment form using the research ethics
- system. If the named Principal Investigator or Supervisor leaves the employment of the University during the course of this approval, the approval will lapse. Therefore it will be necessary to create and submit an amendment form within the research ethics system.
- It is the responsibility of the Principal Investigator/Supervisor to inform all the investigators of the terms of the approval.

Kind regards,

Health and Life Sciences Research Ethics Committee (Psychology, Health and Society)

iphsrec@liverpool.ac.uk

0151 795 5420

Appendix J – Participant Study Advertisement

‘VOLUNTEERS REQUIRED FOR PSYCHOLOGY STUDY’

Study Title: *An Investigation into the Deprivation of Liberty Safeguards (DOLS) with people with Brain Injuries*

My name is Jade Scott and I am a trainee clinical psychologist conducting this research on the Doctorate in Clinical Psychology programme at The University of Liverpool.

What is the study about?

The purpose of the study is to understand what the process is to ‘making a decision about whether or not DOLS are applied for’ in individuals with an Acquired Brain Injury (ABI). The study is looking to recruit **professionals** working in a brain injury setting whom have been involved in this decision-making process in the last 12 months. You may be any type of professional (psychiatrist, psychologist, social worker, occupational therapist, service manager etc).

What does the study involve?

If you decide you want to take part in the study, you would be asked to attend an interview within your workplace which would last for around one hour. The interview would be audio recorded and later transcribed. During the interview we would talk about decisions you have made regarding applying for/administering a DOLS or not. This may include asking you questions like “do you think the process could be improved in anyway”.

Eligibility:

Male and Female professionals working in a brain injury setting

Must have been involved in the DOLS decision making process over the past 12 months

Over the age of 18

Fluent in English

To receive a participation information sheet with more information about the study or if you have any queries or questions about the study please do not hesitate to contact me on

07850696194 or you can email me at jade.scott@liverpool.ac.uk

Appendix K – Participant Study Information Sheet

PARTICIPANT INFORMATION SHEET

Title of the research project: An investigation into the Deprivation of Liberty Safeguards (DOLS) in people with brain injuries.

Name of researcher(s): Jade Scott, Stephen Weatherhead, Stephen Mullin.

You are being invited to participate in a research study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to understand what the process is for deciding whether Deprivation of Liberty Safeguards (DOLS) are implemented with an individual who has an Acquired Brain Injury (ABI).

Why have I been chosen to take part?

You have been approached because I want to talk to professionals whom are involved in deciding whether Deprivation of Liberty Safeguards (DOLS) should be applied for/administered in individuals with an ABI or not.

Do I have to take part?

No. It is completely up to you to decide whether you would like to take part in this study or not. If you decide you do not want to take part this will not affect your work with the service. There are no negative consequences to not taking part in this research.

What will happen if I take part?

If you decide to take part in the study, you may be asked to take part in an interview with me. As I can only recruit up to 14 participants, I may not be able to interview everyone whom expresses an interest in taking part. However, I will let you know by September 2019 if you are not needed in the study.

If you are asked to attend an interview, I will answer any questions you have before the interview begins. The interview will take approximately one hour to complete, and it will be audio recorded. The interview can stop when you want it to stop and if you would like some breaks throughout, we can ensure that happens too.

We will talk about experiences you have in relation to Deprivation of Liberty Safeguards (DOLS) in the context of brain injuries. This may include asking you questions like “what are the positives and negatives of the process”. The interview will take place at your workplace. If you have your own office the interview can take place there, if not we will book a private room on your work site.

I might ask if I can interview you a second time to further explore some of the ideas we discussed in the first interview. It is up to you if you want to do that second interview or not.

How will my data be used?

The university processes personal data as part of its research and teaching activities in accordance with the lawful basis of ‘public task,’ and in accordance with the University’s purpose of “advancing education, learning and research for the public benefit.

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University’s research. The principle investigator, Dr Stephen Weatherhead acts as the Data Processor for this study, and any queries relating to the handling of your personal data can be sent to Dr Stephen Weatherhead at ste.liverpool@ac.uk.

Further information on how your data will be used can be found in the table below.

How will my data be collected?	Through a one to one, face to face interview using a Dictaphone to audio record
How will my data be stored?	On an electronic computer and anonymised
How long will my data be stored for?	10 years
What measures are in place to protect the security and confidentiality of my data?	Personal data will be stored on a secure university computer in password protected files with only the research team having access. Audio recordings will be deleted as soon as they have been transcribed into an anonymised written document.
Will my data be anonymised?	Yes, nobody will know what you say in the interviews. I will ask if I can use quotes of what you said for the write up of the research. Any quotes I use will be anonymised. This means I will not use your name next to the quote but will ask you to choose a name that I can use instead. The typed version of your interview will be made anonymous by removing any identifiable information, including your name.
How will my data be used?	Data will be used to develop a theoretical model to explain what is understood by the DOLS decision making process. This will be presented in a thesis report for academic purposes and in a paper which will aim to be published in a scientific journal.
Who will have access to my data?	The research team: Dr Stephen Weatherhead (Consultant Clinical Psychologist), Dr Stephen Mullin (Clinical Neuropsychologist) and Jade Scott (Trainee Clinical Psychologist/ student researcher)

Will my data be archived for use in other research projects in the future?	Yes, your anonymised data may be used for further research projects in the future.
How will my data be destroyed?	Dr Stephen Weatherhead will delete your data from the electronic files after 10 years.

Are there any risks in taking part?

Although it is hoped that there will be no risks of taking part, it may be possible that some of the questions elicit difficult emotions. Should you experience any difficulties from taking part please feel free to contact the researcher. Alternatively, there will be some de-brief information at the end of the study which will provide information of who you can contact should you require any help or support after participating.

Furthermore, if the researcher becomes concerned about unethical practice, then confidentiality cannot be guaranteed. If necessary, for the protection of service-users, staff or the general public, the researcher may need to raise issues of unethical practice with her research supervisor and/or with your service manager. The researcher will always speak with you first about this, before deciding with you how best to move forward should this happen.

Are there any benefits in taking part?

Although you may find participating interesting, there are no direct benefits to you in taking part. This research is intended to find ways to improve clinical practice around DOLS decision making processes in individuals with an ABI.

What will happen to the results of the study?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. I will present the results back to the services that I have recruited from. I will also send you a brief summary report of the results should you wish to receive one. You will not be identifiable at any point in the research or when disseminating results.

What will happen if I want to stop taking part?

If you do decide to take part, you will be free to withdraw your participation at any time, without explanation, and without incurring a disadvantage. However, you will only be able to withdraw your data from the study **up to one week** after the interview. After this time your data may already be anonymised, and it will therefore not be possible to withdraw your data. None of your data will be used if you withdraw prior to this one-week period.

You can withdraw from the study by contacting me on **07850696194** or **jade.scott@liverpool.ac.uk.**

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the main researcher Jade Scott at jade.scott@liverpool.ac.uk and we will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the Research Ethics and Integrity Office at ethics@liv.ac.uk. When contacting the Research and Integrity Office, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involves, and the details of the complain you wish to make.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

Who can I contact if I have further questions?

If you have any questions you can contact:
Jade Scott
Doctorate in Clinical Psychology Programme
University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB
07850696194

Principal Investigator

Dr Stephen Weatherhead
Doctorate in Clinical Psychology
University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB
07775644760
ste@liverpoool.ac.uk

Student Investigator

Jade Scott
Doctorate in Clinical Psychology
University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB
07850696194
jade.scott@liverpool.ac.uk

Appendix L – Participant Consent Form

UNIVERSITY OF LIVERPOOL

PARTICIPANT CONSENT FORM

Title of the research project: An investigation into the Deprivation of Liberty Safeguards (DOLS) in people with brain injuries.

Name of researcher(s): Jade Scott, Stephen Weatherhead, Stephen Mullin.

Please initial box

1. I confirm that I have read the information sheet dated.................... for the above study, or it has been read to me. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that taking part in this study involves an audio recorded interview which will be made into an anonymised written transcript. ☐

3. I understand that my audio recording will be deleted as soon as it has been transcribed into a written document. ☐

4. I understand that confidentiality cannot be guaranteed if the researcher becomes concerned about my fitness to practice, but will speak to me first about this before deciding on how to Move forwards. ☐

5. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time during completion of the interview without giving any reason and without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline which will end the study. ☐

6. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to my data being anonymised, which will take place **one week after my initial interview**. I understand that following **one week from my interview date**, I will no longer be able to request access to or Withdrawal of the information. ☐

7. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Liverpool until it is fully anonymised and then deposited in the archive for sharing and use by other authorised researchers to support other research in the future. ☐

8. I understand that signed consent forms and a transcript of my interview will be retained in The University of Liverpool, Whelan Building, Department of Clinical Psychology with only the research team having access to it until August 2030. ☐

9. I understand that the information from my interview will be put together with other participants' data, anonymised and may be published. ☐

10. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

11. I consent to the University of Liverpool keeping written transcriptions of the study for 10 years after the study has finished. ☐

11. I consent to take part in the study. ☐

________________	________________	________________
Name of Participant	Date	Signature
________________	________________	________________
Name of Person taking consent	Date	Signature

Chief Investigator

Dr Stephen Weatherhead
Doctorate in Clinical Psychology
The University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB
07775644760
ste@liverpoool.ac.uk

Principal Investigator

Jade Scott
Doctorate in Clinical Psychology
The University of Liverpool, Whelan Building
Brownlow Hill, Liverpool
L69 3GB
07850696194
jade.scott@liverpool.ac.uk

Appendix M – Participant Debrief Form

UNIVERSITY OF
LIVERPOOL

DEBRIEF

Thank you for taking part in this study.

What was the study about?

This study intends to investigate how the Deprivation of Liberty Safeguards (DOLS) are used and practiced amongst professionals working with people with brain injuries.

The interview you have completed allow us to investigate this and see what processes are most important in understanding how this decision is made.

The findings are likely to have important implications for clinical practice.

Please feel free to ask the researcher if you have any further questions.

Resources in the event of distress?

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

If you are an NHS professional working for xxxx you can contact your Occupational Health Service by calling **xxxxx**

Alternatively, for both NHS and non-NHS professionals you can contact your GP or the Samaritans helpline on **08457 90 90 90**.

Who can I contact if I have further questions about the research?

If you have any questions please contact me: Jade Scott, Doctorate in Clinical Psychology Training Programme, Whelan Building, University of Liverpool, Liverpool, L69 3GB. Email: jade.scott@liverpool.ac.uk Tel: 07850696194

If you do not feel you can come to me you can alternatively contact my supervisor Dr Stephen Weatherhead, email: ste@liverpool.ac.uk Tel: 07775644760

If you remain unhappy or have a complaint you which you feel you cannot come to myself or my supervisor with then you should contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Appendix N – Topic Guide Version 1 & 2

Interview Guide

This guide is intended to facilitate a conversation about the topic of interest. It is not a structured series of questions to be asked and will be utilised flexibly according to participant responses.

Checklist of things to be covered prior to the interview:

Introductions

Explanation of research

Confidentiality revisited

Opportunity to ask questions

Demographic questions (gender, age, job role, ethnicity)

Participants will be asked to talk freely about their experiences of Deprivation of Liberty Safeguards (DOLS) in the context of brain injury.

The content of the interview will be dictated by the participant and the following questions will be used with prompts if they are not covered naturally in the course of conversation.

Begin by asking participant to describe their job role and involvement with DOLS.

1. **What is currently happening clinically regarding DOLS decision making?**

Under what circumstances would you apply for a DOLS?

How successful do you think this process is?

How collaborative do you think the process is?

If not successful or collaborative, why not?

Who is involved in the DOLS decision making process?

What are the positives of each of these people being involved?

Are there any negatives to these people being involved?

Should anyone else be involved?

What kind of impact does DOLS have on a person with a brain injury?

What happens if a service-user disagrees with your decision to apply for a DOLS?

What happens if another professional disagrees with your decision to apply for a DOLS?

2. How does DOLS fit with the Mental Capacity Act (MCA)?

How does the MCA impact on the decision making in DOLS?

3. What do people think need to change about the DOLS decision making process?

What are the strengths of the process?

What is the weakness of the process?

What prevents the ‘DOLS decision making process’ from looking how you want it to?

Prompts (where appropriate)

Can you tell me a little bit more about that?

How do you feel about that?

What was that like for you?

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Interview Guide V2

This guide is intended to facilitate a conversation about the topic of interest. It is not a structured series of questions to be asked and will be utilised flexibly according to participant responses.

Checklist of things to be covered prior to the interview:

Introductions

Explanation of research

Confidentiality revisited

Opportunity to ask questions

Demographic questions (gender, age, job role, ethnicity)

Participants will be asked to talk freely about their experiences of Deprivation of Liberty Safeguards (DOLS) in the context of brain injury.

The content of the interview will be dictated by the participant and the following questions will be used with prompts if they are not covered naturally in the course of conversation.

Begin by asking participant to describe their job role and involvement with DOLS.

1. **What is currently happening clinically regarding DOLS decision making?**

Under what circumstances would you apply for a DOLS?

How does DoLS fit with your day-to-day job role?

How successful do you think this process is?

How collaborative do you think the process is?

If not successful or collaborative, why not?

Who is involved in the DOLS decision making process?

What are the positives of each of these people being involved?

Are there any negatives to these people being involved?

How would you describe the communication between BIA's and practitioners that complete the initial DoLS application?

Should anyone else be involved?

What kind of impact does DOLS have on a person with a brain injury?

What happens if a service-user disagrees with your decision to apply for a DOLS?

What happens if another professional disagrees with your decision to apply for a DOLS?

2. How does DOLS fit with the Mental Capacity Act (MCA)?

How does the MCA impact on the decision making in DOLS?

3. What do people think need to change about the DOLS decision making process?

What are the strengths of the process?

What is the weakness of the process?

What prevents the 'DOLS decision making process' from looking how you want it to?

Additional questions

Can you tell me about any training you have had on DOLS? Was it sufficient? If not why not?

How does the environment you work in impact on the DOLS decision making process?

Are there any differences when completing a DOLS MCA assessment for someone with a brain injury in comparison to someone with a different diagnosis, e.g. dementia or learning disability? If so, can you explain what these differences are?

If you were unsure whether someone with a brain injury required a DOLS, what would you do? How would this make you feel?

What would be the consequences if you incorrectly applied for DOLS for someone who didn't need it?

What would be the consequences if you incorrectly didn’t apply for DOLS for someone who did need it?

Prompts (where appropriate)

Can you tell me a little bit more about that?

How do you feel about that?

What was that like for you?

Appendix O – Reflexive Statement

Researcher Reflexive Memo

In line with Charmaz (2014) recommendations, this memo aims to highlight the influence the researcher imposes on the process of research regarding their: background, experience, prior assumptions, and epistemological stance.

Reflective statemen

I am a 26-year-old, white, female, trainee clinical psychologist, with experience of working in brain injury services. My interest in the use of the deprivation of liberty safeguards (DOLS) emerged from the 12 months I spent working therapeutically with a client who had suffered a traumatic brain injury. The client suffered from numerous life-changing difficulties following their brain injury, however, despite the multitude of difficulties they experienced, the thing they struggled with the most was the significant deterioration in the their mental health following being deprived of their liberty. I was struck by the fact that this client had admitted themselves to the rehabilitation unit as an ‘informal patient’ but was later deemed to not have capacity to make decisions about their care and residence and was subsequently deprived of their liberty. What interested me the most was the fact that this client was only deprived of their liberty at the point of wanting to self-discharge to return home. The timing of this made me wonder about how professionals were making the decision to apply for DOLS and on what basis they were making that decision.

The client I am referring to was placed on a DOLS for two years. During this time, their mental health deteriorated, they became a risk to themselves and to other people; they did not engage in any cognitive rehabilitation and they made numerous attempts to abscond from the unit. Working therapeutically with someone when their distress was magnified by the legislation placed upon them was a challenge. From the perspective of a therapist, I witnessed the significant impact this had on client’s mental health and wellbeing and I began to wonder whether the cost of being on a DOLS (for this individual) outweighed the benefits.

My hope is that, together, this research and systematic review will start to build a picture of how legislation is used in clinical practice. From this, I hope I can develop new ideas and recommendations that will increase professional understanding of legislation and enable safer and less restrictive practice.

Expectations of findings

I expect to find inconsistencies in how the DOLS is used and practiced amongst professionals. I suspect that ‘type of profession’ will play a part in how decisions are made. For instance, I suspect that those with job roles that involve a higher level of responsibility e.g. service managers, may be more; cautious and risk adverse, whereas, other professions such as Neuropsychologists may pay more attention to cognitive and emotional difficulties when making decisions given their skills in the conduct of holistic assessments.

Given that individuals with a brain injury have a unique trajectory of difficulties, I anticipate that there will be an increased level of confusion and struggle amongst profession's when deciding whether or not someone may have capacity to decide on their care and residence. Brain injury is often known as a 'hidden disability' as some individuals may look and present as though nothing has changed. I feel this may add an additional layer of complexity as to how professionals make decisions within this client group.

Epistemological stance

I have chosen grounded theory methodology in order to remove myself as much as possible from my own pre-conceived ideas, perspectives, and interactions with people. Charmaz's (2000) approach aligns with my own epistemological stance by viewing the research as being constructed rather than induced. With this, I understand that as a researcher I am part of the phenomenon I am studying, part of the data collection and part of the analysis I produce. In line with Charmaz (2000), any theoretical portrayal of my research will be an interpretive portrayal of the phenomenon not an exact picture of it.

I am aware that I will need to revisit this page of preconceptions to ensure that participants' narratives that are similar to this have not been led by my interview questions. I understand that it may be the case that I expect certain responses or over interpret such responses to align with my own assumptions and ideas. Field notes, reflective memo's, revisiting this statement and discussions in supervision will help minimise my subjectivity and potential bias. I will also keep a reflective journal throughout the process to think about my own feelings and thought processes that may also impact on my interpretations.

Appendix P – Excerpts from Reflective Journal

Reflective diary

N.B. what I learnt from interview, impressions of interview's experiences and reactions, how does it question pre-existing ideas

The focus of the study I am conducting is around the use of the deprivation of liberty safeguards in a brain injury population. The adoption of this focus is purely out of personal interest and affiliation. I am passionate to pursue research in this area because of my personal involvement with a client whom experienced significant behavioural and mental health difficulties following being deprived of their liberty. As such I had developed an interest in the use of legislation in clinical practice and the impact this may have on individuals. However, I was conscious of the problem of being 'too close' to the study and this having the potential of influencing my data analysis. To avoid the potential of over familiarisation, I decided to keep a reflective diary to record my personal views, thought processes and interview dynamics throughout the study.

Interview 1 - *'Paula'*

This was my first grounded theory interview and I was feeling slightly anxious and unsure if I was asking the right or relevant questions about 'the process of decision making'. At the start of the interview, I found myself really thinking about what I should ask next and weighing up whether I should allow the participant to talk freely or whether I should be more directive and keep them focused on the questions I had asked. As a result, I think I perhaps did not actively listen as much as I normally would in an interview context. It is perhaps worth noting that my first participant was a community manager who was in a position of authority and power. Perhaps the difference in roles and power played into my feelings of anxiety and uncertainty. As time progressed my anxiety eased, perhaps as a result of the rapport that we built. I then felt calmer and more able to listen and digest what the participant was saying.

The participant spoke a great deal, at one point I recall them saying that their 'brain was firing', although this was exciting from a researcher's perspective, it was also often difficult to jump in with a question or follow the thread of conversation. As this was my first interview, I made a conscious decision to step back and allow the interviewee to talk without being too directive.

Paula's spoke very negatively about the use of DoLS in clinical practice and I found myself thinking that I completely agreed with her and also feeling relieved to hear this coming from someone with years of experience in this field of work. However, I am aware that I already have my own biases and that this may have fed into the type of questions I asked or the way I presented in the room. Once I have transcribed my interview, I must ensure that I go back and check my questions to ensure that they were not leading or biased in any way. It will also be helpful to listen to the interview again with this in mind.

Interview 2 - *‘Ben’*

I was feeling less nervous for my second interview. It is perhaps interesting to note that this interview was with a Clinical Neuropsychologist, perhaps his job role provided some safety, familiarity, and certainty for me.

One of the things that caught my attention was the interviewee’s uncertainty and hesitancy when talking about DoLS. They were keen to keep pointing out that their views are “biased” because they are employed as an expert for the court and therefore ‘only make decisions about people who have already been placed on a DoLS whom are contesting it’. The interviewee mentioned a couple of times that this was “just from his experience” and “just his viewpoint”. I got a sense that the interviewee was aware of their own limitations and potential biases in his decision making. I found this interesting, I suppose my expectations were that this person would be confident about their decision-making processes given that they are often employed by the supreme court as an ‘expert’ in DoLS cases. However, on reflection I am mindful that being overly confident about DoLS decision making may be dangerous and tainted with more bias given that it can be a very complex and difficult process to disentangle. I realise that this questioning of the self and reflective thinking is helpful for aiding deeper thinking and counteracting our own biases and is perhaps a very useful skill for professionals to have.

Interview 5 - ‘Chen’

Chen is a medic working on a neuro-rehabilitation unit in a hospital setting. I found this interview overwhelming and quite concerning, which I will discuss further in supervision. Chen seemed to be in a rush and seemed short when answering questions, I noticed that she struggled to answer some questions leaving long pauses where she would say ‘I don’t know how to answer that’ – this gave me the impression that Chen did not know as much as other interviewee’s. She seemed very matter of fact in her answers and was under the impression that the DoLS legislation was a waste of time. I felt as though Chen was very risk-orientated and got the impression that anyone that showed a slight cognitive impairment would be placed on DoLS without a thorough assessment. Chen was open with the fact that DoLS is last on her priority list and open about the fact that she found the legislation useless and that it had not changed anything about her practice. She was also very critical of other staff members such as nurses and psychologists for not doing capacity assessments. Chen felt everyone should do them because ‘they are not hard’. DoLS felt as though it was a massive inconvenience to her. I think the content and Chen’s attitude to DoLS made me feel slightly uncomfortable which perhaps manifested in me rushing through the interview and accepting some blunt and matter of fact comments without probing further. This was my shortest interview yet at just 42 minutes. However, the interview with Chen offered a new understanding of DoLS decision-making- one that is of inconvenience and one that feels confounded by time and resource restraints. Overall, it was interesting to hear a different perspective on DoLS, I am eager to interview other medics to see if a similar narrative emerges.

Appendix Q – Example Memo

Case Memo

Participant 1 – 'Paula'

Hypotheses

- *Physical safety of the service-user being deprived is prioritised over emotional safety*
- *Experience improves understanding and application of MCA & DOLS legislation*
- *Fear of blame and anxiety around disagreeing with other professionals' feeds into professionals taking a risk-adverse approach to their decision making – this then leads to restrictive practice.*
- *Knowing the person being deprived, understanding their human rights, communicating effectively with other professionals, and having a clear understanding of the persons diagnosis feeds into a positive risk-taking approach to the decision making.*

Narrative

'Paula' works as a community manager; part of her role involves completing DoLS assessments. Paula completes approximately 10 DoLS assessments per year which is an 'add-on' to her current role, this often requires her to complete DoLS assessments out of hours, e.g. at weekends or after 5pm through the week.

Paula's narrative about the DoLS decision making process seemed very negative. A strong theme that emerged was that of the 'misuse' and 'misunderstanding' of DoLS, particularly in relation to care-home staff (Paula felt that hospital staff were better due to being more concerned about CQC inspections). Paula spoke about past cases whereby service-users had been wrongly placed under the DoLS legislation and restricted unnecessarily. At one point she related the misuse of the legislation to the abuse scandals documented on panorama. Despite the negative stories and negative experiences of DoLS in clinical practice, Paula appeared to suggest that none of this was intentional and that it was more likely to be linked to professionals feeling that patient 'safety' should always be a priority, I felt as though Paula was suggesting that professionals could justify their overly restrictive decisions because they believed that it was in the patients 'best interest' to keep them safe at all costs.

There was also a storyline relating to capacity assessments being more complex and difficult to complete in a brain injury population in contrast to other client groups e.g. those with dementia or a learning disability. Paula mentioned that this was because a brain injury can present as more of a hidden disability, whereby the service-user can present in a structured interview as though they are fine. Paula spoke about the importance of understanding the impact of brain injury, particularly insight difficulties when assessing for decisions around care and residence.

Throughout Paula's narrative she mentioned different factors that may impact on professional decision making. Some of these factors were thought to contribute to professionals being more risk-adverse e.g.:

- Concerns around court of protection/coroner's court
- Feeling as though patient 'safety' is a priority and always in a person's best interest
- A focus on physical safety rather than emotional safety
- Concerns around 'pin numbers' and job security
- Service-users presenting with risky behaviour, e.g. attempting to abscond.
- Anxiety around disagreeing with other professionals when risk is high, and the decision is not 'clear cut'
- Emotions clouding decision making – particularly when risk is involved

Factors that Paula described as contributing to more positive risk taking in professionals included:

- Knowing about the person's history and how they had previously made decisions
- Knowing enough about the person
- Having proof and evidence to back up why certain decisions have been made
- Being clear on the processes behind the decision making
- Communicating with other professionals and getting their opinion
- Clear understanding of diagnosis, physical evidence e.g. brain scan and talking to brain injury specialists to learn more about the implications of the damage on day to day functioning.
- Consideration of human rights

Within Paula's narrative she also spoke about how applying for a DoLS was a 'reactive' process rather than a 'proactive' one. She mentioned that some professionals 'just slap people on a DoLS' insinuating a lack of thought and thorough assessment.

Paula also spoke about some of the administrative limitations of DoLS. She spoke about how a lot of capacity assessments are just 'tick-box' exercises, lacking detail. She also mentioned that there was a time delay and a back log of assessments which meant that people's liberty may be restricted for longer than is necessary.

Finally, Paula spoke about how difficult it is for some service-users to challenge DoLS. There was a sense that 'quieter' service-users that are not 'actively' trying to leave tend to be 'unheard' and take a lower priority. Paula was particularly concerned about some the new changes that will be coming into place with the DoLS, one of which includes cutting out independent DoLS assessors for the people that are not protesting DoLS. Paula was concerned about this as it is the managing authorities who will decide whether someone is protesting. Paula fears that 'quieter' and 'less challenging' service-users will be unheard and felt this change was 'dangerous' creating a further power-imbalance. Paula also expressed her concerns about the new changes placing more responsibility on care homes. She feels there is a hidden agenda behind such changes, one which includes cutting cost and workload.

Emerging Themes / in vivo codes

'Physical safety vs emotional safety'/ paternalism

It appears the focus for professional's decision making is predominantly about keeping someone *physically* safe. The implications of this seem to contribute to service-user's levels of distress and frustration.

"The person is so distressed…that whole point about it being a gilded cage, you know, why keep someone physically safe if they are so miserable and trying to escape."

There appears to be a lack of a cost-benefit analysis from professionals – decisions appear to be very black and white with a strong focus on physical safety. I wonder if the legislation also reflects this lack of parity of esteem and whether this influences the decision-making process too?

'Misunderstanding & misuse of the legislation'

Misuse seems to be linked to a lack of knowledge and non-intentional. In Paula's narrative, misuse of DoLS seems to be happening mostly in care homes…

"You will see a lot of incredibly restrictive practices…you will see stuff on panorama that is absolutely horrific but the majority of abuse is not happening like that, it's not that violence really, it's the small things, like restricting people's lives."

"To keep the assessment in house feels…dangerous." – Misuse mostly documented at care homes. It would be interesting to speak to the managing authorities working in these settings to hear their perspective too.

"The biggest problem is around the lack of knowledge around what is lawful, what is in somebody's best interest, erm what is an objection…and how to deal with it"

"That was the first time it struck me…does anyone, did anyone really understand about what it is that we are actually doing…"

Risk-aversion vs positive risk taking

"Risk aversion is all about blame, they don't want to be blamed".

Blame culture – professionals seem frightened to take positive risks due to worries about their 'pin numbers', having to attend the court of protection or coroners court. This fear of making the 'wrong' decision and the consequences of such seems to contribute to professionals being more risk adverse. Professionals seem to have difficulty grasping that DoLS is a safeguard and not just about restriction.

“I don’t think they recognise the significance because there is this idea of ‘oh we are doing it in their best interest we are trying to keep them safe’. There is an underlying feeling that professionals are overly restrictive in their decision making yet this seems to be in the context of in the “best interest of the client”.

‘Decisions are made for people not with people’

“…if you have got a brain injury…you suddenly become something less than people who don’t have any of those labels and so ‘we have to look after them’ [sarcasm], that kind of patronising at best, dehumanising at worst means decision are just made for people”.

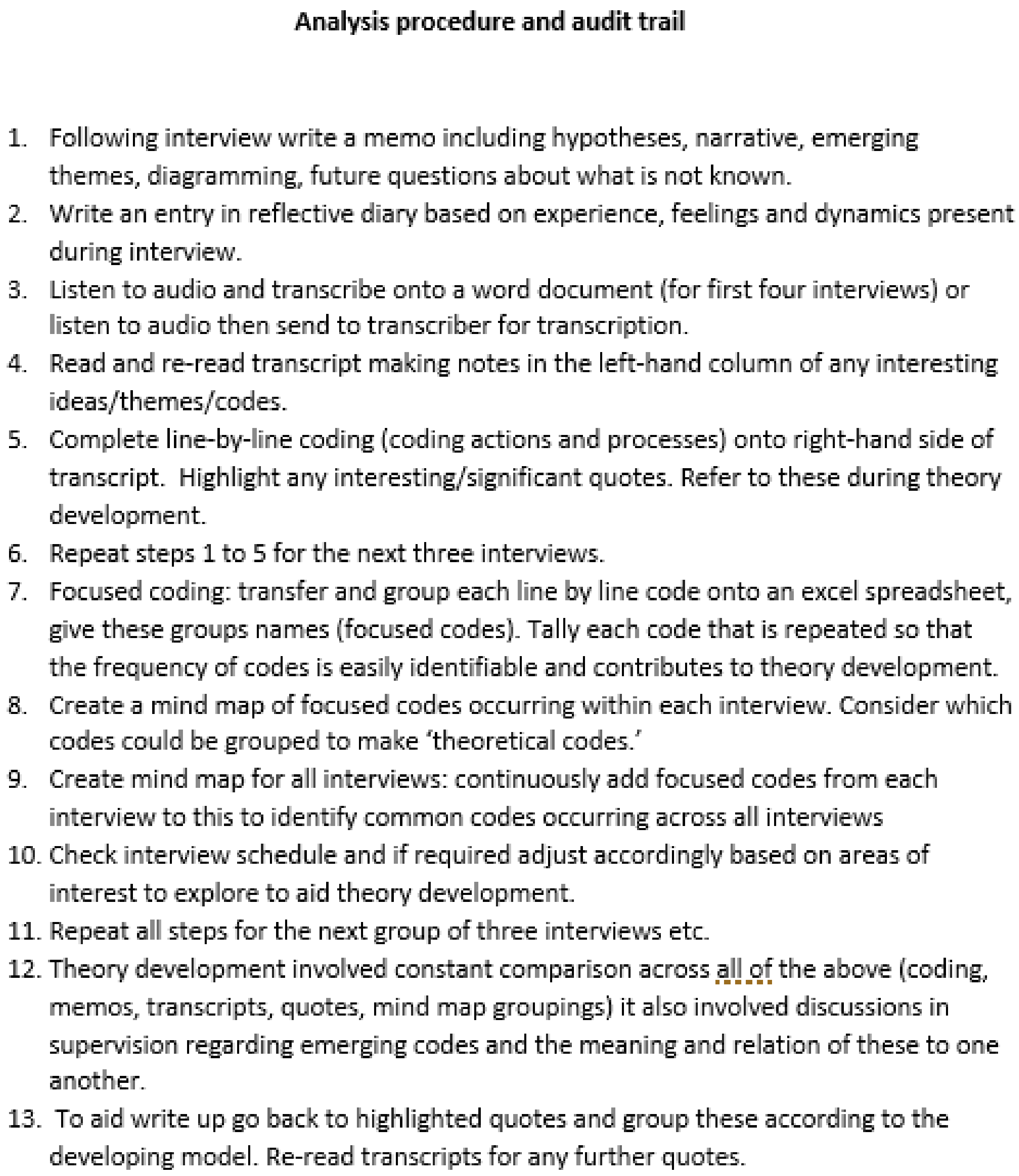
What is not known?

Positive use of DoLS? Is it all negative? I would be interested to hear from professionals from a different background that work in different settings to hear more about their perspectives.

How DoLS is used in hospital settings, do they experience the same problems as care homes? If not, why not?

It seems that patient safety is key in the decision-making process, but I would also like to know if there are any personal factors that impact on professional decision making. I am keen to learn more about professionals that take positive-risks (i.e. a more balanced approach to the decision-making) and what it is about them that enables them to do this.

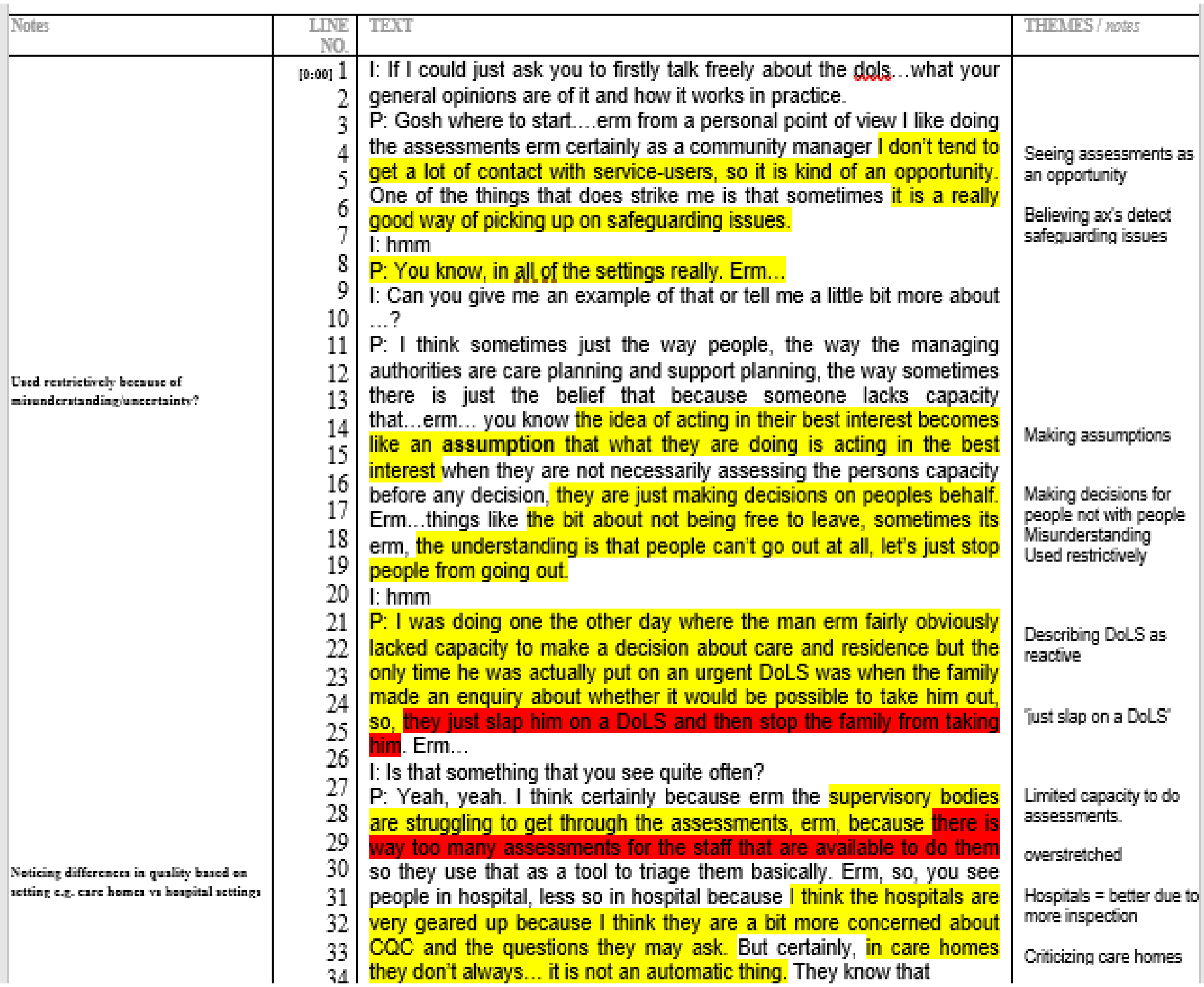
Appendix R – Analysis procedure and audit trail



Analysis procedure and audit trail

1. Following interview write a memo including hypotheses, narrative, emerging themes, diagramming, future questions about what is not known.
2. Write an entry in reflective diary based on experience, feelings and dynamics present during interview.
3. Listen to audio and transcribe onto a word document (for first four interviews) or listen to audio then send to transcriber for transcription.
4. Read and re-read transcript making notes in the left-hand column of any interesting ideas/themes/codes.
5. Complete line-by-line coding (coding actions and processes) onto right-hand side of transcript. Highlight any interesting/significant quotes. Refer to these during theory development.
6. Repeat steps 1 to 5 for the next three interviews.
7. Focused coding: transfer and group each line by line code onto an excel spreadsheet, give these groups names (focused codes). Tally each code that is repeated so that the frequency of codes is easily identifiable and contributes to theory development.
8. Create a mind map of focused codes occurring within each interview. Consider which codes could be grouped to make 'theoretical codes.'
9. Create mind map for all interviews: continuously add focused codes from each interview to this to identify common codes occurring across all interviews
10. Check interview schedule and if required adjust accordingly based on areas of interest to explore to aid theory development.
11. Repeat all steps for the next group of three interviews etc.
12. Theory development involved constant comparison across all of the above (coding, memos, transcripts, quotes, mind map groupings) it also involved discussions in supervision regarding emerging codes and the meaning and relation of these to one another.
13. To aid write up go back to highlighted quotes and group these according to the developing model. Re-read transcripts for any further quotes.

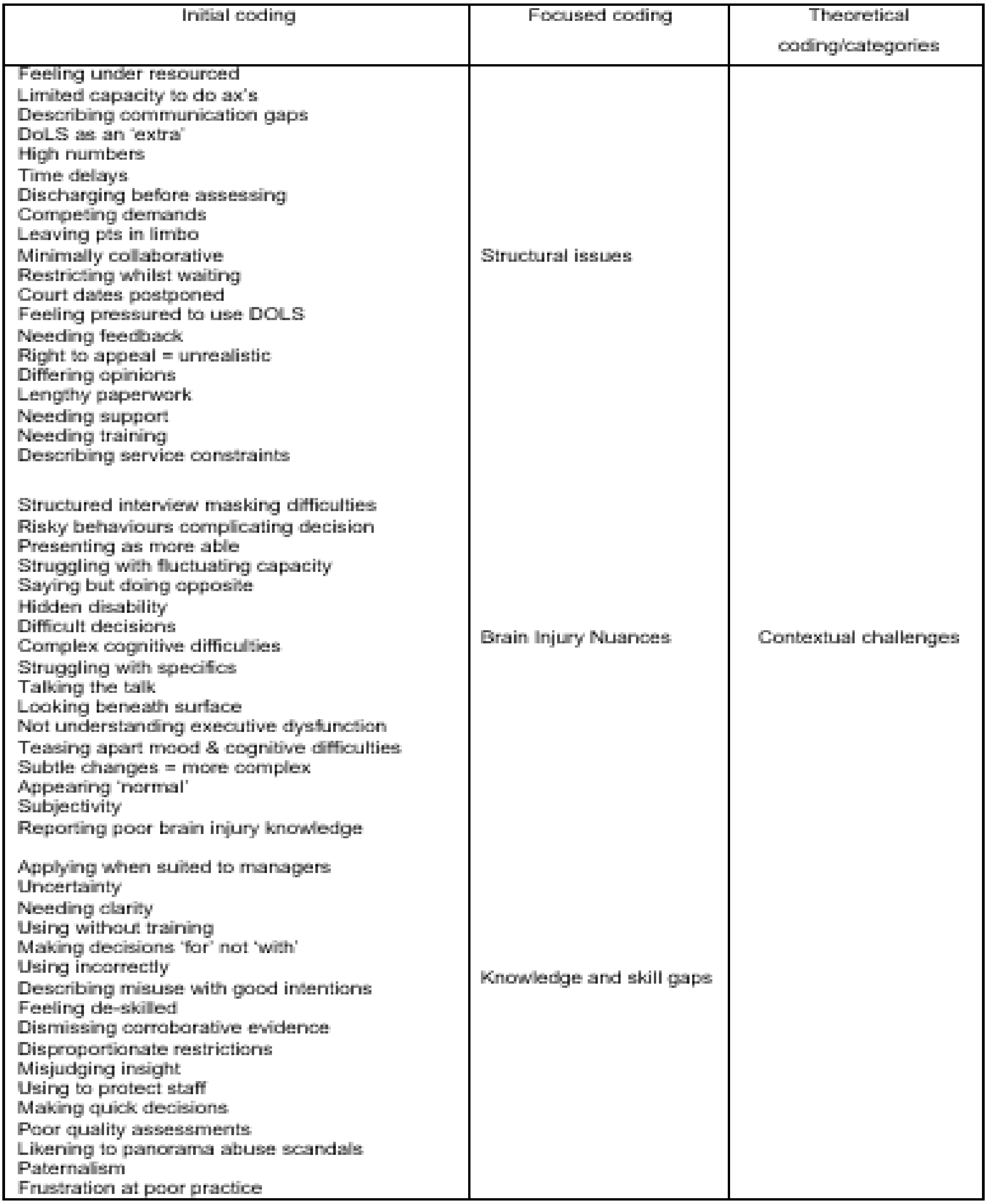
Appendix S - Excerpts of validation coding checks from both primary and secondary researchers



Notes	LINE NO.	TEXT	THEMES / *notes*
Used restrictively because of misunderstanding/uncertainty? Noticing differences in quality based on setting e.g. care homes vs hospital settings	[0:00] 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34	I: If I could just ask you to firstly talk freely about the dols…what your general opinions are of it and how it works in practice. P: Gosh where to start….erm from a personal point of view I like doing the assessments erm certainly as a community manager I don't tend to get a lot of contact with service-users, so it is kind of an opportunity. One of the things that does strike me is that sometimes it is a really good way of picking up on safeguarding issues. I: hmm P: You know, in all of the settings really. Erm… I: Can you give me an example of that or tell me a little bit more about …? P: I think sometimes just the way people, the way the managing authorities are care planning and support planning, the way sometimes there is just the belief that because someone lacks capacity that…erm… you know the idea of acting in their best interest becomes like an **assumption** that what they are doing is acting in the best interest when they are not necessarily assessing the persons capacity before any decision, they are just making decisions on peoples behalf. Erm…things like the bit about not being free to leave, sometimes its erm, the understanding is that people can't go out at all, let's just stop people from going out. I: hmm P: I was doing one the other day where the man erm fairly obviously lacked capacity to make a decision about care and residence but the only time he was actually put on an urgent DoLS was when the family made an enquiry about whether it would be possible to take him out, so, they just slap him on a DoLS and then stop the family from taking him. Erm… I: Is that something that you see quite often? P: Yeah, yeah. I think certainly because erm the supervisory bodies are struggling to get through the assessments, erm, because there is way too many assessments for the staff that are available to do them so they use that as a tool to triage them basically. Erm, so, you see people in hospital, less so in hospital because I think the hospitals are very geared up because I think they are a bit more concerned about CQC and the questions they may ask. But certainly, in care homes they don't always… it is not an automatic thing. They know that	Seeing assessments as an opportunity Believing ax's detect safeguarding issues Making assumptions Making decisions for people not with people Misunderstanding Used restrictively Describing DoLS as reactive 'just slap on a DoLS' Limited capacity to do assessments. overstretched Hospitals = better due to more inspection Criticizing care homes

Notes	LINE NO.	TEXT	THEMES / *notes*
	[0:00] 1	I: If I could just ask you to firstly talk freely about the DoLS…what your general opinions are of it and how it works in practice.	
Positive experience for personal and professional development	3	**P: Gosh where to start….erm from a personal point of view I like doing the assessments erm certainly as a community manager I don't tend to get a lot of contact with service-users, so it is kind of an opportunity. One of the things that does strike me is that sometimes it is a really good way of picking up on safeguarding issues.**	Like doing them Helps identify safeguarding issues
	8	I: hmm	
	9	**P: You know, in all of the settings really. Erm…**	
	10	I: Can you give me an example of that or tell me a little bit more about …?	
Sometimes people are using the legislation to restrict people based on assumptions rather than focussed assessments.	12	**P: I think sometimes just the way people, the way the managing authorities are care planning and support planning, the way sometimes there is just the belief that because someone lacks capacity that…erm… you know the idea of acting in their best interest becomes like an assumption that what they are doing is acting in the best interest when they are not necessarily assessing the persons capacity before any decision, they are just making decisions on peoples behalf. Erm…things like the bit about not being free to leave, sometimes its erm, the understanding is that people can't go out at all, let's just stop people from going out.**	Assumption-laden Pre-judging outcome Used restrictively
	22	I: hmm	
	23	**P: I was doing one the other day where the man erm fairly obviously lacked capacity to make a decision about care and residence but the only time he was actually put on an urgent DoLS was when the family made an enquiry about whether it would be possible to take him out, so, they just slap him on a DoLS and then stop the family from taking him. Erm…**	'just slap on a DoLS'
	28	I: Is that something that you see quite often?	
Inconsistent application of legislation, which can be heavily influenced by other motivating factors.	29	**P: Yeah, yeah. I think certainly because erm the supervisory bodies are struggling to get through the assessments, erm, because there is way too many assessments for the staff that are available to do them so they use that as a tool to triage them basically. Erm, so, you see people in hospital….less so in hospital because I think the hospitals are very geared up because I think they are a bit more concerned about CQC and the questions they may ask. But certainly, in care homes they don't always… it is not an automatic thing. They know that somebody**	Hospitals are better due to more scrutiny.

Appendix T – Example of how the category ‘Contextual Challenges’ was developed



Initial coding	Focused coding	Theoretical coding/categories
Feeling under resourced Limited capacity to do ax’s Describing communication gaps DoLS as an ‘extra’ High numbers Time delays Discharging before assessing Competing demands Leaving pts in limbo Minimally collaborative Restricting whilst waiting Court dates postponed Feeling pressured to use DOLS Needing feedback Right to appeal = unrealistic Differing opinions Lengthy paperwork Needing support Needing training Describing service constraints	Structural issues	Contextual challenges
Structured interview masking difficulties Risky behaviours complicating decision Presenting as more able Struggling with fluctuating capacity Saying but doing opposite Hidden disability Difficult decisions Complex cognitive difficulties Struggling with specifics Talking the talk Looking beneath surface Not understanding executive dysfunction Teasing apart mood & cognitive difficulties Subtle changes = more complex Appearing ‘normal’ Subjectivity Reporting poor brain injury knowledge	Brain Injury Nuances	
Applying when suited to managers Uncertainty Needing clarity Using without training Making decisions ‘for’ not ‘with’ Using incorrectly Describing misuse with good intentions Feeling de-skilled Dismissing corroborative evidence Disproportionate restrictions Misjudging insight Using to protect staff Making quick decisions Poor quality assessments Likening to panorama abuse scandals Paternalism Frustration at poor practice	Knowledge and skill gaps	

Appendix U – A table showing how the empirical paper met Elliot et als' (1999) guidelines on quality in qualitative research

Guidelines	How these were met
'Owning one's perspective'	The researcher specified their personal, theoretical, and methodological anticipations. A reflexive memo was written prior to the commencement of data collection and reflexivity was discussed and documented throughout via supervision and a reflective journal. The researcher followed a social constructionist position (Charmaz, 2014).
'Situating the sample'	Participant demographic information was provided. Detailed narratives were captured in memo's and further reflections were documented in a reflective journal.
Grounding in examples	Direct quotes were embedded in the results section. Line by line coding was utilised to stay close to the data. Memo's also incorporated quotes to stay close to data.
Providing credibility checks	Two researchers independently coded segments of data (appendix) Transcripts were reviewed and discussed with another researcher to support development of interview technique.
Coherence	An example of the coding framework was provided (appendix…) An integrative visual and narrative summary of the data (describing the

	relationship between categories) is provided in the results section. Memo’s incorporating the development of categories and relationships between categories capture how the data fits together. The analysis process was documented (appendix…) providing a clear audit trail.
Accomplishing general vs. specific research tasks	The researcher carried out 12 interviews with a range of practitioners working in different ABI settings. Discussion section refers to how conclusions from the current study can only be applied to the group studied.
Resonating with readers	Elements of the model were presented to the last four participants’ during their interviews – all participants reported that the model resonated with their experiences and was highly relevant to their practice.