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How should best interests decisions concerning end-stage kidney disease care for adults be made?

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The BIRD Study

How should best interests decisions concerning
end-stage kidney disease care for adults be made?

Jordan A. Parsons

A dissertation submitted to the University of Bristol in accordance with the requirements for award of
the degree of Doctor of Philosophy in the Faculty of Health Sciences.

Bristol Medical School

2023

83,941 words

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Let's get ethical, ethical. I wanna get ethical. Let's get into ethics, yeah.

- Michael Scott & Holly Flax, *The Office*

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Abstract

This thesis investigates “best interests” decisions concerning the care of adults with or approaching end-stage kidney failure. I focus on the ethico-legal dimensions of questions of dialysis provision versus conservative kidney management. Through an empirical bioethics approach, I complement my normative inquiry with qualitative exploration of the views and experiences of three stakeholder groups: nephrologists, renal nurses, and “consultees” (family members).

Limited existing literature lacks consensus on *how* these decisions should be made, but overwhelmingly recognises difficulties in involving various stakeholders and manoeuvring towards an appropriate decision without conflict. There is acknowledgement of the complexity of balancing medical and non-medical factors, with particular reference to what the patient might value. Participants in my own empirical research similarly highlighted areas of conflict in their own experiences. Whilst wanting to respect the patient’s own care preferences, healthcare professionals and consultees alike spoke of a difficulty in accurately identifying such preferences. For professionals, resulting disagreements had the potential to lead them down the “path of least resistance” in trying to maintain relationships with those close to the patient.

Employing a process of reflective equilibrium, I combine my own intuitions with the perspectives identified in the literature and my empirical data to reach a set of coherent positions on *how* these best interests decisions should be made. I argue that active discussions should begin in advance of any significant care decision arising. These should focus on exploring not only what care options the patient might want, but also how the patient might want any future best interests decision to be approached. Further, these discussions should include the clarification of stakeholder roles in best interests decisions and sensitively set expectations – following which, strong communication should remain consistent. In addition, I highlight where research is needed to supplement my recommendations.

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To my supervisors, Jon and Fergus: thank you enormously for putting up with me over the last few years. I am fully aware I have a tendency to run before I can walk, so I do appreciate you keeping my eye on the ball where necessary and pushing me to tackle challenging questions.

Empirical research cannot be done solo, so my enduring gratitude to those who helped along the way by driving recruitment efforts and making this project possible. Notably, Indy, Amy, and Sonia. Thanks also to all my participants for sharing not only their time, but their very personal experiences – their voices underpin this work.

I am forever indebted to the best PhD buddy I could have hoped for – Harleen. Our conversations over the last few years, both about the subjects of our theses and methodology, have undoubtedly improved my work. Indeed, several of the articles I have published throughout my PhD are with Harleen, as we do enjoy having a good rant together. Thank you also for the many Nando's trips where we could freely vent, helping me drag myself through the PhD!

Huge thanks to my academic wife, Chloe, for keeping me entertained with various side projects throughout my PhD. You know I am easily distracted by new ideas for papers and just run with it, giving me a break from the frustration of deciding what I think “best interests” really means. And thanks to her real husband for putting up with us...

Finally, thank you to everyone who has discussed ideas with me, read (sometimes truly, truly awful) drafts of my work, or simply let me rage about questionable journal articles over wine. For brevity (read: fear of missing someone out) I will not list you all here, but you know who you are.

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Author's Declaration

I declare that the work in this dissertation was carried out in accordance with the requirements of the University's Regulations and Code of Practice for Research Degree Programmes and that it has not been submitted for any other academic award. Except where indicated by specific reference in the text, the work is the candidate's own work. Work done in collaboration with, or with the assistance of, others, is indicated as such. Any views expressed in the dissertation are those of the author.

Monday 23 January 2023

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COVID-19 Statement

The main impact of the COVID-19 pandemic on my research was in the empirical phase. This affected my research ethics approvals, study site setup, recruitment, and ethnography.

My IRAS forms were ready to submit in early March 2020, but the HRA then stopped considering research that did not relate to COVID-19. I was, therefore, unable to submit for research ethics approval until October 2020. This had a knock-on effect, shortening my recruitment, analysis, and write-up periods. Whilst I managed to shift the order I completed parts of the project to lessen the impact, it was still notable.

I initially planned – and obtained research ethics approvals for – three recruitment sites. One of them withdrew at the last minute because of pandemic pressures on their unit. This further limited recruitment opportunities as I had to reach the same number of participants from a smaller pool.

Originally, I intended to complement my interview study with an ethnography. I considered this particularly important as I am not myself from a healthcare background. Due to pandemic-related restrictions on in-person interactions, it was not feasible for me to spend the amount of time at study sites that an ethnography necessitates. I planned to use the ethnography, in part, for data triangulation purposes, which I ended up unable to do. I was able to undertake several site visits at times when restrictions were eased but was unable to get the level of exposure to the context I had hoped.

Whilst the impact of the pandemic was primarily in relation to the empirical phase, the knock-on effect meant I was left with a shorter period to conduct my ethico-legal analysis using the data generated.

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Publications

Below is a list of published works completed during this PhD, both arising out of my doctoral work and other projects carried out during my PhD. Those arising out of my doctoral work include a contributor statement where I am not the sole author.

Doctoral work:

Book chapters:

- 1) **Parsons JA**. 2021. 'Death or dialysis: The value of burdensome life-extending treatments for the cognitively impaired'. In Schildmann J, Buch C, Zerth J (eds.). *Defining the Value of Medical Interventions: Interdisciplinary Analyses*. Stuttgart: Kohlhammer.

Journal articles:

- 1) **Parsons JA**, Johal HK, Parker J, Romanis EC. 2023. Translational or translationable? A call for ethno-immersion in (empirical) bioethics research. *Bioethics*. [online first] <https://doi.org/10.1111/bioe.13184>
-
Parsons conceived the work. All authors wrote the first draft and contributed to critical revision. All authors approved the final version to be published.
- 2) Johal HK, Finnerty A, **Parsons JA**. 2022. "Harmful" choices and subjectivity: against an externalist approach to capacity assessments. *American Journal of Bioethics* 22(10):78-81.
-
Johal conceived the work and wrote the first draft. All authors contributed to critical revision. All authors approved the final version to be published.
- 3) **Parsons JA**, Johal HK. 2021. In defence of the bioethics scoping review: largely systematic literature reviewing with broad utility. *Bioethics* 36(4):423-433.
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Parsons conceived the work. Both authors wrote the first draft and contributed to critical revision. Both authors approved the final version to be published.
- 4) **Parsons JA**, Taylor D, Caskey FC, Ives J. 2021. Ethical duties of nephrologists: when patients are nonadherent to treatment. *Seminars in Nephrology* 41(3):262-271.
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Parsons conceived the work and wrote the first draft. All authors contributed to critical revision. All authors approved the final version to be published.

- 5) **Parsons JA**, Ives J. 2021. Dialysis decisions concerning cognitively impaired adults: a scoping literature review. *BMC Medical Ethics* 22:24.
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Parsons conceived the work and wrote the first draft. Both authors contributed to critical revision. Both authors approved the final version to be published.
- 6) Martin DE, **Parsons JA**, Caskey FC, Harris D, Jha V. 2020. Ethics of kidney care in the era of COVID-19. *Kidney International* 98(6):1424-1433.
-
Parsons and Martin conceived the work and wrote the first draft. All authors contributed to critical revision. All authors approved the final version to be published.
- 7) **Parsons JA**, Martin DE. 2020. A call for dialysis-specific resource allocation guidelines during COVID-19. *American Journal of Bioethics* 20(7):199-201.
-
Parsons conceived the work. Both authors wrote the first draft and contributed to critical revision. Both authors approved the final version to be published.
- 8) **Parsons JA**, Johal HK. 2020. Best interests v resource allocation: could COVID-19 cloud decision-making for the cognitively impaired? *Journal of Medical Ethics* 46(7):447-450.
-
Parsons conceived the work. Both authors wrote the first draft and contributed to critical revision. Both authors approved the final version to be published.

Other:

- 1) **Parsons JA**, Cairns P, Ives J. 2021. Translational Bioethics Workshop: “Translational Bioethics: A distinctive entity or emperor’s new clothes?”. *EACME Newsletter*, December 2021:21-24.
- 2) **Parsons JA**. 2020. Ethical issues in restraining patients for dialysis. *Open Justice Court of Protection Project*. <<https://openjusticecourttoprotection.org/2020/10/21/ethical-issues-in-restraining-patients-for-dialysis/>>.

Other works published in the course of this PhD:

Books:

- 1) **Parsons JA**, Romanis EC. 2021. *Early Medical Abortion, Equality of Access, and the Telemedical Imperative*. Oxford: Oxford University Press.

Journal articles:

- 1) **Parsons JA**. 2022. Improvidence, precaution, and the logical-empirical disconnect in UK health policy. *Health Care Analysis* [online first] <https://doi.org/10.1007/s10728-022-00450-8>.

- 2) Romanis EC, **Parsons JA**. 2022. Directed and conditional uterus donation. *Journal of Medical Ethics* 48(11):810-815.
- 3) Romanis EC, Mullock A, **Parsons JA**. 2021. The excessive regulation of early abortion medication in the United Kingdom: the case for reform. *Medical Law Review* 30(1):4-32.
- 4) **Parsons JA**, Venter B. 2021. Deemed consent for organ donation in Northern Ireland. *Lancet Regional Health Europe* 12:100254.
- 5) **Parsons JA**, Romanis EC. 2021. The case for telemedical early medical abortion in England: dispelling adult safeguarding concerns. *Health Care Analysis* 30:73-96.
- 6) Romanis EC, **Parsons JA**, Salter I, Hampton T. 2021. Safeguarding and teleconsultation for abortion. *Lancet* 398(10299):555-558.
- 7) **Parsons JA**. 2021. Early analysis of deemed consent: why Moorlock's critique is mistaken. *Journal of Law and the Biosciences* 8(2):lsab025.
- 8) **Parsons JA**. 2021. Deemed consent for organ donation: a comparison of the English and Scottish approaches. *Journal of Law and the Biosciences* 8(1):lsab003.
- 9) **Parsons JA**. 2021. The telemedical imperative. *Bioethics* 35(4):298-306.
- 10) **Parsons JA**, Baker PE. 2022 [2020 online]. From proband to provider: is there an obligation to inform genetic relatives of actionable risks discovered through direct-to-consumer genetic testing? *Journal of Medical Ethics* 48(3):205-212.
- 11) **Parsons JA**, Romanis EC. 2021 [2020 online]. 2020 developments in the provision of early medical abortion by telemedicine in the UK. *Health Policy* 125(1):17-21.
- 12) Romanis EC, **Parsons JA**. 2020. Legal and policy responses to the delivery of abortion care during COVID-19. *International Journal of Gynecology & Obstetrics* 151(3):479-486.
- 13) **Parsons JA**, Moorlock G. 2020. A global pandemic is not a good time to introduce "opt-out" for organ donation. *Medical Law International* 20(2):155-166.
- 14) **Parsons JA**. 2020. 2017-19 governmental decisions to allow home use of misoprostol for early medical abortion in the UK. *Health Policy* 124(7):679-683.
- 15) Romanis EC, **Parsons JA**, Hodson N. 2020. COVID-19 and reproductive justice in Great Britain and the United States: ensuring access to abortion care during a global pandemic. *Journal of Law and the Biosciences* 7(1):lsaa027.

Other:

- 1) Romanis EC, **Parsons JA**, Hampton T. 2021. Why change to abortion laws during the pandemic should remain. *The Conversation*. <<https://theconversation.com/why-changes-to-abortion-laws-during-the-pandemic-should-remain-162378>>.
- 2) Baker PE, **Parsons JA**. 2020. "We think you may be at risk of a genetic disease". Should direct-to-consumer genetic testing companies contact at-risk relatives? *Journal of Medical Ethics Blog*. <<https://blogs.bmj.com/medical-ethics/2020/12/11/we-think-you-may-be-at-risk-of-a-genetic-disease-should-direct-to-consumer-genetic-testing-companies-contact-at-risk-relatives/>>.
- 3) Romanis EC, **Parsons JA**. 2020. Access to remote abortion services should not be temporary. *BMJ Opinion*. <<https://blogs.bmj.com/bmj/2020/04/02/elizabeth-chloe-romanis-jordan-parsons-access-remote-abortion-services-should-not-temporary/>>.
- 4) Hodson N, Romanis EC, **Parsons JA**. 2020. Abortion and COVID-19: MPs should beware anti-abortion letters. *BMJ Sexual & Reproductive Health Blog*. <<https://blogs.bmj.com/bmjournals/2020/03/26/abortion-covid19-letters/>>.
- 5) Romanis EC, **Parsons JA**, Hodson N. 2020. COVID-19 and Abortion Care Update: Department of Health and Social Care "Error". *BMJ Sexual & Reproductive Health Blog*. <<https://blogs.bmj.com/bmjournals/2020/03/24/covid-19-abortion-3/>>.
- 6) Romanis EC, **Parsons JA**, Hodson N. 2020. COVID-19 and Remote Access to Abortion Care: An Update. *BMJ Sexual & Reproductive Health Blog*. <<https://blogs.bmj.com/bmjournals/2020/03/23/covid-19-abortion-update/>>.

- 7) Romanis EC, **Parsons JA**. 2020. COVID-19 and abortion care: why we need remote access to reproductive health services. *BMJ Sexual & Reproductive Health Blog*. <<https://blogs.bmj.com/bmj/srh/2020/03/21/covid-19-abortion/>>.

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List of Abbreviations

| | |
|--------------|--|
| ACP | Advance care planning |
| AKI | Acute kidney injury |
| BMA | British Medical Association |
| CKD | Chronic kidney disease |
| CKM | Conservative kidney management |
| eGFR | Estimated glomerular filtration rate |
| ELSA | Ethical, legal, and social aspects |
| ELSI | Ethical, legal, and social implications |
| ESKD | End-stage kidney disease |
| GMC | General Medical Council |
| HCPs | Healthcare professionals |
| HD | Haemodialysis |
| HRA | Health Research Authority |
| IMCA | Independent mental capacity advocate |
| KRT | Kidney replacement therapy |
| LPA-HW | Lasting power of attorney for health and wellbeing |
| MCA 2005 | Mental Capacity Act 2005 |
| MeSH | Medical Subject Headings |
| NICE | National Institute for Health and Care Excellence |
| PD | Peritoneal dialysis |
| PICO | Population, intervention, comparison, outcome |
| PVS | Persistent vegetative state |
| Quasi-LPA-HW | Quasi lasting power of attorney for health and wellbeing |
| UNCRPD | United Nations Convention on the Rights of Persons with Disabilities |

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List of Legal Sources

Statutes:

United Kingdom:

Equality Act 2010

Mental Capacity Act 2005

Mental Capacity (Amendment) Act 2019

Other jurisdictions:

Mental Capacity Act 2008 [Singapore]

United Nations Convention on the Rights of Persons with Disabilities 2008 [international]

Cases:

United Kingdom:

Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67

Airedale NHS Trust v Bland [1993] A.C. 789

An NHS Trust and others v Y and another [2018] UKSC 46

Briggs v Briggs & Ors [2016] EWCOP 53

Chatterton v Gerson [1981] 1 All E.R. 257

Heart of England NHS Foundation Trust v JB [2014] EWCOP 342

IM v LM, AB and Liverpool CC [2014] EWCA Civ 37

Kings College Hospital NHS Foundation Trust v C & Anor [2015] EWCOP 80

King's College Hospital NHS Foundation Trust v Thomas, Haastrup, and Haastrup [2018] EWHC 127(Fam)

London Borough of Tower Hamlets v PB [2020] EWCOP 34

Montgomery v Lanarkshire Health Board [2015] UKSC 11

R (Burke) v General Medical Council [2005] EWCA Civ 1003

Re C (Adult: Refusal of Treatment) [1994] 1 W.L.R. 290

Re G (TJ) [2010] EWCOP 300

Re P (Urgent Medical Treatment) [2020] 2 WLUK 194

Re T (Adult: Refusal of Treatment) [1993] Fam 95

Other jurisdictions:

Commissioner of Correction v. Myers 399 N.E.2d 452 (Mass. 1979) [United States]

Introduction

Treatment decisions made with, for, and on behalf of adult¹ patients who are judged to lack decision-making capacity² are, by their very nature, challenging. People may lack decision-making capacity for a variety of reasons, which the National Institute for Health and Care Excellence (NICE) summarises into ‘illness, injury or disability’.³ Examples noted in the Code of Practice that accompanies the Mental Capacity Act 2005 (MCA 2005) include mental illness, dementia, significant learning disabilities, delirium, and the symptoms of alcohol or drug use.⁴ Decisions made about the care of individuals affected by such cognitive impairments⁵ require the decision maker(s) to determine the most appropriate way to proceed with (non-)treatment when, in some cases, the outcome can have a huge bearing on the patient’s future – potentially even preventing a future for the patient where end-of-life care decisions are concerned. In Western societies that value individual patient autonomy highly, it may be especially complicated navigating input from various directions in an attempt to make the “right” decision,⁶ whether that be an attempt to replicate the decision the patient would have made if they had been able, to apply some rather more detached, objective concept of the “best” option, or something in between.

¹ I am concerned specifically with adults, which I take to mean those aged 18 or over. Where a patient is under 18, an entirely different legal (and, depending on one’s view, ethical) framework applies. To explore both in reasonable depth would be far beyond the scope of this project.

² The wording *are judged to* is intentional. For reasons that I will come to discuss throughout this thesis, a finding of incapacity does not necessarily mean that the patient lacks decision-making capacity. Such findings are sometimes the subject of criticism due to an inescapable level of subjectivity. Hereafter I will refer to “patients who lack decision-making capacity” to economise on words, but the “are judged to” should be presumed.

³ National Institute for Health and Care Excellence. 2018. *Decision-making and mental capacity*. <<https://www.nice.org.uk/guidance/ng108>>.

⁴ Department of Constitutional Affairs. 2007. *Mental Capacity Act 2005 Code of Practice*. London: The Stationery Office, 44. It should be noted that this is by no means an exhaustive list.

⁵ I will hereafter use “cognitive impairment” as a collective term for all causes of impaired decision-making capacity.

⁶ Specifically in the context of dialysis decisions, which are the focus of this thesis, Grönlund and colleagues found that nephrologists can feel ‘trapped in irresolution’ when faced with diverging opinions of various parties. See Grönlund CECF, Dahlqvist V, Söderberg AIS. 2011. Feeling trapped and being torn: physicians’ narratives about ethical dilemmas in haemodialysis care that evoke a troubled conscience. *BMC Medical Ethics* 12:8, 6 [author emphasis].

In England and Wales, such decisions are, per the MCA 2005,⁷ to be made in the “Best Interests”⁸ of the patient. I will come to explicate this concept shortly. Or, rather, aim at something of an explanation, as the precise meaning of Best Interests is notably difficult to pin down.⁹ Indeed, this was more recently made clear by Birchley in his highlighting of the range of conceptualisations found in the literature.¹⁰ In the words of seasoned Court of Protection¹¹ judge Hedley J, ‘you will search statutes, regulations and decided cases in vain for a definition of ‘[B]est [I]nterests’’.¹² It is perhaps no surprise, then, that the term Best Interests has come under fire, being described as a ‘vehicle for poor decision-making’¹³ – where its meaning is unclear, consistent and legally (and, by extension, ethically) defensible application is challenging.

One area where Best Interests decisions prove especially complex is in kidney care – in particular, decisions concerning dialysis for patients with or approaching end-stage kidney disease (ESKD; also referred to as kidney failure¹⁴). As a care option, dialysis is not straightforward. The initiation and continuation of dialysis requires a significant commitment from the patient (and, in reality, those in close relationships with the patient – albeit commitment of a different nature). It is not a “quick fix”, but a long-term commitment to regular, invasive medical care. Whilst there are different types of

⁷ The Mental Capacity (Amendment) Act 2019 has since come into force. However, no amendments therein affect the subject matter of this thesis.

⁸ It is important to note that the language of “best interests” is not only used in relation to the Mental Capacity Act 2005. Often – and especially in countries, such as the US, where there is no such statutory concept – it is used in a more general sense to refer to a course of action that is (potentially paternalistically) considered “good” for the patient. To distinguish usages, the former will be referred to as “Best Interests” (note the capitalisation) and the latter as “best interests”.

⁹ Taylor HJ. 2016. What are ‘best interests’? A critical evaluation of ‘best interests’ decision-making in clinical practice. *Medical Law Review* 24(2):176-205; Donnelly M. 2009. Best interests, patient participation and the Mental Capacity Act 2005. *Medical Law Review* 17(1):1-29.

¹⁰ Birchley G. 2021. The theorisation of ‘best interests’ in bioethical accounts of decision-making. *BMC Medical Ethics* 22:68.

¹¹ The Court of Protection is one of the courts of England and Wales, with jurisdiction over matters concerning individuals who lack decision-making capacity. It was created by section 45 of the Mental Capacity Act 2005, meaning all decisions concerning the newly established *statutory* principle of Best Interests are now heard before it. I specify the *statutory* principle of Best Interests because it had previously evolved in case law, with such cases having been heard in other courts. I will discuss this evolution further shortly.

¹² Hedley M. 2016. *The Modern Judge: Power, Responsibility and Society’s Expectations*. Bristol: LexisNexis, 63.

¹³ These were the words of Dr Claud Regnard, a Consultant in Palliative Care Medicine, when appearing before the House of Lords Select Committee on the Mental Capacity Act 2005 during their 2013/14 session. House of Lords Select Committee on the Mental Capacity Act 2005. 2014. *Mental Capacity Act 2005: post-legislative scrutiny*. London: The Stationery Office Limited, 45.

¹⁴ I will refer to ESKD and kidney failure interchangeably throughout this thesis.

dialysis – which I will discuss later in this chapter – that can be burdensome in different ways, the common option of in-centre haemodialysis (HD)¹⁵ generally requires the patient to attend a dialysis centre thrice weekly, for sessions of roughly four hours.¹⁶ Patient experiences differ, so generalisations can be problematic, but patients frequently report this treatment taking its toll in terms of, for example, physical exhaustion¹⁷ and strained relationships.¹⁸ When a patient is in a position to make this decision themselves, balancing the benefits and burdens in line with their own values and preferences, the provision of such burdensome care is relatively easily justified in terms of respect for patient autonomy.¹⁹ When a patient with or approaching ESKD lacks decision-making capacity in relation to dialysis, however, those responsible for making the decision face the difficult task of deciding whether this life-sustaining, though potentially life(style)-changing, care is the right option for that individual patient. In some cases, this decision may have to be made with no or minimal information about the patient's own desires.

Bringing together these two challenging areas, this empirical bioethics project seeks to determine how Best Interests ought to be understood and practiced in the context of adult patients with or approaching ESKD in England and Wales. To inform such a determination, I consider whether theoretical concepts of Best Interests – both ethical and legal – align with clinical practice in relation to decisions about maintenance dialysis. I bring together two strands of research to enable this: (1) theoretical and empirical literature, and (2) stakeholder perspectives, collected through qualitative interviews. Combining these data and exploring them through a process of reflective equilibrium (*see* 2.3.2 and 6.1), I will seek to answer the ‘practical ‘ought’ question’²⁰ of “how should Best Interests decisions concerning end-stage kidney disease care for adults be made?”.

¹⁵ HD is the common option in England and Wales, which is the focus of this project. This is not the case everywhere, as I will explain later in this chapter.

¹⁶ Dialysis schedules can vary depending on the needs of individual patients, such that some may attend just once a week, and others four, five times. However, thrice weekly is a standard routine.

¹⁷ Bossola M, Vulpio C, Tazza L. 2011. Fatigue in chronic dialysis patients. *Seminars in Dialysis* 24(5):550-555.

¹⁸ Neumann D, Lamprecht J, Robinski M, Mau W, Girndt M. 2018. Social relationships and their impact on health-related outcomes in peritoneal versus haemodialysis patients: a prospective cohort study. *Nephrology Dialysis Transplantation* 33(7):1235-1244.

¹⁹ Here I refer to the specific manifestation of autonomy that is informed consent. I will detail this shortly.

²⁰ Sheehan M, Dunn M. 2013. On the nature and sociology of bioethics. *Health Care Analysis* 21:54-69, 57 [italics removed].

In this chapter, I provide a background to the key concepts at play in this thesis and their role in the justification of this research. This chapter serves, then, to both establish the need for this project and provide the reader with necessary background understanding. One chapter is insufficient to acknowledge the magnitude and specifics of the two primary issues which meet in this project – Best Interests and care for patients with or approaching ESKD – so I will provide only an overview before revisiting the various concepts as they arise throughout this thesis. At this point, it is also worth noting that, whilst the legal framework in which this research is rooted is that of England and Wales, much of the broader discussion is likely to prove equally pertinent in other jurisdictions, even where the legal system bears no similarities to the English law concept of Best Interests. This is in part because my analysis is, first and foremost, ethical in nature, but also because examples of the application of legal concepts can prove useful even in other jurisdictions even if there is only limited overlap.

1.1 Background to mental capacity and best interests

It is first necessary to detail the legal nature of Best Interests so that one may understand the requirements kidney health professionals are subject to in the treatment of patients with both cognitive impairments and ESKD. This, in turn, requires some background to informed consent and decision-making capacity as precursors to the need for a Best Interests decision. Here, then, I briefly note the importance of informed consent to medical treatment, before discussing the nature of decision-making capacity, and, finally, the role of the Best Interests standard. In doing so, both legal and ethical aspects will be discussed.

1.1.1 Informed consent

In Western medical ethics, respect for patient autonomy is a prevalent idea. It is fair to say that there is, as yet, no consensus as to precisely how autonomy ought to be conceptualised,²¹ but there is at least significant agreement on (some conception of) it being important.²² So much so that some scholars – notably Gillon – have, somewhat oxymoronically, declared respect for autonomy as ‘first among equals’²³ in reference to Beauchamp and Childress’ widely cited four principles approach to bioethics.²⁴ Whilst I cannot go as far as to agree with Gillon in affording respect for autonomy such primacy, it is largely self-evident that, save some particular circumstances that I will touch on shortly, providing only that care which the patient agrees to has some *prima facie* value as a principle.²⁵ In medical law – and, as such, in medical practice (save *malpractice*) – respect for patient autonomy has manifested as the doctrine of informed consent.²⁶ As this thesis focuses on instances where informed consent is not deemed feasible, I will only briefly outline the concept here to provide context.

²¹ To be clear, there is an important distinction between autonomy *per se* and the *right to* autonomy. Whilst the right to autonomy (with certain constraints) is a more or less agreed point, what it means for someone to exercise this right is rather more complex. There is a wealth of literature debating the concept of individual autonomy we ought to ascribe to which I will not enter into here (though I will revisit this question later in this thesis). Nonetheless, for now, the variation even within a single edited collection sufficiently demonstrates the fractured nature of this debate. See Taylor JS (ed.). 2005. *Personal Autonomy: New Essays on Personal Autonomy and Its Role in Contemporary Moral Philosophy*. New York: Cambridge University Press. Contributors to this collection endorse a range of conceptions, including more Kantian ideas, procedural accounts, and feminist critiques.

²² The right to autonomy is ordinarily conceptualised in line with negative liberty, *per* Berlin. See Berlin I. 1969. *Four Essays on Liberty*. Oxford: Oxford University Press. The focus of philosophical scholarship on autonomy might be considered to have historically been to the detriment of important considerations regarding those who lack decision-making capacity. Buchanan AE, Brock DW. 1990. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge: Cambridge University Press, 2-4.

²³ Gillon R. 2003. Ethics needs principles – four can encompass the rest – and respect for autonomy should be “first among equals”. *Journal of Medical Ethics* 29(5):307-312. Gillon has – rightly, to my mind – been criticised for the at best poorly supported and at worst self-defeating nature of his ‘first among equals’ claim. Dawson A, Gerrard E. 2006. In defence of moral imperialism: four equal and universal *prima facie* principles. *Journal of Medical Ethics* 32(4):200-204.

²⁴ Beauchamp TL, Childress JF. 2019. *Principles of Biomedical Ethics*. 8th edition. New York: Oxford University Press.

²⁵ Whether this value is intrinsic or instrumental is itself a matter of contention. Whilst scholars such as Gillon might suggest the former, others take the position that respect for autonomy is of instrumental value in promoting the wellbeing of patients. See Varelius J. 2006. The value of autonomy in medical ethics. *Medicine, Health Care and Philosophy* 9:377-388.

²⁶ There are other (somewhat related) reasons why one might value an individual’s personal choices, which may have been influential in the development of informed consent as a concept. For example, the right to dignity, the right to liberty, and, rather more pragmatically, the promotion of a good doctor-patient relationship. For further discussion of the role of these principles, see Herring J. 2009. Losing it? Losing what? The law and dementia. *Child and Family Law Quarterly* 21(1):3-29.

At its core, informed consent is about a patient being able to make a choice in line with their own values and preferences as to what care they wish to (not) receive. Moving away from a “doctor knows best” mentality, informed consent seeks to empower patients to understand their condition, their options, and how these (mis)align with their values. Per *Montgomery v Lanarkshire Health Board*, it entails a positive right to be informed of material risks that one might attach significance to, resulting in a duty on doctors to inform patients about material risks that are determined based on the ‘needs, concerns and circumstances of the individual patient, to the extent that they are or ought to be known to the doctor’.²⁷ Further, patients must be informed of material risks in relation to ‘any reasonable alternative or variant treatments’.²⁸ It is not, then, a simple matter of the doctor informing the patient of pertinent information about the treatment that the *doctor* considers most appropriate, presenting the patient with an either/or decision. Rather, pertinent information must be provided about the range of reasonable (i.e., clinically indicated) alternatives so that the patient can choose between them. It must be remembered, however, that the duty of doctors to provide this information is based on the patient’s right to it, and that is a right that the patient can waive. The Supreme Court, invoking the so-called “right not to know”, was clear that a patient can choose not to be informed of these material risks.²⁹ *Montgomery*, then, can be considered as having confirmed informed consent as patient centred.³⁰ Interestingly, the judgment also references the idea of choice in healthcare as ‘consumers’.³¹

Of course, this does not entirely erode the doctor’s role and clinical discretion. It is still for the doctor, possessing the appropriate clinical expertise, to determine what those reasonable treatment options are. It may be that there is only a single treatment option in a given situation. Patients do not have the right to demand care that is not clinically indicated.³² That being said, a reasonable option does *not* mean one which the doctor considers wise.

²⁷ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, at para 73, per Lords Kerr and Reed.

²⁸ *Ibid*, at para 87.

²⁹ *Ibid*, at para 85.

³⁰ Farrell AM, Brazier M. 2015. Not so new directions in the law of consent? Examining *Montgomery v Lanarkshire Health Board*. *Journal of Medical Ethics* 42(2):85-88, 88.

³¹ *Montgomery* (n27) at para 75. For a discussion of the possible implications of this acceptance of consumerism, see Cave E, Milo C. 2020. Informing patients: the *Bolam* legacy. *Medical Law International* 20(2):103-130.

³² Taylor (n9) 180. See also *R (Burke) v General Medical Council* [2005] EWCA Civ 1003, at para 50.

The requirement of informed consent has limits. In emergency situations, the doctrine of necessity might be invoked to provide care in the absence of informed consent. The General Medical Council's *Decision making and consent* guidance states:

'In an emergency, if a patient is unconscious or you otherwise conclude that they lack capacity and it's not possible to find out their wishes, you can provide treatment that is *immediately* necessary to *save their life* or to prevent a *serious* deterioration of their condition'.³³

Aside from emergency situations, the other key justification for care being provided in the absence of informed consent is where a patient lacks decision-making capacity. In such circumstances, a Best Interests decision *may* be the appropriate course of action. I emphasise *may* because there are alternative means of a decision being reached that must be considered first, which are intended to be (though whether they are in practice may be contested) more autonomy respecting. The next two sections outline decision-making capacity and Best Interests, respectively – two concepts that are key to this thesis.

1.1.2 Decision-making capacity

If we agree that informed consent is something of a gold standard in treatment decision making,³⁴ regardless of our reasons for doing so, we must simultaneously acknowledge that making an informed decision – particularly when it comes to hugely complex healthcare decisions with potentially life-changing impact – is not straightforward for all individuals. Informed consent as a right and informed

³³ General Medical Council. 2020. *Decision making and consent*. Manchester: General Medical Council, at para 63 [emphasis added].

³⁴ It is worth noting here that the MCA 2005 is not applicable only to medical decisions. Throughout this thesis, however, it will only be considered in a medical context. As such, any mention of the rights of *patients* should not be misinterpreted as a misunderstanding of the scope of the Act.

consent as a capability must be understood as distinct concepts that may or may not coexist in a given context. What enables us to establish the coexistence (or not) of these two aspects of informed consent is mental capacity. Kong writes that '[a]t its core, the concept of mental capacity captures the simple intuition that we need to display a level of decision-making competence in order for our choices to be respected'.³⁵ Gunn describes it as the 'ability or skill' required 'to ensure the primacy of respect for a person's autonomy'.³⁶ In that sense, then, it is an all-or-nothing concept; one meets the threshold of decision-making capacity or not, meaning they are considered able to make their own decision or not. As such, whilst we might all be said to hold the *right* to informed consent, mental capacity is a prerequisite for one's (legal) *capability* in terms of realising this right. This works as a headline, but it is rather more nuanced in law (and, indeed, practice). It is no surprise, then, that there are examples of mental capacity determinations 'which any fair-minded observer would consider to be problematic'.³⁷

First, one must understand that decision-making capacity is specific to a particular decision at a particular time. This is apparent in the MCA 2005 in that it talks about 'a decision' and 'the decision' rather than 'decisions' plural. Further, the Code of Practice clearly states that '[a] person's capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made'.³⁸ The timing and complexity of decisions varies, so the capacity of an individual to make them can vary correspondingly. As such, a person is not simply deemed to lack decision-making capacity, only for this to remain a permanent characteristic of theirs. It is, of course, true that an individual may be in a situation whereby they lack decision-making capacity in relation to all decisions, and that such a situation continues for what is anticipated to be until their death. Take, for example, a patient in a coma who is not expected to recover – such a patient is unable to make even the most trivial of decisions. For the most part, however, this is not the case. An individual with some level of learning difficulty may have capacity to decide what they want for lunch but not whether they reside in supported living accommodation. An individual with fluctuating capacity may have capacity to make a decision

³⁵ Kong C. 2017. *Mental Capacity in Relationship: Decision-Making, Dialogue, and Autonomy*. Cambridge: Cambridge University Press, 1.

³⁶ Gunn M. 1994. The meaning of incapacity. *Medical Law Review* 2:8-29, 8.

³⁷ Ruck Keene A, Kane NB, Kim SYH, Owen GS. 2019. Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection. *International Journal of Law and Psychiatry* 62:56-76, 57.

³⁸ Department of Constitutional Affairs (n4) 40.

one day but lack capacity to make that same decision the following day. In short, generalisations cannot be made about an individual's decision-making capacity.

Relatedly, one of the MCA 2005's five principles is that '[a] person must be assumed to have capacity unless it is established that he lacks capacity'.³⁹ This means that certain patient characteristics that instinctively feel capacity related (a neurodegenerative disease, for example) cannot be taken as *necessarily* indicative of a lack of capacity. Similarly, a history of lacking decision-making capacity cannot be taken as demonstrative of a lack of capacity in a given situation. Whilst the MCA 2005 put this principle on the statute book, it had long been recognised at common law.⁴⁰

The importance of capacity as both time and decision specific is further apparent in the third principle. Principle 3 affirms the right of patients to make decisions that their doctor(s) may consider poor, by stating that '[a] person is not to be treated as unable to make a decision merely because he makes an unwise decision'.⁴¹ Under this principle, a doctor must not consider a patient to lack decision-making capacity on the basis that they disagree with the decision. Unless there is an alternative, valid reason to question the decision-making capacity of the patient, it is required of the doctor to allow a patient to make a decision that will, for example, result in their death.⁴² A patient's right to make "poor" decisions is considered so important that, when a patient does lack capacity and a Best Interests decision becomes necessary, 'the intention of the [Mental Capacity] Act is to allow a protected person as far as possible to make the same mistakes as all other human beings are at liberty to make and not infrequently do'.⁴³

In *Heart of England NHS Foundation Trust v JB*, Peter Jackson J emphasised the importance of the third principle: 'the temptation to base a judgement of a person's capacity upon whether they seem to have made a good or bad decision, and in particular upon whether they have accepted or rejected

³⁹ S.1 (2) Mental Capacity Act 2005. It is worth at this point noting the customary use of male pronouns in legislation and that this is not an exclusion of those to whom such pronouns do not apply from the remit of such legislation. For accuracy, I will continue with this custom in any direct quotations.

⁴⁰ Department of Constitutional Affairs (n4).

⁴¹ S.1 (4) Mental Capacity Act 2005.

⁴² This is famously true of Jehovah's Witnesses who choose to decline blood transfusions.

⁴³ *IM v LM, AB and Liverpool CC* [2014] EWCA Civ 37, at para 88, per Leveson J.

medical advice, is absolutely to be avoided. [...] Many who suffer from mental illness are well able to make decisions about their medical treatment, and it is important not to make unjustified assumptions to the contrary'.⁴⁴ That being said, the other extreme is equally undesirable; it would be problematic to be overcautious in never questioning the capacity of someone with a particular diagnosis because, ultimately, there will be many situations in which such individuals do lack capacity. The law, then, lays its hat somewhere in the middle. That the third principle includes the word 'merely' indicates that a decision considered unwise may be indicative of a lack of decision-making capacity. However, the principle requires of the assessor further information to reach a conclusion of incapacity – an unwise decision *alone* is insufficient.⁴⁵

Where it is considered that an individual *may* lack capacity to make a particular decision at the material time (which ought to be arrived at only upon consideration of the abovementioned principles), a capacity assessment is required. In England and Wales, the MCA 2005 imposes a two-limb test, incorporating a functional and diagnostic element. Whilst it logically comes second, I will explain the diagnostic test first as it is more straightforward and less controversial. Essentially, the diagnostic test stipulates that an individual is deemed to lack capacity if they fail the functional test *because of* 'an impairment of, or a disturbance in the function of, the mind or brain'.⁴⁶ If someone fails the functional test for some other reason – for example, they have impaired hearing and did not catch everything a healthcare professional was explaining – this is insufficient for a finding of incapacity. Indeed, this particular example highlights one of the MCA 2005's principles, that '[a] person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success'.⁴⁷ The individual with impaired hearing may be helped to satisfy the functional test by the provision of written information.

The functional test for capacity entails a procedural determination of capacity based on *how* the patient reaches their expressed decision – assuming, that is, that the patient expresses a decision, which

⁴⁴ *Heart of England NHS Foundation Trust v JB* [2014] EWCOP 342, at para 7.

⁴⁵ Herring (n26) 6.

⁴⁶ S.2 (1) Mental Capacity Act 2005.

⁴⁷ S.1 (3) Mental Capacity Act 2005.

will not always be the case (for example, where the patient is in a coma), hence step four below. It is stipulated that a person lacks decision-making capacity (in relation to the matter in question at the time in question) where they are unable to:

- (1) understand the information relevant to the decision,
- (2) retain that information,
- (3) use or weigh that information as part of the process of making the decision, or
- (4) communicate their decision (whether by talking, using sign language, or any other means).⁴⁸

In keeping with the apparent all-or-nothing nature of mental capacity, the person must only fall short on *one* of these four criteria to be deemed to lack the pertinent decision-making capacity. That being said, in line with MCA 2005's principles, the burden of proof is on whoever believes that the individual in question lacks capacity.⁴⁹ By and large, the MCA 2005's functional test for capacity aligns with the approach outlined by Appelbaum and Grisso, entailing four components: (1) understanding, (2) appreciation, (3) reasoning, and (4) communication of choice.⁵⁰ Appelbaum and Grisso's intention was to highlight points of commonality in legal standards of competence across jurisdictions, noting that such standards may not encompass all four,⁵¹ though it is immediately apparent that the MCA 2005 does encompass all four.

This idea of a functional test could be seen in *Re T* over a decade before the MCA 2005,⁵² wherein Lord Donaldson opined that a patient can make a choice for reasons that are 'rational, irrational,

⁴⁸ S.3 (1) Mental Capacity Act 2005.

⁴⁹ S.1 (2) Mental Capacity Act 2005.

⁵⁰ Appelbaum PS, Grisso T. 1988. Assessing patients' capacities to consent to treatment. *New England Journal of Medicine* 319(25):1635-1638, 1635-1636. Appelbaum and Grisso name these components slightly differently and place them in an alternate order, but I have tweaked things for a more linear understanding that can be better mapped onto the MCA 2005.

⁵¹ *Ibid*, 1635.

⁵² Gunn highlights what might be considered an earlier iteration in *Chatterton v Gerson* [1981] 1 All E.R. 257, wherein Bristow J employed a low level, "broad terms" approach to capacity. See Gunn (n36) 10.

unknown or even non-existent’,⁵³ and that such a choice ought to be respected regardless of any perceived perversity unless ‘there are other reasons for doubting his capacity to decide’.⁵⁴ This indicates a procedural understanding of capacity that was later more explicitly endorsed in *Re C*.⁵⁵ In *Re C*, Thorpe J outlined three stages to a patient’s decision in order for it to be capacitous:

‘(1) to take in and retain treatment information, (2) to believe it and (3) to weigh that information, balancing risks and needs’.⁵⁶

The way in which these three stages acted as precursors to the MCA 2005’s functional test is apparent. Only the final stage of the functional test – communicating the decision – is missing from Thorpe J’s explanation, but this can be taken as implied for it is essential to demonstrating the other three.

The choice of a functional test entailed the rejection of two notable alternatives: a status-based test and an outcome-based test. A status-based test assumes (in)capacity based on the patient’s diagnosis, thereby making blanket judgements, such as patients with dementia being unable to make their own healthcare decisions.⁵⁷ An outcome-based test deems decisions that are, in the assessor’s view, “bad” to be indicative of incapacity, imposing an “objective” (though ultimately subjective in that it is the assessor’s view that is determinative) conception of the good. Early in the inception of the MCA 2005, the Law Commission rejected both options as inconsistent with the underlying aims of the legislation.⁵⁸ Indeed, both are now quite clearly dismissed as inappropriate approaches in the MCA 2005 principles – as earlier noted, a person cannot be deemed to lack capacity unless all practicable

⁵³ *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, at para 102.

⁵⁴ *Ibid*, at para 113.

⁵⁵ *Re C (Adult: Refusal of Treatment)* [1994] 1 W.L.R. 290.

⁵⁶ *Ibid*, at page 292.

⁵⁷ See my discussion of *Heart of England NHS Foundation Trust v JB* above, in which Peter Jackson J highlights the rejection of this approach.

⁵⁸ The Law Commission. 1995. *Mental Incapacity: Item 9 of the Fourth programme of Law Reform: Mentally Incapacitated Adults*. London: Her Majesty’s Stationery Office, at paras 3.3 and 3.4. The underlying aim being ‘enabling and encouraging people to take for themselves any decision which they have capacity to take’ (para 3.3).

steps to help them have been taken without success⁵⁹ (a rejection of the status-based test), nor can incapacity be based on the person making an unwise decision⁶⁰ (a rejection of the outcome-based test). As such, the resulting functional test is, '[a]t least in theory [...] impartial towards the decision's content, values, or consequences'.⁶¹

Whilst there are clear shortcomings of the status-based and outcome-based tests, that is not to say that the settled on functional test is flawless. Kapp, for example, characterises the suggestion that professionals can draw 'neat, clean, dyadic' distinctions between capacity and incapacity as 'the law's naive presumption'.⁶² In practice, suggests Kapp, the determination of decisional capacity is a rather more 'complex and uncertain matter'.⁶³ The Committee on the Rights of Persons with Disabilities similarly contends that the functional test is flawed in how it 'presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right – the right to equal recognition before the law'.⁶⁴ What the Committee highlights to be required by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is that 'support be provided in the exercise of legal capacity'.⁶⁵ Of course, the MCA 2005's functional test does require that, where appropriate, an explanation is given to a patient in a way they can understand – i.e., 'using simple language, visual aids or any other means'.⁶⁶ Nonetheless, as Ruck Keene and colleagues rightly note, in responding to situations when an individual is unable to make their decisions, whether their legal capacity is respected on an equal basis will 'depend upon the nature

⁵⁹ S.1 (3) Mental Capacity Act 2005.

⁶⁰ S.1 (4) Mental Capacity Act 2005.

⁶¹ Kong (n35) 21.

⁶² Kapp MB. 2002. Decisional capacity in theory and practice: legal process versus 'bumbling through'. *Aging & Mental Health* 6(4):413-417, 414. Whilst Kapp is writing in the US context, it remains that a similar presumption exists in English law.

⁶³ *Ibid.*

⁶⁴ Committee on the Rights of Persons with Disabilities. 2014. *General comment No. 1 (2014): Article 12: Equal recognition before the law*. <https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en>, at para 15. The right to equal recognition before the law which the Committee refers to is that afforded to individuals by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, to which the UK has been a signatory since 2007. The Committee's critique is also grounded in its criticism of the failure of much mental capacity legislation to recognise that '[l]egal capacity and mental capacity are distinct concepts' (para 13).

⁶⁵ *Ibid.*, at para 15.

⁶⁶ S.3 (2) Mental Capacity Act 2005.

of that response’.⁶⁷ As such, it may be that paternalism too readily creeps in under the MCA 2005 in the way indicated by the Committee – this I will consider later in this thesis.

Beyond the procedural feasibility of a functional test of capacity, Knauer levies the ‘outside critique’ against it, claiming that it ‘rests on a falsely neutral standard’.⁶⁸ She posits that, in effect, a functional test may easily collapse into an outcome-based test, due to the difficulty of evaluating the individual’s decision-making process ‘without also considering the quality and social desirability of the decision ultimately reached’.⁶⁹ Where this happens, argues Knauer, historically marginalized groups may fall victim to inappropriate conclusions of incapacity for making choices that fail to conform with the court’s⁷⁰ ‘unstated value system’.⁷¹ It is certainly reasonable to note that *entirely* removing these subjective value judgements from capacity assessments is an impossibility. Nonetheless, some would suggest that, through education, progress can be made in this regard such that assessors are ‘aware of their own values’ and are careful ‘not to be prejudiced when meeting someone with a different value base’.⁷² Along these lines, Kong details so-called ‘hermeneutic competence’ which represents a shift in the focus of competency *away* from the individual with the cognitive impairment and *towards* those responsible for responding to them (inclusive of the medical professional making a Best Interests decision).⁷³ This incorporates ‘self-reflection, humility, and deliberative respect’ and ‘demands critical scrutiny of our own prejudices and assumptions’.⁷⁴ Whether awareness would lead to a lack of prejudice is questionable, for even conscious bias can prove influential at times. A review by the Equality and Human Rights Commission found that unconscious bias training can help in *reducing* implicit bias but

⁶⁷ Ruck Keene *et al.* (n37) 57. Kong and colleagues relatedly argue that the consideration of precedent in deliberation would ‘violate the base normative requirements of the MCA’s values-based approach’. Kong C, Coggon J, Dunn M, Cooper P. 2019. Judging values and participation in mental capacity law. *Laws* 8(1):3, 17.

⁶⁸ Knauer NJ. 2003. Defining capacity: balancing the competing interests of autonomy and need. *Temple Political & Civil Rights Law Review* 12:321-347, 347.

⁶⁹ *Ibid*, 343.

⁷⁰ Knauer is commenting on these matters within the courtroom, but a similar ‘unstated value system’ might be said to exist where a capacity assessment is conducted in a clinical environment.

⁷¹ Knauer (n68) 347.

⁷² Gunn (n36) 21.

⁷³ Kong (n35) 184. I will revisit Kong’s proposal in depth later in this thesis (*see* 6.2.2).

⁷⁴ *Ibid*, 197.

cannot eliminate it.⁷⁵ The strength of Gunn's defence, it seems, rests on the standard of impartiality considered – perhaps if the bar is set as “sufficient objectivity” rather than “total objectivity”, awareness will be adequate.

Finally, there is a question over whether this approach to capacity is inappropriately exclusionary. Kong and Ruck Keene suggest that the MCA 2005 focuses too much on the isolated individual when it comes to their ability to make decisions and problematically disregards the important interplay between the individual and their context.⁷⁶ This critique centres on the extreme focus of the MCA 2005's conception of decision-making capacity on the individual as an entirely independent decision maker. Kapp similarly comments that ‘[i]n real life, autonomy in making personal choices is often not exercised in the atomistic and sequential manner embodied in legal theory’.⁷⁷ An atomistic conception of autonomy, then, may be problematic, which has led such scholars to focus on a more relational account – something that will be explored further later in this thesis.

I will not explore these any further at this stage for I am merely highlighting that the functional test's suitability is not a matter of consensus. Indeed, that there are shortcomings with these three commonly recognised options demonstrates the challenge of having a fixed test for decision-making capacity. Perhaps, then, Roth and colleagues were correct in claiming that the ‘search for a single test of competency is a search for a Holy Grail’.⁷⁸

⁷⁵ Equality and Human Rights Commission. 2018. *Unconscious bias training: An assessment of the evidence for effectiveness*. Manchester: Equality and Human Rights Commission, 7. The report also notes that the evidence presents a mixed picture and that there is a need for further research.

⁷⁶ Kong C, Ruck Keene A. 2019. *Overcoming Challenges in the Mental Capacity Act 2005*. London: Jessica Kingsley.

⁷⁷ Kapp (n62) 414.

⁷⁸ Roth LH, Meisel A, Lidz CW. 1977. Tests of competency to consent to treatment. *American Journal of Psychiatry* 134(3):279-284, 283.

1.1.3 Best Interests⁷⁹

Where a patient is confirmed through capacity assessment as lacking capacity to make the decision concerned and there is no legally valid proxy decision maker in place,⁸⁰ a Best Interests decision must be made. All decisions made on behalf of a patient must be made in that patient's Best Interests, but "Best Interests decision" also functions as a noun when this point is reached – an important distinction when also considering the more general use of the language of best interests in medical practice.

Section 4 of the MCA 2005 details the requirements of parties involved in the making of Best Interests decisions. However, as earlier mentioned, a definition of Best Interests remains 'elusive'.⁸¹ In their post-legislative scrutiny of the Act, the House of Lords Select Committee on the MCA 2005 concluded that there was poor understanding across the board, including health and social care professionals.⁸² Evidence from the British Institute of Learning Disabilities suggested that 'all too often '[B]est [I]nterests' is interpreted in a medical/paternalistic sense that is wholly at odds with that set out in the Act'.⁸³ It is this lack of clarity that makes the realm of Best Interests decision making such a rich area of study. Nonetheless, some key features have emerged as central to the concept of Best Interests.

Whilst the MCA 2005 stipulates consideration of the patient's past and present wishes and feelings⁸⁴ and 'factors that he would be likely to consider if he were able to do so',⁸⁵ the Best Interests standard is widely understood to be intended as an objective test. Indeed, the MCA 2005 explicitly states that it is *not* substituted judgement but is 'an objective test as to what would be in the person's

⁷⁹ Here I will provide a somewhat light touch chronology of developments prior to the enactment of the MCA 2005, as is sufficient for my purposes. For a more detailed history, see Donnelly (n9).

⁸⁰ For example, a donee of a lasting power of attorney or court-appointed deputy where the decision is within the scope of their authority. Such proxy decision-makers, however, must still decide in the Best Interests of the patient. I am making this distinction in decision-makers – focussing on those who have not been formally appointed – as it is such instances which I am concerned with. I.e., where the care decision would automatically fall to the patient's doctor.

⁸¹ Donnelly (n9) 28. Despite confusion as to the precise meaning of Best Interests, the standard has become an export of the English legal system. Singapore all but replicated it just a few years later in its Mental Capacity Act 2008.

⁸² House of Lords Select Committee on the Mental Capacity Act 2005 (n10) 23.

⁸³ *Ibid*, 45

⁸⁴ S.4 (6) (a) Mental Capacity Act 2005.

⁸⁵ S.4 (6) (c) Mental Capacity Act 2005.

[B]est [I]nterests’.⁸⁶ This, note Ruck Keene and colleagues, makes it possible for a decision to be taken that ‘does not accord with the person’s known wishes and feelings’.⁸⁷ In *Re G (TJ)*, Morgan J stated that ‘it is absolutely clear that the ultimate test for the court is the test of [B]est [I]nterests and not the test of substituted judgment’.⁸⁸ He went on, however, to note that ‘the substituted judgment can be relevant and is not excluded from consideration’.⁸⁹ Years later, in the first case concerning the MCA 2005 to reach the Supreme Court, it was confirmed that the test requires the consideration of matters from the point of view of the patient:

‘decision-makers must [...] try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be’.⁹⁰

Whilst *Aintree* confirms that the wishes and feelings of the patient are to carry weight in Best Interests decisions, how much weight is a matter of contention. Kong and colleagues note that the patient’s values and preferences being taken to have some amount of normative status in Best Interests decisions needs more detail as a position; it could mean enacting the patient’s wishes regardless of content or merely facilitating the patient’s voice being heard.⁹¹ In *Briggs*, it was suggested that the patient’s wishes ought not to be considered determinative,⁹² as fits with the earlier reasoning in *Aintree*.⁹³

⁸⁶ Explanatory Notes to the Mental Capacity Act 2005, at para 28.

⁸⁷ Ruck Keene *et al.* (n37) 59.

⁸⁸ *Re G (TJ)* [2010] EWCOP 300, at para 55.

⁸⁹ *Ibid.*

⁹⁰ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, at para 39.

⁹¹ Kong *et al.* (n67) 4-5. Kong and colleagues are here talking about Best Interests decisions in a judicial rather than clinical context, but their comment on the clarity of the Best Interests concept is applicable in both. Indeed, if the courts are unclear, it is reasonable to assume that clinicians will similarly struggle. Taylor observes that ‘[c]linical decision makers may be ill-equipped to manage complexities in the law that even the courts appear to find challenging’. See Taylor (n9) 178.

⁹² *Briggs v Briggs & Ors* [2016] EWCOP 53, at para 55.

⁹³ Indeed, the earlier quoted passage from *Aintree* is immediately preceded by mention of several other factors that it is considered essential for the decision maker to consider. *Aintree* (n90) at para 39. Charles J, in *Briggs*, cites this very passage from *Aintree*. *Briggs* (n92) at para 55, per Charles J.

There is an interesting temporal distinction between the MCA 2005's functional test for capacity and its requirements of a Best Interests decision – and one which I will touch on later in this thesis. As earlier outlined, the functional test assesses capacity at the relevant time and in relation to the relevant decision, thereby protecting the patient's right to make a “bad” decision in the moment provided their reasoning meets certain procedural standards. Where the patient is deemed to lack capacity and a Best Interests decision is made, however, the MCA 2005 requires the decision maker to take a more historic view in considering the patient's past wishes and feelings. There is, then, an apparent disconnect – is there more value in a patient's current or past preferences?

These two approaches can be mapped onto what Coggon has framed as “current desire autonomy” and “best desire autonomy”.⁹⁴ Current desire autonomy is, as one might suspect, a focus on action decided based on an individual's immediate inclinations. Best desire autonomy is concerned with making decisions on the basis of the individual's ‘overall desire given his own values, even if this runs contrary to his immediate desire’.⁹⁵ The in-the-moment spirit of the functional test for capacity is, then, suggestive of current desire autonomy – which Huxtable deems the ‘least substantive’ of the three⁹⁶ – whereas deliberation inclusive of the patient's values and preferences indicates the pursuit of best desire autonomy. A third conception discussed by Coggon is “ideal desire autonomy”, which aligns with Kantian ideas of an objective autonomy – i.e., a decision is autonomous where it is universalizable.⁹⁷ This ideal desire autonomy, suggests Coggon, comes to the fore where there is no information as to what the patient would want, such as cases of permanent incapacity⁹⁸ - understandably, scenarios such as this necessitate some level of “objective good” to be endorsed, else a decision may never be reached.⁹⁹ As such, it may be that a Best Interests adjudication could embody either best desire

⁹⁴ Coggon J. 2007. Varied and principled understandings of autonomy in English law: justifiable inconsistency or blinkered moralism? *Health Care Analysis* 15:235-255, 240. Coggon details three conceptions of autonomy, which he acknowledges as having been earlier outlined in a different form by Lindley. See Lindley R. 1986. *Autonomy*. Basingstoke: MacMillan.

⁹⁵ Coggon (n94) 240.

⁹⁶ Huxtable R. 2014. Autonomy, best interests and the public interest: treatment, non-treatment and the values of medical law. *Medical Law Review* 22(4):459-493, 462.

⁹⁷ *Ibid*, 240-241.

⁹⁸ *Ibid*, 241-242.

⁹⁹ By no means do I intend here to brush aside the sheer complexity of establishing an objective good. As Coggon himself acknowledges, ‘choosing the ideals remains a controversial matter’. Coggon (n94) 244. Even in the

autonomy *or* ideal desire autonomy, depending on the availability of knowledge pertaining to the patient's own values and preferences. This ostensible lack of consistency is important to acknowledge at this early stage, though it is not necessarily problematic unless the result is inappropriate decisions (determined by some other standard). I will not dwell on this here but will revisit when pertinent in later discussion. For now, I simply wish to highlight what appears to be internal inconsistency in the MCA's conception of autonomy which raises the question of what it really means for a particular decision to be in a patient's Best Interests.

In accounting for the decision the patient would likely have made if able, the MCA 2005 requires that "consultees" are approached in a process of information gathering.¹⁰⁰ This generally includes close relatives and friends, though the inclusion of anyone 'interested in his welfare'¹⁰¹ broadens the scope to include, where appropriate, consulting with, for example, a faith leader. Where it is considered that there is no one appropriate to act as a consultee and the decision in question concerns serious medical treatment, an Independent Mental Capacity Advocate (IMCA) may be appointed for the patient.¹⁰² The purpose of consultees – or, where applicable, IMCAs – is to support and represent the patient in Best Interests decisions. In the case of consultees, this is predicated on a presumption that those with an interest in the patient's welfare will have a better understanding of what the patient's values and preferences are, thus assisting in determining the substituted judgement element of a Best Interests decision. Consultees and IMCAs, in theory, act to limit a "doctor knows best" approach.

Beyond the concept of Best Interests in law, there are important philosophical considerations. For example, DeGrazia comments on the importance of considering value theory in discussions of Best Interests.¹⁰³ He explores three key accounts of value theory – mental statism, desire accounts, and

context of life-saving treatment, the invocation of *in dubio pro vita* (if in doubt, favour life) may not always be appropriate. However, this is not the place for this discussion, and it will be had later in this thesis.

¹⁰⁰ S.4 (7) Mental Capacity Act 2005.

¹⁰¹ S.4 (7) (b) Mental Capacity Act 2005.

¹⁰² S.37 (1) Mental Capacity Act 2005. Per section 38 (1) of the MCA 2005, the same applies where the decision concerns arrangements about the patient's accommodation in a hospital or care home. See also Department of Constitutional Affairs (n4) 179.

¹⁰³ DeGrazia D. 1995. Value theory and the best interest standard. *Bioethics* 9(1):50-61.

objective list accounts¹⁰⁴ – highlighting the benefits and drawbacks of each. Mental statism and desire accounts can both be considered subjective accounts of prudential value¹⁰⁵ – the former considers the good as having a certain conscious mental state¹⁰⁶ whilst the latter views good as consisting of the satisfaction of one's desires or preferences.¹⁰⁷ They ultimately come down to the individual's perspective in some way. Objective list accounts, in contrast, see value in certain states of affairs 'regardless of whether one desires them and whether they are satisfying or enjoyable'¹⁰⁸ – these values are taken as objective. That being said, an objective list approach may be slightly misleading in its naming. DeGrazia notes how such lists may include more subjective items, such as autonomy, arguing that concessions to subjective theories are an important aspect of any contender.¹⁰⁹ Further, these concessions – alongside various revisions and adaptations of all three accounts – might be considered as somewhat blurring the classification; an objective list approach with 'significant concessions to subjectivism' may, in reality, reflect a desire account more than it would some other objective list accounts.¹¹⁰ Regardless of the shortcomings of the three approaches and any blurring of lines between them, Huxtable notes that elements of all three have reared their heads in case law.¹¹¹

Applying these approaches in practice may or may not be suitable depending on the scenario. Desire accounts, for example, may be challenging to implement where a patient has never possessed decision-making capacity and is extremely limited in their ability to communicate any preferences. One might map this onto Coggon's accounts of autonomy above – desire accounts might align with Coggon's best desire autonomy, whereby respect for the patient's overall values and preferences is prioritised even if contrary to immediate desires. Similarly, an objective list approach might map onto Coggon's ideal desire autonomy with its Kantian universalizability element – a more objective approach might be better suited to scenarios where the patient's values and preferences are not and cannot be

¹⁰⁴ These three accounts are largely similar to what Parfit explains as theories of self-interest. See Parfit D. 1987. *Reasons and Persons*. Oxford: Clarendon Press, 493.

¹⁰⁵ DeGrazia (n103) 55.

¹⁰⁶ *Ibid*, 52.

¹⁰⁷ *Ibid*, 54.

¹⁰⁸ *Ibid*, 55.

¹⁰⁹ *Ibid*.

¹¹⁰ *Ibid*, 60.

¹¹¹ Huxtable (n96).

known. That being said, an objective list approach inevitably entails a difficulty in deciding what ought to feature on the list, as, in discussing the example of a patient in a persistent vegetative state (PVS), DeGrazia comments that '[w]hat is striking here is how differently these objective list approaches might interpret a PVS patient's [B]est [I]nterests, without any of them being clearly unreasonable'.¹¹² In essence, this is a comment on the subjective manner in which people can apply objective criteria. Whilst it may be possible to have criteria that are objective to the point of being "fool proof", such criteria might equally be considered so rigid as to be problematic in some of the wide range of scenarios in which Best Interests decisions are made. Thus, whilst an objective approach might be favoured in principle for the purposes of consistency and fairness, it may actually be that pluralism is important in the context of Best Interests to account for the distinct particulars of each situation.¹¹³

Kopelman, in responding to criticisms of the Best Interests standard, holds that the standard does have a use in making reasonable, practical decisions in particular situations.¹¹⁴ She argues that many of these criticisms misfire as they conflate two distinct meanings of Best Interests: (1) an expression of moral/legal/medical/social ideals that one suggests should guide choices; and (2) a tool in making practical and reasonable decisions.¹¹⁵ This ties in with the earlier distinction I made between best interests in its general usage and Best Interests per the MCA 2005 – the former is a more general statement of what one views as the ideal "good", whereas the latter 'does not require what is ideal but what is reasonable'.¹¹⁶ Kopelman outlines three 'necessary and jointly sufficient' features of Best Interests (in its practical usage) that guide decision makers in selecting from options that 'reasonable persons of good will would consider acceptable in similar circumstances'.¹¹⁷ The decision maker(s) must use the best available information to assess the patient's immediate and long-term interests and prioritise the option that, in line with those interests, maximizes the benefits and minimizes the burdens;

¹¹² DeGrazia (n103) 60.

¹¹³ Perhaps something of a value "horses for courses" applies in Best Interests adjudications. Indeed, Gylling rightly argues that '[t]he complexity of our world and the diversity of our value systems make it clear that no single comprehensive interpretation of morality is realistically possible'. Gylling HA. 2004. Autonomy revisited. *Cambridge Quarterly of Healthcare Ethics* 13(1):41-46, 45.

¹¹⁴ Kopelman LM. 2007. The best interests standard for incompetent or incapacitated persons of all ages. *Journal of Law, Medicine & Ethics* 35(1):187-196.

¹¹⁵ *Ibid*, 187.

¹¹⁶ *Ibid*.

¹¹⁷ *Ibid*, 188.

decision makers need not reach the same decisions as to what is best, provided their decisions ‘meet a minimum threshold of acceptable care’; and choices must be compatible with moral and legal duties to patients who lack decision-making capacity.¹¹⁸ This approach might be considered to encapsulate elements of those outlined by DeGrazia – it includes objectivity in factoring in moral and legal duties and meeting what would have to be established as the minimum threshold of acceptable care, whilst permitting subjectivity in determining the patient’s own immediate and long-term interests. It also recognises, like DeGrazia, the value of pluralism here.

Which, if any, of these philosophical approaches to Best Interests is to be preferred in the context of dialysis decisions it is too soon to say. Indeed, it may transpire that none are desirable in their present forms. There is also the question of how they are and/or might be employed within the context of the MCA 2005, and whether a disconnect between any preferred approach and the MCA 2005 is indicative of a need for changes to the legal framework. At this point, I simply wish to highlight the complexity of Best Interests as a concept before compounding this complexity with the challenging reality of kidney failure care pathways.

1.2 Background to end-stage kidney disease

Chronic kidney disease (CKD) – whereby an individual’s kidneys lose some amount of function – affects a significant proportion of the world’s population. As of 2017, its global prevalence is estimated at 9.1%, representing 697.5 million patients and an increase of 29.3% since 1990.¹¹⁹ As such, it is no surprise that, according to the Global Burden of Disease Study, CKD rose from 27th in 1990 to 18th in 2010 in global death ranks – only HIV/AIDS saw a larger climbing in the ranking.¹²⁰ In England, a 2012

¹¹⁸ *Ibid*, 188-189.

¹¹⁹ GBD Chronic Kidney Disease Collaboration. 2020. Global, regional, and national burden of chronic kidney disease, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 395(10225):709-733.

¹²⁰ Lozano R, Naghavi M, Foreman K, Lim S, *et al.* 2012. Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 380(9859):2095-2128, 2113.

report noted that more than 1.8 million people in England had diagnosed CKD at the time, with a further 1 million expected to be undiagnosed.¹²¹ It further highlighted the financial costs of CKD, accounting for £1 in every £77 of NHS expenditure in the year 2009-10.¹²² CKD, then, does not represent a niche area of healthcare.

Patients with CKD face several medical risks: they may progress to ESKD;¹²³ they are more likely to suffer a temporary (further) reduction in their kidney function (known as an acute kidney injury; AKI);¹²⁴ they are at an increased risk of cardiovascular diseases;¹²⁵ and more.¹²⁶ My focus in this thesis is on those patients who have reached or are very nearly approaching the point of ESKD. A patient is considered to have progressed to ESKD when their estimated glomerular filtration rate (eGFR)¹²⁷ falls below 15ml/min/1.73m², representing a reduction in kidney function to c. <15%.¹²⁸ ESKD is also known as stage 5 CKD (of five stages), and it is at this point that the patient's condition has deteriorated to the point that the question of dialysis (and alternatives) is raised.¹²⁹ That being said,

¹²¹ NHS Kidney Care. 2012. *Chronic Kidney Disease in England: The Human and Financial Cost*. < <https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Chronic-Kidney-Disease-in-England-The-Human-and-Financial-Cost.pdf> >, 5.

¹²² *Ibid.*

¹²³ Those that progress to ESKD are the focus of this thesis. It is important to recognise that such patients are very much the minority, with only c. 2% of those with CKD progressing to kidney failure. See National Health Service. *Overview: chronic kidney disease*. < <https://www.nhs.uk/conditions/kidney-disease/> >.

¹²⁴ Hsu RK, Hsu C. 2016. The role of acute kidney injury in chronic kidney disease. *Seminars in Nephrology* 36(4):283-292. Whereas patients with CKD are at a heightened risk of an AKI, individuals who do not have CKD may also develop an AKI. AKIs can ordinarily be treated to restore the patient's previous renal function. However, AKIs are a risk factor for the development of CKD. See Chawla LS, Eggers PW, Star RA, Kimmel PL. 2014. Acute kidney injury and chronic kidney disease as interconnected syndromes. *New England Journal of Medicine* 371:58-66.

¹²⁵ Gansevoort RT, Correa-Rotter R, Hemmelgarn BR, Jafar TH, *et al.* 2013. Chronic kidney disease and cardiovascular risk: epidemiology, mechanisms, and prevention. *Lancet* 382(9889):339-352.

¹²⁶ National Kidney Foundation. 2002. K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification and stratification. *American Journal of Kidney Diseases* 39(2)(suppl 1):S1-S266.

¹²⁷ eGFR is the estimated rate at which a patient's kidneys are filtering the blood and removing waste products (such as creatinine). It is *estimated* because the test is not the most accurate measure of kidney function. Nonetheless, it is the commonly used test of kidney function and is often performed alongside a urine test that measures protein in the urine.

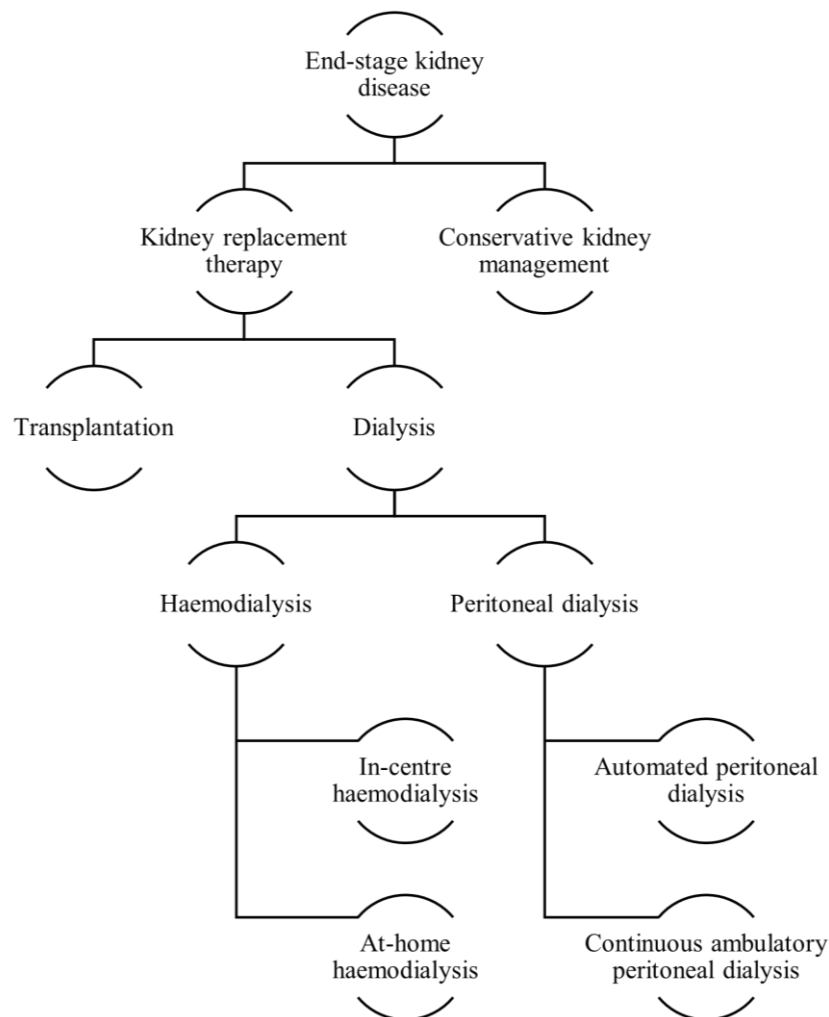
¹²⁸ Percentage is roughly estimated based on the number of millilitres in a patient's eGFR – 15ml/min/1.73² = 15%. Again, this is not entirely accurate and is used in part to explain things simply to patients.

¹²⁹ The care of patients in stages 1-4 largely consists of observation and controlling risk factors, though patients with Stage 4 CKD may begin planning for ESKD and thinking about care pathway options.

the patient's kidney function will ordinarily have dropped further by the time they commence dialysis – a mean eGFR of 7.2ml/min/1.73m² in 2020.¹³⁰

Several options exist for the care of patients with or approaching ESKD, which can be placed into three broad categories: transplantation, dialysis, and conservative management (*see Figure 1*). Both transplantation and dialysis are forms of kidney replacement therapy (KRT) but are importantly different so are considered separate broad classifications. Each of these three options will now be detailed.

Figure 1. End-stage kidney disease care pathways



¹³⁰ UK Renal Registry. 2022. *UK Renal Registry 24th Annual Report – data to 21/12/2020*. <https://ukkidney.org/sites/renal.org/files/publication/file-attachments/24th_UKRR_ANNUAL_REPORT_BOOK%20version%203_0.pdf>, chapter 2 page 6.

1.2.1 Transplantation

Whilst not a *cure*, the closest thing to a cure for ESKD is a kidney transplant. A successful transplant removes the need for regular, and often invasive, medical intervention to keep the patient alive. This can easily be considered preferable on several fronts; not only can it lessen (but not entirely remove) the burden of care on the patient (and, indeed, any family or friends caring for the patient¹³¹), but it is generally far more cost effective from the point of view of the NHS.¹³² For the most part, then, transplantation will be pursued where possible. However, as mentioned, a transplant is not a *cure*. At present, there is no actual cure for ESKD, and a kidney transplant represents a *temporary* solution. Myriad factors can affect the lifespan of a transplanted kidney – notably whether it came from a living or deceased donor, with living donor kidneys generally affording better graft and patient survival¹³³ – but it is commonly considered to be between 15 and 25 years.¹³⁴

Receipt of a transplanted kidney also does not mean a return to “normal” life for as long as the organ lasts. Transplant recipients ordinarily need to remain on immunosuppressant drugs to prevent their body rejecting the transplanted kidney. As a result of long-term use of immunosuppressants, the immune systems of transplant recipients are weakened such that they are more vulnerable to

¹³¹ Rasmussen SEVP, Eno A, Bowring MG, Lifshitz R, *et al.* 2020. Kidney dyads: caregiver burden and relationship strain among partners of dialysis and transplant patients. *Transplantation Direct* 6(7):e566.

¹³² In general, transplantation is cost effective relative to dialysis, but ‘health and economic benefits associated with transplantation are less prominent for patients with older age, comorbidities, and long wait times’. See Fu R, Sekercioglu N, Berta W, Coyte PC. 2020. Cost-effectiveness of deceased-donor renal transplant versus dialysis to treat end-stage renal disease: a systematic review. *Transplantation Direct* 6(2):e522, 9. Age, then, may be viewed as an important factor in these care decisions, as will be explored throughout this thesis. See also Yang F, Liao M, Wang P, Yang Z, Liu Y. 2021. The cost-effectiveness of kidney replacement therapy modalities: a systematic review of full economic evaluations. *Applied Health Economics and Health Policy* 19:163-180.

¹³³ Fuggle SV, Allen JE, Johnson RJ, Collett D, *et al.*, on behalf of the Kidney Advisory Group of NHS Blood and Transplant. 2010. Factors affecting graft and patient survival after live donor kidney transplantation in the UK. *Transplantation* 89(6):694-701.

¹³⁴ NHS Blood and Transplant. *Kidney transplant FAQs*. <<https://www.nhsbt.nhs.uk/organ-transplantation/kidney/is-a-kidney-transplant-right-for-you/kidney-transplant-faqs/>>.

infections.¹³⁵ Hence reports of increased rates of and severity of COVID-19 infection in kidney transplant recipients.¹³⁶

Lifestyle changes are also generally required in relation to diet and fitness. For example, following a restricted diet, stopping smoking, regular exercise (following recovery from surgery), and avoiding exceeding recommended alcohol limits.¹³⁷ In part, this is to help manage hypertension. Hypertension is a common comorbidity in patients with CKD, and cardiovascular disease is the leading cause of death in recipients of kidney transplants.¹³⁸ Lifestyle changes can reduce the likelihood of cardiovascular events in transplant recipients, though, at present, there is considered to be a need for further research into hypertension in such patients.¹³⁹

Whilst the focus of this thesis is on dialysis – and largely in situations where the patient is, for whatever reason, unable/unlikely to receive a transplant kidney in the near future – I highlight the nature of life post-transplant here simply to acknowledge that a transplant is not a cure, nor is it a temporary return to the patient's pre-ESKD life. It is understandable why it is the preferred option for those with or approaching kidney failure, but it is by no means a silver bullet. Further, it must be remembered that a transplant is not always an option, whether due to clinical viability or organ availability. There is a widely acknowledged shortage of organs for transplantation, both in the UK¹⁴⁰ and globally.¹⁴¹ Whilst a significant proportion of the KRT population in the UK will receive a kidney transplant – 57% as of end of year 2020¹⁴² – it remains that many die without one. NHS Blood and Transplant data show that

¹³⁵ Karuthu S, Blumberg EA. 2012. Common infections in kidney transplant recipients. *Clinical Journal of the American Society of Nephrology* 7(12):2058-2070.

¹³⁶ Elias M, Pievani D, Randoux C, Louis K, *et al.* 2020. COVID-19 infection in kidney transplant recipients: disease incidence and clinical outcomes. *Journal of the American Society of Nephrology* 31(10):2413-2423; Banerjee D, Popoola J, Shah S, Ster IC, Quan V, Phanish M. 2020. COVID-19 infection in kidney transplant recipients. *Kidney International* 97(6):1076-1082.

¹³⁷ National Health Service. *Living with: Kidney transplant*. <<https://www.nhs.uk/conditions/kidney-transplant/living-with/>>.

¹³⁸ Ying T, Shi B, Kelly PJ, Pilmore H, Clayton PA, Chadban SJ. 2020. Death after kidney transplantation: an analysis by era and time post-transplant. *Journal of the American Society of Nephrology* 21(12):2887-2899.

¹³⁹ Loutradis C, Sarafidis P, Marinaki S, Berry M, *et al.* 2021. Role of hypertension in kidney transplant recipients. *Journal of Human Hypertension* 35:958-969.

¹⁴⁰ NHS Blood and Transplant. 2022. *Organ and Tissue Donation and Transplantation Activity Report 2021/22*. <<https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/27108/activity-report-2021-2022.pdf>>.

¹⁴¹ Global Observatory on Donation and Transplantation. 2022. *Global Report on Organ Donation and Transplantation 2020: Activity and legislative & organizational issues*. <<https://www.transplant-observatory.org/wp-content/uploads/2022/07/2020-Global-report-para-web.pdf>>.

¹⁴² UK Renal Registry (n130) 82.

adult patients wait on average 550 days for a kidney transplant, ranging from a median of 161 to 790 days depending on the patient's blood group.¹⁴³ There is also significant variation based on patient ethnicity, ranging from a median of 573 days for White patients to 736 for Asian and 900 for Black.¹⁴⁴ As such, even if the patient is to be added to the transplant waiting list, it is likely that there will be a need for an alternative in the interim. Where transplantation is, for whatever reason, not an immediate option, maintenance (or chronic) dialysis¹⁴⁵ is the other choice of KRT.

Whilst transplantation is a valid treatment option for those with cognitive impairments – by which I mean it is not an absolute contraindication – my focus hereafter is on dialysis. This is because Best Interests decisions about dialysis are more challenging due to the harm-benefit considerations involved. Where a suitable kidney is available to be transplanted into a patient, it is most likely going to be deemed in their Best Interests to proceed.¹⁴⁶ Even with the potential challenges with post-transplant care for someone with certain cognitive impairments, the benefits of transplantation clearly outweigh the harms. With dialysis, however, this is less clear. The harms of dialysis can be significant and repeated even if it is preserving someone's life, and where there is cognitive impairment some such harms may be exacerbated (for example, adherence to regular dialysis sessions where the patient may get distressed, not entirely understanding what is happening). There is also the fact that Best Interests decisions concerning dialysis affect more people than do decisions about transplantation. Even those who receive a transplant may require a period on dialysis whilst on the transplant waiting list. As such,

¹⁴³ NHS Blood and Transplant (n140) 38. The median waiting time in this latest annual report is lower than the previous year, though still represents a significant amount of time. Given the long waits for kidney transplants, pre-emptive transplant – meaning prior to the patient's kidney function deteriorating to the point that dialysis is required – is often not possible. This is despite pre-emptive kidney transplantation being preferable due to improved patient and graft survival rates. See Abramowicz D, Hazzan M, Maggiore U, Peruzzi L, *et al.*, for the Descartes Working Group and the European Renal Best Practice (ERBP) Advisory Board. 2015. Does pre-emptive transplantation versus post start of dialysis transplantation with a kidney from a living donor improve outcomes after transplantation? A systematic literature review and position statement by the Descartes Working Group and ERBP. *Nephrology Dialysis Transplantation* 31(5):691-697.

¹⁴⁴ NHS Blood and Transplant (n140) 39.

¹⁴⁵ Maintenance dialysis refers specifically to dialysis provided long term for those with ESKD. Dialysis may also be provided for patients with AKIs, in which case it is referred to as acute dialysis. Hereafter, any mention of dialysis should be taken as referring to maintenance dialysis unless otherwise specified.

¹⁴⁶ That is not to suggest that Best Interests decisions about transplantation are not challenging, as there are myriad factors at play.

I will set aside transplantation at this juncture to focus on the question of Best Interests decisions concerning dialysis.

1.2.2 Dialysis

Dialysis is, in effect, an artificial kidney (as opposed to a replacement real kidney through transplantation). It replicates some of the functions of the kidneys by “cleaning” the patient’s blood – i.e., removing toxins and excess fluid. In doing so, dialysis helps to keep a patient’s eGFR high enough – though waste clearance does remain low in patients and dialysis does not replicate a fully functioning native kidney. There are three key types of dialysis that a patient might have: (1) in-centre HD; (2) at-home HD; and (3) peritoneal dialysis (PD).

In-centre HD and at-home HD are the same procedure but, unsurprisingly, differ in the location of treatment. HD requires access to the bloodstream to be established so that the patient’s blood can be removed from the body, filtered, and then returned to the body. Access is ordinarily created by arteriovenous fistula (joining of a vein and an artery), arteriovenous graft (joining of a vein and an artery using a small artificial tube), or central venous catheter (two tubes – one in, one out – inserted into a large vein). During a HD session, the access is used so that the patient’s blood can be pumped through a dialysis machine to remove waste and excess water. Whilst schedules can, for numerous reasons, vary, it is most common for a patient undergoing HD to have three sessions per week, each lasting for roughly four hours.¹⁴⁷ As such, patients having in-centre HD must regularly attend a dialysis unit.¹⁴⁸

The alternative to HD – PD – is an at-home option. PD works on the same basic principle, though uses the peritoneum to filter the patient’s blood rather than an artificial alternative as in HD. In

¹⁴⁷ During the COVID-19 pandemic, some centres examined the feasibility of reducing HD frequency. Lodge and colleagues, for example, temporarily moved some patients to twice weekly HD, finding that it was suitable option for select patients. Lodge MDS, Abeygunaratne T, Alderson H, Ali I, *et al.* 2020. Safely reducing haemodialysis frequency during the COVID-19 pandemic. *BMC Nephrology* 21:532.

¹⁴⁸ Those having HD at home still have regular clinic appointments, but they will be less frequent. They may even be reduced further by use of telemedicine where an appointment is to discuss the patient’s care rather than to carry out any tests that would necessitate in-person attendance.

using part of the patient's own body as a filter, PD takes place continuously rather than at scheduled times – this means levels of toxins and excess fluid remain more stable than with HD. For PD to take place, the peritoneal cavity is filled with dialysate (dialysis fluid) using a catheter. The waste products, which would otherwise have passed into the urine, collect in the fluid, which is then drained and disposed of during a dialysate exchange.

There are different types of PD, which alter the way that dialysate exchanges take place and, relatedly, how frequently they take place. Continuous ambulatory PD requires manual dialysate exchanges. Using this method, the patient fills the peritoneal cavity with dialysate, draining it after 4-8 hours. These manual exchanges take place several times a day, but are simple to do and the patient is able to continue with various stationary activities (such as reading or watching television) whilst carrying it out. The alternative method – automated PD – sees dialysate exchanges done by machine. This is ordinarily performed for around eight to 12 hours overnight, with no further exchanges then required throughout the day. Automated PD is often preferred due to the lifestyle benefits it affords patients, not having to carry out exchanges throughout the day. However, it is not an option for all patients, for various reasons including patient size and the nature of their peritoneal membrane. Unlike in-centre HD, PD requires an initial period of training for patients.¹⁴⁹ Regular consultations will also be required to monitor certain blood parameters as indicators of dialysis clearance, so whilst PD does reduce clinic attendance, it does not entirely remove it.

In-centre HD is overwhelmingly the most common dialysis modality in the UK, accounting for 71.6% of new incident patients in 2020 compared with 0.4% for at-home HD and 22.1% for PD.¹⁵⁰ Part of the reason for in-centre HD being more common than at-home HD is that the former is more straightforward – it does not require the patient to be assessed for suitability and for the patient and a

¹⁴⁹ Ensuring patient competency in PD raises challenges in itself, including on the side of healthcare professionals and their role in providing education. See Mehrotra R. 2018. Peritoneal dialysis education: challenges and innovation. *Seminars in Dialysis* 21(2):107-110.

¹⁵⁰ UK Renal Registry (n130) 15. 5.9% of patients have transplant as their reported modality, hence the dialysis figures not totalling 100%. This contrasts to 8.4% in 2019. The drop is likely attributable – at least in part – to the COVID-19 pandemic.

carer (usually a relative) to be trained to carry out the process. Patients sometimes switch to other dialysis modalities (or receive transplants) after initiation, but HD remains most common.¹⁵¹

Other modalities are more commonly used in other countries. For example, in stark contrast with the UK, PD is by far the most common modality in Hong Kong, with a PD:HD ratio of 76.2:23.8 in 2013.¹⁵² The frequency with which different dialysis modalities are chosen can be affected by various factors – a change to Medicare payment reform in the US resulted in increased use of PD (the cheaper option).¹⁵³

1.2.3 Conservative kidney management

KRT is not an appropriate option for all patients. Where a transplant is neither feasible nor likely, and dialysis is deemed too burdensome (either by the patient themselves or on their behalf), conservative kidney management (CKM)¹⁵⁴ is the alternative. In essence, CKM is the same package of care minus dialysis itself – ‘planned holistic patient-centered care [that] does not include dialysis’.¹⁵⁵ A patient receiving CKM will still attend regular consultations, they might stick to a renal diet, and there will usually be interventions to delay the progression of kidney disease and minimise adverse events.¹⁵⁶

CKM is sometimes thought of as “giving up” and simply readying the patient for death. It is true that CKM is not an option with a significant survival benefit, and patients on a CKM pathway will

¹⁵¹ *Ibid.*, 16.

¹⁵² Leung CB, Cheung WL, Li PKT. 2015. Renal registry in Hong Kong – the first 20 years. *Kidney International Supplements* 5(1):33-38, 34. This is largely attributable to Hong Kong’s “peritoneal dialysis first” policy, established in 1985. See Yu AW-Y, Chau K-F, Ho Y-W, Li PK-T. 2007. Development of the “peritoneal dialysis first” model in Hong Kong. *Peritoneal Dialysis International* 27(2 suppl):53-55.

¹⁵³ Sloan CE, Coffman CJ, Sanders LL, Maciejewski ML, *et al.* 2019. Trends in peritoneal dialysis use in the United States after Medicare payment reform. *Clinical Journal of the American Society of Nephrology* 14(12):1763-1772.

¹⁵⁴ There is variation in terminology used to describe such care. For example, it is sometimes referred to as conservative care. See Okamoto I, Tonkin-Crine S, Rayner H, Murtagh FEM, *et al.* 2015. Conservative care for ESRD in the United Kingdom: a national survey. *Clinical Journal of the American Society of Nephrology* 10(1):120-126.

¹⁵⁵ Davison SN, Levin A, Moss AH, Jha V, *et al.* 2015. Executive summary of the KDIGO controversies conference on supportive care in chronic kidney disease: developing a roadmap to improving quality care. *Kidney International* 88(3):447-459, 453.

¹⁵⁶ *Ibid.*

ordinarily engage in end-of-life planning.¹⁵⁷ As such, the characterisation of “giving up”, whilst still problematic, might seem appropriate with some patients. For others, however, CKM may provide a similar life expectancy to dialysis. In elderly patients with several comorbidities, dialysis may only be expected to provide a few years of life, and non-dialytic care may provide similar survival. Even if dialysis is expected to provide such a patient a small survival benefit relative to CKM, it may be that the patient would prioritise quality of life in their final years by avoiding regular hospital visits and the rigours of dialysis. However, there is limited evidence as to the precise differences in the person-centred outcomes that matter to patients, such as quality of life and symptom burden. Indeed, a current study is comparing care pathways in preparation for dialysis and CKM to enable more informed choices between the two for patients with decision-making capacity¹⁵⁸ – though such findings will prove equally useful in Best Interests determinations.

It is also important to note that CKM remains a choice even for patients who have the option of dialysis. The literature suggests that CKM may not always seem to be a choice for patients, with dialysis sometimes presented as the only real option.¹⁵⁹ Ideally, all options would be presented on an equal footing to patients, enabling a choice based on each patient’s preferences. Nonetheless, even where there is a biased presentation of options, CKM is a legitimate choice for any patient with or approaching kidney failure.

There are, then, several care options for patients with or approaching kidney failure. Whilst certain options may appear the obvious choice for certain patient groups, such generalisations can be

¹⁵⁷ Davison SN, Tupala B, Wasylynyuk BA, Siu V, Sinnarajah A, Triscott J. 2019. Recommendations for the care of patients receiving conservative kidney management. *Clinical Journal of the American Society of Nephrology* 14(4):626-634.

¹⁵⁸ Murphy E, Burns A, Murtagh FEM, Rooshenas L, Caskey FJ. 2020. The Prepare for Kidney Care Study: prepare for renal dialysis versus responsive management in advanced chronic kidney disease. *Nephrology Dialysis Transplantation* 36(6):975-982. This study might also contribute to overcoming the recognised global variation in CKM provision in terms of availability, accessibility, and quality. See Lunney M, Bello AK, Levin A, Tam-Tham H, *et al.* 2021. Availability, accessibility, and quality of conservative kidney management worldwide. *Clinical Journal of the American Society of Nephrology* 16(1):79-87.

¹⁵⁹ Noble H, Meyer J, Bridges J, Kelly D, Johnson B. 2009. Reasons renal patients give for deciding not to dialyze: a prospective qualitative interview study. *Dialysis and Transplantation* 38(3):82-89[1-5].

problematic. Also problematic are biases among nephrologists as to preferred care options.¹⁶⁰ The differences between the options may or may not align with a particular patient's own values and preferences, and, in keeping with the nature of informed consent per *Montgomery*, it is for the doctor to present all reasonable alternatives rather than that which they consider most appropriate for the patient. Similarly, where the patient lacks decision-making capacity, all reasonable alternatives must be appropriately considered in making a Best Interests decision.

1.3 Situating the study

Having provided a background to the two key elements which are combined in this thesis, I will bring them together to demonstrate the importance of this research. To do so, I will look to two key considerations. First, existing research into reasons why patients decide to forego dialysis when they have the requisite decision-making capacity. Second, characteristics of the ESKD population – particularly in terms of the prevalence of cognitive impairment.

First, though, it is worth noting the relevance of the history of dialysis provision in England and Wales (and, indeed, beyond). During the infancy of dialysis in the 1960s, its availability was limited. As such, resource allocation and patient suitability questions that are largely unnecessary today governed who would receive treatment. The minority who did receive dialysis had ‘kidney disease in a fairly pure form, uncomplicated by other afflictions. They are both physically strong and emotionally mature enough to endure the treatment’.¹⁶¹ A now well-known committee in Seattle's Swedish Hospital, made up of members of the public, was responsible for choosing between candidates. However, doctors would first screen prospective patients and not even present to the committee those deemed ‘medically

¹⁶⁰ Jha V, Martin DE, Bargman JM, Davies S, *et al.* 2017. Ethical issues in dialysis therapy. *Lancet* 389(10081):1851-1856, 1852. In some contexts, there may even be financial incentives for nephrologists to make certain decisions, though this is not a notable issue in the UK.

¹⁶¹ Alexander S. 1962. *They decide who lives, who dies.* <https://books.google.ch/books?id=qUoEAAAAMBAJ&lpg=PA1&dq=life+magazine+nov+1962&pg=PA101&redir_esc=y#v=onepage&q&f=false>, 104.

or psychiatrically unsuitable'.¹⁶² In the early days of dialysis, then, the patient population I am concerned with in this thesis would have been almost entirely deemed ineligible. Their cognitive impairment, in addition to other common comorbidities, would have been sufficient to exclude them from a dialysis programme. Therefore, Best Interests decisions – initially as formulated at common law, then the MCA 2005 – would not have been made in this setting. This is an issue that has developed more recently and will continue to grow as the proportion of the CKD population with later-stage CKD is predicted to increase.¹⁶³

1.3.1 Decisions to forego dialysis

Patients *with* decision-making capacity in relation to dialysis frequently choose to forego the treatment in favour of CKM. Whilst for some this may be perceived as the equivalent to choosing death, the significant burden of dialysis makes the decision to opt for CKM not entirely surprising. Indeed, a 2016 piece in *Le Monde* was entitled 'dialysis is a prison'.¹⁶⁴ Those who decide against initiating dialysis do so for myriad reasons, though there are some common themes that have been found to arise in qualitative research.

Noble and colleagues,¹⁶⁵ through interviewing capacitous patients who had made the decision to forego dialysis, noted several commonly provided reasons. As might be expected, the arduous nature of dialysis featured. One participant talked about the 'wear and tear' and how that was not, for him, worth it. Similarly, several participants noted the difficulties they would face in getting to the hospital three times a week for dialysis, especially given the mobility issues of some. Interestingly, some

¹⁶² *Ibid*, 106.

¹⁶³ Kidney Research UK. 2023. *Kidney disease: a UK public health emergency. The health economics of kidney disease to 2033*. < https://www.kidneyresearchuk.org/wp-content/uploads/2023/06/Economics-of-Kidney-Disease-full-report_accessible.pdf>, 16.

¹⁶⁴ Pre-translation: 'La dialyse est une prison'. *Le Monde*. 2016. *La dialyse est une prison: allégeons les peines!* < https://www.lemonde.fr/sciences/article/2016/05/16/la-dialyse-est-une-prison-allegeons-les-peines_4920416_1650684.html>. This piece comments on an article published shortly before in *The Lancet* which detailed how dialysis can contribute to poor quality of life. _____. 2016. Live and let dialyse. *Lancet* 387(10032):1969.

¹⁶⁵ Noble *et al.* (n159).

participants mentioned their having witnessed family undergo dialysis. One talked of seeing others suffer through the therapy and concluded that ‘dead better [*sic*]’.¹⁶⁶ The final theme discussed by Noble and colleagues is age; some older patients felt that the strain of dialysis was something to avoid in their later years as the benefit was limited.¹⁶⁷

A further theme which comes out of this paper – though the authors do not address it – is a want not to be a burden to loved ones. One participant with osteoarthritis said of her 70-year-old brother: ‘I can’t ask him to bring me up here every day and then come and get me. I wouldn’t...it’s not fair’.¹⁶⁸ This is especially interesting for the subject matter of this thesis because a Best Interests decision is supposed to consider what is best for the patient, not the patient’s family. However, it might be that, where they are in the position to make their own care decisions, patients with ESKD *do* consider the impact their undergoing dialysis might have on those around them. *If* a Best Interests decision is intended to best enable the patient’s autonomy – which I am not necessarily endorsing at this point – then we might question whether impact on family and friends ought to be factored in. This is something I will return to later in this thesis.

Other studies with similar aims corroborate these findings.¹⁶⁹ Again, the burden of travel to attend dialysis sessions, old age and the inevitability of death (participant age range of 74 to 96), and not wanting to burden or nuisance their family were key themes arising.¹⁷⁰ One participant in a study by Johnston and Noble, much like in that of Noble and colleagues discussed above, reflected on how his decision to forego dialysis had been influenced by witnessing a family member’s ‘traumatic’ experience on dialysis.¹⁷¹ Others talked about a reluctance to become dependent on medical treatment in terms of loss of autonomy.¹⁷²

¹⁶⁶ *Ibid.*, 3.

¹⁶⁷ Whilst not specified in the paper, it is fair to assume that what was meant by this was, at least in part, limited scope for dialysis to extend life.

¹⁶⁸ Noble *et al.* (n159) 3.

¹⁶⁹ Johnston S, Noble H. 2012. Factors influencing patients with stage 5 chronic kidney disease to opt for conservative management: a practitioner research study. *Journal of Clinical Nursing* 21(9-10):1215-1222; Visser A, Dijkstra GJ, Kuiper D, de Jong PE, *et al.* 2009. Accepting or declining dialysis: considerations taken into account by elderly patients with end-stage renal disease. *Journal of Nephrology* 22(6):794-799.

¹⁷⁰ *Ibid.*

¹⁷¹ Johnston and Noble (n169) 1219.

¹⁷² Visser *et al.* (n169) 797.

The right to refuse medical treatment is, as earlier noted, confirmed in case law. Refusal of dialysis specifically has been upheld in England and Wales in cases where a patient did not want to sacrifice her “sparkly” lifestyle¹⁷³ and where a patient with dementia was distressed at the time of *some* scheduled dialysis sessions (thereby allowing the underdialysis of that patient at her will).¹⁷⁴ Similarly, in the US case of *Myers*,¹⁷⁵ a prisoner was permitted to refuse dialysis in protest of his placement in a prison of a higher security level than he felt appropriate – this right is, then, not exclusive to English law. Some of these cases will be revisited, but for now they highlight the legally recognised right to refuse dialysis discussed earlier in this chapter and some of the reasons courts have, provided the standard of mental capacity is satisfied, permitted.

Given this right to refuse dialysis and the various reasons for doing so given by those who have, it must be recognised that some patients who lack the decision-making capacity to refuse dialysis would likely choose to do so if they could. If one were to endorse either current desire autonomy or best desire autonomy, then, it must be that, sometimes, dialysis is deemed *not* to be in the Best Interests of patients with ESKD who lack decision-making capacity.¹⁷⁶ Per ideal desire autonomy, however, there remains room for debate on how these reasons for refusal might affect a Best Interests decision.

1.3.2 The ESKD population

In the UK, as in much of the world, the ESKD population largely comprises elderly patients. New incident KRT patients in 2020 had a median age of 63.7, with 47.1% of patients aged 65+.¹⁷⁷ Of note, there is variation along the lines of ethnicity; the median age was higher for White (65.9) patients and lower for South Asian (61.2) and Black (56.2) patients.¹⁷⁸ Relatedly, there is a greater burden of ESKD

¹⁷³ *Kings College Hospital NHS Foundation Trust v C & Anor* [2015] EWCOP 80.

¹⁷⁴ *Re P (Urgent Medical Treatment)* [2020] 2 WLUK 194.

¹⁷⁵ *Commissioner of Correction v. Myers* 399 N.E.2d 452 (Mass. 1979).

¹⁷⁶ Parsons JA. 2021. ‘Death or dialysis: the value of burdensome life-extending treatments for the cognitively impaired’. In Schildmann J, Buch C, Zerth J (eds). *Defining the Value of Medical Interventions: Normative and Empirical Challenges*. Stuttgart: Kohlhammer.

¹⁷⁷ UK Renal Registry (n130) 12.

¹⁷⁸ *Ibid.*

on non-White ethnicities. Of 2018 new incident KRT patients in the UK, 75.1% were White, 12.8% South Asian, and 7.6% Black.¹⁷⁹ This contrasts with ethnic diversity in the general population – per the 2021 census,¹⁸⁰ 81.7% of the population of England and Wales is White, 9.3% is Asian, and 4% is Black.¹⁸¹

Given that patients with or approaching kidney failure are often aged 65 years or older, comorbidities are common. In a study of patients with stage 3 CKD (i.e., not yet at the point where KRT is to be considered) with a mean age of 72.9 ± 9 , just 4% had no comorbidities.¹⁸² A far more significant proportion – 40% – had more than two comorbidities.¹⁸³ Common among these comorbidities were hypertension (87.8% prevalence), painful condition (30.4% prevalence) and anaemia (24% prevalence).¹⁸⁴ Isolated CKD, then, is uncommon, which inevitably factors into treatment decisions, be they made by the patient themselves or by another on the patient's behalf.

There is also a high prevalence of cognitive impairment in the dialysis population, and more broadly in the ESKD population.¹⁸⁵ One study of HD patients aged 55 years and older found that only 12.7% had normal cognition, with a significant 37.3% having severe impairment.¹⁸⁶ Similarly in patients receiving PD, one study found 31.4% to have severe cognitive impairment, compared with just 12.9% in the study's non-CKD cohort.¹⁸⁷ This is, at least in part, attributable to the age of many patients in the ESKD population; such a significant proportion being more than 65 years old makes for an

¹⁷⁹ *Ibid.*

¹⁸⁰ This is not a perfect comparison as the census data are for England and Wales whilst the renal registry data are for the whole of the UK. Nonetheless, it is accurate enough to illustrate the point.

¹⁸¹ Office for National Statistics. 2022. *Ethnic group, England and Wales: Census 2021*. <<https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/bulletins/ethnicgroupenglandandwales/census2021>>, 3. The balance of ethnicities in England and Wales is changing over time, with a decrease in those identifying as White.

¹⁸² Fraser SDS, Roderick PJ, May CR, McIntyre N, *et al.* 2015. The burden of comorbidity in people with chronic kidney disease stage 3: a cohort study. *BMC Nephrology* 16:193, 3.

¹⁸³ *Ibid.*

¹⁸⁴ *Ibid.*, 6.

¹⁸⁵ Pereira AA, Weiner DE, Scott T, Sarnak MJ. 2005. Cognitive function in dialysis patients. *American Journal of Kidney Diseases* 45(3):448-462; Murray AM. 2008. Cognitive impairment in the aging dialysis and chronic kidney disease populations: an occult burden. *Advances in Chronic Kidney Disease* 15(2):123-132.

¹⁸⁶ Murray AM, Tupper DE, Knopman DS, Gilbertson DT, *et al.* 2006. Cognitive impairment in hemodialysis patients is common. *Neurology* 67(2):216-223.

¹⁸⁷ Kalirao P, Pederson S, Foley RN, Kolste A, *et al.* 2011. Cognitive impairment in peritoneal dialysis patients. *American Journal of Kidney Diseases* 57(4):612-620.

increased prevalence of neurodegenerative diseases such as dementia.¹⁸⁸ It may also be contributed to by the patient's poor kidney function, with research indicating CKD as a risk factor for cognitive decline.¹⁸⁹

Not only does the prevalence of cognitive impairment create challenges in treatment decision making, but it has been found to be an independent predictor of mortality in dialysis patients.¹⁹⁰ Griva and colleagues found this to be the case after a 7-year observation period of patients on dialysis (a mixture of in-centre HD, at-home HD, and PD) even adjusting for demographic, medical, and psychological factors.¹⁹¹ Tonelli and colleagues found discordant comorbidities (inclusive of dementia) and mental health conditions were, in addition to concordant comorbidities (such as diabetes and hypertension), associated with adverse outcomes in patients with CKD.¹⁹² This creates a situation whereby a patient's cognitive impairment necessitates a challenging Best Interests decision, which is further complicated by the independent impact that cognitive impairment could have on the patient's condition – even if one favoured an approach of applying known reasoning of patients with decision-making capacity to Best Interests decisions, this cannot be neatly done when such reasoning necessarily excludes this additional factor that affects both quality and quantity of life.

1.4 Summary

The purpose of this chapter was to justify the need for this research, at least in a preliminary manner to be further demonstrated by my literature review. This need rests on the fact that the Best Interests

¹⁸⁸ Dementia prevalence increases with age. See Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. 2013. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia* 9(1):63-75.

¹⁸⁹ Etgen T. 2015. Kidney disease as a determinant of cognitive decline and dementia. *Alzheimer's Research and Therapy* 7:29; Sasaki Y, Marioni R, Kasai M, Ishii H, Yamaguchi S, Meguro K. 2011. Chronic kidney disease: a risk factor for dementia onset: a population-based study. The Osaki-Tajiri project. *Journal of the American Geriatrics Society* 59(7):1175-1181.

¹⁹⁰ Griva K, Stygall J, Hankins M, Davenport A, Harrison M, Newman SP. 2010. Cognitive impairment and 7-year mortality in dialysis patients. *American Journal of Kidney Diseases* 56(4):693-703.

¹⁹¹ *Ibid*, 699.

¹⁹² Tonelli M, Wiebe N, Guthrie B, James MT, *et al.* 2015. Comorbidity as a driver of adverse outcomes in people with chronic kidney disease. *Kidney International* 88(4):859-866.

standard itself lacks clarity and that, in the context of kidney care, these decisions are especially challenging and high stakes.

Decisions concerning maintenance dialysis for patients with or approaching kidney failure can be considered somewhat unique. Initiating dialysis is to start a regular, invasive intervention that will generally continue for the remainder of the patient's life, ordinarily requiring a significant alternation to that patient's lifestyle and routine. Even other long-term treatment decisions, such as ventilatory support in the intensive care setting, can be distinguished from dialysis. Whereas the decision for a patient to remain on life support may be regularly revisited, the continuation of treatment becomes passive after initiation – withdrawing treatment that would require the care team to “do something”. With dialysis, the treatment is similarly long term, but requires regular active decisions. Whilst a full Best Interests meeting will not be called regarding each session of dialysis, the decision on each day to begin that session (for example, in connecting the patient to the dialysis machine) is still being made,¹⁹³ potentially in the face of a reluctant patient, to actively treat in the patient's Best Interests. It is the nature of dialysis as *very* long-term, consistently stopping and starting for that very long period, highly invasive, and potentially hugely burdensome that makes its initiation and continuation especially challenging decisions even for patients who can provide informed consent. Where the patient lacks decision-making capacity, ensuring the “right” decisions is made on their behalf adds a layer of complexity to the challenge.

1.5 Thesis roadmap

Chapter 2: Methodology explains and justifies the methodology I have chosen for this project. It demonstrates how the different elements of this thesis will be brought together in Chapter 6.

¹⁹³ Whether this is viewed as an active decision by those involved is another matter.

Chapter 3: Literature Review is the beginning of this inquiry. It provides details of the approach used for a scoping review of both the empirical and normative literature concerning the research question and, in doing so, further highlights the importance of this project.

Chapter 4: Empirical Methods details the approach taken in conducting qualitative interviews about Best Interests decisions across two NHS sites in England. It outlines the study protocol followed for data generation and the approach to data analysis employed.

Chapter 5: Empirical Findings presents the data generated through the qualitative interviews. Exploring the views and experiences of participants around several themes, it concludes by highlighting some key areas of incoherence, thereby foregrounding the discussion within Chapter 6.

Chapter 6: Reflective Equilibrium is where I bring together the different strands of this project to consider how they do (not) and/or can(not) be reconciled. It works towards a coherent position that gives fair consideration to the range of perspectives explored, seeking to answer the underlying research question of this thesis.

Chapter 7: Conclusions provides a brief summary of this project and reiterates its conclusions. In doing so, it clarifies recommendations for future practice and highlights research needs identified. Here I also reflect on the process of conducting this study and the limitations of my results.

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Methodology

In this chapter, I provide an overview of the project's methodological underpinnings. This project is very much at the intersection of several disciplines – notably philosophy, medicine, law, and the social sciences. Best Interests is a legal concept applied in a clinical context,¹⁹⁴ but one with a strong ethical element. Further, the fact that Best Interests concerns patients who lack decision-making capacity necessitates some consideration of disability more broadly.

I begin by outlining what I consider bioethics to be, before considering its relationship with law. The reason I discuss the relationship between bioethics and law and not bioethics and any of the many other disciplines it engages with is due to the nature of this project. The Best Interests test may have parallels with ethical theory, but it is ultimately a test set out in statute. Whilst this is an empirical bioethics project, in this first section I am concerned with bioethics in its broader sense rather than empirical bioethics specifically.

I will then turn my attention specifically to empirical bioethics and chart the so-called “empirical turn” in bioethics. In doing so, I detail some popular critiques of bioethics – notably those from the social sciences. Here I will also outline the is-ought problem and its relevance to this project. Building on this discussion of empirical bioethics, I will explain the specific empirical bioethics approaches and methods that were used throughout this project. These include: The Bristol Framework; reflective equilibrium; and translational bioethics.

The final section of this chapter concerns critical disability theory. Whilst brief, the mention of critical disability theory is essential in a project that concerns the care of patients who are, by definition,

¹⁹⁴ The MCA 2005 does apply in certain non-clinical contexts too, but these are not my concern in this thesis.

disabled.¹⁹⁵ It will act as a background consideration throughout this thesis and be explicitly drawn on where appropriate.

2.1 Bioethics and Law

2.1.1 Bioethics as a discipline?

What bioethics is – before empirical bioethics is considered – remains a question that has not been definitively answered. Instinctively, one might consider it to be applied ethics, which it is often referred to as.¹⁹⁶ Applied ethics, however, implies a top-down approach whereby moral principles are *applied* to moral issues – in this case, medicine.¹⁹⁷ This may be the case for some bioethics scholarship, but often a less top-down approach is followed (as is the case in this thesis).

Callahan wrote in the 1970s that '[b]ioethics is not yet a full discipline', because bioethicists, on the whole, arrive at the field from another discipline,¹⁹⁸ 'more or less inventing it as they go'.¹⁹⁹ Writing during what are widely considered the early years of bioethics, Callahan's perspective is entirely understandable. However, the issue was (and arguably still is) that bioethics is not a neat fit in any of its feeder disciplines. This is clearly demonstrated by the fact that "bioethics centres" are found in philosophy departments, medical schools, law schools, theology departments, and likely various other academic homes. Further, bioethics can be considered a broad church given the variety of

¹⁹⁵ Often people associate the term "disabled" with physical disability – sometimes more specifically with wheelchair users. This is itself problematic, but for now I will simply acknowledge that cognitive impairment also constitutes a disability.

¹⁹⁶ Veatch RM. 2007. Is bioethics applied ethics? *Kennedy Institute of Ethics Journal* 17(1):1-2. See also Chan S. 2015. A bioethics for all seasons. *Journal of Medical Ethics* 41:17-21.

¹⁹⁷ Baker R, McCullough LB. 2007. Medical ethics' appropriation of moral philosophy: the case of the sympathetic and the unsympathetic physician. *Kennedy Institute of Ethics Journal* 17(1):3-22. Baker and McCullough discuss a level of reliance on substantive theories such as deontology and utilitarianism.

¹⁹⁸ This is true of me also. Having come from a political science background, I am perhaps more predisposed towards the importance of clear, actionable recommendations than some bioethics scholars have historically been.

¹⁹⁹ Callahan D. 1974. Bioethics as a discipline. *The Hastings Center Studies* 1(1):66-73, 68.

disciplines from which it draws.²⁰⁰ Almost five decades on from Callahan's claim, then, is bioethics yet a discipline in its own right?

To answer this question, it is useful to consider Callahan's definition of a "discipline". He described it as entailing 'specific training, refined methodologies, [and] distinctive approaches and commitments'.²⁰¹ These criteria have now been met to some extent and in some settings. That there are many bioethics centres globally offering courses specifically in bioethics certainly fulfils the specific training criterion.²⁰² As for refined methodologies, there are now several that were developed specifically for use in bioethics research – most commonly in empirical bioethics.²⁰³ Having been developed within bioethics, these methodologies can overcome Callahan's concern that a bioethics methodology is wrong if it has not been 'specifically developed for ethical problems of medicine and biology'.²⁰⁴ However, such methodologies cannot realistically be considered canonical even if they are accepted as standard among certain groups of bioethicists. Indeed, that Rawls' reflective equilibrium – which I will come to outline shortly – still receives significant airtime in bioethics scholarship demonstrates that these explicitly bioethics methodologies are not accepted by all. It is not entirely clear what constitute distinctive approaches and commitments, but this point may be met in part by distinct methodologies (including broader approaches such as The Bristol Framework²⁰⁵), as well as direct engagement with stakeholders (whether by including them as participants in empirical work or by some form of patient and public involvement). However, again, it is not clear that these aspects of bioethics scholarship are sufficiently widely endorsed to satisfy Callahan's criteria. Indeed, Montgomery comments that despite the realities I have just outlined making bioethics appear as something distinct,

²⁰⁰ Huxtable R. 2016. 'Friends, foes, flatmates: on the relationship between law and (empirical) bioethics'. In Ives J, Dunn M, Cribb A (eds). *Empirical Bioethics: Theoretical and Practical Perspectives*. Cambridge: Cambridge University Press, 86.

²⁰¹ Callahan (n199) 66.

²⁰² As earlier highlighted, such centres exist in various university departments. Undoubtedly, the training will vary between, say, a medical school and a law school. Nonetheless, the training is in "bioethics".

²⁰³ See, for example, Ives J, Dunn M, Cribb A (eds). 2016. *Empirical Bioethics: Theoretical and Practical Perspectives*. Cambridge: Cambridge University Press.

²⁰⁴ Callahan (n199) 72.

²⁰⁵ This will be outlined later in this chapter.

‘it does not follow that there is a discrete academic discipline’.²⁰⁶ O’Neill similarly contends that ‘[b]ioethics is not a discipline, nor even a new discipline; I doubt whether it will ever be a discipline’.²⁰⁷

On balance, then, it appears that bioethics cannot yet (and, if one agrees with O’Neill, never will be) be considered a distinct discipline per Callahan’s definition – a definition which seems perfectly reasonable.²⁰⁸ It may be that bioethics is heading in that direction, but it is not yet there, even if the terminology of discipline is sometimes used to describe bioethics.²⁰⁹ What, then, can bioethics be considered? Prialx suggests that bioethics is better understood as an ‘expert community’.²¹⁰ Along similar lines, Frith and Draper use the term ‘communities of practice’.²¹¹ Such characterisations are perhaps more reflective of the fact that bioethics scholars continue to come from, and often work within, various disciplines – they are almost tied together by a mutual interest in a particular area of inquiry, often entailing interdisciplinary working. Indeed, O’Neill presents a similar depiction of bioethics as a ‘meeting ground for a number of disciplines, discourses and organisations concerned with ethical, legal and social questions raised by advances in medicine, science and biotechnology’.²¹² Whilst these various phrasings might be considered as having very slight differences, they broadly centre on the idea that bioethics ought to be considered a *field*, whereby ‘what counts as a field is driven by a set of questions’.²¹³ As such, whilst recognising that there is by no means consensus on this matter, I will proceed referring to bioethics as a field – and one that is notably interdisciplinary.

²⁰⁶ Montgomery J. 2016. Bioethics as a governance practice. *Health Care Analysis* 24:3-23, 7.

²⁰⁷ O’Neill O. 2002. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press, 1.

²⁰⁸ More recently, Sheehan and Dunn have commented on this issue with a somewhat similar, if slightly less demanding, definition, stating that ‘disciplines are closely tied to methodologies and traditions of thought’. Sheehan and Dunn (n20) 61.

²⁰⁹ The Berman Institute of Bioethics and Johns Hopkins University, for example, states that ‘[a]lthough bioethics began as a multi-disciplinary field of study, it is now a full-fledged discipline in its own right’. Johns Hopkins Berman Institute of Bioethics. *What is bioethics? It’s complicated*. <<https://bioethics.jhu.edu/about/what-is-bioethics/>>.

²¹⁰ Prialx N. 2013. The troubled identity of the bioethicist. *Health Care Analysis* 21:6-19, 17

²¹¹ Frith L, Draper H. 2016. ‘Publishing research in empirical bioethics: quality, disciplines and expertise’. In Ives J, Dunn M, Cribb A (eds). *Empirical Bioethics: Theoretical and Practical Perspectives*. Cambridge: Cambridge University Press, 238.

²¹² O’Neill (n207) 1.

²¹³ Sheehan and Dunn (n20) 61.

2.1.2 The relationship between bioethics and law

Bioethics and (medical) law²¹⁴ are inescapably related as they ‘share much of the same turf’.²¹⁵ The nature of this relationship, however, is up for debate, and scholars from both sides have weighed in.²¹⁶ Law as the codification of ethics is a commonly espoused view,²¹⁷ but one that I will discard immediately as too simplistic. In medicine especially, there is often significant disconnect between law and ethics. This can often be attributed to the simple fact that many ethical questions are complex and polarising whilst law must take a side. Inevitably, when the law takes a side, it does not align with the opposing ethical school of thought.²¹⁸ I will also set aside the suggestion of Lord Justice Hoffman in *Bland* that medical ethics ‘be formed by the law rather than the reverse’,²¹⁹ as this, to my mind, would undermine the purpose of bioethics. For bioethics to be guided by the law in this way would prevent, or at least limit, the ability of bioethics to criticise the law as unfit for purpose. Further, many bioethical issues which scholars explore are not (yet) covered by the law where they concern, for example, emerging technologies.

Whilst law can certainly factor into ethical argumentation, it cannot necessarily be appealed to as a source of moral authority. To claim that the law says *x* so we should do *x* is to present an incomplete argument²²⁰ – one would need first to establish the moral premise that we ought to follow the law. Hence Gray’s assertion that law is not an ideal: ‘it is not that which ought to be, but that which is’.²²¹ Meinkoff

²¹⁴ In this section I will use ‘law’ and ‘the law’ interchangeably and not distinguish between official sources of law, law as practice, and law as an academic discipline. Not making this distinction might ordinarily be problematic, but for the purposes of discussing this relationship it is not.

²¹⁵ Sullivan M, Reynolds D. 1998. Where law and bioethics meet...and where they don’t!! *University of Detroit Mercy Law Review* 75:607–620, 620.

²¹⁶ More broadly concerning the relationship between law and ethics, the Hart-Devlin debate provides interesting points on how popular morality should (not) influence the law. This is worth reflecting on in relation to the nature of empirical bioethics and the is-ought problem, both of which will be explored in this chapter.

²¹⁷ See Sullivan and Reynolds (n215) 608.

²¹⁸ Consider abortion, which remains a criminal offence in England and Wales despite widespread acceptance of the practice. There are many who argue that the law is unethical in preventing widespread access to abortion. Yes, abortion can be lawful under certain conditions, but the failure to decriminalise it can be considered a political decision to avoid upsetting a vocal minority. See Sheldon S, Wellings K (eds). 2020. *Decriminalising Abortion in the UK: What Would It Mean?* Bristol: Policy Press.

²¹⁹ *Airedale NHS Trust v Bland* [1993] A.C. 789.

²²⁰ I will consider this in greater depth shortly when discussing the is-ought problem.

²²¹ Gray J. 1909. *The Nature and Sources of the Law*. New York: Columbia University Press, 213.

goes as far as to argue that the law is often devoid of moral function.²²² This I consider going too far, as the law is still an endorsement of a particular moral position – just not necessarily the position one agrees with. Rather, when a particular moral position becomes law, it shifts from an ought to an is. There may, however, be issues in the other direction. Miola suggests that if the law is to look to medical ethics, identifiable answers as to what is “right” and “wrong” would need to be provided.²²³ Evidently there is a complex relationship at play here.

Huxtable suggests that law’s experience might be of benefit to the relatively junior bioethicist.²²⁴ Approaching the question from the perspective of having a legal background but now working predominantly in bioethics, Huxtable suggests that bioethics would do well to be receptive to what law can teach it in terms of seeking to influence human activity, noting how law ‘checks that bioethics’ recipes are palatable’²²⁵ – law can test bioethical concepts. This thesis certainly aligns with Huxtable’s suggestions. In considering how Best Interests has played out in the context of dialysis decisions, I am considering the importance of beneficence. Looking to the reality of these decisions, I explore how practice relates to normative bioethical thought on how such decisions ought to be made. This allows me to question whether Best Interests as per the MCA 2005 is fit for purpose, or whether it is in need of a ‘bioethical bolt-on’.²²⁶ Thus whilst I agree with Gray that law is about the is rather than the ought, it simultaneously can provide an important testing ground – by *endorsing* particular ethical positions rather than *doing* ethics itself.

Shapiro describes a bridging role for bioethics, helping relieve the tension between the ‘slow deliberation’ of law and the ‘rapid changes’ of science.²²⁷ As bioethics has a foothold in both science (in this case medicine) and law, he suggests that it is ‘essential for bioethicists to make their voices

²²² Menikoff J. 2001. *Law and Bioethics: An Introduction*. Washington: Georgetown University Press, 2. It is worth noting that Menikoff is writing in the US context, but his point is equally applicable this side of the Atlantic. Indeed, he is presenting an argument of legal positivism.

²²³ Miola J. 2004. Medical law and medical ethics – complementary or corrosive? *Medical Law International* 6:251-274, 270.

²²⁴ Huxtable (200).

²²⁵ *Ibid*, 92.

²²⁶ *Ibid*, 95.

²²⁷ Shapiro ZE. 2017. Bioethics in the law. *The Hastings Center Report* 47(1).

heard'.²²⁸ Indeed, Brassington has described how the law might invite ethics 'into the conversation'.²²⁹ But this raises the question of *how* bioethicists can ensure they are heard.

A tiered system of bioethical work is set out by Miola as an observation, comprising the formal, semi-formal, and unofficial sectors.²³⁰ The formal sector is the General Medical Council (GMC) alone,²³¹ as it is the only body with the statutory power to provide ethical guidance to doctors. The semi-formal sector includes organisations that have no statutory standing but do dispense advice that is, broadly speaking, influential – for example, the British Medical Association (BMA) and the Royal Colleges. Finally, the unofficial sector acts as a catch-all for others engaged in bioethical debates and contributes 'by far the largest volume of discourse to the subject of medical ethics'.²³² Miola notes that whilst pressure groups and religious organisations fall within the unofficial sector, it is predominantly populated by academics.²³³ If bioethics research conducted in the unofficial sector is to be in some way influential, then, it may be that it needs to seek to influence the formal or semi-formal sectors. Whilst the divisions between sectors may not be perfectly clean – blurred lines being common in bioethics – I suggest that academic bioethics research pushing beyond the unofficial sector in pursuit of influence may be worthwhile. Depending on the nature of one's research, a researcher may even aim higher at directly influencing primary legislation, somewhat bypassing Miola's formal sector entirely.

A possible route to such influence is to recognise and work within what Miola terms the 'symbiotic relationship' between medical law and bioethics.²³⁴ Depending on the issue in which one is interested, the law is a useful place to begin ethical inquiry. Providing there is relevant legislation²³⁵ – which may exclude some speculative bioethics – it is beneficial to engage with it initially and consider

²²⁸ *Ibid.*

²²⁹ Brassington I. 2018. On the relationship between medical ethics and the law. *Medical Law Review* 26(2):225-245, 239.

²³⁰ Miola (n223). See also Miola J. 2006. The relationship between medical law and ethics. *Clinical Ethics* 1:22-25.

²³¹ Miola is writing in the context of the UK. As such, the makeup of the sectors would vary in other countries. That is, of course, if this proposed system were considered applicable elsewhere. However, I will not dwell on the question of the system's international reach as this thesis concerns England and Wales.

²³² Miola (n223) 253.

²³³ Miola, 2006 (n230) 23.

²³⁴ Miola J. 2007. *Medical Ethics and Medical Law: A Symbiotic Relationship*. London: Hart.

²³⁵ This may involve deep diving into academic literature in which scholars have suggested how legislation might apply to an issue in the absence of legislation that is explicitly designed to address it.

how things *are* ahead of considering how things *ought to be*.²³⁶ That is the case in this thesis, as I have not isolated the question of dialysis for the cognitively impaired as a purely ethical concern but have engaged with the legal reality of such decisions too. Taking the current legal reality as a starting point enables one to frame any suggested revisions appropriately, recognising precisely where changes would need to happen. Rather than making sweeping claims about an idealised end point, one can indicate clear routes to this hoped for final destination.

2.2 Background to empirical bioethics

The history of empirical bioethics is far shorter than that of its parent, and it is arguably still finding its feet.²³⁷ Here I will consider the development of empirical bioethics and whether it falls foul of the is-ought problem. It is not realistic to here propose a means of overcoming the is-ought problem, though it is important to acknowledge it and suggest how I will largely seek to avoid it.

2.2.1 The “empirical turn” in bioethics

In 2008, Herrera posed the question ‘is it time for bioethics to go empirical?’.²³⁸ Certainly, “empirical bioethics” was already around in 2008 – albeit, perhaps, not in as developed a state as it is today.²³⁹ Borry and colleagues wrote of the so-called ‘empirical turn in bioethics’ several years prior,²⁴⁰ and in a qualitative analysis found that a not insignificant minority of articles published in nine bioethics

²³⁶ One might even say this is essential.

²³⁷ That is not to say that empirical bioethics today is beset with blunders, rather that consensus is still being sought on how best to define and practice empirical bioethics. See Ives J, Dunn M, Molewijk B, Schildmann J, *et al.* 2018. Standards of practice in empirical bioethics research: towards a consensus. *BMC Medical Ethics* 19:68.

²³⁸ Herrera C. 2008. Is it time for bioethics to go empirical? *Bioethics* 22(3):137-146.

²³⁹ Paton has suggested that feminist bioethics made early contributions to the development of empirical bioethics, with several early calls for a sociological bioethics, but such contributions have been largely side-lined. Paton A. 2017. No longer “handmaiden”: the role of social and sociological theory in bioethics. *International Journal of Feminist Approaches to Bioethics* 10(1):30-49.

²⁴⁰ Borry P, Schotsmans P, Dierickx K. 2005. The birth of the empirical turn in bioethics. *Bioethics* 19(1):49-71.

journals²⁴¹ between 1990 and 2003 used an empirical design, steadily increasing from 5.4% in 1990 to 15.4% in 2003.²⁴² An update was provided by Wangmo and colleagues in 2018, demonstrating the continued trend towards empirical bioethics; the proportion of empirical papers found in the same nine journals increased from 14.9% in 2004 to 17.8% in 2015.²⁴³ Whilst these may not all be what can be considered empirical bioethics – some, for example, being empirical studies of bioethical issues – the increase is still indicative of a shift.

Broadly speaking, the “empirical turn” describes the introduction of the social sciences and their empirical research methods into bioethics research. It grew out of a recognition that the experiences and perspectives of stakeholders on a particular issue are essential to ethical analysis if the intended goal is the production of practicable recommendations, and that the traditional ivory tower may in fact be a poor workplace for applied ethics of this nature. As Rapp, an anthropologist, noted in her study of the social impact of amniocentesis in the US, the participants were ‘moral philosophers of the private’.²⁴⁴ Those experiencing the services and technologies that we discuss in bioethics – as providers, recipients, and even bystanders with a vested interest – are thinking through the ethical issues from their perspectives as they live them. As such, they can be considered an untapped resource in bioethics – or at least, now, a partially tapped resource. This is true whether the methodology used is participatory (i.e., participants are actively part of the research *with* the researcher) or consumerist (i.e., data are generated purely for use *by* the researcher) in nature, as the former is still making use of this “resource” even if as part of some form of coproduction.

²⁴¹ The nine journals were *Bioethics*, *Cambridge Quarterly of Healthcare Ethics*, *Hastings Center Report*, *Journal of Clinical Ethics*, *Journal of Medical Ethics*, *Kennedy Institute of Ethics Journal*, *Nursing Ethics*, *Christian Bioethics*, and *Theoretical Medicine and Bioethics*.

²⁴² Borry P, Schotsmans P, Dierickx K. 2006. Empirical research in bioethics journals. A qualitative analysis. *Journal of Medical Ethics* 32(4):240-245.

²⁴³ Wangmo T, Hauri S, Gennet E, Anane-Sarpong E, Provoost V, Elger BS. 2018. An update on the “empirical turn” in bioethics: analysis of empirical research in nine bioethics journals. *BMC Medical Ethics* 19:6.

²⁴⁴ Rapp R. 2000. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge, 306.

A recent European consensus paper²⁴⁵ suggested that empirical bioethics research ‘should integrate empirical methods with ethical argument’²⁴⁶ to address ‘a normative issue that is oriented towards practice’.²⁴⁷ Empirical bioethics is not, then, a descriptive endeavour; empirical findings are not simply a source of justification for normative positions, but must be integrated with them.²⁴⁸ The intended result is a normative conclusion that is more informed by the reality of the issue in question and thus more practicably robust.

Borry and colleagues suggest three reasons for the rise of empirical bioethics: ‘(1) dissatisfaction with the dominant applied method in bioethics, (2) the influence of clinical ethics, and (3) the appearance of evidence-based approaches’.²⁴⁹ Among other reasons outlined, they suggest that historically there was little room for the social sciences in bioethics as its evolution saw it ‘originally grafted onto theology and philosophy’.²⁵⁰ Early empirical contributions to the field were not widely acknowledged as more die-hard ethicists questioned their contribution to normative work.²⁵¹ Such attitudes, however, began to change. In his 1980 Shattuck Lecture, for example, Callahan called for bioethicists to work more closely with the social sciences.²⁵² A significant point in this development, suggest Borry and colleagues, was the 1997 addition to the *Journal of Medical Ethics*’ author guidelines for empirical research.²⁵³

²⁴⁵ It should be noted that the authors totalled only 16 and from only five countries in Europe. As such – and as the authors themselves note – the consensus cannot be deemed representative of the field of bioethics. Nonetheless, it is a useful representation of leading views on the question.

²⁴⁶ Ives *et al.* (n237) 8.

²⁴⁷ *Ibid.*, 7.

²⁴⁸ I will touch on the relationship between the empirical and the normative later in this chapter.

²⁴⁹ Borry *et al.* (n240) 52.

²⁵⁰ *Ibid.*, 55.

²⁵¹ *Ibid.*, 61.

²⁵² Callahan D. 1980. Shattuck lecture – contemporary biomedical ethics. *New England Journal of Medicine* 302(22):1228-1233, 1233. This is an interesting, and arguably natural, development in Callahan’s position given my earlier discussion of his defining of the field of bioethics.

²⁵³ Borry *et al.* (n240) 62-63. I am unable to source the original revision of the author guidelines. Interestingly, the journal *Clinical Ethics* has had a dedicated empirical ethics section since its first issue in 2006, which shows how far the integration had come even though the section editor noted that the decision might have ‘come as a surprise to some readers’. Williams C. 2006. Editorial. *Clinical Ethics* 1:37-38, 37.

Building on my earlier characterisation of the wider field of bioethics, I adopt the position of the European consensus paper. By integrating empirical data and ethical reasoning, I will seek to answer what Sheehan and Dunn term a ‘practical ‘ought’ question’.²⁵⁴

2.2.2 Empirical bioethics on trial

The “empirical turn” in bioethics has been the subject of much debate of late.²⁵⁵ Whilst critiques have been proffered from various directions, I will focus on those from the social sciences and philosophy perspectives.²⁵⁶

Social sciences critiques of bioethics are longstanding. Even as early as 2007, De Vries and colleagues asserted that ‘[i]t is old news that social science and bioethics do not get along’.²⁵⁷ Originally, bioethics was criticised for its lack of a role for the social sciences, with Haimes expressing her surprise at this given the increasingly present acronym, ELSA²⁵⁸ (ethical, legal, and social aspects).²⁵⁹ The often described linear relationship (or linear model) affords the social sciences a ‘handmaiden’²⁶⁰ role, gathering the pertinent facts for bioethicists to apply their ‘explicitly normative techniques’ to.²⁶¹ However, argued Nelson, bioethicists might do well to recognise the tools of social sciences as providing access to a ‘repository of moral understandings’.²⁶² Beyond simple facts, then, a stronger integration with the social sciences allows bioethics to expand normative inquiry. Of course, it would

²⁵⁴ Sheehan and Dunn (n20) 57 [italics removed]. I will discuss this further later in this chapter.

²⁵⁵ Ives *et al.* (n237) 1.

²⁵⁶ The latter will be addressed primarily in the next section but will be touched on here.

²⁵⁷ De Vries RG, Turner L, Orfali K, Bosk CL. 2007. Social science and bioethics: morality from the ground up. *Clinical Ethics* 2(1):33-35, 33.

²⁵⁸ It is now more common to see ELSI – implications rather than aspects.

²⁵⁹ Haimes E. 2002. What can the social sciences contribute to the study of ethics? Theoretical, empirical and substantive considerations. *Bioethics* 16(2):89-113, 90. The suggestion here is that ethics and law are the more dominant forces in this supposed group effort. This is unsurprising given my earlier discussion of the relationship between law and bioethics.

²⁶⁰ *Ibid*, 89.

²⁶¹ Nelson JL. 2000. Moral teachings from unexpected quarters: lessons for bioethics from the social sciences and managed care. *Hastings Center Report* 30(1):12-17, 13.

²⁶² *Ibid*, 12.

be important to avoid slipping into descriptive ethics, but provided one is careful of that then Nelson's discussion certainly demonstrates the benefits of empirical bioethics.

Noting widespread historical criticism of bioethics – specifically from the social sciences – Herrera suggested that the introduction of social science approaches 'would lead to a different [field], not necessarily a better one'.²⁶³ Herrera is right to note that the result would be a different field, as empirical bioethics has undoubtedly developed as a distinguishable entity; even if one does not view it as wholly distinct, it is at least somewhat different to more traditional, philosophical bioethics. As for whether it is better, I would suggest that the development of empirical bioethics has improved the broader field of bioethics – or, at the very least, is on a trajectory to do so. Empirical bioethics has not replaced and need not replace philosophical bioethics; both offer different and important perspectives. But the greater engagement with the empirical realities of the subjects of research questions that empirical bioethics affords can only increase the practicability of conclusions; sensitivity to lived experience ought to at least minimise the possibility of entirely out-of-touch recommendations. Nonetheless, criticisms have continued following the move to integrate social sciences in bioethics research.

Zussman, on highlighting what he considered an empirical disconnect, suggested a potential solution to be a somewhat radical restructuring of bioethics, which he posited would result in the boundaries between the social sciences and philosophy²⁶⁴ 'close to disappearing'.²⁶⁵ Alternatively, though somewhat similarly, Hoffmaster proposed that bioethics look to ethnography as a lifeline.²⁶⁶ Critical of applied ethics, Hoffmaster noted that

²⁶³ Herrera (n238) 145. Herrera uses the language of discipline, but I have replaced this with field in line with my earlier discussion of how bioethics ought to be characterised.

²⁶⁴ By which he means bioethics – specifically philosophical bioethics.

²⁶⁵ Zussman R. 2000. The contribution of sociology to medical ethics. *Hastings Center Report* 30(1):7-11, 10

²⁶⁶ Hoffmaster B. 1992. Can ethnography save the life of medical ethics? *Social Science & Medicine* 35(12):1421-1431. Hoffmaster wrote this particular paper long before many of the criticisms I have outlined, but he was similarly responding to a charge of bioethics' early top down, applied ethics approach.

‘moral decision making is a search for a feasible, appropriate response to a particular situation, not the application of a method that in virtue of its extreme generality is insensitive to the particularities that structure the situation’.²⁶⁷

In tailoring moral decision making to a particular situation, suggests Hoffmaster, the bioethicist ought to investigate how the moral problem in question is perceived by the affected parties and avoid the application of deductive reasoning. Hence ethnography as a means to such an end. More recently, Hoffmaster has reaffirmed his view that bioethics, even following the empirical turn, ‘remains ensconced in moral philosophy and constrained by its assumptions’.²⁶⁸

For Hedgecoe, the solution is what he terms ‘critical bioethics’.²⁶⁹ This he suggested as the appropriate evolution, citing the historical development from purely philosophical bioethics to the linear model. Hedgecoe’s proposal does not necessitate the bioethicist developing a social science toolkit, but instead engaging fully with the social sciences literature in advance of the standard bioethics debates.²⁷⁰ The researcher must use empirical data not simply to support pre-existing conclusions, but to potentially challenge or undermine a theoretical framework,²⁷¹ thus becoming an inductive endeavour rather than a prescriptive, top down approach.²⁷² Further, he calls for reflexivity,²⁷³ which may be in the form of simple acknowledgement of reflexivity’s importance,²⁷⁴ or a more involved running commentary.²⁷⁵ Whatever form it takes, greater reflexivity may help in overcoming the possible subjectivity of reflective

²⁶⁷ *Ibid*, 1426.

²⁶⁸ Hoffmaster B. 2017. From applied ethics to empirical ethics to contextual ethics. *Bioethics* 32(2):119-125, 120.

²⁶⁹ Hedgecoe AM. 2004. Critical bioethics: beyond the social science critique of applied ethics. *Bioethics* 18(2):120-143.

²⁷⁰ *Ibid*, 136.

²⁷¹ *Ibid*, 137.

²⁷² *Ibid*, 129. I do not entirely agree with Hedgecoe’s suggestion that philosophical bioethics was/is prescriptive but acknowledge that it may be more so than empirical bioethics.

²⁷³ *Ibid*, 138.

²⁷⁴ See Myers G. 1990. *Writing Biology: Texts in the Social Construction of Scientific Knowledge*. Madison, WS: University of Wisconsin Press.

²⁷⁵ See Mulkay M. 1985. *The Word and the World*. London: Allen and Unwin; Ashmore M. 1989. *The Reflexive Thesis: Wrihting Sociology of Scientific Knowledge*. Chicago: University of Chicago Press.

equilibrium²⁷⁶ – where, of course, it is deployed.²⁷⁷ Nonetheless, Hedgecoe notes that bioethics should not collapse into social science, as ‘philosophy is a crucial discipline in [bioethics]’²⁷⁸ and ‘[t]he importance of empirical research should not stop critical bioethicists from making normative judgements’²⁷⁹ – to lose this element might result in a descriptive bioethics that ceases to challenge problematic systems and practices. Unsurprisingly, then, Hedgecoe is not convinced by Hoffmaster’s suggestion of ethnography as an answer, deeming it an ‘aggressive take-over bid’ that would ‘reduce the role of the philosopher to a worryingly unspecified level’.²⁸⁰ Whilst I do see strong value in ethnography as a key part of empirical bioethics,²⁸¹ I cannot help but side with Hedgecoe and his defence of the need for bioethics to remain distinct from social science. Bioethics should draw on social science and benefit from its offering without morphing into its malnourished sibling. It is important to reserve the right to deem even total consensus amongst stakeholders in a given context unethical, as ethics is not a democratic endeavour.

On reflection, many of these criticisms of empirical bioethics – as might be assumed simply from the years of publication – are arguably somewhat outdated. Without suggesting that empirical bioethics has entirely overcome these critiques, it is clear from the methodological developments of recent years that a concerted effort has been made to more comprehensively fuse bioethics and the social sciences.²⁸² As highlighted by Strong and colleagues, many criticisms of empirical bioethics concern ambiguity in how the researcher is to translate empirical findings into normative theory, but answers to this critique are growing.²⁸³ The appropriate use of empirical bioethics bridging methodologies does not incorporate the social sciences in a distinctly linear research process. Whilst for simplicity of explanation, overviews such as The Bristol Framework (*see* 2.3.1) may appear to

²⁷⁶ Reflective equilibrium will be discussed in depth later in this chapter.

²⁷⁷ A further call for reflexivity in philosophical bioethics research can be found in Ives J, Dunn M. 2010. Who’s arguing? A call for reflexivity in bioethics. *Bioethics* 24(5):256-265.

²⁷⁸ Hedgecoe (n269) 134.

²⁷⁹ *Ibid*, 135.

²⁸⁰ *Ibid*, 129.

²⁸¹ As will be discussed shortly (*see* 2.3.3), I advocate strongly for ethnography-like activity in empirical bioethics, feeling it is essential for reasons of immersion in the pertinent context.

²⁸² This will become more apparent later in this chapter as I introduce specific methodologies.

²⁸³ Strong KA, Lipworth W, Kerridge I. 2018. The strengths and limitations of empirical bioethics. *Journal of Law and Medicine* 18(2):316-319, 319.

distinguish the “social sciences section”, the reality is that they are intended as inherently iterative approaches. Analysed empirical data are not to remain static as a researcher moves into a normative phase of a project, but remain, in the immortal words of Diane Abbott MP, a moving picture; the normative and empirical remain in dialogue throughout. Undoubtedly some fine tuning is in order, but it is fair to say that the relationship has progressed beyond the handmaiden role of the social sciences where one approaches empirical bioethics properly.

Before moving to outline the specific empirical bioethics approaches adopted in this project, I will consider a possible philosophical shortcoming of empirical bioethics. Namely, the is-ought problem. This has been alluded to in the discussion of the complex relationship between bioethics and the social sciences, though it requires more detailed engagement.

2.2.3 The is-ought problem

As noted in the previous section, there is a risk with empirical bioethics that it becomes a descriptive enterprise. This is not necessarily cause for concern but becomes so where there is unreflective use of such description to make normative claims. Where this happens, such scholarship makes the leap from empirical fact to normative position without due argumentation.²⁸⁴ Such a critique has been aimed at the empirical bioethics enterprise.²⁸⁵

The so-called is-ought problem²⁸⁶ originates in the work of David Hume. Hume remarked that:

²⁸⁴ Provoost V. 2015. Secondary use of empirical research data in medical ethics papers on gamete donation: forms of use and pitfalls. *Monash Bioethics Review* 33:64-77.

²⁸⁵ Strong *et al.* (n283) 318-319; Widdershoven G, van der Scheer L. 2008. ‘Theory and methodology of empirical ethics: a pragmatic hermeneutic perspective’. In Widdershoven G, McMillan J, Hope T, van der Scheer L (eds). *Empirical Ethics in Psychiatry*. New York: Oxford University Press.

²⁸⁶ This is sometimes conflated with the fact/value distinction and/or the naturalistic fallacy. However, it is important to recognise that there are differences between the three concepts – particularly between the first two and the naturalistic fallacy. See Dodd J, Stern-Gillet S. 1995. The is/ought gap, the fact/value distinction and the naturalistic fallacy. *Dialogue* 34(4):727-746. Nonetheless, I will still consider the points raised in this debate where they are described in any of these three ways, provided it is clear that it is the is-ought problem that is being discussed by the author(s). For a discussion of all three concepts specifically in the context of empirical bioethics, see De Vries R, Gordijn B. 2009. Empirical ethics and its alleged meta-ethical fallacies. *Bioethics* 23(4):193-201.

‘[i]n every system of morality, which I have hitherto met with, [the author] makes observations concerning human affairs; when of a sudden I am surpriz’d to find, that instead of the usual copulations of propositions, *is*, and *is not*, I meet with no proposition that is not connected with an *ought*, or an *ought not*. This change is imperceptible; but is, however, of the last consequence. For as this *ought*, or *ought not*, expresses some new relation or affirmation, ‘tis necessary that it shou’d be observ’d and explain’d; and at the same time that a reason should be given, for what seems altogether inconceivable, how this new relation can be a deduction from others, which are entirely different from it. But as authors do not commonly use this precaution, I shall presume to recommend it to the readers; and am persuaded, that this small attention wou’d subvert all the vulgar systems of morality, and let us see, that the distinction of vice and virtue is not founded merely on the relations of objects, nor is perceiv’d by reason’.²⁸⁷

Here Hume is drawing what he perceives to be a necessary distinction between the descriptive (what *is* the case) and the normative (what *ought to be* the case),²⁸⁸ arguing that the latter cannot be derived merely²⁸⁹ from the former. Spielthener nicely summarises it thus: ‘people who are trying to infer normative conclusions from non-normative premises are making a significant logical mistake’.²⁹⁰ To contextualise this in relation to this thesis, Hume would suggest that just because cognitively impaired patients with kidney failure are routinely dialyzed²⁹¹ it does not logically follow that they should be (or vice versa).

²⁸⁷ Hume D. 1739/1896. *A Treatise of Human Nature*, reprinted from the original edition in three volumes and edited, with an analytical index, by Selby-Bigge LA. Oxford: Clarendon Press, 469-470 [author emphasis].

²⁸⁸ This focus on separating the two resulted in the name “Hume’s Guillotine”.

²⁸⁹ It is worth noting that Hume uses the qualifier ‘merely’, suggesting that the descriptive can play at least some role in determining the normative. This is important in my later discussion of empirical bioethics methodologies, in which this is very much the case.

²⁹⁰ Spielthener G. 2017. The *is-ought* problem in practical ethics. *HEC Forum* 29:277-292, 279.

²⁹¹ This is not necessarily true but is deployed here hypothetically.

The is-ought problem has been criticised on several counts, with some suggesting that Hume himself has been misinterpreted on this point.²⁹² Here I will consider just one criticism – that of Prior. Prior has argued that both premises and conclusions can consist of both normative and descriptive components, and that we can therefore derive an ought from an is – an is statement may still entail some normative component, and thus an ought can logically be derived from it.²⁹³ Spielthener notes how the counterexamples to the is-ought problem presented by Prior have caused proponents of the problem to narrow their interpretation of Hume’s thesis, moving from the relationship between the descriptive and the normative to that between the *purely* descriptive and the *purely* normative.²⁹⁴ This overcomes Prior’s critique by discarding compound premises and conclusions from the is-ought problem’s remit. The product of this is the revised position of ‘[n]o purely normative sentence which is not logically true is deducible from any consistent set of purely descriptive sentences’.²⁹⁵

Necessary interplay between the descriptive and normative is apparent in that to reach conclusions through the application of normative principles, they can be applied only in combination with factual information. We can only conclude that Best Interests decisions concerning dialysis are being made badly if we combine (a) the normative claim that it is not in the Best Interests of a patient with a cognitive impairment to be dialyzed with (b) the descriptive (empirical) claim²⁹⁶ that nephrologists usually dialyze patients with cognitive impairments. Or, of course, the reverse. The

²⁹² Nelson notes that some consider it false to ascribe the common phrase “you cannot get an ought from an is” to Hume, for he does not actually say that such a deduction is impossible (note the extract from Hume’s *Treatise* above). Nelson MT. 2019. ‘Is/ought fallacy’. In Arp R, Barbone S, Bruce M (eds). *Bad Arguments: 100 of the Most Important Fallacies in Western Philosophy*. Oxford: Wiley, 361. Further, MacIntyre highlights a disconnect between the usage of the word “deduction” today and when Hume was writing, suggesting that this disconnect can account for a level of misinterpretation of Hume’s famous passage. MacIntyre AC. 1959. Hume on “is” and “ought”. *The Philosophical Review* 68(4):451-468, 460.

²⁹³ Prior AN. 1960. The autonomy of ethics. *Australasian Journal of Philosophy* 38(3):199-206.

²⁹⁴ Spielthener (n290) 281.

²⁹⁵ Schurz G. 1991. How far can Hume’s is-ought thesis be generalized? *Journal of Philosophical Logic* 20(1):37-95, 39 [italics removed]. Schurz terms this new position the ‘special Hume thesis’ as it excludes compound premises and conclusions (meaning those that contain both descriptive and normative components). He notes that to merely discard that which does not fit is unsatisfactory, and therefore goes on to establish the ‘general Hume thesis’ to suitably accommodate compound premises and conclusions. However, for the purposes of this thesis I will continue in applying the ‘special Hume thesis’, meaning the assumption that there is an implicit ‘purely’ qualifier to the is and ought.

²⁹⁶ Which, of course, must be factually accurate for the argument to be sound.

empirical data thus inform the normative inquiry to indicate the realistic consequences of a certain action.²⁹⁷

The descriptive may also, according to some, modify ethical principles.²⁹⁸ This does not, argues Spielthener, undermine Hume's thesis because the modification is itself justified by normative principles; as such, modification 'does not involve an *is-ought* inference'.²⁹⁹ For example, we might hold the following two principles:

- (1) we should never dialyze a patient with kidney failure who is not also being added to the transplant waiting list, because such a patient will be forced to suffer the burdens of dialysis for the remainder of her life; and
- (2) patient preferences are important in treatment decision making.

Should empirical evidence demonstrate that some patients who will never be added to the transplant waiting list nonetheless wish to undertake dialysis, our two principles conflict. As such, we might modify (1) to hold that we should not dialyze such a patient *as default*. This would not be inferring an ought (we should not dialyze as default) exclusively from an is (discovering the preferences of some such patients) but modifying principle (1) to ensure coherence with principle (2); the descriptive is merely highlighting a discordance.

That some might consider this modification to be in breach of Hume's thesis demonstrates the importance of stating an argument completely. To simply state when modifying principle (1) that we should not automatically dialyze patients who are not being added to the transplant waiting list because some want dialysis could be construed as inferring an ought from an is as a result of elliptical reasoning.

²⁹⁷ This does, of course, assume a broadly consequentialist foundation to one's understanding of the function of bioethics. As such, I note here that I am operating on such a foundation. That is not to say that I believe bioethics is about simply applying some form of utilitarianism to a moral problem in medicine to "calculate" the answer. Rather, an understanding of the feasibility of certain outcomes is important to assess the ethical standing of a particular course of action in an area as practical as medicine – utilitarian arguments may then be dismissed.

²⁹⁸ See, for example, Hedecoe (n269).

²⁹⁹ Spielthener (n290) 284 [author emphasis].

However, when it is also explained that principle (2) was already at play, the reasoning is complete, and the is-ought distinction remains intact.

It is important to recognise that empirical bioethics is not descriptive ethics – we are not just saying what people think by way of simply reporting data – but is a normative-ethical endeavour that seeks to ‘combine insights from normative disciplines and empirical sciences’.³⁰⁰ In doing so, it is important to avoid what Salloch and colleagues have termed ‘[e]thics by opinion poll’.³⁰¹ The methodological approaches I will now outline seek to avoid this eventuality, allowing ample room for normative reasoning.

2.3 Approaches to empirical bioethics

I earlier discussed the so-called “empirical turn” in bioethics. Since empirical bioethics developed into a recognisable sub-field,³⁰² there has been a wealth of scholarship seeking to lay out appropriate methods and methodologies. There is not space here to explore even a few of them in particular depth, so I will instead focus on those which I adopted for this project.

2.3.1 The Bristol Framework

In approaching this project as a whole, it was necessary to consider a broad framework in which to work. For this, I looked to the Mapping-Framing-Shaping framework (colloquially “The Bristol Framework”) proposed by Huxtable and Ives.³⁰³

³⁰⁰ *Ibid*, 278.

³⁰¹ Salloch S, Vollmann J, Schildmann J. 2014. Ethics by opinion poll? The functions of attitudes research for normative deliberations in medical ethics. *Journal of Medical Ethics* 40(9):597-602.

³⁰² Which can be contrasted with philosophical bioethics. See Ives J, Draper H. 2009. Appropriate methodologies for empirical bioethics: it’s all relative. *Bioethics* 23(4):249-258.

³⁰³ Huxtable R, Ives J. 2019. Mapping, framing, shaping: a framework for empirical bioethics research projects. *BMC Medical Ethics* 20:86.

To explain this approach, Huxtable and Ives use a landscaping metaphor. First, one surveys the landscape to ‘get a sense of the general terrain’ and what one might want to do.³⁰⁴ The purpose of this first, mapping, stage is to understand the current state of things. Second is exploration of specific identified areas of the mapped terrain. In keeping with the metaphor, this second, framing, stage is similar to commissioning specialist surveys ‘to tell us, for example, what kind of bedrock is present, how stable certain areas are, whether there are any endangered species that must be protected’,³⁰⁵ allowing one, in the research context, to understand how key stakeholders experience the issue at question. Third and final is the shaping stage – the landscaper is able to build a vision, ‘[a]rmed with an intimate understanding and knowledge of the terrain’.³⁰⁶ For the researcher, this amounts to formulating recommendations based on findings and analyses, combining understandings of theory and practice to arrive at a normative conclusion.

Applying this framework, the stages of my project can be organised as follows:

- Mapping: Literature review (*see Chapter 3*)
- Framing: Qualitative interviews (*see Chapters 4 and 5*)
- Shaping: Reflective equilibrium³⁰⁷ (*see 2.3.2 and Chapter 6*)

At first glance, this framework may appear as an attempt to reinvent the wheel. Indeed, its authors note that empirical studies in the social and health sciences will generally follow this pattern of literature review, followed by the generation and analysis of empirical data, before arriving at recommendations.³⁰⁸ However, it is this mirroring of other fields that affords this framework strength;

³⁰⁴ *Ibid.*, 2.

³⁰⁵ *Ibid.*, 3.

³⁰⁶ *Ibid.*

³⁰⁷ Arguably the reflective equilibrium methodology pervades more than just the last phase of The Bristol Framework. However, the process of reaching coherence between different elements that I will outline in my later discussion of reflective equilibrium, which really is the core of the methodology, fits more squarely in the “shaping” phase.

³⁰⁸ Huxtable and Ives (n303) 5.

it adds a sort of credibility. Further, the final stage sees a departure from other fields. The methodologies required of the “shaping” phase are inherently different to those of other areas of health research, for they uniquely ‘bridge the abstract and the empirical to propose normative recommendations’.³⁰⁹

The “shaping” phase of The Bristol Framework is intentionally left somewhat open, in that it allows for the introduction of the researcher’s bridging methodology of choice.³¹⁰ In this case, I will use reflective equilibrium,³¹¹ which I will come to explain shortly. This flexibility is because The Bristol Framework is intended as a broader structure for conducting a research project within – a sort of meta-methodology. Further, it is the addition of one of these other bridging methodologies that places The Bristol Framework firmly within the confines of “empirical bioethics”; without that necessary element to find coherence between the abstract and the empirical,³¹² the process of mapping, framing, and shaping describes many a research project.³¹³

2.3.2 Reflective equilibrium

Reflective equilibrium is a technique whereby the individual seeks coherence between their beliefs and intuitions and existing theoretical positions. It is a popular methodology in bioethics, such that it has been commented that ‘the air is abuzz with reflective equilibrium’.³¹⁴ Whilst such a claim was made almost 15 years ago and may be said to be less true today, it remains that reflective equilibrium – or at least adapted versions – is still to be commonly found within empirical bioethics. Technically, reflective equilibrium is the result of the process,³¹⁵ but I will use the term also to refer to the process both for ease of reading and in recognition of its common usage nowadays.

³⁰⁹ *Ibid.*

³¹⁰ That is not to say that the first two phases leave no room for manoeuvre. The researcher can introduce whichever literature review and data generation methods desired. My choices will be outlined and justified later in this thesis (*see Chapters 3 and 4*).

³¹¹ Rawls J. 1999[1971]. *A Theory of Justice: Revised Edition*. Cambridge, MA: Harvard University Press.

³¹² Assuming a coherentist bridging methodology is being employed, as is the case with this project.

³¹³ Huxtable and Ives (n303).

³¹⁴ Arras JD. 2009. ‘The way we reason now: reflective equilibrium in bioethics’. In Steinbock B (ed). *The Oxford Handbook of Bioethics*. Oxford: Oxford University Press, 46.

³¹⁵ Rawls – and others since – discussed *reaching* reflective equilibrium rather than *doing* it.

Reflective equilibrium is often attributed to Rawls,³¹⁶ though arguably he merely labelled (and built on) an existing approach.³¹⁷ Rawls' proposal is deeply coherentist, and rests on the premise that our beliefs are justified if and only if they are consistent across problems. As such, any beliefs and principles must be revisable in the face of inconsistency to permit this coherence. The process involves the researcher's 'considered judg[e]ments',³¹⁸ moral principles generalised from these judgements, and practical cases.

Considered judgements are often referred to as "intuitions", perhaps because they are based on the individual's innate sense of justice, though Rawls himself did not use this term. They are, in essence, our instinctive beliefs and feelings about things – for example, on hearing a child has been killed we might consider this to be wrong. However, only those which we are most confident in are *considered* judgements. We cannot, notes Rawls, rely entirely on our considered judgements as they 'are no doubt subject to certain irregularities and distortions despite the fact that they are rendered under favorable circumstances'.³¹⁹ Indeed, Daniels notes that whilst they are "considered", they are still essentially opinions, which often result from 'self-interests, self-deception, historical and cultural accident, hidden class bias, and so on'.³²⁰ However, for the purposes of reflective equilibrium, they are considered as having 'a certain initial credibility'.³²¹

³¹⁶ Rawls (n311). This is a revised edition of Rawls' original 1971 work, and it is the revised edition that I will look to for the purposes of this discussion. An earlier outline was provided by Rawls in 1951 but was not at that point fully formed as reflective equilibrium. Rawls J. 1951. Outline of a decision procedure for ethics. *The Philosophical Review* 60(2):177-197. Whilst attributed to Rawls, several authors have developed reflective equilibrium further. Most notably, Norman Daniels.

³¹⁷ An approach similar to that which we now term reflective equilibrium arguably originated a decade or so before Rawls' *A Theory of Justice*, with wider discussions of inductive logic in the context of the scientific method by the likes of Goodman. See Goodman N. 1955. *Fact, Fiction and Forecast*. Cambridge, MA: Harvard University Press.

³¹⁸ As Rawls was based in the US, he used the American English *judgment* rather than the (non-legal) British English *judgement*. Considered judgements for the purposes of Rawls' reflective equilibrium are not related to legal judgments. As such, I will proceed with the British English *judgement* in discussion of reflective equilibrium. Further, in ethical writing they are often referred to as considered *moral* judgements. See Daniels N. 1979. Reflective equilibrium and theory acceptance in ethics. *Journal of Philosophy* 76(5):256-282, 258. Rawls did not himself make this addition, but it is a reasonable addition for the use of reflective equilibrium in the realm of moral philosophy as opposed to its origination in political philosophy.

³¹⁹ Rawls (n311) 42. Favourable circumstances in this case means the fact that these judgements arise out of our sense of justice.

³²⁰ Daniels (n318) 265.

³²¹ Rawls J. 1974-1975. The independence of moral theory. *Proceedings and Addresses of the American Philosophical Association* 48:5-22, 8. Daniels explains this as giving us 'the effect of intuitionism without any fairy tales about epistemic priority'. Daniels (n318) 265.

Based on these judgements, the individual then seeks to generalise them, resulting in a moral principle that can be applied in other situations. This may be likened to the scientific method, whereby considered judgements are a series of data points from which the researcher inductively formulates a principle that makes sense of them. Continuing with the above example, we might arrive at the generalised principle that we should not kill innocents. The result of the process thus far – completed with several considered judgements – is a set of principles which the individual considers to be morally defensible.³²²

This set of principles is (probably) then put to the test in certain practical cases in which two or more of the principles appear to conflict, or where a single principle proves internally inconsistent. Consider a terrorist hijacking of a plane, with that plane heading towards a building containing thousands of people. Suppose in this scenario the only way to prevent that plane flying directly into the building is to shoot it down. To do so would save the lives of those in the building but would cause the death of innocent passengers on the plane. It would be reasonable to intuit that shooting down the plane is the right course of action in an altogether awful situation. However, this intuition (or considered judgement) conflicts with the already established principle that we ought not to kill innocents. As such, we must either discard or revise the considered judgement and/or principle. In a utilitarian fashion, such a revision might be to proceed with the principle that we ought not to kill innocents, unless doing so is necessary to save a larger number of innocents. In carrying out this process of deliberative adjustment, our new principle represents reflective equilibrium. Broadly speaking, the product is a coherent ‘scheme of principles’.³²³ It is in this stage of deliberative adjustment that an empirical research component can be inserted, taking it from a theoretical enterprise to an empirical bioethics methodology. Rather than relying on hypothetical test cases or those drawn from existing literature, one can use empirical methods to generate data that are directly applicable to the research question. This enables more relevant and realistic practical test cases, improving the defensibility of the reflective equilibrium reached. I provide a slightly more practical explanation of this process in Chapter 4.

³²² In Rawls’ case, the result was a set of principles integral to a just society.

³²³ Rawls (n321).

It is important to note that throughout this process, no judgements or principles are sufficiently epistemically privileged as to be impervious to removal or revision. Whilst some must initially be firm enough to begin the process – more a practical reason than anything else – Rawls notes that ‘there are no judg[e]ments on any level of generality that are in principle immune to revision’.³²⁴ All may be dropped, revised, reformulated, or expanded to reach ‘a systematic organization’.³²⁵

However, this set of principles arrived at as outlined is to be considered *narrow* reflective equilibrium, as opposed to the more comprehensive result of *wide* reflective equilibrium.³²⁶ The distinction was elaborated on by Rawls a few years after he initially laid out his theory.³²⁷ If we rely only on our own considered judgements as applicable to practical cases, the result is limited and may be better thought of as a descriptive account rather than a normative one; a more personal set of coherent beliefs that may well lack wider appeal. To establish a more convincing set of principles that others may be inclined to adopt, we must widen the net regarding what principles we seek coherence between. Beyond our own intuitive judgements, we must look to existing theories and include them in the process of reaching coherence. Arras outlines this inclusivity, explaining how a researcher who feels a particular moral outlook or background theory is missing can simply include it in the process.³²⁸ Consider a consumerism metaphor. I put my set of beliefs that I have arrived at following the process earlier outlined (narrow reflective equilibrium) on the market. Having created it myself, I think it is a fantastic set of beliefs. However, there are many other sets of beliefs – some far more established – available to shoppers. Some may have features that are more desirable, and so they sell more. For my set of beliefs to be more competitive on the market, I need to do my market research and improve my offering –

³²⁴ *Ibid*, 8.

³²⁵ *Ibid*.

³²⁶ There is also a further stage of *full* reflective equilibrium, wherein everyone in society has achieved the same *wide* reflective equilibrium – ‘a public conception of justice’. Rawls J. 2001. *Justice As Fairness: A Restatement*. Cambridge, MA: Harvard University Press, 31. Floyd neatly outlines the distinction between the three types of reflective equilibrium. Floyd J. 2017 [2015 online]. Rawls’ methodological blueprint. *European Journal of Political Theory* 16(3):367-381

³²⁷ Rawls (n321). Rawls later noted it as unfortunate that he did not use the terminology of “narrow” and “wide” in *A Theory of Justice*. Rawls (n326) 31. It has, however, been suggested that wide reflective equilibrium is implicit in *A Theory of Justice*. See Daniels (n318) 257.

³²⁸ Arras (n314) 55.

perhaps taking on elements of my competitors' offerings. As such, wide reflective equilibrium can be considered a sort of philosophical market research.

The move to wide reflective equilibrium seems only natural, and Daniels has argued that the move was necessary for the success of the theory.³²⁹ However, Rawls acknowledges that wide reflective equilibrium can only be so wide. It is simply not realistic to test our considered judgements against all possible alternatives. What we must instead do is get as close as is feasible, meaning to look to 'the predominant conceptions familiar to us from the philosophical tradition'.³³⁰

Reflective equilibrium, whilst popular, has been criticised on several counts. First, the subjectivity of considered judgements has been argued to result in arbitrary conclusions.³³¹ Thus, even if reflective equilibrium is coherent – which is also disputed – the inescapability of individual prejudices is suggested to undermine it. The mention of coherence brings me to another critique.³³² Strong does not consider wide reflective equilibrium *in practice* to qualify as a coherentist method.³³³ He argues that coherence requires equality of types of knowledge, whereas reflective equilibrium, when applied, is highly susceptible to affording greater epistemic importance to considered judgements – for the simple fact that we tend to privilege our own views and may struggle to duly question them in the face of opposing positions. As such, 'the sort of consensus that [wide reflective equilibrium] seeks to achieve would seem, in fact, to be out of reach'.³³⁴ Griffin similarly comments that '[i]t is especially in ethics that intuitions have risen so far above their epistemological station'.³³⁵ In particular, Strong, in acknowledging Rawls' caveat that we cannot account for all possible principles – be they confirming

³²⁹ Daniels N. 1996. *Justice and Justification: Reflective Equilibrium in Theory and Practice*. Cambridge: Cambridge University Press, 6.

³³⁰ Rawls (n321) 8.

³³¹ Strong C. 2010. Theoretical and practical problems with wide reflective equilibrium in bioethics. *Theoretical Medicine and Bioethics* 31:123-140, 134-135; Singer P. 1974. Sidgwick and reflective equilibrium. *The Monist* 58(3):490-517, 494. Of note, Singer was writing at a similar time to Rawls' article which built on the ideas of *A Theory of Justice* and explicitly detailed wide reflective equilibrium. Singer, therefore, is unlikely to have read it prior to detailing this particular critique (the fact Singer has not cited this later work of Rawls suggests that this is the case).

³³² I will not here discuss the broader criticisms of coherentism.

³³³ Strong (n331). Strong specifically discusses wide reflective equilibrium, dismissing narrow reflective equilibrium early on. Strong (n331) 128.

³³⁴ *Ibid*, 131.

³³⁵ Griffin J. 1996. *Value Judgement: Improving our Ethical Beliefs*. Oxford: Oxford University Press, 5.

or otherwise – questions when the researcher is to know that she has included enough components.³³⁶ Relying on, as Rawls puts it, ‘the predominant conceptions familiar to us from the philosophical tradition’,³³⁷ opens reflective equilibrium up to subjectivity beyond the initial considered judgements; what if the researcher is not aware of certain important conceptions? This is particularly problematic where reflective equilibrium is being used outside of philosophy, as researchers are less likely to be aware of the main theories of normative ethics.³³⁸

Whilst the inclusivity of wide reflective equilibrium might appeal to some, Arras raises a pragmatic concern. To reach wide reflective equilibrium, a researcher would have to account for the major – and often conflicting – ethical theories of, for example, utilitarianism and virtue ethics, which is, quite frankly, a daunting prospect.³³⁹ Indeed, whilst this may result in a more robust conclusion, it is an undertaking that most would likely consider too significant in bioethics where action guidance is often sought as a product of research. Whilst the development of wide reflective equilibrium may have been necessary to overcome the charge of inherent subjectivism, the result is, for some, ‘hopelessly clunky and complex’.³⁴⁰

Despite these criticisms, reflective equilibrium is the methodology used in this thesis. Many of these criticisms centre on the supposed subjectivity of reflective equilibrium, looking to the epistemic privilege afforded to one’s own perspective as a starting point. Regardless of wide reflective equilibrium’s attempt to overcome such critiques, I question just how necessary this is. Or, rather, whether such shortcomings are in any way unique to reflective equilibrium. I struggle to see how any methodology can remove the subjectivity inherent in normative work – the very nature of ethics is such that it cannot be wholly detached from a researcher’s own perspective. Even if my own judgements are to initially be afforded such weight in deliberation, this is not a cause for concern provided there is acknowledgement of this. Hence the importance of transparency and reflexivity. I make no claims as to

³³⁶ Strong (n331) 133-134.

³³⁷ Rawls (n321) 8.

³³⁸ Strong (n332) 133. This point is especially relevant in bioethics, as bioethicists do not all have a philosophy background – some even come from a purely clinical background where exposure to ethical theory has been notably lacking historically.

³³⁹ Arras (n314) 55-56.

³⁴⁰ *Ibid.*, 69.

the objectivity of what follows in this thesis, nor do I think total objectivity would be entirely appropriate in such a project.

There are many alternative methodologies I might have used, including those purpose built for empirical bioethics – of which there is a growing number.³⁴¹ For example, Ives’ ‘reflexive balancing’,³⁴² Frith’s ‘symbiotic empirical ethics’,³⁴³ and Parker’s ‘teleological expressivism’.³⁴⁴ All of these methodologies have their benefits, such that all would have, to some degree, been usable in this project. Nonetheless, I have chosen reflective equilibrium for several reasons. First, a coherentist approach fits well with the pragmatic focus of my research question. Second, reflective equilibrium as a coherentist approach offers sufficient flexibility to allow workability whilst providing a methodologically robust process. Third, that it benefits from a tenure that these other methodologies currently lack. On this final reason, it was important that I was able to properly understand and apply a methodology, and reflective equilibrium has been around for so long that one can very easily find examples of its use and even discussions of how to employ it³⁴⁵ – something the others, as new kids on the methodological block, are absent.³⁴⁶

2.3.3 Translational bioethics

Despite the empirical turn in bioethics, one may still question whether the field is providing recommendations that, for the purposes of translation into practice and policy, are useful. Certainly,

³⁴¹ A systematic review by Davies and colleagues found 33 such options in the bioethics literature. Davies R, Ives J, Dunn M. 2015. A systematic review of empirical bioethics methodologies. *BMC Medical Ethics* 16:15.

³⁴² Ives J. 2014. A method of reflexive balancing in a pragmatic, interdisciplinary and reflexive bioethics. *Bioethics* 28(6):302-312.

³⁴³ Frith L. 2010. Symbiotic empirical ethics: a practical methodology. *Bioethics* 26(4):198-206.

³⁴⁴ Parker M. 2009. Two concepts of empirical ethics. *Bioethics* 23(4):202-213.

³⁴⁵ For example, that of Birchley, which I will revisit in Chapter 6. See Birchley G. 2015. *Judging Best Interests in Paediatric Intensive Care: The Location, Scope and Basis of Decision Making*. Bristol: University of Bristol [thesis].

³⁴⁶ That reflective equilibrium retains so much airtime in the bioethics literature suggests that I may not be alone in my preference for the more established. This may also be, in part, due to scholars remaining as yet unconvinced of the alternatives. Whilst not writing specifically in the bioethics context, Floyd writes that ‘[t]he ultimate defence of Rawls’ method [...] is that unless we can construct an alternative, together with a convincing argument regarding its superiority, we should just ‘keep calm and carry on’’. Floyd (n326) 378.

engagement with the lived experiences of stakeholders plays an important role in the practicability of recommendations, but how such recommendations can be appropriately formulated for implementation is a separate question. Such a question has been explored to some degree under the heading of translational bioethics.³⁴⁷

This was a question I found myself asking a lot throughout this project, perhaps influenced by my own disciplinary background in political science. Given the limited literature in this area, myself and some colleagues ran a workshop to discuss these issues,³⁴⁸ following which we are currently editing a journal special issue that will expand on the conversations had. In the absence of this special issue,³⁴⁹ I will here reflect on my own contribution.³⁵⁰

In the questions around translational bioethics, I find myself positioned away from the linear view of it as something done at the end as is the case with translational research in the health sciences more generally. Rather, I suggest that translational considerations ought to be present throughout a project, framed more so as a focus on the translatability of recommendations.³⁵¹ That may be said to be the focus of empirical bioethics already, but I have a concern that empirical bioethics done in a certain way (which it sometimes is) may result in excessive bias. For example, if a study comprises only stakeholder interviews, the picture of that context the researcher ends up with is wholly reliant on the accuracy of the data provided by participants. Especially if the researcher is coming to that context as

³⁴⁷ Baeroe K. 2014. Translational ethics: an analytical framework of translational movements between theory and practice and a sketch of a comprehensive approach. *BMC Medical Ethics* 15:71; Cribb A. 2010. Translational ethics? The theory-practice gap in medical ethics. *Journal of Medical Ethics* 36(4):207-210.

³⁴⁸ This was secondary to the PhD itself and was arranged in collaboration with Pam Cairns and Jonathan Ives. Thanks to the Institute of Medical Ethics for funding the workshop.

³⁴⁹ Contributions are still undergoing the peer review process, with an anticipated 2023 publication.

³⁵⁰ My contribution to the special issue was written with Harlen Kaur Johal, Joshua Parker, and Elizabeth Chloe Romanis. Whilst drawing heavily on our joint work, what I present here reflects my own thoughts and not necessarily those of my co-authors. Hence, I write in the singular first person. Further, I provide only a brief overview here given space constraints – a far more detailed exploration is contained in our recently published article: Parsons JA, Johal HK, Parker J, Romanis EC. 2023. Translational or translationable? A call for ethno-immersion in (empirical) bioethics research. *Bioethics*. [online first] <https://doi.org/10.1111/bioe.13184>.

³⁵¹ Such a suggestion has recently been made by Sisk and colleagues, with the presentation of an implementation science framework for bioethics. Sisk BA, Mozersky J, Antes AL, DuBois JM. 2020. The “ought-is” problem: an implementation science framework for translating ethical norms into practice. *American Journal of Bioethics* 20(4):62-70.

an outsider, as is often the case with bioethics research.³⁵² Data generation methods such as interviews can, to some degree, be thought of as taking place in controlled conditions; they are not the same as direct engagement with the context but are instead an engagement with a participant's perspective of that context. Whilst qualitative data is inherently subjective, and does not claim to be anything other, reliance on a single data generation method entails a level of subjectivity beyond what I suggest should be considered reasonable where one intends to go on and make recommendations out of such data. Of course, this is why we have triangulation in qualitative research, in an attempt to alleviate this risk through 'the observation of the research issue from (at least) two different points'.³⁵³ But formal triangulation activities can be resource intensive, in some cases amounting to conducting two or more studies simultaneously. I suggest that there is an alternative which can be thought of as contributing to this underlying goal of triangulation without entailing such a burden on the researcher.³⁵⁴

This proposal is for a complementary³⁵⁵ ethnographic approach of "ethno-immersion",³⁵⁶ capturing the essence of ethnography but in a more informal manner – and not ending with a written account of that experience. Ethnography-like approaches to bioethics have been floated since at least 1990 when Jennings highlighted the benefits through his study of neonatal intensive care.³⁵⁷ More recently, Parker has argued that 'ethnography offers the possibility of a bioethics better informed about the meaning and intersubjective significance of the situation under consideration'.³⁵⁸ I do not, then, purport to be suggesting anything ground-breaking here. To a degree, this is a note on the importance of reviving this discussion and recognising the central role an ethnographic approach could play as empirical bioethics continues to grow as a field.

³⁵² Whilst there are many healthcare professionals working in bioethics research, it is reasonable to assume that the majority of those in the field come from other, non-clinical disciplinary backgrounds. This means that they do not have the same background knowledge of the environment developed first hand.

³⁵³ Flick U. 2004. 'Triangulation in qualitative research'. In Flick U, von Kardorff E, Steinke I (eds.). *A Companion to Qualitative Research*. London, UK: SAGE.

³⁵⁴ That is not to say that we ought not to conduct mixed methods research in bioethics. Rather, this should not be essential when one considers practicalities.

³⁵⁵ Specifically complementary as this is in no way intended to denigrate data generation through methods such as interviews.

³⁵⁶ Parsons *et al.* (n350).

³⁵⁷ Jennings B. 1990. 'Ethics and ethnography in neonatal intensive care'. In Weisz G (ed.). *Social Science Perspectives on Medical Ethics*. Dordrecht, NL: Kluwer Academic Publishers.

³⁵⁸ Parker M. 2007. Ethnography/ethics. *Social Science & Medicine* 65(11): 2248-2259.

What I propose is very much like ethnography, but not quite the same. I am here suggesting a more informal process whereby the researcher gets as much exposure as possible to the context being investigated, but not as a formal data generation process – i.e., an *ethnography* will not be written up. The goal is not a rich written account of the context but is an exercise in the researcher's own familiarisation. By simply spending time in the context – be that through joining ward rounds, sitting in on consultations, or whatever else is fitting for that particular project – the researcher can begin to develop their own understanding of how interactions take place. Having done this, any later analysis of data generated through alternative methods is likely to be far more nuanced. That is not to say that it will be free of bias as ethno-immersion is unavoidably subject to the researcher's own take on what they observe, but it will at least afford an additional perspective that may end up challenging the researcher's interpretation of their data. The process may even have an impact before data generation takes place, in that ethno-immersion could contribute to the development of a topic guide for interviews or focus groups. A good example of how this approach can be beneficial is the work of Moazam on conflicts between modern bioethics and the traditional societal practices of Pakistan.³⁵⁹ Moazam interviewed stakeholders as well as spending significant time in the hospital observing their interactions. Whilst she did conduct this as a formal ethnography, her writing demonstrates how this time spent in the context affected her interpretation of interview data – we can take this as “showing your workings” to see the value of ethno-immersion, as her detailed descriptions of the context (as it was a formal ethnography) show clearly the interplay between both sets of data.

I arrived at this suggestion largely through necessity. As I will come to outline in Chapter 4, I originally intended to conduct an ethnography as part of this project, by which I mean a formal ethnography inclusive of the write-up. When COVID-19 rendered this impossible, I had to settle for maximising my time spent in the clinical environment even though it would not be feasible to write this up as an ethnography. That is not to suggest that this proposal is inherently better than a formal

³⁵⁹ Moazam F. 2006. *Bioethics and Organ Transplantation in a Muslim Society: A Study in Culture, Ethnography, and Religion*. Bloomington, IN: Indiana University Press.

ethnography, rather this is how I arrived at it – they are different, with neither necessarily (to my view) better than the other.

Bringing this back to the idea of translational bioethics, I see ethno-immersion as vital to the translatability of any conclusions in an empirical bioethics study. For such conclusions to be perceived as credible by stakeholders, they need to demonstrate an awareness of the reality to which they are to be applied. For example, for any of my recommendations around Best Interests decisions in renal care to be thought of as reasonable by healthcare professionals working in that area, they need to acknowledge how things actually happen and not entail outlandish suggestions that simply could not be actioned even if desired. This sort of understanding, I suggest, cannot be gathered from reading and interviewing – they certainly help, but are limited in their inability to help one get a true picture of the day-to-day. Certainly, through spending time in the context myself I have found that many of my thoughts about my research question have changed. Some perceptions I had of renal units, fed largely by the literature, turned out to be somewhat skewed, and certainly oversimplified on several fronts. I would imagine the recommendations I provide later in this thesis would have been rather more idealistic had I not spent the time I did on renal units. A more detailed account of my personal ethno-immersive experience is detailed in Appendix A.

2.4 Critical disability theory

In addition to the already outlined methodological approaches, throughout this thesis I will take account of critical disability theory. The positioning of disability considerations in bioethics has, some suggest, been historically limited.³⁶⁰ This is disputed,³⁶¹ but what is certain is that disability is an important

³⁶⁰ Kuczewski MG. 2001. Disability: an agenda for bioethics. *American Journal of Bioethics* 1(3): 36-44, 36.

³⁶¹ Mahowald MB. 2001. Disability? Long on the agenda for some bioethicists. *American Journal of Bioethics* 1(3):45-46.

element of many bioethical issues.³⁶² Disability is certainly an important aspect of Best Interests, as the patients concerned can be considered disabled. The UNCRPD defines disabled persons as those with ‘long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.³⁶³ The UNCRPD does not explain ‘long-term’, though the Equality Act 2010 defines it as a minimum of 12 months (including how long it is anticipated to last) or, if the person is likely to die in the next 12 months, for the rest of the person’s life.³⁶⁴ If the impairment is recurring, it is also covered by this definition.³⁶⁵ This does, of course, exclude those who are cognitively impaired to the extent of being subject to a Best Interests decision but as a temporary and non-recurring event; a capacity assessment is time specific, whereas this definition of disability requires an extended period of affect. However, I will include persons affected by a temporary and non-recurring instance of cognitive impairment in my definition of disabled for the purposes of this thesis, thereby removing the ‘long-term’ criterion from the UNCRPD definition.

Minich argues that disability studies is a methodology, which involves ‘scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations’.³⁶⁶ This position is seconded by Schalk, who agrees that disability studies is not a ‘subject-oriented area of study’.³⁶⁷ Critical disability theory, then, is not about studying disability, but employing a critical perspective in research. It is about acknowledging disability as a social construct rather than an inevitable consequence of impairment.³⁶⁸

³⁶² Certainly, it is becoming a larger area of research. For example, the first issue of *The Journal of Philosophy of Disability* published its first issue in 2021. Reynolds JM, Burke TB. 2021. Introducing the Journal of Philosophy of Disability. *Journal of Philosophy of Disability* 1:3-10.

³⁶³ Article 1 United Nations Convention on the Rights of Persons with Disabilities 2008.

³⁶⁴ Sch.1 (2) (1) Equality Act 2010.

³⁶⁵ Sch.1 (2) (2) Equality Act 2010.

³⁶⁶ Minich JA. 2016. Enabling whom? Critical disability studies now. *Lateral* 5.1.

³⁶⁷ Schalk S. 2017. Critical disability studies as methodology. *Lateral* 6.1.

³⁶⁸ Hosking DL. 2008. *Critical Disability Theory*. Presented at the 4th Biennial Disability Studies Conference at Lancaster University. <https://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2008/papers/hosking2008.pdf>, 7. This does, to some disagree, require the researcher to endorse the social model of disability of which some are highly critical. Nonetheless, for my purposes, an initial acceptance of the social model of disability as methodology rather than normative claim is useful for the purposes of critical analysis.

The need for this perspective when considering Best Interests is important because autonomy as commonly understood is heavily reliant on non-interference, thereby potentially precluding cognitively impaired persons from its remit. Kong and Ruck Keene argue that:

‘if our ideal of autonomy comprises disembodied, able-bodied (and typically male) traits, we will miss the ways in which those with different ways of interacting with their environment actually display skilful ways of coping which contribute to their autonomy’.³⁶⁹

In terms of the social construct understanding, it is the operation of decision making for/with patients with cognitive impairments that might cause them to be disabled. Our focus on what is “normal” in medical decision making can all too easily prevent means of allowing cognitively impaired patients from guiding their own care when they may be able to. Indeed, the history of the treatment of those with intellectual disabilities highlights how this may be a hangover from the period of the great incarceration.³⁷⁰ With suitable measures in place – for example, speech and language therapy – the way decisions about the care of patients with cognitive impairments are made might be differently understood.

Critical disability theory is a large and growing body of work, and it is not feasible for me to engage with it in significant depth. However, for the purposes of this project, I acknowledged the traditional understanding of autonomy and how it relates to disability. I have been conscious of social constructs that might lead to a patient being deemed unable to make her own care decisions, and account for this in my analysis by acknowledging and questioning paternalism where it arises as well as revisiting my own analysis critically to try and avoid assuming disability where there is none.

³⁶⁹ Kong and Ruck Keene (n76) 40. This will be revisited in depth in Chapter 6.

³⁷⁰ Jarrett explains the limitations of society’s efforts to better integrate and respect those with intellectual disabilities, such that ‘[w]e grant a form of conditional social tenure, a precarious semi-acceptance in which people can belong as long as they recognize a set of limitations and restrictions that we place around them, an invisible asylum wall constructed from the bricks of bureaucracy and social policy’. Jarrett S. 2020. *Those They Called Idiots: The idea of the disabled mind from 1700 to the present day*. London: Reaktion Books, 11.

2.5 Summary

What I hope this chapter has achieved is a justification of the various methodological elements that are drawn upon throughout this thesis. I will predominantly operate within The Bristol Framework, utilising reflective equilibrium. Other considerations, such as critical disability studies, will be secondary methodological elements which will be more influential in the finer details of analysis. Finally, I will return to the question of translational bioethics towards the end of this thesis. Whilst I have sought to consider aspects of translational bioethics as outlined, the lack of formally presented methodological considerations in the literature makes it more a point of reflection on bioethics methodology as a whole.

Literature Review³⁷¹

This chapter details the scoping review conducted as part of the first, mapping³⁷² phase of this project. In synthesising evidence that responds to the question “what is known and theorised about how decisions about maintenance dialysis are and should be made with, for, and on behalf of adult patients who lack decision-making capacity?”, it constitutes an element for consideration within the reflective equilibrium process (*see Chapter 2*). In that sense, it enabled me to establish a solid – though not exhaustive³⁷³ – foundational understanding of what was known and theorised about the issue at hand.

Through this scoping review, six main themes were developed: involving various parties; objectivity; cultural sensitivity; medical versus non-medical factors; managing nonadherent patients; and substituted judgement. Discrete sub-themes were developed within each broad theme – all of which are detailed shortly.

Before delving into this literature review, I would like to acknowledge that the language used throughout this chapter has a certain leaning towards dialysis rather than a more open, objective portrayal of dialysis and CKM. The framing of the research question this scoping review addressed may be seen as suggesting dialysis to be the obvious choice. This is at odds with the importance of unbiased presentation of options that I have already discussed, and which remains a key thread throughout this thesis. However, as this scoping review was conducted towards the beginning of this project and is now published, I have not amended this language for the purposes of this thesis.

³⁷¹ An adapted version of this chapter has been published as part of this PhD. See Parsons JA, Ives J. 2021. Dialysis decisions concerning cognitively impaired adults: a scoping literature review. *BMC Medical Ethics* 22:24. For the contributor statement, see the front matter of this thesis.

³⁷² Huxtable and Ives (n303).

³⁷³ As I will come to discuss momentarily, a scoping review, whilst systematic, is not as systematic as a more traditional systematic review. It is possible that some papers were not retrieved and thus were not instrumental to this background knowledge. Nonetheless, a scoping review does provide an extensive overview of existing research and was sufficient for my purposes.

3.1 Choosing an approach

My decision to conduct a scoping review rather than any alternative review type was largely based on the reasons I have articulated in a publication tied to this project.³⁷⁴ For reasons of space, I will not detail these reasons in depth here. Nonetheless, I will briefly summarise for the purposes of this thesis.

The systematic review is viewed as the gold standard of literature reviews in the health sciences, and for good reason. It incorporates thorough search methods to identify relevant papers, quality appraisal to exclude those papers that lack necessary methodological rigour, and synthesis of findings to provide an overview of the state of knowledge around a particular question. Whilst beneficial in the health sciences, in bioethics research these elements can be problematic.

Problems arise in relation to what a colleague and I refer to as the ‘normative-empirical dilemma’.³⁷⁵ Normative and empirical literature are inherently different, so combining them to be dealt with by the same methods presents challenges – challenges which the systematic review cannot overcome. To apply any formalised method of quality appraisal to normative literature is questionable, as such literature does not conform to the same accepted standard for research that, for example, clinical trials do. Whether or not someone considers a piece of normative work of sufficient quality is hugely subjective and may come down to something as trivial as whether they agree with the argument. It is, then, misguided to attempt to include normative literature in a systematic review as it simply does not fit.

Similar concerns arise in terms of how results might be viewed. A systematic review is intended to highlight the state of knowledge, providing an overview that can be considered in developing policy. This cannot be done with normative literature, again due to subjectivity. For example, the frequency of a particular argument in no way indicates that it is the better argument, or that policy should be based on it. We should be wary, then, of people taking what a review of normative literature finds as action

³⁷⁴ Parsons JA, Johal HK. 2022. In defence of the bioethics scoping review: largely systematic literature reviewing with broad utility. *Bioethics* 36(4):423-433. For the contributor statement, see the front matter of this thesis.

³⁷⁵ *Ibid*, 427.

guiding. The term “systematic review” carries certain connotations in this regard that should be avoided when one is dealing with normative scholarship.

Given these issues, the focus of some on cementing the place of systematic reviews in bioethics ought to be a matter of concern. A desire for the credibility the title “systematic review” may garner in certain circles should not be prioritised over the methodological suitability of literature review methods to a particular project. It appears to be something of an attempt at ‘keeping up with the methodological Joneses’,³⁷⁶ particularly where bioethics research is taking place within medical schools.

With the systematic review unsuitable to bioethics research, then, an appropriate alternative is the scoping review. The method is described shortly (*see* 3.2) but, in brief, it incorporates systematic elements much like those of a systematic review whilst introducing more space for critical engagement with the included literature (rather than the more objective approach intended in a systematic review). A robust search strategy is still employed, but there is no exclusion on the basis of quality – if it fits the bill in terms of thematic relevance, it is included. Whilst one may reach conclusions that are intended to be more action guiding (a scoping review of clinical studies is not uncommon) there is not the same weight of expectation that it will provide practicable conclusions. It can be more critically discursive in its conclusion, existing as something of a reader’s digest that indicates no case for a change to policy or practice. This is far better suited to reviewing normative literature given the matters of subjectivity already noted. Whilst one might choose to combine normative and empirical scholarship in a scoping review – which is precisely the approach taken in this project – it at least allows for the appropriate examination of the normative.

As noted above, this is very much a brief overview of my reasoning. For a more detailed explanation, one can look to my article on scoping reviews.³⁷⁷ In particular, this article maps both the systematic review and scoping review in relation to alternative approaches, doing so against the criteria of “critical” and “systematic”.

³⁷⁶ *Ibid*, 424.

³⁷⁷ *Ibid*.

3.2 Methods

Arksey and O'Malley detail a six-stage process for conducting scoping reviews: (1) identifying the research question; (2) identifying relevant papers;³⁷⁸ (3) paper selection; (4) charting the data; and (5) collating, summarizing, and reporting the results.³⁷⁹ The sixth stage – consultation with practitioners/consumers – is an optional stage that Arksey and O'Malley recommend in line with Oliver's suggestion that systematic reviews – and, by extension, scoping reviews – can be enhanced in terms of utility if both practitioners and consumers contribute to the work.³⁸⁰ Whilst this final stage was not carried out as part of the scoping review itself, informal consultation with my supervisory team and several other researchers in both bioethics and nephrology before, during, and after conducting the review can be thought of as having provided some of these benefits. Further, when this project is taken as a whole, the empirical work undertaken after this scoping review can also be considered as having played a somewhat similar role.

3.2.1 Stage 1: Identifying the research question

Systematic reviews in the health sciences traditionally use the PICO (population, intervention, comparison, outcome) model, as focus is necessary because of the specific questions they usually seek answers to. Indeed, they are usually seeking to capture all relevant literature to definitively determine the state of knowledge. However, the PICO model was not suitable for my purposes. This review was exploratory and, as such, required an intentionally broad (though not too broad) question.

³⁷⁸ Arksey and O'Malley use the term “studies” rather than “papers”. I specifically use “papers” as it is more inclusive; not all records included in this review are “studies”. Nonetheless, in my later discussion I do refer to studies where appropriate.

³⁷⁹ Arksey H, O'Malley L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8(1):19-32. It is important to note that Arksey and O'Malley did not originate the scoping review approach, nor is their outline the only one available. Nonetheless, I have selected it for its acceptance in the literature and ease of application.

³⁸⁰ Oliver S. 2001. ‘Making research more useful: integrating different perspective and different methods’. In Oliver S, Peersman G (eds.). *Using Research for Effective Health Promotion*. Buckingham: Open University Press.

The research question(s) for this scoping review was developed following informal discussions with several nephrologists and ethicists. In keeping with the wider question and purpose of this thesis, this scoping review mapped evidence pertaining to the following primary research question:

What is known and theorised about how decisions about maintenance dialysis are and should be made with, for, and on behalf of adult patients who lack decision-making capacity?

In doing so, it also sought to answer the following secondary research questions:

- (1) How are decisions about maintenance dialysis for adult patients who lack decision-making capacity made in practice?
- (2) How do different stakeholders understand the process of making decisions about maintenance dialysis for adult patients who lack decision-making capacity?
- (3) What normative arguments exist concerning how decisions about maintenance dialysis should be made with, for, and on behalf of adult patients who lack decision-making capacity?

Answering these questions ahead of the qualitative interviews that followed was important. Not only did the results of this scoping review broaden my understanding of the complexity of the issues at play and how nephrologists might approach them, but, more specifically, it helped in the shaping of the topic guides used for the qualitative interviews. I outline what influence this review had on the formulation of topic guides towards the end of this chapter.

Of note, these research questions do not use the phrase “Best Interests”. Whilst I have already made the distinction between the phrase in its broader usage and how it is understood in the context of the MCA 2005, for the avoidance of confusion I here deploy more general and descriptive terminology.

Further, this is more appropriate as some of the papers that I will come to discuss were published in the context of another decision-making system, such as substituted judgement.

3.2.2 Stage 2: Identifying relevant papers

Relevant papers were identified by searching several research databases. A preliminary search was carried out in February 2020 using Ovid MEDLINE(R). This search was conducted with reference to the research questions already detailed, and with assistance from a medical librarian.³⁸¹ The purpose of this search was to identify search terms, abbreviations, and Medical Subject Headings (MeSH) terms used frequently in the area with which the research questions are concerned. Following this search, the final search string was decided on (*see Table 1*).³⁸²

Table 1. Final search string

| Facet 1 | | Facet 2 | | Facet 3 |
|-------------------------------------|----------|------------------------------------|----------|-----------------------------|
| exp Decision Making (MeSH) | A | exp Mental Competency (MeSH) | A | exp Renal Dialysis (MeSH) |
| OR | N | OR | N | OR |
| exp Clinical Decision-Making (MeSH) | D | exp Dementia (MeSH) | D | dialysis.tw |
| OR | | OR | | OR |
| substituted judgment.tw | | mentally incapacitated patient*.tw | | kidney failure.tw |
| OR | | OR | | OR |
| surrogate decision maker.tw | | mental capacity act.tw | | renal failure.tw |
| OR | | OR | | OR |
| best interest*.tw | | cognitively impaired.tw | | end-stage kidney disease.tw |
| | | OR | | |
| | | cognitive impairment.tw | | |

³⁸¹ I would like to express my gratitude for the hero of the University of Bristol Medical Library that is Sarah Herring for her help in this.

³⁸² There is some variation in the MeSH terms used by each database, so this search string was altered slightly when necessary.

Using this search string, the final search was carried out on 3 March 2020 on five databases: Ovid MEDLINE(R), Embase, PsychINFO, The Cochrane Library, and Web of Science. These databases were selected based on their indexing of relevant journals. All databases were searched from 1961 (when maintenance dialysis was introduced in the UK) to the day of the search.³⁸³

3.2.2.1 Ancillary search strategies

In addition to online searches, the reference lists of papers included following the application of inclusion and exclusion criteria (see below) were hand searched for additional potentially relevant papers. Papers on reference lists were considered for relevance based on their titles, and those deemed likely to be suitable for inclusion were screened in full.

3.2.3 Stage 3: Paper selection

Once papers were identified as per Stage 2, they were subjected to a screening process to determine which papers would be included (*see Figure 2*). Initially, all duplicate papers were removed. I then screened the titles and abstracts of all remaining papers according to pre-specified inclusion and exclusion criteria and classified them as “include”, “exclude”, or “unsure”. The inclusion and exclusion criteria were as follows:

Inclusion:

- Papers, books, book chapters (hereafter referred to collectively as papers)

³⁸³ Some databases did not return results up to the day of the search as they update their records on a weekly basis. The databases which did not return papers published up to and including the day of the search were PsychINFO (up to and including February week 4, 2020) and Embase (up to and including week 9, 2020).

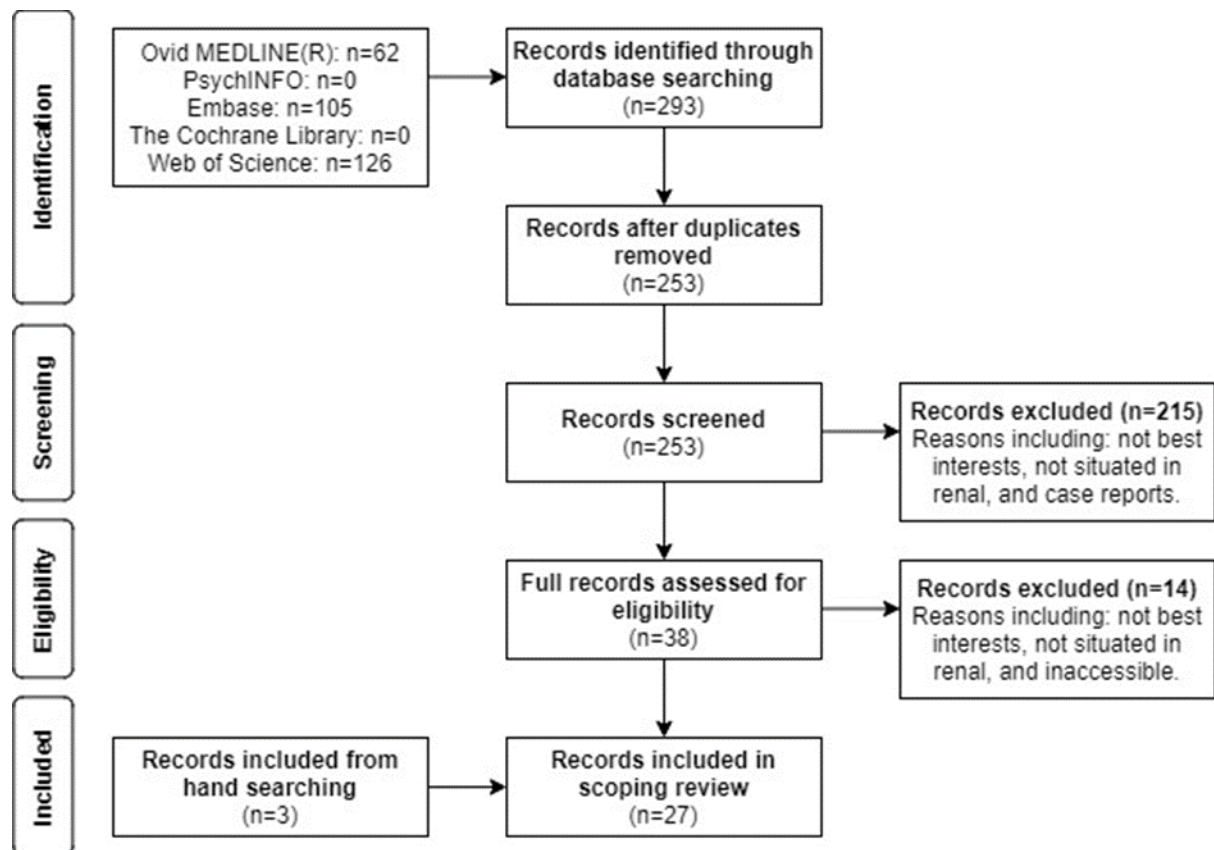
- Papers that report on empirical studies about how decisions about dialysis are made with, for, and on behalf of adult patients who lack decision-making capacity (this does not have to be the primary focus of the paper)
- Papers that discuss how decisions about dialysis should be made with, for, and on behalf of adult patients who lack decision-making capacity (this does not have to be the primary focus of the paper)
- Papers published since 1961 (the year in which maintenance dialysis was introduced in the UK)
- Papers published in English³⁸⁴

Exclusion:

- Grey literature, including journalism
- Case reports
- Papers not situated in renal care
- Papers about paediatric or neonatal renal care
- Papers that do not reference Best Interests or lack of capacity
- Papers not in English

A random sample of 10% of the “include” and “exclude” lists, as well as all of those classified as “unsure”, were screened by a second reviewer (one of my supervisors). Whilst there was initial agreement on the classification of most papers, there were some discrepancies that necessitated discussion. Had discussions not resolved disagreements, a third reviewer would have reviewed the paper(s) in question and the majority decision carried; this did not prove necessary. Several papers did not have an abstract or had an abstract which did not allow for a decision as to its inclusion or exclusion to be made confidently. To ensure an accurate decision, the full texts of these papers were screened against the inclusion and exclusion criteria.

³⁸⁴ I did not have the resources to arrange translational of papers.

Figure 2. PRISMA diagram of paper identification

Following discussion with the second reviewer, papers on the “include” list, as well as those with no/unclear abstracts, were screened in full against the inclusion and exclusion criteria. 14 papers were excluded at this point, including one which could not be accessed (despite all reasonable efforts being made).³⁸⁵ 24 papers were identified as fitting the inclusion criteria and were included in the review.

Following the selection of included papers, the titles in all reference lists were screened to identify further papers that might have fitted the inclusion criteria. The screening process outlined above

³⁸⁵ Paris JJ, Moss AH. 1993. "Medical futility" (part two): guidelines on use of renal dialysis. *Clinical Ethics Report* 7(3):1-5.

was then repeated for all additional papers identified in this way. Only three papers were found this way that were deemed suitable for inclusion.³⁸⁶

The final list of papers deemed to fit the inclusion criteria was then compiled for data extraction. This list totalled 27 papers (24 from database searches and three from ancillary searching), comprising a mixture of empirical and normative work.

3.2.4 Stage 4: Charting the data

Once a final list of papers to include was compiled, I read each through twice, extracting data on the second reading. The data were charted using Microsoft Excel based on the following paper characteristics:

- i. Paper (author(s) and year of publication)
- ii. Country of origin
- iii. Aim(s) of paper
- iv. Method(s)/study type
- v. Results
- vi. Reflections from reviewer³⁸⁷

To aid reliability, the second reviewer reviewed a sample of 10% of the papers in full. This was to check that I had been consistent and accurate in my charting of the data, and to identify any contentious aspects of, for example, classification.

³⁸⁶ One of these three papers (Cady, 1990) was not strictly found in the reference list of an already included paper. One of the already included papers was a commentary on it and mentioned it but did not directly reference it.

³⁸⁷ Under this heading, I noted my initial thoughts on possible codes.

3.2.5 Stage 5: Collating, summarizing, and reporting the results

An inductive, data-driven approach to analysing the charted data was taken, employing thematic analysis.³⁸⁸ Thematic analysis is used for ‘analysing and reporting patterns’ in data,³⁸⁹ which are then described ‘in words rather than numbers’.³⁹⁰ As such, any language indicative of frequency ought not to be taken as a representation of significance. The data were not quantitatively analysed, and such language is used merely to provide a sense of those views and findings that were more or less prevalent in the papers.

Broadly, six main themes were developed: “involving various parties”; “objectivity”; “cultural sensitivity”; “medical versus non-medical factors”; “managing nonadherent patients”; and “substituted judgement”. Discrete sub-themes were developed within each broad theme – all of which are detailed in the next section.

3.3 Results

Before detailing the results of this review, it is worth briefly noting the geography of the included papers. The wider concern of this project is with Best Interests as per the MCA 2005. Of note, however, very few included papers originated in England and Wales (or the wider UK). As demonstrated by **Table 2**, only five of 27 papers originated in the UK (of these, one was an international collaboration, and another concerned an Australian case). The US, on the other hand, accounted for 16 papers. This must be taken into account when reading the results, as a range of jurisdictions are represented and perspectives from the US represent the simple majority of papers.

³⁸⁸ Braun V, Clarke V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2):77-101; Braun V, Clarke V. 2019. Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health* 11(4):589-597. A more detailed explanation of thematic analysis is provided in Chapter 4.

³⁸⁹ Braun and Clarke, 2006 (n388) 79.

³⁹⁰ Bowling A. 2009. *Research Methods in Health: Investigating Health and Health Services*. 3rd ed. Maidenhead: Open University Press, 380.

Table 2. Countries of origin of included papers

| Paper | Country/ies |
|--|---|
| Ang <i>et al.</i> (2009) | Singapore |
| Brennan <i>et al.</i> (2017) | Australia, Canada, United States & United Kingdom |
| Cady (1990) | United States |
| Campbell <i>et al.</i> (2011) | United States |
| Clement <i>et al.</i> (2005) | France |
| Conneen <i>et al.</i> (1998) | United States |
| Davison and Holley (2008) | Canada |
| DeCamp (2011) | United States |
| Feely <i>et al.</i> (2014) | United States |
| Foote <i>et al.</i> (2014) | Australia & New Zealand |
| Grubb (1998) | United Kingdom |
| Jones and McCullough (2014) | United States |
| Kaye and Lella (1986) | Canada |
| Keating <i>et al.</i> (1994) | United States |
| MacPhail <i>et al.</i> (2015) | Australia |
| McDougall (2005) | United Kingdom (concerning an Australian case) |
| Moss <i>et al.</i> (1993) | United States |
| Munoz Silva and Kjellstrand (1988) | United States |
| O'Dowd <i>et al.</i> (1998) | United States |
| O'Rourke <i>et al.</i> (2019) | United Kingdom |
| Perkins (1990) | United States |
| Pruchno <i>et al.</i> (2005) | United States |
| Scott <i>et al.</i> (2018) | United Kingdom |
| Sehgal <i>et al.</i> (1996) | United States, Germany & Japan |
| Spike (2000) | United States |
| Spike (2007) | United States |
| Ying <i>et al.</i> (2014) | Canada |
| Totals: Singapore (n=1) New Zealand (n=1) France (n=1) Germany (n=1) Japan (n=1) Australia (n=4) Canada (n=5) United Kingdom (n=5) United States (n=16) | |

Between these jurisdictions there are likely to be both significant and nuanced differences in the prevailing social and cultural values and norms that inform medical decision making, legislative frameworks, and how healthcare systems operate. This variation will inevitably affect how decisions are made with, for, and on behalf of adult patients who lack decision-making capacity, as such decisions are embedded within the systems in which they are made. As I will come to discuss, the concept of atomistic autonomy is more highly valued in some countries than in others, with some favouring a more communitarian approach – and this will be reflected in both the way that decisions are intuitively made and by the legislative, institutional, and professional frameworks within which such decisions have to be made. Even within a single country, of course, there will be cultural variation that can affect

perceptions of the decision-making process in a healthcare setting. This latter issue will be highlighted as a minor, but nonetheless important, theme arising from the literature. Equally, the structure of healthcare systems is likely to play an important role, with some of the represented jurisdictions operating insurance-based healthcare and others operating some form of publicly funded system. This kind of difference, again, may explain variation in the way that decisions are made with, for, and on behalf of persons who lack decision-making capacity, even when prevailing values are shared. Whilst my aim in this chapter is not to undertake comparative analysis of this kind, I will consider this as and when it becomes relevant to the discussion. Time, too, will make a difference. Given the years searched, there will even be an evolution of legal stances – the MCA 2005 itself came into force more than 40 years into the search period.

3.3.1 Involving various parties

Perhaps the most prominent theme from the literature is the complexity of these decisions in terms of which parties are and/or ought to be involved. When the patient is unable to make an autonomous decision about their own care, who should be involved in making the decision for them – and especially what balance of influence is appropriate – is not straightforward. The primary focus of the literature in this regard is the role of patients with cognitive impairments themselves and those close to them. However, there is also some discussion of interaction between professionals involved in the care of such patients.

3.3.1.1 Involving the patient

Even where the patient lacks the necessary mental capacity for dialysis decisions, the value of that patient being involved in decisions about their own care is highlighted. This is, in general, framed in terms of recognising the importance of patient autonomy, even though such patients would not be

deemed capable of autonomous choice. Some papers consider a duty on nephrologists to prepare for situations in which a patient has lost decision-making capacity. However, it is noted that patient wishes are often unclear.³⁹¹

First, Brennan and colleagues note that dementia does not necessarily mean a patient lacks decision-making capacity,³⁹² which reflects the principles of the MCA 2005. They argue that where capacity is uncertain, an assessment ought to be carried out. This is echoed by MacPhail and colleagues who assert the importance of recognising capacity as decision specific and that, therefore, patients with dementia (especially mild to moderate) may well be able to meaningfully participate in decisions about their own care.³⁹³

There appears to be strong support for some form of care planning as a means of involving patients in decisions about their own care.³⁹⁴ This is in part due to a recognition that a decline in a patient's cognitive functioning may go unnoticed until a critical incident, at which point it is too late to involve them in the decision-making process,³⁹⁵ but also that making decisions may prove less traumatic

³⁹¹ Feely MA, Albright RC, Thorsteinsdottir B, Moss AH, Swetz KM. 2014. Ethical challenges with hemodialysis patients who lack decision-making capacity: behavioral issues, surrogate decision-makers, and end-of-life situations. *Kidney International* 86(3):475-480. Feely and colleagues discuss medical, ethical, legal, and psychosocial challenges in caring for cognitively impaired patients with or approaching kidney failure.

³⁹² Brennan F, Stewart C, Burgess H, Davison SN, Moss AH, Murtagh FEM, Germain M, Tranter S, Brown M. 2017. Time to improve informed consent for dialysis: an international perspective. *Clinical Journal of the American Society of Nephrology* 12(6):1001-1009. Brennan and colleagues consider the ethical and legal requirements for valid informed consent to dialysis.

³⁹³ MacPhail A, Ibrahim JE, Fetherstonhaugh D, Levidiotis V. 2015. The overuse, underuse, and misuse of dialysis in ESKD patients with dementia. *Seminars in Dialysis* 28(5):490-496. MacPhail and colleagues seek to provide a framework of clinical considerations specific to patients with dementia and kidney failure, with a focus on decisions to initiate, forego, or withdraw dialysis.

³⁹⁴ *Ibid*; Conneen S, Tzamaloukas AH, Adler K, Keller LK, Bordenave K, Murata GH. 1998. Withdrawal from dialysis: ethical issues. *Dialysis & Transplantation* 27(4):200, 202-204; Kaye M, Lella JW. 1986. Discontinuation of dialysis therapy in the demented patient. *American Journal of Nephrology* 6(1):75-79; Keating RF, Moss AH, Sorkin MI, Paris JJ. 1994. Stopping dialysis of an incompetent patient over the family's objection: is it ever ethical and legal? *Journal of the American Society of Nephrology* 4(11):1879-1883; Pruchno RA, Lemay Jr EP, Field L, Levinsky NG. 2005. Spouse as health care proxy for dialysis patients: whose preferences matter? *Gerontologist* 45(6):812-819; Spike JP. 2007. Responding to requests for dialysis for severely demented and brain injured patients. *Seminars in Dialysis* 20(5):387-390. Conneen and colleagues provide an overview of ethical issues concerning dialysis withdrawal. Kaye and Lella present a framework for ethically managing the withdrawal from dialysis of patients who have become permanently demented, based in part on a questionnaire completed by dialysis staff and both dialysis and transplant patients. Keating and colleagues discuss the case of an elderly woman who has lost decision making capacity, and whose clinicians and family disagree on the best choice of care plan. Pruchno and colleagues analyse data on the preferences of spouses in dialysis decisions, comparing them with the preferences of patients. Spike discusses how to respond to dialysis requests from patients who are either severely demented or brain injured and provides some suggested guidelines.

³⁹⁵ MacPhail *et al.* (n393).

when the patient's own wishes are known.³⁹⁶ In a study by Scott and colleagues,³⁹⁷ several nephrologists viewed advance care planning (ACP) as a way of avoiding the need for a Best Interests decision. However, other participants in the same study felt it inappropriate to always follow previously stated patient preferences as it may be hard for patients to anticipate how they will feel about different treatment options ahead of time and the change in their health status may affect their preferences.³⁹⁸ This was also highlighted by Conneen and colleagues.³⁹⁹ Further, Clement and colleagues found that only 58% of French nephrologists participating in their study said they would be influenced by a patient's refusal to initiate dialysis, and that the majority would not respect a patient's request to discontinue dialysis (whether of 'sound mind' or not).⁴⁰⁰

In anticipation of a patient being unable to make their own dialysis decision, Keating and colleagues note the importance of advance directives as a specific form of ACP, and argue that they should be respected as a reflection of patient wishes.⁴⁰¹ Similarly, Ang and colleagues raise the idea of Ulysses contracts⁴⁰² as a means of capturing patients' earlier stated preferences in case their cognition starts to decline.⁴⁰³ However, DeCamp details a case in which the patient had written a living will, but the terms used were so general as to be practically useless.⁴⁰⁴ It is important, then, according to some,

³⁹⁶ Conneen *et al.* (n394).

³⁹⁷ Scott J, Owen-Smith A, Tonkin-Crine S, Rayner H, Roderick P, Okamoto I, Leydon G, Caskey F, Methven S. 2018. Decision-making for people with dementia and advanced kidney disease: a secondary qualitative analysis of interviews from the Conservative Kidney Management Assessment of Practice Patterns Study. *BMJ Open* 8(11):e022385. Scott and colleagues report secondary qualitative analysis of 60 semi-structured interviews across nine UK renal centres, considering how professionals value and discuss CKM.

³⁹⁸ *Ibid.*

³⁹⁹ Conneen *et al.* (n394).

⁴⁰⁰ Clement R, Chevalet P, Rodat O, Ould-Aoudia V, Berger M. 2005. Withholding or withdrawing dialysis in the elderly: the perspective of a western region of France. *Nephrology Dialysis Transplantation* 20(11):2446-2452. Clement and colleagues report the results of 17 interviews with French nephrologists across six nephrology units, considering the withholding or withdrawing of dialysis in the elderly.

⁴⁰¹ Keating *et al.* (n394).

⁴⁰² A Ulysses contract, in this context, is a decision made by a person with decision-making capacity with the intention of binding that person to that decision in future. This is the principle applied to advance directives. The Ulysses contract is based on the story of Ulysses (Odysseus in the original Greek), whereby he foresaw irrational thoughts on approaching the Sirens so instructed his men to prevent him going to them regardless of his later actions and instructions.

⁴⁰³ Ang A, Loke PC, Campbell AV, Chong SA. 2009. Live or let die: ethical issues in a psychiatric patient with end-stage renal failure. *Annals of the Academy of Medicine Singapore* 38(4):370-374. Ang and colleagues report a case in Singapore of a woman with schizoaffective disorder and kidney failure.

⁴⁰⁴ DeCamp M. 2011. Case study. Conjectural mixed motives. Commentary. *Hastings Center Report* 41(1):11-12. De Camp provides a commentary on a case where an ethics consultation was requested to consider whether a caregiver's burden undermined his legitimacy as a surrogate decision maker when recommending the withdrawal of his father's dialysis.

for there to be good communication between patients and surrogate decision makers before the need for a decision to be made arises.⁴⁰⁵ Such communication, it is suggested, should consider the preferences of the patient at different points in the progression of their illnesses to understand when they might change their view; this should also involve the surrogate decision maker developing an understanding of the reasons *why* the patient has the preferences they do so that they can better make decisions (consistent with those reasons) if faced with a scenario that had not been discussed.⁴⁰⁶ Kaye and Lella go on to argue for the documentation of these discussions, as well as regularly revisiting them.⁴⁰⁷ MacPhail and colleagues also advocate for regular cognitive assessments to allow impairment to be discovered quickly.⁴⁰⁸

However, Kaye and Lella also suggest that it can be appropriate to set aside the known wishes of the patient when doing so may benefit the family, going as far as to suggest it is mandatory unless the patient is undoubtedly experiencing severe suffering.⁴⁰⁹ This point is made in response to the particular case they discuss, in which the family later wrote to clinical staff explaining that on reflection they recognise that their insistence on keeping their relative alive on dialysis was a result of them thinking of themselves. The family justified this, stating that they do not consider it wrong to have done so as ‘this helpless man was bringing out something good from all of us’.⁴¹⁰ On this, Kaye and Lella also argue that the reverse can be true; if clinical staff and the family feel that the continuation of dialysis will cause unnecessary suffering, dialysis may be discontinued even if the patient had made clear that they wanted to continue.⁴¹¹ This is an outlier insofar as it questions the underlying importance of the patient’s own preferences (which other scholars have deemed of great importance and to be followed if known⁴¹²), and suggests that the interests of the family should be explicitly considered.⁴¹³

⁴⁰⁵ Kaye and Lella (n394); Pruchno *et al.* (n394).

⁴⁰⁶ Pruchno *et al.* (n394).

⁴⁰⁷ Kaye and Lella (n394).

⁴⁰⁸ MacPhail *et al.* (n393).

⁴⁰⁹ Kaye and Lella (n394).

⁴¹⁰ *Ibid*, 77.

⁴¹¹ *Ibid*.

⁴¹² Keating *et al.* (n394).

⁴¹³ The dominance of the family in decision making will be discussed shortly.

It must be noted, however, that in practice patients may not be involved in decisions about their care to the degree that this literature suggests they should. Some papers noted that patients may be overlooked due to a perception that cognitive impairment precludes any informed decision making, in part because of the complexity of dialysis.⁴¹⁴ Indeed, McDougall discusses a specific patient and notes that she cannot be involved in the decision due to her dementia.⁴¹⁵ Scott and colleagues found there to be divided appreciation of ACP,⁴¹⁶ which seems to again suggest exclusion rather than inclusion of patient views. On balance, this may be in part explained by the fact that a patient's ACP may show that they do not want dialysis if they develop dementia but provide insufficient details to act on; in practice, the preferences of patients vary between mild, moderate, and advanced dementia, with many wanting to forego dialysis only in the event of advanced dementia.⁴¹⁷

3.3.1.2 Family dominance

A particularly prominent sub-theme is that of family dominance in decision making. Whilst there is recognition that nephrologists are not obliged to provide treatment they consider inappropriate or excessively burdensome⁴¹⁸ and some nephrologists noted that they do not consider the family's decisions to be of primary importance,⁴¹⁹ some of the included papers reported that a fear of complaints or litigation can lead nephrologists to agree to the demands of relatives even when they think them not

⁴¹⁴ MacPhail *et al.* (n393); Scott *et al.* (n397).

⁴¹⁵ McDougall R. 2005. Best interests, dementia, and end of life decision-making: the case of Mrs S. *Monash Bioethics Review* 24(3):36-46. McDougall presents an ethical analysis of an Australian case in which the hospital treating an elderly woman with dementia wanted to withdraw her from dialysis.

⁴¹⁶ Scott *et al.* (n397).

⁴¹⁷ MacPhail *et al.* (n393).

⁴¹⁸ Brennan *et al.* (n392).

⁴¹⁹ Foote C, Morton RL, Jardine M, Gallagher M, Brown M, Howard K, Cass A. 2014. COnsiderations of Nephrologists when SuggestIng Dialysis in Elderly patients with Renal failure (CONSIDER): a discrete choice experiment. *Nephrology Dialysis Transplantation* 29(12):2302-2309; Perkins HS. 1990. Another ethics consultant looks at Mr. B's case: commentary on "An ethical dilemma. *Journal of Clinical Ethics* 1(2):126-132. Foote and colleagues present the results of a discrete choice experiment that was conducted among 159 Australian nephrologists. The discrete choice experiment sought to understand the relative influence of patient characteristics on dialysis recommendations. Perkins provides a commentary on the case of a 78-year-old man who was being considered for dialysis after an extended period in intensive care following surgery and later deterioration.

to be in the patient's best interests – so-called “defensive medicine”.⁴²⁰ Moss and colleagues found that 99% of dialysis unit medical directors surveyed would consult the family on care decisions concerning a patient who develops dementia.⁴²¹ In one US case, the clinical team agreed to the demands of an insistent family after being advised to do so by the hospital's legal team, because the family were substantial donors to that hospital.⁴²² In another, the wishes of the patient were, in essence, overridden by his daughter; a 72-year-old male had received two kidney transplants and did not want to return to dialysis if the second failed, but when it did fail his daughter insisted and the patient finally agreed.⁴²³ The line between persuasion and coercion was not clear in this case, and whilst this particular example concerns a patient who was able to agree himself, it is still demonstrative of the dominance of family in dialysis decisions, and it is reasonable to assume that this would be more pronounced in cases of patients with cognitive impairments.

This represents a clear disparity between generally accepted theory and practice. Theory tells us that the patient comes first and that decisions ought to reflect what is best for the patient, accounting for what the patient would likely have wanted. In practice, there is evidence that suggests this often does not happen. It is noteworthy, when considering family dominance in decision making, that there is evidence of families frequently failing to reflect the choices the patient would have made – generally being more in favour of life-sustaining treatment.⁴²⁴ MacPhail and colleagues also note that families mostly choose dialysis, but also that they often report being uninformed and unprepared to make these decisions.⁴²⁵

⁴²⁰ Feely *et al.* (n391); Keating *et al.* (n394); Ang *et al.* (n403). The issue of litigation was raised in the US context, with Feely and colleagues specifically noting a lesser tolerance for dangerous behaviour in the UK.

⁴²¹ Moss AH, Stocking CB, Sachs GA, Siegler M. 1993. Variation in the attitudes of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. *Journal of the American Society of Nephrology* 4(2):229-234. Moss and colleagues surveyed dialysis unit medical directors in the US on their attitudes toward decisions to withhold and withdraw dialysis. They specifically surveyed medical directors, which they justified on the basis that, compared to nephrologists more generally, medical directors would have more experience and be more knowledgeable of the demographics of their centre's population.

⁴²² Jones JW, McCullough LB. 2014. Extending life or prolonging death: when is enough actually too much? *Journal of Vascular Surgery* 60(2):521-522. Jones and McCullough discuss the fictitious case of an elderly man with dementia and kidney failure who is referred for vascular access to allow dialysis.

⁴²³ Brennan *et al.* (n392).

⁴²⁴ Keating *et al.* (n394); Pruchno *et al.* (n394).

⁴²⁵ MacPhail *et al.* (n393).

Whilst some argue that family should be involved in decisions⁴²⁶ - generally on the basis that they will represent the interests of the patient⁴²⁷ - there are equally concerns that substituted judgement (which is used in many legal jurisdictions as a way of making these decisions) may not be appropriate where the relative who is making the decisions would be the primary caregiver – especially in countries where the carer burden is significant.⁴²⁸ Relatives may also be unsuitable proxies if they do not know the patient well.⁴²⁹ This leads Keating and colleagues to argue that there is no moral authority for family to make medical decisions which do not reflect the patient’s wishes and, as such, nephrologists need not automatically comply with family decisions⁴³⁰ – and this reflects the “Best Interests” system in England and Wales. Perkins similarly employs fiduciary principles to argue that the clinician is responsible for ensuring that any decision making adequately protects the interests of the patient with cognitive impairment, which may mean making a decision without the input of the patient’s relatives.⁴³¹

Notwithstanding those difficulties and differences, there is broad consensus across the included papers that the family ought to be afforded *some* role in the decision-making process. Munoz Silva and Kjellstrand found there to be a trend in families taking a larger role in these decisions over time (having charted such decisions in the US from 1970 to 1983).⁴³² This is perhaps unsurprising at a time when medical paternalism was coming into question; where patient autonomy is not possible, vesting the decision-making power in the family might be considered preferable to the judgement of the treating nephrologist.⁴³³

Arguably at one extreme, Kaye and Lella reason that where there is a ‘significant benefit to be gained by the family’ – meaning some sort of solace or an opportunity for family members living far

⁴²⁶ Ang *et al.* (n403).

⁴²⁷ Keating *et al.* (n394).

⁴²⁸ DeCamp (n404).

⁴²⁹ Perkins (n419).

⁴³⁰ Keating *et al.* (n394).

⁴³¹ Perkins (n419).

⁴³² Munoz Silva JE, Kjellstrand CM. 1988. Withdrawing life support. Do families and physicians decide as patients do? *Nephron* 48(3):201-205. Munoz Silva and Kjellstrand compared the cases of 66 patients with decision-making capacity who chose to withdraw from dialysis and 66 patients without decision-making capacity who were withdrawn from dialysis because of decisions by families and physicians.

⁴³³ It should be noted that such an approach is prevalent in the US but is less so in England and Wales. Certainly, families are consulted, but the practice of Best Interests is intended as an alternative given the shortcomings of substitute decision making.

away to come and say goodbye – it would be ‘mandatory’ to override the previously stated wishes of the patient and keep them on dialysis.⁴³⁴ Such a position places the interests of family on par with, or even above, those of the patient.

Others have advocated for positions that still generally favour the family being central in the decision-making process,⁴³⁵ but fall significantly short of giving preference to their interests.⁴³⁶ For example, O’Dowd and colleagues, reflecting on a case in which they had prevented the brother of an incapacitated patient acting as proxy decision maker despite the patient having previously expressed such a preference, describe how they later came to regret that decision.⁴³⁷ They concluded that it would have been ‘better to go with the nonstranger surrogate than for us, who are all strangers, to make the decision’.⁴³⁸ Consulting the family extensively is similarly valued by Keating and colleagues, though they remain strongly supportive of the position that doctors are not obliged to provide any treatment they do not consider appropriate, and that there is no moral authority for families to make decisions independent of either the patients’ wishes or best interests.⁴³⁹ They do, however, strongly imply the family is a very powerful actor who they would not want to go against, preferring to transfer a patient to another care provider⁴⁴⁰ rather than provide treatment against the family’s wishes. Before doing so, however, they advocate attempting to understand the reasons for the family’s position, as this may highlight an easily resolved misunderstanding and help find resolution.⁴⁴¹ It is noteworthy that Keating and colleagues maintain this position, which implicitly accepts a significant role for family, despite noting how studies have demonstrated that families frequently fail to reflect the choices the patient would have made.⁴⁴²

⁴³⁴ Kaye and Lella (n394) 78.

⁴³⁵ Conneen *et al.* (n394); Keating *et al.* (n394); O’Dowd MA, Jaramilo J, Dubler N, Gomez MF. 1998. A noncompliant patient with fluctuating capacity. *General Hospital Psychiatry* 20(5):317-324. O’Dowd and colleagues report and discuss the case of a patient in the US who was noncompliant with dialysis.

⁴³⁶ Again, the differences between countries are highlighted here. All three of these studies originated in the US.

⁴³⁷ O’Dowd *et al.* (n435).

⁴³⁸ *Ibid.*, 324.

⁴³⁹ Keating *et al.* (n394).

⁴⁴⁰ This study originated in the US, where the transfer of patients between providers is more common than in England and Wales.

⁴⁴¹ Keating *et al.* (n394).

⁴⁴² *Ibid.*

Support for such a significant role for family is not, however, unanimous. McDougall writes:

‘[a]lthough there is generally a very important role for families in medical decision-making for incompetent patients, this role should be highly sensitive to the specific details of the patient’s situation and the nature of the particular family involved’.⁴⁴³

This position arises out of the case discussed by McDougall, in which she considers the view of the family to be wrong.⁴⁴⁴ This led her to question the common assumption that the family ought to act as decision makers for patients with dementia, as the family’s understanding of the patient’s values becomes less important in the face of the patient’s loss of self.⁴⁴⁵

3.3.1.3 Wider communication

Given the complexity of decisions concerning the initiation of, or withdrawal from, dialysis, it is unsurprising that strong communication arose as a sub-theme. Good communication between all parties is stressed as important, but particularly the central triad of patient, family, and dialysis team.⁴⁴⁶ In communicating with families, Brennan and colleagues write, ‘[n]ephrologists should be bilingual; they should speak the plain language of their patients and the technical language of their discipline’.⁴⁴⁷ This echoes the point made by Keating and colleagues that if a nephrologist does not feel that dialysis is appropriate they should seek to understand the reasons for families wanting continued treatment, as it may be based on a misunderstanding.⁴⁴⁸

⁴⁴³ McDougall (n415) 45.

⁴⁴⁴ *Ibid.*

⁴⁴⁵ Further discussion of this idea of ‘loss of self’ is to be found in my later discussion of substituted judgement.

⁴⁴⁶ Keating *et al.* (n394); Ang *et al.* (n403).

⁴⁴⁷ Brennan *et al.* (n392) 1006.

⁴⁴⁸ Keating *et al.* (n394).

Communication between professionals is also considered important.⁴⁴⁹ In their study, however, Scott and colleagues reported variation in how this was reflected in practice, with some interview participants reporting regular multidisciplinary Best Interests meetings whilst others reported situations in which the decision came down to what the consultant thought best.⁴⁵⁰ Some suggest that the involvement of other nephrologists in consultations may be appropriate where disagreement arises that presents a challenge to shared decision making,⁴⁵¹ and that a second opinion may even enable patient wishes to be understood more fully.⁴⁵² This is considered especially important by Ang and colleagues when the patient has multiple illnesses and is receiving care from doctors of other specialties.⁴⁵³

Jones and McCullough discuss a particular case in which a vascular surgeon receives a patient referral to establish vascular access for dialysis but does not believe that it is in the best interests of the patient.⁴⁵⁴ They argue it would be appropriate in such a scenario for the vascular surgeon to meet with the referring nephrologist to discuss the patient's care and raise concerns.⁴⁵⁵ For Kaye and Lella, the benefit of having input from other professionals, such as nurses and social workers, is the avoidance of a decision being made solely by the patient's nephrologist.⁴⁵⁶ The common thread here is the importance of seeking interprofessional agreement and the presumed benefit of reaching consensus from multiple perspectives; it is considered preferable to involve a broad range of individuals with an interest in the patient's care and have all parties on the same page regarding the care plan.

Some – notably those situated in the US – specifically discussed the potential role of clinical ethics committees/consultation.⁴⁵⁷ Feely and colleagues note that, in their experience, more difficult decisions about dialysis initiation tend to go to an ethics consultation, which they suggest is an appropriate course of action where there is no clear way forward.⁴⁵⁸ Similarly, Conneen and colleagues

⁴⁴⁹ Feely *et al.* (n391); Kaye and Lella (n394); Scott *et al.* (n397); Clement *et al.* (n400); Ang *et al.* (n403); Jones and McCullough (n422).

⁴⁵⁰ Scott *et al.* (n397).

⁴⁵¹ Feely *et al.* (n391).

⁴⁵² Clement *et al.* (n400).

⁴⁵³ Ang *et al.* (n403).

⁴⁵⁴ Jones and McCullough (n422).

⁴⁵⁵ *Ibid.*

⁴⁵⁶ Kaye and Lella (n394).

⁴⁵⁷ Feely *et al.* (n391); Conneen *et al.* (n394); Keating *et al.* (n394).

⁴⁵⁸ Feely *et al.* (n391).

consider ethics consultations a good way of discussing options in a non-adversarial and non-threatening forum – they do, however, stress the importance of documenting deliberations.⁴⁵⁹

What the literature demonstrates is some agreement that a collaborative approach is preferable to the subjective opinion of one nephrologist, and that good communication is essential to that.

3.3.2 Objectivity

Despite the value associated with shared decision making and the importance of individualised decisions, there is a clear concern in the included papers that both nephrologists and families may struggle to approach cases objectively – which indicates that value is placed on objective decision making.

3.3.2.1 *Validity of all care options*

One sub-theme arising is the importance of all care options being presented in a broadly objective manner, accompanied by appropriate information, thereby allowing the patient (or substitute decision maker, consultee etc.) to make an informed decision (or advise) without undue influence. Foote and colleagues found that some nephrologists dislike the phrase “recommend dialysis”, as a recommendation is not objective.⁴⁶⁰ Some note the importance of maintaining a neutral balance by explaining that CKM is not abandonment or opting out of treatment, but is a valid choice.⁴⁶¹ Beyond simply noting that all options are treatment, Spike suggests that nephrologists ought to reassure family

⁴⁵⁹ Conneen *et al.* (n394).

⁴⁶⁰ Foote *et al.* (n419).

⁴⁶¹ Brennan *et al.* (n392); MacPhail *et al.* (n393).

that it is both legal and ethical to stop treatment that offers no hope of meaningful recovery.⁴⁶² Spike also raises the possibility of enlisting the help of a local hospice to explain alternative options.⁴⁶³

However, reports of practice in the literature do not align with this idea of the importance of objectivity. CKM is often not raised as an option for patients⁴⁶⁴ and, argue Ying and colleagues, social expectations and other pressures have a tendency to lead to overdialysis.⁴⁶⁵ A case discussed by Ang and colleagues involved a patient who was eventually persuaded to go for dialysis – the option the nephrologist thought best⁴⁶⁶ - suggesting a lack of objectivity in how options were presented. Indeed, some nephrologists have been found to doubt the validity of patient refusals of treatment in the context of ESKD, assuming that a refusal is indicative of psychological problems.⁴⁶⁷

There is also a risk of dominant clinician views proving problematic before a patient even reaches the point of dialysis discussion. Campbell and colleagues found that primary care providers were less likely to refer patients with old age and moderate dementia to a nephrologist, with 257/680 accounted for in the study not being referred despite meeting the threshold for referral as per guidelines.⁴⁶⁸ This suggests that the reported tendency of nephrologists towards dialysis (noted above) is not shared by primary care providers. Nonetheless, it appears that the line between professional advice (coupled with the objective provision of information) and coercion is an interesting one that might be somewhat blurred at times. As such, Foote and colleagues argue that nephrologists should promote objectivity and consistency by recognizing their treatment preferences and the factors underpinning them.⁴⁶⁹

⁴⁶² Spike (n394).

⁴⁶³ *Ibid.*

⁴⁶⁴ Brennan *et al.* (n392).

⁴⁶⁵ Ying I, Levitt Z, Jassal SV. 2014. Should an elderly patient with stage V CKD and dementia be started on dialysis? *Clinical Journal of the American Society of Nephrology* 9(5):971-977. Ying and colleagues discuss whether an elderly patient with both kidney failure and dementia ought to be started on dialysis.

⁴⁶⁶ Ang *et al.* (n403).

⁴⁶⁷ Clement *et al.* (n400).

⁴⁶⁸ Campbell KH, Smith SG, Hemmerich J, Stankus N, Fox C, Mold JW, O'Hare AM, Chin MH, Dale W. 2011. Patient and provider determinants of nephrology referral in older adults with severe chronic kidney disease: a survey of provider decision making. *BMC Nephrology* 12:47. Campbell and colleagues report the results of a survey based on vignettes, which sought to determine when primary care providers would refer a patient to a nephrologist.

⁴⁶⁹ Foote *et al.* (n419).

3.3.2.2 Difficulties with family detachment

Family members – and indeed unrelated individuals who are close to patients and might be involved in care decisions – have also been found to struggle with objectively assessing treatment options. Patients often prefer family members to provide input when making decisions.⁴⁷⁰ However, as noted above, the assumption that the family will decide in the best interests of the patient may not always be correct,⁴⁷¹ and families have been found to make decisions more in their own interests than those of the patient.⁴⁷² For example, instances have been reported in the literature of carers preferring patients to receive in-centre haemodialysis as it gives them a rest a few times a week,⁴⁷³ and Spike noted a case in which the care team had concerns that a patient's wife agreed to the withdrawal of dialysis only because she was fed up.⁴⁷⁴ Scott and colleagues report a common belief among some nephrologists that families who want aggressive treatment do not fully appreciate the rigours of dialysis, and may be unwilling to accept mortality; some were reported to opine that some families harbour the unrealistic expectation that dialysis will cure all of their loved one's issues.⁴⁷⁵

Brennan and colleagues highlight that patients sometimes make decisions themselves (where they can) on the basis of the perceived needs and wants of their family,⁴⁷⁶ demonstrating the strength of family influence. Ang and colleagues suggest that it may be hard for family who are the main caregivers not to bring their own judgement into decisions when the caregiver burden and financial expenses are significant.⁴⁷⁷ Seconding this, DeCamp asks whether substituted judgement will be pure when the deciding party is the primary caregiver⁴⁷⁸ – arguably there would always be some conflict of interest.

⁴⁷⁰ DeCamp (n404).

⁴⁷¹ Conneen *et al.* (n394).

⁴⁷² Scott *et al.* (n397).

⁴⁷³ *Ibid.*

⁴⁷⁴ Spike J. 2000. Narrative unity and the unraveling of personal identity: dialysis, dementia, stroke, and advance directives. *Journal of Clinical Ethics* 11(4):367-372. Spike discusses the case of an elderly patient with declining cognition who required dialysis.

⁴⁷⁵ Scott *et al.* (n397).

⁴⁷⁶ Brennan *et al.* (n392).

⁴⁷⁷ Ang *et al.* (n403).

⁴⁷⁸ DeCamp (n404).

3.3.3 Cultural sensitivity

Another theme arising in the included papers is cultural sensitivity. This is particularly relevant given my earlier discussion of respecting patient autonomy, which does not hold the central importance everywhere that it does in Western cultures. As such, Davison and Holley suggest that ACP and other ‘autonomy respecting’ interventions may not be suitable if self-determination is not important within the patient’s culture.⁴⁷⁹

In some cultures, the head of the family assumes the decision-making role⁴⁸⁰ and atomistic autonomy is replaced by the idea of the relational self.⁴⁸¹ In a study comparing the role of advance directives between countries, Sehgal and colleagues found Japanese nephrologists to be far less willing to follow an advance directive when the patient’s family disagree with it; willingness of nephrologists to withdraw dialysis in line with an advance directive fell from 88% when the family agreed to 19% when the family disagreed.⁴⁸² Sehgal and colleagues posit a possible reason for this to be the greater emphasis on social relatedness in Japan as opposed to the notion of the autonomous self, going on to note that in Japan it is not uncommon for doctors and families to make care decisions on behalf of *competent* patients.⁴⁸³

For patients whose culture requires the family to be responsible for care, peritoneal dialysis may be preferable as it is an at-home option; Davison and Holley argue that it is important to consider cultural factors in deciding on treatment modality.⁴⁸⁴ However, it is highlighted as equally important that no assumptions are made, as patients may have blended cultural perspectives if they have moved

⁴⁷⁹ Davison SN, Holley JL. 2008. Ethical issues in the care of vulnerable chronic kidney disease patients: the elderly, cognitively impaired, and those from different cultural backgrounds. *Advances in Chronic Kidney Disease* 15(2):177-185. Davison and Holley consider what ethical issues arise in caring for patients with kidney failure, with a particular focus on the elderly, the cognitively impaired, and patients from varied cultural backgrounds.

⁴⁸⁰ Brennan *et al.* (n392).

⁴⁸¹ Davison and Holley (n479).

⁴⁸² Sehgal AR, Weisheit C, Miura Y, Butzlaff M, Kielstein R, Taguchi Y. 1996. Advance directives and withdrawal of dialysis in the United States, Germany, and Japan. *Journal of the American Medical Association* 276(20):1652-1656. Sehgal and colleagues present the results of a questionnaire which asked nephrologists in the US, Germany, and Japan whether they would continue or discontinue dialysis in eight hypothetical cases.

⁴⁸³ *Ibid.*

⁴⁸⁴ Davison and Holley (n479).

from, for example, a non-Western country to a Western country.⁴⁸⁵ Overall, then, there is a suggestion that nephrologists ought to be culturally sensitive and open to different values, whilst making no assumptions.

3.3.4 Medical versus non-medical factors

No two patient cases are entirely alike, and myriad factors may contribute to a conclusion about the best course of action in any given situation. Many such factors are identified in the literature, ranging from family support to survival benefit. Of course, there is also complex interplay between these factors, and various trade-offs that might be considered. As noted by Clement and colleagues, decisions are often a risk-benefit assessment that accounts for both clinical (medical) and social factors (non-medical).⁴⁸⁶

3.3.4.1 Medical factors

The included literature clearly conveys the message that these decisions are not as simple as ESKD necessitating dialysis. The clinical status (including co-morbidities) of patients beyond kidney function is also relevant, and the presence of cognitive impairment itself is felt by some to be relevant to the dialysis decision.

In several of the included papers, it was shown that some participants and authors felt that the presence of cognitive impairment itself was justification for denying dialysis.⁴⁸⁷ One participant clearly stated, 'I don't think severely demented patients should be dialysed'.⁴⁸⁸ Spike argues that when a patient has suffered a permanent loss of cognition, the presumption should move from the continuation of life-

⁴⁸⁵ *Ibid.*

⁴⁸⁶ Clement *et al.* (n400).

⁴⁸⁷ *Ibid*; Foote *et al.* (n419).

⁴⁸⁸ Foote *et al.* (n419) 2307.

sustaining treatment to its withdrawal.⁴⁸⁹ Davison and Holley are less certain, but suggest that profound neurological impairment might justify the foregoing of dialysis.⁴⁹⁰ The reasoning behind this, suggest Conneen and colleagues, is that when a patient is cognitively impaired – dementia being the focus of their article – dialysis no longer accomplishes the goal of permitting function as a human being, but instead prolongs the dying process.⁴⁹¹ This view is echoed by Keating and colleagues.⁴⁹² However, Moss and colleagues found there to be little agreement among dialysis unit medical directors as to whether they would continue dialysis for a patient who develops dementia and has no advance directive.⁴⁹³

The findings of Foote and colleagues demonstrate a higher likelihood of a patient being recommended for dialysis if they have preserved cognition,⁴⁹⁴ which was similarly found by Munoz Silva and Kjellstrand in the context of permanently unconscious patients.⁴⁹⁵ In noting that evidence suggests a typical patient with dementia will not get a survival benefit from dialysis, MacPhail and colleagues argue that an individual decision is necessary.⁴⁹⁶ They argue that this prevents generalisations impacting on care, as some patients with dementia may get a survival benefit. On individualised decisions for patients with both ESKD and dementia, Ying and colleagues also highlight that generic rules can result in socioeconomic disadvantage, as less educated patients are more likely to be diagnosed with dementia.⁴⁹⁷

Survival benefit is generally considered an important factor. MacPhail and colleagues argue the need to consider illness trajectory, noting that older patients are likely to gain only negligible survival benefit.⁴⁹⁸ A participant in a study by Foote and colleagues said that one of his general principles is ‘to avoid dialysis in the population >80’.⁴⁹⁹ The reason for this view is not made clear, though is likely attributable to consideration around survival benefit. Clement and colleagues also found that prognosis

⁴⁸⁹ Spike (n394).

⁴⁹⁰ Davison and Holley (n479).

⁴⁹¹ Conneen *et al.* (n394).

⁴⁹² Keating *et al.* (n394).

⁴⁹³ Moss *et al.* (n421).

⁴⁹⁴ Foote *et al.* (n419).

⁴⁹⁵ Munoz Silva and Kjellstrand (n432).

⁴⁹⁶ MacPhail *et al.* (n393).

⁴⁹⁷ Clement *et al.* (n400). They note that tests of cognitive ability look for signs that more educated individuals are more likely to demonstrate.

⁴⁹⁸ MacPhail *et al.* (n393).

⁴⁹⁹ Foote *et al.* (n419) 2307.

was an important consideration among participants in their study.⁵⁰⁰ It is when survival benefit is limited, and the patient has multimorbidity – including dementia – that CKM is most frequently considered.⁵⁰¹ Davison and Holley also consider comorbidities as particularly relevant, arguing that withholding dialysis may be appropriate if the patient has a non-renal terminal condition.⁵⁰²

Clearly, the presence of comorbidities does impact on how beneficial dialysis can be, and there seems to be widespread support for comorbidities being relevant to dialysis initiation decisions. However, there appears to be disagreement about how influential comorbidities ought to be, and whether cognitive impairment in particular is an appropriate candidate for a blanket exclusion criterion.

3.3.4.2 Non-medical factors

As important as medical factors appear to be in decisions, the literature also demonstrates a consistent appreciation of non-medical factors. Quality of life is widely considered relevant to dialysis initiation decisions,⁵⁰³ which reflects an acknowledgement of how burdensome dialysis can be. Foote and colleagues found that nephrologists, when making recommendations for dialysis, were willing to forego 12 months of survival if it would avoid a significant decrease in the patient's quality of life.⁵⁰⁴ However, others highlight how an attitude of “treat what you can” sometimes results in the continuation of treatment despite, for example, severe frailty.⁵⁰⁵ Nonetheless, in considering quality of life, MacPhail

⁵⁰⁰ Clement *et al.* (n400).

⁵⁰¹ Scott *et al.* (n397).

⁵⁰² Davison and Holley (n479).

⁵⁰³ Feely *et al.* (n391); MacPhail *et al.* (n393); Spike (n394); Scott *et al.* (n397); Clement *et al.* (n400); McDougall (n415); Foote *et al.* (n419).

⁵⁰⁴ Foote *et al.* (n419). The question of survival benefit and what patients will and will not sacrifice is currently being explored through discrete choice experiment as part of The UNPACK Study. Hole B. 2017. *The UNPACK study: Understanding treatment preferences of older Patients and their families deciding between dialysis and comprehensive conservative Care for Kidney failure*. <<https://fundingawards.nihr.ac.uk/award/DRF-2017-10-127>>.

⁵⁰⁵ Feely *et al.* (n391).

and colleagues argue that it should be routinely evaluated; the current focus on efficacy in clinical reviews is, they suggest, too narrow.⁵⁰⁶

If quality of life is an important factor, the question of how it should be measured and accounted for becomes important. Some appear to automatically associate cognitive impairment with low quality of life. Spike, for example, suggests that those with advanced dementia or a severe and irreversible brain injury get no benefit from dialysis as they are no longer capable of enjoying life.⁵⁰⁷ Some participants in Scott and colleagues' study questioned whether patients with cognitive impairment have sufficient quality of life, especially if they are bed bound and have to attend dialysis sessions on a stretcher.⁵⁰⁸ Along similar lines, Kaye and Lella focus on a distinction between biological life and a 'higher variant' which is specifically human; 'life' in the body (i.e. respiration, heart beat, excretion) permanently without awareness, or a minimal ability to relate to other people, is life without the essence of humanity'.⁵⁰⁹ To keep such a patient on dialysis is, they argue, to prolong dying rather than life, which is 'morally unsound'.⁵¹⁰ However, MacPhail and colleagues note that quality of life can be very similar for patients on dialysis and those undergoing CKM, with the main difference being that dialysis patients generally spend more time in hospital and are therefore more likely to die there.⁵¹¹ This is important to consider as whilst quality of life may be comparable more generally between dialysis and CKM, some patients will much prefer to minimise time spent at hospital; in particular, some will not want to die there.

When considering quality of life, it is usually important to engage with the patient to ascertain their own views. However, acknowledging the challenges of involving patients with cognitive impairments (specifically those with dementia) in decisions about their own care – as I have discussed above – McDougall suggests one approach may be to consider the interests and preferences of dementia

⁵⁰⁶ MacPhail *et al.* (n393).

⁵⁰⁷ Spike (n394).

⁵⁰⁸ Scott *et al.* (n397).

⁵⁰⁹ Kaye and Lella (n394) 77.

⁵¹⁰ *Ibid.*

⁵¹¹ MacPhail *et al.* (n393).

patients generally.⁵¹² Patients living with dementia will not necessarily experience life on dialysis to be of low quality, for example.

There is little support in the literature reviewed for consideration of resources in dialysis decisions. Spike does consider dialyzing patients with permanent cognitive impairments a violation of the responsibility to use resources wisely,⁵¹³ though this view is unique among the studies included. Further, Spike acknowledges that those with less severe dementia sometimes appear happy, so it may not be easy to draw the line.⁵¹⁴ Cady discusses a hypothetical case in which the renal team cite significant use of resources as a reason for not wanting the patient to initiate dialysis, though they still appeal primarily to questions of harm and benefit to the individual patient.⁵¹⁵ She goes on to argue that the distributive justice argument is ‘weak at best’ as such an approach at the patient level ‘undermines the integrity and violates the trust inherent in the physician-patient and/or nurse-patient relationship’.⁵¹⁶ Conneen and colleagues reject a utilitarian approach to resource allocation in favour of individual best interests.⁵¹⁷ Further, both McDougall and Kaye and Lella argue that nephrologists should ignore wider issues of cost and resource allocation when making decisions for individual patients.⁵¹⁸

The importance of support outside of the clinical setting was highlighted in some papers. Several studies discussed the importance of support systems, with Foote and colleagues noting the importance of family inclination towards dialysis.⁵¹⁹ Scott and colleagues found that some nephrologists even consider family support to be more important to the success of dialysis than age or clinical condition.⁵²⁰ Of note, however, they highlight that support is also important to the success of CKM.⁵²¹

⁵¹² McDougall (n415).

⁵¹³ Spike (n394).

⁵¹⁴ *Ibid.*

⁵¹⁵ Cady PA. 1990. An ethical dilemma in clinical practice: termination versus continuation of life-sustaining treatment. *Journal of Clinical Ethics* 1(2):123-126. Cady provides a commentary on the case of a 78-year-old man who was being considered for dialysis after an extended period in intensive care following surgery and later deterioration – the same as Perkins (n419).

⁵¹⁶ Cady (n515) 126.

⁵¹⁷ Conneen *et al.* (n394).

⁵¹⁸ Kaye and Lella (n394); McDougall (n415).

⁵¹⁹ Foote *et al.* (n419).

⁵²⁰ Scott *et al.* (n397).

⁵²¹ *Ibid.*

The extent to which support networks might factor into the decision between dialysis and CKM is, then, not clear.

Nonetheless, O'Rourke and colleagues argue that it is appropriate to account for carer burden, including both actual and opportunity costs.⁵²² This is interesting given my earlier discussion of family dominance in decisions, with relatives sometimes found to have agreed to the patient foregoing dialysis as it would be too burdensome for those relatives. However, equally, I highlighted those who chose to keep a patient alive for their own benefit, something which both Keating and colleagues and McDougall consider inappropriate. Both argue that subjecting a patient to dialysis in order to provide an emotional benefit to the family is unacceptable,⁵²³ with Keating and colleagues making a Kantian argument that to do so would be treating that patient as a means to an end.⁵²⁴

A final non-medical factor that was commonly discussed was patient nonadherence. As this was particularly dominant in the papers, I have decided to discuss it separately in the next section.

3.3.5 Managing nonadherent patients

There is widespread recognition that nephrologists are under no obligation to provide dialysis where they consider it inappropriate or excessively burdensome.⁵²⁵ Spike notes the importance of being willing to withdraw treatment when it is no longer beneficial.⁵²⁶ One possible reason for withdrawing (or, indeed, withholding) care is nonadherence.

As dialysis (specifically in-centre haemodialysis) requires the patient to sit still for an extended period, when a patient becomes agitated and tries to remove needles there is a risk of harm not only to

⁵²² O'Rourke G, Methven S, Lloyd L. 2019. To dialyse or not to dialyse - is that the question? A psychosocial perspective on dilemmas concerning dialysis for people with dementia. *Dementia* 18(4):1341-1353. O'Rourke and colleagues present the results of a literature review that considers a psychosocial perspective on dialysis dilemmas concerning patients with dementia.

⁵²³ Keating *et al.* (n394); McDougall (n415).

⁵²⁴ Keating *et al.* (n394).

⁵²⁵ Brennan *et al.* (n392); MacPhail *et al.* (n393); Spike (n394).

⁵²⁶ Spike (n394).

the patient but to anyone else present. In such situations, the option of restraining the patient for the duration of treatment might be considered. O'Dowd and colleagues present a US case in which a patient with fluctuating capacity was dialyzed against his will whilst the care team awaited a court decision about whether continued dialysis was in his best interests.⁵²⁷ The court later authorised the hospital to take all measures necessary to provide treatment, including sedation.⁵²⁸ The following passage describes the resulting situation:

'[w]e ended up deciding that he would be treated against his will which at times involved dragging a kicking, screaming, hitting person, who may have been HIV+, down to dialysis, strapping him down for 4 hours, putting needles in his arms, and dialyzing him. The dialysis staff was not happy about this and it wasn't clear that it was the best thing or the right thing to do'.⁵²⁹

In this case the staff were uncomfortable with the situation and were undecided whether dialysis under physical restraint was best for the patient. In another case (this one in England and Wales), discussed by Grubb, the clinical team sought a declaration from the court that it was in the best interests of a patient who lacked decision-making capacity, and was uncooperative, to not impose haemodialysis.⁵³⁰ The court agreed, which the author suggests could be because the judge did not consider the regular use of a high degree of force to be in a patient's best interests. Feely and colleagues also consider a case of a violently resistant patient who, when not on dialysis, clearly expressed a desire to continue with therapy.⁵³¹ The clinical team was unsure of the best way to proceed in terms of respecting the patient's

⁵²⁷ O'Dowd *et al.* (n435).

⁵²⁸ *Ibid.*

⁵²⁹ *Ibid.*, 322.

⁵³⁰ Grubb A. 1998. Refusal of treatment (incompetent patient): best interests and practicality -- Re D (Medical Treatment: Mentally Disabled Patient). *Medical Law Review* 6(1):103-105. Grubb comments on a case in England and Wales in which a patient with a history of psychiatric problems requires dialysis. This paper did originate from England and Wales but was published prior to the enactment of the MCA 2005. As such, whilst the language of best interests is used, it ought to be taken in its more general sense.

⁵³¹ Feely *et al.* (n391).

autonomy and ensuring the safety of both the patient and those around him.⁵³² McDougall notes that a patient removing needles several times during treatment is a clear sign of distress⁵³³ – the implication being that distress is contrary to their interests.

Ying and colleagues argue that where a patient is agitated and restraint becomes necessary to perform dialysis, the restraint should be taken as an additional harm to be considered in the benefit/burden analysis.⁵³⁴ In addition, Feely and colleagues suggest it is appropriate to consider the safety of others in these situations, and that discontinuation of dialysis can be justified if the risks to others cannot be mitigated.⁵³⁵ Further, in the context of dialysis trials, Scott and colleagues found that some nephrologists consider that where patient behaviour puts someone at risk it would be appropriate to cease that trial.⁵³⁶ MacPhail and colleagues note that cooperation is generally considered a prerequisite for dialysis in many guidelines, which becomes relevant with patients with dementia as an outpatient dialysis centre is not a dementia friendly environment.⁵³⁷ Whereas the aforementioned scholars do not go as far as to suggest an automatic ruling out of dialysis where restraint is necessary, Spike does, making the case that the need for restraint is *prima facie* evidence that dialysis is no longer justified.⁵³⁸ Further, in an earlier paper, Spike discussed a wife who was more strongly in favour of discontinuing her husband's dialysis when she found out he would have to be sedated for every session.⁵³⁹

It may be that freedom from restraint is more highly valued than the life extension dialysis affords, from the perspectives of both nephrologists and those close to patients. That being the case, to forcibly dialyze a patient who is severely uncooperative might usually be deemed not to be in their Best Interests.

⁵³² *Ibid.*

⁵³³ McDougall (n415).

⁵³⁴ Ying *et al.* (n465).

⁵³⁵ Feely *et al.* (n391).

⁵³⁶ Scott *et al.* (n397).

⁵³⁷ MacPhail *et al.* (n393).

⁵³⁸ Spike (n394).

⁵³⁹ Spike (n474).

3.3.6 Substituted judgement

Demonstrative of the strong representation of the US context in the literature, there is significant discussion of substituted judgement. There is also some (albeit negligible) discussion of an alternative best interests approach - though it should be noted that such discussions are not necessarily of “Best Interests” in the context of the MCA 2005, but best interests as an ethical principle. Nonetheless, substituted judgement was the far more dominant theme.

There is certainly evidence of support for the view that, when making a treatment decision for patients lacking capacity, families have a duty to replicate as far as possible the choice that the patient would have made themselves⁵⁴⁰ – this is substituted judgement. However, there is disagreement over whether substituted decisions are made properly. It is highlighted by some that surrogate decision makers frequently fail to predict patient preferences correctly,⁵⁴¹ and argued that this can undermine the principle of respect for autonomy that underpins substituted judgement approaches.⁵⁴² In contrast, Munoz Silva and Kjellstrand suggest that substituted judgement is generally used wisely, as they found little difference between patients who chose to stop dialysis themselves and those who had the decision to stop made for them by another in terms of type of, site of, and time on dialysis.⁵⁴³ Regardless of whether one considers substituted judgement appropriate, Cady highlights that it may not be reliable because the people to whom the decision would fall may decline to make decisions on behalf of the patient.⁵⁴⁴

For substituted judgement to work, McDougall argues that the patient at the time of the decision must be understood to be the same as the patient known by the surrogate decision maker.⁵⁴⁵ Patients with dementia, however, suffer ‘discontinuity of self’, so McDougall argues that appropriateness of substituted judgement ought to be questioned – especially where the previous and current interests of

⁵⁴⁰ Conneen *et al.* (n394); Keating *et al.* (n394).

⁵⁴¹ DeCamp (n404).

⁵⁴² Pruchno *et al.* (n394).

⁵⁴³ Munoz Silva and Kjellstrand (n432).

⁵⁴⁴ Cady (n515).

⁵⁴⁵ McDougall (n415).

the patient conflict.⁵⁴⁶ Even without this discontinuity, Perkins suggests that a relative acting as a substitute decision maker may be unsuitable in that role if they do not know the patient well.⁵⁴⁷

The importance of individualised decisions is also stressed. MacPhail and colleagues call for this individualised approach in the context of patients with dementia to avoid the provision of inappropriate treatments, noting the importance of early, patient-centred discussion of treatment options,⁵⁴⁸ but their point can certainly be expanded to include any cognitive impairment. In particular, those with fluctuating capacity would stand to benefit, as they are not always unable to make their own care decisions.⁵⁴⁹

Whilst it is not widely discussed, a distinction is drawn in the literature between substituted judgement and Best Interests.⁵⁵⁰ McDougall highlights criticism of the patient-focused nature of the Best Interests approach, as it does not consider morally relevant burden to others.⁵⁵¹ Even if a patient-focused approach is taken, MacPhail and colleagues argue the need to regularly revisit decisions, as what is initially appropriate may become unacceptably burdensome as the patient's cognitive impairment (dementia is the focus in this paper) progresses.⁵⁵² Perkins also seems to touch on the idea of Best Interests, albeit without labelling it as such, when he notes that '[t]he physicians and nurses should interview his [a hypothetical patient] niece, neighbors [sic], bowling teammates, and friends from the senior citizens' center to learn about Mr. B's life style, joys, and previously expressed wishes about medical care'.⁵⁵³

Substituted judgement is very clearly the main focus of the literature. Very little attention is paid to the alternative of Best Interests in the context of dialysis decisions. This is not entirely surprising as the majority of the literature is written in the US context, and it spans more than three decades. Nonetheless, shortcomings of both approaches are highlighted.

⁵⁴⁶ *Ibid.*

⁵⁴⁷ Perkins (n419).

⁵⁴⁸ MacPhail *et al.* (n393).

⁵⁴⁹ Grubb (n530).

⁵⁵⁰ Ang *et al.* (n403).

⁵⁵¹ McDougall (n415).

⁵⁵² MacPhail *et al.* (n393).

⁵⁵³ Perkins (n419) 131.

3.4 Discussion

This scoping review has brought together a range of arguments and evidence pertaining to dialysis decisions made with, for, and on behalf of adults with cognitive impairments with or approaching ESKD. What is hugely apparent from the literature is that there is little consensus on any aspect of this topic. In part, this can be attributed to the range of jurisdictions and years covered – it is to be expected that there will be differences across borders and that ideas will change over time.

Whilst patients are at the centre of these decisions, there are many other stakeholders with arguably legitimate interests who would like to, do, and often should contribute to the decision-making process. However, accommodating all legitimate interests is a difficult balancing act. Families are highlighted as often being dominant in these decisions, which is problematic in several ways. It should be noted that the way families are portrayed may not be a fair reflection of all families in these scenarios, but it remains that this idea of dominance is clearly highlighted in the included papers. First, it is suggested that families often fail to accurately represent the patient's preferences, whether intentionally or not.⁵⁵⁴ Families also tend to favour dialysis in almost all situations, generally viewing it as a default “safe” option.⁵⁵⁵ Sometimes, families may choose to keep the patient alive because doing so is in their own interests (such as wanting to spend more time with them), which is supported by some of the literature.⁵⁵⁶ This seems to be based on the consequentialist argument that everyone's interests matter equally, and so there should be no default assumption that the interests of the patient outweigh those of affected relatives. Family decision makers may also have unrealistic expectations of what dialysis can do for their relative in terms of curing several ills. The role of the family does vary across jurisdictions, and (in this review) appears most significant in the US, which some have suggested is the result of a more litigious and money-oriented health care system.⁵⁵⁷ The literature included in this review represents a range of jurisdictions (as detailed earlier in this paper), and the significance placed on the

⁵⁵⁴ Keating *et al.* (n394); Pruchno *et al.* (n394).

⁵⁵⁵ *Ibid.*

⁵⁵⁶ Kaye and Lella (n394).

⁵⁵⁷ Feely *et al.* (n391); Keating *et al.* (n394); Ang *et al.* (n403).

family in decisions in the US is not necessarily a legal issue,⁵⁵⁸ but the ethical concerns raised about it are clear. Regardless of any merit one sees in this approach, it is not in keeping with the requirements of England and Wales' MCA 2005; the MCA 2005 Code of Practice is clear that what the family wants is not relevant to a Best Interests decision.⁵⁵⁹ Of note, none of the studies highlighting family dominance in decisions originated in the UK. Excluding those that were published prior to the enactment of the MCA 2005, one possible explanation for this is that the law is being well applied and that the role of the family is being limited to reporting the patient's views and preferences. Another possible explanation is that the kind of research that could expose family dominance in these decisions is not being done in the UK, or that participants in such studies are aware of how they should and should not present accounts of decision making to be consistent with the law. This highlights a research need that this project seeks to satisfy.

Cultural variation is also highlighted as a potential reason for dominant involvement of the family. The importance of autonomy is a heavily Western perspective, and some cultures favour less individualistic approaches to care decisions.⁵⁶⁰ This raises important questions about how clinicians should navigate complex decisions about medical treatment with, for, and on behalf of patients without decision-making capacity when such patients are from cultural backgrounds that value autonomy differently and have different expectations and norms about the role of family in decision making. The particular risk is that we make wrong assumptions about what a person with a cognitive impairment would want, based solely on their apparent cultural background. Whether clinicians make cultural assumptions or consult those close to the patient to ascertain pertinent cultural values, a further challenge may arise in simultaneously navigating these cultural values and the requirements of legislation. Considering two different countries where autonomy is generally highly valued, this may be more straightforward in the US, for example, where (for whatever reason) overt family involvement (or dominance) appears more usual, but in England and Wales (in the context of the MCA 2005), even

⁵⁵⁸ By which I mean the MCA 2005 is not applicable in the US. Instead, a legal model that affords more decisional power to the family exists.

⁵⁵⁹ Department for Constitutional Affairs (n4).

⁵⁶⁰ Brennan *et al.* (n392); Davison and Holley (n479).

if it is apparent that the patient lacking decision-making capacity holds values that clearly point to the family as favoured decision makers, the law still does not permit the family to act as surrogate decision makers in the absence of a formal proxy appointment. Thus, when the patient's perceived preferences (which the MCA 2005 says must be considered) do not align with the Act's assignment of decision-making roles, it becomes very difficult to be sensitive to this particular aspect of cultural difference. There was limited discussion of the complexities of cultural sensitivity in the literature, but this is an important point to consider in a scenario where the family are looked to as representatives of the patient's own views and preferences.

Overall, it is clear from the literature that families – or, more accurately, those close to the patient – tend to play a significant role in the decision-making process. However, whilst this clinical reality is somewhat reflected in theoretical stances, there is a disconnect. Arguments as to how decisions *should* be made tend to favour a more balanced approach whereby a nephrologist can justifiably question the input of a family and decline to proceed with its request when, from the perspective of the nephrologist, that request is not in the Best Interests of the patient. This supports the MCA 2005's creation of the consultee role, even if decisions are not always made this way in practice.

Whilst family dominance appears common, there is recognition of the importance of other perspectives. In particular, given how common comorbidities are in the ESKD population, the importance of inter-specialty communication is raised.⁵⁶¹ As individuals beyond the renal team will often be involved in the care of a patient with ESKD, there is a suggestion that a decision is better if some sort of consensus is reached. However, according to the literature, this is not always the case in practice.⁵⁶² Whilst some clinicians were reported in empirical studies to consider it important to present care options objectively and avoid undue influence,⁵⁶³ in several cases nephrologists appear to doubt patient refusals and consider them indicative of psychological problems.⁵⁶⁴ Those in the latter category may consider it acceptable not to take these refusals as informed, autonomous refusals and therefore act

⁵⁶¹ Feely *et al.* (n391); Kaye and Lella (n394); Scott *et al.* (n397); Clement *et al.* (n400); Ang *et al.* (n403); Jones and McCullough (n422).

⁵⁶² Scott *et al.* (n397).

⁵⁶³ Foote *et al.* (n419).

⁵⁶⁴ Clement *et al.* (n400).

paternalistically. In the context of the Best Interests approach in England and Wales, to treat a patient as lacking decision-making solely on the basis that their decision is not perceived by the clinician as “good”, “right”, or “wise” is contrary to section 1(4) of the MCA 2005 which protects the right of patients to make “unwise” decisions.

A final, and important, related point is that the literature considers ways of avoiding the need for these decisions in the first place. Various forms of ACP are highlighted as a way of respecting the patient’s own wishes,⁵⁶⁵ thereby avoiding potential family dominance and/or paternalism. However, discussion of the pitfalls of such approaches also arises.⁵⁶⁶ On a practical note, there is the importance of the level of detail in advance discussions. With dementia, for example, the care preferences of a patient can realistically be expected to be different depending on whether they have mild, moderate, or severe dementia. Distinguishing between these as part of ACP can be challenging, first because the gaps between mild and moderate and moderate and severe may be difficult to grasp in advance, and second because ACPs may not contain the necessary level of specificity. Going beyond a discussion of care preferences in the abstract, and considering the patient’s views on treatment in very specific scenarios, can help avoid situations in which recorded patient wishes in relation to future contexts are unclear, but to do so effectively would require such detail so as to be hugely cumbersome. That is before one accounts for the need to keep such plans up to date, and the difficulties raised by the problem of the discontinuous self.

It is perhaps unsurprising that the literature devotes a good deal of space to quality of life, and how it does and ought to factor in decisions about dialysis. This arose in many papers,⁵⁶⁷ though different positions were taken. Whilst some favoured quality of life over quantity (to an extent),⁵⁶⁸ others highlighted the presence of a “treat what you can” attitude.⁵⁶⁹ Of particular interest, some

⁵⁶⁵ MacPhail *et al.* (n393); Conneen *et al.* (n394); Kaye and Lella (n394); Keating *et al.* (n394); Pruchno *et al.* (n394); Spike (n394).

⁵⁶⁶ DeCamp (n404).

⁵⁶⁷ Feely *et al.* (n391); MacPhail *et al.* (n393); Spike (n394); Scott *et al.* (n397); Clement *et al.* (n400); Foote *et al.* (n419).

⁵⁶⁸ Foote *et al.* (n419).

⁵⁶⁹ Feely *et al.* (n391).

suggested that cognitive impairment entails a compromised quality of life.⁵⁷⁰ Whilst this will certainly be the case for some, it would be wrong to suggest that all individuals with cognitive impairments suffer a reduced quality of life or that any reduction in quality on that basis means life is no longer of value. The broad consensus in the literature – to consider the impact on the individual patient rather than make blanket judgements – suggests a broad acceptance of the need to respect autonomy, avoid assumptions, and adopt a person-centred approach to these decisions.

A further theme I particularly want to highlight is nonadherence. Even if dialysis appears to be clearly in the Best Interests of a patient, resistance in various forms presents an obstacle to care provision. When a patient is nonadherent, there are risks not only to the patient but to those around them – Hashmi and Moss list examples such as physical abuse and requiring unscheduled extra treatments due to treatment nonadherence.⁵⁷¹ Restraint might seem an obvious remedy, but this is not a course of action to be taken lightly. In one case discussed above, there was regret among the clinical team when a patient was restrained for the purposes of dialysis.⁵⁷² There may be a risk of moral distress if clinicians are expected to restrain a patient for dialysis but consider it inappropriate, especially if the restraint is court ordered. Whilst some have suggested cooperation to be a prerequisite of dialysis,⁵⁷³ others are more sympathetic to at least some level of restraint.⁵⁷⁴ The extent to which the need for restraint should be factored into dialysis decisions is a moot point in the literature and is complex and often uncomfortable – perhaps because it captures so dramatically the tension between our aversion to coercion and our desire to protect people we see as vulnerable. Given that our aversion to coercion is generally based on acceptance of the importance of respecting autonomy, it may be worth considering whether the discomfort with constraint comes from latent (but perhaps misplaced) feelings that the patient with a cognitive impairment still has autonomy (which is insulted by coercion) or whether it exposes our concern that the patient still has a right to autonomy that we are consciously or erroneously failing to respect. Whichever – if either – it is, it seems reasonable that the nature of the necessary

⁵⁷⁰ Kaye and Lella (n394); Spike (n394); Scott *et al.* (n397).

⁵⁷¹ Hashmi A, Moss AH. 2008. Treating difficult or disruptive dialysis patients: practical strategies based on ethical principles. *Nature Clinical Practice Nephrology* 4(9):515-520.

⁵⁷² O'Dowd *et al.* (n435).

⁵⁷³ MacPhail *et al.* (n393); Spike (n394).

⁵⁷⁴ Feely *et al.* (n391); Grubb (n530).

restraint might affect the extent to which it is considered acceptable or ethically permissible, as well as the frequency and duration of restraint necessitated by the particular patient's nonadherence.

Especially pertinent to the wider project of which this scoping review is a part is the discussion of the respective merits of the Best Interests and substituted judgement approaches – notably, that the former is mentioned very little. Some suggest that patient preferences should be the sole guiding force in dialysis decisions,⁵⁷⁵ but this is problematised by evidence that surrogate decisions often poorly predict patient preferences.⁵⁷⁶ This is, as some acknowledge, in part related to the important distinction that can be made between the patient known by the surrogate decision maker and the patient as they are at the time of the decision.⁵⁷⁷ The two are not necessarily the same and may be hugely different in terms of how they would view the initiation of dialysis. Perhaps, then, substituted judgement is only appropriate when the two align, but this raises the complex matter of determining whether they do. The difficulty of this might be taken to suggest that the Best Interests approach is preferable as it aims not to make the decision the patient would actually make, but the best decision that the patient could make. However, this is differently complex and raises challenging questions about the extent to which Best Interests decisions are intended to track autonomy, act paternalistically, or track some kind of supposed ideal preference. Either way, this review has highlighted a gap in the literature around Best Interests decisions as described in the MCA and maintenance dialysis.

3.4.1 Limitations

I acknowledge the potential for bias in this scoping review but accept that this kind of research is always subject to personal interpretation of the material. I sought to minimise bias from my interpretation by one of my supervisors reviewing eligibility decisions and analysis throughout and maintaining a questioning and reflexive attitude towards the themes being developed.

⁵⁷⁵ Conneen *et al.* (n394); Keating *et al.* (n394).

⁵⁷⁶ DeCamp (n404).

⁵⁷⁷ McDougall (n415).

The choice of databases aimed at capturing as much relevant literature as possible, but it may be that some has been missed. Further, by limiting my search to these databases I did not include relevant professional guidance. Nonetheless, such guidance is more akin to the “rules” at work and might not be reflective of the realities of clinical practice, so its inclusion would have necessitated a shift in focus.

This review is exploratory and does not seek to provide a definitive overview, nor does it seek to answer the normative questions that it foregrounds. As such, even accounting for these limitations, this review provides a foundation from which future research concerning the provision of dialysis for adults with cognitive impairments can build.

3.5 Conclusions

What this scoping review has demonstrated is that there is significant variation in both the practice and theory of dialysis decision making with, for, and on behalf of adults with cognitive impairments. Decisions made with, for, and on behalf of patients who lack decision-making capacity are almost always challenging but can be more so when care options are as cumbersome as dialysis. Complexity arises in considering who should get a say, how influential their say should be in a decision, and what factors are most relevant to the decision.

This scoping review provides a useful groundwork from which further research can be undertaken and has highlighted a dearth of literature looking at Best Interests decisions and dialysis (as per the MCA 2005) and empirical research on these decisions in England and Wales (and outside of the US generally).

3.6 Research gaps

One thing this scoping review clearly demonstrated⁵⁷⁸ was a need for further research in this area. Perhaps most interesting is that the findings suggest (with the caveat that the evidence base is limited) that what is reported to be best practice does not always happen. There may, then, be a disconnect between how these decisions *should* be made and how they *are* made. This potential disparity demonstrated the need for further scholarship to explore which – if either – is ethically reconcilable. As for whether theory ought to move in line with practice, practice in line with theory, or both should find some middle ground, that is what this thesis will proceed to explore.

Whilst the issues with which this project is concerned ought to be further explored globally – note the geographical spread of the included papers – my focus is on England and Wales. As earlier highlighted, little research was found originating in England and Wales. Further, much of the discussion in the included papers concerned approaches to decisions other than the Best Interests test outlined in the MCA 2005. Such discussion remains useful as, after all, these alternatives may prove to be more ethically appropriate than the requirements of the MCA 2005. However, greater exploration of the role of Best Interests in relation to adult dialysis decisions is needed.

Most notably, this scoping review highlighted a need to consider how these decisions are made for patients who are not elderly and who have cognitive impairments for reasons other than dementia. It is no surprise that elderly patients with dementia feature prominently in the literature as they represent a significant proportion of those who might have a Best Interests decision made concerning dialysis. However, tunnel vision on this particular group may limit the applicability of any resulting conclusions to the broader population of concern – *all* adults with renal failure lacking decision-making capacity for *any* reason. Certainly, the question of dialysis for a 25-year-old with severe learning difficulties would likely raise different matters for discussion than with a 75-year-old with Alzheimer's – the resulting decision may be the same, but the route will differ.

⁵⁷⁸ I use the past tense as this project as a whole has sought to partially plug the identified gap, though the need for further research persists.

These identified research gaps strengthen the case for this project making an important and original contribution to our understanding of this complicated area of clinical practice. Future research may also have increasing importance in the era of COVID-19, given the pandemic's real and potential impact on both kidney care⁵⁷⁹ and decision making for the cognitively impaired.⁵⁸⁰ I will reflect further on remaining research gaps when concluding in Chapter 7.

3.7 Developing topic guides

This formal scoping review⁵⁸¹ was conducted before recruitment commenced for the empirical element of the project. This was intentional, as the findings detailed in this chapter were used to develop the topic guides for the later qualitative interviews. Whilst most of the themes raised in this chapter were anticipated – and, therefore, would have been included in the topic guides regardless – several points discussed were not so expected. Of note:

- Cultural sensitivity, particularly in relation to who should be involved in decisions
- Rights/duties relating to treatment when a patient is nonadherent with dialysis
- The (potential) need for restraint as a factor in dialysis decisions

These unanticipated findings made important additions to the topic guides. Indeed, nonadherence and restraint proved particularly interesting, such that I spent some time considering it in isolation.⁵⁸²

⁵⁷⁹ Martin DE, Parsons JA, Caskey FJ, Harris DCH, Jha V. 2020. Ethics of kidney care in the era of COVID-19. *Kidney International* 98(6):1424-1433.

⁵⁸⁰ Parsons JA, Johal HK. 2020. Best interests versus resource allocation: could COVID-19 cloud decision-making for the cognitively impaired? *Journal of Medical Ethics* 46(7):447-450.

⁵⁸¹ As opposed to the informal literature searches and reading conducted throughout my PhD.

⁵⁸² Parsons JA, Taylor D, Caskey FC, Ives J. 2021. Ethical duties of nephrologists: when patients are nonadherent to treatment. *Seminars in Nephrology* 41(3):262-271; Parsons JA. 2020. 'Ethical issues in restraining patients for dialysis'. *Open Justice Court of Protection Project*. <<https://openjusticecourtofprotection.org/2020/10/21/ethical-issues-in-restraining-patients-for-dialysis/>>.

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Empirical Methods

This chapter provides an outline and justification of the empirical methods used in this study. Further, it details how precisely they were used for my purposes, reflecting the study protocol.

4.1 Qualitative research

The empirical methods used in this study were wholly qualitative – semi-structured stakeholder interviews.⁵⁸³ As such, the empirical elements of this study were exploratory, seeking to understand the perspectives and experiences of *some* stakeholders. Qualitative research, as noted by Bowling, ‘describes in words rather than numbers’.⁵⁸⁴ It is not intended for making generalisations and, therefore, is not designed to produce a large enough dataset to generalise from. Whereas quantitative research provides (or at least often seeks to provide) statistically significant results, qualitative research instead pursues alternative outcomes – namely, rich understandings of participants’ views and experiences that allow for greater detail and nuance in discussion.

Both qualitative and quantitative research are of value when employed appropriately, and the use of qualitative methods was most appropriate for this project because I sought to explore the perspectives and experiences of stakeholders in depth to unpack issues that arise, rather than, say, note the frequency of any given view on the research question. Empirical bioethics is, for the most part, concerned with the integration of *qualitative* data and normative inquiry. As noted in Chapter 2, Salloch and colleagues argue that empirical bioethics researchers ought to be cautious of conducting ‘[e]thics

⁵⁸³ As I will come to discuss shortly, I originally intended to carry out an ethnography as part of this study. This was not possible due to COVID-19 restrictions at study sites.

⁵⁸⁴ Bowling (n390) 380.

by opinion poll',⁵⁸⁵ which may be considered a greater risk when using quantitative data. More people holding a particular view does not necessarily make that view ethically correct.

4.2 Which method(s)?

Having established that qualitative methods were most appropriate for my objectives, I had to decide on which. In the previous section I stated that I used semi-structured stakeholder interviews (and had intended to conduct an ethnography).

The decision to conduct stakeholder interviews – and semi-structured interviews in particular – was for several reasons. First, my overarching methodology of reflective equilibrium necessitates a certain sensitivity to a participant's viewpoint.⁵⁸⁶ To allow the perspectives of participants to confront my own considered moral judgements it was important that they be afforded the freedom to express things in their own terms and that I be able to delve further to ensure I understood them. This lends itself to either semi-structured or unstructured interviews; an overly structured approach may preclude the nuance of participant views that I required. In choosing between these two options, I was led by an ultimate need to answer my research question. Unstructured interviews may provide participants with the opportunity to share as much as they are willing to, but this method runs the risk of veering too far off-piste in following the participant's lead. As such, in balancing a want for detailed understanding of participants' views and experiences and a need to answer specific research questions, I opted for semi-structured interviews.

My original intention was to complement these interviews with an ethnographic study. Indeed, this was included in my research ethics approvals. However, this became unworkable during the COVID-19 pandemic.

⁵⁸⁵ Salloch *et al.* (n301).

⁵⁸⁶ Birchley (n345).

The reasoning behind an ethnography was primarily to ensure the accuracy of my understanding of the context in which Best Interests decisions concerning dialysis are made. Whilst desk-based research and stakeholder interviews provide a detailed understanding of the context, there are undoubtedly elements they cannot provide. For example, the finer details of how the dialysis unit runs day-to-day and how professionals interact informally. Observing Best Interests meetings in particular⁵⁸⁷ would have allowed data triangulation,⁵⁸⁸ acting as something of a check on the recall of those present when interviewed. Stakeholder interviews are inherently subjective – from both sides⁵⁸⁹ – so I wanted to witness the Best Interests process for myself to note any differences in what participants describe.

In the absence of a formalised ethnography, I instead spent as much time as I could at study sites and in informal discussion with professionals. The inability to take the approach I had originally intended led me to reflect on the importance of this nuanced understanding of context in conducting an empirical bioethics project. The result was my work with several colleagues on translational bioethics and our proposal of “ethno-immersion” described in Chapter 2.⁵⁹⁰

For my data analysis, I chose to apply (reflexive) thematic analysis.⁵⁹¹ This was primarily owing to its flexibility; it can be adapted to meet the aims of a particular project whilst still providing the methodological rigour necessary in academic research. Further, it is commonly used in empirical bioethics, meaning I could look to examples of its field-specific employ as I got to grips with it – much like my reasoning behind the choice of reflective equilibrium (*see* 2.3.2). I used the approach outlined by Braun and Clarke. Whilst it is their extensively cited 2006 paper⁵⁹² that provides a more structured “thematic analysis for dummies”, I also note the importance of Braun and Clarke’s more recent work

⁵⁸⁷ I was able to attend one Best Interests meeting during this project, which was very insightful. However, the inability to attend any more prevented me from writing up an ethnography.

⁵⁸⁸ Triangulation, as noted in Chapter 2, entails the use of two (or more) qualitative methods to improve the reliability of analysis – drawing on a view of the research issue from several perspectives (*see* 2.3.3).

⁵⁸⁹ Holstein and Gubrium note interviews to be a process of co-production between interviewer and interviewee – and unavoidably so. Holstein JA, Gubrium JF. 2011. ‘Animating interview narratives’. In Silverman D. (ed). *Qualitative Research*. 3rd edition. London: Sage, 149-167.

⁵⁹⁰ As noted in Chapter 2, an account of my ethno-immersive experience can be found at Appendix A.

⁵⁹¹ Braun and Clarke, 2019 (n388)

⁵⁹² Braun and Clarke, 2006 (n388).

and how it complements the process that I will detail shortly (*see* 4.4.2). Building on their original paper, Braun and Clarke have more recently sought to address what they perceive as confusions in the thematic analysis of many scholars who have cited their work.⁵⁹³ In doing so, they have purposefully rebranded to ‘reflexive [thematic analysis]’⁵⁹⁴ to highlight that themes are developed by the researcher rather than things that emerge independently from the data.⁵⁹⁵ Hence a broader shift to the language of data generation rather than data collection.

In the following two sections, I outline how these methods were used for the generation and analysis of data.

4.3 Data generation

4.3.1 Stakeholder interviews

4.3.1.1 Sampling

Purposive sampling was used to select interview participants with a range of relevant – and different – insights into the area under study. To help ensure a range of perspectives, participants were recruited into four groups:

- Nephrologists, including those at any stage in their specialty renal training
- Renal nurses, including those in any specific nursing roles within renal (ward nurses, specialist nurses, etc.)
- Patients with or approaching kidney failure, including:

⁵⁹³ Braun and Clarke, 2019 (n388) 589; Braun V, Clarke V. 2021. *Thematic Analysis: A Practical Guide*. London: SAGE.

⁵⁹⁴ Braun and Clarke, 2019 (n388) 590.

⁵⁹⁵ Braun V, Clarke V. 2021[2020 online]. Can I use TA? Should I use TA? Should I *not* use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research* 21(1):37-47.

- Patients who lacked capacity to make the dialysis decision for themselves and were going to have a Best Interests decision made about their renal care;
 - Patients who previously lacked capacity to make the dialysis decision for themselves and had already had a Best Interests decision made about their renal care, and who still lacked capacity to make the dialysis decision at the time of participation; and
 - Patients who previously lacked capacity to make the dialysis decision for themselves and had already had a Best Interests decision made about their renal care, but who had since regained capacity to make the dialysis decision at the time of participation
- Consultees, past or present (at the time of participation), for patients with or approaching kidney failure who lacked capacity to make the dialysis decision for themselves

Participants from different categories did not have to be associated. For example, a consultee participant did not have to be a consultee for a patient participant. In addition to fitting one of the above participant categories, participants had to fulfil all the following inclusion criteria:

- Able to provide consent *OR* have a Best Interests decision made in favour of participation
- Willing to participate (demonstrated by consent or assent)
- Able to communicate in English (unless an interpreter can be reasonably found)⁵⁹⁶

4.3.1.2 Recruitment

For the purposes of interviewee recruitment, initial contact with potential participants varied depending on which participant group they fitted (*see 4.3.1.1*) and whether they had decision-making capacity in

⁵⁹⁶ As this study formed part of my PhD, time and budgetary constraints meant that use of interpreters was not ordinarily feasible. Further, no such individuals were identified as potential participants. However, where a suitable individual had been identified and was willing to participate, but was unable to communicate in English, reasonable efforts would have been made to involve an interpreter.

relation to their participation. There were four approaches based on the following classifications: HCPs (including both the nephrologist and renal nurse participant groups); patients *with* capacity to consent to research; patients *without* capacity to consent to research; and consultees.⁵⁹⁷

First, HCPs. The study was advertised to HCPs locally at each study site through announcements. For example, at team meetings and by email. Each site was afforded freedom to make these announcements in ways that best suited the functioning of their unit. These announcements provided an overview of the study and informed potential participants to contact me if they were interested in receiving further information. HCPs who contacted me to express an interest were sent a letter of invitation and participant information sheet (*see Appendix B*). It should be noted, however, that in some cases this further information was sent to interested HCPs directly by a key contact at the relevant study site.⁵⁹⁸ HCPs were, when sent further information, asked to contact me once they had had a chance to review it. When they contacted me, they were given an opportunity to ask any questions they had before confirming whether they wanted to participate.

Second, patients *with* capacity to consent to research. HCPs at study sites were briefed on the inclusion and exclusion criteria for patient participants, enabling them to identify eligible patients through clinical records and personal recollection. Potential patient participants were initially contacted by a suitable HCP – with whom they had a pre-existing relationship – to gauge interest. An overview of the study was provided, and they were asked if their contact information could be shared with me. Those that consented were contacted and provided with a participant information sheet (*see Appendix C*). They were also given the opportunity to ask any questions they had before confirming whether they wanted to participate.

⁵⁹⁷ I describe here the protocol followed concerning patient participants, though it should be noted that due to recruitment difficulties no patients were included in the final study group. These difficulties are discussed later (*see 7.4*).

⁵⁹⁸ At each site, a member of the care team expressed a willingness to assist with recruitment. Due to them having existing professional relationships with many potential participants, these key contacts were provided with a copy of the protocol and relevant study documents so that they could identify potential participants and, in some cases, make the initial approach.

Third, patients *without* capacity to consent to research. If a patient was identified who lacked capacity to consent to participation, a suitable consultee was identified in accordance with the Department of Health and Social Care's⁵⁹⁹ guidance⁶⁰⁰ to advise on the appropriateness of that patient's participation. The consultee was provided with an overview of the study and asked if their contact information could be shared with me. Those that consented were contacted and provided with a consultee information sheet (*see Appendix D*). They were also given the opportunity to ask any questions they had before confirming whether they felt it was appropriate for the patient to participate.

Finally, consultees. Most consultees were identified through discussion with HCPs at study sites. My key contact at each study site helped identify consultees, and all HCP participants were asked at the end of their interview if they could identify any. Potential consultee participants were initially contacted by a suitable HCP – with whom they had a pre-existing relationship – to gauge interest. An overview of the study was provided, and they were asked if their contact information could be shared with me. Those that consented were contacted and provided with a participant information sheet (*see Appendix E*). They were also given the opportunity to ask any questions they had before confirming whether they wanted to participate.

At the point potential participants contacted me to discuss participation, eligibility was confirmed. If an individual was ineligible or the study was full, this was explained to them and they were given the opportunity for their contact details to be kept on record to inform them of the results of the study. For those who were eligible, a mutually convenient time and location was decided upon for the interview to take place. Due to the impact of the COVID-19 pandemic during the data collection period, participants were given the option of participating in their interview remotely using Zoom or Microsoft Teams.⁶⁰¹

⁵⁹⁹ At the time of the guidance's publication, the Department of Health.

⁶⁰⁰ Department of Health Scientific Development and Bioethics Division. 2008. *Guidance on nominating a consultee for research involving adults who lack capacity to consent*. London: Central Office of Information.

⁶⁰¹ A research ethics amendment was submitted to permit this, as the original approvals only covered in-person interviews.

4.3.1.3 Consent and assent

For the purposes of consent and assent, the same process was conducted across participant groups. The only exception was for patient participants who lacked capacity to consent to participation and were therefore enrolled based on the advice of their consultees.

Per the recruitment process outlined above, all participants had received the relevant participant information sheet ahead of their interview and were given an opportunity to ask any questions they might have had. At the beginning of all interviews, participants were asked to confirm that they had received the participant information sheet and were given the opportunity to ask any additional questions. They were then presented with the relevant participant consent form (*see Appendices F-H*) to complete, which reiterated key information (i.e., what would happen with their data and their right to withdraw from the study). Consent forms were then countersigned by myself as witness, and each party retained a copy.

Participants who opted for a remote interview provided consent to participation verbally. As part of the audio recording, I read each statement from the relevant participant consent form aloud and asked the participant to confirm their consent to each individually. The full interview audio recording was later split – one file being the verbal consenting process, the other being the interview itself – and the consent recording retained in lieu of a signed hard copy participant consent form.

For patients who lacked capacity to consent to participation, it was necessary to involve their consultee in deciding whether their participation was appropriate. If it was decided, through discussion between me and the patient's consultee, that the patient's participation would be appropriate, a consultee declaration form was signed (*see Appendix I*), and a suitable time and location was scheduled for the interview. Before starting the interview, the study was explained to the patient, and they were given the opportunity to ask any questions they might have had. Their assent was then sought, giving them an opportunity to themselves decline to participate despite the approval of their consultee.

4.3.1.4 Conduct

Interviews were conducted in line with topic guides, written separately for different participant groups (*see Appendices J-L*; these are the original topic guides prior to the first interview). Topic guides were revised throughout the data generation period whenever it was deemed appropriate based on completed interviews. For example, if a participant raised something of particular relevance that I felt was worth exploring with other participants.

Whilst topic guides were used in all interviews, as the interviews were semi-structured, they were not followed as strict running orders for questions. Rather, topic guides acted as rough checklists of key areas for discussion and prompts for when conversation hit a lull. If a participant ended up providing detailed and useful information in relation to a small number of points on the topic guide, not all topics were necessarily covered during the interview.

All interviews were, as standard, conducted one-to-one between myself and the participant. For patient participants, there was an option to have their consultee present. As the researcher, I presented myself to participants as someone interested in how Best Interests decisions function in practice, clarifying that I am not a healthcare professional.

All interviews were audio recorded to later be transcribed (*see 4.4.1*). Distress protocols were also in place, though did not end up needing to be used. Details of these protocols are outlined shortly (*see 4.3.3.2*).

4.3.2 Ethnography

As noted above, I had originally intended to include an ethnography as part of this study. For reasons beyond my control – i.e., the COVID-19 pandemic – this was not possible. To economise on words, I

will not detail my ethnography plans that did not materialise here. Nonetheless, my approach of ethno-immersion sought to somewhat plug this gap (*see* 2.3.3).

4.3.3 Ethical considerations

4.3.3.1 Research ethics approval

Prior to any recruitment activities, approval for the project was obtained from the Health Research Authority's (HRA) London – Camberwell St. Giles Research Ethics Committee (IRAS reference: 280705) on Tuesday 22 December 2020. These ethical approval documents can be found in Appendices M and N. As HRA approval was obtained, it was not necessary to also seek approval from the University of Bristol or individual study sites. The appropriate administrative processes were followed at each study site before recruitment commenced.

4.3.3.2 Distress protocols

Some of the topics covered in interviews were potentially sensitive. There were, therefore, distress protocols for participants both with and without decision-making capacity (*see Appendices O and P*). Participants were informed in advance of and at the beginning of their interview that they were able to stop the interview at any time. When a participant with decision-making capacity appeared upset or showed signs of distress but did not request for the interview to be stopped, I offered to stop the recording equipment and allow the participant time to themselves if wanted. The participant was informed that they could continue the interview should they wish to, but that they were under no obligation to do so. No pressure was put on participants to resume the interview.

For patient participants who lacked decision-making capacity, additional safeguards were in place in accordance with section 33 of the MCA 2005. It was assumed that the interests of the participant

outweigh those of science and society, and any signs of distress or resistance during the interview would have resulted in the immediate termination of that interview and subsequent withdrawal of that participant from the study.

As earlier noted, neither distress protocol ended up needing to be used, and interviews went ahead with no apparent signs of distress in participants.

4.4 Data analysis

4.4.1 Transcription

Transcription has been described as ‘both an inevitable and problematic step in the qualitative [...] analysis of data consisting of spoken discourse’.⁶⁰² Problematic because transcription as a practice holds a risk of bias.⁶⁰³ For example, the precise use of punctuation can affect the tone a passage of text portrays. Nonetheless, my approach sought to minimise this risk.

All interview recordings were transcribed by UK Transcription.⁶⁰⁴ Recordings were sent to UK Transcription shortly after each interview, or in clusters if several interviews were scheduled in the same week. Once returned, all transcriptions were checked for accuracy against the original recording. In particular, transcriptions were checked for accordance with Mergenthaler and Stinson’s transcription guidelines.⁶⁰⁵

These guidelines advance seven principles which broadly centre on the transcription being as exact a reproduction of the recording as possible, preserving the morphologic naturalness of the recording.⁶⁰⁶ For example, punctuating the transcript in the way that captures the way the interviewee

⁶⁰² Kowal S, O’Connell D. 2014. ‘Transcription as a crucial step of data analysis’. In Flick U (ed.). *The SAGE handbook of qualitative data analysis*. London: SAGE Publications Ltd., 65.

⁶⁰³ *Ibid*, 66.

⁶⁰⁴ UK Transcription. *Transcription Services*. <<https://www.uktranscription.com/>>.

⁶⁰⁵ Mergenthaler E, Stinson C. 1992. Psychotherapy transcription standards. *Psychotherapy Research* 2(2):125-142.

⁶⁰⁶ *Ibid*, 129-130.

spoke as best as possible in the absence of a conversation analysis form of transcription. This was achieved by me listening to the audio recordings whilst reading the transcript to correct any mistakes. At this stage I also added transcription headers containing interviewee characteristics that would later be relevant to analysis, such as the study population group and age. This was done to later ‘facilitate the comparison of narratives’ and highlight patterns arising from a subset of interviewees.⁶⁰⁷ By each transcription involving both myself and a professional transcriber, the risk of bias was reduced, thereby resulting in a suitably objective written record of each interview.

Not having done the transcription myself might lead some to suggest that I was less familiar with the data than I could have been. However, I still listened to each recording to check the transcription and fully immersed myself in the transcriptions themselves. As such, I was still able to ensure familiarity with the data as is necessary for thematic analysis (*see 4.4.2*).

Transcripts were not, as standard, returned to participants for comments and/or corrections. However, this was an option for participants on request.

4.4.2 Thematic analysis

As already noted, I used a method of thematic analysis. Specifically, I used that outlined by Braun and Clarke.⁶⁰⁸ This is the same approach used for my scoping review, and I noted in Chapter 3 that I would provide a more detailed explanation here. Braun and Clarke’s is by no means the only method of thematic analysis, but it may reasonably be considered one of the most widely used methods (if not *the* most widely used).⁶⁰⁹ Braun and Clarke provide a six-phase guide to the process:

⁶⁰⁷ McLellan E, MacQueen KM, Neidig JL. 2003. Beyond the qualitative interview: data preparation and transcription. *Field Methods* 15(1):63-84, 68.

⁶⁰⁸ Braun and Clarke, 2006 (n388).

⁶⁰⁹ The paper outlining Braun and Clarke’s method has been cited more than 100,000 times, demonstrating just how widely used it is.

Familiarizing yourself with your data: In this first phase, I immersed myself in the data by reading it several times. This was active reading by which I searched for meaning rather than a more passive approach that would only have enabled me to provide a precis. If analysing verbal data, some argue that doing your own transcription is an important part of familiarisation.⁶¹⁰ However, if someone else has transcribed the data (as was the case in this study), it is still possible to complete this stage; indeed, Braun and Clarke note the importance of checking transcribing done by someone else for accuracy.⁶¹¹ In this phase, I made notes about what was interesting in the data – these notes assisted me with phase two.

Generating initial codes: Phase two built on the notes made in phase one and required me to ascribe “codes” to the data. That is brief and specific descriptors that highlighted significant pieces of data. In this phase I noted frequent codes and organised them, but these coded data ‘differ[ed] from the units of *analysis* (your themes)’.⁶¹² Braun and Clarke note the importance of resisting the temptation to ‘leap ahead’ and develop themes at this stage.⁶¹³

Searching for themes: After the data had been coded, this next phase entailed organising them into themes. This was a process of considering which codes were related and could be grouped together around a broader idea. Sub-themes were also, in some cases, appropriate within main overarching themes. However, it is important to note that at this stage they were only ‘candidate themes’ that were subject to revision, so those that seemed less significant were not discarded.⁶¹⁴

⁶¹⁰ Bird CM. 2005. How I stopped dreading and learned to love transcription. *Qualitative Inquiry* 11(2):226-248.

⁶¹¹ Braun and Clarke, 2006 (n388) 88.

⁶¹² *Ibid.*

⁶¹³ Braun and Clarke, 2021 (n595) 54.

⁶¹⁴ Braun and Clarke, 2006 (n388) 90.

Reviewing themes: As noted above, the themes devised thus far were candidate themes. They needed refining. Phase four required me to proverbially sort the wheat from the chaff; removing those that lacked sufficient data to support them, combining those that were largely comparable, and breaking down those that were too broad. Each theme needed to be assessed for internal coherence. Then the themes could be considered as a whole – the thematic map – to check that they accurately reflected the full dataset.

Defining and naming themes: The final *analysis* phase was to ascribe appropriate names to themes and sub-themes. As Braun and Clarke note, names should capture the ‘essence’ of what themes are about, identifying what about them is of interest.⁶¹⁵ That being said, it was equally important that names were succinct and provided a clear and immediate sense of what each theme was about.

Producing the report: The final phase was to write up the results of my analysis. This required a complex narrative to be portrayed both concisely and interestingly. It needed to demonstrate the ‘merit and validity’ of my analysis to the reader.⁶¹⁶ Of note, Braun and Clarke explain that the write up must not be merely descriptive; whilst data should not be fabricated, it was important that an argument was made about how the data did (not) answer my research question(s).⁶¹⁷

In carrying out thematic analysis in this study, I used NVivo software (version 12) to manage the coding and organisation of themes.

⁶¹⁵ *Ibid*, 92.

⁶¹⁶ *Ibid*, 93.

⁶¹⁷ *Ibid*.

4.4.3 Timing of analysis

Analysis was conducted gradually throughout the project, with interview transcripts coded as they were received rather than waiting until the completion of data generation. This was intentional as it allowed me to reflect both on the content of the topic guides and my own interview technique, making changes to one or both as required. It also meant that the process of data immersion was easier as I was not rushed, thereby satisfying criterion 11 of Braun and Clarke's 15-point checklist that the researcher ensure that '[e]nough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly'.⁶¹⁸

Nonetheless, it was not until all interview transcripts were analysed that I progressed to the stage of reviewing themes. This was to ensure the themes were driven by the dataset as a whole, rather than them being based on the early interviews and later interviews just cherry picked to fit into existing themes.

4.5 Summary

This chapter has provided a brief but necessary outline of the methods used for the empirical phase of this project. It also highlights where certain elements of my original plan had to be amended or removed entirely as the project progressed. I will reflect further on these necessary changes in Chapter 7, considering their impact on the project and what they have contributed to my learning experience throughout this PhD. A completed COREQ checklist can be found at Appendix Q, including items that will be reported in the proceeding chapters.

⁶¹⁸ *Ibid*, 96.

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Empirical Findings

This chapter focuses on the findings of my empirical work, reporting the results of my thematic analysis as outlined in the previous chapter. Per the Bristol Framework,⁶¹⁹ this chapter acts as a substantial part of the ‘framing’ phase of the wider project.

The empirical data are presented here predominantly in isolation from the theory and literature discussed previously, and from my own developing arguments. Whilst others have previously chosen to interweave their empirical data with theory and literature at this stage,⁶²⁰ in a fashion that is accepted within empirical bioethics as potentially appropriate in some projects,⁶²¹ I have chosen to present my empirical data “separately”. This is because I wish to keep these findings as a distinct strand for now, to be considered in relation to other elements in my later process of reflective equilibrium. Such an approach is suitable given my overall methodology, whereby these data are not the final product of this project. Nonetheless, there will be occasional nods to theory where a participant has framed their view in a particular way.

I present here key themes from the data. My initial intention was to distinguish the principles participants reported appealing to in deciding what they consider to be in an individual’s Best Interests from the practical processes of decision making described. However, during analysis it became apparent that the two are just too intertwined for such an approach to work. As such, these two aspects of a Best Interests decision are combined within the themes discussed.

⁶¹⁹ Huxtable and Ives (n303). See outline in Chapter 2.

⁶²⁰ Morley G. 2018. *What is ‘Moral Distress’ in Nursing and How Should We Respond to It?* Bristol: University of Bristol [thesis]; Jenkins S. 2014. *The Ethical Allocation of Gametes Donated for Fertility Treatment*. Birmingham: University of Birmingham [thesis].

⁶²¹ Ives *et al.* (n237).

Where participants are directly referred to or quoted, a participant number is provided. These numbers are preceded by an abbreviation to indicate the relevant participant group: D for doctors, N for nurses, and C for consultees. For example, N4 is the fourth nurse to be interviewed.

Throughout this discussion I refer to the subject of a Best Interests decision as ‘patient’. I recognise that there is, for good reason, a wider shift towards using the terminology of ‘person’ instead.⁶²² However, I will stick to ‘patient’ for reasons of practicality; to minimise ambiguity in discussing scenarios with a large number of individuals involved.

5.1 Healthcare Professionals

I will first explore the findings from interviews with healthcare professionals. Here I combine the views and experiences of doctor and nurse participants. This is appropriate as, for the most part, professionals spoke more generally about how particular decisions played out and how they conceptualise the idea of Best Interests. However, some did reflect on their particular role in the decision-making process. As such, there are times throughout what follows where I will draw attention to such differences between the two participant groups. Where I am discussing commonalities between the two groups, I will refer to *professionals*, and where a distinction is being made, I will refer to *doctors* and *nurses*. Further, in line with the system of participant numbers outlined above, it will be apparent which of the groups individual participants who are mentioned are from.

As outlined in Chapter 4 data were collected from two sites, and a range of doctors and nurses fell within the inclusion criteria. As highlighted by **Table 3**, a range of experience was represented, both in relation to seniority and area of work. This proved useful in collecting a range of perspectives, as the different nursing roles in particular contribute differently to Best Interests decisions.

⁶²² Wagner EH, Austin BT, Von Korff M. 1996. Organizing care for patients with chronic illness. *Millbank Quarterly* 74(4):511-544; McClimans LM, Dunn M, Slowther A-M. 2011. Health policy, patient-centred care and clinical ethics. *Journal of Evaluation in Clinical Practice* 17(5):913-919.

Table 3: Details of healthcare professional participants

| Doctors | | | | |
|------------|----|---------------------------|--|------------------------------|
| Site | n= | Mean age (range) | Role(s) ⁶²³ (n=) | Interview location |
| Bristol | 6 | 43 (38-51) | Renal consultant (3); Renal registrar (3) | In person (3); Online (3) |
| Birmingham | 6 | 53 (44-62) ⁶²⁴ | Renal consultant (6) | In person (3); Online (3) |
| Nurses | | | | |
| Site | n= | Mean age (range) | Role(s) (n=) | |
| Bristol | 5 | 45 (29-55) | Staff renal nurse (1); Supportive care specialist nurse (1); Transplant specialist nurse (2); Ward sister (1) | In person (5) |
| Birmingham | 4 | 46 (42-48) | Pre-dialysis nurse (1); Renal research nurse (1); Staff renal nurse (1); Supportive care specialist nurse (1) | In person (4) |

From the data collected interviewing professionals, I have developed nine themes: quality of life; prioritising patient preferences; family involvement; collaborative decision making; the path of least resistance; dialysis trials as conflict resolution; communication and culture; attachment to patient and clouded judgement; and making the “right” decision. Whilst they are presented individually, there is significant overlap between these themes.

⁶²³ It should be noted that some doctors who participated also hold secondary roles, such as lead for supportive care. Participants self-identified their roles, and those represented in the table are how they described them when asked.

⁶²⁴ These figures represent the details of five of the six participants. The audio was unclear at the relevant point in the recording of one interview, and it was not possible to follow up with the participant afterwards.

5.1.1 Best Interests and quality of life

In seeking to make a Best Interests decision, professionals overwhelmingly referred to the importance of the patient's quality of life – in many cases, it was considered of paramount importance.

But what we would not do is go down the lines of what we thought might be [...] a treatment that did not give the patient the quality of life that she wanted. (D04)

Some stressed a minimum standard of acceptability, suggesting at least a perceived objective element to quality of life. Those that spoke in these terms stated that they would not pursue a course of action that took a patient's care below what they consider this minimum standard to be. However, there was inconsistency in how professionals perceived the balance between quality and quantity of life, with some favouring quality over quantity, and others favouring quantity over quality:

In my mind, I'm thinking in terms of life quantity and then life quality. (D03)

I think that it should be quality of life and not quantity of life. (N03)

This dichotomy was noted by one professional, who commented: “[y]ou, broadly speaking, have some people who favour longevity, and you have some people who favour self-perceived quality of life” (D08). As much as professionals observe this in their patients and those patients' family members, it appears similarly true of the professionals themselves. Nonetheless, almost all professionals felt that quality of life is a hugely important factor in any Best Interests decision.⁶²⁵

⁶²⁵ Rather than taking the opposite view, those that did not express this position simply did not talk about quality of life in notable depth.

A consistent view of the importance of quality of life was not, however, matched with a consistent definition of quality of life. For some, it was largely about the patient's physical capabilities and, building on that, how being on dialysis might affect their day-to-day life. Professionals commented on factoring in the level of dependence a patient has on those around them and the extent of their mobility; things such as whether the patient can wash by themselves, go for walks, or even just, as one doctor phrased it, "potter around in the house" (D11). It was also felt by some that a decision can be somewhat "simplified" (D03) by ongoing clinical deterioration, in that this can heavily impact quality of life. Suggesting the importance of these quality of life considerations to making a decision, professionals touched on how they might affect a decision, including in the question of dialysis modality.

[J]ust judge what sort of social setting that they have and what kind of dialysis option might suit them better without too much disruption to their usual routine. (D07)

Other professionals described a more holistic view, including things such as the patient's ability to interact with friends and family, as well as less immediately apparent impacts on a patient's life. One nurse spoke in particular about individuals with cognitive impairments perhaps not being able to fully understand the reason why aspects of their care may negatively affect their lifestyle.

So, if you've got complex learning difficulties and chocolate's your favourite thing and I say to you, "[redacted name], if you go on dialysis, you can't eat chocolate anymore because it's high in potassium", and if that's the one thing in your life that you love and I'm going to take it away from you. (N04)

Some even included cognitive function itself as a consideration in determining quality of life. There was a suggestion by some of the importance of sufficient mental capacity for there to be an experiential element of the patient's life.

Of course, their cognitive function as well. If they're severely cognitively impaired, then of course they have no capacity to understand what's going on. (D11)

Nonetheless, the common thread with interpretations of quality of life in this context was very much the "great burdens" (D02) of dialysis and, in tandem, the deterioration of the patient's condition. Several nurses described how they had seen dialysis impact on patients:

[S]itting there for four hours on a machine, feeling tired, feeling sick, maybe in-between times you're just about getting better, and then you got to come back in again. (N03)

I was just thinking of the actual effects of dialysis – the side-effects – just the blood pressure drops, the feeling exhausted and notable to do what you like to do, maybe just sitting there sleeping all the time rather than actually enjoying life. (N05)

Professionals shared a feeling that the process of dialysis can be quite gruelling – whether a patient has a cognitive impairment or not. At the same time, many reflected on a perceived lack of understanding of just how gruelling dialysis can be, both among the general public and healthcare professionals from other specialties. One doctor commented:

You almost need to be doing dialysis and looking after people on dialysis, looking after people through advanced kidney care clinics, to get to see when it doesn't work so well. I

think the more you do it the more you realise that it isn't a walk in the park, that there is significant [...] morbidity from undertaking renal replacement therapy of any type. (D08)

In addition to the impact dialysis itself can have on the patient, professionals also reported considering the practical burdens associated with *attending* in-centre dialysis. Professionals spoke of accounting for things such as whether the patient would have to be brought in on a stretcher, and how much time out of their week dialysis would take accounting for travel and waiting times.

Whilst quality of life was discussed as hugely important to a Best Interests decision, there was very much a feeling among professionals that it is an inherently subjective factor – “a judgement about *perceived* [emphasis added] quality of life” (D01) – such that “it's very difficult for us to judge anyone's quality of life” (D07). Reflecting historically on how such decisions have been made, one professional highlighted how there can sometimes be blanket judgements based on particular circumstances.

In those days – this was 2000 – in those days, we basically wouldn't dialyse people who were in a nursing home, because we didn't believe that they had the quality of life that would benefit from life-sustaining therapy. (D04)

In current practice, professionals spoke more about the importance of considering each patient's quality of life “on an individual basis” (N08).

If they're sitting in a chair and they're watching telly or whatever, if that's what they want to do, that's what they want to do. It doesn't mean to say they haven't got a good quality of life, does it? It's a hard one to balance because everyone's quality of life is different. (N09)

With an eye on this person-centred focus and seeking to ascertain a patient's quality of life, many professionals talked about taking detailed social histories to build a better picture of the patient as a person. These histories were in part described in terms of understanding the patient's quality of life subjectively, in relation to their normal behaviour patterns, recognising the risk of a professional's bias.

If people like getting up in the morning and just watching daytime TV, that might not be what you or I do, but [...] that may be what they choose to do with their life. Who am I to judge that? (D04)

Professionals spoke of forming this understanding, at least in part, through engagement with those close to the patient, including friends, family, and carers (essentially, those who would be considered appropriate consultees under the MCA 2005). Many spoke about family members who "voiced their opinions about their father's [or other family member's] quality of life and what they perceived it to be" (N01). For patients already receiving dialysis, many professionals mentioned discussions with family members to understand whether the dialysis seemed to be making much of a difference to the patient at home. The purpose of these discussions being to build a fuller picture of the patient's quality of life rather than relying solely on what the care team witnesses during their own interactions with the patient. For example, one spoke of a woman who was always "very distressed on the [dialysis] machine" (N02), but whose family explained that this was not the case at home. Another noted some patients "give you the impression that they have a fantastic lifestyle" (D11), but whose family disagree because the patient does nothing at home and needs help with everything.

Such engagement with those close to the patient to understand quality of life has, in the experience of many of the professionals interviewed, sometimes resulted in disagreement. This arose mostly where the family considered the patient's quality of life to be good and the care team felt this not to be the case – the reverse scenario was not raised. Relating to interaction as an aspect of quality of life, one doctor recalled a patient's family who "wanted their mother to be alive even if they're not

able to interact with her” (D11), this being an instance where the care team felt there was a very low quality of life. In such scenarios, many professionals expressed that they feel family members are not thinking about quality of life, in part because of their emotional attachment and struggle to process the deterioration of their loved one’s health. These views will be further explored later in this chapter (*see 5.1.3*).

Another means of exploring a patient’s quality of life that several professionals discussed was home visits by specialist nurses. Such home visits were viewed positively by those who mentioned them, with broad consensus that seeing an individual in their home environment provides a better idea of their quality of life. N01 explained that “[i]n a hospital room, in a hospital bed, or in a clinic appointment, or on a dialysis unit is not the best way to try to understand what a patient wants”. One nurse talked about visiting a patient in the care home where he lived, and the sort of questions that might be asked:

Is he so withdrawn that he doesn't come out of his own bedroom and won't participate in anything or will he go down? For example, at this time of year, is he participating in a carol concert that they've got going on? Has he nodded off and is he quietly sitting, slumped in a chair? Is he engaging and participating? (N07)

For professionals, then, quality of life is a central consideration when making a Best Interests decision. Whilst there is some discrepancy as to what constitutes quality of life and how it should be accounted for, there is consensus on some conception of quality of life proving significant in any decision.

5.1.2 Prioritising patient preferences

This recognition of the individual nature of quality of life was complemented by a professed preoccupation with each patient's preferences about their care. Professionals overwhelmingly appeared to support what they understood to be an autonomy-enhancing/substituted decision view of Best Interests whereby, to the extent possible, they would pursue the course of action they believe the patient would have chosen in the absence of cognitive impairment.

I think the influence was certainly his expressed intent in the past to try and live for the sake of his child, okay? So, you can't switch that off, which fed into our thinking about, "well, what would he want to do were he able to express himself clearly and confidently?". (D03)

I think a lot of it is understanding what matters to them the most and how they live their life and how would that different kind of treatment modality affect them and how would they be receptive to those changes. (D07)

Certainly, if I get a picture, speaking to all concerned, that this is what they [the patient] want, yes, that is going to be the priority. (D09)

I just really, really want people to have what they want at the end of their life rather than what their family wants or their doctor thinks they should have. (N05)

For some, this came, in part, from a hope that their own preferences would be followed if they found themselves in such a situation.

I know if it was me and my family, I'd want them to do what I would want them to do, what decisions I would make, and hopefully they would. (N09)

Professionals highlighted how, as part of the decision-making process, they make efforts to engage the patient. This came from a belief that even if a patient has a cognitive impairment that prevents them from providing informed consent to a treatment plan, that does not necessarily mean they cannot be involved in some way.

[A] very elderly, frail patient from a nursing home who might have a mild degree of vascular dementia, it's very hard to just say that they do not have capacity whatsoever, because a lot of the time, they still come along and tell you various things that they enjoy and various things that they can understand about dialysis. (D07)

Just because somebody can't reach the entire decision, doesn't mean they can't give you any indications at all. You can try to probe how they feel at the moment, are things going well, what's their symptom burden, what sort of a life have they had, what's important to them. Even if they can't, necessarily, weigh up all of the little bits and bobs to make a final decision, you can still learn a lot about them. Taking that time, I think, is quite important. (D08)

As such, there was a lot of discussion of tailoring information to each patient so that they can be as involved in the decision as their impairment allows. One doctor explicitly referenced the MCA 2005 requirement to consider barriers to the patient's ability to make a decision,⁶²⁶ going on to comment:

But you do need to recognise those barriers and not just discard them and go, "well, he doesn't have capacity because he didn't answer any of my questions". It is like, "well, there is a really clear reason for that". (D06)

⁶²⁶ This participant appeared to be referencing the requirement under section 4 (4) to 'permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him'.

Some professionals spoke of calling on colleagues with relevant expertise, such as to support patients with learning difficulties. For example, using visual aids, through which “a lot of them [patients with learning disabilities] understand what’s going on and understand why” (N09). Recognising how the go-to approach to supporting decision making does not suit all patients, one doctor commented:

[Y]ou just need a different way of presenting the same information through, and then their brain is happy latching onto that and then the whole thing begins to make sense, whereas the conventional, “here is a leaflet – read it”, isn’t going to get you anywhere. (D08)

D04 recalled a patient for whom continuity of care was particularly important to their involvement, because “she preferred to receive information from people that she knew and that she trusted”. Despite this particular decision being made during the COVID-19 pandemic and the associated changes to hospital procedures, the care team recognised the importance of this and sought to enable continuity to best involve the patient in the decision.

In seeking to ascertain what the patient’s wishes may be, several professionals spoke again of the value of home visits. As much as these visits, as already discussed, can provide a picture of the patient’s quality of life, professionals also considered them to be useful in exploring the patient’s own values and preferences regarding their care. Some professionals reflected on this in relation to the desire of some patients to please their doctor, meaning that discussions in a clinical setting may not glean an accurate representation of the patient’s true preferences.

Normally, when they come to clinic it is all, “I’m feeling really good”. They do try and make... “Oh yes, I feel fine”, and try and please the professional, don’t they? (N01)

Elderly people, especially if they have some cognitive impairment, in the hospital environment they quite often are a bit nervous, a bit anxious and they often do not express themselves as well as they would do in familiar surroundings at home. (D11)

One doctor recalled a colleague's patient who was struggling on dialysis confiding in him:

He admitted to me and someone else that he didn't want to let his consultant down. That was one of the reasons he wanted to continue therapy. (D04)

This was discussed in the context of the strong bonds that can form between renal professionals and their patients given the chronic nature of the therapeutic relationship. I will explore this in greater depth later in this chapter (*see 5.1.8*).

Some professionals, however, spoke of difficulties where a patient moved between different preferences, resulting in a lack of the clarity that can provide reassurance that a good decision is being reached. For example, one doctor discussed a patient who was gradually losing capacity but, during that process, was expressing varied preferences concerning his treatment:

I think what was difficult was that, of course, his approach was ambivalent, you know, even when capacitous, and so that makes it really difficult. It wasn't that he was continually saying, "no, no, no, no, no, I don't want it, I don't want it, I don't want it", because actually, when questioned at the time, he would say, "no, I understand that I need it", and at times he'd say, "I'm happy to keep on going". But you had this to and fro. In essence, I think he was saying, "I really hate it, I wish I could do without it, but at the moment, I shouldn't stop it because it keeps me alive, but otherwise, I hate it". That sort of behaviour in the lead-up made it really

difficult when his capacity was fluctuating and then capacity had largely gone because you never quite knew what stated wish to hang your hat on. To all intents and purposes, it seemed to be, “keep me alive, but give me the bare minimum of dialysis”. (D03)

This doctor was not alone in a concern as to the reliability of a patient’s previously expressed preferences. Some worried that the fact the situation has changed relative to the one in which the patient expressed those preferences meant they could not be entirely confident the patient would still feel the same.

[N]o one had talked about the possibility that he might be a very different person by the time his kidneys failed. [...] It’s what happens to a lot of people. Person A in 1998 who says, “I might get kidney failure in 20 years”, teleported into 2021 with kidney failure. You’re 22 years older, you’ve aged, and you’ve acquired other problems with your health. Your life has changed. [...] They’re not the same person they were. [...] They might be preferences coming from a mind that’s different from the one beforehand. It’s messy. (D02)

Nonetheless, whilst these concerns were shared by several professionals, it was still largely felt that in the absence of a good reason to doubt the reliability of previously expressed preferences it is best to prioritise them.

I mean if somebody had capacity before, certainly, their decisions prior to them taking ill or prior to them losing capacity is certainly quite important, paramount really. [...] The only reason I would waver from such is if a next of kin comes up to give me a reason to doubt that. (D09)

Further, there was a strong sense that in the chronic setting – as opposed to instances of AKI – patients are generally well known to the care team. This often results, in the view of several professionals, in a clearer picture of what the patient may want.

And I think that is when their long-term consultant can have a real place, as can their dialysis unit. We are fortunate that we often know the patients, or the dialysis units often know the patients, very well and have had conversations with them over many years, which often doesn't happen in other specialities. (D06)

However, whilst there was a clear focus on centring discussion around the known values and preferences of the individual patient, several professionals were clear that they consider there to be limits on this way of making a Best Interests decision.

Effectively, these professionals felt there to be some wriggle room within the Best Interests framework, such that they can veto a more substituted judgement approach of pursuing what P would have decided (or, to be precise, what is felt most likely to be what P would have decided) if the result would be something they cannot personally reconcile with quality care – relating back to the idea of sufficiency in quality of life as discussed above.

Sometimes, it would be what the patient wants, and you may have had conversations prior to them losing capacity to indicate what they may want, but sometimes, the mental capacity affects their physical ability as well to tolerate such an invasive treatment. So the physical aspect might take over from whether or not they can or can't decide and what they want. (N07)

[W]hat we wouldn't do is start crossing thresholds where we thought it was unfair, cruel, or likely to cause her harm, be it physical distress or mental distress. (D04)

In some cases, the impairment that precludes the patient's decision-making capacity is of a nature and/or severity that it is not possible to meaningfully involve them in the decision-making process at all. Professionals spoke of patients being in the room during discussions but "not engaging with any of the conversation" (N01). On such a case, one reflected:

Superficially she says "oh, I'll be fine, and I'll see you all in clinic" – that sort of thing. But there was no decision making on her part at all because she wasn't able to make those- I don't think she understood the process of what we were trying to accomplish for her. (N03)

Sometimes, then, professionals expressed feeling that "[y]ou can't know what that person if they had a voice would want you to do for them" (D02). One spoke of being in a difficult situation of "trying to interpret how they're feeling" (N03).

It is in these cases, which professionals acknowledged to be at one end of a broad spectrum of capacity, that the value of a collaborative decision-making process was highlighted as most valuable. In the absence of the patient's ability to provide any input as to their preferences, the role of the family and multidisciplinary team was viewed as vital to reaching an appropriate decision.

Despite common claims to prioritise the preferences of the patient – even if they may be overridden – it was noted by some professionals that patients are not often present in Best Interests meetings regarding their treatment. Sometimes, instead, P would be engaged with separately. When asked whether patients were ordinarily in these meetings, one nurse stated:

Not usually. Not in the ones that I've been involved in, no. (N07)

This participant went on, however, to explain that sometimes the patient being absent can be beneficial on two fronts. First, the patient may find the discussion distressing if they heard it. Second, the patient not being there may enable the family to speak more freely about their concerns, not wanting to upset the patient. It is interesting that these concerns appear to be applicable only where the patient has some level of cognitive ability – albeit not necessarily sufficient to make a decision – and thus they may be in a position whereby they could engage in the discussion to some degree. However, this experience was not universal, and some professionals expressed a desire to always have the patient present in discussions about them – one doctor characterised this as their “default position” (D08).

It appears, then, that there are inconsistencies in how precisely a patient will be engaged in a Best Interests decision about their care. Though this is not surprising when the experiences of professionals are taken as a whole. Many commented on these inconsistencies and how they feel there are no rules as to how exactly a Best Interests decision ought to be made.

There’ll be different ways. Do you reach a consensus decision with whatever it is, Socratic-type things? Do you have a vote? Do you have to have a majority? Do you have to have everyone say the same thing? There are no rules. (D02)

5.1.3 Family involvement

The most prominently discussed aspect of Best Interests decisions raised by professionals was the involvement of the patient’s family. A range of perspectives on this were discussed. Whilst most professionals overwhelmingly saw real value in the family’s involvement, this was often accompanied by a frustration with how difficult such involvement can be.

Professionals largely talked about the benefits of involving the patient’s family in terms of knowledge and understanding of the patient. Even though they may have cared for the patient for many

years, professionals recognised that the patient's family have a more intimate understanding of what they would want, such that many professionals stated they would "add a fair amount of weight to what they [the family] say" (D03).

[Consider whether] a family member can support the patterns, values, or preferences they [the patient] had beforehand. [...] it's meant to be the role of a family member. What would he want us to have done? (D02)

They're not brought in, they're there. They're part of this family of what's going on. (D02)

Particularly where the patient in question lacks decision-making capacity to the extent that they are entirely unable to engage in the decision-making process, this process may be "virtually entirely in discussion with family" (D10). Indeed, the value placed on the input of family members was highlighted by professionals who spoke about patients who had no family to consult and how such situations are "a little bit more tricky" (N07).

However, in engaging with the family for this purpose, professionals highlighted the risk that what the family themselves want may become enmeshed with their reporting of what the patient would want.

Family, of course, can be a very interesting beast because families will not necessarily- They'll project a combination of what they want and what they think the patient would want. (D08)

What they think is best comes out, but I try and frame it for the patient because my first responsibility is to the patient. Even at the moment, it's not actually directly to the family. (D03)

You would hope the family can give you an idea of what the patient would want, but equally they will always give you what they would want too. (D06)

Being unable to always clearly distinguish the two was discussed as a problem by some professionals. One doctor spoke of how the line is often “really blurred” (D06), and that even if you suspect a family member is only expressing their personal view “you are never going to call them out on that” (D06). Indeed, many professionals spoke of the difficulties of challenging a family member when it is felt they are not necessarily providing information as to the patient’s personal views and preferences

Nonetheless, there was some acknowledgement that the role of healthcare professionals encompasses an element of having to “treat the family as well” (D09). As such, even where there is a clear distinction between what the family want themselves, and what they are saying the patient would want, the former was still felt to be relevant, because “the family have to be happy with those decisions” (D06). Further, it may be important to consider the wider family’s interests when certain options may entail a caring burden on the family.

It’s “who’s going to look after them?”, “how are they going to be managed?”, and I think that’s another thing to address. (N04)

It’s certainly not merely a case of objective information as to how the patient manages at home or how they’re cared for at home. It does take into account the family views independent of the patient as well as what the patient’s views might have been. (D10)

Some professionals expressed a preference for having a single family representative to participate in the decision-making process. They often cited the additional challenges of navigating several family member opinions at once that may or may not align, which “is actually quite difficult to resolve” (D11).

I will always want a family representative, yes, first and foremost, rather than having lots of different conversations over the time, but I would allow a safe space meeting for people to come in, other members of the family, to represent their views in a meeting. But, on the day-to-day management, one nominated representative. (D04)

That being said, the utility of larger meetings, in which several family members may attend, was expressed by several professionals. Albeit as serving a different purpose – that of ensuring everyone understands what is going on – and therefore not at odds with those who favour a single family representative. In some cases, a full family meeting was viewed almost as a matter of efficiency.

The most productive family meetings were when they were all there. And that to me sounds scary and crazy, to have that many people together, but if you can communicate a clear plan to all of them at the same time. (D06)

That being said, professionals commented on how COVID-19 affected their ability to take this approach. The need to reduce the number and frequency of visitors, as well as using videoconferencing for discussions, led many to feel that the decision-making process became rather “tricky” (N07) and “disjointed” (D06).

We tried to engage with all members of the family, but again, it was during COVID. We were only meant to be having two visitors in at a time. (N01)

When engaging with the family, professionals suggested they were less resistant to the opinions the family expressed if they entailed a non-dialytic route. Explaining a situation when the wife of one

patient explained that her husband had, when he had capacity, expressed that he would not want anything invasive, one doctor stated:

Obviously, that is clearly indicating that dialysis is not an option. By breaking down the conversation into simple instructions, also we involved other family like a daughter and their GP, all very clear, the patient would have not wanted this, so it was quite easy really because we decided this the same day, and then we put him on renal supportive care. (D05)

This may, however, be explained by the overarching suggestion of professionals that family members have a tendency to favour active treatment beyond what the care team consider appropriate. Assuming this is the case, one would expect a scenario whereby the care team feel dialysis is appropriate but the family disagrees to be somewhat uncommon.

When seeking to understand the family's perspective on a decision – which was stressed as both necessary and useful – professionals spoke at length about challenging situations in which disagreements between the family and care team arose.

Occasionally you do get into situations whereby families are really quite insistent, we hold an opinion which is not the same, and then it's ethically and morally and legally really quite a difficult situation because, actually, if you're going to make a [B]est [I]nterests decision you have to take notice of what the next of kin says. (D08)

Such situations were suggested to necessitate quite firm reminding of family members that it is the patient's doctor who is responsible for the final decision.

But I do think when it gets a bit tricky, we sometimes do have to say, “look, it is not a family decision. We will need to make the decision. But we want to involve you and want to make sure that everybody is happy that we are making the right decision”. (D06)

One of the things that bothers me, and this is whether you’re making a [B]est [I]nterests decision in dialysis or anything else, is if you’re not careful families will get the impression that they’re making the physical decision when, actually, that’s not the construct that we’re working in. (D08)

Certainly, the family members of the patient I was talking about believed it was their decision. Definitely believed it was their decision. (N09)

One nurse (N02) discussed a patient whose son insisted she remain on dialysis regardless of the deterioration of her condition, whilst the care team were clear that they could not safely dialyse a patient in her condition. The situation had to be escalated, with the patient’s consultant having to write to the family to explain that dialysis would be stopping. The whole process – during which dialysis continued – “took at least nine months” (N02). It appears that attempts to minimise conflict with family members can result in patient’s continuing to receive care that is not considered by the care team to be in their Best Interests. This will be discussed further shortly (*see 5.1.5 and 5.1.6*).

Very clearly, professionals felt that understanding of the legal basis of a Best Interests decision was (quite understandably) often lacking in family members. The need to clarify with family that they are not able to make a final decision, balanced against a desire to keep them actively involved for the benefits they bring to the process, was highlighted as a particular challenge in Best Interests decision making. Further, in some cases, professionals highlighted how the family can dislike the legal reality so much that “[n]o matter how you phrase the things it doesn’t work” (D05).

On this idea of explaining to family members the role they have in a Best Interests decision, there were reflections by some on the transition of patients from paediatric to adult care and the

changing role of the family. N04 spoke of the difficulties of making a patient's parents understand that when their child turns 18, they will not have the same decision-making power. She explained how parents may feel like a lot is changing at once, in that the change in the decision-making role comes when their child is being transferred to another care team, when discussions about possible kidney transplantation may also be taking place. It is something to be navigated "very delicately" (N04). Out of recognition of these challenges, one nurse described how changes to the process of transition from paediatric to adult care were made.

[W]e have now introduced another step where we go to the children's hospital when they're about 16 and meet them and their families, so that we can start addressing anything like this. So, when they come to us at 18, it's not the first time anyone's told the parents that they won't be making the decisions. (N04)

In addition to misunderstandings as to the law, there was a strong feeling that disagreements between families and the care team are often attributable to the family misunderstanding the (clinical) nature and purpose of dialysis. Many professionals felt that family members often take the view that "dialysis will solve everything" (N02), which can cause them to push for active treatment on false bases.

People, I think, often think medicine can cure everything and we can make everybody live to 200 and we know all the answers. And we just don't. And they really struggled with that I think. (D06)

This view was often highlighted as resulting in an assumption on the part of family members that dialysis will be provided; that it is not a question of whether it is appropriate. Professionals spoke of family members talking about dialysis as curative. This caused one nurse to draw a comparison with

cancer care, suggesting that dialysis seems to be associated with more unrealistic expectations than some other treatments.

[D]ialysis is almost seen by some people as a cure, which it's not. It's a treatment. It's like chemotherapy. If chemotherapy wasn't working- I don't know because I've never worked in oncology or haematology, but it's almost more accepted by the general population that their cancer treatment hasn't worked. [...] Whereas dialysis, it's like, "as long as you can get through those doors and as long as you're breathing at the end of it, that is good enough".
(N07)

In discussing issues of understanding, one nurse noted that where there is a family member who is clinically trained "we don't have much difficulty for this kind of decision making" (N06).

Lack of understanding being a common challenge, one doctor commented that "[o]ur job is, to a large extent, about education" (D08). In overcoming this difficulty through discussion and education, the value of time was clearly highlighted by many professionals.

Sometimes, actually, you just need to accept that more time is needed, maybe, to come to a decision. (D03)

Several spoke about how they "try not to have to rush the decision making" (D07), because time may also allow the care team to demonstrate to the family that they have explored all options, with some professionals talking about lengthy processes of ruling things out to reassure family members. In some circumstances, this may result in a patient continuing to receive active treatment until the point that the decision is "[m]ore palatable to everybody involved" (D06).

I'm always – I try to be – as sensitive to it as possible. Obviously, they're situations in which you have to give the family time, especially if at all one is thinking about withdrawing care. [...] It's very important that you give the family time to, sometimes, come to see what you're seeing. (D09)

As such, with more complicated situations, the lead consultant may “bend over backwards” (N03) and there may be a series of meetings, accompanied by further information.

First meeting it won't agree, then we'll ask them to come again, we'll give more information, and we'll give more time to them to think. Then we'll ask them to come back again. (N06)

So, it's become quite a repeated...numerous attempts. You're trying to get them to understand what might be going on and what choices that they make might be suitable for them. (D07)

Nonetheless, one was candid about time pressures and a perceived situation whereby professionals sometimes “take an opportunistic time to make those decisions” (N01).

Even where these decisions are afforded time, this is not without issue. Some professionals spoke of patients who “died prior to a resolution within the [B]est [I]nterests, sort of, process” (N01).

Further, if, given time, agreement between the care team and the family is reached, several professionals still spoke of these decisions as being stressful – both doctors and nurses shared this feeling. This was highlighted as widely understood. Indeed, one doctor – a registrar – commented on the prospect of taking a leading role in Best Interests decisions as their career progresses:

The family have always come round. But often it is a lot later than you had originally planned with the families. That is not something I am looking forward to doing as a consultant. (D06)

In addition to misunderstanding the realities of care, many professionals spoke of the emotional investment of family members and how this could make them “want someone to live for as long as possible” (D02).

If you look from their point of view, they can’t even think, “my father or my mother is dying”, because emotionally they are attached to the patient and they can’t digest that, “my dad or my mum is dying”. They might want to extend their life, so sometimes if they take the decision do not resuscitate, if something happened, they sometimes grieve more if, “father would be alive if by allowing them to resuscitate”. So, it’s emotional attachment. I think that’s the main reason, maybe, they don’t want to take a strong decision. (N06)

Many spoke of how the heightened emotions were “very palpable” (D09) during Best Interests discussions. Nonetheless, there was recognition that this was a natural response from family members and that it must be respected and carefully navigated.

[S]ometimes relatives’ connections to a person can affect how objective they can be because part of what they feel should happen stems from what they want to happen, based on their own feelings, which is perfectly human. (D08)

Yes, it can do. It can. It can, but why wouldn’t it? It’s not unreasonable for it to cloud their judgement. (N07)

Professionals largely agreed that, in certain situations of disagreement, there is a need to go against what the family are calling for, even if this could damage that relationship. For the most part, the feeling was that such situations are those in which dialysing a patient will actively cause harm to the patient. One doctor very clearly made the connection to the Hippocratic Oath in discussing this.

Actually, if it's the family are desperate for him to carry on dialysis, but I actually have concrete proof of harm, well, first, do no harm, at that point the ethical situation is quite different. I would draw a line there. If the family were then to insist: A, they can't really, legally, insist. B, yes, I would end up, if necessary, taking that to the Court of Protection and saying, "look...". At that point, I would expect the Court to support me. (D08)

Situations in which questions of sedation and restraint arose were also felt by many professionals to necessitate an active resistance to the family's demands.

One doctor distinguished the appropriateness of restraint in situations where there is a prospect of the patient's impairment being reversed, framing this in terms of the proportionality element of the MCA 2005.

I think that can be a challenge because whilst, if there's a reversible element to the need for restraint, that is fine, so I think we can do that. I think that's sensible because there's an end in sight which is a tolerable treatment that is effective and life-sustaining. But I have looked after people where there is no end in sight, that they have such profound learning difficulties, which is what this patient had, that they could come to physical harm through regular dialysis or through restraint. (D04)

This doctor was clear that where the impairment is not reversible, they would feel it appropriate to resist the family's calls for restraint.

In other cases, professionals recalled family members volunteering themselves to restrain a patient, which were met with resistance.

So occasionally they did try and do that, and they would be like, "we can hold him down so you can dialyse him". And it was like, "no, that is not how it works". (D06)

Professionals' objections to restraint were primarily based on what they perceived as unacceptable harm to the patient, regardless of whether that restraint is physical or chemical. One spoke of a patient who had been prescribed antipsychotic medication which, in turn, made it unsafe to dialyse him because of how drowsy he became.

Wanting to avoid such harm, restraint was only suggested to be acceptable in limited situations. In addition to reversible impairment as discussed above, some professionals also felt restraint could be appropriate to enable a patient's dialysis *occasionally*, provided that patient would dialyse without restraint most of the time.

Well, what you say to them is that, "yes, once in a while if they are really restless or agitated, yes, we can sedate, but it's not something we can do on a regular basis as a preventative measure". (D11)

Indeed, the importance ascribed to this being an option in very few cases was such that some professionals spoke of patients having reduced dialysis as a result of difficulties dialysing them at some sessions or nonadherence. D03 recalled one patient who did not properly follow his care plan, including

not always turning up to dialysis sessions, who therefore ended up requiring emergency dialysis on several occasions.

In contrast with this idea of notably dominant family members, professionals did speak of family members who are less willing to take a strong role in decisions and are “relatively hands-off” (D11) – even if a less common scenario. This was suggested to be for various reasons, but most often there was a feeling that some family members may find the responsibility too much, such that they may, depending on the eventual decision reached, feel that they have caused the death of a family member.

We all die. It's about the ones that are left behind, sometimes, and putting the onus of responsibility, particularly around capacity, on somebody who may not have the skillset to deal with it. It's a member of their [the patient's] family. We've [the care team] been through it a few times before. Have they been through it before? I doubt it, so that might not be fair, mightn't it, yes? (D04)

You will, equally, have other people who don't even want to take any part in the discussion for fear that they may be contributing, in any way, to a decision that they may or may not be comfortable with later on. (D08)

[T]here's a feeling, perhaps, sometimes, from family that "I don't want to be seen to be taking part in a discussion that's almost against keeping my loved one alive". (N07)

One nurse recounted an experience in which a patient's wife – who held lasting power of attorney for health and wellbeing (LPA-HW) for the patient – “obviously wanted what was best for her husband” (N01) but appeared to find the process of making a decision daunting. Reflecting, this nurse commented how this situation “highlighted to me that decision making is quite onerous on the relative” (N01).

In some situations, the family member may clearly express their desire to step back from the decision-making process and leave it to the care team.

But she had said previously, when she had been to see him on the ward, that she wanted us to make the decision. (N08)

So, whilst in some situations it may be about tactfully resisting the pressure of the patient's family, other times professionals may instead need to reassure less forthcoming family members that they do not have to make the decision themselves.⁶²⁷

We don't want the family to feel pressurised. And I think we all try and make sure that the family realise that it is not them having to make a decision. It is us. (D06)

Regardless of how involved the family may want to be, some professionals were honest in admitting that they sometimes approach this part of a Best Interests decision with a preconceived view of how things ought to proceed.

Then I would like to facilitate their involvement in ongoing care, but – and I'll be frank – with a steer of what I think is the best way forward. (D04)

I'd say we probably, usually, would've made up, shall I put it this way, two thirds of our mind [before meeting with the patient's family]. (D10)

This contrasts with others who spoke of being “quite happy to modify my plan based on our discussions, which will be ongoing” (D09). Indeed, some spoke of how they seek to enter meetings with family

⁶²⁷ In the case discussed by this participant, the wife holding an LPA-HW for her husband meant that it was not a Best Interests decision per section 4 of the MCA 2005. Nonetheless, this reflection highlights how family members sometimes find the feeling of responsibility for such an important care decision.

members with an open mind, presenting the patient's options objectively. Albeit with a recognition that total objectivity is challenging.

So I think we do start very objectively and try to be objective [...] but of course we are humans and we have biases. (D11)

Contrasting the involvement of family with the involvement of an IMCA, one doctor commented:

[W]ith the family, obviously the nature of it is, you could argue, more collaborative I suppose. (D09)

The suggestion being that the family have a greater (personal and emotional) stake in things than an IMCA, and thus professionals might be more open to a frank discussion. This willingness to change one's position, however, often was noted as resulting in trials of dialysis, on which some professionals had conflicting views. This will be discussed in more depth shortly (*see 5.1.6*).

5.1.4 Collaborative decision making

Professionals recognised that, in the absence of an alternative legally appointed decision maker, the lead consultant takes responsibility for the final decision. Nonetheless, there was extensive discussion of the collaborative processes taking place in the lead up to this final decision. This was largely framed as a feature of a formal Best Interests meeting, in that professionals consider such an approach a "very useful and efficient way to try to get everybody together and come to a consensus" (D07).

The parties that would be involved in a Best Interests decision were discussed as bespoke to a patient's situation. Professionals described the involvement of various members of the renal team that are involved in the patient's care, clinical colleagues from other relevant specialties (such as general practice and psychiatry), family members, social workers, IMCAs, and any other relevant individuals, with the combination varying between patients. Some instances were also discussed where learning disability specialists were engaged to try and involve the patient as much as possible.

It was explained that this broad, collaborative process is considered beneficial to reaching the appropriate decision through a "broad opinion" (D10).

What you're just meant to do is involve all of the right people and somehow the ball bearing falls into the right hole. (D02)

Getting people involved in a decision is actually a strength, I think. It makes things go smoothly. (D09)

Of note, however, several doctors reflected on how their recognition of the value of a collaborative process has come with experience.

Perhaps, as a younger nephrologist, I would've been somewhat more rigid. [...] You, sort of, learn that it requires a lot of time and a lot of exploration and a lot of discussion with the family from all sorts of members of the healthcare team. So, yes, you become more nuanced to the softer aspects of doing it. (D10)

In these collaborative decisions, there was a particular focus on the involvement of professionals who are familiar with the patient, whether within the renal team or external to it.

I need some support, so someone who knows her a bit longer-term probably will be more helpful. (D05)

A common example of this being the great importance doctors attached to the role of nurses in Best Interests decisions. I have already discussed how specialist nurses are considered useful in carrying out home visits to better understand the patient's quality of life and home situation. Indeed, the value of specialist nurses was stressed by several doctors, in that these nurses become "expert in that situation" (D01) and that their presence "helps in terms of those [Best Interests] decisions" (D09). Dialysis nurses were similarly acknowledged by many doctors for the important role they can play in these decisions, often because, in the case of patients already on dialysis, the dialysis nurses "get to know the family members who come" (D06).

However, not all nurses felt valued in this way. One dialysis nurse explained that they are not asked for input when a Best Interest meeting is taking place, and instead are just informed of the outcome and what care they will be expected to provide. Several stated that they would like to be more involved in Best Interests decisions, feeling that they have an important perspective.

It would be nice to be more involved, especially if you've been there to initiate the first dialysis and you've probably been there for the first couple of dialysis sessions and you've either seen an improvement or you haven't seen an improvement. It would be nice to be asked and involved. (N09)

I think we actually should be, definitely, more involved in that. To be an advocate for the patient, because we know them, probably, better than the doctors know them. We know their little quirks and their little routines in the hospital. We're there doing their personal care. We have those chats with them. I think we're not involved as much [in Best Interests decisions] as we could be. (N05)

It was also suggested by some nurses that specialist nurses may sometimes be a little out of touch if they have not been directly providing care for a while.

Of the nurses who felt they are listened to by doctors, there was a sense that their level of experience – or even just age – plays a part.

[S]o it gets easier the longer you're here because you get to an age where you're older than some of them [the doctors]. (N07)

[I]t depends on whether they're [the doctors] talking to an experienced nurse. I've been on the ward for nearly five years and all the doctors and consultants know me, so they listen to me when I've got a concern. If a more junior member or somebody who hasn't been there long, they might not be so-. (N05)

Similarly, some doctors reflected on how “challenging a consultant is a very uncomfortable feeling” (D05) when you are more junior. It is only when they reached more senior (but not yet consultant) levels that some doctors felt able to question the decision made by a consultant.

Several professionals discussed their experiences of working with IMCAs. Though it was generally acknowledged that the involvement of an IMCA is uncommon because patients usually have family members who are willing to assume the consultee role.

Those who spoke positively of an IMCA's involvement were mostly surprised by this, implying a view that, in general, IMCAs are not considered valuable additions to the decision-making process.

I was amazed at, in particular – and this is not my experience of IMCAs – the common sense that was shown with the direction of the IMCA about the fact that this is a reasonable thing

to do. [...] I have come across IMCAs in the past who believe that we should be sedating patients to facilitate treatment. I think once you get into that realm of, “yes, sure, we can do it, we can knock people out to deliver treatment”, but actually that is bordering on matters that I feel very uncomfortable with. (D04)

This feeling that IMCAs are not ordinarily useful was based largely on professionals’ querying of an IMCA’s knowledge and expertise. Professionals spoke of assuming that IMCAs were not medically trained, in some cases suggesting they may – rightly or wrongly – be taken less seriously as a result. One questioned, “[i]f they don’t have knowledge of the sorts of treatment that you’re putting somebody through, can they fully represent the person that they’re there to represent? I don’t know” (N07).

Given this attitude, it is perhaps unsurprising that many professionals viewed the role of an IMCA as something of a “checkpoint” (D08) to “buttress things legally” (D09). This view was strengthened by one professional who explained how an IMCA would likely be engaged *after* the care team had reached a decision. In effect, many professionals who spoke of involving IMCAs felt that an IMCA’s agreement with a decision provided reassurance as to the legal standing of that decision and, as a result, “peace of mind” (N08). It was suggested to be largely procedural, as opposed to more collaborative engagement with family members.

Nonetheless, several professionals saw a benefit to IMCAs in that they do not have the emotional connection to the patient that can affect the objectivity of family members. IMCAs, then, can be “truly independent and objective” (D08). A similar view was expressed of carers.

I sometimes think that carers can see the bigger picture. I think to have a family member – and I’m not saying it’s wrong – but you’re very, very close to the situation. (N03)

On discussing matters within the renal team, many professionals spoke about their colleagues being very supportive, and the existence of a culture of openness such that they can ask for advice or a second opinion if desired. One doctor, still completing their specialty training, explained that, whilst a feeling of hierarchy exists, their consultant colleagues “are always available” and “very supportive” (D05). Several trainees described situations in which they had to approach senior colleagues with difficult decisions and felt listened to, with one joking that “we often offer our opinions, even if it is not asked for” (D06). This was emphasised in the context of inpatients, who are largely cared for by trainees.

Not only trainees found the ability to confer with colleagues useful. Many consultants spoke of the benefits of a second opinion when faced with a particularly challenging decision.

These are quite difficult decisions for us to make, so I think that we should have a process in place where additional opinions are part of our normal working practice. (D04)

For some, this was about obtaining an outsider’s perspective, from a colleague who is not involved with the patient in question.

I think it is also helpful to have someone who is not directly involved in the patient’s care. It is helpful to have someone who is not directly involved as a sort of objective view. (D01)

Often this was felt necessary when the doctor has a long-term relationship with the patient and, as a result, possible emotional attachment. This idea of attachment to long-term patients and its ability to cloud a professional’s judgement will be discussed more later in this chapter (*see 5.1.8*).

Others explained that a second opinion may be called for out of humility in the event of a disagreement between the doctor and the patient’s family.

If there's disagreement – and there often is disagreement – I think that a lack of arrogance on the medical professionals' side is very, very helpful. So, asking for additional opinions. (D04)

This need to step back was felt by both doctors and nurses. Reflecting on this need for self-awareness, coupled with the culture of supportiveness among colleagues, one nurse explained:

I know the patient, I know inside out about the patient, so if I feel it is difficult to make a decision on their behalf, then I can contact my colleagues or I can contact my seniors or managers, then they will be attending the meeting either with me or I can step back. (N06)

This supportive environment was described by several as extending beyond the decision making itself. Recognising that Best Interests decisions, particularly where they entail discontinuing dialysis, can be extremely challenging and take their emotional toll on professionals, professionals spoke of casual supportive conversations in the office, in some cases as a debrief if a colleague “feels she needs to chat about what might have gone right or what might have gone wrong” (N03).

Overall, then, professionals felt that it is best practice for a Best Interests decision to be made as the result of discussions involving a range of parties. Even if the final decision is to be officially made by the patient's consultant, professionals felt that this decision should not be made by that doctor in isolation.

5.1.5 The path of least resistance

As much as professionals want to do what they perceive to be the “right” thing for their patients, the reality of the decision-making landscape was often characterised as being under pressure from several directions.

Notably, where disagreement between the care team and the patient’s family arises it is generally thought of as not worth allowing conflict to escalate to the point of damaged relationships and potential court proceedings. The result, then, is a situation whereby professionals can often find themselves pursuing what they described as the “path of least resistance” (D02) or “easiest way forward” (N01) even if they do not consider it to be in the patient’s Best Interests. Professionals mostly commented on the realisation of such a scenario when the family are insistent on the patient undergoing dialysis – whether that be an initiation or continuation – when the care team feels that the patient will struggle to tolerate the burdens of dialysis and/or has an overall low quality of life, such that the burdens of dialysis outweigh any benefit.

[I]n the textbook it is always easy, say, “family will never be able to make the decision for patients”. But actually, we all know as a medical practitioner if there is a strong objection from the family things are always quite difficult to move on. (D05)

Professionals characterised this approach as defensive medicine, commenting on what they consider an unfortunate state of affairs whereby they must always have an eye on the potential for formal complaints from family members. This was reflected on as something of a shift that some had encountered during their careers, whereby there is an increased culture of complaints where patients and their families are not satisfied with the care received. Whilst it was acknowledged that a right to complain is important, some professionals expressed concern that, in the context of patients who lack decision-making capacity

whose family members are making complaints, a general movement towards defensive medicine can prove detrimental.

If there is a default [of providing dialysis to avoid conflict], someone who hasn't got a voice is particularly vulnerable to that. (D02)

It should be about protecting the patient, but I think [...] in the current world, it's about protecting yourself. I'm afraid it really is. (D04)

Indeed, this idea of defensive medicine was, for some professionals, about the avoidance of legal action as much as maintaining positive relationships with the family members of patients. Some reflected on situations where this approach resulted in a Best Interests decision being made that they did not actually feel was in the Best Interests of the patient.

Sometimes we end up outside of what we would think is necessarily the right thing to do, but actually the families are so insistent that our other option is to end in the Court of Protection and have some extremely horrific situation for everyone involved. (D08)

This is also something that was observed by nurses who were involved in discussions though not with ultimate responsibility for the final decision. One described a situation where they felt the doctor who had to make the decision was put in a difficult position by the patient's family.

I think more that the consultant was being led by the family. I really do. Because knowing that consultant, I don't think he probably would have done it. I think he was being pushed into a corner. Whether that was right or wrong, I don't know. (N09)

Whilst taking this path and proceeding in line with the views of family members, even if not in agreement with them, professionals noted that pressure to do so can come from various directions. As much as family members may seek to dominate the decision-making process, there was a feeling that the hospital itself – meaning management and the hospital lawyers – may sometimes pressure healthcare professionals to do what the family want in the event of conflict. Professionals suggested that it can sometimes feel as though there is an ever-looming threat of legal proceedings which the hospital wants to avoid, even at the expense of patients who may find themselves undergoing treatment that is hugely burdensome.

The Trust solicitors are very scared of litigation. So, I think there are some times when we do them [the family's wishes] because we feel backed into a corner, and it is very difficult. Then you're very defensive and reticent because your views are very different to the family's views. (N04)

There appears to be a suggestion, then, that members of the care team do not always feel able to do what they think is in the Best Interests of a patient. Some professionals spoke of the distress that can come from not following the wishes of P's family members. They recounted the experiences of either themselves or their colleagues having received complaints, in some cases resulting in Court of Protection hearings. Those who had not themselves been involved in cases that reached this point still noted an element of word-of-mouth as to what it is like.

I've never been [to the Court of Protection], but I'm told it's something that you never forget. It's an experience. I had a girlfriend – it broke her. She actually jacked in being a nurse because it was so traumatic. So touch wood, I've never been through that situation. (N03)

However, the feeling of wanting to do the “right” thing for the patient was recognised as necessitating the Court of Protection in some cases.

If it’s the only way that I have to ensure that the person is looked after properly then we’ll do it, we’ll go there [Court of Protection] because we have to. The ultimate person I’m looking after is that patient. (D08)

However, this doctor did reflect on the confrontational nature of pursuing legal avenues of conflict resolution and how this has a negative effect even if the outcome is what the care team consider to be in the patient’s Best Interests. D08 highlighted how a decision not to dialyze a patient does not mean abandonment because “you still need to look after them” with “all the other good stuff”. Indeed, the provision of such non-dialytic care still requires a continuing relationship with the patient’s family, which legal proceedings can hugely damage.

One of the things that going to the Court of Protection fundamentally means is that you and the family have lost that therapeutic relationship. (D08)

This professional stressed that this potential for a severed relationship makes the Court of Protection a last resort for them – a feeling echoed by most professionals. Instead, participants felt it better to “try and reason with them [the family]” (D11) so as to avoid things reaching this stage.

Building on this idea of protecting oneself from possible complaints and legal action, professionals stressed the importance of extensively documenting discussions to the point that records are “fantastically accurate and legible” (D04). One doctor highlighted the possible benefits down the line, recounting his experience of a subsequent complaint.

The family wrote to the GMC about anyone that had been involved in the care, and we were, as a unit, eight, nine of us were investigated by the GMC for our role in his care and subsequent death. Having everything in writing, even though it was time-consuming, was fantastically helpful. (D04)

Accurate documentation was also highlighted as important in demonstrating that a Best Interests decision taking place at all was appropriate. One nurse described situations in which she was not clear, on reading the patient's notes, how decisions had been made. This left her feeling strongly that all stages of the process should be well documented – not just the final Best Interests decision itself.

My opinion is, it should be documented at that stage, that the patient hasn't got capacity. I think they should make a capacity assessment. You know, "we have done a capacity assessment and that patient has not got the capacity". [...] It should be clearly documented that that process took place and what steps we did to involve the patient and what is important to the patient. (N01)

Professionals overall expressed a feeling that they are often in a difficult situation of having to provide care that they do not think is appropriate. The need to maintain relationships with family members and avoid complaints can cause them to follow this path of least resistance and agree to demands of family members that go against their own view of the patient's Best Interests.

5.1.6 Dialysis trials as conflict resolution

As something of a middle ground between entirely succumbing to the will of family members and risking the Court of Protection in conflict situations, many professionals raised the idea of dialysis trials. It was suggested that offering to provide dialysis on a trial basis, with the intention of revisiting the decision soon after, could defuse a situation and help maintain the relationship between the care team and the family. In effect, dialysis trials were discussed as a compromise.

So, occasionally, it's a trial where it's not very clear where there might still be some areas of conflict, both within that individual or around that individual, and they're not sure and not committed, then sometimes a trial of the therapy is quite helpful. I don't do it as a routine. (D03)

Trials of dialysis are a polite way of avoiding conflict and proving, one way or another, to that mediated group, that you've done everything you possibly can and it wasn't a success. Because it's a trial, it has only been for a couple of months, so we probably haven't caused harm, yes? But it's a fudge. It's a fudge. (D04)

[E]ven if I'm convinced that this is not the right thing for this patient, I do accommodate. I've been known to accommodate the opinion of a family to the point that, yes, we try dialysis. Obviously, one tends to try to circumscribe it in a sense that, "yes, we will try this. If this happens, this happens, then we know we've tried and we'll stop". [...] I always find that a less combative, less adversarial, approach and that's what I tend to use in my practice. (D09)

These professionals admitted that trials may be started in situations where they do not feel it is good for the patient. Indeed, one said they would "not dig my heel in" (D07) and decide not to dialyse the patient when the family objects even if "complication and the risk from dialysis might still be high" (D07).

That this course of action was often discussed in terms of something that had to be done in these instances of conflict suggests that those around the patient – their consultees – can strongly influence decisions, to the point that professionals may set aside what they feel is best for the patient.

Whilst there was widespread recognition that dialysis trials do happen, and for various reasons, some professionals expressed discomfort at their increasing prevalence.

[I]f there's doubt, sometimes people then go for a trial, which I don't particularly agree, the overuse of trial dialysis. [...] If you are in doubt, people will just say, "dialyse if you're in doubt", and people say, "give them a trial", which means that you let them dialyse. [...] So, your limit of dialysing people becomes very, very low. (D07)

This discomfort, at least in part, stems from a feeling that "[o]nce it starts, it's very hard to stop" (D07). Professionals explained the difficulties of ending a dialysis trial in situations where the reason for doing so is not immediately clear to family members who may be pushing for continued dialysis. For example, one doctor suggested that the "trajectory becomes clear" (D10) in most cases, such as regular hospital admissions during the trial making apparent the "natural end of the trial" (D10).

However, recognising the difficulties in discontinuing a dialysis trial, one doctor outlined the very particular approach he takes to avoid further conflict when the decision is revisited. When starting a trial, he sets very clear parameters as to what "improvement" is going to be measured by – ensuring there is not a general (and very subjective) focus on whether the patient feels better.

The definition of how they feel, the fact that they got accustomed to having dialysis is often taken as they're feeling better or feeling well. You need to be very specific. That's my personal view, is that if you're very specific about when you would stop, what are the things that you are looking for after a month and to either continue or discontinue, that's very helpful. (D11)

This feeling that it is difficult to stop dialysis once it starts fed into discussion by many professionals about differences and similarities between withholding care and withdrawing care. Though there appeared to be a preference for the language of discontinuing or not carrying on rather than withdrawing due to the negative connotations of the latter.

There were very mixed views on this distinction as to whether they ought to be viewed as in any way different, assuming all other aspects are similar. One doctor was explicit that neither is “more existentially challenging, or ethically questionable, or anything like that” (D02). For some, then, they are comparable. However, others were less sure.

I think I would argue perhaps more strongly to not start the treatment, rather than them to not continue it. Because this is the difference between starting something and stopping something. (D01)

For some, this distinction comes from feelings conveyed by family members, which can make it more difficult to pursue the route of discontinuing dialysis.

Almost, for the family, it [stopping dialysis] feels like active killing for them, that you’re actively stopping something so that they can die from not having it, rather than you not offering it before. (D07)

Many spoke of instances where dialysis was being withdrawn out of recognition that the care is no longer improving the patient’s condition, but that family members sometimes struggled to accept this and instead viewed it as akin to some form of euthanasia.

Despite the strong element of compromise in the starting of dialysis trials, some professionals did explain that trials can provide useful information to make a more final Best Interests decision.

[B]y that point, people have lived with dialysis. They know what it means to have the hospital transport turn up at 6:45 in the morning 15 years after you've retired and having to be ready for that. Get driven in, do the dialysis. The machine goes down and the shouting patient over there. (D02)

Relatedly, some spoke of trials in terms of allowing time to make a particularly difficult decision, especially if the patient's condition is quickly deteriorating.

[W]hat might happen is there might be a decision made to do some dialysis to stabilise the situation and make it less likely that the patient would, in the short term, deteriorate, to allow that conversation to happen. So, I suppose you might do that. I cannot recall a situation of having done that, but I have seen that done. (D01)

Dialysis trials, then, were characterised as fulfilling two purposes. First, they prevent the relationship between the care team and the patient's family breaking down in the event of disagreement by the two meeting somewhere in the middle. Second, they can provide more – and very useful – information about how the patient tolerates dialysis and whether it improves the patient's condition, and time to reach a decision.

5.1.7 Communication and culture

Whether pursuing the path of least resistance and agreeing to the demands of family or, in contrast, being firm and explaining that a different course of action is going to be followed, professionals were clear that “good communication and good listening skills are the key” (D07). Whilst communication between professionals was touched on, the stress was very much on communication with family members. This was consistently highlighted, both in general and in the more formal setting of a Best Interests meeting.

I think you just have to be supportive and explain the purpose of the meeting. With many things, if you set it up well at the beginning then you will get out of it what you need which is a logically reasoned, defensible, decision with the support of everyone in the room which is ultimately, truly, in the [B]est [I]nterests of the patient. That’s the purpose of having the discussion, isn’t it? (D08)

It’s an art form in itself, chairing one of these sorts of meetings, because you have to try to make sure that fairly early on the family get a chance to represent what they’re thinking. Otherwise, if you just present, “this is what we think is going to happen, now what do you think?”, well, you’ve sort of disenfranchised them to start off with. (D08)

So, for me, the main thing was communication, and I think that’s really, really important in these situations, that everybody feels they have their voice heard. They might not get the answers they want, they might not get the outcome they want, but they need to have their voices heard because it’s very important that that’s a two-way process. (N03)

The reported benefits of communication were primarily centred around establishing rapport and trust with family members.

It helped us build a relationship because we were having almost daily conversations with at least one or two members of the family. (D06)

Ensuring good communication has been, in the experience of many professionals, challenging where language barriers arise. Where the patient and their family do not speak English with sufficient fluency, professionals spoke of concerns that this could become “complicated” (N04) in terms of the decision-making process.

Several professionals spoke of situations where the patient does not speak English but their family – generally their children – do. Whilst professional interpreters would ordinarily be used for formal meetings, sometimes these English-speaking family members may end up taking on that role.

I think maybe one of the family meetings we had a formal interpreter, but most of the time we used the family members. (D06)

In such situations, there may be a fear that the interpretation being provided is not entirely reflective of what the patient is saying.

[I]t’s difficult sometimes to know how much the son is putting his view of her wishes as opposed to what her wishes might be independently. (D10)

There was also some discussion of the impact of COVID-19 on these situations, whereby an in-person interpreter is not possible. The use of telephone interpretation services was felt to be “limited” (N04).

Whilst not a reliable approach to ensuring communication, several professionals did note the benefits of having multilingual colleagues. In some situations – largely where the discussion is not hugely significant – it was suggested to be far simpler to involve a colleague who speaks the language of the patient and/or family. This is, however, dependent on there being such a colleague to call on.

[I]f my colleague wants me to help, I can help to explain the procedure to the patient.

Sometimes the patient doesn't speak English and my colleague only speaks English, then she will sometimes ask me. (N06)

In addition to the language barrier, many professionals commented on how this often comes in tandem with religious and cultural difference.

Well, the language barrier is one, but with that goes culture. (D11)

Many professionals spoke of previous patients who held certain religious or cultural views around death, which in some cases were at odds with the withdrawal of treatment. Further, expectations of the decision-making process itself might be coloured by assumptions made about the background of the patient.

Their decision making is different, and they don't always agree with healthcare professionals, quite definitely. (N01)

Culturally, people coming from Africa or Asia are more dependent on the doctor to decide on their behalf. (D11)

I think you find different expectations based on people's backgrounds, from all kinds of different types of background, whether it's education, whether it's culture, or whatever. There are certainly some people who believe that they, de facto, have a right to direct a loved one's care. Sometimes, even when the loved one is still fully competent, you'll have sons, daughters, etc. come in and say, "no, this is what you're doing for my relative". (D08)

[I]t tends to differ from different cultures as to how much influence family feel that they should have over decisions that are made. (N07)

Interestingly, though, there was a suggestion that where the patient may be more willing to leave things to the doctor, their family may still intervene and seek to influence the decision. Some professionals noted family members who became insistent on treatment based on a feeling of guilt concerning a previous relative.

A lot of them, when you talk to them, there's always been something that's happened to a different relative, and they've never felt that they've done as much as they could have done. I've had that quite a few times. (N09)

In some cases, this might also be based on the historic treatment of certain groups, and a resulting lack of trust in the medical establishment among some patients and family members.

It's a faith and it speaks about where people come from, where we come from, how they perceive their role in society historically in the UK, whether the medics are treating them as humans or as equals, lots and lots of factors, and then also different perceptions over life and death. (D04)

There was, then, extensive reflection from professionals on the difficulties of reconciling the expectations of a diverse patient population with the requirements of the MCA 2005. A want to be culturally sensitive was, by some, felt to be challenging when the legal framework does not permit what family members want.

5.1.8 Attachment to patient and clouded judgement

A common thread where professionals talked about disagreements during the decision-making process was, as mentioned previously, the perceived inability of some family members to take a holistic view of what is in the patient's Best Interests – their judgement being somewhat clouded by their emotional connection and desire not to lose a loved one. Some framed this in contrast to what was felt to be the more objective approach of professionals, but many reflected on the long-term nature of renal care and how professionals can often develop a strong attachment to patients they have been caring for over many years. Such attachment can, for some professionals, add an additional layer of difficulty to the Best Interests decision-making process.

You might have a patient who has been on the ward for ages, for weeks, or, for instance, someone who has been on renal replacement therapy for years. There are often those situations where there has been a long-term relationship with one of the clinicians, for instance, or with the team. The patients who have been known to us for years and we have seen them through transplants and so on. Then there might be discussions about continuing or stopping dialysis, for instance. Those are more difficult when there is a relationship with the patient that has gone on for a long time. (D01)

The strength of these long-term relationships was apparent when many professionals became quite animated when talking about certain patients that they had long cared for.

I do have this feeling when someone is known really well, a very loved patient, and “oh, I want to see him again”. (D05)

[Patient] loves everyone and he’d spend the whole time hugging everyone [...] He’s absolutely adorable. Once he meets you once, he’d never, ever forget your name [...] we all adore [patient]. Yes, you can’t not. (N04)

One professional even used the terminology of “a little family” (N08) to describe the dialysis ward, with another noting a “renal unit feeling that the patient is ours” (D01).

Whether these strong relationships are beneficial to Best Interests decision making was a point of disagreement amongst professionals. One professional expressed concern that, unchecked, this attachment can be detrimental to patient care – in much the same way that professionals felt the emotions of family members could result in a desire for overdialysis.

Some of my medical colleagues will continue the treatment for a lot longer than what we would probably normally engage with if they have known them [the patient] a long time. (N01)

In contrast, there was a suggestion from some professionals that this long-term relationship could prove to be a benefit in the decision-making process. This was framed in terms of the idea of prioritising patient preferences already discussed, with this strong relationship providing greater reassurance as to what the patient would want if they were able to make the decision.

I think a lot of the time, the better that you know them, the better you understand what is important for them [...] you tend to be in sync with their decision making. (D07)

Ultimately, many professionals felt that their desire to do the “right” thing was sufficient to overcome the potential negative effects of an emotional attachment to a patient.

[T]here are many, many patients that have come through here that I’ve felt quite an affinity or an attachment to, but you don’t want to see that person suffer. So I wouldn’t stick them on dialysis because I didn’t want them to [die]. (N07)

It was felt that the subjectivity of these emotional attachments to patients can be set aside as required to enable a decision to be made with suitable objectivity. Further, many professionals spoke of drawing on the support of colleagues if they feel that their attachment to a patient may be getting in the way of the decision – the idea of second opinions already discussed (*see 5.1.4*). When asked whether this attachment could be a problem when making a Best Interests decision, one professional commented:

I think it could be. For me, one of the ways I mitigate against that is to get one of my colleagues to help. (D09)

Relatedly, some highlight the importance of stepping aside if necessary, implying an assumption that impartiality is to be valued.

If you are too close to a patient, then I think sometimes you have to be able to say, “actually, I’m not the best person, I’ll send a colleague” [...] you have to be allowed to say, “actually, I don’t think I’m being completely impartial here, I need to be able to step away”. (N03)

5.1.9 Making the “right” decision

Through all these challenges in the Best Interests decision-making process that professionals discussed, many repeatedly stressed that their ultimate aim is very much to make the “right” decision.

I knew I wanted to offer dialysis but, also, the challenge is, obviously, you’re doing something that may cause discomfort, may actually even lead to death, and you just want to be sure that, yes, you’re actually doing the right thing. (D09)

And the best interests meetings I’ve been to, people bend over backwards. They’ll even have another meeting to decide [...] we’re almost wanting to be doubly certain with somebody who hasn’t got capacity to make sure that we’re making the right decision, which is good. (N03)

[T]he consultant that was then looking after him on the ward decided, actually, we need a best interests meeting, just to make sure that, again, we’re doing the right thing for the patient. (N08)

This goal was repeatedly discussed alongside widespread recognition that these decisions are inherently difficult. Indeed, one doctor reflected specifically on the divide between theory/guidance and clinical practice:

It's rarely as black and white as your ethics textbook and your legal handbook will tell you.

(D02)

In seeking this "right" decision, and along the way navigating the various challenges already discussed, the value of time was repeatedly raised by professionals.

Sometimes, actually, you just need to accept that more time is needed, maybe, to come to a decision. (D03)

[A]ccepting that such decisions require multiple meetings of healthcare professionals with family members, for example. It's going to be a slow evolution in thinking and decision-making, it may take some time. (D10)

Several more senior professionals noted how this was something they had grown to appreciate more with experience, causing them to initiate discussions early – particularly where they anticipate there may be some complexities.

I may be imagining, but I think I can sense what may be a much more, call it, tense or difficult situation. I can sort of sense it and then, when you sort of sense it, you can start engaging quite early on, sort of pre-empting what may turn out to be. So, you can start doing that. I think that comes from experience really. (D09)

This was not only about affording the family time to come to terms with a potentially highly distressing situation, but also for professionals to reassure themselves that nothing important has been missed. One doctor, for example, in discussing a long-term dialysis patient who had been admitted as an inpatient

with what initially appeared to be an acute incident, said that taking time over the decision was in no small part about ruling out curative avenues:

[F]or us to make sure that, “This absolutely is not reversible, and it is the right thing to do. And this is chronic. This isn’t acute. And the best thing to do here is to stop because we don’t really have any other long-term options”. (D06)

As much as the desire to make the “right” decision was prevalent, professionals were very forthcoming about their fallibility. For reasons already discussed – such as attachment to long-term patients – and various others, many reported that it tends to be more about making a decision that is good enough rather than clearly the “right” thing. The unpredictability of a patient’s condition, such that there will always be exceptions to what research and experience suggest is to be expected, was raised as a reason to “have a degree of humility that you don’t actually know everything” (D08). Indeed, one doctor reflected:

As much as I have an opinion that this might not be the right thing for the patient, obviously there’re a few times that I have been surprised. The patient [whom I did not think would tolerate dialysis] has dialysis and thrives. (D09)

One doctor candidly encapsulated this feeling that was consistent across most professionals:

You never know whether you got it right 100% - you can’t do. This is dealing with human beings which are soft and squidgy and not 100% like a robot. You can’t predict it. This is the same, you won’t always make your [B]est [I]nterests decisions correct. The metric for me,

with any of these decisions, is basically if I walk out of the room and don't think about it anymore, don't dwell on it, don't run back through it, don't think, "Oops." Then you've made a reasonable decision. (D08)

Essentially, many professionals centred the ideas of consensus and comfort. With these decisions often being complex and the "right" choice not always being clear, professionals felt they could at least reconcile these challenges in a consensus decision that left all parties feeling comfortable with the chosen path.

I think what we're trying to do is find something that we're all comfortable with. That's important – that we all agree it is actually genuinely appropriate for that person that we're talking about. (D08)

I think it needs to be a shared decision with input from the family and other professionals to come up with a solution that everyone is happy with. (N05)

5.2 Consultees

The term "consultee" is used to denote any individual that would come under the remit of section 4(7) of the MCA 2005. Whilst this is broad and can include a range of individuals,⁶²⁸ it most commonly means members of the patient's family.

In recruiting consultees, the eligibility criteria were, in line with the MCA 2005, kept broad. I was as open to talking to a patient's partner as their relevant faith leader. However, it ended up that all consultees recruited were family members. Whilst it is hard to speculate on the reasons for this, it

⁶²⁸ Department of Constitutional Affairs (n4).

may be a reflection of the reality of how Best Interests decisions are often made. Indeed, HCPs interviewed spoke almost exclusively of family members as consultees.

Table 4 illustrates the relationships participants had to patients. They are all immediate family. That half of consultee participants were P's children can most likely be attributed to the fact that the sorts of patients concerned are often elderly, so many may no longer have living parents or spouses.

Table 4: Details of consultee participants

| Consultees | | | |
|------------|----|---------------------------|------------------------------|
| Site | n= | Relationship to P (n=) | Interview location |
| Bristol | 3 | Parent (1); Spouse (2) | In person (3) |
| Birmingham | 3 | Child (3) | In person (1); Online (2) |

From the data from consultee interviews, five themes were developed: quality of life and the acceptance of mortality; prioritising patient preferences; family involvement; opposition to the Best Interests approach; and importance of communication. As with the healthcare professional data, there is some inevitable overlap between these themes. It may also be noted that there is some crossover with the themes discussed around healthcare professionals – this will be touched on towards the end of this chapter (*see* 5.3) and further explored in the next chapter.

5.2.1 Quality of life and the acceptance of mortality

The need to accept mortality was discussed by several consultees, often in relation to quality of life. It was suggested that a point comes where it is not appropriate to continue prolonging P's life where there

is inadequate quality of life. However, where the line as to sufficient quality of life is to be drawn was not discussed at length, and conceptions of burden expressed were variable.

Unlike healthcare professionals, the consultees recognised positive aspects of what may be perceived as burdens. Some commented positively on how the practical aspects of dialysis – which some may see as a significant inconvenience to day-to-day life – can actually contribute to the quality of life of a patient by providing more of a social life. One described their mother's enjoyment during a typical dialysis day.

My mum loves it. She loves the attention. She is the belle of the ball. They come in. They knock on the door. She raises her head. She is all smiles. She waves like the Queen because she knows that they are there. Honestly if you are getting an image in your head this is exactly what it's like. They say, "Good morning, ma'am. Are you okay?" They say to her, and she very gracefully nods a yes with a smile on her face. Then they help her onto the stretcher, and she goes into the ambulance, and she gets a bit of fresh air. She gets to see her front garden. She gets to see the neighbours and the neighbours wave to her and say hello to her. Then she goes to the ambulance, and then she has a ride and she loves it. Then she goes through then and they welcome her at the other end. They are used to her. They know it's [patient] and they come and see my mum. For her it is not traumatic. For her it's a complete doss. It's a day out. She absolutely loves it. (C04)

The subjectivity of this experience, however, became apparent when, in contrast, several consultees spoke of the boredom and even frustration their loved one felt during dialysis sessions. C02 explained how their husband was an active person who was not used to sitting still for extended periods.

The first session, he was really fed up because lying on a bed for four hours. He doesn't watch the TV all that much. He doesn't watch it at home. I got some audio books for him to listen to, but he doesn't read normally anyway. So, he didn't want to do that. I brought this iPad in, he didn't want to do that, because he doesn't do that at home. You know, it's not in his nature to do those things. [...] So, he found the first session very frustrating. (C02)

Overall, there was a definite sense that even if there is sufficient quality of life – and potentially even some unanticipated positives – it is inevitable that dialysis compromises it to some extent.

It was very tiring for her. It took a lot of her energy, and she didn't have that quality of life that she would have when you don't have dialysis. [...] Bathing, all the things like that were hard for her. She couldn't do the things that she used to be able to do easily at all. So, it did, it changed her life, and I'm quite aware of that. (C05)

There was a strong feeling by some consultees that at-home care was better for quality of life – at least in the case of their loved one. One explained how they were clear on wanting peritoneal dialysis rather than haemodialysis on the basis that it could be provided at home as possible before fully understanding what that might entail, such was the strength of this feeling.

So, when we went along and saw her, we said, “well, it's going to be the peritoneal because we want to do it at home”, without really, at that point, realising what was involved with either, practically. (C02)

This preference seemed to come primarily from the greater mobility afforded by peritoneal dialysis, with several consultees mentioning the desire to continue going on holiday with the patient as they had previously – both their desire to and P's. However, there was also a recognition that it could still be “a bit of a mission to organise” (C03) the continuation of peritoneal dialysis when on holiday due to the logistical requirements. C03 therefore explained the compromise whereby they would only holiday within the country and not attempt to travel abroad. So whilst the ability to maintain a level of geographical mobility was highlighted as important to a patient's quality of life, this was very much tempered by practical considerations that can still be limiting with any dialysis modality.

This preference for at-home care extended, for some consultees,⁶²⁹ to the end of the patient's life, with a desire for the patient to die at home. For C03, the determination to ensure their loved one would die at home came from their knowledge that it was what the patient wanted.

I think if you find yourself in the situation that we were in with [patient] towards the end, it would be very easy to just shrug your shoulders and say, "okay, then, we'll just leave him here", but this isn't what we wanted. (C03)

This surety over what the patient wanted came from various casual conversations with their loved one in the past – whilst acknowledging that it was also, incidentally, what they would have wanted.

So, we sort of spoke light-heartedly about it, but I did know that it would be better for him and he would be happier at home. And when I explained different things lucidly to him, I'd say, "if you were at home, you could have the dog on the bed with you. You could have

⁶²⁹ Not many consultees reflected on this, but that can be primarily attributed to the fact the patients they are consultees for are alive.

people talking to you", which is exactly what happened. And he would say, "yes. Yeah, that would be nice". (C03)

In practice, some consultees reflected on the point at which they accepted mortality in relation to their loved one – though it should be noted that the patients for whom some participants are consultees are still alive, so this was not raised with all. In many cases, this acceptance came after a period of deterioration. In one case, an exit site infection was what ultimately led to a decision to withdraw dialysis once it was “recognised it was not getting any better regardless of all the antibiotics he’d been taking for the infection around the site and putting ointments on it and different things” (C03). This was something on which this consultee and the patient’s care team agreed. Similarly, C01 spoke of the “total agreement” with the care team that P was reaching the end of his life and on how they should proceed, including a decision not to resuscitate.

It was always a question of, “once this gets out of hand, do you want him to go into surgery, do you want the next level of treatment which might involve resuscitation, do you want him intubated?”. We said, “no, no, no, no, we [P’s family acting as consultees] don’t want any of that”. You know, “when it comes it comes”. That was clearly what they thought should happen, so there wasn’t any sort of- It was all very consensual, the whole thing. (C01)

Others spoke of cultural and religious factors in determining the acceptance of mortality. For example, Islamic views on the preservation of life.

All life, for us in Islam, should be preserved. When it's gone, we believe, there's nothing in the world, the best doctor in the world won't be able to save you because your time has come

to go. There's no intervention in the world that could save you. But until that time, until that time, you should try to preserve life in the best way you can with the means necessary. (C06)

In some cases, these views on the preservation of life were discussed as being at odds with the views of the care team on accepting mortality. Disagreement on this most fundamental aspect of the decision-making process – i.e., whether the focus is on continuing to preserve P's life in a given situation – often led to conflict.

What comes across from consultees' discussions of quality of life and the acceptance of mortality is how individual they perceive it to be. Many of the concerns they discuss in relation to disagreements with the care team related to a feeling that the care team did not properly understand the individual circumstances of their loved one. This suggests that they would largely oppose some objective measure being used, which fits with some of the concerns many raised with the Best Interests approach in general (*see* 5.2.4).

Whilst many consultees spoke of the quality of life their loved one was maintaining, they largely refrained from taking any credit for this. This is despite many of them describing the significant input they provide day-to-day, making personal sacrifices to ensure their loved one is comfortable and able to continue enjoying life. When P was on peritoneal dialysis, this would be carrying out the fluid exchanges, whereas if P was attending a hospital for haemodialysis, it would be making sure P was ready for hospital transport and then meeting P at the hospital to keep them company. For some, it extended to care beyond dialysis.

I have had to move in with my mum, although I have my own place. I'm there most nights. I'm there. I get a knock on the door from the carer when my mum needs personal care through the night with bowel motions and stuff like that. I'm always on hand. (C04)

This consultee also described spending four months staying in hospital with their mother to ensure she received a good standard of care.

For one consultee, there was an importance in their role as P's child to understand the care that was being provided. After researching things and asking many questions of the care team, C06 and their siblings took turns to spend dialysis sessions with their mother not only for company, but to monitor machines and alert the care team if they felt something was needed.

Before I could allow you to take care of my mum, I should know how to take care of my mum first. [...] Anything else, because my mum can't speak, if she's feeling poorly, I speak to the doctors and I say, "look, her temperature is rising. She's sneezing". Whatever it is. "I can see that she's a bit chesty. Let's get her blood tests done". So, we would do a blood test.

(C06)

This level of personal sacrifice for the benefit of another is significant. Whilst many people may regularly check in on an elderly relative, it is quite another to move in with them and provide daily care. However, consultees barely recognised their actions as sacrifice, suggesting that it was just natural and did not feel as though they had made an active choice to affect their life in these ways. One did acknowledge that providing peritoneal dialysis for their husband was "quite a lonely thing to take on, and quite a commitment" (C03), and another explained that it "did take a strain on me at times" (C04), but still neither hesitated to do so.

I didn't think of, "well, how is this going to affect my life?", because my mum's always been a part of my life. No matter what I'm doing, she's a part of that equation. Wherever she is or whatever she's going to be doing, you know, she's always in my world. (C05)

Perhaps, then, the quality of life an individual on dialysis maintains is strongly linked to the network around them and the extent to which their loved ones are willing to take a role in their ongoing care.⁶³⁰ There was certainly a sense from consultees that had they left it to the health and care system exclusively, their loved one would not have had a standard of care they felt was appropriate – and may not even still be alive. Indeed, one noted the surprise of the care team that their mother is still alive, which they attribute to the care both that they provide themselves as P's child, but also the care package they advocated for as support.

Most of the doctors can't believe she is still with us; she is still alive. But it is because the level of care makes a huge difference. (C04)

5.2.2 Prioritising patient preferences

When asked, most consultees explained that they considered their role in any decision to be as something of a proxy representative of P, providing the answers they felt P would have save incapacity – and advocating for them. This being more so a description of substituted decision making which, as earlier discussed, the MCA 2005 explicitly states BI is not.

My role has always been- Well, you know, in the beginning, it was always as a daughter. It was always to think, “but what would my mum want? How is my mum going to feel about this?”. Especially after the stroke because she couldn't speak for herself. It was always, yes,

⁶³⁰ There are certainly indications of such a phenomenon in the wider literature. See, for example: Lee AR, Wolf R, Contento I, Verdeli H, Green PHR. 2015. Coeliac disease: the association between quality of life and social support network participation. *Journal of Human Nutrition and Diabetics* **29**(3):383-390; Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. 2010. Unmet needs, quality of life and support networks of people with dementia living at home. *Health and Quality of Life Outcomes* **8**:132.

from a point of being a daughter and thinking that, you know, “mum would do this”, or, “mum would want that”. (C05)

It is important to note that several of those interviewed did hold LPA-HW, which was discussed in terms of formalising this proxy role. This will be discussed in greater depth shortly (*see 5.2.4*).

Whilst the patients concerned were deemed to lack capacity to make a decision about dialysis, consultees did reflect on attempts to involve P in any decision out of a recognition that P may still be able to play some role. To that extent, consultees took a supporting role in enabling P’s involvement.

So, it wasn’t like my mum was ever left out or they didn’t acknowledge her. It never felt like that. They did come in, and as they got to know my mum, they knew what she was able to do and what she couldn’t maybe do. So, yes, but she was always consulted, and then we jumped in where we needed to. (C05)

In some cases, this entailed specific protocols being built around the specific communication needs of P. This was discussed as an approach where P is unable to communicate verbally and those close to them have figured out alternative means of communication that they consider effective. One consultee explained how such a protocol was devised with the patient’s school and then provided to the care team:

We encouraged them [the care team] to address the questions to us while keeping him in mind and reassuring- Holding his [P’s] hand, whatever. [...] It was always a debate as to how much he could understand, even for us. We didn’t sign with him; we didn’t think he could cope with that. We used physical- We basically just hugged him and stroked him, and so forth, to reassure him, and encouraged everyone else to do the same. (C01)

Such an approach was described as intended to reassure P, such that if P would allow a procedure without resistance if comfortable with it, with P's consultees being able to recognise what they perceived as signs of P's disagreement. This, reflected C01, was "a bit of education for the doctors" at times. It was acknowledged that the care team would need the support of those close to P where there are specific communication needs.

Nonetheless, there was a recognition that there are limits to how much patients with a certain level of cognitive impairment could be involved. Even with additional efforts to involve P, consultees recognised that decisions could not ultimately be made by P due to the impairment. It was indicated that efforts to involve patients in these circumstances may therefore be somewhat tokenistic, wherein P does not make – or is not anticipated to make – any meaningful contribution to the decision.

He was, but, yes, he was involved. We did discuss it with him. But that's as far as, I suppose, it goes, really. [...] So, in a sense, he probably wasn't involved in that final decision about the haemodialysis. (C02)

This consultee also queried whether any preference expressed by P could necessarily be taken as representative. This concern was rooted in P's disposition as trying to please a healthcare professional and just going along with things to avoid confrontation.

[H]e would have just said to the doctor, "do what you...". He's not a confrontational person at all. He would go along with whatever the doctor said he thought was best. [...] I mean, it's an acceptance because I think that's the bit of the nature of dementia really, isn't it, you know, sort of, "everyone else can make the decisions for me". (C02)

As such, there was more of a focus on the consultees putting forward what they felt P would have wanted. In some cases, this was informed by past conversations with P wherein pertinent views were expressed, sometimes because it was “a long time ago that we knew it would end with dialysis” (C02). C04, for example, reflected on P’s previous decisions concerning renal care before losing capacity.

Okay, so at that point mum could talk. She could breathe, so she was involved in that decision. We had some dialogue with her, me and my sister, and it was very much a family decision once my mum was informed about what it means. She wants to live. She wants to stay alive. It was just a case of, “well, that’s what you need to do now, mum, if you want to stay alive”.
(C04)

In representing P’s views, some consultees reflected on religious factors and the importance of P’s religious beliefs being considered in any treatment decision.

[T]here are religious aspects that you've got to cover for people – individuals with religious beliefs of keeping someone alive, the treatment that they should get, the treatment that should be withdrawn from them. These kinds of things, if you live in the society that we're living in, we have to take that kind of stuff on board. (C06)

Recalling some conflicts with the care team about the importance of keeping P alive in line with P’s own religious beliefs, C06 commented on the challenge of the care team not necessarily understanding the viewpoint.

Some people [understood], but then you can't blame someone not understanding it. They're not ignorant – it's just that they don't know about it. (C06)

Whilst acknowledging that professionals may not always understand these views, there was a hint of frustration with consultees not feeling heard in expressing them on behalf of P.

Overall, then, consultees took their role to be that of advocate and source of information, bringing to the table that more intimate knowledge of P that the care team generally lacks. This was a role they felt quite passionately about, portraying a sense of duty to P in ensuring appropriate decisions were made. Though many noted how this conception of their role was not always in alignment with the role they ended up with in practice, as will be explored in the following section.

5.2.3 Family involvement

Consultees spoke extensively of the nature and extent of their role in Best Interests decisions. In particular, how their interactions with healthcare professionals played out. Some felt that they were actively making the decision rather than being consulted on what might be appropriate, seemingly at odds with the process outlined by the MCA 2005.

I always felt that the consultant and, as I said, the doctor on the ward, they were, normally, but on that one occasion, giving us the information and were definitely asking us to make the decision. Yes, so I never felt they were making the decision for us, no. (C02)

Others, however, felt less of an effort from professionals to engage them. Some demonstrated a clear understanding of their role in law, such that they had arranged LPA-HW ahead of time to ensure their role in decisions.

I think you'd be asked questions, but if you didn't have that power of attorney, then it would be that, in a way, you were being asked because it's a polite thing to do to ask you what you think should be done. But the reality is if you don't have power of attorney, whatever you're trying to get done quite likely wouldn't be done. (C06)

This understanding came largely from past experiences of other relatives' healthcare. More specifically, the decision to arrange LPA-HW was, for some, down to a negative past experience – they were highly critical of the Best Interests approach and the role it affords family members in law (*see 5.2.4*).

For those who felt they were not as involved as they would have liked in decisions, there was a suggestion that they had no choice but to stand their ground at times. C04, for example, spoke of having a background in caring and thus being very willing to take on such responsibilities around their mother's care to prevent her ending up in a care home. Whilst the care team were initially reluctant, they were eventually convinced.

Then we [members of P's family] were able to come in together with our joint decision and say, "right. This is what we want and we are not budging". Then they themselves [the care team] went, "oh, okay then. How do we go about making this happen?". Then making it happen. [...] Just because my mum can't speak for herself it doesn't mean that that need will not be met. (C04)

A similar scenario was recalled by C03, whereby P was allowed to be cared for at home towards the end of his life. It was the consultee's feeling that this was allowed primarily because of the family's previous experience of providing that level of care to another relative – in effect, that the care team allowed it purely because the family knew what they were committing to.

Yeah, they never sort of queried what we were saying, although they would have done- I would imagine that if somebody had said what we were saying but hadn't got the knowledge that my son had got. (C03)

It may be, then, that the options available within the remit of a patient's Best Interests are, for professionals, affected by the caring experience of the patient's family (and the extent to which that family advocates for a certain option).

Whilst they acknowledge that there was often one family member acting as something of a spokesperson for the purposes of communicating with healthcare professionals, consultees spoke of wider family involvement outside of the clinical setting.

[I]t's a combined decision, let's put it like that. But, to be fair, it's probably more the whole family, rather than just myself and my husband [their husband being the patient]. (C02)

For some, this led to internal family conflicts over what was in P's Best Interests.

I would say he [interviewee's brother] has been the main decision-maker and I've been consulted all the way, but sometimes, you know, we did disagree on things. [...] We had to

work together the best we could and think about my mum. She was number one. I don't know how, but we managed and we actually are in a good place now. (C05)

These conflicts were suggested to be, at least in part, down to the flurry of emotions being felt. Indeed, many spoke of the emotional impact of the decision-making process at "a very intense time" (C04). For C05, the desire to ensure the right decision was made for P weighed on them.

[I]t was scary. It was like you don't want to make the wrong decision. You don't want her to suffer more than what she's doing already. [...] It is pressure. It is daunting. (C05)

Another reflected on the pressure of being involved in the decision and how, for some, the ability to leave it to someone else may actually be preferred. Leaving the decision to someone else was suggested as a means of creating someone else to blame should there be any issues with the course of action chosen. Asked whether it is important that family members are engaged in the decision-making process, C04 responded:

The easy answer would be yes. Yes, that would be the easy answer. But the more difficult answer would be not everybody can handle it. Not everybody wants to handle it. They are quite happy to let another person take the blame. You know this faceless person. It's so easy to let this faceless person take the blame for their own ability or inabilities. (C04)

The decision being made by someone else has the potential to create a blame game, as acknowledged by one consultee. In the event of a particular incident when P's condition deteriorated, C06 spoke of

the upset it caused and what was perceived as a natural response of wanting to hold someone accountable.

I remember we went in, we asked what happened because, all of a sudden, it happened to my mum. She came in fit and well. Obviously, you're upset. That's why you have all these questions. They are going to be natural questions, how it happened. You're going to look to blame someone. Deep inside, you're going to look to blame someone. It's a natural thing that happens. (C06)

For most consultees interviewed, the patient in question began to receive kidney care when already an adult. One consultee, however, reflected on when the patient – their child – was being treated in a paediatric unit. They spoke of how professionals demonstrated a “natural respect” for what the parents did, and that “they at least made us feel that we were the primary carers and that nothing that they did would be done without our knowledge or consent” (C01). When this patient transitioned to adult care, whereupon the legal role of the parents changed, the consultee still commented on feeling heavily involved in decisions:

It went on as before. I can't remember an instance when somebody said, “he's 18, it's not for you to decide”. There was none of that, no. (C01)

5.2.4 Opposition to the Best Interests approach

Many consultees were, to varying degrees, critical of the Best Interests decision-making approach. For some, this criticism arose during the particular Best Interests process they were being asked about – i.e.,

a decision about their loved one's dialysis. As earlier noted, several of those interviewed held LPA-HW. Most explained this was due to a desire to avoid a Best Interests decision being made, their discomfort with the process stemming from a past experience. The general feeling was that the close family of P ought to have a far more significant role than they felt the Best Interests approach provides, with some going as far as to suggest the decision should be made entirely by the family. It was suggested that LPA-HW was an appropriate way of securing this, as the Best Interests approach introduces an element of luck in terms of the doctor that ends up making the decision.

It doesn't work. It doesn't work at all. It's a flawed system. That's my God honest truth. It's a flawed system. You know when you go to a cashier, you have some that are nice, some that are not nice, some that are going to smile? You can't put your luck on people, "I might get a good service today", and wish you have a good doctor. (C06)

Those with past experience were clear on their role in the absence of LPA-HW, such that they would be consulted rather than having the ability to decide.

I think I'd reached the stage where I thought, if you like, I need to feel as though I would be in charge if I had to, and that if I had to make a decision, rather than just saying, "this is what I want", I would need to have a document. I would need to have power of attorney. [...] I think that you wouldn't have the option to make the decisions if you didn't have power of attorney. (C03)

[I]f you don't have an LPA, you have no right of say in anything. The doctors are going to make a choice on your loved ones. At that point, you have no right. (C06)

In line with what consultees considered their role to be in the Best Interests process, there was also a strong feeling that their role when holding LPA-HW was to make the decision the patient would if they were able. As noted above, the perception was that LPA-HW effectively formalises this proxy role.

I think when you're doing that power of attorney, you have to acknowledge the fact that you're doing what they would want to do – 100% it's what they want to do. (C03)

When you make a decision as an LPA holder, you can't make a decision on your feelings. I can't make a decision on how I feel. [...] It's what she would do. [...] Now, I have views different to my mum, but my view doesn't matter when it's concerning her. (C06)

There was frustration expressed that the ability to advocate for their loved one in this way was stunted in the absence of LPA-HW. For C03, what the patient would have wanted was very clearly to die at home, and they felt that the care team would not have allowed that if it were not for the LPA-HW. C06 expressed a similar concern about what would have happened in the absence of LPA-HW:

So, had we not had the LPA, my mum would have been off the ventilator, and she wouldn't be here today. That decision was made against the hospital and had to be kept because we knew the legal aspect of it, and that's the only reason that, God willing, my mum is here. (C06)

Both, then, felt that a Best Interests decision would not have resulted in the course of action the patient would have wanted. Given this, C06 also voiced frustration for those who may lack knowledge of options such as LPA-HW and may find themselves in the position of a Best Interests decision.

I don't think there's enough information out there for people to go and protect their families because a lot of people don't know about LPAs and stuff like that and how it could help.
(C06)

The majority of consultees spoken to took issue with the Best Interests approach, albeit to varying degrees. Their primary issue with the approach was the lack of decision-making power family members are guaranteed by law. Whilst some felt that, in practice, they were still making the decisions, there was a sense that this came down to luck in which doctor P had. With the life of a loved one potentially on the line, consultees felt it important that they have some authority in the decision so that they can fulfil that self-perceived role as proxy and advocate.

5.2.5 Importance of communication

Something that cut through all other themes quite strongly was a feeling amongst consultees that good communication is essential. As has already been touched on, consultees considered it important for HCPs to communicate well not only with them, but with P – making a point of not excluding P because they are unable to consent to dialysis.

[H]onestly, one of the biggest things that I've learnt during this process, and still to this moment with my mum, all the staff, is communication. I know it sounds so fickle, but it is the biggest thing, you know, the communication. It's like if you don't understand something, then say. Don't just go home thinking, "oh, I needed to ask this and I didn't". And they are willing to help. Yes, they are willing to help. They want you to be clear on what they're going to do. (C05)

Many spoke of positive experiences whereby professionals communicated very well.

It was a meeting of them letting us know what was going on, and then we're giving our points. You know, it was very balanced. It was very equal. We were allowed to give our thoughts, views on my mum's care. We were allowed to ask questions openly, and by this time, we had known them a while as well. So, it was quite comfortable, and we came out of there. Well, I came out of there knowing what's going to happen, you know, what they're doing with my mum, why they're doing it and why they're suggesting what they want to do. So, they were good. Those meetings, they were helpful. So, yes, that's what I feel about them. (C05)

There were, however, reflections on the limitations of some of the resources provided. In particular, how the use of visual aids instead of more traditional written resources could improve understanding both for P and their consultee(s). Feeling that the booklets provided were difficult to understand, C02 took to the internet to find something more intelligible. In particular, this was because they felt a responsibility to help P understand, which in turn required them to have a suitably strong understanding to pass information on in a way P would comprehend.

So, we spent a lot of time before anything happened then, looking at the videos particularly, because they are animated and that does help a little bit. (C02)

Several consultees recounted experiences wherein they were unhappy with the approach taken by a professional. This largely entailed individuals who were rather more brusque in manner than consultees would have liked, somewhat skirting around the more interpersonal aspects of the interaction. Some, however, were more extreme. C06 detailed a long process whereby the family felt accused of making

poor decisions for P and not properly listened to.⁶³¹ In a series of interactions with professionals, they felt that “the LPA pretty much was thrown out of the window” (C06) in favour of the care team’s view of P’s Best Interests. This even resulted in a period wherein the care team raised a formal concern over the LPA-HW, which was then suspended pending investigation. For this consultee, the whole process proved draining and felt like a fight against the care team.

We were in a battlefield – we were fighting the world. I wasn't taking care of my mum. I was fighting the world. I was fighting [hospital]. Me and my siblings were fighting [hospital].
(C06)

Whilst this was the only example of the relationship between the family and the care team breaking down to this extent, a similar sense of disenfranchisement was felt by many consultees due to poor communication.

In some cases, there was a sense that clinical pressures and practicalities sometimes created issues with communication. C01 described the difficulty of taking P’s bloods but there being a particular phlebotomist at the hospital who was able to. Despite failed attempts by other clinicians and P being clearly distressed, requests that this phlebotomist be called were rebuffed.

Oh well, “no, I’m afraid he’s not on the ward or not available to answer”. You know, “in hospital you can’t always have who you want”. There was one occasion when two people had a go and I said, “this doesn’t work”. It was somebody quite senior and, I felt, rather fancied themselves at doing this slightly menial work. “Oh, I can remember”. Then failing. [Patient] would be in tears and it was very upsetting. (C01)

⁶³¹ In this case, members of the family held LPA-HW.

This consultee did acknowledge that “you can’t just have a personal phlebotomist to come in whenever you want” (C01) but still felt that the way it was dealt with was poor.

Beyond the nature of communication, several consultees expressed concerns over the content of communication. Some felt that healthcare professionals were not always as forthcoming with information as they would have liked. Recalling an incident where the patient had peritonitis that was particularly difficult to treat and they had asked about how common it was, one consultee explained:

I get the feeling that they only give you as much information as they think you need, not everything. They hold back a bit. (C03)

The reason, this particular consultee speculated, was something of a protection from too much information “because normal people wouldn’t want to hear it” (C03). It was the failure of the care team to recognise that some *would* want to hear it that this consultee took issue with – a criticism of a perceived default position of protecting people from information overload.

Another consultee felt that resource pressures on professionals were part of the reason for lack of information being provided. C04 described several aspects of P’s care that the family were initially told were not possible, only to later find out there were options available – for example, a mitten to stop P grabbing tubes.

There was a lot of misinformation. There was a lot of pressure, withholding truths. We found out later on that actually that’s not true. [...] [T]he pressure is on them to clear the bed. (C04)

Amongst those with LPA-HW, a view was expressed that “maybe they’re [the care team] a bit more careful about what they say to you and maybe they give you more information than somebody that

didn't have it [LPA-HW]" (C03). The suggestion being that a family member without LPA-HW may only be given selected information by the care team, preventing that family member from building a full picture of options available.

In contrast, C02 felt that the doctor they dealt with was "very clear and did give both sides of the coin". When a decision between dialysis modalities had to be made, this consultee did not feel pushed into a particular option, finding both to have been explained in comparable depth. Though this was following what C02 perceived as an assumption that dialysis would happen and all that remained was to choose a modality.

Participants, then, reported varied experiences of discussing options with the care team, and differences in what and how information was presented. But overall, there was a desire amongst consultees for clinicians to be forthcoming with clear, objective information on the options available for the patient.

Continuity in the care team was also considered important to this. One consultee spoke of an unpleasant experience with a doctor who was filling in for the consultant they usually saw, in which that doctor advised against dialysis on the basis of the patient having dementia, because "people with dementia don't look after things properly and they get infected" (C02). There was a sense that continuity was better for building a good relationship between the patient, consultee(s), and care team given it is long-term care in this setting.

It has been much better because we've not had to keep explaining things from the beginning.

You know, we've built quite a good rapport with them, and they've got to know my mum.

(C05)

It was for this reason that one expressed frustration with their loved one being moved between treatment centres.

We even changed hospitals from one to another. It was all different. It was a new crowd, and then having to build bonds very quickly with this new lot of people who were going to be responsible for Mum's life, it was a lot. It was a lot. (C04)

5.3 Summary

To ensure clarity, I presented my findings in relation to healthcare professionals and to consultees separately. However, as is likely apparent by this stage, there is significant crossover. This crossover is not only in things discussed but, at times, in views expressed about those things. In this section, I will briefly explore some of this crossover as well as points on which the two groups appear to diverge quite significantly. Though for reasons of space, I will not exhaust these differences and similarities. Instead, I have focused primarily on those most relevant to my research questions.

A key takeaway from both above discussions is the perceived importance of respecting P's autonomy. Professionals and consultees alike stressed that P was central to any Best Interests decision and that P's views and preferences ought to be the focus. To that extent, both align with the assumptions underpinning the MCA 2005. It is in the strength of that focus, however, that we see some divergence.⁶³²

For consultees, focussing on what P would have wanted – to the extent that this can be “known” – is paramount. Contrary to the MCA 2005, consultees seemed to endorse a substituted judgement model, wherein the decision P would have made is followed even if it is felt to be a poor decision. Professionals, on the other hand, stressed limits to this approach. Whilst they saw the decision P would have made as significant and an ideal starting point, they did feel it important that this can be departed from when it is felt appropriate in line with their conception of what is in P's Best Interests. Essentially, professionals' views aligned more closely with the MCA 2005 on this point. This is perhaps

⁶³² It is worth noting at this point that for the purposes of this comparison there will be some generalisations of the two groups. Naturally, they are not homogenous groups. Even agreement amongst my participants does not indicate a position generalisable beyond my sample. It is still, however, reasonable to take the prevailing view in each group for comparative purposes at this juncture.

a product of their training and experience more so than their natural inclination, with many professionals regularly mentioning the principles of the MCA 2005 in a way that suggested they are easily recalled – though this, whilst plausible, is speculative.

Most interestingly, though, in terms of the desire to respect the decision P would have made, is the difference between healthcare professionals and consultees in how confident they were with that knowledge. Professionals were far more worried about getting things wrong and being unsure of what P would have wanted, whereas consultees were, for the most part, quite sure of this.

Of course, consultees interviewed were all close family members of P, which most likely accounts for this to at least some degree. It is reasonable to say that a family member would know P – particularly historically, to understand P's views and preferences over time – better than a healthcare professional, even where that professional has been interacting with P for many years (as is often the case in the area of medicine concerned). At the same time, however, how sure a consultee may be of what P would have wanted may be something to be cautious of, particularly when considered around the literature on continuity of self and the question of whether P in the clinical condition of requiring dialysis would hold the same views and preferences as they may have when thinking about it more hypothetically.

Professionals did express concern over the conviction with which family members would present historic understandings of P as intended to guide a Best Interests decision. They highlighted the reality that even concerning their own care people can be quite inaccurate in predicting what they would want in the future, even with non-invasive care. As such, professionals were very open to accounting for past wishes and preferences of P but stopped short of viewing them in the way they would a formalised advance decision. Again, this idea of effectively having a Best Interests trump card was felt important.

It was this that seemed to be at the core of disagreements in the course of decision making; consultees wanted *x* because they felt it was what P would have chosen, but the care team felt *y* was in P's Best Interests, where *x* and *y* are ordinarily starkly different courses of treatment. Consultees largely

framed this as an example of the care team not recognising the individual circumstances of P or P's personal views and preferences (including religious convictions). Professionals, however, felt that this often resulted from consultees finding it difficult to accept P's mortality, and that consultees were too emotionally involved to take a more objective view of what may be in P's Best Interests. Both, then, continue to perceive their position as pursuing what is best for P, feeling that what the other is advocating for is somehow the wrong choice for P.

However, as discussed earlier, the response of professionals in this scenario was often to minimise conflict by pursuing a "path of least resistance" and moving in the direction of the family's position. This sometimes entailed providing dialysis when they did not consider it to be in P's Best Interests – in some cases, this being framed as a trial of dialysis. Thus, whilst they talked about it being important that there was scope to go against what consultees suggested P would have decided, in reality they reported often going *with* such suggestions to avoid too significantly damaging the therapeutic relationship – with the recognition that, to some extent, they are treating the family as well as P.

Professionals did recognise that this approach to managing disagreements may be at the cost of P's Best Interests. To some extent, they acknowledged that the decision was no longer focused entirely on P and instead was accounting for the views of family. This was recognised as not strictly within the model of the MCA 2005 but felt unavoidable when the family are insistent – particularly if taking things to the Court of Protection seems likely should the family's decision not be followed.

It should be noted, however, that professionals were clear that there were limits to how much they would concede to consultees. Where they felt that providing dialysis would be particularly harmful to P, professionals were clear that they would go against the view of consultees and, if necessary, take things to the Court of Protection. The key question here, then, is where that cut-off is, and this was not clearly expressed.

This feeds into the question of whether the Best Interests system's core nature is appropriate, wherein ultimate decision-making power does *not* fall to P's family but, rather, to the professional. Professionals and consultees generally took opposing stances on the appropriateness. Most consultees

felt that the family should decide, with many being strongly critical of the Best Interests system. Those who were not critical of the system tended to describe their involvement in decisions as quite central, such that they felt that they were making the decision – albeit with support from and agreement with the care team.

In contrast, professionals spoke of how vital input from consultees (and family members in particular) is to making a Best Interests decision, but largely felt that it was appropriate for them to have the final say and an ability to go against what they were advised P would have decided. Reasoning for this position involved a combination of protecting P *and* consultees; protecting P from a decision that is more in the interests of their consultee(s) and protecting consultees from the emotional burden of such a significant decision. But, as just discussed, professionals did not seem minded to exercise this discretion where they faced significant opposition from consultees. In practice, then, one might conclude that professionals are also willing to endorse more of a substituted judgement approach, though are perhaps less consciously committed to it.

Overall, both groups framed interactions as (at least sometimes) adversarial in nature. Consultees spoke of the importance of good communication for collaborative decision making, and professionals of their attempts to reach consensus by engaging with consultees. However, these interactions sometimes broke down when the two parties had diverging views of P's Best Interests. It came across that a genuine middle ground – by which I mean one both parties wholeheartedly endorse – is generally unlikely, and that an out-of-court resolution would more often come from one party going along with the other's position without actually having been convinced that it is in P's Best Interests. Only where both parties happen to agree on the appropriate way forward did participants feel that the Best Interests process could go smoothly.

To some degree, then, the Best Interests process may be said not to be fit for purpose considering these views and experiences. At the very least, there seems to be a need for some additional element of the broader care pathway to ease tensions when a Best Interests decision becomes necessary.

How the issues highlighted through these data might be handled – even if that means accepting their inevitability and continuing as before – will be the focus of the next chapter.

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Reflective Equilibrium

This thesis ultimately seeks to consider how Best Interests decisions should be made concerning care pathways for those with or approaching kidney failure. What I have done so far is highlight theoretical approaches to this question and provide an insight into the practical reality of this decision-making landscape. In this chapter, as noted in Chapter 2, I will be bringing together these different strands of the study in a process of reflective equilibrium. This will enable me to consider the interplay between the strands, critically appraise them, and ultimately move towards a coherent position that at least recognises the various perspectives even if it discards some. It is through this process that the value of my empirical bioethics approach becomes apparent, as the practical limitations of some normative positions come through and better enable me to reach a coherent position that speaks to the reality of this care setting. This hugely valuable insight would be absent in a purely normative study.

Drawing on what is raised by both the literature and empirical data presented earlier, I will consider five main areas in this chapter. By no means do I suggest that this is an exhaustive exploration of the issues or that everything raised falls within these five. Rather, they are those that I felt stood out as key concerns and, more specifically, those on which there is some level of incoherence in need of discussion. Inevitably, then, those I have chosen to focus on are somewhat guided by my own perspective – others may have discarded some of these issues as less contentious and instead focussed on points I have set aside. Whilst there are downsides to this, such as the potential exclusion of an important consideration, I have sought to minimise this through reflexivity. Indeed, the approach of reflective equilibrium requires me to challenge my own perspective as I work towards a coherent position, removing the possibility of straightforwardly avoiding the thorny issues (*see* 2.3.2). Further, Rawls acknowledges that wide reflective equilibrium can only be so wide, permitting the reasonable exclusion of some positions.

It is also worth noting at this stage that the coherent position I work towards in this chapter, and the resulting recommendations, by no means purports to “solve” Best Interests. Best Interests decisions

are, by their very nature, complex, and I do not consider there to be any quick fix for avoiding the difficulty they pose. However, with small changes to the processes around these decisions I suggest that we can at least improve the quality of decisions, as well as the experience of the process for those involved. Minor tweaks and something of a conceptual reorientation, which will be proposed in this chapter, may prove beneficial in this regard.

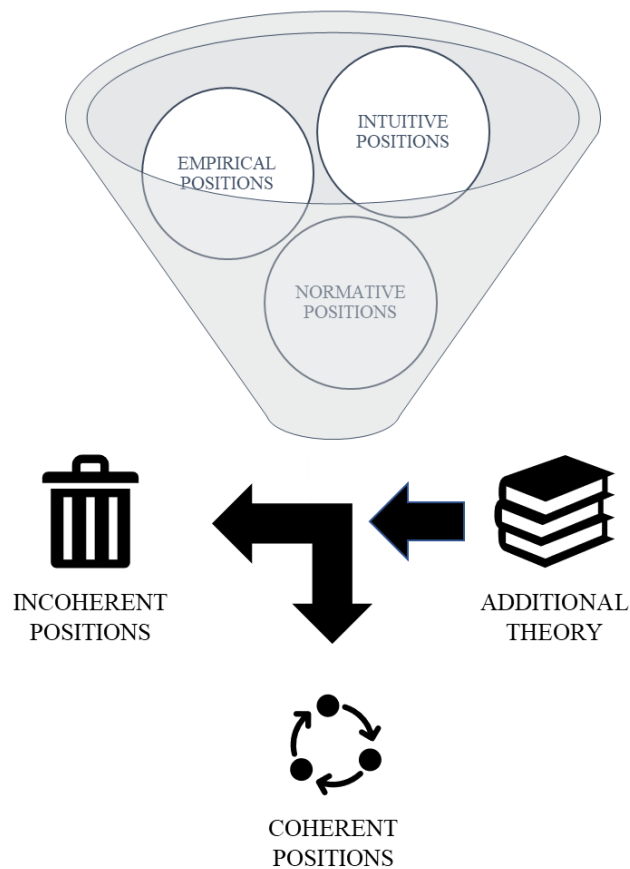
Before delving into my discussion, I will briefly recap what reflective equilibrium is and how this chapter will proceed in utilising it.

6.1 Reflective equilibrium

Rawls outlined reflective equilibrium as a means of seeking coherence between one's beliefs and intuitions and existing theoretical positions (*see* 2.3.2). Such coherence is essential to this approach, as it is ultimately built on the idea that beliefs are justified only where they are consistent across problems. The wide reflective equilibrium approach I employ here brings together these intuitive positions of the individual with existing normative positions, requiring the revision or discarding of some in the event of disagreement over the appropriate response to a given situation. The nature of this project as empirical bioethics requires that I add to the mix the positions identified from the collected data – i.e., the views and experiences of professionals and consultees. These three elements – my intuitive positions, normative positions from the literature, and empirical positions from my data – are brought together in a deliberative process to seek coherence between them. My scoping review alone cannot be relied on to identify all relevant normative positions – nor is it realistic to expect that *all* relevant normative positions will be identified and considered – so new theoretical perspectives will be introduced throughout this process as and when they contribute to discussion.⁶³³ Here I borrow the artistic flair of Birchley to illustrate this process:⁶³⁴

⁶³³ These additional perspectives were organically identified by wider reading throughout this project.

⁶³⁴ Birchley (n345).

Figure 3. The process of reflective equilibrium

Ultimately, I am concerned with reaching a position that is not only ethically defensible, but which can be considered feasible and reasonably satisfactory to both professionals and consultees. Therefore, the empirical positions are integral to this process; reliance on my intuitions and theoretical perspectives alone may enable coherence, but the resulting coherent position may prove entirely unreflective of the reality of Best Interests decision making in renal care. Cautious to avoid the realms of ideal theory, I give full consideration to the views and experiences expressed by study participants even where they are strongly at odds with my intuitions and existing normative positions.⁶³⁵

⁶³⁵ This is similarly required by Ives' reflexive balancing, which in many ways took reflective equilibrium as a starting point. Ives (n342). There is, then, some broader recognition in the evolution of empirical bioethics methodology that views we may perceive as more "out there" still require consideration in pursuit of coherence.

6.2 Achieving coherence

As noted above, there are five key areas I will consider in this chapter: respecting P's autonomy; ascertaining P's views and preferences; family involvement; rotten (medical) compromise; and second and independent opinions. There is, of course, much overlap between these five areas. However, this is inevitable; there is no neat way to divide this discussion to entirely prevent overlap given the inherent interconnectedness of the issues. I will bring the five discussions together more coherently towards the end of the chapter.

6.2.1 Respecting P's autonomy

In the previous chapter, I noted a shared view amongst professionals and consultees that respecting P's autonomy ought to be a central consideration in a Best Interests decision. It was felt across the board that to diverge from P's preferences should require a strong reason, as to do so is to undermine P's autonomy (some went as far as suggesting such divergence is never justified). Implicit in this view is the position that autonomy and decision-making capacity are to be understood differently – the patient who is deemed to lack decision-making capacity retains some manner of autonomy that remains deserving of respect. I will here explore this relationship between capacity and autonomy before discussing what this might mean for how Best Interests decisions should be approached depending on the level of impairment P suffers from.

This implied view of distinguishing autonomy and decision-making capacity is, to some degree, consistent with both the literature and the MCA 2005 itself. That the MCA 2005 requires consideration of P's 'past and present wishes and feelings'⁶³⁶ suggests that its intention was not to render P a mere problem to be solved, but to foster some manner of empowerment of P in relation to their own care even in the absence of decision-making capacity. We can draw from this that Best Interests was not

⁶³⁶ S.4 (6) (a) Mental Capacity Act 2005.

intended to be a wholly paternalistic view of what is good for P, even if there is a role for paternalism as one of several factors. Indeed, Baker stresses that the MCA 2005 should be about ‘empowerment first and foremost, protection second and when needed’.⁶³⁷ This legal perspective on the relationship between capacity and autonomy was highlighted by Hayden J in *London Borough of Tower Hamlets v PB*: ‘The obligation of this Court to protect P is not confined to physical, emotional or medical welfare, it extends in all cases and at all times to the protection of P’s autonomy’.⁶³⁸ Further stressing the importance of this distinction between capacity and autonomy, Kong and Ruck Keene write that ‘[a]n unduly narrow concept of autonomy risks at the same time both excluding individuals with impairments from respect for their decisions and potentially sanctioning their mistreatment and abuse’.⁶³⁹

The test for capacity within the MCA 2005 is simply that: a test for *capacity*. It is not a test for autonomy or the individual’s inherent ability to possess preferences. A finding of incapacity and the resulting instigation of the Best Interests process is purely a statement that, at that moment in time, P is not able to understand and reason towards a decision on the specific question concerned. Whether the professional making the finding of incapacity is led purely by consideration of P’s capacity is another question, but the law recognises it as a comment only on time- and decision-specific capacity.⁶⁴⁰ A finding of incapacity is a removal of the label informed consent from any resulting decision, but not a blanket removal of P’s right to respect and dignity. An individual can be deemed to lack capacity simply for an inability to communicate their decision, even if they satisfy the other elements of assessment.

There is, then, an apparent consensus on the point that there is *some* distinction between capacity and autonomy, and one with which I find myself in agreement. However, the nature of that distinction is heavily reliant on how autonomy is conceptualised. Whilst participants spoke regularly of the importance of autonomy, they (quite understandably) did not provide detailed descriptions of the account of autonomy they endorse. To some degree, it appeared to be used as something of a buzz word. I do not mean that as a criticism as such, just that the word was perhaps being used as a proxy for

⁶³⁷ Baker D. 2017. ‘Mental Capacity Act and adult safeguarding’. In Cooper A, White E (eds). *Safeguarding Adults Under the Care Act 2014*. London: Jessica Kingsley, 129.

⁶³⁸ *London Borough of Tower Hamlets v PB* [2020] EWCOP 34, at para 51.

⁶³⁹ Kong and Ruck Keene (n76) 33.

⁶⁴⁰ S.2 (1) Mental Capacity Act 2005.

something else. Participants clearly understood what their underlying point was when speaking of the value of autonomy, but this understanding is likely inconsistent with detailed philosophical accounts of autonomy.

Where, in interviews, I attempted to unpick what participants – professionals and consultees alike – were getting at when referring to respecting P’s autonomy, they tended towards an idea of preferences. In talking around the idea of autonomy, participants often referred to “what they [P] want” (2D03) and reflected on, for example, whether “mum would want that” (2C02). They placed decisional weight on an understanding of what P would like in that situation. For the most part, such discussion was not accompanied by ideas around understanding and reasoning, which are often considered at least relevant to autonomy, if not central.⁶⁴¹ Seemingly, then, what participants spoke of in terms of autonomy is not quite autonomy. Rather, they were advocating strongly for the importance of P’s preferences to any decision. P was framed more as a holder of preferences that are due respect than as an autonomous agent, even though the word autonomy was used.

In considering the perspectives of participants in a process of reflective equilibrium, then, I will take this expressed view of the importance of respecting P’s autonomy as an intended view of the importance of respecting P’s preferences – and respecting them to quite an extent given the strength of feeling amongst participants. Equipped with this clarification, it is now possible to revisit the question of the relationship between capacity and autonomy.

This preference-based understanding goes against a strongly paternalistic view of Best Interests. It disagrees with a position that, at the point an individual is deemed to lack decision-making capacity, they revert to a status of entirely lacking preferences; suggesting this to infantilise P unnecessarily. We can, then, recalibrate to explore the relationship between capacity and *preferences* rather than capacity and *autonomy*.

This distinction is vital because conflation of capacity and preferences lays a path to oppression – a failure to recognise that preferences may persist where capacity ceases may lead to unnecessarily

⁶⁴¹ Taylor (n21); Beauchamp and Childress (n24).

paternalistic decision making of the sort that participants seemingly oppose. This is something made clear by the UN Committee on the Rights of Persons with Disabilities, which stressed that Article 12(3) of the Convention requires respect for the ‘rights, will and *preferences* of persons with disabilities’.⁶⁴² Several consultees stressed that they still considered P to be aware of what was going on at the time a decision was being made and to have a clear preference regarding their care, even where there was agreement between the family and care team that P could not make the decision for lack of capacity. That preference being one that they considered central to any decision even though P could not instigate it by way of informed consent. Some consultees felt that P’s continued ability to express preferences at the time of the decision was not fully acknowledged by the care team and that the consultee-ascertained preference of P was not taken seriously. To some degree, this aligns with the caution expressed by professionals around the reliability of P’s ascertained preferences (*see* 6.2.2). It may be reasonable to question the reliability of these ascertained preferences, and the reasonableness of such questioning may well be tied to the nature and extent of P’s impairment. Nonetheless, the view of consultees was that insufficient account was taken. This concern necessitates exploration as, considered alongside the suggestion of professionals that respecting P’s preferences is of huge importance, it may be taken as an indication of inconsistency on the part of professionals. Here, there is a clear need for the consideration of additional theory, for which I turn to the work of Young.

Young’s work on oppression is helpful here in highlighting the importance of recognising and taking seriously any identifiable preferences of P. Young outlines five categories of oppression: exploitation, marginalization, powerlessness, cultural imperialism, and violence.⁶⁴³ Some may immediately align with a general conception of oppression that many of us hold – cultural imperialism and violence in particular speaking to a history of empire. But, as Young articulates, oppression ought to be understood more as an umbrella term, and it is the powerlessness category that is of particular relevance here.

⁶⁴² Committee on the Rights of Persons with Disabilities (n64) at para 17 [emphasis added].

⁶⁴³ Young IM. 2011. *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press, 40.

Powerlessness as a form of oppression is described as ‘inhibition in the development of one’s capacities, lack of decisionmaking [*sic*] power in one’s working life, and exposure to disrespectful treatment because of the status one occupies’.⁶⁴⁴ Young’s framing of ‘lack of decisionmaking [*sic*] power *in one’s working life*’⁶⁴⁵ is due to her focus being modern political theory and its treatment of political subjects – hence a focus on one’s working life as a contribution to the societal whole. Here, I broaden this conceptualisation of powerlessness to lack of decision-making power in one’s life *in relation to health and social care*.

This idea of powerlessness has evident parallels with the realm of mental capacity and Best Interests. Whilst arguably true in general, this is especially so where one conflates capacity and preferences. Such a conflation has historically featured in Western philosophy, in which ‘disability has been understood above all as lack and privation’.⁶⁴⁶ If incapacity is taken as cause for a blanket exclusion from a decision – meaning an entire lack of involvement in the decision, be that active or passive – P can be considered to have had the development of their capacities inhibited by the decision-making system and to have suffered a deprivation of decision-making power in their own life. In the absence of decision-making capacity, an inability to still contribute to the decision is equivalent to having one’s preferences denied; such exclusion from the process implies that capacity and preferences are the same, and that lack of the former somehow precludes the latter. Depending on how the Best Interests decision then proceeds, there is a possibility that P is also exposed to disrespectful treatment because of the status they occupy – that status being an individual lacking decision-making capacity. For example, if the outcome of a Best Interests decision made without P’s involvement is entirely incompatible with P’s preferences and entails the provision of treatment that can be considered anything more than trivial in terms of its harms, P can be considered to have been treated disrespectfully on the basis of cognitive impairment – we would not accept similar treatment of an adult *with* decision-making capacity. This also aligns with Kong and Ruck-Keene’s concerns over the potential sanctioning of

⁶⁴⁴ *Ibid*, 58.

⁶⁴⁵ *Ibid* [emphasis added].

⁶⁴⁶ Reynolds JM. 2022. *The Life Worth Living: Disability, Pain, and Morality*. Minneapolis, MN: University of Minnesota Press, 2.

mistreatment and abuse.⁶⁴⁷ So, when P is judged to lack decision-making capacity and this is taken as synonymous with a lack of preferences, P becomes a victim of a form of oppression. That is not to say that someone can never lack decision-making capacity and preferences simultaneously. Rather, they are simply not equivalent, and preferences can persist in the absence of decision-making capacity – they just become far more difficult to engage with (*see* 6.2.2).

Throughout the Best Interests process, then, it is necessary to maintain an awareness of the possibility of P still holding preferences and the need to respect them. Indeed, I would suggest that P continuing to hold preferences is likely in most cases. Unless suffering a disorder of consciousness,⁶⁴⁸ most will have some idea of what they like and dislike, even if in very basic terms which they have significant difficulties communicating. Nonetheless, there remains the possibility that P's ability to communicate preferences will be so impaired at the material time that we cannot rely on such a direct preference-respecting account of Best Interests. P simply letting a treatment happen cannot be taken as a preference; an absence of physical resistance is insufficient for this purpose. I will further discuss how P's preferences might be ascertained shortly (*see* 6.2.2), but to first finish this discussion of respect for P's preferences I will consider what this might entail where P is unable to express a clear preference. In such scenarios, we may instead wish to take a historical view of P's preferences, potentially being led by a previously expressed preference.⁶⁴⁹ It seems prudent, then, to look to the idea of precedent autonomy.

Whilst the term is thrown about a lot in the literature, there does appear to be a lack of consensus on the definition of precedent autonomy. Broadly, as the name suggests, precedent autonomy concerns respect for an individual's past expression of autonomy. Davis has attempted to provide a more definitive account.⁶⁵⁰ In relation to individuals who are in a position of incapacity, Davis considers whether a suitably relevant previously expressed preference should be respected. He contends that

⁶⁴⁷ Kong and Ruck-Keene (n76).

⁶⁴⁸ Arguably, those in a minimally conscious state may not be included for my purposes due to the possibility of their occasional ability to communicate in some way. However, a detailed discussion of this would be an unnecessary tangent.

⁶⁴⁹ Such a preference not having been formalised into an advance directive, else we would not be within the realm of Best Interests decisions.

⁶⁵⁰ Davis JK. 2002. The concept of precedent autonomy. *Bioethics* 16(2):114-133.

respecting such a preference can only rightly be considered an example of precedent autonomy where it can be taken as a *former* preference. The test he provides to confirm whether it is a former preference is the reaffirmation proposal:

‘If the agent is unable to form a preference in his actual circumstances, then his preference in those circumstances is whatever he earlier preferred, provided he would reaffirm that preference in hypothetical circumstances just like his current circumstances’.⁶⁵¹

If P would *not* reaffirm the preference, it becomes a former preference and thus precedent autonomy comes into play. If P *would* reaffirm the preference, we move into the realm of ordinary autonomy. Essentially, for Davis, it is precedent autonomy if past preferences are respected when no longer held (determined as a ‘hypothetical reaffirmation’⁶⁵²).

Importantly, Davis suggests that reasons for a preference are an integral part of that preference. A continued preference only satisfies the reaffirmation proposal if the reasons for that preference remain the same – the same preference for different reasons relegates the earlier iteration of that preference to the status of former preference.⁶⁵³ I will dissect aspects of Davis’ account shortly, but at least for now it seems that per his account of precedent autonomy, the instances I am concerned with would not in fact be examples of precedent autonomy at all. By application of this idea of hypothetical reaffirmation, P’s past preferences can move to be considered as ordinary autonomy in situations whereby P is unable to communicate present preferences. For consistency with my earlier framing of autonomy in terms of preferences, I will refer to precedent preferences and ordinary preferences hereafter.

Broadly, I would endorse Davis’ suggestion around hypothetical reaffirmation setting aside the label of precedent preferences. If it seems reasonable to assume that P would maintain that preference

⁶⁵¹ *Ibid*, 120.

⁶⁵² *Ibid*, 121.

⁶⁵³ *Ibid*, 121.

– i.e., where there is no clearly identified reason to think that P’s preferences would have changed in a relevant way – then I suggest that such preferences are treated in the same way as preferences expressed by P at the time of the Best Interests decision. This may feel intuitively strange, but it must be remembered that preferences expressed by P at the time of the Best Interests decision are still not autonomous choices leading to informed consent – they still occupy a lesser status that, whilst deserving of respect, can potentially be overridden. Whilst for the individual with decision-making capacity we would favour present preferences,⁶⁵⁴ this ought not necessarily to apply where that individual lacks decision-making capacity. P’s past and present preferences are both less than autonomous so, given the possibility of discontinuity of self and associated issues of verifiability, we should afford them an initial equality.

Where I depart from Davis, however, is in the importance of reasons behind those preferences. I do not disagree that reasons behind preferences are important to our broader understanding of autonomy. In a more general sense, I would suggest reasons to be significant. However, in the context with which I am concerned, P most likely lacks the ability to reason towards a decision – hence having been deemed to lack decision-making capacity. Even though Davis is concerned with this idea of a hypothetical reaffirmation, it seems unnecessary to require that the continuation of a preference relies on the continuation of P’s reasons for that preference. My point here being that if P has a relevant past preference, for which the reasons are understood, then a straightforward agreement with that preference in the present should be sufficient to deem it the same preference and subsequently respect it. Continuation of reasons may well be taken to strengthen our confidence in the preference but should not be a requirement.

There is a definite air of “do the best with what you have” about my suggestion. Indeed, that is central to my argument here. Davis’ requirement for the continuation of reasons is overly idealistic for the context of those lacking decision-making capacity. If we want to respect the preferences of P, it is appropriate to relax the demands of our account of preferences. Within reason, of course, but a

⁶⁵⁴ Anyone seeking to argue that we should override the decision of an individual with decision-making capacity in pursuit of their past preferences would, to my mind, have their work cut out.

relaxation nonetheless. Maintaining such a demanding bar for preferences is to again risk conflating them with capacity and paving the way to some manner of oppression; it allows paternalism to rear its head where I consider it inappropriate, much in the way highlighted by the Committee on the Rights of Persons with Disabilities.⁶⁵⁵ Equally, given the distinction between preferences and capacity already discussed, this relaxation should have no implication for P's decision-making capacity – slightly lowering the demands of preferences for those who lack decision-making capacity is not to suggest that they should be treated as able to provide informed consent.

Following this understanding, there is no need for the concept of precedent preferences at all where P is able to provide some indication of preferences at the material time that roughly aligns with previously expressed preferences, even if that indication is a fairly simplistic suggestion of assent. Rather, they can be viewed as what Davis presents as ordinary preferences, being taken as a confirmation that P is sufficiently happy with their previously expressed preferences. There remains, however, the question of how to proceed where P expresses either a conflicting preference or no preference at the material time. In such situations, we cannot rely on this rough and ready longitudinal view of P's preferences. Nonetheless, such situations received very limited mention in interviews, and example Best Interest discussions described by participants mostly entailed P being able to somehow communicate preferences even if in a very limited way. For this reason, I will set aside this aspect of discussion and stay true to the data.

In my discussion of autonomy/preferences thus far, I have implicitly endorsed something of a procedural account. I have touched on the idea of P having a role in a decision despite lacking decision-making capacity, contributing an understanding of their own preferences. This is owing to my favouring of a highly subjective account of autonomy that aligns with informed consent and the right to make “unwise” decisions. Hence, I dismiss here an objective list approach to value as guiding Best Interests decisions, as this would require the endorsement (and thus imposition) of certain values even if P rejects them (*see 1.1.3*). Whilst DeGrazia does explain that an objective list approach may include subjective

⁶⁵⁵ Committee on the Rights of Persons with Disabilities (n64). For further discussion of the Committee's position, see 1.1.2.

elements,⁶⁵⁶ doing so undermines the objective nature of the supposedly objective goods. Where subjective elements are introduced, an “objective” list approach can lose its objectivity and ultimately is at risk of collapsing into a quasi-desire account – particularly where autonomy is included as a subjective element. Even if an objective list approach is considered internally valid in the presence of such subjective elements, that something like autonomy just becomes a fraction of the relevant decision-making material is still to suggest that it is, at best, of marginal importance, rather than primary.

As I noted in Chapter 1, a more objective view may be beneficial in the event that P’s desires are not and cannot be known because there are no subjective preferences to consider. However, I am here concerned with instances where there is some means of ascertaining preferences.⁶⁵⁷ Equipped with such information, an objective list approach to Best Interests can be readily dismissed in light of the need to continue respecting P’s preferences throughout the decision-making process. To some degree, this view marries that expressed by Morgan J in *Re G (TJ)* that ‘substituted judgment can be relevant and is not excluded from consideration’.⁶⁵⁸ Although Morgan J’s stipulation *could* similarly align with an objective list approach in that he indicates that substituted judgement – which we can, where it is successful, take as a representation of P’s autonomy – *can be relevant*. Indeed, the MCA 2005 is explicit that its requirement is ‘an objective test as to what would be in the person’s [B]est [I]nterests’.⁶⁵⁹

An objective list approach is inherently at odds with respect for preferences. Even if a truly objective list were possible, to impose it would still be to undermine the individual. Just as there is a recognised right to make an unwise decision, so must we be able to depart from values that are somehow viewed as objective; self-rule must permit us to go against the grain, so to speak. The Supreme Court has also been clear on its desire to avoid too prescriptive an approach to Best Interests, with Lady Hale explaining that ‘[t]he courts have been most reluctant to lay down general principles which must guide the decisions. Every patient, every case, is different and must be decided on its own facts’.⁶⁶⁰ This

⁶⁵⁶ DeGrazia (n103) 55.

⁶⁵⁷ I will revisit questions of ascertaining such information shortly (*see* 6.2.2 and 6.2.3).

⁶⁵⁸ *Re G (TJ)* (n88).

⁶⁵⁹ Explanatory notes to the Mental Capacity Act 2005, at para 28.

⁶⁶⁰ *Aintree* (n90) at para 36.

individualistic nature of Best Interests decisions – much like any medical decision – is incompatible with an objective list approach, hence my dismissal of it as an adequate account.

Such a perspective is also apparent in the views of consultees. Several questioned the right of a doctor to decide what is right, with a focus on the doctor having medical expertise and, by extension, not necessarily possessing some other form of expertise considered necessary for such a decision. These consultees noted that they did not view the dialysis decision as a purely medical one and that, as such, it should not fall to someone whose decision-making process would focus on medical factors. The medical view was, in effect, framed as somewhat objective. Consultees felt that the view of a doctor would not represent a subjective understanding of what is right for P, such as where P held particular religious views (*see* 5.2.2).

Coggon and Kong make an interesting observation in relation to the idea of objectivity as it appears to be presented by some consultees. Highlighting debates in the House of Lords wherein it is argued that a decision maker must take an objective view of P's Best Interests,⁶⁶¹ they suggest that such an understanding of objectivity may force a 'conceptual wedge between [B]est [I]nterests and the *subjective viewpoint of D* [the decision maker], and not necessarily between [B]est [I]nterests and *P's unwise/subjective decisions*'.⁶⁶² In effect, objectivity understood in this way is for the protection of P from the *decision maker's* subjectivity.

So, whilst consultees may see an objective approach as problematic, perhaps the type of subjectivity that would be an alternative is yet less desirable if we follow the reasoning of consultees, as it introduces additional wriggle room for an individual professional to impose a value system. This is particularly interesting when considered against the view of many professionals that the long-term nature of renal care often leads to them being very emotionally attached to their patients, with some going as far as to question whether it may sometimes cloud objectivity – recall the nurse who observed the continuation of treatment 'for a lot longer than what we would probably normally engage with'

⁶⁶¹ HL Deb 10 January 2005, vol 668, col 15.

⁶⁶² Coggon J, Kong C. 2021. From best interests to better interests? Values, unwisdom and objectivity in mental capacity law. *Cambridge Law Journal* 80(2):245-273, 253 [author emphasis].

(1N01) because there was a strong relationship with P. Whilst some consultees feel that professionals may be too *detached* from P to make a suitably preference-respecting decision, some professionals worry that they may too *attached* to P to make a suitably objective decision. It appears, then, that there are slightly divergent views here on both how things do happen and how they should happen. Nonetheless, the desire of professionals to set aside emotional attachment to P is ultimately based on their desire to make the decision that is “right” for P, rooted in a concern that emotional investment in P’s life can lead to a decision that favours life extension too doggedly – warm subjectivity can be as problematic as cold objectivity.

It can be concluded that objectivity in Best Interests decisions is neither possible nor desirable; preferences (in their role as autonomy outlined above) are and should be subjective, and to set them aside in pursuit of an “objective” good is to treat P in a manner that would never be considered appropriate for the individual with decision-making capacity, thereby bringing us back to that idea of oppression as powerlessness. An ideal approach, then, would avoid an attempted objective take on P’s Best Interests, but similarly keep the subjectivity of parties other than P in check. So, whilst the law may pass decision-making authority to the doctor, this should not be understood as the decision becoming an overtly paternalistic “doctor knows best”. With authority comes responsibility, and this responsibility ought to involve a recognition of P’s continued preferences despite cognitive impairment.

So, whatever form the decision-making process takes, it should place P’s preferences at its centre. Where it is feasible to discern a reasonable sense of what P would have chosen in the situation, that choice ought ordinarily to be the course of action deemed to be in P’s Best Interests. Whilst my argument here certainly moves in the direction of substituted judgement, I would not go quite so far. In no small part, this is because the strength of P’s ascertained preferences will be variable in different scenarios – just because there is an *indication* of what P would want, that does not mean that we should put full confidence in that being what P would *definitely* want. Rather, my suggestion is that any indication of what P would want should be the starting point of any Best Interests decision, and the standard of reason required to dismiss this should be high. It should be possible to pursue an alternative course of action, but only where there is a suitably strong reason to do so – which *may* relate to lack of

confidence in the reliability of the ascertained preferences of P. For example, if there is good reason to believe a past statement may not reflect the present P.

This better aligns Best Interests with our understanding of autonomy in informed consent, in that a professional's view of what is good for us should not determine a decision.⁶⁶³ My approach treats P's ascertainable preferences as more than just one of many factors to consider, centring them as something of a first draft decision.

This focus on P's preferences, however, must be recognised as not interfering with the role of the professional in determining what is clinically indicated. Just as the patient with capacity cannot demand any treatment they desire, so must the options available within a Best Interests decision be limited by medical suitability. This does place a responsibility on the professional to identify the line between clinical indication and their own view of P's Best Interests, as dialysis may be deemed a reasonable option in response to P's condition even if, taken holistically, the professional does not consider it in P's Best Interests. If in doubt, an additional impartial opinion may be an appropriate option – this will be discussed shortly (*see* 6.2.5).

RECOMMENDATION

Provided they are within the remit of what is clinically indicated, professionals should treat any ascertainable preferences of P as a starting point in any Best Interests decision. These preferences should be viewed as guiding, being overridden only where there is reasonable doubt over their reliability. Where necessary, past preferences can similarly be viewed as guiding, providing there is some small indication that P would still endorse them.

6.2.2 Ascertaining P's preferences

Whilst agreeing that P's preferences are key, there was divergence between participants on how such information is to be ascertained and engaged with. Consultees largely expressed a confidence in their understanding of what P would have wanted, drawing on a mixture of direct conversations about such

⁶⁶³ This was made clear in *Montgomery* (n27).

a decision in the past, their long-term relationship with P and an accompanying understanding of P's mind, and perceptions of P's reactions to discussions and medical procedures. Professionals, on the other hand, were a little more cautious about claiming to have an accurate view of the decision P would likely have made.

This difference is highlighted further by an expressed scepticism amongst professionals in the confidence of consultees in P's preferences. The value of consultees' input in Best Interests decisions – largely discussed in terms of their intimate understanding of P – was overwhelmingly acknowledged by professionals, but this was accompanied by a worry that this closeness may preclude a sufficiently objective take on P's Best Interests. In essence, that consultees can be so emotionally involved that they may misrepresent P's preferences, whether intentionally or not.⁶⁶⁴ This was a particular concern in relation to the application of P's historically expressed preferences, which professionals questioned the reliability of.

In the literature, there is a similar scepticism regarding the reliability of what are taken as P's preferences. If this is based on past wishes through some manner of advance care planning, some of the literature recognises that individuals may struggle to think forward to how they would feel about particular care options when in a different state of health – this brings into question any view expressed in this way.⁶⁶⁵ If P's family are to be relied upon to provide an insight into P's preferences, so too are various scholars worried about the accuracy of what may be put forward.⁶⁶⁶ Evidently, there is disagreement as to how reliably P's family can provide information on P's preferences. This is potentially hugely problematic as the family may be considered the only source of such information in many cases. If one is to take the position that we can put our confidence in neither P's past preferences nor P's family's understanding of P's preferences, respect for P's autonomy becomes really very challenging. One may legitimately question where else such information may be sourced.

⁶⁶⁴ This relates back to the mirror discussion above, whereby the question arose as to the attachment of professionals to P in some cases.

⁶⁶⁵ Scott *et al.* (n397).

⁶⁶⁶ Keating *et al.* (n394); Pruchno *et al.* (n394).

On the question of the reliability of past preferences, the concerns of professionals should be considered valid. As noted in Chapter 3, McDougall raises the issue of discontinuity of self, whereby P at the time of the decision may be very different to P at the point past preferences were expressed.⁶⁶⁷ If so, it is not reasonable to say that those past preferences represent P's autonomous choice for the purposes of some manner of substituted judgement.

However, there is a degree to which such information is the best a decision can draw on if person-centred care, by way of respect for autonomy, is to be prioritised (which I have already highlighted the importance of through a respect for preferences framing). Unless one wishes to apply a clinical, objective test for when dialysis is to be provided when P lacks decision-making capacity,⁶⁶⁸ it seems inescapable that P's past preferences come to the fore – as highlighted earlier in this chapter. Certainly, this is endorsed by the MCA 2005 as a key consideration in any Best Interests decision.⁶⁶⁹ There is also a precedent for respecting past preferences in healthcare more broadly, such as the use of advance directives. Whilst there is still a worry over reliability in the advance directives literature,⁶⁷⁰ the system remains on the basis that it is often as close to autonomy respecting as one can get – again returning to my point about the need to avoid being overly idealistic in a situation where traditional understandings of autonomy are not fit for purpose.

My own considered moral judgement on this is that any past preferences are important insights, but how such information is brought to the table is the point of contention. Whilst there is also concern about the reliability of P's past preferences in general, the concerns expressed by professionals were in part owing to the fact such information was generally brought forward by P's consultees. Professionals worried that the information presented as P's own preferences would inevitably be a mixture of P's and the consultees', and that it is a near impossible task to cleanly separate the two. That is not to say that there is any intended malice in the consultee's input but, rather, there is a risk that consultees who also

⁶⁶⁷ McDougall (n415).

⁶⁶⁸ Such an "objective" test seems implausible even if one were to consider it appropriate, given the difficulty of predicting just how an individual will fare on dialysis.

⁶⁶⁹ S.4 (5) Mental Capacity Act 2005.

⁶⁷⁰ May T. 1997. Reassessing the reliability of advance directives. *Cambridge Quarterly of Healthcare Ethics* 6(3):325-338.

act as care givers, ‘who are often under enormous strain, may make decisions in the name of beneficence that weaken and destroy any semblance of dignity or respect for the individual’s personhood’.⁶⁷¹

In order to afford professionals – who, in law, make the final decision – sufficient confidence in P’s past preferences as a key consideration, it may be preferable that they are themselves involved in the discovery of such information. This will not always be feasible, but patients approaching kidney failure are generally under the care of a renal team for many years before the need to decide on dialysis becomes necessary. Indeed, professionals highlighted this benefit of renal care that many specialties lack – long-term relationships and conversations over many years.⁶⁷² With many patients, then, there is some level of opportunity to discuss things ahead of time.

Consider a patient – Pat – who has recently been diagnosed with Stage 4 CKD and her eGFR is dropping slowly but steadily. She is unlikely to need renal replacement therapy for a while and she has no degree of cognitive impairment. As her kidney function gradually declines, Pat will have regular meetings with her consultant to monitor it and other aspects of her condition. Without the need for lengthy discussions, these interactions present a possibility to at least raise the prospect of dialysis at some point being indicated. A gradual stream of information and a chance to ask questions has benefits for all patients in that they will better understand what lies ahead and, for those who are able to provide informed consent for dialysis down the line, it prevents a sudden bombardment with important information at what might well be a very stressful time. For those whose cognition goes on to decline, such interactions are a prime opportunity for professionals to build a picture for themselves of what is important to P.

Of course, forward-looking discussions will be fairly standard in these consultations, and I am not suggesting that there is currently a total absence of this gradual development of a patient’s understanding. My focus here is on such conversations being as much about the professional building an understanding of P’s preferences as P building an understanding of the possible direction of care.

⁶⁷¹ Halpern J, Owen A. 2021. ‘Scaffolding autonomy: respecting persons in shared decision making’. In Lantos JD (ed). *The Ethics of Shared Decision Making*. Oxford: Oxford University Press, 60-61.

⁶⁷² Though they also highlighted the downside that this can lead to a level of emotional attachment that has the potential to add a layer of difficulty to a Best Interests decision, as already discussed.

Through these discussions, the professional can attempt to build an understanding of P's preferences and underlying values more abstractly, so they can then be applied to a concrete decision down the line if required. For example, a strong desire expressed by P to avoid clinical environments as it is highly distressing may be later taken to favour at-home dialysis options. That is not to say that a deep understanding of P will be achieved, but at least a better understanding than can be expected in the absence of this approach. As such, both general and specific preferences may prove useful to any later Best Interests decision. To some degree, this would be led by P based on the strength of any preferences they have. If there is something very specific about which P feels very strongly, they might want a more detailed record of that made. On the other hand, more general comments might be recorded even if they will require greater interpretation in a later Best Interests decision.

I do not suggest this as a process exclusively between patient and professional. Certainly, family members are likely to be present at various points, making contributions to care discussions. Such is the nature of healthcare decision making – with any significant treatment decision, most people discuss it with those close to them, even if they ultimately disregard the opinions returned. This input is, as acknowledged by professionals, invaluable. My suggestion is more about the professional playing a role to build confidence in an understanding of P's preferences. Further, to prevent unnecessary confusion down the line, detailed records should be kept of these discussions.

What I am manoeuvring towards here is a means of respecting what Coggon termed 'best desire autonomy' (*see 1.1.3*).⁶⁷³ To recap, best desire autonomy considers the appropriate decision that which accounts for P's 'overall desire given his own values, even if this runs contrary to his immediate desire'.⁶⁷⁴ Whilst informed consent where a patient has decision-making capacity maps more closely onto current desire autonomy – in effect, not requiring the individual to demonstrate how their decision in any way aligns with their more deeply held values – such an approach is precluded in the case of a patient who lacks decision-making capacity. The only way this could conceivably be achieved is by treating P as able to provide informed consent and taking as authoritative the preference expressed at

⁶⁷³ Coggon (n94) 240.

⁶⁷⁴ *Ibid.*

the time. Such an approach is essentially endorsed by the UNCRPD, in particular through General Comment No. 1 of the Committee.⁶⁷⁵ The Committee states that no one with a disability – inclusive of cognitive impairment – should be denied legal capacity. Such is the Committee’s interpretation of the Article 12 right to equal recognition before the law.

However, this approach fails to recognise that P’s cognitive impairment does have relevance even if it does not entirely remove their right to respect for their preferences. As Kong has highlighted, this radical freedom denies the ‘contingent link between the concept of legal capacity and mental capacity’.⁶⁷⁶ No matter the efforts to support P in making a decision, the impact of a cognitive impairment on their decision-making capabilities cannot always be overcome. To afford legal capacity so unconditionally in this way risks causing harm and can certainly not be said to represent a true respect for P’s autonomy, simply because such cognitive impairment prevents P from understanding the relevant information and communicating their own decision – hence a failing of the functional test. Given how significant a decision to commence dialysis is, the Committee’s approach to cognitive impairment is not satisfactory.

This proposed process of gradual discussion of preferences ahead of time is, then, a means of enabling respect for best desire autonomy. To strengthen the reliability of such discussions, it is important that they take place – at least on some occasions – in P’s own home environment. Francis notes that ‘[f]or some, capacities may increase or decrease with the social or physical setting, or even with the time of day’.⁶⁷⁷ Participants also spoke of the environment as important, particularly in relation to better understanding P’s living situation and quality of life. Recall, N07 spoke of visiting a patient in a care home and exploring the extent of P’s engagement in activities versus his being withdrawn in his own room (*see 5.1.1*). In a study of legal practitioners’ views of Best Interests decisions made in the court setting, it was similarly suggested that ‘direct meetings may be better supported, more comfortable, and more meaningful for P if they take place within P’s own surroundings’ given that

⁶⁷⁵ Committee on the Rights of Persons with Disabilities (n64).

⁶⁷⁶ Kong C. 2022. ‘The significance of strong evaluation and narrativity in supporting capacity’. In Donnelly M, Harding R, Taşcioğlu E (eds.). *Supporting Legal Capacity in Socio-Legal Context*. Oxford: Hart Publishing, 61.

⁶⁷⁷ Francis L. 2021. Supported decision-making: the CRPD, non-discrimination, and strategies for recognizing persons’ choice about their good. *The Journal of Philosophy of Disability* 1:57-77, 59.

‘participants noted that the additional benefit of being in P’s usual environment was that it would help to put P in context, providing intuitive impressions that might otherwise remain overlooked’.⁶⁷⁸

Being in one’s own environment can provide a sense of control, such that it is the healthcare professional who is the outsider who is coming to you. Particularly if someone has any level of anxiety in unfamiliar environments, a consultation taking place in their home allows them time to get comfortable and feel at ease – clinical environments can be quite fast-paced and things can feel rushed, preventing some people from getting to the point of feeling comfortable with their surroundings before they have to speak with a professional. It may also reduce instances of P just going along with the suggestions of the professional, which was highlighted by professionals as a concern in interactions with patients. Thus, whilst P may still lack decision-making capacity during this pre-emptive discussion process, engaging with them in their own environment may bring about better results in terms of understanding P’s preferences over time.

There is a risk that this process could be distressing for some people. They may already be struggling to come to terms with the reality that they have CKD and do not want to be thinking about dialysis when they still retain significant native kidney function. They may also worry about cognitive decline being expected in them if it is raised by a professional. However, incidentally, this process may reduce such distress. Framing this process as standard procedure rather than something indicated by P’s condition could be more reassuring. They may feel less worried it will happen or is happening to them in particular as the professional is not engaging in such discussions based on an identified concern. Further, it is common for such exploratory questions of a potentially sensitive nature that may prove unnecessary for some patients to be asked in various areas of healthcare, particularly in relation to safeguarding.⁶⁷⁹ Undoubtedly, there will be some who find this process distressing, but this can be

⁶⁷⁸ Kong C, Stickler R, Cooper P, Watkins M, Dunn M. 2022. Justifying and practising effective participation in the Court of Protection: an empirical study. *Journal of Law and Society* 49(4):702-725, 717.

⁶⁷⁹ For example, when trying to access sexual health testing kits a patient will commonly be asked whether they have been forced into having sex or have been offered money for sex, even though the answer to both will be in the negative for most people.

considered a proportionate harm in light of the potential benefit should such discussions prove useful to a future Best Interests decision.

A further important consideration is the burden in requiring professionals to engage in such discussions with patients, particularly in the case of patients with whom they would not ordinarily do so. It is clearly not realistic to expect that all patients under the care of a renal unit undergo extensive discussions about their preferences, as many will never progress to the point where a decision about KRT is necessary, let alone require a Best Interests decision. One approach to more appropriately directing these discussions would be to explore the value of prediction models. Of late, there has been an increased uptake of certain predictive tools in making decisions about kidney care; a move away from blanket approaches. For example, the Kidney Failure Risk Equation.⁶⁸⁰ It may be, then, that there is a role for prediction models in deciding which patients should be actively encouraged to engage in these advance discussions. Certainly, in terms of use of resources – which cannot be entirely disregarded even if one feels it should not be heavily guiding – this would be beneficial. I suggest, therefore, that this is an important area for future research to explore. In the meantime, however, this must reasonably be a matter for professional discretion in determining which patients are at higher risk of both KRT and cognitive impairment. In exercising such discretion, it is important that professionals duly consider the value of past expressed preferences in Best Interests decisions as I have outlined.

Whilst this process is important to understanding P's preferences, it is not to be viewed as a substitute for P's involvement in any Best Interests decision that may take place. Indeed, this longitudinal view of P's preferences can contribute to greater involvement of P at the time a decision must be made. This is because exercising one's capacities, even where there is impairment, can be considered a practiced art: 'people may improve in their decision-making skills as they engage in them. Or they may become increasingly passive when others seem to take over for them or not even listen to them'.⁶⁸¹

⁶⁸⁰ The Kidney Failure Risk Equation. <<https://kidneyfailurerisk.co.uk/>>; Peeters MK, van Zuilen AD, van den Brand JA, Bots ML, et al. 2013. Validation of the kidney failure risk equation in European CKD patients. *Nephrology Dialysis Transplantation* 28(7):1773-1779.

⁶⁸¹ Francis (n677) 59.

The work of Kong⁶⁸² around ‘absorbed coping’ and ‘hermeneutic competence’ makes an extremely useful contribution to understanding here. Kong’s exploration of mental capacity embodies a relational account of autonomy and the social model of disability, proposing that an improved approach to decision making in the context of possible lack of capacity can better respect P’s autonomy through increased involvement in decisions about their care.

First, Kong’s exposition of absorbed coping. Drawing on the work of Dreyfus around ‘skillful coping’,⁶⁸³ Kong highlights how those with cognitive impairments are short-changed by the all-or-nothing conception of capacity that requires us to demonstrate sufficient competence in making decisions if our choices are to be respected.⁶⁸⁴ Critical of a highly atomistic view of autonomy, she highlights the importance of relationships and social context to capacity. She describes absorbed coping as an ‘equilibrium we seek in our perceptual, embodied interactions with the world’.⁶⁸⁵ Essentially, even those with impairments “cope” in the world as they are similarly in this quest for equilibrium. A comparable idea is found in autism studies, where it is instead known as ‘camouflaging’.⁶⁸⁶ Hull and colleagues describe a process whereby a person with autism will develop an ability to present in a particular way that conceals their autism, which may be driven by either internal (personal goals) or external (societal expectations) demands.⁶⁸⁷ Historically, too, Jarrett highlights how prior to the practice of institutionalising those with intellectual disabilities in the mid-nineteenth century this coping was enabled by something of a community approach, such that these individuals ‘were accepted, they belonged, and were seen as naturally belonging, their differences absorbed into the everyday lives of communities’.⁶⁸⁸

⁶⁸² Kong (n35).

⁶⁸³ Dreyfus HL. 2005. Overcoming the myth of the mental: how philosophers can profit from the phenomenology of everyday expertise. *Proceedings and Addresses of the American Philosophical Association* 79(2):47-65.

⁶⁸⁴ Kong (n35) 1.

⁶⁸⁵ *Ibid.*, 80.

⁶⁸⁶ Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai M-C, Mandy W. 2017. “Putting on my best normal”: social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders* 47:2519-2534.

⁶⁸⁷ *Ibid.*

⁶⁸⁸ Jarrett (n370) 10.

Kong's contention is that more individualistic views of autonomy are overly binary and do not allow for a spectrum of capacity that is more so the reality given absorbed coping. This view seems entirely plausible, and certainly speaks to the decision-specific nature of capacity. Whilst for practical purposes it may be easier to say someone either has capacity or not – assessed through demonstration of a particular idea of 'ability or skill'⁶⁸⁹ – a sudden tipping point is not a realistic representation of the human condition. Even amongst those we consider as having decision-making capacity, there is variation in the extent to which they have understood and thought through treatment options when providing informed consent. As noted in Chapter 1, Kapp argues that 'atomistic and sequential' conception of autonomy often found in legal theory does not reflect the practice of autonomy in 'real life'.⁶⁹⁰ This I cannot help but agree with.

Of course, even a spectrum view entails some individuals being entirely without capacity and non-autonomous – patients who are not conscious cannot be actively involved in a decision however one chooses to characterise autonomy. Even some conscious patients may be unable to play an active role in a decision where they are significantly impaired. But to shift our understanding in the way Kong advocates is 'sufficiently inclusive towards individuals with impairment, yet demanding enough to make autonomy an achievement nonetheless'.⁶⁹¹

We can, then, engage P more fully in decisions even in the presence of cognitive impairment, it just may entail different means of interaction and understanding. According to some of the literature, this is something that does not happen enough, with several authors speaking of a perception that the mere presence of a cognitive impairment precludes P's involvement in decision making.⁶⁹² Consultee participants echoed this in feeling that there was little effort by professionals to engage P.

That brings us to the complementary concept of hermeneutic competence. Kong details hermeneutic competence as something professionals ought to be equipped with, comprising three components: (1) phenomenological awareness; (2) dialogical openness; and (3) nurturing relations-to-

⁶⁸⁹ Gunn (n36) 8.

⁶⁹⁰ Kapp (n62) 414.

⁶⁹¹ Kong (n35) 100.

⁶⁹² MacPhail *et al.* (n393); Scott *et al.* (n397).

self.⁶⁹³ Phenomenological awareness relates directly to absorbed coping in requiring one to recognise subjective experience and engagement with the world, with a focus on adapting spaces to ‘help establish a shared experiential world with those who have impairments’.⁶⁹⁴ Complementing this, dialogical openness ‘incorporates self-reflection, humility, and deliberative respect’,⁶⁹⁵ moving towards avoiding those with impairments becoming passive bystanders in decisions about their care. Finally, nurturing relations-to-self requires recognition of P to enable P’s development of self-respect, self-trust, and self-esteem, thereby promoting P’s autonomy on the basis that one’s identity as a competent adult crucially depends on others’ recognizing you as such’.⁶⁹⁶

So, what does this offer the present discussion? In combination, these elements of hermeneutic competence call on the professional to be more aware of the experience of P and work towards enabling P to be involved in any decisions about their care to the greatest degree feasible. It shifts the burden from P having to demonstrate certain competencies to others having to recognise and enable it. In doing so, it can also contribute to the avoidance of oppression as powerlessness per Young (*see* 6.2.1). This somewhat aligns with the view of the UN Committee on the Rights of Persons with Disabilities, which stated that ‘support’ per Article 12(3) of the Convention ‘can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences’.⁶⁹⁷ However, it departs from the UNCRPD in that hermeneutic competence is more about engaging P in what is still a Best Interests decision, rather than relying on it to realise legal capacity.⁶⁹⁸ With P’s right to autonomy constructed around absorbed coping – i.e., recognising the extent to which P may be able to exercise autonomy in an atypical manner, and may be able to contribute to a decision even if only partially – hermeneutic competence can be taken as a related duty on professionals to respect this. With professionals and

⁶⁹³ Kong (n35) 191.

⁶⁹⁴ *Ibid*, 192.

⁶⁹⁵ *Ibid*, 197.

⁶⁹⁶ Nelson HL. 2001. *Damaged Identities, Narrative Repair*. Ithaca, NY: Cornell University Press, 81-82.

⁶⁹⁷ Committee on the Rights of Persons with Disabilities (n64) at para 17.

⁶⁹⁸ Of course, approaches endorsed as hermeneutic competence may result in an individual no longer being deemed to lack decision-making capacity, but that is not the sole goal as Kong’s work rests on the premise that cognitive impairment cannot always be overcome to the point of enabling informed consent. I will touch on this again shortly.

consultees alike stressing the centrality of P's preferences in any Best Interests decision, approaches to enabling P's involvement that hermeneutic competence calls for should be viewed positively across the board.

There are some parallels here with the more commonly recognised social model of disability – though Kong does not align herself with this model.⁶⁹⁹ The social model posits that disability is the result of society's structuring to meet the needs of those perceived as typical, and a subsequent failure to incorporate the needs of those who diverge from this norm.⁷⁰⁰ With Kong's framing of hermeneutic competence, the professional can seek to minimise this failure by taking the necessary steps to involve P in the decision, making it a decision *with* rather than *about* P. Kong's other work provides a practical example of hermeneutic competence, wherein a Court of Protection judge is making a decision as to P's residency needs:

'the judge asked P to draw a picture of where he would like to live and P drew himself in a house with his parents outside it. When the judge used this drawing to explore P's views, P was able to explain that his parents were not in the house as they would only be visiting him'.⁷⁰¹

Here we can see how somewhat "outside the box" thinking might lead to a better understanding of P's preferences, following a recognition that P is unable to express such preferences in an entirely typical manner. Such efforts may be similarly effective where a Best Interests decision is to be made in the clinical context.

As well as the approach of the professional to engaging with P and taking seriously what P expresses, a big part of hermeneutic competence is recognising the relational nature of capacity and

⁶⁹⁹ Kong considers it as an oversimplification of impairment in framing it as value neutral. Kong (n35) 151.

⁷⁰⁰ Oliver M. 1983. *Social Work with Disabled People*. Basingstoke: Macmillan Education; Oliver M. 2013. The social model of disability: thirty years on. *Disability & Society* 28(7):1024-1026.

⁷⁰¹ Kong *et al.* (n678) 15.

autonomy and thereby engaging with those close to P – Kong’s commitment to such an understanding requires the involvement of those the MCA 2005 would characterise as consultees as central to facilitating hermeneutic competence. For example, P’s atypical communication may be best understood by those who are with P day-to-day, whereas a professional who has less frequent interactions with P may not be as capable of picking up on precise communicative cues. Similarly, it is also about drawing on the expertise of other professionals. For example, speech and language therapists may be useful if P is viewed as unable to communicate preferences, as it may just be that P can only communicate in a way the professional is not able to identify – certainly, this speaks to the view of consultees that they are not always listened to when they note an understanding of what P is communicating. Dialogical openness may even entail the seeking of an independent opinion as I will come to discuss shortly (*see* 6.2.5). For some at the more capacitous end of the incapacity spectrum, hermeneutic competence may result in them being deemed as having decision-making capacity, enabling them to provide informed consent rather than needing a Best Interests decision at all. This relates back to my discussion of the cliff edge view of capacity, as Jackson notes how even those with capacity require some support to realise that capacity – for example, provision of information in a different language.⁷⁰²

It was clear that professionals interviewed recognised this need to try and engage with P, albeit to varying degrees. The concerns of consultees, however, suggest that there may be a need for improvement on this front. Certainly, if efforts in supporting P are minimal, the professional might be considered ‘teetering always on the brink of neglect’.⁷⁰³ This could feasibly be addressed through more tailored guidance for professionals but, realistically, it would likely require investment at a higher level to make the resources available – it is more than just the professional’s approach, also requiring the involvement of others with relevant expertise. Such efforts in ascertaining P’s preferences may be

⁷⁰² Jackson E. 2018. From ‘doctor knows best’ to dignity: placing adults who lack capacity at the centre of decisions about their medical treatment. *Modern Law Review* 81(2):247-281, 248.

⁷⁰³ Dunn M, Foster C. 2010. Autonomy and welfare as *amici curiae*. *Medical Law Review* 18(1):86-95, 89.

difficult and take significant time but are obligations under the Equality Act 2010.⁷⁰⁴ These obligations are similarly found in both the MCA 2005⁷⁰⁵ and its Code of Practice.⁷⁰⁶

As a word of caution, though, there is a definite balance to strike here. Efforts to involve P are evidently important to meaningfully attempt to safeguard their preferences, but at the point a Best Interests decision is being made it must also be recognised that P's ability to participate is likely in some way impaired. Several participants spoke of instances of P being party to discussions and attempts at involvement which proved somewhat tokenistic in light of P's apparent inability to engage. This was not only an experience of professionals, but some consultees also found their loved one was present in such meetings more physically than mentally. Whether these examples were a genuine inability of P to engage or a prime example of where hermeneutic competence is beneficial I cannot be sure, but in at least some cases the former will be true. Unless efforts at engagement result in P being deemed to have decision-making capacity, P's involvement does not constitute informed consent. Martin and colleagues note that 'whatever "respect" means in this context, it must be something stronger than "consider", even though it is less than "be absolutely bound by"'.⁷⁰⁷ Hence the proposed process of gradually understanding P's preferences which can then be explored alongside engagement with P at the time of the decision. Combined, these approaches can build a reasonably reliable picture of what P would want, and in a way that involved various parties to contribute to shared understanding and potentially minimise conflict. This may not then be strictly followed, but any departure from it ought to require significant justification given it is as close to autonomy respecting as is seemingly feasible.

RECOMMENDATION

Continued, active efforts should be made by professionals to understand P's preferences. This should begin when P comes under the care of the renal team – even if P has no cognitive impairment at that time – and revisited regularly. The extent of efforts to ascertain P's preferences may be variable in line with the extent of any cognitive impairment. Preferences recorded may be general or specific.

⁷⁰⁴ S.20 Equality Act 2010; Jackson (n702) 261.

⁷⁰⁵ S.4 (4) Mental Capacity Act 2005.

⁷⁰⁶ Para 1.2 imposes a duty to 'maximise' the participation of P in any Best Interests decision.

⁷⁰⁷ Martin W, Michalowski S, Jütten T, Burch M. 2014. *Achieving CRPD compliance: is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disabilities? If not, what next?* University of Essex: Essex Autonomy Project.

6.2.3 Family involvement

The point on which there appears to be greatest consensus amongst professionals, consultees, and the literature is on the importance of the family being part of the decision-making process (where present and willing). Consultees were very clear that they felt they should have a central – perhaps even deciding – role in any decision about their loved one’s care. Indeed, many favoured a role much like LPA-HW as a default, to ensure the family take on this role even if P had not taken the legal steps to implement LPA-HW. For professionals, the importance of family involvement was nicely summarised by one who explained: “They’re not brought in, they’re there. They’re part of what’s going on” (D02). The input of family was overwhelmingly felt by professionals to be vital, primarily in the form of their intimate knowledge of P. The literature, too, highlights the benefits of family involvement, and this view certainly aligns with the MCA 2005 given the existence of the consultee role.

However, whilst there was agreement on the fact of family involvement being important, the precise nature and extent of that role was perhaps the point of least coherence. Consultees tended to feel decisions should fall to family, whereas professionals were sceptical of such an approach, instead favouring a collaborative role for family but the decision ultimately being made by the professional. Both the literature and the law align with professionals here. Many authors profess the need for caution when involving family, touching on various reasons why them having anything beyond a consultative role could be detrimental to P’s interests.⁷⁰⁸ That the MCA 2005 – in notable contrast to the legal system of many other countries – vests decision-making authority in the professional clearly sends the message that it is not a decision to be made by family.

Given that consultees are the outliers here, I will first turn to their perspective. Those interviewed all happened to be family members, so I will use the language of consultees and family interchangeably here. The perspective of consultees was clear that they felt their role in a decision should be significant, with many going as far as to state that the decision should fall to the family.

⁷⁰⁸ DeCamp (n404); Perkins (n419).

Acknowledging their own lack of medical expertise, family very much valued the input of the care team but did not think it appropriate for a doctor to make the final decision on their loved one's care. They feared motivations other than P's Best Interests coming to the fore when a healthcare professional makes a decision, such as freeing up resources where P's care is particularly costly (which is the case with dialysis). They also felt that they were better placed to represent P's preferences, going back to the point of prioritising P's preferences wherever possible. In essence, consultees opposed what they perceived as a paternalistic situation, somewhat aligning themselves with the logic of informed consent but viewing themselves as proxy. Indeed, strong opposition to the Best Interests system from consultees framed something akin to substituted judgement as an appropriate alternative, with many suggesting that it should be family highlighting what P would have decided and that being respected (*see* 5.2.4).

Concerns from professionals and the literature about family having such a significant role question aspects of the reasoning of consultees here. Whilst agreeing that family were generally better placed to represent P's preferences, professionals were wary of the confidence with which family sometimes presented what P would have wanted or the decision P would have made. This has already been discussed, so I will not dwell too much here, save noting that this concern has similar relevance to the precise role of the family in decisions.

Another concern raised by professionals and the literature centres on the motivation of family, with the question arising as to whether it is always good. Whilst one would hope that in most cases the family would be coming at the decision from a good place, with P's Best Interests very much at heart, there is a risk that ethically problematic motivations may arise. This can happen in both directions – i.e., resulting in a decision to either accept or refuse dialysis for a reason other than P's Best Interests. If the family have a significant caring burden in relation to P, a desire to relieve that may influence a decision. There is likely a greater risk where the family members involved are somewhat estranged from P but were identified as a relative to speak to. For example, there may be a desire to access an inheritance. On the other side, dialysis may be chosen by family simply because they cannot face losing their loved one, and they may not recognise where P's quality of life is notably decreased. This is certainly a concern professionals expressed quite firmly, feeling that disagreements over P's quality of

life were the root of many conflicts. In all these scenarios, the P-centred nature of Best Interests is undermined as the family's interests are the motivation.

This latter point on quality of life feeds into the worry of professionals that family may not fully understand the nature of the care options being considered – i.e., they may not comprehend how burdensome dialysis can be for a patient due to a lack of prior knowledge. The rigours not only of dialysis itself, but the wider changes to one's life it necessitates, were discussed at length by professionals. There was a feeling that sometimes family underestimate the impact choosing dialysis can have on P, and that it is something they may not fully understand until they have been through it.⁷⁰⁹ Whatever role the family takes, there may be call for better communication of information.

Given these priorities and concerns, there is a need to consider what role the family should take in Best Interests decisions, conscious of their motivations and level of understanding. For professionals, the role of family should be primarily that of collaborative provider of information. For consultees, their role should be more guiding, to the point of authoritative. This presents a possible impasse in the continued commitment to respecting P's preferences. On the one hand, the recognised importance of respecting the preferences of P suggests we take seriously any they have previously expressed, as noted by family, particularly as they may be part of a very limited pool of information concerning what P might want. On the other hand, past preferences cannot always reliably be taken as an indication of what P would want at the pertinent time – to blindly base a decision on them runs the risk of overlooking a change in P's preferences that may have been quite drastic – and they may be poorly represented by family. Whilst I have already stressed the importance of P's preferences, what I will propose here in relation to the family's potential role in representing those preferences is in many ways a belt and braces approach⁷¹⁰ – we should be accounting for P's preferences that are ascertainable (*see 6.2.1 and 6.2.2*) but must still be conscious of their limitations in some scenarios and have an appropriate course of action for instances where P's preferences are not easily ascertained and/or are deemed unreliable.

⁷⁰⁹ To some degree, this might be addressed by a trial of dialysis. I come to discuss this further shortly (*see 6.2.4*).

⁷¹⁰ A shout out here to my supervisor, Jonathan Ives, for using the phrase “belt and braces” so much that I have somehow found myself a victim of vernacular osmosis.

An obvious way to marry the two perspectives, with both ceding some ground, is to say that P's past preferences where represented by family should be strongly considered but not taken as guiding. This is, for the most part, the current status quo. However, whilst it seems wise to suggest previously expressed preferences should not be blindly followed, this compromise seems, to me, something of a cop out. It inadvertently leans more towards questioning the reliability of P's past preferences and, in doing so, deprioritising the respect for P's preferences that should be centred. This is precisely one of the issues with the MCA 2005. The wording of section 4 is that one must 'consider' P's 'past and present wishes and feelings', but the Explanatory Notes to the Act are clear that this is very much limited to consideration as 'Best [I]nterests is not a test of "substituted judgement" (what the person would have wanted)'.

As an alternative means of overcoming this lack of confidence in *what* P would decide, it seems more prudent to implement a more substituted judgement approach in relation to *how* P would want the decision to be made. One might say that the ideal response is for LPA-HW to have been established in advance, provided P wants the decision to be made by their family – some will very clearly not want this. The sheer passion with which consultees spoke of the importance of LPA-HW is hard to ignore.⁷¹¹ Putting LPA-HW in place would vest the decision-making authority in the family and prevent a Best Interests decision arising. Family would not then have to feel they are fighting to be heard, and professionals would not need to worry as much about the views expressed by P's family.⁷¹² However, this response to the problem is of limited utility. It requires P to have previously been in a position of having sufficient decision-making capacity to arrange LPA-HW, which, quite understandably, requires a high threshold of capacity be met. Certainly, making patients aware of the option of LPA-HW when they are new to the renal unit would be beneficial, but that does not help with those who are already cognitively impaired on presentation. We need an alternative that works in such situations.

⁷¹¹ This passion does not indicate the right, but does at least necessitate reasonable consideration.

⁷¹² Of course, they may still worry if they feel the decision the family is making is poor. If they are particularly concerned, they may even put the LPA-HW into question so that it is investigated. Nonetheless, LPA-HW sends a clear message that P wanted their family to take the lead in decisions about their care rather than a healthcare professional.

As an alternative, I propose something of a quasi-LPA-HW, which still maintains a focus on *how* P would want a decision to be made rather than *what* P would decide. Importantly, what I propose here – in relating it to the MCA 2005 principle of decision-specific capacity – would not require the level of understanding and reasoning to consent to LPA-HW. I will expand on this shortly.

When I say substituted judgement in relation to how P would want the decision to be made here, I simply mean the pursuit of a decision-making process that P has previously indicated a preference for. Hence it being something of a quasi-LPA-HW. Given that a key conflict between professionals and consultees appears to be in relation to who has what say in a final Best Interests decision – with both ultimately pushing for what they think is right for P – it may be that at least some conflict could be resolved if both were on the same page regarding roles, and, importantly, that page has been endorsed by P. For example, if P had previously made clear that they would like their children to be central to any decision about their care in future, the care team could more comfortably back what the children then claim P would have wanted, recognising that P at least felt confident their children would make the right decision for them. Similarly, if P stated they would prefer their doctor to decide, it may be easier for the family to cede control out of respect for P.

In practical terms, what I am suggesting is that conversations about decisions in the event of incapacity be had with patients suffering from CKD at the beginning of their time under the care of a renal team. Not necessarily at their very first consultation, but at some point relatively early on. This would be around the point I earlier suggested raising the possibility of LPA-HW would be beneficial. For those who, at this point, have sufficient cognitive impairment to preclude the process of appointing LPA-HW, more informal discussions of how they would like decisions to be made can be had. Even if they lack the required capacity to appoint an LPA-HW, they may well have sufficient capacity to express a preference for having their family in a more significant decision-making role. Similarly, at this point they may make it clear to the healthcare team that they would not like their family to be involved in any decisions. This discussion can then be recorded, to be revisited if a Best Interests decision becomes necessary down the line.

As with my earlier mention of the role prediction models might play, here again this is true. Such models might assist in deciding which patients should be actively encouraged to engage in these advance discussions about LPA-HW and my proposed quasi-LPA-HW approach.

I noted above that, in relation to the MCA 2005, this approach would require a lower standard of capacity than the appointment of an LPA-HW. The reason is essentially due to the legal standing of these discussions, in that there is none. These informal discussions seek to replicate the understanding of P's preferences for decision-making process that LPA-HW confirms, but without shifting ultimate decision-making authority. Similarly, it would not need the level of capacity required to accept or decline dialysis. Given the nature of dialysis and the burdens it entails – it is a life-altering decision – the bar for capacity cannot be set too low. A non-binding decision about how one would prefer a decision to be made can still have that life-altering effect as the nominated party would go on to make a decision about dialysis. However, rather than stipulating a specific treatment option, it simply indicates who P would rather have making decisions – which may even help create an individualised hierarchy of the Best Interests considerations within the MCA 2005.⁷¹³ The chosen party is then able to become suitably informed and reason towards a decision on P's behalf. This approach captures the essence of LPA-HW, but without making any formal changes to any party's legal standing – it is more so a guided process of information gathering.

Navin and colleagues' discussion of capacity to designate a surrogate is useful here.⁷¹⁴ They suggest the standard of capacity that should be required to appoint someone as a surrogate decision maker should be lower than that required to make one's own decisions about their treatment. The former, they argue, 'does not require one of the core components of [decision-making capacity]: that a patient appreciates their clinical condition'.⁷¹⁵ Rather, they suggest that designating a surrogate ought only to require P to '[e]xpress a consistent choice' and '[d]emonstrate a basic understanding'.⁷¹⁶ Whilst I consider Navin and colleagues' capacity requirements a little lax for the *formal* appointment of a

⁷¹³ My thanks to Harleen Kaur Johal for noting this possible by-product.

⁷¹⁴ Navin M, Wasserman JA, Stahl D, Tomlinson T. 2021. The capacity to designate a surrogate is distinct from decisional capacity: normative and empirical considerations. *Journal of Medical Ethics* 48(3):189-192.

⁷¹⁵ *Ibid*, 1.

⁷¹⁶ *Ibid*, 2.

surrogate decision maker – i.e., LPA-HW – due to its binding nature, I do think that their criteria are appropriate for the purposes of my proposed quasi-LPA-HW. Given that my suggestion is about understanding P's preferences informally so that a professional can take them into account in their legal role as decision maker, the bar being lowered in this way is entirely appropriate. For P to simply express that, for example, they would rather their spouse act as an unofficial proxy decision maker need not be any more demanding on P's capacity than a consistent choice and basic understanding.

Given this lack of legal standing, one may question what the point is in this approach. The key benefit of this substituted judgement in relation to the process rather than the outcome introduces a greater sense of reliability and, indeed, reassurance for the professional. Deciding on P's Best Interests remains difficult, but the process is potentially streamlined. We know that people can change their minds about what they would and would not like in terms of medical intervention, which appears to be a key reason for professionals questioning the applicability of consultee provided past preferences in Best Interests decisions. It seems plausible that someone would be less likely to change their mind about a preferred decision-making mechanism – though, I concede, this is by no means an impossibility. If someone has a relationship with their family such that they would trust them to make important decisions about their care, in the absence of some sort of family conflict this trust is likely to remain. More pessimistically, if someone would prefer their family to make a decision out of concern for the motivations of healthcare professionals – i.e., fears around the cost of continued treatment being deemed too burdensome on the healthcare system – they are unlikely to have a sudden change of heart. Of course, it is very much possible that P may change their mind about the role they would like their family to have, but this can be somewhat mitigated by revisiting this discussion on occasion. This enables the professional to either become ever more reassured of P's preference if it does not change over time, or to recognise where it may be unstable to the point of questionable reliability. The professional is still left with a judgement call but is able to make it from a more informed position. Further, conscious of this decision-making arena seldom being ideal, it is important to acknowledge that we accept a possible change of heart as collateral damage when it comes to LPA-HW; it is equally possible that an individual may fall out with a family member after appointing them in this role. At least through this approach I

am advocating, the professional retains the legal authority in the decision which can account for a family rift – though overriding the family in this way if P indicated a preference for the family making a decision should be uncommon.⁷¹⁷

At the same time, this approach affords more flexibility than an advance directive. A consultee's understanding of P's preferences can evolve organically as they interact, whereas an amendment to an advance directive must be specific and at a fixed point in time. Thus, where P may, for example, become gradually more open to the prospect of dialysis as their condition progresses, the understanding of a consultee is more likely to reflect this – particularly if questions of P's capacity prevent changes to an advance directive even where a desire for such changes is identifiable. A Ulysses contract approach introduces too much rigidity as the professional would be bound to pursue a course of action that P may no longer desire.

Of course, with this system I am proposing, at the time a decision must be made, either party may take issue with the process that P previously endorsed. If P had expressed a preference for their doctor making the decision, the family may still insist that the doctor's view of P's Best Interests is not reflective of P's preferences. Further, P's expression of a preferred process would not be legally binding so the decision-making process would still be somewhat collaborative. Nonetheless, this understanding of how P would want a decision to be made at least provides some support for significant disagreement to be resisted. This reconceptualization of the process of discussion and understanding of stakeholder roles arguably satisfies each party to some degree. Whilst a Best Interests decision should not be about keeping everyone involved happy, it certainly helps reduce conflict and enable a clear decision to be reached. Through this proposed approach, the family can be, where it is what P wanted, afforded a more significant role in any decision. Professionals, on the other hand, can be more confident that P's preferences are being accurately identified – with the backup option of overriding the family in more extreme cases where they have reasonable grounds to think P's preferences are not being correctly

⁷¹⁷ Such a rift may not always been identifiable, whether because it is generally well hidden or because P does not feel that they can tell a professional. Nonetheless, where the professional does become aware of one, they can account for this.

voiced. And, ultimately, this approach centres P's preferences, which is stated by both parties as their priority and is strongly favoured in the literature.

This proposal addresses some situations in which P has insufficient decision-making capacity to appoint an LPA-HW, but not all. There will still be those who never had capacity, or at the point of presentation have insufficient capacity even to engage in these informal discussions. Such instances are hugely challenging, and I hold my hands up to say that I have made no notable contribution here to assisting with them. Nonetheless, what I do propose is an incremental improvement with the potential to improve care decisions for a significant range of patients.

RECOMMENDATION

P should be consulted at the earliest opportunity regarding the role they would like their family (or other consultees) to have in any future decision about their care should they be deemed to lack decision-making capacity. The option of LPA-HW should be highlighted where P has sufficient decision-making capacity to instigate this. In any case, P's preferences regarding the role of their family (or other consultees) in future decisions should be recorded and taken into consideration in any future Best Interests decision. This discussion should be revisited periodically for confirmation.

Given this recommendation is more so a reframing of discussions with P and P's family than a change in the decision-making architecture, it would not necessitate any formal policy change and could ultimately be implemented at any time by individual professionals. The professional is still responsible for the final decision, but their understanding of P's Best Interests is potentially based more on what the family thinks – if that is how P desired the decision to be made. To that extent, then, it does rest on the honest engagement of the professional who would still be in a position to “override” the family. Whilst not actively endorsed by the MCA 2005, this is very much compatible with the Act's requirements.

6.2.4 Rotten (medical) compromise

Many professionals spoke of instigating dialysis trials as a means of conflict management where the family were insistent on dialysis against the view of the care team. In situations where the deciding professional felt dialysis was not in P's Best Interests but the family disagreed, some spoke of going against what they considered P's Best Interests to appease the family. In considering the ethical status of such decisions, I will initially afford the view of the professional a certain epistemic privilege. Whilst professionals are fallible – much to their own admission in interviews – professional opinion must count for something. Medicine is not a perfect science, but we accept that research and clinical experience provide reasonably accurate predictions of how things will pan out. Though this is, importantly, in relation to the professional's *clinical* view – a prediction as to how dialysis will affect P's condition is not the same as a view of P's Best Interests.

Before proceeding any further, it is worth acknowledging what some may view as a shortcoming of the discussion that follows. The key example of compromise I am concerned with here is the use of dialysis trials to overcome conflict, with the care team going along with the request of P's family. Some may suggest that this is not a compromise at all but acquiescing, as one party is “winning”. Compromise is often characterised as each side giving some ground – meeting somewhere in between, though not necessarily the middle. According to Benjamin, compromises ‘require concessions by both sides and be able to be seen by the opposing parties as somehow splitting the difference between them’.⁷¹⁸ Indeed, Golding suggests that in compromise neither party can have the outcome they would ideally want.⁷¹⁹ If this is true, dialysis trials started purely to appease P's family may not be examples of compromise at all. However, I suggest that such appeasement does satisfy this definition and still ought rightly to be considered compromise. This comes back to my earlier point about professionals

⁷¹⁸ Benjamin M. 1990. *Splitting the Difference: Compromise and Integrity in Ethics and Politics*. Lawrence, KS: University Press of Kansas, 166.

⁷¹⁹ Golding MP. 1979. ‘The nature of compromise: a preliminary inquiry’. In Pennock JR, Chapman JW (eds). *Compromise in Ethics, Law, and Politics*. New York: New York University Press, 13. This very much brings to mind Patricia Routledge's impeccable characterisation in her *Kitty* monologues, explaining the outcome of an altercation such that ‘we reached a compromise; I got what I wanted and they didn't’.

characterising the use of dialysis trials as compromise. Even though they may recognise that an end to a dialysis trial is highly unlikely, that it is framed as a trial and, at least formally, has the potential to end, means the family can be thought of as having given some ground. Whether the family thinks it has is irrelevant; that the professional has framed it as such is sufficient.

Returning to the discussion at hand, given the apparent prevalence of compromise in Best Interests decisions about dialysis, there is a need to consider whether such compromise can be considered “good” – or, as a minimum standard, ethically defensible. Golding highlights how the literature presents ‘a fundamental disagreement on the rationality and morality of compromise’.⁷²⁰ For some, compromise may be viewed as some form of weakness, whereas others suggest it to be a means of rational agreement in the face of conflict. Whatever side one takes, compromise is an unavoidable feature of everyday life for most of us. Nonetheless, there remains a question over whether it is appropriate when it comes to P’s treatment. Though I recognise that I am here coming at this from a perspective of the various treatment options being on the table, which may not always, in terms of resource availability, be the case.

The view of professionals was very much that compromise, whether in the form of going entirely with what the family wants or commencing a dialysis trial, is far from ideal. Several acknowledged that they have felt they were going against the Best Interests of P in doing so. Nonetheless, it happens as the “path of least resistance” (*see* 5.1.5). Justification, for professionals, is found in the need to maintain a relationship with the family and, consequently, avoid an escalation to the point of the Court of Protection. Viewing court proceedings as unpleasant for all parties, professionals were willing to be flexible and move in the direction of the family to avoid a legal process. This aligns with other studies, such as one with ICU doctors which found that pressure from family and threat of legal action were reasons for what they considered inappropriate admissions.⁷²¹

⁷²⁰ *Ibid*, 5.

⁷²¹ Giannini A, Consonni D. 2006. Physicians’ perceptions and attitudes regarding inappropriate admissions and resource allocation in the intensive care setting. *British Journal of Anaesthesia* 96(1):57-62.

Consultees, by contrast, did not perceive these scenarios as compromise. For them, professionals had agreed to provide the care that was in P's Best Interests, which they had originally been opposed to. Where family had been insistent, they considered this a fight for P's Best Interests rather than a valid disagreement as to what was actually in P's Best Interests. Nonetheless, that professionals, as those with decision-making authority in such situations, viewed it as compromise is sufficient to consider it as such – whether it is compromise is a matter of the internal reasoning of the professional. For example, research has found that nephrologists can struggle telling patients and family that they do not consider dialysis to be appropriate, in part because they feel 'trapped in their uncertainty and afraid of using their authority'.⁷²² If the reason for a trial is genuine uncertainty about the best way to proceed then this does not come under the heading of compromise.

Perspectives found in the literature are somewhat foggy on this matter. Those identified in Chapter 3 provide some discussion of this issue. Kaye and Lella, for example, suggest that it may even be mandatory to set aside known preferences of P for the benefit of P's family unless there is undoubtedly suffering for P.⁷²³ Others felt keeping P alive for the benefit of the family to be entirely inappropriate.⁷²⁴ Whilst not framed as a discussion of compromise, these perspectives are at least indicative of a lack of coherence on these sorts of questions.

Huxtable notes that discussion of compromise is somewhat limited in the bioethics literature,⁷²⁵ though it does arise in relation to euthanasia. However, the idea of principled compromise present in the euthanasia literature is of limited utility here. It is primarily concerned with the overarching legislation concerning euthanasia and reaching a decision on which both sides of the debate surrender some ground.⁷²⁶ Here, I am concerned with compromise in relation to the direct care of a single patient. Given the sheer propinquity of potential harm, this should be viewed differently to the macro decisions

⁷²² Grönlund *et al.* (n6) 5.

⁷²³ Kaye and Lella (n394).

⁷²⁴ Keating *et al.* (n394); McDougall (n415).

⁷²⁵ Huxtable R. 2014. Splitting the difference? Principled compromise and assisted dying. *Bioethics* 28(9):472-480.

⁷²⁶ Holm S. 2010. Euthanasia: agreeing to disagree? *Medicine, Health Care and Philosophy* 13:399-402; Huxtable R, Mullock A. 2015. Voices of discontent? Conscience, compromise, and assisted dying. *Medical Law Review* 23(2):242-262.

around legislation; there is an extent to which a discussion at the policy level is more distant and less directly affecting. At the bedside, compromise of the type I am concerned with is very clearly affecting a specified person, so this sense of detachment cannot be appealed to. That is not to say that compromise in the context with which I am concerned can never be thought of as principled compromise. Rather, the macro-micro distinction I have noted prevents me from efficiently drawing on that existing debate around euthanasia.

Returning to the dialysis context, whilst many argue that the decision should not be made by the family as a matter of principle, there is less discussion in the literature of the extent to which professionals can be expected to resist insistent families. Recognition of defensive medicine is notably more common in the literature than proposed responses to it, with a seeming acceptance of it as an inevitability. Conscious of the importance of an is-ought distinction here, there is a need to find a more satisfactory account. For this, I turn to the work of Margalit.

Margalit writes of so-called “rotten compromises” as those which are to be avoided.⁷²⁷ Whilst Margalit discusses the idea of compromise in the political context, referencing major historical events such as the Munich Agreement, there are points of comparison in how he frames his discussion that prove useful for my purposes in the clinical context.⁷²⁸

A rotten compromise, per Margalit, is ‘an agreement to establish or maintain an inhuman regime, a regime of cruelty and humiliation, that is, a regime that does not treat humans as humans’.⁷²⁹ He argues that there is often a tension between peace and justice, with compromise as the ‘go-between’.⁷³⁰ Whilst justice is an ideal, it may not be achievable, and for the sake of peace (which, in the political context Margalit is concerned with, will generally be a matter of stability) something less than just may have to be accepted. In many cases, such compromise can be deemed acceptable, in part

⁷²⁷ Margalit A. 2010. *On Compromise and Rotten Compromises*. Princeton, NJ: Princeton University Press.

⁷²⁸ I am conscious this use of Margalit’s work may appear hypocritical given my dismissal of the principled compromise literature concerning euthanasia. However, I consider Margalit’s theoretical discussion as more widely applicable, whereas the euthanasia literature referenced is quite strongly grounded in that particular area of policy.

⁷²⁹ *Ibid*, 2.

⁷³⁰ *Ibid*, 8.

because compromise is an essential part of life. Rotten compromises, however, are never permissible for Margalit – even if for the sake of peace.

I am in no way suggesting that the issues Margalit is concerned with represent direct comparisons with those I am discussing. Whilst a poorly made Best Interests decision may cause P harm, this is not remotely on the scale of things, such as genocide, which constitute rotten compromises in the international relations sphere. However, Margalit's thinking can be useful in considering the question of dialysis trials as compromise where the care team and P's family are in staunch disagreement.

Let us consider justice as the "best" decision for the patient – the elusive nature of this concept makes it idealistic in much the same way as justice in Margalit's framing. Peace, on the other hand, constitutes a maintenance of a working relationship between the patient's care team and family – it represents stability in decision making. The question is, then, whether a nephrologist pursuing a dialysis trial for the avoidance of conflict represents *too much* of a dismissal of justice in favour of peace. If it does, then it constitutes a Best Interests version of a rotten compromise – this I will hereafter refer to as a rotten medical compromise.⁷³¹

Of course, a similar situation can arise outside of the Best Interests context. A patient deemed to have decision-making capacity may still find themselves as a pawn in disagreements between their clinician and family, particularly where that patient displays a decidedly agreeable temperament. There is reason to be slightly concerned by this reality too, but less so than where it is a Best Interests decision. At least in the case of the patient with decision-making capacity, it is more possible for them to interject and speak up on their own behalf. Such a patient's diffidence and willingness to agree with, for example, their family, can still largely be considered an informed decision. When we are concerned with a Best Interests decision, the patient lacks the ability to break the disagreement by making the decision

⁷³¹ I specify rotten *medical* compromise solely for distinguishing purposes. With Margalit's terminology having been taken up in the literature and the small but important differences between his meaning and mine, it is preferable to avoid confusion.

themselves. As such, the patient who lacks decision-making capacity is far more vulnerable to this process of compromise which may prove harmful to them.

So, what ought we to consider *too much* of a dismissal of justice in favour of peace in this context? Margalit's definition of a rotten compromise cannot be directly applied here as it, arguably, is a standard that would never be met in the clinical context; it would be a stretch to suggest occasional poor Best Interests decisions constitute an 'inhuman regime'.⁷³² Nonetheless, the framing of a compromise that 'does not treat humans as humans'⁷³³ can be drawn on. Indeed, this can be viewed as an application of Kantian ethics; not treating P as a means to an end.⁷³⁴ Based on this, we might consider a rotten medical compromise to be a Best Interests decision that constitutes an attempt to maintain a working relationship between the patient's care team and family, where this entails any manner of harm to the patient. Such a situation is more treating the family than the patient and prioritising the avoidance of complaints and legal action over the patient; a perceived actioning of the words of the poet George Herbert, 'a lean compromise is better than a fat lawsuit'.⁷³⁵

It might be questioned whether what I am proposing allows too little room for manoeuvre. After all, it is reasonable to recognise that part of the job of a healthcare professional is to "treat" the family as well; patients, for the most part, do not exist independently and family often feature prominently in medical decisions, particularly where a possible outcome is death. Professionals interviewed were accepting of this view. As such, if the provision of dialysis may only cause P mild discomfort, might not the appeasement of P's family be a legitimate reason for a dialysis trial? I contend that the answer is no.

Medicine is inherently harmful, in that almost every treatment results in some level of iatrogenic harm, however trivial. Such harm is generally considered justified on the basis of the intended results of that treatment – i.e., curing an individual of a disease. Central to such routine and informal harm-

⁷³² Margalit (n727) 2.

⁷³³ *Ibid.*

⁷³⁴ It certainly feels fitting to draw on Kant here, as Margalit explicitly draws on such foundations.

⁷³⁵ This quote is widely attributed to the 17th-century poet, though its precise origins are unknown.

benefit calculations is consideration of proportionality.⁷³⁶ We seek to avoid what is viewed as undue and excessive harm in caring for a patient, in line with the Hippocratic Oath and subsequent ideas of nonmaleficence. It is this underlying focus on relieving suffering with minimal inflicted harm that forms the foundations of the doctor-patient relationship. Sacrificing this to avoid conflict with a patient's family is to undermine this foundation of medical practice, as it fails to centre P in decisions about their own care.⁷³⁷

This conceptualisation of rotten medical compromise mirrors what Fiske and Tetlock refer to as a 'taboo trade-off', defined as that which 'violates deeply-held normative intuitions about the integrity, even sanctity, of certain forms of relationship and the moral-political values that derive from those relationships'.⁷³⁸ The doctor-patient relationship is undermined by rotten medical compromise as nonmaleficence – however one comes to define it – is recognised as central to this relationship's integrity.

Effectively, the concern is in both the instrumentalization of the patient in such rotten medical compromises and the possible long-term implications of undermining the doctor-patient relationship in this way (for example, if a particularly high-profile case sees the care team depicted as the villains by the media). To that end, then, both deontological and consequentialist reasoning is identifiable in opposition to rotten medical compromise.

I recognise that in opposing such compromise I am in some ways opposing both consultees and professionals. For consultees, this compromise is recognised more as them securing what they think is in P's Best Interests. For professionals, it is about finding a workable way forward even if they disagree that it is in P's Best Interests. Whilst professionals may recognise the problems with dialysis trials as a compromise, they do not feel empowered to pursue an alternative course of action. The exception being more extreme cases, in which some professionals explained they would insist that dialysis is

⁷³⁶ Indeed, this is explicit in the MCA 2005.

⁷³⁷ It is, of course, possible that P would want to endure some level of harm for the benefit of their loved ones. However, to pursue such a course of action for this reason would be a matter of respecting P's preferences rather than compromising to avoid conflict.

⁷³⁸ Fiske AP, Tetlock PE. 1997. Taboo trade-offs: reactions to transactions that transgress the spheres of justice. *Political Psychology* 18(2):255-297, 256.

inappropriate and would not provide it. But P's Best Interests should not be contingent on being such an extreme case – rotten medical compromise should be avoided across the board.

This ultimately comes back to respect for P's preferences, as earlier discussed (*see 6.2.1*). In making a decision on the basis of what makes P's family happy, P's preferences may fade into the background. It is, of course, possible they will align, but if the motivation is appeasing the family, then that important P centricity is lost. Whilst being overly idealistic about how decisions should be made limits utility, the avoidance of rotten medical compromise is feasible and, indeed, aligns with the MCA 2005. Incidentally, instances where such compromise even becomes a possibility may be largely avoidable through a substituted judgement approach to *how* the decision is made (*see 6.2.3*). With each party respecting the others' roles as preferred by P, disagreements of this nature may only arise in more extreme cases – in which professionals indicate that they would pursue legal avenues if necessary. Nonetheless, my point against rotten medical compromise stands as even if very few they remain unjustifiable.

Despite my case against rotten medical compromise, there remains the question of institutional pressure. Many healthcare professionals spoke of complying with the demands of family members at the instruction of their hospital's legal team (or based on the anticipated instruction), ultimately taking it out of their control. One might suggest, therefore, that the healthcare professional cannot be deemed the compromising party as they are, in effect, acting out of necessity.⁷³⁹ Margalit usefully explores this too, suggesting that acting out of necessity in this manner constitutes coercion: 'coercion as a condition in which, being left with no reasonable alternatives, we do, against our better judgment, what others want us to do'.⁷⁴⁰ Coercion cannot be considered compromise due to the conditions in which it plays out; the professional may want to resist the demands of the family, but is rendered unable to reasonably do so by the instructions of their employer. These eventualities are interesting given the perception of several consultees that professionals are very much part of a system, such that they do not make this

⁷³⁹ A similar feeling of necessity may arise out of fear of the legal system as was apparent in the views of several professionals.

⁷⁴⁰ Margalit (n727) 91.

distinction that enables conflict between professionals and their employers; one commented that '[t]he NHS is a big company. [...] You're not winning against the NHS' (C06).

Where there is such institutional pressure in the direction of rotten medical compromise, there is a clear need for change at a level higher than the individual professional (or even the multidisciplinary team). To ensure decisions are made in a way that can, if scrutinised, be said to be in P's Best Interests, professionals must be supported by their employer to do so.⁷⁴¹ The MCA 2005 vests Best Interests decision-making power in P's doctor, so that doctor must be able to say that they endorse any decision they make. That is not to say that a hospital ought to unquestioningly back its doctors when they oppose the view of P's family. There will be situations when the family's perspective is valid, and the professional will be in the wrong. However, this simply suggests a need for the hospital to consider both sides rather than immediately aligning with family to prevent legal proceedings.

Rotten medical compromise, then, is something to be avoided. Out of recognition of P's continued preferences as distinct from capacity, a decision made on the basis of avoiding conflict with the family cannot be defensible in any but the most trivial of decisions – certainly not that of dialysis. To do so is to instrumentalise P rather than centre them in questions about their own care. There is something to be said for a professional also treating the family, particularly where P lacks decision-making capacity, but this should not extend to undermining P's own Best Interests.

RECOMMENDATION

Professionals should avoid pursuing a course of action requested by P's family (or other consultees) where they are confident that it is not in P's Best Interests. To support professionals to do this, hospital legal teams should uphold the MCA 2005's allocation of roles in Best Interests decisions and, where appropriate, support professionals to decline the requests of family members (or other consultees).

⁷⁴¹ One may here question whether, in the absence of such support, it would ever be appropriate for professionals to resist their employer in favour of P's Best Interests. This is beyond the scope of my discussion here but is an interesting point for a future ponder.

6.2.5 Second and independent opinions

Much of what I have discussed so far is more sympathetic towards the views of professionals and their role in making Best Interests decisions. This largely comes down to the compelling point of emotional investment and how this might affect the ability of those close to P to stand back and make an overarching assessment of P's Best Interests. A desire not to lose a loved one was felt by professionals to lead consultees to push for dialysis in cases where the care team felt it was inappropriate. Whilst many consultees spoke of the importance of them putting forward P's preferences and not their own, there was still a strong sense that keeping their loved one alive was the overriding goal. This is something widely acknowledged in the literature, where it is suggested that family members tend towards a life-sustaining view even if that does not align with what the patient would have decided.⁷⁴²

However, it must also be acknowledged that professionals do not come at decisions wholly objectively. In addition to bringing their own values, many spoke fondly of their positive relationships with patients over many years and a sense of attachment. Whilst they generally felt that this did not interfere with their ability to make a Best Interests decision, the possibility of it doing so must be recognised. After all, consultees did not feel that they were being guided by their personal desire to keep P alive, which professionals ascribed to consultees struggling to step back. So, as important as it is to avoid a consultee's desire not to lose their loved one influence a decision, we should also be cautious of a professional's long-term caring relationship with P having sway. Certainly, there are benefits to this relationship, as already discussed (*see* 5.1.8). But if it starts to interfere with how P's Best Interests are viewed then we again come back to the risk of side-lining P's preferences.

One approach to mitigating this, which was touched on by some professionals, is involving a colleague for a second opinion. Specifically, a colleague who has not been involved in caring for P – an outsider of sorts, who will not have the long-term caring relationship. Professionals spoke about this as uncommon, with some suggesting it may be appropriate for it to become a more integral part of the

⁷⁴² Keating *et al.* (n394); Pruchno *et al.* (n394).

decision-making process. Indeed, GMC guidance on resolving disagreements suggests consultation with colleagues.⁷⁴³ There are, however, many issues with such an approach. If a professional seeks a second opinion for their own benefit, in that they have identified something like an attachment to the patient that could cloud their judgement, it may be helpful. The professional who is genuinely open to what their colleague thinks can make good use of this approach. However, this may heighten tensions where there is already disagreement between the care team and P's family. Involvement of another professional may be perceived by the family as the first professional seeking support to resist the family's requests.⁷⁴⁴

Further, it risks being performative when the professional is confident in their perspective. That professional may, consciously or not, go to a colleague whose opinion they can reliably predict, choosing someone they know will agree with them. Whilst this may bolster the legal position of the professional in making a Best Interests decision the family disagree with, as they can evidence agreement with a colleague, it may worsen their relationship with the family. This certainly speaks to the view of one consultee who questioned the value of a second opinion from another hospital employee. They felt that someone whose salary is also paid by the NHS could not be independent in such a scenario. Regardless of how accurate these views are, the perception of a second opinion process by the family is the important point here. If the family perceives it as performative, it is somewhat meaningless either way. Recognising some of these issues but still feeling a second opinion to be a 'crucial part of the scrutiny' in complex decisions, Lady Black stressed in the case of *Re Y* that:

‘the clinician who provides the second opinion must (so far as reasonably practical in the circumstances of the case) be external to the organisation caring for the patient, and is

⁷⁴³ General Medical Council (n33) at para 92.

⁷⁴⁴ In *Haastrup* – which, it must be acknowledged, is a case concerning paediatric treatment decision making – a family member sought their own expert, only to perceive collusion where that expert agreed with the treating professionals. *King's College Hospital NHS Foundation Trust v Thomas, Haastrup, and Haastrup* [2018] EWHC 127(Fam). Perhaps, then, it is about the second opinion provided as much as the perceived independence of the individual providing it. See Austin L, Huxtable R. 2019. 'Resolving disagreements about the care of critically ill children: evaluating existing processes and setting the research agenda'. In Goold I, Herring J, Auckland C (eds.). *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Gard*. Oxford: Hart Publishing.

expected to carry out his or her own examination of the patient, consider and evaluate the medical records, review information about the patient's best interests, and make his or her own judgement as to whether the decision [...] is in the [B]est [I]nterests of the patient. Thus the interests of patients and their families are safeguarded, as far as possible, against errors in diagnosis and evaluation, premature decisions, and local variations in practice'.⁷⁴⁵

However, it remains that the family may still perceive the professional providing a second opinion as an "insider", regardless of their actual status, and perception is a significant part of the issue.

One must also be conscious of the power dynamics at play in this environment. Again, a second opinion can very easily come across as two professionals "ganging up" on the family to push through a decision, even where the second opinion is sought from outside the trust. The family may already feel vulnerable where they perceive their situation as fighting for their loved one's life, which could be worsened by the increased power imbalance created by the involvement of another professional.

Given these concerns, I suggest the practice of second opinions from colleagues to be of very limited use in these complex decisions – particularly when instigated by the professional. It risks being insufficiently impartial, both in perception and reality, and may well do more harm than good to an already strained relationship between professional and family.

Perhaps, then, there is a need for an independent, non-clinical party to be involved in such situations. Not necessarily to take up the decision-making role, but to provide an impartial opinion. There remains a possibility that anyone brought in who agrees with the professional will be viewed by the family as lacking such impartiality, but likely less so than with the professional's own colleague. Similarly, the professional may take issue with an impartial view that goes against their opinion, perhaps questioning their qualification for involvement – certainly, the view of IMCAs amongst professionals interviewed was not positive. Nonetheless, an impartial party can consider both sides of the

⁷⁴⁵ *An NHS Trust and others v Y and another* [2018] UKSC 46, at para 124. This case concerned provision of CANH, which represents a suitable enough comparator for my purposes.

disagreement absent any emotional attachment to P and provide a view as to the appropriate way forward. Where there is no one suitable to act as a consultee for a Best Interests decision, an IMCA will be appointed to represent P. The intention is to fill the role of consultee – albeit in a slightly different way. It seems that it may also be appropriate for an IMCA, or similar, to be involved where there *is* an appropriate consultee but there is disagreement as to P’s Best Interests. I will hereafter refer to this IMCA-like role in instances where there is a consultee as “advocate” for the avoidance of confusion.⁷⁴⁶

Certain shortcomings of the current IMCA system must be highlighted as, for my purposes especially, they necessitate change. It seems reasonable to say that two key pieces of information in making a Best Interests decision are: (1) an indication of P’s preferences, and (2) an understanding of the care pathways available and what they entail. It seems similarly reasonable to say that an IMCA possesses neither. Whilst they can discuss with relevant people in each case to develop some level of awareness, they cannot fully understand these elements. So, an advocate (where there is a consultee) could be making a judgement on whether dialysis is appropriate with limited understanding of dialysis and limited understanding of P, which raises the question as to how seriously any recommendation should be taken.

On the matter of P’s preferences, we must reconcile ourselves with the fact an advocate would only ever possess a basic understanding of this, developed at the time they are brought into the situation. On the matter of understanding the care pathways available and what they entail, however, it is certainly possible to improve things. Under the current IMCA system, such knowledge is precluded by the fact an IMCA could be called to any decision in any specialty. To develop the breadth of knowledge this would require is a substantial undertaking that is not necessary. Rather, by adapting the system to introduce specialist advocates, the scope of necessary knowledge is significantly reduced. One could be a renal advocate, thereby developing a good understanding of the different dialysis modalities and conservative management.⁷⁴⁷ This would not have to be precise medical knowledge – I am not

⁷⁴⁶ One may, at this point, be thinking that this is a role already fulfilled by a clinical ethics committee. However, for reasons which I will come to shortly, I do not consider the involvement of a clinical ethics committee to be an appropriate response in these circumstances.

⁷⁴⁷ And, of course, the other aspects of renal care that are not substantially included in this thesis.

suggesting this is a role for someone with a healthcare background – but a broad understanding of what the different options entail and how they may affect a patient. They may spend time engaging with patients receiving different care options to develop this understanding, and their knowledge would build organically as they are involved in more decisions with some similar elements. This developed knowledge is not akin to *medical* expertise but is a form of expertise that could be hugely useful in aiding the specialist advocate role.

A specialist advocate would prove more useful in a Best Interests decision as they can still introduce some impartiality whilst understanding what is being considered. This understanding is, from the perspective of professionals, vital to the decision. Just as professionals expressed concern that consultees do not always comprehend what dialysis entails, so would the lack of this knowledge in an advocate be problematic.

One possible concern with this proposal is that the family may perceive a specialist advocate as another healthcare professional, viewing the process no differently to a second opinion. This would entail the same issues outlined above around the process appearing tokenistic and worsening the relationship. Whilst the risk of this cannot be entirely removed, appropriate presentation can help. In practical terms, a specialist advocate would have to cover a larger geographical area for there to be sufficient need for their role. This may help slightly allay consultee concerns about partiality as the specialist advocate would be able to explain that they work across the region/country and are not embedded in that particular trust. An advocate that does not specialise and works within a small geographical area may easily be perceived as one of the care team as they may be more familiar with professionals and the particular hospital's functioning. Given the importance of perception to the success of this quasi-mediative role, the advocate presenting as an "outsider" in this way can help reassure family members of impartiality.

The use of a specialist advocate, then, is another means of assisting where there is conflict between the care team and the family. Rather than bringing in other doctors, which may worsen the relationship with the family, an impartial third party can assess the situation and provide an opinion that advocates for P's Best Interests *from a position of understanding the options*. This may help protect P's

preferences from being undermined by emotional attachment guiding decisions whilst simultaneously letting the family know that the decision is being taken seriously and the professional recognises that they may be wrong. Being trained as a specialist renal advocate would also address the concern expressed by some professionals that IMCAs under the current system lack sufficient knowledge of the care options they are weighing up. With decision-making authority remaining with the professional and simply being informed by the specialist advocate's opinion, this approach – much like the existing IMCA system – does not run counter to the requirements of the MCA 2005.

RECOMMENDATION

Second opinions within the care team should be avoided, particularly at the instigation of a member of the care team. Instead, a system of specialist advocates should be established, enabling professionals to involve a specialist renal advocate in the event of an impasse between the care team and P's family.

I noted earlier that some may feel the role of the specialist advocate I have outlined could be undertaken by a clinical ethics committee. In some cases, such a committee may indeed perform this sort of role. However, in these delicate situations, the involvement of a clinical ethics committee does not seem to me a helpful option. Huxtable has suggested that '[p]rovided that its members reflect a diversity of moral world views [...] then a committee can clearly help to split the difference on fraught moral matters'.⁷⁴⁸ As noted in Chapter 3, some scholars similarly feel this to be a suitable approach in questions of dialysis initiation.⁷⁴⁹ However, at least in the context I am concerned with, I disagree. Whilst a committee may certainly be able to provide an opinion, its acceptance by those involved in the conflict is a different matter. For example, the very mention of "committee" may be perceived by the family as some sort of high-level, institutional process whereby the decision is being taken out of their hands entirely to be decided in a back office. That is not to say that the family would be wholly excluded in this way, but they may feel this way, and in such challenging decisions perception is as important as reality. Further, with it being a trust clinical ethics committee, the issue may again arise as to thinking

⁷⁴⁸ Huxtable R. 2007. *Euthanasia, ethics and the law: from conflict to compromise*. Oxford: Routledge-Cavendish, 155.

⁷⁴⁹ Feely *et al.* (n391); Conneen *et al.* (n394).

it will automatically side with the care team. As with the perception family may have of a second medical opinion, accuracy is irrelevant. If family feel that the system is working against them, conflict resolution is unlikely to ensue.

Whilst I have suggested a system of specialist advocates as a preferred approach to this issue, my dismissal of alternatives is primarily based on presumptions about how they may unfold. It may be that families would not respond negatively to the involvement of a clinical ethics committee in the way I have suggested and that there is no need for a system of specialist advocates. It seems to me that a specialist advocate is the most appropriate way forward, but this was not directly explored in the empirical phase of this project, and I recognise the possibility that another option may prove more appropriate. This is something to be addressed by future research; there is a need for a particular party to fulfil this role of impartial advocate, but precisely what form that party should take is a somewhat open question. Relatedly, future research can consider the cost-effectiveness of this role and different variations of it, as an appropriate wide reflective equilibrium necessitates such broad considerations. For now, it seems feasible that these recommendations may prevent some decisions ending up in the Court of Protection, thereby saving significant legal costs – but this is, of course, logical conjecture.

6.3 Summary

This chapter has sought to bring together the various moving parts of this thesis and progress towards a coherent position that entails recommendations. A running thread through all of the five discussions is that of centring P in any Best Interests decision. Indeed, I have strongly framed P's ascertainable preferences as a vital starting point in any such decision, only to be set aside where there is good reason for doing so. This ultimately comes down to a desire to respect P's autonomy, and the pursuit of P's preferences being the closest we can reasonably get to that; and, in doing so, avoid falling into an overly paternalistic system. Secondary to this respect for P's preferences is an associated practical requirement for P's involvement in any Best Interests decision – the absence of decision-making capacity ought not to be taken as a total inability to engage in the process.

Further, I have considered the roles of various parties in Best Interests decisions and how they might contribute to such an approach. Whilst duly acknowledging the important role those close to P play in the process, I have ultimately advanced the position that they should not necessarily be afforded the deciding role that consultee participants leaned towards – thus siding with the existing framing of their role within the MCA 2005. This is primarily out of a concern voiced by professionals, and corroborated by the literature, that consultees may struggle to present P's preferences in a way that is not deeply entangled with their own. I have argued that professionals should genuinely involve P's family in a decision but, where necessary, stand their ground in furthering P's Best Interests. Compromise purely for the purposes of avoiding conflict with family is not justifiable and professionals should be supported at an institutional level in resisting this.

Nonetheless, conflict is very much acknowledged as somewhat unavoidable in some situations. Finally, then, I explored the role of second and independent opinions in trying to manage instances of conflict. Recognising the shortcomings of a second *medical* opinion model, I have proposed something akin to the IMCA system but for use where there is disagreement between the care team and P's family. This specialist advocate can contribute an impartial opinion to help ease tensions and hopefully move towards an accepted Best Interests decisions without the need for things to progress to legal action.

If there is one obvious critique of the recommendations provided in this chapter, it is that they are almost all marginal-at-best changes. I have made no sweeping claims about the need for legislative change or a total overhaul of the Best Interests system. There are ultimately two reasons for this. First, the process of reflective equilibrium did not lead me to such conclusions. The coherent position reached, having taken due account of various conflicting perspectives, just so happens to entail a series of small shifts in the way we think about and execute the current Best Interests process. Second, I have been conscious throughout this thesis to remain realistic. I have no doubt that with substantial financial investment, Best Interests decisions could be improved. Certainly not all of them, but many could be bettered by professionals having far more time to spend with patients and families and increased numbers of specialist professionals who dedicate their time to these complicated decisions. However, the reality is that to recommend such things would be somewhat meaningless – the NHS is chronically

underfunded, and convincing commissioners that they should invest in Best Interests decisions over priorities such as building hospital capacity is a fool's errand. Many of my recommendations do entail marginal increases in resources. For example, additional discussions with patients throughout their care journey. However, I believe I have kept the extent of these recommendations within the realms of reality, such that professionals could make some movement in this direction within current confines.

Perhaps the boldest recommendation made – and that which would entail more resources – is the call for a system of specialist advocates to be engaged where there is significant disagreement between the care team and P's family. I must acknowledge that such a recommendation coming to fruition is hugely optimistic, even if there were widespread support for it. Nonetheless, in pursuit of a more ethically defensible approach to Best Interests decisions that recognises the reality of possible conflict, I stand by this recommendation as important even if my most idealistic.

Conclusion

This thesis has explored the question: “how should Best Interests decisions concerning end-stage kidney disease care for adults be made?”. In doing so, it has sought to provide some insight into how these difficult decisions are made and suggest how things may be improved not only for the benefit of P, but for all those involved in such decisions. I in no way suggest that I have “solved” Best Interests – not even just in the context of kidney care. Nonetheless, my findings and resulting discussion do offer recommendations for how certain (mostly relatively minor) changes to how such decisions are made might be beneficial. In such an underexplored area, this has the potential to make an important contribution, even if just in sparking further discussion of these issues.

This final chapter serves several purposes. First, I summarise the chapters that precede it, reiterating the key findings of this thesis. Second, I briefly outline my recommendations for practice and research, demonstrating the original contribution this thesis makes to the field. Third, I acknowledge certain limitations of this project and what they mean for my recommendations. Finally, I reflect on the process of conducting this study as my doctoral research and, importantly, what I have learned from it to apply to my future research.

7.1 Thesis summary

Chapter 1 introduced the key concepts and problems that pertain to this thesis. Notably, mental capacity, Best Interests, and ESKD and its care pathways. In providing a preliminary exploration of these issues, this chapter highlighted the importance of this project, demonstrating its potential to improve the quality of care for a particular group of patients by beginning to fill a notable gap in the literature.

My methodology was outlined in Chapter 2. Importantly, given the nature of this project, I explored the relationship between bioethics and law, before considering recent developments in

empirical bioethics. The Bristol Framework, reflective equilibrium, and translational bioethics were explained as the methodological commitments of this project. Finally, I noted the relevance and – to my view – importance of critical disability theory to a project such as this, which became a background consideration throughout.

In Chapter 3, I reported on a scoping review conducted to more systematically gather existing perspectives on the research question within the literature. This review was broadly conceived to include international literature. Whilst my underlying focus in this project is the English law context, the more abstract medical and ethical discussions around decision making are applicable even if authored in and concerning other jurisdictions. Importantly, the findings of this review informed the initial development of the topic guides that were used in my empirical study.

Moving towards the central empirical phase of the project, Chapter 4 detailed the empirical methods employed to gather the views and experiences of stakeholders. Highlighting why qualitative research was most appropriate for the study objectives, I decided on semi-structured interviews with stakeholders: nephrologists; renal nurses; patients;⁷⁵⁰ and consultees. This chapter also described my initial intention to conduct an ethnography and the reasons why this was unable to proceed. Finally, I detailed my data analysis approach using Braun and Clarke’s reflexive thematic analysis.

Following the empirical study as outlined in Chapter 4, Chapter 5 reported the findings from stakeholder interviews. Nephrologists and renal nurses were grouped as “healthcare professionals” during analysis, whereas consultees were kept separate due to the significantly different perspective from which they engaged in decisions. Amongst healthcare professionals, nine themes were generated: Best Interests and quality of life; prioritising patient preferences; family involvement; collaborative decision making; the path of least resistance; dialysis trials as conflict resolution; communication and culture; attachment to patient and clouded judgement; and making the “right” decision. With some crossover with healthcare professionals, but also divergence, five themes were generated from consultee

⁷⁵⁰ As already noted, the patient group was unfortunately dropped in the later stages of the project due to recruitment difficulties.

interviews: quality of life and the acceptance of mortality; prioritising patient preferences; family involvement; opposition to the Best Interests approach; and importance of communication.

In Chapter 6 – preceding this concluding chapter – I brought together the different strands of this project in a process of reflective equilibrium. Points of agreement between healthcare professionals and consultees were acknowledged, as well as points on which they were polarised. Five key discussions were presented, incorporating the range of views and experiences captured through stakeholder interviews: respecting P's autonomy; ascertaining P's preferences; family involvement; rotten (medical) compromise; and second and independent opinions. These represented jumping off points for discussion which was then complemented by revisiting the literature explored in Chapters 1 and 2. Finally, I moved towards a set of coherent positions on these discussions and drew recommendations – though, importantly, highlighting where such positions and recommendations are tentative pending further research.

7.2 Recommendations for practice

The process of Best Interests decision making in practice is unavoidably complex. Even where all parties are agreed on the course of action that represents P's Best Interests, the very fact that P is unable to make a decision about their own care can leave some sense of unease in a community that so strongly favours individual autonomy. This was found to create a risk of overly paternalistic decisions as something of a “better safe than sorry” approach.

Further, as was clear from the experiences of many participants, stakeholders generally have certain expectations of what others involved in decisions will do. These expectations may or may not marry with what those other stakeholders see their own role as.

Owing to these, and other, factors, it was found that there is often the possibility of conflict between stakeholders. Certainly, the running thread across participant groups was Best Interests decisions being the subject of disagreements between various stakeholders, to the extent that the

possibility of legal action sometimes arises. For the most part, my recommendations for practice focus on alleviating some of the pressures, misconceptions, and confusions that can lead to such conflict. They are mostly those explicitly recommended in Chapter 6, with some more general suggestions that were more so implied previously.

- 1) Continued, active efforts should be made by professionals to understand P's preferences. This should begin when P comes under the care of the renal team – even if P has no cognitive impairment at that time – and revisited regularly. The extent of efforts to ascertain P's preferences may be variable in line with the extent of any cognitive impairment. Preferences recorded may be general or specific.
- 2) P should be consulted at the earliest opportunity regarding the role they would like their family (or other consultees) to have in any future decision about their care should they be deemed to lack decision-making capacity. The option of LPA-HW should be highlighted where P has sufficient decision-making capacity to instigate this. In any case, P's preferences regarding the role of their family (or other consultees) in future decisions should be recorded and taken into consideration in any future Best Interests decision. This discussion should be revisited periodically for confirmation.
- 3) Provided they are within the remit of what is clinically indicated, professionals should treat any ascertainable preferences of P as a starting point in any Best Interests decision. These preferences should be viewed as guiding, being overridden only where there is reasonable doubt over their reliability. Where necessary, past preferences can similarly be viewed as guiding, providing there is some small indication that P would still endorse them.
- 4) Professionals should avoid pursuing a course of action requested by P's family (or other consultees) where they are confident that it is not in P's Best Interests. To support professionals to do this, hospital legal teams should uphold the MCA 2005's allocation of roles in Best Interests decisions and, where appropriate, support professionals to resist the demands of family members (or other consultees).

- 5) Second opinions within the care team should be avoided, particularly at the instigation of a member of the care team. Instead, a system of specialist advocates should be established, enabling professionals to involve a specialist renal advocate in the event of an impasse between the care team and P's family.
- 6) There should be clear and consistent communication from the care team with P and any other stakeholders. This should include information as to the roles different stakeholders have in a Best Interests decision to avoid misconceptions during future discussions. Where appropriate, additional efforts should be made to educate P's consultees about the process ahead of a decision being made to prevent a later feeling of disenfranchisement.
- 7) In all interactions – particularly in relation to some of the advance discussions mentioned in other recommendations above – there should be clear record keeping. This allows all stakeholders to be clear on what has been previously discussed and agreed. Further, should a case result in a complaint and/or Court of Protection hearing, these records will provide similar clarity.

These recommendations for practice could largely be introduced through Best Interests guidance and training that is specifically tailored to the kidney care context. This could go beyond the generic mental capacity training that many HCPs currently undergo, instead being built around scenarios that are more commonly faced in relation to patients with CKD. Any such training would, I suggest, need to be developed through a process of coproduction – not only involving HCPs, but also patients and consultees.⁷⁵¹

⁷⁵¹ After initial submission of this thesis, but before final upload, I was awarded funding by Kidney Research UK to develop new training and associated resources to improve Best Interests decision making concerning CKD in England and Wales. This work will be conducted with my co-investigators Prof Fergus Caskey, Ms Amy Verinder, and Dr Harleen Kaur Johal.

7.3 Recommendations for research

Despite having arrived at the above recommendations for practice, there remain certain unknowns that relate directly to some of these recommendations. In a sense, then, I must caveat them as potentially subject to revision. Whilst I have confidence in them at present, I am open to supplemental evidence coming to light that suggests they are in need of revision (an ongoing process of reflective equilibrium, if you will). In particular, there are several areas where I suggest research is most urgently needed to complement what this study has produced.

- 1) Whilst I have highlighted the need for some impartial party to become involved where there is staunch disagreement between P's care team and family, my favouring of a specialist renal advocate taking on this role may prove ill-suited. There is a need for further research to explore the precise form this impartial party should take, whether that be the specialist renal advocate, an ethics committee of some form, or something entirely different.
- 2) Relatedly, there is a need for work in health economics to explore the cost-effectiveness of different aspects of my recommendations. In particular, the introduction of a system of specialist renal advocates which would entail significant costs. If such a system can result in the avoidance of costly court cases then the investment may be justified, but this does need to be assessed. It is important in a wide reflective equilibrium that matters such as resource allocation are accounted for in higher, system-level decisions such as this, as costs ultimately are a key factor in practical decisions.
- 3) Some of my recommendations for practice could prove hugely cumbersome if a large number of patients fall within their remit. For example, discussions around future dialysis preferences, LPA-HW, and my proposed model of quasi-LPA-HW for those who end up never reaching kidney failure may be seen as unnecessary and a waste of resources. Research is needed to

explore the role of prediction models in narrowing down the scope of these recommendations, building on the uptake of the Kidney Failure Risk Equation.

7.4 Limitations

Whilst the findings of this study and resulting recommendations represent a significant contribution to the field, there are limitations that must be recognised. For the most part, these limitations relate to the empirical work detailed in Chapters 4 and 5,⁷⁵² but this invariably affects the discussion that followed in Chapter 6. These limitations do not profoundly affect the defensibility of this work but are nonetheless worthy of note.

First is the sample of professionals. My sample is inevitably skewed by various factors relating to who would be willing to participate. Professionals who agreed to participate may have been those more conscious of difficulties with the use of the MCA 2005 in decisions about dialysis – possibly through reflection on their personal experience – which would mean I have missed certain perspectives of those who are perfectly confident in their approach to Best Interests. Similarly, professionals may have been more willing to participate if they see CKM as a care pathway deserving of equal consideration alongside dialysis, thereby not falling within the group characterised within the literature as assuming dialysis to be the obvious choice.

With consultees, too, those who agreed to participate may represent those with certain types of experience of a Best Interests decision – i.e., at either end of the spectrum. Certainly, most consultees who participated were either largely complimentary or largely critical of their experience. My consultee sample was also affected by the choices of professionals who assisted with recruitment. For example, they may not have wanted to suggest a consultee they anticipated would be critical of the care that professional provided. Of course, some consultees were highly critical, suggesting this skew was not significantly the case, but it may still be applicable.

⁷⁵² There are also limitations contained to the scoping review reported in Chapter 3, which are outlined in that chapter (*see* 3.4.1).

There is also the fact that I ended up recruiting from only two renal centres. It may be that practice varies hugely across the country and that this did not come through in the data due to the recruitment pathways. Whilst I have framed them as limitations, these matters of sampling and recruitment in no way represent fatal flaws in this research. Generalisation is not the goal of qualitative research, but it is still important to acknowledge that my findings represent only the views and experiences of (a select group of) professionals and consultees at just two centres. The data remain valuable in providing a rich insight into the views and experiences of relevant stakeholders. These views and experiences need not be universal to be considered worthy of attention, particularly where care provision is intended to be individualised.

I consider the most significant limitation of this study to be the failure to recruit patients. It was my intention from the beginning to do so, such that necessary research ethics approval was obtained, but recruitment difficulties meant that my final sample included none. These difficulties initially stemmed from my recruitment protocol for this participant group, in that I was reliant wholly on HCPs suggesting patients who may be suitable. Few suggestions were forthcoming, in part because some HCPs seemed reluctant to put forward a patient they perceived as vulnerable. At the point at which the shortcomings of this approach were apparent, I amended my protocol to allow recruitment through patient organisations, but this was similarly unsuccessful. With the benefit of hindsight, hitting my original recruitment target for this group would have required a far larger number of recruitment sites with significant buy-in from at least one HCP at each to help facilitate recruitment. I believe strongly in the importance of patients having a voice in research that ultimately concerns them and am reticent to put significant weight on conclusions drawn without appropriate representation of this perspective. However, I did have to operate within the constraints – both temporal and budgetary – of a PhD, which eventually resulted in this participant group being excluded.

A final limitation is that I was unable to present my proposed recommendations to stakeholders. Whilst I consider my recommendations to be reasonable and rooted in the data, the perspectives of relevant stakeholders as to their strength and suitability are still important. For this reason, I had intended to hold stakeholder workshops towards the end of my PhD. These would have been an

opportunity to present my findings before discussing my recommendations, enabling me to revise them as appropriate in light of feedback. Given the knock-on effect of recruitment delays, I did not have sufficient time to conduct these workshops.⁷⁵³ As such, this represents an opportunity for follow-on work.⁷⁵⁴

7.5 Reflections

As much as it is also about producing good research, a PhD is a learning process. This was my first time conducting qualitative research and, in hindsight, I would absolutely have done certain things differently. However, importantly, these things are more about making things less challenging for myself throughout the project rather than hugely affecting the relevance of conclusions reached and recommendations proposed. Here I reflect on a few such things.

Many of these learnings concern the process of recruitment and data generation, including planning for this in the early stages of a project. Having such a small number of study sites made recruiting enough participants hugely challenging. This was especially true of the patient group, as the inclusion criteria were necessarily very precise. Having a larger number of recruitment sites would have allowed me to “play the odds” and more easily hit recruitment targets. In this particular project, it may also have meant I would not have had to drop the patient group – something I was hugely reluctant to do.

As well as recruitment sites, I could also have refined the inclusion criteria for participants further. In the consultee group, it ended up that several participants actually had LPA-HW relevant to the decision. As such, the decisions were not technically Best Interests decisions. Whilst these participants were not strictly ineligible on this basis, it may have helped with recruitment if I had

⁷⁵³ See COVID-19 Statement.

⁷⁵⁴ To an extent, these stakeholder workshops will be incorporated into a follow-on project I am currently carrying out, as earlier mentioned.

actively sought out such individuals, thus increasing the pool. Initially, I did not consider their perspectives relevant, but having ended up interviewing those with LPA-HW it became apparent that their views and experiences on decisions made on behalf of someone lacking decision-making capacity made a huge contribution to this project. They, in a sense, represent the other side; decisions that have not had to proceed to Best Interests. Given that several had LPA-HW following past experiences of Best Interests decisions, their having experienced both processes enabled them to reflect on the Best Interests system from an entirely different perspective that would have been absent if I had excluded them in line with my original intention.

To some degree, these learning points all come down to planning. Had I spent more time thinking through the full journey of the project at the beginning – i.e., before applying for research ethics approvals – I may have avoided some of these later pitfalls. Of course, there were time restraints as with all such projects, but even delaying a few weeks and engaging in more informal discussions with stakeholders may have resulted in a stronger protocol. Nonetheless, the iterative nature of research is such that no amount of planning could anticipate all possible eventualities and accepting that reality is a notable takeaway from my doctoral studies.

As noted above, these hiccups do not diminish the contribution of this thesis. Rather, they are reflections on my own development as a researcher that will enable me to go into future projects better prepared.

7.6 Concluding remarks

Amongst the extensive discussion throughout this thesis and various recommendations made, my conclusion boils down to three key points. First, the central importance of P-centricity in any Best Interests decision. Across all participant groups there was a strong desire to respect P's preferences in making a decision. This is complemented by several positions in the literature and, to a somewhat debatable degree, the MCA 2005. Whilst Best Interests is not a system of substituted judgement – nor

do I suggest that it should be – it remains important that P’s autonomy is duly respected in the form of attention to any ascertainable preferences. The difficulty comes in how those preferences can be understood and how reliable they are considered to be; the lack of decision-making capacity necessarily means that P is not recognised as communicating a demonstrably informed and reasoned view, which may cause some to take any expressed preference with a pinch of salt. My recommendations around early conversations and planning ahead seek to support respect for P’s preferences by providing stakeholders with greater confidence in them, whilst at the same time acknowledging the reality of clinical pressures and practicalities.

Second, and very much building on the first, is the need for clear communication in all interactions. Interview participants recounted experiences of disagreement between stakeholders in Best Interests decisions which, in some cases, was suggested to be attributable to misunderstandings over what a Best Interests decision is (in law). For example, P’s family not realising that it is the professional who makes the final decision and the role of a consultee is to contribute. Whilst stakeholders may not always be happy with how things are progressing, clear communication at least removes one potential source of conflict and makes it possible for everyone to be on the same page. This communication may even extend to additional efforts in educating consultees as to their role in a Best Interests decision, again focused on the prevention of misunderstandings.

Third, and final, is the need for professionals to be supported to act in what they consider to be P’s Best Interests where conflict arises. Following the path of least resistance as described in Chapters 5 and 6 is hugely problematic in using P as a means to maintaining a good relationship with P’s family. Nonetheless, it appears to happen, in part because professionals do not always feel that, in reality, they can do anything else. Disagreements are inevitable at times in such complex and emotionally charged decisions, and the importance of a positive, collaborative process has its limits where the result is potential harm to P. In more extreme cases, professionals may have to “pull rank”, so to speak, and explain to P’s consultees that a decision they oppose is being made. It is ultimately P that professionals owe a duty of care to, and they must be supported by their colleagues and employer to pursue P’s Best Interests in difficult situations as required by the MCA 2005.

Importantly, none of these suggestions require legislative change. They are predominantly small changes to practice that could be instigated by individual professionals or renal units. The most substantial recommendation is the establishment of a system of specialist renal advocates. Again, this would not require legislative change, but would necessitate country-wide collaboration and the support of professional bodies – not to mention considerable funding. This would require significant buy-in and so is rather more ambitious, but the smaller recommendations are there for evaluation.

Whilst Best Interests decisions in the context of kidney care will continue to be challenging at times, with disagreements never entirely avoidable, there are small changes that can be made to improve the care of these patients. This project makes a significant and novel contribution to our understanding of a previously underexplored area, recommending means of improving the quality of Best Interests decisions whilst identifying areas in need of future research.

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Appendix A: Ethno-immersion

In Chapter 2, I outlined the approach of ethno-immersion I carried out throughout my PhD to build a better understanding of the reality of clinical practice in the area with which my research is concerned. Coming from a non-clinical background myself and recognising the limitations of an overreliance on the picture painted by the literature, this was vitally important in enabling a more nuanced and contextualised understanding of the data generated through stakeholder interviews.

Here, I will provide an overview of the ethno-immersive activities I undertook to build this understanding and reflect on the process. Some of the observations I describe took place at just one of my study sites, others took place at both. I will discuss all activities in the plural for the avoidance of identification of others where I only did something once.

Importantly, I began my ethno-immersive experience very early on in the project – and certainly before the first stakeholder interview. I wanted to ensure some level of contextual understanding before any data generation to help me respond to participants and further explore their views and experiences. In the early stages, I shadowed healthcare professionals at outpatient ESKD clinics and joined inpatient ward rounds. My intention was very much to ensure breadth of experience – observing interactions with patients at varying stages of CKD and undergoing different care pathways, as well as those with more acute kidney problems. These observations enabled me to see how discussions about care took place between healthcare professionals, patients, and patients' family, friends, and carers. For example, the way certain treatment options were framed and the varying levels of deference to professionals shown. Ahead of the ward rounds, I also attended handover meetings, giving me an insight into some of the discussions that take place about patients and their care between healthcare professionals. These were useful background before joining the ward rounds as I could match up discussions from the handover meetings with discussions with those patients.

I also spent time on outpatient dialysis wards, seeing patients arrive for their regular sessions. Having previously read about how gruelling dialysis can be, it was beneficial to see for myself how

patients were during sessions – some as the literature would suggest, others more lively. It was during these visits that I had the most informal chats, which provided useful insights. Some of these were with patients and those sitting with them during their dialysis sessions, talking about their day and their experience of dialysis. Others were conversations with various healthcare professionals – consultants, renal trainees, foundation doctors, dialysis nurses, specialist nurses, etc. – about a variety of things (i.e., not only about the topic of my research, but about healthcare more generally). In some ways, these informal conversations helped in shaping my approach to stakeholder interviews. Both in flagging possible topics to raise and in giving me more experience of interacting with stakeholders when discussing their own views and experiences about sensitive topics.

Finally, in a less general setting, I observed both home visits to discuss care planning and Best Interests meetings held at the hospital. Home visits allowed me to see interactions with patients and their loved ones in their own environment – it was the healthcare professionals that were more so out of their comfort zone. Discussion of the finer details of living arrangements and how different care options might (not) fit well took place, and the healthcare professionals were able to chat more informally with patients and their loved ones with less time pressure (they still had to limit the length of the visit to some degree, but were not against the clock in the same way as outpatient clinics with a fixed schedule of appointments).

I had originally planned to conduct an ethnography of Best Interests meetings as part of the study, but when this became unfeasible, I instead took the opportunity to sit in on any that I could (too few to write an ethnography). This really allowed me to see the best interests process in action at its more formal culmination. The various other observations described involved informal discussions about what might be in a patient's best interests, but attending best interests meetings was a window into how conversations went at the point where a decision actually had to be made. Having read literature about what makes a "good" best interests decision – both in content and approach – it was useful to see how this aligned with reality.

Whilst my PhD study focuses on patients with cognitive impairments, my observations included patients with decision-making capacity whose consultations were to facilitate their own

decisions about their care. It was still useful to see this side of practice as it improved my understanding of how a patient's care journey might progress in the absence of cognitive impairment, allowing me to recognise differences in how interactions might be approached.

My ethno-immersive experience overall gave me a valuable insight into the reality of clinical practice around ESKD. Coming from a non-clinical background, this was invaluable. Whilst many of my interactions were rather brief, combined they were hugely useful to my understanding. Those I interacted with as part of this process were largely open and willing to let me observe things and ask questions. I was able to witness various power dynamics playing out and an array of approaches to interactions taken by healthcare professionals. I also met with a range of patients, both with and without cognitive impairments and with differing levels of knowledge surrounding their health.

Some of my observations also acted to challenge depictions from my background reading. For example, whereas some literature suggests that dialysis often exists as a default in practice regardless of the patient's situation, I saw rather more balanced discussions of options in many interactions. Seeing some of the perspectives from the literature challenged in this way helped me to set aside certain expectations ahead of stakeholder interviews, leaving me more open to a range of views and experiences.

Having undergone this process of ethno-immersion was also beneficial when it came to analysis of the data generated through stakeholder interviews. For example, the background understanding of practice I had developed resulted in points raised during interviews making more sense to me. In the absence of these observations, it is likely my analysis would have been rather more blunt and underdeveloped, reducing the practicability of resulting recommendations.

I stress again that my observations as part of ethno-immersion were not formal data generation exercises. They were purely for my own benefit in better understanding clinical practice in the area I was researching and, as such, I make no claims as to the generalisability or even accuracy of what I have described here.

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Appendix B: Participant Information Sheet – Healthcare Professional

| | |
|--|-------------------------------|
| Participant information sheet (HCP) | IRAS ID: 280705 |
|  | |
| The BIRD Study Participant Information Sheet | |
| <i>Why is this study being conducted?</i> | |
| <p>The purpose of this study is to understand how treatment decisions are made for patients with low kidney function who are unable to make the decisions themselves. This study is using interviews to understand the full process and to explore the experiences and views of those involved.</p> | |
| <i>What would taking part involve?</i> | |
| <p>Participation in the study would involve taking part in a single interview, which would last between 40 and 60 minutes. This interview would most likely take place at [name of hospital] at a time that suits you. It is possible for interviews to take place elsewhere if you would prefer, but the location would need to be quiet and reasonably private to ensure you feel comfortable talking about your experiences and views. You would be able to take a break at any point during the interview.</p> | |
| <i>Can I take part?</i> | |
| <p>You are eligible to take part if you are a healthcare worker in a renal unit who has been involved in a best interests decision concerning the initiation of dialysis or [conservative kidney management].</p> | |
| <i>Do I have to take part?</i> | |
| <p>No, you do not have to take part in the study. Taking part is entirely optional, and you do not have to provide a reason for choosing not to take part.</p> | |
| <i>What are the benefits of taking part?</i> | |
| <p>There are no significant material benefits to taking part in the study (aside from a small token of thanks). However, the opportunity to talk openly about your experiences of the treatment decision-making process may be something you will enjoy.</p> | |
| Best Interests in Renal Dialysis | v2.0 |
| | 7 th December 2020 |

Participant information sheet (HCP)

IRAS ID: 280705

What are the risks of taking part?

There are no obvious risks to taking part in the study. Taking part involves a single interview and you can decide what you are willing to talk about. However, it is possible that some topics that will be raised will upset you. If this happens, you can stop the interview at any point, and you will not have to continue or restart it.

If you are upset by anything that is discussed in the interview, you will be provided with contact details of organisations that will be able to help you.

What do I get for taking part?

As a token of thanks for taking part in the study, you will receive a £20 Love2shop voucher as a thank you for your time. You will also be reimbursed for any travel to and from the interview, so taking part will not cost you anything. You must keep any receipts and/or tickets from public transport and bring them with you to the interview, as you will need these to be reimbursed. [details of how to claim reimbursement will be provided].

What will be done with any information I give?

All data will be managed in line with GDPR (EU General Data Protection Regulation). Interviews will be audio recorded, and the recording will be used to produce a written record (transcript). You will not be referred to by name on this written record. Information you provide will be used for research purposes only, and words you use may be directly quoted in publications. Any use of your words will be anonymised.

All information you provide will be stored securely so that only the researchers on the study are able to access it. It will be stored for 5 years.

In the unlikely event that you say anything during the interview that causes the researchers to be concerned about your own immediate safety, or the safety of others (including malpractice), we may be obliged to break confidentiality and report this to the appropriate authorities. You will be told at the time if this happens.

How will information about me be used?

We will need to use information from you for this research project. This information will include your name and contact details. We will only use this information to ensure the research is being done properly or to contact you if needed.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Participant information sheet (HCP)

IRAS ID: 280705

We need to manage your information in specific ways for the research to be reliable. This means that you will be able to view a copy of your interview transcript if requested, but you will not be able to change it.

Where can I find out more about how my information is used?

You can find out more about how we use your information in several ways:

- Visit www.hra.nhs.uk/information-about-patients/
- Ask one of the research team
- Send an email to jordan.parsons@bristol.ac.uk
- Contact the University of Bristol's Data Protection Officer: [email]

What if I want to leave the study after starting?

You will be able to fully withdraw from the study until one week after the interview, and you will not have to provide a reason for doing so. If you withdraw from the study after the interview, all recordings and transcripts of your interview will be destroyed. After this week, the data will have been analysed and it will be impossible to remove it from the research.

Who has reviewed the study?

This study received a favourable opinion from the NHS Health Research Authority's London – Camberwell St Giles Research Ethics Committee on Tuesday 22nd December 2020. It was subsequently approved by the NHS Health Research Authority (REC reference: 20/LO/1233).

Who is organising and funding the research?

This research is being conducted by the University of Bristol. It is funded by the Wellcome Trust as part of the BABEL project (Balancing Best Interests in Healthcare Ethics and Law).

I would like to take part – what do I do now?

If you would like to take part, you should contact Jordan Parsons by telephone or email:

[jordan.parsons@bristol.ac.uk]

[mobile number]

Your eligibility has already been checked but will need to be confirmed with you. With your permission, you will then be entered into the study and a suitable date, time, and location for the interview will be discussed with you.

Participant information sheet (HCP)

IRAS ID: 280705

I would not like to take part – what do I do now?

If you would not like to take part, you do not have to do anything. A member of your clinical team may mention the study to you at some point, but you do not have to provide a reason for not wanting to take part.

What if there is a problem?

If you wish to make a complaint about anything to do with the study, you may contact either of the following:

Dr Jonathan Ives, Deputy Director, University of Bristol Centre for Ethics in Medicine

j.ives@bristol.ac.uk

University of Bristol Research Governance

research-governance@bristol.ac.uk

[North Bristol NHS Trust] Patient Advice and Liaison Service

[complaints@nbt.nhs.uk]

Thank you for reading this information.

Appendix C: Participant Information Sheet – Patient with Capacity

Participant information sheet (patient with decision making capacity)

IRAS ID: 280705



The BIRD Study Participant Information Sheet

Why is this study being conducted?

The purpose of this study is to understand how treatment decisions are made for patients with low kidney function who are unable to make the decisions themselves. This study is using interviews to understand the full process and to explore the experiences and views of those involved. We think it is important to find out about the experiences and views of everybody in the process, so are not only interviewing health care professionals.

What would taking part involve?

Participation in the study would involve taking part in a single interview in person, which would last between 40 and 60 minutes. This interview would most likely take place at [name of hospital] at a time that suits you. It is possible for interviews to take place elsewhere if you would prefer, but the location would need to be quiet and reasonably private to ensure you feel comfortable talking about your experiences and views. You would be able to take a break at any point during the interview.

Can I take part?

You are eligible to take part if you:

- Are attending kidney clinic, and are having or have had dialysis and [conservative care] treatment options explained to you; and
- Are unable to take on board all the information needed to make the decision to have dialysis or [conservative care] yourself.

Do I have to take part?

No, you do not have to take part in the study. Taking part is entirely optional, and you do not have to provide a reason for choosing not to take part.

Best Interests in Renal Dialysis

v2.0

7th December 2020

Participant information sheet (patient with decision making capacity)

IRAS ID: 280705

What are the benefits of taking part?

There are no significant material benefits to taking part in the study (aside from a small token of thanks). However, the opportunity to talk openly about your experiences of the treatment decision-making process may be something you will enjoy.

What are the risks of taking part?

There are no obvious risks to taking part in the study. Taking part involves a single interview and you can decide what you are willing to talk about. However, it is possible that some topics that will be raised will upset you. If this happens, you can stop the interview at any point, and you will not have to continue or restart it.

If you are upset by anything that is discussed in the interview, you will be provided with contact details of organisations that will be able to help you.

What do I get for taking part?

As a token of thanks for taking part in the study, you will receive a £20 Love2shop voucher as a thank you for your time. You will also be reimbursed for any travel to and from the interview, so taking part will not cost you anything. You must keep any receipts and/or tickets from public transport and bring them with you to the interview, as you will need these to be reimbursed. [details of how to claim reimbursement will be provided].

What will be done with any information I give?

All data will be managed in line with GDPR (EU General Data Protection Regulation). Interviews will be audio recorded, and the recording will be used to produce a written record (transcript). You will not be referred to by name on this written record. Information you provide will be used for research purposes only, and words you use may be directly quoted in publications. Any use of your words will be anonymised.

All information you provide will be stored securely so that only the researchers on the study are able to access it. It will be stored for 5 years.

In the unlikely event that you say anything during the interview that causes the researchers to be concerned about your own immediate safety, or the safety of others (including malpractice), we may be obliged to break confidentiality and report this to the appropriate authorities. You will be told at the time if this happens.

How will information about me be used?

We will need to use information from you for this research project. This information will include your name and contact details. We will only use this information to ensure the research is being done properly or to contact you if needed.

Participant information sheet (patient with decision making capacity)

IRAS ID: 280705

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your information in specific ways for the research to be reliable. This means that you will be able to view a copy of your interview transcript if requested, but you will not be able to change it.

Where can I find out more about how my information is used?

You can find out more about how we use your information in several ways:

- Visit www.hra.nhs.uk/information-about-patients/
- Ask one of the research team
- Send an email to jordan.parsons@bristol.ac.uk
- Contact the University of Bristol's Data Protection Officer: [email]

What if I want to leave the study after starting?

You will be able to fully withdraw from the study until one week after the interview, and you will not have to provide a reason for doing so. If you withdraw from the study after the interview, all recordings and transcripts of your interview will be destroyed. After this week, the data will have been analysed and it will be impossible to remove it from the research.

Who has reviewed the study?

This study received a favourable opinion from the NHS Health Research Authority's London – Camberwell St Giles Research Ethics Committee on Tuesday 22nd December 2020. It was subsequently approved by the NHS Health Research Authority (REC reference: 20/LO/1233).

Who is organising and funding the research?

This research is being conducted by the University of Bristol. It is funded by the Wellcome Trust as part of the BABEL project (Balancing Best Interests in Healthcare Ethics and Law).

I would like to take part – what do I do now?

If you would like to take part, you should contact Jordan Parsons by telephone or email:

[jordan.parsons@bristol.ac.uk]

[mobile number]

Participant information sheet (patient with decision making capacity)

IRAS ID: 280705

Your eligibility has already been checked but will need to be confirmed with you. With your permission, you will then be entered into the study and a suitable date, time, and location for the interview will be discussed with you.

I would not like to take part – what do I do now?

If you would not like to take part, you do not have to do anything. A member of your clinical team may mention the study to you at some point, but you do not have to provide a reason for not wanting to take part.

What if there is a problem?

If you wish to make a complaint about anything to do with the study, you may contact either of the following:

Dr Jonathan Ives, Deputy Director, University of Bristol Centre for Ethics in Medicine

j.ives@bristol.ac.uk

University of Bristol Research Governance

research-governance@bristol.ac.uk

[North Bristol NHS Trust] Patient Advice and Liaison Service

[complaints@nbt.nhs.uk]

Thank you for reading this information.

Appendix D: Consultee Information Sheet – Patient without Capacity

Consultee information sheet (patient without decision making capacity)

IRAS ID: 280705



The BIRD Study Participant Information Sheet

Why is this study being conducted?

The purpose of this study is to understand how treatment decisions are made for patients with low kidney function who are unable to make the decisions themselves. This study is using interviews to understand the full process and to explore the experiences and views of those involved. We think it is important to find out about the experiences and views of everybody in the process, so are not only interviewing health care professionals.

What would taking part involve?

Participation in the study would involve taking part in a single interview in person, which would last between 40 and 60 minutes. This interview would most likely take place at [name of hospital] at a time that suits you. It is possible for interviews to take place elsewhere if you would prefer, but the location would need to be quiet and reasonably private to ensure you feel comfortable talking about your experiences and views. You would be able to take a break at any point during the interview.

Can I take part?

You are eligible to take part if you:

- Are attending kidney clinic, and are having or have had dialysis and [conservative care] treatment options explained to you; and
- Are unable to take on board all the information needed to make the decision to have dialysis or [conservative care] yourself.

Do I have to take part?

No, you do not have to take part in the study. Taking part is entirely optional, and you do not have to provide a reason for choosing not to take part.

Consultee information sheet (patient without decision making capacity)

IRAS ID: 280705

What are the benefits of taking part?

There are no significant material benefits to taking part in the study (aside from a small token of thanks). However, the opportunity to talk openly about your experiences of the treatment decision-making process may be something you will enjoy.

What are the risks of taking part?

There are no obvious risks to taking part in the study. Taking part involves a single interview and you can decide what you are willing to talk about. However, it is possible that some topics that will be raised will upset you. If this happens, you can stop the interview at any point, and you will not have to continue or restart it.

If you are upset by anything that is discussed in the interview, you will be provided with contact details of organisations that will be able to help you.

What do I get for taking part?

As a token of thanks for taking part in the study, you will receive a £20 Love2shop voucher as a thank you for your time. You will also be reimbursed for any travel to and from the interview, so taking part will not cost you anything. You must keep any receipts and/or tickets from public transport and bring them with you to the interview, as you will need these to be reimbursed. [details of how to claim reimbursement will be provided].

What will be done with any information I give?

All data will be managed in line with GDPR (EU General Data Protection Regulation). Interviews will be audio recorded, and the recording will be used to produce a written record (transcript). You will not be referred to by name on this written record. Information you provide will be used for research purposes only, and words you use may be directly quoted in publications. Any use of your words will be anonymised.

All information you provide will be stored securely so that only the researchers on the study are able to access it. It will be stored for 5 years.

In the unlikely event that you say anything during the interview that causes the researchers to be concerned about your own immediate safety, or the safety of others (including malpractice), we may be obliged to break confidentiality and report this to the appropriate authorities. You will be told at the time if this happens.

How will information about me be used?

We will need to use information from you for this research project. This information will include your name and contact details. We will only use this information to ensure the research is being done properly or to contact you if needed.

Consultee information sheet (patient without decision making capacity)

IRAS ID: 280705

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your information in specific ways for the research to be reliable. This means that you will be able to view a copy of your interview transcript if requested, but you will not be able to change it.

Where can I find out more about how my information is used?

You can find out more about how we use your information in several ways:

- Visit www.hra.nhs.uk/information-about-patients/
- Ask one of the research team
- Send an email to jordan.parsons@bristol.ac.uk
- Contact the University of Bristol's Data Protection Officer: [email]

What if I want to leave the study after starting?

You will be able to fully withdraw from the study until one week after the interview, and you will not have to provide a reason for doing so. If you withdraw from the study after the interview, all recordings and transcripts of your interview will be destroyed. After this week, the data will have been analysed and it will be impossible to remove it from the research.

Who has reviewed the study?

This study received a favourable opinion from the NHS Health Research Authority's London – Camberwell St Giles Research Ethics Committee on Tuesday 22nd December 2020. It was subsequently approved by the NHS Health Research Authority (REC reference: 20/LO/1233).

Who is organising and funding the research?

This research is being conducted by the University of Bristol. It is funded by the Wellcome Trust as part of the BABEL project (Balancing Best Interests in Healthcare Ethics and Law).

I would like to take part – what do I do now?

If you would like to take part, you should contact Jordan Parsons by telephone or email:

[jordan.parsons@bristol.ac.uk]

[mobile number]

Consultee information sheet (patient without decision making capacity)

IRAS ID: 280705

Your eligibility has already been checked but will need to be confirmed with you. With your permission, you will then be entered into the study and a suitable date, time, and location for the interview will be discussed with you.

I would not like to take part – what do I do now?

If you would not like to take part, you do not have to do anything. A member of your clinical team may mention the study to you at some point, but you do not have to provide a reason for not wanting to take part.

What if there is a problem?

If you wish to make a complaint about anything to do with the study, you may contact either of the following:

Dr Jonathan Ives, Deputy Director, University of Bristol Centre for Ethics in Medicine

j.ives@bristol.ac.uk

University of Bristol Research Governance

research-governance@bristol.ac.uk

[North Bristol NHS Trust] Patient Advice and Liaison Service

[\[complaints@nbt.nhs.uk\]](mailto:complaints@nbt.nhs.uk)

Thank you for reading this information.

Appendix E: Participant Information Sheet – Consultee

Participant information sheet (consultee)

IRAS ID: 280705



The BIRD Study Participant Information Sheet

Why is this study being conducted?

The purpose of this study is to understand how treatment decisions are made for patients with low kidney function who are unable to make the decisions themselves. This study is using interviews to understand the full process and to explore the experiences and views of those involved. We think it is important to find out about the experiences and views of everybody in the process, so are not only interviewing health care professionals.

What would taking part involve?

Participation in the study would involve taking part in a single interview in person, which would last between 40 and 60 minutes. This interview would most likely take place at [name of hospital] at a time that suits you. It is possible for interviews to take place elsewhere if you would prefer, but the location would need to be quiet and reasonably private to ensure you feel comfortable talking about your experiences and views. You would be able to take a break at any point during the interview.

Can I take part?

You are eligible to take part if you:

- Are named by a person with kidney failure as someone to be consulted on treatment decisions; or
- Are caring for, or interested in the welfare of, a person with kidney failure.

For clarity, this includes close family and friends.

Do I have to take part?

No, you do not have to take part in the study. Taking part is entirely optional, and you do not have to provide a reason for choosing not to take part.

Participant information sheet (consultee)

IRAS ID: 280705

What are the benefits of taking part?

There are no significant material benefits to taking part in the study (aside from a small token of thanks). However, the opportunity to talk openly about your experiences of the treatment decision-making process may be something you will enjoy.

What are the risks of taking part?

There are no obvious risks to taking part in the study. Taking part involves a single interview and you can decide what you are willing to talk about. However, it is possible that some topics that will be raised will upset you. If this happens, you can stop the interview at any point, and you will not have to continue or restart it.

If you are upset by anything that is discussed in the interview, you will be provided with contact details of organisations that will be able to help you.

What do I get for taking part?

As a token of thanks for taking part in the study, you will receive a £20 Love2shop voucher as a thank you for your time. You will also be reimbursed for any travel to and from the interview, so taking part will not cost you anything. You must keep any receipts and/or tickets from public transport and bring them with you to the interview, as you will need these to be reimbursed. [details of how to claim reimbursement will be provided]

What will be done with any information I give?

All data will be managed in line with GDPR (EU General Data Protection Regulation). Interviews will be audio recorded, and the recording will be used to produce a written record (transcript). You will not be referred to by name on this written record. Information you provide will be used for research purposes only, and words you use may be directly quoted in publications. Any use of your words will be anonymised.

All information you provide will be stored securely so that only the researchers on the study are able to access it. It will be stored for 5 years.

In the unlikely event that you say anything during the interview that causes the researchers to be concerned about your own immediate safety, or the safety of others (including malpractice), we may be obliged to break confidentiality and report this to the appropriate authorities. You will be told at the time if this happens.

How will information about me be used?

We will need to use information from you for this research project. This information will include your name and contact details. We will only use this information to ensure the research is being done properly or to contact you if needed.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Participant information sheet (consultee)

IRAS ID: 280705

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your information in specific ways for the research to be reliable. This means that you will be able to view a copy of your interview transcript if requested, but you will not be able to change it.

Where can I find out more about how my information is used?

You can find out more about how we use your information in several ways:

- Visit www.hra.nhs.uk/information-about-patients/
- Ask one of the research team
- Send an email to jordan.parsons@bristol.ac.uk
- Contact the University of Bristol's Data Protection Officer: [email]

What if I want to leave the study after starting?

You will be able to fully withdraw from the study until one week after the interview, and you will not have to provide a reason for doing so. If you withdraw from the study after the interview, all recordings and transcripts of your interview will be destroyed. After this week, the data will have been analysed and it will be impossible to remove it from the research.

Who has reviewed the study?

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Who is organising and funding the research?

This research is being conducted by the University of Bristol. It is funded by the Wellcome Trust as part of the BABEL project (Balancing Best Interests in Healthcare Ethics and Law).

I would like to take part – what do I do now?

If you would like to take part, you should contact Jordan Parsons by telephone or email:

[jordan.parsons@bristol.ac.uk]

[mobile number]

Participant information sheet (consultee)

IRAS ID: 280705

Your eligibility has already been checked but will need to be confirmed with you. With your permission, you will then be entered into the study and a suitable date, time, and location for the interview will be discussed with you.

I would not like to take part – what do I do now?

If you would not like to take part, you do not have to do anything.

What if there is a problem?

If you wish to make a complaint about anything to do with the study, you may contact either of the following:

Dr Jonathan Ives, Deputy Director, University of Bristol Centre for Ethics in Medicine

j.ives@bristol.ac.uk

University of Bristol Research Governance


research-governance@bristol.ac.uk

[North Bristol NHS Trust] Patient Advice and Liaison Service

[complaints@nbt.nhs.uk]

Appendix F: Consent Form – Healthcare Professional

| | |
|--------------------------------|-----------------|
| Participant consent form (HCP) | IRAS ID: 280705 |
|--------------------------------|-----------------|



The BIRD Study
Participant Consent Form

Participant ID: _____

This form is to confirm that you consent to participate in the study. Please read each point below and initial the adjacent box (do not tick) if you agree. If you agree with each point, please fill in your name, signature, and today's date at the bottom of the page under 'participant'. Please also indicate whether you consent to your data being anonymously archived for future researchers to use.

| | |
|--|--------------------------|
| 1. I confirm that I have read and understood the participant information sheet [v2.0, December 2020] for the above study. I have had enough time to consider this information and to ask any questions I have had about it, and these questions have been answered to my satisfaction. | <input type="checkbox"/> |
| 2. I understand that participating in this study is voluntary, and I do not have to take part. If I do not take part, I understand that my healthcare or employment will not be affected in any ways. | <input type="checkbox"/> |
| 3. I understand that I am free to withdraw from the study until one week after my interview without giving a reason. I understand that I am unable to withdraw more than one week after my interview. | <input type="checkbox"/> |
| 4. I understand that I am being asked to take part in a single interview to talk about my experiences of making decisions concerning dialysis for patients who lack capacity. I understand that this interview will be audio recorded. | <input type="checkbox"/> |
| 5. I understand that a written record (transcript) of this interview will be made from the audio recording. I understand that I will not be referred to by name on this written record. | <input type="checkbox"/> |
| 6. I understand that the researchers on this study will use the information I provide for research purposes only, and that words I use may be directly quoted in publications. I understand that my words will be anonymised, and nothing I say will be personally attributed to me. | <input type="checkbox"/> |
| 7. I understand that in the event that I say anything during the interview that causes the interviewer to be concerned about my own immediate safety, or the safety of others (including malpractice), the interviewer may be obliged to break confidentiality and report this to the appropriate authorities. | <input type="checkbox"/> |

| | | |
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| Best Interests in Renal Dialysis | v2.0 | 7 th December 2020 |
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Participant consent form (HCP)

IRAS ID: 280705

8. I agree to participate in this study.

☐

With your permission, we would like to make your data (the transcript) anonymously available through a research archive at the end of this study. This will allow other researchers to request access for their own research purposes, and you will be in no way identifiable to them. Please initial one of the boxes below (do not tick) to confirm whether you consent to this happening.

Yes, you may anonymously archive my data.

☐

No, you may not anonymously archive my data.

☐*Participant:*

Name: _____ Signature: _____ Date: _____


Researcher (as witness):

Name: _____ Signature: _____ Date: _____

Two copies are to be signed. One is to be given to the participant, and the other kept by the researcher.

Appendix G: Consent Form – Patient with Capacity

Participant consent form (patient with decision making capacity) IRAS ID: 280705



The BIRD Study
Participant Consent Form

Participant ID: _____

This form is to confirm that you consent to participate in the study. Please read each point below and initial the adjacent box (do not tick) if you agree. If you agree with each point, please fill in your name, signature, and today's date at the bottom of the page under 'participant'. Please also indicate whether you consent to your data being anonymously archived for future researchers to use.

1. I confirm that I have read and understood the participant information sheet [v2.0, December 2020] for the above study. I have had enough time to consider this information and to ask any questions I have had about it, and these questions have been answered to my satisfaction. ☐
2. I understand that participating in this study is voluntary, and I do not have to take part. If I do not take part, I understand that my healthcare will not be affected in any way. ☐
3. I understand that I am free to withdraw from the study until one week after my interview without giving a reason. I understand that I am unable to withdraw more than one week after my interview. ☐
4. I understand that I am being asked to take part in a single interview to talk about my experiences of involvement in decisions concerning the treatment/care of a patient who could not make decisions for themselves. I understand that this will be audio recorded. ☐
5. I understand that a written record (transcript) of this interview will be made from the audio recording. I understand that I will not be referred to by name on this written record. ☐
6. I understand that the researchers on this study will use the information I provide for research purposes only, and that words I use may be directly quoted in publications. I understand that my words will be anonymised, and nothing I say will be personally attributed to me. ☐
7. I understand that in the event that I say anything during the interview that causes the interviewer to be concerned about my own immediate safety, or the safety of others (including malpractice), the interviewer may be obliged to break confidentiality and report this to the appropriate authorities. ☐
8. I agree to participate in this study. ☐

Best Interests in Renal Dialysis v2.0 7th December 2020

Participant consent form (patient with decision making capacity)

IRAS ID: 280705

With your permission, we would like to make your data (the transcript) anonymously available through a research archive at the end of this study. This will allow other researchers to request access for their own research purposes, and you will be in no way identifiable to them. Please initial one of the boxes below (do not tick) to confirm whether you consent to this happening.

Yes, you may anonymously archive
my data.

☐

No, you may not anonymously archive
my data.

☐

Participant:

Name: _____ Signature: _____ Date: _____


Researcher (as witness):

Name: _____ Signature: _____ Date: _____

Two copies are to be signed. One is to be given to the participant, and the other kept by the researcher.

Appendix H: Consent Form – Consultee

| | |
|--------------------------------------|-----------------|
| Participant consent form (consultee) | IRAS ID: 280705 |
|--------------------------------------|-----------------|



The BIRD Study
Participant Consent Form

Participant ID: _____

This form is to confirm that you consent to participate in the study. Please read each point below and initial the adjacent box (do not tick) if you agree. If you agree with each point, please fill in your name, signature, and today's date at the bottom of the page under 'participant'. Please also indicate whether you consent to your data being anonymously archived for future researchers to use.

1. I confirm that I have read and understood the participant information sheet [v2.0, December 2020] for the above study. I have had enough time to consider this information and to ask any questions I have had about it, and these questions have been answered to my satisfaction. ☐
2. I understand that participating in this study is voluntary, and I do not have to take part. If I do not take part, I understand that my healthcare and the healthcare of the patient I am a consultee for will not be affected in any way. ☐
3. I understand that I am free to withdraw from the study until one week after my interview without giving a reason. I understand that I am unable to withdraw more than one week after my interview. ☐
4. I understand that I am being asked to take part in a single interview to talk about my experiences of involvement in decisions concerning the treatment/care of a patient who could not make decisions for themselves. I understand that this will be audio recorded. ☐
5. I understand that a written record (transcript) of this interview will be made from the audio recording. I understand that I will not be referred to by name on this written record. ☐
6. I understand that the researchers on this study will use the information I provide for research purposes only, and that words I use may be directly quoted in publications. I understand that my words will be anonymised, and nothing I say will be personally attributed to me. ☐
7. I understand that in the event that I say anything during the interview that causes the interviewer to be concerned about my own immediate safety, or the safety of others (including malpractice), the interviewer may be obliged to break confidentiality and report this to the appropriate authorities. ☐

| | | |
|----------------------------------|------|-------------------------------|
| Best Interests in Renal Dialysis | v2.0 | 7 th December 2020 |
|----------------------------------|------|-------------------------------|

Participant consent form (consultee)

IRAS ID: 280705

8. I agree to participate in this study.

☐

With your permission, we would like to make your data (the transcript) anonymously available through a research archive at the end of this study. This will allow other researchers to request access for their own research purposes, and you will be in no way identifiable to them. Please initial one of the boxes below (do not tick) to confirm whether you consent to this happening.

Yes, you may anonymously archive my data.

☐

No, you may not anonymously archive my data.

☐*Participant:*

Name: _____ Signature: _____ Date: _____

Researcher (as witness):

Name: _____ Signature: _____ Date: _____

Two copies are to be signed. One is to be given to the participant, and the other kept by the researcher.

Appendix I: Consultee Declaration Form

Consultee declaration form (patient without decision making capacity)

IRAS ID: 280705



The BIRD Study Consultee Declaration Form

Participant ID: _____

This form is to confirm that you approve of the patient's participation in the study. Please read each point below and initial the adjacent box (do not tick) if you agree. If you agree with each point, please fill in your name, signature, today's date, and your relationship to the patient at the bottom of the page under 'consultee'. Please also indicate whether you approve of the patient's data being anonymously archived for future researchers to use.

1. I confirm that I have read and understood the consultee information sheet [v2.0, December 2020] for the above study. I have had enough time to consider this information and to ask any questions I have had about it, and these questions have been answered to my satisfaction. ☐
2. In my opinion, the patient would not object to participating in the study. ☐
3. I understand that I can request that the patient is withdrawn from the study until one week after the interview, without providing a reason, and that this will not affect the patient's care or legal rights. ☐
4. I understand that relevant sections of the patient's care record and data collected during the study may be looked at by responsible individuals from the University of Bristol or from regulatory authorities, where it is relevant to the patient's taking part in this study. ☐
5. I understand that in the event that the patient says anything during the interview that causes the interviewer to be concerned about the patient's immediate safety, or the safety of others (including malpractice), the interviewer may be obliged to break confidentiality and report this to the appropriate authorities. ☐
6. I approve of the patient's participation in this study. ☐

Consultee declaration form (patient without decision making capacity)

IRAS ID: 280705

We would like to make the patient's data (the transcript) anonymously available through a research archive at the end of this study. This will allow other researchers to request access for their own research purposes, and you will be in no way identifiable to them. Please initial one of the boxes below (do not tick) to confirm whether you approve of this happening.

Yes, I approve of you anonymously archiving the patient's data.

☐

No, I do not approve of you anonymously archiving the patient's data.

☐

Consultee:

Name: _____ Signature: _____ Date: _____

Relationship to patient: _____

Researcher (as witness):

Name: _____ Signature: _____ Date: _____

Two copies are to be signed. One is to be given to the consultee, and the other kept by the researcher.

Appendix J: Topic Guide – Healthcare Professional

Topic guide (HCP)

Topic Guide (HCP)

The interview will begin with the introductory questions to cover consent and logistics, then the interviewer will begin with a broad opening question to make the participant comfortable and allow the participant to lead the interview. Following this, the interview will be semi-structured and follow the topics raised by the participant. The interviewer will raise the topics outlined below are covered if they are not raised by the participant. All questions below are examples.

Introduction:

- Thank participant for agreeing to participate
- Introduce myself and the purpose of this research
- Confirm the participant has received and read the information sheet
- Confirm the participant's consent
- Explain that the participant may stop the interview and withdraw at any time
- Ask the participant if they have any questions
- Reconfirm that the participant is happy to continue

Broad opening question:

- Tell me about your experience of making decisions regarding dialysis for patients who lack the capacity to provide informed consent
- How do you approach best interests decisions concerning dialysis?
- How often are you faced with patients with kidney failure who lack the capacity to consent to treatment?

Topics:

- Understanding of best interests
 - What do you understand the requirements of a best interests decision to be?
 - When do you think a best interests decision is required?
- Experiences of best interests decision-making
 - Have you been involved in many best interests decisions?
 - Talk me through these cases.
- Involving the patient
 - What efforts are made to involve the patient in the decision?
 - Does this vary depending on the extent to which the patient is incapacitated?
 - To what extent do you attempt to respect the apparent preferences of the patient?
- Involving the medical team
 - Who else on the medical team is involved?
 - What weight is placed on different people's views?
- Involving the consultees
 - Are consultees involved in decisions?
 - To what extent are they involved?
 - How do you handle situations whereby you disagree with the consultees?

Topic guide (HCP)

- What sort of people do you think should be consultees?
- Balancing conflicting opinions
 - Do the opinions of any one party tend to carry greater weight in the decision?
 - Is there an attempt to reach consensus, or just acknowledgement that someone is always going to disagree with the decision?
- Other factors considered
 - Aside from purely clinical factors, what else do you consider?
 - Do you consider the burden on the consultees in transporting the patient to and from clinic?
 - Is there anything you feel is a relevant factor which you do not consider (perhaps because you are not allowed to)?
- Predisposition
 - When approaching these decisions, do you feel that you err more on the side of dialysis or CKM?
- Guidance
 - Are there any particular sources of guidance you look to on these issues?
 - To what extent do you use them?
 - Do you find them useful?
 - What additional guidance would you like to be available?

Conclusion:

- Is there anything you would like to add to any of the topics we have discussed?
- Is there anything else you would like to discuss?
- Have you got any questions for me?
- Thank the participant for their participation
- Remind the participant of sources of support should they need them following the interview
- Remind the participant that they have one week in which to withdraw from the study

Appendix K: Topic Guide – Patient

Topic guide (patient)

Topic Guide (Patient)

The interview will begin with the introductory questions to cover consent and logistics (some will not be relevant if the participant is participating following a BI decision), then the interviewer will begin with a broad opening question to make the participant comfortable and allow the participant to lead the interview. Following this, the interview will be semi-structured and follow the topics raised by the participant. The interviewer will raise the topics outlined below are covered if they are not raised by the participant. All questions below are examples.

Introduction:

- Thank participant for agreeing to participate
- Introduce myself and the purpose of this research
- Confirm the participant has received and read the information sheet
- Confirm the participant's consent
- Explain that the participant may stop the interview and withdraw at any time
- Ask the participant if they have any questions
- Reconfirm that the participant is happy to continue

Broad opening question:

- Tell me about your experience of treatment decisions being made on your behalf
- How was the process of deciding whether you started dialysis for you?

Topics:

- Involvement in decision
 - How involved were you in the decision?
 - Did you feel that your voice was heard?
- Preferences
 - How did you feel about the idea of dialysis?
 - What did you know about dialysis? What were you told?
- Roles of other parties
 - Who else was involved in the decision?
 - Was there one person who took charge? Who was that?
 - Was everyone given a chance to contribute?
- Consultees
 - Did you feel like your consultee(s) represented your views well?
 - Did you choose your consultee(s)?
- Outcome
 - Were you happy with the outcome?
 - Is there anything you wish had been different?

Conclusion:

Topic guide (patient)

- Is there anything you would like to add to any of the topics we have discussed?
- Is there anything else you would like to discuss?
- Have you got any questions for me?
- Thank the participant for their participation
- Remind the participant of sources of support should they need them following the interview
- Remind the participant that they have one week in which to withdraw from the study

Appendix L: Topic Guide – Consultee

Topic guide (consultee)

Topic Guide (Consultee)

The interview will begin with the introductory questions to cover consent and logistics, then the interviewer will begin with a broad opening question to make the participant comfortable and allow the participant to lead the interview. Following this, the interview will be semi-structured and follow the topics raised by the participant. The interviewer will raise the topics outlined below are covered if they are not raised by the participant. All questions below are examples.

Introduction:

- Thank participant for agreeing to participate
- Introduce myself and the purpose of this research
- Confirm the participant has received and read the information sheet
- Confirm the participant's consent
- Explain that the participant may stop the interview and withdraw at any time
- Ask the participant if they have any questions
- Reconfirm that the participant is happy to continue

Broad opening question:

- Tell me about your experience of being involved in your friend/relative's care decisions
- Did you find it to be a positive experience overall?

Topics:

- Understanding of role
 - Did you understand what the role of a consultee was before this?
 - What do you perceive to be the purpose of a consultee?
- Becoming a consultee
 - How did you come to be a consultee?
 - Were you expecting it?
- Involvement
 - Did you feel listened to?
 - In what ways were you involved?
 - Did the medical team make an effort to explain things clearly?
 - Were you the only consultee?
- Reflection
 - Do you feel you fulfilled the purpose of a consultee well?
 - Do you think the right decision was reached?
 - Do you think the way things were done was appropriate?
 - Was being a consultee what you expected?
 - Do you think the role of consultees is important?
 - Who do you think makes an appropriate consultee?

Topic guide (consultee)

Conclusion:

- Is there anything you would like to add to any of the topics we have discussed?
- Is there anything else you would like to discuss?
- Have you got any questions for me?
- Thank the participant for their participation
- Remind the participant of sources of support should they need them following the interview
- Remind the participant that they have one week in which to withdraw from the study

Appendix M: Research Ethics Committee Favourable Opinion



London - Camberwell St Giles Research Ethics Committee

Ground Floor
Temple Quay House
2 The Square
Bristol
BS1 6PN

Telephone: 0207 1048138

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

22 December 2020

Mr Jordan Parsons
Oakfield House
Oakfield Grove
Bristol
BS82BN

Dear Mr Parsons

| | |
|-------------------------|---|
| Study title: | How should best interests decisions concerning the initiation of maintenance dialysis for adults be made? |
| REC reference: | 20/LO/1233 |
| Protocol number: | 2020-4500 |
| IRAS project ID: | 280705 |

Thank you for your letter of 17 December 2020 , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005 (England and Wales)

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005 (England and Wales). The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Mental Capacity Act (Northern Ireland) 2016

The Committee approved this research project for the purposes of the Mental Capacity Act (Northern Ireland) 2016. The Committee is satisfied that the requirements of Part 8 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Compliance with the Mental Capacity Act – The Committee agreed the following:Relevance of the research to the impairing condition

The Committee stated that the relevance of the research to the impairing condition would depend on the reasons why participants had gone into renal failure and needed renal dialysis. Members agreed that participants would come under the Mental Capacity Act if they lost capacity of impairing treatment or condition.

The Committee agreed the research was connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

Justification for including adults lacking capacity to meet the research objectives

The Committee queried whether the researchers had justified including adults lacking capacity to meet the research objectives and agreed that further clarification on why the research could not be carried out as effectively if it was confined to participants able to give consent.

Members agreed that the study would generate valuable data, but justification was needed to include adults lacking capacity to consent.

The Committee stated that it was not possible to get a sense from the researchers what proportion of participants would lack the capacity to consent.

The researchers agreed to take this forward.

It was noted that the Chief investigator had completed an NHS Health Education England e-learning course on 'Assessing Mental Capacity' and would also seek advice from Dr Fergus Caskey, Consultant Senior Lecturer and other HCPs at research sites as needed.

Arrangements for appointing consultees

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 135 of the Mental Capacity Act (Northern Ireland) 2016) to advise on whether participants lacking capacity should take part and on what their wishes and feelings would have likely to have been if they had capacity.

Members noted that all patient participants who lack capacity to consent to research would have lacked capacity to consent to dialysis, and so suitable consultees would have been identified by the clinical team. Otherwise, Mr Parsons would take advice from the healthcare professionals at the research site as to who an appropriate consultee would be.

Mr Parsons would also speak to patients, and family/friends/others who were close to patients and could act as a consultee. The Committee stated that this approach was not too controversial.

The Committee advised the researchers that some consultees would have medical Power of Attorney (POA) which was different to the standard POA arrangements. The researchers were asked if it would be possible to include only consultees with POA as they would be used to making decisions on behalf of their friend/family member.

Mr Parsons replied to say that it would be a different decision process for consultees who had medical POA as these consultees would actively make a decision as opposed to best interest.

Dr Ives added that participants with consultees who had medical POA were excluded from taking part in the study. The study was looking at best interest, and someone with medical POA would not be acting in the best interest of the participant so they would not be included in the study.

Members were satisfied with this response.

After discussion the Committee agreed that reasonable arrangements were in place for appointing consultees.

Balance between benefit and risk, burden and intrusion

The Committee noted that the researcher had stated in the IRAS REC application form (question B4) that the research would not have the potential to benefit participants who were unable to consent for themselves.

Mr Parsons clarified that the answer provided for question B4 was answered incorrectly and that the research did have the potential to benefit participants who were unable to consent for themselves.

Dr Ives added that participants who lacked the capacity to consent would find it cathartic to talk about their experience of decisions being made about the treatment.

Members were content with this response.

The researchers were asked if it would be possible to schedule in a 5-minute break 20-25-minutes into the interview to allow participants to have a break and provide refreshments.

Participants who were happy to continue with the interview without a break would be allowed to continue if they wished to.

Mr Parsons agreed to include a break during the interview and to include a statement on this in the information sheets.

Members were content with this response.

It was unclear when the researchers would obtain consent to observe clinical meetings and Mr Parsons clarified that clinicians would be informed as far in advance of the meeting as possible, but it would also depend on when the meeting was arranged, as sometimes the meetings were arranged at last minute. There would be an opportunity to request consent to observe a clinical meeting before the meeting, and again at the beginning.

Members acknowledged this response and advised researchers that there was a risk that patient identifiable information could be disclosed during a clinical meeting regarding a patient who had not consented to take part in the study.

The researchers responded to say that the patient could object to their information being disclosed and the issue would be discussed with the clinical care team.

The Committee accepted this response.

The Committee agreed that the research has the potential to benefit participants lacking capacity without imposing a disproportionate burden on them.

Additional safeguards

The Committee was satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 137 of the Mental Capacity Act (Northern Ireland) 2016).

The REC was satisfied, from the information in the application and any further assurances given during the review that the additional safeguards set out in Section 33 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Section 137 of the Mental Capacity Act (Northern Ireland) 2016 will be complied with during the conduct of the research.

The Committee noted that additional safeguards as follows:

Nothing will be done in the course of the research:

(a) to which research participants lacking capacity appear to object (unless it is to protect them from harm or reduce/prevent pain or discomfort)

(b) which would be contrary to any known advance decision or statement they have made. If research participants indicate in any way that they wish to be withdrawn from the project, they must be withdrawn without delay, except where this involves stopping treatment and there could be a significant risk to their health.

Research participants lacking capacity must also be withdrawn if any of the criteria set out in Section 32 of the Mental Capacity Act 2005 (England and Wales) and the equivalent Sections

135 and 136 of the Mental Capacity Act (Northern Ireland) 2016 no longer apply. In conducting the research, the interests of research participants must be assumed to outweigh those of science and society.

Information for consultees

The Committee considered that the information to be provided to consultees about the proposed research was not adequate.

The information sheet for participants was well written and laid out, however the information sheets for consultees required revisions which would be outlined to the applicant.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|---------|-----------------|
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoB insurance letter] | | 15 October 2020 |
| Interview schedules or topic guides for participants [Topic guide (consultee) v1.0] | v1.0 | 15 October 2020 |
| Interview schedules or topic guides for participants [Topic guide (HCP) v1.0] | v1.0 | 15 October 2020 |
| Interview schedules or topic guides for participants [Topic guide (patient) v1.0] | v1.0 | 15 October 2020 |

| | | |
|--|------|------------------|
| IRAS Application Form [IRAS_Form_30102020] | | 30 October 2020 |
| IRAS Checklist XML [Checklist_17122020] | | 17 December 2020 |
| Letters of invitation to participant [Letter of invitation (consultee) v1.0] | v1.0 | 15 October 2020 |
| Letters of invitation to participant [Letter of invitation (HCP) v1.0] | v1.0 | 15 October 2020 |
| Letters of invitation to participant [Letter of invitation (patient with decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Distress protocol (participants with decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Distress protocol (participants without decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Standard letter/email of ineligibility v1.0] | v1.0 | 15 October 2020 |
| Other [Standard letter/email when recruitment has closed v1.0] | v1.0 | 15 October 2020 |
| Other [Recruitment flowchart (consultee) v1.0] | v1.0 | 15 October 2020 |
| Other [Recruitment flowchart (HCP) v1.0] | v1.0 | 15 October 2020 |
| Other [Recruitment flowchart (patient with decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Recruitment flowchart (patient without decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Consultee information sheet (patient without decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Consultee declaration form (patient without decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Other [Caskey CV] | v1.0 | 15 October 2020 |
| Other [Staff email template v1.0] | v1.0 | 15 October 2020 |
| Other [Consultee information sheet (patient without decision making capacity) v2.0] | v2.0 | 07 December 2020 |
| Other [Consultee declaration form (patient without decision making capacity) v2.0] | v2.0 | 07 December 2020 |
| Other [Revision Notes] | v1.0 | 12 December 2020 |
| Participant consent form [Participant consent form (patient with decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Participant consent form [Participant consent form (consultee) v2.0] | v2.0 | 07 December 2020 |
| Participant consent form [Participant consent form (HCP) v2.0] | v2.0 | 07 December 2020 |
| Participant consent form [Participant consent form (patient with decision making capacity) v2.0] | v2.0 | 07 December 2020 |
| Participant information sheet (PIS) [Simplified participant information sheet (patient without decision making capacity) v1.0] | v1.0 | 15 October 2020 |
| Participant information sheet (PIS) [Participant information sheet (consultee) v2.0] | v2.0 | 07 December 2020 |
| Participant information sheet (PIS) [Participant information sheet (HCP) v2.0] | v2.0 | 07 December 2020 |
| Participant information sheet (PIS) [Participant information sheet (patient with decision making capacity) v2.0] | v2.0 | 15 October 2020 |
| Research protocol or project proposal [Protocol v2.0] | v2.0 | 12 December 2020 |
| Summary CV for Chief Investigator (CI) [Parsons CV] | v1.0 | 15 October 2020 |
| Summary CV for student [Parsons CV] | v1.0 | 15 October 2020 |
| Summary CV for supervisor (student research) [Ives CV] | v1.0 | 15 October 2020 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

| |
|--|
| IRAS project ID: 280705 Please quote this number on all correspondence |
|--|

With the Committee's best wishes for the success of this project.

Yours sincerely



PP
Mr John Richardson
Chair

Email: camberwellstgiles.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for
researchers"

Copy to: Mr Adam Taylor, Sponsor contact

Appendix N: Health Research Authority Approval



Mr Jordan Parsons
Oakfield House
Oakfield Grove
Bristol
BS82BN

22 December 2020

Dear Mr Parsons



Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

| | |
|------------------|---|
| Study title: | How should best interests decisions concerning the initiation of maintenance dialysis for adults be made? |
| IRAS project ID: | 280705 |
| Protocol number: | 2020-4500 |
| REC reference: | 20/LO/1233 |
| Sponsor | University of Bristol |

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

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 280705. Please quote this on all correspondence.

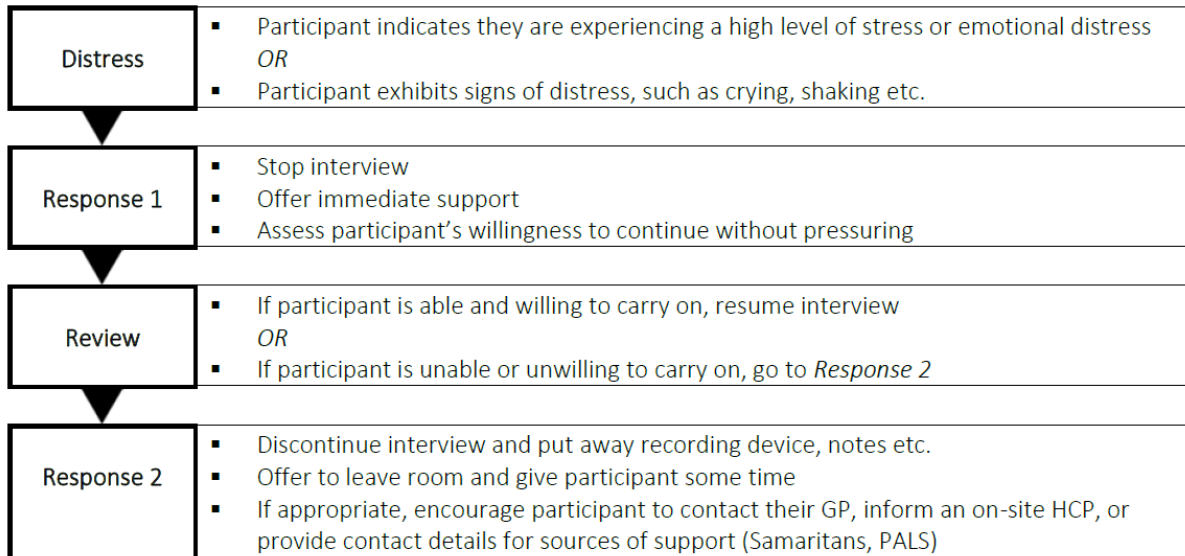
Yours sincerely,

Natalie Wilson
Approvals Manager

Email: camberwellstiles.rec@hra.nhs.uk

Copy to: *Mr Adam Taylor, University of Bristol, Sponsor contact*

Appendix O: Distress Protocol – Participants with Capacity



Adapted from Draucker and colleagues (2009).

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Appendix P: Distress Protocol – Participants without Capacity

| | |
|----------|---|
| Distress | <ul style="list-style-type: none">▪ Participant indicates they are experiencing a high level of stress or emotional distress <i>OR</i>▪ Participant exhibits signs of distress, such as crying, shaking etc. |
| Response | <ul style="list-style-type: none">▪ Discontinue interview▪ Offer immediate support▪ Notify relevant on-site HCP and, if appropriate, any family members present |

Adapted from Draucker and colleagues (2009).

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Appendix Q: COREQ checklist

The below checklist signposts the reporting in this thesis against the consolidated criteria for reporting qualitative research (COREQ). Where items are identified as reported “Below”, the relevant information can be found below the checklist.

| No | Item | Reported |
|--|--|--|
| Domain 1: Research Team and Reflexivity | | |
| 1 | Interviewer/facilitator | Below |
| 2 | Credentials | Below |
| 3 | Occupation | Below |
| 4 | Gender | Below |
| 5 | Experience and training | Below |
| 6 | Relation established | - |
| 7 | Participant knowledge of the interviewer | Section 4.3.1.4 |
| 8 | Interviewer characteristics | Appendix A |
| Domain 2: Study Design | | |
| 9 | Methodological orientation and theory | Chapter 2, section 4.2, section 4.4.2 |
| 10 | Sampling | Section 4.3.1.1 |
| 11 | Method of approach | Section 4.3.1.2 |
| 12 | Sample size | Section 5.1 (Table 3), section 5.2 (Table 4) |
| 13 | Non-participation | - |
| 14 | Setting of data collection | Section 5.1 (Table 3), section 5.2 (Table 4) |
| 15 | Presence of non-participants | - |
| 16 | Description of sample | Section 5.1 (Table 3), section 5.2 (Table 4) |
| 17 | Interview guide | Appendices J, K, and L |
| 18 | Repeat interviews | - |
| 19 | Audio/visual recording | Section 4.3.1.4 |
| 20 | Field notes | - |
| 21 | Duration | - |
| 22 | Data saturation | - |
| 23 | Transcripts returned | Section 4.4.1 |
| Domain 3: Analysis and Findings | | |
| 24 | Number of data coders | Below |
| 25 | Description of the coding tree | - |
| 26 | Derivation of themes | Section 4.4.2 |
| 27 | Software | Section 4.4.2 |
| 28 | Participant checking | - |
| 29 | Quotations presented | Chapter 5 |
| 30 | Data and findings consistent | Chapter 5 |
| 31 | Clarity of major themes | Chapter 5 |
| 32 | Clarity of minor themes | Chapter 5 |

Additional checklist information:

(1) I was the sole interviewer in this study.

(2) My credentials at the beginning of the study were BA(Hons) Politics and MScR Population Health Science – Healthcare Ethics and Law.

(3) My occupation for the duration of the study was postgraduate research student.

(4) Male.

(5) Both before and during this study, I undertook several training courses: Introduction to Research Governance (University of Bristol); Introduction to Qualitative Research Methods (University of Bristol); Questionnaire Design, Application, and Data Interpretation (University of Bristol); Introduction to Qualitative Methods for Health Economics (University of Bristol); Empirical Bioethics Training Course (University of Bristol); Assessing Mental Capacity (NHS Health Education England); Safeguarding Adults Level 1 (NHS Health Education England); Safeguarding Adults Level 2 (NHS Health Education England). During the study, I also worked on several other qualitative research projects employing the same methods.

(24) I was the sole data coder in this study.

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