Disorders of consciousness: shaping a medical humanities initiative
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The aim of this initiative is to set the ground work to develop research in cultural understandings of, and responses to, severe brain disorders (vegetative and minimally conscious states). This is a troubling and cutting edge area of developing biomedicine and health care ethics – an area which exemplifies many of the challenges of medicine in society. The ultimate aim would be to help develop a humanities initiative which could inform improved decision-making (on a social and individual level) about how science, technology and medicine can best be deployed to maximise human health and well-being.

1. Introduction

The rapid increase in the diagnosis of disorders of consciousness in the West is linked to late 20th/early 21st century technology. In particular, modern medical technology and resuscitation techniques have helped ensure the survival of people who would previously have died. While such interventions allow some patients a clearly positive outcome, others are left with severe and long term disorders of consciousness (and, given existing knowledge about severe brain injury, it is hard to predict in advance the outcome for any individual patient). Thus such technologies (combined with particular sets of social and political imperatives) have 'produced new neurological syndromes of severe, and usually irreversible, cognitive and motor disabilities' (Cranford, 2002, 129; also Demertzi et al, 2009, 148; Laureys and Boly, 2008). Indeed anthropologists go so far as to talk of new 'technologically produced' life forms - 'liminal beings' who 'hover in an ambiguous zone' and 'force a remapping of the notions of life, death, and person', throwing up new ethical and cultural debates (Kaufman and Morgan, 2005, 330).[i]

Disorders of consciousness throw up key ethical/moral dilemmas in the delivery of health care and the development and application of both well-established and cutting-edge medical technologies. Such disorders challenge core, and often competing, social values about identity, personhood, human dignity, care and quality of life - and even the definition of 'life' itself (Farah, 2008, Fins et al, 2008, 4, Roskies, 2002, Varelius, 2009). Research with medical and nursing professionals reveals divided opinions about the impact of medical interventions (and cutting-edge developments) in this field and highlight some unresolved (and some would say irresolvable) dilemmas).[ii] While some view disorder of consciousness as a relatively successful outcome involving saving life, others feel that they personally would rather be dead than be left in a long term vegetative or a minimally conscious state – and believe that such outcomes can be 'worse than death' for some patients and their families (Demertzi et al., 2010). Such division among professionals in the field is also reflected in the diverse reactions of family members – some believe that a person in VS/MCS retains quality of life or they invest in hope for the future (e.g. that time, or advances such as stem cell research, may restore their loved ones to a reasonable quality of life). Others believe their loved ones would prefer to be dead (and in some cases take legal action to allow their lives to end, or take the law into their own hands through 'mercy killing' – e.g. see recent UK Inglis case).

Disorders of consciousness raise crucial questions about how we organise social, clinical, political, legal and technological responses to ethical challenges and balance individual rights against social goods.[iii] Such disorders also prompt reflection about the cultural imaginings which inform

any such responses, as well as how we make decisions under conditions of risk and uncertainty, and how to mobilise evolving science and technology in the care of such patients (e.g. fMRI techniques to improve diagnosis and understanding).

All these questions are rooted in a longer history of trying to understand the brain (or 'mind' or 'consciousness') as well as debates about how we should respond to the limits of human knowledge. The questions raised around disorders of consciousness are also embedded in long-standing debates about personhood, autonomy, and the rights of persons/citizens - debates that date back to the earliest philosophers.[iv] Social, political, scientific and technological changes mean that these fundamental questions play out against an ever changing back drop, but there is no doubt that neuroscience around disorders of consciousness raises questions that 'go to the heart of our humanity and asks us to grapple with fundamental questions about the self' (Fins, 2005, 565).

There is currently a volatile interface between social/legal/ethical/public understanding of disorders of consciousness and:

1. Scientific and social debates about specific neuroscience technologies, especially functional magnetic resonance imagining [fMRI] which, according to its proponents, heralds 'a new era for coma and consciousness science' (Owen et al 2009)[v]
2. The *categorisation* of disorders of consciousness (especially Vegetative State [VS], and the new category of 'Minimally Conscious State' [MCS][vi]
3. The history of policy-making/legislation/judgements around decision-making for individuals with disorders of consciousness. These range from end-of-life decision-making in the courts (e.g. the controversial Terri Schiavo case in the US) to the Mental Capacity Act 2005 in England and Wales which sets out a framework for making 'best interests' decisions for those judged to lack capacity.

There is a rapidly emerging research agenda around such areas. However, the *intersections* between neuro-scientific advances, clinical categories and ethical/social/legal/cultural responses are still nascent and under-researched. This is partly due to the early stage of development of some of the key technologies/categories/policies and the evolving context in which they are situated. For example:

1. fMRI scanning only began to appear in the literature from 1991 (Illes et al 2003) and its potential and limitations in detecting 'consciousness', and the social and ethical issues it prompts, are still subject to intense debate.
2. Understandings of disorders of consciousness are in flux. Notwithstanding considerable interested from the late-nineteenth century in the medical nature of consciousness and neuro-anatomy it was not until 1972 that the 'Vegetative' State was initially defined. The 'higher level' disorder - Minimally Conscious State - was only officially defined in 2002 (Giacino et al, 2002) and remains a contested and uncertain category (Widjicks, 2006).[vii] At the same time those with disorders of consciousness have often been misdiagnosed and, sometimes neglected for rehabilitation or follow-up (making it difficult to make epidemiologically based predictions) (Fins et al., 2007a) – and fMRI may have a crucial role in changing this (Fins, 2006).
3. Legal and policy responses are still bedding down or contested. The US has seen a huge struggle over the role of the courts in such matters (Fins, 2006, 170) and the UK's legislative/clinical responses are still evolving (Lewis, 2007). The Mental Capacity Act (2005), for example, is still rolling out into clinical practice in England and Wales. Although many parts of this Act are simply meant to spell out standard good practice and principles (especially that treatment of the mentally incapacitated patient should respect their prior

values and beliefs) some clinicians are concerned that it is inappropriate to apply such practice/principles in situations of relative uncertainty such as those surrounding disorders of consciousness.

Research in these areas is also still often fragmented across professional/ disciplinary boundaries. For example, with some key exceptions, bioethicists and philosophers have presented sophisticated theories about 'personhood' when discussing vegetative state but sometimes seem distant from practical clinical/family decision-making concerns or from critique of bioethics from a disability rights perspective (Newell, 2006). Neuroscientists with expertise in fMRI or VS/MCS often work closely with neuroethicists, but rarely reference debates about capacity and decision-making such as those which played out around the Mental Capacity Act in the England and Wales (Hughes, 2010) (Partly, perhaps because some of the leading figures here are based in the US). [viii] Those who draft legislation about mental capacity are more focussed on people with lesser impairments than the profound disorders of consciousness that characterise VS/MCS. They may also be unaware of some of the scientific debates in this field and disengaged from the practical challenges facing clinicians making life/death decisions on a day-to-day basis.

There is an urgent need to develop research which would build a medical humanities agenda into the complex and rapidly evolving set of concerns surrounding disorders of consciousness. Science and medicine, the primary custodians of people with disorders of consciousness, are not able to resolve the problems on their own. Indeed, Joseph Fins, the incoming President of the American Society of Bioethics and Humanities specifically notes the necessity for such an initiative. Scientific developments in the field of disorders of consciousness, he declares, cannot go forward responsibly without both an appreciation of the 'lived experience' and 'existential challenges' facing families dealing with severe brain injury and a sustained humanities initiative to inform and contextualise scientific/medical advances (Fins, 2009)[ix]. A cross-disciplinary set of humanities symposia and research projects could help address some of the current gaps in understanding as well as create and consolidate new inter-disciplinary networks. This will help to address a crucial area of social debate/ need, refine clinical ethical decision-making for a wider variety of 'stakeholders' and contribute to wider intellectual debate in the medical humanities as a whole.

2. Specific aims and approach for this bid

The focus of the symposia sessions will be on what each contributor identifies as the crucial issues for personhood, capacity, cultural representation and individual/social/ethical decision-making – and what would improve decision-making in this area at a practical level. It will also examine what they think might be the key questions from a medical humanities perspective. Crucially, the aim will be to unpick what type of research they think is needed, or what form of deployment of research findings would actually be helpful and I will explore ideas about the symposia and research projects that they believe might help take the debate forward. Initial discussions have already generated a rich range of ideas. Responses suggest a great deal of enthusiasm for both the possibility of a symposia series and for new medical humanities initiatives around disorders of consciousness. Ideas for developing future research are presented in the appendix. The list presented there gives a flavour of the type of issues that could be addressed. I have organised these under headings of 'ethics', 'history' or 'law' etc - but crucially each research bid would be designed to address the intersection between evolving neuroscience technologies/categories and the shifting legal, cultural and social structures surrounding disorders of consciousness. Some future bids might be appropriate for co-funding by the AHRC, ESRC, Medical Research Council or the Nuffield Trust. The Wellcome Trust, however, is uniquely placed to help seed a new medical humanities initiative in this important area.

3. My expertise/interest

I have worked across a wide range of social and humanities areas with a focus on health/science and risk. I originally trained in social anthropology (Cambridge University), and have worked in the Department of Social and Political Sciences (Cambridge), the Medical Research Council's medical sociology unit (Glasgow) and the Department of Sociology and Anthropology (Brunel). I am now Professor of Media and Communication research at Cardiff University and also a member of *Cesagen* - the ESRC Centre for Economic and Social Aspects of Genomics.

I have a long track-record of research into a wide range of health/science related areas from my first project examining how hospital staffing structures influence care (Green et al., 1986) to a whole series of projects exploring the impact of diverse health communication strategies or emerging health crises such as AIDS (Miller et al., 1998). Since the 1990s I have focussed on studying how societies make sense of health, science and risk issues (e.g. see Kitzinger and Reilly, 1997, Kitzinger, 1999). In particular my research examines the social, ethical and legal debates around emerging biomedical science. My work includes research on the Human Genome Project (for the Wellcome Trust) and a series of ESRC-funded projects on GM crops, stem cell research, and nanotechnology (e.g. Haran et al., 2008., Kitzinger and Williams, 2005, Kitzinger et al 2007, Henderson et al., 2007, Horlick-Jones et al. 2007, Williams et al 2003).

For the last seven years I have been Director of a 'Risk, Health and Science' research group at Cardiff University which examines how debates play out through scientific papers, NGO activity, policy making, press releases, journalistic practices, media representation, and public understandings. I have led major research projects (totalling several million pounds) for a wide variety of bodies from the ESRC to the Office of Science and Technology and I have published 5 books and over 100 articles/chapters across a range of relevant issues. [For further info. see: www.cardiff.ac.uk/jomec/research/researchgroups/riskscienceandhealth] and [www.cardiff.ac.uk/jomec/contactsandpeople/profiles/kitzinger].

In developing work in the area of neuroscience I am building on my existing expertise in the social, cultural and ethical debates about biomedical science. In addition I am informed about some of the complex challenges in this area because I have a relative with severe brain injury (see Kitzinger and Kitzinger, 2010). I am also a Court-appointed Health and Welfare Deputy – an appointment which gives me authority to accept or refuse routine medical treatment on behalf of someone with mental incapacities. This is a new legal appointment in the England and Wales (with fewer than 200 appointees since the posts were established in 2007) – and gives me additional insight into the legal/clinical/social/political dilemmas surrounding disorders of consciousness. My experience as a Deputy gives me a 'ground-up' experience of some issues facing clinical practitioners and families. This will complement my academic track record in delivering methodologically rigorous and high-quality social science/humanities research on issues of key social significance.

4. Overall institutional context

I have an established international reputation and network which, I believe, places me in an ideal position to develop the proposed initiative. My work will also be carried out within the context of Cardiff University's excellent network of leading science, social science and humanities researchers – and existing centres of expertise which unite them (e.g. *Cesagen).* Cardiff University has strong collaborative networks both in academic and clinical research in neuroscience. These include: Cardiff University Brain Research Imaging Centre (CUBRIC); MRC Centre for Neuropsychiatric Genetics and Genomics in School of Medicine; Cardiff Neurosciences Centre (CNC); Cardiff Ageing Science and Older People Network,; Science, Medicine and the Imagination Research Group. This is fertile ground for developing future collaborations around the medical humanities – as well as linking with expertise both nationally and internationally in the future.

5. APPENDIX - ideas for medical humanities research

The list below presents some of the ideas for medical humanities research around disorders of consciousness that have already evolved from discussion with key experts in the field. The list is very ambitious, and is merely indicative of the type of work that might be built up under this rubric. The research/symposia areas presented here are *not*, of course, fully developed practical ideas, and vary in the extent that they have been discussed. Each area of research also overlaps – or could be held in tension with each other. The list is presented here simply to give a flavour of the type of issues that could be addressed.

Part of the point of my scoping exercise funded by the present bid would be to assess the best ways in which research, symposia or other forms of engagement might best be deployed and focussed, as well as ensuring that the most outstanding people with relevant expertise were enrolled in future initiatives around disorders of consciousness in ways which ensured true inter-disciplinarity.

A.1. History
In order to understand current dilemmas and controversies around disorders of consciousness there is a need for contextualisation through in-depth historical (and, where possible, cross-cultural) studies of changing conceptions of consciousness, personhood and the boundaries of 'mental capacity' combined with an examination of how these have been represented in a range of domains from the medical and policy-making to the social and culture. This touches on many fields from the neglected post-1945 history of psychiatry to an examination of the difficult questions that have surrounded when patients were deemed 'brain dead' and the medico-legal context which has informed debates about consent.

Such historical analysis could explore how disorders of consciousness have been represented across a broad range of practices and forms, including philosophy, ethics, science and politics (e.g. media, scientific papers, professional guidelines and policy papers). It could specifically include an historical analysis of the struggle to create different labels (such as MCS) and how these informed practice and individual and institutional decision-making, as well as the role of new medical technologies that helped 'produce' or 'examine' disorders of consciousness (e.g. coma and coma recovery and VS/MCS). The historical perspective could particularly focus on the last forty years following the definition of Vegetative State – but would be placed in context of a much longer history of theorising about the brain, personhood and decision-making on behalf of the mentally incapacitated, including issues around the rise of 'informed consent', changing concepts of patient autonomy and the authority of medical experts, and the notion of 'the individual'. Cross-cultural comparison, especially given important work in these areas in France and in the United States, would also be an important potential approach to complement the historical lens.

Alongside this history of 'disorders of consciousness' a parallel strand could explore this history of how erstwhile cutting edge technologies come to be 'routine' and how 'the technological imperative is sustain through social practices and treatment settings in which 'choice' is both constructed and limited by clinical realities that make the use of the newest technologies and procedures inevitable' (Kaufman, 2000, 72).

A.2. Ethics and philosophy
Disorders of consciousness raise profound ethical dilemmas and philosophical questions. Research addressing the ethical dimensions could include a review examining the historically shifting bioethical /philosophical debates around disorders of consciousness and examine how these vary cross-culturally. This could be combined with empirically-rooted research paying

particular attention to the 21st century *empirical* ethical decision-making in just one or two countries.

A very practical and focussed example of a project under this rubric could examine decision-making in disorders of consciousness in the UK – exploring how clinical team and families (and any other bodies that become involved) come to decisions about the appropriate treatment for those with disorders of consciousness. In particular it would be important to test how the notions of capacity, personhood, autonomy and 'best interests' are mobilised in such decision-making across England, and Wales (and Scotland which operated under a different Act) - and how these play out in relation to different ethical/philosophical ideas. For example, research could examine core questions such as:

- How are patient's 'prior values, beliefs, wishes and feelings' (key criteria under the MCA) mobilised in discussion of a patient's best interests?
- How are the patient's prior values ascertained?
- How is disagreement managed?
- How are the patient's prior values weighed against other considerations (including notions of the 'non-person' or the potential 'new' or radically changed person that could emerge from VS/ MCS with severe neurological deficit?)

This could include 'live data', interviews and/or setting up workshops during which participants are asked to review and reflect on case studies – and consider how ethical and robust decision-making might be enhanced in practice – and how these relate to a wide range of philosophical questions.

Elaborating on this could involve detailed exploration of ethical decision-making across *time and place* (and the deployment of professional guidelines and legislation in relation to any such decision-making). The *time* dimension could examine ethical reasoning at different times in the trajectory of patients' diagnosis and potential recovery. Time is a crucial component of the ethical decision-making in relation to any chronic disorder/disease but is especially significant in disorders of consciousness. This is not only because of the different professionals that become involved at different stages (e.g. from the intensive care consultant to the neurosurgeon and rehab professionals) but that different 'windows of opportunity' for decision-making are open or closed at different points during the trajectory of the patient's diagnosis. Also, crucially, (at least at present) 'only time will tell' where a patient will fall along an uncertain prognostic continuum and, unlike people facing a progressive or degenerative disease such as dementia, the underlying trajectory post brain injury can be 'up' as well as 'down'. Some rehab specialists also emphasise the biographical rupture than can follow brain injury – suggesting that, therefore, the 'new person' should not be judged by the values and beliefs of the former inhabitant of the same body.

The *place* dimension in ethical decision-making is crucial because the patient is unable to make decisions for themselves – decision-making can therefore become a particularly elaborate negotiation between different family members and different clinicians as well as cross-cutting a variety of other sites. Decision-making *sites* to be examined could include the patient's family, the multi-disciplinary clinical team, the hospital's clinical ethics forum and faith advisors, professional associations, the fMRI research group, legal hearings etc. It would also place decision-making in context of relationships – both power and institutional relationships (e.g. clinicians/families; management/employee) and kinship and citizenship (Rapp and Gingsburg, 2001).

This area of research could include particular attention to how decisions are made in situations of everyday, routinised practice within social organisations. It could also examine how ethics play out in relation to discrimination, hope, risk and uncertainty (linking to the broader literature in this field e.g. the major ESRC 'Social Contexts and Responses to Risk initiative – in which I was involved).

The uncertainties here include the extent to which families really know what a patient would have wanted (see extensive research on surrogate judgements) as well as what they feel they know about who the patient could become – and how this intersects with their own feelings and moral judgements. Uncertainties also include the patients' trajectory from intensive care onwards and – in the case of MCS - the islets/step changes in awareness and inconsistencies which are the very 'hallmark' of a state such as MCS (Giacino, 2004, 296). Uncertainty may also be generated by rapidly shifting understandings of disorders of consciousness in general and advances in technologies for studying the brain in particular.[x] Indeed, communicating uncertainty is seen as one of the central tasks for clinicians (Hemphill and White, 2009, vii).

A longitudinal research design might be useful here to track some of the issues as they evolve over time, and different sites of study would be important. There are also many possibilities here for different research designs to be explored here. These could include, for example

- In-depth ethnographies of how ethical negotiations work within one cultural setting e.g. how abstract legal concepts such as 'best interests' (as defined by the MCA) actually play out in a clinical setting or in the debate of a hospital clinical ethics committee. In-depth action research might also be a productive way forward – e.g. following attempts to evolve new models of good ethical practice in a particular Trust.

- Systematic analysis of interaction between consultants and the families with whom they are working to explore how ethics are framed in this context and also working with families in 'digital story-telling' – allowing their stories to be told in new ways, to explore ethical dilemmas outside what is learnt in the consultation setting or straightforward interviews

- bringing together families, clinicians, policy makers and ethicists and other stake-holders outside the institutional power-structures and boundaries in which they usually work to develop creative debate reflecting on ethics and decision-making.

Ethical debates here also, of course, go beyond the decision for the *individual* patient/family/clinician – the ethical concerns include:

- the broader questions of the economic costs to the health system. (The estimated costs of sustaining a patient in a MCS is £1500,000 per annum. Given the increasing numbers of people with such disorders of consciousness, and their increased life expectancy, this has a significant impact on health expenditure)

- the 'risk' to professional roles (or liabilities) and how decision-making processes about ethics may be partly shaped by institutional concerns (e.g. protecting staff or considering the legal/reputational risks to the organisation)

- the risk to core moral imperatives, social taboos/structures, and to disabled people - subject both to discrimination and to paternalism confining their choices about treatment (Werth, 2005).

 It would be important to examine how such ethical concerns are incorporated into, or ignored, in 'best interests' decisions for individuals, as well as how they play out in wider cultural debates.

Part of the impact of this research would be to address the challenges for healthcare practice and policy, and to ensure insights from the research engaged policy makers, public health experts and healthcare practitioners in the difficult area of how to take decisions on behalf of individuals in a vegetative or minimally conscious state – and evolve an appropriate social and medical response.

A.3. Cultural imaginings of disorders of consciousness: science, literature and the media (traditional and 'new media')

This area of enquiry could include a study of the shifting cultural representations of disorders of consciousness (e.g. coma and coma recovery and VS/MCS), the medical technologies that help 'produce' or examine such states (e.g. fMRI) and the legislative decision-making processes around such state (e.g. court cases considering withdrawal of artificial food and hydration).

Disorders of consciousness are often represented in film and soap opera (Widjicks and Widjicks, 2006; Fins et al., 2007b) – ranging from the all too convenient coma and temporary loss of memory that helps a plot twist to the rich, metaphorical exploration (see for example, discussion of Almodovar's film '*Talk to Her*', Fins, 2009, 142-144). The cultural imaginations that surround disorders of consciousness also draws on myth and fairytale (e.g. sleeping beauty) and literature is a rich strata of study in its own right. For example, recent literary fictions that draw imaginatively on VS or MCS could be examined in the context of a longer literary history of disordered consciousness such as George Eliot's Silas Marner which deals with issues around cataleptic states or Sax Rohmer's Fu-Manchu novels, in which Dr. Fu-Manchu has a serum that induces a state of catalepsy so extreme as to be indistinguishable from death. There are also, of course, many science fictions that deal with consciousness, its disorders and neuroscience type interventions in a variety of ways (e.g. the work of Huxley or Philip K. Dick).

Literary, cultural and visual analysis tools need not only be applied to fiction but can also be usefully tested on (auto)biographical narratives produced by family members or 'survivors' of serious brain injury (alongside memoirs by those in Locked in syndrome) and scientific, policy and news reporting (e.g. visual analysis of the brain 'lighting up' in multiple colours in fMRI scan displays) (see Dumit, 2005 for his work on PET scans). This could also be combined with a broader sociology of journalism to examine the fierce cultural debate around individual and social/legal responses to disorders of consciousness (including 'mercy killings' and 'right-to-die' court cases).

A programme of work on cultural representation would also usefully include the internet. There are, for example, various websites now providing information about brain injury (and often also promoting legal services too) and these deserve detailed analysis (e.g. see www.waiting.com). The internet is also a site where 'home video' of comatose/vegetative/minimally aware patients are sometimes displayed by families as a medium to help tell particular narratives about medicine and personhood - to promote particular understandings of the ethical issues, and sometimes to fundraise for particular types of interventions or promote specific decision-making (e.g. in the Terri Schiavo case) (Quill, 2005, Walker, 2006, Cranford, 2007). Such 'citizen media sites' are increasingly recognised as an important area of cultural activism and can create impetus for policy and shifts in public understandings.

A.4. Law

This research could include examining how the law in relation to disorders of consciousness operates across different countries, and how this has changed over time. One focus, for example, could be how this plays out in relation to debates about the 'best interests' of patients and society, and the role of surrogate decision-making, both in relation to 'right to die' and 'right to care' debates – as well as issues around the involvement of people without capacity in clinical trials or projects examining innovative interventions/assessments (including fMRI).

Within the UK, for example, this research could examine how the courts have responded to 'right to die' cases since the 1993 Bland case (the first vegetative patient to have ANH withdrawal allowed by a UK court) and how they are now responding to the new category of MCS. The

minimally conscious state is emerging as a highly contested area of legal debate. According to Cranford: 'Just as the first quarter-century of the right-to-die movement may be exemplified by the medical, legal, and ethical assessments of brain death and the vegetative state, so the first quarter century of the new millennium may be the era of patients who are substantially neurologically impaired but conscious to a variable degree. Perhaps MCS will capture the essence of this next wave' (Cranford, 2002, 130)

Research into the application of the law could also explore how the Mental Capacity Act has operated since it first came into force in 2007 – and has it has informed professional guidelines (e.g. the GMC guidelines) and practice. This could include examining how best interests decisions are being informed by the MCA guidelines at a clinical level and how Advance Decisions (legally binding since 2007) have been tested – especially in the face of the uncertainty, changing social/medical context, 'biographical rupture' associated with disorders of consciousness and the suggestion that fMRI can identify brain activity (and even deliberate brain activity modulation) in some patients previously thought to be completely unaware (see Lewis, 2007). Comparison with other countries such as the US would be a valuable part of this research (Moselli, 2006).[xi]

A.5. Mediating fMRI: from scientific paper to headline, from bench to bedside, from experiment to social reconstruction

FMRI work (and other types of technology) with individuals diagnosed as VS/MCS raise important ethical, social and philosophical questions. This area of research could explore how such questions can be addressed and innovative techniques translated into practice to enhance human health care. Any such research could place developing fMRI technologies and practice in broader historical context – referencing the body of work which explores how some technologies gain social/political acceptance, promotion and investment – and exploring debates about how technologies can best be deployed (and might, in practice, actually operate). It would track how fMRI research on disorders of consciousness is developing and establishing a public profile and reshaping ideas about consciousness – as well as exploring sites of criticism or resistance. It could draw on Sociology of Science and Technology Studies [SST] and Media/Cultural Studies approaches to include laboratory ethnographies, and tracking any 'real time' moves from scientific paper to media or even 'bench to bedside/ lab to court room (see Raccine et al 2005) as well as broader SST analysis.

Any 'laboratory ethnography' would ideally involve the cooperation of at least one of the major scientific teams active in fMRI scanning and disorders of consciousness (e.g. the MRC Cognition and Brain Sciences Unit in Cambridge). I would hope that the researchers might be interested in such a project as they have, for example, already attracted criticism about the implications their work has for decision-making and treatment (Wilkinson et al., 2008), and well as for the mass media representation of their work and have themselves commented on the 'vexing' issue this raises (Schiff and Fins, 2007). Those working in the field also call for improving public communication strategies and the need for empirical work on the public communication of neuroscience (Illes et al, 2010; Raccine et al., 2010).

It is also clear that the use of fMRI for disorders of consciousness could usefully be understood by linking it to the broader enquiry into how brain research translates into practice and how 'the new brain sciences' impact on the social, political and personal. (See Rose & Franklin, www.lse.ac.uk/collections/BIOS/translating_neurobiological_research.htma; also Rose, 2007 and the major ESRC-funded study on 'Brain, Self and Society in the 21st Century' - www.lse.ac.uk/collections/brainSelfSociety/). (See also 'Constituting Neurological Subjects http://www.neuro-societies.ed.ac.uk/background.html)

This offers opportunities for theorising the use of fMRI with disorders of consciousness in relation to other technologies such as PET (Dunit, 2004) and wider debates about governance and the historical 'emergence of consciousness studies as a 'trading zone' (Galison) in which experimental, philosophical and experiential accounts are dialectically engaged' (Maasen, 2007, 252; see also Levey, 2007).

A.6. Communication about, and making sense of, 'consciousness' and decision-making

This research area could include examining how families and diverse professionals communicate and how they construct consciousness and/or personhood/identity and/or capacity and think about the brain/mind using: technological information/visuals about the individual patient (e.g. brain scans); direct informal encounters with the patient (e.g. his/her movements, gestures and vocalisations); and systematic tests of the patient (via the formal use of tests such as SMART) (e.g. see Kaufman, 2003; Bird-David and Israeli, 201). It would examine such communication and sense-making activities alongside people's use of other sources of information e.g. epidemiological statistics, professional research and reports of cutting edge studies (e.g. fMRI information about some research subjects classified as VS/MCS) and media coverage of 'miracle' coma recovery stories and breakthroughs (e.g. Belgian 'coma man' assisted communication story).

The focus could be on how such communication and sense-making activities interface with decision-making on behalf of those with disorders of consciousness – including the transparency of decision-making, gate keeping processes, and attributions of agency, responsibility and the weighting of 'best interests' and diverse ethical concerns. Some of this research could use detailed interactional data examining doctor-family communication with the aim of developing training packs to help improve doctor-patient communication or highlight good practice. Such research might also help develop on-line resources.

In addition, empirical work could examine both sense-making in the clinical and in the domestic setting where some VS/MCS patients are cared for within kinship networks – and include examining family experiences of coping with the challenges of serious brain injury. This could be explored in dialogue with philosophical, feminist, and theological debates about personhood and caring relationships informed by disability studies theory and radical critiques of traditional ideas of what constitutes a 'person' versus 'a human' (e.g. Kittay, 2008).

This study could include looking at how different cultural, political and religious influences, and people's own experiences of impairments, inform sense-making and communication, and their own views of agency, moral judgements, and decision-making.[xii] Crucially it would be important to include here not only those family members who continue to engage with the patient, but also those who have *withdrawn* – sometimes because attempts at ongoing connection are experienced as too disempowering, painful or 'senseless'. (The latter constitute a group which, are seldom available to provide feedback to clinicians and cannot be contacted via support groups. Their voices remain absent from the existing literature in this field).

A.7. Public understandings/knowledges, and public engagement initiatives

This could include a study of public understandings, and hopes and fears, about disorders of consciousness and emerging neuroscience technologies, as well as specifically examining 'audience reception of media representations', and how people 'learn to see' representations of the brain (Dumit, 2004). In addition, such research could include (or lead to) active interventions such as 'citizens' juries' debating the issues and/or a wide range of imaginative public engagement initiatives. This might build on the model developed in relation to human genetics (and, indeed, learn from the challenges and contradictions thrown up by some work). Indeed, some commentators point to the importance of transferring recent work in ethics spurred by the Human

Genome projects onto some neuroethics problems (Roskies, 2002, 21) and there are calls for fMRI developments to follow the model of human genetics research in opening up a multi-directional relationship of communication about ethics with the so-called 'lay public' (Racine et al., 2005). At the same time 'neuroethics' is seen to raise distinctive questions too (Roskies, 2002, 21). Again, one strand of any such research might take a lead from some of the imaginative initiatives already established around brain sciences more generally including collaborations with artists (e.g. see the LSE/ NCY collaboration - http://www.neuroculture.org/index1.html). This could include would, for example, developing collaborations with Dr Jamie Lewis - based at the MRC Centre for neuropsychiatric genetics and genomics with responsibility for their public engagement programme. Dr Lewis has already been in discussions with is Bridgette Keehan - a writer and theatre director keen to work up a piece about coma/vegetative state.

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Endnotes

[i] Such new life forms can also be linked to debates about changing social/technological contexts leading to the increase in survival of preterm babies at the beginnings of life (e.g. see Nuffield Council on Bioethics, 2006), and an aging population with dementia at the ends of life – although disorders of consciousness also raise distinct issues too. Any enquiry in this field also has important links to the long-standing body of literature on the impacts of reproductive technologies and how these have involved redefinitions of life, relationships and choices (e.g. Franklin, 1997; Pfeffer, 1993).

[ii] Ethnographic work highlights how some professionals working to save and sustain the life of those with disorders of consciousness express profound ambivalence. As one nurse manager of a specialist unit comments: '...the unit exists because for the majority of patients, somebody either made no decision or made the wrong decision at some point in time during treatment. And so I have not seen any reason, from the intellectual and fiscal end of things, for what we are doing. From the emotional end of things, I mean, I totally understand. I couldn't – just randomly – say "we're going to pull the plug on all these patients'

(quoted in Kaufman, 2000, 72). On the other hand research with people with severe physical disabilities (including locked in syndrome) suggests that quality of life may be judged differently from 'inside' states of impairment (although severe cognitive disability by definition makes it hard to survey opinion from this constituency). The challenge according to Fins (2006) is to adopt an approach that is 'affirming the right to care' and 'preserving the right to die' via a 'palliative neuroethics of care' (Fins, 2006, 169. 176).

[iii] Broader social issues beyond the question of the best interests of the individual come into play in this debate. These include the distribution of family and health care resources on the one hand, for example, and the implications for social relations on the other. Crippen (2004), argues, that it is better that 'some indolent shells of humanity...be maintained in a hopeless condition' than that we risk falling into 'the pitfalls of individuals assassinating innocents capriciously' (Crippen, 2004, 81). Disputes about what counts as a mere 'shell' of humanity, as well as wider issues about the nature of a caring society and the threat to disabled people are also key concerns e.g. see disability rights critics such as 'Not Dead Yet' (especially re activism in the US in the Terri Schiavo case; see also special issue of *Journal of Disability Studies*, 2005 16 (1)).

[iv] Disorders of Consciousness debates can also be located in more recent history – e.g. re-visiting ethics discussion which were held only a few decades ago about 'when bodies outlive persons' and whether twitches and shivering and movements in 'brain dead' persons should be treated as evidence of intentionality/consciousness (Lock, 2002, Youngner, 1999, Zaner, 1988).

[v] The development of interventions such as 'Deep Brain Stimulation' is similarly controversial (Canavero, 2010, Weisleder, 2010, Fins et al., 2010). These would also be considered, but probably remain outside the main focus of work proposed here.

[vi] MCS involves some awareness of self or environment (at least intermittently). There is no data collected routinely about patients in VS or MCS. Estimates for VS in the US range between 4 to 10 per 100,000 people (Royal Hospital for NeuroDisability, http://www.rhn.org.uk/hci_003.asp). Estimate of the number of people in a MCS vary widely due to its relatively new categorisation and poor diagnosis (Fins et al 2007a) – however anecdotal evidence suggests that it may be a widespread and increasing phenomena – for example as reflected in the changing nature of care home residents. One neuroscientist suggested to me that numbers of MCS patients are rising as safety devices such as the car airbag – are contributing to people surviving car crashes in a minimally conscious state (rather than being either vegetative or dead). The wars in Iraq and Afghanistan have also resulted in a spike in the incidence of people surviving with traumatic brain injury – through a combination of the type of weapons used and the improved body armour and emergency medical available to troops (Fins, 2009, 133).

[vii] 'Locked in syndrome' would be excluded from this discussion, except for comparative purposes, as it is not a 'disorder of consciousness'– and the person does not lack 'mental capacity' – it therefore raises some very specific issues which would be outside the remit of exploration (Demertzi et al, 2008). However as Locked in syndrome is sometimes misdiagnosed as vegetative some overlapping concerns would be an important consideration.

[viii]They are also, of course, often collaborations internationally across very different policy contexts (the US, the UK, Belgium) where different legislation and diverse cultural and historical factors come into play.

[ix] The US is beginning to develop a relevant medical humanities agenda – with neuroethics a thriving 'discipline', and the disorders of consciousness issue being brought to the fore by fierce cultural conflict around the Terri Schiavo case culminating in 2005. The Social Sciences and Humanities research council has recently funded projects at Stanford University on topics such as neuroethics, the US press reporting of fMRI, and on ''Public Understanding of Neuroscience and the Terri Schiavo Case'. This will be useful work to reference in any such programme in the UK, including comparing the different cultural, political and legal context.

x Any such research could usefully link with the German project on the 'Neuroethics of Chronic Consciousness Disorders', supported by the German Ministry of Education and Research at the Interdisciplinary Center of Palliative Medicine, Munich University Hospital, Germany. This project which is developing an interview study exploring the experiences and attitudes of the patients' health care professionals and family caregivers. Also useful links could be made with the Neuroethics Research Unit at Montreal University.

xi There are huge differences in cultures, social attitudes and professional and legal practice across Europe and North America in relation to many of the key issues here. One documented difference, among many, is that North Americans diverge from Europe 'in the role acknowledged to surrogates in the decisional process, as in Europe'. Moselli et al (2006) state that, compared to the US 'restraints and reserves to accept surrogates as decision makers seem still strong and a paternalistic approach at the end-of-life is still present' (Moselli et al., 2006). This statement it turn raises questions about the extent to which 'surrogate judgments' really are accurate reflections of what the person themselves would have wanted – and how this is tested and evaluated.

xii Media studies work consistently highlights that people are more dependent on media images where they have no prior personal and direct encounters with an issue. Disorders of consciousness propel lay people into very strange territory, under huge stress, even while intimately connected to the 'known' image and body of their loved ones. Anecdotal evidence from clinicians suggests that people's prior understandings of coma (e.g. as portrayed in fiction) may impact on the type of decisions that think are appropriate and that media reports of emerging scientific research (e.g. re stem cell or fMRI research) are already impacting on relatives' hopes and fears, and may add support to relatives seeking to challenge the treating clinician's diagnosis and approach. This anecdotal evidence is complemented by some academic work on the impact of media representation in this sphere (e.g. see Widjicks and Widjicks, 2006 – on the potential impact of coma representation in films).