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End-of-life Decisions for Patients with Prolonged Disorders of Consciousness in England and Wales: Time for Neuroscience-informed Improvements

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Title Page

Title of the article: End-of-life decisions for patients with prolonged disorders of consciousness in England and Wales: time for neuroscience-informed improvements

Short title: Improving end-of-life decisions for PDOC patients

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End-of-life decisions for patients with prolonged disorders of consciousness in England and Wales: time for neuroscience-informed improvements

Abstract

This article explores how the law of England and Wales¹ has responded thus far to medical and clinical advances that have enabled patients with prolonged disorders of consciousness (PDOC) to survive. The authors argue that, whilst the courts have taken account of much of the science, they are now lagging behind, with the result that some patients are being denied their legal rights under the Mental Capacity Act 2005. The article further argues that English law does not comply with the United Kingdom's commitments under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Stressing the need for the law to keep in step with advances in science, the article concludes with robust recommendations for improvements, based on the latest research in neuroscience, to the way in which life-sustaining treatment decisions are made. This would mean that the wishes of patients, including those with covert awareness, can be better reflected in best interests assessments.

Key words: best interests, covert awareness, CRPD, English law, life-sustaining treatment, Mental Capacity Act, PDOC, prolonged disorders of consciousness

Background

In 1993 the English courts were called upon, for the first² time, to decide whether withdrawal of life-sustaining treatment for a patient in a persistent vegetative state (PVS)³ was lawful. Throughout the three hearings⁴ the Official Solicitor argued that the proposed actions would amount to murder.⁵ The patient, Tony Bland, had been in PVS for over three years following injuries sustained in the Hillsborough disaster.⁶ His condition was described as "extreme".⁷ The President of the Family Division of the High Court summed up his position:

"He has no feeling, no awareness, nor can he experience anything relating to his surroundings. To his parents and family he is "dead." His spirit has left him and all that remains is the shell of his body."⁸

It was proposed that the nasogastric tube through which Tony was fed should be removed and that no antibiotic treatment should be initiated if infection arose. It was anticipated that without sustenance he would die within about two weeks. Sir Thomas Bingham in the Court of Appeal described the case as one which raised "moral, legal and ethical questions of a profound and fundamental nature, questions literally of life and death."⁹ His fellow Court of Appeal judge, Hoffman LJ, posed the question even more dramatically, referring to public concerns raising the question: "Is the court to assume the role of God and decide who should live and who should die?"¹⁰

The importance of "best interests"

The judges in the House of Lords unanimously decided that it was lawful to withdraw life-sustaining treatment. Four out of five judges focussed on the patient's best interests in arriving at their conclusions. They did not formulate the question as to whether it was in the patient's "best interests" to die, but rather as Lord Browne-Wilkinson expressed it: "the critical decision to be made is whether it is in the best interests of Anthony Bland to continue the invasive medical care involved in artificial feeding."¹¹ The remaining judge, Lord Mustill, did not discount the importance generally of the patient's interests, but considered that in this case the patient had no interest: "All hope of

recovery has now been abandoned. Thus, although the termination of his life is not in the best interests of Anthony Bland, his best interests in being kept alive have also disappeared".¹² This subtly different line of reasoning led him to the same outcome: "the justification for the invasive care and treatment, together with the duty to provide it have also gone."¹³

Life-sustaining treatment was withdrawn and Tony Bland died. Following his death, the Reverend James Morrow laid an information asking the local justices to issue a summons charging the doctor responsible for Tony Bland's care with murder. The magistrates refused. Their decision was upheld by the High Court.¹⁴

Best interests and the Mental Capacity Act 2005

In *Bland* both Lord Browne-Wilkinson¹⁵ and Lord Mustill¹⁶ had called on Parliament to consider the issues raised by the case. Similarly, when dismissing the attempt to initiate a prosecution for murder, the High Court¹⁷ said that the Reverend Morrow should go to Parliament if he wanted the law to be changed. Parliament did consider the matter and in introducing the second reading of The Mental Capacity Bill in 2005, the Lord Chancellor, Lord Falconer, referred to the case of Tony Bland

"The Bill preserves the jurisdiction exercised in the Tony Bland case, and restates the principles applied in that case. These are very difficult decisions, even for a court. In making them the decision-maker must act in the best interests of the patient. Above all, he must make an objective assessment. The decision cannot simply be the personal value judgment of the decision-maker—the decision-maker cannot say, "If I were in the patient's position, I would want to die"—nor can it be motivated by the desire to bring about the death of the patient.

...

In the vast majority of cases, providing treatment will therefore be the best interests conclusion. But we all know of those difficult cases... where there is no prospect of recovery of consciousness or sensate brain activity because of the extent of brain damage...

Any decision must be on the basis of the decision-maker's objective judgment of what is in the best interests of the patient. That will in some cases involve concluding that treatment that might otherwise prolong life should be withheld."¹⁸

The Act reflects this approach. Section 1(5) of the Act states: "An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests." Best interests are not explicitly defined in the Act, but section 4 does identify relevant factors which should be taken into account by any person or court determining a person's best interests:

"Section 4

...

- (6) He must consider, so far as is reasonably ascertainable—
- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
 - (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.
- (7) He must take into account, if it is practicable and appropriate to consult them, the views of—

- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
 - (b) anyone engaged in caring for the person or interested in his welfare,
 - (c) any donee of a lasting power of attorney granted by the person, and
 - (d) any deputy appointed for the person by the court,
- as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6)."¹⁹

Other provisions in the Act provided that an adult with capacity could make an advance decision to refuse treatment²⁰ including life-sustaining treatment.²¹ If the individual lacked capacity when a treatment decision needed to be made, the advance decision would be followed.

The need to go to court: the initial understanding

In the course of the hearings to determine whether Tony Bland's life-sustaining treatment should be discontinued, the President of the Family Division hearing the case alone in the High Court,²² the three judges in the Court of Appeal,²³ and four of the five judges in the House of Lords²⁴ all expressed the view that, before life-sustaining treatment was withdrawn in similar circumstances, cases should be taken to the Family Division of the High Court. The Mental Capacity Act 2005 (MCA) did not change this procedure.

However, neither Tony Bland's case nor the MCA opened the floodgates; the courts instead dealing with a trickle rather than a flood of cases. These end-of-life cases involving PVS patients basically followed the reasoning in *Bland*, but did clarify some issues. In *Re G*²⁵ the courts had to consider the situation where, unlike in *Bland*, the patient's family disagreed with the medical view that artificial nutrition and hydration (ANH) should be withdrawn. It was held that it was lawful, notwithstanding the opposition of the patient's mother, to withdraw the artificial feeding process from a patient in PVS. In *NHS Trust A v M; NHS Trust B v H*²⁶ the impact of the 1998 Human Rights Act was considered. It was held that it was lawful to withdraw ANH for two PVS patients²⁷ and that this would not contravene the right to life set out in Schedule 1 of the Human Rights Act 1998. *Re D*²⁸ explored the distinction between being in a vegetative state (VS) and PVS²⁹ in a case concerning a patient who exhibited the symptoms of VS but did not meet the PVS criteria because certain stimuli led to her make involuntary eye movements. The judge concluded that there was "no evidence of any meaningful life whatsoever" and that D was "suffering what is rightly termed a 'living death'".³⁰ A declaration that her life-sustaining treatment could be withdrawn was granted.

Judicial development of the best interests test for MCS patients

In *W v M*³¹ Justice Baker faced a subtly different scenario. He had to decide whether ANH should be withdrawn from a woman, M, who had suffered "extensive and irreparable brain damage"³² as a result of viral encephalitis. In February 2003 M had fallen into a coma, and when she emerged from the coma she was diagnosed as being in VS. In 2007 her family had applied to the Family Division of the High Court for a declaration that her doctors could lawfully discontinue and withdraw treatment including ANH. Following this application, M was re-assessed and classified as being in a minimally conscious state (MCS). The idea of MCS as a state between full consciousness and VS had become a subject of scientific discussion in the 1990s,³³ the term being defined and criteria for diagnosis being set out in 2002.³⁴

W v M was the first case in which the English courts had been asked to authorise the withdrawal of ANH from an MCS patient.³⁵ Justice Baker characterised the difference between MCS and VS, saying of M that "she is recognisably alive in a way that a patient in the vegetative state is not."³⁶ This was

in his view a very significant distinction. The test remained the patient's best interests, but as the judge noted: "In VS cases, the balance falls in one direction in every case – in favour of withdrawal."³⁷ In MCS cases Justice Baker proposed that a "balance sheet" approach should be adopted.³⁸ In carrying out this balancing act in M's case, a number of factors were considered including: the importance of preserving life,³⁹ M's wishes and feelings,⁴⁰ the extent to which M was in pain,⁴¹ M's enjoyment of life,⁴² her prospects of recovery,⁴³ her dignity,⁴⁴ and the wishes and feelings of her family and her carers.⁴⁵ Justice Baker accepted that M was often in pain and had virtually no prospect of recovery. He noted the view of M's family that M was "fiercely independent" and "would have hated to be looked after".⁴⁶ He also accepted their uncontested evidence that before she had become ill when she was watching television coverage of the Tony Bland case she had expressed the view that he should be allowed to die.⁴⁷ Nevertheless he concluded that "the importance of preserving life is the decisive factor in this case."⁴⁸

The case is interesting for the emphasis on the science. Reference is made to a "bundle of research articles"⁴⁹ being produced to support the expert evidence, and no fewer than seven papers are referred to in the judgment.⁵⁰ The reference to scientific papers in part was probably a product of the disagreements between the experts who were not only in disagreement as to the ultimate issue as to whether ANH should be withdrawn, but also disagreed as to whether M had a high or a low level of consciousness for a patient in MCS, whether M's experiences were on balance positive or negative, and whether it was in her interests to be exposed to more stimulation.⁵¹

Since *W v M* the idea of the court carrying out a balancing act in cases involving MCS patients has continued.⁵² In *Aintree University Hospitals NHS Foundation Trust v James*⁵³ the Supreme Court affirmed the Court of Appeal's decision⁵⁴ that the appropriate test is the patient's best interests. Lady Hale explaining the role of the court as being "to decide whether a particular treatment is in the best interests of a patient who is incapable of making that decision for himself."⁵⁵ She noted that it is not enough that clinicians follow accepted medical practice; all the circumstances including both medical and non-medical factors must be taken into account, noting that the patient's preferences "are an important component in deciding where his best interests lie."⁵⁶

The need to go to court revisited

In *An NHS Trust v Y*⁵⁷ the Supreme Court held that it was not necessary to go to court to seek an order permitting the withdrawal of life-sustaining treatment if the patient's family and doctors agreed that withdrawal was in the patient's best interests. The Supreme Court proposed some safeguards: the provisions of the MCA must be followed, as must "relevant guidance".^{58 59} Essentially this guidance sets out the required clinical procedures, and explains the best interests test that must be applied. Under the guidance, clinicians lead the decision-making process despite its not being a purely clinical process.⁶⁰ This quicker and cheaper approach brings the withdrawal of ANH more in line with the vast majority of medical procedures – such as the use of life-saving antibiotics – where reference to the courts is not required. However, it comes with risks attached. There is a potential knowledge imbalance. Families are very likely to be dependent on the medical team's assessment of the patient's prognosis. Factors other than the patient's best interests may start to creep in. NHS Trusts working with overstretched budgets are going to be aware of the costs of keeping PDOC patients alive and of the costs of going to court.⁶¹ Additionally, irrespective of whether clinicians favour maintaining or withdrawing life-sustaining treatment, patients' families may feel pressured not to fight that decision – either because they are emotionally and physically drained or because, as legal aid is not available, they cannot afford it.⁶²

VS or MCS? An important legal distinction

The decision in *An NHS Trust v Y* does not rule out the involvement of the courts. If there is no agreement, or if the application of the best interests test is finely balanced, cases should still be taken to court.⁶³ The courts will continue to apply the best interests test. How they do this depends on the categorisation of the patient. As previously noted, Justice Baker commented in *W v M* “In VS cases, the balance falls in one direction in every case – in favour of withdrawal.”⁶⁴ Legal commentators have also noted this distinction⁶⁵ and even though there is now at least one reported case in which continuing ANH has been held to be in the best interests of a VS patient;⁶⁶ the reality remains that a diagnosis of PVS will almost inevitably lead to a court decision to support the withdrawal of ANH.

The related problem of misdiagnosis

The problem of misdiagnosis is well known. In 1993 Nancy Childs et al. found that 37% of patients who were diagnosed as in coma or PVS still had some level of awareness.⁶⁷ Three years later, Keith Andrews et al. found 43% of patients diagnosed as VS to be misdiagnosed, noting:

“Recognition of awareness is essential if an optimal quality of life is to be achieved and to avoid inappropriate approaches to the courts for a declaration for withdrawal of tube feeding.”⁶⁸

Childs’ and Andrews’ studies pre-dated the publication in 2002 of criteria for diagnosing MCS.⁶⁹ Since then, the courts have provided guidance as to the steps that should be undertaken. In *W v M*, having heard evidence about the use of the Wessex Head Injury Matrix (WHIM) and the Sensory Modality Assessment and Rehabilitation Technique (SMART), Justice Baker stated that no application

“for an order authorising withdrawal of ANH from a patient in VS or MCS should be made unless (1) a SMART assessment (or similarly validated equivalent) has been carried out to provide a diagnosis of the patient’s disorder of consciousness and (2) in the case of a patient diagnosed as being in a MCS, a series of WHIM assessments has been carried out over time with a view to tracking the patient’s progress and recovery (if any) through the MCS.”⁷⁰

The 2018 guidance from the Royal College of Physicians (RCP) and the British Medical Association (BMA) is now the “relevant guidance”, having superseded the interim guidance referred to by the Supreme Court in *An NHS Trust v Y*. The 2018 guidance notes that: “Misdiagnosis of VS and MCS is very common in non-specialist settings”.⁷¹ As a result, the guide recommends assessment in a specialist PDOC facility over a suggested period of three to four months using the Coma Recovery Scale (CSR-R) and WHIM. The use of CSR-R accords with the recommendation of Caroline Schnakers et al. who found that 43% of patients with disorders of consciousness in specialist neurological care settings were misdiagnosed as VS.⁷² The rates of misdiagnosis from less specialist settings would, presumably, have been even more disturbing.

However, the courts have already faced the situation where experts disagree⁷³ and cases where experts expressed apparently entrenched positions.⁷⁴ Worryingly, it is clear that the three- to four-month recommended timescale may not always be observed. In *TG*,⁷⁵ despite the opposition of the family, a case to withdraw life-sustaining treatment was brought by the hospital only two months after the patient has been diagnosed as VS even though the guidance at that time was that VS should not be regarded as PVS until six months had elapsed. Cynics might argue that removing the need to go to court raises the possibility that clinicians might seek an “independent” second opinion, as required under the guidance,⁷⁶ from an expert who they think likely to support their view. The previous system, where cases were routinely taken to court, reduced this risk as the Official Solicitor would normally appoint an independent expert.

Best interests – the wrong test?

In 2009, the UK ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. Article 12(2) of the CRPD requires that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Under English law, patients who have capacity can refuse treatment including life-sustaining treatment. They can also request treatment, though they cannot insist on it. Patients who have made advance decisions, but who retain capacity, can change their minds. However, PDOC patients are viewed by the courts and the medical profession as lacking capacity because of their disability. This means that they do not have legal capacity on an equal basis in relation to possibly the most important aspect of life – a decision whether or not to end that life.

Article 12(3) places a further responsibility on States: “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” To some extent the MCA attempts to achieve this. Patients are assumed to have capacity until it is established that they lack capacity.⁷⁷ They are not to be treated as lacking the capacity to make decisions until all practicable steps have been taken to enable them to make that decision.⁷⁸ However, in terms of compliance the most problematic question is whether the best interests test complies with Article 12(4) which requires that States must “ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person”.

In 2014 the United Nations Committee on the Rights of Persons with Disabilities (the Committee) adopted its first General Comment (*On Equal Recognition Before the Law*) (CRPD_GC1) which states that:

“The “best interests” principle is not a safeguard which complies with article 12 in relation to adults. The “will and preferences” paradigm must replace the “best interests” paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.”⁷⁹

In the light of CRPD_GC1 a review of the MCA conducted by the Essex Autonomy Project for the Ministry of Justice unsurprisingly concluded that:

“The best-interests decision-making framework of Section 4 of the MCA fails to satisfy the requirements of CRPD 12(4), which requires safeguards to ensure respect for the rights, will and preferences of disabled persons in matters pertaining to the exercise of legal capacity.”⁸⁰

Notwithstanding CRPD_GC1 and the Essex Autonomy Project’s findings, there has been no reform of the best interests test contained in the MCA, and no discernible change in the interpretation of that test by the courts.⁸¹

The result is that the law in England and Wales does not comply with the CRPD. If it did, it would give primacy to the patient’s “will and preferences”, with the focus being on the patient’s views at the time when any medical decision needed to be made or, if that could not be ascertained, it would be on the previously expressed will and preferences of the patient. This is not what happens when the best interests test is applied, although the patient’s wishes are a factor in that test.

Whether the MCA should be amended to comply with the CRPD is beyond the scope of this article, as is the question of whether the court’s interpretation of the MCA’s best interests test should be altered to conform to the CRPD.⁸²

Classifying PDOC patients – lessons from neuroscience

Currently assessments of PDOC using CSR-R, WHIM or SMART are based on overt behavioural responses. Patients showing no overt behavioural signs of awareness will be classified as VS and assumed to be unaware.⁸³ Patients showing inconsistent, but reproducible, signs of awareness will be classed as being at least MCS.⁸⁴ However, it is now well established that there are patients who show no external signs of awareness, but who are aware.

Changes suggesting awareness have been observed in the regional cerebral blood flow of a PVS patient when read to by his mother.⁸⁵ Robust activity in the right fusiform gyrus, the so-called 'human face area', has been seen in a PVS patient shown familiar faces.⁸⁶ Response to speech in the so-called 'language centres' in the brain of VS patients has been observed,⁸⁷ with greater brain activity when a PVS patient's own name is mentioned.⁸⁸ The best evidence of awareness has been seen when patients diagnosed as VS have responded to commands by deliberately modulating their brain activity – a capacity that will be explored more fully in the next section. More recently comparisons of the brain activity when watching extracts from suspenseful films have demonstrated similar frontal and parietal cortex activity in some VS patients to that in healthy controls.⁸⁹

Whether these patients who demonstrate covert awareness, but no overt behavioural signs of awareness should be categorised as an additional PDOC category or categorised within the existing options is debatable. Descriptions such as "functionally locked in",⁹⁰ "covertly conscious",⁹¹ "behaviourally nonresponsive patient with residual covert awareness"⁹² or having "cognitive motor dissociation"⁹³ are useful in illustrating that some patients do not fit neatly into the VS/MCS binary divide.

The English courts have already shown a willingness to acknowledge medical advances – in *Bland* they recognised VS; in *W v M* they recognised MCS; more recently, they have recognised a subdivision within MCS between MCS+ and MCS-.⁹⁴ They should now recognise the covertly aware.

The focus on levels of consciousness implies that consciousness comes in degrees, whereas arguably the primary distinction is whether or not the individual is conscious.⁹⁵ Tim Bayne et al. reject the idea that individuals can "be ordered on the basis of how conscious they are",⁹⁶ instead arguing for a more nuanced multidimensional system of classification.⁹⁷ In a sense the courts' practice of looking at the individual facts of each case reflects this more nuanced approach. On the other hand, the judicial approach of differentiating between VS and MCS cases militates against this – especially when one considers that the VS cases will include some patients whose covert consciousness has not been recognised by behavioural tests.

Perhaps a more promising approach would be to change the classification assessment measures.⁹⁸ It is now more than a decade since Martin Coleman et al. (2009) wrote about the need to move to the "routine use of brain imaging to aid the clinical diagnosis of disorders of consciousness".⁹⁹ Misdiagnosis rates of around 40% have already been noted. Standardised tests such as WHIM, SMART and CSR-R may improve accuracy. However, these measures are still based on "clinicians' subjective opinions of the patient's responses".¹⁰⁰

"This subjectivity of assessment may lead to high levels of misdiagnosis by those who are less experienced in their use, or indeed by experienced assessors when behavioural signs are minimal or entirely absent."¹⁰¹

These tests will fail to identify behaviourally nonresponsive patients with residual covert awareness. Such patients will be diagnosed as VS because they are overtly unresponsive; however, they are not wakeful without awareness – the essence of VS.

An independent review of studies of covert awareness looking at 37 published studies involving a total of 1,041 patients found that about 15% of patients diagnosed as VS are covertly aware.¹⁰² Potentially this affects prognosis and assessments of best interests. Haibo Di et al. in a review of 15 studies,¹⁰³ and Coleman et al. in a study of 41 patients,¹⁰⁴ have shown that functional neuroimaging results can help predict recovery. Similar benefits may also be found through the use of high-density EEG.¹⁰⁵ It is possible that fMRI could also improve the assessment of coma patients, but that is beyond the scope of this article.¹⁰⁶ Some patients can respond to commands at the bedside; some can do so only by modulating their brain activity; some can do both.¹⁰⁷ Assessments designed to detect covert awareness should not replace behavioural tests but should complement those tests. Those who display no awareness using either form of test may lack awareness, or it may be that existing tests cannot discern their awareness. The impact of recent neuroscientific research is not limited to the classification of PDOC.

Communicating with PDOC patients – an important step forward

For the law, another development which is potentially even more significant is the ability to communicate with some PDOC patients. The use of functional magnetic resonance imaging (fMRI) to enable patients who cannot otherwise communicate to respond to questions has profound implications, not just for the treatment of PDOC patients but also for medical and judicial decision-making. Building on earlier research,¹⁰⁸ Martin Monti et al.¹⁰⁹ asked 54 PDOC patients (23 diagnosed as VS, 31 as MCS) to think about hitting a tennis ball (motor imagery) and then to think about navigating their home or the streets of a familiar city (navigation imagery). Five out of 54 patients could “willfully modulate their brain activity”. Four of the five had been diagnosed as VS. This means that 17% of the 23 patients diagnosed as VS were aware and could follow commands. Of the five patients, four could respond to yes/no questions by thinking about the motor imagery for example for “yes” and the navigation imagery for “no”.¹¹⁰ By testing them on questions for which the answer was subsequently discoverable, for example “Do you have any brothers?”, the accuracy of their answers could be checked. The ability to respond accurately to such questions demonstrates that patients who remained unable to establish any traditional bedside communication such as through speech, limb movement or eye blinks could nevertheless exhibit sustained attention, language comprehension, response selection and working memory.¹¹¹ Importantly, this provides a model by which the views of these PDOC patients can be ascertained for questions for which the answer is not known.

Using fMRI for PDOC patients is challenging. Aside from questions of cost, and issues as to the availability of scanners,¹¹² there are risks of patients suffering physical stress, problems associated with involuntary movement, and – particularly in the case of patients who have suffered traumatic injuries – the fact that any metal implants such as plates and pins will rule out the use of fMRI.¹¹³ One alternative to fMRI is electroencephalography (EEG). Using a similar brain-activation approach, three (19%) of 16 patients diagnosed as VS using the CSR-R tests were able to “repeatedly and reliably generate appropriate EEG responses to two distinct commands, despite being behaviourally entirely unresponsive”.¹¹⁴ These findings have been challenged¹¹⁵ and robustly defended.¹¹⁶ If EEG tests could be proved reliable, they would be a cheaper and much easier-to-administer alternative to fMRI. Three of those who challenged the EEG findings were themselves involved in a smaller investigation which found that EEG could be used to elicit responses from MCS and locked-in-state patients.¹¹⁷ Their conclusion that “EEG power spectral analysis demonstrates evidence for performance of mental imagery tasks in healthy controls and patients with severe brain injury”

suggests that this approach could provide a route to communication with some PDOC patients. Another portable and relatively cheap potential alternative is functional near-infrared spectroscopy (fNIRS).¹¹⁸

Communicating with PDOC patients – the legal ramifications

There has been discussion as to whether behaviourally nonresponsive patients who retain high-level cognitive faculties could have capacity,¹¹⁹ but this examination was not focussed on legal capacity as defined under the MCA. Under the MCA “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 a disturbance in the functioning of, the mind or brain.”¹²⁰

Section 3 sets out that:

“(1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).”

The MCA presumes that individuals have capacity¹²¹ and requires “all practicable steps to be taken” to ascertain whether they have capacity.¹²² It is questionable whether this requirement has been discharged if no attempt has been made to discover whether PDOC patients are covertly aware and, if they are, if no attempt has been made to enable them to make the decision. It should be noted that in assessing patients’ capacity “unjustified assumptions” are not to be made as a result of any condition that they have.¹²³ Nevertheless it is likely to be very difficult for patients who are not able to ask questions and who are only able to answer yes/no style questions to satisfy those assessing their capacity that on balance¹²⁴ they have legal capacity. However, this is not the end of the matter.

If one were to follow the CRPD the next step would be to “ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person”.¹²⁵ This would mean the focus for patients deemed not to have capacity would be to respect their rights and ascertain their will and preferences. As noted, under English law patients have the right to request treatment, though they cannot insist on it, and have the right to refuse treatment including life-sustaining treatment. Patients who have made advance decisions have the right to change their mind. For some PDOC patients their ability to wilfully modulate their brain activity could provide a means by which they could communicate their wishes.

Alternatively, adopting the MCA’s best interests test,¹²⁶ the ability of some PDOC patients to communicate through wilful modulation of brain activity should be informing their medical treatment. Assessment of best interests should include the patient’s wishes, feelings, beliefs and values – past and present. If a patient’s present views can be ascertained then, then so far as is practicable, they must be considered.¹²⁷

Many of the factors that the courts consider in applying the best interests test could be much better informed if the patient’s views were obtained. The list produced by Justice Baker J. in *W v M* has regularly been followed. It includes the patient’s wishes and feelings, the patient’s enjoyment of life, the patient’s dignity and whether the patient is in pain. Assessing these matters is difficult for a court or others assessing a patient’s best interests. Family members, carers and medical staff can –

and often do – disagree. Passing comments made by the patient long ago can take on great, possibly unwarranted, significance. Personal views of family, carers or clinicians may distort assessments of the patient’s views. There is no check to see what the patient actually thinks. Whereas if the view of the patient could be obtained, even if the patient were deemed to lack capacity, it would transform the best interests assessment. Other factors might change in the light of the patient’s testimony. If the patient states that she is in constant pain, has no quality of life and wishes to die, this will surely affect the views of all concerned. Conversely, if the patient responds that she is happy, is in no pain and enjoys her life, then this, too, should influence the views of medical staff, carers and her family.

In *Gross v Switzerland* the European Court of Human Rights noted that:

“in an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or medical decrepitude which conflict with strongly held ideas of self and personal identity.”¹²⁸

On the other hand, Andrew Peterson et al. note that “the inner mental lives of some patients clinically diagnosed as vegetative may be far richer than previously assumed”.¹²⁹ Failing to ascertain a patient’s view in those cases where it can be discovered is scandalous and fails to meet the requirements of the MCA: as science advances, so must the law.

Recommendations

1. There should be a systematic review of the effectiveness of CSR-R, WHIM and SMART in assessing PDOC patients in light of their inability to recognise behaviourally nonresponsive patients with residual covert awareness.
2. All reasonably practicable steps should be undertaken to ascertain whether PDOC patients who are diagnosed as VS are in fact behaviourally nonresponsive patients with residual covert awareness.
3. In all best interests assessments relating to life-sustaining treatment, an independent party should be appointed to represent the patient’s interests.
4. In all best interests assessments, including all cases where the question as to whether life-sustaining treatment should be withdrawn is being considered, all reasonably practicable steps should be taken to discover patients’ current wishes.
 - If patients’ current wishes cannot be ascertained, then all reasonably practicable steps should be taken to ascertain their quality of life, including whether they are in pain and whether they gain pleasure from life.
5. In all cases where PDOC patients have made advance decisions, all reasonably practicable steps should be taken to discover whether they have changed their minds. If so, their advance decisions should be disregarded and best interests assessments should be made.
6. Non-means tested legal aid should be available to close family members wishing to take best interests assessments on life-sustaining treatment to court.

¹ Hereinafter English law

² *Airedale NHS Trust v Bland* [1993] AC 789. Reference to it being the first such case to come before the English courts is at 797F per Sir Stephen Brown P.

³ Sir Stephen Brown P explained that the term PVS meant “a state of complete unawareness” (see note 2 at 795D) and as being “irreversible” and “not susceptible to any improvement” (at 797B). The terms VS and PVS have been used in this article rather than the less pejorative Unresponsive Wakefulness Syndrome (UWS) because these are the terms used by the English courts. For an argument for the use of the term UWS see: Laureys S, Celesia GG, Cohadon F, Lavrijzen J, León-Carrión J, Sannita WG, Szabon L, Schmutzhard E, von Wild KR, Zeman A, Dolce G and the European Task Force on Disorders of Consciousness, Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome, *BMC Medicine*, 2010, 8, 68.

⁴ The case was heard first in the Family Division of the High Court, then on appeal by the Court of Appeal and the House of Lords – the three decisions being reported together - see note 2.

⁵ See note 2 at 813G-815G and 835A-838A per James Munby QC representing the Official Solicitor. The essence of Munby’s argument being found at 835D-E: “It is murder deliberately to hasten death by however short a period of time. “No doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life.” *Reg. v. Adams* (unreported), 8 April 1957.” Prior to going to court, the hospital authorities had consulted the local coroner as to whether they could lawfully withdraw treatment and had been advised that such a course of action ran the risk of criminal prosecution. See note 2 at 796C-D per Sir Stephen Brown P.

⁶ Tony Bland’s death was the last of the 96 deaths that arose in the crush that ensued when too many football fans were allowed onto a section of the terraces at the Hillsborough football ground.

⁷ See note 2 at 879G per Lord Browne-Wilkinson.

⁸ *Ibid* at 804D per Sir Stephen Brown P.

⁹ *Ibid* at 808D per Sir Thomas Bingham MR.

¹⁰ *Ibid* at 825E per Hoffman LJ.

¹¹ *Ibid* at 884B per Lord Browne-Wilkinson. Lord Keith at 859C-D: “In my judgment it does no violence to the principle to hold that it is lawful to cease to give medical treatment and care to a P.V.S. patient who has been in that state for over three years, considering that to do so involves invasive manipulation of the patient’s body to which he has not consented and which confers no benefit upon him.” Lord Goff at 868C-D: “The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.” Lord Lowry at 876G-H “Even though the intention to bring about the patient’s death is there, there is no proposed guilty act because, if it is not in the interests of an insentient patient to continue the life-supporting care and treatment, the doctor would be acting unlawfully if he continued the care and treatment and would perform no guilty act by discontinuing.”

¹² *Ibid* at 897H per Lord Mustill.

¹³ *Ibid* at 898D.

¹⁴ *R v Bingley Magistrates’ Court, ex parte the Reverend James Morrow*, *The Times* 28 April 1994.

¹⁵ See note 2 at 880B and 885E.

¹⁶ *Ibid* at 890C and 891B.

¹⁷ See note 14 per Staughton LJ.

¹⁸ HL Deb 10 January 2005 vol 668 cc11-26, 15.

¹⁹ MCA s4 (6) & (7).

²⁰ MCA s24.

²¹ MCA s25 (5) & (6).

²² See note 2 at 805F per Sir Stephen Brown P.

²³ *Ibid* at 815G-816A per Sir Thomas Bingham MR, 824C-D per Butler-Sloss LJ, and 834D-E per Hoffman LJ.

²⁴ *Ibid* at 859 E-G per Lord Keith, 873F-H and 874D-E per Lord Goff, 875F-G per Lord Lowry and 885E-F per Lord Browne-Wilkinson.

²⁵ *Re G* [1995] 2 FCR 46.

²⁶ *NHS Trust A v M; NHS Trust B v H* [2001] Fam 348

²⁷ The terms ‘persistent vegetative state’ and ‘permanent vegetative state’ have both been used by the English courts; no significant distinction has been drawn between the two states by the courts and in this article the acronym PVS is used to cover both.

²⁸ *Re D* [1998] 1 FLR 411

²⁹ Following *Bland*, the House of Lords’ Select Committee on Medical Ethics had called for PVS to be defined and a code of practice developed relating to its management. The resultant guidelines produced by the Royal College of Physicians and published in the *Journal of the Royal College of Physicians* in 1996 were considered in some detail in *Re D* see particularly [1998] 1 FLR 411,

³⁰ Both quotes [1998] 1 FLR 411, 420, per Sir Stephen Brown P.

³¹ *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor) and others* [2011] EWHC 2443 (Fam).

³² *Ibid* at [1].

³³ See for example: American Congress of Rehabilitation Medicine. Recommendations for use of uniform nomenclature pertinent to persons with severe alterations in consciousness. *Arch Phys Med Rehabil* 1995, 76: 205-209; Giacino JT, Zasler ND, Outcome after severe traumatic brain injury: coma, the vegetative state, and the minimally responsive state. *J Head Trauma Rehabil* 1995; 10;40-56; Giacino JT, Klamar K. The Vegetative and Minimally Conscious States: A Comparison of Clinical Features and Functional Outcome. *J Head Trauma Rehabil* 1997; 12(4):36-51; Giacino JT, Zasler ND, Katz DI, Kelly JP, Rosenberg JH, Filley CM, Development of Practice Guidelines for Assessment and Management of the Vegetative and Minimally Conscious States, *J Head Trauma Rehabil* 1997; 12(4):79-89.

³⁴ Giacino JT, Ashwal S, Childs N, Cranford R, Jennett B, Katz DI, Kelly JP, Rosenberg JH, Whyte J, Zafonte RD, Zasler ND. The Minimally Conscious State: Definition and Diagnostic Criteria, *Neurology* Feb 2002, 58 (3) 349-353.

³⁵ See note 31 at [4].

³⁶ *Ibid* at [221].

³⁷ *Ibid* at [35].

³⁸ *Ibid* at [246]. This approach had previously been developed by Thorpe LJ in *Re A (medical treatment; male sterilisation)* [2000] 1 FCR 193.

³⁹ See note 32 at [220] – [222].

⁴⁰ *Ibid* at [223] – [230].

⁴¹ *Ibid* at [231] – [233].

⁴² *Ibid* at [234] – [237].

⁴³ *Ibid* at [238] – [239].

⁴⁴ *Ibid* at [240] – [241].

⁴⁵ *Ibid* at [242].

⁴⁶ *Ibid* at [107].

⁴⁷ *Ibid* at [225].

⁴⁸ *Ibid* at [249].

⁴⁹ *Ibid* at [104].

⁵⁰ (1) Seel RT, Sheer M, Whyte J, Katz DI, Giacino JT, Rosenbaum AM, Hammond FM, Kalmar K, Pape TL-B, Zafonte R, Biester RC, Knellin D, Kean J, Zasler N. ‘Assessment scales for disorders of consciousness: evidence based recommendations for clinical practice and research’ *Arch Phys Med Rehabil* Vol 91 (12), December 2010; (2) Jennett B, Plum F: Persistent Vegetative State After Brain Damage (A syndrome in search of a name). *Lancet* 1972, 1:734-737; (3) Giacino JT, Kalmar K. ‘Diagnostic and prognostic guidelines for the vegetative and minimally conscious states’ *Neuropsychol Rehabil* 1593-4), July-September 2005, 166-174; (4) Giacino JT, et al. 2002, (see note 35) (5) Lammi MH, Smith VH, Tate RL, Taylor CM. ‘The minimally conscious state and recovery potential: A follow-up study 2 to 5 years after traumatic brain injury’ *Arch Phys Med Rehabil* Vol 86 (4), April 2005, 746-754; (6) Luauté J, Maucourt-Boulch B, Tell L, Quelard F, Sarraf T, Iwaz J, Boisson D, Fischer C. ‘Long-term outcomes of chronic minimally conscious and vegetative states’ *Neurology* 75, July 2010, 246-252, (7) Royal College of Physicians. *The Vegetative State*. London: RCP, 2003.

⁵¹ See note 31 particularly [189] – [218].

⁵² See for example *In the Matter of Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust v TG & OG* [2019] EWCOP 21 where Justice Cohen states at [28]: “I have had to do what is sometimes called a balance sheet exercise.” The balance sheet approach has sometimes been criticised for example in *M v Mrs. N (By her litigation friend, the Official Solicitor), Bury Clinical Commissioning Group, A Care Provider* [2015] EWCOP 76 Justice Hayden stated at [70] that “I consider that a formulaic ‘balance sheet’ approach to Mrs. N’s best interests is artificial.” Nevertheless, in both this case and in *Abertawe Bro Morgannwg University Local Health Board v RY (by his litigation friend the Official Solicitor), CP* [2016] EWCOP 57 where he repeated his earlier criticism, he still carried out a balancing act in weighing up the arguments for and against providing treatment.

⁵³ [2013] UKSC 67.

⁵⁴ *Aintree University Hospitals NHS Foundation Trust v James* [2013] EWCA Civ 65 in particular Sir Alan Ward at [50].

⁵⁵ See note 53 at [18].

⁵⁶ *Ibid* at [24].

⁵⁷ *An NHS Trust and others v Y (Intensive Care Society and others intervening)* [2019] AC 978.

⁵⁸ In her judgment (ibid at [75]) Lady Black JSC refers to four guides - the most recent being the interim guidance document produced in December 2017 by the General Medical Council (GMC), the British Medical Association (BMA) and the Royal College of Physicians (RCP) entitled *Decisions to withdraw clinically-assisted nutrition and hydration (CANH) from patients in permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset profound brain injury*. In 2018 this guide was replaced by the RCP and BMA's *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales*. This new guidance has been endorsed by the GMC.

⁵⁹ See note 53 at [126].

⁶⁰ In *Bland* see note 2 Munby QC had argued at 855F "If the matter is dealt with out of court then the decision is taken by doctors out of court who are not experts in moral and ethical issues." Similarly, in *Y* see note 58 at [89] the Official Solicitor highlighted the dangers of wrong conclusions as to the patient's best interests.

⁶¹ See Halliday S, Formby A, Cookson R, An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration From Patients in the Permanent Vegetative State, *Medical Law Review*, 2015, 23, 4, 556-587 in which they estimate the cost of taking a withdrawal of CANH case to court as being approximately £53,000 and the cost of looking after a patient in PVS as £92,000 per annum.

⁶² In *W v M* (see note 31) Justice Baker called for consideration to be given to providing families with non-means tested legal aid [260].

⁶³ See note 57 at [125].

⁶⁴ Supra note 38.

⁶⁵ See for example this comment on the delay caused by taking cases to court: "Unlike cases where the patient has been diagnosed as being in the MCS, such delay is not required for the purposes of judicial scrutiny of the best interests determination. The question of best interests has already been settled as a matter of law by the *Bland* case." Halliday S, Formby A, Cookson R, An Assessment of the Court's Role in the Withdrawal of Clinically Assisted Nutrition and Hydration from Patients in the Permanent Vegetative State, *Medical Law Review*, 23, 4, 556-587, 575.

⁶⁶ In *Royal Bournemouth v TG* (see note 52) it was held that continued treatment of a VS patient was in the patient's best interests because of her and her family's strong religious beliefs. By contrast in *NHS v VT* [2013] EWHC B26 similar arguments based on the religious beliefs of an MCS patient and his family failed. A possible distinction was that in VT's case the question was whether VT should be resuscitated whereas in TG's case the question was about withdrawal of ANH.

⁶⁷ Childs NL, Mercer WN, Childs HW, Accuracy of diagnosis of persistent vegetative state, *Neurology*, 1993, 43 (8) 1465.

⁶⁸ Andrews K, Murphy L, Munday R, Littlewood C, Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit *BMJ* 1996, 313, 13.

⁶⁹ See note 34.

⁷⁰ See note 31 at [259].

⁷¹ RCP and BMA *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales*, 2018, 51.

⁷² Schnakers C, Vanhaudenhuyse A, Giacino J, Ventura M, Boly M, Majerus S, Moonen G, Laureys S, 'Diagnostic accuracy of the vegetative and minimally conscious state: Clinical consensus versus standardized neurobehavioral assessment', *BMC Neurology* 2009 9, 35.

⁷³ See for example: *Re D (Medical Treatment)* [1998] 2 FLR 36; *NHS Trust A v H* [2001] 2 FLR 501; *A (A Child)* [2016] EWCA Civ 759.

⁷⁴ In *W v M* it is stated that "Mr Badwan expressed the view that ANH should never be withdrawn from a patient in MCS, although in re-examination he conceded that if such a patient was in the terminal stages of a disease such as cancer different circumstances would apply." See note 32 at [198].

⁷⁵ See note 52.

⁷⁶ The 2018 guidance (page 10) requires that "all reasonable steps should be taken to get a second clinical opinion where it is proposed to stop, or not start, CANH and the patient is not within hours or days of death." The second-opinion clinician should have relevant knowledge and experience, should not be part of the treating team and should be able to act independently.

⁷⁷ MCA s1 (2).

⁷⁸ MCA s1 (3).

⁷⁹ Committee on the Rights of Persons with Disabilities, 11th Session, General Comment No.1 (2014), para 21

⁸⁰ Martin W, Michalowski S, Jütten T, Burch M, *Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disabilities? If not, what next?* Essex Autonomy Project, 2014, Executive Summary

⁸¹ In *NHS Windsor and Maidenhead Clinical Commissioning Group v SP (by her litigation friend the Official Solicitor) (Withdrawal of CANH)* [2018] EWCOP 11 a case in which doctors and family all favoured withdrawal of CANH for a PVS patient there was passing mention at [26] of the CRPD in the course of the judgment that CANH could be withdrawn from a patient in PVS.

⁸² For discussion as to the merits or otherwise of the CRPD see for example: Szmukler G, "Capacity", "best interests", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities, *World Psychiatry*, 2019, 18(1), 34-41.

⁸³ Jennett B, Plum F, Persistent vegetative state after brain damage, *Lancet* 299 (7753) 734-737; The Multi-Society Task Force on PVS, Medical aspects of the persistent vegetative state, *N Engl J Med* 330 (21) 1499-1508.

⁸⁴ Giacino JT, Ashwal S, Childs N, Cranford R, Jennett B, Katz DI, Kelly JP, Rosenberg JH, Whyte J, Zafonte RD, Zasler ND. The Minimally Conscious State: Definition and Diagnostic Criteria, *Neurology* Feb 2002, 58 (3) 349-353; Giacino JT, Kalmar K. 'Diagnostic and prognostic guidelines for the vegetative and minimally conscious states' *Neuropsychol Rehabil* 1593-4), July-September 2005, 166-174.

⁸⁵ de Jong BM, Willemsen ATM, Paans AMJ, Regional cerebral blood flow changes related to affective speech presentation in persistent vegetative state, *Clin Neurol Neurosurg*, 1997, 99(3) 213-216.

⁸⁶ Menon DK, Owen AM, Williams EJ, Minhas PS, Allen CM, Boniface SJ, Pickard JD, Cortical processing in persistent vegetative state, *Lancet*, 1998, 352(9123), 200.

⁸⁷ Fernández-Espejo D, Junqué C, Vendrell P, Bernabeu M, Roig T, Bargalló N, Mercader JM, Cerebral response to speech in vegetative and minimally conscious states after traumatic brain injury, *Brain Inj* 2008, 22(11) 882-890.

⁸⁸ Qin P, Di H, Liu Y, Yu S, Gong Q, Duncan N, Weng X, Laureys S, Northoff G, Anterior cingulate activity and the self in disorders of consciousness *Hum Brain Mapp*, 2010, 31(12), 1993-2002.

⁸⁹ Naci L, Cusack R, Anello M, Owen AM, A common neural code for similar conscious experiences in different individuals, *Proc Natl Acad Sci USA* 2014, 111, 14277-14282; Sinai L, Owen AM, Naci L, Mapping preserved real-world cognition in severely brain-injured patients, *Front Biosci (Landmark Ed)* 2017, 22, 815-823; Naci L, Sinai L, Owen AM, Detecting and interpreting conscious experiences in behaviourally non-responsive patients, *NeuroImage*, 2017, 145(Pt.B), 304-313; Haugg A, Cusack R, Gonzalez-Lara LE, Sorger B, Owen AM, Naci L, Do Patients Thought to Lack Consciousness Retain the Capacity for Internal as Well as External Awareness? *Front Neurol*, 2018, 9:492.

⁹⁰ Bruno MA, Vanhauzenhuysse A, Thibaut A, Moonen G, Laureys S, 'From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndromes: recent advances in our understanding of disorders of consciousness, *J Neurol*, 2011, 258, 1373-1384.

⁹¹ See for example: Johnson LSM, Implications of Recent Neuroscientific Findings in Patients with Disorders of Consciousness, *Neuroethics*, 2010, 3, 185-190; Pistoia F, Sarà M, Is there a Cartesian Renaissance of the Mind or Is It Time for a New Taxonomy for Low Responsive States, *Journal of Neurotrauma*, 2012, 29, 13, 2328-2331.

⁹² Peterson A, Naci L, Weiher C, Cruse D, Fernández-Espejo D, Graham M, Owen AM, Assessing Decision-Making Capacity in the Behaviourally Nonresponsive Patient With Residual Covert Awareness, *AJOB Neuroscience*, 2013, 4(4), 3-14.

⁹³ Schiff ND, Cognitive motor dissociation following severe brain injury, *JAMA Neurology*, 2015, 72(12), 1413-1415.

⁹⁴ The subdivision of MCS into MCS⁺ (denoting higher levels of consciousness) and MCS⁻ (lower levels) can be traced to Bruno MA, Vanhauzenhuysse A, Thibaut A, Moonen G, Laureys S, 'From unresponsive wakefulness to minimally conscious PLUS and functional locked-in syndromes: recent advances in our understanding of disorders of consciousness, *J Neurol*, 2011, 258, 1373-1384. The subclassification has been noted by the English courts, see for example: *Abertawe Bro Morgannwg University Local Health Board v RY (by his litigation friend the Official Solicitor)*, CP [2017] EWCOP 2 where Hayden J refused the Health Board's request for the withdrawal of the tracheostomy and the termination of deep suctioning as not being in the patient's best interests. In a finely balanced judgment Hayden J took the evidence of RY's increasing awareness evidenced in part by his recategorization as MCS⁺ as a factor in holding that treatment should continue.

⁹⁵ Bayne T, Hohwy J, Owen AM, Are There Levels of Consciousness? *Trends in Cognitive Sciences*, 2016 20, 6, 405-413.

⁹⁶ *Ibid* at 406

⁹⁷ Bayne T, Hohwy J, Owen AM, 'Reforming the Taxonomy in Disorders of Consciousness *Ann Neurol*, 2017, 3, DOI 10.102/ana.25088

⁹⁸ See Kondziella D, Friburg CK, Frokjaer VG, Fabricius M, Møller K, Preserved consciousness in vegetative and minimally conscious states: systematic review and meta-analysis *J Neurol Neurosurg Psychiatry*, 2016, 87, 485-

492; Coleman MR, Davis MH, Rodd JM, Robson T, Ali A, Owen AM, Pickard JD, Towards the routine use of brain imaging to aid the clinical diagnosis of disorders of consciousness, *Brain*, 2009, 132, 9, 2541–2552; Laureys S, Giacino JT, Schiff ND, Schabus N, Owen AM, How should functional imaging of patient with disorders of consciousness contribute to the clinical diagnosis of disorders of consciousness contribute to their clinical rehabilitation needs? *Curr Opin Neurol*, 2006, 19, 520-527; Schiff N, Bringing neuroimaging tools closer to diagnostic use in the severely injured brain, *Brain*, 2007, 130 2482-2483.

⁹⁹ See note 99 Coleman MR at al. 2009. For a more recent call see Owen AM, The Search for Consciousness, *Neuron*, 2019, 102, May 8, 526-528, 527.

¹⁰⁰ Cruse D, Monti MM, Owen AM, Neuroimaging in disorders of consciousness; contributions to diagnosis and prognosis, *Future Neurol*, 2011, 6 (2) 1-9, 1.

¹⁰¹ Ibid.

¹⁰² See note 98, Kondziella et al. 2016..

¹⁰³ Di H, Boly M, Weng X, Ledoux D, Laureys S, Neuroimaging activation studies in the vegetative state: predictors of recovery? *Clin Med*, 2008, 8(5), 502-507;

¹⁰⁴ See note 98 Coleman et al. 2009

¹⁰⁵ Claasen J, Doyle K, Matory A, Couch C, Burger KM, Velazquez A, Okonkwo JU, King JR, Park S, Agarwal S, Roh D, Megjhani M, Eliseyev A, Connolly ES, Rohaut B, Detection of brain activation in unresponsive patients with acute brain injury, *New England Journal of Medicine*, 2019 380 (26), 2497-2505.

¹⁰⁶ In Weijer C, Bruni T, Gofton T, Young GB, Norton L, Peterson A, Owen AM, Ethical considerations in functional magnetic resonance imaging research in acutely comatose patients, *Brain*, 2015, 1-8 at 3 the authors write: “We believe that functional MRI research in acutely comatose patients has considerable promise.”

¹⁰⁷ Monti MM, Rosenberg M, Finoia P, Kamau E, Pickard JD, Owen AM, Thalamo-frontal connectivity mediates top-down cognitive functions in disorders of consciousness, *Neurology*, 2015, Jan 13, 84(2), 167-173

¹⁰⁸ Owen AM, Coleman MR, Boly M, Davis MH, Laureys S, Pickard JD, Detecting awareness in the vegetative state. *Science* 2006, 313 (5792), 1402; Boly M, Coleman MR, Davis MH, Hampshire A, Bor D, Moonen G, Maquet J, Pickard JD, Laureys S, Owen AM, When thoughts become action: an fMRI paradigm to study volitional brain activity in non-communicative brain injured patients, *Neuroimage* 2007, 36, 979-992.

¹⁰⁹ Monti, MM, Vanhaudenhuyse, A, Coleman MR, Boly M, Pickard JD, Tshibanda L, Owen AM, Laureys S, Willful Modulation of Brain Activity in Disorders of Consciousness, *N Engl J Med* 2010, 362, (7) 579-589.

¹¹⁰ One patient could complete the motor imagery task, but not the spatial imagery task.

¹¹¹ See note 99, Owen 2019 at 526.

¹¹² In Fernández-Espejo D, Norton L, Owen AM, The Clinical Utility of fMRI for Identifying Covert Awareness in the Vegetative State: A Comparison of Sensitivity between 3T and 1.5T, *PLoS ONE* 9(4): e95082 the authors conclude that clinical 1.5T MRI scanners can detect awareness with a reliability to that obtained by 3T scanners in research settings.

¹¹³ Cruse D, Chennu S, Bekinschtein, TA, Fernández-Espejo D, Pickard JD, Laureys S, Owen AM, Bedside detection of awareness in the vegetative state: a cohort study, *The Lancet*, 2012, 378, 9809, 2088-2094.

¹¹⁴ Ibid at 2088

¹¹⁵ Goldfine AM, Bardin JC, Noirhomme Q, Fins JJ, Schiff ND, Reanalysis of “Bedside detection of awareness in the vegetative state: a cohort study,” *The Lancet*, 2012, 381, 9863, 289-291.

¹¹⁶ Cruse D, Chennu S, Bekinschtein, TA, Fernández-Espejo D, Pickard JD, Laureys S, Owen AM, Reanalysis of “Bedside detection of awareness in the vegetative state: a cohort study” – Authors’ reply, *The Lancet*, 2012, 381, 9863, 291-292.

¹¹⁷ Goldfine AM, Victor JD, Conte MM, Bardin JC, Schiff ND, Determination of awareness in patients with severe brain injury using EEG power spectral analysis, *Clinical Neurophysiology*, 2011, 122, 11, 2157-2168.

¹¹⁸ Abdalmalak A, Milej D, Diop M, Shokouhi M, Naci L, Owen AM, St. Lawrence K, Can time-resolved NIRS provide the sensitivity to detect brain activity during motor imagery consistently? *Biomedical Optics Express*, 2017, 8, 4, 2162-2172; Rupawala M, Dehghani H, Lucas SJE, Tino P, Cruse D, Shining a Light on Awareness: A Review of Functional Near-Infrared Spectroscopy for Prolonged Disorders of Consciousness, *Front Neurol*, 2018, 9:350

¹¹⁹ Peterson A, Naci L, Weijer C, Cruse D, Fernández-Espejo D, Graham M, Owen AM, Assessing Decision-Making Capacity in the Behaviourally Nonresponsive Patient With Residual Covert Awareness, *AJOB Neuroscience*, 2013, 4(4), 3-14.

¹²⁰ MCA s2(1)

¹²¹ MCA s1(2)

¹²² MCA s1(3)

¹²³ MCA s2(3)

¹²⁴ The test is on the balance of probabilities (MCA s2(4))

¹²⁵ Article 12(4) CRPD

¹²⁶ MCA s4

¹²⁷ MCA s4(6)(a)

¹²⁸ *Gross v Switzerland* (2014) 58 EHRR 7 at para 58.

¹²⁹ Peterson et al. see note 92 at 4