'Best Interests’ Decision-Making and the Role of the Court in Protecting Patients with Prolonged Disorders of Consciousness

Thesis

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‘Best Interests’ Decision-Making and the Role of the Court in Protecting Patients with Prolonged Disorders of Consciousness

Adam Tanner

Thesis submitted in accordance with the requirements of The Open University for the degree of Doctor of Philosophy

Law School
Faculty of Business and Law
The Open University
March 2022
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I would like to thank all of those who took the time out of the schedules to help me in completing this work through interviews or informal conversations. Thank you also to the judges of the Court of Protection, who allowed me to observe their proceedings and were willing to help in any way they could. To Sylvie Bacquet for providing me with valuable opportunities to lecture and write, thank you for helping me get started in my academic career.

My greatest thank you goes to my family and friends, who have provided me with endless encouragement and patience throughout this time. It would not have been possible without you all. To my parents for always encouraging me and spending the time listening to me ramble on about my work, even when they were not interested, it has always helped me immensely. I have been extremely lucky to be surrounded by such supportive friends and family who motivate me to do better every day. To my great-great Auntie Ivy, who sadly passed away at 100 years old this year. To Ezra, the youngest member of my wonderful family, who brings us all so much joy.

Finally, this thesis concerns people who are at the end of their life and their families and friends. The cases I have observed are often traumatic for everybody involved. I hope this thesis can go some way in the future to improving the experience of those unable to communicate their wishes. I would like to thank every person involved in the cases I observed or reference, and dedicate this work to them.
# Table of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full term</th>
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<tbody>
<tr>
<td>ADRT</td>
<td>Advance Decision to Refuse Treatment</td>
</tr>
<tr>
<td>ANH</td>
<td>Artificial nutrition and hydration</td>
</tr>
<tr>
<td>BMA</td>
<td>British Medical Association</td>
</tr>
<tr>
<td>CA</td>
<td>Court of Appeal</td>
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<tr>
<td>CANH</td>
<td>Clinically assisted nutrition and hydration</td>
</tr>
<tr>
<td>CMD</td>
<td>Cognitive-motor dissociation</td>
</tr>
<tr>
<td>The Code</td>
<td>Mental Capacity Act 2005 Code of Practice</td>
</tr>
<tr>
<td>CoP</td>
<td>Court of Protection</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardiopulmonary resuscitation</td>
</tr>
<tr>
<td>CRPD</td>
<td>United Nations Convention on The Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>CRS-R</td>
<td>JFK Coma Recovery Scale – Revised</td>
</tr>
<tr>
<td>CVP</td>
<td>Cloud Video Platform</td>
</tr>
<tr>
<td>DDE</td>
<td>Doctrine of Double Effect</td>
</tr>
<tr>
<td>DOC</td>
<td>Disorder of Consciousness</td>
</tr>
<tr>
<td>DoLS</td>
<td>Deprivation of Liberty Safeguards</td>
</tr>
<tr>
<td>ECHR</td>
<td>European Convention on Human Rights</td>
</tr>
<tr>
<td>ECtHR</td>
<td>European Court of Human Rights</td>
</tr>
<tr>
<td>EEG</td>
<td>Electroencephalogram</td>
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<tr>
<td>fMRI</td>
<td>Functional magnetic resonance imaging</td>
</tr>
<tr>
<td>GDPR</td>
<td>UK General Data Protection Regulation</td>
</tr>
<tr>
<td>HMCTS</td>
<td>Her Majesty’s Court and Tribunal Service</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>LST</td>
<td>Life-sustaining treatment</td>
</tr>
<tr>
<td>MCA 2005</td>
<td>Mental Capacity Act 2005</td>
</tr>
<tr>
<td>MCS</td>
<td>Minimally conscious state</td>
</tr>
<tr>
<td>MOJ</td>
<td>Ministry of Justice</td>
</tr>
<tr>
<td>OS</td>
<td>Official Solicitor</td>
</tr>
<tr>
<td>P</td>
<td>Protected party</td>
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<tr>
<td>PDOC</td>
<td>Prolonged disorder of consciousness</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
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<td>--------------</td>
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<tr>
<td>PEG</td>
<td>Percutaneous endoscopic gastrostomy</td>
</tr>
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<td>PET</td>
<td>Positron emission tomography</td>
</tr>
<tr>
<td>PVS</td>
<td>Persistent/permanent vegetative state</td>
</tr>
<tr>
<td>RCJ</td>
<td>Royal Courts of Justice</td>
</tr>
<tr>
<td>RCP</td>
<td>Royal College of Physicians</td>
</tr>
<tr>
<td>SCOTUS</td>
<td>Supreme Court of the United States</td>
</tr>
<tr>
<td>SMART</td>
<td>Sensory Modality Assessment and Rehabilitation Technique</td>
</tr>
<tr>
<td>TO</td>
<td>Transparency Order</td>
</tr>
<tr>
<td>UHCDA</td>
<td>Uniform Health-Care Decisions Act</td>
</tr>
<tr>
<td>UKSC</td>
<td>United Kingdom Supreme Court</td>
</tr>
<tr>
<td>UWS</td>
<td>Unresponsive Wakefulness Syndrome</td>
</tr>
<tr>
<td>VNS</td>
<td>Vagus Nerve Stimulation</td>
</tr>
<tr>
<td>VS</td>
<td>Vegetative state</td>
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<tr>
<td>WHIM</td>
<td>Wessex Head Injury Matrix</td>
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</table>
Abstract

The current law and practice surrounding decision-making for adult patients who lack capacity, because they are in a prolonged disorder of consciousness, leaves these vulnerable patients without adequate protections to ensure their voices are heard. The Mental Capacity Act 2005 and subsequent case law have established that the test to be applied in such cases is whether the decision being made is in the “best interests” of the patient. This thesis looks at how the legal test of best interests is understood and how it is used in practice by doctors and lawyers. It argues that there is a critical misunderstanding of what is meant by best interests, and as a result, vulnerable patients are not having their rights protected.

The main thrust of this thesis stems from empirical research into how decisions are made in practice by both clinicians and lawyers; this research takes the form of a series of interviews with leading practitioners and a number of observations of Court of Protection hearings to see first-hand whether decision-makers are following the established law.

The empirical work highlights the levels of misunderstanding and poor application of the best interests standard. The interviews identified that the proportion of professionals who do not have an adequate understanding of the law relating to decision-making is perhaps even worse than has been stated in some previous pieces of research. The observations of the Court of Protection indicate that there is a wide discrepancy between what professionals say they do and what they actually do. These observations also uncovered several problems in the current system such as the length of delays and the weight given to expert evidence.

This thesis concludes that the law is ultimately misunderstood and incorrectly applied on a routine basis by people whose job is to protect vulnerable parties. The recent developments in the law, by the Supreme Court, potentially go against the foundations of why the Mental Capacity Act 2005 was introduced. There is further consideration as to what future reforms are needed to ensure a patient-centred decision-making framework.
Chapter One: 
Introduction

1.1 Introduction

This thesis began as an attempt to answer one core question: is the law of England and Wales doing all it can to protect vulnerable adults when making decisions regarding the end of their lives? It has proceeded through the extraordinary period of the COVID-19 pandemic, which created new challenges. The pandemic led to the focus of this thesis changing when the Court of Protection moved its hearings online, affording me the ability to have greater access to witness how decisions are made for vulnerable adults.

I explore how decision-making is conducted for adult patients who are in a prolonged disorder of consciousness (PODC) as a result of being in a vegetative state (VS) or minimally conscious state (MCS). The primary focus is on cases of adults who suffered catastrophic brain injuries and have been left without capacity to make decisions regarding their welfare, including the continuation of artificial nutrition and hydration (ANH) and other life-sustaining treatment (LST). This area of law is governed by the Mental Capacity Act 2005 (MCA 2005) and an extensive catalogue of case law; mental capacity law is also regulated by guidance from both medical and legal bodies. I have analysed these regulations, statutes and case law, however, the key focus of this thesis is how these regulations operate in *practice*, in both medical settings and legal proceedings.

Over the past five years, there has been an increase in media reporting and social media discussion relating to end-of-life care. These primarily emanated through cases of sick children who had LST withdrawn, as well as increased coverage of assisted suicide legalisation; however, there were also significant legal developments concerning adult patients over the past five years. Those discussions and developments form the basis of asking whether our law and practice is doing all it can to ensure the best for vulnerable patients. Although this thesis looks primarily at adults with PODC, the fundamental principles that underpin it can be applied to a range of people and situations. This introductory chapter will outline the main themes and questions that this thesis seeks to answer, and the methods used to achieve this.
1.2 Research questions

This thesis aims to analyse how medical decisions are made for adult patients who are in a prolonged disorder of consciousness and whether the current process adequately protects such patients. This requires an exploration of how lawyers and doctors understand what best interests means, and how the best interests test operates in practice. In addition to this, it also seeks to identify the best ways of ensuring a patient-centred process. The answers to the following research questions will contribute to this aim:

1. What is the current understanding of the 'best interests' test?
2. Is there a consistent application of the 'best interests' test by doctors, lawyers and the courts?
3. What is, and what should be, the role of the Court of Protection, post-Re Y?
4. If patient-centred decision-making is desirable, is there a role for emerging technologies in achieving that aim?

1.3 Research methods and methodology

My research contains a combination of both theoretical and empirical research, this enables me to compare how the MCA 2005 is understood in theory with how it is applied in practice. The theoretical research uses a doctrinal approach, which allows for an in-depth analysis of the legal background to the law regarding decision-making for patients who lack capacity and an analysis of the law as it currently stands. This critical analysis of both the case law and current literature is complemented and advanced through the use of empirical research, the findings of which are subjected to qualitative content analysis, using Nvivo, a piece of qualitative data analysis software. This approach provides a “careful, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings”. This combination of methods enables me to provide a thorough critical analysis of the law and a rich and in-depth account of how that law is perceived and applied.

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This research predominantly follows a social constructionist approach, relying on an epistemological understanding that the social world does not contain objective truths. It follows that the social world cannot be studied in the same manner as the natural sciences, because the researcher’s ideas and beliefs shape the social world that they are investigating. For example, in conducting interviews and observations, my personal interpretations of what is being said will inform my understanding of the outcomes. David Carson says that researchers following this framework will tend to use more flexible approaches in completing their research; the social constructionist approach enables me to realise the individual realities being lived by various people and groups, which a positivist methodology would not allow. The social constructionist stance aims to interpret various social situations and realities rather than offer broad generalisations. A fundamental underpinning of my thesis is that there are no universal rights but a plethora of perceived rights that various groups have established and changed over time. This approach led me to decide to undertake interviews and observations that allow a greater depth of understanding of the multiple realities that exist within the medical and legal communities. It allowed me to investigate the multiple belief systems that co-exist amongst professionals caring for those who lack capacity and how the rights of patients can often be attributed different weight based on subcultural influences.

This thesis will make it apparent that multiple realities exist simultaneously for the various parties within a case, be it the clinicians, patients, or families. This research, therefore, takes a relativist ontological approach, taking an understanding that social phenomena are a product of a person’s perceptions. This is the belief that a class of people have properties, such as their morality, only because of external forces and not as a matter of mere existence. This is to say that two doctors may have entirely opposing views on how one should regard the views of a PDOC patient, despite having undertaken the same training. Their individual belief systems will have been moulded by external factors, meaning there is no one way in which legal or medical communities see these issues.

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2 David Carson et al, Qualitative Marketing Research (2001, Sage publications) 3.
3 Merry-Jo Levers, ‘Philosophical Paradigms, Grounded Theory, and Perspectives on Emergence’ (2013) 1 SAGE Open.
1.3.1 Doctrinal research

This thesis begins with doctrinal or ‘black letter law’ research. This is an investigation into legal rules and procedures, an analysis of the theory behind them, and an examination of how they interact. Paul Chynoweth has said, “legal researchers have always struggled to explain the nature of their activities to colleagues in other disciplines”.⁴ Nigel Duncan and Terry Hutchinson have argued that through an analysis of the legal literature, case law and legislation, the doctrinal method seeks to explain irregularities and ambiguities in the law. They argue that it may often appear from the outside that the doctrinal method is the act of locating what some disciplines may consider to be secondary sources and merely compiling them into a report, which is not the case. The doctrinal method is the act of reading new information into the existing law and thereby determining its limitations.⁵ Chynoweth has also noted that there is no real difference between the academic doctrinal method and how lawyers and judges analyse the law in a courtroom, as the main aim in both is to answer “what is the law?”.⁶ The doctrinal method requires an in-depth level of research into the background of the legal principles. The complex and ever-changing nature of capacity law means that the doctrinal method offers significant benefit in understanding how the law has evolved over centuries to get to where it is today. The doctrinal approach does not look just at where the law is now; it requires an understanding of the background issues.

The doctrinal approach is adopted in Chapter Two, where I critically analyse the legislation, cases, literature, and their underpinning principles. This offers a foundation for the four research questions and examines the theoretical understanding of the key themes, as opposed to their application. Douglas Vick has said that doctrinal analysis is often thought to be “intellectually rigid, inflexible, and inward-looking”;⁷ however, this thesis does not rely solely on doctrinal analysis.

I started my doctrinal analysis of the case law by searching key terms on legal research databases Westlaw and LexisNexis. I decided that, as there is a constant string of cases relating

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⁵ Terry Hutchinson and Nigel Duncan, Defining and Describing What We Do: Doctrinal Legal Research (2012) Deakin law review 17, 109-110.
⁶ n 4 (Chynoweth).
to the MCA 2005, I would base this chapter around two key cases: Airedale NHS Trust v Bland [1993] AC 789 and Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. I used the cases cited by the Supreme Court in James as the foundation for my understanding of the evolution of the law over the preceding 20 years. I also used BAILII.org as a source to keep up to date with reported Court of Protection cases.

Mental capacity law is often discussed through the wording of the MCA 2005 and the subsequent case law, using doctrinal analysis. The primary aim of this thesis is to offer a critical and thorough examination of how decision-making occurs in practice. Although the history of the law is initially discussed through the use of doctrinal analysis, this thesis goes one step further, investigating how the MCA 2005 and any accompanying guidance operate in practice; this was achieved through the use of other qualitative methods, which are discussed below.

1.3.2 Interviews

I began undertaking my empirical research by interviewing medical and legal practitioners, as well as other academics, who are currently practising, are recently retired, or are academics in the field of mental capacity law and/or medicine.

Interviewees

All interviewees were chosen very carefully and were established experts in their respective fields. I initially approached experts who had helped author the British Medical Association guidance (explained further in Chapter Two), as well as seeking out counsel from relevant published judgments. Interviewees came predominantly from law and medicine, as this is generally where the debate is most prevalent; however, two participants were academics in other fields, they were chosen because they have extensive experience of PDOC cases and could offer valuable additional insights. All interviewees were promised anonymity and countersigned formal confidentiality agreements to this effect. Interviewees were sent an initial email to establish whether they would be willing to take part in an interview, attached to this email (Appendix A) was a document that provided a brief overview of the research as well as a consent form (Appendix B).
The plan for this thesis included interviews with the judiciary; however, the Ministry of Justice (MOJ) had recently updated its rules for research and initially rejected the proposal due to the sensitive nature of the topic. After the initial rejection by the MOJ, I decided to expand the number of interviewees from non-judicial legal and medical backgrounds. All my additional participants responded very quickly and were happy to help.

**Semi-structured interviews**

Each interview was semi-structured. A list of 10 open-ended questions (Appendix C) acted as the basis for each interview and allowed the interviewee to contribute their knowledge and opinion with whatever depth they wished.

Flexibility is vital when conducting semi-structured interviews as they are intended to act as free-flowing, informal conversations that allow interviewers to change the topics of conversation dependent on the interviewee’s responses to gain greater detail. The duration of the interviews ranged from 30 minutes to more than two hours, depending on the participant. Fifteen of the 19 interviews were conducted face-to-face at the interviewees’ offices or homes; the remaining four interviews were conducted remotely via Skype.

All interviews were audio-recorded for transcription purposes, all of which were transcribed by me. In accordance with the terms of my ethics approval, every audio file was destroyed within 30 days of the interview, following approval of the transcript by the interviewee.

**Thematic analysis**

In analysing more than 120,000 words of transcription from the interviews, I adopted a thematic analysis to categorise the responses and display the information in a coherent and condensed manner whilst showing the entire picture. I have adopted the approach advocated by Virginia Braun and Victoria Clarke; thematic analysis allows me to record recurring themes and patterns within my dataset to try to better understand and uncover the various beliefs of

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those I was interviewing. This process allows for the data to be presented throughout this thesis in a logical manner, linking together shared thoughts and ideas.

The primary process used when conducting a thematic analysis is known as ‘coding’, which is said to stem from grounded theory.\(^\text{10}\) Coding is not unique to thematic analysis, but it forms a crucial aspect of it. Coding is an analytical process that allows for the categorisation of data. In 2005, Ian Hay said that there is a two-stage approach to coding, beginning with a simple discovery of overall themes before the researcher undertakes a more in-depth analysis to uncover specific patterns.\(^\text{11}\)

Johnny Saldana says that, when undertaking coding, there are six questions that a researcher must ask, regardless of their discipline or research purpose:\(^\text{12}\)

1) What are people doing? What are they trying to accomplish?
2) How exactly, do they do this? What specific means and/or strategies do they use?
3) How do members talk about, characterise, and understand what is going on?
4) What assumptions are they making?
5) What did I learn from these notes?
6) Why did I include them?\(^\text{13}\)

Saldana adds that a seventh question every researcher should ask themselves is “what strikes you?”\(^\text{14}\) He says that the researcher should ask what surprising or unexpected things came out of the data. My chosen interviewees were not all likely to agree with each other and so it is crucial to use a method that ensures I am able to understand each individual’s point of view and try to understand why they may feel the way they do. Saldana’s seventh question is very important to my research, as it is the unexpected responses and findings that I am truly seeking. The unexpected answers are the key to uncovering why decisions are made in the manner they are and why unanimity does not exist in this area of practice.

\(^{11}\) Ian Hay, Qualitative research methods in human geography (2005, OUP 2nd Edn).
\(^{13}\) \textit{ibid.}
\(^{14}\) \textit{ibid.}
Two different forms of thematic analysis exist: inductive and deductive. An inductive approach is where the researcher allows the dataset to determine what the themes are. When following a deductive approach, the researcher already has an idea of the themes which will likely come from the dataset. This research used a deductive approach, as the literature review undertaken in Chapter Two informed what questions would be asked of the interviewees and broke down the diverse beliefs and opinions expressed in publications.

Braun and Clarke outline seven steps that a researcher must go through when undertaking a thematic analysis: transcription, reading, coding, identifying themes, reviewing themes, naming themes and finalising their analysis. Each question had its own set of unique codes, which depended on the answers being given. A code is a word or phrase in the dataset that is highlighted as being beneficial. Data can be coded, and themes can be identified at either semantic or latent levels, and a thematic analysis can be focused on either or both of these levels.

Braun and Clarke say that semantic codes and themes identify the surface understanding of the data and that no further depth is required. Latent codes, however, are seeking to understand underlying principles and patterns. The latter requires the researcher to conduct much more interpretation of the data. The difference between a theme and a code should be identified. Braun and Clarke use the analogy of a brick and a wall; the codes are the individual bricks that the researcher uses to establish the wall, which is the broader theme they represent.

In this thesis, I established latent codes from the literature review and any initial thoughts having conducted the interviews. The semantic codes derived from unexpected quotations from the interviews that do not fall under another code. After fully coding the transcripts, the fourth step of Braun and Clarke’s plan is to identify themes. Themes are found through the identification of patterns and frequency of codes within the data. The frequency of the codes helps to determine whether or not an answer given is popular amongst the interviewees and may indicate that the idea has a factual foundation. However, infrequently used codes can still help answer the research questions. Therefore, when reviewing the themes, two things must be

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17 ibid.
taken into consideration: the frequency of the code and its relevance to the research question. I developed themes by comparing the codes identified in the interviews and linking them with the issues that had been previously identified in my literature review. Each theme has a broad description, and quotations were coded from the interviews, illustrating each theme accurately and concisely. The themes evolved as the interviews were coded more intricately, and more commonalities were identified.

In Chapter Three, the themes and sub-themes form the headings and sub-headings of each section. The sub-headings represent the answers that occurred most frequently, were novel, or directly contributed to answering the research questions. Some material was deemed to have no relevance to the research questions, for example, when interviewees talked about other areas of law or other uses of the MCA 2005. Although researchers seek to remain unbiased, it is vital to acknowledge that it is often challenging when the researcher’s views are inevitably reflected in the themes and codes they choose for their analysis. Braun and Clarke said that what is vital is that “the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them as decisions”.

1.3.3 Court observations

In 2016 the Court of Protection (CoP) introduced a pilot scheme that allowed members of the public and press to attend hearings in the CoP for the first time. This scheme reversed the prior rule that all CoP hearings were to be held in private, thereby affording researchers greater access to the CoP. When I requested access to observe an individual case, I informed the court of my purpose in attending the hearing, and counsel was free to ask for me or any other members of the public, to be excluded. On three occasions, I was asked to leave a hearing because a party objected to public attendance; on each occasion, this was unrelated to my research or particular attendance.

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18 Braun and Clarke (n 15).
19 Braun and Clarke (n 9).
Confidentiality of all protected parties in the CoP is paramount and, since the introduction of the scheme of automatic Transparency Orders (TO), it would be a criminal offence to name any party listed on an individual TO. My notes taken during these observations were password-protected and stored on an encrypted flash drive. After the hearings concluded, my notes were anonymised. I do not use any information in this thesis that could lead to the identification, or ‘jigsaw identification’\(^{21}\) of the protected party (P) or any other person or institution.

The language of the CoP refers to the party at the centre of the case as ‘P’, meaning protected party. This is not to be confused with the use of P to mean patient. For the purposes of this thesis, the use of the term ‘P’ will refer to the protected party, as understood by the CoP. All information in Chapter Four derives directly from the hearings, or I have additionally sourced information from news articles, which are already in the public domain.

After an email exchange with the CoP, I was informed that I was not required to make a research application to the Ministry of Justice, under the Data Access Panel programme, in order to conduct observations of the CoP. This was because I was not seeking to access privileged information, or private data. All of the information contained within this thesis would be available to any member of the public who wished to observe CoP proceedings. I did not receive any additional case files or information from the courts. A similar piece of observational work of the CoP was conducted in 2015 to 2016, and published in 2020, by Jaime Lindsey.\(^{22}\) Lindsey observed eight cases with permission of the Ministry of Justice soon after the initial relaxation of the prohibition on public attendance. She was concerned with the use of expert evidence in the CoP, and she noted some issues similar to those that I have addressed in Chapters Four and Five, such as the unreported nature of the majority of cases.

The practicalities of accessing hearings were made more straightforward due to the lockdown restrictions placed throughout the United Kingdom in response to the COVID-19 pandemic in March 2020. Before the pandemic, one would have had to attend the physical court if one wished to observe in person. As the CoP operates as a series of satellite courts throughout


England and Wales, there is a court in almost every city, which would have required a significantly greater length of time to observe the range of cases I observed. On March 31st, 2020, Hayden J issued guidance to judges of the CoP that no hearings were to take place in person if a remote hearing was possible. Hayden J said that “remote hearings are the default position until further direction”. This meant that hearings were held via remote platforms, such as Microsoft Teams, Zoom, or the purpose-built government Cloud Video Platform (CVP).

Case listings are put online the evening prior to the hearing on both CourtServe and the Royal Court of Justice (RCJ) Cause List website. The RCJ listings provide no context to the case being heard. They are listed in this general format (copied from the RCJ and anonymised):

Before MRS JUSTICE XXX  
Also sitting as a Judge of the Court of Protection  
Friday, 1 January 2020  
At 10:30 AM  
Applications in Court as in Chambers  
FOR HEARING IN OPEN COURT  
COP 123456789 Re ‘XX’ MS Teams Hearing

It was, therefore, difficult to assess whether any specific listing would be relevant to my thesis. In regional courts, which are provided on CourtServe, there is often a brief summary of the issues to be decided. They are more commonly listed in this format (copied from CourtServe and anonymised):

2:00 PM  
COP 123456789; X -v- X; a) conduct these proceedings; b) decide where she should live; c) decide what care and support she needs; directions hearing; Attended Hearing; PUBLIC - WITH REPORTING RESTRICTIONS T/E 1 HOUR

If the hearing took place in the RCJ, I would send an email to their central inbox requesting to observe the case. The email template used is attached in Appendix D. Over time I developed email contact with the clerks for each of the High Court Judges who sit in the CoP. After I had made these contacts, I was able to gain access to RCJ hearings with much greater ease.

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23 Mr Justice Hayden, ‘Remote Access to the Court of Protection Guidance’ (Judiciary, 31 March 2020)  
The central inbox for the RCJ and regional courts is inundated with emails from parties and other interested individuals, and my emails were often overlooked as a result. Similarly, phone lines were often too busy throughout the pandemic to make telephone contact with the courts. There were several cases that I had hoped I would be able to observe, but which I was unable to attend owing to administrative issues or non-responses.

There are certain weaknesses attributable to observations generally, including the ability of the observer to be objective and unbiased in perceiving, noting and reporting the parties’ actions. The ability to attend these hearings and become known to individual judges and their clerks was highly beneficial, but also increased the risk of affecting how I would perceive the court and the individual judges, due to their varying levels of helpfulness towards me. In several cases, there were other public observers or counsel with whom I was familiar; this enabled me to discuss the cases, in accordance with any TO, and ensure my interpretations were not skewed so far as practicable.

Following each observation, I reviewed my contemporaneous notes and ensured they were accurate representations the proceedings. I then coded each set of observation notes in a similar manner to my interviews, using deductive and inductive themes. Some inductive themes – such as participation, delay, and transparency – emerged from the observations as they were not previously thought to be an issue.

1.4 Ethics

Prior to conducting my empirical research, I applied to the Open University (OU) Human Research Ethics Committee (HREC), as my research included human subjects. As the matters discussed in the interview had the potential to be sensitive in nature, such as discussions around death and dying, it was necessary for my proposal to undergo a full review. The full HREC procedure can be found on the OU’s website. It includes outlining any potentially sensitive topics, management of data, how I will recruit participants, and my research method and methodology.

HREC were initially concerned about my proposal to name the interview participants within this thesis; however, after discussion, they granted a favourable opinion (HREC/2982/Tanner) on the understanding that each participant must give positive confirmation that they are willing to be named and have the option to withdraw that consent. Ultimately, I decided not to name my interviewees due to a split in the number of those who were comfortable to be named.

Subsequently, I approached HREC to enquire about the need to receive ethical approval to conduct court observations. As there were no active participants with whom I would be talking, and the observations I was making were open to the public, I was informed that I did not need to submit a full ethics review and was instead granted a favourable opinion by Chair’s action.

My initial HREC application was submitted prior to the implementation of the General Data Protection Regulation (GDPR) and was therefore subject, at the time, to the Data Protection Act 1998. I undertook GDPR training in May 2018 and ensured that all data was kept securely in compliance with the Regulation. The UK GDPR was superseded on 31 December 2020 by the Data Protection, Privacy and Electronic Communications (Amendments etc) (EU Exit) Regulations 2019 (S.I. 2019/419), therefore all data protection is guided by this new legislation.

1.5 Overview of the thesis

In seeking to answer the four questions outlined in section 1.2, the thesis is divided into five chapters that address the theoretical understanding of the substantive issues and then the application of this understanding by doctors and lawyers.

In Chapter Two, I provide a critical analysis of the literature and case law of decision-making for PDOC patients. The chapter starts with the historical development of medical and legal principles of how the state sought to protect patients who lacked capacity; the chapter outlines the historical case of *Airedale NHS Trust v Bland*\(^{25}\) and analyses the impact it had on the foundation of modern capacity law. Chapter Two also explores the theoretical and medical understanding of prolonged disorders of consciousness and how they are diagnosed and treated. Thereafter, there is an analysis of the role of the CoP plays in the declaratory relief process and how the decision in *An NHS Trust and others v Y*\(^{26}\) has potentially changed the process. The

\(^{25}\) *Airedale NHS Trust v Bland* [1993] AC 789.

\(^{26}\) *An NHS Trust and others v Y* (by his litigation friend, the Official Solicitor) [2018] UKSC 46.
chapter concludes with a critical discussion on the best interests standard and a brief examination of how it compares to the standard used in some other jurisdictions and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

In Chapter Three, I outline the first of my two empirical studies, which are aimed at understanding how the law currently operates in practice. I detail the interviews I conducted with doctors and lawyers, discussing topics covered in Chapter Two. These interview responses are broken down into three categories: declaratory relief, clinical issues, and the future. I argue that there may be a lack of consistency between the way in which individual professionals are approaching best interests decision-making and how the jurisprudence has indicated it should operate.

In Chapter Four, which covers my observations in the CoP, I extend the evaluation of how the best interests test is applied. I offer a critical analysis of how judges within the CoP vary in their understanding of best interests. This chapter also highlights how patient-centred decision-making works in reality and discusses whether the patient is always truly at the centre of the court process. These observations raise a number of other issues, including transparency, delay and contradictions between theory and practice.

In Chapter Five, I outline the issues I have identified throughout this thesis and make recommendations as to how the law should be reformed to ensure a patient-centred decision-making framework. This chapter concludes with recommendations for future research on topics that arose throughout this thesis.
Chapter Two:
The development of mental capacity law

2.1 Introduction

This chapter begins by outlining the foundations of the law in relation to mental capacity and how it has evolved over centuries to protect vulnerable people who are unable to make their own decisions. The law on mental capacity has seen significant change over the past three decades, and because of this, there has been a considerable amount of confusion and debate around what the law actually is in England and Wales. This chapter looks at three critical areas of debate: the clinical process, the declaratory relief process and best interests decision-making.

The clinical process, how a PDOC patient is diagnosed as being in either a persistent vegetative state (PVS) or a minimally conscious state, was established by the regulating medical bodies almost two decades ago. A series of internationally used tests are used to diagnose a PDOC patient. This chapter will highlight the issues of misdiagnosis and raise questions on whether there are alternative technologies that could supplement the diagnostic and prognostic systems currently in place.

This chapter will also look at how the courts’ role has changed significantly over the past 30 years and how certain key legal cases have transformed the declaratory relief process. The CoP is a relatively new introduction into the courts of England and Wales; how it functions has not been researched in any great detail. This chapter will outline the functions of the CoP and how they have changed during the course of the COVID-19 pandemic. Finally, this chapter will discuss the best interests standard of decision-making, what it means, and whether there are better alternatives.

This thesis avoids being drawn into discussion and engagement with themes that are regularly discussed in work around end-of-life, such as dignity and autonomy. Similarly, this work is concerned primarily with the day-to-day practice in the courts and care facilities of England and Wales and so I have not explored case law relating to the rights found in the European Convention on Human Rights in any depth. These issues have all been addressed by various
authors\textsuperscript{27} and I therefore decided to focus on a less researched angle, namely the day-to-day practice of the decision-makers.

2.2 Clinical background

This section will outline what is meant by a prolonged disorder of consciousness (PDOC) and the diagnostic techniques which are most commonly used to determine the level of consciousness a patient may have. Further to this, issues with the current diagnostic practices will be discussed, including any potential for misdiagnosis that the current standard may possess and whether there are new technologies emerging that could assist the existing diagnostic framework.

2.2.1 Prolonged disorders of consciousness

Current medical understanding of PDOC stems from a series of studies conducted in the 1950s;\textsuperscript{28} during this time, doctors began to understand that people have varying states of consciousness, although the degree to which this was the case was not yet fully understood. This section will examine the three most commonly identified forms of PDOC: coma, VS and MCS. A parliamentary paper estimates that there are between 4,000 – 16,000 VS patients in UK hospitals and other institutions\textsuperscript{29} the same paper also estimates that there up to 48,000 MCS patients in the UK; there are currently no figures for the number of coma patients in the UK.\textsuperscript{30}

2.2.1.1 Coma

According to the Royal College of Physicians (RCP) National Clinical Guidelines, coma is "A state of unrousable unresponsiveness".\textsuperscript{31} When in a coma, the patient cannot be awakened and does not respond to any external stimuli; the RCP guidance says that the state of unresponsiveness must last for six hours for a patient to be diagnosed as comatose. Doctors


\textsuperscript{29} Sarah Bunn and Zoe Fritz, Vegetative and Minimally Conscious States (POST Note 489, Parliamentary Office of Science and Technology, March 2015), 1.

\textsuperscript{30} ibid.

\textsuperscript{31} Royal College of Physicians, \textit{Prolonged disorders of consciousness: National clinical guidelines} (Royal College of Physicians, 2013) 3.
assess the consciousness of a patient using the Glasgow Coma Scale. During the initial stages of a coma, it is likely that the patient will be placed in an intensive care unit (ICU). Coma is referred to as a transient state\textsuperscript{32} as — unlike VS and MCS — it will usually only last at most a few weeks, during which time the patient will either gradually improve or will move towards VS or MCS.\textsuperscript{33}

Although coma is the most common type of PDOC, it does not usually create much debate or critique. This is likely due to the common nature of coma within day-to-day medical practice. This thesis will, therefore, not address issues specific to coma patients. However, many of the issues that affect vegetative and minimally conscious patients are also applicable to comatose patients and will, therefore, be covered within this thesis.

\subsection*{2.2.1.2 Vegetative state}

The VS was first recognised as a medical disorder in 1940 by German doctor Ernst Kretschmer who coined the term \textit{apallic syndrome} (meaning ‘without cortex’).\textsuperscript{34} However, it was not until 1972 that the term ‘persistent vegetative state’ was established as a definition for patients who have remained in a VS for an extended period.\textsuperscript{35} Today there is increased use of a new term, \textit{unresponsive wakefulness syndrome} (UWS), as a replacement for VS; clinicians and academics have sought to find a new term to move away from the negative connotations which follow the term ‘vegetative’ and describing a patient as being ‘vegetable-like’. Steven Laureys and the European Task Force on Disorders of Consciousness have said that clinicians and families often feel uncomfortable with the pejorative nature of calling a patient a ‘vegetable’; the task force instead prefers to emphasise the individual human rights and personhood of the patient.\textsuperscript{36} Laureys, like Andreas Bender, also believes that the term ‘syndrome’ offers a better insight into the realities of the disorder than that of ‘state’;\textsuperscript{37} PDOCs are not a fixed state of being,

\begin{itemize}
\item Steven Laureys \textit{et al.}, ‘Coma’ (2009) \textit{Encyclopaedia of Neuroscience} 1133-1142.
\item Bryan Jennett and Fred Plum, ‘Persistent vegetative state after brain damage. A syndrome in search of a name’ (1972) 1 \textit{Lancet} 734-737.
\item Laureys (n 34) [68].
\item Andreas Bender \textit{et al.}, ‘Persistent Vegetative State and Minimally Conscious State A Systematic Review and Meta-Analysis of Diagnostic Procedures’ (2015) 112 Deutsches Ärzteblatt Internationa 235.
\end{itemize}
patients often move between MCS and VS and therefore 'syndrome' is said to better reflect this sliding scale of consciousness.  

Although Laureys is undoubtedly correct about the negative connotations associated with the term ‘vegetative’, this thesis is best served at this stage by continuing to use the more established terminology to ensure ease of understanding. Furthermore, the use of the word ‘unresponsive’ is not in keeping with many of the themes that this thesis will investigate. The discussion surrounding the change in terminology is nonetheless one that should continue amongst medical professionals and regulating bodies.

The criteria in the 2020 RCP guidelines for diagnosing a patient as being in a VS are that the patient must display no evidence of awareness of self or their environment and must also be unable to communicate or demonstrate voluntary behaviours. Patients in a VS are said to open and close their eyes in an apparent sleep-wake cycle, and are also likely to be able to thermoregulate their bodies and show signs of respiration. The RCP guidance on VS dictates that the disorder can only be described as ‘permanent’ if it has persisted for six months. The 2013 RCP guidance also differentiated between patients who suffered a traumatic and non-traumatic brain injury. The 2013 guidance stated that a patient must be in a VS for 12 months following a traumatic brain injury (such as following a car crash), and six months from any other cause (such as a lack of oxygen in the brain). The current guidance means that before six months have passed, the patient is in a persistent or chronic VS rather than a permanent VS.

2.2.1.3 Minimally conscious state

MCS was first defined and differentiated from the VS in 2002 by the Aspen Neurobehavioral Conference Workgroup. MCS covers a wide-ranging diagnostic spectrum, which encompasses a multitude of possible evidential behaviours; it is because of this that the MCS is itself broken down into two subcategories: MCS+ and MCS−. According to the RCP, patients

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38 Laureys (n 34).
40 Laureys (n 34).
41 RCP (n 39) [36].
42 ibid, 37.
along the MCS spectrum retain some cognitive processing capacity and show limited — but reproducible — behaviours; these behaviours range from following simple commands or signifying yes/no responses to questions; patients may also demonstrate some form of intelligible verbalisation. The crucial difference between the MCS and PVS is that the diagnostic criteria for the MCS require the replicability of evidential behaviours; reproducing these behaviours is affected by how complex the required behaviour is, or how consistent the patient’s behaviour is. The RCP identifies that diagnosis may require an extended period of assessment to obtain the required replicability.

Marie Bruno suggested that the further subcategorisations of MCS+ help differentiate between patients who are verging on full consciousness and those who are heading towards PVS. MCS+ is the diagnosis given to patients who demonstrate higher levels of behavioural response; it is when the patient can follow commands, verbalise or gesticulate in response to questions. In contrast, patients deemed to be MCS− will have minimal behavioural responses; the patient may track a moving object with their eyes or make appropriate movements towards external stimuli but will not make significant and consistent verbalisations or gesticulations. The RCP has identified a need for further medical research to be conducted to determine the prognostic benefit of these further subcategories.

It is vital to make these distinctions between VS and MCS, because the ramifications for patients when they are unclear can be a matter of life and death. The law has created a presumption that when a patient is in a PVS, it is no longer in their best interests to continue receiving life-sustaining treatment. However, when a patient is diagnosed as being in MCS, the decision-maker must undertake a balancing exercise to decide what decision would be in this individual patient’s best interests. Because of this legal differentiation, issues surrounding diagnosis and misdiagnosis are so crucial, as two separate decision-making structures have emerged.

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44 RCP (n 39) [29].
45 ibid.
46 Giacino (n 43).
47 RCP (n 39) [29].
49 RCP (n 39) [30].
2.2.2 Diagnostic methods

In December 2018, the British Medical Association released its updated guidance for doctors who are making decisions for patients who lack the capacity to consent; this guidance was updated again in September 2020. Within the full 2018 guidance, the BMA provided a pro forma for doctors to follow when making decisions to withdraw clinically assisted nutrition and hydration (CANH). This pro forma includes a checklist of formal diagnostic assessments that should be undertaken. A recent review has found that there are thirteen diagnostic methods currently used throughout the world, with five being the most commonly adopted. The BMA and RCP recommend the use of three of these five methods in the UK for determining a patient’s level of consciousness: Wessex Head Injury Matrix (WHIM), JFK Coma Recovery Scale – Revised (CRS-R) and the Sensory Modality Assessment and Rehabilitation Technique (SMART).

2.2.2.1 Wessex Head Injury Matrix

The WHIM assessment tool (Appendix E) is the most commonly used instrument within the UK for diagnosing PDOC patients. The assessment focuses on the observable actions or inactions of the patient; WHIM comprises a 62-item hierarchical framework of observable behaviours that cover the patient's interactions, communicative abilities, and cognitive functioning. The purpose of WHIM is to "monitor changes in a (sic) individual's level responsiveness and interaction with their environment, as they progress from coma".

WHIM lists 62 behaviours, such as "eyes open briefly", and offers an operational definition of what is considered a successful demonstration for each behaviour, for example, "less than 30 seconds". The observer will then tick the box to say that they have witnessed the patient fulfil this behaviour or will leave it blank if they have not. The BMA's 2018 guidance states that the patient should have had a minimum of 10 WHIM ratings as part of the PDOC diagnostic pro forma. A benefit of the WHIM technique is that doctors are not the only people able to apply it; family members can use WHIM as a framework to monitor their interactions with the patient. Although WHIM was not originally designed as a diagnostic tool for PDOC, the RCP has

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52 ibid.
nonetheless described it as being “valid and reliable”\textsuperscript{53} in this context. The RCP has, however, noted that WHIM is often criticised for its “over-reliance on visual stimuli”,\textsuperscript{54} meaning other potential areas of outward manifestation are not covered in as much depth.

\subsection*{2.2.2.2 JFK Coma Recovery Scale – Revised}

The CRS-R is the most commonly used diagnostic tool in the USA and parts of Europe;\textsuperscript{55} Giacino devised the scale in 1991 to assist in the differential diagnosis and treatment planning of PDOC patients.\textsuperscript{56} Much like the WHIM assessment, SMART consists of a hierarchical scale of various observable actions, which begin with no action and gradually move up the scale towards consistent and meaningful movements. The CRS-R breaks this down into 23 observable actions, which separate into six sub-scales:

- auditory function scale,
- visual function scale,
- motor function scale,
- oromotor/verbal function scale,
- communication scale, and
- arousal scale.

The items on each of the subscales range from reflexive actions at the bottom, to more cognitively motivated actions towards the top. Scoring is standardised and is determined upon whether the action is fulfilled or not. Giacino produced an extensive companion guide to the CRS-R, which outlines what it takes for a patient to fulfil each of the actions listed on the subscales.\textsuperscript{57}

Since its revision in 2004, the CRS-R has been the subject of a considerable amount of research; Caroline Schnakers used the CRS-R to show that — when followed correctly — the risks of

\textsuperscript{54} RCP (n.39) [51].
\textsuperscript{55} Turner-Stokes (n 50).
misdiagnosis are much less than when doctors had been using non-standardised methods of assessment. Despite this, the CRS-R is not able to identify all the levels of PDOC accurately; Andreas Bender has noted that it "may not be sensitive enough to identify all patients who are in MCS". Therefore, the CRS-R may be unable to identify MCS patients; instead, it may place all these patients into a category of lower consciousness, namely VS.

2.2.2.3 Sensory Modality Assessment and Rehabilitation Technique

A SMART assessment is undertaken over 10 sessions in a three-week period and consists of formal and informal assessment components. During the formal component, the patient is observed by the assessor to see their reactions to the stimulation of each of their five senses: smell, sight, taste, touch and hearing. Much like the WHIM and CRS-R assessment tools, SMART utilises a hierarchical scale to ascertain patient responses; the scale ranges from Level 1 (no response) to Level 5 (ability to differentiate stimuli). The commonality amongst all three assessment tools means that, should a doctor undertake all three assessments, they are easily comparable for diagnostic purposes.

The informal element of the SMART assessment involves questionnaires and observations from family, friends and carers. Those closest to the patient will be asked about the patient's lifestyle and general communicative abilities; they will also be asked to observe any attempts at communication he may display during his day-to-day activities. Helen Gill-Thwaites, the creator of the SMART technique, has said that it "possesses the sensitivity to identify subtle changes in behaviour and potential function in the VS patient and can identify the initial point of awareness, thus potentially optimising the patient's quality of life."

These three diagnostic techniques have been developed over the last three decades and continue to be refined, to establish the most accurate diagnosis. However, these methods may not offer the most accurate representation of a patient's current levels of consciousness and could lead to worrying levels of misdiagnosis.

61 ibid.
2.2.3 Misdiagnosis rates

In 1993, the same year in which the *Bland* case was decided, a study by Nancy Childs *et al.* concluded that around 37% of patients who were referred to a neuro-rehabilitation facility were found to have been incorrectly diagnosed as being in PVS or comatose.62 This study is particularly notable because it identifies a potential need for specialist neurology facilities, rather than diagnosis taking place within a generalised care setting.

Three years later, Keith Andrews conducted a study that revealed a rate of misdiagnosis of 43%.63 Andrews emphasised that the rate of misdiagnosis is so high, yet there are too few specialists, making the diagnosis and management of PDOC patients much more difficult.64 It should be noted that misdiagnosis in the 1990s is different to misdiagnosis in 2021. When these studies were conducted, misdiagnosis referred to whether a patient was in PVS, coma or full consciousness. Today misdiagnosis can mean incorrectly placing a patient on a growing scale of consciousness, meaning there is much more room for mistakes to be made.

Simon Halliday and Adam Formby have been critical of these two studies, as they are more than 20 years old and may not reflect the current state of medical science. For example, the MCS as a PDOC category had not been identified until 2002 — six years after the Andrews study.65 Halliday and Formby further noted that many of the earlier studies were not in keeping with the now accepted six to twelve-month diagnostic period for traumatic brain injury and a separate six-month diagnosis for non-traumatic brain injury. They conclude that these studies do not represent the current understanding of medical science and should carry little weight.66

However, the distinctions between traumatic and non-traumatic diagnosis may no longer be relevant when determining withdrawal, as the number of patients who have recovered post-12 months is not insignificant. Furthermore, senior medical professionals — such as Lynn Turner-Stokes — have acknowledged that MCS patients are misdiagnosed at a high rate. However,

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62 Nancy Childs *et al.* ‘Accuracy of Diagnosis of Persistent Vegetative State’ (1993) 43 *Neurology* 1465 LP.
65 Giacino (n 43).
Turner-Stokes contends that when doctors follow WHIM, SMART and the CRS-R, it should significantly prevent this, as in her view they are incredibly comprehensive assessment tools; despite this, she says that the "congruence" between these methods requires further investigation.\(^{67}\)

Despite this criticism, two further studies have shown that diagnostic accuracy has not improved since the study by Andrews in 1996. Caroline Schnakers reported in 2009 that vegetative state patients are misdiagnosed at a rate of 41%;\(^{68}\) in this study — the largest to date — 103 prospective patients were observed, and of the 44 diagnosed as VS, 18 were found in fact to be in MCS. Furthermore, of the 41 diagnosed as MCS, 10% had emerged back into full levels of consciousness in accordance with the CRS-R. Schnakers concluded that, although diagnosis in this area is crucial, the figures have not improved at all in the last 25 years and a critical concern exists surrounding the current methods of diagnosis.\(^{69}\)

Similarly, Dr Mohamed Rady of the Mayo Clinic in the USA reaffirmed the figure of 41% in his 2017 article. He claims that the "criteria and definitions of the three levels of DOC (disorder of consciousness) has (sic) not been validated scientifically."\(^{70}\) and that as a result of incorrect diagnosis, patients could have their lives prematurely ended as a result of treatment withdrawal. Rady is one of the few medical doctors who have disagreed with the current consensus. He does not believe society has yet reached a point where medical science has a complete understanding of the spectrum of consciousness. Although neuro-technologies have advanced dramatically since the early case law, doctors are still not clear on either diagnosis or prognosis of PDOC patients. The study by Schnakers is crucial, as it was conducted after the identification of MCS. Therefore, the criticism by Halliday and Formby that the studies were outdated may be questioned.

When Lord Goff, in *Airedale NHS Trust v Bland*,\(^{71}\) suggested that the courts retain an overview of these cases until a substantive body of practice was built up, which will be discussed in


\(^{68}\) Schnakers (n 58).

\(^{69}\) ibid.


\(^{71}\) *Airedale NHS Trust v Bland* [1993] AC 789.
greater detail in section 2.4.1, he did so because of the fear that the medical and legal professions may be unaware of all the scientific facts and therefore make mistakes. The high rates of misdiagnosis of patients in a PVS may be one of the strongest points to reinforce Lord Goff's argument that medical science has yet to advance to the extent he envisioned a quarter of a century ago, as Rady has indicated.

The levels of misdiagnosis discussed above are incredibly troubling, yet the medical community does not appear to be too concerned by these repeated studies. For example, Derick Wade has stated that most misdiagnoses have "minor clinical significance, with a patient crossing an artificial boundary within a spectrum". Wade believes that little difference exists between PVS and MCS from either a diagnostic or prognostic viewpoint; he believes that a PVS or MCS diagnosis is a matter of semantics. Wade contends that the MCS/PVS distinction is based upon an artificial differentiation between behaviours that should not carry any clinical significance; moreover, he argues that we should see these patients on a continuous spectrum of consciousness and not treat them differently. While this might be true from a medical perspective, the legal consequences of not differentiating are potentially very significant for the patient.

A practical point of law needs addressing with such an assertion: a patient in a PVS does not automatically trigger a balancing exercise, and in-depth scrutiny from the CoP, whereas a patient in an MCS does. Without this distinction, it could mean that patients with higher levels of consciousness could be deprived of their legal right to a full and fair hearing in court. It is a grave concern that a significant amount of evidence continues to exist that life-threatening misdiagnosis continues to occur. It should not be dismissed as a matter of labelling, as these labels can have the effect of a patient having life-sustaining treatment withdrawn, perhaps prematurely.

The case study of a patient named Scott Routley, discussed at section 2.2.4.2, emphasises how crucial it is to have a correct diagnosis: his incorrect diagnosis of PVS lasted for 12 years. In the UK, this diagnosis could well have prompted an application to the CoP to withdraw care, and he may have had his CANH withdrawn without a full evidential hearing. Routley's case is

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just one of many, highlighting the importance of research into emerging neuro-rehabilitation and diagnostic techniques.

The medical literature seeks to portray PDOC patients as being on a continuous spectrum, where very little difference exists between VS and MCS, whereas the law places the two into distinct categories which can have life or death consequences for the patient. Wade's contention that it is of little clinical significance may well be accurate and will be explored more in future chapters; however, these definitions can have significant reverberating effects for the patient within the current framework.

Gill-Thwaites states that "at present, in the absence of internationally agreed guidelines and standards, decisions to withdraw nutrition and hydration are being based on potential inconsistencies in assessment and management of the patient". She further argues that, as the current methods of diagnosis rely heavily on how doctors interpret the patient's behaviours, it is highly arbitrary and it "places the patient in a modern-day life lottery"; she says that this is a result of patients often being left in non-specialist settings with doctors who are inadequately trained to deal with these cases. Gill-Thwaites identifies five key factors as contributing to the rate of misdiagnosis:

1) Differential diagnosis and definitions,
2) The assessor's knowledge, experience and availability,
3) The assessment tool,
4) Involvement of the family and carers, and
5) The patient's management.

Frequent clinical misdiagnosis is a very serious issue and remains a genuine challenge for the medical profession to address and overcome. If MCS patients are frequently misdiagnosed as being in a PVS, they may at best be being subjected to immense emotional suffering due to their heightened consciousness, and at worst, may have their life prematurely ended. These worryingly high rates of clinical misdiagnosis have led to increased efforts being made by

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75 ibid 1327.
76 ibid.
small number of clinicians to research new and innovative ways to offer a more accurate diagnosis for MCS patients.

2.2.4 Emerging technologies

The concerning figures and rates of misdiagnosis in past studies has led to research being conducted into new and emerging technologies to be able to not only diagnose where the patient may fall on the spectrum of consciousness, but also potentially communicate with him. This section will look at the research which has been conducted into three different technologies, two of which are still experimental but have shown promising results.

2.2.4.1 Electroencephalogram

An electroencephalogram (EEG) records brain activity by attaching small electrode sensors to the patient's scalp in the form of a net cap. These sensors pick up electrical signals being produced by the brain, which are then shown on a computer in the form of wavy lines; doctors will interpret these readings to identify changes in electrical activity in the brain. EEGs are a widespread medical procedure, often used when testing the electrical activity in the brain of patients who have epilepsy. Clinicians commonly use EEGs of PDOC patients to identify the current electrical activity in the patient's brain for prognostic evaluation as they are "relatively low cost" and convenient.77

In recent years EEG research has increasingly been used in an attempt to unlock a patient's hidden consciousness; Damian Cruse assessed 16 patients who had been diagnosed as being in a VS and compared their results to those of 12 healthy control subjects.78 Patients were asked to imagine following a command, such as moving their toes or clenching their fist. Of the 16 VS patients, three were able to provide replicable responses; although this is not a majority of those tested, it does indicate that some patients diagnosed as VS have a demonstrably higher consciousness under the right circumstances. Another important finding in this study was that no correlation existed between those 16 patients' ability to respond and whether the cause of the brain injury was traumatic or non-traumatic. The RCP guidance on PDOC allows for

diagnosis after a much shorter period following a non-traumatic injury, as they are deemed less likely to recover; however, Cruse may be indicating that this assumption could be fundamentally flawed. Although Cruse’s study had a relatively small sample size, the findings are nonetheless important and suggest that further research into this area is desirable.

One aspect of EEG testing promoted by Cruse is that EEGs are "cheap, portable, widely available and objective".79 EEG machines are available in almost every hospital in the country; doctors frequently use them at a patient's bedside without the need for transfer to specialist units. Therefore, the costs associated with EEGs are much lower than other techniques which will be discussed in this section.

However, EEGs have been criticised for their high probability of producing false positives, due to outside factors; it is suggested that patients may potentially appear to demonstrate a higher level of cognitive function with an EEG than they possess. Andrew Peterson has noted that a difficulty with EEG testing arises from trying to control and account for what are known as "movement artifacts".80 Any minor movement during the scan has the potential to create noise on the results and therefore give the illusion of enhanced cognition.81 Peterson contends that it is almost impossible to stop this from happening, and therefore, all results should take into consideration the chance that they may have recorded false positives.82

Despite this, a 2019 study conducted by Nicholas Schiff, Chananel Braiman and others (the Schiff Study), has received praise for its advancement in using EEGs to unlock hidden consciousness in PDOC patients.83 The Schiff study has identified that, when connected to an EEG, patients diagnosed as being in a PDOC reacted to the voices of people they knew, in much the same way as healthy control subjects. In his study, 21 PDOC patients had a family member tell them stories of their own lives while being observed using an EEG; these results were compared to the EEG responses of thirteen healthy control subjects who had Alice in Wonderland read aloud to them. The patients then underwent functional magnetic resonance

79 ibid.
82 Peterson (n. 80).
imaging (fMRI) to determine whether they could imagine themselves undertaking more complex tasks, such as playing tennis. This study revealed that those patients who demonstrated the normally expected EEG reactions to human speech could also imagine the tasks in the fMRI tests; however, patients who were unable to imagine the activities in the fMRI task also showed a lack of cognitive response to the EEG assessment.

Neurologist Brian Edlow called this a "ground-breaking" study, which allows doctors to recognise covert consciousness with the EEG, which can be further unlocked with an fMRI. Although fMRI machines may be costly, this study allows doctors to narrow down the potential patients for whom it may benefit by using the much more cost-effective EEG machines. If an EEG is able to identify patients with a higher consciousness at a relatively low cost, it could mean that doctors need not worry about the cost issue of sending patients for expensive fMRI scans.

2.2.4.2 Functional imaging

Over the past two decades, there has been increased interest in studies researching the use of functional magnetic resonance imaging technology on patients with PDOC. FMRI scans can indicate which areas of the brain are active at any given time by assessing the blood-oxygen levels; this allows doctors to potentially identify heightened neural activity in a patient's brain in response to being asked to undertake various mental imagery tasks.

A study conducted by Martin Monti of 54 patients, who were either in MCS or PVS, found that five patients were able to "wilfully modulate their brain activity". This study identified that a small — but not insignificant — number of PDOC patients have brain activity that is not dissimilar to that of a fully conscious adult. Patients were asked to answer simple 'yes' or 'no'

85 Adrian Owen et al. 'Detecting awareness in the vegetative state' (2006) 313 Science 1402.
86 Paul Catley and Stephanie Pywell, 'The ethical imperative of ascertaining and respecting the wishes of the minimally conscious state patient facing a life or death decision' in D Sturma et al (eds), Jahrbuch für Wissenschaft und Ethik Band 19 (Berlin, De Gruyter, 2014) 77-90.
questions by visualising different activities to indicate their response. Monti’s conclusion to the study was that, through the use of neuroimaging techniques, some patients diagnosed as being in a PVS or MCS should be reclassified, as their levels of consciousness differed from what traditional bedside tests were indicating. One patient in Monti’s study showed no signs of consciousness through the standard bedside detection assessments but was able to give responses to yes or no questions posed to him while undergoing an fMRI.

As discussed above, Scott Routley had been diagnosed as having been in a PVS for 12 years. Routley was able to confirm, via fMRI, the current year as well as the name of his carer; more crucially, Routley was able to indicate to the assessors that he was not in any pain. This case study indicates that patients who may show all the outward signs of being in a PVS maybe possess a much higher level of consciousness.

Nonetheless, Damian Cruse has noted the various challenges that affect fMRI, including the considerable cost associated with the scanners and their lack of availability within most hospitals and neuro-rehabilitation facilities throughout the UK. Cruse has also pointed to the physical toll that fMRI may have on a patient; he says that the stress incurred by the patient during transfer to and from fMRI facilities is "substantial". Furthermore, he has argued that a significant complication with fMRI is that many patients who have suffered from traumatic injuries will likely have had invasive surgeries of some kind during their initial ICU treatment. These surgeries may have included the implantation of metal pins, screws or plates; therefore, they would be unable to take part in an fMRI study due to the machine’s magnetic field.

Peterson, Cruse and Owen have all pointed to the reliability of fMRI in the research setting as a reason why further clinical studies and expansion into real-life practice should occur as soon as possible. Peterson has said that the chances of a patient undertaking an fMRI and producing a false positive by reliably and repeatedly activating the appropriate areas of the brain are

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89 ibid.
91 ibid.
92 The cost associated with fMRI machines has been discussed here, Stephanie Pywell, ‘Potential legal implications of advances in neuroimaging techniques for the clinical management of patients with disorders of consciousness’ in Sturmer, D, Jahrbuch für Wissenschaft und Ethik (2015, Berlin, De Gruyter) 114-146
93 Cruse (n 87).
94 ibid.
"incalculably low". Over the last 15 years, a considerable amount of research has been conducted into the effectiveness of fMRI's in differentiating between VS and MCS and whether they can be used to find hidden consciousness, which may otherwise be missed.

In 2019, Athena Demertzi released a study conducted on 112 patients who had received a diagnosis of either PVS or MCS. She showed that VS patients were more likely to respond to less complex decisions, as less of the brain was required to make the decision. MCS patients' neurological activity was found to fall somewhere between a healthy brain and that of a person in VS; she identified more advanced activity occurring in various regions of the brains of MCS patients when they were asked to imagine themselves undertaking certain tasks. Tristan Bekinschtein of Cambridge University has said that the results of this extensive study were "brutally consistent". Similarly, Anthony Hudetz has also praised the Demertzi study, saying that it will help to "provide insight into whether particular rehabilitation methods or other treatments are working" and that it has the potential to "ultimately help doctors and families make difficult decisions about continuing life support." Demertzi's research is the latest of a series of studies which have affirmed the usefulness of fMRI in detecting brain functioning which is not discovered using traditional bedside techniques.

Although Demertzi's study is the largest sample size to date, other studies have indicated a significant number of PDOC patients have awareness left undetected by the CRS-R. In 2014, Johan Stender, testing 70 PDOC patients, found that 32% of the patients that had been unresponsive to the CRS-R showed brain activity compatible with MCS when fMRI was used; of those patients who were responsive to fMRI, 69% went on to regain some level of consciousness. Similarly, Silvia Marino found that 10 of his 23 observed PVS patients demonstrated brain activity similar to that of an MCS patient. These 10 patients all demonstrated significant clinical improvement within six months, moving into MCS. These

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95 Peterson (n 80).
97 ibid.
99 ibid.
studies have shown similarly higher levels of consciousness in PDOC patients, with an increasing number of studies showing similar results.\textsuperscript{102}

The studies discussed above indicate that a patient’s inability to react to stimuli at the bedside, such as a light in the eyes or a strike to the knee, is not a reliable indicator of their level of consciousness. The inability to react to external physical stimuli is a sign of a disorder known as cognitive-motor dissociation (CMD);\textsuperscript{103} a patient with CMD may be able to react in the same manner as a cognitively healthy patient, but their ability to outwardly demonstrate that is impaired by the damage to their central nervous system. Further to this, Dr Jacob Sitt has indicated that an advantage of the fMRI over that of the EEG is that a doctor is able to tell the specific region of the brain being used during the assessments and can link this to what is known about that area’s properties; EEGs only show that electrical pulses are occurring within the brain, not which areas are being utilised.

Despite these studies, some of which are large scale, the governing medical bodies in the UK have been reluctant to invest in using fMRIs as part of the standard diagnostic framework. The science behind finding hidden consciousness is still being developed, and as such further large-scale research projects will be required for us to understand the effectiveness and applicability of fMRIs. Nonetheless, the findings in these studies clearly indicate that there is a significant number of patients who have levels of cognition which traditional testing is missing. Wide-ranging clinical trials into the effectiveness of fMRI is the next logical step, following the positive outcomes of these smaller studies.

\textsuperscript{102} For further studies, which have shown similar results see: Martin Coleman et al, ‘Do Vegetative Patients Retain Aspects of Language Comprehension? Evidence from fMRI’ (2007) 130 Brain 2494.
\textsuperscript{103} Monti (n 88) 579.
2.2.4.3 Vagus nerve stimulation

In addition to EEG and fMRI there is an experimental procedure known as Vagus nerve stimulation (VNS). The vagus nerve is a part of the body responsible for a wide variety of tasks, such as maintaining a steady heart rate and keeping the gastrointestinal tract working; the vagus nerve also serves to carry sensory information to and from the brain from many vital organs and controls several automatic and subconscious functions, which maintain a person’s wakefulness.\(^{104}\) VNS has, for several decades, been an established practice in treating patients with drug-resistant epilepsy.\(^{105}\) The procedure requires implanting a small generator under the skin in the patient’s upper chest, under the collar bone. Wires are connected to the vagus nerve and send regular mild electrical pulses to the vagus nerve in the patient's neck.\(^{106}\)

![Vagus Nerve Stimulation model from The Mayo Clinic\(^{107}\)](image)

There are very few studies exploring the use of VNS on patients who suffer from PDOC; however, the studies which exist display a positive future outlook on its continued use and investment potential.

\(^{107}\) ibid.
One such study, conducted by Martina Corazzol in 2017, indicates that VNS has the potential to "modulate large scale human brain activity" and most crucially "alleviate disorders of consciousness". In this study, Corazzol researched a 35-year-old man who was left in a vegetative state following a car accident 15 years previously. The clinicians performed PET scans and EEGs on the patient's brain before having the stimulator implanted, and then observing him over the next six months; during that time, they periodically increased the strength of the electrical impulses sent to the vagus nerve. The team reported a series of objective improvements in the patient by the end of the study, including the ability to track the examiner through their voice, demonstrating a greater expression of emotions when hearing his favourite music and continually opening his eyes wider when being addressed. The patient was reassessed following the six-month study period using the CRS-R and was found to now be in an MCS. EEGs of the patient's brain taken before and after VNS showed that he had made a significant improvement and that there was a considerable increase in cerebral activity following the procedure.

A further study by Chen Shi, a neurologist from New York University, is taking a much broader look into the use of VNS on PDOC patients; he believes that “compelling evidence exists” that VNS has a positive impact in improving a patient’s outcome after traumatic brain injury. He also points out that if patients have their level of consciousness raised from VS to MCS, their chances of recovery are greatly improved, as MCS patients “have significantly more favourable outcomes by 1-year post-injury than those diagnosed with VS”.

Of course, these studies cannot be thought to be representative or instructive towards future practice at this moment due to their limited scope; however, these studies do offer the beginning of a conversation and an invitation for doctors and medical researchers to conduct further studies into its usage. Despite the small sampling, these studies indicate a much more significant debate concerning what the RCP guidance tells us about recovery. As Reid Hoshide has said in reviewing this research, the VNS mechanism aiding patients to awaken or gain increased levels of consciousness is a “humble reminder of the brain’s mysterious, yet

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110 ibid.
modifiable, connections”.

While some may see a PDOC diagnosis as a definitive statement of futility of treatment, these advances indicate that this may not be the case in the future and that clinicians should start acting with caution when they label a patient as having no chance of recovery.

The courts and medical guidance assume that treatment is futile once a specific period has passed (6 or 12 months), as the prognosis is almost guaranteed. However, as Dr Michele Lammi has indicated, the “length of time that MCS patients are in MCS may not predict their outcome”. This view is similarly held by Andreas Bender, who said that VNS and other such advances in medical science mean that the assumptions held by the governing medical bodies, that recovery or regaining consciousness is unlikely after a given point, must be rethought.

The use of fMRIs on PDOC patients has undergone a significant number of clinical trials, which have shown consistently promising results. When coupled with EEG vocal recognition testing, fMRI demonstrates an even greater level of success. The leading medical bodies in the UK have not indicated within guidance documents why fMRI have yet to be implemented into a diagnostic framework. Further to this, although VNS is a well-recognised treatment for certain conditions, there is not yet enough known about its usefulness in helping PDOC patients. There are currently further studies being undertaken that may, in years to come, determine whether VNS should also be incorporated into a treatment plan for PDOC patients.

### 2.3 Principles of medical law

Several fundamental issues must be understood to inform the background to cases concerning CANH withdrawal from PDOC patients. The debate in the UK concerning end-of-life medical decisions often focuses predominantly on assisted dying and euthanasia; this section will establish the background to capacity law and how it is different from the debates surrounding euthanasia and assisted dying.

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112 Shi (n 109) [2].

2.3.1 History of the protection of mentally incompetent patients

The history of the role of the court in protecting people who lack capacity is by no means straightforward; it has evolved over hundreds of years out of a somewhat tenuous beginning. Through its prerogative powers, the Crown claimed a duty of care over the most vulnerable members of the realm. The Crown assumed jurisdiction over the mentally incompetent during Edward I's reign, which came to be known as the parens patriae jurisdiction.\(^{114}\) The King historically claimed "wardship over all natural fools and idiots".\(^{115}\) 1540 saw the creation of the Court of Wards and Liveries, and the Royal prerogative power was vested in this Court, and the Court soon expanded their jurisdiction to cover persons who were then known as "lunatics";\(^{116}\) these were people who were not born mentally incapacitated but became so later in life.\(^{117}\)

Margaret McGlynn notes that this power stemmed from the King's duty to defend not only the natural land of his realm but also the individual members. She quotes William Staunford, who portrays the parens patriae obligations and rights as one of the earliest forms of state paternalism.\(^{118}\) The parens patriae powers remained for over 400 years until 1959, when the Mental Health Act revoked the Royal Warrant and inadvertently abolished the court's jurisdiction.\(^{119}\) It would remain that way for several decades, with no new law being created by the courts until Anthony Bland's case made its way to the House of Lords.

*Airedale NHS Trust v Bland*\(^{120}\) was concerned with the withdrawal of ANH from a patient, Anthony Bland, who was in a PVS. Bland was a young football fan who was seriously injured during the crush at the Hillsborough disaster in 1989; his case was the first time the House of Lords was asked to consider an application to withdraw life-sustaining treatment from a PVS patient. The case occurred due to the treating physicians being threatened with criminal


\(^{115}\) Custer (n 114) [195].

\(^{116}\) ibid [197].


\(^{118}\) ibid [6].


\(^{120}\) [1993] AC 789.
prosecution for murder. Therefore, the NHS Trust sought clarification on any potential liability and whether doctors were allowed to withdraw futile care from seriously injured patients.

2.3.2 Euthanasia

The term “passive euthanasia” is often used to refer to the withholding or withdrawal of life-sustaining treatment; this is not the case in England and Wales where euthanasia is generally taken to mean a situation in which a doctor or other caregiver takes proactive steps to bring about a patient's death. In the case of Bland, the Court of Appeal and the House of Lords made it clear that there is a fundamental distinction to be made between euthanasia and the withdrawal of medical treatment. The ethical and legal distinction between the two acts is reliant upon the intention of the doctors performing the act; when a doctor withdraws LST from a patient, they are doing so with the intention of ceasing futile treatment. A doctor's primary intention when withdrawing treatment is not to kill their patient. In contrast, a doctor who is committing euthanasia has a primary intention to end that patient's life.

The BMA guidance states that when a doctor withdraws treatment, the cause of death is considered to be the underlying illness and not the act of withdrawal. In euthanasia cases, it is the provision of some form of medication that leads to the patient's death and not the cessation of treatment. Assisting in somebody's death is outlawed in England and Wales by the Suicide Act 1961, however it should be noted that euthanasia is not covered by this Act as it applies only to the situation of a person helping another to commit suicide. This thesis will not look at the ethics of, nor the ongoing debate surrounding, the legalisation of assisted suicide or euthanasia.

2.3.3 The doctrine of double effect

The ethical and legal debates surrounding medical intervention at the end of life have been ongoing for centuries. While not strictly related to this thesis, the doctrine of double effect (DDE) demonstrates the often-far-reaching powers doctors have over vulnerable patients, particularly those near the end of their life. DDE is the well-established principle that an action

121 ibid [866].
122 British Medical Association, Clinically assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales (London, BMA 2020) 15.
123 Suicide Act 1961, s2(1).
can have two known effects, a primary and a secondary effect; a doctor can perform an act that will knowingly hasten a patient’s death, as long as the patient's death was not the primary intention of the doctor.\textsuperscript{124}

Lizzie Tuckey and Anne Slowther explain that DDE is applied in practice when a patient is in severe discomfort, commonly towards the end of a terminal illness, and usual doses of pain relief are no longer working. In this situation, DDE allows the doctor to prescribe higher doses of pain relief, as long as their primary intention was to relieve the patient's suffering. Tuckey and Slowther say that "Higher doses of these drugs may cause respiratory depression and shorten the patient's life. The proportion of deaths that are preceded by the administration of high doses of analgesia is thought to be as high as 26% in some European countries".\textsuperscript{125}

Although this may be an ethically controversial doctrine, the law on DDE has been settled since the 1957 case of \textit{R v Adams}.\textsuperscript{126} In this case, Dr Adams was acquitted of murder based on DDE, as he had not been motivated by his desire to kill his patient but instead by his wish to alleviate the patient's pain and suffering. Although the patient's death was a foreseeable side effect, it was not his primary intention and so did not amount to murder under English criminal law.

DDE is an illustrative example of the leniency and often vast powers afforded to doctors and the vagueness of solutions offered by the law to regulate their actions. Although DDE is a vital part of English medical law, it will not be considered further in this thesis.

2.4 Declaratory relief process

In 2018 the UK Supreme Court made a definitive ruling on the role of the court in proceedings regarding the withdrawal of life-sustaining treatment from patients in PDOC. Prior to this ruling, it was considered a part of the legacy of the decision in \textit{Bland} that there was a requirement for decision-makers to make an application to the court for approval to withhold or withdraw treatment. However, this section will illustrate that, following the ruling in \textit{Bland}, the law became extremely confused and led to judicial and academic disagreement.

\textsuperscript{124} Lizzie Tuckey and Anne Slowther, ‘The Doctrine of Double Effect and End-of-Life Decisions’ (2009) 4 \textit{Clinical Ethics} 12
\textsuperscript{125} ibid [13].
\textsuperscript{126} \textit{R v Adams} [1957] Crim LR, 365.
Prior to *Bland*, the House of Lords had decided the case of *Re F*,\(^{127}\) which focused on the forced sterilisation of a young woman who was mentally incompetent, in which Lord Griffiths said:

> It is not satisfactory to leave this grave decision with all its social implications in the hands of those having the care of the patient with only the expectation that they will have the wisdom to obtain a declaration of lawfulness. The law ought to be that they must obtain the approval of the court.\(^{128}\)

*Re F* established that any clinician wishing to undertake medical decisions of a serious nature on a mentally incompetent patient should seek court approval;\(^{129}\) it was not, however, until a few years later that this was applied directly to PDOC patients.

### 2.4.1 In the beginning: Bland

The case of Anthony Bland, the facts of which have been outlined above, represents the beginning of a 25-year long debate concerning the role of the court in deciding whether to withdraw LST. The case was brought before the court due to the legal uncertainty the NHS Trust found themselves in should they decide to withdraw care from Mr Bland.

In addition to answering this uncertainty, *Bland* also created a new legal expectation that the court should always be involved in withdrawal proceedings by way of the declaratory relief procedure. In the House of Lords, Lord Goff approved a statement from Sir Thomas Bingham MR in the Court of Appeal as to why the declaratory relief process should be sought:

> This was in my respectful view a wise ruling, directed to the protection of patients, the protection of doctors, the reassurance of patients' families and the reassurance of the public. The practice proposed seems to me desirable. It may very well be that with the passage of time a body of experience and practice will build up which will obviate the need for application in every case, but for the time being I am satisfied that the practice which the President described should be followed.\(^{130}\)

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\(^{127}\) *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.


\(^{129}\) ibid.

\(^{130}\) [1993] AC 789, 873 (Lord Goff).
Further to Lord Goff’s reasoning, Lord Lowry stated that to allow the treating physician to decide to withdraw care unilaterally would be to make the doctor a “judge in his own cause”.\textsuperscript{131} This is to say that the courts must offer some form of oversight to ensure patients’ rights are being considered, and that it is not merely a clinical decision.

It is clear from Lord Goff’s statement that he did not envision the court maintaining control over these matters indefinitely; he was looking towards the future, to a time in which the medical and legal professions had gained a better understanding of PDOC and the decision-making process. It was suggested to Lord Goff that the court only be used when (1) there was diagnostic/prognostic disagreement, or (2) when there was disagreement between doctors and the patient’s family.\textsuperscript{132} However, Lord Goff believed that cases of this kind should remain under the purview of the President of the Family Division for the immediate future.

The House of Lords' decision in Bland set the stage for the next two decades of debate between legal and medical professionals as to what Lord Goff meant when he said that applications to the court were a matter of best practice. Did he create a new legal rule, or was it merely a suggestion as to how doctors should conduct their business?

Although this thesis focuses on how doctors and lawyers make best interests decisions in practice, the theoretical debates surrounding the decision in Bland should not be overlooked entirely. For example, a significant debate exists surrounding the ethical underpinnings of the judgment and whether the House of Lords was correct from an ethical perspective in defining medical withdrawal as an omission rather than an act. John Finnis has, for example, argued that the law was left “misshapen and indefensible”\textsuperscript{133} and was very critical of the way Lord Hoffman described Anthony Bland’s body as being a mere vessel. Similarly, Andrew McGee\textsuperscript{134} and John Keown\textsuperscript{135} have provided significant additional insight in the ethical and moral debate surrounding withdrawal of treatment. These debates, though fruitful grounds for theoretical discussions, do not merit inclusion into this thesis because they shed no light on the current state of decision-making in care settings and courts in England and Wales, which is the primary focus of this research.

\textsuperscript{131} ibid [875] (Lord Lowry).
\textsuperscript{132} ibid [874] (Lord Goff).
Parliament established the Joint Committee on the Draft Mental Incapacity Bill to codify the issues raised in *Bland*. The Committee recommended in 2002 that certain cases *always* be taken before the Court of Protection: these included “the withdrawal of artificial nutrition and hydration from patients in a vegetative state”. The outcome of the Committee was the Mental Capacity Act 2005, the guiding piece of legislation for all matters related to people who lacked decision-making capacity.

### 2.4.2 The Mental Capacity Act 2005 and the Code of Practice

The Mental Capacity Act 2005 (MCA 2005), which covers England and Wales, represented a paradigm shift in the law governing mental capacity; it aimed to provide, for the first time, a statutory framework for decision-making for those who lack capacity. The declaratory relief process is not directly addressed within the text of the MCA 2005; the Act is instead supported by The Code of Practice (The Code), which was required to be laid before both Houses of Parliament without being voted down. The introductory note to The Code explains that it has statutory force, which means that specified groups of people have a legal duty to have regard to what is contained within it. It produces non-exhaustive explanatory notes on key definitions and considerations to be had when deciding best interests, supported decision-making, lasting powers of attorney, advance decisions and other issues covered by the MCA 2005.

The MCA 2005 further established the CoP and defined its powers as the superior court of record on all matters relating to the MCA 2005. The primary purpose of the CoP is to decide whether a person lacks the capacity to make decisions for themselves, and if they do to make decisions on their behalf which are determined to be in their best interests. Section 6.18 of The Code states that some treatment decisions are so serious that the CoP “must” be asked to make the decision; one of the four treatment areas specified in this section as being so serious is “the proposed withholding or withdrawal of artificial nutrition from a patient in a permanent

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137 Mental Capacity Act 2005, s 42.
139 Mental Capacity Act 2005, s 45 – 46.
vegetative state".\textsuperscript{140} It should be noted that MCS was not included in this section, despite having been a recognised medical diagnosis for five years before the publication of The Code.

In the case of \textit{Aintree University Hospitals NHS Foundation Trust v James (Aintree)}\textsuperscript{141} (which is examined in greater depth in 2.4.3), it was held by the Supreme Court that doctors were under no obligation to provide patients with any treatment which they do not consider to be in their best interests. However, Raanan Gillon notes that there is a contradiction between this ruling and s 6.18 of The Code, and it may result in clinicians being uncertain about what takes precedence.\textsuperscript{142}

The \textit{Aintree} and \textit{Re M}\textsuperscript{143} decisions offer contradicting views on the duties of a doctor. In \textit{Re M}, Baker J held \textit{obiter} that all cases concerning withdrawal of CANH should be brought before the CoP; this decision was made despite evidence given by the patient’s family that she would not have wished to remain alive in her current state.\textsuperscript{144} Gillon argues that medical professionals may not differentiate between legal obligation and medical “best practice”; doctors may be left confused by the contradictory state of the law and fear punitive action, should they not be following the correct course.\textsuperscript{145} However, barrister Alexander Ruck-Keene has stated that doctors need not fear any punishment, as The Code is merely guidance and not mandatory under these circumstances.\textsuperscript{146}

There appears to be a stark disconnect between what the legal theory said, and the practical reality experienced by doctors in the years following \textit{Bland}. While the exact legal obligation, or perceived legal obligation, has been debated by academics from both the medical and legal spheres for more than two decades, it should not detract from the fundamental question of whether the court \textit{should} have an overview. There is a considerable lack of analysis of the law. The majority of the available literature comes from medical and sociological academics; few

\begin{footnotes}
\item[140] ibid [6.18].
\item[141] \textit{Aintree University Hospitals NHS Foundation Trust v James} [2013] UKSC 67.
\item[143] \textit{W v M} [2011] EWHC 2443 (Fam).
\item[144] ibid 82.
\item[145] ibid.
\end{footnotes}
legal academics have written about this disconnect in any depth, and there are fundamental disagreements amongst them.\textsuperscript{147}

\textbf{2.4.3 Beyond Bland}

In the years following the decision in \textit{Bland}, the courts were split and indecisive on the requirement for declaratory relief proceedings; this is indicated in the case of \textit{Re S},\textsuperscript{148} where Thorpe LJ noted that extreme caution should be observed when parties decide not to make an application to the court. In addition to this, he indicated his belief that the declaratory relief process is the continuation of the history of the \textit{parens patriae} doctrine:

\begin{quote}
[W]hilst the decision in \textit{In Re F} signposted the inadvertent loss of the \textit{parens patriae} jurisdiction in relation to incompetent adults, the alternative jurisdiction which it established, the declaratory decree, was to be exercised upon the same basis.\textsuperscript{149}
\end{quote}

Thorpe LJ indicated that the historic \textit{parens patriae} jurisdiction is today being carried out by the office of the Official Solicitor (OS).\textsuperscript{150} The OS's role is to act on behalf of people who lack the capacity to make decisions; she is empowered to act as a decision-maker and to send lawyers to court to represent the person. Further to Thorpe LJ’s ruling, the court in \textit{Re S} believed that, even if two doctors agreed that withdrawal should occur, an application should be made to the court to ensure the patient's best interests are followed. The court further stressed:

\begin{quote}
The courts are not overburdened with applications in this field. Indeed, they are rare. In view of the importance of the subject, if a particular case lies anywhere near the boundary line it should be referred to the court by way of application for a declaration of lawfulness.\textsuperscript{151}
\end{quote}

\begin{footnotes}
\textsuperscript{147} Ruck-Keene (n 146) and Halliday \textit{et al} (n 66).
\textsuperscript{148} \textit{In Re S} (Adult patient: Sterilisation) [2001] Fam 15 (CA) (Civ).
\textsuperscript{149} \textit{ibid} [30].
\textsuperscript{150} Custer (n 114).
\textsuperscript{151} \textit{Re S} (n 148) [32].
\end{footnotes}
Although this case was concerning the forced sterilisation of a woman who lacked capacity, the courts have historically used such cases to justify their decisions in withdrawal cases through the use of analogy. Although it must be used with some caution, *Re S* relates to serious medical treatment and has previously been cited by the court in end-of-life cases as it pertains to autonomy and the protection of a patient’s best interests.

The point of over-burdening the CoP may well have been accurate at the time, and will likely hold true again soon; however, as a result of the COVID-19 pandemic, the courts have understandably been overwhelmed with a backlog of cases. This is a point covered in greater depth in Chapters Four and Five.

These rulings are not, however, illustrative of all court rulings since *Bland*, for example, an application was made in the case of *R (Burke) v GMC* by a man who wished to ensure that, should he be rendered incapacitated, he would continue to be given nutrition and hydration. Mr Burke was concerned about the lack of a statutory legal obligation on doctors to seek court approval. However, the Court of Appeal was steadfast in its decision that the court of first instance was wrong to decide “that there is a legal duty to obtain court approval to the withdrawal of ANH in the circumstances that he identifies”. The CA instead emphasised Lord Goff’s wording of best practice, and stated that at no time had the court moved from best practice to legal obligation; moreover, the CA strengthened their argument by saying that should there be such an obligation, the court system would be inundated with cases concerning withdrawal of treatment, predicting 10 new applications every day.

Adding to the uncertainty, in 2011, Mr Justice Baker stated that the legal position following *Bland* is a mandatory requirement for CoP applications:

> So far as ANH is concerned, the legal position has been clear since the decision in *Bland* and is as set out in the Practice Direction: all decisions

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152 For example, it was quoted in *Airedale NHS Trust v Bland* *(n 25)* and *W v M* *(n 143)*.
153 *R (Burke) v General Medical Council* [2005] EWCA Civ 1003.
154 *ibid* [5].
155 *ibid* [70].
156 *ibid*. 

about the proposed withholding or withdrawal of ANH from a person in a PVS or MCS should always be brought to the court.  

However, Ruck-Keene has noted that Baker J was answering a question which the CoP had not been asked to consider; therefore, he says this should be taken as little more than *obiter dicta* and should not be seen to carry any significant legal weight.  

Mr Justice Baker voiced his views in a 2016 lecture at Oxford University, where he again criticised any suggestion that the declaratory relief process should no longer be required. He was unswerving in his view that judicial oversight was needed, saying that the position envisioned by Lord Goff in *Bland* had not yet been met; in his view, a significant body of legal and medical knowledge is yet to be acquired, which would make the role of the courts unnecessary. Baker J did, however, echo Lord Goff in saying that a time will come when applications *should* be rare. Further to this, he reiterated that in his opinion, “applications to the court should continue to be obligatory in all cases where the withdrawal of ANH is proposed, at least for the time being”.  

A significant trend emerged in 2017 of cases coming before the CoP asking what the role of the court should be in cases where medical professionals and families agree on the withdrawal of treatment. This trend began with the case of *Briggs*, in which Lady Justice King stated that there is nothing contained within any legal document that imposes any obligation on doctors to apply to the CoP when all parties are in agreement. However, this was not the question before King LJ in this case. Her statement was *obiter dicta*; the OS therefore contended in *Briggs* that this should carry very little weight in the eyes of the law.  

Following *Briggs* was the case of *Re M* in which Mr Justice Jackson was directly answering a question concerning CoP involvement in withdrawal proceedings. In his ruling, Jackson J agreed with the earlier *Briggs* judgment that doctors are under no legal obligation to go to...  

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157 W v M (n 143) [82].  
158 Ruck-Keene (n 146) 435.  
160 Director of Legal Aid Casework v Briggs [2017] EWCA Civ 1169.  
161 *ibid* [26].  
The OS argued that, as she had not been party to *Re M* and therefore had no right of appeal, the judgment could produce nothing more than *obiter dicta* on the issue. The OS further argued that it is not for lower courts to make this decision; she contended that it was a decision to be made by either Parliament or the Supreme Court.  

### 2.4.4 The current law: *Re Y*

Less than two months after the decision in *Re M*, the argument put forward by the OS was again rejected by the CoP in another new case, *Re Y*. However, unlike the judges in the previous cases, Mrs Justice O’Farrell stated clearly that her decision was binding only on the facts of the case in front of her, and not of general application. What did, however, result from this decision was the live case which would enable a direct ruling on declaratory relief.

Mr Y, a banker in his fifties, suffered a cardiac arrest in June 2017, leading to severe cerebral hypoxia and severe brain damage, and he fell unconscious. Mr Y never awoke from this state of unconsciousness and relied on CANH, via a PEG tube, to obtain the nutrition necessary to sustain his life. Three months later, by the end of September 2017, his doctors had concluded that Mr Y was in a PDOC and the chances of him regaining any meaningful consciousness without severe cognitive issues were slim. In October, a second consultant agreed with the initial diagnosis and stated that he believed Mr Y to be in a VS, with no prospect of improvement. Mr Y’s wife and children all believed that he would not wish to be kept alive under these circumstances, that he would find it dehumanising; his family and clinical team were in agreement that CANH should be withdrawn, as it would no longer be in his best interests to receive what they perceived as futile treatment.

Unlike the previous cases concerning the declaratory relief process, this application was not seeking a declaration that withdrawal would be lawful; instead, the NHS Trust treating Mr Y sought a much broader declaration from the CoP. They asked for a declaration that:

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163 *Ibid* [37].
164 *Ibid* [34].
165 *Re M* (*n* 162).
1) It was not mandatory to seek the court’s approval to withdraw/withhold CANH from a patient with PDOC when the family and clinical teams are in agreement; and

2) That no civil or criminal liability would result if CANH were to be withdrawn.\textsuperscript{167}

The case was first heard in the Court of Protection on November 10, 2017, which concluded that there was no common law duty to refer withdrawal cases to the CoP. O’Farrell J’s judgment is best summed up in paragraph 52:

[W]here the clinicians have followed the Mental Capacity Act and good medical practice, there is no dispute with the family of the person who lacks capacity or others interested in his welfare, and no other doubts or concerns have been identified, there is no requirement to bring the matter before the court.\textsuperscript{168}

The OS immediately requested permission to appeal the decision and was given leave to “leapfrog” the Court of Appeal and head directly for a permissions hearing before the Supreme Court (UKSC). Sadly, Mr Y died on December 22, 2017, prior to the UKSC hearing the case; nonetheless, the UKSC decided that there were issues of general public importance within Mr Y’s case and allowed a full hearing to occur in February 2018.

Within the judgment, written by Lady Black, the Supreme Court was critical of the non-uniformity of the current law; the Supreme Court acknowledged that guiding medical and legal documents state the importance of declaratory relief proceedings in different ways. They further stated that The Code was not “entirely consistent in its approach”, as the terms “must” and “should” are used interchangeably; therefore, the Supreme Court believed that doctors were left not knowing whether they should approach the CoP, or whether they must approach the CoP as part of a legal requirement. Lady Black asserted that this lack of clarity makes it difficult to know what the will of Parliament was when it passed The Code through both Houses.

\textsuperscript{167} ibid.
\textsuperscript{168} Re Y (n 166) [52].
It may not be accurate to say that the will of Parliament when passing the MCA 2005 is unknown, as the Act’s foundations may potentially be found elsewhere. The explanatory notes to the MCA 2005 state that the Act is based on the recommendations of both the Law Commission and the Joint Committee on the Draft Mental Incapacity Bill. Firstly, the Joint Committee report recommended that certain decisions should always be taken to the CoP and that the withdrawal of ANH is one of those decisions which always required recourse to the court. Furthermore, the Law Commission report states:

We recommend that the discontinuance of artificial sustenance to an unconscious patient with no activity in the cerebral cortex and no prospect of recovery should require either (1) the approval of the court, (2) the consent of an attorney or manager or (3) if an order of the Secretary of State so provides, a certificate by an independent medical practitioner.

During the two-day Supreme Court hearing, Lady Hale asked Richard Gordon QC, representing the OS, to make investigations as to why Parliament did not include these recommendations in the MCA 2005. Having made inquiries, Mr Gordon found that the Joint Committee had decided to recommend that the requirement for court applications be included within The Code, not the Act itself. He explained that the reason for this was to enable a more fluid transition when the time came that court applications were no longer necessary, as The Code can be amended with greater ease than an Act of Parliament.

Nonetheless, the Supreme Court was not persuaded by this argument, despite the MCA 2005 stating in its explanatory notes that these two documents form the Act’s foundations. Instead, the Supreme Court placed its emphasis on the use of a second opinion from an independent clinician. Lady Black stated:

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The second opinion, as contemplated in the guidance... is, in my view, a crucial part of the scrutiny that is essential for decisions of this sort... Thus the interests of patients and their families are safeguarded, as far as possible, against errors in diagnosis and evaluation, premature decisions, and local variations in practice.173

The Supreme Court believed that the issues of misdiagnosis and overall safeguarding of vulnerable patients can be solved by obtaining a second opinion from an independent clinician. Despite this decision, the OS continues to contend that cases of this type should have an independent — and non-medical — third party who serves the patient's best interests. Without the mandatory application process or a non-medical overseer, ultimate decision-making power is potentially being given solely to medical professionals, many of whom are not trained adequately in the nuances of the best interests test, as will be further discussed later in this chapter.

Charles Foster has criticised the ruling for taking a “dangerous step backwards”174 and reviving medical paternalism. He argues that Re Y has shifted decision-making away from the patient and back to clinicians, and in doing so has frustrated the fundamental aims of the MCA 2005. In Foster’s view, the judgment of Lady Black usurped the function of the law and placed utmost importance upon the medical guidance documents. He argues that the holistic best interests assessment is not one to be conducted by doctors at the bedside; Foster states that the assessment “is essentially a value judgement” and that “[c]linicians have nothing to contribute to the identification or assessment of the relevant values. To say that they have is wrong in law.”175 He emphasises that giving a louder voice to medical professionals risks drowning out the views of the non-professionals, particularly the patient; he believes that this shift in emphasis is changing the value judgment into a “professional declaration”.176

Wade has said that Foster is entirely incorrect in his assertion that Re Y has seen a return of medical paternalism; Wade believes that Re Y has returned power to families and the patient. He asserts that there is no risk of non-professional voices being drowned out, as decision-

173 Re Y (n 166) [45].
175 ibid.
176 ibid.
making requires a “multidisciplinary discussion” with all interested parties. Wade argues that not only is Foster incorrect in his assessment of Re Y but that the judgment is a welcome, and factually correct, assertion of what the law already was.

These two conflicting views illustrate that this debate is far from over and that Re Y may raise more questions than it answers. Notwithstanding this ruling, the question remains as to whether the declaratory relief process should be mandatory, and who best serves the patient's interests.

In the three years since the decision in Re Y, little appears to have changed regarding applications being made to the CoP. Celia Kitzinger has stated that she has observed that clinicians remain in somewhat of a holding pattern with PDOC patients. She contends that in most cases, unless a family member raises a concern about continued treatment, clinicians continue to give treatment. Since Re Y, the number of applications being received by the CoP regarding LST withdrawal from PDOC patients remains at similar levels to pre-Re Y. In 2017 the CoP published five judgments relating to the withdrawal of LST, and in 2020, there were six published judgments. Whether Re Y has affected legal and medical practice is, therefore, in doubt.

**The law since Re Y**

In the years since Re Y, the CoP has not seen any decrease in cases concerning withdrawal and how the CoP have decided the majority of cases has not dramatically changed, except for two notable exceptions.

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179 Abertawe Bro Morgannwg University Local Health Board v RY & Anor (Rev 1) [2017] EWCOP 2

180 A Clinical Commissioning Group v AF & Ors [2020] EWCOP 16

181 Barnsley Hospital NHS Foundation Trust v MSP [2020] EWCOP 26

182 Avon and Wiltshire Mental Health Partnership v WA & Anor (Rev 1) [2020] EWCOP 37

183 Northamptonshire Healthcare NHS Foundation Trust v AB [2020] EWCOP 40

184 An NHS Trust v AF & Anor [2020] EWCOP 55

185 University Hospitals Plymouth NHS Trust v RS & Anor [2020] EWCOP 70.
In 2018, when *Re Y* was being decided, Windsor NHS Trust applied to the CoP for an order that CANH was no longer in the patient’s best interests. In this case, *NHS Windsor CCG v SP*, the CoP was invited to rule on the application without a formal hearing; they instead decided, solely on the application papers, that withdrawal was not in the patient’s best interests. This was a noticeable shift from previous cases, where full evidential hearings were common practice even where parties were in agreement. However, this case does provide an example of how independent oversight of a decision can be achieved without the often-laborious task of full in-person hearings, where parties are in agreement. The current issue of backlogging cases and the need for quicker decisions to be made, means that the ability to decide cases on paper is a potentially dramatic step forward. It maintains an independent overview of these serious cases while allowing for decisions to be reached without the need for drawn-out CoP hearings.

Another notable case, which was heard in 2019, is *Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust v TG*. This case is notable because the CoP made the decision that it was in the TG’s best interests to have CANH continue. Mr Justice Cohen emphasised how TG must be central to the decision; TG was a devout Catholic whose daughter said that her mother would not accept anyone other than God facilitating her death. Furthermore, it should be noted that this application was made just two months after TG had suffered her initial cardiac arrest, despite RCP guidance stating that six months is required before a vegetative state can be considered permanent.

Following *Re Y*, the CoP has had to introduce new rules and guidelines for how and when to make applications concerning withdrawal or withholding of CANH. Accordingly, in January 2020, Hayden J issued guidance on when decision-makers should consider making an application to the CoP (quoted verbatim):

Situations where consideration should be given to bringing an application to Court

8. If, at the conclusion of the medical decision-making process, there remain concerns that the way forward in any case is:

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181 *NHS Windsor And Maidenhead Clinical Commissioning Group v SP (Withdrawal of CANH) [2018] EWCOP 11.*

(a) finely balanced, or
(b) there is a difference of medical opinion, or
(c) a lack of agreement as to a proposed course of action from those with an interest in the person’s welfare, or
(d) there is a potential conflict of interest on the part of those involved in the decision-making process
(Not an exhaustive list)

Then it is highly probable that an application to the Court of Protection is appropriate. In such an event consideration must always be given as to whether an application to the Court of Protection is required.

9. Where any of the matters at paragraph 8 above arise and the decision relates to the provision of life-sustaining treatment an application to the Court of Protection must be made. This is to be regarded as an inalienable facet of the individual’s rights, guaranteed by the European Convention on Human Rights (‘ECHR’). For the avoidance of any doubt, this specifically includes the withdrawal or withholding of clinically assisted nutrition and hydration.183

This guidance makes it clear that the current position of the CoP is that there must be an application where there is any disagreement. Hayden J, however, fails to define what is meant by the term ‘finely balanced’, which causes even more confusion. A potentially finely balanced decision for one clinical team may not seem so finely balanced for another.

2.4.5 Academic commentary

The debate on whether there should be mandatory CoP applications remains substantively unaffected by the decision in Re Y. To answer whether an obligation should exist, it is necessary to examine what the reasons both for and against such a mandate may be. An appropriate

starting point for such an examination is the four justificatory headings that Lord Goff gave in his judgment in *Bland*, where the debate began:

1) for the protection of the patient,
2) for the protection of the doctor,
3) for the relief and reassurance of the family, and
4) for the reassurance of the public as a whole.\textsuperscript{184}

*Protection of the patient*

It is a generally accepted notion in medical law that the patient’s autonomy and right to self-determination is a founding principle of medical treatment; the common law has long held that a patient with capacity should be free to make their own medical choices, unhindered by interference from outside influence.\textsuperscript{185} The criminal law says that the touching of another person without their consent constitutes an assault, a rule that also applies to medical treatment. The case of *Re T*\textsuperscript{186} demonstrated that should a doctor act against a patient's express wishes, they could be liable for criminal prosecution. The Code reiterates that the underlying philosophy of the MCA 2005 is to ensure the patient’s best interests, autonomy and broader welfare concerns are respected. The declaratory relief process is intended to act as a mechanism to ensure the safeguarding of these principles.

Turner-Stokes of the RCP has argued that mandatory court applications are unnecessary for the protection of the patient. She says that there is no requirement to apply to the Court for any other serious medical treatments that doctors routinely perform; on an almost daily basis, doctors will perform cardiopulmonary resuscitation (CPR), provide life-saving antibiotics, and undertake other life-or-death decisions without having recourse to the Court.\textsuperscript{187} These decisions require the doctor to undertake the same best interests assessment required for withdrawing CANH, yet there is trust that doctors can undertake such an assessment (which occur much more frequently) without the need for judicial oversight.\textsuperscript{188} The question to be asked is why the

\textsuperscript{184} [1993] AC 789 [873].
\textsuperscript{186} Re T (Adult: Refusal of Treatment) (1993) Fam 95.
\textsuperscript{188} ibid 473.
law has sought to carve out an exception to clinical decision-making when it concerns the withdrawal of CANH.

Protection of the doctor

The case of Bland was initiated by Bland’s treating physician, who was concerned about potential criminal liability if he were to withdraw care from Bland. In the case, the coroner advised that should doctors proceed with withdrawing LST they would likely face criminal prosecution.\(^{189}\) The physician later recalled:

I was visited at the hospital by a detective from Keighley Criminal Investigation Department (CID). He informed me that if I withdrew treatment and Tony died, I would be charged with murder.\(^{190}\)

Although Bland confirmed that doctors would be unlikely to face criminal prosecution if they were acting in a patient’s best interests, it was not until the Supreme Court ruling in Aintree\(^{191}\) that it was confirmed that doctors are protected by the MCA 2005. As long as doctors are acting reasonably, and following what they believe to be in the best interests of their patient, they will be protected by the MCA 2005; section 5 of the Act states that if a patient lacks capacity, and a doctor has sought to follow their best interests when making their decision, the doctor would not incur any criminal liability.\(^{192}\) Similarly, at sections 6.26 – 6.34, The Code reiterates what medical professionals need to do to ensure they are not liable for prosecution.\(^{193}\) Therefore, this would appear to be an area that has long since been resolved; the declaratory relief process would not seem to offer any further protection for doctors.

\(^{189}\) [1993] AC 789, 796.


\(^{191}\) James (n 141).


\(^{193}\) The Code (n 138) [100] – [103].
Relief and reassurance of the family

One area in which there has been a considerable increase in academic analysis in recent years has been how the court process affects the patients’ families, rather than the patients themselves. Although some authors, such as Jenny and Celia Kitzinger and Halliday, have publicised the negative features of the process on the families, their studies have also identified several positive features the process has had for them.

Jenny and Celia Kitzinger have co-authored an extensive piece of research into the views of 51 families who have gone through the court application process. They found that the majority of families do not wish to consider CANH withdrawal, even once they have accepted the futility of treatment; the most commonly cited reason for this was that the thought of starving their loved one to death horrified them and that they would not wish for that to be on their conscience. Although family members may reach the point of wishing to withdraw care, they do not want to be the one to have — in their mind — killed their loved one by agreeing to it. Although it has been argued that the evidence for the process offering reassurance to the families is “at best mixed”, the Kitzingers research showed several family members interviewed felt relieved that the burden was passed on to the CoP rather than the family.

In addition to this, the role of the CoP as offering “therapeutic jurisprudence” cannot be understated; it is in this role that the court arguably best serves the families of the patients on a personal level. The CoP has been said to act as a chief mourner, to formally commemorate the patient and reassure the families that they have made the correct decision, and the burden does not fall on them. While it may seem insignificant and perhaps outside a court’s traditional purview, it has been shown to comfort the families through a difficult time. However, authors such as the Kitzingers have overlooked the crucial work that other academics have applauded the CoP for performing.

195 ibid.
An assessment of the current literature on the impact upon the families reveals a very confused body of work with no real answers. The research conducted by the Kitzingers shows that families continue to be split on their opinion of what role the CoP should play, and the authors contend that going to the CoP is often a negative experience for the families.199 This shows that questions remain about whether the law is indeed helpful in offering relief and reassurance to families.

Reassurance of the public

The final justification given by Lord Goff in Bland was that the courts should seek to maintain an overview so as to keep the general public reassured. In recent years right-wing and/or religious commentators in America have dominated the social media debate concerning end-of-life care in the UK; these voices have suggested that the NHS has established death panels to end the lives of the sick and elderly.200 It was precisely these views that Lord Goff had hoped to avoid as he wished to reassure the public that this is not the beginning of the so-called ‘slippery slope’ towards euthanasia.

Invariably, when the general public engages in a debate concerning end-of-life care for those unable to make decisions, the discussion is going to drift towards the assisted dying and euthanasia debates. These two topics dominate research, and public discourse, in the end-of-life discussion and the issues may well be conflated. It is also plausible that, without knowing the nuances of the medicine or the law, the public could view the withdrawal of CANH as murder. Halliday quotes a study from the USA which found that 29% of people believed that it was indeed murder;201 similarly, the Pew Research Centre found that there is a growing percentage of Americans, around 31-37%, who believe doctors should never allow a patient to die if they can do anything at all to prevent it.202 It should, however, be noted that these data from the USA may not represent public attitudes in the UK. Although there is some evidence

199 Celia Kitzinger et al. ‘Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: family experiences’ (2016) Journal of Medical Ethics 11-17.
to suggest similar public attitudes, the US judicial rulings have historically swayed towards providing life-sustaining treatment indefinitely, which is not the view taken by British courts.\textsuperscript{203}

With an increasing divide on end-of-life regulation and the common misconception that PDOC cases and assisted dying cases are the same, this aspect of Lord Goff’s judgment is perhaps more relevant than ever. The rise of social commentary being dominated by discussions on Twitter and other social media platforms leads to a vast amount of disinformation making its way into public discourse and can have serious adverse effects on how these cases are perceived. This is most clearly illustrated by how the American right portrayed the NHS as holding “death panels” during the cases of newborn babies Alfie Evans and Charlie Gard, which has subsequently become a commonly held view of the NHS among the American social conservatives.\textsuperscript{204}

2.5 Best interests

Vulnerable patients have an inalienable right under Article 2 of the European Convention of Human Rights (ECHR) to have their life respected. A patient who cannot communicate their wishes loses their ability to make it known which treatments they would like to have and whether they would or would not wish to continue living in a PDOC. The courts and common law have sought to find a balance where patient wishes can be heard in making life-and-death decisions. This section outlines the development of the current best interests assessment, considers whether it aligns with the UK’s obligations under international conventions, and reviews the tests followed in other jurisdictions.

\textsuperscript{203} For more information see the cases of Terri Schiavo and Nancy Cruzan. Bryan Jennett, ‘Persistent vegetative state and the right to die: Britain and the United States’ (1991) 301 BMJ 1256.

\textsuperscript{204} See the following links for further information:
2.5.1 The Mental Capacity Act 2005 and the Code of Practice

Prior to the passage of the MCA 2005, there was no clear understanding of the decision-making framework for patients who lacked capacity. Helen Taylor asserts that following the abolition of the historic *parens patriae* jurisdiction, doctors had a duty to treat their patients but were often fearful of assault charges. This was due to neither the court nor the patient’s family having the legal power to authorise treatment on an incompetent adult.\(^{205}\) There was a “gap in the welfare jurisdiction”,\(^{206}\) one which Taylor, Mary Donnelly, and Antal Szerletics say was initially filled in by the case of *Re F*.\(^{207}\)

In *Re F*, the High Court recognised that there was no statutory basis for judicial involvement in cases concerning medical treatment but that “it was open to the court under its inherent jurisdiction to make a declaration that a proposed operation was in a patient's best interests”.\(^{208}\) This inherent jurisdiction is the mechanism that enabled the House of Lords in *Bland* to further expand upon the new concept of ‘best interests’.\(^{209}\) Although Lady Butler-Sloss made it clear in *Bland* that the views and personality of the patient would be taken into consideration,\(^{210}\) John Coggan contends that the test which evolved out of *Bland* was “*Bolam*-esque”\(^{211}\) because it was essentially that of best medical interests.\(^{212}\) Over the next two decades, there was a gradual push away from this medicalised test towards a patient-centred standard based on both *Bolam* and non-medical factors.\(^{213}\)

Following this gradual shift in the decision-making process, the MCA 2005 finally placed the best interests standard on a legislative footing for the first time. Section 1(5) of the MCA 2005 requires that “an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests”.\(^{214}\) However, the Act itself does not

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\(^{206}\) Szerletics (n 119) 1,7.


\(^{208}\) *ibid*.

\(^{209}\) Szerletics (n 119).

\(^{210}\) *Bland* (n 25) (Butler-Sloss LJ).


\(^{212}\) The *Bolam* test derived from a 1957 tort law case regarding the standard of care expected of doctors. It was held in that case that a doctor would have acted reasonably had his actions been in line with a practice accepted by responsible body of medical opinion. Szerletics, (n 119) 9.

\(^{213}\) Donnelly (n 198) 318.

\(^{214}\) Mental Capacity Act 2005, s1(5).
define what is meant by the term “best interests”; section 4 of the Act simply lays out a checklist of factors to be taken into consideration; it does not explain when these are to be considered or the weighting of the factors.\footnote{Szerletics (n 119)} Section 4(2) of the Act states that the decision-maker must “consider all the relevant circumstances” when deciding what is in the patient’s best interests. What is meant by “relevant circumstances” is later ill-defined by subsection (11), which states:

\begin{quote}
(11) “Relevant circumstances” are those—
\begin{enumerate}
\item of which the person making the determination is aware, and
\item which it would be reasonable to regard as relevant.\footnote{Mental Capacity Act 2005, s 4(11)}
\end{enumerate}
\end{quote}

The ambiguity surrounding the precise nature of what constitutes best interests means that decision-makers, who are primarily doctors, are inevitably left to make subjective decisions about what is in a patient’s best interests; what one doctor may find a relevant circumstance, another may not.

In addition to the Act, The Code — while offering a discussion on best interests — offers no further help in defining the key terms. The Code lists examples of ways in which a decision-maker may be able to determine the views of the patient, including their:

\begin{itemize}
\item cultural background
\item religious beliefs
\item political convictions, or
\item past behaviour or habits.\footnote{The Code (n 138) Para 5.46.}
\end{itemize}

However, The Code fails to explain the significance of any factor in the decision-making process or the weight that a decision-maker should attribute to any of them. The MCA and The Code also outline people whom the decision-maker has a duty to consult when making a decision, including:

\begin{itemize}
\item anyone the person has previously named as someone they want to be consulted,
\end{itemize}
• anyone involved in the caring for the person,
• anyone interested in their welfare (for example, family carers, other close relatives),
• an attorney appointed by the person under a lasting power of attorney.218

The Code makes clear that all the people listed by the MCA are to be considered equally even when they do not agree with one another; there is no hierarchical list of people to be consulted. Despite the introduction of The Code, the statutory documents remain of very little help in understanding what the best interests test actually is. Szerletics stated that “[t]he introduction of the statutory checklist in the MCA did little to clarify how the different elements of best interests shall be balanced against each other”.219

In the years since the passage of the MCA 2005, the courts have taken a significant interest in defining what is meant by best interests, although often coming to very contradictory and opposing views. Helen Taylor says that the common law has given four very distinct interpretations of how best interests have been interpreted over the years by the court:

1) Best interests as determined by the patient’s clinical needs,
2) Best interests taking into account a subjective evaluation of the patient’s wider social and welfare preferences, separately and subsequent to the doctor's determination of clinical interests,
3) Best interests as an objective evaluation of what the ‘reasonable’ patient’s preferences would be, if the patient in question’s views are not known,
4) Best interests as a conflation of clinical and wider welfare issues.220

These four possible interpretations highlight the need to properly codify the best interests test in a much more substantive manner, as the courts have used all of these approaches in the past two decades. The flexibility of the MCA 2005 may well be said to be a positive characteristic, yet when it lacks certainty for the clinicians, families, and lawyers, it may arguably be said to do more harm than good.

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218 The Code (n 138) Para 5.49.
219 Szerletics (n 119) 17.
220 Taylor (n 205).
2.5.2 Established law: Aintree v James

Although the courts have applied all four interpretations listed by Taylor at different times, the second item on her list is the currently accepted legal definition of best interests. This understanding comes as a result of the first case brought under the MCA 2005 to reach the Supreme Court, Aintree v James (Aintree). This case was concerned with the best interests of David James, a 68-year-old man who had suffered a stroke, cardiac arrest and multiple organ failure, which led to severe neurological deterioration. In September 2012, the NHS Trust issued CoP proceedings, seeking a declaration that it would be in James’s best interests to withhold life-sustaining treatment. James’s family did not agree with the clinical team that such treatment should be withheld.

The CoP determined that although LST did not offer James a chance to be cured, it would allow him to return to a quality of life that he may regard as worthwhile. However, on appeal to the Court of Appeal, this view was rejected. Sir Alan Ward concluded that the proper test of futility was whether the treatment has “the real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering”. Ward LJ believed that although James’s interests must be taken into consideration, “they must give way to what is best in his medical interests.”

Arden LJ took a different approach from Ward LJ, arguing that when a patient’s wishes cannot be ascertained, the court should assume his wishes would be that of the reasonable person, who would reject futile or burdensome treatment. The Court of Appeal decided to uphold the Trust’s appeal; there were no prospects of recovery, and any further treatment options were futile by the standard given by Ward LJ. Although David James had unfortunately died by the time of the Court of Appeal judgment, the Supreme Court gave leave to appeal in July 2013.

Although the Supreme Court disagreed with the Court of Appeal’s approach, Lady Hale found that the CA was, in fact, correct to come to the conclusion it did because James had significantly deteriorated prior to the appeal hearing. The key outcome from the Supreme Court judgment

221 An NHS Trust v DJ & Ors [2012] EWCOP 3524 [84].
222 Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 [35].
223 Aintree University Hospitals NHS Foundation Trust v David James (by his litigation friend, the Official Solicitor) [2013] EWCA Civ 65 (CA).
was a set of authoritative statements on a variety of issues pertaining to the MCA 2005 and general decision-making for serious medical treatment, which can be summarised as follows:

1) Treatment is not ‘futile’ if it brings some benefit to the patient, even if it has no effect on the underlying disease or disability. Recovery does not mean a return to full health but returning to a quality of life that the patient would regard as worthwhile.224

2) Decision-makers must identify best interests by considering matters from the patient’s point of view, and not considering what a “reasonable patient” would want in that situation.225

The most important statement of the law found in the judgment defined what is meant by the best interests standard. Lady Hale stated that the correct question that decision-makers should be asking is whether continued treatment is in the patient’s best interests, not whether it is in his best interests to withhold or withdraw treatment:

"...the focus is on whether it is in the patient's best interests to give the treatment, rather than on whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it.226

Lady Hale made it clear that the best interests standard is not a medicalised assessment, as Sir Alan Ward had suggested. She stated that best interests must incorporate the patient’s welfare in the broadest possible sense:

[I]n considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success;

225 ibid [45].
226 ibid [22].
they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.\textsuperscript{227}

Lady Hale continued:

But insofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.\textsuperscript{228}

Therefore, following the \textit{Aintree} decision, the best interests test is best summarised as being a holistic assessment of the patient’s wishes and feelings, his medical status, the views of interested parties and any other relevant information to that individual patient.

\section*{2.5.3 After Aintree}

Following the Supreme Court decision in \textit{Aintree}, there seems to have been a shift — in the reported case law — towards an increased emphasis on the individual patient's wishes and feelings.

An example of how the CoP may have begun to give primacy to the wishes and feelings of the patient can be seen in the case of \textit{Wye Valley NHS Trust v B};\textsuperscript{229} although \textit{Wye Valley} is not a case concerning PDOC, it is an illustration of the broader application of the best interests standard following \textit{Aintree}. Mr B was a 73-year-old man who was admitted to hospital for a chronic foot ulcer. He had difficulty looking after himself and was described as “fiercely independent”.\textsuperscript{230} He was diagnosed with paranoid schizophrenia when he was younger and was

\begin{thebibliography}{99}
\bibitem{227} \textit{Ibid} [39].
\bibitem{228} \textit{Ibid} [45].
\bibitem{229} \textit{Wye Valley NHS Trust v B} [2015] EWCOP 60.
\bibitem{230} \textit{Ibid} [21].
\end{thebibliography}
taking antipsychotic medication. He had experienced hallucinations for several years and claimed to hear the voice of the Virgin Mary, who wanted him to be Catholic.231

Mr B was admitted to hospital in July 2014 and was detained under the Mental Health Act 1983. He refused treatment for his diabetes and infected foot, and his foot infection had caused a systemic infection. Wye Valley NHS Trust proposed amputation of the infected foot and applied to the CoP to determine Mr B’s capacity to refuse the surgery. Medical opinion was that an amputation above the knee was the only option and that Mr B would die from septicaemia without the surgery.232 Notwithstanding the medical opinion, Mr B opposed the surgical intervention and stated: “Even if I’m going to die, I don’t want the operation.”233 Jackson J decided that Mr B lacked the capacity to refuse consent to the amputation as he did not understand the reality of his situation. When applying the best interests standard, the NHS Trust argued that Mr B’s views were entitled to less weight than those of a person with capacity. However, Jackson J stated that a person’s incapacity is not an “off-switch” for their rights, and as such no less weight should be automatically attributed to it.234 The CoP, therefore, decided that Mr B’s wish not to have his leg amputated should be respected, as it would not be in his best interests to go against his expressed wishes, even if they were a result of his disability.

Lucy Series argues that Wye Valley demonstrates a “shift in court’s culture towards growing engagement with the person and their identity”;235 however, she states that it is premature to say that the MCA does not need amending to give legislative pre-eminence to wishes and feelings, as the decision-maker still holds considerable discretionary powers. More recently, in Briggs v Briggs,236 Mr Justice Charles was of the view that if P’s wishes and feelings could be ascertained with sufficient certainty, then “it should generally prevail over the very strong presumption in favour of preserving life”.237 The views of Mr Briggs’ family, that he would not have consented to continued CANH, were afforded considerable weight.

231 ibid.
232 ibid [28].
233 ibid [37].
234 ibid [11].
236 Briggs v Briggs (no 2) [2016] EWCOP 53.
237 ibid [62].
This thesis does not offer analysis of every case before the courts since Briggs as the majority of cases discuss the same core issues and ideas and as such would offer nothing new to this work; instead, I have included discussion on the most prominent cases that created new law, offered opposing views, or included an issue raised that was unexpected or uncommon.

The published case-law post-Aintree in relation to the withdrawal of CANH appears to have taken a much more patient-centred approach than the tests established in Bland and Re F. However, following the Aintree decision the Law Commission produced a report on “Mental Capacity and Deprivation of Liberty” which stresses the need for further reforms to be made.238

The Law Commission criticises the law for failing to give decision-makers sufficient certainty or clarity about the emphasis to be placed upon a patient’s wishes and feelings.239 They argue that without a legislative amendment to section 4 of the MCA 2005 the weight attached to any factor can vary on the facts of the case. Furthermore, the Commission states that circumstances have changed; the MCA 2005 is based upon reports from the 1990s, before the Human Rights Act 1998, and the ratification of the United Nations Convention on the Rights of Persons with Disabilities. Therefore, they say that the MCA 2005 is outdated and needs to be amended to reflect the primacy of patient’s wishes and feelings.240

**Checklists**

Checklists are used within the medical profession while making diagnostic and prognostic decisions, as they allow for some form of baseline understanding of the patient's current position. Over the past two decades, NHS Trusts and teaching hospitals have sought to ensure that their doctors follow the best interests assessment mandated by law. In attempting this, many Trusts have produced checklist documents for clinical staff to follow to ensure that the assessment is being carried out correctly. The BMA recommend that clinicians should follow a checklist within both their 2018 and 2020 guidance.241

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239 *ibid* para 11.18.
240 *ibid* paras 14.2 - 14.6.
Although this document was produced after extensive consultation with medical and legal experts, many hospitals within England and Wales have created their own checklists. Some, such as those used by the Royal United NHS Foundation Trust and Southern Health NHS Foundation Trust (Appendix F), are only five pages long. Its discussion on best interests begins with "A patient's best interests are not limited to their best medical interests. Other factors which form part of the best interests decision include…". No mention is made of the fact that patient beliefs and values are to be a guiding principle; in fact, the starting point of this checklist is medical best interests.

Other checklists, such as that used by the Black Country Partnership NHS Foundation Trust (Appendix G) and the Hertfordshire Partnership University NHS Foundation Trust (Appendix H), do not start by discussing medical best interests; instead, they focus on the patient’s wishes and feelings. The most detailed checklist currently in use is that of the Black Country Partnership NHS Foundation Trust, whose 18-page document includes in-depth instructions on ascertaining a patient’s past and present wishes, value system, and a non-exhaustive list of people who should be consulted. However, one issue that does arise is that on page 16, at the end of the best interests checklist, the document states (original emphasis): "If there are any conflicts in the above consultations, there needs to be an attempt to reach a consensus. However, the decision maker makes final decision."

Like the others, this document makes no reference to the fact that where a conflict arises concerning treatment decisions, the case must be referred to the Court of Protection. They appear to suggest that the decision-maker, who in this context will be the doctor, can override any objections made by the parties he must consult. This lack of clarity surrounding checklists for clinicians, even where they are appropriate and actively followed, remains an issue that needs to be addressed.

**Advance decisions to refuse treatment**

Following Aintree, the core of the best interests decision-making process is what the patient would have wanted to happen. A decision-maker must put themselves in the patient’s position and decide what wishes and feelings they would express if they had the capacity to communicate their current desires. One way a patient is able to have his voice heard by a future
decision-maker is through the use of an advance decision to refuse treatment (ADRT). An ADRT allows a person to set out their wish to refuse medical treatment in advance, and it can be used should they lose the capacity to make such decisions in the future. ADRT’s have statutory force, as established within section 25 of the MCA 2005. However, in order for an ADRT to refuse LST to be legally valid, it must follow specific rules, which are explicitly laid out within the Act:

5) An advance decision is not applicable to life-sustaining treatment unless
   (a) the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and
   (b) the decision and statement comply with subsection (6).

(6) A decision or statement complies with this subsection only if
   (a) it is in writing,
   (b) it is signed by P or by another person in P's presence and by P's direction,
   (c) the signature is made or acknowledged by P in the presence of a witness, and
   (d) the witness signs it, or acknowledges his signature, in P's presence.

Celia Kitzinger has noted that ADRTs were a controversial topic when they were included in the MCA 2005, particularly with religious advocacy groups, who believed it was allowing for a form of euthanasia. The use of ADRTs may be the most direct way a decision-maker can understand whether or not a patient would have wished to refuse LST. However, the uptake of ADRTs appears to be amongst the lowest in the western world. In 2014, a YouGov poll suggested that only 4% of people in England had made an ADRT, compared to 10-20% in other western European countries. The literature on the effectiveness of ADRTs in PDOC patients is sparse, likely due to this extremely low uptake.

2.5.4 The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was ratified by the United Kingdom in 2006, joining 177 other signatory countries. The CRPD is a human

rights instrument that the UN says aims to stop persons with disabilities from being viewed as “objects”.246 The Convention was devised to promote, protect and ensure that people with disabilities enjoy full equality under the law. Beverley Clough has asserted that the CRPD has the potential to create a paradigm shift within mental capacity law. She says that this is achieved through creating “ruptures in accepted knowledge“247 by questioning the fundamentals of disability law. She maintains that the CRPD has the potential to do this through its expansion of the rights afforded to people with disabilities, which state laws are not currently offering.

The majority of the literature in the legal field concerning the CRPD focuses on Article 12, the right to equal recognition before the law. More specifically, the focus has been placed upon two subsections of the article:

- Article 12 (2): “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”; 248
- Article 12 (4): “States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.”249

Peter Bartlett and Mary Donnelly have asserted that the MCA 2005 is incompatible with the CRPD and that the UK is failing to meet its obligations under the Convention. As Donnelly explains, the lack of compliance by the UK stems from the MCA 2005 failing to give preferential treatment to the will and preferences of the patient.250

The non-compliance of the UK is best seen in light of General Comment no. 1 of the UN Committee on the CRPD. Clough says the Committee took a “hard line”251 towards any policy

249 ibid Article 12 (4).
250 Donnelly (n 198) 319
251 Clough (n 247) 247.
that distinguishes between those with and those without disabilities. The Committee stated that any form of substitute decision-making — such as the best interests standard within the MCA 2005 — naturally differentiates people with disabilities from those without, which breaches the anti-discrimination provision in Article 12. Furthermore, the Committee asserted that there are no circumstances under which the patient’s will and preferences should not be followed. In April 2014, their position was unequivocal when they stated:

All forms of support in the exercise of legal capacity, including more intensive forms of support, must be based on the will and preferences of the person, not on what is perceived as being in his or her objective best interests.

Court of Protection Judge Denzil Lush has pointed out that the MCA 2005 covers a significant amount of what the Committee highlights. He says that the Committee envisages “something much more robust than the system we currently have in place”; they call for the abolition of all substituted decision-making and best interests frameworks, to shift to a test with a sole focus on the patient's wishes. Following the Committee’s comments, the Ministry of Justice launched the Essex Autonomy Project to prepare a report answering whether the UK was compliant with the Convention. In 2014, they published their final report, *Achieving CRPD Compliance*, which concluded that the MCA 2005 was not fully compliant with the Convention. The report found that the best interests framework fails to satisfy Article 12; the definition of mental capacity within the MCA 2005 violates the Convention’s anti-discrimination provision as it differentiates between those with and those without capacity.

However, the report ultimately concluded that the Committee was incorrect to require the abolition of all substitute decision-making frameworks. Donnelly has similarly concluded that the Committee is correct in its disdain towards the best interests standard and its championing of patients’ rights, but rejects the abolition of all substituted decision making.

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252 Committee on the Rights of Persons with Disabilities, ‘General comment No.1’ (2014) [29].
255 ibid [1].
256 Donnelly (n 198) 331–332.
Committee suggested that where a patient's will and preferences cannot be ascertained, the decision-maker should follow the “best interpretation” of their will and preferences.\(^{257}\) The best interpretations paradigm is not a reasonable alternative and would make way for “legal subterfuge”, allowing best interests decision-makers to have hidden and un-vetted powers.\(^{258}\) This model would arguably give decision-makers even more power than the system the Committee are critical of; a “best interpretation” framework would appear to be no different from any substituted-decision paradigm.

Since General Comment number 1, there has been a change in the approach taken by the CoP in these cases. Ruck-Keene has said that the CoP has “organically complied”,\(^ {259}\) to some degree, with the CRPD in recent years. The case law discussed above would appear to indicate a shift towards the CoP putting much greater emphasis on the patient's wishes and feelings.\(^ {260}\)

Despite this gradual change, Emily Jackson contends that the UK is still non-compliant with the CRPD\(^ {261}\) as sections 1 and 4 of the MCA 2005 remain unchanged; therefore, there is nothing, in theory, stopping subsequent High Court or Supreme Court decisions attributing less weight to the wishes and feelings of the patient. Jackson advocates for a more robust mental capacity statute, which gives primacy to patients' views on its face. She states that the MCA 2005 would need to create a rebuttable presumption in favour of always following the patient’s wishes and beliefs.\(^ {262}\) Under this regime, the starting point for the CoP would be for the judges to ask themselves, “what has mattered most over the course of his/her [the patient’s] life?”\(^ {263}\)

Although there has been a progression towards CRPD compliance, and patient-centred care, there are at least two issues that have been identified by the Essex report which need addressing:

1) Clinical confusion: Following Re Y, the decision-makers, now likely to be medical professionals, will have an increased role in conducting checks on


\(^{258}\) ibid.

\(^{259}\) Ruck-Keene (n 146).


\(^{261}\) Emily Jackson, ‘From doctor knows best to dignity: Placing adults who lack capacity at the centre of decisions about the medical treatment’ (2018) 81 MLR 247, 266.

\(^{262}\) ibid, 280.

\(^{263}\) ibid.
the patient’s wishes. However, many of the studies below indicate a severe lack of training and understanding amongst medical professionals as to what constitutes best interests; and

2) **Who should be consulted?** There is also an assumption that certain groups, such as close family and carers, have a greater understanding of a patient’s wishes and feelings. This assumption has not been met with any substantial academic challenge as to why these groups will automatically know the patient better than others who are close to the patient.

### 2.5.5 Academic commentary

#### Clinical confusion

Research conducted by Taylor and Donnelly has shown a critical level of misunderstanding of the best interests standard by medical practitioners, perhaps as a result of the mixed signals offered by the judiciary and governing medical bodies.\(^{264}\) Taylor contends that many doctors are still following the judgment from the Court of Appeal in *Aintree*, rather than the much broader definition offered by the Supreme Court. They are regularly making decisions based on best *medical* interests, rather than considering the broader welfare concerns of the patient.

Taylor and Donnelly’s research supports with the findings of the House of Lords Select Committee on the MCA 2005, which said that “the concept of best interests as defined by the Act [MCA 2005] was not well understood, in part because it was at odds with the concept of best interests as it is used in the medical or clinical sense”.\(^{265}\) The Committee further reported that medical practitioners defined best interests as “a clinical decision – and just saw it as a matter of clinical judgment”.\(^{266}\) These findings are not in keeping with the current law of best interests as laid out by Baroness Hale in *Aintree*. It would appear the medical profession is reverting to the outdated *Bolam*-inspired test from *Re F* and *Bland*.

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\(^{264}\) Taylor (*n* 205) 193.


\(^{266}\) Taylor (*n* 205) 188.
Taylor has also noted that a study conducted by Paul Willner shows that only 66% of medical practitioners surveyed were able to identify that they must conduct a best interests assessment once a capacity test has been performed. She also found that the majority of doctors, while having knowledge of the MCA 2005, could not explain how the test applied in the real world; for example, only half of the participants were able to correctly identify parties who should be consulted when undertaking a best interests assessment.267 There would, therefore, appear to be an inadequacy in the training of practitioners on the best interests assessment, which will undoubtedly have a negative effect on patients who are in the care of these clinicians. As Donnelly notes, it is for reasons such as this that the MCA 2005 needs to be more assertive on its face; the Act must actively call for the primary consideration of a patient’s wishes.268 In addition, she states that a stronger statute would ensure doctors understand that they are not merely conducting a best medical interests assessment. Because of such studies, any call for further decision-making at the bedside is somewhat problematic. If best interests investigations are left to medical professionals to carry out, then there is a risk that inadequately trained medical professionals may be putting the rights and freedoms of a patient at risk.

**Who should be consulted?**

The question of who should be consulted when deciding on a patient’s best interests has historically been controversial, with certain judgments placing little weight on the views of the family.269 However, as seen previously, the weight afforded to views of the family has risen dramatically since 2016.

Section 4(7) of the MCA 2005 and paragraphs 5.49 - 5.55 of The Code make provision for the consultation of members of the patient’s family, carers, friends and any other person who may be able to assist the decision-maker in ascertaining P’s wishes and feelings.270 Within The Code, it is said that the decision-maker has a duty to “take into account” the views of “anyone interested in their welfare”.271

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268 Donnelly (n 198).

269 See for example: In Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment) [2011] EWHC 2443 (Fam).

270 The Code (n 138) [5.49]-[5.55].

271 ibid.
It has been reported that the Kitzingers felt ignored when their sister was in a PDOC, despite contending that they knew she would have wanted.\textsuperscript{272} While this may be correct in many cases, it cannot merely be assumed that the patient’s family or friends have any more significant insight. As Donnelly noted, “the people consulted inevitably have different perspectives, conflicts may arise among them as to the wishes of the person lacking capacity”.\textsuperscript{273}

Donnelly recites at length a powerful example of a young boy with learning difficulties who pushed away a balloon and how the parents, teachers, and researchers interpreted this to have entirely different motivations. It was seen as fear of balloons, as him playing with the balloon and also difficulty controlling his body;\textsuperscript{274} these opinions are entirely opposed to each other. In the example given, the decision-maker would likely place much greater trust in the family’s views as they are his primary carers. However, two opposing — and arguably equally reliable — opinions exist from the teachers and researcher. There is always a risk that the decision-maker may be closing their mind to conflicting yet equally credible evidence based on perceived close ties with a particular individual.

Paula Case, in conducting empirical research into the CoP, has observed that there is a risk of medicalising the construction of P’s capacity and that the CoP has seemingly “endorsed mental capacity as largely the domain of medical expertise”. Case has argued that there has at times been a tendency for the CoP to defer to medical opinion, but that the family offers a “safeguard against excessive deference to medical opinion”.\textsuperscript{275} Helen Marshall has similarly critiqued the best interests test as relying too heavily on opinion, which is portrayed as fact, and that “the best interests process is subject to prejudice and bias, particularly as information-gathering from family can be time-consuming and unreliable”.\textsuperscript{276}

\textsuperscript{273} Donnelly (n 198) 18.
\textsuperscript{274} ibid.
The question which must be emphasised is how the decision-maker knows whom to turn to for this advice. For example, Catherine Donovan has investigated the lives of LGBT+ people in society and found that they had two kinds of ‘family’: a family of origin and a family of choice. Some LGBT+ people may be reluctant to express their sexual identity to their family, meaning that perhaps their closest relatives may have no real sense of the things the patient would likely take into consideration. The questions surrounding who should be consulted is a very live issue, one which should not be overlooked because of the understandably emotional pleas of a patient’s family members. It is impossible to know whether a patient’s mother or best friend would – or could – tell doctors what the patient would actually desire when they are incapacitated.

Taylor further notes that the current legal discourse does not seem to wish to acknowledge the unreliability of information received from a patient’s family. When the CoP says they are placing weight on the views of the patient, that is not what they are doing; in fact, they are really placing weight on what the patient’s family has said the patient would want, a distinction rarely addressed. The views of a patient’s family are inherently biased. They may believe they are doing what the patient wants but will likely project their views on the patient. When these opinions are being weighed up by the CoP as if they are fact, and given substantial weight, then it would appear to be a slow shift towards a fully substituted judgement system, which the CoP has firmly rejected.

Wayne Martin of the Essex Autonomy Project does not see this as negative; he argues that the patient’s views should not be the sole consideration, and that the law should move away from the hyper-individualistic nature of current patient-centred discourse. Martin says that any such decision intrinsically has other people’s interests wrapped up within it, “A patient has an interest in recovering from her illness, but so do her family, employer, care providers etc.” Therefore, the views of third parties may well be important to the overall best interests picture, despite the courts traditionally having refused to consider third party considerations.

278 Taylor (n 205).
280 ibid.
281 Szerletics (n 119) 23.
The fundamental reason any of these issues exist is that doctors are unable to speak directly with a patient in a PDOC and ascertain their wishes and feelings; if doctors were able to communicate with a patient, there would be no need to resort to any form of substituted decision-making or court approval. The use of fMRI technology may one day offer a way of ascertaining some PDOC patients’ wishes and feelings. As Monti asserted, it was only through neuroimaging techniques that one of the patients in his study — who had been diagnosed as being PVS — was able to communicate in any manner with his doctors.282 These studies give rise to a hope that, for up to 20% of PDOC patients,283 the answer to the question “who should be consulted?” may eventually be “the patient”.

2.6 Approaches in other jurisdictions

Understanding the decision-making process within the UK is the paramount consideration of this thesis. However, it is useful to consider briefly how other jurisdictions handle decision-making for people who lack capacity, and whether the UK’s best interests test could benefit from other jurisdictions’ experiences. In this section, three jurisdictions’ approaches will be discussed: the USA, the Netherlands and Japan. These were the three countries which the House of Lords Select Committee addressed when consulting about mental capacity prior to the MCA 2005 and have the most explicit alternatives to the current approach in England and Wales.

2.6.1 USA: The substituted judgment approach

Unlike the law in England, the United States has no federally mandated legal process for the withdrawal of treatment. Instead, the law is decided on a state level, meaning a multitude of decision-making processes exist simultaneously.

The most famous legal case in the United States is that of Terri Schiavo, who, at age 26, suffered a cardiac arrest and was eventually diagnosed as being a PVS. Schiavo’s parents wished for LST to be maintained, but her husband argued that this is not what she would want and she should be allowed to die peacefully. Schiavo’s case received considerable international press and political attention for over 15 years; during this time, Schiavo’s feeding tube was

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282 Monti et al. (n 88).
283 ibid.
removed and reinserted on multiple occasions. The case saw interventions at every level of the US government from the Governor of Florida, through to the then President of the United States George W. Bush, who attempted to enact new legislation blocking the withdrawal of treatment; in 2005, the US Supreme Court (SCOTUS) finally cleared the way for her LST to be withdrawn.

The reason the Schiavo case was so controversial at the time was that in 1990 SCOTUS had ruled that the parents of a patient in PDOC must present “clear and convincing” evidence as to what the patient herself would have wanted. SCOTUS allowed for states to require high levels of evidential certainty in ascertaining if a patient would have forgone LST in their situation. The USA places considerable weight upon the patient’s autonomy to make their own voluntary decisions. American lawyer Suzanne Rode has said that “the United States is quite alone” in its steadfast position that personal choice is the primary value to be considered. She points out that historically, courts in the USA will often ignore the families and loved ones of the patients and the views of medical professionals in favour of pursuing the goal of autonomy.

Rode further points out that the substituted judgement standard is the most commonly used decision-making apparatus in the USA and that several states have created a hierarchical list of surrogate decision-makers. However, some states have laws prohibiting surrogates from considering the use of the objective best interests standard. In some states, a surrogate decision-maker is only allowed to make decisions based on what the patient’s wishes would be.

In 1993 the National Conference of Commissioners on Uniform State Laws approved the Uniform Health-Care Decisions Act (UHCDA). Several states adopted the UHCDA either in whole or in part. The Act allowed for advance decisions, for patients to refuse medical treatment and ensured the substituted judgement standard; furthermore, the Act provided a list of surrogate decision-makers in order of priority:

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284 *Cruzan v Director, Missouri Department of Health* (1990) 497 U.S 261.


286 ibid [478].

287 ibid [485]

Also, see *In Re Guardianship of Browning* (1990).

288 California, Alaska, Delaware, Alabama, Mississippi, New Mexico, Maine and Hawaii
• spouse of the patient,
• adult child,
• parent,
• adult sibling,
• an adult who has exhibited special care and concern for the patient.

In the event of disagreement between family members of the same hierarchical rank, the medical professional is to follow the majority decision.

Following the Schiavo case, the debate in the United States concerning end-of-life proceedings re-emerged into the public consciousness and found its way back into the state legislatures. Rode indicates that Oklahoma, for example, introduced a Bill to prohibit the removal of hydration from a patient. New Jersey, South Carolina and Florida similarly proposed Bills that would make the removal of treatment an offence against disabled persons. The backlash against the withdrawal of treatment from some states is not at all reflective of the country as a whole. Assisted-dying, for example, is available in 10 jurisdictions within the USA (as of February 1, 2021) and has been available in Oregon since 1994.

In 2018 the American Academy of Neurology released updated recommendations which stated that clinicians should identify and treat all of a patient’s subsidiary issues and strive to obtain the highest level of consciousness from a patient before they seek to diagnose them. They further recommended that clinicians should inform families that patients in a MCS, and those who have suffered from a traumatic brain injury, are often associated with a more favourable outcome than PVS and non-traumatic patients. Similarly, the Academy further stated that when clinicians discuss prognosis with families, they should avoid making statements suggesting a “universally poor prognosis” for all PDOC patients. This approach would arguably seem to advance a position of continued care, attempting to downplay the significance of a PDOC diagnosis and persuade family members to maintain treatment.

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289 Rode (n 285).
Rode has said that the system followed in the United States, in which patients’ wishes are given paramount importance, has led to the US relying “on a fiction about what the patient would want”. Rode is saying that in relying on a substituted judgment of patients’ beliefs, they are simply handing over decisions to people who are taking nothing more than an educated guess. She advocates that the United States should adopt some of the factors considered in other jurisdictions:

[...]instead of steadfastly adhering to the myth that we can somehow know what the patient would have wanted in absence of a clear directive, we should incorporate some of the methods utilised in countries that value an objective perspective of the patient’s best interests and wishes of the patient’s family members.292

The lack of uniformity within the United States has led to a general lack of understanding of how end-of-life decisions will be made state-to-state. As Rode points out, in trying to ensure a patient’s voice is heard above all else, the patient’s views may actually end up being side-lined in favour of the beliefs of whoever makes the substituted judgement. There is a clear agenda in some states to allow treatment to continue as long as possible.

2.6.2 Japan: The family-oriented approach

Although patient-centred decision-making is on the rise in English courts, other jurisdictions take the views of a patient’s family as inseparable from those of the patient and place a considerable amount of weight upon them.293 In some east and south-eastern Asian countries, the voice of the family and loved ones of the patient is often considered to be the voice that matters most. Tomoaki Tsuchida has said that in Japanese culture, it is not socially acceptable to act only in one's own interests without consideration of the impact on the family and community.294

292 Rode (n 285) [503].
Kaoruko Aita, of the University of Tokyo, has indicated that in Japan, the withdrawal of LST — even with a patient’s advance directive — can constitute a criminal act, although this has not yet been tested in court. She further explains that physicians in Japan are largely free from interference from the law and that decisions are made in most part by doctors in conversation with family members.

In jurisdictions like Japan, it is not uncommon that treatment decisions for terminal patients, both fully conscious and those who are not conscious, are made without the patient ever knowing that they have a terminal illness. Instead, physicians will consult with the patient's family on what they would want for him. Rode contends that this has transferred into cases concerning withdrawal as there is no country-wide policy for end-of-life treatment in Japan; each individual case falls on the doctors and the family to decide.

A survey conducted in 2016 found that in these family-orientated cultures, such as Japan and Korea, around 70% of physicians believed it was for the family to make decisions concerning the withdrawal of treatment. Despite this, the physicians of all countries surveyed stated that they do not believe that family members can accurately reflect a patient’s wishes (63% in Japan, 77% in China and 53% in Korea); furthermore, more than 50% of physicians in all three countries had experienced conflict with a family member or guardian.

Although the process of relying on families is preferred in these countries due to the close nature of their relationship to the patient, it may not be the most reflective, reliable, or efficient means of decision-making. Furthermore, this strict family-oriented approach may ignore the patient’s wishes altogether and would not be in keeping with the general spirit of medical law in the UK. It is also likely that such an approach would fail to meet the standards expected under the ECHR and the right to life, as a patient would not be able to make their own informed decisions about their life-or-death medical options.

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296 Rode (n 285) [497].
298 ibid [633].
2.6.3 The Netherlands: The ‘doctor knows best’ approach

In 1989 the Arnhem Court of Appeal in The Netherlands heard the case of Ineke Stinissen. At the age of 31, she had given birth by Caesarean section in 1974 and been left in a PVS, following several mistakes during the procedure. Ms Stinissen remained in a VS for nearly 16 years, during which time her husband requested that the removal of her feeding tube, believing that is what she would have wanted; the nursing home and doctors refused to remove the feeding tube, and legal proceedings ensued. The Court of Appeal ruled that the artificial feeding of Ms Stinissen was a medical procedure, and as such, the opinions of the medical staff took precedence over that of the husband. However, they did say that the husband would be free to move Ms Stinissen to another facility that may be more amenable to his requests.

Sjef Gevers has said that the Netherlands uses a ‘doctor knows best’ approach that looks at the prevailing body of medical opinion.299 As a result, the Netherlands' courts have generally allowed doctors to override representations from third parties about what the patient would have wanted, as long as they can back up their assertions with a sufficient body of medical opinion. Although this is the state of the current law in The Netherlands, Gevers has pointed out that it is unlikely that doctors will completely ignore families who are adamant about what the patient would have wanted.300

The court's position on the withdrawal of treatment in the Netherlands may seem contradictory to the very liberal stance the country has taken towards other end-of-life laws. In 2002, the state passed a law allowing for not only assisted dying but also euthanasia. The reason for this is most likely due to this law being rooted in the ability of people with the capacity to make their own free choices. With cases concerning the withdrawal of treatment the individual lacks capacity, and therefore their wishes or desires are not being expressly heard.301

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300 ibid.
301 ibid

See also, Inez de Beaufort, Patients in a Persistent Vegetative State — A Dutch Perspective (2005) 9 N Engl J Med 2373.
2.7 Commentary

The literature and case law from the past three decades have highlighted a considerable number of existing issues in how England and Wales make decisions for PDOC patients concerning CANH withdrawal. These can be placed into three categories: diagnostic issues, declaratory relief issues, and best interests issues.

The first section of this chapter addressed the concerns surrounding the significant number of misdiagnoses of PDOC patients. Although some authors have disregarded the misdiagnosis figures as being out of date, the replicability of the studies is a definite cause for concern. When a patient is diagnosed by the traditional techniques as being in a PVS, they run the risk of having their treatment being withdrawn without a full balancing exercise being undertaken. The court has ruled that there is a presumption that treatment for PVS patients is futile. Therefore, if a patient has a higher level of consciousness and is actually in an MCS, they may have their treatment prematurely withdrawn from them. Because of this, the research conducted into emerging technologies, such as fMRI, is increasingly important. FMRI has the potential to unlock hidden levels of consciousness and allow doctors to communicate with PDOC patients in a manner that the traditional bedside tests do not allow. However, at present, fMRIs are not a part of the diagnostic framework recommended by the leading medical bodies. There is, therefore, a question to be asked as to why they have not been included and whether there is a place for them in the future of PDOC diagnosis.

Re Y has, in theory, fundamentally changed the landscape of how decisions are made concerning the withdrawal of CANH from PDOC patients. Many doctors, lawyers, and judges had long believed that cases of this kind had to go before the court for a determination; this is no longer the case. However, this relatively new judgment leaves several questions to be answered, including whether it was the correct decision, and whether it has changed the decision-making process in the years since.

This chapter has identified that the UK's best interests decision-making framework is fraught with complications and confusion. The current standard to be applied is that which is found within the case of Aintree; decision-makers should be making best interests decision of a holistic nature, encompassing a wide range of welfare issues that apply to the individual patient. The test is not one of the best medical interests. There appears to be considerable confusion
within the medical profession; evidence suggests a considerable lack of understanding of the current standard. The reasons for this lack of understanding have yet to be explored and need further investigation. Similarly, there is still considerable debate about whether the best interests standard is even the most appropriate means of ensuring the patient’s views are heard and followed.

Finally, in 2020, the entire world was impacted by the COVID-19 pandemic, and this extended to the operation of the Court of Protection. One of the most significant criticisms of the CoP has been the delay between application and final hearing. The CoP began virtual hearings throughout the pandemic, which allowed for a much greater number of hearings to reach the CoP. The effectiveness of these hearings will be evaluated in greater detail in Chapter Four. However, throughout the pandemic, the CoP has had to take on a type of case that it had not foreseen – vaccination cases. A significant amount of CoP time in late 2020 and early 2021 has been spent dealing with questions around COVID-19 vaccinations for those who are unable to consent. Although outside of the scope of this thesis, it is an issue still affecting the CoP at present.
Chapter Three:
Interviews

3.1 Introduction

The literature review revealed that there are several areas of this topic that are still regularly debated. The literature indicated that doctors and lawyers are interpreting the law, procedures and guidance in multiple different ways and that doctors themselves cannot seem to agree on the procedures. It was because there was a distinct difference in views of what fundamental principles meant that I decided to conduct a series of interviews with lawyers, doctors, and academics who have first-hand experience in dealing with PDOC cases. It is the differences or similarity in viewpoints withing and between the different professions that is of paramount importance to this research. Clinical staff and lawyers are the two groups of professionals most involved in decision-making for PDOC patients, and as such they have the most first-hand experience to be able to share. Prior to conducting the interviews it was anticipated that lawyers would be able to recite what the current law entails and that the medical professionals would be able to say how they interpret, understand and put the law into practice.

These interviews aimed to identify where differences of opinion exist on the most prominent issues, such as what is meant by best interests, the role of the court and the future of diagnostic medicine. In the literature review, lawyers, doctors, and other academics often state their opinion without explaining why they hold that belief. These interviews allowed me the opportunity to explore in greater detail why they believe their interpretation of these issues is the correct one.

[One]… may, however, expect to find the magical tool for finally uncovering the treasures of meaning hidden in the many pages of opaque interview transcripts… [one] will be disappointed…The central task of interview analysis rests with the researcher, with the thematic questions he or she has asked from the start of the investigation and followed up through designing, interviewing and transcribing.\textsuperscript{302}

In total, 20 interviews took place, of which 10 involved practising lawyers or academic lawyers, eight medical doctors or academics, and two other academics with expert knowledge in the area. One legal academic asked for their work to be removed due to an ongoing clash of interests that had arisen. One medical professional similarly asked for any direct quotation to be avoided as many of their answers may lead to their identification, that person’s responses will still be included in the statistical overview. There are, therefore, 19 participants.

3.1.1 Interviews

The research method and methodology used in this thesis are discussed in greater detail in Chapter 1; however, the sections below provide a brief overview of the method used to conduct these interviews.

All interviewees were chosen because they were long-time professionals and experts in their respective fields. They came predominantly from the legal and medical fields; however, two participants were professors in other fields, with knowledge and experience of PDOC cases. Each interview was semi-structured. A list of 10 structured questions (Appendix C) acted as the guide to each interview but allowed the interviewee to contribute as much as they liked, to get the most information from the interviewee. I also asked supplemental questions that arose out of interviewees’ responses.

In Chapter Two, I outlined my use of thematic analysis as the methodology for analysing more than 100,000 words of interview transcripts, all of which were transcribed by me. Thematic analysis adopts themes that frequently appear throughout a body of text. In this chapter, the themes and sub-themes are demonstrated by the headings and sub-headings of each section. The sub-headings represent the most frequently expressed answers, answers to the question which are novel, or answers which directly contribute to the research question in another way. Some material was deemed to not have relevance to the research questions, for example, when interviewees began to talk about other areas of law or other uses of the MCA 2005.

Interviews initially took place in person throughout the latter half of 2019; however, in 2020, when the COVID-19 pandemic hit, remaining interviews and follow-ups were conducted via remote means. Planned follow-up interviews with medical practitioners were not always possible in 2020 due to the pandemic. Throughout this chapter, interviewees are introduced by
a description of their role but are subsequently referred to as lawyer A, B, C or clinician A, B, C. The title ‘Lawyer’ refers to both academic and practising lawyers, ‘Clinician’ refers to an array of medical professionals who will be individually identified by a letter and a brief note about their specialism. A complete list of interviewee professions can be found in Appendix I. Interviewees are assigned letters according to the order in which the interviews took place.

3.2 Declaratory relief

Chapter Two explored the literature related to the declaratory relief process, its history, and continued use. The literature clearly showed that there was a divergence of opinion on the usefulness of the Court of Protection (CoP) in this area, particularly following the Supreme Court judgment in Re Y. The subsequent discussion by experts in publications and on social media led to this series of questions. This question's main aim was to understand the interviewees' views on Re Y and the continued role and purpose of the court.

The responses to these questions are broken down into the two main questions:

i) Views on the decision in Re Y

ii) Views on the continued role of the court post-Re Y

3.2.1 The decision in Re Y

All interviewees were asked their general feelings on the decision in Re Y and whether, in their opinion, it was a welcome one, had gone too far, erred in any particular way or did not go far enough. Each interviewee was asked some variation of the following question. The use of particular language differed depending on the specialist knowledge of the person being interviewed:

I would like to understand your general thoughts on the case of Re Y.

Do you feel that the decision in Re Y was a welcome one?
The responses were mixed but skewed heavily towards a generally positive view of the decision, with 14 subjects saying that they believed the UKSC’s decision in *Re Y* to be a welcome one.

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Table 1

There was a divide in responses between those with medical backgrounds and those with legal backgrounds; doctors predominantly saw *Re Y* as a favourable decision, whilst lawyers were divided on their feelings towards the case.

3.2.1.1 A welcome decision

This section covers the three most often cited reasons why interviewees believed that the decision in *Re Y* was a welcome one. The three most frequent reasons were the belief that the decision brought PDOC cases in line with other areas of medical treatment, that it relieved
families of the distress of the legal process and that Re Y was simply stating what the law already was and made no change to the actual legal position.

**Falling in line**

One of the most frequently held favourable opinions on Re Y was that it arguably brought the rules surrounding the withdrawal of care from PDOC patients in line with other critical medical decisions. This was a point that was raised throughout every interview with both medical and legal professionals. A professor of law, Lawyer A, made this argument very concisely:

> [I]t gets rid of perhaps an unjustifiable distinction between cases in which life-prolonging treatment can be and is withdrawn without going to court, for example, in intensive care units where it’s quite normal, and nobody thinks you have to go to court.\(^{303}\)

Similarly, another medical law professor, Lawyer B, stated that:

> [T]here’s definitely much to welcome in this decision; it means that these patients won’t be oddly singled out by the judiciary, when others aren’t afforded that extra layer of protection.\(^{304}\)

A lawyer who has represented the interests of the Official Solicitor, Lawyer D, made similar remarks about why Re Y has simply brought these cases in line with general practice within the United Kingdom:

> I think it must be the right decision. If only again, just looking at the practicality and the reality of the decisions faced every day up and down the country. Decisions are being made which are about the withdrawal of treatment for people on behalf or in respect of people who don't have the capacity to consent to those arrangements, and we just know that those decisions are being made all the time without going to court.\(^{305}\)

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\(^{303}\) Interview with interviewee 1 (October 1, 2019).

\(^{304}\) Interview with interviewee 2 (October 3, 2019).

\(^{305}\) Interview with interviewee 6 (October 6, 2019).
Clinician A, a consultant neurologist, said that, prior to *Re Y*, PDOC cases were made “too special” by creating this dichotomy between how PVS/MCS patients are treated and decisions are made for coma patients. He went on to say:

> [E]ither you trust people to do their jobs properly and get help when they can't, or you don't. If you don't, then we're going to need a second opinion on every single person in the country, and that's ridiculous.\(^{306}\)

This argument extends on the debate posed in the previous chapter, that doctors routinely make decisions as to whether or not to prescribe antibiotics in life-threatening circumstances and yet are not required to make an application to the court in order to do so. Society trusts that doctors can unilaterally undertake assessments on a routine basis.

**Emotional distress for families**

Another of the most often cited reasons why *Re Y* was said to be a welcome decision was that interviewees found that it would be a relief for the loved ones of patients to no longer be mandated to take their cases to the CoP and deal with any stress that may follow.

A clinical neurologist, Clinician E, who has seen these cases on a number of occasions, stated that:

> I don’t think people quite understand just how much stress the families of these patients are put under. This kind of alleviates that a little bit and, well, allows for a much smoother process within the hospital.\(^{307}\)

Similarly, Lawyer A believed that, although *Re Y* was crucial in bringing the law in line with other medical procedures, he believed that the most praiseworthy aspect of the judgment was the relief it would give to the families who no longer had to go to court:

> The more important reason why I think it was a welcome decision is that the reality of the need for court approval is to introduce stress, anxiety and delay.

\(^{306}\) Interview with interviewee 3 (October 4, 2019).

\(^{307}\) Interview with interviewee 12 (November 6, 2019).
for families, and that’s not a good thing. So, I think getting rid of a source of delay, stress and anxiety for families is probably a good thing.\footnote{Interview with interviewee 1 (October 1, 2019).}

A neurorehabilitation specialist, Clinician C, stated that he believed this judgment allows for a much more useful discussion to take place between doctors and families without the court looming over their heads. He believed that many families held off on withdrawing treatment they knew to be futile just because they feared having to go to court and stand up in front of people.

I don't think one can overestimate the number of people who didn't do anything because the law was involved. Not because they disagree with the law or anything, but it is just they were frightened of the law. They would say things like "no, I don't think we should carry on, but I'm not going to go to court", "I don't want to stand up in court", "I don't want to be publicly seen" so I think it was very good for that.\footnote{Interview with interviewee 10 (October 27, 2019).}

The fear of standing up in court was similarly something covered in Chapter Two of this thesis and was mentioned by two doctors and three lawyers as one of the most positive aspects of the Re Y decision.

\textit{It was never a requirement}

A third commonly cited reason why the decision in Re Y was said to be welcome was that the decision did not actually change the law; instead, 10 of those interviewed believed that it merely stated what many already had known. Twelve interviewees made some form of comment about Re Y not changing the law at all, but merely restating that there is no mandatory declaratory relief process.

The literature review in Chapter Two showed that a debate exists as to whether the declaratory relief process was made mandatory by the decision in Bland or whether it was merely a matter of best practice that doctors should make an application to the CoP for an order. This split in opinion was evidenced in the results of my interviews. For example, one barrister, Lawyer E,
stated that even if *Bland* did not create a legal requirement, it had the same effect on the way the courts operated:

> The Supreme Court most definitely overstated their view that there was no requirement (for declaratory relief), even some of the most senior judges were working on the assumption that there was a requirement, so I don’t buy that one bit.\(^\text{310}\)

However, not everyone held the same view; the majority of interviewees believed that *Bland* had essentially stated that its ruling was not permanent and that the House of Lords was awaiting a day in which it was no longer needed. For example, Lawyer D stated that he:

> [W]asn’t surprised by it one bit, *Bland* kind of envisaged *Re Y* coming much sooner than it did, but it didn’t exactly lay down definitive law. We moved on from *Bland*.\(^\text{311}\)

### 3.2.1.2 An unwelcome decision

Although the majority of those interviewed expressed their belief that *Re Y* was a welcome decision for several reasons, it was by no means unanimous amongst doctors and lawyers. All except one of the medical doctors interviewed saw *Re Y* as an entirely welcome decision; however, this was not the case for the legal professionals. Four of the nine legal professionals interviewed had some misgivings with the decision.

#### A return to medical paternalism

One reason given by two of the four legal professionals was that *Re Y* was not advancing the law concerning medical treatment. Two lawyers said that the decision seems to be regressing to a time where doctors were given ultimate control over the life and death of a patient:

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\(^{310}\) Interview with interviewee 7 (October 16, 2019).

\(^{311}\) Interview with interviewee 6 (October 6, 2019).
Re Y is a step back against the general trend in medical law. So, it kicks against all the principles articulated in Montgomery\textsuperscript{312} and so on, all of which have tended to minimise the doctor’s role.\textsuperscript{313}

Similarly, Lawyer H, a professor of law and former barrister, said that this decision was “giving the power of life and death to a set of medical guidelines, wielded by doctors”.\textsuperscript{314} These interviewees expressed concern that the UK was reverting to a Bolam-esque style of medical treatment that was focused more on the doctor than on the patient. They feared doctors would be more likely to take an approach that is best for the needs of the hospital or the NHS, rather than undertaking the holistic approach provided for in the MCA 2005.\textsuperscript{315}

Further to this, it was argued by Lawyer A that the decision in Re Y was “perpetuating the medical model of self”,\textsuperscript{316} he argued that Re Y assumes only doctors are equipped to make determinations about whether a patient is living a worthwhile life and as such the decision by nature becomes medicalised, as that will be doctors’ main focus.

Doctor knows best

Another argument expressed by three of those who saw Re Y as an unwelcome decision was that the ruling might prove to remove the voice of those who know the patient best. It was argued that there is a chance that the families will follow a doctor’s recommendations simply because of their situational power and influence.\textsuperscript{317}

Lawyer A stated that this was a “worrying” prospect because doctors and clinical personnel (such as nurses and carers):

[S]hare the same agenda. The doctors want the bed, the carer wants the time they spend caring back. So, there’s potentially a sinister conflict of interest.\textsuperscript{318}

\textsuperscript{312}The case of Montgomery v Lanarkshire Health Board [2015] UKSC 11 overruled the former Bolam test of medical negligence and introduced a general duty on doctors to disclose risks to a patient.
\textsuperscript{313}Interview with interviewee 1 (October 1, 2019).
\textsuperscript{314}Interview with interviewee 14 (November 18, 2019).
\textsuperscript{315}Interviewee 1 (October 1, 2019) and Interviewee 14 (November 18, 2019).
\textsuperscript{316}Interview with interviewee 1 (October 1, 2019).
\textsuperscript{317}Interview with interviewee 14 (November 18, 2019).
\textsuperscript{318}Interview with interviewee 1 (October 1, 2019).
However, Clinician C argued against this, saying that it is “inhumane” and entirely untrue to suggest that doctors are motivated by ulterior motives, such as the need for beds or funding.319

3.2.2 The need for continued oversight post-Re Y

All interviewees were asked for their thoughts on whether they believed there is any need for continued CoP oversight. The following question was posed to every individual interviewed:

Do you think that there is still a place for a declaratory relief process of some kind, or perhaps some form of overview away from the courtroom setting?

Every interviewee agreed that there is a need for some form of declaratory relief process. It was universally agreed that the CoP must always be an option where there is a disagreement between the parties. Three interviewees suggested that Re Y had gone too far and that the CoP has a much more valuable role than the Supreme Court gave it credit for. Furthermore, 10 interviewees mentioned some form of possible mediation taking place as an intermediate step between the bedside and the CoP; however, interviewees had different ideas about how this mediation may occur.

3.2.2.1 The Court

Clinician A argued that the CoP is essentially just ordering a second opinion, which they ultimately follow, and that the clinicians can do this at the bedside. He believed that this makes the CoP’s role redundant in all but a few cases:

You've got the clinician and the family, and they don't agree either way, then if withdrawal is being considered you have to get a second opinion anyway, so get your second opinion then. So, you've already got your second opinion which may well settle it. In a withdrawal case, having got a second opinion, and assuming they support withdrawal, and you can't manage to sort

319 Interview with interviewee 13 (November 7, 2019).
of bridge the gap, then you go to mediation. There are mediation services, so you go to mediation, and you get a third opinion in a sense.320

However, Lawyer D argued that Re Y had overstepped the mark in reducing the importance of the CoP in these cases and that it does have a vital role, which should continue:

So, it is plain that there is a need in lots of cases for declaratory relief. It seems to me that Re Y’s insistence that the only time that declaratory relief is needed is in the event of a dispute between carers and doctors is worrying.321

Lawyer A agreed with this concern, arguing that keeping the decision solely within the medical setting can be dangerous in protecting the rights of the patient:

Very often, the doctors and the carers will share the same agenda, the doctors want the bed, the carers want the proceeds of the will or the time they spend caring back. So, there’s a potentially sinister conflict of interests in many determinations of best interests in PDOC cases.322

3.2.2.2 Mediation

Ten interviewees spoke about the helpfulness of mediation in trying to resolve problems before they make their way to court. All 10 interviewees expressed their support for mediation, but some had their doubts as to whether it is effective. For example, Lawyer E expressed support for a different kind of independent oversight. He suggested a tribunal of some kind that would consist of parties from all fields, much like the Magistrate system:

So, it does seem to me that if you don’t have a requirement to have these things adjudicated by a judge, and I can see the economic and court time reasons for not having that requirement, that you do need some sort of independent oversight, some sort of arbitration. It seems to me that that could be done rather cheaply and expeditiously by a panel on which there are

320 Interview with interviewee 3 (October 4, 2019).
321 Interview with interviewee 6 (October 6, 2019).
322 Interview with interviewee 1 (October 1, 2019).
independent clinicians, chaired by an independent lawyer, and some sort of lay representation. Without the sort of adversarial context in which litigation happens and without the need for exhaustive disclosure and continual expert reports, which are the kind of things that make litigation so time-consuming and costly.\textsuperscript{323}

Lawyer B did not share the same enthusiasm for mediation. She likened the process to that in the Family Court. In her experience where there is a disagreement about such a vital issue, the parties will simply want to go to the court for resolution, if the Family Court is representative:

What we know about the use of mediation in family law… there’s a lot of mediation in divorce, is that mediation tends to work best when people are able to talk to each other. When people have gone beyond being able to see each other’s point of view, it works less well, and in a lot of these cases they may have gone beyond the talking stage.\textsuperscript{324}

Similarly, Clinician C argued that although mediation is a cost-effective and a good idea in theory when there is a disagreement over issues such as withdrawal of treatment, it is unlikely to be settled without a judge:

I'm not sure that when you've got a disagreement, and you've been through a second opinion, probably a third opinion, and a mediator then they are not going to be satisfied with anything else. If there's always the Court at the end they're going to want to go to court. So, either you say you can't go to court, which you couldn't, or you go to court.\textsuperscript{325}

The argument that the court cannot be avoided, or ruled out entirely, was a frequent response by almost all interviewees, regardless of how they felt about the outcome of \textit{Re Y}:

So, in a sense mediation, where there’s disagreement, you could try it and certainly might be worth trying before you go to court, but I think you would

\textsuperscript{323} Interview with interviewee 7 (October 16, 2019).
\textsuperscript{324} Interview with interviewee 2 (October 3, 2019).
\textsuperscript{325} Interview with interviewee 10 (October 3, 2019).
always need access to a court where you just can’t get people to agree with each other. Whether it’s done via a kind of clinical ethics committee, or an in-hospital attempt to talk things through with some external person. I think it’s probably a good idea, because nobody wants to go to court unless they absolutely have to.\footnote{ibid.}

### 3.3 The decision-making process

Chapter Two identified issues surrounding decision-makers’ understanding of the best interests standard. The literature suggested that clinicians have an insufficient understanding of what is involved in undertaking a best interests decision. Therefore, this section addresses different professionals’ views of best interests and whether they consider that decision-makers continue to have a poor understanding of the assessment standard. This section also analyses interviewees’ views on the reported misdiagnosis figures and whether interviewees were able to suggest any potential alternative to the current decision-making standard.

#### 3.3.1 Best interests

Interviewees were asked what they believe the best interests standard to be, in an attempt to uncover the application of the MCA in everyday practice.

#### 3.3.1.1 What is the ‘best interests’ test?

The same question was asked to all interviewees:

\textit{How would you define the term ‘best interests’ as it pertains to the Mental Capacity Act, as you see it, versus how the law may see it?}

The responses to this question were divided; some interviewees found that their interpretation of best interests and the definition offered by the Supreme Court is the same. It was argued by four participants (three clinicians and one lawyer) that the current understanding and application of best interests do not align with the letter of the law.
The most commonly held view of what constitutes a best interests decision was that the decision-maker must make a multifaceted decision, which does not rely solely on medical grounds or solely on the views of the individual patient or those around him. Lawyer C, a professor of law and former clinician, articulated the argument that a best interests decision includes the consideration of several factors; she argued that everyone varies in their beliefs, and so two decisions are never alike:

[P]art of it is just clinically what would be the best thing that would lead to the best health outcome. But it's not just that... we all vary in terms of our priorities and values and beliefs, and so that's some sort of quasi-objective medical idea of what's in somebody’s best interests is affected by their previous wishes, their present wishes, and the values that mattered to them when they had capacity.\(^\text{327}\)

She further added that the law aligns with her views, as there has been an increased focus on the views of the patient in recent years:

I would say there’s a very strong component which in my view, and now in the law, is a very strong component of saying that what mattered most to the person, what the person would have wanted, is what's in their best interests in almost all such situations.\(^\text{328}\)

Clinician C also emphasised the importance placed upon the individual patient’s wishes:

I would consider the best interests test to be what it says, which is to take into account a person’s past express wishes.\(^\text{329}\)

He developed this by explaining what he would consider constituting an *express* wish:

It’s unlikely that anybody's ever said "I wish if I’m like this that this..." it’s much more likely they're going to say "if ever that happens to me.." about

\(^{327}\) Interview with interviewee 5 (October 6, 2019).
\(^{328}\) *ibid.*
\(^{329}\) Interview with interviewee 10 (October 27, 2019).
something they've read “I wouldn't want to carry on”, I count that as an express wish, although it's clearly not done in that way.\footnote{330 ibid.}

He further explained that while many clinicians may apply a medical best interests approach, making diagnosis and prognosis the priority, he does not see it that way, and any doctor who has read the guidance correctly should not see it that way either. He summarised the primary considerations a decision-maker should have when making a best interests decision:

\[ \text{[T]heir wishes (maybe past), their attitude towards healthcare interventions and their expressed, or previously expressed, reaction towards the indignity of being cared for in that situation.} \footnote{331 ibid.} \]

In addition to those considerations, he also argued that a person’s “current experience”\footnote{332 ibid.} should also be taken into account, defining that as being the patient’s subconscious; however, he states that this does not necessarily mean they have a subconscious in a way which allows them to retain and reflect on information, but a manner which allows them to be aware of their environment:

An obvious example, which would apply to almost everybody, would be if they were nursed on a bed with no clothes on, in the freezing cold with loud noise and flashing lights, it is likely that they would do this (signalled grasping his shoulders, as if shivering). Whereas if he was on a nice and warm sunlit beach, with the waves waving away and nice music and seagulls they would be relaxed.

I think, for many of them, familiar voices, soft sounds, pleasant environment it all has to be considered an experience, and some of that experience is just the nursing care experience. I think you have to take into account what they would be aware of as an experience if they have awareness, and I leave an open question as to whether there is an internal "them" experiencing it, but there is certainly a bodily reaction to different environment.\footnote{333 ibid.}
Lawyer G, a barrister who has represented NHS Trusts and patients with PDOC, briefly summarised the current law and stated that it is judicial rulings that have primarily informed his understanding of the best interests standard:

So as things stand now, the way I approach it is that although the definition in the Mental Capacity Act says what it says, the case law since, and in particular the Supreme Court judgment, in the case of James and Aintree, placing a greater emphasis on the past and present wishes and feelings of the individual. Although those wishes and feelings are not determinative, they are the most significant factor to be taken into account of that best interest decision-making process.  

All interviewees accepted that the current law, found in Aintree, places increased emphasis on the patient’s wishes; however, six interviewees noted that there is a difference between what is said by the MCA 2005 and what has been said by the courts.

Lawyer B argued that the reason some confusion surrounds best interests decision-making might be because the MCA 2005 is not precise in defining what the test should involve:

I think that there is my issue with the law. The Act (MCA 2005) doesn't say that those, the person’s wishes and beliefs, have priority. I think the judges are applying it so that it does. I’m not sure that all doctors are applying it so that it does. So, I definitely think that judges are. I think there's a sort of slight misfortune in the sense that there's a bit of discrepancy between different sources of advice to the doctors.  

Similarly, Lawyer H, a professor of law, commented on why Section 4 of the MCA 2005 has been so controversial and how decision-makers who may not have adequately considered a patient’s wishes use it as a defence:

That's why it's so successful and so popular and also so controversial, because when we see a judge come up with an outcome that people don't like, they

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334 Interview with interviewee 9 (October 21, 2019).
335 Interview with interviewee 2 (October 3, 2019).
say, oh, well, that he's got it wrong. And of course, in law, they haven't got it wrong. They've made an evaluative decision. That's exactly what best interest is. It was deliberately designed to be a kind of empty vessel for changing social values. It's not legally wrong. We just disagree.\textsuperscript{336}

These two interviewees were critical not only of Section 4 of the MCA 2005 but also the manner in which some judges have described the attention to be given to the wishes and feelings of a patient. They each explained that when a doctor is conducting a best interests evaluation, they can look to Section 4 and reasonably decide whatever they wish, as long as they follow the process:

There are certain procedures and discursive rituals that person has to go through to comply with the Section 4 checklist. So, they have to consult with various people. They have to involve the person as far as practicable and they have to give what a judge recently called "due regard" to the person's wishes, feelings, values and beliefs. But once they've been through those rituals and processes and paid due regard, the whole point about best interests is there is nothing to determine what result they end up with.\textsuperscript{337}

Nonetheless, not every interviewee believed that the best interests test is as set out in Aintree. Lawyer A acknowledged that Aintree had established a precedent that placed a patient’s wishes at the forefront of decision making; however, he believed that the test should instead be based on “human thriving”:

Best interests is everything pertaining to a person's thriving. So, to determine best interests you need to have a philosophically coherent account of what it means to live as a thriving human being; obviously the emphasis that people put on the bullet point answers to what it amounts to live as a thriving human being in this strange world can be very different. I guess that we'll all agree on certain core values but the real interest and the real point for litigation lie in the non-shared accounts of what it amounts to be a thriving human.\textsuperscript{338}

\textsuperscript{336} Interview with interviewee 14 (November 18, 2019).
\textsuperscript{337} Interview with interviewee 2 (October 3, 2019).
\textsuperscript{338} Interview with interviewee 1 (October 1, 2019).
He expressed the view that what is central to human thriving is the interlocking web of relationships we all find ourselves in which impact who we are as people and that, as a result of these social relationships, we are not autonomous beings who have neatly planned-out lives and desires. Instead, he argues that we must take into consideration all of those external factors that make up our sense of self. If a decision-maker omits to include the “nexus of relationships in which the patient exists”, they are going to have worrying results.  

He went on to say that although the expressed wishes of the patient form part of this web that defines us, it is not the only important factor. Expanding on what he means by ‘human thriving’, he explained that his theory is based on the philosophy of Communitarianism, which emphasises the individual's connection to their community:

What I think is probably distinctive about my account of human thriving, and therefore my account of best interests would be, is the weight that I would give to a communitarian model of the person. So, I've never met an autonomistic man, and if I did I certainly wouldn't like him; he would be appalling company at dinner, he'd be icy, he'd be self-centred. And it does seem to me to be pretty worrying if we have a whole superstructure of medical ethics which is based on the proposition that this deeply unattractive character, who doesn't exist thank goodness, is the paradigm to which we all ought to approximate.

I've never met someone who has a neatly drafted life plan, departure from which they would regard as entirely heretical. So, my model of the human is one whose shape is determined entirely by the pressure of all the entities around him or her.

Although there was a general consensus among interviewees that best interests is a patient-centred discourse, there is still clearly some debate on what exactly that entails.

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339 ibid.
340 ibid.
3.3.1.2 Do clinicians understand best interests?

Chapter Two outlined a substantial amount of literature that suggests a high percentage of medical professionals lack a complete understanding of what the best interests test entails. Each interviewee was asked the following question:

_The House of Lords Committee on the Mental Capacity Act 2005 said that a substantial number of clinicians do not understand the concept of best interests or fail to undertake it accurately. Do you think that that is an accurate depiction of the clinical reality?_

This question received consistent responses from the interviewees; every person interviewed expressed the belief that the statement and findings from the House of Lords Select Committee (which can be found in section 2.5.5) were accurate to some extent. Although the interviewees offered different explanations as to why this may be the case.

Eight of those interviewed offered more than one potential explanation; therefore, the responses to this question do not fit uniformly into a professional divide.

One barrister, Lawyer G, blamed the lack of understanding some clinicians have on what he believes is the medicalisation of the best interests standard, doctors putting medical interests above all other considerations, he explained:

![Figure 2](image-url)
That is plainly an accurate position; it harks back to what Butler-Sloss said all those years ago about the necessity to remember the best interests is not confined to medical best interests. So, doctors are trained in medicine, and therefore doctors tend to see what is medical. They also do not spend as much time simply by the bedside as the relatives, or even the nurses. So, consistently in litigation about the withdrawal of life-sustaining treatment you see the doctors saying that there’s no point in life being sustained and the nurses, who see more the patient, indicating there's much more to live for. This is all a consequence of the medicalisation of best interests test.  

Lawyer B gave a similar explanation as to why the understanding of best interests is so low throughout the medical community:

[A]ll the available evidence in the public domain indicates that a significant proportion, if not the majority, don't follow that checklist. And I think there's probably a number of reasons for that: I think one reason is that doctors have been brought up talking about the best interests of the patient where what has been meant is medical best interests. The same way that lawyers have a kind of internal concept of legal best interests. And those concepts don't map directly onto what is meant by Section 4.

I'm sure they have a different understanding of it. And I think also that's one of the other reasons for the enduring popularity of best interests is it's very closely tied up to how professionals see themselves and the value of what they do.

Clinician C responded by saying that not only were the House of Lords Select Committee correct in saying that clinicians do not understand best interests, but that they did not go far enough. This doctor went on to say of the House of Lords Select Committee report:

341 Interview with interviewee 9 (October 21, 2019).
342 Interview with interviewee 2 (October 3, 2019).
I think it was a huge understatement. Virtually no clinicians understand, now I'd put it down to 5%. The number of people who say this was done "in their best interests" without the slightest idea of what they're talking about. They equate best interests with preserving life and extending life; they equate best interests with doing the treatment which I have to offer. So, I think the House of Lords was grossly underestimating the ignorance of best interests as a philosophical idea and, as they report, the understanding of mental capacity is abysmal, and of the Act is abysmal. There's a case I’m in at the moment where it's obvious the clinicians don't, and the CCG\textsuperscript{343} doesn't.\textsuperscript{344}

Interviewees repeatedly identified an evident gap in the clinical understanding of the best interests standard. For example, Clinician G responded by saying:

Yes, I think that's right. So I think there seems to be quite a lot of evidence that clinicians haven't necessarily grasped that the way in which the law has in a sense changed since the Mental Capacity Act, with [sic] the sort of Aintree purpose of best interests is to consider matters from the patient's point of view.\textsuperscript{345}

Eight interviewees expressed displeasure with the Select Committee’s findings while also agreeing that they are accurate. However, one barrister, Lawyer F, gave a different account of why the issue of clinical misunderstanding may not be a priority for doctors and, as such, why the Select Committee’s report may not be quite as important:

[A]ll of this is just, in reality, low down on their (doctors’) list of priorities because they've got the whole world of horrendously complicated medicine to understand to do their jobs effectively. I mean, I completely get that understanding the legal framework comes low down on their priorities. I know it shouldn't be that way, but that is the reality of the situation. That's

\textsuperscript{343} Clinical Commissioning Group.
\textsuperscript{344} Interview with interviewee 10 (October 27, 2019).
\textsuperscript{345} Interview with interviewee 17 (December 9, 2019).
why more than ten years down the line, there hasn't been a greater impact from Aintree, and I don’t see why it would change.\textsuperscript{346}

Interviewees were then asked a follow-up question about how they would suggest improving the understanding of best interests, to ensure clinicians are following the spirit of the law. Of the 19 interviewees asked this follow up question, 12 gave a response.

\textit{What would you say needs to be done to improve clinical understanding of best interests, to ensure a more holistic assessment is being carried out?}

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Table 2

The responses to this question were mainly concerned with three issues: the training of the doctors, the Mental Capacity Act, and the supplementary guidance. Although interviewees had different feelings about all three of these issues, they all identified one or more of them as areas in need of reform to ensure clinicians are carrying out holistic best interests assessments.

Clinician C responded by suggesting a complete revision of the foundations of the MCA 2005. He believed there was a fundamental misunderstanding of the clinical decision-making process and that the current law makes it unfeasible to conduct continuous best interests assessments about every single issue that may arise. He suggests that doctors need to be trusted to do their job and the current system is an arduous process:

\textsuperscript{346} Interview with interviewee 8 (October 19, 2019).
I think the whole Mental Capacity Act needs to be revisited. The things that I would do is, first of all, to get rid in the Health Service of the emphasis upon consent for operation and get rid, in the Act, of the emphasis on capacity for a single issue. I think the whole fault is a single issue. And it was illustrated to me very vividly quite recently, I had to do a best interests assessment on somebody with contractures, so their arms are stuck like this — actually it was their legs — so much so that you can't really clean the skin and it's breaking down. The question was to refer them to a surgeon to cut the tendon to extend it, and that needed to be discussed, so we called the best interests meeting.

[Removed] came as the CCG rep, and she was obviously somebody who was trained. She said we have to have it about the particular issue, but that's not the way life is. The issue is not 'do we do an operation'; the issue is 'we have a problem here, what's the best way to do it that is in his best interests'. Am I going to do about ten complete reassessments for each one of the options when you've got to compare them?

So, I think you really need to get away from this fixation, because everybody's been trained. Mandatory training is universal, and nobody knows it. Mandatory training absolutely failed, and it's failed because it's set in the context of a unique decision, yes/no about a particular treatment. It's a fixation upon the particular, the way it's phrased and the way it’s put, the decision is not 'do we do this, or do we not do this', it is 'how do we best manage this'.

Six of the 12 respondents mentioned the need for updated guidance, either from a regulating medical body or an updated Code of Practice. Doctor D, a long-term care consultant, said that new step-by-step guidelines for clinicians need to be produced:

I guess what doctors need is very clear guidance, GMC guidance perhaps, sort of good practice guidance, which is just the sort of the toolkits that the

347 Interview with interviewee 10 (October 27, 2019).
BMA produce which are sort of step by step guides. I think there also, obviously this is happening, there needs to be a new Code of Practice I mean that’s in progress, I believe.348

Lawyer H, a medical law professor, reiterated the argument that clearer and more accessible guidance is needed, not just for doctors, but for all parties involved in making these decisions:

The Code of Practice is meant to be more user friendly than the piece of legislation or law reports. So, I think that would be it would be good if the Code of Practice would give stronger guidance to doctors. I think, in addition, it’s important for clinicians to know this, but it's also really important for patients when they're thinking about advance care planning but also for families to know where they stand. So, I think this sort of accessible guidance on how decisions are made people who lack capacity is important for more than just clinicians, there are other constituencies.349

Similarly, Lawyer A criticised both the MCA 2005 and the Code for different reasons from those given above: he believes that the law places incorrect emphasis on single decision-makers, who are usually doctors, and therefore make clinical-based decisions.

Well, I think there is a real problem in the MCA and the Code of Practice that the designation, or the perceived designation, of one decision-maker; if it's a medical decision then the decision-maker tends to be regarded as the doctor who's making a quintessentially medical decision. I would like to see that notion of a single decision-maker excised. I don't see that you can expect one person and particularly one doctor – whose view is necessarily a medicalised one – to perform a holistic best interests determination which necessarily entails a triangulation of lots of perspectives. That's the main thing you need to get rid of is the notion of single decision-makers.

348 Interview with interviewee 11 (November 3, 2019).
349 Interview with interviewee 14 (November 18, 2019).
The second thing is, is that you need to have a lot more medical education; you need to try to educate doctors out of the paternalism, which infuses lots of their decision-making. That might mean no more than getting them to etch on their subconscious the necessity to consult widely with the relatives and carers, which is embodied in the Act.\textsuperscript{350}

Five of those who gave answers made similar suggestions concerning the improvement of medical education. Firstly, Lawyer F suggested that although it would seem that more education is the right thing to do, maybe there is a reason why it is not the solution:

I actually don't know at all to what extent people going through training to become doctors are taught the Mental Capacity Act routinely, and if they already are taught it then that suggests to me that more teaching at the training stages maybe isn't the answer, because it doesn't seem to stay with them through their practice. As a lawyer, I don’t think I should comment on the best way to get that message out to doctors if I’m honest.\textsuperscript{351}

However, another lawyer took exception to any suggestion that a doctor is not always acting in a patient’s best interests. Lawyer C, a former clinician, believes that even if they are not following the letter of the law, the doctors are likely just following the lead of those who taught them.

You know, it just seems absolutely outrageous, the suggestion that you wouldn't act in their best interests. And so if the doctor already has quite a clear sense of what is medical best interests, and that's a sense that would be shared by those who would have taught him, those who supervised him, other professionals. To then come up with a different solution is going to be quite difficult for them because they are already going to have a strong sense of what best interests is that comes from their own professional and cultural background. But I should say that I've met quite a few doctors, particularly younger doctors, who do have a much more kind of liberal sense of what best

\textsuperscript{350} Interview with interviewee 1 (October 1, 2019).
\textsuperscript{351} Interview with interviewee 8 (October 19, 2019).
interests is, that it may be person-centred. It might be that they've just been brought up in a different academic tradition when training as medics.\textsuperscript{352}

This view on best interests gives some hope for the future, but as long as junior doctors are trained by clinicians who do not understand best interests, there will be an endless cycle.

3.3.2 Whose views matter?

A substantial body of literature, identified in the previous chapter, calls into question the balancing of views when trying to uncover what the patient would have wanted. It was suggested, in section 2.5.5, that the voice of a patient’s family is often being confused as that of the patient. It is also a concern that people may be given a say in what the patient would have wanted when it is unknown if they are representing them correctly. It was because of this debate that all interviewees were asked the following question:

\textit{When undertaking a best interests assessment, a number of views are taken into consideration, including those of the patient, the family and other interested parties. How do you feel a decision-maker should balance all of these views?}

3.3.2.1 The patient

Lawyer B believes that the best interests assessment, at its core, is supposed to prioritise the patient’s views and that that needs to be made more apparent:

So, I think my own view is that…the law needs to be clearer so that there's no doubt that the individual's wishes, beliefs, values, it’s a sort of cluster of interests, are the most important consideration.\textsuperscript{353}

However, she expressed doubt that this is happening in practice, saying:

\begin{flushright}
\textsuperscript{352} Interview with interviewee 5 (October 6, 2019).
\textsuperscript{353} Interview with interviewee 2 (October 3, 2019).
\end{flushright}
I think the worry is that again doctors may not know what to do if they're faced with family members where they're not sure that that really represents what that person would have wanted.\textsuperscript{354}

Clinician C responded to the question in a similar vein by saying that he believes patients’ wishes are the central concern but that it is not as simple as that. He gave examples of a time where the patient’s wishes may intersect with those of the family, and that the patient may be deciding to either accept or refuse treatment based on the distress caused to the family:

It strikes me that if someone implicitly or explicitly has said: "I wouldn’t want to cause distress to my family" or "I wouldn’t want to use up all their money" or anything like that, then you have to say what is going to be the effect of X living 10 years on their daughter, their mother, their whoever it might be — including their friends, although I think that may be less arguable — that’s a factor you have to take into account. So, I’m not taking into account the stress of the relatives \textit{per se}, but how the individual patient would perceive that.\textsuperscript{355}

The best interests assessment is not a one-sided process; Lawyer E, who has represented both patients and NHS Trusts, emphasised that it requires the views of a number of people, despite how medical staff may perceive the test:

There needs to be a collaborative process of decision making and, although that sounds unwieldy, and sounds as if it perhaps adds nothing to the process prescribed by the Act. It would (a) reach accord in many more instances than one might think at first blush but also would result in a different sort of process of decision-making than is often reached. Doctors tend, in my experience, to say, "ok we’ll listen to what the relatives say" and "yes tick, we’ve taken it on-board, and then we will make the decision". That whole emphasis on medical decision-making needs to change, and it can only be changed by insisting on a procedurally collegial form of best interests determination.\textsuperscript{356}

\textsuperscript{354} \textit{ibid.}
\textsuperscript{355} Interview with interviewee 10 (October 27, 2019).
\textsuperscript{356} Interview with interviewee 7 (October 16, 2019).
However, not everyone was so firm in their support for patient-centred best interests determinations. Lawyer A argued that the patient in the bed could not possibly be said to be the same person as the one who previously expressed any wishes and, therefore, any kind of advance decision or past statement should not be determinative.

Completely different people may arise out of the ashes of the person who made the advance decision and has effectively ceased to exist. It seems to me to be problematic to regard advance directives as the warrant of execution of a completely new person, related to the old person only by the accident of occupying the body composed of some of the same cells as the person who made the advance decision.\(^{357}\)

While the phrasing of the above quotation may be unfortunate, the point being made is of note. The patient who can be seen in the bed is likely to have different priorities than the person they were before their accident. The question of what this patient would want instead of what the man he was before would want could arguably be the central question to the best interests exercise.

### 3.3.2.2 The family and others

Lawyer C responded about the unusual situation in Britain that families’ voices are not heard, and compared our situation to the rest of the world when explaining why all views should be heard:

> So, I think the first thing I would reflect back to you and your question is everybody's got a conflict of interest, that is unavoidable. The question is, what is the nature of those conflicts of interest? How are they best managed? And in most other jurisdictions, it would be doctors’ conflicts of interest that the system is concerned with managing and not families and it's a very British perspective to be so sceptical of families.

> In almost every other Commonwealth jurisdiction in the world, it would be the friends and family automatically making that choice. So if you look at

\(^{357}\) Interview with interviewee 1 (October 1, 2019).
surrogacy laws in the USA and Canada, Australia and many European
countries, if you have someone who lacks capacity and is unable to make a
choice and they haven't got a guardian, which is going to be most people,
what happens when they lack capacity is not that doctors make a best interests
decision. Doctors, in fact, would be regarded as having massive conflicts of
interest to make that decision. The person who'd make that decision would
usually be a relative chosen from a statutory list.  

She continued by making the comparison to the rules under the United Nations Convention on
the Rights of Persons with Disabilities. Under the CRPD, she believes that more weight would
be given to a much more comprehensive range of considerations.

I think in CRPD circles, there's a lot more of an embrace of, what are called
in general comment number one, “diverse methods of communication”
including methods that would be highly controversial, like facilitated
communication.

So, what I would say is, I think, yes, absolutely. Anyone who can bring a
piece of information to the table about what the person would have wanted
is going to be taken very seriously in CRPD terms. But I think if you have
situations like, for example, the case of W v M, where the woman concerned
does appear to be manifesting behaviours, indicate a degree of pleasure, like
laughing or looking at ducks or tapping a hand to music. I actually think the
CRPD world might put quite a lot of weight on that in a way that perhaps
isn't being taken as seriously in kind of circles [sic], which want to put much
stronger emphasis on who the person was previously.  

The previous chapter of this thesis noted studies concerning how LGBT patients often have a
family of birth and of choice and are often victims of their partner's views being ignored.
Lawyer I, a retired barrister, acknowledged that there are issues with creating lists or
nominating certain people to act as designated guardians in these situations. He noted, for

358 Interview with interviewee 5 (October 6, 2019).
359 ibid.
example, that people in same-sex relationships may find themselves stuck if the country they are in when they fall ill does not respect or recognise those marriages.\textsuperscript{360}

Clinician B, a trauma specialist, said that he also does not believe there should be any kind of hierarchy in whose views are listened to:

I would resist any sort of weighting system on relationship, as in blood-relationship. It would be impossible to do, but you could have a weighting system on the closeness of emotional contact and experience of this person.\textsuperscript{361}

Similarly, Clinician C pointed out how certain people may know more about a patient’s views on end-of-life issues, and argued that a statutory hierarchy of decision-makers do not work:

You could have gone on a hiking trip around America when you were 20 or 30 or something and had some really quite life-threatening thing and a very good friend with you and had a very long discussion about what would have happened and so on, it might reveal a whole lot. Thirty years later, that person might be the only person who knows what you felt, nobody else might know. You need to do it on an individualised basis.\textsuperscript{362}

Three interviewees mentioned the argument that families may seek to benefit from the death of a loved one and so may push their personal agenda to achieve their goal; however, none of the interviewees accepted that as a valid premise or reason for concern. For example, Clinician C said:

I know that in the past there have been lawyers and others who believe that families just want to get rid of them, so they don’t have to pay, or for financial reasons. I think that’s just inhumane to say; I think that it's totally untrue and

\textsuperscript{360} Interview with interviewee 16 (December 3, 2019).
\textsuperscript{361} Interview with interviewee 10 (October 27, 2019).
\textsuperscript{362} Interview with interviewee 5 (October 6, 2019).
I've seen people have had quite large sums of money at stake and they've been aware of it.\textsuperscript{363}

Five lawyers who answered this question expressed some concern about families passing off their wishes as those of the patient. Lawyer F, whose views were very similar to those of two others, was concerned about the amount of CoP time spent attempting to distinguish a patient’s views from those who know him:

[A]n awful lot of the judge’s time in contested cases is trying to distinguish between real and assumed patient wishes, when they are expressed through the lips of a relative.\textsuperscript{364}

Whose views are being heard is crucial to best interests decision-making. If the views of the family are being passed off as those of the patient, then it cannot possibly be said that a patient-centred decision-making structure is being followed. The issue of who knows the patient best was discussed at length in the previous chapter, and how families present this in the CoP will be seen further in Chapter Four.

3.3.3 Misdiagnosis

Section 2.2.3 of the previous chapter illustrated that a significant number of studies have been conducted, which indicate high levels of misdiagnosis. These studies indicate that between 37\% and 43\% of patients had a much higher consciousness than their initial diagnosis. All interviewees were asked the same question, based on this literature:

\textit{There has been a lot written about the potential rates of misdiagnosis of around 40\% of minimally conscious patients. How do you feel about these figures and studies?}

\textsuperscript{363} Interview with interviewee 13 (November 7, 2019).
\textsuperscript{364} Interview with interviewee 8 (October 19, 2019).
The responses to this question showed that views fell into two main categories: the misdiagnosis rates are accurate, and a serious concern, or misdiagnosis is based on labels that should not exist between PVS and MCS. All interviewees were asked the same question; four stated that they did not know enough to answer the question, eight interviewees mentioned that it was based on the use of improper labels, and seven expressed concerns about the rates of misdiagnosis.

### 3.3.3.1 False Labels

Clinician C summarised the argument that the PVS/MCS distinction is no longer relevant and is to blame for the figures of misdiagnosis that have been quoted in numerous studies.

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Table 3
First of all, the 40% misdiagnosis is a complete misunderstanding. The way that that is perceived by families is that this person is not minimally conscious or vegetative, it is that they are fully aware. They think of it as complete misdiagnosis in the sense of catastrophically wrong, and that's a complete misrepresentation.

Misdiagnosis, if you wish to call it that, is saying "well I believe that localising sound means they are aware" and all you're arguing about is whether or not some particular reaction means they are aware or not. So, the 40% is rubbish. It actually doesn't matter anymore; I don't mind if I call them vegetative, minimally conscious minus, minimally conscious plus or emerged or whatever you like. The question is what's in their best interests.

As I've said, I've got three people already where we've withdrawn feeding who undoubtedly are conscious and aware, you have to doubt what level of awareness. So, I don't think it really matters at all. They could be vegetative, they can be MCS−, MCS+, MCS++ or whatever you might invent - it’s immaterial.365

Lawyer G made a similar observation on the need to perhaps move on from the perceived binary divide between PVS and MCS:

I think things have moved on really in that respect. I don't think there is any particular need because I think the case law, over the last three or four years in particular, has been clear that there it’s not particularly helpful for there to be this sort of distinction between MCS and vegetative state. One of the judgments … Mr Justice Hayden … said something to that effect of there is no clear white line between the two and nor does he need to work out where this particular patient falls on that spectrum to make his decision in this case, because he's got a clear enough picture of what her actual medical situation is, and what the future holds for her, and what her wishes and feelings would be in these particular circumstances… you didn't need to draw that

365 Interview with interviewee 10 (October 27, 2019).
distinction. And I mean, again, I'm not a clinician, but I know what the current thinking is on this specifically. But my understanding is that the clinicians involved moving away from being a particularly helpful distinction between the two terms.\textsuperscript{366}

Similarly, Lawyer B has said that the misdiagnosis debate hinges on the distinction between PVS and MCS, and so if this classification is abandoned, then the debate ceases to exist:

The only thing I would say about the labels is I think we should get rid of them, in if we can move towards just “prolonged disorders of consciousness” that's much better. I think the word “vegetative” is really really problematic for families. So, I think maybe to just say there are patients with prolonged disorders of consciousness and those existing on a spectrum may be more helpful than having this sort of binary “is he vegetative or minimally conscious”. I definitely think we've got to get rid of vegetative. It might have been okay in 1993. But I think now it just is not way to describe people, and that sort of helps with the issue of misdiagnosis, if you just treat them all the same.\textsuperscript{367}

3.3.3.2 A continuing issue

Although there is a considerable argument made that misdiagnosis is no longer an issue, and that we should simply drop the PVS/MCS distinction, seven doctors and lawyers still raised issues about the high rates of misdiagnosis. Lawyer H responded saying that:

It’s clearly really worrying. If the diagnosis is what really enables treatment withdrawal and the diagnosis isn't reliable that's obviously a serious concern which needs much further analysis regardless of if people think the terms are no longer relevant, which is a fair point to make.\textsuperscript{368}

\textsuperscript{366} Interview with interviewee 9 (October 21, 2019).
\textsuperscript{367} Interview with interviewee 2 (October 21, 2019).
\textsuperscript{368} Interview with interviewee 14 (November 18, 2019).
This argument was also propounded by a barrister, Lawyer F, who questioned the tools used to diagnose patients. He also points out that it is disagreement over this distinction that often leads to CoP review and a patient being found to have higher consciousness:

I see no reason to question these very worrying statistics. Everything I know about the crudity of the tools used to probe for the indicators of consciousness suggests that those figures are likely to be right. … we did an audit of the number of cases, litigated cases, about withdrawal of treatment in PDOC patients which had been altered, which litigation had altered the outcome in other words where a medical decision to withdraw had been overturned by the judge. Now, the methodology by that very informal audit was not considered to be sufficiently robust enough to present those findings to the Court. But, from memory, it was something like one third of medical decisions to withdraw were found by the judge not to be in the best interests of the patient, which is the same order of magnitude as the figures you’ve quoted about misdiagnosis.369

Similarly, Lawyer H commented on how the PVS/MCS distinction leads to different levels of scrutiny and that misdiagnosis means patients with potentially higher levels of consciousness are not receiving the treatment they deserve:

There tends to be an assumption that if a diagnosis of PVS is made, then that’s the end of the story, you withdraw, and there are no legitimate interests to be considered. If the diagnosis is MCS, then there’s something to talk about. I don’t wish to see any patient who is MCS be bypassed by a fault in the diagnostic mechanism.370

3.3.4 Conforming with the Convention

The literature analysed in section 2.5.4 revealed a consensus that the United Kingdom is non-compliant with the UNCRPD. As a result of this finding, interviewees were asked whether they

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369 Interview with interviewee 8 (October 19, 2019).
370 Interview with interviewee 14 (November 18, 2019).
believed the UK should try to comply with the UNCRPD and their thoughts on it. The following question was asked of all interviewees:

*Do you believe that the United Kingdom has come more in line with Article 12 of the UNCRPD, and what do you feel, if anything, the UK should do to achieve this?*

The answers to this question fell primarily into two distinct themes: people who believed the UK does not need to comply and are comfortable with our current system, and people who believe the UK are non-compliant and need to strive to come in line with the CRPD but are currently far removed from it. The responses to this question yielded the highest number of people not offering a response or stating that they were unqualified to comment. Only two of the eight clinicians and five of the nine lawyers gave substantive answers to the question. The lack of responses was not unexpected, the CRPD is not mentioned in any great detail in UK guidance, and so many doctors may not even be aware of its existence.
<table>
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Table 4

3.3.4.1 The UK should strive to come in line with the CRPD

Lawyer C, a professor of medical law, was adamant the idea that the UK has come in line with the CRPD in any way was laughable, explaining that although other jurisdictions have adopted elements of the MCA 2005, they have not followed the UK’s best interests standard:

No, no, absolutely not. I mean, we haven't. Nothing's changed, the statute hasn't changed, and I think that was really disappointing. I thought the Law Commission's recommendation was a modest step towards this radical vision connected with Article 12. And I think it's worth highlighting that whilst there are elements of the Mental Capacity Act that have kind of colonised mental capacity laws around the world, so you'll find the 'functional test' in legislation all around the world. You'll find principles of 'least restriction', 'presumption of capacity' and various things in laws around the world. What is really interesting is that best interests hasn't had that same appeal to other jurisdictions.  

Lawyer B expressed a similar opinion, explaining that the government had had the chance to change the best interests standard into something that complied with the CRPD, but opted not to:

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371 Interview with interviewee 5 (October 6, 2019).
[W]hat was interesting about the Law Commission's consultation is that actually there was quite a lot of support for adapting best interests, not junking it, but putting a greater emphasis on the person's wishes and feelings, and initially, the government seemed to be on board with that, and then when the Bill was brought forward in July last year (2018), it had been dropped.372

Another explanation given as to why some interviewees feel the CRPD should be adopted into English law is that ‘wishes and feelings’ place the patient more firmly at the centre of the decision. Lawyer G, for example, noted that the CRPD does not merely look backwards to a patient's life, but looks at who they are now, something best interests does not prioritise:

I guess the key to remember with the CRPD is it doesn't have this binary concept of capacity and incapacity. But what that means is even a person who lacks capacity, his behaviour is going to be taken as an indication of their will and preferences. What you then do with a conflict between past and present us is a really difficult question that the CRPD doesn't answer, but it does certainly make it much more complicated, I think than views, which just say past autonomous self always has priority over recent incapacitated self.373

3.3.4.2 The UK’s current standard is appropriate

Lawyer I was highly critical of what the aims of the CRPD are and the fact that these aims have changed over the years. He believes actual compliance is not needed and that instead, the UK has closely followed the spirit of the Convention:

I think people who go into the CRPD hoping for a clear-cut answer of what it does or doesn't require are just fundamentally misguided. If you look at, for example, the European Convention on Human Rights, what it required in 1951 is very different to what it requires in 2019. What the drafters thought it was trying to do versus what the ratifying states thought they were agreeing to I feel are two different things. I don’t think we can achieve it as General

372 Interview with interviewee 2 (October 3, 2019).
373 Interview with interviewee 9 (October 21, 2019).
Comment 1\textsuperscript{374} would layout. I think the MCA is our attempt to stay in line and it's not perfect, but it works and is realistic.\textsuperscript{375}

Despite this, Lawyer D argued that although the wording of the MCA 2005 has not changed, the courts have moved themselves towards compliance with the spirit of the Convention:

[J]udges of the Court of Protection themselves are making decisions that are often putting a greater emphasis on the patient's wishes and feelings. And we can see that particularly strongly in the PVS and MCS cases, to the point of essentially compliance with the CRPD.\textsuperscript{376}

Nonetheless, Lawyer B argued against that point, stating that although it may be true for PVS and MCS cases, that does not resolve the overall issue with the standard within the MCA 2005:

I think if you only look at PVS and MCS cases, you might come out with the view that we're almost Article 12 compliant. But what I would say is I think that judges are much more comfortable with allowing someone with a very, very serious disorder of consciousness to die than they are with the respecting of people's wishes and feelings in other domains. So, if you look at best interests decisions around people with learning disabilities and sex or learning disabilities and their own medical decisions, you will see far fewer cases where the person's wishes and feelings appear to be determinative.\textsuperscript{377}

The question concerning the CRPD received the fewest responses, perhaps indicating a wide-ranging lack of knowledge of Article 12. The UK signed up to the CRPD with an obligation to create a patient-centred decision-making framework based on “will and preferences”. The suggestion that the UK has essentially complied with the CRPD is not enough to satisfy the issues found in General Comment no 1, that the best interests standard does not adequately protect a patient’s autonomy. What should also be remembered is that the best interests

\textsuperscript{374} General Comment Number 1 is the statement made by the UN Committee on the CRPD which is outlined at section 2.5.4. This statement asserted that ‘will and preferences’ must be the way decisions are made for those who lack capacity.

\textsuperscript{375} Interview with interviewee 16 (December 3, 2019).

\textsuperscript{376} Interview with interviewee 6 (October 6, 2019).

\textsuperscript{377} Interview with interviewee 2 (October 3, 2019).
standard applies beyond end-of-life decisions, and as had been mentioned, courts regularly dismiss the views of people who are conscious but lack capacity. If the courts are willing to override the views of a conscious patient, then there is increased concern about how they will make decisions for those who lack consciousness.

3.4 The future

The literature review showed that there was considerable doubt raised about the current technology being used to diagnose patients who are in PDOC. However, there is a substantial body of literature from various groups of academic scientists and clinicians that suggest that there are new and emerging technologies, which may allow for greater exploration of the patient’s wishes and feelings. Although these technologies may be years from being perfected for wider clinical use, it is pertinent to this thesis to understand what the feelings are amongst the professional community in the UK.

3.4.1 Emerging technologies

When interviewed regarding their views on the use of functional magnetic resonance imaging (fMRI), electroencephalograms (EEGs), and other such technology concerning PDOC patients, all interviewees were asked the same question, with a focus on fMRI but broadly asking about any emerging technology. The question each participant was asked was:

*Current diagnostic methods are often criticised, and research has been increasing over the past two decades into alternative diagnostic techniques. How do you feel about emerging technologies such as functional magnetic resonance imaging or EEGs being incorporated into a potential diagnostic framework in the future?*
As shown in figure 5, the responses to this question were almost evenly divided: eight interviewees indicated a negative feeling towards introducing fMRI technology into the diagnostic framework, and nine offered a more positive view. Two interviewees (both lawyers) stated that they did not feel qualified to make any judgment on their use and so refrained from providing a definitive view.

<table>
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The themes that derived from the answers to this question were not binary, like many other questions; instead, interviewees often offered both praise and criticism of fMRI technology. However, a majority of the interviewees appeared to have the same thought, that the technology is ground-breaking, but they would not want it part of the diagnostic framework at the present time.
3.4.1.1 Doing all we can

Every interviewee who agreed with pursuing fMRI as an addition to a diagnostic or decision-making framework made some type of statement which reflected the ethical debate surrounding the duty of care owed to a patient by those treating them or working on behalf of their interests. This came in many forms, Lawyer C, for example, believed that doctors have a duty to put their patients’ best interests at the forefront of all decisions. She went on to argue that this means doing all this possible to find out what that individual patient would want:

I think there's a sort of sense there is like 'we have an absolute ethical and now legal imperative to use any available means to try. And I think Gerard Quinn talks about "spark the will" or "kindle the will "or "discern the will". I think definitely these new technologies of fMRI or EEG or something would be part of that.\textsuperscript{378}

She stated that, of course, there will be downsides with it and that “it's never going to be perfect”, but that is why she particularly advocates that the UK should follow the CRPD. She believes that, unlike the best interests standard, the CRPD allows for an examination of the patient’s current wishes and not an abstract painting of what they once thought.\textsuperscript{379} Similarly, Lawyer G, who has acted on behalf of the Office of the Official Solicitor, has stated that we should undoubtedly be embracing these technologies if they work. He believed that lawyers hold a duty of care for the patient, similar to any doctor, to ensure that the patient’s wishes are heard:

I think that we, as lawyers, work on behalf of the patient, right? So how can we be said to be doing what’s best for our client…the patient, if we don’t try everything to know what they’d have wanted. Taking a best guess doesn’t really happen in any other scenario.\textsuperscript{380}

\textsuperscript{378} Interview with interviewee 5 (October 6, 2019).
\textsuperscript{379} \textit{Ibid.}
\textsuperscript{380} Interview with interviewee 9 (October 21, 2019).
3.4.1.2 What is fMRI really showing us?

Interviewees were split over what it is fMRI really shows us. Seven out of eight interviewees who disagreed with using fMRI believed that the technology does not uncover any kind of hidden consciousness. Similarly, interviewees were divided over the relevance of it, even if it does uncover hidden consciousness.

Clinician C argued that just because a patient may have the brain capacity to suddenly respond to a particular question or make an audible statement, which we may perceive as having meaning, it does not mean that the patient is conscious. He states that all this shows is that for a small period of time, the patient had an increased processing power and that it does not mean it is permanent. He went on to argue that if we use the metric of ‘states’ such as PVS and MCS to discuss consciousness, then one could argue that a person lacks capacity when they are in slow-wave sleep, as they are unresponsive; he added:

[W]e all vary, and people who have got prolonged disorders of consciousness are more responsive at certain times than other times, that’s quite normal, that’s human. It's biological. All biological and variable things have peaks and spikes.381

Similarly, Lawyer A stated that humans are made up of an amalgam of our conscious and subconscious selves, and that most of what is being seen in ordinary life comes from the subconscious. He states:

[M]ost of the effect which you’re seeing is nothing to do anything which is going on at a level which is demonstrable at a functional imaging level of any sort.382

He further stated that we do not know where the “seat of ‘self’ is”, and so he would be cautious about using fMRI, as he believes that it could be used to:

381 Interview with interviewee 10 (October 27, 2019).
382 Interview with interviewee 1 (October 1, 2019).
[G]ive a sort of spurious scientific gloss to what is essentially an unevidenced metaphysical speculation about what constitutes a human. That seems to me to be fundamentalism and not science.383

As covered in Chapter Two, several studies have been conducted by Adrian Owen, and a small number of other neuroscientists, that have concluded that PDOC patients are able to demonstrate brain activity similar to that of a fully conscious person. However, this has not been universally received, welcomed or accepted. Clinician C gave the most concise answer to this question, stating:

The way Adrian Owen and others talk about it, it’s as if inside there's some hugely normal and intact personality struggling to get out. What we know absolutely, is that people who recover slowly, and do recover, don't come out as fully formed people who can have long intelligent conversations, they come out incredibly severely cognitively impaired. So it's just implausible that inside the unconscious person there's some ongoing personality who's having thoughts and experiences, wishing they could close their eyes or worrying about their wife and then, when they wake up, they don't even know who their wife is and can hardly control their limbs. It's just implausible.384

Lawyer C, a former neurological consultant, was similarly concerned by Owen's language, which seems to suggest that these patients are suffering from locked-in syndrome rather than PDOC, and therefore gives the impression of higher levels of consciousness. However, she called the use of fMRIs “extraordinary” and stated that the ability for a vegetative patient to imagine walking from room to room, or playing tennis, “is quite scary (positive)” and therefore should be added to a diagnostic framework as soon as clinical trials can be held.385

3.4.1.3 Practicality

One of the most commonly expressed views concerned the practicalities of actually performing an fMRI on a patient who is in a PDOC. Several interviewees gave different examples of why

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383 ibid.
384 Interview with interviewee 10 (October 27, 2019).
385 Interview with interviewee 5 (October 6, 2019).
this would be impractical. Six of the eight interviewees who did not believe fMRI had a place in a diagnostic or decision-making framework pointed towards whether or not all patients would be able to use the machines. Clinician E stated that a considerable number of PDOC patients are not eligible to use an fMRI machine due to metal implants or other such restrictions. He claims that because of this, by its nature, it cannot be included in a set of mandatory national guidelines.

In addition to this, Clinician C stated that fMRI can be ruled out as many patients are unable to use the machine. This clinician explained that patients in a PDOC will likely have severe respiratory needs and will be required to be continuously connected to several machines that would not allow for them to be placed in an fMRI scanner. Furthermore, Clinician G stated that patients in a PDOC have often undergone a variety of serious and invasive procedures, many of which may have required metal implants, which is especially the case for PDOC patients who have suffered a traumatic accident. These metal implants would make them unsuitable for fMRI.

The argument that fMRI cannot form part of a national guideline as it is not able to be used on all patients should not carry much weight. Not every patient is eligible for every treatment. Many patients who have cancer are not able to receive chemotherapy for a variety of reasons; this does not mean it should not be an option on the national guidance. To disregard a potential treatment so quickly, simply as it cannot be used on every patient is worrying way for doctors to look at emerging technologies.

Lawyer C stated that, although fMRI is still an “open question”, those with a duty of care to vulnerable patients owe it to them to try every alternative to understand what they want. She said that, regardless of any practical deficits:

[T]here's an absolute imperative. You don't give up. You don't give up on the idea that there's a human person in there and you've got to find out what they want.

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386 Interview with interviewee 12 (November 6, 2019).
387 Interview with interviewee 10 (October 27, 2019).
388 ibid.
389 Interview with interviewee 17 (December 6, 2019).
390 Interview with interviewee 5 (October 6, 2019).
She believed that people are resistant to change and will try to delay any advancement or change that may try to take away from the current ‘doctor knows best’ ideals of thinking.

### 3.4.2 Reform of the Mental Capacity Act 2005

The final question asked of interviewees was designed to uncover what, if anything, each of them would wish to see changed within the MCA 2005 to ensure that patients’ rights are respected. All interviewees had their own views on the MCA 2005, and whether it needs amendment; responses have been divided into three main themes. They were asked the following question:

*What changes, if any, would you wish to recommend to amend the MCA 2005 to protect the rights of patients and ensure the spirit of the current law is followed?*

Lawyer B, a medical law professor, commented how perhaps a debate is to be had over whether the MCA 2005 should be replaced in its entirety, stating:

> It's interesting to think whether or not it’s time to introduce a whole new piece of legislation, because I guess 2005 now is quite a long time ago.

> I think there's a really interesting question as to whether in the next 10 years it would make sense to just scrap both the Mental Health Act and the Mental Capacity Act. The trouble is the government obviously doesn't have any time to do anything.  

Sixteen interviewees gave substantive answers, and each suggested at least one amendment which could be made.

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391 Interview with interviewee 2 (October 27, 2019).
3.4.2.1 The problem does not sit with the MCA 2005

Five interviewees found the wording of the question curious, as they did not believe the MCA 2005 needs amending per se, but that people making decisions just need to actually familiarise themselves with the act and consistently comply with it. Lawyer F, a barrister, stated:

Many people have said that what needs to happen rather than amending the Act is for it to actually happen. So, something like the supported decision-making principle, you know that you can’t say someone lacks capacity until you have taken all measures to try to support them to make a decision unsuccessfully, clearly, that doesn't happen in practice.392

Similarly, Clinician C said that the right which is being ignored by the MCA 2005 is the patient’s right to be treated according to what the Act actually says. He believes that the House of Lords Select Committee was correct in its assertion that there was a complete failure to use the Act correctly and that it is “Used accidentally, used wrongly on purpose, and not used at all in a majority of cases.”393

A medical law professor, Lawyer H, said that rather than amending the MCA 2005, which he believed to be adequately drafted, the aim should be to amend the guidance to ensure people understand the Act:

I think the Act has got to be written in a way that's legally sound and I'm sure it could be tailored a little bit, but I think the Act has probably got to stay in a fairly legally defined way. I think the guidance needs to be tailored, the guidance going to clinical people needs to be tailored for clinical people, the guidance going to social workers, dealing with learning disability in the community, needs to be totally different. There needs to be much more tailoring of the guidance that tells you how you apply the act in your situation and get away a bit from dogmatic forms which constrain thinking. It's just

392 Interview with interviewee 8 (October 19, 2019).
393 Interview with interviewee 10 (October 27, 2019).
written in a way which is just not clinically relevant. The content of the Act is, in my view, pretty sensible. It's the way it's being used or interpreted.\textsuperscript{394}

These responses are in-line with the finding that there is a severe lack of understanding of the MCA 2005. Doctors and lawyers believe that the Act itself is, for the most part, relatively well structured but that the application at the bedside by decision-makers who do not understand the principles of the Act is the issue.

3.4.2.2 Reform of section 4

Nine of those who gave answers pointed to section 4 of the MCA 2005 as the area that most needs addressing, to varying degrees. Five lawyers and four doctors commented on section 4. The most widely held view, that was stated by seven of these nine interviewees, was that section 4 needs to give a clear priority to the wishes of the patient:

I think section 4 needs to be amended, and I think it needs to give priority to the patient's wishes and feeling explicitly. You could make them the "paramount consideration". I don't think you make them always binding because you need to give room for situations where somebody's wishes and feelings are a result of a phobia or a delusion. So, I certainly don't think what the person says they want is always what should happen, but I think it very much should be the first consideration.\textsuperscript{395}

Similarly, Clinician C responded by saying that, no matter what section 4 says, doctors simply are not following it, as they “don’t think it applies to them”. He continued by giving an example:

A colleague of mine, a rehab consultant who should know better, with a patient in a prolonged disorder of consciousness, said, "so you mean we should have been doing best interests decisions on this patient?" he'd been looking after him for a year. You have to just think, where do I even start? If

\textsuperscript{394} Interview with interviewee 14 (November 18, 2019).
\textsuperscript{395} Interview with interviewee 2 (October 3, 2019).
they don’t even think to have an assessment of the patient’s wishes then I
don’t know where we go.\textsuperscript{396}

These responses were asking for an amendment to the law to ensure that patient wishes were
the key consideration in the best interests assessment. Two interviewees went further in their
assertions about section 4, believing that it needed to be abandoned entirely:

I would scrap best interests, I think for as long as we keep the language of
best interests, doctors, social workers and others are going to keep slipping
into these highly medicalised, highly paternalistic narratives, no matter what
the detail of section 4 says.\textsuperscript{397}

Similarly, another clinician stated that she would

[R]eplace section 4 with a clear best wishes paradigm, one which can’t be
fudged or bent to mean whatever someone wishes.\textsuperscript{398}

It is a striking statement from one clinician to state that junior doctors he is training did not
understand when a best interests assessment was necessary. It is even more alarming that a
doctor was responsible for a patient for a year, and this had not been identified.

3.4.2.3 Reform of section 5

An issue raised by only one person but worthy of discussion, concerns Section 5 of the MCA
2005. Section 5 provides that a decision-maker does not incur any liability if P lacked capacity,
and they believed they were acting in the best interests of the patient. One barrister expressed
displeasure with this part of the Act, and advocated that it should be removed:

I think the general defence is a really problematic mechanism for deciding or
rather not deciding who makes decisions. I think its transferred huge amounts
of power to health and social care professionals with very few breaks. I think

\textsuperscript{396} Interview with interviewee 10 (October 27, 2019).
\textsuperscript{397} Interview with interviewee 1 (October 1, 2019).
\textsuperscript{398} Interview with interviewee 5 (October 27, 2019).
that’s why we’ve ended up with the DoLS\textsuperscript{399} and the Court of Protection being used so regularly now.\textsuperscript{400}

3.5 Conclusion

These interviews aimed to identify how legal and medical professionals understand the current legal and medical landscape, and to provide additional insight into the issues identified in Chapter Two regarding the decision-making process in PDOC cases. They also showed that a number of clear areas of contention continue to exist.

The decision in \textit{Re Y} split interviewees’ opinions on what it actually achieved. Interviewees believed that the decision would lead to a sense of relief from family members of PDOC patients, as they would no longer have the CoP looming over them. The relief of the family comes only when cases are still not regularly going to the CoP as a matter of practice; the continued frequency of CoP applications will be addressed throughout the next two chapters.

The majority of interviewees believed that \textit{Re Y} did not create any new law and that \textit{Bland} never created a binding process for PDOC decision-making. However, it would not be correct to say that the law was clear post-\textit{Bland} and many interviewees acknowledged that professionals had acted as though there \textit{was} a binding mandate for the next 25 years. There are other concerns raised in this chapter about whether \textit{Re Y} may be signalling a return to a ‘doctor knows best’ approach to decision-making; if this is the case, then it would go against the decision in \textit{Aintree} and the evolution towards a patient-centred process that the courts have been promoting in recent years.

There was a universal agreement that there remains a need for some form of independent overview in cases where there is disagreement. The form which this independent overview should take raises further questions as some interviewees suggested that a non-judicial tribunal could be utilised, while others saw the CoP as the only suitable venue.

\textsuperscript{399} Deprivation of Liberty Safeguards. DoLS was introduced as an amendment to the MCA 2005. The safeguards ensue that people who lack capacity to consent to care or treatment are sufficiently protected should the arrangements deprive them of their liberty. For more information concerning DoLS, see the following link <https://www.mind.org.uk/information-support/legal-rights/mental-capacity-act-2005/deprivation-of-liberty/> Accessed 23 May 2021.

\textsuperscript{400} Interview with interviewee 9 (October 21, 2019).
The interviews demonstrated that the conclusions reached in Chapter Two concerning the lack of understanding of best interests were well-founded. Clinicians and lawyers both agreed that there was a widespread lack of understanding of the broader welfare considerations that should constitute a best interests decision. Interviewees offered several suggestions on how clinicians could be better informed, including a more robust Code of Practice. It became clear that decision-makers are routinely not following the statutory checklist in section 4 MCA 2005, which outlines what best interests decisions include, and it was suggested that there needs to be potential reform of the Act to give a more prominent protection to the views of the patient. The interviews suggest that there is an increased medicalisation of best interests at present, as doctors are the most common decision-makers and are likely to put weight and emphasis on patients' clinical needs.

The literature reviewed in Chapter Two suggested there was concern about the rates of misdiagnosis of PDOC patients; however, the interviewees were split on whether this concern has any foundation. Instead, the responses have opened up further questions about whether there is any continued need to differentiate between PVS and MCS patients. Despite this, doubt was raised about the reliability of the diagnostic techniques used to make those distinctions. This doubt lends increased confidence in the suggestion that fMRI could be introduced into a future diagnostic framework. Although there possibly were some criticisms of what fMRI scans are indicating, the evidence presented in Chapter Two does not agree with these points of contention.

This chapter has sought to identify what professionals think about the key issues of decision-making for patients who lack capacity; the next chapter seeks to analyse, through observations of Court of Protection cases, how professionals apply these principles in practice.
Chapter Four: Observations

4.1 Introduction

The COVID-19 pandemic made it increasingly difficult to continue to conduct interviews or contact people who had previously been interviewed for clarification of comments, as a significant number of my interviewees were from the medical profession. As it was no longer possible to expand my interviews, I decided to undertake observations of hearings in the CoP. From May to October 2020, I attended 26 virtual CoP hearings, using various video-conferencing platforms such as Zoom and Microsoft Teams. This was an opportunity to observe CoP hearings with much greater ease than would usually have been the case; the CoP sits in cities throughout England and Wales, and so the lockdown restrictions meant that I was able to attend remote hearings throughout the country without having to travel.

The CoP is often referred to as a “secretive” court, making decisions behind closed doors in hearings that are not accessible to the public. Christopher Booker referred to the court as the “most sinister” and “most secretive” court in the UK. Although the CoP may conduct some of its business in a closed court, a practice used by all courts, the public and press are often free to attend the hearings should they wish. The public, however, does not seem to know this, and often hearings are listed as being ‘private’; this simply means permission must be granted at the discretion of each individual judge, usually in discussion with counsel. These observations aimed to ascertain whether the CoP truly is a secretive court, how hearings are conducted, how judges interact with the evidence, and whether the CoP is ensuring that each patient is being put at the centre of the decision-making process.

Not all cases dealt directly with the removal of clinically assisted nutrition and hydration (CANH); however, best interests decisions were being made, irrespective of the facts of the case, and the way in which the CoP handles best interests in any type of case is relevant to the core purpose of this research. When an application is made to observe a remote hearing before the CoP sitting at the Royal Courts of Justice, the public does not know the issues involved in the case. In some lower courts, the case listing will give a summary of the orders being sought. This means that I often asked to observe a case and was unable to know, until the case began, whether the facts were pertinent to my research aim.

Three of the cases I attended were vacated part-way through the hearing, and five of the hearings did not include a best interests determination, as the judgment was reserved for another day, so I was not able to hear any judicial reasoning. Four other cases were hearings to vary orders and therefore lasted little time. In one hearing, I was asked to remove myself as the parties had decided, after opening the case, to continue the hearing ‘in chambers’. These 13 cases are not included in this chapter, as they did not involve any best interests determinations or discussion. Of the remaining 13 hearings, which I will refer to by numbers 1-13, four concerned CANH, seven concerned other serious medical interventions, including life-sustaining treatment (LST), one concerned whether a patient had the capacity to decide his care facility, and one concerned a property and welfare attorney appointment. Judgments have since been published for five cases; all other cases are currently unreported. Cases are kept anonymous in this thesis to preserve the identity of the parties. This is to lessen the risk of any form of ‘jigsaw identification’ of the protected party.

As explained in 1.3.3, throughout this chapter any mention of ‘P’ refers to the protected party, whom the case is concerning. Not every party was in a clinical environment, and it should therefore not be taken to mean a medical patient as not all parties to the proceedings were inpatients in a medical facility.

4.1.1 Transparency order

In all cases, I am subject to a transparency order (TO), which prohibits the identification of certain parties involved in the cases. Each case had individual reporting restrictions, and as such, which parties, places or things are prohibited from being identified are case-specific. The TOs do, however, allow for publication relating to the proceedings and facts of the case. Below
is an example of one of the orders, which is representative of an order produced in what the CoP calls the “standard form” (copied verbatim, including capitalisations):

(8) Subject to further order of the Court this Injunction:
   (i) does not prevent the Persons Bound by this Injunction:
      (a) reporting or commenting upon these proceedings, save in so far as such reports or comments are prohibited pursuant to paragraph (6) above,
      (b) reporting or commenting upon proceedings in the Court of Protection generally or in relation to applications similar to this one,
      (c) publishing information relating to any part of a hearing in a court in England and Wales (including a coroner’s court) in which the court was sitting in public and did not itself make any order restricting publication

All transparency orders, although different in their wording, allow for the publication of material. Two TO’s, from Cases 12 and 13, were much more restrictive and do not allow for the identification of several possibly identifying yet essential factors of the case. As a result, these two cases will have less detailed summaries. TOs are public documents and are not reserved for those who attend a hearing.

All parties will be anonymised using initials that do not relate to their true identities. It should be noted that not all hearings served a physical injunction, a warning was instead read to those in attendance before the case began, stating that an order applied in the standard terms. In some cases, I was personally named on the injunctions, orders, or other court materials to ensure that I understood the obligations imposed on me. Every case discussion is in keeping with any orders of the CoP. The judges in each case were made aware of the purpose of my attendance and permitted me on that basis.

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403 Transparency order from Mr Justice Hayden, dated 30 June 2020.
4.1.2 Method

I undertook direct non-participant observations of the CoP via video conferencing software. Direct observation is a means of watching subjects in their familiar environment without seeking to alter the process. My method of observation was overt in nature as all of the individuals in a CoP hearing were aware of the purpose of my observations.

Although my method sought to be as non-intrusive as possible, it has become apparent that my presence, and the presence of other observers, had a significant degree of influence over how the CoP has navigated virtual hearings throughout the COVID-19 pandemic. This influence will be discussed further in section 4.3.4 of this chapter.

Throughout the hearings, I sat silently and took detailed handwritten or typed notes of the evidence being presented and the statements being made by lawyers, doctors, and judges. In a number of cases, there were other observers in the hearing with whom I was able to correspond to ensure the accuracy of my notes. All of my notes were transferred to a word-processed document and were password-protected. Unfortunately, audio recording is still prohibited within the CoP; therefore, all direct quotations are as accurate as possible but are not to be assumed as verbatim quotations of the hearing, although they do reflect what was being said.

4.2 Observations

This section includes three sub-sections: summaries of the cases, best interests and court process. Each sub-section discusses examples of a selection of the hearings observed and illustrate how the parties in the court (the judge, counsel, doctors etc.) applied the principles of best interests. Certain cases have been released into the public domain via judgments, news reports or blogs; where this is the case certain parties will be named, as per the publicly available information. I observed cases in front of all three tiers of CoP judges.

This approach was deliberately adopted to observe whether best interests practices vary according to the tier of the judge hearing the case. Tiers of judges are unique to the Court of Protection and are defined in Rule 2.1 of the 2017 Rules. The levels can be summarised as follows:
• A Tier 1 Judge is a district judge of the County Court;
• A Tier 2 Judge is a circuit judge, a recorder, a judge (or deputy judge) of the Upper Tribunal, or any judge nominated under s46 MCA 2005;
• A Tier 3 Judge is the President, Vice-President, Master of the Rolls, Lord Chief Justice, or any other judge (or deputy judge) of the High Court or Court of Appeal.

How cases are allocated is based on the issues to be decided. In 2020, Hayden J, in his role as Vice-President of the Family Division of the RCJ, issued practice guidance on how case managers should allocate cases, stating:

Where a decision has been made to pursue an application to the court in relation to a serious medical treatment decision or in respect of a case involving an ethical dilemma, in an untested area, the proceedings (including permission, the giving of any directions, and any hearing) must be conducted by a Tier 3 judge, unless the Senior Judge or a Tier 3 judge determines to the contrary.\(^405\)

The case summaries will mention which tier of judge heard the case.

4.2.1 Case summaries

This section will briefly outline the facts and judgments of the 13 observed cases, most of which have been unreported. Only five of the 13 observed cases received a publicly published judgment on BAILII; the remaining cases received judgment *ex tempore*, where the judges produced no written document themselves, but counsel would transcribe the oral judgment and have it approved. Therefore, the majority of the cases detailed below cannot be found through a case law search. Where cases have a published judgment, it will be referenced via a footnote.

Not all cases summarised below concern PDOC or the withdrawal of treatment, however, every case concerns the application of best interests as that is the standard applied in all CoP cases.

The way in which the CoP and experts handle best interests is therefore of relevance regardless of the context of the case. Furthermore, other cases raised issues such as delay in the CoP or by counsel, which has a clear impact on the welfare of parties concerned. All the cases summarised below offered some form of directly relevant information to decision-making or the ability of the Court of Protection to adequately fulfil its functions.

Case 1

This case concerneda young man, WA, who was on hunger strike as a result of a Home Office decision that imposed a date of birth upon him that he does not recognise. The Home Office determined that WA was older than he claimed to be. The young man had fled Hamas and had endured significant amounts of physical and mental torture at their hands, before eventually finding his way, alone, to Britain. WA believed that the removal of his date of birth represented a violation of his most fundamental rights and struck at the core of his personal identity. Throughout the hearing, he stated that his date of birth was one of the only things that remained with him from his birth parents, whom Hamas murdered. He will not commit the Home Office-ordered date of birth to memory, and as a result, has been denied opportunities he wishes to pursue. This rejection led him to refuse to eat, which ultimately meant that he has ended up in a critical condition in hospital. He required a nasogastric (NG) tube to be able to receive sufficient nutrition to sustain his life.

The judge, Mr Justice Hayden (Tier 3 Judge), remarked on several occasions throughout, that decisions under the MCA 2005 are patient-centred. The young man in question was a party to the Microsoft Teams hearing from his hospital bed, alongside his British foster mother and father, and was able to engage every step of the way. Hayden J was extremely careful not to overwhelm WA whilst he was ill in his hospital bed and therefore took frequent breaks.

The decision was made that WA lacked the capacity to make decisions relating to his nutrition; he held an “overvalued idea” concerning his date of birth, which meant that he could not make decisions concerning anything linked with it. However, the judge said that the decision concerning whether or not WA accepts food rests solely with WA. It was decided that WA should be supported in his decision-making by doctors and loved ones, but that if WA does not wish to receive NG tube feeding, then that is his choice to make, despite his lacking capacity.

Case 2

This case concerned a potential below-knee amputation of a 61-year-old man, PA, with a long history of mental health issues. He had paranoid schizophrenia, which had rendered him unable to consent to treatment for a severe infection in his foot. He refused to allow doctors to assess the severity of the infection, despite having had a partial amputation of his foot six weeks earlier; therefore, the NHS Trust sought an order to allow PA to be placed under a general anaesthetic and have a below-knee amputation performed.

During the week of the hearing, there had been a slight shift in PA’s willingness to have medical intervention; he was allowing his doctor to assess the wound visually but was still not allowing him to touch him. The doctor’s assessment was that the infection might not be as widespread as he had once believed. The NHS Trust therefore sought an amended order which would allow for a complex series of events to occur. They asked the Tier 3 judge to grant an order that would declare it is in PA’s best interests to undergo exploratory surgery under a general anaesthetic, where the doctor will seek to debride the wound of any necrotic flesh and then sterilise and dress it. However, the Trust asked the CoP to give discretion to the surgeon on the day and allow him to perform a below-knee amputation then and there, should the exploratory surgery reveal a much more severe level of damage.

The CoP granted the order sought by the Trust that would allow for the exploratory surgery and potentially a below-knee amputation. After hearing evidence from PA’s doctor, brother and son who all believed it was in his best interests, the judge came to this conclusion, despite PA stating that he did not wish for any further medical interventions.

Case 3

This case, before a Tier 3 Judge, concerned an 18-year-old girl, A, who had been in care since 2009 and suffered from a reactive attachment disorder; she is said to pose a serious risk to herself and others. The court was asked to make a declaration concerning the residency and care for A, and give a ruling on which members of her family can and cannot have contact with her while she is in her placement. Several placements were identified for A, but they repeatedly

407 The Mayo Clinic defines a reactive attachment disorder as being a “rare but serious condition in which an infant or young child doesn’t establish healthy attachments with parents or caregivers” see more here <https://www.mayoclinic.org/diseases-conditions/reactive-attachment-disorder/symptoms-causes/syc-20352939> Accessed 6 October 2020.
fell through, owing to A’s mental health issues causing distress to the placement managers. As a result of this, this case has been before the CoP on numerous occasions over the past few months and is yet to be resolved.

Case 4

The person at the centre of this case, F, was a woman in her mid-40s with granulosa cell cancer,\textsuperscript{408} for which she had refused treatment. F’s doctors submitted that the tumour had grown, and as a result, F was in increasing pain. Doctors suggested that she should have a total hysterectomy with an oophorectomy.\textsuperscript{409} F continued to refuse any consent for the operations to take place. This hearing was a directions hearing before a Tier 3 judge; its purpose was to agree on what future steps should be taken to make a determination on F’s capacity and best interests. There were numerous direct exchanges between F and the judge throughout this hearing.

Case 5

This case concerned an 80-year-old man, JS, who suffered a severe stroke in 2016 and had a percutaneous endoscopic gastrostomy (PEG) tube inserted a month later to administer CANH. At a separate hearing, many months previously, JS had been found to lack capacity; it was decided at that hearing to be in JS’s best interests for CANH to remain via the PEG tube. The PEG tube had fallen out, and as a matter of course, the NHS Trust sought a declaration that it would be in his best interests to have the tube re-inserted. The Official Solicitor supported the application on behalf of JS but was opposed by JS’s daughter (K). K believed that her father would want to be removed from the PEG and be allowed to pass away.

The Tier 3 judge was being asked to decide whether JS’s circumstances had substantially changed from the last time his case was before the CoP, as if there was not a material change, he would not have jurisdiction to overturn a fellow High Court judge’s ruling. Ultimately, it was decided that it was in JS’s best interests to have the PEG tube re-inserted: JS still had some

\textsuperscript{408} Granulosa cell tumour of the ovaries is a rare form of ovarian cancer, for more information see the Genetic and Rare Diseases Information Center '<https://rarediseases.info.nih.gov/diseases/8642/granulosa-cell-tumor-of-the-ovary>' > Accessed 2 November 2020.

\textsuperscript{409} This includes the removal of both the womb and the ovaries. For more information see the following links 'https://www.mayoclinic.org/tests-procedures/oophorectomy/in-depth/breast-cancer/art-20047337' and 'https://www.nhs.uk/conditions/hysterectomy/' > Accessed 2 November 2020.
kind of quality of life, and in the absence of an advance decision, there was no evidence of what JS would have wished.

Case 6

The young woman at the centre of this case, D, suffered from anorexia nervosa and was said to be in a “severe and chronic” state; the illness had caused increasingly debilitating effects, and she was considered to be in the end stages of her life. D weighed approximately four stone and was so fragile that there was an imminent risk of death from cardiac arrest. Therefore, the NHS Trust was seeking a court declaration that D lacked capacity and it would not be in her best interests to receive any further medical treatment for anorexia nervosa. Any further treatment to D was deemed to be too risky, as her fragility was so profound that the insertion of an NG tube would likely result in her death. D was herself in agreement with this, she did not wish to receive any further treatment, and her family was supportive of the application.

The Tier 3 Judge decided that the nature of anorexia nervosa meant that D did not have sufficient capacity to make any decision regarding her nutrition; nonetheless, the judge stated that D was an “intelligent and emotionally responsive young woman who is both thoughtful, articulate and insightful in terms of the position in which she now finds herself”. The order was granted that it would be in D’s best interests to cease receiving any treatment for her anorexia nervosa.

Case 7

This case, before a Tier 3 Judge, was fraught with issues about representation and parties being present for the virtual CoP hearing. The patient, NB, was diagnosed with dementia and was being treated in hospital for COVID-19 and pneumonia. Issues arose with regards to the care and placement plan NB would receive on his assumed discharge from the hospital. This hearing was heard on two consecutive days as, on the first day of the hearing, some counsel had failed to attend the Microsoft Teams hearing. These issues of communication and delay will be addressed further later in this chapter.
Case 8

This case, heard before a Tier 1 Judge, concerned L, who was in a care home but wished to move back to his private residence, as he had made it clear that he did not wish to be in any care facility. However, L’s home was deemed unsafe for him to live in and would require extensive renovations, costing over £100,000 plus VAT. The cost of these renovations, as well as the proposed care plan, would come from L, who was said to have the financial means to afford it.

The CoP decided that the work on L’s home should be carried out, but there is a “delicate balance” that must be followed. This balance was to enable the renovations to be completed while at the same time ensuring that L still recognised it as his home, and ensuring he did not suffer any distress. The judge clearly stated that the renovations would not need to go above and beyond what is necessary to make it safe and habitable for L and his carer.

Case 9

The person at the centre of this case, G, was a woman in her late 30s who had end-stage kidney failure. Doctors said that G had a “complex” psychotic illness, which the applicant Trust said meant she lacked capacity over decisions regarding dialysis treatment. G refused dialysis for several weeks; although she had recently agreed to two sessions, this agreement could not be relied on consistently. The Tier 3 judge was consequently asked to grant an order that it was in G’s best interests to receive dialysis treatment and that restraint may be used to administer it.

The issue before the CoP was that G had stated that she did not wish to receive dialysis and would not accept that it would save her life. The judge also had to consider the fact that given G’s need for dialysis would be regular, the judge would be authorising restraint for an unknown number of occasions. G suffered from paranoia and was said to have been delusional and erratic; it was submitted that restraining her would exacerbate her paranoia. The order sought by the Trust was ultimately granted, as the judge saw it as necessary “to save the life of this still-young woman”, who had lost capacity, even if for only a temporary length of time.

Case 10

This case concerned J, a 30-year-old man with a severe learning disability, autism spectrum disorder, communication difficulties, obesity, and diabetes. J had a history of drug abuse and
of inappropriate sexual behaviour, which has involved police action. The local authority sought a s16 MCA 2005 personal welfare order, that would enable them to remove J from his mother’s home and move him to a placement. Evidence was heard that J’s mother would leave J alone for extended periods and would not give him his diabetes medication, which were serious welfare concerns for the local authority. The local authority became further concerned when J’s mother stated that she would kill her son should the CoP order he be taken away from her.

This case was ongoing for several months and found itself before both Tier 1 and Tier 2 judges throughout five hearings, spanning six months. The initial order to remove J was granted, and he was taken to placement X. This placement later broke down, and J was again arrested by police and sectioned under the Mental Health Act, Section 2. At the time of writing, it is still an ongoing case that has had several orders granted, all of which have later been taken back to the CoP due to placements falling through or concerns from the Official Solicitor about adequate safeguarding or consideration of J’s wishes and feelings.

**Case 11**

These proceedings related to L, a woman in her late 20s who has a personality disorder, significant learning disabilities, and diabetes. Her learning disability and personality disorder have led her to self-harm and suffer from fears of abandonment. The Tier 3 judge was asked to decide three things: whether L required continued 24/7 support and observation, whether the local authority should replace L’s mother as her property and affairs deputy, and whether the mother should become L’s personal welfare deputy.

These issues arose as L expressed that she no longer wished for her mother to control her finances, as L claimed that her mother would regularly refuse to buy L what she needed, a claim that the mother rejected. At the time of the hearing, L was living in her own flat, with a package of care, and had been allowed an increased amount of independence, leading to her forming sexual relationships, some of which were described as ‘exploitive’.

The judge said that these legal proceedings had been ongoing for more than a year and were used as a ‘crutch’. Therefore, the judge was clear that the proceedings must be brought to an end, for L’s sake, and that some form of stability be sought. It was ordered that the council
would control L’s finances and that she would no longer require 24/7 care but should have frequent support.

The judge was also critical that L was allowed to leave the country to go on holiday, in the middle of the COVID-19 pandemic, and that her carer had accompanied her. The court saw this as being entirely against the aims of trying to keep L safe.

*Case 12*

This case concerned KB, a woman in her mid-30s who had suffered a hypoxic brain injury at birth, which left her with significant learning difficulties. This case was under much greater reporting restrictions than the cases mentioned above, including restrictions on a number of details that describe KB and the names of other public bodies involved. Despite being under 24-hour care and in receipt of an extensive care package from the local authority, KB was the victim of rape and subsequently became pregnant. Evidence suggested that her disabilities were so profound that she would not be able to have a vaginal birth, as she could not follow any professional instruction given to her. Therefore, the applicant, A London NHS Trust, sought an order from a Tier 3 Judge that it was in KB’s best interests to undergo a Caesarean section.

There were issues raised as to the length of time it had taken the NHS Trust and local authority to make an application to the CoP; the MCA 2005 guidance advises that cases such as this should be brought before the CoP swiftly. When KB’s pregnancy was first noticed and brought to the attention of her GP, she was 22 weeks pregnant; however, delays meant that by the time KB’s case was discussed by senior consultants, she had passed the point at which termination was possible, despite it being on record as being an issue to be addressed. Three months passed between the initial date of KB’s GP visit and when the application was made to the CoP, a delay that the judge criticised during *ex tempore* judgment.

The judge granted the order sought on the grounds that KB’s lack of understanding meant that should she go to full term and have a vaginal birth, it would be deeply traumatic for her as she could not even understand the concept of a baby growing inside her.
Case 13

P (per the transparency order), a British national, suffered a severe hypoxic brain injury while in another European country and was left with a prolonged disorder of consciousness. Similar to Case 12, this case also had a very restrictive transparency order that diverged from the standard order. There are many factors relating to P, that cannot be mentioned. His treatment was part-funded by the NHS and partly by the authorities in the second jurisdiction, where he resided at the time of the hearing. It is proposed that P returned to England to receive care and treatment here, as his family was having to pay a daily “top-up” fee for medical treatment by the local jurisdiction, a cost that they said they could not afford for much longer. Furthermore, the local jurisdiction would not continue to fund treatment indefinitely. There were further issues raised before the Tier 3 Judge as to whether or not P would wish to receive care in England or in the second jurisdiction, something that could not be agreed upon between counsel for P’s wife and counsel for P.

There is, however, nothing to suggest that P was imminently facing the end of life; P’s family in the other jurisdiction said that he would communicate to them via facial movements, and the medical team said he displayed emotion, such as crying. In a private hearing, it was ultimately decided that P should be allowed to return to Britain to receive palliative care rather than remain in another jurisdiction, at great expense and distress to some members of his family. Although I was informed of the outcome of this hearing, the public were excluded at the request of P’s wife.

4.2.2 Best interests

This section will cover how the best interests standard was applied in the 13 hearings. In the previous two chapters, it has been clear that there is much contention around the meaning and application of the term best interests. The purpose of these observations was to see how the CoP, and other parties within the hearings, interpret and apply the best interests standard in practice; this contrasts with their theoretical understanding, which was evidenced within Chapters Two and Three of this thesis.
This section will illustrate the varying ways in which the best interests standard was applied throughout these hearings and how judges and lawyers had differing interpretations of what constitutes patient-centred decision-making.

**Wishes and feelings**

Chapters One and Two have shown that there has been a shift in the understanding of the best interests test over the last 25 years. There is now a much greater emphasis being placed on the views of the patient. Throughout these observations, it was clear that judges and counsel were making a conscious effort to ensure that each patient’s wishes and feelings were being addressed; however, the extent of the discussion, the depth of the analysis and the weight given to them varied greatly in every hearing. This section will discuss the different ways in which wishes and feelings were handled in the cases observed.

Cases 1 and 6 were the epitome of patient-centred discourse within the CoP. A very significant amount of time was devoted in Case 1 to hearing directly from the patient. The judge, Hayden J, wanted to know everything about WA and who he was as a person before making any decisions. This case was scheduled to last for two days but was extended for an additional day to allow WA to take his time in having discussions with the judge about his friends, family, hobbies and background. Regard was had for WA’s Islamic upbringing, his strong will and determination, and his feeling of hopelessness in the face of the Home Office’s refusal to rehear his case. WA was able, in this case, to neatly explain to all present precisely what he wanted to happen. He did not wish to die, WA said that he had a happy life and loved his family greatly; however, he did not feel able to continue living when such a large part of his identity had been stripped from him. At one point, Hayden J asked WA how he manages to reconcile his desire to be allowed to refuse nutrition and hydration, and therefore inevitably die, with his Islamic faith. Hayden J was visibly surprised by WA acknowledging that he knew there was a contradiction and just hoped God would forgive him. Despite it being decided that WA lacked capacity, it was said that his wishes should be honoured and that doctors and the family could not overrule them. Hayden J said that any further decisions must be made by WA alone, in consultation with doctors and his family, but they must not seek to make him do anything that makes him uncomfortable.
Similarly, Case 6 put the patient completely at the centre of decision-making. Although the patient, D, did not speak directly with the judge, due to her frailty, she did provide an unequivocal statement to the court. In her statement, D said that “it would be like being punished twice: once by having the illness, and once in an attempt to ‘treat’ it”. Treatment options were limited, and expert evidence suggested that there would be severe trauma to D should doctors try to undertake a coercive feeding regime. D understood that without this treatment, she would die, and she was content with that reality. Throughout the hearing, the judge would consistently return to what D was like and what she wanted.

Despite the judge’s finding that D lacked capacity to make decisions relating to her nutrition, the judge ruled that D’s wishes and feelings must be honoured, as her views on continued treatment were clear, and they aligned with much of the evidence given by expert witnesses. D’s solicitor read aloud a lengthy statement from D that described her treatment, how she was “held down by my legs with a tube thrust forcefully… up my nose”. She recalled how she had been left covered in bruises, lied to and blackmailed by those attempting to treat her. This degrading treatment and the illness itself, which she said was a part of her and like a voice, led her to make this decision. She was clear that it was her decision and her “voice” that led her to this.

At the conclusion of the hearing, before judgment had been handed down, the judge assured D that she would not go against D’s express wishes and that it would not be in her best interests to undergo any further treatment. The judge did this to ensure that D would not be left nervously awaiting judgment and scared that she was being ignored.

However, not every case went into such depths in considering the wishes and feelings of P; some cases barely mentioned the person’s belief system or dismissed it within a very short space of time. In Case 2, for example, there was minimal discussion of PA’s wishes and feelings, other than to say that he vehemently expressed that he did not want any further medical intervention. PA’s brother and son gave evidence to the court, both saying that he would not want any invasive surgery. PA’s son did, however, state “I think if he understood the life-threatening situation he’s in, he would be on board with the surgery. But he doesn’t seem to understand.”
This case is reminiscent of multiple CoP cases concerning the amputation of the extremities of a patient who is deemed to lack capacity, such as *Wye Valley* v *B*. The difference, however, between this case and *Wye Valley* is that X could not comprehend the outcome of his refusal to accept treatment; B, in *Wye Valley*, was able to discuss that he knew he would die and that he was content with that. There was seemingly an assumption from all parties in the court that because X was refusing treatment of such a serious nature, he must not be thinking rationally, and it was clearly in his best interests to overrule his incapacitous wishes. Little discussion of X’s wishes or the principle of wishes and feelings occurred during the proceedings. During the judge’s oral judgment, she stated:

I record that there is no evidence that this is one of those difficult cases where P in any sense understands the risk, or for whatever reason, is willing to accept the risk that he may die. There is no evidence that he is resisting an operation or further treatment out of some deeply felt religious or other belief system. It simply seems to be a case where he has no insight into his condition.  

Therefore, it seems that the best interests decision, in this case, was not made by evaluating the current or prior wishes of X; instead, it was made by evaluating his current ability to comprehend the risks versus the evidence given by the doctor as to the seriousness of the infection.

Unlike Case 6, described above, the hearing of Case 9 involved G writing statements to the court, expressing how she did not want to receive dialysis treatment; however, due to her incapacity, G did not accept that the treatment would be lifesaving. G suffered from severe delusional paranoia, believing that doctors were trying to control her, and her expressed wish not to be restrained and receive dialysis was overruled. Ultimately it was said that G has a mental illness that she can recover from, and so the judge decided that G could not be said to want to die and that her delusions were disconnecting her from her true beliefs. The judge tried to get G to speak directly to him but instead had to hear her wishes and feelings based on written submissions, as G had expressed a wish not to speak to the court.

410 [2015] EWCOP 60.
411 Note – this transcription was written during the course of the hearing and so may not be entirely accurate but does represent the words used by the judge as closely as possible.
G’s wishes and feelings were, like the cases mentioned above, very clear. However, these wishes and feelings were seen to be the result of her mental illness and not of who P actually is at the time of making the decision. Therefore, the judge chose to strike an extremely tight balance between hearing what G had to say and deciding what weight to attach to those views.

**Direct participation of P**

In recent years, particularly since the introduction of the CoP Rules 2017, there has been a greater emphasis placed on the participation of P in hearings concerning their own capacity. The Court of Protection Handbook notes that there is a string of cases from the European Court of Human Rights that require proper participation by P in order to remain compliant with Article 6 and 8 rights.\(^{412}\) Consequently, rule 1.2 of the CoP Rules requires that the court make a direction concerning P’s adequate participation within the initial directions hearing. Participation may be through an intermediary, or r1.2(2)(d) provides for P to address the judge who is determining the application. Although it is not a legal requirement for the judge to speak directly with P, there has been a trend within judicial statements and decisions in recent years for judges to visit P in their hospital or care home. My observations, however, took place amidst nationwide COVID-19 restrictions, meaning travel to hospitals and care homes would not be permitted. Mr Justice Hayden has issued guidance on how P’s voice can best be heard during these times, stating that “imaginative ideas are welcome, to ensure that P participates in their proceedings where they are able to so do safely and proportionately.”\(^{413}\)

In five\(^{414}\) of the 13 observed cases, judges were persistent in their wish to communicate in person with the patient in some form. These observations took place under COVID-19 lockdown restrictions, so it was not possible for any of the judges to physically attend a hospital to see any of the patients they were discussing. Instead, judges were able to have the patient physically present in hearings through remote video conferencing. In three of the five cases, judges spoke directly with the patient via remote software, and in two cases, there was an express wish by the judge to communicate with P, but it was not possible due to technical issues or P’s refusal to engage in any discussion.

\(^{412}\) Ruck Keene \((n\ \text{404})\) [297].


\(^{414}\) Cases 1, 4, 5, 9 and 10.
During Case 1, WA was visible only to the judge, via an iPad in the judge’s chambers; this was done to maintain the patient’s privacy while he was critically ill in his hospital bed. Contrastingly, in Case 10, the judge stated throughout the hearing that she wished to set up a direct line of communication with J and that she wished it to be facilitated as soon as possible; however, counsel made inquiries and found that the patient, who has schizophrenia, would not speak to the judge. This cannot be blamed on the judge, who did her best to include J in his hearing and ensure his voice could be heard; Court of Protection hearings are always likely to be fraught with issues about whether P is physically able to take part in the hearing simply due to the nature of the matters before the CoP. This issue was further evidenced in Case 9, where the court invited G to take part in her hearing on at least three occasions. In this case, G provided a written statement to the court but stated that she did not wish to “speak to a stranger”.

Despite this, the judge continued, unsuccessfully, to ask counsel to make contact again with her throughout the hearing to see if she would talk to him. The issue of the participation of P was also shown in Case 5, where JS was unable to communicate fluently, due to a severe stroke which rendered him with limited functionality. In cases such as this, it is not reasonable to expect the judge to speak directly with JS, as there would be no benefit to putting the patient under increased levels of strain when they have limited or no communication abilities. However, cases in which P is entirely non-communicative are rare. It is much more likely that P has some form of communication ability but may not wish to take part due to their mental impairment.

The help that P may provide to the court’s understanding can be evidenced in Case 4. In this case, F joined the hearing via telephone (she did not wish to be seen by members of the public) and was significantly involved in her hearing. F was interjecting when counsel was presenting evidence and was asking questions to the court, which the judge took the time to explain to her calmly and clearly. She was, for example, confused about the process behind a capacity assessment, and the judge took the time to ensure that she correctly understood how decisions are made. The judge further took the time to listen to all of F’s views on the case and noted that she made some very crucial points and arguments, which counsel had not raised. F stated that she did not wish to discuss her treatment options with capacity assessors and that a person whose capacity was not in doubt would not need to explain their reasoning for not wishing to discuss it. The judge agreed that the process has an inherent bias that P can only prove her capacity by doing precisely the thing she does not wish to do. This was one of many
interventions by a P that ultimately benefited the court in learning more about P as a person and what her belief system is.

However, this is not always the manner in which the CoP seeks to involve P in their proceedings, as envisaged by Mr Justice Hayden. In the majority of cases, P’s participation is not direct. There are cases where judges have stated that they do not need to speak to P to try to understand them on an individual level, before making decisions concerning their welfare. In Case 3, for example, the father of A asked for the judge to take the time to speak to A, to understand who she is and what she would want. The judge said to the father that counsel is here for that reason and that it is not the role of the judge. The clearly distraught father continued to plead for his daughter, but his request was refused.

Similarly, two more cases (2 and 8) were conducted with judges merely stating that the rule requiring P’s participation was being adhered to through the presence of the Official Solicitor. This is compliant with rule 1.2 but is not what Hayden J had hoped for when issuing his guidance. At no point during the course of Cases 2, 3 and 8 did any counsel object or urge the judge to speak directly with P. In Case 2, PA had clear views on not wanting treatment and, although he had schizophrenia that rendered him incapacitous, this does not preclude him from having a view on his treatment. A patient who lacks the capacity to make treatment decisions is entitled to express their incapacitous views and wishes; the judge can then decide what weight to attach to those views in making their decision.

The shift within the CoP, to speak directly with the subject of the proceedings is to ensure that the views of the protected party are being adequately represented and are not overshadowed by the views of other interested parties. This is, of course, not to suggest that counsel and the Official Solicitor are not adequately presenting P’s views; however, in the absence of an advance decision, only one person can really know what P wants, and that is P him/herself. If P is wholly unable to communicate, such as in some PDOC cases, judges often defer to the experts or to those who knew P best.

*If not P, then who?*

The patient was not the only voice heard throughout these cases; in seven of the 13 cases, family members, friends or carers either spoke to the court or provided written submissions.
Similarly, in every case, expert witnesses either spoke in the hearing in-person or provided written evidence. The weight which was attached to these two different groups of people varied greatly throughout the hearings. It appeared that when the family members’ views were in agreement with the expert evidence presented, they were more likely to be followed; however, when family members disagreed and presented their own evidence, it was likely to have less weight attached to it.

Case 5 illustrates where expert or professional evidence outweighed the views and evidence presented by a member of JS’s family. In this case, JS’s daughter (K) gave demonstrably emotive evidence where she laid out the reasons why her father would not wish to be kept alive via artificial nutrition and hydration. K argued that her father, who had worked for the NHS for over 30 years, had repeatedly told all his family that he would not want to be a “body in a bed” and that he would be “horrified” to think he was a burden to the NHS. She spoke at great length to the court in-person and was questioned by all parties on why she believed her father would not want this treatment. She contended that he could “be put in a cupboard” and would not know the difference, that his value of life had deteriorated to that extent. However, K had not seen her father in almost a year due to the COVID-19 pandemic. She had also refused video calls with him, as she claimed the nursing home would not let the calls be in private, a point the nursing home did not accept. Her evidence was that when she had seen JS, who had been in this state since 2016, he could not speak to her or express any real emotion and had zero quality of life.

However, in this case, evidence was also given by an expert witness, Dr X, and by the care home manager where JS was living. The doctor gave evidence that JS could likely live for a number of years, and they expected him to recover from the pneumonia he was currently suffering from and return to his pre-pneumonia health. Dr X believed that JS was extremely well-nourished and not showing signs of any kind of immediate deterioration in his health. Similarly, the care home gave evidence that JS had interacted with the staff and had expressed that he was “not unhappy” with his current situation. The care home said that JS expressed emotion at things such as poetry and demonstrated limited communication.

While the judge in this case gave a large amount of court time to K, he ultimately decided that her evidence did not outweigh that of the expert and other professional witnesses. The judge
stated that he did not agree with the description of JS’s life provided by K and was instead more inclined to follow the evidence of the care home.

The judge in Case 2, however, gave greater weight to the evidence provided by PA’s brother and son, who were both in agreement with the view of the expert witness, Dr G. The judge relied heavily on the evidence provided by Dr G, as both the applicant Trust and the Official Solicitor were in agreement that his suggested surgery was the correct course of action. As the views of PA’s brother and son accorded with the evidence of Dr G, the judge was able to grant the order with no opposing discussion. Although PA himself was resisting the surgery, his son gave evidence, cited previously, that PA does not understand the life-threatening nature of the infection. His brother stated that although PA “won’t be happy whatsoever”, he will come to understand. It was the evidence of Dr G, supplemented by the family of PA, that helped the judge conclude that it was in PA’s best interests to overrule his stated wishes and feelings and go forward with the exploratory surgery, and potential amputation.

Case 12 illustrated the difficulty the CoP faces when P’s closest family and friends are in disagreement about what P would have wanted. KB and his wife were in the middle of a divorce when he entered a PDOC in a foreign country. His wife was content with KB remaining in the other jurisdiction, and his treatment ceasing when it could no longer be afforded. KB’s siblings, however, said that he would want to have his final months in Britain. This case highlights the delicate nature of who evidence should be taken from and what weight should be attached to it. Although interviewees in the previous chapter rejected the notion of ulterior motives in people giving evidence, it was clearly raised as an issue in this case.

4.2.3 Court process

These observations also identified another set of issues with the way in which the CoP functions and its ability to hear cases adequately. It was clear that there are time constraints and communication issues amongst the parties to the proceedings which could have serious effects on the effectiveness of the court to hear cases of such a serious nature properly.
Communication and delay

In six cases, the judge commented on a lack of communication between the parties and the court. In Case 3 the judge was highly critical of the fact that she only had sight of crucial documents about A’s current welfare in the moments leading up to the hearing. The judge said that “producing documents this late doesn’t help justice” and that it is incredibly hard for a judge to decide whether to deprive someone of their liberty in a fair manner when documents are produced this late into the hearing. Similarly, in Case 7, the judge commented that the bundles being produced were extremely large and produced at the last minute, which the judge would not be able to read in time. She stated that Hayden J had “made his views clear” on bundles that were not concise and sought to diverge off-topic. The often-extraordinary length of bundles is something that Sir James Munby, the former President of the Court of Protection, said “must stop” and that arguments must be distilled to ensure that the court can work efficiently to identify and deal with the primary issues.415

The issue of delays within mental capacity cases falls not just within the Court of Protection itself and how it is operated but also externally from the CoP and leads to decisions not ending up in the CoP in the timely manner they should do. Case 7 was an example of the delays within the CoP itself. In this hearing, counsel for the Official Solicitor was present, but no counsel from the NHS Trust or Local Authority either appeared or served the court with position statements or a reason for their lack of attendance. This case, concerning serious medical treatment, had to be postponed continually throughout the day while counsel attempted to find out why the NHS Trust and Local Authority had not instructed counsel. Enquiries were made throughout the day, and counsel was found for the local authority, although she was without instruction. On the second day of the hearing, the NHS Trust found counsel, but parties were still with minimal information. The judge stated that “what is required now is communication and clear lines of communication at that”. The case was ultimately delayed for an entire week, to fit it into the next available hearing date.

The Court of Protection has, like all courts throughout the COVID-19 pandemic, accumulated a significant backlog of cases. In November 2020, Her Majesty’s Courts and Tribunals Service

released a report into the effects of COVID-19 on the Family Court. Although the courts are now beginning to see a return to pre-COVID delay and completion levels, they say that there is still only a 70-80% completion rate in the Family Division.\footnote{HMCTS, ‘COVID-19: Overview of HMCTS Recovery for Civil and Family Courts and Tribunals’ (HMCTS, November 2020) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/932496/HMCTS_CFT_Recovery_Plan_v2b.pdf> Accessed 1 March 2021.} These backlogs have led to judges being keenly aware in nearly every hearing about the length of time until they are able to hear any subsequent applications in the case. In Cases 10, 11 and 13, judges commented on how “packed” or “busy” their diaries are in finding adequate time to have final hearings. This leads to judges not having the time to read all of the information before them. Instead, judges are relying on counsel to take them through information already submitted to the court. In Cases 2 and 13, both matters of serious medical intervention, the judges noted that certain statements from parties had been received but not read.

In Case 10, five hearings came before the CoP over the course of six months, before both Tier 1 and Tier 2 Judges. When the case came before a district judge in August, questions were raised by the Official Solicitor about whether the proposed care home and carers were sufficiently skilled or experienced to adequately care for J. When the case came back to the CoP, more than six weeks later, these crucial issues of J’s welfare had still not been investigated or answered by the local authority. Therefore, after a day-long hearing, nothing of note had been achieved, and the case had to be adjourned for a further three weeks.

Cases being delayed due to counsel or witnesses not being present, or because of a lack of court time, or because issues that should have been investigated had not been, often led to the patient’s life and welfare being left in the balance. Cases concerning serious issues of welfare or medical care take months to reach a final hearing, during which time the patient, his family and friends and other parties are left in limbo, without an answer as to how the patient’s best interests are being met.

Case 12 clearly demonstrated the impact that delays in making applications to the CoP regarding serious medical issues can have. In that case, the application to the CoP was not made until nearly three months after KB’s pregnancy became known to doctors, and several weeks after best interests decisions had been made by doctors caring for her. Furthermore, the Official
Solicitor, who would be acting on behalf of KB, was “notified weeks after the date when she should have been. As a result, the Official Solicitor has had to deal with a complex and sensitive case at very short notice”. The judge in this hearing noted that Hayden J had produced guidance in January 2020 that the Official Solicitor must be given as much time as possible. Hayden J had also stated in previous cases that although delay is not part of the MCA 2005, “it is to be read into that Act as a facet of Article 6 and Article 8. It is self-evident and indeed striking that delay is likely to be inimical to P's welfare and best interests”. 417

The judge stated that delay in Case 12 did not likely change the outcome of the case, as termination of the pregnancy was not likely to occur regardless of delay due to the family’s religious beliefs. Regardless of whether this may have been the case for this particular patient, the fact that the OS was not a party to the best interests decisions being made for several weeks means that there was an inequity of representation on behalf of KB’s wishes and feelings.

The judicial tier system that the CoP uses means that issues concerning serious medical intervention are handled by justices of the High Court, rather than the regional County Court judges. It was clear throughout my observations that Tier 3 judges have backlogged calendars and often have to delay other cases so as to hear these urgent matters, as there is a relatively small number of Tier 3 judges who hear such cases. Other cases, which are not deemed to be of such a serious nature, can go before a Tier 1 or 2 judge, despite the legal principles behind best interests being the same in all cases.

*Transparency in the Court of Protection*

Mr Justice Hayden has been a strong proponent of transparency in the Court of Protection, as the media have frequently criticised it as being a “secretive court”.418 Therefore, in 2016 a transparency project was launched within the CoP to allow members of the press and public to attend hearings but subject to reporting restrictions.419

In a document released at the start of the COVID-19 Pandemic, Mr Justice Hayden wished to emphasise that even during lockdown regulations, he wanted to ensure that transparency was

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418 Booker (n 402).

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maintained, saying: “The culture of the CoP is one of transparency, and I am determined to maintain this insofar as possible.”\textsuperscript{420} The majority of cases heard by the CoP do not receive a written judgment that is published to BAILII and freely available to the public. Hayden J advised his judges that, during this time of remote hearings, judges should seek to use written judgments to better inform the public, stating: “The Rules permit the judge to make public such information before the court, documents, judgments etc. as s/he thinks fit. Greater use of published judgments is a means by which the public may be able to access the court during this time.”\textsuperscript{421}

The Court of Protection is not a court whereby one can simply walk into the room and attend any hearing he or she wishes. Hearings are listed as either ‘private’ or ‘public’, and in both instances, the judge must give permission for somebody to attend the hearing. Throughout these observations, when a hearing was listed as ‘public’, permission was never refused. The fact that permission must be granted for someone to attend a ‘public’ hearing seems to be a contradiction in terms; how can something be genuinely public if the judge can arbitrarily refuse permission? Similarly, in my experience, a large number of court staff were unaware that CoP hearings could be attended by the public, as I received replies to my requests stating that it would not be possible and I then had to inform them that this was not the case.

The CoP is not a single physical court; it sits in the County Court of almost every city in England and Wales, usually before a District or Circuit Judge, with its main base being in London. These hearings before Tier 1 and 2 judges are more often listed as ‘private’ than cases that sit at the Royal Courts of Justice before a Tier 3 judge. This is due to Hayden J’s insistence that High Court hearings are usually dealing with issues of such importance that it is almost always in the public interest for outside scrutiny to be able to take place. In a case that I observed, but have not discussed in this chapter, Hayden J had listed the matter as public but then proceeded to “take it into chambers” very shortly after the hearing began. He noted that he is always “extremely hesitant” to take matters into chambers and that it would only happen in exceptional circumstances, as he is dedicated to the idea of transparency in the CoP.

\textsuperscript{420} Hayden J (n 413) [54].
\textsuperscript{421} \textit{ibid} [63].
There is, however, still a long way to go with transparency within the CoP. There is a fragmented system whereby a person wishing to attend a hearing must contact a central email box for the region, from which it is common to receive no response. Furthermore, the public can only gain 24-hour advance knowledge of a case being heard (via courtserve.net), so, without developing private contacts within the individual courts, it can be challenging to attend a hearing. There is no centralised system on how a case is listed; in some instances, the issues discussed in the case are listed alongside the hearing, whereas others provide no information. In addition to this, there is still a system of transparency orders in place, which vary from case to case, with some more restrictive than others.

In most cases, it is forbidden to publish P's name, which is understandable; however, in other cases, the identity of the treating Trust, the Local Authority, area of the country or anything that could lead to “jigsaw identification” were also restricted, often without sufficient reason or justification. In some instances this is acceptable, but in others, for the sake of accountability and transparency, it can often be overly restrictive. The identity of public bodies should rarely be held from the public in cases of such importance that they have gone before a Tier 3 CoP judge.

However, the Court of Protection is still a relatively young court that sat in secret for the majority of its early existence.\textsuperscript{422} Therefore, it is still a work in progress, but one that does still have a number of identifiable flaws that should be addressed to enable the public to be a part of these hearings, making some of the most serious life and death decisions in the country.

4.3 Commentary

The number of professionals who take part in matters concerning the Court of Protection is relatively small compared to some other areas of the law. These observations allowed me to see how people who write about PDOC, best interests, or the CoP deal with these matters in reality rather than theoretically.

The remainder of this section will discuss the issues that were apparent throughout the observations, some of which were not anticipated to be such prominent flaws in the current

\textsuperscript{422} The Court of Protection was established in 2007 and heard all cases in private, until it began trialling a transparency project for the press and public in 2015.
system when the observations began. Issues such as the practicalities of the operation of the CoP became apparent, as well as transparency and the principle of open justice, which I had not previously anticipated being so prominent,

4.3.1 Patient-centred hearings

These observations showed a varying manner in which individual judges would approach not only hearing directly from the patients themselves, but also how much time and effort would be taken to unravel and understand their wishes and feelings. Section 4(6) MCA 2005 states that a decision-maker, the judge, must take into consideration P’s past and present wishes and feelings, beliefs and values. Every judge in every case adhered to the letter of the MCA 2005 and considered wishes and feelings, it was the extent of that consideration that is worthy of discussion.

In five of the 10 final hearings (Cases 1, 6, 8, 10, 11), the judge followed P's wishes and feelings or did their utmost to ensure that they made an order that reflected them as closely as possible. In three cases (2, 5 and 9), the judge overruled the evidence presented as to P's wishes and followed the views of others who gave evidence. This is exemplified by Case 5, where the family of JS presented vast amounts of evidence that P would not wish to remain in his current state. The judge, however, believed that the expert evidence was more compelling and therefore ordered that treatment should continue.

The cases above that highlight how patient-centred discourse can best work in practice are not novel, and are not difficult to achieve. Even where a patient is deemed to lack capacity, they have the right to have their views heard. A judge has the power to determine the weight which they attribute to any piece of evidence.

Cases 6 and 9 offer a clear opposing view on how statements made by P can be given different amounts of weight by the judge. Evidence was submitted in Case 9 that G wished to live and that she would accept treatment when her children came to visit her. These actions could not be reconciled with her incapacitous statements about wishing to refuse life-saving treatment. This decision is unlike the statements made by P in Case 6, where D was ruled to have the capacity to litigate her case, and that she was fully cognisant of the repercussions of refusing treatment. This is why it is of importance always to hear the evidence first-hand, if at all
possible. Even if P expresses views while lacking capacity, they have a right to be heard by the court and balanced against the views of experts and other interested parties. It is undoubtedly a tough job to try to uncover the feelings of a person who has schizophrenia, but it does not mean that it should not at least be attempted. To not hear the wishes and feelings of P as directly and in as much detail as possible goes against the spirit of patient-centred discourse.

While advocates are in court to represent the patient and provide the judge with information about P’s wishes and feelings, this cannot offer the same degree of insight as hearing from the patient directly, even if P’s submission is in written format. There is no substitute for P’s own words, even if they are in a written or less cogent form than those of experts. The judge can benefit from communicating directly with the patient and getting to understand them on a one-to-one basis. This is not possible when dealing with the withdrawal of CANH from some PDOC patients, unless the use of fMRI and EEGs, is introduced into general practice, which may enable a proportion of PDOC patients to have their views heard directly.

4.3.2 Delay

A degree of delay within HMCTS is entirely understandable amidst the backdrop of the COVID-19 pandemic and the fact that the CoP has had to move its proceedings into remote hearings. Remote hearings are not always conducive to long, emotive and complex legal proceedings. Throughout the observations, there were a number of issues, ranging from links not being provided to counsel, internet connection issues with witnesses, or parties not understanding how to use the technology. This is an expected and inevitable consequence of having to move these cases onto remote platforms; however, it causes delays of sometimes days or even weeks if the case must be rescheduled to the next available slot.

However, delays within the CoP cannot be levelled solely at COVID-19 and the use of remote hearings. Sir James Munby said that “cases in the Court of Protection, demonstrate systemic failures which have contributed to a culture in which unacceptable delay is far too readily tolerated.”

The observations in Cases 10 and 11 show that some matters sit before the CoP for months or years without any resolution. Case 11, for example, was subject to a final order in October 2020 after more than a year of CoP hearings, the judge in that case continued to

speak about the possibility of “further proceedings”. Of course, delays in the CoP are determined by the external forces exerted upon it, when demand is high diary space is limited, when local authorities or NHS Trusts are unsure about what to do they will often be delayed in initiating proceedings; furthermore, when the court system is underfunded it leads to delays in processing and hearing of cases.

If the NHS Trust does not make the application to the CoP in the timely manner expected of them or even inform the Official Solicitor when they should have, it will have adverse impacts on the patient. It was fortunate that in Case 12, as far as is known, there was very little change in the end result; however, this will not always be the case for issues of serious medical interventions. Delays of up to three months could completely go against the patient’s welfare and ignore their best interests in favour of the interests of the Trust or LA as P’s suffering may be being extended longer than necessary.

**4.3.3 The ‘Secret Court’**

Although there has been a conscious effort made by Hayden J, and other senior judges, to try to make the Court of Protection more open and accountable to public scrutiny, there is a long way to go. The Court of Protection still does not operate like other branches of the High Court, as stated above, hearings are still considered ‘private’ and permission to attend must be sought out from the judge. In three cases, that are not recorded in this chapter, I was provided with the links to attend the ‘public’ hearings and, at different points, was asked to leave the hearing. In two of those cases, the hearing did not open before an application was made by counsel to exclude the public, which was accepted without reasons being given to those in attendance. In one case, the reasoning was at least given why the public was being asked to leave, which unfortunately cannot be published in this thesis.

The use of transparency orders, which have been mentioned above, can often give the CoP the image of a secret court. In Case 12, a reporting restriction was placed on proceedings, which prohibited the naming of the local authority or the NHS Trust; this reporting restriction was challenged by the Press Association Media Group (PAMG), due to the case having potential public interest ramifications after a vulnerable woman was raped while in receipt of care from a local authority. PAMG wished to challenge the order because they argued that lessons could not be learned if the press and the public cannot hold public bodies accountable for any failings
that may have occurred. Case 12 is not an anomaly in recent cases with restrictive TOs. In May 2020, the same reporter from PAMG challenged a similar reporting restriction in the case of *PA Media Group v London Borough of Haringey*.\textsuperscript{424} In his judgment Hayden J had to weigh up the Article 8 privacy rights of P against the Article 10 right to free expression and he ultimately decided that it was in the public interest to know when local authorities have failed in their duties.

The Court of Protection’s guidance of automated reporting restrictions\textsuperscript{425} ultimately risks counsel for the public bodies inserting restrictions related to their clients, should any criticism arise. In the case of *Haringey*, the Local Authority sought for its name to be excluded from public reporting, and were initially granted it, even though the issues the local authority was being accused of in the case were identical to existing criticisms of *Haringey*. Hayden J stated that the press’s uncovering of these existing criticisms “strikes me as a graphic illustration of the importance of scrutiny of public bodies and the Family Court system by lively and forensically curious journalism”.\textsuperscript{426} Lessons cannot possibly be learnt if the Court of Protection continues to make transparency orders which often hinder any dialogue on crucial issues of public importance.

Throughout the time of my observations, the Open Justice Court of Protection Project,\textsuperscript{427} which seeks to bring accountability and transparency to the CoP, was launched by Professor Celia Kitzinger. Judges often commented on the increased attendance by members of the public, which they were not used to. This became very apparent when Mr Justice Hayden issued guidance to the CoP judges to start opening cases with a brief introduction of the facts and history of the case, for the benefit of observers. During my initial observations, I had to approach counsel before or after the hearing or ask the judge to get an understanding of the case; however, it is now standard practice for counsel to offer an introduction to their cases for public benefit. It should be noted that not all judges seem to have taken to this; Mr Justice Mostyn abruptly interrupted counsel, who offered an introductory speech, stating that he does not see it as his function to offer some “grand explanation” of the proceedings to those who

\textsuperscript{424} [2020] EWHC 1282.
\textsuperscript{426} *Haringey* (n 424) [13].
wish to come and see a hearing. Such comments are entirely contrary to the fundamental principles of open justice and the image the CoP is seeking to shake off.

It is to be hoped that there is a period of further reform in the years ahead. The CoP has changed drastically over the course of the COVID-19 pandemic and has had to become more hospitable to public observers. Not all judges are yet following the lead of Hayden J, but hopefully they will soon. The CoP is not the ‘secret court’ that some journalists have accused it of being but it certainly has a long way to go to shake that image off. In the final chapter of this thesis, I focus on the areas of reform that I believe should be made to address these existing issues.
Chapter Five: 
Conclusions and recommendations

5.1 Introduction

This thesis has sought to understand how professionals in the legal and medical professions make best interests decisions for adult patients who are in prolonged disorders of consciousness. I have striven to answer four main research questions:

1. What is the current understanding of the 'best interests' test?
2. Is there a consistent application of the 'best interests' test by doctors, lawyers and the courts?
3. What is, and what should be, the role of the Court of Protection, post-Re Y?
4. If patient-centred decision-making is desirable, is there a role for emerging technologies in achieving that aim?

Throughout this chapter, these four questions will be addressed by referencing all of the previous three chapters’ findings. Chapter Two addressed the current understanding in existing literature and case law and highlighted a considerable gap in the understanding of several key issues by both medical practitioners and lawyers. These findings provided a background to the interviews conducted with leading legal and medical experts; these interviews showed that the understanding of issues such as best interests and misdiagnosis was as low as the House of Lords Select Committee had suggested in their report, discussed in Chapter Two. Chapter Four further identified issues not necessarily with lawyers and doctors, but with the CoP itself, its processes and the lack of uniformity among some members of the senior judiciary.

I have argued throughout that the law and practice surrounding PDOC patients’ needs to improve in various ways so as to better protect and empower patients and understand their needs. I have identified the areas in which the law, the legal profession and the medical profession fall short of achieving these objectives. At present, PDOC patients' wishes and feelings are addressed as a matter of course so as to fulfil the requirement of the MCA 2005, not necessarily because they are understood. This thesis has shown how this system is not in keeping with the spirit of the MCA 2005, the case law, or the CRPD.
I was uniquely positioned in the second half of my research due to the COVID-19 pandemic. As well as gaining access to interview senior practitioners, the CoP was forced to move its hearings to remote platforms, which enabled me far greater access than would have been the case had they remained in-person. I have been able to view cases being heard throughout the country with every level of the judiciary. This has proven to be an invaluable insight into the workings of CoP hearings.

This chapter will outline my findings in the two core research areas: best interests and declaratory relief proceedings. It will then go on to identify the ways in which law and practice can be reformed to better protect vulnerable patients.

5.2 Best interests

The meaning of best interests has greatly evolved through more than a century of English law. In Chapter Two I addressed the history of the protection of vulnerable patients and the *parens patriae* doctrine. Best interests has an equally lengthy history, Lord Chelmsford spoke about the best interests of a child in 1843, 428 150 years before the case of *Bland*. Just over 25 years ago the House of Lords established the modern best interests assessment as one of best medical interests. Patient's wishes and feelings came second to medical professionals' views and whether the proposed treatment offered the patient any benefit.

Following *Bland*, Parliament produced a Select Committee report into capacity law, which culminated in the passage of the Mental Capacity Act 2005. After the introduction of the MCA 2005, the case law rapidly evolved, before the Supreme Court ultimately ruled in the case of *Aintree University Hospitals NHS Foundation Trust v James*429 that the best interests standard is much broader than the scope laid out in *Bland*. Lady Hale held that decision-makers must consider a patient’s welfare in the widest possible sense, taking into account medical, social and psychological welfare. She also emphasised that these decisions are centred around the patients’ beliefs; decision-makers must try and put themselves in P’s place and find out what he would have wanted. Lady Hale rejected the idea that one can apply a test of a *reasonable patient*; the best interests test is a subjective standard and not an objective one.

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428 *Johnstone v Beattie* [1843-60] All ER Rep 576.
In Chapter Two, I identified procedures used in some other jurisdictions to make decisions, including the UN CRPD. My research supports the view that the MCA 2005 is incompatible with the CRPD, as it does not give preferential treatment to what the UN Committee calls the ‘will and preferences’ of P. Two interviewees argued that the MCA 2005 is nowhere close to complying with the UK’s obligations under the Convention and that the only way this could change would be to rewrite the MCA 2005. This reform of the MCA was advocated to clarify that P’s will and preferences are the starting point of all decision-making.

However, one interviewee did suggest that although the legislation is incompatible, judges within the CoP often operate in a manner that does in fact put P’s wishes at the forefront of decision-making. This view is supported by some of my observations of the CoP in action, as reported in Chapter Four.

In the majority of observed cases, judges’ principal concerns were what P would have wanted, and his current wellbeing. In three cases, the judges either ruled against P’s believed wishes or stated that they had no desire to talk to them directly. As it is currently structured, the law is not compliant with the CRPD. Although the MCA 2005, when taken together with the judgment of Aintree and how judges ordinarily handle these cases, goes a long way to becoming compliant with the CRPD, it is still not entirely fulfilling the UK’s obligations. The CRPD says that the patient’s will and preferences are the dominating factor and not merely one of a multitude of factors. The only way the MCA 2005 and the CRPD can be harmonised is by a substantial reform of section 4 of the MCA 2005.

5.2.1 Understanding and application of best interests

The current best interests standard is found within section 5 of the MCA 2005, as interpreted by Lady Hale in the case of Aintree. How the medical and legal professions have interpreted this, and whether this standard is adequately applied, is what this thesis has sought to address.

It is clear that there is a distinct difference between how a large proportion of doctors and lawyers understand best interests and how one should conduct a best interests assessment. The House of Lords Select Committee concluded that a substantial number of clinicians fail to undertake the best interests test accurately.
Best interests are the core of mental capacity law concerning PDOC patients. The lack of basic understanding of the meaning of best interests is a serious cause for concern. In Chapter Three, I identified a widely accepted view that medical professionals still do not follow the judgment in *Aintree*; instead, a large proportion of medics are pursuing a medical agenda when making these decisions. A senior medical consultant asserted during interview that less than 5% of clinicians understand best interests, which may have been lower than reality, but is in keeping with the general understanding that this is a serious issue that needs to be addressed. Doctors are taught to think in terms of medical need, and this was apparent throughout my observations and interviews. I heard first-hand evidence given by 19 doctors in the 13 cases, and 16 doctors made no mention whatsoever of the patient beyond a diagnosis/prognosis: ‘best interests’, in their submissions, never encompassed the patient’s broader welfare concerns.

As noted in Chapter Three, Case has conducted some similar observations; however, she argues that the ability of the CoP to consider evidence from family and friends is a safeguard against the court placing too great a weight on medical or other expert opinion. While this may be the case in theory, my observations of the CoP do not agree with this finding; the CoP appeared to continue to defer to the views of medical staff far more often, even in the face of lay evidence to the contrary.

The same cannot be said for nurses and carers, who are more likely to spend much more time than the treating physician at a patient’s bedside. This was evidenced in statements made during my interviews, by both lawyers and doctors, who argued that in disputed cases it was often the case that carers, rather than lead clinicians, would say that P had shown greater levels of consciousness. My observations confirmed that carers and nurses would focus much more on P’s wellbeing when called to give evidence. Carers were much more likely to talk about P as a person, what he likes or dislikes, and his level of comfort; similarly, they were more likely to have a greater understanding – through frequent conversations with P’s friends and family – of what P was like before losing capacity.
Checklists

Checklists are used within the medical profession while making diagnostic and prognostic decisions, as they allow for some form of baseline understanding of the patient’s current position. However, four interviewees mentioned that the best interests checklists produced by hospitals are often ignored or only partially followed. In fact, one clinician said that he actively tells those he is teaching not to use the provided checklists.

In Chapter Two, I showed that checklists used throughout the NHS are by no means standardised. Although the BMA released a version in their 2019/2020 guidance, it is not used by every hospital in England and Wales. I identified at least five other checklists that are commonly used, all of which differed from one another. Some of the checklists asked several questions to ensure that P’s wishes and feelings were being heard, while others listed P’s wishes as merely one of a multitude of issues to consider with no greater weight.

Far from clearly telling doctors the procedures specified by the MCA 2005, these checklists simply add more confusion. Ensuring that doctors understand they are not making a best medical interests decision is vital. However, it is also essential to ensure that they understand that the test being applied considers welfare in the widest possible sense. Having a form that starts like the one produced by the Black Country Partnership NHS Trust430 ensures that doctors understand the various factors they must consider. A common thread throughout all of these checklists is an indicator that there is a belief that doctors are sole decision-makers. Making decisions regarding CANH withdrawal should involve a collaborative approach of the entire clinical team and parties closest to the patient. The MCA does not identify any particular individual as a primary decision-maker, although this role falls on the lead clinician in practice. The 2020 BMA guidance, reiterating the decision in Re Y, states that "the Court of Protection remains the ultimate decision-maker, and can and should be asked to decide"431 where there is any disagreement.

The lack of uniformity across the NHS of the checklists provided to clinicians is symptomatic of the broader misunderstanding of the best interests standard. Coupled with the fact that half of the doctors interviewed said they did not use the checklists at all, it raises questions about how clinicians should be best trained to ensure they understand the test. The BMA's full guidance from September 2020 includes a simplified checklist, which concludes by saying "if there is no agreement, give information about what action is being taken". This requires the treating physician to know the next action to be taken should be to seek a form of mediation, or for an application to the CoP. Evidence from interviews, literature and observation indicates that there is a significant number of doctors who do not know this information.

This process requires doctors to act, essentially, as the lead on decision-making concerning withdrawing treatment from PDOC patients, although the ultimate decision is not theirs alone. This process means that the family and friends of a patient are likely following the clinical team's lead, as they will often believe that the doctor knows best. Throughout my literature review and subsequent empirical research, it became clear that a power imbalance exists between decision-making doctors and the patient's family, both at the bedside and in CoP. Although it is likely that the people who are able to help the most in describing who P was before being in a PDOC are the family and friends, there appears to be general deference to the views of the doctor. The greater emphasis placed on 'expert' evidence is addressed further in this chapter.

Patient involvement

Section 4(4) of the MCA 2005 states that, when making a best interests decision, a decision-maker must “so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him”. In cases concerning the withdrawal of CANH from PDOC patients, it is impossible to ascertain directly from P what his wishes would be. However, section 4(6)(a)-(c) states that a decision-maker must consider P’s wishes and feelings, beliefs and values, and any written statements. I have raised concerns in previous chapters about whether or not P’s views are adequately represented by a system that relies on conversations with P’s

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432 ibid.
433 Mental Capacity Act 2005, s.4(4).
loved ones, who will likely be making large assumptions about P’s wishes and feelings based on their own understandably emotional opinions.

I identified in Chapter Two that it is a widely held view that P rarely participates in CoP proceedings. Through the observations I conducted, this view was proved to be correct. P was directly involved in less than half of the cases I observed. The issue with this is that the CoP Handbook states that the European Court of Human Rights has made it increasingly clear that P should be urged to participate so as to safeguard their Article 6 and 8 rights under the ECHR. What is meant by ‘participation’ is not that P must give evidence directly to the court or have complete control over the decision-making process. Participation can be facilitated in a number of ways that respect their autonomy and their wishes and feelings. This does not mean that the CoP cannot ultimately overrule them. What is important is the process of hearing P and ensuring that a balanced decision has been made without an assumption that the views of professionals are always correct.

In each case where P intervened or had a chance to have their voice directly heard, the court benefited greatly. Even in cases where P displayed erratic behaviour, as a result of schizophrenia, for example, the CoP benefited by being able to see, hear and understand P’s views and reasoning despite their lack of capacity. In cases where the judges actively dismissed hearing from P, where it would have been possible, it led to a much less thorough hearing, with more significant discussion of hypothetics.

Ascertaining P’s wishes and feelings

The current understanding of best interests, which should be applied throughout England and Wales, must place P’s wishes and feelings at the centre of the decision-making framework. The way in which a PDOC patient’s views are heard is very different from the ways of ascertaining other incapacitous people’s views, so the burden of representing these views falls on the family, friends, and those who knew P.

435 X and Y v Croatia App no 5193/90 (ECHR, 2 November 2011), Shukaturov v Russia App no 4409/05 (ECHR, 2008).
One little-used feature of the MCA 2005 that could arguably solve this issue of not being able to talk to P is through an expansion in the creation of Advance Decisions to Refuse Treatment (ADRTs). ADRTs are, if made in accordance with s.25 MCA 2005, legally binding upon decision-makers and health professionals. If a valid and applicable ADRT exists, it has the effect of being as if P currently has the capacity to make the decision. I raised questions in Chapters Two and Three regarding how long an ADRT should be in place and still be valid. If someone makes an ADRT refusing treatment 25 years prior to losing capacity, should the ADRT indeed be said to represent P’s current wishes and feelings now that they are in a PDOC? Within the intervening period, a lot could have changed in P’s life: getting married, having children, undergoing conversion to a religion, or merely changing views.

A blanket requirement to follow ADRTs, whether they are two weeks old or 25 years old, leads to further doubt about whether the decision-maker is truly following P’s current wishes and feelings. There is a need to differentiate between hypothetical future wishes and feelings and the current wishes of P. However, within the current diagnostic framework, it is impossible to ascertain P’s current state of mind. The failing of the MCA 2005 results from how vague the text is in defining not only what wishes and feelings means but the weight to be attached to them. The CRPD has been much clearer in asserting that wishes and feelings mean what P wants at this specific moment, not a hypothetical future wish. The United Nations Committee on the CRPD clearly stated that prior declarations should not override the wishes and feelings of people who have become disabled. The CoP retains the power under s.26(4) MCA 2005 to declare whether ADRTs are valid or applicable, although there are very few judgments in which the CoP is reported as having ruled on their validity.

Where an ADRT does not exist, articulating what P would have wanted falls largely on his loved ones. Hayden J has stated that “In many cases, I have found family and friends to be, as I have set out above, the only real conduit through which P’s wishes can be communicated”. This is true, because PDOC patients cannot verbally communicate their wishes to the decision-maker. The accuracy, helpfulness, and weight to be attached to the views of loved ones has been debated throughout this thesis.

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436 An ADRT to refuse life-sustaining treatment must, unlike any other ADRT, be in writing, signed with a witness, signed by a witness, and include a specific statement that the ADRT applies even if there is a risk to life.
437 *Abertawe Bro Morgannwg University Local Health Board v RY & Anor* [2017] EWCOP 2, 34-38.
In Chapter Three, there was a clear division between interviewees regarding the extent to which family members can provide an adequate understanding of a PDOC patient's views. Five interviewees expressed some concern over whether P's loved ones are passing off their opinions as the views of P. Despite this, most interviewees believed that it was entirely unfounded to think that P’s family would have an ulterior motive to requesting the withdrawal of CANH. Similarly, it was quite forcefully stated in the literature in Chapter Two, and repeated in interviews, that it is a rather British perspective to cast doubt upon the families. It was suggested that, in most other Commonwealth jurisdictions, such decisions would inevitably be made by P’s friends and family.

My case observations from Chapter Four and the analysis of the existing case law in Chapter Two suggest that P’s family's views seem to be given great weight only in cases where they agree with the medical professionals' views. In four of the cases I observed, the family did not agree with the assessments made by medical professionals, and in each of those cases, the judge opted to attach greater weight to the clinicians' views. It is incredibly hard for a judge to attempt to distinguish the views, and often emotional response, of the family from the views of P. One of the cases discussed in Chapter Four, Case 5, was the clearest example of when a very close family member who gave clear and credible evidence as to P’s desire not to receive CANH was overruled. In that case, more than half of the hearing was spent discussing diagnosis and prognosis, with very little time devoted to allowing P’s daughter to express what P would want. The case law discussed in Chapter Two, and many statements made by interviewees, support the view that family members’ views are disregarded, and often seen as an obstacle to overcome, unless they support clinicians’ opinions.

A decision-maker must undertake a difficult balancing act when they consider evidence provided on behalf of P. The case law in Chapter Two and evidence from interviews and observations suggest that family evidence is more likely to be reliable than not, but is not infallible. There is evidently a heavy presumption that family and friends will automatically know who P is and was. Case 12 highlights how close family members can hold different views and how the patient’s spouse may not always be the best person to turn to make decisions. The study into LGBT patients, 438 reported in Chapter Two, casts serious doubt on this presumption. People do not tell their spouses, siblings and friends absolutely everything, and yet in CoP

438 Donovan (n 277) [689].
hearings and at the bedside, there is an assumption that P did precisely that. Decision-makers need to act with caution when balancing evidence from anyone other than P, which is why ADRTs are of such importance.

Within the current decision-making framework, the best way the decision-maker can fulfil their duty to ascertain P’s wishes is to ensure evidence is collected from as many parties as possible. Doctors need to be sure about the diagnosis they are giving P, whether MCS or PVS, and family and friends similarly need to be confident about what they express as being P’s wishes and feelings.

For doctors the importance of diagnostic accuracy can be a matter of life and death. In Chapter Two and Three there was a lot of evidence that suggested the distinction between PVS and MCS was archaic, and we should instead see every patient as sitting on a spectrum. This position appears to be entirely supported by the modern scientific understanding of capacity. The issue is that the law has not yet caught up. There is a presumption in law that a patient in a PVS has no realistic prospect of recovery and as such the presumption is in favour of withdrawing treatment. No such presumption exists for MCS patients, for whom a balancing exercise will be performed. While this distinction exists in law, and while there is a continued concern about misdiagnosis it would not be appropriate to risk patients with higher levels of capacity prematurely losing their lives.

The views of the experts and P’s close contacts are not always going to align. The spirit of the CRPD and Aintree is that P’s wishes are at the centre of the decision and not the personal views of any party, this is why an independent overview of these decisions offers a way to attempt this difficult balancing act.

**Emerging Technologies**

In Chapters Two and Three, this thesis addressed the suggestion that emerging technologies can enable decision-makers to communicate with some PDOC patients. Where there is no valid ADRT, it may be the case that technologies such as fMRI can play a role in uncovering hidden levels of consciousness. Even in situations where a valid ADRT does exist these new technologies can still be of great help in potentially understanding whether the patient wishes to stick to their previously expressed wishes.
The studies, discussed in Chapter Two, conducted primarily by Professors Adrian Owen and Martin Monti, have consistently provided positive and encouraging results. FMRI scans can indicate which areas of the brain are active at any given time, by assessing the blood-oxygen levels; by doing this, a doctor can potentially identify hidden levels of consciousness in a patient’s brain when they are asked to undertake specific mental imagery tasks. Patients who were completely unresponsive, using the traditional bedside tests, were found to be able to indicate their levels of pain using these techniques. These studies have shown that the outward signs of a PVS do not necessarily mean that the patient’s neurological state mirrors that.

Similarly, in recent years, several large-scale studies have been conducted into PDOC patients using EEGs, some of which have been called “ground-breaking”. EEGs are commonly used throughout medical practice and are part of most systems of diagnosis on PDOC patients used in the UK. The study by Schiff, Braiman and others, cited in Chapter Two (section 2.4.1), has shown that there is great potential for EEGs and fMRIs to work in tandem to identify higher levels of awareness and cognition.

Despite these promising studies, interviewees expressed mixed views on their usefulness. The majority of doctors opposed the idea of introducing fMRI as they believed that they do not show what is being hypothesised. Some doctors believed that fMRIs may indicate a higher level of cognition for a brief period of time, but that does not change diagnosis or prognosis. It was called “implausible” by one interviewee to think that PVS patients had some hidden consciousness. This view was not universal. Half of the interviewees believed that doctors and lawyers are duty-bound to do all they can to ensure that decision-makers ascertain and follow a patient's wishes and feelings. Doctors and lawyers work to ensure the best possible outcome for their patient/client; in working towards this aim, there is an ethical imperative to at least try to see if these technologies could allow a better understanding of PDOC patients' wishes.

Even if only a small percentage of patients in a PDOC were to communicate via an fMRI successfully, this would significantly improve the current situation. If doctors could obviate the need to try and guess P’s wishes and feelings by asking him directly, they would be acting entirely in accordance with the spirit of the MCA 2005, as interpreted in Aintree.

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Currently, it does not seem that there is any desire within the wider medical or legal community to seek to have such diagnostic tools implemented into a decision-making framework. FMRI was mentioned in only one case that I observed, when a doctor was asked whether it had been thought about and dismissed it with a single “no”. Although the literature is still relatively young, these studies show much promise for the future of understanding the wishes and feelings of PDOC patients.

5.3 Declaratory relief

I have sought to answer what the current role of the CoP is in cases concerning the withdrawal of CANH from PDOC patients. I have also attempted to examine whether this current standard works and whether there are alternatives which may offer greater protection to vulnerable PDOC patients. In this section, I outline my conclusions of the changes Re Y has brought in and whether these changes are welcome.

5.3.1 Re Y: Declaratory relief requirement

Chapter Two outlined the history of the court's role in CANH withdrawal cases; it was commonly thought that the Bland judgment had created a common law requirement that decision-makers must seek court authorisation to withdraw CANH. In 2018, 25 years after the decision in Bland, the Supreme Court ruled that this was not the case, there was never any legal requirement to apply to the CoP. Instead, the Supreme Court held that the House of Lords “recommended…as a matter of good practice” that application be made to the court. The Supreme Court gave no weight to Baker J’s obiter view in Re M, where he argued that such a requirement did exist.

I have investigated whether the case of Re Y has achieved any practical effects over the past three years. In Chapter Two, I outlined that post-Re Y an application to the CoP should now only be made where there is a disagreement about treatment, diagnosis or prognosis, or where the issue of best interests is finely balanced. Nearly three-quarters of interviewees, both doctors and lawyers, regarded Re Y as a welcome decision. The majority of interviewees felt that the

440 W v M and others [2011] EWHC 2443 (Fam).
Supreme Court had brought the law in line with how other life-and-death medical decisions are commonly made, and that doctors can be trusted to make best interests decisions. However, some felt that this case represented a step back, towards a system focused more on the doctor than the patient. Several interviewees felt that there may be a limited number of reasons why an application would still be needed, but the majority believed that it was appropriate for doctors to be trusted to make a judgement.

The reality of Re Y’s impact is very different from the apparent simplicity of the ruling. Although there is no longer any legal obligation to make an application to the CoP, there is no evidence to suggest that the number of applications being received by the court concerning serious medical treatment has reduced in any significant way. The court is still fighting a backlog and is receiving a variety of applications daily at all levels, with little change from the rates pre-2018, the year Re Y was decided. Judges made frequent comments in my observations about whether or not a case should ever have come before the CoP, as all parties were in agreement. There appears to be a consistent pattern within the medical profession, even since Re Y, of not wishing to make the final decision. Doctors continue to pass the decision to the CoP, even where all parties agree with the prognosis and treatment plan. Celia Kitzinger, of the Open Justice Court of Protection Project, has stated that in the years since Re Y it seems as though the starting position within hospitals is to continue treatment regardless of prognosis, unless a family member suggests withdrawal.441 This has been the position I also observed throughout my CoP observations. In all withdrawal cases covered in Chapter Four, the patients had been receiving treatment for several months or years before the hearing took place, as doctors were maintaining treatment as the default action.

There has not been an update on the numbers of people in nursing homes and hospitals with PDOC since 2015, so no estimate of whether Re Y has reduced the number of patients currently in a PDOC can be made. All indicators point to no significant change in when an application is made to the CoP. Throughout my observations, it became clear that even where doctors are sure of what is in P’s best interests, the responsible Trust continues to seek reassurance from the CoP in the form of declaratory relief. Of course, there will have been cases throughout the country since 2018, where LST has been withdrawn without a court application, but it does not

seem to have affected the number of cases before the CoP. In 2017, there were five reported judgments\textsuperscript{442} relating to the continuation of LST, and six\textsuperscript{443} such judgments were published in 2020. These figures are based only on cases reported on BAILII, and there are undoubtedly more cases that have come before the CoP but have not been subject to written judgment, as had been my experience during observations. The CoP has the need to work expeditiously due to the emergency nature of many of their hearings, so judges often give judgment \textit{ex tempore} without any publicly published judgment. Those in the hearing itself will be able to hear a judgment, or often a note is passed down to counsel, or a transcript ordered, but the wider public will be entirely unaware of the hearing unless it is reported by the media.

The lack of published judgments continues to give the CoP an aura of secrecy. I encountered several reasons why judgments are not written out or published, the most common of which was the expense to the public purse of a transcript being produced of an oral judgment. While this argument is understandable, judges could simply produce a note of their own, without resorting to external transcription services at public expense.

Despite the ruling in \textit{Re Y}, there are still other medical treatment issues that \textit{must} come before the CoP for determination; in his January 2020 guidance,\textsuperscript{444} which is outlined in Chapter Two, Hayden J set out a non-exhaustive list of scenarios which may require a CoP application. This list included sterilisation, insertion of contraceptive devices, and experimental treatment.

The question must be raised as to why these circumstances are regarded as legal exceptions when PDOC cases are not. Hayden J states that these issues involve a “serious interference with the person’s rights under the ECHR”\textsuperscript{445}. It seems hard to justify a position that says the

\textsuperscript{442} Abertawe Bro Morgannwg University Local Health Board v RY & Anor (Rev 1) [2017] EWCOP 2
\textsuperscript{443} Abertawe Bro Morgannwg University Local Health Board v Lewis [2017] EWCOP 31
\textsuperscript{444} M v A Hospital [2017] EWCOP 19
\textsuperscript{445} PL v Sutton Clinical Commissioning Group & Anor [2017] EWCOP 22
\textsuperscript{446} Salford Royal NHS Foundation Trust v Mrs P & Anor (Rev 1) [2017] EWCOP 23.
\textsuperscript{447} A Clinical Commissioning Group v AF & Ors [2020] EWCOP 16
\textsuperscript{448} Barnsley Hospital NHS Foundation Trust v MSP [2020] EWCOP 26
\textsuperscript{449} Avon and Wiltshire Mental Health Partnership v WA & Anor (Rev 1) [2020] EWCOP 37
\textsuperscript{450} Northamptonshire Healthcare NHS Foundation Trust v AB [2020] EWCOP 40
\textsuperscript{451} An NHS Trust v AF & Anor [2020] EWCOP 55
\textsuperscript{452} University Hospitals Plymouth NHS Trust v RS & Anor [2020] EWCOP 70.
\textsuperscript{453} Applications Relating to Medical Treatment: Guidance Authorised by The Honourable Mr Justice Hayden, The Vice President of The Court of Protection [2020] EWCOP 2 [10].
\textsuperscript{454} ibid.
insertion of a contraceptive device constitutes a “serious interference” and the removal of life-sustaining treatment does not.

The Supreme Court in *Re Y* may have been too confident in its assertion that there has never been a requirement to bring matters to the CoP. Since the decision in *Bland*, the legal and medical professions, including a significant number of judges, operated on the belief that there was such a requirement. The Supreme Court itself lacked decisiveness in its judgment, using terms such as applications “can and should be made”. Equivocal language is not helpful to decision-makers who are unsure whether it is appropriate or not to make an application. Using words such as “can”, “should”, and “desirable” can lead to uncertainty and thus risks patients remaining in PDOC in hospitals when a CoP hearing and withdrawal of treatment may well be in their best interests.

*The role of judges*

The role of judges and how they make decisions for PDOC patients has been central to this thesis, but there is virtually no literature about how judges in the Court of Protection act, think, see their role, or make their judgments. Although these judges frequently make decisions that are a matter of life and death, very little is known about them. In Chapter Two, I highlighted how different judges have interpreted the court’s role in these proceedings: Baker J believed all cases must come before the court, whereas other decisions were made at the same time, that expressed the exact opposite. Baker J saw the role of the CoP as offering an extra layer of protection on a complex matter in both medicine and law. In Chapter Four, I evaluated the differences in approaches taken by judges to best interests determinations, which were not always in the spirit of the current law. Despite Mr Justice Hayden's best efforts to issue guidance to the judges of the Family Division, judges show varying levels of empathy, attention to detail and willingness to give time to these important matters.

As said above, the CoP commonly follows evidence provided by an expert witness, and as such, they are usually guided towards their decision by counsel and the medical professionals. I was rarely surprised by the outcome of a hearing, especially when expert evidence had been given. However, in one case in Chapter Four, Hayden J was being urged to follow the views

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446 *An NHS Trust and Others v Y and Another* [2018] UKSC 46.
of the majority and not to make a decision that could be controversial, to which he responded: “I think you’ve urged caution on everything, and sometimes one has to be bold”. This statement does not reflect the general tone of judges throughout the CoP, which I found was to act with caution and follow the least contentious course.

Lord Judge said that judges must have “moral courage” to make some decisions that “will be unpopular with the politicians or the media and the public”.447 I believe it is extremely rare for judges in the CoP to act boldly. In my experience, they make decisions which accord with views of the experts in the majority of cases. Judges who had no desire to speak to P or actively spoke out against P’s participation during the course of the hearing are, in my estimation, failing to keep with the spirit of the MCA, the guidance of Hayden J, and the ruling in Aintree.

5.4 Future reform

There is an evident lack of harmony between the letter of the legislation, the case law, international law, and how practitioners interpret and apply the principles at the bedside. I have highlighted the high levels of misunderstanding of the best interests standard and the lack of continuity in the declaratory relief process. There are a large number of discrepancies in the current decision-making framework, which I have identified in the previous chapters, which I believe weaken the rights of PDOC patients and do not allow for their wishes and feelings to be at the centre of the process.

5.4.1 Best interests

Reform of the Mental Capacity Act 2005

I have identified that a clash exists between decision-making, as prescribed by the MCA 2005, the CRPD and the current understanding of patient-centred decision-making. Section 4 of the MCA 2005 lists the issues to be taken into consideration when making a decision, but it fails to name any singular consideration as paramount. As Jackson argued, the continued existence of section 4 of the MCA 2005 means that the UK will ultimately always fail to comply fully

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with the CRPD. Whether or not judges have sought to bring current practice in line with the CRPD organically through case law, there is nothing to stop a subsequent superior court from taking a different course of action. The current safeguard for vulnerable patients is therefore inadequate; only statutory reform can achieve the necessary result.

Section 4(6) MCA 2005 says that a decision-maker “must consider, so far as is reasonably ascertainable (a) the person’s past and present wishes and feelings”, alongside a number of other considerations, Section 4 of the MCA 2005 should be rewritten to remove the multiple other factors to be considered and should state on its face that the primary factor when making a decision is what P would want to happen.

A decision-maker must be obliged to place the views of a patient at the centre of the decision-making process, above all other considerations, and ask themselves a series of questions aimed at determining P’s views. These questions should include asking what decision P would currently make if he had the capacity, what were the things that mattered most to her throughout her life and what would she say are her core beliefs.

Although I do not believe that P’s family and friends' views should be determinative, it will be necessary for a decision-maker to consult with all those who knew P closely. When a disputed case makes its way to the CoP, this evidence should be under much more intense scrutiny than what it was in the cases that I observed. This scrutiny ensures that views expressed represent the patient’s wishes, not those of the person giving evidence. The Essex Autonomy Project, as discussed in Chapter Two, raised issues with the lack of research or questioning around why certain groups should be assumed to have greater understanding of what the patient would want. Additional scrutiny in court of those who claim to know what P would have wanted could alleviate some of this concern and thereby ensure that practice complied more closely with the requirements of the CRPD.

In creating a list of factors to be given consideration, the MCA 2005 has ultimately been left too vague on the most important issues and had the effect of passing the issues on to the individual decision-makers to decide what best interests meant. Medical science and the law

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448 Jackson (n 260).
449 Martin et al. (n 254).
have developed significantly since 2005, and as such the Act has become outdated. It is time to replace the legislation with an Act more representative of the spirit of the CRPD and the decision in *Aintree*, where P’s views are at the core, and the diagnosis does not determine the outcome.

**Advance decisions**

In trying to ascertain the wishes and feelings of a patient in a PDOC, written instruments or other such recorded first-hand views are the most accurate way to determine what P’s views were prior to being in a PDOC. The MCA 2005 provides for one specific way for P to refuse LST, which is through a valid advance decision. Unfortunately, it appears that very few people in the UK have made an ADRT or recorded their views on LST in any manner, for use should they ever lack capacity. Numerous organisations and charities offer free services to create ADRTs, although often referring to them as ‘living wills’. Throughout my observations of the CoP and analysis of existing case law, it has become clear that more must be done to convince members of the public to create ADRTs. This simple action could result in far fewer cases being required to go before the CoP and relieve families of the distress of attending full court hearings.

As identified in Chapter Two, polling suggests that the public are not aware that ADRTs exist and as such, there needs to be widespread public education. Hospitals and GP surgeries have taken part in a nationwide sepsis awareness campaign in recent years, with posters and signage throughout NHS buildings. Public health awareness campaigns are not uncommon and can go a long way in educating people about the existence of ADRTs. There are three more simple methods that could be used to spread awareness and encourage people to fill out an ADRT form. Firstly, I propose that patients be given information about ADRTs and how to create a legally binding decision when they register with a new GP surgery. A second way large sections of the public can be reached is to issue ADRT information packs when starting University. The UK government has spent a significant amount of money throughout 2020 and 2021 on developing an NHS phone app that allows patients to update their COVID-19 records and organ donation records, as well as other vital patient information. Now that this application

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450 YouGov (π 244).
is established, it would be a simple task to add an option to create an ADRT, that automatically registers with your GP via your patient records on the app.

These are all low-cost solutions to an issue that costs the NHS, HMCTS, and family members a substantial amount of money each year, should a CoP hearing be required. Continuing treatment for a PVS patient costs around £7,500\textsuperscript{452} per month, and the fees accumulated by an applicant of a CoP hearing are estimated to be at least £30,000 and can be over £50,000.\textsuperscript{453} The significant fees for a CoP hearing that families incur could be avoided simply by ensuring loved ones have a valid ADRT.

I have identified my concern about the length of time an ADRT has existed and its continued applicability. There are practical ways in which the current NHS infrastructure can enable a decision-maker to obtain the most up-to-date views of P. Although ADRTs may not represent P’s \textit{current} wishes while he is in a PDOC, having recently updated documents can add a greater level of reassurance that the decision is correct.

I would suggest that, much like the NHS sends reminders for regular check-ups, there could be a reminder every five years for a person to update their ADRT. With the use of modern technology such as mass text messaging, emails, and in-app messages, these services can be provided at a lower cost than previously possible. ADRTs are not infallible; a form filled out many years ago may continue to be accurate for some but not for others. While the current medical framework is unable to ascertain a PDOC patient’s \textit{current} wishes and feelings, ADRT’s remain the most accurate record of wishes and should be expanded as widely as possible. An example of a model ADRT form, created by the Alzheimer’s Society, can be found at Appendix J.

\textsuperscript{452} Sarah Bunn and Zoe Fritz, \textit{Vegetative and Minimally Conscious States} (POST Note 489, Parliamentary Office of Science and Technology, March 2015), 1.
Emerging technologies

I have investigated the potential for various new and emerging technologies that could enable a decision-maker to better understand P’s current wishes and feelings. There is an ethical imperative to do all that is possible for a patient and understand his wishes and feelings, and so if any of these technologies can enable a decision-maker to understand P’s views better, they should be introduced, when approved for wider use in the diagnostic framework by the regulating medical bodies. The evidence suggests that there is a place in the decision-making framework for some of these technologies; in experimental situations, they have proven to show a form of hidden consciousness in some PDOC patients. I have focused on the use of two technologies: EEG vocal recognition and fMRI.

EEGs are commonplace in hospitals throughout the UK, and following the 2019 study by Schiff, Braiman and others, there is reason to believe that they should be used to identify whether a PDOC patient has any neurological reaction to hearing a familiar voice. If they have a positive cognitive response over a sustained period, they should, if practicable, be assessed via an fMRI to potentially unlock hidden levels of consciousness. The evidence indicates that those who show a positive EEG can also successfully communicate via an fMRI. When these technologies have been approved for use within the UK, a new diagnostic framework should replace the current structure. This new framework is proposed and outlined in the flow chart below.

This new model would continue to use the well-established WHIM, SMART and CRS-R diagnostic tools to try and ascertain where P falls on the spectrum of consciousness. It is suggested that doctors would proceed to conduct an EEG vocal recognition task, coupled with an fMRI. I would recommend this due to the troubling misdiagnosis figures, where patients have been regularly found to have higher levels of consciousness than that which is attributed to them at the bedside. The studies using these new technologies have highlighted the failures of the establishes diagnostic tools to see beyond the observable, when for some patients there is much more to be seen.

454 Braiman et al. (n 83).
However, eligibility for these new techniques is not universal; high-resolution MRI machines are costly, which not all patients are eligible to use even if they were available. As identified in Chapter Two, patients who have suffered major traumatic accidents may have had metal pins or other items inserted inside them, which would make them ineligible. I reject the two interviewees' assertion that fMRIs cannot be included in national guidance because of these restrictions. Some patients will not be eligible for fMRI due to machines they will have to be connected to or because of the presence of metal objects within the body. That should not, however, stop other patients from benefiting from their use if they are eligible. Where a patient is not eligible, they would continue to use the current diagnostic model, but this would hopefully allow for a percentage of PDOC patients to be afforded an extra opportunity to communicate their wishes and feelings.

The content in this section is summarised in the following flow charts:
Proposed future diagnostic framework

Undertake RCP recommended diagnostic procedure (CRS-R, WHIM and SMART)

Is P eligible for an fMRI? *

YES

Conduct EEG vocal recognition examination

NO

Is there a positive response to vocal recognition?

YES

Conduct function Magnetic Resonance Imaging

NO

Was P able to communicate via fMRI?

YES

Repeat fMRI as appropriate to confirm response

NO

Ask P their views on withdrawal of CANH

Proceed with best interests assessment
Continue to revise the care plan, unless a disagreement is unable to be resolved within a reasonable amount of time.
5.4.2 Declaratory relief

Requirement to go to Court

In the 28 years since the decision in *Bland*, the medical community’s understanding of the spectrum of PDOCs has continued to evolve at a rapid pace. In *Bland*, the House of Lords were fearful of the unknown, and that they may have been denying a patient a potential opportunity to emerge from a PDOC at a later stage. We now have a much greater understanding of the likelihood that a person in a PVS may transition to an MCS+/- and doctors are now able to make a more accurate prognosis.

The literature in Chapter Two demonstrated a widespread lack of understanding of the best interests standard and the weight that should be afforded to the patient's wishes. These findings were further substantiated by the interview I conducted and explored in Chapter Three. The entire process is medicalised, to the detriment of understanding what P would have wanted. Once diagnosis/prognosis has been established, the questions to be asked should focus entirely on P’s wishes and feelings.

The checklists, which the BMA and RCP recommend physicians use give little reassurance that best interests assessments are being carried out in a manner that addresses P’s wishes and feelings in any detail. The forms focus heavily on diagnosis/prognosis and then consist of little more than tick-box exercises to ensure that they have considered a patient’s family and friends. Doctors are not trained to think about a patient’s wider welfare concerns, as envisaged by Lady Hale, and nor should they be. It is not appropriate for a doctor to have to try to understand their patients’ broader belief systems when other professionals are trained to conduct such assessments.

The decision in *Re Y* rested on the basis that one cannot differentiate CANH from other life-sustaining treatments, such as the administration of antibiotics. Antibiotics are prescribed to and withdrawn from millions of people throughout the country for various issues, they are not a novel form of treatment. Simply because CANH and antibiotics both sustain life cannot, in

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456 See Taylor (*n* 205); and House of Lords Select Committee on the Mental Capacity Act 2005 (*n* 264)
my opinion, render them equivalent. The correct comparison would be whether a doctor should withdraw life-saving antibiotics that are working midway through the course of treatment.

Some form of third-party oversight helps to identify contentious issues between the parties and allows for a greater level of clarity and discussion than that which happens at the bedside. I observed that the CoP has helped in some cases to facilitate productive discussion, culminating in parties realising that their disagreements were easily resolved, had they communicated effectively.

The CoP allows for a professionally moderated forum where facts can be laid bare and analysed in-depth, which does not appear to occur within the hospital setting. Doctors are under significant time constraints and may not be able to dedicate the amount of time they would like to investigate P’s wishes and understand any disagreements fully. The CoP was established with this primary goal in mind, and as such, it continues to have an immeasurable benefit to all parties in PDOC cases.

Even where it appears that there is an agreement between all parties that CANH should be withdrawn, there should be some form of independent review. This review does not need to be conducted by the CoP but could instead be a member of the Public Guardian’s Office or a bench of magistrates. This safeguard ensures that the family and friends of P are not merely going along with what the more experienced doctors are suggesting. If issues are subsequently identified, then the CoP would be ready to have a full hearing. Protecting vulnerable patients is the cornerstone of the MCA 2005, and allowing decisions to occur at the bedside without an outside non-medicalised view, risks losing what P’s family and friend believed P would want.

Therefore, I would suggest that during a best interests assessment, some form of mediation, with a party external to the hospital, is made mandatory. This would honour the ruling in Re Y while continuing to offer added protection for patients without putting added pressure on the courts.
Reform of the Court

Throughout my observations of the CoP, it became clear that there are a number of issues that would benefit from substantial reform; the CoP continues to be criticised for lack of transparency, lack of expeditiousness and structure.

The CoP has been referred to as a ‘secretive court’, with insinuations that it operates behind closed doors, making controversial rulings. The CoP is not a secret court; most hearings within the Royal Courts of Justice are open to all members of the public. The CoP could benefit from ensuring that this fact is better known to the wider public and to some officials. There are, also issues that inhibit the public’s ability to attend these hearings, and as such could foster the feeling of being a ‘secret court’. Government budgetary cutbacks have left the court service severely understaffed in recent years, to the detriment of all parties involved in a hearing. Court staff are simply unable to process requests to attend hearings, as they are overstretched.

Since the start of the COVID-19 pandemic the CoP has taken on a new form, being conducted predominantly via remote video platforms. There has also been a noted increase in members of the public attending these remote hearings now that they are much more easily accessible. My attendance was noted by some judges, who became accustomed to my presence and would acknowledge me at the start of every hearing. Mr Justice Hayden also requested that all judges begin cases by having counsel provide a summary of the case for the benefit of the public observers, stating in one hearing:

Since the pandemic started, we now make a point of opening the case fully, in every case, so that the arrangements of today’s hearings can be fully understood by those viewing virtually in the public gallery.

Despite this improvement, the ability of the CoP to act expeditiously was nonetheless increasingly concerning; this is most clearly shown by the fact that I observed cases for over half a year that never came to a conclusion for a variety of reasons. In some cases, there was a lack of court time, or parties having not produced reports which they acknowledged they had

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457 See Jones and Allen (n 401); and Booker (n 402)
been instructed to, or there had been other delays. It became increasingly apparent to me that local authorities or hospital trusts were making decisions between themselves for months prior to engaging with the OS. Multiple judges made passing comments about the delay in bringing the OS into proceedings, and yet it continues to occur frequently. Local authorities and trusts must be encouraged to understand that the role of the OS is to protect the rights of the patient and that the OS should be involved in proceedings at the earliest possible stage.

The judiciary and the courts are no doubt overwhelmed throughout the criminal and civil divisions, both prior to COVID-19 and further still as a result of the pandemic. These vulnerable patients must not be forgotten or be left unheard as a result of cost-cutting or time-saving. There should be an investigation into how CoP cases can be heard in a timelier manner without sacrificing care and attention to detail. The judicial system has been at the mercy of budgetary cuts, but there must be a will to better serve vulnerable people, that goes above money.

The CoP is currently structured in a manner that reserves the most serious matters to Tier 3 judges of the High Court, who will also be hearing a full list of non-CoP matters on most days. The decisions being made in the CoP are all based on the MCA 2005, any judge who sits within its jurisdiction should therefore have a detailed understanding of the principles of the Act. I, therefore, do not see any reason why the MCA 2005 could not be amended so as to allow for Tier 2 judges to assist in lessening the workload and hearing cases that concern issues of serious medical treatment. If there is a continued desire not to have lower Tier judges decide serious medical issues, there are a significant number of experienced judges who have retired or left the courts who could be of great use in assisting to reduce the backlog and allowing for cases to be heard sooner. COVID-19 has had immeasurable impact on every part of society, mandatory retirement ages for healthy and knowledgeable judges should not be a bar to stop them helping the courts recover from the damage COVID-19 has caused.

5.5 Future research

This thesis has identified several issues, such as the MCA 2005, emerging technologies, the CoP, and the impact of COVID-19 which are all worthy of further research, to the benefit of vulnerable people and the wider public.
During the writing of this thesis, COVID-19 took its hold on the UK, and as such the justice system had to change in ways never before witnessed. Virtual courtrooms began to be used within the Court of Protection, to decide on matters of life and death. Throughout 2020 and 2021 there was continued debate on social media and among CoP users about how efficient and reliable video conferencing platforms were. I believe that over the coming years the justice system would benefit from the ability to hold expeditious hearings via such means. The costs associated with a virtual hearing, as opposed to one which is in-person, are likely to be dramatically lower and the number of cases which can be facilitated in a day could be increased. I have discussed some minor reforms of the CoP within this Chapter, I believe that the impact that COVID-19 has had on the operation of the CoP is something worthy of in-depth research, to try to enable a better court service. In addition to the impact COVID-19 had on the infrastructure of the CoP, the impact that the disease itself had is a timely piece of research of great public importance. Throughout my observations, judges discussed the increasing number of cases where they were asked to rule on whether to authorise P being administered a vaccine. There was also a high number of cases each week concerning treatment options on COVID-19 patients. Although COVID-19 was outside of the scope of this thesis, it had a great impact on the content being discussed within the CoP and as such will likely have caused increased strain on the RCJ.

The research being conducted around the world on emerging technologies is going to have to continue for many years to come. The use of fMRIs is not currently recommended by authorities in the UK as part of the routine diagnostic framework, and as such there is a continued need to ensure that they are as reliable as the current research suggests. Research will also need to be conducted with the leading medical bodies as to how exactly the use of fMRI can be implemented into the current framework.

5.6 Final reflections

At the outset I summarised the core question this thesis initially sought to answer: Is the law of England and Wales doing all it can to protect vulnerable adults when making decisions regarding the end of their lives?

During the period of this research being conducted, the law and policy relating to how decisions are made for adult PDOC patients has changed dramatically. In 2019, the Supreme Court made
one of the most significant developments in the law in a generation when it ruled that there is no mandatory declaratory relief process for PDOC patients. This ruling, which I believe left questions unanswered, has reopened debates which have existed since the decision in *Bland*; the debates around the role of the court, who a decision-maker should be and where a patient’s wishes and feelings fall into the discussion.

I believe this thesis has answered much more than the core question I expressed at the start. It has laid the foundations for further, much needed, research. I was placed in a unique position as a result of the COVID-19 pandemic and was able to see first-hand the positives and negatives of the how the current system works. The number of cases appearing before the CoP has not reduced since *Re Y* in any significant way, and all indicators suggest that hospitals continue to provide LST until a family member raises the issue at the same rate. In the last few months of this research, after my observations had finished, the CoP began to hear a number of cases relating to COVID-19; these cases included withdrawing treatment from those who had contracted it as well as deciding whether people who lacked capacity should be given the vaccine, sometimes against the will of loved ones. These are issues that prove that the work of the CoP is ever evolving. How the best interests test meets novel situations like COVID is going to be a greatly debated topic for years to come

Further to this, throughout the duration of my research results into the use of some emerging technologies, such as fMRI, have continued to show promising results. These findings indicate that at some point in the future, we may be able to understand the true wishes and feelings of some patients who cannot communicate at the bedside without relying on second-hand anecdotal evidence.

Fundamentally this thesis aimed to show how there remains a lack of understanding of the very core principles of the MCA 2005. Best interests is not well understood throughout the legal and medical professions and is far too often misunderstood to mean best *medical* interests. More significant guidance needs to be produced for doctors to use at the bedside, which outlines their obligations to PDOC patients alongside more consistent training of those who are likely to manage PDOC patients.

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*NHS Tameside & Glossop CCG v CR [2021] EWCOP 19.*
I have witnessed first-hand the range of levels of capacity that comes before the CoP and cannot see how a one-size-fits-all approach can ever be justified. The need for a form of oversight, be it through the CoP or another intermediary, is of continued importance despite the Supreme Court's ruling. Nuance is key to dealing with matters of capacity. How a decision-maker can be made to be sure that what they are proposing is what the patient would have wanted is of the utmost importance.

I have been privileged to be uniquely positioned to research this area throughout the COVID-19 pandemic, which has allowed me unprecedented access to witness the CoP in action and has afforded me the opportunity of seeing first-hand the need to strengthen protections for vulnerable patients. I believe that the courts of England and Wales are making significant steps towards ensuring patient-centred decision-making; however, they are not where they should be yet. After the decision in Aintree, the position has been unequivocal: the views of the patient are the centre of the entire process. Some judges, lawyers and doctors do not yet work on this premise or even know that this is the case. The current law is outdated, misunderstood, applied incorrectly, and not fit for purpose.
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Appendix A:
Email to prospective interviewees

Good Afternoon,

My name is Adam Tanner. I am a PhD researcher in law looking at mental capacity legislation for patients who have a prolonged disorder of consciousness. I am looking to conduct a series of interviews with professionals in the field to ascertain areas in need of reform and how decisions are made for patients with disorders of consciousness. The research is concerned with the role of the Court of Protection moving forward, post Re Y, and any other reforms to the Mental Capacity Act 2005 which may strengthen its purpose. I will seek to ask your opinions on the adequacy of the best interests test, appropriate safeguarding measures, advancing technologies and other related matters.

The interview itself would be around 30 minutes long and would take the form of an open discussion, with key points of interest to guide us. I wish to capture the thoughts of professionals as to what they would do to reform and strengthen the MCA 2005, the rights of patients and the practicalities of the Law.

If you are willing to participate in the interview, I will arrange either a sit-down interview or Skype interview whichever suits you best. I will seek to arrange a time which best suits you in October through December.

Would you please let me know if you are able to take part in this short interview and I will endeavour to send over the formalised information sheets and consent forms.

Thank you for taking the time to consider this research.

Yours sincerely,

Adam Tanner
Appendix B:
Information sheet and consent form

The Open University Law School
Walton Hall
Milton Keynes
MK7 6AA

Participant Information Sheet-
Mental Capacity Act and treatment for those who lack capacity

Hello,

Thank you for taking the time to consider participating in a research interview relating to the Mental Capacity Act 2005.

I am carrying out research as part of a PhD in Law, researching end-of-life treatment for those who lack capacity. My aim is to undertake a thorough review of the case-law and statutes in this area, as well as the medical and clinical guidance, and to propose any changes I believe would improve the law in this regard. I am approaching a number of prospective participants whom I know are specialists in this field.

I estimate that it will take 30 - 60 minutes for this interview to take place; it will be held in a semi-structured interview style, allowing for a more in-depth discussion of the issues which are important to you. The topics to be covered in this interview are to include: the need for an application to be made to the court for serious medical treatment, the application of the ‘best interests’ test, and any future reforms in the area of medical treatment for those lacking capacity.

The purpose of the data collected from this project is to inform any recommendations I am to make in my PhD thesis.

All of the data collected from these interviews will be stored in a password-protected document on an encrypted hard drive and will not be included in any spreadsheets or other documents other than the interview transcript. The Consent Form offers you the option of indicating whether you would permit audio-recording or written note-taking during your interview, and whether your answers may be used within my thesis and any other publications or must remain off-the-record.

If you agree to the use of your answers in my thesis and other publications, your anonymised interview transcript will be available only to me during the research
project. When the project is complete, the anonymised transcript will be stored by The Open University for a period of 10 years so that other researchers may refer to it if they wish to do so.

You may request termination of the interview at any time. If you do this, you may also request that I provide you with my notes or delete my recording of the interview, and there will be no mention of your participation.

You may withdraw your consent for the inclusion of your interview material in the project at any time within four weeks after the completion of the interview. After this date, it is likely that your interview material will have been included in written work, so it will not be possible for it to be withdrawn.

If you would like a summary of the findings of my project, please indicate this on the Consent Form.

This project is funded by a grant provided by The Open University Faculty of Business and Law through a studentship grant.

If you would like to know more you can contact me on the details provided above.

Thank you again for your consideration of this request.

Yours faithfully,

Adam Tanner
Consent Form:
Mental Capacity Act and treatment for those who lack capacity

Thank you for considering taking part in this research project. It is important that you understand your involvement in the project.

In order to ensure that this is the case, please indicate your acceptance or otherwise of each of the following numbered statements, and sign where indicated at the bottom of this form.

- **If you accept a statement, please click the check box to put a cross**

1. I have read and understood the written information about the project.
   - (Check Box)

2. I understand that my participation is voluntary, and that I may withdraw from the study at any time during the interview up to the time in which the interviewer provides me with a transcript of our interview. I understand that I can withdraw by contacting the researcher, whose details are given on the Participant Information Sheet.
   - (Check Box)

3. I agree that the interview may be audio-recorded and understand that any audio recordings will be destroyed and not retained, within 30 days of a written transcript.
   - (Check Box)

4. I agree to my comments being used in the researcher’s thesis.
   - (Check Box)

5. I understand that the anonymised transcript of my interview will be stored by The Open University for a minimum period of 10 years.
   - (Check Box)

6. I would like a written summary of the findings of this project to be sent to me at the following email address [please use clear block capital letters]:

   _____________________________________________________________

   208
I agree to take part in the project, and for any data generated by my participation to be used in the ways that I have agreed to above, some of which are more fully described in the Participant Information Sheet.

Name of participant: _________________________________
Date: _________________________________
Signature: _________________________________

Researcher: Adam Tanner
Date: _________________________________
Signature: _________________________________
Appendix C: Interview questions

This appendix shows the template interview questions that were used to guide every interview I undertook. As explained within the thesis, not all questions were asked verbatim to each interviewee.

1) Firstly, in the simplest way possible, how would you define the term “best interests” as it pertains to the MCA, versus how the law may see it?

2) When undertaking a best interests assessment, a number of views are taken into consideration, including those of the patient, the family and other interested parties. How do you feel a decision-maker should balance all of these views?

3) The House of Lords Committee on the Mental Capacity Act 2005 said that a substantial number of clinicians do not understand the concept of best interests or fail to undertake it accurately. Do you think that that is an accurate depiction of the clinical reality?

4) What would you say needs to be done to improve clinical understanding of best interests, to ensure a more holistic assessment is being carried out?

5) There has been a lot written about the potential rates of misdiagnosis of around 40% of minimally conscious patients. How do you feel about these figures?

6) Sticking with diagnosis, Current diagnostic methods are often criticised, and research has been increasing over the past two decades into alternative diagnostic techniques. How do you feel about emerging technologies such as functional magnetic resonance imaging or EEGs being incorporated into a potential diagnostic framework in the future?

7) Moving away from the clinical. I would like to understand your general thoughts on the case of Re Y. Do you feel that the decision in Re Y was a welcome one?

8) Do you think that there is still a place for a declaratory relief process of some kind, or perhaps some form of overview away from the courtroom setting?

9) What changes, if any, would you wish to recommend to amend the MCA 2005 to protect the rights of patients and ensure the spirit of the current law is followed?

10) Do you believe that the United Kingdom has come more in line with Article 12 of the UNCRPD, and what do you feel, if anything, the UK should do to achieve this?
Appendix D:
Email to Court

This appendix shows the draft email that I used for my contact with the Court of Protection. The email included my name, reason to attend and the hearing I wished to observe.

From: Adam.Tanner
Sent: COP XXXXX RE: XX

Good evening,

I am a PhD researcher with the Open University, researching how the Court of Protection operates and how decisions are made for those who lack capacity. Would it please be possible to attend the remote public hearing, COP XXXXXXX, listed for XXXX before Mr Justice XXXX.

If you could pass this information on to Mr Justice XXXX’s clerk it would be greatly appreciated and I would be happy to have a discussion with the Clerk or judge if necessary. Please see the hearing details listed below:

Before MRS JUSTICE XXXX
Also sitting as a Judge of the Court of Protection
Tuesday, 6 October, 2020
At 02:00 PM
FOR HEARING IN OPEN COURT
COP XXXXX RE: XX  MS Teams Hearing

Thank you for your help.
Kind regards,
Adam Tanner
07896XXXXXX

Adam Tanner  |  PhD Researcher in Law
The Open University Law School, Michael Young Building DG Wing, Walton Hall, Milton Keynes, MK7 8AA
adam.tanner@open.ac.uk
Appendix C shows a copy of a blank test sheet for the Wessex Head Injury Matrix, that clinicians should complete when carrying out diagnostic and prognostic tests on a patient in a prolonged disorder of consciousness.

### The Wessex Head Injury Matrix

<table>
<thead>
<tr>
<th>Behaviour observed</th>
<th>Operational definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Eyes open briefly</td>
<td>Last for more than 30 seconds.</td>
</tr>
<tr>
<td>2 Eyes open for extended period</td>
<td>Movements in random manner.</td>
</tr>
<tr>
<td>3 Eyes open but do not focus on object/person</td>
<td>Movements in random manner.</td>
</tr>
<tr>
<td>4 Attention held momentarily by dominant stimulus</td>
<td>No response to verbal or tactile stimulation.</td>
</tr>
<tr>
<td>5 Looks at person briefly</td>
<td>Not looking at person.</td>
</tr>
<tr>
<td>6 Vocalisation, to express feelings</td>
<td>No response to verbal or tactile stimulation.</td>
</tr>
<tr>
<td>7 Grinding of teeth/lowering of teeth</td>
<td>Teeth clenching in response to a loud noise.</td>
</tr>
<tr>
<td>8 Makes eye contact</td>
<td>Patient’s eyes move in the same direction as the examiner’s eyes.</td>
</tr>
<tr>
<td>9 Patient looks at person who is talking to him/her</td>
<td>Patient looks at someone else.</td>
</tr>
<tr>
<td>10 Involuntary movements</td>
<td>Patient moves in response to a loud noise.</td>
</tr>
<tr>
<td>11 Marked arousal &amp; agitation prior to sedation</td>
<td>Patient becomes increasingly restless and agitated immediately after sedation.</td>
</tr>
<tr>
<td>12 Eyes follow person moving in line of vision</td>
<td>Patient’s eyes move in the same direction as the examiner’s eyes.</td>
</tr>
<tr>
<td>13 Looks at person giving attention</td>
<td>Patient looks at the examiner.</td>
</tr>
<tr>
<td>14 Mechanical vocalisation (e.g. yawn, sigh, etc.)</td>
<td>Patient makes a sound when talking.</td>
</tr>
<tr>
<td>15 Performs physical movement on verbal request</td>
<td>Patient moves in response to a loud noise.</td>
</tr>
<tr>
<td>16 Tense head/eyes to look when someone is talking</td>
<td>Patient moves in response to a loud noise.</td>
</tr>
<tr>
<td>17 Watches person moving in line of vision</td>
<td>Patient looks at the examiner.</td>
</tr>
<tr>
<td>18 Tracks for 3-5 seconds</td>
<td>Patient’s eyes move in response to a loud noise.</td>
</tr>
<tr>
<td>19 Speaks in whispered tones</td>
<td>Patient makes a sound when talking.</td>
</tr>
<tr>
<td>20 Vocalises to express mood or needs</td>
<td>Patient makes a sound when talking.</td>
</tr>
<tr>
<td>21 Crying</td>
<td>Patient’s eyes move in response to a loud noise.</td>
</tr>
<tr>
<td>22 Track a source of sound</td>
<td>Patient looks at the examiner.</td>
</tr>
<tr>
<td>23 Shows collective response to preferred people</td>
<td>Patient looks at the examiner.</td>
</tr>
</tbody>
</table>
Appendix F: 
Checklist 1

This appendix shows a copy of the consent form and best interests checklist used by Royal United NHS Foundation Trust.

Royal United Hospitals NHS Foundation Trust

Consent form 4

Form for adults who are unable to consent to investigation or treatment

Patient details (or pre-printed label)

Patient's surname/family name…………………………
Patient's first names ………………………………………
Date of birth ……………………………………………..
Responsible health professional…………………………
Job title …………………………………………………
NHS number (or other identifier)…………………………

☐ Male ☐ Female

Special requirements ……………………………………
(eg other language/other communication method)

To be retained in patient’s notes
Patient identifier/label

All sections to be completed by health professional proposing the procedure

A Details of procedure or course of treatment proposed

(NB see guidance to health professionals overleaf for details of situations where court approval must first be sought)

B Assessment of patient’s capacity

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because:

☐ the patient is unable to comprehend and retain information material to the decision; and/or
☐ the patient is unable to use and weigh this information in the decision-making process; or
☐ the patient is unconscious

Further details (excluding where patient unconscious): for example how above judgements reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful.

C Assessment of patient’s best interests

To the best of my knowledge, the patient has not refused this procedure in a valid advance directive. Where possible and appropriate, I have consulted with colleagues and those close to the patient, and I believe the procedure to be in the patient’s best interests because:

(Where incapacity is likely to be temporary, for example if patient unconscious, or where patient has fluctuating capacity)

The treatment cannot wait until the patient recovers capacity because:
D Involvement of the patient’s family and others close to the patient

The final responsibility for determining whether a procedure is in an incapacitated patient’s best interests lies with the health professional performing the procedure. However, it is good practice to consult with those close to the patient (eg spouse/partner, family and friends, carer, supporter or advocate) unless you have good reason to believe that the patient would not have wished particular individuals to be consulted, or unless the urgency of their situation prevents this. “Best interests” go far wider than “best medical interests”, and include factors such as the patient’s wishes and beliefs when competent, their current wishes, their general well-being and their spiritual and religious welfare.

(to be signed by a person or persons close to the patient, if they wish)

I/We have been involved in a discussion with the relevant health professionals over the treatment of……………………………(patient’s name). I/We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. I/We also understand that treatment can lawfully be provided if it is in his/her best interests to receive it.

Any other comments (including any concerns about decision)

Name …………………………………..Relationship to patient………………………………………
Address (if not the same as patient)……………………………………………………………………
………………………………………………………………………………………………………………
………………………………………………………………………………………………………………

Signature ……………………………………..Date……………………………..

If a person close to the patient was not available in person, has this matter been discussed in any other way (eg over the telephone?)
☐ Yes  ☐ No

Details:

Signature of health professional proposing treatment

The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient’s condition with those close to him or her, and taken their knowledge of the patient’s views and beliefs into account in determining his or her best interests.

I have/have not sought a second opinion.

Signature:…………………………………..Date ………………………………..
Name (PRINT) ………………………………..Job title ………………………………..

Where second opinion sought, s/he should sign below to confirm agreement:

Signature:…………………………………..Date ………………………………..
Name (PRINT) ………………………………..Job title ………………………………..
Guidance to health professionals (to be read in conjunction with consent policy)

This form should only be used where it would be usual to seek written consent but an adult patient (18 or over) lacks capacity to give or withhold consent to treatment. If an adult has capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the Mental Health Act 1983, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has clearly refused particular treatment in advance of their loss of capacity (for example in an advance directive or ‘living will’), then you must abide by that refusal if it was validly made and is applicable to the circumstances. For further information on the law on consent, see the Department of Health’s Reference guide to consent for examination or treatment (www.doh.gov.uk/consent).

When treatment can be given to a patient who is unable to consent

For treatment to be given to a patient who is unable to consent, the following must apply:

- the patient must lack the capacity (‘competence’) to give or withhold consent to this procedure AND
- the procedure must be in the patient’s best interests.

Capacity

A patient will lack capacity to consent to a particular intervention if he or she is:

- unable to comprehend and retain information material to the decision, especially as to the consequences of having, or not having, the intervention in question; and/or
- unable to use and weigh this information in the decision-making process.

Before making a judgement that a patient lacks capacity you must take all steps reasonable in the circumstances to assist the patient in taking their own decisions (this will clearly not apply if the patient is unconscious). This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates or supporters.

Capacity is ‘decision-specific’: a patient may lack capacity to take a particular complex decision, but be quite able to take other more straightforward decisions or parts of decisions.

Best interests

A patient’s best interests are not limited to their best medical interests. Other factors which form part of the best interests decision include:

- the wishes and beliefs of the patient when competent
- their current wishes
- their general well-being
- their spiritual and religious welfare

Two incapacitated patients, whose physical condition is identical, may therefore have different best interests.

Unless the patient has clearly indicated that particular individuals should not be involved in their care, or unless the urgency of their situation prevents it, you should attempt to involve people close to the patient (spouse/partner, family and friends, carer, supporter or advocate) in the decision-making process. Those close to the patient cannot require you to provide particular treatment which you do not believe to be clinically appropriate. However they will know the patient much better than you do, and therefore are likely to be able to provide valuable information about the patient’s wishes and values.

Second opinions and court involvement

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient’s condition prevents this. Donation of regenerative tissue such as bone marrow, sterilisation for contraceptive purposes and withdrawal of artificial nutrition or hydration from a patient in PVS must never be undertaken without prior

High Court approval. High Court approval can also be sought where there are doubts about the patient’s capacity or best interests.
Appendix G: Checklist 2

This appendix contains a partial copy of the Black Country partnership Best Interests Checklist.


### Best Interests Checklist for Use by Health and Social Care Staff Working with Person Lacking Capacity in Relation to a Decision (Appendix 2b)

<table>
<thead>
<tr>
<th>Patient/User Name:</th>
<th>DOB:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID No (NHS or Social Care):</td>
<td></td>
</tr>
</tbody>
</table>

**DETECTION**

Record in the space below the decision for which person lacks capacity

<table>
<thead>
<tr>
<th>CHECKLIST</th>
<th>Please circle appropriate answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Has an 'advance decision or 'advance refusal' been made about the decision in question (only in relation to healthcare decision), and is it still relevant?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>2) Have you considered whether it is likely that the person may have capacity at some time in future and whether a delay in decision-making will allow them to make that decision themselves?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>3) Have you encouraged as far as is practicable that person's involvement in actions undertaken on their behalf or in any decisions affecting them?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>4) Have you considered as much as is practicable the person’s past and present wishes and preferences about the matter in question?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>5) Have you considered any relevant written statement the person may have made when they did have capacity?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>6) Have you considered the beliefs and values that would be likely to influence the person’s attitude to the decision in question, i.e. religious, cultural and lifestyle choices?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>7) Have you taken into account other factors that the person would be likely to consider in relation to the matter, i.e. emotional bonds or family obligations in deciding how to spend money or where to reside?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>8) Have you considered alternative actions that produce less restriction on the person’s rights and freedoms?</td>
<td>Yes  No</td>
</tr>
<tr>
<td>9) Have you consulted and taken into account the views of other key people as to what would be in a person’s best interests and gathered information on their wishes, feelings, values, beliefs?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>a) Anyone named in advance as someone to be consulted?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>b) Carers, family, spouses or partners?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>c) Others with an interest in their welfare, friends, voluntary workers, other professionals?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>d) Any Lasting Power of Attorney?</td>
<td>Yes  No  N/A</td>
</tr>
<tr>
<td>e) Any Deputy appointed by the Court of Protection?</td>
<td>Yes  No  N/A</td>
</tr>
</tbody>
</table>

If there are any conflicts in the above consultations, there needs to be an attempt to reach a consensus. However, the decision maker makes final decision.
If there is an answer ‘No’ in question 2 to 9, then staff should question whether they are acting in best interests. If no-one is available to consult and/or if there is serious conflict of opinion and the decision and eligibility relates to decisions identified in Section 4 of the local policy and procedure, then an IMCA referral should be considered.

**Staff should evidence their consultations in the space below:** (continue on a separate sheet where necessary but firmly attach it to this document).

<table>
<thead>
<tr>
<th>Name and job title of worker:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Job title:</td>
</tr>
</tbody>
</table>

Date of Decision Making/Best Interests Consideration:
Where do I go for further advice or information?

- MCA and DoLS Practitioner

Training
Staff may receive training in relation to this procedure, where it is identified in their appraisal as part of the specific development needs for their role and responsibilities. Please refer to the Trust’s Mandatory & Risk Management Training Needs Analysis for further details on training requirements, target audiences and update frequencies.

Monitoring / Review of this Procedure
In the event of planned change in the process(es) described within this document or an incident involving the described process(es) within the review cycle, this SOP will be reviewed and revised as necessary to maintain its accuracy and effectiveness.

Equality Impact Assessment
Please refer to overarching policy

Data Protection Act and Freedom of Information Act
Please refer to overarching policy
This appendix contains the consent form and best interests checklist for Hertfordshire NHS trust with an information guide for clinicians to follow when filling it out.

Appendix H: Checklist 3

**Consent Form 4**

**Adults who lack the capacity to consent to investigation or treatment**

Patient details (or pre-printed label)

- Patient's surname/family name: ____________________________
- Patient's first name: ____________________________
- Date of Birth: ____________________________
- NHS number: ____________________________
- Responsible health professional: ____________________________
- Job title: ____________________________
- Registration number: ____________________________
- Special requirements: ____________________________
- Other language; other communication method: ____________________________

**Name of proposed procedure or course of treatment** (include brief explanation if medical term not clear)

- Description of procedure or course of treatment: ____________________________

**Assessment of patient’s capacity** (in accordance with the Mental Capacity Act)

- I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because of an impairment of the mind or brain or disturbance affecting the way their mind or brain works (for example, a disability, condition or trauma, or the effect of drugs or alcohol) and they cannot do one or more of the following:
  - understand information about the procedure or course of treatment
  - retain that information in their mind
  - use or weigh that information as part of the decision-making process, or
  - communicate their decision (by talking, using sign language or any other means)

Further details of this assessment (for example how above judgements reached, which colleagues consulted, what attempts were made to assist the patient to make his or her own decision and why these were not successful):

**Advance decision to refuse medical treatment**

This patient has (not make decision as appropriate) made an advanced decision to refuse medical treatment.

Where an advance decision to refuse medical treatment has been made, please document the details of the treatment to be refused here:

Where, to the best of your knowledge, the patient has (not re-made decision as appropriate) made an advanced decision to refuse medical treatment, please document the details of the decision here:

**Lasting Power of Attorney / Court Appointed Deputy**

If the patient has authorised an attorney to make decisions about the procedure in question under a Lasting Power of Attorney or as a Court Appointed Deputy (delete as appropriate), I have considered the relevant circumstances relating to the decision under the heading ‘Assessment of patient’s best interests’ and believe the procedure to be in the patient’s best interests. Any other comments (including the circumstances considered in assessing the patient’s best interests):

**Signature** ____________________________ Date ____________________________

**Independent Mental Capacity Advocate (IMCA)**

For decisions about serious medical treatment, where there is no one appropriate to consult other than paid staff, has an Independent Mental Capacity Advocate (IMCA) been instructed? Yes ☐ No ☐

Record full details of the conversations, and the outcome, in the patient’s medical records.

**Signature of health professional proposing treatment**

The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient’s condition with those close to him or her, and taken their knowledge of the patient’s views and beliefs into account in determining his or her best interests.

**Signature** ____________________________ Date ____________________________

**Name (PRINT)** ____________________________ Job Title ____________________________

Where a second health professional’s opinion is sought, he/she should sign below to confirm agreement:

**Signature** ____________________________ Date ____________________________

**Name (PRINT)** ____________________________ Job Title ____________________________
Guidance to health professionals (to be read in conjunction with consent policy)

What a consent form is for

This form should only be used where it would be usual to seek written consent but an adult patient (18 or over) lacks capacity to give or withhold consent to treatment. If an adult has capacity to accept or refuse treatment, they should use the standard consent form I if they choose to have treatment. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of part IV of the Mental Health Act 1983, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has made a valid advance decision to refuse treatment that is applicable to the proposed treatment then you must abide by that refusal.

For further information on the law on consent, see Department of Health’s Reference guide to consent for examination or treatment (www.doh.gov.uk/consent).

When treatment can be given to a patient who lacks the capacity to consent

All decisions made on behalf of a patient who lacks capacity must be made in accordance with the Mental Capacity Act 2005. More information about the Act is given in the Code of Practice. Treatment can be given to a patient who is unable to consent if:

- the patient lacks the capacity to give or withhold consent to this procedure AND
- the procedure is in the patient’s best interests.

Capacity

A person lacks capacity if they have an impairment or disturbance (for example, a disability, condition or trauma, or the effect of drugs or alcohol) that affects the way their mind or brain works which means that they are unable to make a specific decision at the time it needs to be made. It does not matter if the impairment or disturbance is permanent or temporary.

You must take all steps reasonable in the circumstances to assist the patient in taking their own decisions. This may involve explaining what is involved in very simple language, using pictures and communication and decision aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates (as distinct from an IMCA as set out below) or supporters. Sometimes it may be necessary for a formal assessment to be carried out by a suitably qualified professional.

Capacity is ‘decision-specific’; a patient may lack capacity to take a particular complex decision, but be able to take other more straightforward decisions or parts of decisions. Capacity can also fluctuate over time and you should consider whether the person is likely to regain capacity and if so whether the decision can wait until they regain capacity.

A person is unable to make a decision if they cannot do one or more of the following:

- Understand the information given to them that is relevant to the decision.
- Retain that information long enough to be able to make the decision.
- Use or weigh up the information as part of the decision-making process.
- Communicate their decision - this could be by talking or using sign language and includes simple muscle movements such as blinking an eye or squeezing a hand.

Best interests

Treatment may be provided in an incapacitated adult’s best interests provided that the patient has not made a valid and applicable Advance Decision refusing the specific treatment. The Mental Capacity Act requires that a health professional must consider all the relevant circumstances relating to the decision in question, including, as far as possible:

- the person’s past and present wishes and feelings (in particular if they have been written down)
- any beliefs and values (e.g. religious, cultural or moral) that would be likely to influence the decision in question and any other relevant factors
- the other factors that the person would be likely to consider if they were able to do so.

When determining what is in a person’s best interests a health professional must not make assumptions about someone’s best interests merely on the basis of the person’s age or appearance, condition or any aspect of their behaviour. If the decision concerns the provision or withdrawal of life-sustaining treatment the health professional must not be motivated by a desire to bring about the person’s death.

The Act also requires that, as far as possible, health professionals must consult other people, if it is appropriate to do so, and take into account of their views as to what would be in the best interests of the person lacking capacity, especially anyone previously named by the person lacking capacity as someone to be consulted and anyone engaging in care for patient and their family and friends.

Independent Mental Capacity Advocate (IMCA)

The Mental Capacity Act introduced a duty on the NHS to instruct an Independent Mental Capacity Advocate (IMCA) in serious medical treatment decisions when a person who lacks capacity to make a decision has no one who can speak for them, other than paid staff. IMCAS are not decision makers for the person who lacks capacity. They are there to support and represent that person and to ensure that decision making for people who lack capacity is done appropriately and in accordance with the Act.

Lasting Power of Attorney and Court Appointed Deputy

A person over the age of 18 can appoint an attorney to look after their health and welfare decisions, if they lack the capacity to make such decisions in the future. Under a Lasting Power of Attorney (LPA) the attorney can make decisions that are as valid as those made by patients themselves when they have capacity. The LPA may specify limits to the attorney’s authority and the LPA must specify whether or not the attorney has the authority to make decisions about life-sustaining treatment. The attorney can only, therefore, make decisions as authorised in the LPA and must make decisions in the person’s best interests.

The Court of Protection can appoint a deputy to make decisions on behalf of a person who lacks capacity. Decisions for personal welfare decisions will only be required in the most difficult cases where important and necessary actions cannot be carried out without the court’s authority or where there is no other way of settling the matter in the best interests of the person who lacks capacity. If a deputy has been appointed to make treatment decisions on behalf of a person who lacks capacity then it is the deputy rather than the health professional who makes the treatment decision and the deputy must make decisions in the patient’s best interests.

Second opinions and court involvement

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient’s condition prevents this. The Court of Protection deals with serious decisions affecting personal welfare matters, including healthcare, which were previously dealt with by the High Court. Cases involving:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS)
- cases involving organ, bone marrow or peripheral blood stem cell (PBSC) donation by an adult who lacks capacity to consent
- cases involving the proposed non-therapeutic sterilisation of a person who lacks capacity to consent to this (e.g. for contraceptive purposes)
- all other cases where there is a doubt or dispute about whether a particular treatment will be in a person’s best interests (include cases involving ethical dilemmas in untested areas)

should be referred to the Court for approval. The Court can be asked to make a decision in cases where there are doubts about the patient’s capacity and also about the validity or applicability of an advance decision to refuse treatment.
Consent Form 4

Adults who lack the capacity to consent to investigation or treatment

Patient details (or pre-printed label)

Patient's surname/family name............................................ Patient's first names............................................

Date of Birth................................................................. Male □ Female □

NHS number........................................................................ PID........................................................................

Responsible health professional........................................... Registration number............................................

Job title................................................................................ Special requirements ...................................................

(eg other language/other communication method)

Name of proposed procedure or course of treatment (include brief explanation if medical term not clear):

Assessment of patient's capacity (in accordance with the Mental Capacity Act)

I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because of an impairment of the mind or brain or disturbance affecting the way their mind or brain works (for example, a disability, condition or trauma, or the effect of drugs or alcohol) and they cannot do one or more of the following:

- understand information about the procedure or course of treatment
- retain that information in their mind
- use or weigh that information as part of the decision-making process, or
- communicate their decision (by talking, using sign language or any other means)

Further details of this assessment: (for example how above judgements reached, which colleagues consulted, what attempts were made to assist the patient to make his or her own decision and why these were not successful)

Advance decision to refuse medical treatment

This patient has not (indicate as appropriate) made an advance decision to refuse medical treatment. Where an advance decision to refuse medical treatment has been made, please document the details of the treatment to be refused here:

Where, to the best of your knowledge, the patient has not refused this procedure in a valid Advance Decision, please continue to the next section.

Lasting Power of Attorney/ Court Appointed Deputy

If the patient has authorised an attorney to make decisions about the procedure in question under a Lasting Power of Attorney or a Court Appointed Deputy has been authorised to make decisions about the procedure in question, they have authority to make decisions in the patient's best interests.

Signature of attorney or deputy:

I have been authorised to make decisions about the procedure in question under a Lasting Power of Attorney / as a Court Appointed Deputy (delete as appropriate). I have considered the relevant circumstances relating to the decision under the heading 'Assessment of patient's best interests' and believe the procedure to be in the patient's best interests. Any other comments (including the circumstances considered in assessing the patient's best interests):

Name:.............................................................................. Address:.................................................................
Signature:.......................................................................... Date:.................................................................

Assessment of patient's best interests

As far as is reasonably possible, I have considered the person's past and present wishes and feelings (in particular if they have been written down) and any beliefs and values that would likely influence the decision in question. As far as possible, I have consulted other people (those involved in caring for the patient, interested in their welfare or the patient has said should be consulted) as appropriate. I have considered the patient's best interests in accordance with the requirements of the Mental Capacity Act and believe the procedure to be in their best interests because:

Where the lack of capacity is likely to be temporary, for example if patient is unconscious, or where patient has fluctuating capacity, complete the following section:

The treatment cannot wait until the patient recovers capacity because:

Involvement of the patient’s family and others close to the patient

The final responsibility for determining whether a procedure is in an incapacitated patient's best interests lies with the health professional performing the procedure. However, it is good practice to consult with those close to the patient (eg spouse/partner, family friends, carer, supporter or advocate) unless you have good reason to believe that the patient would not have wished for particular individuals to be consulted, or unless the urgency of their situation prevents this. “Best interests” go far wider than “best medical interests”, and include factors such as the patient's wishes and beliefs when competent, their current wishes, their general well-being and their spiritual and religious welfare.

To be signed below by a person or persons close to the patient, if they wish:

If I have been involved in a discussion with the relevant health professionals over the treatment of (patient's name) / We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. / We also understand that this treatment can lawfully be provided as it is in his/her best interests to receive it.

Any other comments (including any concerns about decision):

Name:.............................................................................. Relationship to patient:...........................................
Address (if not the same as patient):............................................... Date:.................................................................
Signature:..............................................................................

Independent Mental Capacity Advocate (IMCA)

For decisions about serious medical treatment, where there is no one appropriate to consult other than paid staff, has an Independent Mental Capacity Advocate (IMCA) been instructed? □ Yes □ No

Record full details of the conversations, and the outcome, in the patient's medical records.

Signature of health professional proposing treatment

The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient's condition with those close to him or her, and taken their knowledge of the patient's views and beliefs into account in determining his or her best interests.

Signature:.............................................................................. Date:.................................................................
Name (PRINT):...................................................................... Job Title:.................................................................

If a person close to the patient is not available in person, has this matter been discussed in any other way (eg over the telephone)? □ Yes □ No

Where a second health professional's opinion is sought, he/she should sign below to confirm agreement:

Signature:.............................................................................. Date:.................................................................
Name (PRINT):...................................................................... Job Title:.................................................................

Copy accepted by patient: yes / no (please ring)

YELLOW COPY: CASE NOTES  WHITE COPY: PATIENT
Appendix I: Interviewees

This appendix contains an outline of my list of interviewees. This table allows for my interviewees professions to be easily seen and cross referenced with the pseudonym given to them for the purposes of this thesis. Each interviewee was given a letter based on the date of their initial interview.

<table>
<thead>
<tr>
<th>Interview Number</th>
<th>Profession</th>
<th>Pseudonym</th>
<th>Date of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewee 1</td>
<td>Professor of Law / Barrister</td>
<td>Lawyer A</td>
<td>October 1, 2019</td>
</tr>
<tr>
<td>Interviewee 2</td>
<td>Professor of Law</td>
<td>Lawyer B</td>
<td>October 3, 2019</td>
</tr>
<tr>
<td>Interviewee 3</td>
<td>Consultant Neurologist</td>
<td>Clinician A</td>
<td>October 4, 2019</td>
</tr>
<tr>
<td>Interviewee 4</td>
<td>Trauma Specialist</td>
<td>Clinician B</td>
<td>October 4, 2019</td>
</tr>
<tr>
<td>Interviewee 5</td>
<td>Professor of Law / Neurologist</td>
<td>Lawyer C</td>
<td>October 6, 2019</td>
</tr>
<tr>
<td>Interviewee 6</td>
<td>Barrister</td>
<td>Lawyer D</td>
<td>October 6, 2019</td>
</tr>
<tr>
<td>Interviewee 7</td>
<td>Barrister</td>
<td>Lawyer E</td>
<td>October 16, 2019</td>
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<tr>
<td>Interviewee 8</td>
<td>Barrister</td>
<td>Lawyer F</td>
<td>October 19, 2019</td>
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<td>Interviewee 9</td>
<td>Barrister</td>
<td>Lawyer G</td>
<td>October 21, 2019</td>
</tr>
<tr>
<td>Interviewee 10</td>
<td>Neurorehabilitation Specialist</td>
<td>Clinician C</td>
<td>October 27, 2019</td>
</tr>
<tr>
<td>Interviewee 11</td>
<td>Consultant - Long Term Care</td>
<td>Clinician D</td>
<td>November 3, 2019</td>
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<tr>
<td>Interviewee 12</td>
<td>Neurologist</td>
<td>Clinician E</td>
<td>November 6, 2019</td>
</tr>
<tr>
<td>Interviewee 13</td>
<td>Consultant - Trauma Care</td>
<td>Clinician F</td>
<td>November 7, 2019</td>
</tr>
<tr>
<td>Interviewee 14</td>
<td>Professor of Law / Former Barrister</td>
<td>Lawyer H</td>
<td>November 18, 2019</td>
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<tr>
<td>Interviewee 15</td>
<td>Professor</td>
<td>Academic 1</td>
<td>November 25, 2019</td>
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<td>Interviewee 16</td>
<td>Barrister</td>
<td>Lawyer I</td>
<td>December 3, 2019</td>
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<td>Interviewee 17</td>
<td>Neurosurgeon</td>
<td>Clinician G</td>
<td>December 6, 2019</td>
</tr>
<tr>
<td>Interviewee 18</td>
<td>Professor</td>
<td>Academic 2</td>
<td>December 9, 2019</td>
</tr>
<tr>
<td>Interviewee 19</td>
<td>Doctor</td>
<td>Clinician H</td>
<td>December 11, 2019</td>
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</table>
Appendix J:
Advance decision to refuse treatment

Attached to this appendix is a copy of a model advance decision to refuse treatment, that has been prepared for use by the Alzheimer’s Society.

Advance decision to refuse treatment

It is important to read factsheet 463, ‘Advance decisions and advance statements’ before filling out this form.

You can use this form to write down any specific treatments that you would not want to be given in the future, if you do not have mental capacity to refuse those treatments yourself at the time. It is helpful to include as much detail as you can, so it is better to write down the circumstances in which you would not want to receive the treatment.

This form will only be used if you do not have mental capacity to decide about having the specified treatment. It cannot be used to refuse basic care, comfort and support.

If you are refusing treatment which is, or could be, life-sustaining, you must state specifically that you are refusing it even if your life is at risk as a result.

First name, middle name(s), surname

Date of birth

Address

Postcode

Please state any distinguishing physical marks (to identify me in an emergency):

NHS number (if known)
My values

You can explain why you are making this advance decision and what you value in life. This section is optional. You can set out any principles that are important to you, and that relate to how you are treated and cared for.

If you are refusing life-sustaining treatment you can explain how you want to be looked after at the end of your life. You could include any religious faith, spiritual beliefs or values that you have.

This information may be helpful for medical professionals, and may also help your family and friends to understand the decision you have made.

Refusal of treatment

I do not want to receive the specific treatment below in the circumstances specified next to each treatment.

If you are refusing a treatment that is or may be life-sustaining (such as artificial feeding or hydration, cardiopulmonary resuscitation or antibiotics) you must state in the box where you have described the treatment: ‘I am refusing this treatment even if my life is at risk as a result.’

For example, if you have written that you refuse artificial feeding or hydration you should write ‘I refuse artificial feeding or hydration, even if my life is at risk as a result’.

I refuse the following specific treatments: In these circumstances:

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________

___________________________________________________________________________
Signature

An advance decision to refuse life-sustaining treatment must be signed by you, or by another person in your presence and by your direction.

It must also be witnessed by someone else. The witness must be physically present when you (or the person you have directed to sign) sign and must watch the signing happen. Even if you are not refusing life-sustaining treatment it is a good idea to sign this form and have it witnessed.

I make this decision to refuse treatment voluntarily and I have mental capacity to do so.

<table>
<thead>
<tr>
<th>My signature (or signature in my presence of the person directed by me to sign)</th>
<th>Date of signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witness name</td>
<td>Relationship of witness to you</td>
</tr>
<tr>
<td>Witness address</td>
<td>Postcode</td>
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</tbody>
</table>

I confirm that this advance decision refusing treatment was signed by the person making it, voluntarily, in my presence.

<table>
<thead>
<tr>
<th>Witness signature</th>
<th>Date of witness signature</th>
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</thead>
</table>

Details of healthcare professionals (optional)

I have discussed this decision with:

(name of healthcare professional, this may or may not be your GP)

<table>
<thead>
<tr>
<th>Job title</th>
<th>Phone number</th>
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</thead>
</table>

Address of their workplace

Do they have a copy of this decision? Yes No

If different from the above, my GP is:

<table>
<thead>
<tr>
<th>Phone number</th>
<th>Postcode</th>
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</table>

Address of their workplace

Does your GP have a copy of this decision? Yes No
## Details of people who know about this decision (optional)

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone number</th>
<th>Relationship to you</th>
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## Details of anyone you have appointed as your attorney under a Lasting power of attorney for health and welfare

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## Review dates (optional)

This advance decision to refuse treatment was reviewed, and confirmed by me on:

<table>
<thead>
<tr>
<th>Date</th>
<th>Signed</th>
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