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Should people in the minimally conscious state have a (recognised) right to reassessment?

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Introduction

Phenomenal developments in medical science means that many individuals can now survive catastrophic brain injuries which would have been fatal previously. In emergency situations it is often impossible to predict clinical outcomes accurately and a range of aggressive emergency interventions will be carried out usually to give individuals the very best chance of survival.

Nevertheless, some ~~for~~ survivors ~~will be~~ ~~are~~ left with seriously compromised levels of consciousness which can persist for months, years or even decades. The umbrella concept of 'Prolonged Disorders of Consciousness' (PDOC) is used for the group of conditions that range from the vegetative state (VS)⁴ to the minimally conscious state (MCS). Vegetative state is defined as a state of 'wakefulness without awareness' as these patients show sleep-wake cycles and a range of reflexive and spontaneous behaviours. People in minimally conscious state, on the other hand, exhibit minimal and inconsistent signs of awareness.⁵ While some MCS patients show awareness by looking at people or objects for only few seconds (low MCS); others may be at a level where simple choices can be made, even if this is only on occasions (high MCS).⁶

People with PDOC require repeated assessments by experienced clinicians in order to differentiate MCS from VS and to identify those who will benefit from focused rehabilitation so that inconsistent behaviours may become the norm.⁷ Although dependant on others for all their care, patients in PDOC do not

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⁴ The essential clinical criteria of the vegetative state is that of wakefulness with complete lack of awareness of the self or environment and the absence of any purposive response to external stimuli. The descriptor of 'unresponsive wakefulness syndrome' is also used in the clinical literature.

⁵ Royal College of Physicians, *Prolonged disorders of consciousness: national clinical guidelines* (2013) Royal College of Physicians, London.

⁶ Bekinschtein T, Tiberti C, Niklison J, Tamashiro M, Ron M, Carpintiero S, et al. Assessing level of consciousness and cognitive changes from vegetative state to full recovery. *Neuropsychological rehabilitation*. 2005;15(3-4):307-22.

⁷ Giacino JT. The minimally conscious state: defining the borders of consciousness *Prog Brain Res*. 2005;150:381-95.

usually need to be connected to any life support machines. They are, for example, often able to sit out in special supported wheelchairs for short periods of time. They often show a range of reflexive and spontaneous behaviours such as the grasp reflex, bite reflex, chewing, teeth grinding, facial movements and make groaning sounds. These reflex and spontaneous responses may be interpreted wrongly as conscious and purposeful behaviours by their relatives, or even by inexperienced clinicians. Patients ~~They~~ may also react to painful stimuli by grimaces or withdrawal reflexes. Although people in VS are not believed to experience either pain or pleasure⁸ the ability of minimally conscious patients to perceive pain and distress is well recognised.⁹

For the purposes of the Mental Capacity Act 2005¹⁰ people in MCS can be assumed normally to lack capacity to make decisions for themselves and these must be made by decision-makers in their best interests.¹¹ Decision-making will ~~extends~~ from the ~~more~~ mundane, such as what to wear and where to sit, to those profound and often pivotal decisions that concern whether to commence, withdraw or withhold life-sustaining treatment.

A considerable body of case law and academic commentary has developed with a particular focus on end-of-life decisions. The foundation of the development of the common law in this area was the decision of *Airedale NHS Trust v Bland*¹² where the House of Lords arguably effectively ‘crossed the Rubicon’ in deciding that withdrawal of life sustaining treatment would be lawful and in the best interests of a man who had been in VS for several years. The common law position for patients in VS now appears to be well-settled in that provided that a definitive diagnosis has been reached, as confirmed by robust evidence and sufficient passage of time,¹³ the court will usually declare

⁸ Schnakers C, Zasler ND, Pain assessment and management in disorders of consciousness. (2007) *Curr Opin Neurol* 20 :620-6.

⁹ Boly M, Faymonville ME, Schnakers C, Peigneux P et al., Perception of pain in the minimally conscious state with PET activation: an observational study. *Lancet Neurol*. 2008 Nov;7(11):1013-20; Demertzi A, Schnakers C, Ledoux D, Chatette C, Bruno MA et al., Different beliefs about pain perception in the vegetative and minimally conscious states: a European survey of medical and paramedical professionals. (2009) *Prog Brain Res* 177: 329-38.

¹⁰ Section 2(1) of the Mental Capacity Act 2005 states that “For the purposes of this Act a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain.”

¹¹ Section 1(5) Mental Capacity Act 2005.

¹² *Airedale Trust v Bland* [1993] AC 789.

¹³ Royal College of Physicians, *Prolonged disorders of consciousness: national clinical guidelines* (2013) Royal College of Physicians, London. Page 35.

that withdrawal of clinically assisted nutrition and hydration (CANH) is in the person's best interests.¹⁴ The situation is different for patients in MCS where evaluations of best interests will involve proper consideration of the advantages and disadvantages of each proposed course of action using a 'balance sheet' approach.¹⁵ The jurisprudence in the area of best interests decision making for patients in MCS is complex and burgeoning and now includes a decision of the Supreme Court.¹⁶

Expert care and treatment of patients in MCS is expensive¹⁷ and accurate assessment, and reassessment, is necessary for optimal management as well as appropriate targeting of health care resources. Nevertheless, diagnosis and accurate prediction of clinical prognosis is inordinately difficult and requires regular assessment by health professionals with specific expertise.¹⁸ Most current diagnostic and evaluative techniques are based on subjective observations to detect patient awareness of themselves and their environments.¹⁹ Regular review of a patient's initial diagnosis and assessment ~~as to~~ of whether transitions from VS to MCS (or *vice versa*) has occurred is vital to determine that person's prognosis. Regular review is also necessary to fund appropriate rehabilitation regimes and ultimately underpin decisions to withdraw life-sustaining treatment where this is deemed to be in the person's best interests. Accurate assessment can facilitate targeting of advanced rehabilitation programmes and escalate care to benefit those who ~~stand~~ have most to gain. In fact, there is evidence that intensive treatment and

¹⁴ Mason K, Laurie G, McCall Smith A. Mason & McCall Smith Medical Law & Ethics (2014) page 543.

¹⁵ This balancing exercise articulated in *Re A (Male Sterilisation)* [2000] 1 FLR 549 by Thorpe LJ is qualitative rather than numerical. The balance sheet is not usually considered appropriate in confirmed cases of VS because all relevant factors tend to fall on one side of the scale.

¹⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591.

¹⁷ Current estimates suggest that it costs around £7,500 a month to care for a patient in a VS and that costs for patients in a MCS are likely to be similar: Formby A, Cookson R, Halliday S (2015) Cost analysis of the Legal Declaratory Relief for Withdrawing Clinically Assisted Nutrition and Hydration (CANH) from Patients in the Permanent Vegetative State (PVS) in England and Wales CHE Research Paper 108 University of York.

¹⁸ Hirschberg R, Giacino JT. The vegetative and minimally conscious states: Diagnosis, Prognosis and Treatment. *Neuro Clin.* (2011): 29(4): 773-786.

¹⁹ Accurate diagnosis and assessment is considered to be difficult for several reasons that include: mental or physical disabilities that can impede the patient's ability to respond; changes in the conditions of patients who are medically unstable; and because patient's responses may be inconsistent or delayed (Houses of Parliament Parliamentary Office of Science and Technology, Vegetative and Minimally Conscious States, Postnote, (2015). No. 489, March available at <http://researchbriefings.files.parliament.uk/documents/POST-PN-489/POST-PN-489.pdf>.

rehabilitation may facilitate recovery of consciousness in people with MCS.²⁰ Prevention of medical and neurological complications such as infections, pressure sore and seizures; achievement of good posture; use of specialist treatment techniques and medications are shown to help recovery in PDOC. However, implementation of ~~such~~-complex rehabilitation interventions usually requires s input from ~~highly~~-specialist healthcare professionals. On the other hand, since re-evaluation also serves to identify those for whom further treatment is no longer in their best interests, it may pinpoint where therapy can be de-escalated or withheld appropriately.

The question to be asked, therefore, is whether people in MCS should have a 'right' to be reassessed. To explore this issue a qualitative empirical approach was used. Four focus groups were used as the data gathering tool to ascertain policy and views of senior decision-makers including consultants in intensive care medicine and neurological rehabilitation, therapists, nurses, specialist care home managers and lawyers.²¹ The emergent themes from the data are contextualised within a theoretical framework against a backdrop of recent common law and professional guidance in England and Wales.

Background

(a) Clinical

In Britain there are no reliable statistics on the incidence, or prevalence, of the number of people in MCS. Estimates extrapolated from patients in UK nursing homes range from 4,000-16,000 for patients in VS and three times that figure for people in MCS.²² Since these figures do not include patients in the acute sector, or those cared for at home, these figures could be far higher. Those people within this unknown cohort who are cared for within the community,

²⁰Andrews K. Recovery of patients after four months or more in the persistent vegetative state. *BMJ* 1993;306:1597-600.

²¹ The authors would like to thank De Montfort University for generously sponsoring this project under a Research Investment Funding initiative.

²² Houses of Parliament Parliamentary Office of Science and Technology, Vegetative and Minimally Conscious States, Postnote, (2015) No. 489, March available at <http://researchbriefings.files.parliament.uk/documents/POST-PN-489/POST-PN-489.pdf>.

may never have been formally reassessed since their initial diagnosis.²³ This means that transition from VS to MCS and *vice versa* may not have been recognised. By implication this means that an unknown number of patients may be missing out on (or even denied) the benefits of focused rehabilitation, or alternatively are being kept alive in situations where continued treatment is no longer in their best interests.

Best practice mandates that reassessment should occur at regular intervals following initial diagnosis²⁴ to identify and act upon changes in conscious awareness and clinical condition. It is hoped that following publication of best practice guidelines all patients who are newly diagnosed as being in the MCS are more likely to receive appropriate reassessment.²⁵ Regular assessment and review is the lynchpin for ascertaining whether a reversible cause for the disorder of consciousness can be identified and treated. It also underpins appropriate targeting of clinical management and efforts to rehabilitate as well as decisions about treatment withdrawal.

Assessment and ~~re-assess~~reassessment strategies have developed very considerably and particularly over the last decade. Early forms of neurological assessment such as the Glasgow Coma Scale are still employed in the acute stages and these offer reliable and objective initial and subsequent assessments to be carried out. Later on, once the patient's condition has stabilised more nuanced behavioural assessment scales are relied upon for clinical re-evaluation such as the Coma Recovery Scale-Revised (~~CRS-R~~),²⁶ the Sensory Modality Assessment Technique (SMART)²⁷ and the Wessex Head Injury Matrix (WHIM).²⁸ Current clinical guidance recommends one or more of

²³ Gill-Thwaites H. Lotteries, loopholes and luck: Misdiagnosis in the vegetative state patient. *Brain Injury*, December 2006; 20(13–14): 1321–1328.

²⁴ Hirshberg R, Giacino JT. The Vegetative and Minimally Conscious States: Diagnosis, Prognosis and Treatment. *Neuro Clin* 2011 29(4) 777-786.

²⁵ Since this research project commenced shortly after publication of the Royal College of Physicians guidelines this knowledge might not have filtered down to all decision-makers.

²⁶ [Giacino, J T Kalmar K, Coma Recovery Scale-revised: Administration and scoring guidelines \(2004\) Available at http://www.tbims.org/combi/crs/CRS%20Syllabus.pdf \(accessed 12th March 2016\).](http://www.tbims.org/combi/crs/CRS%20Syllabus.pdf)

²⁷ [Gill-Thwaites H, 'The Sensory Modality Assessment Rehabilitation Technique - A tool for assessment and treatment of patients with severe brain injury in a vegetative state \(1997\) Brain Injury 11 \(10\).](#)

²⁸ [Shiel A, Horn SA, Wilson BA, et al., The Wessex Head Injury Matrix \(WHIM\) main scale: a preliminary report on a scale to assess and monitor patient recovery after severe head injury \(2000\). Clin Rehabil 14:408–16.](#)

these three assessments are used over time for purposes of formal structured assessment. Even more cutting-edge developments are currently being investigated such as the use of functional Magnetic Resonance Imaging (fMRI) and Positron Emission Tomography (PET) scanning for diagnostic and prognostic purposes although their use has yet to be confirmed in clinical practice.²⁹

(b) Legal

All decisions for adults who lack capacity must be made in their best interests in accordance with the Mental Capacity Act 2005.³⁰ The Act requires that all decision-makers, including health professionals, ascertain the person's best interests in accordance with seven statutory steps to identify those factors which are relevant to the decision to be made.³¹ In end of life situations which concern adults who lack capacity, doctors must apply the best interests checklist and their clinical skills to determine whether life-sustaining treatment is in the person's best interests.³² Where commencing or continuing treatment is considered to be either futile, overly burdensome or intolerable, it might well be in that person's best interests to withhold or withdraw treatment, including that which sustains life. However, a balance will need to be drawn. For people in VS or MCS the law also requires that all decisions to withdraw clinically assisted nutrition and hydration (CANH) must be approved by the court by way of declaratory relief.³³ This compares with most other clinical circumstances that do not concern withdrawal of CANH people in MCS or VS,³⁴ where decisions are referred to the court only where a person's best interests are challenged by interested parties or at least contested in some

²⁹ Stender J, Gosseries O, Bruno MA, Charland-Verville V. Diagnostic precision of PET imaging and functional MRI in disorders of consciousness: a clinical validation study. (2014) *Lancet* 9;384(9942):514-22.

³⁰ Section 1(4) of the Mental Capacity Act 2005 requires that "an act done, or decision made, ... for or on behalf of a person who lacks capacity must be done, or made, in his best interests."

³¹ Section 4 of the Mental Capacity Act 2005.

³² Para 5.33 of the Mental Capacity Act 2005 Code of Practice.

³³ ~~By section 15(1)(c) of the Mental Capacity Act 2005 the court may make declarations as to the lawfulness or otherwise of any act done, or yet to be done, in relation to that person.~~ *Court of Protection Rules (2007)* Practice Direction 9E: *Applications Relating to Serious Medical Treatment (para. 5a)* requires that all decisions about the proposed withholding or withdrawal of CANH from a person in a VS or MCS are brought to the court for a declaration of best interests. Available at: <https://www.judiciary.gov.uk/publications/practice-direction-9e-applications-relating-to-serious-medical-treatment-effective-from-1-july-2015/> Accessed on 12th March 2016.

³⁴ Practice Direction 9E and section 15 of the Mental Capacity Act 2005. Other serious treatment decisions (such as therapeutic sterilisation) also require declaratory relief from the Court of Protection.

other way. For people in definitive VS, who have no awareness of themselves or their environments, the principle assumption is that life-sustaining treatment is not in their best interests because it is futile. In the case of Bland it was argued that for Arguably, for the persons in permanent VS, it is must be a matter of complete indifference to them whether they live or die.³⁵ For this reason the mandatory requirement for court approval for persons in VS has been criticised on the basis that there is no legal basis for treating this group of patients differently from that of ~~any~~ others.³⁶

This particular perspective, however, fails to recognise that people in VS and MCS are not actively dying: they are usually often not terminally ill. With appropriate care and medical attention they may live for some considerable time. This is apparent even if a 'ceiling of care' is introduced on clinical grounds, meaning that specified treatments are to be withheld in the event of an acute life-threatening event, or clinical deterioration, are to be withheld. Furthermore, for people in VS or MCS withdrawal of CANH, even when this is incontrovertibly in the person's best interests, can result in a prolonged dying process over several days, particularly where the body of the brain damaged person is otherwise in very good health.³⁷

For the purposes of the law and withdrawal of treatment decisions, the distinction between diagnosed MCS compared with permanent VS is self-evident. The courts apply different deliberations that can lead potentially to very different outcomes. In the United Kingdom the seminal decision that considered the best interests of the person in permanent VS was *Airedale Trust v Bland*.³⁸ Anthony Bland had sustained catastrophic head injuries which led to him being in permanent VS following an incident at a football stadium in 1989. After three years, following which there had been no improvement in his condition, the hospital sought a declaration that withdrawal of assisted

³⁵ *Airedale trust v Bland* [1993] AC 789. per Lord Keith.

³⁶ Lewis P. Withdrawal of treatment from a patient in a permanent vegetative state: judicial involvement and innovative "treatment". *Med L Rev* 2007; 15:392–9.

³⁷ Withdrawal of treatment from patients who are terminally ill will typically occur within hours or days whereas death following withdrawal of CANH from patients in VS or MCS can take days or even weeks: Wade DT. Ethical issues in diagnosis and management of patients in the permanent vegetative state. *BMJ* 2001;322:352.

³⁸ *Airedale Trust v Bland* [1993] 1 AC 789.

nutrition and hydration would be lawful.³⁹ The House of Lords justified its unanimous decision ultimately on the basis that it was not in Anthony Bland's best interests to prolong his life where no benefit could be derived from treatment.⁴⁰ Lord Mustill, whilst concurring with the decision, expressed his concerns that through the medium of the court, one group of citizens had authority to terminate the lives of another. For this reason he cautioned that the court's role must be to examine rigorously the process by which the solution is reached, as well as the legal foundations upon which decisions rest. The fear was that ~~the~~ pressures created by this very extreme case could distort the law and lead to anomalies in future cases where issues were similar but more finely balanced.⁴¹ In the years that followed *Bland* it certainly seems that these fears about encroaching precedent did in fact materialise, at least incrementally, to other less definitive situations of VS or 'near-VS' conditions.⁴² These decisions confirm that for people diagnosed definitively as being in permanent VS the decisions of the courts will fall in favour of withdrawal of life-sustaining treatment.⁴³ In these circumstances it appears that for people in permanent VS the court's role is little more than an exercise to confirm the diagnosis following which a declaration that treatment withdrawal will be lawful is made.⁴⁴

That same certainty does not extend to decisions for people who are minimally conscious, even though applications to the court are also required prior to withdrawal of treatment. Decisions that concern withdrawal of treatment from persons in a MCS are less certain and are made using a balance sheet approach. Factors of perceived benefits from continuation or initiation of treatment will be weighed against countervailing disadvantages. The outcome of applications to the court ~~are~~ therefore dependent upon a range of fact and

³⁹ Ibid. at 885.

⁴⁰ Ibid. at 885.

⁴¹ Ibid. at 886.

⁴² Several cases followed *Bland* where the safeguards referred to in that case were incrementally side-lined. For example, *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403; *Re G* [1995] 3 Med L Rev 80; *Swindon and Marlborough NHS Trust v S* [1995] 3 Med LR 84; *Re D* (1997) 38 BMLR 1; *Re H (adult: incompetent)* (1997) 38 BMLR 11.

⁴³ The cases heard between *Bland* and *Aintree University Hospitals NHS Foundation Trust v James* [2014] A.C. 591 were complicated, to some extent, in that the clinical criteria for diagnosing MCS were published only in 2002. It seems likely that some of the patients previously thought to be in VS were likely to have been in MCS.

⁴⁴ Practice Note (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults who Lack Capacity) [2006] 2 FLR 373.

specific circumstances.⁴⁵ For example, in *M (Adult Patient) (Minimally Conscious: Withdrawal of Treatment)*⁴⁶ despite relatively strong evidence of the woman's own prior views, it was determined that M's positive experiences, alongside the fundamental starting point of respect for the sanctity of life, tipped the scales in favour of continuation of treatment despite evidence that she could experience pain and discomfort and ~~countervailing~~ evidence from her family that she would not have wished to live her life in ~~the~~ circumstances such as these she was in.

For this reason accurate assessment as to whether a person is vegetative or minimally conscious and whether that condition is permanent or not is the cornerstone of appropriate decision-making. For this reason disputes as to accurate diagnosis can lead to adjournment and considerable delay in legal proceedings. Accurate evaluation is therefore subject to considerable judicial scrutiny in determining whether withdrawal of CANH, or withholding other forms of life-sustaining treatment, is in the person's best interests.⁴⁷

The empirical research study

(a) Methodology

The ~~fundamental~~ research question that was asked was whether there should be a right to ~~re-assess~~ reassessment for patients in a MCS. Self-selected participants, who were all senior decision-makers in their fields, were invited on the basis of their interest and specific expertise. Since reassessment decisions typically involve multidisciplinary teams a range of participants were invited including and included health professionals, lawyers and policy-makers.⁴⁸ Given that reassessment decisions tend to be collective decisions focus groups were selected as the method of choice in order to explore group norms and attitudes. Focus groups are also a recognised technique that can be used to explore divergent views and opinions and are therefore particularly useful for obtaining multiple perspectives on a topic. The inevitable interaction

⁴⁵ *W v M* [2012] 1 All ER 1313.

⁴⁶ [2012] 1 WLR 1653.

⁴⁷ *CWM TAF University v F* (2015) EWHC 2533 (Fam).

⁴⁸ Health professionals included consultants in Rehabilitation Medicine, General practitioners with a special interest in neurology, specialist anaesthetists, neurologists, medical negligence lawyers, specialist residential care managers and commissioners, occupational and speech therapists, physiotherapists and specialist nurses.

that occurs between group members encourages direct questioning and can lead to re-evaluation of personal and possibly previously unrecognised perspectives. It was also anticipated that interactions between the participants (as senior decision-makers in their respective fields) would encourage tacit challenging of professional group norms and hopefully expose underlying tacit assumptions which could not be accessed easily with alternative qualitative approaches, such as elite interviews.⁴⁹

Four focus groups were held with a total of 29 participants with each group comprising between 5 and 11 individuals. Sessions lasted around two hours and duration were moderated by ~~an~~ experienced facilitators to encourage exploration of the ~~consider the~~ research question from myriad multiple perspectives.⁵⁰ Prior to commencement participants had been ~~were~~ briefed on the study rationale and the approach to be used. A standard set of preconceived prompts were available to initiate and stimulate further discussion if required. At the start of each session the participants were advised to communicate and interact with one another, rather than with the facilitators who intervened, on occasion, to explore areas of ambiguity and to challenge apparent inconsistencies. All sessions were voice recorded and augmented by written notes that were used to inform initial axial coding and subsequent relational statements that emerged.

Verbatim transcripts were created within a week of each session and verified for accuracy against the voice recordings. These were colour coded to ensure that speech extractions could be contextualised appropriately during each session and to identify and track each participant's personal contribution. Unabridged transcripts were used for the subsequent analysis to enhance the rigor of the methodology.⁵¹

The transcripts were analysed using the tenets of grounded theory methodology.⁵² Three phases of coding were used to arrive at a model that provided an explanation of the focus group results. Grounded theory

⁴⁹ Duggleby W. 'What about focus group interaction data?' (2005) *Qualitative Health Research* 15(6) 832-840.

⁵⁰ This project received advance ethical clearance from De Montfort University.

⁵¹ Bloor M, Frankland J, Thomas M, Robson K, *Focus groups in social research* (London: 2001).

⁵² For a useful discussion of grounded theory see Charmaz K, *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis* (Sage, 2006).

methodology uses induction and interpretation, rather than deductive reasoning, to arrive at an explanation that is derived from, or “grounded” in the data. This means that rather than testing a hypothesis, grounded theory builds an explanation of the data that is collected.⁵³

While there are many academically accepted variants on grounded theory, all agree that analysis is done through a series of data interpretation of increasing levels of abstraction.⁵⁴ The first stage of analysis for this research was initial coding, where the focus group transcripts were examined and an initial list of codes were identified.⁵⁵ The second stage of axial coding involved analysis of these initial codes which were then used to answer a series of questions about the environment in which decisions about whether to ~~re-assess~~reassess patients were taken.⁵⁶ The third stage involved relational statements development was built from the process of axial coding.⁵⁷ The relational statements construct an account and justification, from which the grounded theory or explanation begins to emerge.⁵⁸ In the final stage of analysis, a grounded theory was derived from the relational statements. Subsequent discussions of the research team took place to agree on areas of convergence and to ensure that critical issues had not been overlooked.⁵⁹

(b) Results

In every group it became palpably clear that the influence of seemingly capricious chance factors, such as ‘being in the wrong place at the wrong time’ could have a profound and significant impact upon clinical outcomes and subsequent opportunities for rehabilitation. Seemingly fortuitous variables could exert considerable influence on clinical outcomes. Chance events such as where, when and how the index injury occurred, whether and where emergency expert acute care was provided, and also whether clinical

⁵³ Charmaz K, pages 4-5. See also Strauss A, Corbin J, *Basics of Qualitative Research* (Sage Publications, 2nd edition, 1998), 12-14.

⁵⁴ See Charmaz K, 4-10.

⁵⁵ See Charmaz K, 47-50.

⁵⁶ For a discussion on axial coding, see Strauss A, Corbin J, 123-142, and also Scott Wilson K, *Relating the Categories in Grounded Theory Analysis: Using a Conditional Relationship Guide and Reflective Coding Matrix* (2004) 9(1) *The Qualitative Report* 112.

⁵⁷ See Strauss A, Corbin J 145-146.

⁵⁸ Ibid.

⁵⁹ ~~In-depth Further~~ methodological details for this study can be found in “Grounded theory analysis of a focus group study: should minimally conscious people have a right to reassessment? Sargent S, Samanta J, Yelden K (2016) *SAGE Research Methods Case Study* IN PRESS.

rehabilitation expertise was readily available, all played significant roles in influencing the outcomes for patients.

The variability and range of opinion as to what constituted an ‘initial’ assessment was also a striking factor. Variables such as where the injury occurred and whether emergency neurological care was readily available influenced very considerably the early diagnosis and whether intensive care or referral to a centre of excellence was made. Further areas of shared concern centred on the lack of predictability in the constitution of clinical and other decision-making teams, during the initial acute stage as well as after stabilisation. The availability of expert neurological and rehabilitation acumen was considered to be crucially important.⁶⁰

Considerations of rights-based expectations was considered to be of secondary importance in this context. ~~and even against recognition of current focus on patients’ enforceable rights.~~ In fact, this conception of legally enforceable rights was not considered to be part of the reality for determining whether a patient could, or should, be clinically reassessed. What emerged in the discussions was that many factors which that could not be predicted, or controlled for, could influence very considerably whether a person would be referred to a relevant considered for referral for specialist for re-assessreassessment. From the participants’ perspective it was evident that whether formalised reassessment took place depended mainly upon who, or what, was insisting that a pressing for clinical review took to take place. The main drivers identified came from family members, close relatives, or carers as well as commissioning bodies or even the courts.

A shared concern of several participants was the perceived lack of a clear ~~medical~~ evidence base from which to proceed by way of clinical protocols or definitive guidance. This was noteworthy on several counts. At the time that the focus groups were held evidence based clinical guidance from the Royal College of Physicians had just been published. This guidance is intended to

⁶⁰ Although the central findings from each group were similar there were apparent differences of emphasis in each. However, no obvious influence (for example from the occupational make-up or majority specialism of the participants) was apparent. Two of the groups looked at reassessment mainly from the perspectives of treatment withdrawal decisions. One was particularly impressed by the influence of contextual factors on whether a patient would be reassessed and the final group also considered newer developments in reassessment strategies and what this might mean for future management.

systemise the approach to diagnosis, management, and end-of-life care for people in VS and MCS.⁶¹ It is certainly possible that at the time of the study this guidance had not been ~~digested, responded to,~~ or acted upon, by the majority of participants, although some participants were very familiar already. Nevertheless, participants from across the board from primary care ~~through across-~~to specialist rehabilitation services expressed concern about the apparent dearth of a coherent structure to guide decision-making. The new Royal College of Physicians Guidelines states that all patients in PDOC should have at least an annual review, ~~or re-assess~~reassessment, by an appropriately skilled assessor until either they emerge from PDOC or they die.⁶² Nevertheless, this is still yet to become the norm or even the expected best practice on account of access availability to specialist care as well as ~~and~~ resource constraints.

Decisions to reassess clinically depended on factors such as where the patient was, the composition and knowledge of the treatment team and whether family or friends were advocating for further review. These triggers were what led, usually, to decisions to ~~re-assess~~reassess. However, ~~re-assess~~reassessment is only one of a range of options that might occur when consideration is made of the patient's condition and prognosis.

(c) Statement of Grounded Theory

On the basis of the data a two-part enquiry into ~~re-assess~~reassessment could be discerned: first, whether the question of ~~re-assess~~reassessment was ever raised; and second, whether that re-assessment would be provided.

The issue of whether re-assessment was likely to be raised was influenced strongly by the presence of interested others: whether the person in MCS had highly involved family or friends who would raise the possibility with the care team, and whether the treatment team within the clinical setting had sufficient specialist knowledge and expertise in assessment, reassessment and research regimes. Without these variables in place, it was considered unlikely that the issue of (re)assessment would arise unless this was triggered ultimately by preparation, or evidential presentation, for an application to the court that

⁶¹ Royal College of Physicians. Prolonged disorders of consciousness: National clinical guidelines. London, RCP. 2013.

⁶² Ibid. page 43

withholding or withdrawing~~ing at~~ treatment would be lawful and in a person's best interests.

On the evidence of the data once the issue of reassessment had arisen, whether or not it was carried out also depended upon a range of variables. Potential conflicts could arise between hospital management, or perhaps commissioning bodies who might be concerned about appropriate use of resources, or that scarce resources ought to be ~~are~~ targeted at people with more predictable clinical outcomes or response to rehabilitation or treatment. Ultimately, the decision to ~~re-assess~~ reassess lies with the treating clinician. Doctors must grapple with myriad issues. These include recognition of what resources are available and the need to follow evidence-based guidance. Further potential tensions included possible constraints of commissioning regimes and bodies, and referral opportunities. All of these factors would influence decision-making within the framework of regulatory and professional ethical obligations.

~~Re-assess~~ Reassessment could result in a range of outcomes for people in MCS. Positive reassessment results often led to intensification of efforts to stimulate and rehabilitate the patient to greater and more sustained levels of conscious awareness. Results of clinical review could lead to decisions to maintain the status quo and schedule further review for a future time. It is also possible to find that continued efforts to rehabilitate are no longer in the best interests of the person which would prompt an application to the court for declaratory relief.

The emergent theoretical basis for ~~re-assess~~ reassessment is a decision-making process that is context-driven. In the practical healthcare arena the issue of whether a legal right to ~~re-assess~~ reassessment exists is lost ultimately in the highly subjective and uncertain environment in which the question and provision of ~~re-assess~~ reassessment occurs.⁶³ In view of the implications for potential rehabilitation and ultimately the possible withholding or withdrawal of life-sustaining treatment for people in MCS the fundamental question is to what extent should access to ~~re-assess~~ reassessment be underpinned as a legal or (at least) a moral right within a formal procedural framework?

⁶³ Nevertheless, caution is required to avoid making inferences beyond the study population.

Implications of this study and discussion

(a) Rights based analysis

Minimally conscious adults are perhaps the paradigmatic category of people who lack decision-making capacity.⁶⁴ Notwithstanding this, the conclusion that people lack decision-making capacity is not an "off-switch" for their rights and freedoms.⁶⁵ In the context of the rights-based arena suffering, or at least the potential to suffer, has to be taken seriously.⁶⁶ Without appropriate assessment and review the possibility of failure to recognise covert suffering, or even emergence to a higher state of conscious awareness, is all too real.

It is certainly possible that life in a MCS might be worse than being in a VS.⁶⁷ **a** This factor **that** prompted considerable critical commentary **following of** the court's decision not to authorise withdrawal of treatment in *W v M*:⁶⁸ the first case in the United Kingdom to consider an application for authorisation to withdraw CANH from a person in MCS.⁶⁹ This view, however, is not universally held. Chan and Tipoe, for example, consider that the value of life of a person should have nothing to do with an outsider's perspective of the intensity or duration of that person's positive and negative experiences. Only **the** **person** **herself** can determine whether her life is worth living and to do otherwise is to risk **real** discrimination.⁷⁰

But according to a rights-based analysis, to what extent do people in MCS have a 'right' to be **re-assessreassessed**? A fundamental distinction is often drawn between legal and moral rights. Legal scholars typically consider 'rights' as being those interests that exist in the terrain of entitlements and obligations.

⁶⁴ On the basis of section 3(1) of the Mental Capacity Act 2005 which states that "a person is unable to make a decision for himself if he is unable to (a) understand the information relevant to the decision (b) retain that information (c) use or weigh that information as part of the process of making the decision, or (d) communicate that decision (whether by talking, using sign language or any other means).

⁶⁵ *Wye Valley NHS Trust v B* [2015] EWCOP 60 at para 11 per Jackson J.

⁶⁶ Yamin AE, 'Will we take suffering seriously? Reflections on health means and why we should care?' (2008) 10(1) *Health and Human Rights: An International Journal* 45.

⁶⁶ Johnson LSM, 'The what applying a human rights framework to health means and why we should care?' (2008) 10(1) *Health and Human Rights: An International Journal* 45.

⁶⁷ Johnson LSM, 'The right to die in the minimally conscious state' (2011) *JME* 37: 175-8.

⁶⁸ *W v M* [2012] 1 All ER 1313.

⁶⁹ Wilkinson D, Savulescu J, 'Is it better to be minimally conscious than vegetative?' *JME* 2013;39:557-8; Jackson, E, 'The minimally conscious state and treatment withdrawal: *W v M*' *JME* (2012) 39 (9) 559-561.

⁷⁰ Chan TK, Tipoe GL, 'Should we continue treatment for M? The benefits of living' *JME* (2014);40:131-133.

If such a right is violated the right bearer will be assured of a remedy from a court or other adjudicative body.⁷¹ According to this analysis, if a right is without a remedy it reverts to being little more than a mere aspirational statement.⁷²

Dworkian conceptions of rights tend to distinguish between positive rights, which call for affirmative action, and those supposedly negative or libertarian rights that require public bodies to abstain from interference or at least to refrain from specific conduct. Examples of positive rights typically include those which incorporate economic and social elements such as rights to health and access to public healthcare resources. Nevertheless, this seemingly pragmatic distinction starts to break down in that to some extent recognition of any right requires at least some measure of positive action by providers.⁷³ Enforcement of positive rights, for instance, might be achieved only when public providers actively prevent conduct that limits access to existing services.

A conventional stance in law is that positive rights cannot, or will not, be enforced by public providers of healthcare due to the government's reluctance to allocate resources as a legal remedy. For this reason there is a significant difference between remedies designed to prevent public providers from acting in a certain way, and remedies designed to compel parties to deliver particular services. In granting the latter an adjudicator steps into the role of policy-maker regarding the allocation of resources which is fundamentally a legislative function.⁷⁴ Nevertheless, conceiving of rights as being only those which are legally enforceable seems to be a very narrow perception indeed.

Similar distinctions are drawn sometimes between rights based on enforceability or justiciability in the context of the hypothetical non-justiciability of economic and social rights. These debates neglect the range of possibilities for judicial enforcement of rights amongst different courts as well as the jurisdictional powers of individual courts.⁷⁵ This analysis also neglects

⁷¹ Dworkin R, *Taking rights seriously* (1977) page 82-90; Finnis J, *Natural Law and Natural Rights* (1980).

⁷² *Ibid* p299-301.

⁷³ Shue H, *Basic rights, Subsistence, Affluence and US Foreign Policy* (2nd Ed, Princeton University Press 1996).

⁷⁴ Kinney ED, Clark BA, *Provision for Health and Health Care in the Constitutions of the Countries of the World*, (2004) Vol 37 *Cornell International Law Journal* 285.

⁷⁵ Murphy T, *Health and Human Rights* Hart Publishing 2013.

the potential influence of economic and social rights even if these are technically unenforceable by the courts.⁷⁶

Forecasts about perceived growth in patient rights are influencing public perceptions about healthcare provision.⁷⁷ It has been similarly acknowledged the 'radical shift' in public attitudes and society's focus on individuals' enforceable rights.⁷⁸

In this study, however, the data and its analysis failed to show that traditional conceptions of legal 'rights' was at the forefront of decision-makers' minds when dealing with ~~re-assess~~reassessment decisions. Instead, concerns tended to be focused on the perceived dearth of set protocols, relevant expertise, and the capricious influence of chance factors that could all contribute to the outcome. In terms of rights-based discourse the law is clear that there are no substantive rights to medical treatment or any particular diagnostic modalities. A patient, or her relatives, cannot demand and expect to receive a healthcare intervention that is not deemed to be clinically appropriate. Lord Donaldson's clear assertion that "doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contraindicated or for some other reason is a treatment which they could not consciously administer"⁷⁹ is still accurate and good law today. Similarly, the Court of Appeal's assertion in *Burke*, still rings true that while doctors are expected to consider patient requests for specific treatments the decision to offer that treatment remains a clinical one.⁸⁰ To some degree the recognition that the courts will not override clinical judgement has morphed into established judicial practice and almost a point of principle.⁸¹ In fact, to use a "declaration of the court to twist the arm of some other clinician, as yet unidentified, to carry out these procedures or to put pressure upon the Secretary of State to provide a hospital where these procedures may be

⁷⁶ The UNESCO Universal Declaration on Bioethics and Human Rights (2005) and the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (ETS No 164) (The Oviedo Convention, 1997) exemplify the significance of so called 'non-enforceable' rights.

⁷⁷ British Medical Association, *Medical Ethics Today* (2004) BMJ Publishing Group p24.

⁷⁸ Woolf LCJ, Are the courts excessively deferential to the medical profession? *Med Law Rev* (2001) 9(1):1-16.

⁷⁹ *Re J* [1991] 3 All ER 930 at 934.

⁸⁰ *R (Burke) v General Medical Council* [2005] EWCA Civ 1003.

⁸¹ Montgomery J, Conscientious objection: personal and professional ethics in the public square (2015) *Med L Rev* 23(22) 200 at 205.

undertaken is an abuse of the process of the court and should not be tolerated.”⁸² This position has been confirmed more recently in the context of people in MCS.⁸³ So, to what extent are questions about positive rights to reassessment meaningless for this group of patients? Evidently the law, as well as the study participants, assert in unison that there are no positive enforceable legal rights to reassessment. As long ago as 1992 Lord Donaldson could not conceive of any circumstances in which the court would require doctors to adopt an intervention or course of treatment which was contraindicated as not being in the best interests of their patients. But today, Although doctors are still duty bound to treat patients in accordance with their clinical judgement there is evidence of increasing judicial intervention in decision-making.⁸⁴

This is not to downplay the significance of moral claims to reassessment. Although traditional moral rights theorists such as Grotius and Locke have tended to associate moral rights as being powers associated with liberties, modern conventions and declarations of human rights typically extend these to incorporate social and economic rights. Ultimately though, moral rights, as with legal rights, tend to be correlatives of duties. A positive claim for reassessment, for example, would require a suitably qualified e-clinicians to give effect to that right which would then become their duty.

Notwithstanding these established principles it appears that a quiet and largely unnoticed shift is occurring ~~has occurred~~ albeit perhaps only in the context of applications to the court for withholding or withdrawal or treatment decisions from patients in MCS or VS. The courts now require that ‘every step’ is taken to ‘diagnose the patient’s true condition’ before any application is made to the court.⁸⁵ For these purposes, assessment tools such as SMART and WHIM play a ‘crucial role’ in ascertain the patient’s clinical condition.⁸⁶ It seems that for these purposes at least, reassessment techniques such as SMART and WHIM have now become part of the law.

⁸² *R (Burke) v General Medical Council* [2005] EWCA Civ 1003 para. 38.

⁸³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; *AVS and a NHS Foundation Trust* [2011] EWCA Civ 7, per LJ Ward at para. 35.

⁸⁴ Mason JK, Laurie GT. *Mason & McCall Smith’s Law & Medical Ethics* (2011) OUP.

⁸⁵ *Re M (Adult Patient) (Minimally Conscious state: Withdrawal of Treatment)* [2012] EWHC 2443 (Fam) Baker J. para. 259.

⁸⁶ *Ibid.* para 258.

(b) The concept of “Fairness”: A just and equitable access to re-evaluation

A cross cutting theme that was evident across all four focus groups was concern about the commissioning of re-assessreassessments. At times, and particularly amongst clinical participantsstaff, there was a palpable reluctance to consider whether lack of resources might operate as a potential constraint against access to re-assessreassessment. The inherent challenges of commissioning care more generally for patients in MCS was recognised due to the inherent clinical instability of people in this group and particularly during in the acute phase following initial injury. Further challenges involved the labyrinthine complexities caused by different funding regimes that apply in respect of medical and social care.⁸⁷ In England, for example, the first three to four months of care is paid for usually by NHS England and continued subsequently by Clinical Commissioning Groups.⁸⁸ Recognised problems with this arrangement include potential conflicts of interests in respect of paying for and supplying long-term care. Decisions to purchase expensive items of equipment such as specialist wheelchairs, for example, might be postponed so that a subsequent funder would bear the cost ultimately.⁸⁹ Clearly, systems that permit perverse incentives such as these do not place patient need and best interests at centre-stage.

Tensions between providers and commissioners of healthcare are all too apparent in publicly funded healthcare systems. Commissioning bodies have duties to provide comprehensive services to communities as a whole and decisions based on collective justice have to be made by application of fair and consistent principles. In order for commissioners to achieve their statutory purpose, competing interests of communities and patient groups have to be weighed and balanced against each other.⁹⁰ According to macroeconomic principles it follows that decisions to invest in one area of need is likely to be achieved to the detriment of another. The tensions are further increased in

⁸⁷ Houses of Parliament Parliamentary Office of Science and Technology, Vegetative and Minimally Conscious States, Postnote, (2015) No. 489, March available at <http://researchbriefings.files.parliament.uk/documents/POST-PN-489/POST-PN-489.pdf>.

⁸⁸ Ibid.

⁸⁹ Ibid.

⁹⁰ Newdick C, Derrett S, Access, Equity and the Role of Rights in Healthcare. Health Care Analysis (2006) 14: 157-168 p 159.

that clinicians owe a duty of care to each of their patients, rather than to society in general.

Claims that concern positive rights to public resources are considered to be challenging as far as legal enforceability is concerned. As unelected bodies the courts have been reluctant to arbitrate over individual rights to healthcare and other economic resources since favouring one group will invariably constrain the ability of other groups to benefit. Recognition of individual rights may be won only at the expense of the right of equal access for equal need.⁹¹

Recognition of substantive rights provide legally enforceable access to specific resources whereas procedural rights serve to guarantee that a decision about access will be made according to an appropriate process.⁹² For this reason the courts have tended to differentiate between procedural and substantive rights and are more amenable to adjudicate where allegations concern procedural impropriety.⁹³ Although English law has been reluctant to grant substantive rights of access, on occasion such rights have been created.⁹⁴ Although it has been suggested that too much recognition of substantive rights might undermine equity and fairness within the NHS,⁹⁵ an unanswered question remains. How does one achieve equity with public resources, such as healthcare, when ranking of priorities between competing interests are inherently subjective and upon which the views of reasonable people might well differ.

Allocating health care resources is a nexus that involves multiple compromises to be made to accommodate competing demands and constraints. The court's recognition that "difficult and agonising judgements have to be made as to how a limited budget is best allocated to the maximum advantage of the maximum number of patients"⁹⁶ is still true today. Policy choices have to be made by the state to apportion fair distributions to protect competing rights and interests particularly in a publicly funded health care environment. Notwithstanding the court's traditional reluctance to become embroiled in

⁹¹ Ibid at p162.

⁹² Ibid at p160.

⁹³ *Re J (a minor)* [1992] 4 All ER 614; *R v Cambridge DHA, ex parte B* [1995] 2 All ER 129.

⁹⁴ Newdick C, Derrett S, Access, Equity and the Role of Rights in Healthcare. *Health Care Analysis* (2006) 14: 157-168 at 162.

⁹⁵ Ibid. at p163.

⁹⁶ *R v Cambridge DHA ex p B* [1995] 2 All ER 129 *per* Thomas Bingham MR.

resource allocation decisions, relatively recent and mainly politically driven changes are being introduced. The NHS Constitution, introduced as part of the Health Act 2009, for example, sets out the right to receive NHS services free of charge, apart from limited exceptions.⁹⁷ This specifically includes the right to receive treatments, drugs and programmes that have been recommended by NICE if these are deemed clinically appropriate.⁹⁸ Nevertheless, there is widespread confusion about enforceability since much of the constitution consists of pledges or aims rather than enforceable rights. Despite a clear expectation that they should be delivered, there is little evidence of enforceable potential.⁹⁹ Positive rights to health care are often rightly regarded as economic freedoms and as such are more contentious for public policy when compared with negative rights to be free from state interference.¹⁰⁰ Nevertheless, the Government is coming under increasing pressure to create and recognise tangible rights to health care.¹⁰¹

While the Health Act 2009 only makes provision that all providers of NHS services must have regard to the Constitution, there is no legal enforceability of the NHS's "pledges" within the document. The NHS Constitution in itself does not confer new rights or change the law, instead it is a declaratory document of rights that already exist. These rights are underpinned by statute or the Common Law and are effectively legal rights, but as yet no single piece of legislation sets out to detail these rights. In reality the pledges within the NHS Constitution are little more than statements of principle. This means that commissioners and other funding bodies should consider the NHS

⁹⁷ NHS Constitution (26 March -2013).

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/NHSConstitution/Documents/2013/the-nhs-constitution-for-england-2013.pdf>.

⁹⁸ NICE (the National Institute for Health and Care Excellence) is an independent organisation producing guidance on drugs and treatments. 'Recommended for use by NICE' refers to a type of NICE recommendation set out in legislation. The relevant health body is obliged to fund specified NICE recommendations from a date no longer than three months from the publication of the recommendation unless, in certain limited circumstances, a longer period is specified.

⁹⁹ Hudson B, NHS constitution has barely achieved anything since it was introduced (21 August 2015) Guardian <http://www.theguardian.com/healthcare-network/2015/aug/21/nhs-constitution-achieved-nothing-since-introduced>.

¹⁰⁰ Newdick C, Derrett S, Access, Equity and the Role of Rights in Healthcare. *Health Care Analysis* (2006) 14: 157-168 p 159.

¹⁰¹ A typical example is the NHS 'Your right: urgent two-week referral' for patients suspected to have cancer.

Constitution when making decisions but that the pledges themselves are ultimately unenforceable.¹⁰²

(c) Treatment withdrawal

Following enactment of the Mental Capacity Act 2005 the Court of Protection must be involved in all decisions to withdraw CANH from people in MCS by means of a declaration that to do so would be in the person's best interests.¹⁰³ For patients in VS the court's role is to ascertain sufficient proof that the condition is permanent, whereupon declaratory relief will be granted. This is not the same for patients in the MCS. In these circumstances the court must examine carefully the substantive diagnosis and the premises of its base with very considerable care. The outcomes of applications for declaratory relief indicate that whether withdrawal of CANH is in the person's best interests is entirely fact dependent and sensitive. It is therefore vitally important that every step is taken to diagnose a person's true condition before declaratory relief is applied for.¹⁰⁴

In the first case to consider whether CANH should be withdrawn from a woman in MCS Baker J. directed that standardised assessment would always be necessary prior to making an application to the court.¹⁰⁵ This was on the basis that every step could be taken to ascertain the patient's true condition before a decision could be made. He stated that no application for an order authorising the withdrawal of CANH from a person in MCS should be made unless a SMART or WHIM assessment, or other validated equivalent, had been carried out over a period of time to track the person's progress and recovery. This then surely leads to a tension with the principle that judges should not override professional judgements or apply 'pressure upon the Secretary of State' to provide facilities for these procedures to be carried out.¹⁰⁶

¹⁰² Patients Association, The NHS Constitution: Fact or Fiction <http://www.patients-association.org.uk/wp-content/uploads/2014/07/NHS-Constitution-Fact-or-Fiction.pdf>.

¹⁰³ Section 15 of the Mental Capacity Act 2005; Court of Protection Rules (S.I. 2007/1744) Practice Direction 9E.

¹⁰⁴ *CWM TAF University (applicant) v F* [2015] EWHC 2533 (Fam) para 13.

¹⁰⁵ *W v M* [2012] 1 All ER 1313.

¹⁰⁶ *Burke, R (on the application of) v General Medical Council* [2005] EWCA para 38.

Similarly, as the court recognised in *Re P*¹⁰⁷ current best practice guidance provides that diagnosis of VS or MCS should be based upon the results from validated structured assessment tools. For Newton J. the case before him was yet “another stark example of the absolute necessity for a structured assessment to have occurred” since “misdiagnosis (of people who are said to be in a vegetative state but are in truth in a minimally conscious state) [and] ... ~~misdiagnosis~~ is said to be some 40%.”¹⁰⁸ While Newton J. did not suspect any *malafides* of the treating clinicians the difficulties of reaching a definitive diagnosis without the benefit of rigorous and reliable assessment and reassessment techniques were considerable. In these circumstances it was considered to be an ‘absolute necessity’ for proper neurological assessment to be carried out, ideally with MRI at established intervals, in order to bring together a comprehensive evidence base before reaching the ultimate conclusion as to the level of awareness of the patient. Not to do so was to risk ‘cataclysmic injustice’ to the vulnerable person concerned.¹⁰⁹

Accurate diagnosis of the MCS is a complex process requiring assessment at several points in time by a multi-disciplinary team of experts. Assessment and reassessment is further complicated in that the patient’s responses may be delayed, inconsistent and influenced by a range of confounding factors. Clinical conditions can change over time and there is always a degree of subjectivity involved when carrying out and interpreting the findings, together with input from a wide range of sources and health professional disciplines including physiotherapy, occupational therapy, speech and language therapy, neuropsychology, nursing and rehabilitation medicine.¹¹⁰ Theis diagnosis should then be confirmed by a second senior consultant. According to current guidelines of the Royal College of Physicians the initial assessment prior to an application to the court should include a comprehensive medical assessment by means of a validated structured neurological assessment tool such as the

¹⁰⁷ *Re P* [2015] EWCOP 42.

¹⁰⁸ *Re P* [2015] EWCOP 42 at para 8.

¹⁰⁹ *Re P* [2015] EWCOP 42 para 48.

¹¹⁰ Royal College of Physicians, *Prolonged disorders of consciousness: national clinical guidelines* (2013) Royal College of Physicians, London. At 14.

WHIM or SMART. Best interests meetings prior to an application to the court are also required in consultation with the patient's relatives.¹¹¹

In contrast to people diagnosed definitively in permanent VS, the law offers little substantive guidance as to whether withdrawal of life-sustaining treatment will be in the best interests of a person who is minimally conscious, ~~in best interests~~. Whereas a precedent was set in *Bland* that it is not in the best interests of person in definitive permanent VS to be maintained in life by CANH, no equivalent ruling exists in relation to MCS patients.¹¹² Each case has to be considered on its own merits. In *W v M*¹¹³ the court held, in a controversial decision, that it was in the best interests of the woman to continue life support together with provision of enhanced efforts to rehabilitate her in order to enhance her quality of life. This finding verdict, however, was not repeated in *United Lincolnshire Hospitals NHS Trust v N*¹¹⁴ where the Court of Protection declared that it was lawful and in the patient's best interests for her clinicians (a) not to make any further attempt to secure a means of providing artificial nutrition; and (b) to withdraw the provision of intravenous fluids. The decision concerned 'withholding' rather than 'withdrawing' treatment.

It appears, very strongly, that the court will use a balance sheet approach to determine the best interests of the person concerned provided that a robust and definitive diagnosis has been reached with the latter being of fundamental importance. In *CWM TAF*¹¹⁵, for example, even though the case concerned a patient suspected to be in permanent VS, the court pronounced on the lack of assessments which had been carried out for the purposes of the hearing. These were considered to have been carried out by practitioners who lacked the requisite training and expertise. Reference was once again made to the Royal College of Physician's guidance that required that "assessors for the diagnosis of which the court is concerned should meet the minimum

¹¹¹ Section 4 of the Mental Capacity Act 2005.

¹¹² *Airedale Trust v Bland* [1993] AC 789.

¹¹³ *W v M* [2012] 1 All ER 1313.

¹¹⁴ *United Lincolnshire Hospitals NHS Trust v N* [2014] EWCOP 16.

¹¹⁵ *CWM TAF University (applicant) v F* [2015] EWHC 2533 (Fam) *para* 13. This case concerned an application for a declaration that withdrawal of CANH would be in the best interests of a patient in a permanent VS. The declaration was not given on the basis that clinical evaluations had been insufficiently robust and had not been carried out by experts with the requisite level of skill.

requirements set out, both as to experience and training".¹¹⁶ The application was therefore refused on the basis that the judge did not feel confident that this requirement had been met.

Conclusion

On the basis of this empirical study it is suggested that whether patients in a MCS have access to a range of specialist advanced diagnostic techniques is due largely to the vagaries of circumstances and most notably to the availability of skilled health professionals and access to validated structured neurological assessment tools and expertise. But to what extent should reassessment be considered as a right, rather than a mere twist of fate governed by chance availability of specialist resources?

Current law that concerns people in MCS reveals very clearly that applications for declaratory relief will be countenanced only following assessment by SMART and WHIM (or other similarly validated tool) to confirm the person's true diagnosis. Nevertheless, reliance on definitive diagnostic assessment and reassessment at this time is perhaps too late to meet the ~~for the~~ real best interests of the person concerned. Surely the best interests of the person would mandate that accurate and reliable assessment is carried out at an earlier stage to inform and underpin the very best rehabilitation and treatment efforts to provide them with every opportunity to enhance their quality of life, or alternatively to withdraw treatment where continuation is futile and no longer best for the person ~~in the best interests of the person~~ concerned.

Using a grounded theory approach the key emergent themes from the analysis were that context driven factors provided the trigger for (re)assessment and that 'supported' patients had a greater likelihood of accessing specialist (re)assessment services. A key finding of the study was the notable lack of an expectation of a right to reassessment, at least in the legal sense.

Nonetheless, a right was recognised as conceived as a moral normative expectation. Ultimately, there was no unified or coherent decision-making approach to decisions to reassess. On the basis of these findings it ~~is~~ appears that if a right to reassessment is to have real meaning then there is a need to

¹¹⁶ Royal College of Physicians, *Prolonged disorders of consciousness: national clinical guidelines* (2013) Royal College of Physicians, London. Section 2.

commit to the rights based agenda for this patient group whose interests might otherwise be marginalised. However, it has become clear from recent determinations that expert assessment has now become a mandatory expectation before declaratory relief will be provided by the courts but only when withdrawal or withholding of treatment is being considered.¹¹⁷

It is apparent that there is no right to reassessment, as holistically defined. This aligns with established common law principles that there is no definitive right to any form of medical treatment or diagnostic intervention. Notwithstanding this, best practice guidance from the Royal College of Physicians mandates that reassessment is a cornerstone of good clinical care for this patient group and ought to be carried out at least annually. As such ~~perhaps it is hoped that annual~~ reassessment will perhaps become established as the new *Bolam* standard for care for this patient group.¹¹⁸ At the same time advanced diagnostic and assessment tools and strategies used to assess neurological condition and status have been demanded by courts to underpin their decisions as to whether withdrawal of life-sustaining treatment is in the best interests of people in MCS.¹¹⁹ This development is perhaps the strongest indication that the use of advanced diagnostic techniques, at least for the purposes of best interests adjudications, has already become a legal requirement.

Reassessment at this particular time in the patient's journey when withdrawal of CANH is being considered is at this stage perhaps at its very least useful from the perspective of the best interests on the person. Advanced reassessment techniques are expensive and time-consuming. Notwithstanding their obvious use to ascertain whether or not the patient's best interests is to stay alive, reassessment carried out at an earlier stage could be more positively targeted with better use of scarce healthcare resources. A positive outcome can be expected to lead to greater and more focused rehabilitative efforts and better outcomes for intensive use of resources, whereas negative findings may consolidate thoughts towards withdrawal of heroic efforts to keep the patient alive. More tangible evidence that the patient's condition is permanent may

¹¹⁷ All the case law stemming from *W v M* [2012] 1 All ER 1313 to the present.

¹¹⁸ Samanta A, Mello M, Foster C, Tingle J, Samanta J, The role of clinical guidelines in medical litigation: a shift from the *Bolam* standard? (2006) *Med Law Rev* 14(3) 321-366.

¹¹⁹ *W v M* [2012] 1 All ER 1313; *CWM TAF University v F* [2015] EWHC 2533 (Fam).

provide earlier and more reliable bases for decisions to withdraw life-sustaining treatment, where this is considered to be best for the patient. Meeting this challenge is a duty for which those responsible can, and must, be held accountable.

These 'rights' which now evidently receive judicial recognition should be required and implemented at an earlier stage of the journey of a patient's life in MCS and most certainly before a stage where withholding or withdrawal of life-sustaining treatment is being contemplated.