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A Delphi Survey of Practitioner's Understanding of Mental Capacity

Journal:	<i>The Journal of Adult Protection</i>
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Manuscript Type:	Research Paper
Keywords:	Mental capacity, Professional capacity, Legislation, Best Interest, Consensus, Deprivation of liberty

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The Journal of Adult Protection

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3 TITLE: A Delphi Survey of Practitioner's Understanding of Mental Capacity
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5 ABSTRACT:

- 6 • Purpose
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 - 8 ○ This paper presents the findings of a study considering the
9 application of the Mental Capacity Act and Deprivation of Liberty
10 Safeguards. Practitioners from a range of professions were
11 recruited to provide their views of how to respond to a variety of
12 scenarios. GPs, nurses, social workers, physio/occupational
13 therapists and care assistants were recruited to participate.
 - 14 • Design/methodology/approach
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 - 16 ○ This study used the Delphi method to elicit participant views and
17 generate consensus of opinion. The Delphi method recommends a
18 large sample for heterogeneous groups, and round one had 98
19 participants from six different professional groups.
 - 20 • Findings
21
 - 22 ○ Participants did not respond consistently to the scenarios, but
23 disagreed most significantly when patient decisions conflicted with
24 clinical advice, and when to conduct a capacity assessment. These
25 responses suggest that clinical responses vary significantly
26 between individuals (even within settings or professions), and that
27 the application of MCA is complicated and nuanced, requiring time
28 for reflection to avoid paternalistic clinical interventions.
 - 29 • Originality/value
30
 - 31 ○ Previous studies have not used a Delphi method to consider the
32 application of MCA/DoLS. Because of this methods focus on
33 developing consensus, it is uniquely suited to considering this
34 practice issue. As a result, these findings present more developed
35 understanding of the complexity and challenges for practitioner
36 responses to some relatively common clinical scenarios,
37 suggesting the need for greater clarity for practitioners.
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Context

The Mental Capacity Act 2005 (MCA) sought to provide a framework for decision making by health and social care providers and professionals, relating to adults who may not have the capacity to make decisions for themselves. Prior to its implementation, there was insufficient legal guidance in situations requiring self-determination; for example, an adult lacking capacity as a result of dementia who is unable to make decisions regarding her care. Although previous decision making was guided by common law, practice in health and social care was largely influenced by a paternalistic culture that reduced the agency of patients (Samuel, 2014). In an attempt to protect individuals and provide a clear legal framework to guide practice, the Law Commission initiated a process that culminated in the MCA.

Outline of the MCA

The MCA applies to people over the age of 16 in England and Wales where there are concerns about a person's decision making ability. It is underpinned by five enduring principles of care, seeking to place the individual at the heart of decision making. These five principles are: the presumption of capacity; supporting individuals to make decisions; the right to make an 'unwise decision'; the 'best interest principle'; and the 'least restriction principle'. Section two of the MCA requires professionals to presume that a person has capacity unless there is reason to believe otherwise. The legal presumption in favour of capacity is based on functional terms, including the ability to understand, retain, and evaluate relevant information, as well as being able to communicate any decision (Willner et al. 2013). The best interest principle (Section four) requires the care provider to act in the best interest of the individual instead of expedience or budget. The best interest principle also obliges care providers to encourage the participation of the individual in any decision about them. When a lack of capacity is proven, the individual without capacity must be given the necessary support to make a decision. In such circumstances applying a best interest decision is crucial to providing appropriate care. However, this means that decisions can be contentious as the response can vary widely depending on the decision-maker (Martin et al 2009).

The 2005 European Court of Human Rights (ECtHR) ruling on *HL v United Kingdom* marked a watershed in mental capacity law and policy in the UK. This case found that a man had been deprived of his liberty, because he did not have capacity to decide whether to be admitted to a hospital, and he was held against his parents' wishes. The UK was deemed to have violated article 5 of the ECHR and concluded that English and Welsh law were insufficiently robust to meet the requirements of the law guarding the right to liberty and security. As a result, the Deprivation of Liberty Safeguards (DoLS) were inserted into the law, making the

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3 rights of patients an increasingly important consideration for health and social
4 care.
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6 A Select Committee post-legislative scrutiny report indicated that there was lack
7 of awareness and knowledge about the MCA (House of Lords, 2014). They noted
8 that a prevailing culture of paternalism and risk-aversion had prevented the Act
9 from becoming embedded into practice (ibid.). After consulting with a range of
10 stakeholders (including adults with learning disabilities and advocacy groups for
11 people with dementia), the overwhelming evidence showed a range of concerns:
12 poor implementation; low awareness; a lack of understanding; and ongoing
13 tensions between the MCA's empowering influence for patients and the
14 safeguarding responsibilities it places on professionals (House of Lords, 2014).
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18 The evidence from the report suggested a range of practice dilemmas, which
19 influenced the study outlined in this paper. This study has sought to understand
20 the experience of health and social care practitioners using the MCA and DoLS.
21 The Law Commission (2017) also suggested that the DoLS is not fit for purpose,
22 identifying that professionals lack understanding of its application as well the
23 complexities associated with applying the procedure. Parliament is currently
24 considering how to alter these procedures, although changes have been slowed
25 down because of the focus on Brexit (McNicoll, 2017). Despite the potential
26 change to the DoLS, much of the current procedures proposed are anticipated to
27 remain the same (Age UK, 2017; Spencer, 2017).
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33 After a review of the MCA DoLS, the Law Commission (2017) has concluded that
34 it is not fit for purpose and proposed 'Liberty Protection Safeguards'. Included in
35 the recommendations are provisions for enhanced rights to advocacy, greater
36 prominence to the rights of persons to be deprived of liberty, widening the scope
37 to cover 16 and 17 year olds and simplifying the best interest process. Such
38 concerns highlight flaws in the current law, and the challenges that practitioners
39 have to contend with. A gap seems to exist in the literature about studies on the
40 impact the law has had on practice and this study is an effort to contribute to
41 bridging the gap. The challenge service providers have to contend with is
42 translating the notion of the individual i.e. patient or other service user (PSU) as
43 any other rights bearing individual whose rights and liberties are not lost simply
44 because of the condition, from theory to practice
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49 Service providers have a duty to ensure that PSU's exercise the right to make
50 their own decisions. However, where they lacked capacity, the best interest
51 principle must underpin any decisions made on their behalf. The notion of best
52 interest is not new, but for many years it has underpinned a paternalistic.
53 According to the Law Commission (2017). "...health and social care
54 professionals and the Court of Protection often failed to consider the person's
55 wishes and feelings, and that the concept of best interests was often interpreted
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3 in a medical and paternalistic sense.” In health and social care, the concept of
4 paternalism has played a key role in the relationship between the patient or
5 service user and the doctor or other professional providing a service (Komrad,
6 1983). It implies the physician makes decisions for the patient based what he or
7 she believes is in the patient’s best interest, so they health system has thrived on
8 the notion that the physician or professional knows best (Murgic et al, 2015). So
9 while the notion of autonomy of the individual is a legally protected value, it is
10 important to understand what the challenges are in practice, where the old ideas
11 of best interest must be abandoned in favour of the wishes and preferences of
12 the patient.
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18 **Research Strategy**

19 This study sought to understand health and social care practitioners’ knowledge
20 of MCA/DoLS; how these frameworks are applied in practice; to determine
21 practitioners’ consensus about good practice within the relevant policy
22 frameworks; and sought to map out the understanding of representatives from
23 the different areas of practice (Boulkedid et al, 2011). To gather their
24 perceptions, participants were presented with everyday scenarios in hospital and
25 social care settings and asked how they respond. This enabled the researchers
26 to identify key differences in staff understandings of safeguarding and how the
27 differences may impact on practice. The views of a range of professionals were
28 sought in the study, including nurses, social workers and healthcare assistants
29 and doctors.
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34 **Methodology**

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36 A Delphi survey was used to study how practitioners understand and use the
37 MCA. This method was chosen to engage both experts and stakeholders, without
38 relying on one individual’s expert opinion (Olaf 1967). A Delphi method typically
39 elicits the views of a group of experts, who are individuals with knowledge of the
40 subject. It is an iterative approach to collecting information with the anonymous
41 results of the first round being shared with participants prior to the second and
42 subsequent rounds (Skumolski et al 2007). This process allows a Delphi to
43 develop convergences of opinion and build consensus. Surveys are generally
44 used to identify “what is,” but the Delphi technique goes further by attempting to
45 address “what could/should be” (Miller, 2006 cited in Hsu and Stanford 2007).
46 Because of the iterative process, it helps to transform opinion into group
47 consensus, and broadens knowledge on an issue of interest (Hasson et al 2000).
48 While the Delphi method is the preferred group technique for consensus building,
49 Kendall et al. (1992 cited in Okoli and Pawlawski, 2004) have also pointed out
50 this approach can use differences of opinion to inform further scenarios. Using
51 the Delphi can test whether there was consensus on the understanding and
52 practice of the MCA and whether consensus could be built, if found to be lacking.
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3 Delphi methods can be used for both qualitative and quantitative data collection.
4 Data from the first round of a Delphi can be analysed either by qualitative coding
5 or statistical summarizing (Skumolski et al 2007). However, by focusing on
6 consensus building, the method sacrifices the best opinion for a watered down
7 version of it. This is not unique to the Delphi technique as other forms of group
8 work such as nominal groups (Powell 2003 p.377) use structured meetings to
9 elicit the views of experts. **Using scenarios for decision making has the potential
10 for exposing variations in decisions among professionals and their colleagues
11 given the same circumstances. This has been demonstrated in studies using the
12 vignette method such as the Hughes' (1998) study of drug injecting and HIV risk
13 and safer behaviour, Reader et al (2017) and impossible decision making and
14 the risk of trade-offs in ICU.**

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19 Investigating the MCA in practice is a complex issue, and required the
20 participants from a range of professions and different areas of health and social
21 care. **It reflects the range of areas in health and social care that the law on
22 mental capacity affects and what happens in practice.** The Delphi Survey allowed
23 for this complexity and meant a broad understanding of the reality on the ground
24 could be reached. Participants in this study could be in different locations and still
25 participate in the research because of their knowledge and practice experience.
26 This allowed the participants a degree of anonymity, allowing them to express
27 their views free of influences. Hanafin (2005, p.10) suggests that anonymity
28 encourages experts to make statements on the basis of their personal knowledge
29 and experience, rather than a more cautious institutional position. Anonymity is a
30 feature of strength because it allows participants to express their views without
31 the influence of dominant characters and the inability of the researcher to trace
32 back responses to an individual leads to a lack of accountability (Sackman 1975).
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38 Ethical issues considered in the research strategy were approved by a Research
39 Ethics Committee. The study involved eliciting from respondents potentially
40 sensitive information regarding their understanding and practice in the context of
41 the Mental Capacity Act 2005. The sensitive issues included the potential for
42 revealing poor practice. Key issues considered included confidentiality and
43 anonymity.
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48 **Composition and Sampling**

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50 Delphi methods utilise a panel of experts with specialist knowledge and
51 qualifications as well as participants who are experts by experience (Iqbal and
52 Pison-Young 2009). However, the idea of experts is problematic, and has been
53 described as misleading and overstated with a potential for bias (McKenna,
54 1994; Sackman 1975; Strauss and Ziegler 1975). Keeney et al (2001) have
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3 argued, "Simply because individuals have knowledge of a particular topic does
4 not necessarily mean that they are experts" (p 196). In an attempt to ensure
5 participants had a working knowledge of the issue, this study recruited health and
6 social care practitioners that use the MCA and DoLS in their practice. This
7 provided a varied group covering the range of experiences of people working
8 with the legislation. Participants were experts because of their ongoing practice
9 experience of using MCA/DoLS, and not because they held leadership roles in
10 their organisation.
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14 Participants were purposively recruited. The aim was not to find a representative
15 sample, but to find frontline staff with knowledge and experience using the
16 legislative framework of the MCA. The study recruited people with first-hand
17 experience of using the MCA regularly whilst caring for individuals in either
18 hospital or social care settings. Snowballing was also used to expand the
19 sample, allowing participants to invite their colleagues with relevant experience
20 (Habibi et al 2014).
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24 It was important that the sample was a heterogeneous group, including a diverse
25 sample of professionals that covered the range of scenarios that health and
26 social care workers experience; whose practice involved decision making using
27 the MCA/DoLS. Where there is a homogenous sample, Skulmoski et al (2007)
28 have argued that a sample size of 10 – 15 may yield sufficient results. But a
29 heterogeneous group requires a larger sample, as the heterogeneity delays the
30 important step of building consensus, creating a longer process of analysing data
31 and verifying results (Delbeq et al 1975 cited in Skulmoski et al 2007). The study
32 recruited 5 groups of professionals and included 50 nurses and 30 care workers,
33 10 social workers, 5 occupational therapists, and 5 doctors to participate in the
34 first round of the survey. They were from acute settings and residential care for
35 the elderly. The number of respondents dropped significantly in the second
36 round, with only 12 respondents.
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41 Even with such a large sample, the response rate in the second round fell
42 drastically. It is generally agreed that experts who participate in such studies are
43 hard to engage with because of other commitments (Hsu and Sandford, 2007).
44 Ludwig (1994) suggests a drawback to using Delphi methods is that the
45 questionnaire method may significantly slow the process, with several days or
46 weeks between rounds (ibid.). In addition, the iterative process causes further
47 delays, posing a challenge to Delphi investigators to speed up the process. After
48 several emails to participants, the response was still very low, which suggested
49 the interest and commitment had waned. Hsu and Sandford (2007) recommend
50 telephone contacts to overcome the problem however, this could easily lead to
51 coercion, which would diminish the voluntary nature of the process. However, in
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3 this case non-respondents were slowing the process down, so several weeks
4 after the deadline, the round had to be closed. Hence the low response rate.
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7 The study sought a diverse array of situational contexts, from comparatively
8 minor to life-changing and even life-ending decisions, because of the wide scope
9 of the MCA. Because the topic considered how the MCA applies across a wide
10 range of circumstances, as a result the sample included professional and non-
11 professional staff such as nurses, social workers, care workers, physiotherapists
12 and GPs (Alghrani, 2016 p.312). The sample included this range because they
13 all use the MCA in their daily practice.
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17 Recruiting a diverse sample required engagement with a range of organisations.
18 Organisational gatekeepers were able to identify relevant managers (from both
19 acute and care home settings). These contacts were able to recruit members of
20 staff for participation. Participants were invited to attend a workshop, and asked
21 to complete the study questionnaires. This approach was used because of the
22 advantages of face to face interviews following the first round, which helped
23 increase the response rate (McKenna 1994 cited in Hasson et al. 2000). Face to
24 face encounters are time consuming, but significantly improve the quality of
25 qualitative data.
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29 The questionnaire required 30 minutes to complete. Both an online and in-person
30 version were used, and each iteration was open for 6 weeks, with weekly
31 participation reminders.
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34 **Questionnaire Design**

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36 The questionnaire presented several scenarios describing practice situations,
37 with questions requiring participants to demonstrate knowledge and
38 understanding of the MCA and to describe how they would respond to these
39 scenarios. The survey included questions related to each scenario, exploring the
40 application of the MCA/DoLS and participants' understanding.
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43 Because the findings are so indelibly linked to the scenarios, it is necessary to
44 outline them here. There were five scenarios in the first iteration of the
45 questionnaire, and are outlined in turn below:
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48 **Scenario one:**

49 Described a patient with a learning disability in hospital being treated for
50 chest injuries. She was in distress, causing her to interfere with treatment.
51 The scenario suggested the staff thought there was a need to sedate her
52 in order to allow treatment to be provided. This accompanying questions
53 sought to explore if participants would consider sedating this patient
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irrespective of her capacity, to establish how staff deal with clinical situations where a patient's behaviour, attitude, decisions, and decision-making capacity presents a risk for the patient's own safety.

Scenario two:

Described a 15 year old child in hospital for arrhythmia refuses treatment. Her parents agreed with clinical advice that she needed treatment, but the girl refused. The key issue was to find out how participants managed the different wishes, and how they recommended to treat her, since, due to her age, she was not covered under the MCA.

Scenario three:

Presented a situation involving a patient with a history of anxiety and paranoia who refused a life-saving blood transfusion, stating that he 'did not want anyone's blood'. This sought to gather participants' responses when capacity and mental health issues are both present in a clinical situation. Would participants assess the decision making capacity of such a patient, or defer, as is recommended, to mental health legislation? Furthermore, would it make a difference if the patient refused a blood transfusion on religious grounds?

Scenario four:

Presented a widespread care home situation where a new resident arrived but did not to settle, and immediately insisted on returning to her home; notwithstanding that she lived alone and had suffered frequent falls on the stairs. This scenario sought to understand whether respondents feel that such a patient should be deprived of her liberties.

Scenario five:

Asked whether the capacity-making ability of an older, frail person should be questioned when they were making decisions that could harm him/her financially. It sought to probe participants' understanding of the 'unwise decision'.

Results

Sample

Profession		Number	Percentage	
General Practitioner Doctor		4	4.08%	
Nurses	Nurse	37	47	37.75%
	Practice Nurse	8		8.16%
				47.95%

	Community/District Nurse	2		2.04%	
Care Assistants	Healthcare Assistant	2	29	2.04%	29.59%
	Care Assistant (care/nursing home)	27		27.55%	
Social worker		7		7.14%	
Allied Health Professionals* (e.g. Occupational and Physio therapists)		2		2.04%	
No profession indicated		9		9.18%	
Total		98		100%	

* groups with few respondents collapsed to obscure individuals

A total of 150 practitioners were invited to participate, and 98 agreed. The sample included: 47 nurses (47.95%); 29 care assistants (29.6%); seven social workers (7.14%); two physio/occupational therapists (2.04%); and four GPs (4.08%).

Findings – Round one

Considering that the scenarios targeted specific elements of the MCA principles, responses were not as consistent as might be expected. The following provides more detail, but in general, participants often disagreed about the appropriate response to the situation, even within professional groupings. However, it is worth noting that in the first round, while there was a fair degree of consensus about the need for best interest assessment among professionals. It was clear that there was still a small group of professionals made up of nurses and occupational/physiotherapists who were of the view that best interest decisions should be made for patients and other service users regardless of whether they have capacity. They were of the view that the decisions made by these patients were unwise and detrimental to their well-being.

In another scenario, a large number (63%) from all the professional and non-professional groups were of the view that a patient who refused a blood transfusion should be assessed for capacity, while an equally large number (56%) were of the view that the patient's view must be respected, including all GP participants. It was also significant that more than 25% of participant care

workers indicated it would make a difference if the patient refused blood transfusion on grounds of religion.

There was no consensus on deprivation of liberty issues, with an almost even spread of opinions among both professionals and non-professionals. For example, when responding to the case of an older man making an unwise decision about spending his money, there was an even spread of views with less than 20% of participants suggesting variously that no action is needed; there was a need to raise a safeguarding alert; or a need for a best interest assessment and checking for powers of attorney. It is worth noting that a higher percentage of care workers (25% and 29%) than any other professional group proposed best interest assessments and powers of attorney. This may be an indication of the willingness of care workers to pass on the responsibility of making such decision decisions to more senior staff; one care worker stated “They can get approval from higher authorities to her care and what action must be taken based on her psychiatric report and behaviour”

Scenario one

Almost half of respondents (45%) stated there is no need to sedate the patient with a learning disability, even if her actions were putting her health and wellbeing at risk, as long as she does not lack capacity. However, 22.4% disagreed, suggesting they thought sedation was necessary, contending that intervention is required, even if it means overriding the decision of a patient who is deemed to have capacity. 60.2% of respondents indicated there was a need for a best interest assessment (BIA) in a situation where the patient lacked capacity. However, a small number of respondents (6%), all nurses, did not suggest there was need for a BIA. They appeared to suggest that a patient without capacity had a right to refuse sedation. A smaller number of respondents (3%) including two nurses and one social worker suggested they thought this was an emergency situation, which could not wait for the formal process of conducting a BIA and recommended immediate treatment against the patient's wishes.

Scenario two

This scenario generated a more varied response, with the largest proportion (38%) suggesting the patient could be treated in accordance with parental consent against her wishes, because she was a minor. A much smaller proportion (10%) suggested the patient's capacity would determine whether to prioritise her or her parents' wishes. However, there was no consensus on whether a patient who was 15 years of age has capacity to make decisions. 6.12% advised a mental capacity assessment before treating the patient against her wishes, but in line with parental consent. Another small proportion, 8.2%, including three nurses, three social workers and two doctors, suggested the need for Gillick competence testing. 12.24% of nurses advocated applying the MCA

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3 while only 6.12% suggested the MCA did not apply here. The case of a minor
4 falls outside the scope of the MCA, however, it was included to gain an
5 understanding of respondents' knowledge of what was within and without the
6 scope of the MCA. Also, it provided insight into how complex situations are dealt
7 with in practice and whether staff recognized a situation where, for e.g. Section
8 21 of the MCA provided a transfer of proceedings of a matter related to persons
9 below 18 years. Such knowledge was limited, however, admittedly respondents
10 were mainly from adult health and social care services.
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14 *Scenario three*

15 Responses to this scenario showed no consensus about how to deal with a
16 patient who refused blood. 63% of respondents (mainly nurses and care
17 assistants) suggested staff could assess the decision making capacity of the
18 patient. But a number of respondents indicated this approach depended on the
19 qualifications of available staff. However, 13.2% of respondents suggested the
20 patient was too ill to undergo an assessment, and 56% thought the clinical team
21 should respect the patient's decision. This last group included all GP participants,
22 a small number of nurses, and some care assistants and social workers who
23 agreed that the patient's decision to refuse a blood transfusion should be
24 respected. 28.6% of respondents stated their actions would be no different if the
25 patient refused blood on religious grounds, but over a quarter (27%), mostly
26 care assistants, stated that refusal on religious grounds would make a difference
27 to their assessment. This indicated a willingness to respect the views of the
28 patient if refusal was based on religious belief. Such views potentially
29 demonstrates a willingness to accept religious beliefs as valid reasoning for what
30 would otherwise be seen as an unwise decision. While a majority of respondents
31 suggested a capacity assessment was necessary, it was surprising that a third of
32 respondents did not suggest this was needed.
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39 *Scenario four*

40 26.5% of respondents to scenario four, advocated that it was in the best interest
41 of woman to have a mental capacity assessment. A small proportion of
42 respondents, 6.12%, suggested that a DoLS application was needed, primarily
43 because her wish to return home was deemed an unwise decision. When
44 participants were asked whether she should have her liberty deprived, 13% of
45 nurses, 17.24% of care assistants and 14.3% of social workers suggested a BIA
46 was needed. A significant proportion of respondents (36.2% of nurses, 34.5% of
47 care assistants and 50% of doctors) argued the patient should not be deprived of
48 her liberties with a smaller number of respondents (15% of nurses, 17.24% of
49 care assistants and 25% of doctors) arguing that the patient's liberty must be
50 deprived for her own safety. Participants on both side of the argument suggested
51 the best interest of the patient influenced their decision. For example, one
52 participant stated "No, in best interest of patient if at all possible." Responses to
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3 this scenario did not provide a clear consensus about whether a capacity
4 assessment was needed regarding her requests to return home. Generally, when
5 considering depriving the patient of her liberty, slightly more than half of
6 respondents disagreed, which is not a strong consensus.
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9 *Scenario five*

10 This scenario, about an older person's use of money (an 'unwise decision'), also
11 created conflicting responses. A sizable minority, 14.28% of respondents (23.4%
12 of nurses and 10.34% of carers), suggested no action should be taken to stop
13 the older person spending his money as he wished. A similar proportion of
14 respondents, 14.28%(17.02% of nurse participants, 17.24% of care assistants
15 and 14.3% of social workers) indicated they would raise a safeguarding alert,
16 while a small number of practitioners (10.63% of nurses and 14.3% of social
17 workers) suggested recommending Powers of Attorney and Lasting Powers of
18 Attorney. A slightly higher proportion, 17.35% of respondents (21.3% of nurses
19 17.24% of care assistants and 29% of social workers), suggested a BIA was
20 required. Some respondents (17.02% of nurses, 7% of care assistants, and 25%
21 of doctors) suggested checking for lasting powers of attorney or applying to the
22 Court of Protection. There were no strong views provided by respondents, even
23 when considering their responses grouped by profession. Responses did not
24 provide a consensus about how to deal with an unwise decision.
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30 **Second Round Delphi Survey**

31 An important part of a Delphi study is to provide a summary of findings from the
32 first round to the second round. This summary allowed participants to consider
33 their responses in relation to the sample's perspective of issues and to identify
34 how their views related to the general consensus.
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38 Profession	39 Number	40 Percentage
41 Nurses* (including 42 practice nurses)	43 88	44 66.6%
45 Social work, care 46 assistants and Allied 47 Health Professionals*	48 4	33.32%
49 Total	12	99.92%

*groups
with
few
respon

50 dents collapsed to obscure individuals

51 Participant attrition was a challenge in this study and there were significantly
52 fewer respondents in round two. Round one included 98 participants, and nearly
53 50% nurses. In the second round there were twelve respondents, with 66.6%
54 being nurses. Care workers were the second largest group in round one, nearly
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3 30% of respondents, but in round two this was reduced to 8.33%. GP's
4 constituted 4.08% of respondents round one, but none participated in the second
5 round. Social workers and therapists increased their proportion of participation,
6 (Social workers; 7.14% round one; 8.3% round two: physio/occupational
7 therapists increased from 2.04% to 16.66%). Methodologists recommend that
8 researchers individually engage with each participant, encouraging peer group
9 affiliation, to reduce attrition (Stitt-Gohdes, 2004), which was attempted during
10 round one. In this study, with a variety of professions involved, group
11 heterogeneity was a challenge. The variety of professions and different
12 hierarchical positions in health and social care may have hindered their group
13 cohesion.
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18 **Findings – Round two**

20 **Scenarios**

21 Round two sought to refine the findings from round one, as a result the
22 questionnaire was reduced to three scenarios, focussing on the responses with
23 least consensus.
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25 Scenario one was repeated, and focused on what participants would do if
26 a patient in intensive care with a learning disability refused sedation. The
27 questions were more focussed than in round one, such as 'If he is
28 assessed as lacking capacity, is there a need for a BIA?' This scenario
29 sought to elicit responses about capacity to make decisions.
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32 Scenario two presented a situation where an elderly woman arrives at a
33 care home and immediately makes it clear she wants to leave and return
34 to her own home. This scenario focussed on possible deprivation of liberty
35 after the patient makes an unwise decision.
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38 The third scenario sought to expose a key area of concern from round
39 one, by considering specifically how responses differed depending on their
40 perception of capacity. This scenario presented a middle aged man with a
41 brain injury living in a nursing home. When approached by staff about his
42 deteriorating self-care skills and body odour, he was irritated and refused
43 bathing assistance.
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49 **Scenario one**

50 There was a reduction in the proportion of participants that thought the patient
51 should be sedated, 33.3%, down from 45% round one, even if he had the
52 capacity to refuse treatment. In contrast, 53.3% argued that there was no need
53 for a capacity assessment, which is markedly higher than the 22.4% in round
54 one. In the second round, there was a significant increase in the proportion of
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3 respondents against sedation, but a subsequent drop in the proportion who
4 believed sedation was necessary. The respondents that argued for sedating a
5 patient with capacity who refused treatment is in sharp contrast with the majority
6 view that there is no need for sedation.
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9 **Scenario two**

10 Responses to scenario two provided a range of answers that suggested
11 patience, encouragement, listening to and giving the patient her wish.
12 Interestingly, 25% of respondents suggested a BIA was needed. For example
13 one respondent states, "Do a best interest assessment to determine what can be
14 done? Appreciate Olivia wants to go home. Identify temporary measures to
15 support her at home, such as a commode, until adjustments can be made for her
16 to live at home." Almost half of respondents, 41%, suggested they would not
17 deprive the patient of her liberty even with safety concerns. However, a
18 significant minority of respondents (25%, including some nurses) suggested they
19 would deprive her of liberty in order to keep her safe in the care home until
20 adjustments had been made to her home. Whilst respondents thought
21 undertaking a BIA was in the patient's best interest, there is a concern, raised by
22 Griffiths (2014) that the clinical use of these has been paternalistic. There are a
23 series of judgments about best interest that provide some suggestions about this
24 issue. In the case of R(Burke) v GMC [2005] the High Court stated that to
25 determine the best interests of a patient who is deemed incompetent, a stringent
26 standard must be applied to ascertain whether a patient's life had become
27 "intolerable" (Samantha and Samantha 2005). The Court of Appeal subsequently
28 ruled that the use of the phrase 'best interests' is confined to an objective test
29 used when considering the duty owed patients in need of care and treatment but
30 lacking decision-making capacity. These judgements suggest a systematic
31 approach to determining what is the best interest for a patient, which a quarter of
32 respondents seemed to have suggested. However, responses provided by the
33 majority of participants suggest a trend towards individualism to the extent that it
34 fits with the Public Guardian's individuated view on best interest; which,
35 according to Martin et al (2012 p. 22) is defined as "Anything done for a person
36 who cannot make decisions for themselves must be in their best interests. This
37 means thinking about what is best for the person, and not about what anyone
38 else wants." Martin et al (2012) argue there is growing realization that the needs
39 of others may be a useful consideration when dealing with best interest issues,
40 which contradicts the effects of hyper individualism.
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49 **Scenario three**

50 Responses to scenario three were more consistent, with 58.3% of respondents of
51 the opinion that all support must be given to the patient, providing he has
52 capacity to make decisions. Respondents stated, for example, "Keep
53 encouraging him to have a wash but try different means - if prompts aren't
54 working, try giving him bath and shower gift sets and asking if he had any
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3 concerns about washing which was preventing him from doing so” “Try to
4 encourage him to shower whilst remembering that no two people will necessarily
5 have the same personal hygiene standards and this could easily be his normal.”
6 Other respondents, 41.66%, did not suggest anything contrary, however, they
7 were somewhat unclear about what they would do making such comments as
8 “stop telling”, “approach Josh privately” and “with dignity”. When considering a
9 response if he did not have capacity, 91.6% of participants argued for all
10 necessary support to be provided to help him make the decision. Responses
11 prioritised the rights of the individual to make decisions, contrasting with the
12 paternalistic tendencies often associated with the care of patients, which appears
13 to be contrary to the established practice (Griffiths, 2014 p.1220). This may be an
14 indication that efforts to embed the principles of the MCA in practice are
15 beginning to yield positive results.
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23 **Summary and Discussion**

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25 Using scenarios in a Delphi study originates from the Rand study in the 1960's
26 regarding military technology, and explored the most possible scenarios of the
27 given topic for future predictions (Renzi, A. B. and Freitas, S. 2015); scenarios
28 were based on possible interactions reflecting the reality of practitioners. Vollmar
29 et al (2015) have pointed out that scenarios have limitations, which include the
30 time-consuming nature of creating (therefore cost-intensive), in particular
31 because they consume project resources. Because creating scenarios uses the
32 imagination, information and competency of the experts taking part, there is
33 potential risk of bias, preferences of the experts taking precedence or rejection of
34 what seems too unorthodox, with opinion leaders dominating.
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41 The scenarios used presented a moral dilemma, which is a technique for
42 generating stories from a range of sources to examine beliefs, perceptions and
43 attitudes. The scenarios were stories generated from research findings in
44 collaboration with professionals in the field (Hughes, 1998). They provide a
45 snapshot of a given situation and yet have the advantage of providing
46 respondents the opportunity to discuss issues from a non-personal and less
47 threatening perspective. However, the very non-personal nature of vignettes can
48 be considered a weakness. Hughes (1998) argues that it does not provide the
49 necessary interaction and feedback that is part of social life. While this study
50 might have suffered such disadvantage, there is currently no research tool that
51 can exactly mirror real life experience. However, it has the potential to prompt
52 participants to reflect on similar experiences, meaning they are notably more
53 realistic than traditional surveys (Steiner et al 2016). In order to make the
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scenarios as realistic as possible case studies were researched and social workers, nurses, care workers and safeguarding leads were consulted.

These findings highlight a conundrum in practice about the lack of consensus when practitioners attempt to apply the MCA. The capacity of patients to refuse treatment is a key area of contention requiring further research to resolve uncertainty. This is a key area of concern emerging as an important field of legal, clinical, and behavioural research, which has its origins in studies on psychiatric patients in the 1970's and 80's (Marson and Ingram, 1996, Applebaum *et al.*, 1981). While mental capacity assessment has become a familiar concept for practitioners, the point at which the assessment is triggered was identified inconsistently by participants. It can be argued that the scenarios used in this study demonstrated not a lack of capacity to make a decision, but unwise decisions that challenge practitioners' duty of care for patients. Applebaum (2007) argues that although standards for decision-making capacity for consent to treatment vary somewhat across jurisdictions, they generally include several considerations, including: the abilities to communicate a choice; to understand the relevant information; to appreciate the medical consequences of the situation; and to reason about treatment choices. In a clinical setting, such as a hospital, with a need for quick decisions under pressure, this setting conflicts with considerations that require time and reflection, as well as gathering a variety of views (from patients and caregivers). From the findings of this study, it appears that practitioners are struggling to identify when to assess capacity, and when an unwise decision may conflict with clinical advice.

The lack of consensus demonstrates both consequentialist and deontological positions of ethical judgements in professionals and non-professionals roles. While the consequentialist approach explores consequences of actions in order to identify which choice is likely to yield the most 'good' and least 'bad'. Deontology emphasizes that certain acts are inherently right or wrong, independent of the outcome and asks what one 'ought' to do in relation to duty or obligation. The MCA presents potential ethical conundrums which are a challenge for a Delphi study which aims at consensus building. In studies using the vignette method, a lack of consensus has been attributed to a number of reasons potentially reflected in this study include, a lack of awareness or familiarity with protocols, lack of agreement with guidelines because it limits the autonomy of professionals, professionals have bias, a prevailing paternalistic attitude (Nguyen *et al* 2014).

The lack of consensus in MCA practice has been acknowledged by others (e.g. Clare *et al* 2013, and Bartlett 2014), arguing there is no consensus on how to implement this in the future. However, where there have been indications of consensus, it has been suggested that conclusions or decisions are open to

challenge and especially so in cases where the criteria for detention under the Mental Health Act have been met (Selmes et al, 2010 p.224). Our analysis suggests the lack of consensus was due in part to a lack of understanding of key concepts underpinning the law, and possibly due to the complexity surrounding such issues as capacity decisions, best interest and deprivation of liberty. The complications that arise from these issues include the autonomy of the individual, which is in direct opposition to paternalism, which has been prevalent for many years. In the sedation and blood transfusion scenarios, for example, a lack of consensus arose from the tensions existing between notions of duty of care from professionals and the growing importance of the autonomy of the individual.

There is need for the law to be reviewed in order to incorporate recommendations made by the law commission, but further research is needed to understand the challenge of transferring the aspirations into practice, so that there will be more consensus on the issues to avoid decision paralysis in health and social care.

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3 TITLE: A Delphi Survey of Practitioner's Understanding of Mental Capacity
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5 ABSTRACT:

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- 7 • Purpose
 - 8 ○ This paper presents the findings of a study considering the
 - 9 application of the Mental Capacity Act and Deprivation of Liberty
 - 10 Safeguards. Practitioners from a range of professions were
 - 11 recruited to provide their views of how to respond to a variety of
 - 12 scenarios. GPs, nurses, social workers, physio/occupational
 - 13 therapists and care assistants were recruited to participate.
 - 14 • Design/methodology/approach
 - 15 ○ This study used the Delphi method to elicit participant views and
 - 16 generate consensus of opinion. The Delphi method recommends a
 - 17 large sample for heterogeneous groups, and round one had 98
 - 18 participants from six different professional groups.
 - 19 • Findings
 - 20 ○ Participants did not respond consistently to the scenarios, but
 - 21 disagreed most significantly when patient decisions conflicted with
 - 22 clinical advice, and when to conduct a capacity assessment. These
 - 23 responses suggest that clinical responses vary significantly
 - 24 between individuals (even within settings or professions), and that
 - 25 the application of MCA is complicated and nuanced, requiring time
 - 26 for reflection to avoid paternalistic clinical interventions.
 - 27 • Originality/value
 - 28 ○ Previous studies have not used a Delphi method to consider the
 - 29 application of MCA/DoLS. Because of this methods focus on
 - 30 developing consensus, it is uniquely suited to considering this
 - 31 practice issue. As a result, these findings present more developed
 - 32 understanding of the complexity and challenges for practitioner
 - 33 responses to some relatively common clinical scenarios,
 - 34 suggesting the need for greater clarity for practitioners.
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Context

The Mental Capacity Act 2005 (MCA) sought to provide a framework for decision making by health and social care providers and professionals, relating to adults who may not have the capacity to make decisions for themselves. Prior to its implementation, there was insufficient legal guidance in situations requiring self-determination; for example, an adult lacking capacity as a result of dementia who is unable to make decisions regarding her care. Although previous decision making was guided by common law, practice in health and social care was largely influenced by a paternalistic culture that reduced the agency of patients (Samuel, 2014). In an attempt to protect individuals and provide a clear legal framework to guide practice, the Law Commission initiated a process that culminated in the MCA.

Outline of the MCA

The MCA applies to people over the age of 16 in England and Wales where there are concerns about a person's decision making ability. It is underpinned by five enduring principles of care, seeking to place the individual at the heart of decision making. These five principles are: the presumption of capacity; supporting individuals to make decisions; the right to make an 'unwise decision'; the 'best interest principle'; and the 'least restriction principle'. Section two of the MCA requires professionals to presume that a person has capacity unless there is reason to believe otherwise. The legal presumption in favour of capacity is based on functional terms, including the ability to understand, retain, and evaluate relevant information, as well as being able to communicate any decision (Willner et al. 2013). The best interest principle (Section four) requires the care provider to act in the best interest of the individual instead of expedience or budget. The best interest principle also obliges care providers to encourage the participation of the individual in any decision about them. When lack of capacity is proven, the individual without capacity must be given the necessary support to make a decision. In such circumstances applying a best interest decision is crucial to providing appropriate care. However, this means that decisions can be contentious as the response can vary widely depending on the decision-maker (Martin et al 2009).

The 2005 European Court of Human Rights (ECtHR) ruling on *HL v United Kingdom* marked a watershed in mental capacity law and policy in the UK. This case found that a man had been deprived of his liberty, because he did not have capacity to decide whether to be admitted to a hospital, and he was held against his parents' wishes. The UK was deemed to have violated article 5 of the ECHR and concluded that English and Welsh law were insufficiently robust to meet the requirements of the law guarding the right to liberty and security. As a result, the Deprivation of Liberty Safeguards (DoLS) were inserted into the law, making the

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3 rights of patients an increasingly important consideration for health and social
4 care.
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6 A Select Committee post-legislative scrutiny report indicated that there was lack
7 of awareness and knowledge about the MCA (House of Lords, 2014). They noted
8 that a prevailing culture of paternalism and risk-aversion had prevented the Act
9 from becoming embedded into practice (ibid.). After consulting with a range of
10 stakeholders (including adults with learning disabilities and advocacy groups for
11 people with dementia), the overwhelming evidence showed a range of concerns:
12 poor implementation; low awareness; a lack of understanding; and ongoing
13 tensions between the MCA's empowering influence for patients and the
14 safeguarding responsibilities it places on professionals (House of Lords, 2014).
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18 The evidence from the report suggested a range of practice dilemmas, which
19 influenced the study outlined in this paper. This study has sought to understand
20 the experience of health and social care practitioners using the MCA and DoLS.
21 The Law Commission (2017) also suggested that the DoLS is not fit for purpose,
22 identifying that professionals lack understanding of its application as well the
23 complexities associated with applying the procedure. Parliament is currently
24 considering how to alter these procedures, although changes have been slowed
25 down because of the focus on Brexit (McNicoll, 2017). Despite the potential
26 change to the DoLS, much of the current procedures proposed are anticipated to
27 remain the same (Age UK, 2017; Spencer, 2017).
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33 After a review of the MCA DoLS, the Law Commission (2017) has concluded that
34 it is not fit for purpose and proposed 'Liberty Protection Safeguards'. Included in
35 the recommendations are provisions for enhanced rights to advocacy, greater
36 prominence to the rights of persons to be deprived of liberty, widening the scope
37 to cover 16 and 17 year olds and simplifying the best interest process. Such
38 concerns highlight flaws in the current law, and the challenges that practitioners
39 have to contend with. A gap seems to exist in the literature about studies on the
40 impact the law has had on practice and this study is an effort to contribute to
41 bridging the gap. The challenge service providers have to contend with is
42 translating the notion of the individual i.e. patient or other service user (PSU) as
43 any other rights bearing individual whose rights and liberties are not lost simply
44 because of the condition, from theory to practice
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49 Service providers have a duty to ensure that PSU's exercise the right to make
50 their own decisions. However, where they lacked capacity, the best interest
51 principle must underpin any decisions made on their behalf. The notion of best
52 interest is not new, but for many years it has underpinned a paternalistic.
53 According to the Law Commission (2017). "...health and social care
54 professionals and the Court of Protection often failed to consider the person's
55 wishes and feelings, and that the concept of best interests was often interpreted
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3 in a medical and paternalistic sense.” In health and social care, the concept of
4 paternalism has played a key role in the relationship between the patient or
5 service user and the doctor or other professional providing a service (Komrad,
6 1983). It implies the physician makes decisions for the patient based what he or
7 she believes is in the patient’s best interest, so they health system has thrived on
8 the notion that the physician or professional knows best (Murgic et al, 2015). So
9 while the notion of autonomy of the individual is a legally protected value, it is
10 important to understand what the challenges are in practice, where the old ideas
11 of best interest must be abandoned in favour of the wishes and preferences of
12 the patient.
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18 **Research Strategy**

19 This study sought to understand health and social care practitioners’ knowledge
20 of MCA/DoLS; how these frameworks are applied in practice; to determine
21 practitioners’ consensus about good practice within the relevant policy
22 frameworks; and sought to map out the understanding of representatives from
23 the different areas of practice (Boulkedid et al, 2011). To gather their
24 perceptions, participants were presented with everyday scenarios in hospital and
25 social care settings and asked how they respond. This enabled the researchers
26 to identify key differences in staff understandings of safeguarding and how the
27 differences may impact on practice. The views of a range of professionals were
28 sought in the study, including nurses, social workers and healthcare assistants
29 and doctors.
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34 **Methodology**

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36 A Delphi survey was used to study how practitioners understand and use the
37 MCA. This method was chosen to engage both experts and stakeholders, without
38 relying on one individual’s expert opinion (Olaf 1967). A Delphi method typically
39 elicits the views of a group of experts, who are individuals with knowledge of the
40 subject. It is an iterative approach to collecting information with the anonymous
41 results of the first round being shared with participants prior to the second and
42 subsequent rounds (Skumolski et al 2007). This process allows a Delphi to
43 develop convergences of opinion and build consensus. Surveys are generally
44 used to identify “what is,” but the Delphi technique goes further by attempting to
45 address “what could/should be” (Miller, 2006 cited in Hsu and Stanford 2007).
46 Because of the iterative process, it helps to transform opinion into group
47 consensus, and broadens knowledge on an issue of interest (Hasson et al 2000).
48 While the Delphi method is the preferred group technique for consensus building,
49 Kendall et al. (1992 cited in Okoli and Pawlawski, 2004) have also pointed out
50 this approach can use differences of opinion to inform further scenarios. Using
51 the Delphi can test whether there was consensus on the understanding and
52 practice of the MCA and whether consensus could be built, if found to be lacking.
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3 Delphi methods can be used for both qualitative and quantitative data collection.
4 Data from the first round of a Delphi can be analysed either by qualitative coding
5 or statistical summarizing (Skumolski et al 2007). However, by focusing on
6 consensus building, the method sacrifices the best opinion for a watered down
7 version of it. This is not unique to the Delphi technique as other forms of group
8 work such as nominal groups (Powell 2003 p.377) use structured meetings to
9 elicit the views of experts. **Using scenarios for decision making has the potential
10 for exposing variations in decisions among professionals and their colleagues
11 given the same circumstances. This has been demonstrated in studies using the
12 vignette method such as the Hughes' (1998) study of drug injecting and HIV risk
13 and safer behaviour, Reader et al (2017) and impossible decision making and
14 the risk of trade-offs in ICU.**

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19 Investigating the MCA in practice is a complex issue, and required the
20 participants from a range of professions and different areas of health and social
21 care. **It reflects the range of areas in health and social care that the law on
22 mental capacity affects and what happens in practice.** The Delphi Survey allowed
23 for this complexity and meant a broad understanding of the reality on the ground
24 could be reached. Participants in this study could be in different locations and still
25 participate in the research because of their knowledge and practice experience.
26 This allowed the participants a degree of anonymity, allowing them to express
27 their views free of influences. Hanafin (2005, p.10) suggests that anonymity
28 encourages experts to make statements on the basis of their personal knowledge
29 and experience, rather than a more cautious institutional position. Anonymity is a
30 feature of strength because it allows participants to express their views without
31 the influence of dominant characters and the inability of the researcher to trace
32 back responses to an individual leads to a lack of accountability (Sackman 1975).
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38 Ethical issues considered in the research strategy were approved by a Research
39 Ethics Committee. The study involved eliciting from respondents potentially
40 sensitive information regarding their understanding and practice in the context of
41 the Mental Capacity Act 2005. The sensitive issues included the potential for
42 revealing poor practice. Key issues considered included confidentiality and
43 anonymity.
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48 **Composition and Sampling**

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50 Delphi methods utilise a panel of experts with specialist knowledge and
51 qualifications as well as participants who are experts by experience (Iqbal and
52 Pison-Young 2009). However, the idea of experts is problematic, and has been
53 described as misleading and overstated with a potential for bias (McKenna,
54 1994; Sackman 1975; Strauss and Ziegler 1975). Keeney et al (2001) have
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3 argued, "Simply because individuals have knowledge of a particular topic does
4 not necessarily mean that they are experts" (p 196). In an attempt to ensure
5 participants had a working knowledge of the issue, this study recruited health and
6 social care practitioners that use the MCA and DoLS in their practice. This
7 provided a varied group covering the range of experiences of people working
8 with the legislation. Participants were experts because of their ongoing practice
9 experience of using MCA/DoLS, and not because they held leadership roles in
10 their organisation.
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14 Participants were purposively recruited. The aim was not to find a representative
15 sample, but to find frontline staff with knowledge and experience using the
16 legislative framework of the MCA. The study recruited people with first-hand
17 experience of using the MCA regularly whilst caring for individuals in either
18 hospital or social care settings. Snowballing was also used to expand the
19 sample, allowing participants to invite their colleagues with relevant experience
20 (Habibi et al 2014).
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24 It was important that the sample was a heterogeneous group, including a diverse
25 sample of professionals that covered the range of scenarios that health and
26 social care workers experience; whose practice involved decision making using
27 the MCA/DoLS. Where there is a homogenous sample, Skulmoski et al (2007)
28 have argued that a sample size of 10 – 15 may yield sufficient results. But a
29 heterogeneous group requires a larger sample, as the heterogeneity delays the
30 important step of building consensus, creating a longer process of analysing data
31 and verifying results (Delbeq et al 1975 cited in Skulmoski et al 2007). The study
32 recruited 5 groups of professionals and included 50 nurses and 30 care workers,
33 10 social workers, 5 occupational therapists, and 5 doctors to participate in the
34 first round of the survey. They were from acute settings and residential care for
35 the elderly. The number of respondents dropped significantly in the second
36 round, with only 12 respondents.
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41 Even with such a large sample, the response rate in the second round fell
42 drastically. It is generally agreed that experts who participate in such studies are
43 hard to engage with because of other commitments (Hsu and Sandford, 2007).
44 Ludwig (1994) suggests a drawback to using Delphi methods is that the
45 questionnaire method may significantly slow the process, with several days or
46 weeks between rounds (ibid.). In addition, the iterative process causes further
47 delays, posing a challenge to Delphi investigators to speed up the process. After
48 several emails to participants, the response was still very low, which suggested
49 the interest and commitment had waned. Hsu and Sandford (2007) recommend
50 telephone contacts to overcome the problem however, this could easily lead to
51 coercion, which would diminish the voluntary nature of the process. However, in
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3 this case non-respondents were slowing the process down, so several weeks
4 after the deadline, the round had to be closed. Hence the low response rate.
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7 The study sought a diverse array of situational contexts, from comparatively
8 minor to life-changing and even life-ending decisions, because of the wide scope
9 of the MCA. Because the topic considered how the MCA applies across a wide
10 range of circumstances, as a result the sample included professional and non-
11 professional staff such as nurses, social workers, care workers, physiotherapists
12 and GPs (Alghrani, 2016 p.312). The sample included this range because they
13 all use the MCA in their daily practice.
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17 Recruiting a diverse sample required engagement with a range of organisations.
18 Organisational gatekeepers were able to identify relevant managers (from both
19 acute and care home settings). These contacts were able to recruit members of
20 staff for participation. Participants were invited to attend a workshop, and asked
21 to complete the study questionnaires. This approach was used because of the
22 advantages of face to face interviews following the first round, which helped
23 increase the response rate (McKenna 1994 cited in Hasson et al. 2000). Face to
24 face encounters are time consuming, but significantly improve the quality of
25 qualitative data.
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29 The questionnaire required 30 minutes to complete. Both an online and in-person
30 version were used, and each iteration was open for 6 weeks, with weekly
31 participation reminders.
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34 **Questionnaire Design**

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36 The questionnaire presented several scenarios describing practice situations,
37 with questions requiring participants to demonstrate knowledge and
38 understanding of the MCA and to describe how they would respond to these
39 scenarios. The survey included questions related to each scenario, exploring the
40 application of the MCA/DoLS and participants' understanding.
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43 Because the findings are so indelibly linked to the scenarios, it is necessary to
44 outline them here. There were five scenarios in the first iteration of the
45 questionnaire, and are outlined in turn below:
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48 **Scenario one:**

49 Described a patient with a learning disability in hospital being treated for
50 chest injuries. She was in distress, causing her to interfere with treatment.
51 The scenario suggested the staff thought there was a need to sedate her
52 in order to allow treatment to be provided. This accompanying questions
53 sought to explore if participants would consider sedating this patient
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irrespective of her capacity, to establish how staff deal with clinical situations where a patient's behaviour, attitude, decisions, and decision-making capacity presents a risk for the patient's own safety.

Scenario two:

Described a 15 year old child in hospital for arrhythmia refuses treatment. Her parents agreed with clinical advice that she needed treatment, but the girl refused. The key issue was to find out how participants managed the different wishes, and how they recommended to treat her, since, due to her age, she was not covered under the MCA.

Scenario three:

Presented a situation involving a patient with a history of anxiety and paranoia who refused a life-saving blood transfusion, stating that he 'did not want anyone's blood'. This sought to gather participants' responses when capacity and mental health issues are both present in a clinical situation. Would participants assess the decision making capacity of such a patient, or defer, as is recommended, to mental health legislation? Furthermore, would it make a difference if the patient refused a blood transfusion on religious grounds?

Scenario four:

Presented a widespread care home situation where a new resident arrived but did not to settle, and immediately insisted on returning to her home; notwithstanding that she lived alone and had suffered frequent falls on the stairs. This scenario sought to understand whether respondents feel that such a patient should be deprived of her liberties.

Scenario five:

Asked whether the capacity-making ability of an older, frail person should be questioned when they were making decisions that could harm him/her financially. It sought to probe participants' understanding of the 'unwise decision'.

Results

Sample

Profession		Number	Percentage	
General Practitioner Doctor		4	4.08%	
Nurses	Nurse	37	47	37.75%
	Practice Nurse	8		8.16%
				47.95%

	Community/District Nurse	2		2.04%	
Care Assistants	Healthcare Assistant	2	29	2.04%	29.59%
	Care Assistant (care/nursing home)	27		27.55%	
Social worker		7		7.14%	
Allied Health Professionals* (e.g. Occupational and Physio therapists)		2		2.04%	
No profession indicated		9		9.18%	
Total		98		100%	

* groups with few respondents collapsed to obscure individuals

A total of 150 practitioners were invited to participate, and 98 agreed. The sample included: 47 nurses (47.95%); 29 care assistants (29.6%); seven social workers (7.14%); two physio/occupational therapists (2.04%); and four GPs (4.08%).

Findings – Round one

Considering that the scenarios targeted specific elements of the MCA principles, responses were not as consistent as might be expected. The following provides more detail, but in general, participants often disagreed about the appropriate response to the situation, even within professional groupings. However, it is worth noting that in the first round, while there was a fair degree of consensus about the need for best interest assessment among professionals. It was clear that there was still a small group of professionals made up of nurses and occupational/physiotherapists who were of the view that best interest decisions should be made for patients and other service users regardless of whether they have capacity. They were of the view that the decisions made by these patients were unwise and detrimental to their well-being.

In another scenario, a large number (63%) from all the professional and non-professional groups were of the view that a patient who refused a blood transfusion should be assessed for capacity, while an equally large number (56%) were of the view that the patient's view must be respected, including all GP participants. It was also significant that more than 25% of participant care

workers indicated it would make a difference if the patient refused blood transfusion on grounds of religion.

There was no consensus on deprivation of liberty issues, with an almost even spread of opinions among both professionals and non-professionals. For example, when responding to the case of an older man making an unwise decision about spending his money, there was an even spread of views with less than 20% of participants suggesting variously that no action is needed; there was a need to raise a safeguarding alert; or a need for a best interest assessment and checking for powers of attorney. It is worth noting that a higher percentage of care workers (25% and 29%) than any other professional group proposed best interest assessments and powers of attorney. This may be an indication of the willingness of care workers to pass on the responsibility of making such decision decisions to more senior staff; one care worker stated "They can get approval from higher authorities to her care and what action must be taken based on her psychiatric report and behaviour"

Scenario one

Almost half of respondents (45%) stated there is no need to sedate the patient with a learning disability, even if her actions were putting her health and wellbeing at risk, as long as she does not lack capacity. However, 22.4% disagreed, suggesting they thought sedation was necessary, contending that intervention is required, even if it means overriding the decision of a patient who is deemed to have capacity. 60.2% of respondents indicated there was a need for a best interest assessment (BIA) in a situation where the patient lacked capacity. However, a small number of respondents (6%), all nurses, did not suggest there was need for a BIA. They appeared to suggest that a patient without capacity had a right to refuse sedation. A smaller number of respondents (3%) including two nurses and one social worker suggested they thought this was an emergency situation, which could not wait for the formal process of conducting a BIA and recommended immediate treatment against the patient's wishes.

Scenario two

This scenario generated a more varied response, with the largest proportion (38%) suggesting the patient could be treated in accordance with parental consent against her wishes, because she was a minor. A much smaller proportion (10%) suggested the patient's capacity would determine whether to prioritise her or her parents' wishes. However, there was no consensus on whether a patient who was 15 years of age has capacity to make decisions. 6.12% advised a mental capacity assessment before treating the patient against her wishes, but in line with parental consent. Another small proportion, 8.2%, including three nurses, three social workers and two doctors, suggested the need for Gillick competence testing. 12.24% of nurses advocated applying the MCA

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3 while only 6.12% suggested the MCA did not apply here. The case of a minor
4 falls outside the scope of the MCA, however, it was included to gain an
5 understanding of respondents' knowledge of what was within and without the
6 scope of the MCA. Also, it provided insight into how complex situations are dealt
7 with in practice and whether staff recognized a situation where, for e.g. Section
8 21 of the MCA provided a transfer of proceedings of a matter related to persons
9 below 18 years. Such knowledge was limited, however, admittedly respondents
10 were mainly from adult health and social care services.
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14 *Scenario three*

15 Responses to this scenario showed no consensus about how to deal with a
16 patient who refused blood. 63% of respondents (mainly nurses and care
17 assistants) suggested staff could assess the decision making capacity of the
18 patient. But a number of respondents indicated this approach depended on the
19 qualifications of available staff. However, 13.2% of respondents suggested the
20 patient was too ill to undergo an assessment, and 56% thought the clinical team
21 should respect the patient's decision. This last group included all GP participants,
22 a small number of nurses, and some care assistants and social workers who
23 agreed that the patient's decision to refuse a blood transfusion should be
24 respected. 28.6% of respondents stated their actions would be no different if the
25 patient refused blood on religious grounds, but over a quarter (27%), mostly
26 care assistants, stated that refusal on religious grounds would make a difference
27 to their assessment. This indicated a willingness to respect the views of the
28 patient if refusal was based on religious belief. Such views potentially
29 demonstrates a willingness to accept religious beliefs as valid reasoning for what
30 would otherwise be seen as an unwise decision. While a majority of respondents
31 suggested a capacity assessment was necessary, it was surprising that a third of
32 respondents did not suggest this was needed.
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39 *Scenario four*

40 26.5% of respondents to scenario four, advocated that it was in the best interest
41 of woman to have a mental capacity assessment. A small proportion of
42 respondents, 6.12%, suggested that a DoLS application was needed, primarily
43 because her wish to return home was deemed an unwise decision. When
44 participants were asked whether she should have her liberty deprived, 13% of
45 nurses, 17.24% of care assistants and 14.3% of social workers suggested a BIA
46 was needed. A significant proportion of respondents (36.2% of nurses, 34.5% of
47 care assistants and 50% of doctors) argued the patient should not be deprived of
48 her liberties with a smaller number of respondents (15% of nurses, 17.24% of
49 care assistants and 25% of doctors) arguing that the patient's liberty must be
50 deprived for her own safety. Participants on both side of the argument suggested
51 the best interest of the patient influenced their decision. For example, one
52 participant stated "No, in best interest of patient if at all possible." Responses to
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3 this scenario did not provide a clear consensus about whether a capacity
4 assessment was needed regarding her requests to return home. Generally, when
5 considering depriving the patient of her liberty, slightly more than half of
6 respondents disagreed, which is not a strong consensus.
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9 *Scenario five*

10 This scenario, about an older person's use of money (an 'unwise decision'), also
11 created conflicting responses. A sizable minority, 14.28% of respondents (23.4%
12 of nurses and 10.34% of carers), suggested no action should be taken to stop
13 the older person spending his money as he wished. A similar proportion of
14 respondents, 14.28%(17.02% of nurse participants, 17.24% of care assistants
15 and 14.3% of social workers) indicated they would raise a safeguarding alert,
16 while a small number of practitioners (10.63% of nurses and 14.3% of social
17 workers) suggested recommending Powers of Attorney and Lasting Powers of
18 Attorney. A slightly higher proportion, 17.35% of respondents (21.3% of nurses
19 17.24% of care assistants and 29% of social workers), suggested a BIA was
20 required. Some respondents (17.02% of nurses, 7% of care assistants, and 25%
21 of doctors) suggested checking for lasting powers of attorney or applying to the
22 Court of Protection. There were no strong views provided by respondents, even
23 when considering their responses grouped by profession. Responses did not
24 provide a consensus about how to deal with an unwise decision.
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31 **Second Round Delphi Survey**

32 An important part of a Delphi study is to provide a summary of findings from the
33 first round to the second round. This summary allowed participants to consider
34 their responses in relation to the sample's perspective of issues and to identify
35 how their views related to the general consensus.
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38 Profession	39 Number	40 Percentage
41 Nurses* (including 42 practice nurses)	43 88	44 66.6%
45 Social work, care 46 assistants and Allied 47 Health Professionals*	48 4	33.32%
49 Total	50 12	51 99.92%

*groups
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52 dents collapsed to obscure individuals

53 Participant attrition was a challenge in this study and there were significantly
54 fewer respondents in round two. Round one included 98 participants, and nearly
55 50% nurses. In the second round there were twelve respondents, with 66.6%
56 being nurses. Care workers were the second largest group in round one, nearly
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3 30% of respondents, but in round two this was reduced to 8.33%. GP's
4 constituted 4.08% of respondents round one, but none participated in the second
5 round. Social workers and therapists increased their proportion of participation,
6 (Social workers; 7.14% round one; 8.3% round two: physio/occupational
7 therapists increased from 2.04% to 16.66%). Methodologists recommend that
8 researchers individually engage with each participant, encouraging peer group
9 affiliation, to reduce attrition (Stitt-Gohdes, 2004), which was attempted during
10 round one. In this study, with a variety of professions involved, group
11 heterogeneity was a challenge. The variety of professions and different
12 hierarchical positions in health and social care may have hindered their group
13 cohesion.
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18 **Findings – Round two**

20 **Scenarios**

21 Round two sought to refine the findings from round one, as a result the
22 questionnaire was reduced to three scenarios, focussing on the responses with
23 least consensus.
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25 Scenario one was repeated, and focused on what participants would do if
26 a patient in intensive care with a learning disability refused sedation. The
27 questions were more focussed than in round one, such as 'If he is
28 assessed as lacking capacity, is there a need for a BIA?' This scenario
29 sought to elicit responses about capacity to make decisions.
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32 Scenario two presented a situation where an elderly woman arrives at a
33 care home and immediately makes it clear she wants to leave and return
34 to her own home. This scenario focussed on possible deprivation of liberty
35 after the patient makes an unwise decision.
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38 The third scenario sought to expose a key area of concern from round
39 one, by considering specifically how responses differed depending on their
40 perception of capacity. This scenario presented a middle aged man with a
41 brain injury living in a nursing home. When approached by staff about his
42 deteriorating self-care skills and body odour, he was irritated and refused
43 bathing assistance.
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49 **Scenario one**

50 There was a reduction in the proportion of participants that thought the patient
51 should be sedated, 33.3%, down from 45% round one, even if he had the
52 capacity to refuse treatment. In contrast, 53.3% argued that there was no need
53 for a capacity assessment, which is markedly higher than the 22.4% in round
54 one. In the second round, there was a significant increase in the proportion of
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3 respondents against sedation, but a subsequent drop in the proportion who
4 believed sedation was necessary. The respondents that argued for sedating a
5 patient with capacity who refused treatment is in sharp contrast with the majority
6 view that there is no need for sedation.
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9 **Scenario two**

10 Responses to scenario two provided a range of answers that suggested
11 patience, encouragement, listening to and giving the patient her wish.
12 Interestingly, 25% of respondents suggested a BIA was needed. For example
13 one respondent states, "Do a best interest assessment to determine what can be
14 done? Appreciate Olivia wants to go home. Identify temporary measures to
15 support her at home, such as a commode, until adjustments can be made for her
16 to live at home." Almost half of respondents, 41%, suggested they would not
17 deprive the patient of her liberty even with safety concerns. However, a
18 significant minority of respondents (25%, including some nurses) suggested they
19 would deprive her of liberty in order to keep her safe in the care home until
20 adjustments had been made to her home. Whilst respondents thought
21 undertaking a BIA was in the patient's best interest, there is a concern, raised by
22 Griffiths (2014) that the clinical use of these has been paternalistic. There are a
23 series of judgments about best interest that provide some suggestions about this
24 issue. In the case of R(Burke) v GMC [2005] the High Court stated that to
25 determine the best interests of a patient who is deemed incompetent, a stringent
26 standard must be applied to ascertain whether a patient's life had become
27 "intolerable" (Samantha and Samantha 2005). The Court of Appeal subsequently
28 ruled that the use of the phrase 'best interests' is confined to an objective test
29 used when considering the duty owed patients in need of care and treatment but
30 lacking decision-making capacity. These judgements suggest a systematic
31 approach to determining what is the best interest for a patient, which a quarter of
32 respondents seemed to have suggested. However, responses provided by the
33 majority of participants suggest a trend towards individualism to the extent that it
34 fits with the Public Guardian's individuated view on best interest; which,
35 according to Martin et al (2012 p. 22) is defined as "Anything done for a person
36 who cannot make decisions for themselves must be in their best interests. This
37 means thinking about what is best for the person, and not about what anyone
38 else wants." Martin et al (2012) argue there is growing realization that the needs
39 of others may be a useful consideration when dealing with best interest issues,
40 which contradicts the effects of hyper individualism.
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49 **Scenario three**

50 Responses to scenario three were more consistent, with 58.3% of respondents of
51 the opinion that all support must be given to the patient, providing he has
52 capacity to make decisions. Respondents stated, for example, "Keep
53 encouraging him to have a wash but try different means - if prompts aren't
54 working, try giving him bath and shower gift sets and asking if he had any
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3 concerns about washing which was preventing him from doing so” “Try to
4 encourage him to shower whilst remembering that no two people will necessarily
5 have the same personal hygiene standards and this could easily be his normal.”
6 Other respondents, 41.66%, did not suggest anything contrary, however, they
7 were somewhat unclear about what they would do making such comments as
8 “stop telling”, “approach Josh privately” and “with dignity”. When considering a
9 response if he did not have capacity, 91.6% of participants argued for all
10 necessary support to be provided to help him make the decision. Responses
11 prioritised the rights of the individual to make decisions, contrasting with the
12 paternalistic tendencies often associated with the care of patients, which appears
13 to be contrary to the established practice (Griffiths, 2014 p.1220). This may be an
14 indication that efforts to embed the principles of the MCA in practice are
15 beginning to yield positive results.
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23 **Summary and Discussion**

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25 Using scenarios in a Delphi study originates from the Rand study in the 1960's
26 regarding military technology, and explored the most possible scenarios of the
27 given topic for future predictions (Renzi, A. B. and Freitas, S. 2015); scenarios
28 were based on possible interactions reflecting the reality of practitioners. Vollmar
29 et al (2015) have pointed out that scenarios have limitations, which include the
30 time-consuming nature of creating (therefore cost-intensive), in particular
31 because they consume project resources. Because creating scenarios uses the
32 imagination, information and competency of the experts taking part, there is
33 potential risk of bias, preferences of the experts taking precedence or rejection of
34 what seems too unorthodox, with opinion leaders dominating.
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41 The scenarios used presented a moral dilemma, which is a technique for
42 generating stories from a range of sources to examine beliefs, perceptions and
43 attitudes. The scenarios were stories generated from research findings in
44 collaboration with professionals in the field (Hughes, 1998). They provide a
45 snapshot of a given situation and yet have the advantage of providing
46 respondents the opportunity to discuss issues from a non-personal and less
47 threatening perspective. However, the very non-personal nature of vignettes can
48 be considered a weakness. Hughes (1998) argues that it does not provide the
49 necessary interaction and feedback that is part of social life. While this study
50 might have suffered such disadvantage, there is currently no research tool that
51 can exactly mirror real life experience. However, it has the potential to prompt
52 participants to reflect on similar experiences, meaning they are notably more
53 realistic than traditional surveys (Steiner et al 2016). In order to make the
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scenarios as realistic as possible case studies were researched and social workers, nurses, care workers and safeguarding leads were consulted.

These findings highlight a conundrum in practice about the lack of consensus when practitioners attempt to apply the MCA. The capacity of patients to refuse treatment is a key area of contention requiring further research to resolve uncertainty. This is a key area of concern emerging as an important field of legal, clinical, and behavioural research, which has its origins in studies on psychiatric patients in the 1970's and 80's (Marson and Ingram, 1996, Applebaum *et al.*, 1981). While mental capacity assessment has become a familiar concept for practitioners, the point at which the assessment is triggered was identified inconsistently by participants. It can be argued that the scenarios used in this study demonstrated not a lack of capacity to make a decision, but unwise decisions that challenge practitioners' duty of care for patients. Applebaum (2007) argues that although standards for decision-making capacity for consent to treatment vary somewhat across jurisdictions, they generally include several considerations, including: the abilities to communicate a choice; to understand the relevant information; to appreciate the medical consequences of the situation; and to reason about treatment choices. In a clinical setting, such as a hospital, with a need for quick decisions under pressure, this setting conflicts with considerations that require time and reflection, as well as gathering a variety of views (from patients and caregivers). From the findings of this study, it appears that practitioners are struggling to identify when to assess capacity, and when an unwise decision may conflict with clinical advice.

The lack of consensus demonstrates both consequentialist and deontological positions of ethical judgements in professionals and non-professionals roles. While the consequentialist approach explores consequences of actions in order to identify which choice is likely to yield the most 'good' and least 'bad'. Deontology emphasizes that certain acts are inherently right or wrong, independent of the outcome and asks what one 'ought' to do in relation to duty or obligation. The MCA presents potential ethical conundrums which are a challenge for a Delphi study which aims at consensus building. In studies using the vignette method, a lack of consensus has been attributed to a number of reasons potentially reflected in this study include, a lack of awareness or familiarity with protocols, lack of agreement with guidelines because it limits the autonomy of professionals, professionals have bias, a prevailing paternalistic attitude (Nguyen *et al* 2014).

The lack of consensus in MCA practice has been acknowledged by others (e.g. Clare *et al* 2013, and Bartlett 2014), arguing there is no consensus on how to implement this in the future. However, where there have been indications of consensus, it has been suggested that conclusions or decisions are open to

challenge and especially so in cases where the criteria for detention under the Mental Health Act have been met (Selmes et al, 2010 p.224). Our analysis suggests the lack of consensus was due in part to a lack of understanding of key concepts underpinning the law, and possibly due to the complexity surrounding such issues as capacity decisions, best interest and deprivation of liberty. The complications that arise from these issues include the autonomy of the individual, which is in direct opposition to paternalism, which has been prevalent for many years. In the sedation and blood transfusion scenarios, for example, a lack of consensus arose from the tensions existing between notions of duty of care from professionals and the growing importance of the autonomy of the individual.

There is need for the law to be reviewed in order to incorporate recommendations made by the law commission, but further research is needed to understand the challenge of transferring the aspirations into practice, so that there will be more consensus on the issues to avoid decision paralysis in health and social care.

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3 TITLE: A Delphi Survey of Practitioner's Understanding of Mental Capacity
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5 ABSTRACT:

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- 7 • Purpose
 - 8 ○ This paper presents the findings of a study considering the
 - 9 application of the Mental Capacity Act and Deprivation of Liberty
 - 10 Safeguards. Practitioners from a range of professions were
 - 11 recruited to provide their views of how to respond to a variety of
 - 12 scenarios. GPs, nurses, social workers, physio/occupational
 - 13 therapists and care assistants were recruited to participate.
 - 14 • Design/methodology/approach
 - 15 ○ This study used the Delphi method to elicit participant views and
 - 16 generate consensus of opinion. The Delphi method recommends a
 - 17 large sample for heterogeneous groups, and round one had 98
 - 18 participants from six different professional groups.
 - 19 • Findings
 - 20 ○ Participants did not respond consistently to the scenarios, but
 - 21 disagreed most significantly when patient decisions conflicted with
 - 22 clinical advice, and when to conduct a capacity assessment. These
 - 23 responses suggest that clinical responses vary significantly
 - 24 between individuals (even within settings or professions), and that
 - 25 the application of MCA is complicated and nuanced, requiring time
 - 26 for reflection to avoid paternalistic clinical interventions.
 - 27 • Originality/value
 - 28 ○ Previous studies have not used a Delphi method to consider the
 - 29 application of MCA/DoLS. Because of this methods focus on
 - 30 developing consensus, it is uniquely suited to considering this
 - 31 practice issue. As a result, these findings present more developed
 - 32 understanding of the complexity and challenges for practitioner
 - 33 responses to some relatively common clinical scenarios,
 - 34 suggesting the need for greater clarity for practitioners.
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Context

The Mental Capacity Act 2005 (MCA) sought to provide a framework for decision making by health and social care providers and professionals, relating to adults who may not have the capacity to make decisions for themselves. Prior to its implementation, there was insufficient legal guidance in situations requiring self-determination; for example, an adult lacking capacity as a result of dementia who is unable to make decisions regarding her care. Although previous decision making was guided by common law, practice in health and social care was largely influenced by a paternalistic culture that reduced the agency of patients (Samuel, 2014). In an attempt to protect individuals and provide a clear legal framework to guide practice, the Law Commission initiated a process that culminated in the MCA.

Outline of the MCA

The MCA applies to people over the age of 16 in England and Wales where there are concerns about a person's decision making ability. It is underpinned by five enduring principles of care, seeking to place the individual at the heart of decision making. These five principles are: the presumption of capacity; supporting individuals to make decisions; the right to make an 'unwise decision'; the 'best interest principle'; and the 'least restriction principle'. Section two of the MCA requires professionals to presume that a person has capacity unless there is reason to believe otherwise. The legal presumption in favour of capacity is based on functional terms, including the ability to understand, retain, and evaluate relevant information, as well as being able to communicate any decision (Willner et al. 2013). The best interest principle (Section four) requires the care provider to act in the best interest of the individual instead of expedience or budget. The best interest principle also obliges care providers to encourage the participation of the individual in any decision about them. When lack of capacity is proven, the individual without capacity must be given the necessary support to make a decision. In such circumstances applying a best interest decision is crucial to providing appropriate care. However, this means that decisions can be contentious as the response can vary widely depending on the decision-maker (Martin et al 2009).

The 2005 European Court of Human Rights (ECtHR) ruling on *HL v United Kingdom* marked a watershed in mental capacity law and policy in the UK. This case found that a man had been deprived of his liberty, because he did not have capacity to decide whether to be admitted to a hospital, and he was held against his parents' wishes. The UK was deemed to have violated article 5 of the ECHR and concluded that English and Welsh law were insufficiently robust to meet the requirements of the law guarding the right to liberty and security. As a result, the Deprivation of Liberty Safeguards (DoLS) were inserted into the law, making the

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3 rights of patients an increasingly important consideration for health and social
4 care.
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6 A Select Committee post-legislative scrutiny report indicated that there was lack
7 of awareness and knowledge about the MCA (House of Lords, 2014). They noted
8 that a prevailing culture of paternalism and risk-aversion had prevented the Act
9 from becoming embedded into practice (ibid.). After consulting with a range of
10 stakeholders (including adults with learning disabilities and advocacy groups for
11 people with dementia), the overwhelming evidence showed a range of concerns:
12 poor implementation; low awareness; a lack of understanding; and ongoing
13 tensions between the MCA's empowering influence for patients and the
14 safeguarding responsibilities it places on professionals (House of Lords, 2014).
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18 The evidence from the report suggested a range of practice dilemmas, which
19 influenced the study outlined in this paper. This study has sought to understand
20 the experience of health and social care practitioners using the MCA and DoLS.
21 The Law Commission (2017) also suggested that the DoLS is not fit for purpose,
22 identifying that professionals lack understanding of its application as well the
23 complexities associated with applying the procedure. Parliament is currently
24 considering how to alter these procedures, although changes have been slowed
25 down because of the focus on Brexit (McNicoll, 2017). Despite the potential
26 change to the DoLS, much of the current procedures proposed are anticipated to
27 remain the same (Age UK, 2017; Spencer, 2017).
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33 After a review of the MCA DoLS, the Law Commission (2017) concluded that it
34 was not fit for purpose and proposed 'Liberty Protection Safeguards'. It
35 recommended enhanced rights to advocacy, greater prominence to the rights of
36 persons to be deprived of liberty, widening the scope to cover 16 and 17 year
37 olds and simplifying the best interest process. Such concerns highlight flaws in
38 the current law, and the challenges that practitioners have to contend with. A gap
39 seems to exist in the literature about studies on the impact the law has had on
40 practice and this study is an effort to contribute to bridging the gap. Service
41 providers have to contend with translating the theoretical notion of the patient or
42 other service user (PSU) as rights bearing individuals whose rights and liberties
43 are not lost simply because of their condition into practice
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47 PSU's therefore have the right to make their own decisions. However, where they
48 lacked capacity, the best interest principle must underpin any decisions made on
49 their behalf. Best interest is not a new concept, however, it has it has continued
50 to underpin a paternalistic culture, hence questioning whether best interest is
51 paternalism (Anthony-Pillai, 2018). According to the Law Commission (2017).
52 "...health and social care professionals and the Court of Protection often failed to
53 consider the PSU's wishes and feelings, and that the concept of best interests
54 was often interpreted in a medical and paternalistic sense." Physicians have
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3 been making decisions for patients based the belief that the physician or
4 professional knows best (Murgic et al, 2015; Komrad, 1983). So while the
5 autonomy of the individual PSU is a legally protected value, it does not
6 automatically reflect in practice, as this requires a shift in favour of the wishes
7 and preferences of the patient.
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10 11 12 **Research Strategy**

13 This study sought to understand health and social care practitioners' knowledge
14 of MCA/DoLS; how these frameworks are applied in practice; to determine
15 practitioners' consensus about good practice within the relevant policy
16 frameworks; and sought to map out the understanding of representatives from
17 the different areas of practice (Boukdedid et al, 2011). To gather their
18 perceptions, participants were presented with everyday scenarios in hospital and
19 social care settings and asked how they respond. This enabled the researchers
20 to identify key differences in staff understandings of safeguarding and how the
21 differences may reflect on practice. The views of a range of professionals were
22 sought in the study, including nurses, social workers and healthcare assistants
23 and doctors.
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28 29 **Methodology**

30 A Delphi survey was used to study how practitioners understand and use the
31 MCA. It typically elicits the views of a number of experts, with knowledge of the
32 subject (Olaf 1967). By being selective, representativeness is sacrificed as the
33 focus is on purposively selecting experts (Ashmore et al, 2016). Snowballing was
34 also used to expand the sample, allowing participants to invite their colleagues
35 with relevant experience (Habibi et al 2014). Also, it is an iterative approach to
36 collecting information with the anonymous results of the first round shared with
37 participants prior to the second and subsequent rounds (Skumolski et al 2007).
38 The Delphi technique is good at finding out 'what is', but goes further, to address
39 "what could/should be" (Miller, 2006 cited in Hsu and Stanford 2007). It is an
40 iterative process that helps to transform opinion into group consensus, and
41 broadens knowledge on an issue of interest (Hasson et al 2000). Ludwig (1994)
42 suggests a drawback to using Delphi methods is that the questionnaire and
43 iterative process cause delays.
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48 Participants in this study could be in different locations and still participate in the
49 research because of their knowledge and practice experience. This allowed the
50 participants a degree of anonymity, allowing them to express their views free of
51 influences such as the more cautious institutional position and without the
52 influence of dominant characters (Hanafin, 2005, p.10; Sackman 1975).
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3 Ethical issues considered in the research strategy were approved by a Research
4 Ethics Committee. The study involved eliciting from respondents potentially
5 sensitive information regarding their understanding and practice in the context of
6 the Mental Capacity Act 2005. The sensitive issues included the potential for
7 revealing poor practice. Key issues considered included confidentiality and
8 anonymity.
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11 12 13 **Composition and Sampling**

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15 Delphi methods utilise a panel of experts with specialist knowledge and
16 qualifications as well as participants who are experts by experience (Iqbal and
17 Pison-Young 2009). However, the idea of experts is problematic, and has been
18 described as misleading and overstated with a potential for bias (McKenna,
19 1994; Sackman 1975; Strauss and Ziegler 1975). Keeney et al (2001) have
20 argued, "Simply because individuals have knowledge of a particular topic does
21 not necessarily mean that they are experts" (p 196). This study recruited health
22 and social care practitioners that use the MCA and DoLS in their practice to
23 include the range of experience of people working with the legislation, this
24 included professional and non-professional staff such as nurses, social workers,
25 care workers, physiotherapists and GPs (Alghrani, 2016 p.312). Participants
26 were experts because of their ongoing practice experience of using MCA/DoLS,
27 and not because they held leadership roles in their organisation.
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33 Where there is a homogenous sample, Skulmoski et al (2007) have argued that a
34 sample size of 10 – 15 may yield sufficient results. But a heterogeneous group
35 requires a larger sample, as the heterogeneity delays the important step of
36 building consensus, creating a longer process of analysing data and verifying
37 results (Delbeq et al 1975 cited in Skulmoski et al 2007). The study recruited 5
38 groups of professionals and included 50 nurses and 30 care workers, 10 social
39 workers, 5 occupational therapists, and 5 doctors to participate in the first round
40 of the survey. They were from acute settings and residential care for the elderly.
41 The number of respondents dropped significantly in the second round, with only
42 12 respondents.
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46 It is generally agreed that experts who participate in such studies are hard to
47 engage with because of other commitments (Hsu and Sandford, 2007). Hsu and
48 Sandford (2007) recommend telephone contacts to overcome this problem
49 however, this should be done cautiously to avoid coercion. Also,
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52 53 **Questionnaire Design**

54 The questionnaire presented several scenarios describing practice situations,
55 with questions requiring participants to demonstrate knowledge and
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3 understanding of the MCA and to describe how they would respond to these
4 scenarios. The survey included questions related to each scenario, exploring the
5 application of the MCA/DoLS and participants' understanding.
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8 Scenarios were constructed with corresponding questionnaires to elicit
9 responses on how similar cases are dealt with or will be dealt with. The vignette
10 method demonstrates largely the value of scenarios for decision making. They
11 have the potential for exposing variations in decisions among professionals and
12 their colleagues given the same circumstances, for e.g. This has been
13 demonstrated in studies using the vignette method such as the Hughes' (1998)
14 study of drug injecting and HIV risk and safer behaviour, and impossible decision
15 making and the risk of trade-offs in ICU (Reader et al (2017)).
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18 Using scenarios in a Delphi study originates from the Rand study in the 1960's
19 regarding military technology, and explored the most possible scenarios of the
20 given topic for future predictions (Renzi, A. B. and Freitas, S. 2015); scenarios
21 were based on possible interactions reflecting the reality of practitioners. Vollmar
22 et al (2015) have pointed out that scenarios have limitations. It is time-consuming
23 nature of creating (therefore cost-intensive), in particular because they consume
24 project resources.
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27 The scenarios provided respondents the opportunity to discuss issues from a
28 non-personal and less threatening perspective (Hughes, 1998). However, the
29 very non-personal nature of scenarios in the vignette method can be considered
30 a weakness. Hughes (1998) argues that it does not provide the necessary
31 interaction and feedback that is part of social life. Nonetheless scenarios prompts
32 participants to reflect on similar experiences, which are more realistic than
33 traditional surveys (Steiner et al 2016). In order to make the scenarios as realistic
34 as possible case studies were researched and professionals consulted.
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41 Because the findings are so indelibly linked to the scenarios, it is necessary to
42 outline them here. There were five scenarios in the first iteration of the
43 questionnaire, and are outlined in turn below:
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46 Scenario one:

47 Described a patient with a learning disability in hospital being treated for
48 chest injuries. She was in distress, causing her to interfere with treatment.
49 The scenario suggested the staff thought there was a need to sedate her
50 in order to allow treatment to be provided. This accompanying questions
51 sought to explore if participants would consider sedating this patient
52 irrespective of her capacity, to establish how staff deal with clinical
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situations where a patient's behaviour, attitude, decisions, and decision-making capacity presents a risk for the patient's own safety.

Scenario two:

Described a 15 year old child in hospital for arrhythmia refuses treatment. Her parents agreed with clinical advice that she needed treatment, but the girl refused. The key issue was to find out how participants managed the different wishes, and how they recommended to treat her, since, due to her age, she was not covered under the MCA.

Scenario three:

Presented a situation involving a patient with a history of anxiety and paranoia who refused a life-saving blood transfusion, stating that he 'did not want anyone's blood'. This sought to gather participants' responses when capacity and mental health issues are both present in a clinical situation. Would participants assess the decision making capacity of such a patient, or defer, as is recommended, to mental health legislation? Furthermore, would it make a difference if the patient refused a blood transfusion on religious grounds?

Scenario four:

Presented a widespread care home situation where a new resident arrived but did not to settle, and immediately insisted on returning to her home; notwithstanding that she lived alone and had suffered frequent falls on the stairs. This scenario sought to understand whether respondents feel that such a patient should be deprived of her liberties.

Scenario five:

Asked whether the capacity-making ability of an older, frail person should be questioned when they were making decisions that could harm him/her financially. It sought to probe participants' understanding of the 'unwise decision'.

Results

Sample

Profession		Number	Percentage	
General Practitioner Doctor		4	4.08%	
Nurses	Nurse	37	47	37.75%
	Practice Nurse	8		8.16%
				47.95%

	Community/District Nurse	2		2.04%	
Care Assistants	Healthcare Assistant	2	29	2.04%	29.59%
	Care Assistant (care/nursing home)	27		27.55%	
Social worker		7		7.14%	
Allied Health Professionals* (e.g. Occupational and Physio therapists)		2		2.04%	
No profession indicated		9		9.18%	
Total		98		100%	

* groups with few respondents collapsed to obscure individuals

A total of 150 practitioners were invited to participate, and 98 agreed. The sample included: 47 nurses (47.95%); 29 care assistants (29.6%); seven social workers (7.14%); two physio/occupational therapists (2.04%); and four GPs (4.08%).

Findings – Round one

Considering that the scenarios targeted specific elements of the MCA principles, responses were not as consistent as might be expected. The following provides more detail, but in general, participants often disagreed about the appropriate response to the situation, even within professional groupings. However, it is worth noting that in the first round, while there was a fair degree of consensus about the need for best interest assessment among professionals. It was clear that there was still a small group of professionals made up of nurses and occupational/physiotherapists who were of the view that best interest decisions should be made for patients and other service users regardless of whether they have capacity. They were of the view that the decisions made by these patients were unwise and detrimental to their well-being.

In another scenario, a large number (63%) from all the professional and non-professional groups were of the view that a patient who refused a blood transfusion should be assessed for capacity, while an equally large number (56%) were of the view that the patient's view must be respected, including all GP participants. It was also significant that more than 25% of participant care

workers indicated it would make a difference if the patient refused blood transfusion on grounds of religion.

There was no consensus on deprivation of liberty issues, with an almost even spread of opinions among both professionals and non-professionals. For example, when responding to the case of an older man making an unwise decision about spending his money, there was an even spread of views with less than 20% of participants suggesting variously that no action is needed; there was a need to raise a safeguarding alert; or a need for a best interest assessment and checking for powers of attorney. It is worth noting that a higher percentage of care workers (25% and 29%) than any other professional group proposed best interest assessments and powers of attorney. This may be an indication of the willingness of care workers to pass on the responsibility of making such decision decisions to more senior staff; one care worker stated "They can get approval from higher authorities to her care and what action must be taken based on her psychiatric report and behaviour"

Scenario one

Almost half of respondents (45%) stated there is no need to sedate the patient with a learning disability, even if her actions were putting her health and wellbeing at risk, as long as she does not lack capacity. However, 22.4% disagreed, suggesting they thought sedation was necessary, contending that intervention is required, even if it means overriding the decision of a patient who is deemed to have capacity. 60.2% of respondents indicated there was a need for a best interest assessment (BIA) in a situation where the patient lacked capacity. However, a small number of respondents (6%), all nurses, did not suggest there was need for a BIA. They appeared to suggest that a patient without capacity had a right to refuse sedation. A smaller number of respondents (3%) including two nurses and one social worker suggested they thought this was an emergency situation, which could not wait for the formal process of conducting a BIA and recommended immediate treatment against the patient's wishes.

Scenario two

This scenario generated a more varied response, with the largest proportion (38%) suggesting the patient could be treated in accordance with parental consent against her wishes, because she was a minor. A much smaller proportion (10%) suggested the patient's capacity would determine whether to prioritise her or her parents' wishes. However, there was no consensus on whether a patient who was 15 years of age has capacity to make decisions. 6.12% advised a mental capacity assessment before treating the patient against her wishes, but in line with parental consent. Another small proportion, 8.2%, including three nurses, three social workers and two doctors, suggested the need for Gillick competence testing. 12.24% of nurses advocated applying the MCA

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3 while only 6.12% suggested the MCA did not apply here. The case of a minor
4 falls outside the scope of the MCA, however, it was included to gain an
5 understanding of respondents' knowledge of what was within and without the
6 scope of the MCA. Also, it provided insight into how complex situations are dealt
7 with in practice and whether staff recognized a situation where, for e.g. Section
8 21 of the MCA provided a transfer of proceedings of a matter related to persons
9 below 18 years. Such knowledge was limited, however, admittedly respondents
10 were mainly from adult health and social care services.
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14 *Scenario three*

15 Responses to this scenario showed no consensus about how to deal with a
16 patient who refused blood. 63% of respondents (mainly nurses and care
17 assistants) suggested staff could assess the decision making capacity of the
18 patient. But a number of respondents indicated this approach depended on the
19 qualifications of available staff. However, 13.2% of respondents suggested the
20 patient was too ill to undergo an assessment, and 56% thought the clinical team
21 should respect the patient's decision. This last group included all GP participants,
22 a small number of nurses, and some care assistants and social workers who
23 agreed that the patient's decision to refuse a blood transfusion should be
24 respected. 28.6% of respondents stated their actions would be no different if the
25 patient refused blood on religious grounds, but over a quarter (27%), mostly
26 care assistants, stated that refusal on religious grounds would make a difference
27 to their assessment. This indicated a willingness to respect the views of the
28 patient if refusal was based on religious belief. Such views potentially
29 demonstrates a willingness to accept religious beliefs as valid reasoning for what
30 would otherwise be seen as an unwise decision. While a majority of respondents
31 suggested a capacity assessment was necessary, it was surprising that a third of
32 respondents did not suggest this was needed.
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39 *Scenario four*

40 26.5% of respondents to scenario four, advocated that it was in the best interest
41 of woman to have a mental capacity assessment. A small proportion of
42 respondents, 6.12%, suggested that a DoLS application was needed, primarily
43 because her wish to return home was deemed an unwise decision. When
44 participants were asked whether she should have her liberty deprived, 13% of
45 nurses, 17.24% of care assistants and 14.3% of social workers suggested a BIA
46 was needed. A significant proportion of respondents (36.2% of nurses, 34.5% of
47 care assistants and 50% of doctors) argued the patient should not be deprived of
48 her liberties with a smaller number of respondents (15% of nurses, 17.24% of
49 care assistants and 25% of doctors) arguing that the patient's liberty must be
50 deprived for her own safety. Participants on both side of the argument suggested
51 the best interest of the patient influenced their decision. For example, one
52 participant stated "No, in best interest of patient if at all possible." Responses to
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3 this scenario did not provide a clear consensus about whether a capacity
4 assessment was needed regarding her requests to return home. Generally, when
5 considering depriving the patient of her liberty, slightly more than half of
6 respondents disagreed, which is not a strong consensus.
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9 *Scenario five*

10 This scenario, about an older person's use of money (an 'unwise decision'), also
11 created conflicting responses. A sizable minority, 14.28% of respondents (23.4%
12 of nurses and 10.34% of carers), suggested no action should be taken to stop
13 the older person spending his money as he wished. A similar proportion of
14 respondents, 14.28%(17.02% of nurse participants, 17.24% of care assistants
15 and 14.3% of social workers) indicated they would raise a safeguarding alert,
16 while a small number of practitioners (10.63% of nurses and 14.3% of social
17 workers) suggested recommending Powers of Attorney and Lasting Powers of
18 Attorney. A slightly higher proportion, 17.35% of respondents (21.3% of nurses
19 17.24% of care assistants and 29% of social workers), suggested a BIA was
20 required. Some respondents (17.02% of nurses, 7% of care assistants, and 25%
21 of doctors) suggested checking for lasting powers of attorney or applying to the
22 Court of Protection. There were no strong views provided by respondents, even
23 when considering their responses grouped by profession. Responses did not
24 provide a consensus about how to deal with an unwise decision.
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31 **Second Round Delphi Survey**

32 An important part of a Delphi study is to provide a summary of findings from the
33 first round to the second round. This summary allowed participants to consider
34 their responses in relation to the sample's perspective of issues and to identify
35 how their views related to the general consensus.
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38 Profession	39 Number	40 Percentage
41 Nurses* (including 42 practice nurses)	43 88	44 66.6%
45 Social work, care 46 assistants and Allied 47 Health Professionals*	48 4	33.32%
49 Total	50 12	51 99.92%

*groups
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52 dents collapsed to obscure individuals

53 Participant attrition was a challenge in this study and there were significantly
54 fewer respondents in round two. Round one included 98 participants, and nearly
55 50% nurses. In the second round there were twelve respondents, with 66.6%
56 being nurses. Care workers were the second largest group in round one, nearly
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3 30% of respondents, but in round two this was reduced to 8.33%. GP's
4 constituted 4.08% of respondents round one, but none participated in the second
5 round. Social workers and therapists increased their proportion of participation,
6 (Social workers; 7.14% round one; 8.3% round two: physio/occupational
7 therapists increased from 2.04% to 16.66%). Methodologists recommend that
8 researchers individually engage with each participant, encouraging peer group
9 affiliation, to reduce attrition (Stitt-Gohdes, 2004), which was attempted during
10 round one. In this study, with a variety of professions involved, group
11 heterogeneity was a challenge. The variety of professions and different
12 hierarchical positions in health and social care may have hindered their group
13 cohesion.
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18 **Findings – Round two**

20 **Scenarios**

21 Round two sought to refine the findings from round one, as a result the
22 questionnaire was reduced to three scenarios, focussing on the responses with
23 least consensus.
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25 Scenario one was repeated, and focused on what participants would do if
26 a patient in intensive care with a learning disability refused sedation. The
27 questions were more focussed than in round one, such as 'If he is
28 assessed as lacking capacity, is there a need for a BIA?' This scenario
29 sought to elicit responses about capacity to make decisions.
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32 Scenario two presented a situation where an elderly woman arrives at a
33 care home and immediately makes it clear she wants to leave and return
34 to her own home. This scenario focussed on possible deprivation of liberty
35 after the patient makes an unwise decision.
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38 The third scenario sought to expose a key area of concern from round
39 one, by considering specifically how responses differed depending on their
40 perception of capacity. This scenario presented a middle aged man with a
41 brain injury living in a nursing home. When approached by staff about his
42 deteriorating self-care skills and body odour, he was irritated and refused
43 bathing assistance.
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49 **Scenario one**

50 There was a reduction in the proportion of participants that thought the patient
51 should be sedated, 33.3%, down from 45% round one, even if he had the
52 capacity to refuse treatment. In contrast, 53.3% argued that there was no need
53 for a capacity assessment, which is markedly higher than the 22.4% in round
54 one. In the second round, there was a significant increase in the proportion of
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3 respondents against sedation, but a subsequent drop in the proportion who
4 believed sedation was necessary. The respondents that argued for sedating a
5 patient with capacity who refused treatment is in sharp contrast with the majority
6 view that there is no need for sedation.
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9 **Scenario two**

10 Responses to scenario two provided a range of answers that suggested
11 patience, encouragement, listening to and giving the patient her wish.
12 Interestingly, 25% of respondents suggested a BIA was needed. For example
13 one respondent states, "Do a best interest assessment to determine what can be
14 done? Appreciate Olivia wants to go home. Identify temporary measures to
15 support her at home, such as a commode, until adjustments can be made for her
16 to live at home." Almost half of respondents, 41%, suggested they would not
17 deprive the patient of her liberty even with safety concerns. However, a
18 significant minority of respondents (25%, including some nurses) suggested they
19 would deprive her of liberty in order to keep her safe in the care home until
20 adjustments had been made to her home. Whilst respondents thought
21 undertaking a BIA was in the patient's best interest, there is a concern, raised by
22 Griffiths (2014) that the clinical use of these has been paternalistic. There are a
23 series of judgments about best interest that provide some suggestions about this
24 issue. In the case of R(Burke) v GMC [2005] the High Court stated that to
25 determine the best interests of a patient who is deemed incompetent, a stringent
26 standard must be applied to ascertain whether a patient's life had become
27 "intolerable" (Samantha and Samantha 2005). The Court of Appeal subsequently
28 ruled that the use of the phrase 'best interests' is confined to an objective test
29 used when considering the duty owed patients in need of care and treatment but
30 lacking decision-making capacity. These judgements suggest a systematic
31 approach to determining what the best interest is for a patient, which a quarter of
32 respondents seemed to have suggested. However, responses provided by the
33 majority of participants suggest a trend towards individualism to the extent that it
34 fits with the Public Guardian's individuated view on best interest; which,
35 according to Martin et al (2012 p. 22) is defined as "Anything done for a person
36 who cannot make decisions for themselves must be in their best interests. This
37 means thinking about what is best for the person, and not about what anyone
38 else wants." Martin et al (2012) argue there is growing realization that the needs
39 of others may be a useful consideration when dealing with best interest issues,
40 which contradicts the effects of hyper individualism.
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49 **Scenario three**

50 Responses to scenario three were more consistent, with 58.3% of respondents of
51 the opinion that all support must be given to the patient, providing he has
52 capacity to make decisions. Respondents stated, for example, "Keep
53 encouraging him to have a wash but try different means - if prompts aren't
54 working, try giving him bath and shower gift sets and asking if he had any
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3 concerns about washing which was preventing him from doing so” “Try to
4 encourage him to shower whilst remembering that no two people will necessarily
5 have the same personal hygiene standards and this could easily be his normal.”
6 Other respondents, 41.66%, did not suggest anything contrary, however, they
7 were somewhat unclear about what they would do making such comments as
8 “stop telling”, “approach Josh privately” and “with dignity”. When considering a
9 response if he did not have capacity, 91.6% of participants argued for all
10 necessary support to be provided to help him make the decision. Responses
11 prioritised the rights of the individual to make decisions, contrasting with the
12 paternalistic tendencies often associated with the care of patients, which appears
13 to be contrary to the established practice (Griffiths, 2014 p.1220). This may be an
14 indication that efforts to embed the principles of the MCA in practice are
15 beginning to yield positive results.
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20 21 **Summary and Discussion**

22 These findings highlight a conundrum in practice about the lack of consensus
23 when practitioners attempt to apply the MCA. The capacity of patients to refuse
24 treatment is a key area of contention requiring further research to resolve
25 uncertainty. This is a key area of concern emerging as an important field of legal,
26 clinical, and behavioural research, which has its origins in studies on psychiatric
27 patients in the 1970’s and 80’s (Marson and Ingram, 1996, Applebaum *et al.*,
28 1981). While mental capacity assessment has become a familiar concept for
29 practitioners, the point at which the assessment is triggered was identified
30 inconsistently by participants. It can be argued that the scenarios used in this
31 study demonstrated not a lack of capacity to make a decision, but unwise
32 decisions that challenge practitioners’ duty of care for patients. Applebaum
33 (2007) argues that although standards for decision-making capacity for consent
34 to treatment vary somewhat across jurisdictions, they generally include several
35 considerations, including: the abilities to communicate a choice; to understand
36 the relevant information; to appreciate the medical consequences of the situation;
37 and to reason about treatment choices. In a clinical setting, such as a hospital,
38 with a need for quick decisions under pressure, this setting conflicts with
39 considerations that require time and reflection, as well as gathering a variety of
40 views (from patients and caregivers). From the findings of this study, it appears
41 that practitioners are struggling to identify when to assess capacity, and when an
42 unwise decision may conflict with clinical advice. **This is likely influenced by what
43 respondents may deem complex situations, which make it difficult to carry out an
44 objective assessment of capacity (Murrell and McCalla, 2015).**
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51 The lack of consensus demonstrates both consequentialist and deontological
52 positions of ethical judgements in professional and non-professionals roles
53 (Clarke, 2015; Morgan-Knapp, 2015). While the consequentialist approach
54 explores consequences of actions in order to identify which choice is likely to
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3 yield the most 'good' and least 'bad'. Deontology emphasizes that certain acts
4 are inherently right or wrong, independent of the outcome and asks what one
5 'ought' to do in relation to duty or obligation. This was evident in the response
6 from participants on the issue of sedation. For e.g. one respondent suggested
7 "Is emergency so they have to do the best interest", which suggests the end
8 justifies the means, a consequentialist approach to ethical judgements. On the
9 other hand, another respondent stated "Yes, because this treatment of sedate
10 him is the best thing to do for that person at that moment." This is a deontological
11 position that emphasizes the best interest of the patient is simply the right thing
12 to do regardless of the outcome. There was no sign of consensus after the
13 second round of the survey as there was a percentage increase in responses
14 from the two sides of the argument. In studies using the vignette method, a lack
15 of consensus can be attributed to lack of awareness or familiarity with protocols,
16 lack of agreement with guidelines because it limits the autonomy of
17 professionals, professionals have bias, a prevailing paternalistic attitude (Nguyen
18 et al 2014).

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24 The lack of consensus in MCA practice has been acknowledged by others (e.g.
25 Clare et al 2013, and Bartlett 2014), concluding there is no consensus on how to
26 implement this in the future. Also, there were variations in the understanding and
27 application of concepts such as best interest. In the blood transfusion scenario,
28 for e.g. one proponent of respecting the patients view stated "If it is in
29 accordance with his religious belief and after thorough explanation - a best
30 interest meeting is to be conducted and conducted and if despite his presence
31 and all disciplines meeting he still refused we have to accept and respect his
32 wishes and since he has capacity he could sign for it", while a proponent who
33 opposed this stated, "The relevant clinician should complete a capacity
34 assessment and is required take a Best Interests decision giving appropriate
35 weight to Shujaat's views." It can be argued that the tension between the two
36 views i.e. whether to assess capacity or respect the views of the patient,
37 demonstrates different perspectives of what is in the best interest of the patient
38 (Sandiman and Munthe, 2009), so there is no unified view of what the best
39 interest is.

40 41 42 43 44 **Implications for practice**

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46 It is important to tailor training to improve and deepen understanding of key terms
47 among the different professional groups (Manthorpe et al 2011). The MCA and
48 the Code of Practice give a sense of common understanding, however, the
49 findings of this study potentially reflect practice across the health and social care
50 sector. It is imperative that practitioners are given the kind of training that
51 recognizes shared decision making and its variations. The MCA provides that
52 patients who following assessment have demonstrated a lack capacity should as
53 much as possible be involved in decision making, with assistance to improve
54 their ability to exercise their autonomy (Bingham 2012). However, Sandiman and
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3 Munthe (2009) argue this ranges from a 'Professionally Driven Best Interest
4 Compromise (PDBIC) model', which promotes best interest with the
5 professionals view given prominence and a 'Shared Rational Deliberative
6 Compromise' model, which is driven mainly by patients, but incorporates the
7 professionals view about best interest. It is also worth noting that a PDBIC could
8 be used for influencing patients to accept what is deemed their best interest.
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12 The Law Commission report pushes further the patient centred approach to
13 health and social care. However, practitioners have to face contentious questions
14 about whether it is good that people govern themselves, or to what extent they
15 should do so, as there are challenges around unwise decisions and deprivation
16 of liberty, where practitioners have to wrestle with their personal convictions and
17 law and policy (Coggon and Miola, 2011). Where practice is shaped by a
18 predominantly PDBIC model it could undermine the MCA and set the stage for
19 litigation. Further research is needed to understand the challenge of transferring
20 the aspirations into practice, so that there will be more understanding of what
21 realistic aspirations are, so as to avoid situations of decision paralysis in health
22 and social care.
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The Journal of Adult Protection

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3 TITLE: A Delphi Survey of Practitioner's Understanding of Mental Capacity
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5 ABSTRACT:

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- 7 • Purpose
 - 8 ○ This paper presents the findings of a study considering the
 - 9 application of the Mental Capacity Act and Deprivation of Liberty
 - 10 Safeguards. Practitioners from a range of professions were
 - 11 recruited to provide their views of how to respond to a variety of
 - 12 scenarios. GPs, nurses, social workers, physio/occupational
 - 13 therapists and care assistants were recruited to participate.
 - 14 • Design/methodology/approach
 - 15 ○ This study used the Delphi method to elicit participant views and
 - 16 generate consensus of opinion. The Delphi method recommends a
 - 17 large sample for heterogeneous groups, and round one had 98
 - 18 participants from six different professional groups.
 - 19 • Findings
 - 20 ○ Participants did not respond consistently to the scenarios, but
 - 21 disagreed most significantly when patient decisions conflicted with
 - 22 clinical advice, and when to conduct a capacity assessment. These
 - 23 responses suggest that clinical responses vary significantly
 - 24 between individuals (even within settings or professions), and that
 - 25 the application of MCA is complicated and nuanced, requiring time
 - 26 for reflection to avoid paternalistic clinical interventions.
 - 27 • Originality/value
 - 28 ○ Previous studies have not used a Delphi method to consider the
 - 29 application of MCA/DoLS. Because of this methods focus on
 - 30 developing consensus, it is uniquely suited to considering this
 - 31 practice issue. As a result, these findings present more developed
 - 32 understanding of the complexity and challenges for practitioner
 - 33 responses to some relatively common clinical scenarios,
 - 34 suggesting the need for greater clarity for practitioners.
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Context

The Mental Capacity Act 2005 (MCA) sought to provide a framework for decision making by health and social care providers and professionals, relating to adults who may not have the capacity to make decisions for themselves. Prior to its implementation, there was insufficient legal guidance in situations requiring self-determination; for example, an adult lacking capacity as a result of dementia who is unable to make decisions regarding her care. Although previous decision making was guided by common law, practice in health and social care was largely influenced by a paternalistic culture that reduced the agency of patients (Samuel, 2014). In an attempt to protect individuals and provide a clear legal framework to guide practice, the Law Commission initiated a process that culminated in the MCA.

Outline of the MCA

The MCA applies to people over the age of 16 in England and Wales where there are concerns about a person's decision making ability. It is underpinned by five enduring principles of care, seeking to place the individual at the heart of decision making. These five principles are: the presumption of capacity; supporting individuals to make decisions; the right to make an 'unwise decision'; the 'best interest principle'; and the 'least restriction principle'. Section two of the MCA requires professionals to presume that a person has capacity unless there is reason to believe otherwise. The legal presumption in favour of capacity is based on functional terms, including the ability to understand, retain, and evaluate relevant information, as well as being able to communicate any decision (Willner et al. 2013). The best interest principle (Section four) requires the care provider to act in the best interest of the individual instead of expedience or budget. The best interest principle also obliges care providers to encourage the participation of the individual in any decision about them. When lack of capacity is proven, the individual without capacity must be given the necessary support to make a decision. In such circumstances applying a best interest decision is crucial to providing appropriate care. However, this means that decisions can be contentious as the response can vary widely depending on the decision-maker (Martin et al 2012).

The 2005 European Court of Human Rights (ECtHR) ruling on *HL v United Kingdom* marked a watershed in mental capacity law and policy in the UK. This case found that a man had been deprived of his liberty, because he did not have capacity to decide whether to be admitted to a hospital, and he was held against his parents' wishes. The UK was deemed to have violated article 5 of the ECHR and concluded that English and Welsh law were insufficiently robust to meet the requirements of the law guarding the right to liberty and security. As a result, the Deprivation of Liberty Safeguards (DoLS) were inserted into the law, making the

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3 rights of patients an increasingly important consideration for health and social
4 care.
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6 A Select Committee post-legislative scrutiny report indicated that there was lack
7 of awareness and knowledge about the MCA (House of Lords, 2014). They noted
8 that a prevailing culture of paternalism and risk-aversion had prevented the Act
9 from becoming embedded into practice (ibid.). After consulting with a range of
10 stakeholders (including adults with learning disabilities and advocacy groups for
11 people with dementia), the overwhelming evidence showed a range of concerns:
12 poor implementation; low awareness; a lack of understanding; and ongoing
13 tensions between the MCA's empowering influence for patients and the
14 safeguarding responsibilities it places on professionals (House of Lords, 2014).
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18 The evidence from the report suggested a range of practice dilemmas, which
19 influenced the study outlined in this paper. This study has sought to understand
20 the experience of health and social care practitioners using the MCA and DoLS.
21 The Law Commission (2017) also suggested that the DoLS is not fit for purpose,
22 identifying that professionals lack understanding of its application as well the
23 complexities associated with applying the procedure. Parliament is currently
24 considering how to alter these procedures, although changes have been slowed
25 down because of the focus on Brexit (McNicoll, 2017). Despite the potential
26 change to the DoLS, much of the current procedures proposed are anticipated to
27 remain the same (Age UK, 2017; Spencer, 2017).
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33 After a review of the MCA DoLS, the Law Commission (2017) concluded that it
34 was not fit for purpose and proposed 'Liberty Protection Safeguards'. It
35 recommended enhanced rights to advocacy, greater prominence to the rights of
36 persons to be deprived of liberty, widening the scope to cover 16 and 17 year
37 olds and simplifying the best interest process. Such concerns highlight flaws in
38 the current law, and the challenges that practitioners have to contend with. A gap
39 seems to exist in the literature about studies on the impact the law has had on
40 practice and this study is an effort to contribute to bridging the gap. Service
41 providers have to contend with translating the theoretical notion of the patient or
42 other service user (PSU) as a rights bearing individual whose rights and liberties
43 are not lost simply because of their condition into practice
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47 PSU's therefore have the right to make their own decisions. However, where they
48 lacked capacity, the best interest principle must underpin any decisions made on
49 their behalf. Best interest is not a new concept, however, it has continued to
50 underpin a paternalistic culture, hence questioning whether best interest is
51 paternalism (Anthony-Pillai, 2018). According to the Law Commission (2017).
52 "...health and social care professionals and the Court of Protection often failed to
53 consider the PSU's wishes and feelings, and that the concept of best interests
54 was often interpreted in a medical and paternalistic sense." Physicians have
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3 been making decisions for patients based the belief that the physician or
4 professional knows best (Murgic et al, 2015; Komrad, 1983). So while the
5 autonomy of the individual PSU is a legally protected value, it does not
6 automatically reflect in practice, as this requires a shift in favour of the wishes
7 and preferences of the patient.
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10 11 **Research Strategy**

12 This study sought to understand health and social care practitioners' knowledge
13 of MCA/DoLS; how these frameworks are applied in practice; to determine
14 practitioners' consensus about good practice within the relevant policy
15 frameworks; and sought to map out the understanding of representatives from
16 the different areas of practice (Boukdedid et al, 2011). To gather their
17 perceptions, participants were presented with everyday scenarios in hospital and
18 social care settings and asked how they respond. This enabled the researchers
19 to identify key differences in staff understandings of safeguarding and how the
20 differences may reflect on practice. The views of a range of professionals were
21 sought in the study, including nurses, social workers and healthcare assistants
22 and doctors.
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28 **Methodology**

29 A Delphi survey was used to study how practitioners understand and use the
30 MCA. It typically elicits the views of a number of experts, with knowledge of the
31 subject under study (Helmer, 1967). By being selective, representativeness is
32 sacrificed as the focus is on purposively selecting experts (Ashmore et al, 2016).
33 Snowballing was also used to expand the sample, allowing participants to invite
34 their colleagues with relevant experience (Habibi et al 2014). Also, it is an
35 iterative approach to collecting information with the anonymous results of the first
36 round shared with participants prior to the second and subsequent rounds
37 (Skumolski et al 2007). The Delphi technique is good at finding out 'what is', but
38 goes further, to address "what could/should be" (Miller, 2006 cited in Hsu and
39 Stanford 2007). It is an iterative process that helps to transform opinion into
40 group consensus, and broadens knowledge on an issue of interest (Hasson et al
41 2000). Ludwig (1994) suggests a drawback to using Delphi methods is that the
42 questionnaire and iterative process cause delays.
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48 Participants in this study could be in different locations and still participate in the
49 research because of their knowledge and practice experience. This allowed the
50 participants a degree of anonymity, allowing them to express their views free of
51 influences such as the more cautious institutional position and without the
52 influence of dominant characters (Hanafin, 2004, p.10; Sackman 1975).
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3 Ethical issues considered in the research strategy were approved by a Research
4 Ethics Committee. The study involved eliciting from respondents potentially
5 sensitive information regarding their understanding and practice in the context of
6 the Mental Capacity Act 2005. The sensitive issues included the potential for
7 revealing poor practice. Key issues considered included confidentiality and
8 anonymity.
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11 12 13 **Composition and Sampling**

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15 Delphi methods utilise a panel of experts with specialist knowledge and
16 qualifications as well as participants who are experts by experience (Iqbal and
17 Pison-Young 2009). However, the idea of experts is problematic, and has been
18 described as misleading and overstated with a potential for bias (McKenna,
19 1994; Sackman 1975; Strauss and Ziegler 1975). Keeney et al (2001) have
20 argued, "Simply because individuals have knowledge of a particular topic does
21 not necessarily mean that they are experts" (p 196). This study recruited health
22 and social care practitioners that use the MCA and DoLS in their practice to
23 include the range of experience of people working with the legislation, this
24 included professional and non-professional staff such as nurses, social workers,
25 care workers, physiotherapists and GPs (Alghrani, 2016 p.312). Participants
26 were experts because of their ongoing practice experience of using MCA/DoLS,
27 and not because they held leadership roles in their organisation.
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33 Where there is a homogenous sample, Skulmoski et al (2007) have argued that a
34 sample size of 10 – 15 may yield sufficient results. But a heterogeneous group
35 requires a larger sample, as the heterogeneity delays the important step of
36 building consensus, creating a longer process of analysing data and verifying
37 results (Delbeq et al 1975 cited in Skulmoski et al 2007). The study recruited 5
38 groups of professionals and included 50 nurses and 30 care workers, 10 social
39 workers, 5 occupational therapists, and 5 doctors to participate in the first round
40 of the survey. They were from acute settings and residential care for the elderly.
41 The number of respondents dropped significantly in the second round, with only
42 12 respondents.
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46 It is generally agreed that experts who participate in such studies are hard to
47 engage with because of other commitments (Hsu and Sandford, 2007). Hsu and
48 Sandford (2007) recommend telephone contacts to overcome this problem
49 however, this should be done cautiously to avoid coercion. Also,
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52 53 **Questionnaire Design**

54 The questionnaire presented several scenarios describing practice situations,
55 with questions requiring participants to demonstrate knowledge and
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3 understanding of the MCA and to describe how they would respond to these
4 scenarios. The survey included questions related to each scenario, exploring the
5 application of the MCA/DoLS and participants' understanding.
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8 Scenarios were constructed with corresponding questionnaires to elicit
9 responses on how similar cases are dealt with or will be dealt with. The vignette
10 method demonstrates largely the value of scenarios for decision making. They
11 have the potential for exposing variations in decisions among professionals and
12 their colleagues given the same circumstances, for e.g. this has been
13 demonstrated in studies using the vignette method such as the Hughes' (1998)
14 study of drug injecting and HIV risk and safer behaviour, and impossible decision
15 making and the risk of trade-offs in ICU (Reader et al (2017)).
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18 Using scenarios in a Delphi study originates from the Rand study in the 1960's
19 regarding military technology, and explored the most possible scenarios of the
20 given topic for future predictions (Renzi, and Freitas, 2015); scenarios were
21 based on possible interactions reflecting the reality of practitioners. Vollmar et al
22 (2015) have pointed out that scenarios have limitations. It is time-consuming
23 nature of creating (therefore cost-intensive), in particular because they consume
24 project resources.
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28 The scenarios provided respondents the opportunity to discuss issues from a
29 non-personal and less threatening perspective (Hughes, 1998). However, the
30 very non-personal nature of scenarios in the vignette method can be considered
31 a weakness. Hughes (1998) argues that it does not provide the necessary
32 interaction and feedback that is part of social life. Nonetheless scenarios prompts
33 participants to reflect on similar experiences, which are more realistic than
34 traditional surveys (Steiner et al 2016). In order to make the scenarios as realistic
35 as possible case studies were researched and professionals consulted.
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41 Because the findings are so indelibly linked to the scenarios, it is necessary to
42 outline them here. There were five scenarios in the first iteration of the
43 questionnaire, and are outlined in turn below:
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46 Scenario one:

47 Described a patient with a learning disability in hospital being treated for
48 chest injuries. She was in distress, causing her to interfere with treatment.
49 The scenario suggested the staff thought there was a need to sedate her
50 in order to allow treatment to be provided. This accompanying questions
51 sought to explore if participants would consider sedating this patient
52 irrespective of her capacity, to establish how staff deal with clinical
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situations where a patient's behaviour, attitude, decisions, and decision-making capacity presents a risk for the patient's own safety.

Scenario two:

Described a 15 year old child in hospital for arrhythmia refuses treatment. Her parents agreed with clinical advice that she needed treatment, but the girl refused. The key issue was to find out how participants managed the different wishes, and how they recommended to treat her, since, due to her age, she was not covered under the MCA.

Scenario three:

Presented a situation involving a patient with a history of anxiety and paranoia who refused a life-saving blood transfusion, stating that he 'did not want anyone's blood'. This sought to gather participants' responses when capacity and mental health issues are both present in a clinical situation. Would participants assess the decision making capacity of such a patient, or defer, as is recommended, to mental health legislation? Furthermore, would it make a difference if the patient refused a blood transfusion on religious grounds?

Scenario four:

Presented a widespread care home situation where a new resident arrived but did not to settle, and immediately insisted on returning to her home; notwithstanding that she lived alone and had suffered frequent falls on the stairs. This scenario sought to understand whether respondents feel that such a patient should be deprived of her liberties.

Scenario five:

Asked whether the capacity-making ability of an older, frail person should be questioned when they were making decisions that could harm him/her financially. It sought to probe participants' understanding of the 'unwise decision'.

Results

Sample

Profession		Number		Percentage	
General Practitioner Doctor		4		4.08%	
Nurses	Nurse	37	47	37.75%	47.95%
	Practice Nurse	8		8.16%	

	Community/District Nurse	2		2.04%	
Care Assistants	Healthcare Assistant	2	29	2.04%	29.59%
	Care Assistant (care/nursing home)	27		27.55%	
Social worker		7		7.14%	
Allied Health Professionals* (e.g. Occupational and Physio therapists)		2		2.04%	
No profession indicated		9		9.18%	
Total		98		100%	

* groups with few respondents collapsed to obscure individuals

A total of 150 practitioners were invited to participate, and 98 agreed. The sample included: 47 nurses (47.95%); 29 care assistants (29.6%); seven social workers (7.14%); two physio/occupational therapists (2.04%); and four GPs (4.08%).

Findings – Round one

Considering that the scenarios targeted specific elements of the MCA principles, responses were not as consistent as might be expected. The following provides more detail, but in general, participants often disagreed about the appropriate response to the situation, even within professional groupings. However, it is worth noting that in the first round, while there was a fair degree of consensus about the need for best interest assessment among professionals. It was clear that there was still a small group of professionals made up of nurses and occupational/physiotherapists who were of the view that best interest decisions should be made for patients and other service users regardless of whether they have capacity. They were of the view that the decisions made by these patients were unwise and detrimental to their well-being.

In another scenario, a large number (63%) from all the professional and non-professional groups were of the view that a patient who refused a blood transfusion should be assessed for capacity, while an equally large number (56%) were of the view that the patient's view must be respected, including all GP participants. It was also significant that more than 25% of participant care

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3 workers indicated it would make a difference if the patient refused blood
4 transfusion on grounds of religion.
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7 There was no consensus on deprivation of liberty issues, with an almost even
8 spread of opinions among both professionals and non-professionals. For
9 example, when responding to the case of an older man making an unwise
10 decision about spending his money, there was an even spread of views with less
11 than 20% of participants suggesting variously that no action is needed; there was
12 a need to raise a safeguarding alert; or a need for a best interest assessment
13 and checking for powers of attorney. It is worth noting that a higher percentage of
14 care workers (25% and 29%) than any other professional group proposed best
15 interest assessments and powers of attorney. This may be an indication of the
16 willingness of care workers to pass on the responsibility of making such decision
17 decisions to more senior staff; one care worker stated “They can get approval
18 from higher authorities to her care and what action must be taken based on her
19 psychiatric report and behaviour”
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23 *Scenario one*

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25 Almost half of respondents (45%) stated there is no need to sedate the patient
26 with a learning disability, even if her actions were putting her health and
27 wellbeing at risk, as long as she does not lack capacity. However, 22.4%
28 disagreed, suggesting they thought sedation was necessary, contending that
29 intervention is required, even if it means overriding the decision of a patient who
30 is deemed to have capacity. 60.2% of respondents indicated there was a need
31 for a best interest assessment (BIA) in a situation where the patient lacked
32 capacity. However, a small number of respondents (6%), all nurses, did not
33 suggest there was need for a BIA. They appeared to suggest that a patient
34 without capacity had a right to refuse sedation. A smaller number of respondents
35 (3%) including two nurses and one social worker suggested they thought this
36 was an emergency situation, which could not wait for the formal process of
37 conducting a BIA and recommended immediate treatment against the patient’s
38 wishes.
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43 *Scenario two*

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45 This scenario generated a more varied response, with the largest proportion
46 (38%) suggesting the patient could be treated in accordance with parental
47 consent against her wishes, because she was a minor. A much smaller
48 proportion (10%) suggested the patient’s capacity would determine whether to
49 prioritise her or her parents’ wishes. However, there was no consensus on
50 whether a patient who was 15 years of age has capacity to make decisions.
51 6.12% advised a mental capacity assessment before treating the patient against
52 her wishes, but in line with parental consent. Another small proportion, 8.2%,
53 including three nurses, three social workers and two doctors, suggested the need
54 for Gillick competence testing. 12.24% of nurses advocated applying the MCA
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3 while only 6.12% suggested the MCA did not apply here. The case of a minor
4 falls outside the scope of the MCA, however, it was included to gain an
5 understanding of respondents' knowledge of what was within and without the
6 scope of the MCA. Also, it provided insight into how complex situations are dealt
7 with in practice and whether staff recognized a situation where, for e.g. Section
8 21 of the MCA provided a transfer of proceedings of a matter related to persons
9 below 18 years. Such knowledge was limited, however, admittedly respondents
10 were mainly from adult health and social care services.
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14 *Scenario three*

15 Responses to this scenario showed no consensus about how to deal with a
16 patient who refused blood. 63% of respondents (mainly nurses and care
17 assistants) suggested staff could assess the decision making capacity of the
18 patient. But a number of respondents indicated this approach depended on the
19 qualifications of available staff. However, 13.2% of respondents suggested the
20 patient was too ill to undergo an assessment, and 56% thought the clinical team
21 should respect the patient's decision. This last group included all GP participants,
22 a small number of nurses, and some care assistants and social workers who
23 agreed that the patient's decision to refuse a blood transfusion should be
24 respected. 28.6% of respondents stated their actions would be no different if the
25 patient refused blood on religious grounds, but over a quarter (27%), mostly
26 care assistants, stated that refusal on religious grounds would make a difference
27 to their assessment. This indicated a willingness to respect the views of the
28 patient if refusal was based on religious belief. Such views potentially
29 demonstrates a willingness to accept religious beliefs as valid reasoning for what
30 would otherwise be seen as an unwise decision. While a majority of respondents
31 suggested a capacity assessment was necessary, it was surprising that a third of
32 respondents did not suggest this was needed.
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39 *Scenario four*

40 26.5% of respondents to scenario four, advocated that it was in the best interest
41 of woman to have a mental capacity assessment. A small proportion of
42 respondents, 6.12%, suggested that a DoLS application was needed, primarily
43 because her wish to return home was deemed an unwise decision. When
44 participants were asked whether she should have her liberty deprived, 13% of
45 nurses, 17.24% of care assistants and 14.3% of social workers suggested a BIA
46 was needed. A significant proportion of respondents (36.2% of nurses, 34.5% of
47 care assistants and 50% of doctors) argued the patient should not be deprived of
48 her liberties with a smaller number of respondents (15% of nurses, 17.24% of
49 care assistants and 25% of doctors) arguing that the patient's liberty must be
50 deprived for her own safety. Participants on both side of the argument suggested
51 the best interest of the patient influenced their decision. For example, one
52 participant stated "No, in best interest of patient if at all possible." Responses to
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3 this scenario did not provide a clear consensus about whether a capacity
4 assessment was needed regarding her requests to return home. Generally, when
5 considering depriving the patient of her liberty, slightly more than half of
6 respondents disagreed, which is not a strong consensus.
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9 *Scenario five*

10 This scenario, about an older person's use of money (an 'unwise decision'), also
11 created conflicting responses. A sizable minority, 14.28% of respondents (23.4%
12 of nurses and 10.34% of carers), suggested no action should be taken to stop
13 the older person spending his money as he wished. A similar proportion of
14 respondents, 14.28%(17.02% of nurse participants, 17.24% of care assistants
15 and 14.3% of social workers) indicated they would raise a safeguarding alert,
16 while a small number of practitioners (10.63% of nurses and 14.3% of social
17 workers) suggested recommending Powers of Attorney and Lasting Powers of
18 Attorney. A slightly higher proportion, 17.35% of respondents (21.3% of nurses
19 17.24% of care assistants and 29% of social workers), suggested a BIA was
20 required. Some respondents (17.02% of nurses, 7% of care assistants, and 25%
21 of doctors) suggested checking for lasting powers of attorney or applying to the
22 Court of Protection. There were no strong views provided by respondents, even
23 when considering their responses grouped by profession. Responses did not
24 provide a consensus about how to deal with an unwise decision.
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30 **Second Round Delphi Survey**

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32 An important part of a Delphi study is to provide a summary of findings from the
33 first round to the second round. This summary allowed participants to consider
34 their responses in relation to the sample's perspective of issues and to identify
35 how their views related to the general consensus.
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38 Profession	38 Number	38 Percentage
39 Nurses* (including 40 practice nurses)	88	66.6%
41 42 Social work, care 43 assistants and Allied 44 Health Professionals*	4	33.32%
45 46 Total	12	99.92%

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49 dents collapsed to obscure individuals

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52 Participant attrition was a challenge in this study and there were significantly
53 fewer respondents in round two. Round one included 98 participants, and nearly
54 50% nurses. In the second round there were twelve respondents, with 66.6%
55 being nurses. Care workers were the second largest group in round one, nearly
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3 30% of respondents, but in round two this was reduced to 8.33%. GP's
4 constituted 4.08% of respondents round one, but none participated in the second
5 round. Social workers and therapists increased their proportion of participation,
6 (Social workers; 7.14% round one; 8.3% round two: physio/occupational
7 therapists increased from 2.04% to 16.66%). Methodologists recommend that
8 researchers individually engage with each participant, encouraging peer group
9 affiliation, to reduce attrition (Stitt-Gohdes, 2004), which was attempted during
10 round one. In this study, with a variety of professions involved, group
11 heterogeneity was a challenge. The variety of professions and different
12 hierarchical positions in health and social care may have hindered their group
13 cohesion.
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18 **Findings – Round two**

20 **Scenarios**

21 Round two sought to refine the findings from round one, as a result the
22 questionnaire was reduced to three scenarios, focussing on the responses with
23 least consensus.
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25 Scenario one was repeated, and focused on what participants would do if
26 a patient in intensive care with a learning disability refused sedation. The
27 questions were more focussed than in round one, such as 'If he is
28 assessed as lacking capacity, is there a need for a BIA?' This scenario
29 sought to elicit responses about capacity to make decisions.
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32 Scenario two presented a situation where an elderly woman arrives at a
33 care home and immediately makes it clear she wants to leave and return
34 to her own home. This scenario focussed on possible deprivation of liberty
35 after the patient makes an unwise decision.
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38 The third scenario sought to expose a key area of concern from round
39 one, by considering specifically how responses differed depending on their
40 perception of capacity. This scenario presented a middle aged man with a
41 brain injury living in a nursing home. When approached by staff about his
42 deteriorating self-care skills and body odour, he was irritated and refused
43 bathing assistance.
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49 **Scenario one**

50 There was a reduction in the proportion of participants that thought the patient
51 should be sedated, 33.3%, down from 45% round one, even if he had the
52 capacity to refuse treatment. In contrast, 53.3% argued that there was no need
53 for a capacity assessment, which is markedly higher than the 22.4% in round
54 one. In the second round, there was a significant increase in the proportion of
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3 respondents against sedation, but a subsequent drop in the proportion who
4 believed sedation was necessary. The respondents that argued for sedating a
5 patient with capacity who refused treatment is in sharp contrast with the majority
6 view that there is no need for sedation.
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8 9 **Scenario two**

10 Responses to scenario two provided a range of answers that suggested
11 patience, encouragement, listening to and giving the patient her wish.
12 Interestingly, 25% of respondents suggested a BIA was needed. For example
13 one respondent states, "Do a best interest assessment to determine what can be
14 done? Appreciate Olivia wants to go home. Identify temporary measures to
15 support her at home, such as a commode, until adjustments can be made for her
16 to live at home." Almost half of respondents, 41%, suggested they would not
17 deprive the patient of her liberty even with safety concerns. However, a
18 significant minority of respondents (25%, including some nurses) suggested they
19 would deprive her of liberty in order to keep her safe in the care home until
20 adjustments had been made to her home. Whilst respondents thought
21 undertaking a BIA was in the patient's best interest, there is a concern, raised by
22 Griffiths (2014) that the clinical use of these has been paternalistic. There are a
23 series of judgments about best interest that provide some suggestions about this
24 issue. In the case of R(Burke) v GMC [2005] the High Court stated that to
25 determine the best interests of a patient who is deemed incompetent, a stringent
26 standard must be applied to ascertain whether a patient's life had become
27 "intolerable" (Samantha and Samantha 2005). The Court of Appeal subsequently
28 ruled that the use of the phrase 'best interests' is confined to an objective test
29 used when considering the duty owed patients in need of care and treatment but
30 lacking decision-making capacity. These judgements suggest a systematic
31 approach to determining what the best interest is for a patient, which a quarter of
32 respondents seemed to have suggested. However, responses provided by the
33 majority of participants suggest a trend towards individualism to the extent that it
34 fits with the Public Guardian's individuated view on best interest; which,
35 according to Martin et al (2012 p. 22) is defined as "Anything done for a person
36 who cannot make decisions for themselves must be in their best interests. This
37 means thinking about what is best for the person, and not about what anyone
38 else wants." Martin et al (2012) argue there is growing realization that the needs
39 of others may be a useful consideration when dealing with best interest issues,
40 which contradicts the effects of hyper individualism.
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49 **Scenario three**

50 Responses to scenario three were more consistent, with 58.3% of respondents of
51 the opinion that all support must be given to the patient, providing he has
52 capacity to make decisions. Respondents stated, for example, "Keep
53 encouraging him to have a wash but try different means - if prompts aren't
54 working, try giving him bath and shower gift sets and asking if he had any
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3 concerns about washing which was preventing him from doing so” “Try to
4 encourage him to shower whilst remembering that no two people will necessarily
5 have the same personal hygiene standards and this could easily be his normal.”
6 Other respondents, 41.66%, did not suggest anything contrary, however, they
7 were somewhat unclear about what they would do making such comments as
8 “stop telling”, “approach Josh privately” and “with dignity”. When considering a
9 response if he did not have capacity, 91.6% of participants argued for all
10 necessary support to be provided to help him make the decision. Responses
11 prioritised the rights of the individual to make decisions, contrasting with the
12 paternalistic tendencies often associated with the care of patients, which appears
13 to be contrary to the established practice (Griffiths, 2014 p.1220). This may be an
14 indication that efforts to embed the principles of the MCA in practice are
15 beginning to yield positive results.
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20 **Summary and Discussion**

21 These findings highlight a conundrum in practice about the lack of consensus
22 when practitioners attempt to apply the MCA. The capacity of patients to refuse
23 treatment is a key area of contention requiring further research to resolve
24 uncertainty. This is a key area of concern emerging as an important field of legal,
25 clinical, and behavioural research, which has its origins in studies on psychiatric
26 patients in the 1970’s and 80’s (Marson and Ingram, 1996, Applebaum *et al.*,
27 1981). While mental capacity assessment has become a familiar concept for
28 practitioners, the point at which the assessment is triggered was identified
29 inconsistently by participants. It can be argued that the scenarios used in this
30 study demonstrated not a lack of capacity to make a decision, but unwise
31 decisions that challenge practitioners’ duty of care for patients. Applebaum
32 (2007) argues that although standards for decision-making capacity for consent
33 to treatment vary somewhat across jurisdictions, they generally include several
34 considerations, including: the abilities to communicate a choice; to understand
35 the relevant information; to appreciate the medical consequences of the situation;
36 and to reason about treatment choices. In a clinical setting, such as a hospital,
37 with a need for quick decisions under pressure, this setting conflicts with
38 considerations that require time and reflection, as well as gathering a variety of
39 views (from patients and caregivers). From the findings of this study, it appears
40 that practitioners are struggling to identify when to assess capacity, and when an
41 unwise decision may conflict with clinical advice. This is likely influenced by what
42 respondents may deem complex situations, which make it difficult to carry out an
43 objective assessment of capacity (Murrell and McCalla, 2016).
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51 The lack of consensus demonstrates both consequentialist and deontological
52 positions of ethical judgements in professional and non-professionals roles
53 (Morgan-Knapp, 2015). While the consequentialist approach explores
54 consequences of actions in order to identify which choice is likely to yield the
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3 most 'good' and least 'bad'. Deontology emphasizes that certain acts are
4 inherently right or wrong, independent of the outcome and asks what one 'ought'
5 to do in relation to duty or obligation. This was evident in the response from
6 participants on the issue of sedation. For e.g. one respondent suggested "Is
7 emergency so they have to do the best interest", which suggests the end justifies
8 the means, a consequentialist approach to ethical judgements. On the other
9 hand, another respondent stated "Yes, because this treatment of sedate him is
10 the best thing to do for that person at that moment." This is a deontological
11 position that emphasizes the best interest of the patient is simply the right thing
12 to do regardless of the outcome. There was no sign of consensus after the
13 second round of the survey as there was a percentage increase in responses
14 from the two sides of the argument. In studies using the vignette method, a lack
15 of consensus can be attributed to lack of awareness or familiarity with protocols,
16 lack of agreement with guidelines because it limits the autonomy of
17 professionals, professionals have bias, a prevailing paternalistic attitude (Nguyen
18 et al 2014).

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24 The lack of consensus in MCA practice has been acknowledged by others (e.g.
25 Clare et al 2013, and Bartlett 2014), concluding there is no consensus on how to
26 implement this in the future. Also, there were variations in the understanding and
27 application of concepts such as best interest. In the blood transfusion scenario,
28 for e.g. one proponent of respecting the patients view stated "If it is in
29 accordance with his religious belief and after thorough explanation - a best
30 interest meeting is to be conducted and if despite his presence and all disciplines
31 meeting he still refused we have to accept and respect his wishes and since he
32 has capacity he could sign for it", while a proponent who opposed this stated,
33 "The relevant clinician should complete a capacity assessment and is required
34 take a Best Interests decision giving appropriate weight to Shujaat's views." It
35 can be argued that the tension between the two views i.e. whether to assess
36 capacity or respect the views of the patient, demonstrates different perspectives
37 of what is in the best interest of the patient (Sandiman and Munthe, 2009).

41 **Implications for practice**

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44 It is important to tailor training to improve and deepen understanding of key terms
45 among the different professional groups (Manthorpe et al 2011). The MCA and
46 the Code of Practice give a sense of common understanding, however, the
47 findings of this study demonstrates such common understanding is lacking, a
48 situation which potentially reflects the practice reality across the health and social
49 care sector. It is imperative that instead of providing an unrealistic sense of
50 common understanding, practitioners are given the kind of training that
51 recognizes shared decision making and its variations. The MCA provides that
52 patients who following assessment have demonstrated a lack capacity should as
53 much as possible be involved in decision making, with assistance to improve
54 their ability to exercise their autonomy (Bingham 2012). Sandiman and Munthe
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(2009) have argued such decision making could range from a 'Professionally Driven Best Interest Compromise (PDBIC) model', which promotes best interest with the professionals view given prominence and a 'Shared Rational Deliberative Compromise' model, which is driven mainly by patients, but incorporates the professionals view about best interest. It is also worth noting that a PDBIC could be used for influencing patients to accept what is deemed their best interest.

The Law Commission report pushes further ideas the patient centred approach to health and social care. While this is in line with the climate of patient autonomy, there is contention about whether it is good that people govern themselves, and to what extent they should do so (Coggon and Miola, 2011). Where practice is shaped by a predominantly PDBIC model it could undermine the MCA and set the stage for litigation. Further research is needed to understand the challenge of transferring the aspirations into practice, so that there will be more understanding of what realistic aspirations are, so as to avoid situations of decision paralysis in health and social care.

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