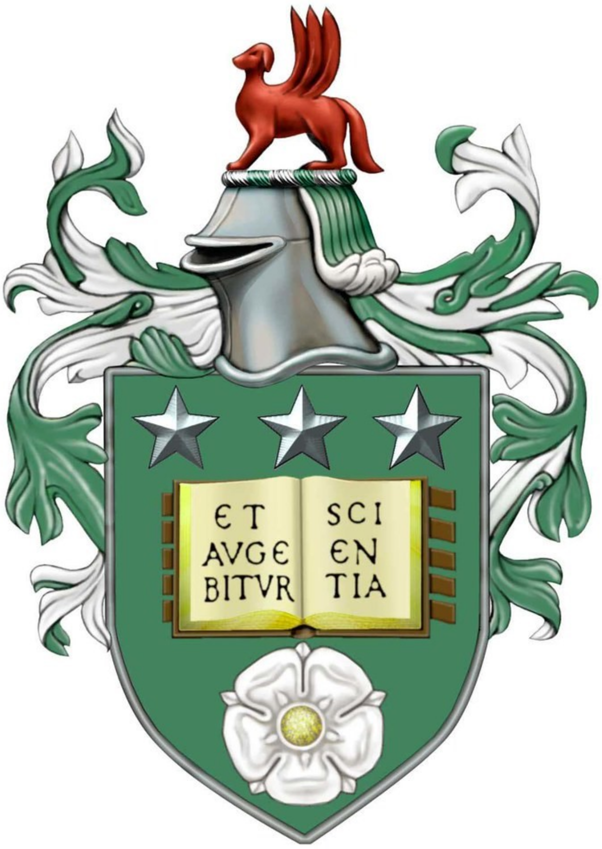
# AN ANALYSIS OF THE ROLE OF THE LAW IN CASES OF PROLONGED DISORDERS OF CONSCIOUSNESS: ARE PATIENTS ADEQUATELY PROTECTED?



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# Abstract

With advances in medicine saving more lives, there has been a parallel emergence of a condition known as Prolonged Disorders of Consciousness (PDOC) wherein damage to the brain affects consciousness. Prolonging patients' lives in states of limited or no awareness continues to raise key legal and ethical issues. A role for the law in PDOC cases was established in 1993 when the House of Lords ruled that it was lawful to withdraw a PDOC patient's life-sustaining treatment, as it was in their best interests to do so. Establishing whether PDOC patients are adequately protected is the core question of this dissertation. This will be accomplished by ascertaining whether the courts' role, the legislative decision-making framework, and the professional guidelines, collectively protect PDOC patients in practice. It will be argued that withdrawing treatment is often the most ethical course of action, and removing the need for court approval in every case is welcome for patient protection. Examining the Mental Capacity Act's section 4 (6) decision-making framework for these patients reveals that the best interests standard alone does not protect them in practice. The only way to ensure adequate protection is to insert a presumption that implements known past wishes and feelings of PDOC patients into best interests decisions. Overall, it will be concluded that PDOC patients are not adequately protected in practice, and this dissertation offers recommendations for improving this, including full implementation of the proposed national PDOC registry without which these patients remain unrecorded and unprotected.

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# Introduction

'The nature of consciousness is by far the most elusive question in science'.[1] With improvements in medicine and care services, from national trauma networks to rehabilitation technologies, our ability to save lives is improving.[2] This has opened up a field of medicine known as Prolonged Disorders of Consciousness (PDOC), in which brain injury impairs consciousness for longer than four weeks.[3] Vegetative State (VS) and Minimally Conscious State (MCS) are the two primary classifications of PDOC. Patients in a VS are awake but show no awareness.[4] This becomes continuing after four weeks and permanent (PVS) after more than six months (non-traumatic brain injury), or more than twelve months (traumatic brain injury), with recovery unlikely.[5] Patients in an MCS, on the other hand, show clear awareness, but it is minimal or inconsistent and typically becomes permanent after several months without improvement.[6] Unprecedented advancements in medical technologies mean that the lives of these vulnerable patients are prolonged, even with a 'ceiling of care' in place.[7] The majority of people lack insight into the potential need to complete an advance decision or lasting power of attorney that communicates their wishes around life-sustaining treatment such as clinically assisted nutrition and hydration (CANH), causing a question to arise on whether prolonging life in this state is lawful and ethical.[8]

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[1] Tarek Gaber, 'Guidelines for Prolonged Disorders of Consciousness: A Paradigm Shift' (2020) 24 Progress in Neurology and Psychiatry 4.

[2] Lynne Turner-Stokes and others, 'End-of-Life Care for Patients with Prolonged Disorders of Consciousness Following Withdrawal of Life-Sustaining Treatment: Experience and Lessons from an 8-Year Cohort' (2022) 22 Clinical Medicine 559.

[3] NHS 'Overview - Disorders of Consciousness' (NHS2019) <https://www.nhs.uk/conditions/disorders-of-consciousness/>.

[4] ibid

[5] ibid.

[6] ibid.

[7] Mohamed Y Rady and Joseph L Verheijde, 'Nonconsensual Withdrawal of Nutrition and Hydration in Prolonged Disorders of Consciousness: Authoritarianism and Trustworthiness in Medicine' (2014) 9 Philosophy, Ethics, and Humanities in Medicine 16.

[8] Mental Capacity Act 2005, ss9 and 24.

The Mental Capacity Act 2005 (MCA) is the legislation that governs this area of the law, underpinned by an extensive body of common law and professional guidelines released by bodies such as the Royal College of Physicians (RCP). The main thrust of this dissertation is to explore the role that the law plays in PDOC cases and answer the core question of whether PDOC patients are adequately protected in practice. The research aims to contribute to the broader field of mental capacity and the notion that a patient's autonomy and protection should not be compromised by impairment of mental capacity. The dissertation also explores the contentious topics of end-of-life decisions, medical ethics, and human rights. Given that the incidence of PDOC cases is likely to increase in prominence in the future, this dissertation is particularly pertinent as it revives the literary debates, offering fresh insights into a relatively quiet area of law that is poorly understood by the public, medical professionals, and lawyers.[9]

To address the research question regarding the level of protection afforded to PDOC patients, an extensive analysis of academic commentary and case law from both medical and legal domains will be conducted. This dissertation will specifically investigate three main research questions. First, it will ask whether changes to the courts' role in PDOC cases have altered patient protection, second whether the best interests standard adequately protects PDOC patients, and finally, whether these patients are at risk of being lost in the system. The structure of this dissertation takes the form of three chapters.

Chapter One will commence by exploring the ethical debates surrounding the withdrawal of CANH and end-of-life decisions for PDOC patients. The discussion will turn to analysing the role of the court in PDOC cases, particularly in terms of making life-or-death decisions. The chapter will focus on the changes from the landmark case of *Airedale NHS Trust v Bland* (*Bland*),[10] in which an English court first allowed a PDOC patient's CANH to be withdrawn, to *An NHS Trust and others v Y and another*

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[9] Lynne Turner-Stokes, 'A Matter of Life and Death: Controversy at the Interface between Clinical and Legal Decision-Making in Prolonged Disorders of Consciousness' (2017) 43 Journal of Medical Ethics 469 <https://jme.bmj.com/content/43/7/469> accessed 3 November 2022, 469.

[10] [1993] AC 789.

(*Y*),[11] which significantly reduced the role of the court. The overall aim is to ascertain whether this modification altered patient protection.

The second chapter will focus on the MCA, specifically, the section 4(6) best interests standard that serves as the foundation for incapacitated adults' decision-making. The chapter aims to determine whether the current legal framework adequately protects PDOC patients and, if not, what reforms could be made to enhance protection. Before examining potential reforms, the discussion will centre on the extent to which decisions consider PDOC patients' past wishes and feelings in practice. It will be concluded that amending the MCA to include a rebuttable presumption requiring decision-makers to implement PDOC patients' past wishes and feelings when doing so would not seriously harm their overall interests, is the only way to ensure adequate patient protection.

Chapter Three aims to investigate the ‘dearth of data’ on this patient group.[12] The analysis will first introduce the guidance that surrounds PDOC, such as the RCP PDOC Guidelines, with a focus on the recommendations of establishing a national PDOC registry to facilitate record-keeping, audits, and external review of care and decision-making.[13] The second section will analyse evidence in the literature regarding the extent to which if at all, these recommendations are being adequately implemented in practice. The dissertation will close with a conclusion.

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[11] [2018] UKSC 46, [2019] AC 978.

[12] Royal College of Physicians, ‘Prolonged Disorders of Consciousness Following Sudden Onset Brain Injury National Clinical Guidelines’ (2020) <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-following-sudden-onset-brain-injury-national-clinical-guidelines> 16.

[13] ibid.

# Chapter One: From *Bland* to *Y* - Have Changes in the Common Law Altered PDOC Patient Protection?

## Introduction

In order to analyse the question posed by this dissertation, Chapter One will examine the ethical debates surrounding the withdrawal of CANH and determine whether changes to the courts' role have affected PDOC patient protection. A revisit of the literature is necessary to offer fresh insights into a relatively quiet area of law, which is not widely known or understood.[14]

The opening chapter is divided into three sections, each aimed at addressing the main question. Section one delves into the 'fierce and emotional debate' of end-of-life decisions in the context of PDOC patients, to assess whether the withdrawal of CANH conflicts or complies with medical ethics and human rights.[15] The section begins by introducing the historical case of *Bland*,[16] which is where the law first played a role in PDOC. The analysis turns to striking a balance between the prolonged harm of life-sustaining treatment and patients' quality of life.[17] Section two focuses on the evolution of the courts' role in PDOC cases, determining whether this has led to an expectation that every withdrawal case requires court approval. The final section hones in on the role of the court by examining the shift in decision-making from judges to treatment teams in the wake of the landmark case of *Y*,[18] to determine whether this has compromised protection.

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[14] Turner-Stokes (n9) 469.

[15] Anna Nowarska, 'To Feed or Not to Feed? Clinical Aspects of Withholding and Withdrawing Food and Fluids at the End of Life' (2011) 10 Advances in Palliative Care Medicine, 3.

[16] *Bland* (n10).

[17] Liliana Teixeira, Nuno Rocha, and Rui Nunes, 'New Taxonomy for Prolonged Disorders of Consciousness May Help with Decisions on Withdrawal of Clinically Assisted Nutrition and Hydration: A Proposed Decision-Making Pathway' (2021) 53 Journal of Rehabilitation Medicine, 6.

[18] *Y* (n11).

The landmark case of *Bland* in 1993, was the first time the withdrawal of a PDOC patient's CANH was questioned in an English court.[19] Airedale NHS Trust, in collaboration with Bland's family, requested the legal cessation of life-sustaining care for the continuing VS patient, arguing it was in his 'best interests.'[20] Before the MCA, best interests involved a balancing exercise of different factors to determine the best course of action.[21] The judiciary ruled that for PDOC patients like Anthony Bland, where a 'ceiling of care' is in place, the withdrawal of CANH can be necessary to allow patients a 'good death', where prospects for a good life are limited.[22] Johnston claims that the court's ruling conveyed the idea that, just because medical care can preserve lives, does not always mean this is the most ethical route.[23] Thus the contentious act of 'cutting the thread of life' sparked discussions on balancing patients' quality of life with the pain and suffering experienced in PDOC,[24] often labelled as a 'fate worse than death'.[25]

The Hippocratic Oath, a source that continues to define medical ethics, emphasises the principles of beneficence and non-maleficence, which uphold 'do no harm' and 'caring for others' as core protection practices.[26] These ethical principles seem to be at odds with the withdrawal of CANH and end-of-life decisions, calling for a careful

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[19] *Bland* (n10).

[20] ibid.

[21] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33; *Re A (Mental Patient: Sterilisation)* [1999] 12 WLUK 657, [2000] 1 FLR 549.

[22] Rady and Verheijde (n7) 1, 16; Texieira and others (n17) 1.

[23] Carolyn Johnston, 'The Weight Attributed to Patient Values in Determining Best Interests' (2012) 39 Journal of Medical Ethics 562, 563.

[24] Margaret Fordham and Choo Han Tek, ''Cutting the Thread of Life'' – the Right to Cease Medical Treatment: *Airedale NHS Trust v Bland'* [1993] Singapore Journal of Legal Studies.

[25] Jenny Kitzinger and Celia Kitzinger, 'The "Window of Opportunity" for Death after Severe Brain Injury: Family Experiences' (2012) 35 Sociology of Health & Illness 1095.

[26] Practo, 'The Practo Blog for Doctors' (*The Practo Blog for Doctors* 10 March 2015) <https://doctors.practo.com/the-hippocratic-oath-the-original-and-revised-version/>; Mary FE Ebeling, *Healthcare and Big Data Digital Specters and Phantom Objects* (New York Palgrave Macmillan Us :Imprint: Palgrave Macmillan 2016) 60; Helen Askitopoulou and Antonis N Vgontzas, 'The Relevance of the Hippocratic Oath to the Ethical and Moral Values of Contemporary Medicine. Part II: Interpretation of the Hippocratic Oath—Today's Perspective' (2018) 27 European Spine Journal 1491.

examination of what ‘harm’ is in these contexts.[27] Researchers like Mohamed and Joseph contend that by downplaying the adverse effects of CANH withdrawal, the RCP 2013 Guidelines on PDOC institutionalise ‘medical authoritarianism.’[28] Studies conducted from the viewpoint of the family concur that, even in situations where family members are certain the patient would prefer to die, the withdrawal process is considered ‘inhumane,’ ‘utterly abhorrent,’ and ‘barbaric.’[29] Fins and others observe how this seems to be particularly true for patients in an MCS,[30] who signal some level of consciousness and interaction with their surroundings,[31] especially considering recovery is a possibility, albeit a very slim one.[32]

The *Bland* judgment also sparked euthanasia debates, with Lord Browne-Wilkinson questioning how death by injection ‘violates traditional values of medicine and society’ while slow death from CANH withdrawal is lawful.[33] The court has approved CANH withdrawal for many PVS patients since Anthony Bland, demonstrating a ‘sharp delineation’ between euthanasia as harmful interference and CANH withdrawal as a lawful omission.[34] To justify this distinction ethically, it is critical to acknowledge the ‘burdens’ associated with sustaining CANH, such as neurorehabilitation, feeding tube

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[27] Celia Kitzinger and Jenny Kitzinger, ‘Withdrawing Artificial Nutrition and Hydration from Minimally Conscious and Vegetative Patients: Family Perspectives’ (2014) 41 Journal of Medical Ethics 157.

[28] Rady and Verheijde (n7) 1,2; Royal College of Physicians, ‘Prolonged Disorders of Consciousness Following Sudden Onset Brain Injury National Clinical Guidelines’ (2013) <https://www.bing.com/ck/a?!&&p=6f11c4fe421efebcJmltdHM9MTcwMjk0NDAwMCZpZ3VpZD0xMDcxMDZhZS1lMjNmLTYwYjAtMTVhOC0xNjdhZTYzZjYyOWUmaW5zaWQ9NTIzMg&ptn=3&ver=2&hsh=3&fclid=107106ae-e23f-60b0-15a8-167ae63f629e&psq=rcp+guidelines+pdoc+2013&u=a1aHR0cHM6Ly93d3cucmNwbG9uZG9uLmFjLnVrL2ZpbGUvMTk4NzYvZG93bmxvYWQ&ntb=1>.

[29] Katja Kuehlmeyer, Gian Domenico Borasio and Ralf J Jox, ‘How Family Caregivers’ Medical and Moral Assumptions Influence Decision Making for Patients in the Vegetative State: A Qualitative Interview Study’ (2012) 38 Journal of Medical Ethics 332; Kitzinger ‘The “Window of Opportunity” for Death after Severe Brain Injury: Family Experiences’ (n25) 1104; Kitzinger ‘Withdrawing Artificial Nutrition and Hydration from Minimally Conscious and Vegetative Patients: Family Perspectives’ (n27).

[30] Joseph J Fins, Nicholas D Schiff and Kathleen M Foley, ‘Late Recovery from the Minimally Conscious State: Ethical and Policy Implications’ (2007) 68 Neurology 304, 307.

[31] Joseph T Giacino et al, ‘The Minimally Conscious State: Definition and Diagnostic Criteria’ (2002) 58 Neurology 506, 350.

[32] Elizabeth Wicks, ‘An NHS Trust and Others v Y and Another [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal’ (2019) 27 Medical Law Review <https://academic.oup.com/medlaw/advance-article/doi/10.1093/medlaw/fwy043/5289589> 330.

[33] *Bland* (n10) (Lord Browne-Wilkinson); Lee Hudson, ‘From Small Beginnings: The Euthanasia of Children with Disabilities in Nazi Germany’ (2011) 47 Journal of Paediatrics and Child Health 508, 511.

[34] Zoe Fritz, ‘Can “Best Interests” Derail the Trolley? Examining Withdrawal of Clinically Assisted Nutrition and Hydration in Patients in the Permanent Vegetative State’ (2016) 43 Journal of Medical Ethics 450, 452-453.

discomfort, and importantly a ‘lack of dignity,’ which outweigh the minimal benefits according to Glannon.[35] To support this, evidence from an eight-year PDOC patient cohort found that most patients die peacefully after withdrawing from CANH.[36] Thus, in contrast to earlier beliefs that end-of-life decisions are unethical, beneficence and non-maleficence can be compromised by the continuation of CANH rather than its withdrawal.[37] Fins and others' previous argument is undermined by acknowledging that MCS patients, who are more capable of feeling pain, experience a greater degree of the aforementioned burdens associated with CANH.[38] This is compounded by evidence that it is often fictitious and unrealistic recovery prospects that justify the harms that MCS patients continue to experience.[39] As such, while the relatives of PDOC patients may prefer the seemingly less invasive options of not resuscitating patients or treating infections, if the withdrawal of treatment is deemed to be in their best interests, this must be respected to prevent further harm.[40]

The withdrawal of CANH touches on the 'right to life', as per Article 2 of the European Convention on Human Rights, which was incorporated into English law by the Human Rights Act 1998.[41] The literature on PDOC is divided on the importance of life's sanctity and respecting its ‘intrinsic value’, while also recognising the need for quality of life, which although inevitably smaller for those lacking mental capacity, must be substantial.[42] This is consistent with the House of Lords' statement in *Bland* that the patient's ‘dignity and memory’ must be given substantial consideration when making decisions regarding their treatment.[43] What is particularly powerful is that under the updated Hippocratic Oath, doctors can be permitted to end a patient's life when this is

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[35] Royal College of Physicians Guidelines (n28) 78 [1]; Walter Glannon, ‘Burdens of ANH Outweigh Benefits in the Minimally Conscious State’ (2013) 39 Journal of Medical Ethics 551.

[36] Turner-Stokes and others (n2) 560.

[37] Glannon (n35) 551.

[38] ibid 552.

[39] Malcolm Fisher and Saxon Ridley, ‘Uncertainty in End-of-Life Care and Shared Decision Making’ (2012) 14 Critical Care and Resuscitation 81-87; Texeira and others (n17) 6.

[40] Kitzinger ‘Withdrawing Artificial Nutrition and Hydration from Minimally Conscious and Vegetative Patients: Family Perspectives’ (n27) 159; Fritz (n34) 453; Turner-Stokes (n9) 470.

[41] Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR), art 2.

[42] Ronald Dworkin, ‘Life’s Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom’ (1993) 31 Choice Reviews Online; Julian C Sheather, ‘Withdrawing and Withholding Artificial Nutrition and Hydration from Patients in a Minimally Conscious State: Re: Mand Its Repercussions’ (2012) 39 Journal of Medical Ethics, 546.

[43] *Bland* (n10) (Mr. Lester).

in their best interests.[44] This change in perspective has made researchers like Jackson and Wicks less certain about the persistence of a presumption in favour of preserving life for PVS patients.[45] However, this is inaccurate, as both ethical principles and care practices always initially strive for rehabilitation, evidenced by the fact that CANH is automatically administered for these patients.[46] Instead, the growing acceptance of CANH withdrawal can be tied to the realisation that treatment is often not in patients' best interests.

The sanctity of life versus quality-of-life debate depends on whether PDOC patients are viewed physiologically or biologically. Even in cases of brain-dead patients, some academics argue that their life still holds value purely as a biological organism.[47] This approach risks reducing PDOC patients to a 'body with organs' and undervalues the importance of patients having the capacity to live somewhat fulfilling lives, which 'futile' treatment cannot provide.[48] The RCP 2020 Guidelines emphasise that if CANH offers no clear benefit, 'all it can do is harm.'[49] Therefore, while it is acknowledged that a patient may only need a minimal PDOC recovery to regain some quality of life, there is ultimately a need for a certain level of functionality and pain management to guarantee that the benefits of maintaining CANH can exceed zero.[50]

Overall, to adequately protect patients from prolonged harm, focusing on patients' quality of life can, has, and will continue to rebut the sanctity of life arguments because, for the majority of PDOC patients, the burdens of CANH outweigh the minimal benefits.[51] The *Bland* case, despite being over 30 years old, continues to influence

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[44] Practoblog (n26).

[45] Emily Jackson, 'The Minimally Conscious State and Treatment Withdrawal: W v M' (2012) 39 Journal of Medical Ethics, 560; Elizabeth Wicks, 'When Is Life Not in Our Own Best Interests? The Best Interests Test as an Unsatisfactory Exception to the Right to Life in the Context of Permanent Vegetative State Cases' (2013) 13 Medical Law International 75, 88; Rady and others (n7) 5.

[46] Wicks "When Is Life Not in Our Own Best Interests' (n45) 88; Charles Foster, 'Withdrawing Treatment from Patients with Prolonged Disorders of Consciousness: The Presumption in Favour of the Maintenance of Life Is Legally Robust' (2020) 47 Journal of Medical Ethics 119.

[47] Glannon (n35) 551.

[48] Fritz (n34) 453; Ray and Verheijde (n7) 5; Texeira and others (n17) 4.

[49] Royal College of Physicians (n12) 91.

[50] Glannon (n35) 552; Wicks 'When Is Life Not in Our Own Best Interests?' (n45) 77.

[51] ibid.

end-of-life care practices, having established the role of the law in PDOC.[52] The following section explores the evolution of the common law since *Bland* and the implications this has for patient protection.[53]

## From *Bland* to *Y*

Since *Bland*, there have been changes in the legal framework surrounding PDOC to adapt to the 'advancing nature' of medicine.[54] The case law has undergone significant evolution, particularly regarding CANH withdrawal.[55] Post-*Bland* cases, like *NHS Trust A v M*; *NHS Trust B v H*,[56] employed the best interests approach to clarify that CANH withdrawal did not contravene a patient's 'right to life'.[57] *Ahsan v University Hospitals Leicester NHS Trust*[58] further highlighted the shift towards best interests, where the patient's pre-PDOC Islamic values favoured life-sustaining care through CANH. However, the first MCS case to reach the Court of Protection, *W v M,*[59] signalled a shift away from this growing trend, with Justice Baker emphasising the 'importance of preserving life' as a decisive factor.[60] Baker assessed the advantages and disadvantages of treatment using a balancing sheet, a technique employed for MCS patients.[61] Despite evidence that M would not want to live in an MCS, including specifics where she said it would be 'better to let Tony Bland die,' Justice Baker persisted in upholding the sanctity of life argument; demonstrating the ongoing nature of the ethical discussions in section one.[62] The fact that this was the first MCS case to

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[52] *Bland* (n10); Piotr Szawarski and Vivek Kakar, 'Classic Cases Revisited: Anthony Bland and Withdrawal of Artificial Nutrition and Hydration in the UK' (2012) 13 Journal of the Intensive Care Society 126, 128.

[53] *Bland* (n10).

[54] ibid (n10); Rob Heywood, 'MOVING on from BLAND: THE EVOLUTION of the LAW and MINIMALLY CONSCIOUS PATIENTS' (2014) 22 Medical Law Review, 548.

[55] Alexander Charles Edward Ruck Keene and Annabel Lee, 'Withdrawing Life-Sustaining Treatment: A Stock-Take of the Legal and Ethical Position' (2019) 45 Journal of Medical Ethics, 794.

[56] [2001] Fam 348, [2001] 1 All ER 801.

[57] *Bland* (n10).

[58] [2006] EWHC 2624, [2007] PIQR P19.

[59] [2011] EWHC 2443, [2012] 1 WLR 110.

[60] ibid (Baker J) [249].

[61] ibid.

[62] Alex Ruck Keene and Cressida Auckland, 'More Presumptions Please: Wishes, Feelings and Best Interests Decision-Making' (2015) 293 Elder Law Journal, 298.

reach the courts, setting it apart from earlier PVS decisions, may have contributed to this unethical reversal in direction.[63]

Nevertheless, protection has since evolved to afford greater weight to the quality of life of both MCS and PVS patients. This is best demonstrated by *Briggs v Briggs* (*Briggs*),[64] where the MCS patient's 'pre-accident views' superseded preserving his life, an approach later followed in *M v A Hospital*.[65] The *Briggs* case evolved from Baker's approach to CANH withdrawal by emphasising that patients' wishes must prevail.[66] This approach was solidified in *Aintree University Hospitals NHS Foundation Trust v James*,[67] where the court upheld a justified departure from the preservation of life as a 'tiebreaker' for end-of-life decisions where there was 'uncontested medical evidence' that the treatment was burdensome.[68] A remarkable shift occurred when the case reached the Supreme Court, and Lady Hale emphasised that the question for treatment teams is whether the act of continuing CANH is lawful, not withdrawing it.[69] Hale concurred with section one's previous assessment, stating that the patient's best interests were not served by invasive procedures that provided 'no positive benefit.'[70]

Since *Bland*, numerous PDOC cases have occurred, with judges making 'life-or-death decisions' outside the scope of medical professionals' purview.[71] This led to the expectation that the judiciary should be involved in these end-of-life decisions, which became known as the declaratory relief procedure.[72] The MCA, a statute concerning

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[63] *W v M* (n59).

[64] [2016] EWCOP 53, [2017] All ER.

[65] ibid [92] [117]; [2017] EWCOP 18, [2018] 1 WLR 465.

[66] *Briggs* (n64) (Justice Charles) [62]; Jenny Kitzinger, Celia Kitzinger and Jakki Cowley, 'When "Sanctity of Life" and "Self-Determination" Clash: Briggs versus Briggs [2016] EWCOP 53 – Implications for Policy and Practice' (2017) 43 Journal of Medical Ethics 446, 447.

[67] *Aintree University Hospitals NHS Foundation Trust v David James and Others* [2013] EWCA Civ 65, [2013] Med LR 110 (Arden LJ, Laws LJ).

[68] Ian Wise QC, 'Withdrawal and Withholding of Medical Treatment for Patients Lacking Capacity Who Are in a Critical Condition - Reflections on the Judgment of the Supreme Court in Aintree University Hospitals NHS Foundation Trust v James' (2014) 82 Medico-Legal Journal, 146; Charles Foster, 'It Is Never Lawful or Ethical to Withdraw Life-Sustaining Treatment from Patients with Prolonged Disorders of Consciousness' (2019) 45 Journal of Medical Ethics 265, 266.

[69] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591 (Lady Hale).

[70] ibid.

[71] *Bland* (n10); Keith Andrews and others, 'Misdiagnosis of the Vegetative State: Retrospective Study in a Rehabilitation Unit' (1996) 313 BMJ (Clinical research ed.) 13 <https://www.ncbi.nlm.nih.gov/pubmed/8664760?dopt=Abstract> .

[72] ibid (Lord Bingham).

‘persons who lack capacity,’ established the Court of Protection to hear cases related to these matters.[73] Likewise, the Joint Committee on the Draft Mental Incapacity Bill, the MCA Code of Practice (the Code), and Practise Direction 9E, all deemed CANH withdrawal as a ‘serious medical treatment’ that should be brought before the Court.[74] Yet when the *Y* judgment was delivered,[75] Lady Black held that if the MCA was followed and there was no disagreement regarding CANH withdrawal being in a patient’s best interests, there was no common law mandatory requirement to seek court approval for these decisions.[76]

A closer look at medical guidance documents reveals inconsistencies around whether this expectation ever amounted to a requirement. As an illustration, consider the 2010 General Medical Council Guide on End-of-Life Care,[77] which mandated that NHS Trusts seek approval from the court; compared with the more recent Interim Guidance that indicates that this should only occur in cases where there is a dispute over what is in the patient’s best interests.[78] In *Y*, Lady Black ruled that the Code's statement that Court of Protection approval ‘should’ be sought is subjective and less mandatory than a phrase like ‘must’.[79] Thus, the argument that the legal framework was ambiguous on this matter has merit, with Richards suggesting the judgment did nothing more than clarify what was already law.[80] Given the already contentious practice of withdrawing

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[73] Mental Capacity Act 2005, ss45 and 50.

[74] Joint Committee on the Draft Mental Incapacity Bill, Draft Mental Incapacity Bill (HL/HC 2002-2003,I) 41; Office of the Public Guardian, ‘Mental Capacity Act Code of Practise’ (2007) <Mental Capacity Act Code of Practice - GOV.UK (www.gov.uk)> s6.18; 9 PD 9E.

[75] *Y* (n11).

[76] ibid (Lady Black).

[77] General Medical Council, ‘Treatment and care towards the end of life: good practice in decision making’ (2010) <Treatment and care towards the end of life - professional standards - GMC (gmc-uk.org)>, para 216.

[78] Royal College of Physicians, ‘Decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset profound brain injury’ Interim guidance for health professionals in England and Wales (2017) https://www.bing.com/ck/a?!&&p=7eb42f6c24d3a0a5JmltdHM9MTY5OTIyODgwMCZpZ3VpZD0xMDcxMDZhZS1lMjNmLTYwYjAtMTVhOC0xNjdhZTYzZjYyOWUmaW5zaWQ9NTE5NQ&ptn=3&hsh=3&fclid=107106ae-e23f-60b0-15a8-167ae63f629e&psq=%27Decisions+to+withdraw+dinically-assisted+nutrition+and+hydration+(CANH)+from+patients+in+permanent+vegetative+state+(PVS)+or+minimally+conscious+state+(MCS)+following+sudden-onset+profound+brain+injury%27+(2017))&u=a1aHR0cHM6Ly93d3cucmNwbG9uZG9uLmFjLnVrL2ZpbGUvODQ2NS9kb3dubG9hZA&ntb=1, 3.

[79] Code of Practice (n74), para 819.

[80] Bernadette Richards, ‘Considering the Boundaries of Decision-Making Authority: An NHS Trust v Y [2018] UKSC 46’ (2019) 16 Journal of Bioethical Inquiry 153, 157.

life-sustaining treatment, it was inevitable that the ruling sparked extensive discussions on patient protection. Much of the literature criticised the court for failing to ‘wrestle the grip of doctors’ on these matters before PDOC case law developed.[81] Therefore, the court’s role in these cases was seen as a major step forward in patient protection and one that could be jeopardised by the ruling in *Y*.[82]

## Has the *Y* Decision Altered Patient Protection?

As Lord Goff stated in *Bland* over 30 years ago, court approval to withdraw CANH was necessary to uphold the protection of patients, as well as provide assurance for families and the public.[83] Yet, most decisions regarding the best interests of PDOC patients are now made 'on the ward.’[84] Medical advancements have transformed PDOC from a quiet field to a feature in many NHS Trusts, necessitating a more efficient system to meet these demands.

Foster argues that the *Y* decision risks placing vulnerable PDOC patients in the hands of ‘harassed clinicians.’[85] The stance of one scholar is inevitably limited, yet the concerns around poor protection are also expressed outside of academic discourse with Justice Baker, Lord Lowry, and Lord Browne-Wilkinson calling for mandatory declaratory relief.[86] Nevertheless, these views are likely outdated given how the law has evolved since they were made.[87] Section two identified the ‘body of experience and practice’ of PDOC that has developed since *Bland*, which arguably lessens the requirement for court supervision in every case.[88] What is particularly striking is that in more recent cases, judges have pointed to the unintended but detrimental effects of needing court approval, from court delays, pressures on treatment teams, and

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[81] Jonathan Montgomery, ‘Law and the Demoralisation of Medicine’ (2006) 26 Legal Studies 185.
[82] *Y* (n11).
[83] *Bland* (n10) (Lord Goff).
[84] Charles Foster, ‘Baby Charlotte—the End of Intolerability’ [2005] Solicitors Journal 1241.
[85] ibid 1241.
[86] *Bland* (n10) [875]; *W v M* (n59) [257].
[87] Ruck Keene and Lee (n55).
[88] *Bland* (n1), [816]; Mental Capacity Act 2005.

emotional strains on families; all of which compromise protection.[89] On the other hand, the sustained ‘complex and controversial nature’ of PDOC continues to raise life-or-death decisions, suggesting some form of ongoing external approval may be warranted, perhaps just not from the judiciary. [90]

It can be challenging to strike a balance between valuing the expertise of medical professionals and simultaneously acknowledging that high-quality physical care and ethical best interests care are two different things.[91] Patient protection may be jeopardised when treatment teams are confident in their clinical care choices and thus do not apply to the Court of Protection when necessary, especially since the onus is on them to submit court applications.[92] This was the situation in *North West London Clinical Commissioning Group v GU* (*GU*),[93] where the Royal Hospital for neuro-disability failed to provide ethical care, resulting in a seven-year ‘inordinate and inexcusable delay’ in determining Mr GU's best interests.[94] The extent to which patient protection was undermined at the PDOC ‘centre of excellence’ is concerning, as it raises questions about how decision-making is conducted elsewhere.[95] Cases like *GU* also raise concerns about the potential effect of *Y* as a ‘rebirth of paternalism’ given

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[89] *Briggs* (n64) (King LK) [26]; *M v A Hospital* (n65) (Justice Peter Jackson); Adam Formby and others, ‘Cost analysis of the legal declaratory relief requirement for withdrawing Clinically Assisted Nutrition and Hydration (CANH) from patients in the Permanent Vegetative State (PVS) in England and Wales’ (2015) Social Policy and Social Work, Centre for Health Economics < Cost analysis of the legal declaratory relief requirement for withdrawing Clinically Assisted Nutrition and Hydration (CANH) from patients in the Permanent Vegetative State (PVS) in England and Wales — York Research Database> accessed 3 November 2023.

[90] *Bland* (n10) (Lord Bingham) [808D]; Wicks ‘An NHS Trust and Others v Y and Another [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal’ (n32) 338.

[91] Jenny Kitzinger, ‘“Burdensome and Futile” Treatment and Dignity Compromised: Poor Practice at a Leading UK Hospital’ (*Open Justice Court of Protection Project*2021) <https://openjusticecourtofprotection.org/2021/11/17/burdensome-and-futile-treatment-and-dignity-compromised-poor-practice-at-a-leading-uk-hospital/> 5.

[92] Emily Jackson, ‘From “Doctor Knows Best” to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions about Their Medical Treatment’ (2018) 81 The Modern Law Review 247, 258; Wicks ‘An NHS Trust and Others v Y and Another [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal’ (n32) 337.

[93] [2021] EWCOP 59, [2021] 11 WLUK 134.

[94] ibid; Kitzinger ‘“Burdensome and Futile” Treatment and Dignity Compromised: Poor Practice at a Leading UK Hospital’ (n91) 6.

[95] ibid 6.

the power of treatment teams, which Foster claims is a 'dangerous step backwards' for protection.[96]

The Official Solicitor in *Y* also noted the risks of amplifying clinician voices, arguing that eliminating the legal and emotional element of court proceedings could potentially leave PDOC patients unheard and unprotected.[97] However, there is no way to guarantee that judicial decision-making could not be equally as paternalistic.[98] Further, patients are frequently left unheard and unprotected during the drawn-out court proceedings themselves, which needlessly delays decisions and prolongs harm. Treatment teams are therefore likely better suited for decision-making power, especially given the strong relationships built with patients and families over time, which judges inevitably lack.[99]

Regardless of who makes the decision, protection is also dependent on how decisions are made, particularly the weight given to the different factors listed in section 4 of the MCA, from the patient's past wishes to other considerations.[100] The number of applications to the Court of Protection for PDOC decisions has remained at similar levels before and after the changes to decision-making.[101] Consequently, it can be assumed that while cases like *GU* raise concerns about patient protection, on the whole, they are a rarity, and the harms associated with legal proceedings remain the most predominant issue in the majority of cases.[102] As such, where the interests of PDOC patients are ascertainable and agreed on, judicial oversight only leads to unlawful delays between the decision to withdraw CANH and actual cessation, prolonging harm and undermining the 'protection of patients.'[103]

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[96] *Y* (n11); *GU* (n93); Charles Foster, 'The Rebirth of Medical Paternalism: An NHS Trust v Y' (2018) 45 Journal of Medical Ethics 3 <https://jme.bmj.com/content/45/1/3>.

[97] Y (n11); Wicks 'An NHS Trust and Others v Y and Another [2018] UKSC 46: Reducing the Role of the Courts in Treatment Withdrawal' (n32) 334.

[98] Muireann Quigley, 'Best Interests, the Power of the Medical Profession, and the Power of the Judiciary' (2008) 16 Health Care Analysis 233, 238.

[99] ibid 237.

[100] ibid 238; Mental Capacity Act 2005, s4 (6).

[101] Adam Tanner, 'Best Interests' Decision-Making and the Role of the Court in Protecting Patients with Prolonged Disorders of Consciousness (2022) PhD thesis The Open University, 50.

[102] *GU* (n93).

[103] *Bland* (n10) (Lord Goff); Simon Halliday, Adam Formby, and Richard Cookson, 'AN ASSESSMENT of the COURT'S ROLE in the WITHDRAWAL of CLINICALLY ASSISTED NUTRITION and HYDRATION from PATIENTS in the PERMANENT VEGETATIVE STATE' (2015) 23 Medical Law Review 556, 575,

In summary, section three has determined that overall *Y* is a positive change for PDOC patient protection. If patients are safeguarded by a framework for decision-making that considers their wishes and feelings rather than a purely clinical assessment, a topic that is covered in Chapter Two, court approval offers little to no benefit.[104]

## Conclusion

Chapter One has considered whether PDOC patients are adequately protected by focusing on the common law that surrounds this advancing field of medicine. With a focus on CANH, the research sought to revive ethical discussions about life-sustaining treatment and its withdrawal, while analysing the role of the court in PDOC.[105] Section one's key finding is that withdrawing CANH is often in the best interests of PDOC patients, and if this is the case, sustaining treatment can constitute unethical prolongation of harm.[106] The ethical principles of beneficence and non-maleficence and the Article 2 'right to life' came to light.[107] A key conclusion was that there is a mistaken assumption that persists in the medico-legal field that death is always the 'harm.'[108] Section two built on these conclusions, examining the evolution of the judicial approach towards PDOC in cases from *Bland* to *Y*, towards better patient protection.[109] The present focus on patient autonomy and quality of life in PDOC cases is a significant shift for protection from older judgments like *W v M*, which prioritised the sanctity of life principle.[110] Lastly, section three entailed a careful examination of the *Y* case which shifted decision-making authority from the Court of Protection to treatment teams in the majority of PDOC cases.[111] The chapter concluded that this

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577; Jenny Kitzinger, 'Delay Is Inimical to P's Welfare: Guidance on Clinically-Assisted Nutrition and Hydration for PDoC Patients' (*Open Justice Court of Protection Project*2020) <https://openjusticecourtofprotection.org/2021/07/15/delay-is-inimical-to-ps-welfare-guidance-on-clinically-assisted-nutrition-and-hydration-for-pdoc-patients/>.

[104] Veronica English and Julian C Sheather, 'Withdrawing Clinically Assisted Nutrition and Hydration (CANH) in Patients with Prolonged Disorders of Consciousness: Is There Still a Role for the Courts?' (2017) 43 Journal of Medical Ethics 476, 480.

[105] *Y* (n11).

[106] Wicks 'When Is Life Not in Our Own Best Interests? (n45).

[107] ECHR, art 2 (n119); Ebling (n26).

[108] Glannon (n35) 551.

[109] *Bland* (n10); *Briggs* (n64); *Aintree* (n69).

[110] *W v M* (n59).

[111] *Y* (n11).

change has likely encouraged protection by reducing the harm to patients and their families associated with lengthy court proceedings.[112] In light of this establishment, Chapter Two focuses on what basis decisions for PDOC patients are made.

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[112] Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103).

# Chapter Two: Does the Best Interests Standard Adequately Protect PDOC Patients?

## Introduction

Since the MCA bases decision-making on the best interests standard, the primary aim of Chapter Two is to ascertain whether PDOC patients are sufficiently protected by this legal framework and, if not, what reforms could enhance protection.[113] These are important questions to ask since evidence in the 2020 PDOC guidelines revealed that there continues to be a lack of understanding and implementation of the best interests standard, yet the discussions around this area of the MCA have progressively reduced.[114] The discussion is therefore vital to ensure that the MCA promotes patient autonomy and dignity, regardless of their capacity.[115]

The structure of this chapter takes the form of two sections. Section one looks at 'the problem' and will firstly provide a brief overview of 'best interests' in section 4 of the MCA, before delving into the protection concerns raised in post-MCA scrutiny.[116] Section two considers 'the solution' and is divided into two parts. In part one, decision-making is examined through the lens of disability, specifically looking at Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) as a solution to protection.[117] An analysis is conducted of General Comment No. 1, wherein the CRPD Committee contended that to guarantee CRPD compliance, 'will and preferences' must replace best interests.[118] Following, part two revisits the case law to highlight the growing judicial emphasis on patient narratives, whilst contending that the best interests standard continues to present challenges for protection.[119] A rebuttable presumption in favour of implementing PDOC patients' known past wishes and

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[113] Mental Capacity Act 2005, s4.

[114] Royal College of Physicians (n12) 106.

[115] Carolyn Johnston, Natalie Banner, and Angela Fenwick, 'Patient Narrative: An "On-Switch" for Evaluating Best Interests' (2016) 38 Journal of Social Welfare and Family Law 249, 261.

[116] House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: post-legislative scrutiny* (The Stationery Office 2014), para 92.

[117] Convention on the Rights of Persons with Disabilities (CRPD), art 12.

[118] United Nations Committee on Convention on the Rights of Persons with Disabilities 'General Comment No. 1 - Article 12 : Equal recognition before the law' (2014) CRPD/C/GC/1.

[119] *Aintree* (n69).

feelings,[120] is balanced against a statutory amendment of the wording of section 4 that would give these factors more weight in best interests decisions.[121]

## The Problem

The section below provides an overview of the best interests standard for decision-making under the MCA. A detailed analysis of the literature regarding the consideration of patients' wishes and feelings within this framework, reveals practical problems that present risks to PDOC patient protection. Decisions about mental incapacity have been based on the 'best interests' of the patient ever since *Re F*,[122] which considered whether doctors could sterilise a mentally ill woman who was incapable of giving consent.[123] The assessment lacked a conceptual framework and was objective, following the *Bolam v Friern Hospital Management Committee* (*Bolam*) principle,*[124]* which 'delegated' decision-making to medical professionals.[125] The MCA formally established best interests as the legal approach to decision-making, to 'empower and protect' incapacitated adults.[126] Section 4 obliges decision-makers to speak to people close to the patient, and consider, so far as is reasonably ascertainable, patients' past and present wishes and feelings, beliefs and values, and other factors the patient would consider if able to do so.[127] This checklist approach to best interests was derived from the Joint Committee Draft Mental Incapacity Bill and the Law Commission Mental Incapacity Report from 1995, which rightfully felt that a single definition of best interests could not be applied to every person and circumstance that the Act

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[120] Wayne Martin, Sabine Michalowski, Timo Jutten and Matthew Burch, 'Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disability? If not, what next?' (2014) Essex Autonomy Project, 47.

[121] Law Commission, *Mental Capacity and Deprivation of Liberty* (Law Com No 372, 2017) para 14.14, 14.16, 14.19.

[122] *Re F* (An Adult: Sterilisation) [1990] 2 AC 1.

[123] ibid.

[124] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

[125] Mary Donnelly, 'BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005' (2008) 17 Medical Law Review 1, 3, 28.

[126] Mental Capacity Act 2005, s1 (5); Martin and others (n122) 1.

[127] Mental Capacity Act 2005, ss4 (6a,6b,6c,7).

addresses.[128] An attempt to encapsulate a 'participative model' of decision-making in the MCA, by inquiring about the patient's wishes, has made significant progress towards protecting incapacitated adults.[129] This contrasts with the 'unpromising' beginning of best interests, which was founded on *Bolam*'s paternalistic ethos that only accounted for the professional's perspective.[130]

Since 'wishes and feelings' lack any legal definition, a good analytical starting point is the Code's emphasis that although 'all reasonable efforts' should be made to identify any 'communication, writing, behaviour, or habits' indicative of these, they will often 'not necessarily be the deciding factor'.[131] It is because of this last point that organisations and academics are concerned that wishes and feelings are not given enough weight in clinical decision-making processes.[132] Justice Munby's deliberate 'flexibility' of best interests in *Re M*,[133] emphasising that consideration of patients' wishes and feelings is 'case-specific' and 'fact-specific,' exacerbated this worry.[134] The MCA's lack of a legal obligation on decision-makers to implement patients' wishes and feelings, even where they are certain and reasonable, risks undermining the importance of enabling incapacitated adults to make autonomous decisions.[135] For PDOC patients, it is then lawful for an end-of-life decision to be made that entirely conflicts with their past wishes and feelings, provided that decision-makers have at the very least attempted to consider them.[136] The harms this risks having on a PDOC patient's autonomy and protection are not to be undermined.

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[128] Law Commission, *Mental Incapacity* (Law Com No 231, 1995) para 3.29; Joint Committee Report, *Draft Mental Incapacity Bill* (HC 2002-03 1083-I) para 85.

[129] Donnelly 'BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005' (n125) 4; Wicks 'When Is Life Not in Our Own Best Interests?' (n45) 75, 94.

[130] *Bolam* (n124); Donnelly 'BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005' (n130) 1, 2.

[131] Mental Capacity Act Code of Practise (n74) para 5.41; 5.38; Derick T Wade and Celia Kitzinger, 'Making Healthcare Decisions in a Person's Best Interests When They Lack Capacity: Clinical Guidance Based on a Review of Evidence' (2019) 33 Clinical Rehabilitation 1575; Owen P O'Sullivan, 'Medical Treatment and Best Interests: Judicial Interpretation of Values, Wishes and Beliefs under the Mental Capacity Act 2005' (2020) 22 The Journal of Adult Protection 165, 167.

[132] Joint Committee Report *Draft Mental Incapacity Bill* (n128) para 89.

[133] *Re M (Statutory Will)* [2009] EWHC 2525 (Fam), [2011] 1 WLR 344 (Justice Munby) [35].

[134] ibid [35]; Joint Committee Report *Draft Mental Incapacity Bill* (n128) para 89.

[135] Mary Donnelly, 'Best Interests in the Mental Capacity Act: Time to Say Goodbye?' (2016) 24 Medical Law Review 318, 329; Lucy Series, 'The Place of Wishes and Feelings in Best Interests Decisions: Wye Valley NHS Trust v Mr B' (2016) 79 The Modern Law Review 1101, 1115.

[136] ibid 1115.

Conversely, scholars like Coggon find the structure of best interests to be both ‘defensible’ and ‘desirable.’[137] Building on this, Quigley and Letts justify their support for the standard by pointing out that the MCA needs to adopt a ‘variable and broad’ approach that takes into account the variety of patients and decisions surrounding mental capacity.[138] On the other hand, Munro, an advocate for taking the wishes and feelings of those lacking capacity seriously, argues that best interests can remain ‘dynamic and responsive’ and simultaneously place a greater duty on decision-makers to implement wishes and feelings.[139] In addition to putting the MCA's ‘participative model’ into practice, Johnston and others note that this duty would enable patients to be the ‘actors’ in decisions made about their own lives, in line with the ethical importance of protecting PDOC patients' autonomy.[140]

The House of Lords' post-MCA scrutiny only strengthened the concerns expressed by academics such as Munro and Johnston and others.[141] Evidence suggests decisions are frequently made without consulting a patient's family or carers, and most harmfully, without considering their wishes and feelings.[142] This indicates a ‘complete failure’ to even apply the MCA in practice, with treatment teams’ ‘professional commitment to rehabilitation’ outweighing their commitment to best interests.[143] According to Donnelly, this problem is particularly harmful to the MCA spectrum's most incapacitated adults, who are the subject of this dissertation.[144] PDOC patients lack the full capacity that other patients may retain to challenge decisions, meaning that this disregard for their previous ‘expertise, emotions, history, and well-being’, directly harms their protection, autonomy, and dignity.[145]

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[137] John Coggon, ‘Best Interests, Public Interest, and the Power of the Medical Profession’ (2008) 16 Health Care Analysis 219.

[138] ibid 225; Quigley (n98) 233, 235; Penny Letts, ‘Mental Capacity Act 2005: The Statutory Principles and Best Interests Test’ (2014) 1 International Journal of Mental Health and Capacity Law 156.

[139] Nell Munro, ‘Taking Wishes and Feelings Seriously: The Views of People Lacking Capacity in Court of Protection Decision-Making’ (2014) 36 Journal of Social Welfare and Family Law 59, 60.

[140] ibid; Johnston and others (n115) 249, 261.

[141] House of Lords (n116) para 107.

[142] ibid.

[143] Wade and Kitzinger (n131), 1572; Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103) 4.

[144] Donnelly ‘BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005’ (n125) 20.

[145] Johnston and others (n115) 249.

The BMA recognised the problem and addressed it in 2018 by issuing CANH guidance that included sections on gathering and using patient information, emphasising that the benefits of CANH 'must' be weighed against patients' wishes and feelings.[146] Nevertheless, even with the additional 2018 guidance, the 2020 PDOC Guidelines note that the best interests framework is still not adequately implemented.[147] Thus, the cumulative evidence raises concerns not only regarding the protection of PDOC patients when their past wishes play no role in decisions, but also about what the solution is if guidance around the MCA has caused little change.

According to O'Sullivan, best interests decisions need to be 'unique, multifaceted, and fundamentally subjective', and the MCA effectively captures this.[148] However, it leaves open the possibility of completely ignoring patients' wishes and feelings by only requiring decision-makers to 'consider' them, without making any formal demands that they use this information in their decisions.[149] As a result, despite the checklist nature of best interests, clinical considerations are naturally given the greatest weight in practice, often leading to decisions that lack autonomy.[150]

To summarise, section one's findings indicate that the discretionary nature of the best interests checklist in section 4 (6) of the MCA, which is used in decision-making for PDOC patients, does not adequately protect them in practice. By disregarding patients' wishes and feelings, decision-makers are failing to comply with their legal and ethical obligations, undermining the value of patient autonomy and dignity in decisions.[151] The following section will examine how PDOC patient protection could be enhanced through alternatives and reforms.

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[146] 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*' (2018) < bma-clinically-assisted-nutrition-hydration-canh-full-guidance.pdf> 62, 65, 106.
[147] ibid.
[148] Sarah Morgan, 'Do No Harm: "Best Interests," Patients' Wishes and the Mental Capacity Act 2005' (2013) 2 Manchester Student Law Review, 236; O'Sullivan (n131) 172.
[149] Mental Capacity Act 2005, s4 (6); Series (n135) 1115.
[150] House of Lords (n116) para 107.
[151] Johnston and others (n115) 249.

## The Solution

Section two considers alternatives to determine the best solution to PDOC patient protection. In part one, the discussion shifts to an analysis of the case made in General Comment No. 1 of the CRPD, ratified by the UK in 2009, to replace best interests with 'will and preferences'.[152] Given that this human rights instrument offers a different perspective of capacity, it is necessary to question if the CRPD could be the answer to better PDOC patient protection.[153]

The 'novel' Article 12 is said to represent a 'paradigm shift' for disability protection, since it guarantees equal recognition of everyone before the law, encouraging legal capacity and autonomous decision-making regardless of disability.[154] There was 'considerable optimism' about the UK's compliance with the CRPD, yet tension has arisen over time between best interests in the MCA and Article 12.[155] Thus, in the same year as the House of Lords' post-MCA scrutiny came General Comment No.1, where the CRPD Committee argued for replacing best interests with 'will and preferences', or, in cases where these are ambiguous, the 'best interpretation' of these.[156] The CRPD advocated for a more supported decision-making framework than that under the MCA, sparking controversy about current compliance.[157]

Minkowitz and Gordon note how decision-making based entirely on an individual's will and preferences improves protection by encouraging self-governance and control, while the framework in Article 12 simultaneously acknowledges the need for support.[158] Nevertheless, the application of a disability rights convention to the unique

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[152] General Comment No.1 (n118).

[153] Wayne Martin, 'The MCA under Scrutiny: Meeting the Challenge of CRPD Compliance' (2015) 32 Elder Law Journal, 2; Donnelly 'Best Interests in the Mental Capacity Act: Time to Say Goodbye? (n135) 318.

[154] CRPD, art 12 (n117); Piers Gooding, 'Navigating the "Flashing Amber Lights" of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' (2015) 15 Human Rights Law Review 45, 46, 47; Renu Barton-Hanson, 'Reforming Best Interests: The Road towards Supported Decision-Making' (2018) 40 Journal of Social Welfare and Family Law 277, 279.

[155] Martin (n153) 1.

[156] ibid; General Comment No.1 (n118) [21] [29].

[157] Martin and others (n120) 37; Gooding (n154) 45.

[158] Robert Gordon, 'The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making' (2000) 23 International Journal of Law and

group of PDOC patients presents inevitable challenges. Gooding acknowledges this, asking ‘what about the person in a coma?’[159] Given the advancements in neuroscience that are making indirect communication with these patients increasingly possible, there is some credit in the argument that guiding decisions for PDOC patients based on the best interpretation of their will and preferences is not wholly ‘inconceivable.’[160] As emphasised throughout, ‘making every word count’ for these patients is important, but there is a fine line between this and interpreting brain signals to build a narrative about their will and preferences towards end-of-life decisions.[161] The risks of getting that narrative wrong could be detrimental. Therefore, to adequately protect PDOC patients, the law must do more than simply comply with Article 12 of the CRPD.[162] This is corroborated by the fact that the majority of those in a PDOC cannot respond to anything at all, let alone express their specific will and preferences. As such, the reality is that there will always be unanswered questions, which no amount of best interpretation can solve.[163]

For PDOC patients, the best interpretation approach would likely be ‘oversimplistic’ and ‘misleading,’ enforcing a fabricated narrative about patients’ will and preferences that harms their autonomy and protection.[164] Consequently, extending the CRPD to the unique group of PDOC patients may restrict protection. As an alternative, Donnelly contends that since ‘will and preferences’ and ‘wishes and feelings’ carry a similar meaning, both CRPD compliance and PDOC patient protection could be increased by strengthening the weight given to wishes and feelings through MCA amendment.[165]

In the PDOC field, prioritising patients' past wishes and feelings within best interests decisions is not a novel concept, and a revisit to the common law aptly illustrates this.

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Psychiatry, 61; Tina Minkowitz, ‘The United Nations Convention on the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions’ (2009) 34 Syracuse Journal of International Law and Commerce, 405.

[159] Gooding (n154) 53.

[160] Lorina Naci and Adiran Owen, ‘Making Every Word Count for Nonresponsive Patients’ (2013) 70 JAMA Neurol, 3686; Gooding (n155) 55.

[161] ibid; Donnelly ‘Best Interests in the Mental Capacity Act: Time to Say Goodbye? (n135) 327.

[162] ibid 319, 320.

[163] ibid 327; Gooding (n154) 53.

[164] ibid 331.

[165] ibid 319, 323; Gooding (n154) 54.

A classic example of this is *Re S*,[166] where Judge Marshall interpreted the MCA as giving prominence to wishes and feelings and in practice, giving rise to a presumption in favour of implementing them unless they are 'irrational,' 'impracticable,' and 'irresponsible'.[167] Marshall's reading of the Act in this way has been labelled a 'serious attempt' to balance patient protection and empowerment within best interests.[168] Justice Baker adopted a very different approach in *W v M*,[169] disregarding M's wishes because they were not specific to nutrition and hydration, despite her relatives' testimony that she would be 'horrified' to live in an MCS.[170] This narrow interpretation of the MCA contributes to the mistaken assumption that specific written statements are required to consider patients' wishes, contradicting the Code's broader focus on behaviour and habits noted earlier.[171] The unpredictable nature of PDOC makes it unlikely that these patients are ever explicit about their feelings toward life-sustaining treatment.[172] Thus, demanding specificity can permit futile treatment, a harm identified in Chapter One, which is exacerbated when this treatment conflicts with the patient's past wishes and feelings.

Ruck-Keene and Auckland evidence a hopeful emphasis on patients' past wishes and feelings, which indirectly aids CRPD compliance.[173] The landmark case of *Aintree University Hospitals NHS Foundation Trust v James (Aintree)*,[174] redefined the role of wishes and feelings within the Act, placing an unprecedented emphasis on PDOC patients' 'characteristics' and 'biography', with Mr James' past wishes at the 'heart of his destiny'.[175] Although lacking the ability to generate statutory change, *Aintree* set a trend for subsequent cases,[176] such as *United Lincolnshire NHS Trust v N*, [177] and

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[166] *Re S* (Protected Persons) [2008] 11 WLUK 631, [2010] 1 WLR 1082 (Judge Marshall).
[167] ibid [55, 56, 57].
[168] Auckland and Ruck-Keene (n62) 295.
[169] *W v M* (n59).
[170] ibid (Justice Baker) [119], [230].
[171] ibid; Johnston and others (n116) 254.
[172] ibid 254.
[173] Auckland and Ruck-Keene (n62) 299, 300.
[174] *Aintree* (n69) [45].
[175] Johnston (n23) 562; Ian Wise QC, 'Withdrawal and Withholding of Medical Treatment for Patients Lacking Capacity Who Are in a Critical Condition - Reflections on the Judgment of the Supreme Court in Aintree University Hospitals NHS Foundation Trust v James' (2014) 82 Medico-Legal Journal, 145; Auckland and Ruck-Keene (n62) 296; Donnelly 'Best Interests in the Mental Capacity Act: Time to Say Goodbye? (n135) 330; Johnston and others (n115) 225; Barton-Hanson (n154) 227.
[176] Series (n135) 1113.
[177] [2014] EWCOP 16, [2014] COPLR 660.

*Sheffield Teaching Hospitals NHS Foundation Trust v TH,*[178] where the judges were 'utterly convinced' by evidence akin to that of *W v M*, that the PDOC patients would not wish to live.[179] *Briggs v Briggs*[180] followed, where Justice Charles emphasised that how PDOC patients lived their lives, and their values and choices, are determinative of what individual quality of life treatment can provide, and thus are inevitably the most appropriate determinator of their best interests.[181]

The more optimistic evidence is, however, restricted to the courts, and thus for as long as the MCA continues to adopt the current approach to best interests, healthcare teams can 'ignore evidence' regarding past wishes and feelings and decisions will 'lack coherence'.[182] Despite these concerns, Wade considers the 2020 PDOC Guidelines' recommendation for best interests meetings to be held with families within two weeks of diagnosis to be an 'excellent start'.[183] In support, Coggon contends that continued assessments, along with better education and training around best interests, will likely lead to greater consideration of wishes and feelings in future decision-making.[184] While these positive aspects of the literature are acknowledged, these arguments are undermined by the abundance of evidence post-*Aintree* which suggests decision-makers still adopt a 'pick and choose' mentality to best interests, considering factors that align with desired clinical outcomes.[185] This is because, despite the MCA's outward appearance of supporting patients' autonomy to decide their outcomes, in reality, it gives decision-makers excessive discretion, which opens the door for autonomy to be infringed.[186]

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[178] [2014] EWCOP 4, [2014] MHLO 37.

[179] *W v M* (n59); United *Lincolnshire NHS Trust v N* (n178) (Justice Pauffley) [66]; ibid (Justice Hayden) [41] [53].

[180] *Briggs* (n64).

[181] ibid (Justice Charles) [56], [119]; Kitzinger and others 'When "Sanctity of Life" and "Self-Determination" Clash: Briggs versus Briggs' (n66) 446, 448.

[182] Munro (n139) 59; Auckland and Ruck-Keene (n62) 295.

[183] Derick T Wade, 'Using Best Interests Meetings for People in a Prolonged Disorder of Consciousness to Improve Clinical and Ethical Management' (2017) 44 Journal of Medical Ethics 336, 340; Royal College of Physicians (n12) 148 s5.1.10 bi.

[184] Coggon (n137) 229, 230, 231.

[185] *Aintree* (n69); Law Commission (n121) para 14.7.

[186] Donnelly 'BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005' (n125) 16; Barton-Hanson (n154) 277.

What is particularly compelling is that the Law Commission's 2017 Report on mental incapacity recommends amendments to section 4 of the MCA, with most of the consultees agreeing that the ‘legislative silence’ must end, to truly protect and empower incapacitated adults.[187] The Commission specifically recommends changing the word ‘consider’ to 'ascertain' wishes and feelings, as well as emphasising that decision-makers ‘must’ give them ‘particular weight’.[188] This echoes the more 'explicit' treatment of wishes and feelings in other jurisdictions, like Australia and Ireland, where it is required that decision-makers 'must give effect' to a patient's ascertainable and practicable will and preferences.[189] Concern that an over-reliance on patients’ wishes and feelings risks marginalising the clinical expertise of treatment teams lacks substance, grounded in an outdated paternalistic perspective which best interests attempt to eradicate.[190] However, critics such as Barton-Hanson, are convincing in their contention that the phrase ‘particular weight’ is significantly ambiguous.[191] Considering the corpus of evidence in section one that decision-makers are taking advantage of the discretion the Act grants, the proposed changes risk continuing to provide decision-makers ‘elbow room’ to ‘pick and choose’ what they believe satisfies ‘particular.’[192]

Alternatively, the Essex Autonomy Project, a key contributor to CRPD compliance literature, proposes a hierarchy amongst the section 4 checklist by arguing for a rebuttable presumption in favour of implementing wishes and feelings.[193] Series asserts that if a presumption in favour of preserving life can operate, patients’ known wishes and feelings can be subject to the same principle.[194] This recommendation nicely acknowledges the 'prima facie moral claim' that everyone has to live their lives

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[187] House of Lords (n116) para 108; Law Commission (n121) para 4.27, 14.6, 14.10, 14.11, 14.14; Barton-Hanson (n154) 278.

[188] Law Commission (n121) para 14.14, 14.16, 14.19.

[189] Assisted Decision-Making (Capacity) Act 2015 (Republic of Ireland), s 8(7)(b); Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws: Final Report, (ALRC Report 124, Sydney 2014) Recommendation 3a; Wicks ‘When Is Life Not in Our Own Best Interests? The Best Interests Test as an Unsatisfactory Exception to the Right to Life in the Context of Permanent Vegetative State Cases’ (n45) 75, 89.

[190] Johnston and others (n115) 260.

[191] Barton-Hanson (n154) 295.

[192] ibid 290.

[193] Martin and others (n120) 47.

[194] Series (n135) 1112.

as they wish, regardless of capacity.[195] Nevertheless, critics of the rebuttable presumption voice concern that protection could be compromised if wishes and feelings are implemented that are ‘unrealistic and impractical.’[196] While a legitimate worry, it is disproved by the fact that the presumption would be rebuttable in cases where wishes are ‘irrational,’ ‘impractical,’ or ‘irresponsible’, to ensure decisions are still in an individual’s best interests.[197] Decision-makers should conduct comprehensive assessments, avoiding a ‘high level of specificity,’ considering PDOC patients’ past narratives and how they align with their current quality of life.[198] For decision-makers to continue to ignore a PDOC patient’s known past wishes and feelings when their life is at stake, is to violate their ‘last vestige of autonomy’; a harm that has room to continue under the Law Commission’s recommendations.[199] Therefore, as Donnelly argues, the only reform that ensures the autonomy and protection of PDOC patients, notwithstanding their current incapacity, is a presumption in favour of implementing their known past wishes and feelings, which could be rebutted if this would be severely against their best interests.[200]

## Conclusion

Chapter Two’s main finding is that the current best interests standard, used for decision-making for incapacitated adults, is not adequately protecting PDOC patients in practice.[201] Section 4 (6) of the MCA's checklist approach, of which patients’ wishes and feelings are just one factor of consideration, provides decision-makers with excessive discretion in selecting which factors determine outcomes, meaning wishes and feelings often play no role.[202] Thus while best interests attempts to encapsulate a participatory approach to decision-making, its application fails to foster patient

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[195] Mark G Kuczewski, ‘Narrative Views of Personal Identity and Substituted Judgment in Surrogate Decision Making’ (1999) 27 Journal of Law, Medicine & Ethics 32, 33.

[196] Law Commission (n121) para 14.9.

[197] *Re S* (n85) [57].

[198] Johnston (n23) 562.

[199] ibid.

[200] Donnelly ‘BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005’ (n125) 15.

[201] Mental Capacity Act 2005, s4.

[202] ibid; Donnelly ‘BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005’ (n125) 16; Barton-Hanson (n154) 277.

narratives, undermining patient autonomy, dignity, and protection.[203] Part one of section two concluded that the CRPD Committee's argument of replacing best interests with 'will and preferences', fails to acknowledge the reality that we often will not be able to interpret PDOC patients' will and preferences, and therefore risks being too narrow and restricting protection.[204] Part two highlighted the growing judicial emphasis on PDOC patients' past wishes and feelings in court decisions, yet concluded that this does little to change the complete failure to consider these factors in everyday decision-making.[205] Recommendations of the Law Commission to give wishes and feelings 'particular weight' in section 4 may still give decision-makers 'elbow room' to override these factors with clinical considerations.[206] The Chapter concluded that amending the MCA to include a rebuttable presumption requiring decision-makers to implement PDOC patients' known past wishes and feelings when doing so would not seriously harm their overall interests, is the only way to ensure adequate protection for PDOC patients.[207] The final chapter will focus on the guidelines that surround PDOC and explore further potential avenues for improving future PDOC protection.

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[203] ibid 1,2; Johnston and others (n115); Wade and Kitzinger (n131) 1572.

[204] General Comment No.1 (n118); Munro (n139) 60.

[205] *Aintree* (n69); House of Lords (n116) para 107.

[206] Law Commission (n121) para 14.14, 14.16, 14.19; Barton-Hanson (n154) 290.

[207] *Re S* (n85) (Judge Marshall) [57]; Martin and others (n120) 47.

# Chapter 3: A National Registry - Are PDOC Patients Still ‘Lost in the System’?

## Introduction

The objective of this final chapter is to investigate the ‘dearth of data’ on PDOC patients.[208] The RCP and the BMA have both acknowledged this issue in their guidelines and for the past 11 years, they have advocated for the creation of a national PDOC registry to facilitate oversight of PDOC care and decision-making.[209] The focus turns to the role of soft law in PDOC patient protection. Where the best interests standard legal framework does not currently offer protection, these recommendations might. The Chapter aims to ascertain whether PDOC patients continue to be ‘lost in the system’ even with these soft law instruments in place.[210] The lack of literature demonstrating the progression of a national registry and the guidelines has informed this line of enquiry.

This third and final chapter comprises two sections with a focus on the recommendations of improved record keeping, a review of the best interests decision-making process and the development of a national registry.[211] The PDOC guidelines are introduced in section one with a discussion centred on consideration of the current pressures associated with PDOC care,[212] and the potential unintended effects the recommendations may have in practice, whilst also concluding that they are ‘invaluable’ for patient protection.[213] Section two then examines whether the guidelines are being adequately integrated into practice within NHS systems. A review of the available literature reveals a strong sense of ‘inertia’ within care systems, with

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[208] Royal College of Physicians (n12) 16.

[209] British Medical Association (n146).

[210] Adrian O’Dowd, ‘Impaired Consciousness: New Guidelines Aim to Ensure People Aren’t “Lost in System”’ (2020) 368 BMJ.

[211] British Medical Association (n146) 54 s5.5; Royal College of Physicians (n12) 116.

[212] Olivia Gosseries and others, ‘Burnout in Healthcare Workers Managing Chronic Patients with Disorders of Consciousness’ (2012) 26 Brain Injury 1493; Manju Sharma-Virk and others, ‘Intensive Neurorehabilitation for Patients with Prolonged Disorders of Consciousness: Protocol of a Mixed-Methods Study Focusing on Outcomes, Ethics and Impact’ (2021) 21 BMC Neurology, 2.

[213] Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103) 3.

practically no internal or external monitoring of these patients taking place.[214] The analysis offers an alternative perspective to that of earlier studies by attributing the ongoing unavailability of an established national registry as the fundamental cause for the absence of a robust and viable monitoring process.

## The Guidelines: The Dearth of Data

Section One provides an overview of the guidance and guidelines that surround PDOC. To address the 'dearth of data' on these patients, this section will focus on recommendations for the development of a national PDOC registry that would arguably facilitate oversight and transparency of record-keeping and decision-making reviews.[215] It is also proposed that the additional demands that the recommendations may impose on healthcare professionals are outweighed by arguments that the guidelines represent a 'paradigm shift' for patient protection.[216]

With advances in modern neurorehabilitation medicine, the survival of patients following a brain injury has increased, with the 'reverse side of the coin' being a rise in the number of patients with PDOC.[217] Since *Bland* and the MCA, the professional guidance that has developed surrounding PDOC attempts to provide those involved in this distinct area of medicine with a means of clarity.[218] In 2018, the BMA published guidance on CANH decisions for adults who lack mental capacity, with support from the RCP.[219] As well as being endorsed by the General Medical Council, in *NHS Cumbria CCG v Rushton*,[220] Justice Hayden found the guidance to be 'extremely helpful'.[221] The RCP 2020 PDOC Guidelines,[222] which updated the 2013 guidelines in

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[214] ibid 4; Alice Gray, Mark Pickering and Stephen Sturman, 'Absence of Monitoring in Withdrawal of Clinically-Assisted Nutrition and Hydration (CANH) and Other Treatments: A Cause for Concern?' (2021) 21 Clinical Medicine 235.
[215] Royal College of Physicians (n12) 16.
[216] Gosseries and others (n212); Gaber (n1) 4.
[217] Sharma-Virk and others (n212) 2.
[218] *Bland* (n10).
[219] British Medical Association (n146).
[220] [2018] EWCOP41, [2018] 12 WLUK 706.
[221] ibid [29] (Justice Hayden).
[222] Royal College of Physicians (n12).

light of significant common law developments and ‘complemented’ the BMA Guidance, are the most influential guidelines for this dissertation.[223] The fact that the foundation of both guidelines is to support ethical and legal decision-making,[224] and address the ‘dearth of formal research-based evidence’;[225] both objectives that work towards better protection for the PDOC cohort, make them significant for this dissertation.

The creation of a national PDOC registry was first recommended within the RCP 2013 guidelines to foster an evidence base that would enable internal and external scrutiny of patient care and protection.[226] In 2018, the BMA found that, despite five years having passed and the incidence of PDOC cases having increased, very little progress had been made in terms of data collection and review.[227] The BMA then emphasised the ‘urgent need’ to address the lack of data on this particular patient group, asserting that clinical record-keeping of decision-making processes would be encouraged by a national database, thereby promoting patient protection.[228] In 2020, there remained little development in the creation of this ‘robust clinical system’ where PDOC patients are treated on an ‘individual, not default basis,’ despite the BMA’s clear urgency on the matter.[229] This lack of action is concerning in light of the earlier finding that these patients are not adequately protected by the best interests standard for care and decision-making. The importance of a national registry for protection was yet again emphasised by the RCP, who went as far as to suggest that PDOC patient records be open to external review as part of Care Quality Commission (CQC) inspections.[230]

Given that two powerful healthcare organisations were demonstrating how they value the need for transparent oversight of patient care to eradicate any paternalistic clinical decision-making, Gaber viewed the guidelines as a ‘paradigm shift’ for PDOC patient protection.[231] The release of expert guidance acknowledging that CANH withdrawal

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[223] *Y* (n11); Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103) 2.
[224] British Medical Association (n146).
[225] Royal College of Physicians (n2) p16.
[226] Royal College of Physicians (n28); Liliana Teixeira, Danielle Blacker and Nuno Rocha, ‘Disorders of Consciousness’, *Multidisciplinary Interventions for People with Diverse Needs - A Training Guide for Teachers, Students, and Professionals* (Bentham Books 2020) 34, 35.
[227] British Medical Association (n146) 55 s5.6.
[228] ibid, 54 s5.5.
[229] Royal College of Physicians (n12) 175.
[230] ibid 116.
[231] Gaber (n1).

may be the best course of action for patient protection in the first place lends credence to this assertion, demonstrating a change in perspective that is in line with the earlier findings of Chapter One.[232] Further, whilst *Y* shifted decision-making power to treatment teams has on the whole promoted patient protection by removing the burdens of the court process,[233] there has since been an ongoing lack of any external scrutiny over the care and protection of these patients.[234] As a result, the Care Quality Commission could potentially 'mitigate' any adverse effects of the lack of the declaratory relief procedure raised in Chapter One.[235] The guidelines are 'invaluable' for protection in this regard because they advise that PDOC patient care be part of inspections undertaken by an independent regulator that ensures 'effective, high-quality' care, while also ensuring that treatment teams are the ultimate decision-makers.[236]

The proposal for a national PDOC registry has received little attention in the literature; conversely, criticism stems from the existing difficulties that PDOC care currently presents for medical professionals. The 'complex task' of 'providing tailored care' to patients, in general, is widely acknowledged, and Sharma-Virk and others highlighted this in 2021, asserting that the additional demands of PDOC exacerbate these existing complexities.[237] Gosseries and others add to this, emphasising that the ethical dimensions of PDOC already make it a 'real clinical challenge' for hospitals.[238] Consequently, considering the need for strict record keeping and the potential 'reputational risks' associated with external scrutiny, a national PDOC registry could place undue strain on an already overburdened system.[239]

However, a significant drawback of these concerns is that the PDOC Guideline Development Group, which involved contributions from numerous experts and stakeholders in the treatment of PDOC patients, was the expert forum that

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[232] British Medical Association (n146).
[233] Quigley (n99) 237.
[234] Wicks 'An NHS Trust v Y' (n32) 338.
[235] Gray and others (n214) 237.
[236] Ian Pete, 'Expansion of the CQC's Role' (2018) 27 British Journal of Nursing, 235; Kitzinger (n5) 3.
[237] Sharma-Virk and others (n212).
[238] Gosseries and others (n212) 1493.
[239] Kitzinger 'Delay Is Inimical to P's Welfare' (n103) 5.

recommended the creation of a national registry.[240] In *NHS Cumbria CCG v Rushton*,[241] Justice Hayden emphasised the depth of knowledge and the multidisciplinary counsel possessed by the guidelines' core representatives.[242] In essence, this indicates that the calls for a national registry are coming from those embedded within the system. Patient care and protection must always come first in clinical settings, outweighing any unintended consequences of a national registry including potential burnout of a minority of healthcare workers.[243]

In summary, the research in section one revealed that since 2013, recommendations for improved record keeping, external scrutiny, and a national PDOC registry have been in place. Theoretically, patient protection should be promoted by the very fact that major healthcare organisations have released these guidance tools. Although there are legitimate worries that the recommendations risk placing additional demands on medical professionals, it was concluded that these concerns are allayed by the proposed need for, and benefits of a registry originated from those providing the care. Therefore, the guidelines and these specific recommendations are overall 'welcome.'[244] The extent to which the recommendations have been implemented in practice will now be examined.

## The Guidelines: In Practice

To determine whether the recommendations for record keeping, reviews, and a registry have been followed, the section that follows will draw on the scant literature that is currently available. The chapter offers new perspectives by stating that the lack of a national registry is directly contributory to the lack of monitoring. The section concludes with reference to the pilot of a registry that is currently being trialled in a

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[240] Royal College of Physicians (n12) 7.
[241] *NHS Cumbria CCG v* Rushton (n220).
[242] ibid (Justice Hayden) [29].
[243] Gosseries and others (n212).
[244] Gray and others (n214) 236.

small number of NHS Trusts and raises thought-provoking questions regarding the potential future protection of this cohort.

A major limitation of any guidelines is that they are a soft law instrument with no binding force, unlike the MCA. For instance, the BMA guidance is not a set of regulations that decision-makers must follow, but rather a 'valuable tool' for treatment teams.[245] Additionally, as emphasised in Chapter Two, even in situations where the recommendations are backed by statute, the guidelines inevitably remain abstract until they are truly put into practice. As a result, there is an ongoing need to monitor the implementation of the guidelines, extending beyond the scope of this dissertation.

As previously outlined the prime driver for this final chapter is the continued paucity of research on the guidelines and how they are being applied in practice. While scholarly commentary is limited, the available evidence is compelling, written by knowledgeable professionals in the field of PDOC, who identify that external scrutiny and record keeping are still not occurring.[246] Kitzinger, co-director of the Coma and Disorders of Consciousness Research Centre, provides insightful commentary on the recommendations.[247] According to Kitzinger's work, there has been 'neither uniform nor comprehensive' adherence to either the BMA guidance or RCP Guidelines.[248] Similarly, Grey and others present evidence of a widespread lack of monitoring of CANH withdrawal decisions and assert that this is an ongoing 'cause for concern' for protection.[249] Their assertion is strong as it is based on Freedom of Information requests made to 342 hospital trusts and Integrated Care Systems, which account for 95% of PDOC care providers.[250] The stark findings were that a year after the RCP 2020 guidelines were released, not a single respondent had implemented monitoring for CANH withdrawal.[251] To compound this finding, the Care Quality Commission was not conducting any external review despite clear recommendation to do so, since there was no legal obligation in place; taking advantage of the non-binding nature of the

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[245] British Medical Association (n146).
[246] Kitzinger 'Delay Is Inimical to P's Welfare' (n103); Gray and others (n214).
[247] Jenny Kitzinger and others, 'People' (*Coma & Disorders of Consciousness Research Centre*) <https://cdoc.org.uk/> accessed 28 February 2024.
[248] Kitzinger 'Delay Is Inimical to P's Welfare' (n103) 4.
[249] Gray and others (n214) 235.
[250] ibid.
[251] ibid.

guidelines.[252] This reaffirms the significance of the role of binding legislation in protecting patients and highlights the necessity of implementing the Chapter Two recommendations for MCA reform.

Mitigation for this lack of action could be explained by the fact that this evidence was generated in 2021, just one year after the RCP guidelines were implemented. However, a major flaw in this line of thinking is that the guidelines for enhanced record keeping and audits, facilitated via a national database, were first proposed in 2013 and subsequently reiterated in 2018 and 2020, giving treatment teams eleven years to adopt and adhere to them. The findings are problematic because the absence of supervision or scrutiny in 'highly complex life-ending treatment decisions,' potentially preys on the mental incapacity of these patients, who are unable to challenge the decisions made or the quality of care received.[253] According to Kitzinger, 'inertia' persists in hospitals, despite the number of patients surviving brain injury and residing in a PDOC increasing.[254] Taken together, the research suggests that for as long as there is a complete 'dearth of data' regarding the identities and locations of these patients, there is the risk that a culture of inertia will persist.[255]

The significance of the lack of a national registry as the primary cause of the absence of monitoring is overlooked in the research conducted thus far, including the studies by Kitzinger and Grey and others. It is unlikely that reviews will occur if there is no information on who these individuals are and where they are located. Since there is currently no validated data about the number of PDOC patients in the UK at this time, these individuals may continue to go unreported and thus unprotected.

2015 data from nursing homes cited by O'Dowd and also Boardman and Bavikatte, two consultants in rehabilitation medicine, estimated that there were between 4000 and 16000 patients in a PVS, with three times as many in an MCS.[256] Advances in medicine during the subsequent nine-year period mean the number of cases surviving

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[252] ibid.

[253] ibid.

[254] Kitzinger 'Delay Is Inimical to P's Welfare' (n103) 4.

[255] Royal College of Physicians (n12) 16.

[256] Houses of Parliament 'Vegetative and Minimally Conscious States' (PN489, 2015); Adam Boardman and Ganesh Bavikatte, 'An Overview of Prolonged Disorders of Consciousness for the General Practitioner' (2020) 13 British Journal of Medical Practitioners 1; O'Dowd (n210) 1.

with PDOC are now likely to be much higher. This suggests that thousands of PDOC patients are still 'lost in the system' and that routine medical decisions, many of which are life-or-death, continue to be made without record or oversight.[257]

The future of PDOC looks promising, with information from the UK Rehabilitation Outcomes Collaborative that the most recent version of the software it uses to collect patient-level data has been extended to facilitate an initial pilot version of the PDOC registry and is currently being trialled in select trusts.[258] Despite a lack of details at the time of writing, the pilot's existence alone indicates that recommendations to establish a 'robust clinical system' for these patients are at last being taken into consideration.[259] Thus, future investigators in the PDOC field ought to conduct additional research on the development of this national registry and what information the data portrays. It is also noteworthy that in their discussion of the future of PDOC patient protection, Boardman and Bavikatte did not limit their emphasis to the necessity of a national registry. Their points about the need for future 'integration with community services' and 'improved education' on PDOC raise wider questions than this dissertation can address.[260] Alternative pathways for longer-term PDOC management that are not directly covered by treatment teams or the law, raise questions about the future role of community organisations and how a more diverse approach to review and scrutiny to promote patient protection may need to be applied.

In summary, although strong evidence from Kitzinger and Grey and others indicates that there is still a general lack of monitoring or scrutiny in the PDOC care system,[261] the future of PDOC looks more promising. Though long overdue, it appears that the BMA and RCP's recommendations are finally being taken into consideration, according to recent information regarding the trial of a pilot registry.[262] In addition to implementing the proposed modifications to section 4 of the MCA, a registry would

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[257] O'Dowd (n210).
[258] UKROC, 'UK ROC - PDOC' (*www.ukroc.org*2024) <https://www.ukroc.org/pdoc> accessed 28 February 2024.
[259] O'Dowd (n210) 1; Royal College of Physicians (n12) 55.
[260] Boardman and Bavikatte (n256) 4.
[261] Kitzinger 'Delay Is Inimical to P's Welfare' (n103); Gray and others (n214).
[262] UKROC (n258).

guarantee that the decisions and care made by these patients are documented and evaluated, enhancing protection.

## Conclusion

The principal discovery of Chapter Three is that, after eleven years of recommendations, there has been little traction for record keeping, internal audits, external reviews, and a national registry of PDOC patients. This has meant that even now, as the number of PDOC patients continues to rise, the treatment and choices made under the best interests standard remain unrecorded, leaving patients ‘lost in the system’.[263] Section one concluded that the guidelines, a large portion of which is consistent with the conclusions reached in Chapters One and Two, have theoretically sparked a ‘paradigm shift’ for patient protection by attempting to address this ‘dearth of data’.[264] According to the analysis, concerns that a national registry would place an undue burden on healthcare professionals are mitigated by the fact that the recommendations originate from the professionals providing PDOC care.[265] The second section discussed strong evidence that demonstrated a failure to follow the recommendations in practice. A system of ‘inertia’ persists according to Kitzinger,[266] with a widespread lack of internal monitoring or external review in practice.[267] However, considering recent information that an initial pilot registry has started to be trialled within some trusts, the Chapter closed with a more optimistic focus on future PDOC protection.[268]

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[263] O’Dowd (n210).
[264] Royal College of Physicians (n12) 16; Gaber (n1).
[265] Gosseries and others (n212) 1493; Royal College of Physicians (n12) 7.
[266] Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103).
[267] Gray and others (n214)
[268] UKROC (n258).

# Conclusion

In summary, this dissertation has examined the role of the law in PDOC cases and identified potential changes that could be introduced to enhance patient protection going forward. An analysis of the role played by the courts, the legislation, and the professional guidelines that govern PDOC, has determined that these patients continue to be inadequately protected in practice. The importance of this dissertation can be attributed to the 'advancing nature' of modern medicine which fosters the development of this patient group.[269] According to my research, PDOC is a field that the general public, medical professionals, and lawyers are unfamiliar with and lack knowledge about, which is why it is so important to look into this ethical area, particularly as it is only going to become more prevalent in the future.[270]

The objective of Chapter One was to explore the evolution of the court's role in PDOC cases, from *Bland* to *Y*, to determine whether changes to decision-making have altered protection.[271] The first section concluded that withdrawing CANH can be in the best interests of PDOC patients. In such cases, continuing life-sustaining treatment is often an unethical route that only prolongs harm given the limited chances of recovery.[272] The research exposed a persistent misconception in the medico-legal community that death is always the 'harm' in these contexts.[273] Section two concluded that the recent judicial emphasis on patient autonomy and quality of life in PDOC cases represents a significant shift in protection, in contrast to earlier rulings that placed a high priority on the sanctity of life. After a careful examination of the *Y* case,[274] which moved decision-making authority from the Court of Protection to treatment teams, it was concluded that this change has on the whole strengthened protection by removing the harms associated with lengthy court proceedings.[275]

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[269] Heywood (n54) 548.
[270] Turner-Stokes (n9) 469.
[271] *Bland* (n10); *Y* (n11).
[272] Wicks 'When Is Life Not in Our Own Best Interests?' (n45).
[273] Glannon (n35) 551.
[274] *Y* (n11).
[275] Kitzinger 'Delay Is Inimical to P's Welfare' (n103).

Chapter Two centred around the section 4 (6) MCA best interests standard which provides the decision-making basis for incapacitated adults. The goal of the chapter was to ascertain whether PDOC patients are sufficiently protected by this legal framework and, if not, what changes could be made to improve protection. The conclusion reached was that patients' wishes and feelings are only one factor taken into account in best interests decisions, which gives decision-makers excessive discretion in deciding which factors determine outcomes.[276] As a result, PDOC patients' past wishes and feelings are frequently ignored in practice, which can be detrimental to their autonomy and protection.[277] In section two, it was concluded that the CRPD Committee's argument to substitute best interests with 'will and preferences', risks restricting protection as it would not take into account the fact that we frequently will not be able to interpret the will and preferences of PDOC patients.[278] My research also found that the Law Commission's recommendations to give wishes and feelings 'particular weight' could still allow decision-makers 'elbow room' to override these factors in favour of clinical considerations.[279] Thus, the only way to guarantee PDOC patients adequate protection is to amend the MCA to include a rebuttable presumption requiring decision-makers to implement the known past wishes and feelings of PDOC patients when doing so would not seriously harm their overall interests.[280]

Chapter Three addressed the 'dearth of data' on PDOC patients.[281] For the past eleven years, the BMA and the RCP have recommended the creation of a national registry to facilitate oversight of PDOC care and decision-making.[282] The chapter sought to answer the question of whether PDOC patients are still 'lost in the system' despite the role that soft law guidelines play.[283] A system of 'inertia' surrounds PDOC, according to the analysis, which indicates that these recommendations are not being followed in

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[276] ibid; Donnelly 'BEST INTERESTS, PATIENT PARTICIPATION and the MENTAL CAPACITY ACT 2005' (n125) 16; Barton-Hanson (n154) 277.
[277] House of Lords (n116) para 107.
[278] General Comment No.1 (n118); Munro (n139) 60.
[279] Law Commission (n121) para 14.14, 14.16, 14.19; Barton-Hanson (n154) 290.
[280] *Re S* (n85) (Judge Marshall) [57]; Martin and others (n120) 47.
[281] Royal College of Physicians (n12) 16.
[282] British Medical Association (n146); Royal College of Physicians (n12), (n28).
[283] O'Dowd (n210).

practice.[284] On the other hand, more promising news regarding the protection of PDOC patients in the future has emerged, with information that some trusts have begun to trial an initial pilot registry.[285]

Given that this dissertation is exclusively based on PDOC, a future researcher could explore whether the points raised apply to other incapacitated groups covered by the MCA. Additionally, considering the ambiguous status of the pilot registry at the time of writing, it is suggested that additional research is necessary to determine whether the national PDOC registry progresses and whether it improves patient protection. Further, though this dissertation did not present a clear prescription for a role for community organisations, it would be beneficial for future studies to investigate this avenue of protection in more detail.

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[284] Kitzinger ‘Delay Is Inimical to P’s Welfare’ (n103).

[285] UKROC (n258).

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