WHAT ARE ‘BEST INTERESTS’? A CRITICAL EVALUATION OF ‘BEST INTERESTS’ DECISION-MAKING IN CLINICAL PRACTICE

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ABSTRACT

Obtaining the patient's consent is usually a prerequisite of any clinical intervention. However, some cognitively impaired patients may not be able to give valid consent. Following years of consultation and legislative review, the Mental Capacity Act 2005 (MCA) provides a statutory framework of ‘best interests’ decision-making on behalf of incapacitated individuals. However, confusion over the meaning and application of the ‘best interests’ standard persists. This paper explores the variation in judicial interpretation of the standard and the complexities of best interests decision-making in clinical practice. Prevailing confusion and risk-averse practices mean that the rights and interests of cognitively impaired individuals continue to be compromised, with evidence to suggest that ‘best interests’ may be conflated with the clinician's evaluation of ‘best medical interests’.

KEYWORDS: Assessing capacity, Autonomy, Best interests, Cognitive impairment, Mental Capacity Act 2005, Presumption of capacity

I. INTRODUCTION

It is a generally accepted principle in healthcare that upholding the ethical principle of autonomy¹ means respecting a patient's right to self-determination or choice.² This is generally interpreted in line with Isaiah Berlin's concept of ‘negative liberty’, and

1 This is notwithstanding the not inconsiderable debate as to the true philosophical meaning of ‘autonomy’, consideration of which extends beyond the scope of this paper, but see, for example, Richard Huxtable, ‘Autonomy, Best Interests and the Public Interest: Treatment, Non-Treatment and the Values of Medical Law’ (2014) 22 Med L Rev. 459–493.

2 TL Beauchamp and JF Childress, *Principles of Biomedical Ethics* (Oxford University Press: New York, 7th edn, 2013).

an individual will be free from interference with his chosen course of action (or inaction).³ This principle is upheld in law and means that medical interventions will generally be unlawful in the absence of the patient's consent,⁴ regardless of how unwise or unjustified the patient's decision may appear.⁵ However, notwithstanding the statutory presumption that adults⁶ have the mental capacity to make healthcare decisions,⁷ the right to decide whether or not to accept the offer of treatment⁸ is limited to the 'mentally competent'⁹ patient.

Historically, the issue of how to proceed with the care of an incapacitated patient raised something of a legal problem; the patient could not provide consent, and neither the court¹⁰ nor any other third party had authority to do so.¹¹ Doctors were faced with an apparent legal dilemma: a duty to provide care on the one hand, conflicting with potential liability in trespass for treating without consent on the other.¹² The House of Lords in *Re F (Mental Patient: Sterilisation)* agreed that this was nonsense¹³ and, following an extensive review of the jurisprudence, concluded that treatment in these circumstances could be justified by the principle of necessity. Treatment would be lawful if the doctor considered it 'to be in the best interests of his patient',¹⁴ and it met the standard set out in *Bolam v. Friern Hospital Management Committee*.¹⁵ In effect, determination of 'best interests' rested with the medical profession.¹⁶

Given this historic context, two fundamental aims of the Mental Capacity Act 2005 (MCA) were to uphold an individual's right to autonomy, balanced with an

3 I Berlin (ed) 'Two Concepts of Liberty' in *Four Essays on Liberty* (Oxford University Press: Oxford, 1969) [122].

4 The general rule is that touching a person without their consent 'is prima facie an assault, a civil trespass to the person and a crime' *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 (CA) [99]. This point was considered in the case of *Ms B v. An NHS Hospital Trust* [2002] All ER (D) 362 (FD), where it was held that a hospital had acted unlawfully by treating a mentally competent patient contrary to her expressed wishes, and a nominal award of damages was made in respect of this.

5 *Re C (an adult: refusal of treatment)* [1994] 1 All ER 819 (FD); MCA s 1 (4); H Taylor, 'Determining Capacity to Consent to Treatment' (2013) 109 Nursing Times 12–14.

6 In these circumstances, adulthood is regarded as the attainment of the age of 16 years. Historically, this presumption was set out in Family Law Reform Act 1969, section 8, but more recently in the MCA, s 2 (5).

7 *Re T (Adult: Refusal of Treatment)* [1993] Fam 95 (CA) [115].

8 Per Lord Scarman *Sidaway v. Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] 1 All ER 643 [649].

9 *Re MB (An Adult: Medical Treatment)* [1997] 2 FCR 541 (CA) [549].

10 The *parens patriae* jurisdiction in respect of adults of 'unsound mind' was dissolved on 1 November 1960 by the combined effect of the enactment of the Mental Health Act 1959, and the annulment of the Royal Warrant. See A Szerletics, *Best Interests Decision-Making Under the Mental Capacity Act Essex Autonomy Project Green Paper Report* (Essex Autonomy Project, University of Essex, 2011) <<http://autonomy.essex.ac.uk/best-interests-decision-making-under-the-mental-capacity-act>> accessed 17 February 2015.

11 See *Re F (Mental Patient: Sterilisation)* 2 WLR 1025 (HL).

12 Although as a matter incidental to the main jurisdictional and procedural issues considered, see, for example, Lord Brandon, *Re F*, *ibid* [1077].

13 Lord Bridge, Lord Griffiths, Lord Goff, and Lord Jauncey of Tulichettle agreed on this point; Lord Brandon dissented and agreed with the position adopted by the Court of Appeal, above, n 11.

14 Per Lord Griffiths, *Re F*, above, n 11 [1080]. See also, Lord Goff of Chieveley, above, n 11 [1088].

15 Above, n 11. Also, *Bolam v. Friern Hospital Management Committee* [1957] 2 All ER 118.

16 See Mary Donnelly, 'Best Interests, Patient Participation and the Mental Capacity Act 2005' (2009) 17 Med L Rev 1–29 [3].

imperative to protect the interests of those unable to do so for themselves.¹⁷ The guiding principle is that an individual 'must be assumed to have capacity unless it is established that he lacks capacity',¹⁸ and even where cognitive function is impaired, 'reasonably practicable' steps must be taken 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'.¹⁹ The presumption of capacity may be rebutted only if the statutory diagnostic²⁰ and functional²¹ tests are satisfied, and at that point, alternative mechanisms for decision-making may be deployed.²² Whilst individuals should, so far as possible, be supported to make their own decisions, others acting on their behalf must 'act in their best interests'.²³ Within healthcare, the treating clinician will be responsible for deciding whether the patient has capacity to consent to the proposed treatment.²⁴ If the patient lacks decision-making capacity, treatment may usually proceed under the general defence provided in section 5 of the MCA,²⁵ providing it is in the patient's best interests.²⁶

On its face, the process of best interests decision-making appears relatively uncontroversial. However, a review of the jurisprudence and other evidence suggests that this is far from the case. This paper argues that not only is the concept of 'best interests' in itself ill defined, but that existing guidance for best interests decision-making is insufficient. It will explore various interpretations of best interests as the legal framework evolved from the common law to the MCA, and it considers ongoing inconsistencies in judicial interpretation of the test of best interests and how this might impact on patient autonomy. The paper goes on to suggest that patient rights may be compounded further by a failure to take into account the complex and subjective process of clinical decision-making that may preclude wider consideration of the patient's wishes and preferences. The evaluation of best interests is subject to prejudice and bias, and information from surrogates may be unreliable. Clinical decision makers may be ill-equipped to manage complexities in the law that even the courts appear to find challenging. Far from the empowering legislation that it set out to be, the MCA may instead be used as a risk management tool. This paper will argue that the application of the best interests standard is, in fact, the tip of a complex decision-making

17 See, for example, The Law Commission, *Mental Incapacity* (Law Comm. No. 231, 1995) <<http://www.bailii.org/ew/other/EWLC/1995/231.html>> accessed 15 December 2015 [26, para. 2.46]; The Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Comm. No. 119, 1991) <<http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/other/EWLC/1991/c119.html&query=title+%28+consultation+%29+and+title+%28+paper+%29&method=boolean>> accessed 15 December 2015 [102, para. 4.18].

18 Mental Capacity Act 2005, at s 1 (2).

19 Ibid, at s 4 (4).

20 Ibid, at s 2 (1).

21 Ibid, at s 3 (1).

22 For example, see n 18, s 9 (1)(a)(b), s 16 (1)(a)(b), s 5 (1), and s 15 (1)(c).

23 Above, n 18, s 4.

24 Although more complex decisions may require a formal assessment of capacity (Department for Constitutional Affairs, *The Mental Capacity Act 2005: Code of Practice* (The Stationery Office: London, 2007) [54–4.42]), where the matter remains uncertain, an application can be made to the Court of Protection for a declaration under MCA s 15 (1).

25 Above, n 18, s 5.

26 Ibid, s 4.

iceberg, in which the individual interests of the patient are subject to multiple levels of screening and funnelling.

II. BEST INTERESTS: A HISTORICAL PERSPECTIVE

Although *Re F*²⁷ gave best interests as the standard for making clinical decisions on behalf of an incapacitated patient, the House of Lords and Court of Appeal offered two distinct interpretations of the standard. The Court of Appeal²⁸ unanimously agreed that the matter of best interests should be distinguished from any evaluation of the standard of care and suggested a two-stage process.²⁹ However, the House of Lords disagreed,³⁰ and Lord Goff of Chieveley asserted that doctors must 'act in the best interests' of the incapacitated patient, whilst at the same time acting 'in accordance with a responsible and competent body of relevant professional opinion, on the principles set down in *Bolam*'.³¹ This appeared to conflate the two elements of the test identified by the Court of Appeal, and whilst it might 'be good practice to consult relatives and others who are concerned with the care of the patient',³² this was not a prerequisite.

Although the Law Commission subsequently agreed that treatment of the incapacitated patient gave rise to two requirements, the first being to avoid tortious liability, with a second obligation to act in the incapacitated patient's best interests, it was not entirely clear how these two elements related.³³ In the absence of any definitive guidance, some took the view that the two elements were conflated, as per the House of Lords in *Re F*.³⁴ However, the Court of Appeal in *Re SL (Adult Patient: Medical Treatment)*³⁵ disagreed and found instead that in the common law, best interests 'extended beyond the duty of a doctor to act in accordance with responsible and competent professional opinion, and would incorporate broader ethical, social, moral welfare considerations'.³⁶

27 Above, n 11.

28 Ibid.

29 Per Neil LJ, whereby the doctor decides first which treatment (if any) is indicated on the basis of the patient's clinical condition and then follows this with a separate evaluation of whether it would be in the patient's wider best interests to proceed with the treatment. Best interests will be determined in accordance, but not conflated with the test in *Bolam* (above, n 15), see also *Re F* above, n 11 [1053B].

30 Lord Brandon dissenting, above, n 11.

31 Above, n 15.

32 Above, n 11 [1088].

33 The Law Commission, *Mental Incapacity* (Law Comm. No. 231, 1995) <<http://www.bailii.org/ew/other/EWLC/1995/231.html>> accessed 15 December 2015 [43; at FN 40].

34 The Law Commission (above, n 33) examined the judgments of Lords Goff (*Re F* above, n 11 [1087 and 1088]) and Griffiths (above, n 11 [1080]). However, it did not consider speeches in *Airedale NHS Trust v. Bland* [1993] 1 All ER 821 (HL) helpful in further clarifying this point, especially given that the professional negligence standard was again referred to by Lord Goff (at pp. 866 and 867) as the standard to apply when considering the issue of best interests (above, n 33 [43; at FN 40]). However, whilst Lord Goff did conflate the tests of best interests with negligence, he also suggested that doctors would be well placed to engage in some wider discussion with colleagues and the patient's relative, of what might be in the patient's best interests (above, n 11 [1088]).

35 *Re SL (adult patient: medical treatment)* [2000] All ER (D) 683 (CA).

36 This is perhaps not surprising given that the President of the Court of Appeal in *Re SL*, *ibid* [683] was Dame Butler-Sloss, who subsequently sat on, and agreed with the unanimous view of the Court of Appeal in *Re F* above, n 11.

This position was later supported by Munby J,³⁷ who, after an extensive review of the jurisprudence³⁸ considered that

[t]he doctor's duty is not merely to act in accordance with a responsible and competent body of relevant professional opinion: his duty is to act in accordance with the patient's best interests . . . the decision as to what is in fact in the patient's best interests is not for the doctor: it is for the patient if competent or, if the patient is incompetent and the matter comes to court, for the judge.³⁹

Whilst the doctor has a duty to decide whether or not a particular course of treatment is indicated, Munby J made clear that 'a doctor, of course, is not obliged, merely because he is a doctor, to provide or to go on providing medical treatment'.⁴⁰ The principle of self-determination provides that the patient may decide only whether to accept or decline an offer of treatment⁴¹; a doctor cannot be compelled to act contrary to their professional judgement to offer treatment that lacks clinical justification.⁴² If treatment is offered, the capacitous patient would consider whether it fits with their wider 'best' interests and make their decision accordingly.⁴³ If a patient lacks capacity, that evaluation of wider interests would be the responsibility of the court.

However, on appeal, Lord Phillips, MR⁴⁴ reversed the decision of Munby J⁴⁵ and rejected his interpretation of the best interests standard. Instead, he regarded the evaluation of best interests as an 'objective'⁴⁶ evaluation of clinical interests and essentially as per the test in *Bolam*.⁴⁷ It would follow, therefore, that what doctors might consider to be clinically indicated might not correlate with the patient's personal wishes.⁴⁸ Whilst the court agreed that no doctor could be compelled to provide treatment that was not clinically indicated, and that competent patients had the right to refuse treatment that did not fit with their wider interests, decisions made on behalf of incapacitated patients would rest on the doctor's professional evaluation of clinical interests. This common law approach had evolved from child care cases, and whilst the care may comply with the common law test in *Bolam*,⁴⁹ the approach was

37 Who had been instructed by the Official Solicitor to act for SL in *Re SL*, above, n 35, and successfully appealed the judge at first instance.

38 *R (on the application of Burke) v. General Medical Council* [2004] EWHC 1879 (QBD). See paras 88–97 for a general consideration of the standard, and paras 98–113 for best interests as specifically related to life-sustaining treatment.

39 *Ibid*, [para. 90].

40 *Ibid*, [para. 84].

41 Per Lord Scarman, above, n 8 [649].

42 Above, n 38 [para. 84].

43 Consider, for example, *Re C*, above, n 5.

44 *R (on the application of Burke) v. General Medical Council* [2005] All ER (D) 445 (Jul) (CA).

45 Above, n 38.

46 Above, n 44 [para. 29].

47 See above, n 15 [122].

48 Above, n 44, Per Lord Phillips, MR.

49 Above, n 15.

potentially 'restrictive'⁵⁰ and confined to medical rather than an individual's broader preferences, values, and interests.

It would therefore appear that the common law⁵¹ framework governing the care of incapacitated patients lacked clarity and consistency, and presented challenges for both patients and their carers.⁵² This was of particular concern given the aging population, and the concomitant increase in the number of people living with progressive cognitive impairment,⁵³ and was central to the development, and subsequent enactment of the MCA.

III. DEFINING 'BEST INTERESTS'

Although *Re F*⁵⁴ established 'best interests' as a guiding principle for decision-making on behalf of incapacitated patients,⁵⁵ there were historic concerns that the concept was 'too vague'.⁵⁶ Whilst some inferences can be made from the jurisprudence, 'best interests' as a concept was not defined, and the common law appeared to offer four distinct interpretations of this standard:

1. Best interests as determined by the patient's clinical needs,⁵⁷
2. Best interests taking into account a subjective evaluation of the patient's wider social and welfare preferences, separately and subsequent to the doctor's determination of clinical interests (or 'best *medical* interests'⁵⁸),⁵⁹
3. Best interests as an objective evaluation of what the 'reasonable' patient's preferences would be, if patient in question's views are not known,⁶⁰
4. Best interest as a conflation of clinical and wider welfare issues.⁶¹

50 The Law Commission, *Mentally Incapacitated Adults and Decision-Making: An Overview* (Law Comm. No. 119, 1991) <<http://www.bailii.org/ew/other/EWLC/1991/c119.pdf>> accessed 15 December 2015 [4.22].

51 As considered, for example in *Re F*, above, n 11.

52 Above, n 33.

53 Above, n 33 [20]; n 50 [3].

54 Above, n 11.

55 Although the Court of Appeal and the House of Lords presented two divergent interpretations of the standard.

56 House of Lords and House of Commons Joint Committee on the Draft Mental Incapacity Bill, *Draft Mental Incapacity Bill* (HL Paper 189-1, HC Paper 1083-1, London, 2003) Volume 1 <<http://www.publications.parliament.uk/pa/jt200203/jtselect/jtdmi/189/189.pdf>> accessed 15 December 2015 [26].

57 For example, Lord Phillips MR and what he referred to as an 'objective test', above, n 44 [para. 29], an approach subsequently adopted by the Court of Appeal in *Aintree University Hospitals NHS Foundation Trust v. David James (by his litigation friend, the Official Solicitor)* [2013] EWCA Civ 65 (CA). See also, Stephen Smith, 'Commentary: Aintree University Hospital NHS Foundation Trust v James [2013] EWCA CIV 65' (2013) 21 Med L Rev 622–631 [626]. The Court of Appeal's judgment was subsequently set aside by the Supreme Court.

58 As this might have been considered historically, per *Bolam*, above, n 15.

59 For example, as per Dame Butler-Sloss in *Re SL*, above, n 35 [683]; Munby J, above, n 38, and the Supreme Court in *Aintree University Hospitals NHS Foundation Trust v. James (by his litigation friend, the Official Solicitor) and others* [2013] UKSC 67 (SC).

60 *Aintree University Hospitals NHS Foundation Trust v. David James (by his litigation friend, the Official Solicitor)* [2013] EWCA Civ 65 (CA) [para. 59] (per Arden LJ).

61 Per the interpretation of some commentators to the Law Commission Review, above, n 33 [43; at FN 40], and the House of Lords in *Re F* above, n 11 (Lord Brandon dissenting).

It therefore appears that drafting of the MCA was based on the agreed principle that best interests would be best articulated through a checklist of factors enabling a flexible approach according to an individual's particular circumstances. So, whilst the legislation explains what must be done in pursuit of best interests,⁶² it provides no further insight into what is actually being pursued. The MCA Code of Practice⁶³ casts no further light, stating only that '[t]he term "best interests" is not actually defined in the Act. This is because so many different types of decisions and actions are covered by the Act, and so many different people and circumstances are affected by it'. It is certainly true that best interests is the guiding standard for decisions as diverse as performing a vasectomy on a man with learning disabilities⁶⁴ to settling a will.⁶⁵

Although drafting of the MCA provided an opportunity to build on the work done by the Law Commission and distinguish between 'best interests' and fulfilling a duty of care in tort,⁶⁶ this was not done. Instead, those applying the MCA are guided only in the requirements for applying the checklist of factors underpinning the standard,⁶⁷ with no further direction as to the point in the decision-making process those principles should be applied. For example, there was some scope to specify that the evaluation of best interests must be made only after determination of 'best medical interests'. Even after the MCA was passed, best interests remains 'an elusive and, in some ways an unsatisfactory concept'.⁶⁸

Not unlike the ethical principle of beneficence, best interests therefore appears to work as some guiding principle which serves to promote the well-being or benefit of the individual.⁶⁹ However, although a broad scope offers a flexible approach, the absence of more definitive guidance can make the determination of best interests challenging. The benefit to, or best interests of, a patient can amount to outcomes as diverse as: the withdrawal of active treatment to enable a peaceful and dignified death of a person in a minimally conscious state⁷⁰; force feeding to sustain the life of a patient with anorexia⁷¹; not proceeding with the amputation of a patient's severely infected leg⁷²; and removing a young woman from her home in order to perform a therapeutic sterilisation operation on her against her will.⁷³ In some of these circumstances, the outcomes appear to sit entirely at odds with the patient's wishes and preferences, and it can be difficult to reconcile the idea of force, and even a hastened

62 Above, n 18 [s 4].

63 Department for Constitutional Affairs, *The Mental Capacity Act 2005: Code of Practice* (The Stationery Office: London, 2007) [68, para. 5.5].

64 *A NHS Trust v. DE* [2013] EWHC 2562 (Fam) (16 August 2013).

65 *Re G (TJ)* [2010] EWHC 3005 (COP).

66 *Re F* above, n 11 [1087 and 1088], per Lord Goff of Chieveley, and also above, *ibid.*, [1080], per Lord Griffiths.

67 Morgan J set out the provisions in MCA s 4 (2) and s 4 (4) but went further by suggesting that 'the terms of s 4(4) may have a bearing on what is meant by "best interests" in the 2005 Act', *Re G (TJ)* [2010] EWHC 3005 (COP) [para. 26].

68 Donnelly, above, n 16 [28].

69 Above, n 2.

70 Hayden MJ considered that it would be 'disrespectful to Mrs N to preserve her further in a manner I think she (emphasis in original) would regard as grotesque'. *Re N* [2015] EWCOP 76 [para. 75].

71 *Re E (Medical Treatment: Anorexia)* (Rev 1) [2012] EWCOP 1639 (COP).

72 *Wye Valley NHS Trust v. B (Rev 1)* [2015] EWCOP 60.

73 *The Mental Health Trust & Ors v. DD & Anor* [2015] EWCOP 4 (COP).

death with best interests. There is a fine balance to be struck between the need to take every necessary action to preserve the patient's life,⁷⁴ and those circumstances where it is recognised that this is no longer appropriate.⁷⁵

The question of uncertainty was raised again by Lady Hale in the first case brought under the MCA to reach the Supreme Court,⁷⁶ *Aintree University Hospitals NHS Foundation Trust v. James (by his litigation friend, the Official Solicitor) and others*.⁷⁷ This case centred on whether withholding specified life-sustaining interventions was in the best interests of Mr James, a 68-year-old man receiving intensive care. The Court of Protection had determined that whilst the proposed treatment offered no prospect of a cure, it did bring with it the opportunity to resume 'a quality of life that [Mr. James] would regard as worthwhile'.⁷⁸ The benefits of the proposed treatment outweighed the potential unpleasant consequences associated with it. The treatment would therefore not be futile, and it would be in Mr James' best interests for doctors to proceed with it, should the need arise. However, the Court of Appeal⁷⁹ rejected this view, considering instead that the test of futility must be whether the treatment has 'the real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering'.⁸⁰

The MCA requires an overall test of best interests, and where an individual lacks capacity to make a decision, s 4 (6)⁸¹ must be applied. This required the Court of Appeal to consider what Mr James' preferences would be, given his likely dependence upon painful and invasive therapeutic interventions for what remained of his life. Although Mr James had shown great resilience in his battle to survive to that point, Sir Alan Ward concluded that 'his wish to survive was unattainable'.⁸² Therefore, although regard must be given to his wishes, 'they must give way to what is best in his medical interests'.⁸³ By focussing on his medical condition, best interests would be determined by his 'medical best interests',⁸⁴ a position apparently congruent with that of Lord Brandon in *Re F*, where he equated 'necessity to treat' with 'best interests'.⁸⁵ This had subsequently been rejected by the Law Commission as being too narrow an approach,⁸⁶ which replaces 'autonomy with judicial paternalism'.⁸⁷

74 For example, n 71 and 73.

75 See, for example, above, n 72 [para. 45].

76 *Aintree University Hospitals NHS Foundation Trust v. James (by his litigation friend, the Official Solicitor) and others* [2013] UKSC 67 (SC) [para. 23].

77 Ibid.

78 *An NHS Trust v. DJ & Ors* [2012] EWCOP 3524 (6 December 2012) [84 (1) (c)].

79 Above, n 60.

80 Ibid [para. 35 (6)].

81 Above, n 18.

82 Above, n 60 [para. 47].

83 Ibid.

84 See Stephen Smith, 'Commentary: Aintree University Hospital NHS Foundation Trust v James [2013] EWCA CIV 65' (2013) 21 Med L Rev 622–631 [626].

85 Above, n 11 [1087 and 1088].

86 Above, n 50.

87 D Feldman, *Civil Liberties and Human Rights in England and Wales* (Oxford University Press: Oxford, 2002) [284].

Arden LJ⁸⁸ went on to offer an alternative view to Sir Alan Ward,⁸⁹ arguing that the MCA required the patient's present wishes to be taken into consideration. Where this was not possible, the court should apply what amounted to an objective test⁹⁰ and 'proceed on the basis that the individual would act as a reasonable individual would act'.⁹¹ Given the knowledge of their poor condition and prognosis, it is unlikely that any reasonable person would choose to accept the interventions proposed for Mr James, and they would therefore not be in his best interests.⁹² The judge at first instance had applied the test of best interests incorrectly, and the Court of Appeal⁹³ found that given there was no prospect of Mr James recovering, the proposed treatment was futile, and the appeal by the Trust caring for Mr James was upheld. Unfortunately, by the time that the Court of Appeal handed down their written judgement,⁹⁴ Mr James had died. The Supreme Court gave Mrs James leave to appeal, given the 'importance of the issues and the different approaches taken by the trial judge and the Court of Appeal to the assessment of the patient's best interests'.⁹⁵

When the appeal reached the Supreme Court in July 2013, Lady Hale rejected the objective test of the 'reasonable patient'⁹⁶ advocated by the Court of Appeal, in favour of a subjective, decision-specific evaluation of individual preferences which 'consider [s] matters from the patient's point of view'.⁹⁷ The Supreme Court advocated a time-specific evaluation of the patient's 'welfare in the widest sense, not just medical but social and psychological'.⁹⁸ Mary Donnelly⁹⁹ also referred to a bi-partite test, which, albeit 'something of a compromise',¹⁰⁰ integrates a subjective element with what she identifies as 'the traditional "objective" assessment of best interests'. She suggested that integrating the subjective element alongside the existing objective best interests standard¹⁰¹ demands welcome attention to the patient's individual needs and circumstances, whilst foregoing the introduction of the substituted judgment standard obviates the need for the 'mental gymnastics'¹⁰² historically required when executing statutory wills. However, whilst coming short of requiring the decision maker to trans-

88 Above, n 60.

89 Albeit arriving at the same conclusion.

90 A common approach at the time, see, for example, above, n 44.

91 And fitting with the third view of best interests, considered, above, n 60 [para. 59].

92 Ibid, [59].

93 Ibid.

94 Ibid.

95 Above, n 76 [para. 15].

96 Ibid, [para. 45].

97 Ibid, [para. 45].

98 Ibid, [para. 39].

99 Mary Donnelly, 'Commentary: Determining Best Interests Under the Mental Capacity Act 2005. In the Matter of G (TJ) [2010] EWHC 3005 (COP)' (2011) 19 Med L Rev 304–313 [313].

100 Ibid, [313].

101 As per the 'balance sheet' approach as set out in *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193, where the potential benefits of a particular intervention are set against counter factors. Also, *ibid*, [306].

102 *ITW v. Z & Ors* [2009] EWHC 2525 (Fam) [para. 29] (Per Munby MJ).

port themselves to a 'hypothetical lucid interval',¹⁰³ there is some suggestion in *Aintree v. James*¹⁰⁴ that the decision maker must make more than a notional evaluation of the incapacitated patient's preferences. Factors for consideration should include not only 'the nature of the medical treatment in question, what it involves and its prospects of success . . .', but they must also evaluate the potential outcome of the treatment for that individual and attempt to ' . . . put themselves in the place of the individual patient and ask what his attitude to the treatment is or would likely to be'.¹⁰⁵ Further, and unlike the Court of Appeal, the Supreme Court held that for a treatment to be in the patient's best interests, it need not have the potential to cure, or even palliate the condition from which the patient is suffering, but need only 'bring some benefit'.¹⁰⁶ The decision makers must endeavour to ascertain the patient's views and attitudes by consulting those responsible for his care or with an interest in him.

Although *Re G (TJ)*¹⁰⁷ relates to the execution of a will, rather than specifically addressing best interests decisions in healthcare, it does offer some insight into how the courts are defining section 4. Morgan J. reviewed the jurisprudence¹⁰⁸ and concluded that an evaluation of best interests involved consideration of the factors set out in section 4, including those given at section 4 (6).¹⁰⁹ This means that 'P's likely decision can be taken into account by the court. This involves an element of substituted judgment being taken into account, together with anything else which is relevant. However, it is absolutely clear that the ultimate test for the court is the test of best interests and not the test of substituted judgment. Nonetheless, the substituted judgment can be relevant and is not excluded from consideration'.¹¹⁰ Morgan MJ suggested that this position was compatible with the judgment of Hoffmann LJ in *Bland*¹¹¹ and subsequently endorsed by Munby MJ in *ITW v. Z and Others*¹¹² where he considered that 'best interests' extends even to the way in which a person is remembered after their death, and when executing a will under the MCA. If this is true for post-mortem management of financial affairs, it would be incongruous to suggest that an evaluation of the patient's views and preferences¹¹³ should not be central to healthcare best interests decisions during their lifetime.

103 Whereby the patient is briefly transported back to a time when they had full cognitive function, equipped with their own particular preferences and views, but with the knowledge and foresight of their present situation, in order to determine on that basis what their decision would be. Per Megarry V-C in *Re D (J)* [1982] 2 All ER 37[43].

104 Above, n 76.

105 Ibid, [39].

106 Above, n 76 [para. 43].

107 Above, n 68.

108 This included a consideration of the speeches made by the Court of Appeal in *Airedale NHS Trust v. Bland* [1993] 1 All ER 821 (CA) [857] in which Hoffman LJ, in particular, recognised the need to include some element of substituted judgment within the test of best interests.

109 Above, n 68 [para. 55].

110 Ibid [para. 55].

111 See above, n 108.

112 [2009] EWHC 2525 (Fam).

113 Were they able to articulate them.

It is evident, therefore, that there is some ongoing variation in how the best interests standard is interpreted. Whilst the Court of Appeal in *Aintree v. James*¹¹⁴ favoured the 'best interests as determined by the patient's clinical needs' approach,¹¹⁵ this was subsequently rejected by the Supreme Court¹¹⁶ in favour of the 'best interests taking into account a subjective evaluation of the patient's wider social and welfare preferences, separately and subsequent to the doctor's determination of clinical interests.'¹¹⁷ That the former was the preferred approach of the Supreme Court was given further credence by Lady Hale, who made the limits of the MCA clear: it 'is concerned with enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further. On an application under this Act, therefore, the court has no greater powers than the patient would have if he were of full capacity.'¹¹⁸ But in order to get to the point of deciding whether or not to accept medical advice, the patient must first seek that advice. For example, a patient experiencing breathlessness and a productive cough has first to decide whether to obtain medical advice and then whether to act on it. The 'powers' referred to by Lady Hale¹¹⁹ appear to extend to both stages of the patient's decision-making.¹²⁰ In a sense, therefore, the MCA builds on principles set out in *Re F*¹²¹ and imposes a wider obligation for doctors caring for a patient who lacks decision-making capacity. The doctor will have a duty to the capacious patient only when they invite a consultation, yet the doctor caring for an incapacitated patient may have a duty to initiate an assessment of the patient's clinical needs.¹²²

IV. TRIGGERING AN ASSESSMENT OF MENTAL CAPACITY

Given that the best interests standard applies only to patients without decision-making capacity, the clinician must first be satisfied that their patient does, in fact, lack capacity to make that decision. But how do clinicians decide that an assessment of capacity is justified? In the years prior to the MCA, there was some suggestion that capacity assessments were linked to the patient's decision outcomes, underpinned by a rebuttable presumption of incapacity, rather than capacity.¹²³ Assessments were generally triggered by a refusal of treatment,¹²⁴ and assessment outcomes were decided

114 Above, n 60. See also commentary by Stephen Smith, above, n 84 [626]. Also, for example, Lord Phillips MR in *R (on the application of Burke) v. General Medical Council*, above, n 44.

115 Above, n 44.

116 Above, n 76.

117 Broadly in line with the 'best medical interests' approach as might have been considered historically—for example, also as per Dame Butler-Sloss in *Re SL*, above, n 35 [683]; Munby J, in *R (on the application of Burke) v. General Medical Council*, above, n 38.

118 Above, n 76 [para. 18].

119 Ibid.

120 See, for example—above, n 70; n 72 and the debate in *The Mental Health Trust & Ors v. DD & Anor* (above, n 73) to follow in this paper.

121 The applicability of the principle of necessity to non-emergency situations, as considered in *Re F* (above, n 11).

122 See the subsequent discussion of *The Mental Health Trust & Ors v. DD & Anor* (above, n 73) [paras 20–32] to follow in this paper.

123 Above, n 50 [103, para. 4.19]. Refer also to previous and subsequent discussion relating to the presumption of incapacity, rather than capacity at n 127, 147, 259, and 283–286.

124 Above, n 5, 7, and 9.

on the basis of the patient's compliance with medical advice.¹²⁵ Neither the MCA nor the MCA Code of Practice¹²⁶ provides detailed guidance on when the statutory presumption of capacity may lawfully be challenged, and evidence suggests that historic practices have persisted beyond the MCA,¹²⁷ with capacity determined on the basis of decision outcomes,¹²⁸ rather than the two-stage statutory test.¹²⁹

Assessment of capacity is therefore generally triggered by a patient's refusal of treatment,¹³⁰ and more so where outcomes carry greater risk. The weight given to the patient's decision will be inversely proportional to perceived risk.¹³¹ Indeed, as Jonathan Herring¹³² put it, '[i]t is not the level of capacity that changes, but rather the weight that is attached to the autonomous decision. Quite simply, not all autonomous decisions carry the same weight.'¹³³ The doctor is instead left to balance a complex range of obligations,¹³⁴ not least the perception of risk to the patient.¹³⁵ Paternalism may arise where the doctor's professional accountability and their duty of care to patients conflict with their obligation to respect the patient's right to autonomy and uphold the statutory presumption of capacity.¹³⁶ Patients may be 'permitted' to make decisions with lower perceived risk; indeed, this option may be welcomed where decisions involve matters that may be morally or ethically contentious. Jonathan Herring went further by suggesting that, in some situations, doctors may welcome the opportunity to defer to the patient's choice; respect for patient autonomy may relieve the doctor of accountability for a potentially contentious decision.¹³⁷

Despite the statutory presumption of capacity and prohibiting evaluation of capacity on the basis of appearance, or the apparent wisdom of decisions, it appears that a more restrictive normative code is applied to some people, such as those with

125 Above, n 33 [33, para. 3.4].

126 Above, n 24.

127 This point is considered subsequently in this paper in relation to *Re E (Medical Treatment: Anorexia)*, above n 71; advance refusals of treatment, and commentary including: Tom Hayes, 'Balancing Principles, Forcing Food: Self-Determination and Best Interests' (2012) 9 J Bioethic Inq 387. Refer also to previous and subsequent discussion relating to the presumption of incapacity, rather than capacity at n 123, 147, 259, and 283–286.

128 M Poole and others, 'Going Home? An Ethnographic Study of Assessment of Capacity and Best Interests in People with Dementia Being Discharged from Hospital' (2014) 14 BMC Geriatrics 1–15 [6].

129 Above, n 18 [ss 2 and 3].

130 See, for example, above, n 5, 7, and 9.

131 And given that any offer of treatment will be on the basis of clinical need (see above, n 44), this can logically apply only to a refusal of treatment.

132 Jonathan Herring, 'Losing It? Losing What? The Law and Dementia' (2009) 21 CFLQ 3–20 [10].

133 Not unlike the single remaining Commandment in George Orwell's *Animal Farm*, declaring that, 'all animals are equal but some animals are more equal than others': George Orwell, *Animal Farm* (Penguin: Harmondsworth, UK, 1951) [114].

134 Including the negative obligations at sections 1 (4) and 2 (3) MCA, above, n 18.

135 P Bastian, L Denson, and L Ward, 'Assessment of Patient's Decision Making Capacity: A Response to a Paper by Professor Darzins' (2011) 57 Aust Occup Ther J 392–393; above, n 121.

136 Above, n 18 [s 1 (2)]; E Mullaly and others, 'Assessment of Decision-Making Capacity: Exploration of Common Practices Among Neuropsychologists' (2007) 42 Aust Psychol 178–186; See also, for example, H Taylor, 'Promoting a Patient's Right to Autonomy: Implications for Primary Healthcare Practitioners. Part 1' (2014) 24 Primary Health Care 36–41; H Taylor, 'Promoting a Patient's Right to Autonomy: Implications for Primary Healthcare Practitioners. Part 2' (2014) 24 Primary Health Care 34–40.

137 Above, n 132 [16].

learning disabilities, mental health problems, and dementia. Unlike other members of society who are at liberty to decide whether or not to take the antibiotics prescribed by their GP, or whether to eat or drink, these decisions may be made on their behalf by doctors influenced by a fear of litigation and professional sanctions, a desire to avoid adverse patient outcomes and the weight of public opinion. The combined effect of this may mean that attempts to balance duty of care to the patient on the one hand, and a respect for their autonomy on the other, is likely to tip in favour of caution.

Assessment of capacity may have a greater impact on some sectors of society than others. Knauer argued that socially marginalised groups have historically been ‘vulnerable to allegations of incapacity’, and their decisions likely to be disregarded if they fail to comply with accepted value norms.¹³⁸ Capacity therefore ‘has the potential to become the ultimate self-fulfilling doctrine: those who exercise approved choices have capacity, whereas those who exercise socially undesirable choices lack capacity’.¹³⁹ Further, there is some suggestion that capacity assessments were performed as a means of justifying decisions made by the team with which they expected the patient to disagree.¹⁴⁰

There is certainly historic evidence that a paternalistic desire to protect those perceived as vulnerable can influence assessments of capacity¹⁴¹ and that this remains an ongoing issue in contemporary health and social care. Indeed, the House of Lords’ Select Committee Report suggests that rather than being considered with the patient at the centre, the best interests standard is frequently ‘interpreted in a medical/paternalistic sense which is wholly at odds with that set out in the Act’.¹⁴² For example, in *CC*,¹⁴³ Baker MJ warned that the evidence of professionals engaged in a working relationship with P may be motivated by a desire to protect P, as seen in some child protection cases. He referred to this as the ‘protective imperative’,¹⁴⁴ where a subjective desire to protect the vulnerable displaces a balanced consideration of the individual’s views and preferences.¹⁴⁵ In these circumstances, ‘professionals, including judges, may objectively conflate a capacity assessment with a best interests analysis’ and consider that greater weight should be placed on outcomes offering ‘physical security and comfort’ than those conferring ‘emotional security and comfort’, for example, when making a choice between living in a nursing home and their own home.¹⁴⁶ If the person concerned does not follow the same line of thinking as those

138 N Knauer ‘Defining Capacity: Balancing the Competing Interests of Autonomy and Need’ (2003) 12 Temp Pol & Civ Rts L Rev 321 [347].

139 Ibid [343].

140 Above, n 128 [7].

141 Above, n 124.

142 House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Incapacity Act 2005: Post-Legislative Scrutiny. Report of Session 2013-2014* (HL paper 139, The Stationery Office, London 2014) <www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf> accessed 15 December 2015 [45].

143 *CC v. KK and STCC* [2012] EWHC 2136, [2013] All ER (D) 57, COP.

144 *Oldham MBC v. GW and PW* [2007] EWHC 136, Fam, <<http://www.familylawweek.co.uk/site.aspx?i=ed703>> accessed 7 December 2015, para. 97, per Ryder J.

145 Above, n 143 [para. 65].

146 Ibid.

making an assessment, this may be regarded as indicative of incapacity and prompt assessment under the provisions of the MCA.¹⁴⁷ Healthcare professionals may find it very difficult to accept that someone would choose to refuse lifesaving treatment, and particularly if their reasons for doing so appear irrational. For example, one recent application to the Court of Protection attracted wide media attention¹⁴⁸ when a woman refused life-sustaining haemodialysis on the grounds that she had no wish to continue living a life that no longer 'sparkles'.¹⁴⁹

As considered previously in this paper, decision makers may be challenged by the need to balance an individual's right to choose on the one hand, with their duty of care for that person on the other. For example, it is known that doctors may be motivated by the fear of liability in tort, and the associated, and uninsured, non-financial costs of 'lost time, the matter of reputational damage, and the expenditure of emotional energy in responding to a malpractice claim',¹⁵⁰ and make decisions 'based on fear of liability rather than patients' best interests'.¹⁵¹ They may adopt a more conservative approach to treatment of their patients than if making the same decision for themselves.¹⁵² Doctors have also been shown to engage in other risk limitation actions, including 'negative defensive' actions, such as removing challenging patients from their list, and 'positive defensive' actions including increased referrals for opinion and diagnostic testing, and prescribing drugs that were not necessary.¹⁵³ If translated into actual clinical practice, this suggests that clinical decisions may be shaped by awareness of potential legal implications, leading the researchers to conclude that '[p]atients cannot blindly trust their doctors'¹⁵⁴ and should challenge their decisions.¹⁵⁵

Although clinical decisions generally¹⁵⁶ sit outside the governance of the MCA framework, they are intrinsically linked.¹⁵⁷ Once the doctor has decided what treatment (if any) is appropriate for the patient's clinical needs, the next course of action (to accept or refuse) will fall within the MCA framework if the patient lacks decision-making

147 Refer also above n 123 and 127 for previous references to this issue. See also, for example, in *EM (by his litigation friend the Official Solicitor) v SC and another* [2012] EWHC 1518, [2012] All ER (D) 42, COP, where an assessment of incapacity appeared to balance on Mr M's desire to return home to a son who had threatened to shoot him. Refer also to previous and subsequent discussion relating to the presumption of incapacity, rather than capacity at n 123, 127, 259, and 283–286.

148 For example, The Guardian, 'Court grants woman right to die after "losing her sparkle"', <<http://www.theguardian.com/uk-news/2015/dec/02/court-grants-impulsive-self-centred-mother-permission-to-die>> accessed 15 December 2015.

149 *Kings College Hospital NHS Foundation Trust v. C & Anor* [2015] EWCOP 80 [para. 8].

150 DP Kessler, N Summerton, and JR Graham, 'Effects of the Medical Liability System in Australia, the UK, and the USA' (2006) 368 *Lancet* 240–246 [241].

151 With there being no indication here that 'best interests' refers to anything other than what is clinically indicated, *ibid* [245].

152 R Garcia-Retamero and M Galesic, 'On Defensive Decision Making: How Doctors Make Decisions for Their Patients' (2012) 17 *Health Expectations* 664–669 [668].

153 Above, n 150.

154 Above, n 152 [668].

155 This refers to the point raised below, n 190, about the acquiescent but incompetent patient who may slip through the MCA net. I Sleeman and K Saunders, 'An Audit of Mental Capacity Assessment on General Medical Wards' (2013) 8 *Clin Ethics* 47–51.

156 This paper has considered that seeking medical opinion may fall within obligations imposed by the MCA, but the clinical decision itself sits outwith this framework, above, n 24.

157 Above, n 76 [para. 18].

capacity. The clinical judgement providing the foundation of the best interests decision may therefore be vulnerable to the clinician's 'personal biases'.¹⁵⁸ This means that two doctors faced with the same decision could arrive at different outcomes and suggests an inherent lack of reliability or consistency within this process.

*The Mental Health Trust & Ors v. DD & Anor*¹⁵⁹ is a particularly tragic case which gives some insight into the challenges facing the courts when required to consider individual preferences that expose a patient to risk. Ms D was a young woman with complex learning disabilities and mental health problems. She had a complicated obstetric and gynaecological history, including the concealment of her pregnancy and self-delivery of infants in what were described as 'grossly unhygienic circumstances'.¹⁶⁰ To the best of the court's knowledge, she had given birth to six children, with no ongoing contact with any of them. A further pregnancy exposed Ms D to the risk of potentially fatal complications and any future children at risk of harm. Despite having requested a therapeutic sterilisation in the past,¹⁶¹ at the time of the application, Ms D preferred to abstain from using reliable contraception.

The first challenge for the court was to establish its jurisdiction in the matter.¹⁶² Although there was a long history of the court's engagement with Ms D's antenatal and postnatal cares,¹⁶³ in the present case, Cobb MJ conceded that the applicant Mental Health Trust's duty to Ms DD was 'regrettably less than clear',¹⁶⁴ given that Ms D 'did not obviously or immediately demand medical treatment'.¹⁶⁵ However, after a detailed review, Cobb MJ concluded that the Applicant's duty to Ms D arose from a combination of various legislation and the common law¹⁶⁶; and that given Ms D's refusal to engage with healthcare professionals on the matter of contraception, the matter could be managed under the provisions of the MCA.¹⁶⁷

Having taken account of Ms D's personal circumstances,¹⁶⁸ and establishing that she lacked capacity to consent to contraceptive treatment (including therapeutic sterilisation), the court was then required to consider whether the s 1 (3) requirements of the MCA¹⁶⁹ had been satisfied. The judgment indicated that during the last pregnancy alone, there were '[t]wenty-five unannounced visits by a range of personnel from social services',¹⁷⁰ which perhaps not surprisingly failed to result in any meaningful

158 Alan Bryman, *Social Research Methods* (Oxford University Press: Oxford, 4th edn, 2012) [289].

159 Above, n 73.

160 Above, n 73 [para. 10].

161 For which she was considered to lack the capacity to consent, *ibid* [para. 35].

162 *Ibid*, [paras 20–32].

163 *Ibid*, [paras 14–19].

164 *Ibid*, [para. 23].

165 *Ibid*, [para. 21].

166 *Ibid*, [para. 24], and following detailed consideration from paras 20–32, and including the Mental Capacity Act 2005, the Human Rights Act 1998, and *Re Z (Local Authority Duty)* [2004] EWHC 2817 (Fam) [2005] 1 FLR 740. This case arose prior to the Care Act 2014, and Cobb MJ recognised that 'this will change to some extent if or when section 1 of the *Care Act 2014* (which appears to consolidate some of the existing statutory duties and create a duty to promote an individual's well-being, including their physical and mental health) is brought into force' [para. 24].

167 *Ibid*, [para. 48].

168 *Ibid*, [paras 48–58].

169 Above, n 18.

170 Above, n 73 [para. 38 (i)].

engagement between Ms D, her partner, and the statutory services. In addition to these visits, further attempts at contact by midwifery services were refuted. Taking this into account against a backdrop in which Ms D remained 'very resistant'¹⁷¹ to engagement with health and social care services, Cobb MJ was satisfied that 'all "practicable steps"'¹⁷² had indeed been taken. The court was then required to consider whether Ms D was likely to have capacity to make this decision at some point in the future,¹⁷³ but the evidence presented on behalf of the Official Solicitor indicated that this was unlikely 'unless [Ms D] is able to develop a personal or professional relationship where she can be supported in making such decisions', albeit that this would be 'vanishingly unlikely for the foreseeable future'.¹⁷⁴

This case presents an undeniably tragic scenario; Ms D was abused as a child, and then lost all six of her own children. When considering whether on balance a therapeutic sterilisation would be in Ms D's best interests, Cobb MJ considered her fertility to be a burden, rather than a benefit to her, 'bringing with it the prospect of on-going long-term intrusion by health and social care services into her life'.¹⁷⁵ Following a section 15 declaration of incapacity, an order was made for her removal to hospital where the surgery could be performed, with the use of force if appropriate. Ms D's preferences in this case were quite clear; she wanted to be left in peace, and for health and social care professionals to leave her to live her life free from interference.¹⁷⁶ The outcome could not be further from that and demonstrates some very uncomfortable issues that may arise when interpreting and applying the MCA.

Although the challenges surrounding the administration of temporary contraception are well documented throughout the case, it is perhaps surprising that no real consideration is given to the context within which the order was being sought. This represented a time of some challenges for Ms D: she had recently given birth; lost contact with one of her children, and had been subject to what might reasonably be regarded as persistent invasions of her privacy. Ms D may also have been suffering from a post-partum exacerbation of her mental illness. Further, whilst undoubtedly representing complex and difficult circumstances, the judgment offers no consideration of the potential impact of four recent confinements (two of which resulted in post-partum delusional disorder¹⁷⁷) on Ms D's decision-making capacity. Also, only brief attention is paid to the impact of Ms D's grief for her lost children on her mental state,¹⁷⁸ despite the observance that she had demonstrated 'warmth and affection towards the baby'.¹⁷⁹ Ms D is described as demonstrating 'occasional hostility',¹⁸⁰ but given the circumstances, perhaps that is understandable. It is interesting that the judge referred to eugenics at two distinct points of the judgment but emphasises that 'this

171 Ibid, [para. 76].

172 Ibid.

173 Above, n 18 [s 4 (3)].

174 Above, n 73 [para. 78].

175 Ibid, [para. 114].

176 Ibid [para. 118].

177 Above, n 73 [para. 66].

178 Ibid, [para. 119].

179 Ibid, [para. 40].

180 Ibid, [para. 17].

case is not about eugenics',¹⁸¹ and that the court was satisfied that there had been no unlawful interference with her human rights,¹⁸² yet it is difficult to imagine other scenarios in which such external interference could be lawfully engaged.

*Mental Health Trust & Ors v. DD & Anor*¹⁸³ represents some very challenging circumstances, within which Ms D undoubtedly felt entirely without control, or audible voice, but where she received legal hearing and representation. This may not be the case generally, where doctors and other clinicians routinely make best interests decisions on behalf of their patients. Whilst there is scope for patients to apply to the Court of Protection for settlement of disagreements about capacity assessments or best interests decisions,¹⁸⁴ the MCA Code of Practice directs complainants to alternative measures, such as mediation¹⁸⁵ and the Patient Advice and Liaison Service (PALS).¹⁸⁶ Given that access to the Court of Protection has been found to be difficult, costly, and time consuming,¹⁸⁷ these alternatives may be preferable. That being said, negotiating their way through these processes may prove too much of a challenge for some patients, despite an awareness that they have all at once become an unheard voice in what amounts to a Kafkaesque experience of being denied the right to make their own decisions.

So, in practice, assessments tend to be triggered only when patients disagree with staff,¹⁸⁸ agreement is conflated with capacity, and vice versa.¹⁸⁹ Whilst 'disagreeable' patients could have their rights unlawfully compromised, there is also potential for the interests of acquiescent, but potentially incapacitated patients to be compromised.¹⁹⁰ If incapacity remains unrecognised, patients will be deprived of the protection offered by the MCA, and the treatment may proceed without any wider evaluation of whether it is in the patient's best interests.¹⁹¹ Sometimes, even where there is uncertainty, the presumption of capacity is upheld when an assessment may be warranted.¹⁹² One witness to the House of Lords Review of the MCA (HOLSC)¹⁹³ suggested that 'the presumption of capacity is a good starting point, but should be questioned more than it is'.¹⁹⁴

It has been mentioned already that the MCA enables the court¹⁹⁵ only to do that which the patient would be able to do if he had capacity,¹⁹⁶ and that is limited to

181 Ibid, [paras 8 and 114].

182 Ibid, [paras 82 and 83].

183 Ibid.

184 See above, n 66 [para. 8.3].

185 Ibid [paras 15.7–15.13].

186 Ibid [paras 15.14–15.21].

187 Above, n 142.

188 Above, n 142 [40]; H Taylor, 'Promoting a Patient's Right to Autonomy: Implications for Primary Healthcare Practitioners. Part 2' (2014) 24 Primary Health Care 34–40.

189 D Okai and others, 'Mental Capacity in Psychiatric Patients: Systematic Review' (2007) 191 Br J Psychiatry 291–297, 295.

190 Above, n 155.

191 Lady Hale recognised that the remit of the MCA is do that which the patient would do for themselves if they had capacity, above, n 76 [para. 18].

192 Above, n 135.

193 Above, n 142.

194 Dr Heslop, the principal investigator of the Confidential Enquiry into premature deaths of people with learning disabilities, see above, n 142 [para. 77].

195 Or anyone else making a best interests decision, for example, see above, n 76 [para. 18].

196 Ibid.

deciding whether to accept or refuse treatment the doctor considers to be clinically indicated.¹⁹⁷ This serves as a useful reminder that even before any wider consideration of best interests, the patient will have been subject to the process of clinical decision-making; an often complex diagnostic, and decision-making process,¹⁹⁸ and one that is potentially vulnerable to subjectivity or bias.¹⁹⁹

V. PRACTITIONER UNDERSTANDING OF THE 'BEST INTERESTS' STANDARD

Returning to the application of the MCA, having made an assessment of incapacity, and assuming that the decision involved is one that falls within their scope,²⁰⁰ the doctor's next step will be to make a best interests decision. However, this paper has already shown that when the Supreme Court set out the best interests standard in *Aintree v. James*,²⁰¹ this represented some variance from the position adopted previously by the Court of Appeal.²⁰² This reflects the inconsistent approach the courts had adopted previously when interpreting and applying the statutory best interests standard and may offer some explanation for the prevailing confusion in clinical practice, with some doctors erroneously continuing to adopt the approach taken by the Court of Appeal in *Aintree v. James*.²⁰³ Having rebutted the presumption of capacity, their next (and only) step will be to make an evaluation of the patient's clinical needs, before proceeding with care on the basis of their best *medical* interests, rather than complying with the correct standard set out by the Supreme Court²⁰⁴ which requires that a clinical evaluation is followed by a wider consideration of the patient's best interests.

Indeed, there is evidence that practitioners do not understand 'the concept of best interests as defined by the Act',²⁰⁵ with one witness to the HOLSC going even further by stating that 'the term "best interests" is probably the most abused and misunderstood phrase in health and social care. It has too often been the vehicle for poor decision-making'.²⁰⁶ Ongoing misunderstanding of the provisions of the MCA can mean that dominance of 'prevailing professional practices' remains uncontested, and input from the patient is largely absent.²⁰⁷ For example, one study²⁰⁸ explored what 11 members of a multidisciplinary palliative care team understood by the term 'best interests'.²⁰⁹ Data

197 Above, n 44.

198 W Crebbin, S Beasley, and D Watters, 'Clinical Decision Making: How Surgeons Do It' (2013) 83 ANZ J Surg 422–428.

199 For example, A Green and others, 'Implicit Bias Among Physicians and Its Prediction of Thrombolysis Decisions for Black and White Patients' (2007) 22 SGIM 1231–1238; L Bogart and others, 'Factors Influencing Physicians' Judgments of Adherence and Treatment Decisions for Patients with HIV Disease' (2001) 21 Med Decis Making 28–36.

200 Above, n 66.

201 Above, n 76.

202 Above, n 60.

203 Ibid.

204 Above, n 76.

205 Above, n 142 [46].

206 Ibid, [45].

207 Ibid, [107].

208 D Harris and I Fineberg, 'Multidisciplinary Palliative Care Teams' Understanding of Mental Capacity Act 2005 "Best Interest" Determinations' (2011) 17 Int J Palliat Nurs 20–25.

collected in the summer of 2009 indicate that half of the group lacked clear understanding of what 'best interests' meant; one respondent suggested that 'best interests' meant that '... [healthcare practitioners] should be making sure we enable somebody to make their own choice before we look at other ways of getting things done'.²¹⁰ Another pondered, '[b]est interests, let me think, we want to make their end as dignified and as symptom free and as good as it can possibly be',²¹¹ whilst a third practitioner identified that '[d]ecisions are obviously very reliant upon whether the patient can tell you... what it actually is they feel would be in their best interests'.²¹² This confusion indicates the need for additional training²¹³ and is suggestive of best interests decision-making prevalent 'prior to the MCA, in which decisions are made by professionals in consideration of desired or perceived outcomes, perceptions of risk, and issues of control and power'.²¹⁴ This suspicion was given credence by evidence presented within the House of Lords Select Committee Report²¹⁵ indicating that, not only was the concept misunderstood, it was possibly being applied in its 'lay or clinical' sense.²¹⁶ Indeed, one witness reported that '[s]taff defined a "best interests" decision as a "clinical decision"—and just saw it as a matter of clinical judgment'.²¹⁷

However, even where training has been undertaken, an improved understanding of the principles of the MCA is not a given. Willner et al.²¹⁸ conducted an evaluation of the knowledge and understanding of a group of healthcare practitioners²¹⁹ both before and after attending a combined MCA workshop and lecture. They found that although the sample had a good factual recall of key principles of the MCA,²²⁰ they were less competent when applying those principles to practise-based scenarios. For example, only 66% of practitioners recognised that in clinical situations, a best interests decision would follow an assessment of incapacity.²²¹ Further, respondents were not sure who should make a best interests decision, were not clear who should be consulted as part of the process,²²² or the matters that should be taken into account when making the decision.

209 Per the MCA, above, n 18.

210 Above, n 208 [22].

211 Ibid.

212 Ibid, [22]. See also n 128 [8].

213 Ibid.

214 Ibid, [24 and 25].

215 Above, n 142.

216 Peter Bartlett, 'Good Act, Poor Implementation: The Report of the House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005' (2014) 157 *Elder LJ* [3], <http://eprints.nottingham.ac.uk/28660/1/Elder_Law_Journal_paper_14_04_02.pdf> accessed 10 June 2015.

217 Above, n 142 [para. 92].

218 P. Willner and others, 'What Do NHS Staff Learn from Training on the Mental Capacity Act (2005)?' (2013) 18 *Legal Criminol Psychol* 83–101.

219 A sample of 80 health and social care practitioners (including doctors, nurses, and social workers) and 6 clerical workers, *ibid*, [83–101].

220 For example, that any decision made on behalf of an incapacitated patient must be in their best interests.

221 However, this reflected a greater awareness than for scenarios considering financial decisions, where only 52% of the sample understood when a best interests decision would be indicated, above, n 218 [91 and 92].

222 Only 60% correctly identified the patient's family, professional care workers, and informal carers as being among those likely to be involved, above, n 218.

These findings highlight the need to reconsider how MCA training is conducted. Indeed, Willner et al²²³ suggested that not all forms of training are fit for the intended purpose; whilst the practitioners in their study generally demonstrated good factual recall of key principles of the MCA, their applied understanding was less accomplished.²²⁴ The researchers identified that there is more to transforming practice than imparting knowledge and instead identified the benefits of providing more opportunities for practitioners to explore how MCA principles such as rebutting the presumption of capacity, and the best interests standard, are applied in practice.²²⁵ This paper will now consider issues specific to the principles set out in section 4.

VI. WHAT WEIGHT TO PUT ON EACH FACTOR?

Having established that a best interests decision is indicated, the doctor must then take into account the complex range of factors set out in section 4. These require the decision maker to involve P 'so far as reasonably practicable'²²⁶ and to take into consideration the views of a range of people associated with the patient 'if it is practicable and appropriate to consult them'.²²⁷ Whilst the MCA appears to place some implied emphasis on the weight to be given to the patient's past and present wishes, feelings, and values,²²⁸ commentators have generally remarked on the lack of any explicit prioritisation of the factors to be taken into account when determining best interests.²²⁹ This sits in line with the recommendation of the Joint Committee on the Draft Mental Incapacity Bill that there should be no weighting, or other ranking, of any of the factors taken into consideration when determining best interests.²³⁰ This recommendation was upheld in the final drafting, so although the MCA sets out a 'checklist' of factors to be taken into account when determining best interests, the Code of Practice emphasises that both this, and the principle of best interests generally, are 'flexible', enabling decision makers to consider each case on an individual basis.²³¹

The value of this flexibility was recognised by Munby MJ,²³² in that it allows decision makers to focus on those factors they recognised to be of key significance or of 'magnetic importance'.²³³ However, whilst there is undeniably some value in this,

223 Ibid, [94].

224 Ibid, [91-92]. See also above, n 128 [2].

225 Practitioners working in the specialist areas of mental health and learning disabilities who had experienced wider opportunity to apply the MCA in practice generally demonstrated a better performance in the interviews. Ibid, [95].

226 Above, n 18 [s 4 (4)].

227 Ibid, [s 4 (7)].

228 At section 4 (7), the MCA lists the people whose views the decision maker 'must take into account, if it is practicable and appropriate to consult them . . . as to what would be in the person's best interests and, *in particular* [emphasis added], as to the matters mentioned in subsection (6)', and infers some imperative to consider the patient's '(a) . . . past and present wishes and feelings . . . (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so', *ibid*, [s 4 (6)].

229 Above, n 99 [308].

230 Above, n 56 [para. 21].

231 Above, n 66 [88, para. 5.62].

232 Above, n 102 [para. 33].

233 Coining a phrase used by Thorpe LJ in cases such as *Crossley v. Crossley* [2007] EWCA Civ 1491 [para. 15], albeit in relation to proceedings for ancillary relief.

deciding what weight to place on each element places some additional burden on the decision maker. The jurisprudence demonstrates that not only is this an involved process,²³⁴ but also that the principle is not applied consistently²³⁵; decision makers may arrive at different outcomes on the same facts.²³⁶ Further, whilst the courts are able to engage in a detailed analysis of the jurisprudence and draw on a range of expert legal and medical opinions, this is unlikely to be an option for clinicians making decisions within exactly the same statutory framework, but most likely within a very different context.²³⁷ Generally, much of the Court of Protection's work is done in camera,²³⁸ which means that those making decisions beyond its confines²³⁹ will be denied the insight and clarification that might be offered by open dissemination, consideration, and review of the decision-making process.²⁴⁰

VII. WHAT WEIGHT TO ATTACH TO THE PATIENT'S WISHES?

As already considered, the MCA allows some flexibility in the relative weighting of information used in decision-making, although it has been suggested that input from the patient should be given particular attention.²⁴¹ However, Munby MJ considered that, whilst the patient's 'wishes and feelings will always be a significant factor',²⁴² the weight placed on these will depend on the facts of the particular case, and '[i]n some cases, in some situations, they may carry much, even, on occasions, preponderant, weight. In other cases, in other situations, and even where the circumstances may have some superficial similarity, they may carry very little weight',²⁴³ and went on to set out what these determinative factors would include. Whilst some appear logical, such as how consistently the views have been articulated, others warrant further evaluation. For example, Munby MJ suggested that the extent of the patient's incapacity should be taken into account, because 'the nearer to the borderline the more weight must in principle be attached to P's wishes and feelings'.²⁴⁴ Here, Munby MJ referred to his judgment in a case heard under the common law,²⁴⁵ in which best interests decisions were made in relation to, among other issues, residence and social contacts. He made reference to Thorpe J *In re C (Adult: Refusal of Treatment)*,²⁴⁶ who considered how to balance between a doctor's duty to preserve life on the one hand and the patient's right to autonomy on the other. Applying the common law test of

234 For example, above, n 71; *Re E*, above, n 102; *ITW v. Z & Ors* above, n 98 [para. 33].

235 This was only too apparent in the case of *Aintree v. James*, above, 76 and 60, where the Supreme Court engaged an approach entirely at odds with the Court of Appeal.

236 See *Aintree v. James*, above, 76 and 60. An example of where doctors may arrive at different outcomes is given in *A NHS Trust v. DE* [2013] EWHC 2562 (Fam) (16 August 2013) where there was a difference in medical opinion as to whether a vasectomy would be in P's best interests.

237 As indicated below, n 288 which considers the difference between *Kerry Woollorton* and *Re E*, above, n 71.

238 Above, 99 [305].

239 Such as doctors and other clinical practitioners.

240 Above, n 99 [305].

241 Above, n 18 [s 4 (4)] and [s 4 (7)].

242 Above, n 102 [para. 35 (i)].

243 *Ibid*, [para. 35 (ii)].

244 *Ibid*, [para. 34 (iii)].

245 *Local Authority X v. MM & Anor* (No. 1) [2007] EWHC 2003 (Fam).

246 Above, n 5.

capacity,²⁴⁷ Thorpe J's view was that where decision-making capacity is unimpaired, 'autonomy weighs heavier, but the further capacity is reduced, the lighter autonomy weighs'.²⁴⁸ Munby MR went on to argue that

[t]he converse is also true. The nearer to the borderline the particular adult, even if she falls on the wrong side of the line, the more weight must in principle be attached to her wishes and feelings, because the greater the distress, the humiliation and indeed it may even be the anger she is likely to feel the better she is able to appreciate that others are taking on her behalf decisions about matters which vitally affect her—matters, it may be, as here, of an intensely private and personal nature.²⁴⁹

However, this analysis suggests a sliding scale of incapacity, rather than the determinative test provided by the MCA.²⁵⁰ Munby also proposed²⁵¹ that the court should consider 'the extent to which P's wishes and feelings are, or are not, rational, sensible, responsible and pragmatically capable of sensible implementation in the particular circumstances'.²⁵² On this basis, the decision maker is required to impose value judgements that appear entirely at odds with the ethos and provisions of the MCA.²⁵³ This sits with a view put forward by Huxtable that whilst medical law appears to value an individual's autonomy, with freedom to choose in line with their own preferences, evidence from both clinical practice and the jurisprudence²⁵⁴ indicate that freedom is limited. For example, Poole et al²⁵⁵ considered the impact value judgements had on the assessment of one patient's wish to be discharged from hospital to a home they describe as 'squalid'.²⁵⁶ There was explicit acknowledgment that the assessment of capacity, and best interests were conflated with an evaluation of risk, indicative of an outcomes approach to assessment of decision-making capacity.²⁵⁷ Disagreement with the multidisciplinary team was likely to be taken as an indication of incapacity²⁵⁸ and indicates that rather than a rebuttable presumption of capacity, in some instances

247 Per Thorpe J '(1) to take in and retain treatment information, (2) to believe it and (3) to weigh that information, balancing risks and needs'. *Ibid*, [822].

248 *Ibid*, [822].

249 Above, n 245 [para. 124].

250 The patient either has capacity to make a particular decision, or he does not. See above, n 18 [ss 2 and 3].

251 Somewhat paradoxically given that these criteria may not be used as part of any evaluation of capacity, above, n 18 [s 1 (4)].

252 Above, n 102 [para. 34 (d)].

253 Yet, the MCA provides that apparent rationality cannot be used as the basis of a determination of capacity, and this position implies a sense of paternalism. See, for example, above, n 18 [s 1 (4)] and [s 2 (3)(b)].

254 See Richard Huxtable, above, n 1 [475 and 476].

255 Above, n 128 [5].

256 *Ibid*, [5 and 6].

257 *Ibid*, [6].

258 Whilst the researchers suggest that practise may have evolved since data were collected between June 2008 and June 2009 (*ibid*, [4]), they counter that with findings of the HOLSC, above, n 142, and their own 'subjective impression [that] if things have changed they have not changed significantly and we are unaware of any research which might suggest otherwise', and is indicative of the outcomes approach to capacity assessment, *ibid*, [6].

patients are being required to rebut a presumption of incapacity.²⁵⁹ Indeed, evidence suggests that historically a patient's inconsistent or anomalous behaviour was often considered sufficient both to rebut the presumption of capacity and negate the need for a formal assessment of capacity. Evidence of cognitive impairment was often regarded as being synonymous with the absence of decision-making capacity.²⁶⁰

Mary Donnelly²⁶¹ raised the 'conceptual dilemma' that may arise if a patient's preferences do not fit with what others consider to be in their best interests or if there is conflict between their past and present wishes, preferences, and/or interests.²⁶² She suggested that in these circumstances, whilst the MCA provides no explicit guidance as to how this dilemma might be resolved, section 25 (2)²⁶³ indicates a 'normative preference for present wishes over past values'.²⁶⁴ Specifically, this section includes a rather curious provision that an advance decision made by the capacious patient,²⁶⁵ but enforceable only when they have lost decision-making capacity,²⁶⁶ will become invalid if²⁶⁷ they have subsequently 'done anything else clearly inconsistent with the advance decision remaining his fixed decision'.²⁶⁸ This applies even if the patient has not taken advantage of the facility to withdraw their advance decision.²⁶⁹ In the absence of any guidance on what weight to be placed on 'inconsistent'²⁷⁰ acts post loss of capacity, or how 'clearly' might be interpreted, it would not only support the normative preference for most recent views²⁷¹ but poses some questions over the durability and utility of advance decisions.

The Devil's Advocate might argue that section 25 (2) (c) provides a very useful reserve option when patients make decisions with which others are not entirely comfortable. For example, some brief consideration of section 25 (2) was made in *Re E (Medical Treatment: Anorexia) (Rev 1)*.²⁷² E was a young woman with a range of complex and serious health issues, including anorexia nervosa and alcohol dependency. She endured a range of unsuccessful treatments over a prolonged period of time, and the Court of

259 See also the discussion that follows (below, n 283–286) in relation to *Re E* (above, n 71), and the work by Tom Coggon, 'Anorexia nervosa, best interests, and the patient's human right to "a wholesale overwhelming of her autonomy": A Local Authority v. E [2012] EWHC 1639 (COP) [2012] HRLR 29' (2014) 22 Med Law Rev 119–130, and T Hayes, 'Balancing Principles, Forcing Food: Self-Determination and Best Interests' (2012) 9 J Bioethic Inq 387, and also discussion above at n 123, 127, and 147.

260 H Taylor, 'The Nursing Assessment of Older Adults' (PhD thesis, University of Coventry, 2005); H Taylor, *Assessing the Nursing and Care Needs of Older Adults* (Radcliffe Publishing Ltd: Oxford, 2005). This also reflects findings from P Sansone and others, 'Determining the Capacity of Demented Nursing Home Residents to Name a Health Care Proxy' (1998) 19 Clin Gerontol 35–50. See also above, n 5.

261 Above, n 16 [28].

262 Consider here, for example, the facts in *Re E*, above, n 71.

263 Above, n 18.

264 Above, n 99 [311].

265 Above, n 19 [s 24 (1)].

266 Ibid, [s 24 (1)(b)].

267 Among other reasons.

268 Above, n 18 [s 25 (2)(c)].

269 Ibid, [s 24 (3)].

270 Refer to Munby MJ (above, n 102 [para. 34 (d)]) where weight is given to factors in apparent conflict with the general ethos of the MCA.

271 Albeit that it may be that these present views might have led to the inference of incapacity, see above, n 124.

272 Above, n 71.

Protection was asked to determine the lawfulness or otherwise of treating her against her wishes.²⁷³ E had made an advance decision stating that if she were close to death, she would accept pain relief but would not wish to be tube fed or receive any additional life support. Jackson J agreed that 'the s. 25 formalities surrounding this decision were complied with'²⁷⁴ and that the decision had not subsequently been withdrawn. Included within the advance decision was an additional note in which E stated: 'If I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision.'²⁷⁵ However, in Jackson MJ's view, this was not 'an instruction that could be binding in the light of MCA s. 25(2)',²⁷⁶ yet he did not explain why this might be so. Despite E's advance decision having been witnessed both by her mother and a mental health professional,²⁷⁷ other opinion suggested that at the time she lacked decision-making capacity. The court accepted this view on the balance of probabilities and thereby obviated the need to consider whether her subsequent behaviour had been inconsistent with her advance decision.²⁷⁸

Overall, the court held that 'the presumption in favour of the preservation of life is not displaced',²⁷⁹ and life-sustaining treatment was considered to be in E's best interests. Further, in circumstances such as these, 'a full, reasoned and contemporaneous assessment evidencing mental capacity to make such a momentous decision' was necessary for an advance decision to be valid.²⁸⁰ Not only is this setting out requirements above what is required by the MCA,²⁸¹ but it is also difficult to see how this is compliant with the principles set out in section 1 of the MCA.²⁸²

Indeed, John Coggon's commentary²⁸³ reflected on this and considered the disquieting implications of Jackson J's judgment.²⁸⁴ He agreed with Tom Hayes²⁸⁵ conclusion that 'Jackson J. seems . . . to have turned the legal presumption of capacity on its head, seeking to rebut a presumption of incapacity'.²⁸⁶ This is an issue considered earlier in this paper which appears to set the evidential bar higher for E and others like her on the basis of her condition than would otherwise be required²⁸⁷ and raises the potential for

273 Among other issues.

274 Above, n 71 [para. 62].

275 Ibid, [para. 63].

276 Ibid.

277 E's consultant psychiatrist who had been treating her for 6 years.

278 Above, n 71 [para. 69].

279 Ibid, [para. 140].

280 Ibid, [para. 65].

281 See above, n 66 [paras 9.24–9.28].

282 And particularly above, n 18 [s 1 (2)] and [s 1 (4)].

283 J Coggon, 'Anorexia Nervosa, Best Interests, and the Patient's Human Right to "a Wholesale Overwhelming of Her Autonomy": A Local Authority v. E.' (2014) 22 Med L Rev 119–130.

284 Per Jackson, MJ above, n 71 [paras 55 and 65].

285 T Hayes, 'Balancing Principles, Forcing Food: Self-Determination and Best Interests' (2012) 9 J Bioethic Inq 387.

286 Above, n 283 [127] (emphasis in original).

287 See commentary at <http://www.39essex.com/cop_cases/a-local-authority-v-e-and-others/> which compares the very different outcomes for E and a young woman called Kerrie Woollorton. Both had suffered long-term mental illness and made advance decisions to refuse life-sustaining treatment. However, Ms Woollorton's decision never received the attention of the Court of Protection, and her wishes were upheld by the doctors caring for her.

discriminatory practice.²⁸⁸ Some consideration of compatibility with the UNCRPD may therefore be warranted.²⁸⁹ Further, there is no suggestion that any 'clearly inconsistent'²⁹⁰ act requires such robust substantiation²⁹¹; guidance in the MCA Code of Practice states only that 'the person has done something that clearly goes against the advance decision which suggests that they have changed their mind'.²⁹²

This offers a somewhat paradoxical and confusing perspective; on the one hand, the patient's mental capacity is so impaired that he is considered unable to make a decision for himself,²⁹³ but having foreseen this possibility, has made advance indication of his preferences. However, on the other hand, when the time comes, the MCA provides that those caring for him must take into account anything that he has done subsequently and potentially whilst in an incapacitated state²⁹⁴ which might give cause to set his advance refusal aside. Given the ongoing evidence that decision-making capacity continues to be assessed on the basis of outcomes,²⁹⁵ it may well be that it was the patient's articulation of their present wishes that led to an assessment of incapacity,²⁹⁶ adding further weight to the HOLSC's view that the MCA's intended aim of personal empowerment has been limited by 'prevailing professional cultures of risk aversion and paternalism'.²⁹⁷

288 UN General Assembly. A/RES/61/106. Full text available at <<http://www.un.org/disabilities/default.asp?id=150>> accessed 8 April 2015 [Article 2].

289 With respect to Jackson MJ in what were very challenging circumstances, the finding of mental incapacity at the time E made her advance decision obviated a further and potentially contentious consideration of whether her subsequent actions had rendered her decision invalid, per s 25 (2) MCA. If E's condition were found to fit the UNCRPD definition of disability (ibid [Article 1]), this may constitute a discriminatory deprivation of E's legal capacity. See P Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 MLR 752–778 [758].

290 Above, n 18 [s 25 (2)(c)].

291 Although a finding of incapacity precluded the need for full consideration of this matter, Jackson MJ suggested that 'E's actual behaviour in refusing food has been entirely consistent with her decision', and that he 'would have been reluctant to conclude that her decision was undermined by trusting statements about what are bound to be deeply mixed feelings'. He referred to comments E made to her doctors and others carers which included her aspirations for the future. On the face of this, it would appear that credence would be given to behaviour—refusal of food—that might, subject to expert review, be considered a manifestation of the condition that the court believed to have rendered her s 24 advance decision invalid, above, n 71 [para. 69].

292 Above, n 66 [170, para. 9.40].

293 Although his views should be garnered, it is not clear what weight they should be given, although clearly somewhere short of total reliance.

294 Despite the advance decision 'overruling' any decisions made by an attorney acting under an LPA set up before the section 24 advance decision (see above, n 66 [168, para. 9.33]). This limitation would not apply to an LPA set up after the advance decision was made (see above, n 66 [paras 9.34 and 9.40]), or a court appointed deputy.

295 As per section IV above, 'Triggering an assessment of mental capacity', this is contrary to the test set out in sections 2 and 3 of the MCA (above, n 18), but see D Harris and I Fineberg, above, n 208 [24 and 25]; also above, n 128; Centre for the Policy on Ageing, *Ageism and Age Discrimination in Social Care in the United Kingdom: A Review From the Literature* (London, 2009) <http://www.cpa.org.uk/information/reviews/CPA-%20ageism_and_age_discrimination_in_social_care-report.pdf> accessed 9 May 2015 [24].

296 Consider, for example, *Re C*, above, n 5, and *CC v. KK and STCC*, above, n 143. See also Richard Huxtable, above, n 1 [463].

297 Above, n 142 [para. 104].

Whilst the present wishes of an incapacitated patient might be sufficient to set aside even a valid advance decision, in other circumstances they may be given little regard. Mary Donnelly reviewed the approach taken by Morgan J in *Re G (TJ)*,²⁹⁸ in which she considered that he 'rather perfunctorily dismissed the possibility of Mrs G's participation in the decision at hand',²⁹⁹ on the grounds that her condition precluded it. Whilst Donnelly accepted that this decision may well have been warranted, she argued that 'the speed with which Morgan J dismissed the possibility of Mrs G's participation draws attention to the risks of a dismissive approach to section 4(4) based on what is "reasonably practicable"'. There is therefore a risk that 'practicality' may be used as grounds for easy dismissal of involvement by the person who lacks capacity and particularly if this requires 'imaginative efforts' to facilitate their participation.³⁰⁰

In the alternative, Mr Justice Hayden provided a very sensitive and comprehensive consideration of the patient's feelings and wishes in *Sheffield Teaching Hospitals NHS Foundation Trust v. TH and another*.³⁰¹ TH was a 52-year-old man who had suffered severe neurological damage subsequent to a seizure thought to be due to alcohol withdrawal. Although TH had made no formal advance decision to refuse treatment, the court heard evidence from a range of witnesses. There was some question as to Mr H's level of consciousness, and while the court awaited the outcome of the relevant assessments, Hayden J recorded his findings in terms of what TH's views would be³⁰² regarding receiving ongoing life-sustaining treatment:

If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case . . . I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation.³⁰³

However, Hayden J then went on to explain that the weight he would ultimately put on these 'views' would depend on how they balanced 'against the available medical options',³⁰⁴ taking care to emphasise that "[w]ishes" and "best interests" should

298 Above, n 68.

299 Above, n 99 [307].

300 Ibid.

301 *Sheffield Teaching Hospitals NHS Foundation Trust v. TH and another* [2014] EWCOP 4 (COP).

302 If he were now able to communicate them.

303 Above, n 301 [para. 53] (per Hayden MJ), contrast with *Re E*, above, n 71 where there was difficulty accepting E's articulated wishes.

304 Above, n 301 [para. 54].

never be conflated, they are entirely separate matters which may ultimately weigh on different sides of the balance sheet'.³⁰⁵ Whilst this demonstrates a deeply empathetic approach to Mr H as an individual, no explicit mention is made of section 4 of the MCA, and how 'best interests' relates to clinical judgement.³⁰⁶

There is some evidence to suggest that the presumption of capacity has been 'applied perversely'³⁰⁷ by some local authorities as a means of avoiding their obligations to provide care to vulnerable adults and to justify 'non-intervention by service providers'.³⁰⁸ If the presumption of capacity is upheld, the patient will be accountable for their decisions.³⁰⁹ However, this paper has established that when the patient lacks capacity, accountability for that decision will rest with the substitute decision maker.³¹⁰ Although the patient's wishes must be taken into consideration, this paper has already argued that 'fear of liability'³¹¹ may prove more influential in an evaluation of best interests. With that in mind, if the patient's wishes sit at odds with best medical opinion, it might be reasonable to assume that there would need to be strong and persuasive argument for the patient's preferences to be used as a definitive factor in a best interests decision. Further, there is evidence to suggest that practitioners routinely reach a values-based, rather than a statutory, best interests decision. For example, one respondent in research conducted by Poole et al³¹² described how their multidisciplinary team made decisions, explaining that the general starting point was deciding, '[r]ight, what do we ultimately want for this person', and then using that to determine a plan of action.

VIII. FAMILY AND OTHERS

Whilst section 4 of the MCA³¹³ gives some indication of who may be involved in reaching a best interests decision, other than the formal lasting power of attorney (LPA),³¹⁴ or individuals specifically named by the patient,³¹⁵ it may not always be clear whose views the doctor should seek. For example, although people with dementia have been shown to be relatively comfortable with the idea of making practical plans for the future and making their care preferences known,³¹⁶ it is also possible that they will not have done so, much less appointed an LPA or nominated someone

305 Ibid [para. 56].

306 Ibid. See, for example paras 7, 19, 20, 21, 23, and 27 where 'best interest' appears to equate to clinical judgment.

307 Above, n 142 [36].

308 Above, n 142 [33].

309 For example, above, n 5.

310 Either the doctor or the court: above, n 66 [54, para. 4.42].

311 For example, above, n 150.

312 Above, 128 [7].

313 Above, n 18 [s 4 (7)]. Also, above, n 66 [84, para. 5.49].

314 Above, n 18 [s 4 (7)(c)]. LPAs may be created under above, n 18 [s 9], but have been considered to be 'under used and not widely known', per above, n 142 [70, para. 179].

315 Ibid, [s 4 (7)(a)].

316 Such as planning funerals, getting their homes modified and putting their financial affairs in order. See, D Janssen and others, 'Predicting Changes in Preferences for Life-Sustaining Treatment Among Patients with Advanced Chronic Organ Failure' (2012) 141 Chest 1251-1259.

to communicate their views and preferences.³¹⁷ This is unfortunate because whilst it would be remiss to carelessly discount the insight these people may give, it would also be misleading to assume that family and other members of the patient's informal support network are able to provide an unfettered representation of the patient's wishes, values, and desires.³¹⁸ Not only may informal caregivers prove to be an unreliable source of even uncontroversial demographic information about the cognitively impaired patient,³¹⁹ but it would also be naïve to assume that genetic proximity equates to a shared and happy family life.³²⁰ The body of research into elder abuse provides strong evidence³²¹ to suggest that not all informal caregivers have assumed their role willingly or with benevolent intentions.³²² Family dynamics are often complex,³²³ and it is not always reasonable to assume that biological relationship is the primary determinant of who is best placed to advise on the patient's beliefs, values, and preferences.³²⁴ However, despite this, the evidence suggests that in most cases, the patient's preference would be for a member of their immediate family, either a spouse or an adult child.³²⁵ Where there is no close family or if there is a history of family disputes, a friend is likely to be the preferred option.³²⁶ Reliance on their wider social community may be of particular pertinence for lesbian, gay, bisexual, and transgender (LGBT) people.³²⁷ This may be something that clinicians neglect to take into account, particularly given that older LGBT may be unwilling to volunteer information about their sexual orientation on the basis of their past experiences of hostility and discrimination.³²⁸ However, it does provide some imperative to look beyond heteronormative expectations.³²⁹

317 Evidence from the HOLSC (above, n 142) suggests that not only are people often unwilling to confront the need for planning in advance of losing decision-making capacity at some point in the future, but that awareness of both the existence and function of LPAs was low. Even where an LPA has been set up, they are four times more likely to cover property and financial affairs than health and welfare—above, n 142 [170, para. 79]. See also *ibid*.

318 It is almost certain that readers will have experienced their own personal moment of bewilderment when opening a much appreciated, but perhaps bemusing gift from a loved one, that gives rise to the question: 'Do they really know me?'

319 LF Feinberg and CJ Whitlatch, 'Are Persons with Cognitive Impairment Able to State Consistent Choices?' (2001) 41 *Gerontologist* 374–382.

320 See, for example, *Re AB, Notification of Statutory Will Application* [2013] EWCOP B39.

321 For example, C Cooper and others, 'Abuse of People with Dementia by Family Carers: Representative Cross Sectional Survey' (2009) *BMJ* 583–586.

322 As demonstrated in *R v, Stone; R v. Dobinson* [1977] 2 All ER 341, and one of the issues considered by Munby M.J. in *ITW v. Z & Ors*, above, n 102.

323 See, for example, *Re AB, Notification of Statutory Will Application* [2013] EWCOP B39 (COP).

324 Above, n 18 [s 4(6)].

325 B Kelly, A Rid, and D Wendler, 'Systematic Review: Individuals' Goals for Surrogate Decision-Making' (2012) 60 *J Am Geriatr Soc* 884–895.

326 *Ibid*.

327 M Hughes and S Kentlyn, 'Older LGBT People's Care Networks and Communities of Practice: A Brief Note' (2011) 54 *Int Soc Work* 436–444.

328 Which may also be referred to as the 'family of choice' as distinct to the 'family of origin': C Donovan, B Heaphy, and J Weeks, 'Citizenship and Same Sex Relationships' (1999) 28 *J Soc Policy* 689–710, [689].

329 L Peachey, *Opening Doors Suffolk: Final Report* (Age UK: Suffolk, 2012) <<http://www.ageuk.org.uk/brandpartnerglobal/suffolkvpp/documents/openingdoors2012.pdf>> accessed 15 April 2015.

Although the MCA³³⁰ sets out whose views the decision maker must take into account, and the Code of Practice specifies that '[d]ecision-makers must show they have thought carefully about who to speak to [in relation to MCA section 4]',³³¹ no ranking of these is provided. The Human Tissue Act 2004 provides an interesting option³³² enabling an individual to nominate a third party to make decisions on their behalf after death. This might be a worthy consideration in relation to the MCA, although for this to confer any benefit, there would need to be significant efforts to promote better uptake of this initiative rather than other mechanisms for nominating preferences under the MCA, such as LPAs and advance refusals of treatment.³³³

Once suitable informants have been located, the doctor must decide what weight to place on the information they provide. Whilst Donnelly suggested that little is generally known about how surrogates make decisions or what motivates their decisions,³³⁴ the literature provides evidence indicating that information from surrogates may be unreliable. Even with the best of intentions, informal carers may collude with the patient to conceal the extent of their condition or, conversely, may foster a state of dependency. Margret Baltes³³⁵ described a range of circumstances in which an individual's capacity to perform a range of functions is progressively limited by their caregiver's unwillingness to 'permit' them to perform these activities independently,³³⁶ usually arising from a desire to protect the patient, or the erroneous perception that the patient was unable to perform a particular task. Either way, this process gradually erodes both the patient's confidence and their ability to act independently and creates a socially imposed disability.³³⁷

IX. CONCLUSION

This paper has explored the challenges faced daily by clinicians required to make best interests decisions on behalf of their patients. The MCA has drawn attention to the need for decision makers to consider a range of issues wider than the patient's clinical interests, yet provides insufficient guidance on how the statutory principles should be applied in practice. The process is fraught with difficulties which prove challenging for the courts and more so for the clinician who lacks the same legal understanding. Not only does some confusion persist as to the true meaning of 'best interests', but inconsistencies in judicial interpretation persist as well. There is no recognition of the role played by clinical decision-making and its inherent bias. The potential unreliability of information obtained from the patient's family remains unacknowledged.

330 Above, n 18 [s 4 (7)].

331 Above, n 66 [para. 5.51].

332 Human Tissue Act 2004 [s 4].

333 Provision for advance refusals of care is provided by the MCA (above, n 18 [ss 24–26]), but uptake of this facility has been shown to be poor; one respondent to the HOLSC Report indicated that although people are likely to have thought about their preferences for care at the end-of life, only 3% of the public had at the time of the Report made an advance refusal of care (above, n 142 [page 75, para 193]).

334 Above, n 16 [15 and 16].

335 Margaret Baltes, *The Many Faces of Dependency in Old Age* (Cambridge University Press: Cambridge, 1996).

336 See H Taylor, *Assessing the Nursing and Care Needs of Older Adults* (Radcliffe Publishing Ltd: Oxford, 2005) [41] for an illustrative example of this process [79 and 80].

337 See M Oliver, 'Social Policy and Disability: Some Theoretical Issues' (1986) 1 *Disabil Handicap Soc* 5–17.

Paradoxically, whilst the MCA is based on the normative presumption that individuals should be involved in decision-making, that right continues to be denied on the basis of decision outcomes.

Despite the heightened awareness of individual rights conferred by the MCA, its provisions remain open to interpretation. Where the patient's wishes are unknown, unclear, or incompatible with the doctor's professional judgement, doctors are likely to continue making decisions based on an evaluation of best clinical interests in the absence of more definitive and accessible guidance in applying the best interests standard.

This paper has demonstrated the need not only for further evaluation of the implementation of the MCA in clinical practice but also for clarification of key statutory principles and more effective mechanisms for educating clinicians engaging with the MCA. Consideration should be paid to establishing some mechanism enabling people to register who they would prefer to be consulted³³⁸ in the event that they lack decision-making capacity. Prevailing confusion and risk-averse practices mean that the rights and interests of cognitively impaired individuals may continue to be compromised, with 'best interests' conflated with the clinician's evaluation of 'best *medical* interests'.

338 Above, n 18 [s 4 (7)].