

fMRI FOR SEVERELY BRAIN-INJURED PATIENTS: A MEDIA ANALYSIS

A thesis submitted for the degree of Doctor of Philosophy

by

Gabrielle Samuel BSc (Hons), MA, PhD

School of Social Sciences

Brunel University

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Abstract

This thesis is set in the context of social science's interest in the generation of expectations, the news media, and neurotechnologies. It is a qualitative case study that examines the nature and impact of news media reporting of some pioneering research, which used functional magnetic resonance imaging in an attempt to diagnose and communicate with severely brain-injured individuals.

Previous news media studies exploring neurotechnologies have been quantitative, or have tended to focus on how or why the news media represents neurotechnologies and/or the impact of the reporting, but rarely all three together. My thesis looks at all three aspects of the news media reporting of my case study. I draw on three sets of empirical data. First, those related to the production of the media - the press releases which reported the research; ten semi-structured interviews with science press officers; and the relevant expert comments posted on the Science Media Centre's website. Second, 51 newspaper articles reporting the research. Third, five semi-structured interviews with relatives of severely brain-injured patients.

I show that the mood of excitement and 'breakthrough' present in the press release reporting of this research was closely echoed in the news coverage. This excitement influenced the views and beliefs of only some of the relatives I interviewed. I then examine the nature of hype and by drawing on Haraway's concept of 'situated knowledges' (1988) I argue that individuals view hype differently depending on their profession, industry and/or socio-cultural background. Finally, I show how whilst both the news media and the scholarly literature portrayed this research as ethically contentious, the issues most prominently discussed by scholars and/or journalists do not necessarily equate with relatives' concerns.

My findings aim to contribute to the sociology of expectations, media theory, the sociology of bioethics and the public understanding of science.

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Author's declaration

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Abbreviations

BSE	Bovine Spongiform Encephalopathy
EEG	Electroencephalography
fMRI	functional Magnetic Resonance Imaging
GM	Genetically Modified
VS	Vegetative State
MCS	Minimally Conscious State
MMR	Measles Mumps and Rubella Vaccine
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
PET	Positron Emission Tomography
US	United States

Chapter 1: Introduction

1.1 Context of thesis

My project forms part of the London and Brighton Translational Ethics Centre (LABTEC) initiative to explore the social, ethical and clinical issues arising from the translation of basic scientific knowledge into innovative medical therapies, with a focus on the neurosciences. This is a five year multi-disciplinary research programme bringing together academics from a range of disciplines such as medical sociology, media studies, ethics, philosophy, and science and technology studies, as well as neurologists and clinicians. Such multi-disciplinary approaches to medical sociology have previously been adopted by scholars with much success (see, for example, (Williams et al., 2003; Ehrich et al., 2012), and have the potential to provide much richer frameworks for analysis. Indeed, multi-disciplinary projects are increasingly being viewed as advantageous modes of researching for many disciplines¹. As previously both a natural scientist (Molecular Geneticist, PhD, and post-doctoral scientist), and a 'bioethicist' (MA, and post-doctoral researcher - empirical research in a multi-disciplinary setting), and now presently researching in the realms of medical sociology, I feel particularly well suited, and indeed very much enjoy working in and across different disciplines. I believe each discipline can bring a unique perspective to a specific research area, which can potentially allow for a much greater understanding of the topic in question.

During the course of my thesis I found it incredibly beneficial to draw on different concepts and ideas from the various disciplines involved in LABTEC to enrich my understanding of my thesis topic and my research findings. Further, in order to develop the media aspect of my thesis I spent some time working with Professor Jenny Kitzinger who is based at the School of Journalism, Media and Cultural studies at Cardiff University. The multi-disciplinary context of the LABTEC project, as well as my background in the natural sciences and in ethics, have played a substantial role in how I approached this thesis, and how I conducted my research and analysed my findings.

¹ There is, however, a growing body of literature which is beginning to explore the difficulties of such approaches to research. For instance, a workshop was recently held at Brunel University which explored issues relating to overlapping work in the sociology and philosophy of science and bioethics ("Crossing the Divides" workshop, Brunel University, May 13th-14th 2013). For another example see the LABTEC Progress Review 2012-2013 pages 5-6. Available at <http://www.brunel.ac.uk/sss/sociology/research/cbas/labtec>.

1.2 Expectations, neurotechnologies and the news media

The framework of my thesis is set in social science's expanding literature in the neurosciences and innovative neurotechnologies, in the generation of expectations about innovative technologies, and in the news media's involvement in creating such expectations.

Innovations in biotechnology and medicine have been repeatedly shown to be associated with narratives of breakthrough and discovery (Brown, 2000; Brown et al., 2006), and a considerable body of sociological literature has shown how such narratives are typically present in much of the news media's portrayals of these technologies (Mulkay, 1994; Conrad, 2001; Caulfield, 2005). As the body of work known as the 'sociology of expectations' has identified, the hype and future-orientated abstractions within such rhetoric are not simply a by-product of innovation. They are, rather, performative – they are employed as strategic resources to secure funding and enrol allies (Brown et al., 2000; Brown & Michael, 2003). Whilst much work has explored in detail how expectations associated with biotechnologies arise and are portrayed in the news media (Nerlich et al., 2002; Kitzinger, 2008), there is much less work exploring how the news media specifically portrays neurotechnologies. Though the rise of neuroscience in contemporary society is beginning to gain the attention of some scholars who are keen to understand how, why and when expectations are associated with neurotechnologies as well as the impact of this. Medical sociological scholars have contributed much to this area of research (Pickersgill, 2011c), however, to date a great deal of the work specifically exploring neurotechnologies in the news media has been limited to broad quantitative type studies, predominantly conducted by neuroethicists (Racine et al., 2005; Racine et al., 2010). Further, many of the studies which have explored the news media's portrayal of neurotechnologies (or, in fact, biotechnologies in general) are typically restricted to an analysis of one or two elements - how a technology is portrayed in the news media, why it is portrayed as it is, or the impact of such portrayals on audiences - though rarely all three together. Similarly, only a handful of studies have focused on a particular biotechnological innovation (none for neurotechnologies) and traced their associated expectations as they are translated from scientific publication to the news media, as well as exploring how such expectations shape individuals' interpretations (for example, see (Miller et al., 1998; Henderson & Kitzinger, 1999; Holliman, 2004). Such case studies are particularly useful as they allow us to explore how ideas and concepts promoted by news sources actually relate to or even influence

the views and beliefs of families, patients, and those who will be the potential users of the technology. My thesis aims to address the limited work in this area by taking a qualitative case-study approach to provide an in-depth analysis of the factors that influence why a specific neurotechnology is portrayed in the news media, and the impact of such portrayals on (potential) users of the technology.

1.3 The growth of neuroscience in contemporary society

Since the early 1990's there has been an enormous increase in neuroscience² funding and research infrastructure - a growth that seems set to continue. In February 2011 the Medical Research Council (MRC) stated that they are "*fully committed to neuroscience research...neuroscience research received more than £123 million in 2009/10 from the MRC*" (Medical Research Council, 2011). The MRC is also leading an initiative to establish an independent and co-ordinated UK network of brain tissue banks³. The Wellcome Trust, too, state on their website that they "*fund a significant portfolio of neuroscience and mental health research - ranging from studies of molecular and cellular components to work on cognition and higher systems*" (Wellcome Trust, 2011a). Indeed, a report produced by the Wellcome Trust in 2011 stated that "*between 1990 and 2009, the Wellcome Trust invested £114 million on human functional brain imaging research (2 per cent of the Trust's funding commitment over this time)*" (Wellcome Trust, 2011b). Such imaging, more commonly called functional Magnetic Resonance Imaging (fMRI), is becoming the imaging method of choice for researchers who examine the physiology and anatomy of the brain. Over the last two or so decades, fMRI has provided new insight in determining which part of the brain handles critical functions such as memories, thought, pain, language, speech, movement, emotion and sensation (Eisenberger et al., 2003; Dvash et al., 2010; Lang et al., 2011; Wilson et al., 2011). fMRI is also well established as a diagnostic tool in clinical settings. For instance, it is used to help monitor the growth and function of brain tumours; to aid in the assessment of the affects of stroke, trauma or degenerative disease, on brain functions; and to act as a guide with the planning of surgery, radiation therapy, or other surgical treatments of the brain.

The use of neurotechnologies such as fMRI are now so widespread that they have been incorporated into a whole range of other avenues of non-scientific, academic and commercial

² Neuroscience is an umbrella term for studying the brain and the nervous system. Recently, neuroscience has been most associated with the study of the brain.

³ <http://www.mrc.ac.uk/Ourresearch/Resourceservices/UKBrainBanksnetwork/index.htm>

research. For example, in lie detection (Lee et al., 2002), neuromarketing⁴ (Lewis & Bridger, 2005), neurocinema⁵ and neuroeconomics⁶ (De Martino et al., 2009; Peterson, 2005). There has also been a rise in neuroculture - whereby artists engage with neuroscientific findings and use these as a new medium for expression (Frazzetto, 2008), and neurolaw and neuroethics - growing disciplines which focus on the ethical and legal issues associated with neuroscience and neurotechnologies.

The proliferation of neuroscience has been joined by an increasing political interest. For example, on July 17th 1990 President George Bush proclaimed 1990-1999 to be 'the decade of the brain' - a ten-year initiative designed to enhance public awareness of the benefits of brain research. Interest has proliferated in the media and throughout society, and neuroscience is now the subject of news reporting all over the world, and is featured in films, books, talk shows, debates, exhibitions and television drama. Increasingly, ideas, images and concepts of the neurosciences are being assimilated into global culture and becoming part of our daily discourses and practices. More recently, in 2013 President Barack Obama made a pitch for more brain research, referring to an initiative aimed to create a map of all human brain activity (Underwood, 2013). It would be hard not to draw analogies with these visions and the almost identical vision created for mapping the human genome in the highly politicised Human Genome Mapping Project (note, for example, the similar use of the 'map' metaphor). UK interest in neuroscience also seems set to continue. The Royal Institution's 2011 Christmas Science Lectures focused on the human brain⁷, and to highlight an example close to home, Brunel University has recently hosted the 'Brunel Brain Awareness Week' in 2012, and a lecture series to mark women's contribution to neuroscience in 2013.

Although neuroscience and neurotechnologies have the potential to discover new drugs and treatments as well as providing new ways of understanding ourselves, many social science scholars have raised concerns about the meaning of the 'neuro' (Brosnan & Michael, 2014) as well as how the findings of neuroscientific research are/will be put into practice and the

⁴ Neuromarketing is the study of how people's brains respond to advertising and other brand-related messages.

⁵ Neurocinema uses brain scanning to look at the ways movies are made, and what will make movies most successful (<http://www.cbc.ca/day6/blog/2011/04/10/neuro-cinema-brain-scans-and-the-future-of-movies/>).

⁶ Neuroeconomics uses brain-imaging techniques to study economic decision-making.

⁷ See <http://www.guardian.co.uk/science/2011/dec/25/royal-institution-christmas-lectures-brain>

implications of this (Joyce, 2008). These include, for example, concerns relating to privacy (Olson, 2005); determining ‘types of different brains’ (Dumit, 2004); and new forms of discrimination and/or identity and personhood (Dumit, 2004). Several scholars have also taken a closer look at the influence of neuroscience on our self-identity, questioning whether it has led to shifts from holistic perceptions of ourselves to more deterministically viewing ourselves as our brains (Farah, 2005). The Royal Society has published a series of four reports linked to its *Brain Waves* project - an initiative exploring what neuroscience has to offer, as well as its potential benefits and limitations - which discusses many of these issues (The Royal Society, December 2011). Concerns about the ethical, social, economic and political impacts of neuroscience have also brought the establishment of various social science initiatives. These include the *Center for Neuroscience and Society* at the University of Pennsylvania and *the Brain, Self and Society*, a three-year project located within the BIOS centre at King’s College London. BIOS has also formed the *European Neuroscience and Society Network* for interdisciplinary discussions of the social implications of the neurosciences, and sociological researchers are increasingly starting to contribute prominently to this field (Rose, 2003a; Abi-Rached, 2008; Abi-Rached & Rose, 2010; Pickersgill et al., 2011; Pickersgill, 2011a; Pickersgill, 2011b; Pickersgill & Van Keulen, 2012; Pickersgill, 2013). A Neuro-Reality-Check conference in Berlin in 2011 (1st-3rd December) brought together sociologists and other scholars interested in questioning the ‘neuro-turn’ in bioscience and other disciplines, and more recently, the Nuffield Council on Bioethics produced a working paper which explores the social and ethical issues surrounding novel neurotechnologies (Nuffield Council on Bioethics, 2013).

Attention is also being drawn to the growing public expectation of neuroscience. Parallels have been drawn to the era of genetics and stem cell research, which also saw a rising critique of the promises and expectations attached to them (Holm, 2002). Philosopher, Professor Tallis - author of *‘Aping mankind’* - presents us with the idea of ‘neuromania’, a fitting term which resonates strongly with ‘genohype’, a term used to describe a similar fascination with genetics in the 1980’s (Tallis, 2011).⁸ He accuses neuroscientists of failing to grasp a fundamental distinction between the brain and the mind, claiming that thoughts cannot be reduced to a particular pattern of neural activity (Tallis, 2011). Philosopher Scruton concurs, arguing that we should recognise that not all

⁸ In the wake of the genohype, scholars have now described a ‘genome fatigue’ in the media. See, for example, Carl Zimmer’s talk at the Joint Genome Institute annual meeting: <http://blogs.discovermagazine.com/loom/2012/04/03/the-genome-beat-or-curing-my-case-of-yet-another-genome-syndrome/>

coherent questions about human nature and conduct are scientific questions⁹, and Sociologist Pickersgill has critiqued the promises of neurotherapies in the area of mental health (Pickersgill, 2011c). There is also an increasing body of literature which has become concerned with how neuroscience is being depicted in the news media, and the role such depictions can play in attributing such expectations and promises to neurotechnologies. Studies have repeatedly pointed to the generally optimistic picture of neurotechnologies presented in the news, often at the expense of the social and ethical issues (Racine et al., 2005; Racine et al., 2006a; Racine et al., 2007a; Racine & Bell, 2008b; Racine et al., 2010; Caulfield et al., 2010; Gilbert & Ovadia, 2011; O'Connor et al., 2012). For example, in relation to fMRI, coverage has been shown to frequently involve *neuro-realism* (presenting fMRI uncritically as real, objective or effective), *neuro-essentialism* (suggesting that fMRI equates personal identity for the brain) and/or *neuro-policy* (media coverage attempting to use fMRI results to promote political and personal agendas) (Racine et al., 2005). And, when bioethicists Racine and colleagues looked at the portrayal of deep brain stimulation (DBS)¹⁰ in the United States (US) and UK print media they showed that 51 per cent of articles were optimistic depictions, whilst only 14 per cent of the analysed papers included ethical content and only 4 per cent emphasized the risks. Among the articles reviewed, 29 per cent contained a 'personal twist,' including first person narratives and descriptions of miracle stories of patients cured of Parkinson's disease, dystonia, and Tourette's syndrome (Racine et al., 2007b). In response to the overly optimistic portrayals of DBS in the media, ethicists Gilbert and Ovadia have called for a new strategy involving journalists and scientists¹¹ in ethical debates (Gilbert & Ovadia, 2011). Racine and colleagues, too, have repeatedly cautioned us to be wary of such depictions of neuroscience, which could ultimately lead to false hope and expectations about neurotechnologies and/or the public misunderstanding neuroscience (Racine et al., 2005; Racine & Bell, 2008b; Illes et al., 2010). These ideas are discussed in more detail in chapter three.

⁹ Professor Roger Scruton writing in the Spectator on 17 March 2012.

¹⁰ DBS (implantation of electrodes in the brain) is a neurotechnology used for many patients who have Parkinson's Disease and/or Dystonia. It is in the experimental stages for diseases such as epilepsy, obsessive compulsive disorder and depression, as well as for individuals defined as having a disorders of consciousness.

¹¹ Throughout this thesis when discussing scientists, this also encompasses clinicians conducting science research.

1.4 The importance of case studies in sociological analysis

As discussed in section 1.2, my thesis develops the body of sociological work in the area of neuroscience and the media by taking a case study approach to explore a specific neurotechnology. Case study approaches are based on the fact that different contexts and different situations vary uniquely in their practices and in the issues they raise. Science offers a useful exemplar: science is often viewed as a singular entity, but science is, of course, a general term (Weigold, 2001) and there are differences between the various disciplines of science, for example, between physics and biology¹². Such diverse professions are socialised differently, conduct science differently, and view the world in a different way. Physicists and biologists will also have different interactions, different issues and concerns (for example, what issues their research raises; how they are funded; how they chose to disseminate research; how they promote themselves). So whilst it is sometimes preferable to, for example, make universal statements or state grand ideas about, for instance, science (or neuroscience) in general, it is also important to recognize that such statements and ideas may play out differently in different situations. We must therefore acknowledge the ‘specifics’; differentiate between various groups; and be wary of ‘lazy’ generalisations. Case studies allow us to do this (George & Bennett, 2004).

Case study approaches are particularly useful when exploring the intricacies of science/health research and/or practice. In fact, much of medical sociological and science and technology studies research is based on qualitative case studies, which allow the researcher to capture the richness of specific interactions, contexts and/or issues. Though we must be cautious: whilst case studies do offer a variety of advantages to studying ‘the detail’ of the social world, because of the nature of this approach, the extent to which findings can be applied to other cases and more generally is something that is contested and varies (George & Bennett, 2004). When conducting case study research, researchers must remain vigilant (as they typically do) and avoid speculative extrapolations of the findings to other areas of practice.

¹² The same, of course, can be said for neuroscience, which also differs in its different modes and/or objects of research.

1.5 My case study: fMRI for severely brain-injured patients

My specific case study explores two specific pieces of research that were published in *Science* (2006) and the *New England Journal of Medicine* (2010). The research was led by Professor Owen, was funded by the MRC, and took place in Cambridge. It examined the possibility of using fMRI in an attempt to diagnose and communicate with severely brain-injured patients (patients who have a disorder of consciousness). The findings generated a peak in news media interest, with headlines including: *Think tennis for yes and home for no: how man trapped in his body 'spoke'* and *New hope after brain research*. The research also generated extensive debate in the ethical literature about the capabilities and various ethical issues surrounding the use of this technology.

This particular case study was chosen as the focus for this thesis for two main reasons. First, I wished to explore the nature of expectations attributed to technologies. This technology is an example of translational research (often referred to as bench-to-bedside research, this research harnesses knowledge from basic scientific research ('the bench') to produce new drugs, devices, and treatment options for patients in the clinical realm ('the bedside') (Woolf, 2008)) and as such already has certain expectations attached to it. As Wainwright and colleagues have noted, "*translational research implies an orientation toward the future...[which] entails expectations about the trajectory from bench to bedside in general*" (Wainwright et al., 2006b: 2054). Holm, for example, has previously shown how, similar to genetic technologies in the 1980's, the presentation to the public of stem cell research has often been characterised by the promise and expectation of huge immediate breakthroughs.¹³ Such presentations, he argues, are clearly problematic as they raise false expectations in seriously ill people (Holm, 2002).

Second, previous research suggests that the associated risks or social/ethical issues of neuroscience research are rarely discussed in the news media.¹⁴ For my case study I wished to explore if/how ethical issues were presented in the news media and whether this was at the expense of, or alongside, the presentation of expectations. Research into, and the care of, severely brain-injured patients raise a number of ethical issues in terms of, for example, treatment

¹³ Genetic research and stem cell research are two notable examples of translational research. Also see, for example, Martin, P., Brown, N. and Kraft, A. (2008a), 'From bedside to bench? Communities of promise, translational research and the making of blood stem cells', *Science as Culture*, 17, 1, 29-41.

¹⁴ Though not always – there are examples in which the news coverage of specific neuroscience research has been associated with much ethical discourse, see for example Racine, E., DuRousseau, D. and Illes, J. (2007a), 'Ethical issues in performance enhancing technologies', *Technology*, 11, 37-53.

plans and end-of-life decision-making.¹⁵ Owen and colleagues' research therefore offered a useful case study to explore this.

Specifically, for my case study, I was interested in exploring how the news media reported Owen and colleagues' research and its attributed expectations and/or ethical issues. Beyond this, I was also interested in exploring how and why Owen and colleagues' research generated such media interest. Science press officers are now considered an integral part of science research¹⁶ dissemination¹⁷, and the press release is the main means that press officers use to disseminate such research to journalists. In fact, the press release is more often than not the main source of access that media journalists have to the research being conducted in science institutions (Rose, 2003b). Further, research has shown that the expectations often attached to innovative technologies in the news media can be directly attributed to the press releases disseminated to publicise the research by the relevant institution, funding body and/or science journal (Woloshin & Schwartz, 2002; Rose, 2003b). Several scholars have previously explored the role of science press officers in the generation of expectations – typically via studies that have analysed a range of science communicators (including science press officers, scientists, journalists and/or editors) and/or a specific science media event (for example, see Nerlich and colleagues' work on how the Human Genome Project was revealed to the public (Nerlich et al., 2002) and Williams and Gajevic's work on animal–human hybrid embryos (Williams & Gajevic, 2013); also see Clegg Smith and colleagues' work on cancer research (Clegg Smith et al., 2010)). This thesis aims to develop this body of work by offering a closer and more in-depth exploration of how science press officers view their role as the writers of press releases; whether they view themselves as the contributors of hype; and how they view and define expectations. By drawing together the sociology of expectations with Donna Haraway's concept of 'situated knowledges' (Haraway, 1988) this thesis aims to provide some explanation as to the nature of hype.

¹⁵ Issues relating to severely brain-injured patients and their care are, of course, much more far reaching than this, but are beyond the scope of this thesis, which focuses on severely brain-injured patients and fMRI.

¹⁶ Throughout the thesis, the term 'science research' also incorporates all aspects of health research.

¹⁷ Scientists and journalists also play a role.

Finally, I was interested in exploring what influence the news media's portrayal of Owen and colleagues' studies had on family members (the (potential) users of the technology). In this way I aim to contribute to previous work which has explored the influence of expectations in the news coverage of health technologies on (potential) users (for example, see (Peddie et al., 2009)) as well as aim to develop work in the sociology of expectations related to analysing the influence of such expectations. Alongside this, I was also interested in how families viewed fMRI (their expectations and concerns) and how/whether such views compared and/or contrasted with how the news coverage presented this research, as well as with how this technology and its associated ethical issues have been framed in the scholarly bioethical literature. This thesis therefore also aims to develop work under the rubric of the 'sociology in bioethics' (Williams & Wainwright, 2013), as well as work which has been conducted on families of those who have a severely brain-injured relative, which has tended to be limited, and focused on families' psychological needs (highlighting issues such as depression or so-called 'prolonged grief disorder') (Kitzinger & Kitzinger, 2013).

My thesis, therefore, has three specific aims:

1. To explore what expectations and ethical issues the news media attributed to Owen and colleagues' research and to examine why this was the case.
2. To explore the implications of the news coverage of Owen and colleagues' research in terms of (potential) users of the fMRI technology, as well as in terms of policy.
3. To use the findings of this thesis to develop the body of work known as the sociology of expectations.

The aims of this thesis will be answered with a series of six research questions:

- (1) How did UK newspapers represent two specific research studies conducted by Owen and colleagues in 2006 and 2010, which used fMRI for severely brain-injured patients?
- (2) How did (a) the MRC funding body and the associated science journals which disseminated the research, and (b) relevant expert comments on the Science Media Centre's website¹⁸, portray the Owen and colleagues' studies in their press releases?
- (3) How do science press officers choose scientific stories to highlight to journalists and why; how do they report science/health research; and how do they view their role?
- (4) What are science press officers' views regarding the news coverage of the Owen and colleagues studies?
- (5) What views and beliefs do families who have a severely brain-injured relative hold about Owen and colleagues' studies?
- (6) What influence did the news coverage of Owen and colleagues' studies have on the views and beliefs of families in relation to the research?

The thesis uses a version of grounded theory and semi-structured interviews to answer these research questions.

Research Question	Qualitative method employed
1	Analysis of newspapers
2	Analysis of press releases / expert comments
3	Interviews with science press officers
4	Interviews with science press officers
5	Interviews with families
6	Interviews with families

¹⁸ The Science Media Centre, also discussed in more detail later, is '*first and foremost a press office for science when science hits the headlines*' <http://www.sciencemediacentre.org/pages/about/IT>

1.6 Structure of thesis

Seven chapters follow this introduction to the thesis. Chapters two and three are literature review chapters. Chapter two introduces the various conditions and diagnoses that relate to severely brain-injured patients and thus fit under the umbrella term ‘disorders of consciousness’. Here I discuss the difficulties involved in diagnosing this subset of individuals and elucidate how Owen and colleagues’ research add development to this area of study. This chapter also provides a description of the fMRI technology and sets out the key debates that have dominated the scholarly literature with relation to the use of fMRI for severely brain-injured patients. Chapter three explores the wealth of existing work on media analysis, the public understanding of science, and the sociology of expectations, all of which inform this thesis. It introduces the ‘cycle of hype’ that is prominent in the dissemination of science research into the public domain, and the role of key actors in this cycle, including scientists and/or their institutions, science press officers, journalists and editors. It also discusses the importance of the news media in shaping the public perception of science/health research, and therefore illuminates the importance of research in this area.

Chapter four considers the methodological frameworks used to guide the research and sets out an account of the research design and the methods used to gather my data. It also addresses the ethical and practical issues that informed and influenced the design of this research project.

Chapters five, six, and seven report my empirical work and data analysis, and as such make up the core of my thesis. In the first of these chapters (chapter five) I show how the news coverage of Owen and colleagues studies’ was surrounded by promises and expectations. By comparing these findings to those from my interviews with family members I highlight a gap between how fMRI was promoted in much of the coverage, and the experiences of families. In chapter six, I report my press release analysis and attribute much of the excitement surrounding the news reporting of Owen and colleagues’ research to the press releases disseminated by the MRC research council. During this chapter I also present the findings from my interviews with science press officers and examine in detail how my interviewees talked about their role in science/health research dissemination; write press releases; and how they talked about the hype and expectations surrounding science/health research. In this way I build up a picture of how and why science/health research is often viewed by many as hyped. In the final results chapter, chapter seven, I present both how the news media portrayed the ethical issues associated with Owen and colleagues’ studies, as well as how family members discussed the ethical issues

important to them about the technology. Before embarking on this, I briefly talk about the difficulties I had throughout this thesis in defining the term ‘ethics’. In the final section of this chapter I compare my findings to the way in which the scholarly literature is discussing and debating the ‘ethical’ issues associated with Owen and colleagues’ studies and point to some differences between these, the issues presented in the news media, and those issues important to family members.

The thesis concludes with a discussion chapter (chapter eight). In this chapter I draw together the results and analysis of the previous core chapters and situate my findings in broader sociological concepts. I show how my findings contribute to the sociology of expectations. I also draw on Haraway’s concept of ‘situated knowledges’ to help explain some of the findings from my science press officer interviews. Here I argue that this concept can help develop the literature on the sociology of expectations by providing at least some explanation for why hype is produced. Following this, the implications of the thesis are discussed, the limitations of the thesis are assessed, recommendations are made, and future work proposed.

Chapter 2: fMRI for severely brain-injured patients

2.1 Introduction

In this first of my two literature review chapters I explore the scientific context of the use of fMRI for severely brain-injured patients – those patients who have a disorder of consciousness. In order to do this, I have divided this chapter into three sections. First, I provide a description of how the medical community defines having a disorder of consciousness, as well as the different conditions which umbrella under this term. This area of medicine is incredibly complicated and transient and only partially understood, however, a good knowledge of this field is critical for a clear understanding of what Owen and his colleagues aimed to achieve from their research. Second, it provides a detailed description of fMRI technology. fMRI technology is used broadly across medicine, and, as discussed in chapter one, its implications are being increasingly discussed by sociologists. My discussion of fMRI in this section is mainly limited to areas I deem relevant to Owen and colleagues research. In my final section I review the scholarly literature which has explored the use of fMRI for severely brain-injured patients paying particular attention to those papers highlighting any associated ethical concerns. As mentioned briefly in the previous chapter, I will later compare the content of this literature with how the ethical issues associated with the fMRI technology were/were not reported in the UK newspapers and/or press releases, as well as with how family members discussed their concerns about the technology.

2.2 Disorders of consciousness

Disorders of consciousness is an umbrella term used to describe a heterogeneous group of individuals who have inhibited consciousness, usually as a result of severe brain injury. Although knowledge about the brain, brain injuries and recovery is still very much limited – for example, there are no proven treatments that are known to improve brain injury¹⁹ - over the past decade there has been a great amount of research into disorders of consciousness. This has led to the advent of a whole host of newly defined brain states. There are presently three main

¹⁹ There are, however, a number of single case reports of certain drugs having a positive affect on an individuals' level of awareness. For example, Ambien (a sleeping pill) has been reported to have dramatic affects in some cases. Such affects have been widely publicised, for example see: <http://health.heraldtribune.com/2011/12/03/a-sleeping-pill-that-seems-to-wake-the-nearly-dead/>

distinguishable disorders of consciousness: the coma, the vegetative state (VS) (persistent or permanent) and the minimally conscious state (MCS).

In a coma a person is alive but unable to move or respond normally to stimuli; lacks a normal sleep-wake cycle; and has their eyes closed. The popular image of being in ‘a coma’ is of an individual, supported by machines, lying in a peaceful sleep like state (Wijdicks & Wijdicks, 2006). A staple device in fiction (films, TV drama and novels) is to have this patient deliver a coherent monologue (implying a fully functioning consciousness beneath the cloak of unconsciousness) and/or to suddenly ‘wake up’ - often with few outstanding neurological problems except perhaps some memory loss convenient to the plot (Kitzinger & Kitzinger, 2013). The factual news media often promote similar images and stories – sometimes presenting scientific inaccuracies and confusing use of terminology (Bernat, 2008; Racine et al., 2008a; Latronico et al., 2011)²⁰ and giving high profile coverage to very rare cases of patients who show some recovery long after clinicians had given up hope (Fins et al., 2007b).²¹

Although comas lasting a few weeks can, in part, resemble the images in fictional and factual media described above (and there are some well documented cases of ‘miracle’ recoveries), the routine reality of long-term coma-like conditions is rather different. A coma is a self-limiting state and only exists in the initial presentation of severe brain injury. After a few weeks in a coma a patient who does not die, or wake up, usually enters either a ‘vegetative’ or a ‘minimally conscious’ state. The reality of these long-term coma-like conditions is rather different from that depicted in the media (Fins, 2008). Clinicians define the VS as ‘wakeful unresponsiveness’. Individuals in a VS have automatic functions such as being able to breathe on their own, having cycles of eye closure and opening (sleep-wake cycle), and may have reflexes such as a startle reflex or retracting from pain, but there is no sign of awareness and no evidence that the patient can perceive the environment or themselves, communicate with others, or form intentions. Patients are usually independent of all machines apart from the one delivering artificial nutrition

²⁰ Also see, for instance, news articles reporting Mandela as being in a “permanent” vegetative state. For example, the Telegraph article *“Nelson Mandela in ‘permanent vegetative state’, court papers say”* (15th October 2013).

²¹ See also, for example:

http://www.sciencedaily.com/releases/2013/05/130523101822.htm?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+sciencedaily%2Ftop_news%2Ftop_science+%28ScienceDaily%3A+Top+News+--+Top+Science%29 and <http://www.wantchinatimes.com/news-subclass-cnt.aspx?cid=1303&MainCatID=13&cid=20130926000022>

and hydration (which keeps VS and some MCS patients alive) (Report of a working party of the Royal College of Physicians, 2003).

The VS may be a transient stage in the recovery from a coma or it may persist until death. *Persistent* VS occurs when the state has continued for four weeks or more. The VS is considered *permanent* after three months, if the initial cause of brain damage was oxygen deprivation (for example, a cardiac arrest), and after 12 months if the initial cause of brain damage was a traumatic brain injury (for example, from a fall or car accident) (Fins, 2008). The prognosis of the VS is influenced by age, the underlying cause, and its current duration. A little over half of those in a VS one month after a trauma will regain awareness, though with other causes, after a month fewer than 20 per cent will recover. For the majority of patients, even if they recover full consciousness after being in VS for some time their prognosis remains very limited. For example, they may recover full consciousness without fully recovering physical abilities or memory, and with only minimal or intermittent ability to understand or communicate with the world around them. In a very small number of well-publicised cases individuals have recovered from a permanent VS. Recently the European Task Force on Disorders of Consciousness have proposed to call the VS ‘unresponsive wakefulness syndrome’ (Bruno et al., 2011).

From the VS a patient may move into the MCS - a new diagnosis only formally defined in 2002 (Giacino et al., 2002). In contrast to the VS, in the MCS individuals fluctuate between levels of unawareness and levels of awareness of themselves and the environment - where they may have emotional responses to family members, say words or phrases and gesture, and/or show evidence of memory, attention and intention. However, awareness may be fleeting (Fins, 2008). The MCS can be sub-categorised as MCS+ for those with high-level behavioural responses (being able to follow a command or saying something that makes ‘sense’) and MCS- for low-behavioural responses (tracking something with their eyes or appropriate smiling and/or crying) (Bruno et al., 2011). The MCS may be a stage on the way to recovery from the VS, may be chronic, or sometimes permanent. Emergence from the MCS is defined by the ability to consistently engage with others and have reproducible recovery of consciousness and an awareness of self, others and environment (Fins, 2008). The prognosis for MCS is more open than for a VS, but as with vegetative patients, such recovery becomes less likely over time, and after several years in an MCS it is unlikely there will be further recovery. Any such recovery is usually associated with severe mental and physical impairment. There have, however, been rare occurrences of dramatic recoveries and emergence from MCS decades after injury, for example

the highly publicised case of Terry Wallis.²² Due to the difficulties of epidemiology studies there is little data on MCS demography (Fins et al., 2007a). Strauss posited that between 112,000 and 280,000 adults and paediatric patients are in an MCS in the US (Strauss et al., 2000), though these figures were extrapolated from a group of paediatric patients. Recently the European Task Force on Disorders of Consciousness have proposed to call the MCS the ‘minimally responsive state’ (Bruno et al., 2011).

At present, differentiation of the VS and MCS rests fundamentally on patient history and physical (bedside/clinical) examination. There are a number of scales used by clinicians to measure the extent of consciousness, though all have their limitations (Demertzi et al., 2008). The most common and widely used tool is the Glasgow Coma Scale, which measures eye, verbal and motor responsiveness, though this scale can be problematic (for example, verbal responses are impossible to measure if the individual has a tracheostomy) and is not sensitive to detect transition from the VS to the MCS. To differentiate the VS and MCS the most appropriate scale is the Coma Recovery Scale-Revised which looks, for example, for visual pursuit and visual fixation. Recently a new scale called the Full Outline of Unresponsiveness score has been proposed as a superior alternative to the Glasgow coma scale (Demertzi et al., 2008).

In spite of these scales, diagnosis of the VS and MCS can be incredibly challenging for a number of reasons. First, due to the fluctuating nature of the MCS, and because individuals in an MCS can lack awareness during a clinical examination, this state of consciousness can be easily missed, even after repeated clinical examinations by neurologists. Second, because of potential complicating injuries such as blindness or deafness, which make it extremely difficult to detect awareness in those who may have otherwise been able to complete the test. Third, the VS can be confused with what is known as locked-in syndrome – often wrongly considered a disorder of consciousness, in this condition the individual is conscious, but completely paralysed and thus unable to communicate, except sometimes by vertical eye movement (the European Task Force on Disorders of Consciousness have proposed to call locked-in syndrome ‘functional locked in syndrome’). And finally, because the lines between the VS and MCS are frequently blurred, with individuals demonstrating varying degrees of brain activity across the states, there is often confusion and ambiguity regarding diagnosis. These challenges are especially problematic in cases where neurologists without sufficient training in the area are called upon to diagnose an individual. Indeed, following a retrospective study, scholars have noted that it is likely that as

²² See, for example, the BBC’s report: <http://news.bbc.co.uk/1/hi/world/africa/3052433.stm>

many as 40 per cent of individuals with a disorder of consciousness are diagnosed incorrectly (Andrews et al., 1996) (more recently confirmed in a study in 2009 (Schnakers et al., 2009b)). This is most likely – the authors suggest - due to the lack of proper diagnosis from a skilled multi-disciplinary team experienced in the management of people with complex disabilities due to brain damage (Andrews et al., 1996). Other scholars have argued the importance of taking into account family observations which they say can be a useful addition to any assessment since their intimacy with the patient may mean they are there to record genuine moments of consciousness. However, such scholars remind us that it is important to also remember that families may sometimes misinterpret reflexes (Turner-Stokes et al., 2012).

2.2.1 Implications for diagnosis

The correct diagnosis of the VS, the MCS, and locked-in syndrome has implications in the clinical context in terms of management, and the need for appropriate treatment and support. For instance, it has been argued that conscious individuals or those with limited consciousness require a variety of clinical and non-clinical treatments such as rehabilitation, therapy and/or pain relief - treatment that may not be relevant to individuals who are unconscious (Laureys et al., 2002; Boly et al., 2008). Though there are others who question this simplistic distinction of consciousness/unconsciousness in terms of pain relief is problematic (Gligorov, 2008; Schnakers et al., 2009a; Tarquini et al., 2012). Alongside this, Fins argues that because of difficulties with diagnosis, clinicians may prematurely foreclose the prospect of recovery from the VS/MCS and view care for patients with a disorder of consciousness as being futile. In such instances patients may be warehoused in nursing homes that limits their access to appropriate neurological and diagnostic tests (Fins et al., 2007b). Moreover, he says, economic pressures can present barriers to the proper assessment and care of patients, which may lead to early discharge from hospitals, or a lack of possible therapy and rehabilitation (Fins et al., 2007b).

It has also been argued that the correct diagnosis of the VS, the MCS, and locked-in syndrome also has implications in terms of end-of-life decision-making. At present, in the UK (and the US) artificial nutrition and hydration can be withdrawn if an individual is deemed permanently vegetative.²³ Such a right to die was first granted in the UK in the widely publicised case of Tony

²³ In most countries it can be withdrawn only if the subject had previously made a formal advance directive or if his/her wishes can be reasonably reconstructed.

Bland²⁴ (similar cases of Karen Ann Quinlan and Terri Schiavo ensued in the US²⁵). Since 1992, less than 60 cases have been brought to court under this legislation, all applications of which have been granted. The Mental Capacity Act 2005 now applies to decisions about the withdrawal of artificial nutrition and hydration from patients who are in an MCS.²⁶ This act states that, for individuals who lack capacity, decisions should be made based on the patient's wishes, feelings and values even if they have not made a valid and applicable advance decision. However, at present there has only been one family who has brought this to the courts. In this highly publicised case of 'M', the family applied to withdraw artificial nutrition and hydration from their minimally conscious daughter on the basis of previous wishes that 'M' made to her family that she did not wish to live in such a state (Jackson, 2013). Their application was rejected²⁷ primarily on the basis that 'M's carers testified that 'M' showed pleasure from activities, and thus it was in her best interest to remain alive. There has been much debate surrounding this controversial decision both in the academic literature (Gillon, 2012; Sheather, 2013; Huxtable, 2013; Johnston, 2013; Mullock, 2013) as well as in the media (Adams, 2012). It is also worth mentioning the recent court case of Tony Nicklinson, who had locked-in syndrome. He applied to court to allow professional assistance to end his life, but his application was declined.²⁸ Thus, such a legal framework creates a legal division between the right to die for conscious/limited conscious individuals (locked-in and MCS individuals) and unconscious (VS) individuals. This has been deemed ethically problematic (Kahane & Savulescu, 2009). Johnson, for example, has argued that *"consciousness should not preclude the withdrawal of life-sustaining treatment for minimally conscious patients any more than it does for other conscious patients"* (Johnson, 2010) because, for example, there is a possibility that life in an MCS - in which patients may be able to feel pain, have an emotional response and have insight into their plight - may be worse than in a VS (Demertzi et al., 2011). Moreover, Fins and colleagues have argued that there is no 'typical' MCS or VS patient – each patient varies in their injury, diagnosis, and prognosis, and this is confounded by the fact that,

²⁴ Tony Bland was left in a VS following the 1989 Hillsborough football stadium disaster. He spent three years in a VS before his feeding tubes were withdrawn and he died in 1992.

²⁵ Karen Ann Quinlan was left in a VS after she collapsed and stopped breathing. Karen Ann Quinlan's parents fought and won the right to remove her respirator in 1976. She lived for a following ten years following this, and eventually died in 1985. Terri Schiavo was in a VS for 15 years following cardiac arrest. She was the centre of a dispute regarding the withdrawal of her artificial nutrition and hydration between her husband and her parents. The courts eventually approved the application for artificial nutrition and hydration withdrawal and she died in 2005.

²⁶ <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

²⁷ W v M.S and A NHS primary care trust [2011] EWHC 2443

²⁸ <http://www.mirror.co.uk/news/top-stories/2011/11/29/locked-in-syndrome-father-in-right-to-die-court-bid-115875-23597738/>

firstly, diagnoses are not fixed but transient and second, that misdiagnosis of the MCS is high (Fins, 2006).

2.3 Neuroimaging and disorders of consciousness

As noted above, neuroscientists have recently made great efforts to facilitate the diagnosis of individuals with a disorder of consciousness, and to try and assess brain function, mental state and consciousness, by innovative neuroimaging technologies, such as Positron Emission Tomography (PET) and fMRI.²⁹ Such techniques aim to determine an individual's level of retained awareness without requiring an obvious or evident movement i.e., they do not rely solely on behavioural tests to measure consciousness (Schiff et al., 2002; Schiff et al., 2005; Owen et al., 2006; Voss et al., 2006; Coleman et al., 2007; Di et al., 2007; Fernandez-Espejo et al., 2011; Rodriguez Moreno et al., 2011). Over the past decade the use of such techniques have shown residual functioning (such as processing of language), and in some cases higher levels of functioning (such as learning and actively maintaining information through time) in VS and/or MCS patients that appear overtly unaware, thereby challenging assumptions about the immutability of severe brain injury as well as diagnostic categories (Bekinschtein et al., 2004; Bekinschtein et al., 2005; Boly et al., 2005; Landsness et al., 2011). The most notable studies - and the ones which form the focus of this thesis - were two reports which used fMRI to suggest the detection of awareness in patients bedside diagnosed as vegetative and/or minimally conscious (Owen et al., 2006; Monti et al., 2010). These reports were conducted by Owen and colleagues at the MRC in Cambridge in 2006 and 2010, in collaboration with a Belgian research team headed by Laureys. In the 2006 study (Owen et al., 2006), Owen and colleagues conducted some tests using fMRI on a 23-year old woman who sustained a traumatic brain injury, and whose clinical assessment concluded that she fulfilled all of the criteria for a diagnosis of VS. One test involved the woman imagining playing a game of tennis and then imagining visiting all the rooms of her house whilst having her brain scanned by fMRI. During these tasks the patient's neural responses were indistinguishable from those observed in healthy volunteers. The authors concluded that *"this patient retained the ability to understand spoken commands and to respond to them through her brain activity"* and *"confirmed beyond any doubt that she was consciously aware of herself and her surroundings"* (page 1402). This finding is incompatible with a diagnosis of 'vegetative' raising the possibility that she

²⁹ Other techniques, such as the administration of various pharmaceuticals, have also been attempted. See, for example, Giacino, J.T., Whyte, J., Bagiella, E. et al. (2012), 'Placebo-controlled trial of amantadine for severe traumatic brain injury', *New England Journal of Medicine*, 366, 819-826.

was either locked in or was now minimally conscious. The girl has now diagnosed as in an MCS by bedside-examination.

In 2010, a subsequent paper by the same research group (Monti et al., 2010) reported on a similar study of 54 individuals with disorders of consciousness. The authors reported that of the 54 patients:

Five were able to wilfully modulate their brain activity. This included one patient bedside diagnosed as minimally conscious, and four patients bedside diagnosed as vegetative. In three of these patients, additional bedside testing revealed some sign of awareness, but in the other two patients no voluntary behaviour could be detected by means of clinical assessment (page 579)

One of the five patients was the same patient discussed in the previous 2006 study (now diagnosed as MCS). They also report that one man, who at the time of scanning showed “*signs of awareness...consistent with the minimally conscious state*” (page 585), was able to use their technique to answer ‘yes’ or ‘no’ to questions during the fMRI. In this case the patient was instructed to respond during the imaging session by using one type of mental imagery for ‘yes’ and the other for ‘no’. The authors concluded that “*with further development this technique could be used by some patients to express their thoughts, control their environment, and increase their quality of life*” (page 589).

Other neuroimaging methods are now likely to play more of a role in both the diagnosis and prognosis of patients bedside diagnosed as vegetative (Bardin & Schiff, 2012; Cruse et al., 2012). For example, fMRI is now being superseded by electroencephalography (EEG) (Fernandez-Espejo et al., 2011; Goldfine et al., 2011; John et al., 2011; Fingelkurts et al., 2013) - a set of electrodes on the scalp that detect electrical signals generated from the brain’s neurons - which may provide a much more accurate assessment for the classification of consciousness. Indeed, in November 2011, Owen and colleagues used EEG to demonstrate awareness in three of the 16 VS patients who took part in their research study (19 per cent) (Cruse et al., 2011). However, it is fMRI which first came onto the public scene and which is the focus of this research. fMRI research for severely brain-injured patients is still continuing (Sharon et al., 2013). For example, Owen and colleagues recent research suggests that a patient who had been in a vegetative state for 12 years before the scanning and subsequent to it, was able to use attention to correctly

communicate answers to several binary questions (Naci & Owen, 2013).³⁰ It is therefore to fMRI where I now move the discussion. Below I provide an account of the fMRI technology, before moving on to discuss the production of fMRI images.

2.4 functional magnetic resonance imaging (fMRI)

fMRI - developed in the early 1990's - is one of a number of neuroimaging (brain scanning) techniques. These techniques, which allow us to examine (image) the brain *in vivo*, have provided fundamental insights into human brain function and development. Due to its nature - it is a safe and non-invasive imaging modality that does not require the use of harmful x-rays, radioisotopes, or invasive diagnostic procedures – this technology is fast becoming a well established diagnostic tool in clinical settings.

Because fMRI is a technological variant of MRI, in order to clearly understand this technology and how it works it is important to first understand MRI. MRI uses magnetic and radio waves to visualise detailed internal structures of the body. The technology is based upon a set of physical principles associated with the behaviour of atoms in a magnetic field. In an MRI machine the magnet causes protons (protons are positively charged particles inside atoms), which normally spin in random directions, to align with the magnetic field. A pulse of radio waves knocks the protons out of alignment. When the radio signal ceases, the protons realign themselves with the magnetic field (proton relaxation times), emitting photons as they do. These photons will differ in energy depending on their environment (i.e. the surrounding tissue). The photons are captured by a receiver and converted into a computer image of the region of the body under diagnosis.

fMRI takes advantage of MRI technology as well as two additional phenomenon to detect small changes in blood oxygenation that occur after increased local brain activity. First, whenever any part of the brain becomes active there is increased oxygenated blood flow (blood containing oxygen in the form of oxy-haemoglobin (haemoglobin carries oxygen around the body)) to that area and a concomitant decrease in deoxy (oxygen free) haemoglobin. And second, iron in haemoglobin causes small distortions in a magnetic field, which are dependent on whether the iron is bound to oxygen. Thus, the different local environments of oxygenated and de-oxygenated blood in the brain can be detected by fMRI via the small distortions in the magnetic field caused by the haemoglobin, and this can then be correlated to 'active' and 'inactive' brain

³⁰ This research also featured on a BBC Panorama episode in November 2012 '*The Mind Reader: Unlocking My Voice*'

regions. The fMRI output data - a series of images of the brain³¹ over a period of time - is commonly known as the blood-oxygen-level dependent (BOLD) signal and provides an indirect measure of increased neural/brain activity.



Figure 2.1: An fMRI scanner³²

Although traditionally medical imaging data has been analysed on radiological film, this is not the case for fMRI, which makes use of digital representation due to the large amount of data contained in the scans. The images produced from fMRI generate the classic and compelling image of different parts of the brain ‘lighting up’.

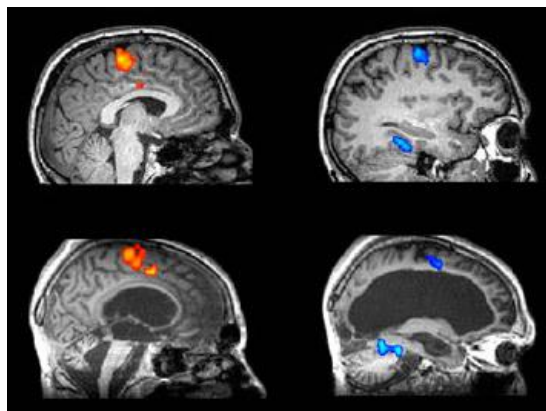


Figure 2.2: Examples of published newspaper fMRI images of the brain ‘lighting up’

³¹ For example, every two seconds

³² Picture sourced from Flickr – a freely accessible database of pictures (non-copyright)

2.4.1 Critiques of medical imaging and fMRI

fMRI has the potential, and is indeed already being used, to diagnose, treat and even prevent illness and diseases. But arguably, this technology does much more than this - it raises a range of ethical, legal and social concerns, as well as affecting our view of the body, disease and cures. Neuroethicist Judy Illes has been a prominent spokesperson discussing many of the ethical debates centred around fMRI (Illes & Kirschen, 2003; Illes et al., 2003; Illes & Racine, 2005; Garnett et al., 2011). Others have also contributed to the literature in this area, which has included debates surrounding: the recruitment of vulnerable groups (Rosen et al., 2002); the misuse of fMRI; informed consent and the question of abnormalities and incidental findings detected during the scan - along with this comes issues relating to the risks attached to such findings, for example, anxiety, and the need for appropriate guidelines (Illes et al., 2002; Grossman & Bernat, 2004; Illes et al., 2006; Kirschen et al., 2006); and the limitations of the technology, for example, how to deal with anatomic differences in the brain, as well as statistical errors, including false-positives and false-negatives (Desmond & Annabel Chen, 2002; Rosen & Gur, 2002). Other concerns raised in the ethical literature include issues relating to confidentiality and privacy (Tovino, 2005), as well discrimination and stigma (including empirical evidence suggesting that fMRI may be able to reduce stigma for mental health patients (Illes et al., 2008)); issues relating to applications of fMRI outside of the research setting (Illes et al., 2003; Illes & Racine, 2005; Feignson, 2006; Appelbaum, 2009; Dresser, 2010); and media representations of the technology. In relation to this latter point Seixas and Basto argue that “*neuroscientists have an ethical duty and a professional responsibility to explain the limitations of the technique they use, and not just promises of mind-reading*” (Seixas & Basto, 2008). As discussed in chapter one, Racine and colleagues have raised similar concerns about the representation of fMRI images in the news media (Racine & Bell, 2008b).

In the realms of the social sciences, several scholars have explored the role of medical images in our society (Beaulieu, 2002; Dumit, 2004; Prasad, 2005a; Prasad, 2005b; van Dijck, 2005; Joyce, 2008; Morana, 2008). In particular they have explored how these images must be understood in relation to the broader socio-technical turn toward visualisation (a tendency to translate the world into the visual) (Joyce, 2008). Joyce has explored the depiction of MRI and its images in the popular media, noting three points. First, MRI scans are compared with the clinical exam and other less expensive technologies, which are always positioned as subjective and inaccurate sources of knowledge. Second, the MRI machine is positioned as a magical actor that is capable

of finding or showing weighty knowledge about the body (Joyce, 2008). Joyce states that these depictions shore up:

The authority of images as an objective source of knowledge that is crucial for the understanding of health and illness. These narratives construct one possible way to understand MRI exams: as providing unmediated access to the physical body, a body that can be known and that exists outside of human relations (page 60)

And third, the MRI image is seen as transparent and objective, interchangeable with parts of the body being scanned instead of being a construction of it. In this sense, these images are seen as being analogous to a photograph – an analogy that suggests that any individual can look at, and understand, the image. The social construction of these images is reflected, for example, in the use of visual metaphors in narratives about MRI that support beliefs that these images reveal the body's interior as a realistic and objective source of knowledge. Imagery metaphors include phrases such as 'to reveal' and 'to provide a window' (Joyce, 2008).

Similarly for fMRI, most contemporary understandings assume it is an unproblematic representation of the structure of the brain. Sociologist Dumit has argued that analogising an fMRI image to a photograph can be misleading since, rather than a snapshot of the brain readily interpretable by the untrained and uninformed, it is a code that is only legible by the trained eye (Dumit, 2004) - a statistical map in the guise of an iconic representation (Illes & Racine, 2005). There are, in fact, numerous steps between image acquisition and interpretation and for this reason the fMRI image is not unproblematic. Lawyer, Feigenson talks about the complexity of fMRI images. He notes, for example, that fMRI measures the *differences* between brain activity in two groups of individuals - the experimental group and the control group - and thus presents a relative, not absolute, measure of brain activity. Second, fMRI results are thresholded for display at an arbitrary level of significance i.e., the difference between activity in the two groups is deemed significant depending on the bar for statistical significance chosen by the researchers. Third, fMRI images seen in publications often represent *average* data, derived from subtracting an average of experimental scans from an average of control scans. i.e., a number of individual scans are averaged in both groups and then subtracted from one another. The resulting pictures, then, cannot be applied for diagnosis of specific individuals. And finally, variability in brain anatomy between all individuals must be normalised when analysing data. In addition, for correct interpretation of the data important features need to be extracted from the image, whether it is

blood flow, tumour size, cortical activity, or the identification of artefacts, and many qualifications, caveats and assumptions must be made (Feigenson, 2006).

There have been other critiques of fMRI. For example, Sociologists Beaulieu has written about issues related to the discrepancy between scientist and lay descriptions of fMRI imaging. Beaulieu highlights that neuroscience researchers use very scientific narratives to describe fMRI as “*serious quantitative systems neuroscience*” (page 76; interview excerpt of trained researcher) whereas it is the pictorial aspects of these representations that predominate in the public’s understanding (Beaulieu, 2002). A comment by a trained physician, reported by Beaulieu, clearly explains this:³³

To the uninitiated, they will see a picture as an activity in the brain and at some level they will see that as the activity and they will forget that it has to be taken into account that that is not the activity, that is a colored representation of a set of statistical values. And those values have been smoothed spatially, and in time, in the case of fMRI. They’ve been warped. They’ve been realigned. They’ve been through all kinds of crunch, and in setting out to simplify, the picture can to some extent deceive (page 75)

One of the consequences of this, Beaulieu argues, is that it allows neuroscientists to have it both ways: to make claims with scientific integrity while providing visually exciting materials for the public to understand intuitively - and because of this understanding gather further support for research (Beaulieu, 2002). Dumit also finds a vast disconnect between the researchers’ nuanced interpretations and the public perception of neuroimages in his book *Picturing Personhood*. Here he un-packs and analyses PET and the production of PET images: “*PET images can sometimes become the central argument, with the text as supplement. In the popular arena, in magazines, newspapers and on television, PET images become the principle message*” (Dumit, 2004: 143). Dumit also notes:

PET images appear as computer-generated, technologically objective scans of particular brains at particular moments. In popular arenas, these brain images are highlighted in frames with very simple, often one-word labels that emphasize differences between the subjects rather than qualify them...having looked at many articles in Newsweek and other mass-media magazines, I had decided that the articles were written precisely to capitalize on the potent transparency and familiarity of these images of difference (Dumit, 2004: 139)

³³ The pictures in brain images are representations of numerical values and it is these numerical values that the researchers are more interested in

2.5 fMRI, severely brain-injured patients, and debates about ethical issues

Since the 2006 publication of Owen and colleagues' research a plethora of academic papers have sought to question, discuss and critique this technology. Some of this literature has contested the claims made by Owen and colleagues about their findings - with challenges ranging from debates about statistical interpretation (Goldfine et al., 2013) to questions about the evidence that the patients in whom Owen and colleagues have discovered consciousness were always really 'vegetative' rather than clearly MCS if good bedside diagnostic techniques had been pursued (Turner-Stokes et al., 2012). Other literature has focused more on the various ethical, social and legal issues that this technology potentially raises.

Specific comment at the time of publication of Owen and colleagues' work included an accompanying perspective by neuroscientist Naccache in 2006 and an editorial by neurologist Ropper in 2010. These papers pointed to some of the limitations of the research and raised some concerns. For instance, Naccache argued: "*we should not generalize from this single patient, who suffered relatively few cerebral lesions, to most other vegetative state patients, who typically have massive structural brain lesions*" (Naccache, 2006: 1395). Ropper discussed similar limitations, though disagreed with Naccache on the point of the level of awareness of the patients. Rather than asserting that the patient possessed a "*rich mental life*" (Naccache, 2006: 1395), Ropper argued that we cannot be certain whether this activation correlates to a conscious "*sentient, much less a competent, person*" (Ropper, 2010: 649). This point was echoed in a Hastings Center Report by Bioethicists Fins and Schiff who argued that the:

Assertion in the accompanying Science commentary by Lionel Naccache that 'the fMRI findings indicate that the existence of a rich mental life' - is simply unjustifiable. The data do not show this. She may possess a rich mental life, but the more likely scenario is that, like many patients in MCS, this woman can follow commands yet remains unable to communicate and carry out goal-directed and intentional behaviors because of generalized cognitive impairment (Fins & Schiff, 2006: 8)

Ropper also pointed the relevance of this technology to end-of-life decisions: "*the first and obvious use of mental signaling by means of functional MRI could be to preserve the patient's autonomy by querying his or*

her wishes regarding continued medical care” (Ropper, 2010: 649). Again, Fins and Schiff have questioned these conclusions (Fins & Schiff, 2006):

Entertaining the possibility of a vegetative patient’s rich mental life is especially alarming when one considers famous right-to-die cases featuring patients in that state (...Schiavo). But the alarm depends partly on a false dichotomy: it is not true that the patient is either in an immutable state of permanent unconsciousness or has a heartwrenchingly normal inner life. In fact, what we must confront is a scale of important gradations - most of which are yet to be discovered and described (page 8)

Beyond these articles, there has been a steady stream of papers - predominantly appearing post-2008 – which have continued to discuss many of the raised by Naccache, Ropper, and Fins and Schiff, as well as other issues. The four most notable sets of papers were published in 2008 and 2013. The first of these appeared in the *American Journal of Bioethics* (volume 8 (9)) in 2008. A target³⁴ article by Fins and colleagues entitled *Neuroimaging and disorders of consciousness: envisioning an ethical research agenda* (Fins et al., 2008) explored an ethical framework for this technology, discussing issues related to patient selection and study design; standardization of the technology; and consideration of informed consent and justice in research. Concluding, Fins and colleagues called for specialised education; guidance for resource allocation; and cost-benefit analyses of the use of neuroimaging studies. Whilst Fins and colleagues’ article raised a number of practical, social and ethical concerns regarding the use of the technology – some of which have also been discussed elsewhere (Illes & Stables, 2012) - the 12 responses to this article in the form of open peer commentaries typical of this journal focused almost exclusively on the concept of consciousness – what is consciousness?; how do we define it?; what is the difference between the absence of consciousness and its minimal presence?; and, importantly, can consciousness be scientifically quantified through the use of neuroimaging techniques – with authors providing a range of varying opinions and viewpoints (Chien-Chang Wu, 2008; Farah, 2008; Levy, 2008; Schwartz & Schwartz, 2008; Wilkinson & Savulescu, 2008). In the wider literature, too, many other scholars have contributed to these more philosophical discussions about what can be extrapolated from the blood flow activity measured via fMRI to consciousness (Fins et al., 2008; Fisher & Appelbaum, 2010; Terwort, 2011; Friedrich, 2013).

³⁴ Prior to publication, this journal invites scholars to comment on target articles in the form of open peer commentaries.

The second set of papers appeared in a 2013 special issue of *Neuroethics*, which focused on the VS. Two of these papers specifically highlighted issues related to fMRI and end-of-life decision-making (Friedrich, 2013; Rodrigue et al., 2013). This is unsurprising since neuroimaging has presented us with a far more complicated and nuanced picture of brain injury suggesting that, whilst it was initially presumed that severe brain injury was permanent, we now know that prognostic outcomes are variable, and it is increasingly inappropriate to view brain injured patients as untreatable. This has upset many of the presumptions that gave rise to the right to die movement that emerged in response to the Quinlan, Schiavo and Bland cases (Fins, 2008), and has also sparked fresh questions regarding whether this technology could be used as a tool for end-of-life decision-making. In one recent UK court case, the official solicitor objected to the withdrawal of treatment from a patient on the grounds that fMRI might reveal covert consciousness (the objection was eventually withdrawn) (Skene et al., 2009) demonstrating how quickly the use of this technology has filtered its way into the courtroom. A similar court case occurred in Canada (Savulescu, 2012).

In their editorial at the beginning of this *Neuroethics* issue, bioethicists Jox and Kuehlmeier bring the relationship between this new technology and questions about end-of-life decision-making to the fore: *“Although many of these neuroscientific results have not been rigorously confirmed, it has already been discussed what they mean for the ethical evaluation of the patient’s condition and how they should influence the clinical decision concerning whether to keep patients alive or not”* (Jox & Kuehlmeier, 2013: 2). In fact, debates discussing end-of-life decision-making have come to predominate much of the ethical literature exploring the use of fMRI for severely brain-injured patients. Fisher and Appelbaum, Sinnott-Armstrong and Schwarzbauer and Schafer have all questioned the potential use of fMRI as a tool in asking those unable to overtly communicate, whether they wish to live or die (Fisher & Appelbaum, 2010; Schwarzbauer & Schafer, 2011; Sinnott-Armstrong, 2011) and the literature ranges from just raising/mentioning the issue, to detailed discussions (Bernat, 2010; Fins, 2010), and has been approached from a legal angle (Eisenberg, 2008; Bressman & Reidler, 2010; Fisher & Appelbaum, 2010); from a philosophical perspective (Friedrich, 2013); and also as a cautionary note. In this latter instance, several scholars have warned that fMRI is still investigational, results are preliminary, and findings may still not be able to predict meaningful recovery (Wilkinson et al., 2009) or allow for communication about end-of-life decisions (Fins & Schiff, 2010; Jox et al., 2012). In particular, Fins and Schiff argue *“the likelihood is that the answers we seek will be vague, misleading, or simply unobtainable, despite all the technology”* (Fins & Schiff, 2010: 23) and Jox and colleagues point out that patients displaying brain

activity “*probably do not possess the legal capacity to fully consent to or refuse life-sustaining treatment because of remaining cognitive deficits and the limits and uncertainties of this communication technique*” (Jox et al., 2012: 734). Such concerns have led Fins and Schiff to declare that “*despite neuroimaging’s investigative promise, like most technologies, we also need to determine when it need not be used*” (my emphasis) (Fins & Schiff, 2010: 23).

The third set of papers appeared in the *American Journal of Bioethics Neuroscience* in 2013. In her target article bioethicist Bendsten argues that, at a minimum, “*there is an ethical obligation to use [fMRI, EEG or other similar technologies] to diagnose more accurately the patient...*”. At a maximum, she says, there is an ethical obligation to investigate further for the possibility of communication (Bendsten, 2013: 50). In this way we can detect those MCS patients who have decision-making capacity, and with these patients we should consider requiring informed consent or assent regarding future treatment (Bendsten, 2013). Ethicist Brukamp has argued a similar point elsewhere, that in the developed world there is an “*obligation to perform fMRI on each patient with a chronic disorder of consciousness*” (Brukamp, 2013: 5) and that “*functional brain imaging should therefore be developed further and then utilized more widely for examining chronic disorders of consciousness*” (Brukamp, 2013: 6).

Responding to Bendsten’s article, many scholars questioned the inherent challenges and complexities involved in assessing decision-making capacity for these patients, pointing out – as has been done before (Fins & Schiff, 2010; Jox et al., 2012) - that the ability to respond to commands does not necessarily equate to full consciousness, and most certainly cannot equate for decision-making capacity (Dirksen & Brown-Saltzman, 2013; Johnson et al., 2013; MacKenzie, 2013; Rich, 2013). Other scholars pointed to the limitations of the technology. Peterson and colleagues (with co-author Dr Owen) discussed how patients needed, but sometimes struggled, to stay still in the scanner; patients produced inconsistent results; and patients were affected by mental exhaustion during the scanning (Peterson et al., 2013b). And Lee and Illes highlighted how “*the information gained from images is a far cry from getting the whole story*” (Lee & Illes, 2013: 58) (note my above discussion on the issues related to processing of fMRI images in general). This is a particularly interesting point in light of the fact that on re-analysing Owen and colleagues’ data from one of their later EEG studies (Cruse et al., 2011), Goldfine and colleagues identified a number of statistical errors (Goldfine et al., 2013). Although EEG technology is of course different to fMRI technology, and so the situation is not strictly analogous, this example does go some way to highlight the complexity and challenge with

statistical analysis of data. Whilst, neuroethicist Illes has previously raised questions about fMRI and neuroimaging more generally and so her comments are unsurprising (Illes et al., 2002; Illes & Kirschen, 2003), Owen's comments on this matter have previously been limited, and so are welcomed³⁵. Elsewhere, other limitations of the technology have been discussed. Jox and colleagues have argued that false negatives could lead to loss of hope and despair for family members, whereas false positives could lead to false hope that their relative will improve (Jox et al., 2012). This is especially relevant given the novelty of the technology and the fluctuating states of the patients (Jox et al., 2012).

The final set of papers, which also appeared in the *American Journal of Bioethics – Neuroscience* in 2013, highlights the speed with which the fMRI technology is being driven forward. The target article for this set of papers – written by Owen and colleagues themselves (Peterson et al., 2013a) – took a conceptual approach to argue that fMRI could and should potentially be used as a standard for assessing capacity in patients who have a disorder of consciousness. Raising such a possibility seems to be a giant leap from the present research phase of this technology, and this was evident from the content of the open peer commentaries published in response to the articles – half of which questioned the ability of fMRI to measure capacity as well as questioning the reductionist view of capacity adopted by the target article authors (Gray Hardcastle & Stewart, 2013; Hynds & Dirksen, 2013; Jox, 2013). By drawing upon preliminary analysis, I was also able to contribute to this debate. Specifically, I questioned the imperative under which fMRI is being integrated into the clinical setting (Samuel, 2013).

Separate to the above discussions, there has been some dialogue about social justice concerns. For instance, Professor of Law, Tovino, says that since costly and difficult transportation would be required to gain access to a machine and specialised personnel (Tovino, 2008) it is necessary to take this into account and reflect on who would pay for this – perhaps, she says, funding bodies if there is an interest in translational research; investors if there is potential to profiteer; or

³⁵ Preceding these articles he had noted only briefly in an editorial in *Future Neurology* that “*the method will not be applicable to all vegetative patients*” (Owen, A.M. (2006), 'When thoughts become actions: functional neuroimaging in the vegetative state', *Future Neurology*, 1, 6, 693-695., page 694). Many patients will have a poor prognosis and in many cases, he states “*standard clinical techniques, including structural MRI may be sufficient to rule out any potential for normal activation, without the need for fMRI*” (page 694). Besides this, he has stated only that “*it is important to emphasize that negative findings in patients who are diagnosed as vegetative cannot be used as evidence for lack of awareness*”. This is because a patient may fall asleep during the scan or may have not properly heard or understood the instructions (Owen, A.M. (2006), 'When thoughts become actions: functional neuroimaging in the vegetative state', *Future Neurology*, 1, 6, 693-695., page 695).

healthcare if there is proven clinical utility. Not all scholars agree with Tovino, Brukamp, for example, dismisses the cost of this technology as relevant, arguing that the importance of a proper diagnosis ethically trumps such concerns (Brukamp, 2013). There has also been some speculative, but very limited, mention about how the use of this technology may affect families (Fins et al., 2008; Bernat, 2010; Tarquini et al., 2012); and in the final paragraph of their paper on end-of-life decision-making, Bressman and Reidler question:

Will the fact that some PVS [persistent VS] or MCS patients may be more aware...inspire more hope for recovery in family members and push them away from withdrawing treatment? Or will the knowledge that a loved one may be somewhat aware of and suffering through such horrible circumstances push them to opposite conclusions? (Bressman & Reidler, 2010: 716)

Jox and colleagues have also written at length about the effect that unrealistic expectations of this technology may have on families (Jox et al., 2012). More detailed accounts of the family experience have been provided by Ethicist Lanoix who, quoting Martone, stated that both Martone and her daughter “*were caught up in a process that dispensed therapy not according to patient's needs but according to an institutional structure*” (Martone, 2001) in (Lanoix, 2008: 36). Lanoix is concerned that “*for Fins...neuroimaging is a way of informing families about the state of their loved ones....my worry...is that neuroimaging will become yet another institutional barrier that families have to navigate*” (Lanoix, 2008: 36).³⁶

Finally, a number of scholars are concerned about the news media’s reporting of fMRI for severely brain-injured patients. In response to a study carried out by Rodriguez-Moreno, which used neuroimaging to show activity of the language network in some patients with a disorder of consciousness (Rodriguez Moreno et al. 2011), Clinician Goldman argued that such studies can lead to speculative interpretations regarding the number of patients with a disorder of consciousness that may show similar activity. The method, he points out, will not be applicable to all patients, and we must remember that selection criteria for such studies may be strict, based on those individuals the researchers feel are most likely to show activation, and thus benefit from the research (Goldman, 2010). These echo concerns by Schlaepfer, who argued, albeit in relation to DBS, that selective reporting of studies can give a misconstrued impression of the technology

³⁶ For a more in-depth account of the burdens faced by families when caring for VS and MCS patients see Giovannetti, A.M., Leonardi, M., Pagani, M. et al. (2013), ‘Burden of caregivers of patients in vegetative state and minimally conscious state’, *Acta Neurologica Scandinavica*, 127, 1, 10-18.

(Schlaepfer & Fins, 2010). Indeed, selective reporting can lead to a confused public argue Racine and Bell. We need to be cautious, say the authors: “*a balanced clinical translation approach needs to incorporate the idea of maximizing the benefits based on the novel insights of research while tackling the existing confusions to prevent harm*” (Racine & Bell, 2008b: 14).

2.6 Conclusion

In conclusion, this chapter has presented a detailed description of the conditions categorised as disorders of consciousness; an account of how fMRI technology works; and has explained how neuroimaging techniques, such as fMRI are being increasingly used in an attempt to diagnose and communicate with patients who have a disorder of consciousness. It has also discussed some of the concerns that have been raised about the use of this technique, as they are described in the academic literature, particularly in the field of bioethics. The most prominent of these concerns are related to consciousness and what this means in terms of the fMRI results, as well as dialogue (for and against) the use of fMRI as a tool for medical and/or end-of-life decision-making. To some degree, scholars have also pointed to the limitations of the technology and raised concerns related to the access and cost of using the technology. There has been speculative discussion about how this technology may affect families, but there is no empirical evidence for this. My thesis aims to bridge this gap. In addition, via my comparison of the content of the work highlighted above with my empirical data I hope to identify which, if any, issues and concerns documented in the academic literature appear/do not appear in the press releases and/or the newspaper articles reporting on these studies, and/or factor/do not factor into family members’ concerns about the technology.

Chapter 3: Science, hype and the news media

3.1 Introduction

In this chapter I provide a discussion of some of the literature that has previously explored the relationship between science, the media, and the public, particularly focusing on research relating to the news media's portrayal of innovative medical/biotechnologies. The relationship between science and the media³⁷ has been intensively examined within the social science community. These researchers, including those interested in media studies, science communication studies, the sociology of expectations, and medical sociology, have explored this association from diverse scholarly and policy-related viewpoints. Such analyses have included a number of broad approaches. First, theorists have been interested in broad questions concerning the interaction between science and the media and potential changes over time. Second, science communication scholars have been interested in how the news media can be used to educate the public about science. And third, scholars from media studies, the sociology of expectations, and medical sociology have been interested in how news about science is produced, how it is represented, and/or how lay communities interpret this news and in turn with what consequences? This is by no means an exhaustive list, but gives some idea of how diversified this field of study has become. This chapter draws on literature from these approaches as they relate to my research questions. I begin by highlighting the important role the news media has to play in the reporting of science and health issues to the public, as well as discussing research exploring the scope of this influence. Next I introduce literature exploring how the news reports science and innovative medical technologies, and some of the issues this raises. I also provide an overview of some of the factors that contribute to such reporting, including a brief discussion of journalist and newsroom pressures, as well as a discussion about the increasing role that scientists and science institutions now play in news media reporting. Several concepts have been proposed to provide a framework for some of the research in this arena – the most prominent of which is the sociology of expectations – and these will also be discussed.

³⁷ The media includes many forms, including the news media (newspapers, broadcast and radio); magazines, films, books and online information.

3.2 Audiences and the news media

Much of the research that examines the relationship between science and the news media relies on the underlying premise that the news media is a primary conduit through which the public - including policymakers and scientists outside of their field of specialty - is educated about scientific advances (Nelkin, 1995; Rogers, 1999; Weimann & Lev, 2006). In fact, recent research has shown that the UK public gets most of their information about science from the news media including daily newspapers (Department for Business, 2011).

There is overwhelming evidence to also show that the news media can shape beliefs, attitudes and perceived norms about science and health; have dramatic influences on behaviours; and can even affect science policy and research strategies (Miller et al., 1998; Nisbet, 2004). For instance, the news media may impact on health decisions; identity and experience of illness, i.e., what it means to have an illness; attitudes towards others, for example, stigma; the image of health professionals; and policy decisions (Kitzinger, 2011). One of the most widely cited examples of news media influence on health decisions is the measles mumps and rubella vaccine (MMR) controversy - though the media attention surrounding the bovine spongiform encephalopathy (BSE) and genetically modified (GM) crops controversies offer equally impressive examples. Briefly, the MMR controversy commenced in 1998 following the widespread news media coverage of a paper by Wakefield and colleagues which reported a study of twelve children whose onset of bowel symptoms along with autism or other disorders followed soon after an MMR vaccination (Wakefield et al., 1998). The research was declared fraudulent in 2011 by the British Medical Journal (Godlee et al., 2011). In spite of this, the inoculation rate for MMR in the UK dropped from 92 per cent prior to publication to below 80 per cent, and there has been a subsequent rise in measles cases (Thomas, 2010). Most recently, in 2013 there was a large outbreak of the measles virus in Wales.

The influence of specific media coverage on public attitudes is not, however, all powerful, and earlier conceptions of the notion that audiences are passive recipients of information have long been dismissed (Hall, 1973; Morley, 1980). Audience readings of various topics have been shown to be diverse, involving resistance as well as alignment with dominant ideas. Moreover, audience experiences have been argued to be fragmentary - as we go about our lives we may at one point in the day hear a report about a health scare on a radio programme, then read about a health policy in the newspaper, then spend the evening channel hopping on the television, seeing a

documentary where a medical breakthrough is described, finishing with reading a magazine where readers' letters about health issues are answered (Livingstone, 1996; Seale, 1999). Alongside this, in terms of science reporting, scholars have shown how individuals are drawn to news sources that confirm and reinforce their pre-existing beliefs³⁸, and in addition, that individuals rely heavily on values, emotions and the framing of science to make sense of science-related issues by taking 'mental shortcuts' rather than paying close attention to news coverage (for a review see (Nisbet, 2009)). McQuail, the mass communication theorist, proposes that the process of learning through the media is thus a process which is often incidental, unplanned and unconscious for the receiver (McQuail, 1979). Audiences are thus now considered 'active' such that interpretation of information depends on the social context in which media messages are received (Nelkin & Lindee, 1995). This may include the readers' personal experience or prior knowledge, and the cumulative influence of previous media reports, popular representations, and other sources of information about science and medicine. Moreover, a number of empirical studies have identified that under certain circumstances audiences may subvert or even re-appropriate media messages in line with existing socio-cultural beliefs (Katz & Liebes, 1985; Shively, 1992).

Exploring the influence of the news media is pragmatically complicated and the extent of 'activeness' of the public is still unclear - though there is currently a lively domain of media reception research, which explores audiences' perceptions and interpretations relating to this audience reception theory (Bush et al., 2001; Heinrichs & Peters, 2004). This research has explored how news media texts work in practice, for example, journalists' use of the term 'body fluids' when describing the transmission of the HIV virus led to respondents thinking it could be transmitted through saliva (Miller et al., 1998). Other scholars have identified which parts of a media text 'work' i.e., shape beliefs; explored diverse audience responses; and identified interactions between meaning (made from text) and social context (how it is engaged with) (Kitzinger, 2011). To give an example related to innovative health technology research, Peddie and colleagues conducted interviews with the general public, and with individuals living with Parkinson's disease, diabetes mellitus or infertility, about embryonic stem cell research and showed that respondents' perceptions about the likely benefits of this technology varied. Moreover, while respondents believed they were not taken in by exaggerated media claims, the authors argued that respondents differed in their susceptibility to media hype (Peddie et al., 2009). In another example, in his exploration of the news media and cloning, Holliman argued

³⁸ Also see work on uses and gratifications in media research, for example, Katz, E., Blumler, J.G. and Gurevitch, M. (1973-1974), 'Uses and Gratifications Research', *The Public Opinion Quarterly*, 37, 4, 509-523.

that the public will choose to interpret and contextualise science on the basis of a number of factors, including their social context, alternative sources of information, education, and pre-existing attitudes, beliefs and experiences (Holliman, 2004).

Whilst empirical research exploring audience reception is increasing, there have been several critiques of audience reception type studies. Livingstone discusses some of these, which include the extent to which audiences are free to interpret texts in different ways; the loss of the importance of the power of texts to determine readings; and whether diversity in readings makes a real difference (Livingstone, 1998). Moreover, Livingstone questions what audience reception work can really tell us past the understanding that audiences' interpretations are influenced by their past experiences and social context. She argues that what is lacking is a clear analytical framework for audience research. The problem for audience research, she says: "*is to determine their significance - which differences reflect idiosyncratic factors and which merit resistant, how far do actual viewing practices undermine the textual and generic structuring of explanation?*" (Livingstone, 1998: 244). She points out that many of the key theoretical issues facing audience research concern the scale of the differences:

Are audiences increasingly fragmented or homogeneous, are readings primarily normative or readings? Clearly it becomes important to relocate these findings of difference within a broader theoretical context (page 244)

3.3 Sensationalist reporting of science/health research

Ransohoff states that sensationalist reporting of science/health research occurs when extravagant claims or interpretations about research findings are made (Ransohoff & Ransohoff, 2001).

Nelkin has argued that "*whilst most journalists try to avoid sensationalist and titillating style, they do tend to magnify events and to overestimate if not sensationalise their significance*" (Nelkin, 1995: 112). For instance, in the reporting of the 'gay gene' in 1993 headlines included: '*It's in the genes – how homosexuals are born to be different*' and '*Proof of a poof*' (Kitzinger, 2005). Virginia Bolton, a consultant embryologist, discusses a more recent – and possibly well known - example in which the publication of the Nuffield council on Bioethics report supporting further research into a technique to prevent the inheritance of mitochondria disease prompted a flurry of publicity with nearly all newspapers using the sensationalist angle 'three parent IVF [in vitro fertilisation]' tag in their headline (Bolton, 2012).

Sensationalism is a relatively broad term and can encompass exaggerated science/health research reporting of both positive and more critical stories. Positive sensationalist i.e., overly optimistic reporting, is particularly evident in the reporting of many innovative medical technologies (though by no means all – for example, consider debates surrounding GM crops and stem cell research). For instance, as mentioned in my introduction chapter, in his analysis of print media Racine showed that portrayals of neurotechnologies are generally optimistic (Racine et al., 2007b; Racine et al., 2010). Mulkay's work on embryos as well as Conrad's work on genetics and genetic technologies also suggest that the news media portrays these technologies optimistically (Mulkay, 1994; Conrad, 2001). Indeed, Conrad argued that reporting on genetics and mental illness has been dominated by a 'genetic optimism frame' (Conrad, 2001). Several other commentators have also observed that the news media frequently overstates the significance of genetic findings (Hubbard & Wald, 1993; Nelkin & Lindee, 1995). For example, in their exploration of news reporting of genetics, Bubela and Caulfield have shown that there is an overemphasis on benefits and under-representation of risks in both scientific and newspaper articles (Bubela & Caulfield, 2004). In another study Caulfield and Bubela showed that nearly two thirds of headlines reporting genetic discoveries had no exaggerated claims - or to look at it another way, a third of headlines were exaggerated (Caulfield & Bubela, 2004).

Seale has offered an insightful analysis of the news media's reporting of health research. He argues that in order to keep audiences entertained, health reporting typically creates and then exploits extreme oppositions (Seale, 2003). A new drug, for example, is either a miracle cure, or a potential Frankenstein's monster. In another example, plant biotechnology can be understood as both a potential antidote for world hunger or as tampering with God's creation (Durant et al., 1998). This tendency to polarize science has also been reported by others. For example, when talking about genetics in the media Nelkin says that it can be "*the medical story of the century*", for it will "*unlock the secrets of life*". But "*Lurking behind every genetic dream come true is a possible Brave New World nightmare...who should play God with man's genes*" (Nelkin, 1996: 1602). But Seale classifies this polarization – or these oppositions further. He argues for five core oppositions: stories that generate fear, for example the BSE food scare; stories that generate fear, but the threat is a person/people, for example, the media's depiction of HIV carriers in the early stages of the emergence of this virus; stories that depict victims, who are typically vulnerable, for example, a sick child; stories of lay heroes; and finally, stories of professional heroes. The lay hero stories, argues Seale, often contain a significant anti-medical component, in which orthodox medicine,

including biotechnologies, are cast as unhelpful or flawed. In sharp contrast, the professional hero can portray scientists and/or technologies as magicians who have the ability to ‘save’ serious disease (Seale, 2003). This latter depiction resonates most strongly with the news reporting of many innovative neurotechnologies.

Alongside Seale’s analysis of health reporting, the reporting of science has also been considered in the context of framing. Scholars examining science reporting via framing analysis argue that science research is presented – or framed – to the public in a specific way. And the way in which a specific science topic is framed can have an influence on public opinion about that topic. Most work under this rubric has been conducted in relation to the reporting of science relevant to science-policy debates and the influence of this on audiences. Nisbet provides a useful and in-depth review of this as well as a discussion of the typology of frames most often used in science-related policy debates (Nisbet, 2009). Examples include ‘social progress’ – a frame that most aligns with the positive sensationalist reporting described earlier in this section; ‘morality/ethics’ – framing science in terms of right and wrong; and ‘conflict/strategy’ – presenting the science as a game among elites, or a battle of personalities to get ahead in science (Nisbet, 2009: 58).

3.3.1 Criticisms of overly optimistic reporting

Many scholars are concerned by the sensationalism seen in much science reporting, especially in the health technology arena (Durant & Hansen, 1995; Caulfield & Bubela, 2004).³⁹ First, some argue that catchy metaphors have a tendency to simplify science (Christidou et al., 2004; Knudsen, 2005), and there are many examples of metaphors portraying science as a series of dramatic events rather than an on-going effort: new drugs are described as ‘magic bullets’ or ‘breakthroughs’; and recent findings are described as ‘revolutionary breakthroughs’ (Nelkin, 1995; Seale, 2003; Cascais, 2005). Nerlich has explored in-depth the use of metaphors in news media reporting of various emerging technologies, including cloning, GM foods and the human genome project (Nerlich et al., 2000; Nerlich et al., 2001; Nerlich et al., 2002) (see section 3.7).

Second, Nelkin and Schäfer have reported that sensationalist reporting can introduce inaccuracies (Nelkin, 1995; Schäfer, 2011) and can “*too often [...] more a subject or consumption than for public scrutiny, more a source of entertainment than of information*” (Nelkin, 1995: 162). Jensen concurs: “*news*

³⁹ Sensationalist reporting can, of course, also have benefits, for example in raising awareness of particular health conditions. In some of my interviews with family members, interviewees spoke about this.

reports of scientific research are rarely hedged[,] do not contain caveats, limitations, or other indicators of scientific uncertainty' (Jensen, 2008: 347). And whilst an independent review which explored the impartiality and accuracy in the BBC's science coverage in 2009-2010 did not find any gross inaccuracies in terms of factual content (Imperial College London, 2011), it did suggest other concerns. For example, only a minority of news items made cautionary comments about scientific claims; only an eighth of broadcast news items and two fifths of online news items included comments from scientists (Imperial College London, 2011).

Third, in terms of medical research/innovative technologies, sensationalist reporting has also been criticized for misleading the public about important issues and leading to false hopes about specific 'medical breakthroughs' (Weimann & Lev, 2006). This is particularly pertinent when the reporting is overly optimistic. Bubela and colleagues argue that omitting timelines may produce an impression in the public's mind that significant therapeutic benefits are imminent since the lay public and experts have very different perceptions of timelines. They state that this is particularly dangerous in regard to stem cell research where people are desperate to gain access to stem cell therapies or 'miracle cures' (Bubela et al., 2009). Petersen has also argued that by framing stories on genetics in terms of hope and promises, and with a limited discussion of limitations and qualifications, the print media may lead people to overlook the importance of changing the economic, political, social, and physical environmental conditions that predispose to disease (Petersen, 2001). And Caulfield and Bubela have argued that repeated exposure of the lay public to sensationalist headlines about genetic discoveries may lead to heightened genetic determinism (Caulfield & Bubela, 2004). Caulfield also argues that a belief in the 'genohype' may lead to several policy challenges. It may be difficult, he says, for biotechnological research to deliver rapid results that live up to the hype, which may lead to the public's faith in biotechnology giving way to the persistent moral concerns surrounding the somewhat controversial technology. In addition, should these high expectations not be met, and the biotechnology hype bubble bursts, investor interest and public support could decline. This, in turn, may tempt those invested in biotechnology to warp their research and funding priorities to focus even more on near-term returns, rather than long-term and ultimately more valuable applications (Caulfield, 2005).

Finally, scholars have reported the use of emotional anchoring - where journalists write with the specific goal of provoking emotions - in science reporting (Höijer, 2010). Such anchoring can be achieved by creating a human-interest angle using individual cases and has the possible

consequence of distorting the broader statistical context of the research findings. Henderson and Kitzinger have discussed this type of ‘soft’ reporting in their work on breast cancer genetics (Henderson & Kitzinger, 1999).

3.4 The newsroom, journalists and science reporting

Whilst scientists and other scholars have accused the news media of sensationalising science/health research, this a simplistic critique of the news media’s reporting of science does not reflect an understanding of the conditions of media production (Seale, 2003; Williams & Clifford, 2009). As Conrad has noted in his discussion of news coverage of genetics, “*what becomes news is not inherent in an event or piece of information, but is defined by interested parties*” (Conrad, 1997: 141). Thus, rather than blaming the news media for such reporting, some media scholars have explored how and why news media is produced as it is. Indeed, Wilkie has previously stated that “*the commercial structure of newspapers is an important background against which to understand the difficulties of science and medical reporting*” (Wilkie, 1996: 1308). In spite of this there has seemed to be a lag in scholarly attention to the views, beliefs, agendas and specific pressures of those who work in the news profession; and the decision-making associated with such roles. Though, there are clearly an increasing number of studies being published (Reed, 2001; Treise & Weigold, 2002; Cooper & Yukimurab, 2002; Geller et al., 2005). This literature, alongside other, older, studies, demonstrates that many journalists frown upon sensationalist health reporting (Cooper & Yukimurab, 2002); believe that reporting should be sober, balanced and focused on the facts (Gunter et al., 1999); and that journalists do try hard to strike a balance in their reporting: “*in journalism the trick is to get as strong as possible a lead and story theme, without going overboard and being absurd so that you destroy yourself*” (Winsten, 1985: 9) - though, how balanced a story is reported depends on the reporter and his/her speciality (Henderson & Kitzinger, 2007; Winsten, 1985). Moreover, Treise and Weigold have reported that many of the science writers they surveyed “*felt that the current formula for successfully communicating science involves hype and publicity that carries with it inherent ethical issues*” (Treise & Weigold, 2002). Against this backdrop, journalists have spoken about the difficulties involved in science and medical reporting, each of which I shall discuss in turn.

First, there very few science and/or medical journalists and, moreover, these journalists are employed to cover broad areas of science - everything from cosmology to genetic engineering (Rose, 2003b; Schäfer, 2011), meaning that they may not always have a full understanding of the

science they are reporting, and may also have increased workloads (Williams & Clifford, 2009). In addition, many *general* reporters, who do not have a clear understanding of science, must cover science, and in fact, the great majority of reporting about science and technology is done by journalists who are non-specialists (Boyce et al., 2007).

Second, the harsh immediacy of daily news media and the continual constraints of tight deadlines (Entwistle, 1995; Winsten, 1985; Reed, 2001; Henderson & Kitzinger, 2007; Williams & Clifford, 2009) factor towards precluding journalists from the careful documentation, nuanced positions, and precautionary qualifications that scientists view as necessary to present their work (Nelkin, 1996; Reed, 2001). Reed reports how one science journalist in her study commented “*cogs and wheels that sort of mesh between media and science are out of synchrony . . . two worlds that operate in slightly different time frames*” (Reed, 2001: 285).

Third, Semir and others have pointed out that science and/or medical journalists have to search for news offering headlines that are interesting not only to the potential reader, but also to their own section colleagues, and even more so to the person in charge of the decision to publish the story and position it in the newspaper i.e., the editor(s) (Winsten, 1985; Entwistle, 1995; de Semir, 1996; Reed, 2001; Henderson & Kitzinger, 2007; Radford, 2009). To convince editors about the newsworthiness of a science story, journalists will have to emphasise the uniqueness of their stories (Nelkin, 1996), and for journalists specializing in science, the relationship between the journalist and the editor, who usually lacks specialist knowledge, can be problematic (Henderson & Kitzinger, 2007). Sensationalist headlines are often chosen by editors to the despair of the journalists. This concern has been raised repeatedly by Fiona Fox, director of the Science Media Centre, and was one of her main driving points to Lord Leveson when she spoke at the Leveson enquiry in 2012 (Fox, 2012).

Finally, there is a lack of reserved news spots, and so science articles must be newsworthy enough to compete with other stories (Winsten, 1985)⁴⁰. Winsten spoke about how one journalist he interviewed commented “*I’m in competition with literally hundreds of stories everyday, political and economic stories of compelling interest*” (Winsten, 1985: 9). Rödder reviews how ‘media logic’ - first reported by Altheide and Snow as a shared preference for a set of news values - amongst them novelty, human interest, timeliness, success and conflict (Altheide & Snow, 1988) – drives what is deemed

⁴⁰ This problem is less of an issue now in the present time due to newspapers publishing online.

newsworthy by science journalists (Rödger, 2011). Entwistle has previously reported similar findings (Entwistle, 1995). Science journalists thus desperately seeking to make their stories newsworthy must act under the principles that established ideas may be old news, and of far less interest than fresh or dramatic, though possibly tentative, research (Nelkin, 1996). In contrast, for scientists, research becomes reliable, and therefore newsworthy, through replication and endorsement by professional colleagues (Nelkin, 1996). The result is a tension between scientists and journalists who “*often differ in their definition of what is newsworthy about science*” (Nelkin, 1996: 1602). Below I discuss this tension in more detail.

3.5 Tensions between scientists and journalists

Some scholars have explored the tensions existing between scientists and journalists to try and deconstruct sensationalist science reporting in more depth (Reed, 2001; Clegg Smith et al., 2010). For example, Nelkin has previously written at length about this. She argues that the most important source of strain between scientists and journalists lies in their different views about the news media’s role in terms of science communication. Scientists, she argues, view the press as a conduit or pipeline, responsible for transmitting science to the public in a way that can be easily understood (Nelkin, 1995; Turney, 1996). Scientists assume, says Nelkin, that the purpose of science journalism is to convey a positive image; they see the media as a means of furthering scientific and medical goals (Nelkin, 1995). Others have written about this more recently (Clegg Smith et al., 2010). For instance, Bubela and colleagues, as well as Rose, have both argued that scientists prefer to be treated as experts and not to be subject to probing. They expect to control the flow of information to the public as they do within their own domain (Nelkin, 1995; Rose, 2003b; Bubela et al., 2009).

Different findings have been reported for science journalists’, who seem to vary more in their perceptions of their role. For example, Winsten’s science journalist interviewees in 1985 characterised journalists’ roles in a variety of ways including ‘translator’, ‘educator’ and ‘reporting the news’ (Winsten, 1985: 7). More recently, some, including Nelkin, report that science journalists are unquestioning and exhibit a rather strong trust in science: “*many journalists are in effect retailing science and technology more than investigating it, identifying with their sources more than challenging them*” (Nelkin, 1995: 64). She also reports that journalists strongly view themselves as explaining science to the audience – a view shared by scientists (Nelkin, 1995; Rose, 2003b). However, some

journalists, says Nelkin in another article, do not see themselves as trumpets for science, and many are beginning to suspect promotional hype (Nelkin, 1996; Wilkie, 1996). Indeed, Schäfer has reviewed research which suggests that rather than scholarly communication and paternalistic public education on behalf of science, science journalists increasingly perceive themselves as engaged in criticism - as watchdogs instead of advocates of science, scrutinizing methods and results (Reed, 2001; Schäfer, 2009). The plurality of these views, suggests Schäfer, may reflect the different specialties of journalism (Schäfer, 2011). There is evidence, for example, that general and specialist reporters have different reporting styles (Henderson & Kitzinger, 2007); that general reporters may be less able to criticise science than specialist reporters (Petersen, 2001), and says Reed, that science journalists appear to be closer to scientists than other journalists in terms of language and the culture of science (Reed, 2001). In fact, some argue that science journalists are *too* close to their sources (Boyce, 2007; Haran et al., 2008).

Beyond the differences highlighted by scholars about the role scientists and journalists each attribute to science reporting, scholars have also pointed to other sources of strain between scientists and journalists (Peters, 1995; Weigold, 2001). Nelkin has argued, for example, that both professions are committed to communicating truth, and that “*the tensions over science reporting have less to do with accuracy than with style*” (Nelkin, 1996: 1601). Readability in the eyes of a journalist may be oversimplification to a scientist (Nelkin, 1996; Reed, 2001; Rödger, 2011). For example, in one study, although journalists felt that reporting in the biotechnology field should be more balanced, the same study found that scientists were more likely than journalists to perceive science reporting as too sensationalist and dramatic (Gunter et al., 1999). This idea – that differences between the professions has more to do with the style and language than accuracy - has been argued more recently by a prominent group of key researchers in the field including Nerlich, Nisbet, Caulfield and Bubela (Bubela et al., 2009). They have also been re-iterated by Reed who, following interviews with scientists, science journalists and news journalists, stated that although science reporting and writing was agreed by all to benefit from more of an emphasis on accuracy, these apparent agreements were nuanced and contained some major tensions and often contradictions (Reed, 2001). However, Ransohoff argues that such an explanation is only a partial picture and that sensationalism may actually be driven by scientists who have their own agenda (Ransohoff & Ransohoff, 2001).⁴¹ Such a point has been re-iterated by many scholars, who argue

⁴¹ Though such agendas are, in themselves problematic. Whilst scientists are increasingly becoming engaged with the media, research suggests that such engagement does not always come without risks for

that sensationalism must be attributed to both the pressures of the newsroom as well as scientists, their employers, and the journals that publish science research. Moreover, it has also been argued that science reporting is influenced more broadly by the public, policymakers, and the like. In this way all of these actors come together to generate a ‘cycle of hype’ (Caulfield, 2005; Lovell-Badge, 2012). Below I discuss literature exploring the role of scientists in news reporting in more depth.

3.6 The rise of science in the news media

Over the last few decades science issues and science research have become progressively more prominent in the news media (Bauer et al., 1995; Nelkin, 1995; Bucchi & Mazzolini, 2003; Boyce et al., 2007). The *Science Times* – the weekly science section of the New York Times – exemplifies this rise in prominence. Clark and Illman showed that during the period from 1980 to 2000 the magazine grew, on average, from 1.7 pages per issue in 1980 to 5.4 pages per issue in 2000. Medicine, health, and behavior received the most attention overall (Clark & Illman, 2006), a trend which has been documented before (Bucchi & Mazzolini, 2003; Boyce et al., 2007) and is reviewed in detail by Rödder (Rödder, 2011). Many factors can be attributed to the rise of science in the news media, and many theories have attempted to encapsulate it, one of which is the medialisisation concept (Weingart, 1998). This concept lies on two key assumptions: an increasing news media attention for scientific issues; and an increasing orientation of science towards the news media. Research relating to this concept, then, systematically analyses and empirically locates such structural change in science (Rödder, 2011). Mediatisation is a similar approach to studying media-related social change and is widely used by media scholars. A prominent difference between the two approaches lies with the fact that mediatisation refers to media effects in general, whereas medialisisation specifically explores the effects of the news media (Rödder, 2011). Below I discuss some of the research these concepts draw upon.

3.6.1 Public understanding of science

In response to decreased public support, understanding, and appreciation for science, in 1985 the Royal Society published a report which showed that while scientific content was important to practically all public issues, the public’s knowledge of science was poor. This poor knowledge was

scientists Porter, J., Williams, C., Wainwright, S. et al. (2012), 'On being a (modern) scientist: risks of public engagement in the interspecies embryo debate', *New Genetics & Society*, 31, 4, 408-423.

thought to be attributable for the decreased support in science. This led to the development of 'Public Understanding of Science' programmes in the UK and other countries, in an effort to promote science (for a review see, for example (Schäfer, 2011)). In these programmes, scientific communication to the public was seen as pivotal, and the roles were clearly defined; the popularization of science was to be achieved, via the news media, by a diffusion of information from science (the sender) to the public (the receiver), and this information was meant to improve the public's deficient scientific literacy – and was thus coined the deficit model.

Whilst the deficit model generated a plethora of science communication with the public, its underlying assumptions were widely and repeatedly criticized, and eventually abandoned (Gregory & Miller, 1998; Schäfer, 2011). First, social science scholars vehemently opposed the view that science was certain knowledge and the only source of expertise. Second, scholars argued that because there are a multitude of publics we must pay close attention to the character and interests of this pluralistic public rather than categorising them as a unified being (Rose, 2003b). Third, in-depth studies have shown that while quantitative surveys typically construct a public that is broadly ignorant, people are resourceful, both at bringing to bear what they already know and at finding out new information (Turney, 1996). And finally, as discussed in section 3.2, research from audience reception studies suggests that people will construct their views about what they hear in the news media by drawing on both other sources of information as well as their social and cultural context, their experiences, and their interests (for example, see (Miller et al., 1998)). The abandonment of the deficit model led to alternative proposals for science communication. One such program – 'public engagement' - argues that knowledge should be produced as the result of public interactions – or engagements – with the public (Grants, 2003; Schäfer, 2009; Rödder, 2011). Through this program, participants have been shown to be more confident and empowered about their ability to participate in science decisions (Nisbet, 2009: 55). Engagement strategies have now been embraced by a variety of institutions, and research suggests that scientists view such strategies as "*a key component of scientific research and innovation*" (Burchell et al., 2009: 6). However, many of the concepts of the deficit model are still very much embedded in our society, and, as other research suggests, are evident in many of the ways scientists and science organizations still interact with the media. For example, Borhelt and others have argued that asymmetrical communication models are still the preferred mode by scientists and of science public relations practice (Borchelt, 2008; Clegg Smith et al., 2010).

3.6.2 Orienting science to the media

The public understanding of science movement is accountable for the orientation of science to the media only in part. Here I mention three additional factors. First, society is changing: scientists are now being held accountable by the public, who no longer recognize and accept the professional elites' privilege of unaccountability (Weingart, 2012). As such, scientists are now expected to take an active role in the diffusion of their research findings and there is evidence that they are typically aware of this expectation and engage with it to varying degrees (Davies, 2008). The communication objectives that drive this push to disseminate new knowledge directly to the public rest partly on the ethical principle that the public has a right to know. This is based around the notion that citizens as taxpayers should have the opportunity to benefit from any knowledge generated from public funds. It also incorporates more diffuse ethical principles of health as a basic human right with health research as one important component (Clegg Smith et al., 2010).

Second, news media attention towards science brought with it a number of news media scandals - well known are the controversies surrounding GM foods, MMR vaccinations and BSE. Such controversies resulted in the publication of the House of Lords Select Committee on Science and Technology's Third Report: Science and Society in 2000. This concluded that more resources need to be dedicated to finding ways "*whereby the scientific community might help non-specialists in the media to cover scientific stories more satisfactorily*" and prompted the establishment of the Science Media Centre, founded to "*help renew public trust in science by working to promote more balanced, accurate and rational coverage of the controversial science stories that now regularly hit the headlines*" (Select Committee on Science and Technology, 2000). In order to improve reporting, researchers are now encouraged to educate news media professionals about the importance of a science and/or medical discovery (Young, 2002).

In response to the above two points, there have been many appeals to scientists to become public communicators by various commissions (e.g., the UK House of Lords); several institutions have introduced guidelines for researchers about how to interact with the media; and hundreds of training workshops have been conducted to prepare scientists for contacts with journalists (Peters et al., 2008). The Wellcome Trust, for instance, now sponsors a *British Science Association Media Fellowship*, whereby researchers can spend 3-8 weeks in the summer in news rooms the BBC, the Guardian, and *Nature*, so that they can "*return to work with media confidence, contacts, and first-class communication skills*" (Looi, 2012). Recent research suggests that scientists now

have a positive view of public engagement (Burchell et al., 2009). And an international mail survey of 1,354 biomedical researchers in five countries - in the US, Japan, Germany, Great Britain, and France - has revealed that interactions with the news media are widespread and largely perceived in a positive light (Peters et al., 2008). However, this relationship between scientists and the public/media is not unproblematic. Several scholars have, for example, pointed to a number of concerns scientists have, or tensions they face, with their public engagement role (Burchell et al., 2009; Clegg Smith et al., 2010; Porter et al., 2012). Further, this research is not in complete agreement with a recent more comprehensive exploration of US and UK scientists' views, which suggests that in spite of favourable personal experiences with journalists, scientists are critical of media coverage generally. Moreover, *"few scientists view their role as an enabler of direct public participation in decision-making through formats such as deliberative meetings, and do not believe there are personal benefits for investing in these activities"* (Besley & Nisbet, 2013: 644).

Finally, as science research funding diminishes, institutions have faced ever rising competition for limited resources. To compete properly and to attract necessary capital from policymakers and investors, scientists and/or their organisations have had to become more media savvy. Ward, for example, talks about how the Royal Society has had to embrace the same modern methods of media relations that other non-science organisations employ (Ward, 2007). He refers to McNair:

Brave is the organisation which ventures into the contemporary political arena without a more or less sophisticated understanding of how the media work and the professional public relations machinery capable of putting that knowledge to good use (McNair, 2011: xiv)

Moreover, as public funds dwindle commercial companies are playing an increasing part in science research (Nelkin, 1996; Wilkie, 1996). There is evidence suggesting that not only is there a growing proportion of authors on scientific papers who are employees of commercial companies, but many researchers are now company directors of new biotech start-up companies (Rose, 2003b) – and as Rose points out, publicity affects share prices (Rose, 2003b)!

All the above factors have prompted scientists and their institutions to play more of a role in the reporting of science/health research to the news media. Much of the promotion of science to the news media has relied on the role played by science press officers and science press releases. It is the literature discussing this phenomenon to which I now turn.

3.7 Scientists, press releases and sensationalist news reporting

Press releases have become increasingly important in science communication as researchers depend on public visibility to ensure funding and journals compete for circulation (Rose, 2003b). Press releases now play a key role in influencing the selection of science for journalists' reporting (de Semir et al., 1998; Stryker, 2002). Bartlett, for example, showed that nearly half the articles in the *Lancet* and *BMJ* had an associated press release, and seven per cent of these articles appeared in at least *The Times* or the *Sun*. Selection of science news thus happened at both a press release and a newspaper level (Bartlett et al., 2002). In addition, in a review of the BBC's science research coverage, three quarters of the BBC broadcast news items concerned stories where the source institution issued a press release (Imperial College London, 2011). One of the researchers on this study stated that there was a lack of questioning claims about science: "*where there is an alternative voice it tends to come from someone challenging the broad values surrounding the field, rather than exploring elements of the study*". This, she says, is tied in with press release culture – journalists are largely dependent on press releases (Imperial College London, 2011).

Moreover, there is a fast growing body of evidence which points much of the news media's sensationalist reporting to the scientists and/or the press releases which are disseminated on their/their employers behalf (Rose, 2003b; Kjaergaard, 2011; Thornton, 2012). Woloshin has shown how press releases frequently promote preliminary research (Woloshin et al., 2009) and that they do not routinely highlight study limitations or the role of industry funding; and that data are often presented using formats that may exaggerate the perceived importance of findings (Woloshin & Schwartz, 2002). Kuriya and colleagues showed similar results in their analysis on the quality of pharmaceutical industry press releases (Kuriya et al., 2008). In one example, the headlines discussed above in relation to gay genes – '*It's in the genes – how homosexuals are born to be different*' and '*Proof of a poof*' – stemmed from not only the press releases disseminated by *Science*, but from the author himself (Kitzinger, 2005). In another study, Racine showed that in Quebec, articles reporting genomics research signed by press agencies were *more* optimistic and less often featured ethical issues than those of journalists (Racine et al., 2006b). Other reports include Bechman and colleagues' exploration of cancer-genetics reporting, including interviews with science press officers, which identified the press release as a source of distortion in the dissemination of science to the lay public (Bechman et al., 2009); and Clegg Smith and colleagues case study exploration of the media production of cancer reporting via interviews with science press officers, scientists and journalists (Clegg Smith et al., 2010).

The interaction of some scientists and/or their institutions and the media has moved far away (if it was ever there) from a passive interaction whereby scientists disseminate their research to journalists hoping it will be written about (Smart, 2003). There are at least a proportion of scientists who are now very proactive about promoting their work.⁴² Nerlich, for example, has explored the affect of a media event staged by two scientists during the human cloning debates in 2001 (Nerlich & Clarke, 2003). Moreover, many science institutions are now proactive about science communication and have devoted more personnel and resources to press releases, professionalized their communication, and have incredibly active public relations departments (Peters et al., 2008; Clegg Smith et al., 2010).

Large-scale, costly 'big science' stories are prime examples of the way in which scientists, policymakers, science press officers and other science communicators have pro-actively promoted science. Williams and Gajevic, for example, have shown how science journalists, key news sources and press officers were involved in a highly organised public relations coalition during the hybrid embryo debate (Williams & Gajevic, 2013). The Human Genome Project also devoted considerable resources to media communication, due in large to the fact that they were operating in a sometimes skeptical social environment (Schäfer, 2011) and detailed work has been conducted on the rhetorical strategies employed by policymakers and scientists (Nerlich et al., 2002; Henderson & Kitzinger, 2007). Scientists consciously engaged in what they themselves deemed lobbying and readily adapted to media demands (Rödder & Schäfer, 2010). They adopted rhetorical strategies that seemed suitable for the news media, and relied on celebrity scientists, exploiting news media interest to augment and sustain public and private support for their field (Rödder, 2009). Moreover, in their media relations, genome researchers pointed out the medical applications and societal benefits of their research, even though these were still uncertain and far in the future. They also engaged in 'symbolic research' by staging media events for public relations purposes at scientifically arbitrary times, for example, when an unfinished version of the genome sequence was presented in June 2000 (Henderson & Kitzinger, 2007). In this instance, to facilitate reporting of the working draft, the press office team from the Wellcome Trust liaised with the Sanger Centre press office to co-produce a comprehensive and detailed press pack for journalists (Henderson & Kitzinger, 2007). Moreover, metaphor and discourse analysis of the original speeches, the press releases and the British press coverage of a White House press conference on the human genome sequencing traced the origin of most of the metaphors and

⁴² See footnote 33.

hyperboles used in the media to scientists' and politicians' attempts to steer the discourse towards public euphoria (Nerlich et al., 2002). For example, Clinton's comparison of the Human Genome Project to a 'map of unknown lands' was adopted by Wellcome Trust press representatives (Nerlich et al., 2002). These representatives also used the 'book' metaphor: "*the first draft of the Book of Humankind has been read*" – a title echoed in many headlines suggesting a strong interaction between the journalists' story frames and the resources fed into them by politicians and scientists.

A wider exploration of the use of metaphors in science reporting shows a similar picture. Articles appearing in mass-circulation science journals such as *Nature*, *Science*, *New Scientist*, *Scientific America*, and *Science News*, for example, have been found to draw extensively on popular imagery and metaphors (Petersen, 1999) and Williams and colleagues have explored the mobilization of metaphors during the ethical debates surrounding embryonic stem cell research (Williams et al., 2003). Nerlich has traced the origins of many metaphors and hyperboles used in the media to scientific discourse (Nerlich & Clarke, 2003). Such metaphors offer ways for researchers to articulate a shared understanding of a biological phenomenon. However, once taken out of context and moved into the sphere of popular culture and popular imagination these metaphors intermingle with other popular metaphors and images, including those from fantasy or science fiction, to develop a new life of their own (Petersen, 2001; Nerlich et al., 2002). For example, Petersen argues that the metaphor 'map' (discussed above) has begun to lose its figurative meaning.

It is clear, from the above discussions that we are in an age where media savvy scientists, science public relations, press releases about science, and science press officers themselves all play a role in shaping the nature of science reporting. Unsurprisingly, several social science scholars have been critical about the social and cultural effects of seeking to promote, publicise, and manage discourse about science in the news media. Peters and colleagues, for example, discuss a number of concerns. First, they argue that an increasing focus on visibility rather than content quality in public communication would call into question the classical societal role of science as an advocate of truth and rationality. Second, strategic communication tends to draw a public image of science that is biased towards, for example, its practical usefulness, and may mislead the public about the character of science. Third, an increasingly strategic orientation may, in the long run, lead to a decay of the currently high level of public trust in academic science. And finally, anticipation of media response may influence decisions in the research process and even in the

framing of research results (Peters et al., 2008). Other scholars have also raised concerns. For example, Petersen argues that because journalists derive much of their news from pre-packed sources and staged events managed by scientists or public relations experts, stories contain little critical commentary or contextual information that would assist readers to reach their own evaluation of research and its significance (Petersen, 2001). And finally, Haran is concerned about the pro-science reporting nature of the Science Media Centre, which via its contribution to the setting of media agendas and to the framing of news stories, has the potential to obfuscate the distinctions between science knowledge, scientific practice and science governance (Haran, 2011).

Outside of the academic literature, there has also been criticism. A recent paper in *Research Fortnight* stated that *“the whole point of university research communications is to ensure that a new discovery or novel finding is communicated in the media without being challenged or questioned”* (Research Fortnight, 2011). Fiona Fox, chief executive of the Science Media Centre, quickly responded:

Science press officers like taking questions from science journalists and many university press officers now encourage academics to use blogs, twitter and online comment facilities to encourage challenges, questioning, debate and discussion (Fox, 2011)

She continued: *“To lump all press officers together and label us uniformly ‘part of the problem’ of modern journalism oversimplifies and demonises the role of a large, intelligent and engaged community”* (Fox, 2011).

Research Fortnight is not alone in its less than positive views of science press officers. Russell, for example, discusses the concerns of Petit, who believes that science news is spoon-fed to the news media through press releases, which now have all the features of a full blown story (Russell, 2008). Macilwain, too, is concerned:

Journalism in science...has evolved into an ugly machine - called ‘churnalism’ by media-watcher Nick Davies and others. This machine delivers inexpensive and safe content, masquerading as news, to an increasingly underwhelmed public...the machine prospers because it serves the short-term interests of its participants. Editors get coherent and up-to-date copy. Writers get bylines. Researchers, universities and funding agencies get clips that show that their work has had ‘impact’. And readers get snippets, such as how red or white wine makes you live longer or less long, to chat about at the water-cooler. None of these groups is benefiting strategically from the arrangement. Science is being misrepresented...[.].The public learns nothing about the actual cut

and thrust of the scientific process, and as a result is beginning to adopt a weary cynicism that can only rebound on science in the long run (Macilwain, 2010: 875)

3.8 The cycle of hype and the sociology of expectations

In this final section of the chapter I introduce the concept of the sociology of expectations and explore how this can be used as a framework to examine how and why the news media over-optimistically report some science. Before doing so, and as an introduction to this concept, I wish to briefly point to some work exploring emerging technologies which has been conducted by science and technology studies scholars. This work argues that many actors, including the media, play a fundamental role in shaping beliefs about a technology. Such actors include the producers of the technology, various industries, politicians and so forth (Joyce, 2008). Moreover, more than just shaping beliefs about a technology, these actors help shape the social forces that drive the development and applications of the technology. As Brown and Webster argue (2004), medical innovations are complex, and reflect a wide-range of interests. The technologies are not, then, value-free and neutral. Finally, technologies are not passive. In this sense, whilst they have interpretive flexibility and may be understood differently across different social and cultural backgrounds, the technology itself can be considered as an active agent in that it too can constrain, shape and enable human action (Latour, 1992; Kline & Pinch, 1999). Much of the work undertaken in science and technology studies has sought to identify exactly how particular interests and particular technologies shape the development and application of technology, and how these technologies subsequently reify or disrupt particular norms and institutions (Timmermans & Berg, 2003; Brown & Webster, 2004). The sociology of expectations has contributed to this work, and I now turn to discuss this concept in more detail.

3.8.1 A sociology of Expectations

Brown states that biotechnology is today synonymous with the language and imagery of futuristic breakthroughs. In fact, says Brown, 'breakthrough' is probably the most powerfully future oriented metaphor within the current disclosure repertoire of science and science journalism (Brown, 2000). The whole area, he says, is characterized by heated aspirations, promises, expectations, hopes, desires and imaginings (Brown, 2003). Brown and others argue that future-abstracts and this hype are put into circulation for a reason – they are performative – that is, they mobilize the future into the present, and have an influence in real time (Michael, 2000;

Brown, 2003; Borup et al., 2006): “*the future of science and technology is actively created in the present through contested claims and counterclaims over its potential*” (Brown et al., 2000: 5). Hedgcoe and Martin neatly explain this idea: “*instead of seeing the speculative claimsas ephemeral and irrelevant, ... they are fundamental to the dynamic processes that create new social-technological networks*” (Hedgcoe & Martin, 2003: 328). Geels and Smit continue:

The reason that...expectations are too optimistic is not that forecasters or futurists are ignorant or shortsighted. Instead, the promises are strategic resources in promise-requirement cycles. Initial promises are set high in order to attract attention from (financial) sponsors, to stimulate agenda-setting processes (both technical and political) and to build ‘protected spaces’. Promises thus play a role in the social processes that are part of technological development (Geels & Smit, 2000: 881-882)

To reiterate, the promise will often be exaggerated in order to command sufficient interest to enroll necessary allies and secure investment. And within these communities of promise, a whole network of mutually binding obligations between innovators, investors, consumers, regulators are bound by such expectations (van Lente, 1993). The whole language of novelty, newness and revolutionary potential is actually part and parcel of the discourse surrounding the early or opening moments of resource and agenda building (Brown et al., 2000).

Inevitably, as time passes and circumstances change, unforeseen problems emerge, and early hype gives way to varying levels of disillusionment. When this occurs, such hopeful clusterings or ‘communities of promise’ fall apart and can be seen to migrate to new fields unsullied by hype’s eventual disappointments. Technological change, argues Brown, is therefore a process of constant oscillation between present and future tenses, between present problems and future solutions. Brown therefore argues that scholars who wish to understand the emergence of any new (bio)technology must therefore explore “*how the future is mobilized in real time to marshal resources, coordinate activities and manage uncertainty*” (Brown & Michael, 2003: 4). This, he and others have termed the sociology of expectations. Research under the rubric of this concept thus includes analysing the social interactions of various actors - researchers, commercial firms, regulatory bodies, ethicists and, of course, the media as they play out to shape the advancement of the technology. It also includes exploring infrastructures, investment and regulation issues as well as examining discursive practices such as metaphors and narratives (Brown et al., 2000; Deuten & Rip, 2000; Wyatt, 2004). Indeed, much of the work outlined in the above sections of this chapter

could be analysed through the lens of the sociology of expectations. A pertinent example is the press release, which Brown argues is the production of research communities seeking to raise the profile of their work as a means of persuading potential patrons of the benefits of investment, or skeptical publics of future benefits. Another example is Rubin's work on the 'therapeutic promise' of human embryonic stem cell research, which he argues played a vital role in shaping and advancing this field of study (Rubin, 2008). Caulfield's thorough examination of the 'genohype' phenomenon provides another example. Here, Caulfield argues that genohype is the product of a cycle of hype fueled by researchers chasing funding, public funding agencies and politicians, and, most importantly, the increasing influence of private sector sponsors seeking to generate enthusiasm and high expectations, as well as significant near-term returns on their investments (Caulfield, 2005). Kitzinger's exploration of how scientists and science communicators worked to restore trust in stem cell science following the Hwang stem cell scandal also acts as a useful case study for the sociology of expectations (Kitzinger, 2008). Scholars have also examined how expectations have shaped the fields of, for example, gene therapy, stem cell therapy and pharmacogenomics (Borup et al., 2006; Brown et al., 2006; Martin, 2001; Hedgecoe & Martin, 2003; Wainwright et al., 2006b). The social patterning of expectations across communities has also been analysed. This patterning has been argued to arise from asymmetries in access to the information on which expectations are based. For example, many of the technical uncertainties of bench and laboratory science are often invisible to the wider public worlds (Brown & Michael, 2003; Hedgecoe & Martin, 2003). Finally, using the case study of the media reports of an impending pandemic of Avian flu, Nerlich and Hall have explored the similarities and differences between the sociology of 'positive' and 'negative' expectations (Nerlich & Halliday, 2007).

Whilst the concept of the sociology of expectations is a valuable framework for exploring the ways in which expectations have social effects, it is important to bear in mind some of the major criticisms that have been raised about this concept. First and foremost, whilst the sociology of expectations is now a popular concept used in much research exploring the development of innovative technologies, many of the ideas contained within the concept are not especially novel, rather, they have been seen before in earlier generations, and also have taken different forms in different disciplines. For example, Nelkin has previously stated that: *"Images of science and technology in the press [...] are often shifting, reflecting current fashions [...]. Today's exaggerated promises – of new fixes, new devices, new cures – become tomorrow's sensationalized problems"* (Nelkin, 1995: 63). And, as I

highlighted above, Macilwain has pointed out that “*the machine prospers because it serves the short-term interests of its participants. Editors get coherent and up-to-date copy. Writers get bylines. Researchers, universities and funding agencies get clips that show that their work has had ‘impact’...*” (Macilwain, 2010: 875).

Second, expectations are not all powerful - they are themselves socially-mediated and some scholars have argued that the affect of promoted expectations will not always be the same, but will vary depending on the social climate in which the expectations are promoted (i.e., expectations attributed to a particular technology may or may not play a role in securing further funding for the technology depending on the social circumstances in which the expectations were promoted) (Wainwright et al., 2008). Third, it is also important to note that the sociology of expectations is limited to an exploration of expectations only, whilst technological innovation is more likely to be shaped by a variety of other factors as well. A focus on expectations may miss these other equally important drivers of technological development. Finally, there has been some critique of the sociology of expectations from scholars exploring sociological approaches to the future. For example, Adam states that the concept: “*Has inevitable problems [as] it must investigate the future from the position of the present with all the dilemmas that arise with inferred or reported ‘unobservable’ futurity*” (Adam, 2005: 7). Along with other concerns, she argues that this concept:

Seems to avoid confrontation with questions about the role of the investigator, [for example] how investigators can disentangle themselves from their own professional expectations, which influence why they do, what they do and how they go about doing it (Adam, 2005: 8)

In spite of these critiques, the concept has its advantages – it has been able to draw a wide variety of research together under one rubric of literary debate, and has allowed for a common ground for discussion of similar ideas.

3.8.2 The rhetoric of hope

Mulkay argues that a rhetoric of hope has become part of the dominant discourse of science (Mulkay, 1993). In this sense, hope is characterized by the view that new and better treatments are imminent, with research and development justified by “*the promise of finding miraculous cures for debilitating illnesses*” (Moreira & Palladino, 2005: 67). There is a growing body of literature exploring this rhetoric of hope (Petersen & Sear, 2011) - also called ‘regimes of hope’ (Moreira & Palladino, 2005) or ‘political economy of hope’ (Delvecchio Good et al., 1990; Brown, 2006) - and social scientists have documented its presence in fields such as cancer treatments

(Delvecchio Good et al., 1990), human embryonic research (Mulkay, 1993), cord blood banking (Martin et al., 2008b) and treatments for Parkinson's disease (Moreira & Palladino, 2005). For example, Delvecchio Good states in relation to her research on cancer care that: *"enthusiasm for medicine's possibilities arises not necessarily from material products with therapeutic efficacy but through the production of ideas, with potential but as-yet-unproven therapeutic efficacy"* (Delvecchio Good, 2007: 274). Brown notes that much of the work exploring the rhetoric of hope aligns with the sociology of expectations (Brown, 2006). In this way the rhetoric of hope is sustained through numerous reiterative practices, involving diverse groups of actors, including biotechnology companies, investors in these companies, policymakers, patient support groups, and charities that focus on specific diseases, who are drawn together in the common cause of keeping all treatment possibilities open. Carlos Novas, for example, has applied the notion of a rhetoric of hope to the kinds of collaborative links that have been established between pharmaceutical companies and patient advocacy organizations (Novas, 2005). Whilst there are clear and evident similarities between the literature exploring the sociology of expectations and that of a political economy of hope, we must be cautious to bear in mind the differences between expectations and hope and be considerate of these. Expectations can be seen as a strong belief that something will happen in the future, whereas hope is more a desire for a certain thing to happen. Expectations and hope are thus two separate entities, each of which can be held without the other. In addition, and importantly, hope is often related to one's own life and attaches to something with personal significance, whereas an expectation can (though, of course does not necessarily) be related to oneself in a more impersonal fashion.

3.9 Conclusion

In this chapter I have provided a review of some of the literature exploring the relationship between science and the news media, focusing on innovative technologies. I discussed how science has frequently been reported as sensationalised in the news media, and discussed some of the concerns scholars have raised about this. I have also explored the role of journalists, scientists, science press officers and science institutions in such sensationalism. Finally, I introduced the concept of the sociology of expectations as a means of helping us understand sensationalist science reporting. Overall, research exploring the agendas and/or perspectives of science press officers and their role in science communication is less researched than other areas, such as the content of science reporting. One strand of this thesis specifically aims to address this

(see chapter six). In the following chapter I describe the methodological approach I took for my thesis, as well as discussing my data collection, data analysis, and ethical considerations.

Chapter 4: Methods

4.1 Introduction

This chapter explores the methodology I used to design my research project and the methods I used to gather and analyse data. To begin with, I provide a brief overview of the methodological and analytical approaches adopted for this thesis. Specifically, in this section I discuss how this qualitative research project draws on elements of grounded theory. I follow this with an in-depth account of my methods, including an extensive discussion of the rationale for research design; the data collection and/or sampling stages; and the process of data analysis. Ethical considerations related to my methods are also discussed.

4.2 Methodological framework

4.2.1 Methodological approach to this thesis

Many social science scholars argue that methodological choices must be based on, and are indeed deeply intertwined with one's ontological and epistemological position. As King and Horrockes argue, *"ontology, epistemology and methodology and methods are all connected and cannot be viewed in isolation"* (King & Horrockes, 2012). To a degree, and in some instances, I believe that this is correct. However, my approach to this thesis is in line with the medical sociologist Seale, who argues that *"researchers can use methodological debates constructively in their research practice without necessarily having to 'solve' paradigmatic [philosophical] disputes"* (Seale, 1999: 3). And that *"research [is] a craft skill, relatively autonomous from the requirement that some people seem to want to impose that it reflects some thoroughly consistent relationship with a philosophical or methodological position"* (Seale, 1999: 17). Thus, although I do not deny the importance of exploring one's own philosophical beliefs about the nature of reality and the construction of knowledge, I reject the notion that such deliberations cannot be separated from the research itself, and in so doing, have chosen a methodology for this thesis separate from any philosophical deliberations and concerns I may have. I must note, however, that whilst taking such a stance, I maintain the importance of understanding such philosophical notions for their valuable use as frameworks for thinking about one's data (and indeed I draw on certain frameworks in the discussion section of this thesis). As Seale states, *"philosophical positions can be understood by social researchers as resources for thinking, rather than taken as problems to be solved before research can proceed"* (Seale, 1999: 25).

4.2.2 Inductive methodological approach

The research questions of this thesis have a descriptive and exploratory orientation and thus necessitate an inductive, qualitative approach. The growth in qualitative research over the last thirty years or so has been substantial (Robson, 1993; Gilbert, 2001; May, 2001) and qualitative research is now so diverse it can be fragmented into a bewildering variety of traditions (Tesch, 1990). This thesis draws on the traditions of one specific inductive qualitative approach - grounded theory. Grounded theory is by far the most widespread and commonly used inductive approach in medical sociology, and indeed the social sciences as a whole, and was pioneered by Glaser and Strauss in 1967 (Glaser & Strauss, 1967).

Glaser & Strauss (1967) developed grounded theory as an alternative to other approaches to sociology at the time which, they argued, were either empirical, but lent themselves towards interpretive bias or “*consisted of lengthy, detailed descriptions which resulted in very small amounts of theory, if any*” (Glaser & Strauss, 1967: 15); or were too disconnected from empirical data entirely. Glaser and Strauss argued that their method addressed these concerns. The method empirically grounded theorizing to data so that abstract conceptualizations could be developed from close analysis of the data. Moreover, it did this, they argued, with scientific rigour - countering as much as possible the interpretive bias they said was often associated with other empirical methods. They accomplished this by the use of a ‘set of procedures’ which would act as “*systematic, yet flexible guidelines for collecting and analyzing qualitative data*” (Charmaz, 2008: 2).

After Glaser and Strauss developed their approach in 1967, they took divergent paths in further developing and evolving the pragmatic use of grounded theory. These two different approaches now represent two different schools of thought about grounded theory and reflect different basic philosophical paradigms. Charmaz’s constructionist approach presents another different, but very popular approach to grounded theory (Charmaz, 2006). In fact, since the initial work in 1967, interest in grounded theory has proliferated so much that it has generated a whole range of perspectives regarding its appropriate application. Kathy Charmaz has noted that “*grounded theory has evolved into a constellation of methods rather than an orthodox unitary approach*” (Charmaz, 2008: 161). The difficulty in establishing a single definition about what constitutes grounded theory is exemplified, says Floersch and colleagues, by the intense debates which still ensue (Floersch et al., 2010). It is not my intention to provide a detailed description of the ongoing discussions about

grounded theory. Rather, the aim of this thesis is to use elements of the methodology of grounded theory as an approach for my research and its analysis. With this intention, it is more important to have a clear understanding of the general principles and framework of the approach, which all grounded theorists agree to adhere to, so as to develop a coherent and rigorous methodological approach which is suitable for my specific research project.

4.2.3 Grounded theory procedures

In quantitative research statistical representativeness is paramount. In contrast, in qualitative research “*selecting informants randomly makes as much sense as seeking information in the library by randomly selecting a book from a randomly selected shelf*” (Morse, 1992: xi-xii). Thus, “*In grounded theory... our concern is with representativeness of concepts*” (Strauss & Corbin, 1990): 190 (my underline) and this is achieved through theoretical sampling. Glaser and Strauss define theoretical sampling as “*the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges*” (Glaser & Strauss, 1967: 45). What this means is that data collection and analysis occur consecutively and inform one and another. Briefly, early on in the study research participants will be selected on the basis of their experiences relevant to the aims of the study. This data will be analysed as it is collected and labels (more commonly called codes or categories) will be assigned to small sections of the text to indicate a conceptual idea. As the study continues, and theory starts to emerge from this coding, individuals are then sampled who have experiences which could extend the theory by revealing new issues or relationships from and/or between the codes. Theoretical sampling, Glaser and Strauss argue, should continue until theoretical saturation is reached. Theoretical saturation, they say, means that “*no additional data are being found whereby a sociologist can develop properties of a category*” (Glaser & Strauss, 1967: 61) i.e., further data collection and analysis “*only adds bulk to the coded data and nothing to the theory*” (Glaser & Strauss, 1967: 111).

Analysis (or coding) of the data in grounded theory is carried out on two levels: overview analysis and line-by-line analysis. First, the interview tapes and transcripts are initially scanned to sensitise the researcher to relevant ideas and themes. This serves to develop ‘theoretical sensitivity’ i.e., an awareness of the theoretical possibilities in the data (Glaser, 1978) and precludes missing alternative conceptualisations which may occur if only intensive analysis of small units of data occurs. And second, microscopic line-by-line coding allows the researcher to develop a detailed and abstract conceptualisation of the data (Strauss, 1987). This detailed coding of conceptual

ideas is carried out via constant comparison. In short, this requires that incidents in the data be first coded into categories. This allows different incidents that have been grouped together by the coding process to be compared. Once, compared, interactions are looked for between categories and their properties. The comparison of codes is constant and rigorous and allows for developing and refining of conceptual categories and their properties as theory is developed.

I agree with Seale who argues that the grounded approach purported by Glaser and Strauss remains a rigorous analytic method, and can still offer much to the contemporary researcher (Seale, 1999). Pragmatically, the integration of data collection and analysis as specified by the grounded approach also has the added benefit of enabling a researcher to avoid feeling overwhelmed by the data, which can often occur when facing a large data set which requires analysis (Strauss, 1987). This point was an important consideration when choosing my methodology for this thesis. However, there have been a number of criticisms of grounded theory (Thomas & James, 2006). I mention two as examples here, which I have considered in my research design. First, Glaser (Glaser, 1978) argues against scholars consulting previous literature prior to fieldwork since in this way researchers are less likely to be misled by prior conceptualisation about a setting, which may, in turn, contaminate an emerging grounded theory. Many have argued against Glaser's approach on the basis that this strategy makes the unrealistic assumption that the researcher approaches his/her work with no preconceived ideas or thoughts (for a discussion see (Field & Morse, 1985)). I agree with these scholars. Before embarking on my data collection for this thesis, I had already conducted previous reviews of relevant literature, and had an understanding about the ways in which the news media typically represented science research. Thus, whilst I tried to remain as objective and rigorous as possible during my analysis, it would be naïve to assume that I was able to completely separate my underlying knowledge and beliefs from my research. And second, one criticism from postmodernism states that grounded theory, which emerged in an era of scientism, is essentially too narrow analytically, resulting in the application of standardised, often mechanistic procedures, which can constrain sociological research (Coffey et al., 1996). I have considered this point when designing my methodology, which does not strictly adhere to grounded theory, but rather uses a modified more relaxed version, and is better termed a 'grounded analysis'. Below I highlight how I conducted my data analysis using a grounded analysis approach.

4.2.4 My approach - grounded analysis

Several scholars have raised concerns that the enthusiasm for grounded theory has at times led to some authors claiming that they have ‘done’ grounded theory when in fact they do not understand clearly what the procedure involves (Bryman, 1988; Silverman, 1998). Melia, for example, makes the point that some studies “*can amount to little more than a nod in the direction of grounded theory*” (Melia, 1996: 376). A common concern here is that such studies are more descriptive in nature, rather than abstract conceptualizations of the data. My methodology, for reasons that I discuss below, adhered to grounded theory procedures only in part, and can therefore only be considered a version of grounded-theory.

First, whilst my methodological approach involved theoretical sampling as much as possible, due to the nature of this research –the research design as well as methodological issues with recruitment, resources and time restrictions (see section 4.3) - I could only sometimes use my data analysis to inform further sampling. For example, during my newspaper analysis (see section 4.3.1) theoretical sampling was not applied. Interviewing family members who have (had) a severely brain-injured relative provided another instance. During data collection for this aspect of the project I was unable to expand my sample of interviewees to test any generated theories because sampling of these interviewees was incredibly difficult (this is discussed further in section 4.3.3.1). I was, however, able to use my data analysis to inform subsequent interviews. For example⁴³, although during the first interview my question route was focused on the fMRI technology, the interviewee spoke at length about her feelings regarding hospitals and their ability to accommodate and provide basic care for severely brain-injured patients. I picked up on this theme in later interviews, and the analysis of this data has contributed to some of the ideas put forward in the thesis. Second, I did not always strictly adhere to the constant comparative method. This was particularly evident during the newspaper analysis and for the interviews with family members. Instead, in these instances, similar to grounded theory, data was coded into categories and these categories were compared. However properties of categories and their possible interactions were sometimes difficult to identify, and even when they were identified, I was unable to test any emerging theories. For example, during the interviews with family members it seemed that interviewees’ views regarding fMRI reflected their past experiences with their relative; the way they described themselves and their coping strategies; as well as their views

⁴³ The examples I provide relate to some of the findings of this thesis. Whilst I have not yet reported my findings, I felt it important to use them as examples at this point, as they help to clearly clarify why and how I chose my methodological approach.

on media and research in general. Because of the small data set, I was unable to explore in more detail specifically how, or if, these properties interacted.

Bartlett and Payne (1997) suggest that research which uses only selected components of grounded theory may be better labelled ‘grounded analyses’ (Bartlett & Payne, 1997). The methodological approach to this thesis fits succinctly into this definition.

4.2.5 My grounded analysis via example

The extracts below provide illustrations of how I conducted my initial coding from the transcribed data. These extracts were taken from an interview conducted with Alison (pseudonym), a family member with a severely brain-injured relative.

Extract 1:

Transcription

We tend to notify each other if there is something in the paper, but unless you’re prepared to read all through every paper every day it's difficult to know when something is going to be published so when we do see something, yes, we’ll avidly read it no matter what it is - whether it's research or y’know someone else has been in this position and has kind of applied to have end of life procedures and things, so yes we do read it and I have seen a few regarding FMRI.

Code

information seeking in groups
reads papers
difficulties finding information
reads everything relevant
interest in end-of-life decisions
aware of fMRI technologies

Extract 2

Transcription

Andrew is on a do not resuscitate order so that if he were to have a heart attack or anything like that he’s not supposed to be resuscitated. I’ve, the family, my two sons, Andrew’s dad we’ve

Code

end-of-life decision-making
group family decision

all agreed that <u>he really wouldn't want to live like</u>	<i>based on relative's beliefs</i>
<u>this</u> being completely helpless y'know, what sort	
of <u>quality of life</u> can there be, erm, however we	<i>quality of life valued</i>
<u>couldn't go to court and ask them to withdraw his</u>	<i>unable to actively end life</i>
<u>feeding</u> , I couldn't do that, I don't know why but	
I couldn't	

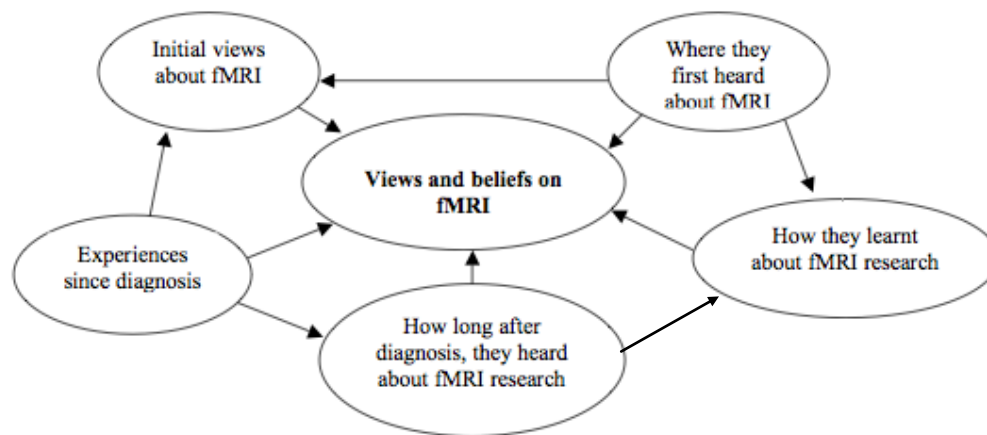
Codes that related to each other were grouped into more conceptual 'umbrella' categories. For instance, most of the codes in the first extract – including *information-seeking in groups*; *reads papers*; *difficulties finding information*; and *reads everything relevant* - formed part of an umbrella category called '*information-seeking*'. This umbrella category contained codes relating to how interviewees sourced information about fMRI, as well as information about other medical or non-medical issues. In another example, the code '*aware of fMRI technologies*' (extract 1) was part of an umbrella category called '*knowledge of fMRI*'. This category included codes relating to how interviewees understood and made sense of fMRI. The properties of related umbrella categories were compared to one and other. For instance, '*information-seeking*' and '*knowledge of fMRI*' were compared. Knowledge about fMRI which was primarily informed from newspapers and/or other sources of the media varied with the type of knowledge gained from clinicians and researchers.

Another example of an umbrella category is '*shared decision-making*', which included the code '*group family decision*' (extract 2). Decisions regarding the treatment and care of interviewees' relatives were often made jointly with other family members. This was particularly true for decisions related to end-of-life decision-making ('*end-of-life decision-making*' was also a separate umbrella category).

A final example of an umbrella category is '*support networks*' which included the codes '*information-seeking in groups*' from extract 1 and '*group family decision*' from extract 2. All interviewees discussed the importance of support networks, which were often composed of family members - though many felt such networks were lacking more broadly, not only in the healthcare setting, but also in terms of patient/carer driven support groups. In fact, many of my interviewees were recruited from a recently established online support network for families and carers of severely brain-injured individuals, which was launched in 2011 to fill such a void. More conceptually, '*support networks*' was part of a larger emergent category called '*ethics*'. This emergent category contained codes relating to ethical issues associated with having a severely brain-injured relative. A comparison of the '*ethics*' category emerging from these interviews with a similar '*ethics*' category

from the newspaper analysis showed some very interesting differences. These findings are discussed in more detail in chapter seven.

In grounded theory “*memos and diagrams are essential, for without these the researcher would have no written record of his analysis. There is no way one can keep the results of such complicated procedures entirely in one's head*” (Strauss & Corbin, 1990: 195). Diagrams are used to summarise and display the relationships between concepts. As an example from my analysis, below is a diagrammatic representation of the views and beliefs of family members who I interviewed about fMRI.



4.3 Data collection

Using the grounded analysis framework discussed above, I embarked on data collection, and data analysis. Below I outline the detailed processes of this for each aspect of the research, including the newspaper and press release analysis, the interviews conducted with science press officers, and the interviews conducted with family members.

4.3.1 Newspaper and press release analysis

The aim of the newspaper analysis was to examine the portrayal of news coverage reporting the use of fMRI for severely brain-injured patients. This section of the research was designed to answer research question 1.

I chose a UK newspaper analysis at the expense of a more thorough analysis of broadcast media and other forms of new media such as online reporting, blogs and tweets for several reasons.

First, two recent studies in the US suggest that newspaper reporting remains the main port of access for the public to read about new developments. In the first instance, an independent researcher, Schoen, wrote in the Huffington Post about a poll he conducted which, amongst other factors, explored the frequency of readership of newspapers and other media regarding the 2008 US election (Schoen, 2008). Of the 2000 people polled, more than three-quarters of adults and 84 per cent of elites read newspapers every day or a few times a week, either in print or online, to inform them about the election. He argued that “*people are still reading newspapers and they are reading them often. Newspapers are still influential*” (Schoen, 2008). The other study was conducted by the Pew Research Center’s Project for Excellence in Journalism. This project surveyed more than 50 media outlets in Baltimore, US - including newspapers, TV and radio stations, websites and blogs - for one week. One result of this study showed that 95 per cent of stories with ‘new information’ (i.e., not repackaged previously published information) came from traditional media – most of them newspapers - and these stories tended to set the narrative agenda for most other media outlets (Pew Research Center's Project for Excellence in Journalism, 2010).

Second, the aim of this research thesis is to explore the how and why news was reported about a particular technology (fMRI for severely brain-injured patients), and family members’ responses to this technology, and its reporting. It is not to provide an in-depth analysis of one aspect of this i.e., news media representation. I would argue that a UK newspaper analysis is sufficient to give a clear enough picture of the portrayal of this reporting in the news media for this purpose. An in-depth exploration of broadcast and other forms of new media would be interesting, in that the analysis could add to the data, but remain out of the scope of this project.

Finally, pragmatically, newspaper texts are more accessible than broadcast and online media. Such texts lend themselves to systematic analysis more than their broadcast and online counterparts. As a medical sociologist researcher novice to the field of media analysis, I considered that a textual analysis would provide the most informative set of reliable results.

4.3.1.1 Data collection

I searched all UK newspapers (national plus regional) on the Nexis® academic database for the month around publication of each of the two fMRI studies (i.e., 8 September to 7 October 2006 and 4 February to 3 March 2010). This database is one of the world’s largest archives of newspapers and printed documents. Headlines, lead paragraphs and body terms were all searched to maximize yields. I used the broad search term ‘brain’ because using the search term ‘fMRI’ risked missing items where technological acronyms had been avoided. The results from the

'brain' search were then skimmed to locate all articles which discussed the fMRI studies. Duplicates were discarded from the sample and when confronted with slightly different versions of the same article (e.g., early or late edition of a newspaper), I kept the most extensive article for analysis. The Nexis[®] search results suggested that some newspapers did not report on the studies. I conducted some additional online searches for these articles during the time periods in order to double-check this, just in case my Nexis[®] search missed some articles. One additional article from the Daily Mail (2010) was identified at this point. I am unsure why it was not in the Nexis[®] database (I checked again). Overall, I identified a total of 51 items (32 straight news reports, 19 commentary pieces; 35 from national papers; 16 from regional papers).

I thought it important to have hard copies⁴⁴ of the newspaper articles on which I conducted my analysis. The reasons for this were two-fold. First, for my analysis I wished to pay close attention to any images that were used during reporting. It is also useful, during analysis, to visualize how articles appear in a newspaper to get a clearer sense of how the reader would have viewed it. And second, I wished to show newspaper clippings of the reporting of these studies to both my science press officers interviewees as well as to the family members I interviewed. I spent some time in the Colindale (North London) section of the British Library where I accessed as many hard copies of the 51 articles as possible. Unfortunately, many of the articles were not available. At the time the library was reducing the number of newspapers it stored as hardcopy and also on negative. I retrieved seven articles reporting on the 2006 study and ten articles reporting on the 2010 study.

In order to answer research question 2, the MRC and *Science* (the journal which published the original 2006 research) press releases reporting on Owen and colleagues' research were accessed via a search online. (There was no journal press release in 2010 because *New England Journal of Medicine* – the journal which published the 2010 study - does not issue press releases). The Science Media Centre's website was also searched for any expert comments that appeared in their 'round up and rapid reaction' page in response to Owen and colleagues' research. The Science Media Centre's aim is to provide evidence-based information about science through the media. The compilation of quotes by the Science Media Centre is typical for research that has the possibility of being misconstrued. The quotes are generally from experts in the field and are

⁴⁴ Whilst soft copies of newspaper reports provide the full text of articles, hard copies allow visualization of layout and images.

designed for journalists to access and use in their news articles to present more balanced discussion.

I commenced coding the texts from each newspaper article and the press releases in Microsoft word, adding comments down the side of the documents to act as codes. However, the data quickly became unmanageable. To allow me to organise the data, and the coding I wished to conduct, I uploaded the documents into NVivo 9 software. Each article and press release was then coded using the coding system described for my grounded analysis above. Emerging categories were compared and contrasted with those categories emerging from other articles and the press releases, from the analysis of interview data, and also with relevant scholarly literature, so that I could identify over-arching concepts.

4.3.2 Interviews with science press officers

The main aim of the interviews I conducted with science press officers was to explore how such press officers chose which scientific stories to highlight to journalists and why; how they report science; and how they construct their views and beliefs about press releases. These interviews were conducted to answer research questions 3 and 4.

The interview methodology was chosen because interviews are “*a flexible and adaptable way of finding things out*” (Robson, 1993: 229) and have become a widely used method of eliciting the viewpoint of participants for qualitative exploratory analysis. This is because the interview facilitates insight into how a respondent structures an issue, and finds meaning in it (Marks and Yardley, 2004).

One way of categorising interviews is according to their degree of structure. At one extreme is the fully structured interview where interviewees are asked a pre-determined set of questions. At the other extreme is the unstructured interview, where the interviewer has a general area of interest, but lets the conversation develop and be driven by the interviewee (Robson, 1993). Standardisation increases, but the richness and capacity to expand the data in the direction of the interviewee’s discussion decreases as one moves from unstructured to structured. For this project I chose the commonly used semi-structured interview, which fits somewhere in the middle of this continuum. Such interviews are based upon an interview guide with typically five to eight questions, plus probes to supplement them if respondents have difficulty elaborating their perspectives (Marks and Yardley, 2004). Questions in the guide can be re-ordered depending on the context of the interview conversation; can be worded and explained differently

depending on the interview; and additional questions can be added and/or removed for each interview depending on relevance (Robson, 1993). The flexibility of this style of interview allowed me to sufficiently explore my research questions broadly and allow the production of rich and interesting qualitative data for analysis. At the same time the interview remained structured enough so that my data remained related and focused to the specific research questions I was trying to answer. My interview guide for interviews with science press officers can be found in appendix one.

Finally, Oppenheim said, *“Probably no other skill is as important to the survey research worker as the ability to conduct good interviews...When taken seriously interviewing is a task of daunting complexity”* (Oppenheim, 1992: 65). When interviewing it was important that I maintained good interviewing skills. In this sense I aimed to be a good listener, to be empathic, but not judgemental, allowing the exploration of the interviewees feelings, and allowing the interviewee’s worldview to come to the fore (Marks and Yardley, 2004).

4.3.2.1 Recruitment

A theoretical sampling approach was adopted when sampling interviewees. For example, I initially aimed to recruit science press officers from two or three different institutions, such as universities, medical research councils and science journals, as this would have made recruitment significantly easier. However, following the analysis of the first interviews I conducted at three distinct institutions, the emerging themes suggested that I would need to continue sampling from a much broader range to see how or if these emerging themes varied across institutions. Science press officers are now typically associated with all large science institutions, including universities, funding bodies/medical research councils, industry, science journals, charity organisations, as well as self-employed, and for this research I wanted to have all these institutions represented.

To commence recruitment I initially contacted a member of the organising committee of Stempra. Stempra is an informal network set up to bring together people working in science communication and as such it offered a good platform to recruit science press officers. The organising committee member was supportive of the research project and sent an email to all members of Stempra via the mailing list requesting that if anyone was interested in taking part in the study, to contact me via email. Three press officers expressed interest in the study and were subsequently interviewed.

Following this process, and following advice from the interviewees regarding recruitment, using a theoretical sampling approach, I started to identify institutions' science press departments throughout the UK through extensive web searches. I contacted press departments in universities, science journals, charity organisations with a science interest, pharmaceutical and biotechnology industries, and media centres to determine if any of their members would be interested in taking part in this research. I initially e-mailed these departments to make contact. If I received no response via e-mail, I telephoned the departments. I telephoned up to three times if there was initially no answer, and up to a further two times if I was asked to call back and there was still no response. Seven science press officers showed interest in the project and were subsequently interviewed.

Although my strategies to recruit science press officers were clearly successful to a degree, such strategies also had significant difficulties. Often the organisations I contacted failed to respond to my repeated e-mails and telephone calls. This was most noticeable from industry organisations and science journal organisations. I sometimes received responses from press officers, who expressed interest in the study, and were in principle happy to be interviewed, but whose schedule meant that they were too busy to be interviewed. In spite of these difficulties I recruited science press officers representing a wide number of institutions, including: industry (n=1); science journals (n=1); science/medicine funding bodies (n=2); charity organizations (n=1); university science departments (n=2); media centres (n=2), and self-employed press officers (n=1).

My initial intention was to continue recruiting more science press officers. However, my analysis suggested that this would be unnecessary as data saturation had been reached for the themes on which I wished to base my analysis. This can be illustrated as follows⁴⁵. After the first few interviews with science press officers it began to emerge how such press officers negotiated their role as a communicator of science research along with their concerns about over hyping science research, and their role as a seller. This negotiation dominated a lot of the discussion and was the main aspect of the interview data which related to my research questions and, particularly, to my data from the other parts of the project which had already been coded. I sampled further science press officers from different institutions to discover how far this theory applied, for example, whether it also applied to press officers in industry. As I continued

⁴⁵ See footnote 43

interviewing the same negotiation was seen and explained similarly and so sampling was stopped. (There were, however, other issues discussed during the interviews, which did not reach data saturation, but were less relevant to the specific research questions I was trying to answer and to the data/coding from the other parts of this project.)

4.3.2.2 The interview process

Some interviewees were unable to commit to face-to-face interviews, and so I conducted both face-to-face and telephone interviews. The use of telephone interviews in qualitative research is uncommon, since scholars have argued that such a mode of interview deprives the researcher of seeing the respondents' informal, nonverbal communication (Creswell, 1998). However, there is increasing literature which argues that this mode of data collection can produce valuable data. For example, Sturges and Hanrahan compared these two interview modes, with specific attention to the themes that emerged from the interviews and to the depth of content and showed that, at least for their research, comparison of the interview transcripts revealed no significant differences in the two types of interviews (Sturges & Hanrahan, 2004). Indeed, they point to literature which argues that there may be benefits to telephone interviews. For example, interviewing on embarrassing or illegal topics; for researcher safety; because of cost; and to access those participants who are reluctant to participate in face-to-face interviews. It is this latter advantage that specifically relates to this project, since some of my interviewees were too busy to commit to meeting in person. Moreover, Novick has systematically reviewed literature which has reported on telephone interviewing for qualitative research and concluded that there is little evidence that data loss or distortion occurs, or that interpretation or quality of findings is compromised when interview data are collected by telephone (Novick, 2008). Whilst I would not argue that telephone interviews are appropriate for all types of interview (e.g., particularly sensitive interviews such as those I conducted with family members), it seemed reasonable for my interviews with science press officers. In light of this, for my research six interviews were conducted (and recorded) by telephone, and four interviews were conducted face-to-face.

Interviews aimed to explore the choices participants make when choosing which scientific stories to highlight to journalists and why; how they report science; and how they construct their views and beliefs about press releases (appendix 1). Interviews commenced with a broad discussion about interviewees' employment background, and their job role. Following this, participants were asked to describe how they write press releases – how they chose the story, how they turn the

story into a press release, and how they disseminate the story. Close attention was paid to the interactions press officers have with scientists and journalists, and their view of such relationships. Participants then discussed a Medical Research Council (MRC) press release and a newspaper article from the Mirror reporting on the 2010 study conducted by Owen and colleagues (interview material was emailed to all respondents prior to the interview so that the interviewees would have time to look over and digest the articles). This particular newspaper article was chosen on the basis of the newspaper analysis, which had shown it to have an overpowering headline, a large visual section, with pictures of brain scans, and a main article which reported the study using strong mobilizations of hope, excitement and expectation. Interviewees were asked their views on the MRC and Mirror reporting style, in particular, whether they liked/disliked the reporting, and what they believed to be the good and bad points. Next participants discussed another press release and newspaper article – this time relating to research by Schiff and colleagues (Schiff et al., 2007), which used DBS on a severely brain-injured patient. As above, interview material was emailed to respondents prior to interview. My reason for choosing these articles related to my previous intention to explore the news media's reporting of Schiff and colleagues' research as part of my thesis. Although I did not pursue this course, the discussion with the science press officers about the reporting of this research was elucidating and helped support my findings, and is thus referred to in results chapter six. To conclude the interview, discussion was generated around participants' beliefs about news media science reporting in general.

Interviews lasted between 43 minutes and 1 hour and 20 minutes and amounted to 279 pages of transcript. Interviews were transcribed externally⁴⁶ and were transcribed immediately following an interview. Transcribed interviews were normally returned within a few days, and up to a week, following the interviews. In this way I could analyse the data prior to moving on to the next interview, as required for a grounded analysis approach. Although I missed the possibility of becoming very close to my data whilst transcribing it myself, I gained much time, and countered this problem by reading the transcripts as soon as I was sent them whilst they were fresh in my mind. I did this whilst listening to the interview and this allowed me to become closer to my data; check the accuracy of the transcription; as well as gain an overall sense of the data, whilst noting any interesting emerging theoretical themes. To allow me to organise the data, and the coding I wished to conduct, I uploaded the interview transcripts into NVivo 9 software (when I

⁴⁶ I have previously had experience with transcribing data.

conducted my newspaper analysis coding in Microsoft word had become unmanageable). Transcripts were then coded using the coding system described for my grounded analysis. For each interview, in addition to the coding I kept a memo. This memo was reasonably short, but did allow me to track any interesting or broad ideas that occurred to me during my analysis. This also helped me to not lose sight of the bigger picture emerging from the data as I meticulously coded it.

Emerging categories were compared and contrasted with each other and with those categories emerging from the analysis of other interview and newspaper data, and also with relevant scholarly literature, so that I could identify over-arching concepts.

4.3.2.3 Demographics

Eight of the interviewees were female and two were male. Although the interviewees were heavily female weighted, my analysis of the interviews did not suggest that this affected the data, and the male interviewees spoke similarly to the females. All interviewees were relatively experienced, having worked in the science press officer industry for at least four years. And while seven of them had been in the industry for between four-to-nine years, three of them had over twenty years experience. Most interviewees had worked in several different institutions as science press officers before their present one and so had amalgamated much experience. For example, one interviewee drew on experience from the NHS, a medical charity organisation, and a research council; another interviewee brought experiences from a science journal as well as a media centre; and a further interviewee had experience at a research council, a charity association and in a business.

4.3.3 Interviews with family members with a severely brain-injured relative

The aim of this element of the research was to explore participants' views and beliefs surrounding the use of fMRI for severely brain-injured patients, as well as their views on the news reporting of such research. These interviews were designed to answer research questions 5 and 6. Interviews were semi-structured and were conducted face-to-face due to the sensitivity of the topic.

When I initially started to think about the research design for this element of the thesis my main focus was to explore the influence of the news media on families' views about the fMRI

technology. I read much literature which reported on the successful use of focus groups for exploring the influence of the news media on respondents' views and beliefs about technologies (Hughes & Kitzinger, 2008; Peddie et al., 2009). The rationale for the use of focus groups stems from the assumption that our views and understanding of a technology such as fMRI emerge from the news media, as well as our surrounding social and cultural environment (Kitzinger, 1994). A focus group thus provides a setting which allows for the examination of such social interaction and communication between participants when discussing the research topic. There were a number of reasons why I chose not to conduct focus groups for my research.

First, pragmatically, recruitment was exceedingly complex and as such I was unable to achieve the minimum number of participants to proceed with a focus group. Second, the group of individuals I wished to interview could be considered a vulnerable group and as such a focus group environment may have been particularly distressing for some interviewees. Finally, I initially wished to speak to *any* individuals who had a severely brain-injured relative about their views about fMRI in relation to the news media. However, consultation with my supervisors and some health professionals helped clarify to me why this would not have been appropriate: because my research focus was on an emerging technology, interviewing individuals who did not have access to this technology may have resulted in significant confusion and/or distress. Because of this I decided to only recruit those individuals who had spoken to their consultants about fMRI for their relative. Thus, rather than wanting to explore how participants' views and experiences about the technology were informed by the news media and played out in a group session, semi-structured interviews (semi-structured; chosen for reasons discussed above) were designed to investigate the experience of specific individuals with the technology and to provide a deeper and more original understanding of different individuals' views and perspectives about the use of fMRI for severely brain-injured patients. During these interviews I was also able to explore how the news media influenced (or did not influence) interviewees' perceptions about the technology.

4.3.3.1 Recruitment

Recruitment for the interviews was particularly problematic. I initially approached Headway by telephone - a brain injury support group that has a number of local groups in London. The convener of all the London groups was very helpful and was happy to advertise my project. An advert was placed in the groups' bulletin of information, which is distributed to local groups each

month. This strategy, however, was unsuccessful. Therefore, I next contacted Putney neuro-rehabilitation hospital. At this hospital patients have access to fMRI if they are deemed eligible. I presented my project to the clinicians and other healthcare workers at the hospital, and the hospital agreed to advertise my research. As a result of this strategy, an individual expressed interest and was later interviewed. This family member, who was part of a brain injury support group which had recently launched their website, placed my advert on their forum page. Five further family members expressed interest as a result of this advert, and were interviewed.

4.3.3.2 Interview process

All interviews were face-to-face (n=5; one interview was conducted as a joint session with husband and wife). Interviews aimed to explore family members' views and beliefs surrounding the use of fMRI for severely brain-injured patients, as well as their views about the news reporting of such research (appendix 2). Interviews commenced with a broad discussion about interviewees' experiences of having a severely brain-injured relative. All interviewees knew about the fMRI studies from their own experiences at the time of interviewing, and so were asked about their understanding and views about this technology. Following this, participants were shown newspaper articles reporting on the studies conducted by Owen and colleagues, from the Daily Mail (2006); the Independent (2006); the Mirror (2010) and The Times (2010). This selection was chosen because they provided a variety of articles from broadsheets, mid-range and tabloid newspapers. Discussion was then generated around participants' beliefs about both the studies conducted by Owen and colleagues, as well as to the associated news media reporting of the research. Family members' attention was particularly drawn to journalists' descriptions of family reactions, the descriptions of severely brain-injured patients, as well as the mobilization of hope, and excitement. These descriptions had been previously coded during the newspaper analysis. Interviewees were also asked about their views in relation to fMRI for their own relative. The interview schedule can be found in appendix two.

Interviews lasted between one to two hours and amounted to 177 pages of transcript. Interview transcripts were uploaded into NVivo 9 software. Transcripts were coded using the coding system described for my grounded analysis. Emerging categories were compared and contrasted with each other and with those categories emerging from the analysis of other interview and newspaper data, and also with relevant scholarly literature, so that I could identify over-arching concepts.

4.3.3.3 Demographics

In total, six individuals, of whom five were women, expressed interest. Each individual (of whom two were related) had experience of having a severely brain-injured relative: three of their relatives remained living with a VS or MCS diagnosis; one had died (while still severely brain-injured); and one had emerged from their disorder of consciousness, although remains severely disabled (see Table 3.1). Four of the families had been offered fMRI scanning for their relative at the time of interviewing, although only three had consented to it. At the point of interviewing, the length of time since their relative's injury ranged from between one-and-a-half to nine years.

Interviewee (pseudonym)	Patient (pseudonym)	Did the patient have fMRI	Results of fMRI (as reported by interviewee)	Time since injury (at time of interview)	Highest diagnosis reached (according to interviewee)
Alison	Andrew	Yes	No awareness detected	4 years	Permanent Vegetative State
Eli	Ethan	Yes	Suggested some awareness	4 years	Minimally Conscious State (now deceased)
Trudy	Tracey	Yes	Suggested some awareness	2 years	Severely disabled
Rachel	Ronald	No – family wanted it, but patient not eligible	n/a	1.5yrs	Permanent Vegetative State
Laura and Neil	Lavena	Suggested but not pursued by family	n/a	9 years	Permanent Vegetative State

Table 4.1: Details of the interviewee sample. Note: all patients who had an fMRI scan did so within 8 months of injury – i.e. prior to obtaining a 'permanent' vegetative diagnosis.

4.4 Ethical consideration and approval

Qualitative research can generate many potential ethical problems. Ethical issues were considered at every stage of the planning process for this thesis to ensure that such problems would be avoided.

4.4.1 Ethics approval

I initially received ethics approval to conduct this research project from King's College London – where I initially commenced my PhD. This was later transferred to Brunel University. I did not commence recruitment or data collection until ethics approval was granted.

My ethics approval was purposely broad to allow for any changes in methodology during the progression of the project, and in line with a grounded analysis approach. This was indeed the case: I initially received ethics approval to interview individuals who had a relative, or cared for someone with a severe brain-injury in a one-on-one or in a focus group setting. As discussed above, my methods were modified as I progressed in my research design and ultimately I only conducted interviews with family members who had (had) a severely brain-injured relative *and* had some sort of experience with the use of fMRI for this condition. The approval letter can be found in appendix three.

4.4.2 Gaining consent from participants

After individuals had expressed an interest in taking part in the project, I provided them with a participant information sheet via email (see appendix four). The participant information sheet contained details of the study: who was conducting the study and why; where and when interviews could be held; what participants can expect during the interview; their rights as participants; relevant other information; as well as the contact details of myself, my supervisor, and of the university ethics committee. Interviewees were given at least 24 hours to digest the information in the participant information sheet and ask any questions if they required. If individuals were happy to proceed I first asked them if they had any questions about the participant information sheet (the only questions were with regards to a more detailed description of my project, which I gave them). Following this, I asked them to complete and sign a consent form. This in all circumstances was done prior to the commencement of the interview.

4.4.3 Withdrawal from the research

Before commencing the interviews I asked each participant if they had any questions. I advised all participants, as per the participant information sheet, that if they were upset at any time during the interview they could ask for the tape to stop recording for a period. They also did not have to

answer all questions in the interview, but could choose which questions they wanted to answer. In one instance, an interviewee asked me to move onto the next question to avoid speaking about a specific subject, which I readily did. Moreover, I told participants that if they were particularly distressed, or for any other reason, they could leave the interview at any time, and that they may withdraw from the study if they choose to prior to the incorporation of any of their data in my data analysis. None of the interviewees asked for this.

4.4.4 Transcription

I used two digital audio recorders to record interviews for transcription and analysis. This was to avoid the problem of losing data because of a digital recorder failing to record properly, and this was explained to each interviewee. I only commenced the interviews once explicit consent has been obtained and once the participants had been warned that the discussions were to be recorded and transcribed and had agreed to this.

4.4.5 Confidentiality

In social research it is vital, and dependent on ethics approval, that the site of a study, and the people within it, remain anonymous. This was achieved in a number of ways. First, interviews were transcribed by an external transcriber who had signed a confidentiality agreement. Second, the transcripts were anonymised with the use of pseudonyms, and contained no personal or identifying information. This was particularly important for family members with a severely brain-injured relative as these participants were recruited from a relatively small population. However, in terms of the family members anonymity still presented a challenge for me in terms of the *context* of much of what interviewees talked. Similar issues were reported by Saunders and colleagues when they analysed their interviews with family members of severely brain-injured relatives (Saunders et al. forthcoming). Saunders proposed a number of strategies for approaching these challenges, including breaking up data so it is less identifiable, altering demographics, and altering identifying information (they discuss the variety of ways in which this can be achieved). In accordance with Saunders and colleagues and to ensure complete anonymity for my participants, I have altered some demographic information in my thesis (Saunders et al., forthcoming). The specific information I altered was carefully chosen so as to have the minimum affect on the integrity of the data. For science press officers, institutions of employment remained unnamed. This was a particularly important consideration for those press officers who

worked in private establishments, such as industry or for a science journal. Finally, soft copies of the interview recordings and transcripts were/are stored on a password-protected computer. All contact details of participants who have taken part in the research are stored on the computer separately to the transcripts.

4.4.6 Distress

I recognised that talking to family members with a severely brain-injured relative about experimental technologies was an ethically-sensitive area. I was particularly concerned that some aspects of the interview may have been distressing for participants who had already experienced much trauma due to the nature of their circumstances, and indeed for myself, as a researcher listening to such experiences. In an attempt to prepare myself for this, I had discussions with Professor Jenny Kitinger at Cardiff University who not only is conducting research into issues related to end-of-life decision-making for families with a severely brain-injured relative, but who also has a sister who is severely brain-injured. These discussions gave me insight into the experiences of families in this situation, as well as providing advice regarding how to conduct myself whilst interviewing. The discussions also provided me with the necessary support, if required, before and after interviews. I spent some time reading a book written by the parents of Karen Ann Quinlan.⁴⁷ Moreover, I read literature that provided information regarding how to manage distressing interviews. Such techniques included using careful decision-making when deciding who should be included in the study (Marks and Yardley, 2004); ensuring the interview protocol commences with a general warming up session, which culminated into a discussion of any sensitive issues; asking questions in careful, well thought out ways (Patton, 2002); having good listening skills; and paying careful attention to the progress of the interview (Sadler, nd). Accordingly, my questions, topic guide and recruitment and stimulus material were carefully designed and worded to avoid misrepresenting the progress of the use of fMRI for severely brain-injured patients. During the interviews I listened and observed the participant to be able to monitor the level of discomfort or distress, and to determine if the participant wanted to slow down, stop or continue (Sadler, nd). Two of the interviewees became distressed at one point. During the first of these instances, when the interviewee became distressed I turned off the recording and asked if she would like to stop the interview. The interviewee felt that, after a brief break, she wanted to continue. During the other interview one of the participants became

⁴⁷ See footnote 25 in chapter two

distressed by one of the newspaper articles I showed her. I removed the article from the table, and asked if she would like to stop the interview. The interviewee was happy to continue, but felt she could not discuss that particular article, and so we proceeded, slowly, on a different subject. Finally, on completion of the interview I asked if any of my interviewees would like the number of either Headways's free nurse-led helpline which can provide support for family members and carers of brain injured individuals, or for the Samaritans (a telephone number on the Headway website) who can provide confidential, non-judgemental, 24 hour emotional support. None of the family members requested these numbers. Following the first interview I discussed how I handled

4.5 Conclusion

In this chapter I have outlined the grounded analysis methodology which I adopted for this study, and I have justified its applicability to this research. I have described and justified the methods I used to collect my data and have discussed each method in turn in terms of my experiences of data-gathering and how I managed and analysed the data. I have also discussed the ethical concerns which this project raised and the process of gaining ethical approval for the project. The following three chapters now present my data analysis.

Chapter 5: News reporting and family responses to fMRI for severely brain-injured patients

5.1 Introduction

In this first of my results chapters I examine how a selection of news media portrayed the two studies conducted by Owen and colleagues. I then compare these portrayals with the family members' views and beliefs about this research. To do this, I initially report my findings from the analysis I conducted on UK newspaper articles which specifically reported Owen and colleagues' research in 2006 and 2010 (n=51). I then report my findings from the interviews I conducted with family members who have (had) a relative with a severe brain-injury. Here, I specifically explore my interviewees' initial impressions of the technology; their views on the technology more broadly; the expectations and hopes they had for the technology, as well as the influence the news media has had in shaping these views. In the final section of this chapter I discuss my findings and situate them more broadly in the academic literature.

5.2 UK newspaper reporting of the fMRI studies

5.2.1 Excitement and expectation about the technology

The vast majority of news articles reporting the Owen and colleagues' studies tended to position the research as a unique breakthrough (either explicitly or implicitly), with journalists using words such as '*ground-breaking*' (The Times and Telegraph, 4 February 2010), '*amazing*' (Mirror, February 4 2010) and '*remarkable*' (Guardian, 11 September 2006; Telegraph, 8 September 2006), to describe the work. One newspaper even suggested the research was a miracle, headlining '*An astonishing breakthrough medical miracle as 'coma' patient talks to docs using brainwaves*' (Sun, 4 February 2010), with another article referencing '*the extraordinary power of brain scanners*' (Daily Telegraph, 8 September 2006). Such terminology, and use of the breakthrough motif (Brown, 2000), gives the impression of a sudden and important occurrence – a result that many researchers have been desperately working towards has finally led to a eureka moment! In so doing it does not reflect the incremental, on-going process within the context of other scientific work – a commonly noted feature of much of the news reporting of science research (Cascais, 2005).

Depictions of the researchers and other scientists further served to amplify the rhetoric of breakthrough. Journalists reported that the research ‘*stunned doctors*’ (Guardian, September 8 and ‘*generated immediate excitement*’ (Guardian, 4 February 2010). The results of this research were described as outcomes not even the researchers themselves expected to achieve and the scientists were said to be ‘*astonished*’ (Dr Owen: reported in n=7 articles), finding the results ‘*startling*’ (Dr Owen: reported in The Times, Telegraph and Express, 8 September 2006) and ‘*spectacular*’ (Dr Nicholas Schiff reported in the Telegraph, 8 September 2010). Moreover, newspapers reported how this research could ‘*fundamentally change the way decisions are taken...*’ (Express, September 8 2006), ‘*which could have huge implications*’ (Sun, February 4 2010), could ‘*dramatically alter[s] the debate...*’ (Mail (b), 8 September 2006), and ‘*changes everything*’ (Mail, 8 September 2010). Such word usage not only aligned with the idea of this research being a sudden, dramatic and important discovery (i.e., a breakthrough), but also conjured images of a massive upheaval that would see existing treatments of vegetative patients supplanted by a new more effective plan incorporating the use of this technology.

Half the news articles (n=16/32; commentaries excluded) orientated the research to the future, describing to varying degrees how fMRI would in the future provide a new route for diagnosis and communication with vegetative patients. This, readers were told, was not only very likely, but would improve the lives of those previously diagnosed as being in a VS. Some journalists talked about future possibilities as uncertain goals - the Daily Mail reported that ‘*it could help doctors improve diagnosis*’ (Daily Mail (b), 8 September 2006), the Independent printed that ‘*the discovery means doctors may in the future be able to ask patients ...whether they are in pain and need more medication*’ (Independent, 4 February 2010), and the Telegraph printed ‘*the method....could in theory....be developed to help her communicate with the outside world*’ (8 September 2006).



Figure 5.1: Examples of UK newspaper headlines reporting Owen and colleagues' studies in 2006 and 2010. Included in this figure are examples from the Mail (top left); the Independent (top right); The Times (middle); and the Mirror (bottom).

However, expectations of fMRI frequently went far beyond the present achievements of the science, with strong, unqualified claims being introduced about the technology's long-term possibilities. Examples included articles in the Guardian (*'The technique is now likely to become a standard way of determining how conscious VS patients are'* (8 September 2006)); the Telegraph (*'showing that one day [scanners] will be a crucial method to see how much the mind has been harmed'* (8 September 2006)); and The Times (*'a ground-breaking experiment that promises to allow some patients who are 'locked-in'...to communicate'* (4 September 2010)). Depicting fMRI in this way implies a certainty about the future prospects of the technology and promotes the idea that this technology will one day be used as a tool for communicating with VS patients. Indeed, the use of the word '*promise*' hints at an oath or vow that guarantees this to be the case. Such depictions give little space for other future possibilities, for instance, the possibility that this technology will not universally have this

capability. It also essentially ‘short-circuits’ out of the picture any further research or intervention that would likely be required to shift this technology from the research realm to clinical application, and thus frames the progression of this technology from basic research into clinical practice as one which is straightforward, un-complex, and uni-directional.

5.2.2 Hope, families and recovery

Throughout many of the news articles fMRI was symbolised as a gift; as hope. Some journalists wrote explicitly about hope in terms of recovery. For example, Julie Wheldon wrote in the Daily Mail that ‘*it is seen as evidence that doctors should never give up hope that a brain-damaged patient could recover*’ (Daily Mail (b), 8 September 2006). Later in the same article, Wheldon stated:

A spokesman for the anti-euthanasia group Care Not Killing, said: ‘This illustrates that even in the most apparently hopeless circumstances, where there is life there is hope. This poor woman is apparently mentally alert despite being physically paralysed and there must be at least a chance that modern medical science can give her the hope of at least a partial recovery

Other journalists spoke more generally about hope: the Sunday Express headline read ‘*New hope after brain research*’ (7 February 2010) and the Guardian headlined ‘*...provides hope for others in similar state*’ (4 February 2010). In the Sun the caption under an image of a young woman looking simply as if she is sleeping peacefully in bed - although a drip/artificial nutrition and hydration bag signals her plight –simply read: ‘*hope...brain study*’ (Sun, 8 September 2006). Finally, journalists talked about hope in terms of families. In this sense, the technology was constructed as something ‘wanted’ and ‘hoped for’. The Guardian reported that the studies ‘*may give hope to close relatives*’ (11 September 2006) and the Mail(b) reported that ‘*it will give hope to victims’ families that when they talk their loved one might be able to hear their words after all*’ (8 September 2006).

In spite of the fact that families of brain injured patients, as well as patients themselves, were the presumed beneficiaries of the amazing breakthroughs, families did not feature as sources in any of the articles. Like the silent patients, who could not be interviewed because of their condition, families too were silenced or ventriloquised. When families were mentioned, journalists mostly framed them as being positive about the research (n=7/9). Reporting described the research as

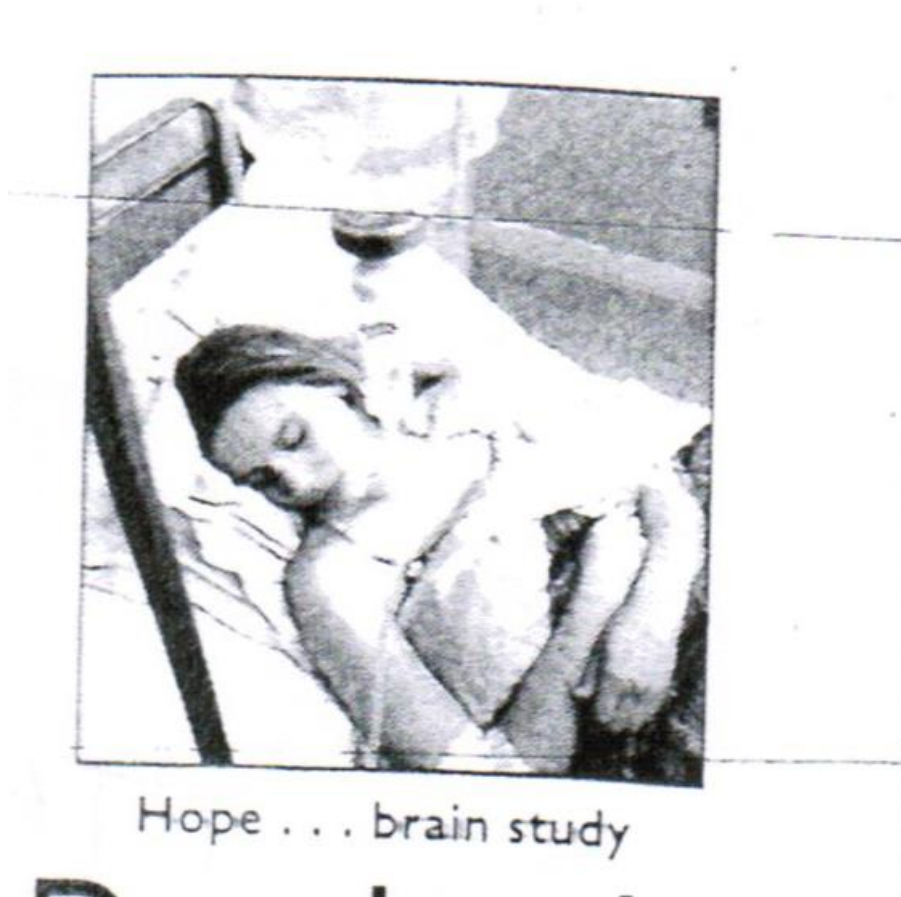


Figure 5.2: Image appearing in the Sun, 8 September 2006

giving families '*comfort*' (The Times, 4 February 2010), that they were '*happy*' with the results (Guardian, 4 February 2010) and that the '*revelation*' produced by fMRI '*gives a huge boost to families*' (Sun, 8 September 2006). Only three reports suggested reactions could be more complicated – two examples were from guest writers. For example, Professor of palliative medicine Ilora Finlay reminded us that: '*it may throw those caring for the patient into turmoil*' (The Times, 4 February 2010) and the specialist Science Editor Roger Highfield mentioned that:

The science team is also uneasy about how the families of vegetative patients will react to the discovery that a patient who...fulfils all the criteria...of vegetative state...could possibly have an inner mental life (Telegraph, 8 September 2006)

Presenting family reactions to the technology in a positive light, as well as objectifying the technology as hope, gives the sense of a technology that is good, that is wanted, and that is

positive. Moreover, objectifying the technology as hope may also act to direct families and the publics' expectations about the prognosis of the VS towards the technology and what it can/may be able to achieve for such patients (possibly at the same time as shifting it away from more realistic expectations for such a prognosis) (Delvecchio Good, 2007). This may be particularly amplified for those individuals who have a severely brain-injured relative and may be looking for hope. This was indeed the case for some of my interviewees and is discussed in more detail in section 5.3.4.

Finally, there was a lack of explicit reference to recovery in terms of severely brain-injured patients, and when recovery was mentioned (n=10) the term was often ill-defined. For example, in the news reporting of the 2006 study, Telegraph readers were told only that '*the ability to recover from...brain damage, caused by a road traffic accident, is much higher [than if the brain is starved of oxygen]*' (8 September 2006), and Guardian readers were informed only that '*the woman...has since been able to follow her reflection in the mirror*' (8 September 2006). Only one article reported that '*.... the longer in a vegetative condition, the worse the chances of recovery and the greater the likelihood of long-term disabilities*' (Daily Mail (b), 8 September 2006). Little reference was made to the fact that recovery of consciousness for patients with a long-term disorder of consciousness is likely to be associated with severe mental and physical impairment. Exceptions were in commentary pieces. For instance, Sheila McLean (Emeritus Professor of Law and Ethics in Medicine) reminded us that:

While this research shows that there may be a level of consciousness in some cases, this does not necessarily imply that recovery is possible; merely that the ability to communicate at a relatively elementary level exists in some cases (Guardian, 5 February 2010)

And an article in the Guardian pointed out that:

Adults typically have a 50% chance of recovering from a persistent vegetative state within the first six months, but after a year, the chances of recovery drop dramatically. Those who recover after longer periods usually experience serious disabilities (8 September 2006)

A lack of explicit reference in most of the news articles to the prognosis and/or recovery of severely brain-injured individuals may act to further promote the rhetoric of hope by failing to pose the question 'hope for what?'

5.2.3 fMRI and the detection of awareness

Within the news articles reporting the studies (i.e., excluding the commentary articles), journalists' descriptions forged a concrete link between the ability of the technology to measure brain activity, and the awareness of the patient(s). For example, The Guardian's journalist wrote that scientists '*used...fMRI...to detect signs of awareness in the woman*' (8 September 2006). These descriptions were also generalised to other vegetative patients. For instance, The Times headline stated that '*Brain scan shows that vegetative patients can think*' (The Times, 8 September 2006), and the Mirror article read '*the case proves those in vegetative comas may be thinking*' (Mirror, 4 February 2010). Such word usage – especially words such as '*proves*' – paints a picture of certainty about the capabilities of this technology to detect awareness. This picture is confounded by a lack of words implicating uncertainty, such as 'maybe' or 'possibly'. Some newspapers (but only a minority; n=10) did question the level of consciousness uncovered by the research and this is discussed in more detail in chapter seven, which explores the way in which ethical issues (including discussions about consciousness) were depicted in the news media.

Some of the reporting did not simply *neglect* to question the level of understanding or potential for communication uncovered by the fMRI research, but actually used language, association or metaphors in ways which implied a quite sophisticated level of awareness. Reports often conjured up images of people with fully functioning brains who were either in temporary comas and might make a good recovery, or who were locked in with a fully functioning brain and consistent awareness. This description of patients who are in a vegetative state is more aligned as a description of those individuals who have locked-in syndrome. In other words, the description is perhaps more similar to the high-profile situation of Jean-Dominique Bauby as portrayed in the book and film *Diving Bell and Butterfly*⁴⁸ (Bauby, 2008). It is quite possible that severely brain-injured individuals are both in disordered states of consciousness and are *also* functionally locked in to some extent, however, the use of the phrase 'locked in' risks implying that patients who show brain activity via fMRI might have fully functioning minds and have merely lost the ability to communicate. The Daily Mail even used the fMRI work with vegetative patients as a hook on which to hang a report about a locked-in individual who had been: '*frozen in his body, unable to move or speak, yearning for someone to hear his silent screams*', and the headline declared '*But just look at him*

⁴⁸ An article in the New Scientist actually referred to Bauby:

IT TOOK Jean-Dominique Bauby hundreds of thousands of blinks to dictate his book about how a stroke had left him paralysed yet still aware. Now comes the remarkable news that neuroscientists have communicated with a man presumed to be in a vegetative state (In conversation with 'vegetative' patients, 6 February 2010).

now... – going on to describe how he now works as a website developer and ‘*is about to embark on a BSc in computer science and be married to a beautiful blond*’ (5 February 2010). Potential confusion about the level of cognitive ability detected via the fMRI studies was compounded by two senior figures who were quoted as stating that fMRI had revealed the patient’s ‘*secret inner world*’ and/or their ‘*rich*’ or ‘*complex*’ inner mental life (e.g. Yorkshire Post, The Times and Daily Mail, 8 September 2006). In addition Professor Frith was quoted in the Daily Mail, the Guardian and the Independent as commenting: ‘*it is difficult to imagine a worse experience than to be a functioning mind trapped in a body over which you have absolutely no control*’ (4 February 2010). As I discussed in chapter two, comments unquestioningly assuming high levels of awareness of these patients have been strongly challenged by other scientists and practitioners in the field (Fins & Schiff, 2006).

fMRI was characterised as a liberating technology, reaching ‘*into the shuttered world of a lost brain damaged patient*’ (Herald, 4 February 2010), opening up opportunities for patients who had been ‘*closed off from the world*’ (Express, Yorkshire Post, and Irish Examiner, 4 February 2010), ‘*unlocking*’ the ‘*inner voice*’ (Telegraph, 4 February 2010) and freeing victims who had been ‘*imprisoned*’ (Guardian, 11 September, 2006) ‘*trapped*’ and ‘*shut off from life*’ (Guardian, 4 February 2010). The Evening Gazette headlined: ‘*Lost patient can answer*’ (4 February 2010). In one instance, writing about the 2010 study, Colin Blakemore, Professor of Neuroscience at the Universities of Oxford and Warwick, opened his generally reflective piece with compelling imagery which analogised a vegetative patient with the (fully conscious) victims of the Haiti earthquake, thus capturing the recurring imagery of rescue which permeated the reporting:

What nightmare could be worse than being buried alive?...this ultimate horror has been transformed from the stuff of bad dreams and B movies to two very different front page stories. First, the uplifting images of people pulled from the rubble of Haiti...And now there is the extraordinary report from neuroscientists who have used a brain scanner to communicate with a very different kind of trapped victim - a patient in a Persistent Vegetative State (5 February 2010)

His imagery paints a picture of fMRI liberating patients who are consistently aware and ‘waiting’ and/or desperate to communicate, but who, up until now, have had no method of communicating with their family and/or their carers. Such depictions down-play the fact that the awareness levels of most patients diagnosed with a disorder of consciousness are in fact low or absent altogether, and thus may give the impression that the use of this technology will be more widespread and applicable than is currently thought to be the case.

Journalists used sophisticated communication metaphors to describe the interaction between the patients in Owen and colleagues' studies and the researchers. In the majority of articles, conversational style metaphors (*'a world-first conversation'*; Daily Mail, 4 February 2010) were employed and patients were described as being able to *'understand'* (*'the woman could understand speech'* (Guardian, 8 September 2006)); *'talk'* (*'Coma patient 'talks' to doctors'* (headlined Sun, 4 February 2010)); *'read'* (*'scientists then read his answers by studying functional magnetic resonance imaging'* (The Times, 4 February 2010)) and *'speak'* (*'Coma victim 'speaks' with his thoughts'* (headlined Mirror, 4 February 2010)). Conversational style metaphors conjure up images of a patient able to engage in a discussion with the research team – perhaps communicating information about him/herself, his/her condition or something relevant and/or personal to him/herself. It also creates a picture of communication which 'flows' and is directly and instantly interpretable, and thus such word usage un-complicates the stringent process that is typically involved in analysing and interpreting the results of an fMRI scan in order to determine the pattern of the patient's brain activity.

In other instances, the communication of patients in the research study was described in more 'science-fiction' terms. For example, the Express printed *'woman...could communicate through brainwaves'* (September 8 2006); the Cambridge News printed: *'Brain waves allow patient to communicate after 5 years'* (4 February 2010); the Independent printed *'scientists have succeeded in reading the mind of a man'* (4 February 2010); and the headlines of the Sunday Times read *'Telepathic leap'* (Sunday Times, 7 February 2010). Indeed, one article opened with: *'Doctors have made a medical breakthrough which would have tasked even the imagination of Hollywood science fiction movie makers'* (Belfast Telegraph, 4 February 2010). Whilst these metaphors are of a different style to those discussed above i.e., they less depict conversation using words, rather they focus on communicating through 'thoughts', *'mind reading'* and *'telepathy'*, they still suggest a very rich communication channel between the patient and the research team. In fact, after reading a newspaper article, one of my interviewees' parents (interviews discussed in section 5.3) had assumed that her relative's mind could indeed be 'read' (*'she thinks it's the machine that will read his mind'*). Moreover, presenting communication in science-fiction terms gives the impression of a technology which is ahead of its time; which is futuristic; which is remarkable; and which has the 'wow' factor. This may lead readers to believe that this technology is something to be impressed and excited by (isn't it fantastic that this technology has been created and we can now do these sorts of things?). It may also lead readers to believe that the technology has abilities far-outreaching its current capabilities. The use of science fiction metaphors in the news reporting of science is extensive and has been noted previously by, for example, (Nerlich et al., 1999; Hughes & Kitzinger, 2008).

5.2.4 Images of brain scans

Of the 17 hard copies of newspaper articles I analysed, the most common image was a graphic illustration of the fMRI scans i.e., brains ‘lighting up’ under the scanner. Figure 5.3 provides two examples of such images. These images, typical of many of the other pictures, simplistically distinguish a ‘healthy’ brain from the ‘brain of vegetative patient’ and divides the responses of the vegetative patient involved in the 2010 study neatly into ‘positive/yes’ and ‘negative/no’ (note the use of orange and blue in the scans to illustrate this). Such imagery suggests that the outcome of using an fMRI machine in the context of this research, as well as generally, results in clear and easily interpretable results which allow an unproblematic separation of distinct ‘brain types’ as well as distinct responses of the brain to specific questions (Dumit, 2004).

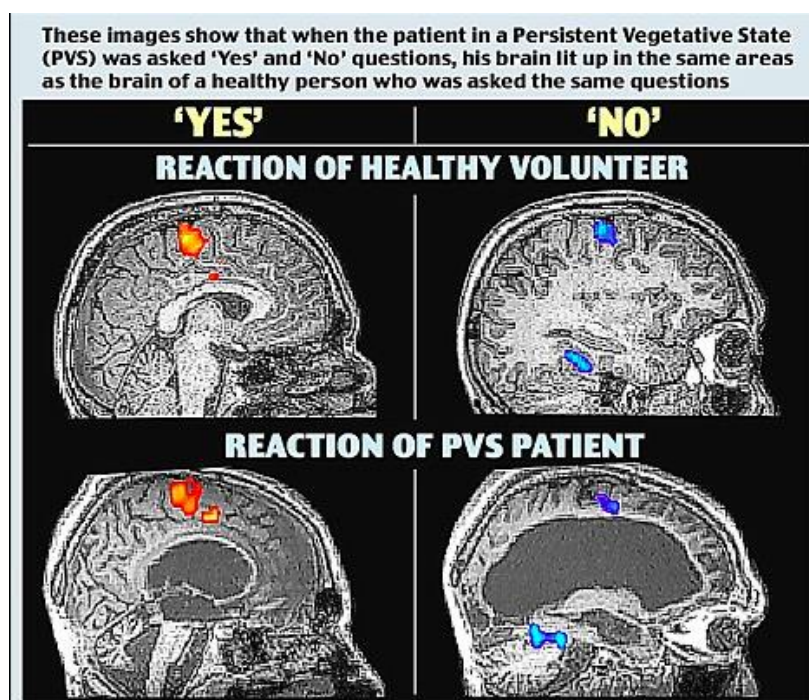


Figure: 5.3: Images of the brain ‘lighting up’. Top: Mirror, 4 February 2010; bottom: Daily Mail, 4 February 2010.

In summary, with few exceptions – mainly from the commentary pieces - the UK newspapers reported the use of fMRI for severely brain-injured patients as a miraculous breakthrough offering a potential ‘voice’, choice and hope for such patients and their families. Moreover, journalists spoke of the expectation for communication with other patients who were ‘trapped’, and paid little attention to their bleak prospects of recovery.

5.3 Interviewees’ views of fMRI

My interviews with family members challenged some of the optimism of the newspaper coverage and offered a more nuanced sense of how families anticipate the future heralded by fMRI, the role and possibility of hope, and their views and experience of ‘recovery’.

5.3.1 Finding out about the research

Four of the interviewees first learnt about Owen and colleagues’ research directly from the news media. Two of these interviewees - Trudy and Rachel - had responses to the studies that mirrored the sort of family reactions anticipated or represented in newspapers – indeed their excitement and hope had been originally directly *triggered* by the media:

I was really, really excited I was, that was the first thing, ‘cause I wanted to find out if there was anything really going on in Tracey and I can remember saying to the nurses at [the hospital] “look at this, this is amazing this is amazing” (Trudy)

I have heard of fMRI when I was looking for miracles...I thought (loud gasp) “wow this is it this is the thing I need for Ronald, it’s going to prove everything” (Rachel)

Both these interviewees thought about offering their relative to the researchers – one was pre-empted by being invited to be part of the research, the other took the initiative herself:

I emailed him through the Cambridge website I said “hello Doctor Adrian Owen”, and then do you know what’s funny? I thought I must be the only one emailing him, and the generic email I got back saying “we receive hundreds of emails from people desperate” you know “like from families after all this” and I thought “oh” (laughs), I naively thought he would see my case and go “oh this women, what a horrible time she has I must ship her here” (Rachel)

It is notable, however that both of these interviewees came across the media articles in the early stages of diagnosis of their relative (within seven months). Media invocations of excitement and hope had less impact on Laura and Neil, whose daughter had been severely brain-injured for much longer. Laura, who first encountered the 2010 study conducted by Owen and colleagues on the news (nine years after her daughter's injury) was *'not excited, no, more question marks I think.....certainly not excited no, I'd never view it as exciting'*. She did question if this was something she would want her daughter to go through but didn't think too much more about it:

[Lavena's brother] was there and we talked about it...and I think as we kind of talked about it and said "oh, you know, I wonder if Lavena would be eligible...But, you know, would we want her to go through that kind of thing"...that was sort of that was as far as it went there

For the other two interviewees it was either a consultant (Alison) or the Cambridge research-team themselves (Eli) who introduced them to the studies. Eli, who had been informed from the outset that the research was unlikely to benefit her husband (*'it was made quite clear to me that sending him to Cambridge would not help Ethan'*), did not have any expectations about the studies: *'No [I didn't have any expectations]... because as I said they were very upfront. This is a research project that...almost certainly won't help Ethan'*. For Alison, whose relative had been diagnosed only three months prior to her meeting with the consultant, it was still too early to have an opinion because *'at that point you're not willing to consider whether someone is in a persistent vegetative state'*.

Interviewees, then, seemed to be much more susceptible to the news media's portrayal of Owen and colleagues' studies if they first heard about the research in the news media soon after their relatives' initial diagnosis. This was likely at a time when they had little experience or understanding of the VS and also a time when they had a lot of initial hope for recovery (discussed below). Possibly once this initial hope diminished – and once participants had more experience of the VS - interviewees seemed much less susceptible to the news media's portrayals of the research. Moreover, interviewees who initially heard about the research via consultants and/or the research team – even in the early stages of diagnosis - also seemed less influenced by news media portrayals of the studies. This perhaps reflects the clinicians' and the research teams' managing of expectations about the technology when initially communicating the research to these interviewees. Indeed, recent research exploring clinicians' managing of family and patient expectations in relation to deep brain stimulation for children with dystonia suggests this to be the case. The findings of this research illustrate the various protocols are put in place by the

clinicians to ensure such expectations remain at a level which reflects the capabilities of the technology (Gardner, 2014)

5.3.2 Interviewees views concerning the technology

Three of the interviewees spoke about being ‘positive’ about the research. For Trudy, whose daughter has made some recovery, and who prefers *‘to read something positive... I don’t like the negative things very much’*, her excitement about the research was contagiously optimistic: *‘I think it’s amazing. I think there is still so much more that we’ll be able to find out about people like Tracey’s brain injury and stuff, it’s just incredible, yeah amazing’*. On being shown a newspaper article reporting the study Trudy described it as *‘brilliant, really brilliant’*, and in response to the journalist’s suggestion that fMRI gives a huge boost to families, she agreed: *‘yeah, gives a huge boost to families it does, it does give a huge boost’*. She found it *‘a huge encouragement that they’re actually finding more and more, you know, about brain injury’*. Her views of the technology therefore aligned in many ways with the rhetoric of excitement with which journalists reported Owen and colleagues’ studies in the newspapers.

Eli, who has also *‘always had a positive slant’*, spoke similarly about the technology: *‘I did feel quite positive about the fact that he’d had these tests and that some good might come of it’*. She was proud of her contribution to the research and to the possibility of helping others, and did not want to accept that it was anything less than positive:

I’d sort of told people that Ethan had had this thing and maybe this was going to help other people. I sort of verbalized that. I didn’t verbalize the negativity [referring to the Houben case⁴⁹] because there’s no point. Because actually it still might be positive. There’s no point in saying “oh that was a mistake and therefore Ethan hasn’t benefited other people”

She and other interviewees viewed these fMRI studies as a small step in improving patients’ quality of life and hoped this might eventually lead to more understanding of brain injury or possibly establishing some rudimentary communication (*‘research is all about...seeing if you can improve somebody’s quality of life’...if you can strap them in an MRI scanner ... and say “are you cold?”*). Eli likened the technology’s potential to the presence of defibrillators at her leisure centre:

⁴⁹ Ron Houben was presumed to be in a VS for 23 years. In 2006 he was re-diagnosed by clinicians as having locked-in syndrome. This claim was later rejected in 2010.

[The possibility of some sort of communication in the future] is a positive thing...there is now a defibrillator at the leisure centre. There wasn't one when Ethan was ill. That's a positive thing. Put it this way, 30 years ago my husband would have died...There wouldn't have been a paramedic. The ambulance staff would have not been trained in the same way...I can be grateful for the small things, you know

In this extract Eli positions fMRI and its potential to help vegetative patients in much the same way to how the newspapers depicted the technology - as still in the realms of research, but something that will certainly some day aid with communication - much the same as how better trained paramedics and better access to defibrillators were previously absent from healthcare but now play an important role.

Finally, for Alison, she too felt '*positive*' about the research, despite the initial disappointing results following her husband, Andrew's, initial fMRI scans. This interviewee, who was pro-research in general (*'it just kind of reinforces the fact that brain injuries are very, very difficult things to deal with...so...the more research that they do into it the better for everybody'*) believed that '*ideally you would think that patients in these conditions could undergo this scanning once a year, or something, to see if there were any changes*'. For Alison, research is something society should pursue, and a certain amount of status should be afforded to fMRI such that the technology should '*ideally*' be integrated into the healthcare of severely brain-injured patients. For all three interviewees, then, their positive views about the use of fMRI shared various similarities with the way in which Owen and colleagues' studies were reported by journalists in terms of the excitement surrounding the technology; the status given to fMRI as a technology that can detect awareness; as well as the technology's certain potential to act as a communication device in the future.

Other interviewees had different views about the research. Rachel, who initially heard about the research in the news media when she was '*looking for miracles*', still finds the technology '*amazing*', but is now much more sceptical of it. She did not want to pursue trying to access this technology for her husband, Ronald: '*it's really fascinating, it is fascinating, I would like to do it sometime but then there's a lot of reasons - my reasons for not wanting to do it outweigh it at the moment*'. These reasons seemed complex but crucially related to her concern that a negative finding from an fMRI scan would '*prove against*' Ronald.

For Laura the research was also '*very, very exciting but*' she was ambivalent about the technology and talks upsettingly about her concerns about the possibility of finding out that (after nine years) her daughter, Lavena, may have some levels of consciousness, Laura said:

We talked about whether or not Lavena [could] go through it... it's like a double edge sword because if we found that there was nothing there in a way that would've been easier ... how do we handle it if there is something there but there's not a damn thing that we can do to get to her to reach her...

In response to a journalist writing '*the revelation gives a huge boost to families of brain injury victims left wondering whether loved ones can bear them*' Laura said:

It would be lovely to think that Lavena knew that mum was speaking wouldn't it...but it would be absolutely terrible to think that she knew what her life was like...because...most people say well at least she doesn't know what's happening ... and when I hear something like that I think well hang on a minute, if they'd had that, and we found that, and we think my poor girl, you know you've been suffering, I would see it as suffering, as like the mental torture for nearly nine years

For this interviewee, then, fMRI was not something to pursue: '*I think my feelings of unease [about fMRI] grew. And a feeling of uncertainty and almost say dread in a way...it's not something that I could personally put Lavena through*'. She reflects that research has to happen, but that '*it's modern technology that has put Lavena where she is today*'. She comments '*I think that they're jumping ahead of themselves. I would actually rather that they hadn't got to Lavena in time...*'. Though she does believe that '*more research needs to be done*'. Laura expresses concern for others who:

Will have a scan but then where do they go from there - what support is there for them. I mean ... you get a case of yes there might be something going on there but actually "sorry but we can't do anything about it"

For Rachel and Laura, then, they were much more ambivalent about the technology, and whilst they still viewed the research as '*exciting*' and '*fascinating*', this was much more entwined in a greater complexity of decisions, choices and emotions. It seemed as though neither interviewees opposed the research and/or the technology *per se*, but rather, relate their ambivalence to their specific situation. It is their precise experience and their relative's diagnosis and/or prognosis which weighs most heavily on their views of fMRI as something they do not wish to pursue for themselves or their relative.

5.3.3 Expectations of fMRI

None of the interviewees questioned fMRI as being able to determine whether patients/their relative had some level of awareness. For example, Eli felt that the technology could help the research team decide if *'somebody who was in a coma was actually bidden in there...'*; and talking about the 'M' case, Trudy said *'has she therefore had an fMRI scan...can they see if there's stuff in there...'*. Indeed, for some interviewees, an immediate benefit of fMRI was that it ensured that their own observations of consciousness were endorsed. For example some thought that they (and often care staff intimately caring for their relative too) saw more consciousness and communication than clinicians acknowledged. As Eli commented: *'it was quite obvious to everybody [care staff and family] that he understood what was going on...I knew he was in there'*, adding *'[the fMRI test meant] they knew he was in there as well'*. A similar point was echoed by Trudy: *'as a mum, you're with them so much more constantly and you see things...and they [the staff] don't believe you'*. (There is a body of literature which has explored the ideology of motherhood, and more specifically, the experiences of mothers caring for disabled/chronically ill children as they act as activists for their child. This work also suggests that the competence of some mothers may be sometimes called into question (Ryan & Runswick-Cole, 2008).) These views about the capabilities of fMRI resonated with the way in which journalists depicted the fMRI technology when reporting Owen and colleagues' studies. Moreover, interviewee's descriptions of *'bidden'* and *'stuff in there'* were rather like the imagery of the trapped earthquake victim used in the Telegraph report cited earlier. For instance, Eli commented that her husband *'was a prime candidate to help them decide...he was trapped'*. This is particularly interesting as Eli is specifically describing her minimally conscious husband using a metaphor that more accurately describes a patient with locked-in syndrome – something that she repeated on other occasions during the interview when she spoke of Ethan being *'still in there'*.

For all my interviewees, their belief that the technology could help with the detection of patients' awareness levels seemed, for them, in some way to symbolise the technology as *'the answer'*. Alison talked about how she thought the technology could give her some answers about her husband, Andrew:

I certainly wasn't ready to consider that that was going to be as good as it got...but having come [to Cambridge]...it was quite a positive experience and I felt optimistic, I suppose, that we could perhaps get some answers. I think that's what I was looking for more than anything was answers about the extent of the brain damage, because nobody really tells you in the beginning [...] One of the things when you have someone in a persistent vegetative state...is knowing what they're

thinking, if they're thinking, how to communicate with them...and I thought if they could find out using scanning...that would be a good thing

Andrew's fMRI findings identified swelling on his brain. Although disappointing, for Alison these findings explained why her husband had not responded well during bedside assessment and was an 'answer' to give to the clinicians who repeatedly had not given her husband *'the full opportunity to show if he was able to respond'* to other tests. A couple of years later, Alison wanted Andrew to have a second fMRI scan so that she could have more answers. She had e-mailed the research team and *'been in contact with a doctor who...did the actual scans'*. This time round she *'just wanted to see literally if they could see any changes in his brain, we've noticed over the last six months maybe there have been slight changes...'*

Trudy also spoke about the fMRI scan providing answers: *'I was really, really excited... 'cause I wanted to find out if there was anything really going on in Tracey'*. For this interviewee, the fMRI tests showed *'Tracey had a learning....ability'*. The improvement in Tracey's diagnosis over the next few years (she is now profoundly brain damaged but able to communicate) was an indication for this interviewee that the scans provided the 'objective truth' – the answer. This truth starkly compared with the clinician's 'lies':

They said "basically you have to understand that what you see now is probably all you're going to get"...and I thought "that's ridiculous...there's got to be more", and they said "well you may [see improvement] up to six months - anything after six months and that is probably it", and that is a lie, that is a lie, a total lie

Not all interviewees viewed 'the answer' as a good thing. For Rachel, her present hesitance contrasted to her initial belief about the technology. Rachel had *'told [her] family "I found this thing it could be the answer to prove he's awake"'*. Similar to Trudy, for this interviewee, this technology was going to give the answers which countered the clinicians more sceptical attitudes: *"'cause we had so much struggle...to show that he was in there...and I thought that would be the answer...that it would fix everything because they would know he's in there..."*. Over the course of time this interviewee's views about the use of fMRI changed. Whilst she still believed the technology could provide answers about whether a patient was aware, she was concerned that such answers would 'prove against' her husband:

I think that fMRI would have preached against him, which is not necessarily what I needed 'cause he is slowly waking up... he had an EEG that proved terrible against him...I decided after that EEG that I did not want the fMRI...I fought so long to have evidence for him I didn't realise these things could work against us...

Now for Rachel, she has '*realised...I don't care what technology's out there because if I can look at him and see what I'm seeing I don't care what anything else says*'. Rather than viewing the technology as the 'expert', she relies on her own instincts and tacit understanding of her relative. Laura also did not want her relative to have an fMRI scan because she was concerned about the answer it would provide. For this interviewee, as discussed above, she worried about the possibility of finding out that (after nine years) her relative may have some levels of consciousness which she '*would see it as suffering as like the mental torture for nearly nine years*'. Laura said:

And I think for us it would just make us feel so much worse. My heart would bleed for Lavena to think there's been something going on there all this time and she's, she's still trapped where she is, and scientists can say "yes there's something going on there but I'm sorry Mrs [X] we can't do anything to help your daughter get out of it"

Finally, for Eli, the fMRI research was not going to benefit her husband since, as discussed above, she '*knew Ethan was in there*'. Rather, she viewed the technology as giving answers about the awareness of others in the future:

If there's one person whose machine is not switched off five years from now because they now know how to ask the questions which get a response, the right response...then that's a positive thing

Overall, these findings resonate with my findings from the previous section. There I showed how, whilst interviewees' views about the use of fMRI varied depending on their and their relative's personal circumstances and experiences, all interviewees viewed (to some degree) the research as exciting, and believed – to varying degrees – that more research should be conducted. Underlying this support for research progression is possibly the belief that this research will eventuate into technology and/or knowledge that will in the future help society and/or individuals. They trust that research and scientific progress will give them 'the answers' to current health problems and issues. It is not hard to imagine, then, that fMRI research may be viewed by

interviewees in light of these underlying beliefs about research and is therefore envisaged as a technology capable of providing ‘answers’ about a patient’s awareness. However, just as interviewee’s support for research progression did not necessarily equate with their views about fMRI, nor do interviewees beliefs about the technology providing answers necessarily equate to a desire to pursue the technology. Rather, the interviewee’s specific circumstances and experiences tied most heavily into these views and desires. For interviewees who did not want to pursue the technology it was as if the answers the technology could provide for patients generally, or ideally, were not the answers they were looking for – this technology, did not align or ‘fit’ with their hopes or expectations for their relative. Put another way, this technology and its capabilities are configured only for an ‘ideal user’ whereby this ideal user’s future hopes, desires and expectations for their relative align closely with the functions and capabilities of the technology. It is only these ‘ideal’ users who view the technology as something that they want to pursue for their relative. Such findings support the main premise of previous work conducted by Woolgar on user-technology relationships in the area of semiotics which states that *“how users “read” machines is constrained because the design and construction of machines entails a process of configuring the user”* (Oudshoorn & Pinch, 2008: 548); see also (Woolgar, 1991; Oudshoorn et al., 2004)).⁵⁰ Or to put another way, Woolgar argues that technology is created and then tested by designers with a specific user in mind – the technology is therefore configured for a particular user and only some of my interviewees could be described as this ‘particular user’. The work by Woolgar has been extended by some scholars who argue that the configuration process can work both ways, and also that it may not necessarily be the designers themselves doing the configuring, but rather other actors, such as public sector agencies and the like (Oudshoorn & Pinch, 2008: 548-549). This would suggest that we cannot ‘point the finger’ at the ‘designers’ of fMRI for severely brain-injured patients (the neuroscientists who developed this technology such as Owen and colleagues) for configuring the technology in such a way. Rather, other actors may have played a role in this process. Such actors could include, for example, patient organisations, which may be activists for more research and/or policy makers who are driving for more translational research. To determine more clearly which actors have played a specific role in the developmental process of fMRI in this context would require a more STS-style approach of analysis. Unfortunately this is beyond the scope of this thesis.

⁵⁰ Beyond semiotic approaches, research of user-technology relationships is a wide area of sociological study. For a review of such research, as well as for a critique of Woolgar’s concept, see Oudshoorn, N. and Pinch, N. (2008), 'User-Technology Relationships: Some Recent Developments', in E. Hackett, O. Amsterdamska, M. Lynch and J. Wajcman (eds.), *The Handbook of Science and Technology Studies* (3rd Edition), Cambridge, MIT Press.

5.3.4 The technology as a 'gift of hope'

'Hope' was a key issue for the interviewees. Whilst hope is an important coping mechanism, it is also a dangerous need, making them vulnerable to 'false hope' in their search for a solution. For instance, interviewees talked a lot about the hope they had for their relative to make a recovery, especially in the early stages of diagnosis. Laura, for example, remarked: *'we just had...such hope didn't we [to her husband] ...we just clung on to everything...[...]... in the early stages we would've done anything...'* Rachel echoed this: *'the thing is when you're going through all the distress and the pain you search for anything don't you'*. Hope came from a variety of places. For some, it came from newspapers - not just new research, but also from miraculous stories: *'there's more and more cases of people stuck in these situations that are coming out and I think those are the things, and those are the people, that give hope...'* (Rachel). For instance, Rachel refers to:

That man with a sliver of a brain...who's like a postman...and you think "well maybe there's people that run against the mill" do you know like that "are doing things a bit differently", and I'd like to know if Ronald's that person

And also to Martin Pistorius⁵¹: *'they've taken years and years and they're like "I can play baseball", so Martin Pistorius...they thought he was PVS [permanent VS] you know, he was in care homes..'* For others hope came from clinicians and nurses. For example, Neil commented: *'these consultants seemed to give you hope...they were looking forward to working with Lavena...'* And Alison remarked:

The doctors are not allowed to give you false hope, so the doctors will tell you as it is but they'll always qualify it with a "y'know, we just don't know how things are going to turn out", the nurses tend to be the ones that say "don't ever give up hope, y'know, we've seen people like this and six months down the line they've come back in to say hello"

Alison spoke about the importance of having initial hope: *'there is a kind of false hope when you're told don't ever give up hope...but then I suppose they don't want you sitting there in a state of despair'*. Though Alison and three other interviewees spoke about how their hope had eventually given way to acceptance:

⁵¹ Pistorius fell sick at age 12 which developed into locked-in syndrome. He remained in this state for over ten years. He recovered and has written a book about his experience called *Ghost Boy*.

I'm not sure exactly how long it takes, certainly more than a year before...you reach a stage of acceptance that this is how it is...y'know we'd like to hope that there would be more, there may be more, but it takes such a long time with severe brain injuries, you're talking years, years and years [...] You have to be realistic about what the chances are for a recovery

And in response to a quote in one of the articles '*where there is life there is hope*', Eli said: '*I'm struggling with that word, not that I don't believe in an after life but it's hope for this life...there was no hope of a recovery*'. She continued:

So basically hope for what?...I would have wanted Ethan back but when [my daughter] says "oh Mummy do you miss my Daddy?" I say "I do, but I wouldn't have him back like that...that was not fair on him, let alone us"...so, no, there was no hope of a full recovery for my husband. That [quote in the article] I don't like

Three participants spoke about the hope they received from the fMRI research. Of these interviewees, only one remained hopeful at the time of interviewing that this technology was going to help their relative (her relative was imminently about to have an fMRI scan). Rachel, as discussed above, had rather discovered this fMRI-directed hope was misplaced, since only a proportion of individuals who have been diagnosed as vegetative may have access to the scanner and/or the mental capacity to eventually communicate, and for most there is a probable prognosis of limited recovery. As mentioned earlier, for her, she prefers to hold onto hope independent of fMRI, rather than being disappointed about any negative results from the scan ('*so that's alright I've got faith in Ronald, I don't need faith in fMRI's*'). In effect, this technology is something that could potentially 'steal' the hope she has that Ronald will recover:

You go in there full of hope like you're going to get the result ... and then when he doesn't [get the result] it's not like it changes my view of him, but it makes me feel a bit downhearted, because whilst it's out there it's not dashed, it's still a hope

Other interviewees were less hopeful about the fMRI studies from the start. This is seen most clearly in Laura and Neil's narratives, which have been discussed above. They expressed dread and fear about the possibility that Lavena might be able to hear her after all:

If I knew that things were going on in Lavena I'd spend much more time with her...I'd talk to her a lot more, and so on, and of course then that would impact...on us all...we'd feel so guilty that we haven't tried harder to get through to her, but yet we know that everything has been done you know...so it's quite a complicated to unravel

However, this interviewee did state that if she had come across the study in the early stages of diagnosis she would have had been hopeful: *'yes we would....we would because in the early stages we would've done anything'*.

Overall, hope for the fMRI research seemed to represent a much deeper and more 'personal' emotion for interviewees than their beliefs about the research in general, and this emotion was directed solely towards their beliefs and expectations about their relative's prognosis i.e., whilst all interviewees could see some benefits to the research *in general* irrespective of their relative's diagnosis / prognosis, this was not the case for how interviewees' viewed the research in terms of 'hope'. Similar to that discussed in the above section, only when interviewees' expectations for their relative aligned with the capabilities of the technology i.e., when they could be considered an 'ideal user', did interviewees speak hopefully about the technology itself. It is interesting that so few participants could be considered 'ideal users', or had any hope for the technology at the time of interviewing. This contrasted with the rhetoric of hope that was so evident throughout journalists' reporting.

5.3.5 A sense of recovery

All of the family members who took part in this study had, by the time of interview, reached a point far removed from any fantasies of full recovery for their relative. For example one of the newspaper articles referenced that a patient might *'embark on a BSc in computer science and be married to a beautiful blond'* (Daily Mail, 5 February 2010). Information from clinicians had made it very clear that any patient who has been vegetative or minimally conscious for a long time is never likely to make a complete recovery – for example, even if they do recover full consciousness they will not fully recover physical abilities or memory, and may be left with severe neurological deficits. Most will always require 24/7 care and never regain the cognitive ability to make their own serious medical decisions, let alone be restored to their former selves. Interviewees had not only learned about this from their clinical teams, they had also seen what recovery meant through their experiences.

In this context interviewees told a very different story of recovery than that implied in the newspaper coverage. While worried that their relative might, in some sense, be ‘trapped’, they did not see fMRI as providing a ‘telepathic leap’, bringing their loved one back to them. They did not think the technology could find the person who was lost, unlocking their prison or rescuing them from the rubble. Their ambitions were more modest – that their relative might, for example, be able to clearly indicate whether they were too hot or too cold. A number of interviewees spoke about the improvements they had witnessed in their relatives’ conditions, giving a picture of what recovery meant to them that was very far removed from that conjured up in some media reports. They made comments such as *‘he yawns now, he never used to yawn...’*. Trudy, for example, spoke about the progression her daughter, Tracey, has made and her sense of future possibilities: *‘at one point the speech and language therapist said she couldn’t really move her mouth at all, she couldn’t poke her tongue out...oh my goodness she does all sorts now, so never say never’* (Trudy). Eli similarly reported some minimal progress in her husband’s condition as the months turned into years: *‘he could turn his head and he would watch and um, once or twice...he tried to talk’*. However, over time, with this slow and minimal progress, and a sense of the narrowing possibilities, hope becoming exhausted. Her perspective is vividly illustrated in her account of her husband’s eventual death. She had rushed to his bedside, filled with grief, but when he appeared to rally for a moment she was also aware that she had no hope left:

He’d calmed down to very light breathing, and it was fairly normal and I actually sat there and in my head I thought “Don’t do this to us. Don’t recover and then three months later do it again, and then six months later do it again. That’s not fair on me or the family”. So, I didn’t wish him dead..., but yes, [the media implies] “where there is life there is hope” - Hope of what?...

5.3.6 Responses to Stimulus Material

In my interviews with participants, I presented them with a number of UK newspaper articles reporting the Owen and colleagues’ studies. I was particularly interested in how Rachel and Alison’s views of such portrayals – the two interviewees whose excitement for the research was directly triggered from the news media – may have changed compared with when they initially came across these articles. In the interview, Rachel spoke about her concerns regarding how the news media portrayed Owen and colleagues studies:

Whilst all you cry for is a bit of hope, I do understand why they don't give you it because when you get given it...you twist what's been said...that's what doctors don't want you to do, they don't want you to hear something different from what they're saying, and that's what the media does

These are the articles you have to be careful of...fascinating reads to the average person...but when you've got a family member...you're flying up there with the newspapers, "what's this? let's do it let's go there now"

Rachel thought the articles reporting the Owen and colleagues' studies were misleading "*cause they give you hope...that's what the media does. It changes everything and makes you think there's answers out there that just aren't*". She comments:

'Cause this makes you think that you're going to speak to them through this magic machine...[but] it's not like something we can carry around with him and I find that really hard

And *'the thing is'* she says:

These things aren't even freely available, they make it seem like you're going to pop into your local hospital...have an fMRI and get your answers...it is so hard to get on a study

As we discussed the articles further she became quite angry: *'what's with the 'talking brain', it makes me want to swear at these articles now I know different'*. And, *'I get a bit angry, I get really angry, when you read it again you think that that's just so wrong, that's not how it works at all'*. Alison also noted that hope from the wrong places, such as the news media, can be problematic: *'it could give you some hope if you didn't know more...that's not good'*. Interestingly in contrast to Rachel, Trudy, whose initial excitement about the research also stemmed directly from the news media, still viewed the articles as a *'huge hope for people in the early stage'*. She spoke about why this was the case:

Other people could be absolutely devastated at that sort of news [being told their relative will not improve] and almost give up, and that is dreadful because, you know, if I'd seen something like this first I might've said to [the clinicians] "hey hang on a minute how can you say that when we're seeing this sort of thing in the press"

The difference in Rachel and Trudy's beliefs at the time of interviewing suggests that their views were not only related to their understanding of the technology and/or the VS, but were also very much tied in with their previous and present personal experiences, including their emotional experiences. For Alison, her experience with the hospital clinicians, as well as the fact that her relative has made some recovery following his fMRI scan, both seemed to be related to her investment in the excitement surrounding the technology similar to that portrayed in the newspaper articles – her experience, in a sense, matched how journalists' depicted families experiences in the newspaper articles. In contrast, Rachel's experiences with her relative, and her learning about the inaccuracies of the newspaper reporting, did not align with the experiences of families depicted in the newspaper articles, and so for her such articles were misleading.

5.4 Summary and discussion

In this chapter I have shown how the two studies conducted by Owen and colleagues were framed in the newspapers as 'miraculous breakthroughs'. Journalists' presentations of these studies were optimistic and focused on the positive implications and future possibilities of this technology as a communication tool that detected signs of awareness. Metaphors were used to describe the excitement of the research, as well as the awareness of patients and the capabilities of communication. Journalists also drew on emotions of hope to give the story a 'human face'. Altogether, this told the story of the technology being *good* – something we want, something we should be excited by, and something we should be hopeful for. As discussed in chapters one and three, my findings are consistent with previous research by Racine and colleagues who noted a general optimism when they analysed fMRI in the print media (Racine et al., 2006a), and also when they analysed neurotechnologies in the print media more generally (Racine et al., 2005). They are also consistent with previous work which has flagged up how media representations of innovative technologies are often optimistic and presented in a positive light (Mulkay, 1994; Nelkin, 1995; Conrad, 2001); are presented in an uncomplicated manner (Mulkay, 1994; Nelkin & Lindee, 1995; Conrad, 2001; Haran et al., 2008); and are portrayed with confident anticipation of a better future through the use of science and technology (Mulkay, 1994). Finally, they are consistent with previous work which has demonstrated journalists' use of metaphors to describe science, health and/or research in order to enact a particular story or outcome (Brown, 2000; Nerlich & Halliday, 2007), as well as journalists' use of the human-interest angle (Seale, 2003) and mobilisation of emotion in an attempt to sell a story (Höijer, 2010; Wahl-Jorgensen, 2013).

As also discussed in chapter three, broad concerns about such over-optimistic representations of innovative technologies have been debated previously (Conrad, 2001; Racine et al., 2006a). To re-iterate, scholars have argued that it may over-simplify the science (Nelkin, 1995; Seale, 2003; Christidou et al., 2004; Cascais, 2005; Knudsen, 2005); it may introduce inaccuracies (Nelkin, 1995; Jensen, 2008; Schäfer, 2011); and it may lead to false hope for families, patients and/or the public about the limits of the technology (Petersen, 2001; Weimann & Lev, 2006; Bubela et al., 2009). I argue here that many of these concerns, as well as other concerns, can be applied to my findings, and I discuss in detail below how and why this is the case.

First, the way in which Owen and colleagues' studies were portrayed in the news articles gave the impression that the authors of this study had suddenly discovered awareness in the VS after a long road of thinking otherwise – a point which, as I stated earlier, Cascais has termed a 'rhetoric of breakthrough' (Cascais, 2005). It is, however, important to remember that the study "*falls in a lineage of a number of studies over the last few years that have been further refining disorders of consciousness*" (Dr Finns, *All things considered*, National Public Radio, September 8 2006). Neurologists skilled in this area understand the complexities of the diagnosis of the VS, and have previously reported brain-imaging data which aims to assess the brain function of VS patients (Schiff et al., 2005; Coleman et al., 2007; Di et al., 2007). In addition, as mentioned in chapter two, the misdiagnosis rate of VS patients has been described as above 40 per cent - a figure that has been argued to be most likely due to the lack of diagnosis from an experienced clinician (Andrews et al., 1996). It is unsurprising, then, that some patients bedside-diagnosed as vegetative may show some signs of awareness. To view the technology as a new miraculous breakthrough seems to over-emphasize the 'suddenness' and 'importance' of the technology. Although the aim of this thesis is not to chart the 'truth' about fMRI, I would argue that the technology may be better viewed as an innovative diagnostic tool that could aid already skilled neurologists in the diagnosis and prognosis of patients who have been bedside-diagnosed as having a disorder of consciousness or locked-in syndrome, so that they can be cared for more appropriately.

Second, excited news portrayals of the technology, as well as the specific use of metaphors which suggest fMRI to be a 'liberating' technology, freeing 'trapped' or 'locked-in' patients, may give the impression that this technology 'works' for many severely brain-injured patients i.e., that this technology can aid communication with severely brain-injured patients, which are unable to

outwardly respond but have a ‘rich mental life’. This is concerning as the majority of patients who have been diagnosed as vegetative or minimally conscious are unlikely to have a ‘complex’ inner life (Fins & Schiff, 2006), and to suggest otherwise may give false hope to families (see below). Such an impression of the technology is also problematic since this technology is still very much in the realms of research, and there are a whole host of technical and other limitations which precludes it from many patients. Owen himself said in an editorial in *Future Neurology* (footnoted in chapter two): “*the method will not be applicable to all vegetative patients...in many...cases, standard clinical techniques, including structural MRI, may be sufficient to rule out any potential for normal activation, without the need for fMRP*” (Owen, 2006: 694). Patients may also be excluded because they have metal plating in/on their head region following facial reconstructive surgery (something that is quite common after a traumatic brain injury) which prohibits them from such machines. And for those patients who are eligible to use the technology, there are a whole number of other possible drawbacks relating to the test procedures which may further prevent the technology from being used as a tool for diagnosis. As discussed in chapter two, individuals must remain very still for the scan, making it particularly difficult for those experiencing muscle spasms, a common feature of those in vegetative or minimally conscious states (Tovino, 2008; Peterson et al., 2013b). I return to these points in chapter seven.

The portrayal of the technology as something that ‘works’ was confounded by the incorporation of fMRI brain scan images in a number of the newspaper articles. Brain images have been suggested to play a role in *neuro-realism* (Racine et al., 2005), possibly due to the simplicity of the message that the brain images afford (Beck, 2010) or because of the great confidence the public has in ‘biological images’ (Beck, 2010). In fact, empirical research by cognitive psychologists McCabe and Castel suggests that the use of brain images in cognitive research is influential to the public, acting as a persuasive power which confers a great deal of scientific credibility (McCabe & Castel, 2008) - work that was corroborated by Weisberg (Weisberg et al., 2008). Borrowing this research from the cognitive psychologists suggests that journalists’ incorporation of brain images from Owen and colleagues’ research may play a role in adding credibility to the research results. However, the images incorporated in the newspaper articles reporting the Owen and colleagues’ studies are *not* the transcendental truth – our world views will inform what we see in the image portrayed, whether it is a rich mental life or just a circuit of activity.

Third, journalists framed the use of fMRI for severely brain-injured patients as a ‘gift of hope’. Such findings resonate with previous research which showed how DBS had been portrayed in the UK and US print media (Racine et al., 2007b). However, whilst the possibility of communication is clearly an achievement, it does not necessarily mean, and is by no means synonymous with, *something to be hopeful for*. Firstly, some ‘hope’ may be misplaced since, as discussed above, only a proportion of individuals diagnosed as vegetative may have the mental capacity to communicate. Thus, framing the technology in this way raises concerns about the possibility of providing ‘false hope’ to families and/or patients. Indeed, in a recent article to Lancet neurology, Jox and colleagues wrote explicitly about their concerns about this in relation to patients who have a disorder of consciousness. Such portrayals, argued the authors, advance the view that this research is the “*ultimate proof*” (page 735) that families have been searching for, to determine if their relative is ‘in there’ (Jox et al., 2012). My findings suggest that in some cases such concerns may be justified. Some participants did in fact talk about the technology in terms of the ‘proof’ they were looking for. Indeed, for two interviewees, their optimism about the technology was directly triggered by the news media’s portrayal of the research, and they talked about emailing the researchers following their initial encounter with the studies to ask if their relative could have a scan. However, media invocations of excitement and hope had less impact on other interviewees who first encountered the studies on the news much later (nine years) after the initial diagnosis of their relative. Such findings caution us to not view the news media’s influence on families’ views and expectations about the technology simplistically. For my interviewees, their susceptibility to the news media’s portrayals of Owen and colleagues’ studies seemed to be shaped by a whole wealth of personal and social factors, including the length of time since their relative’s diagnosis, the experiences they had had since their relative’s diagnosis, and their hopes and expectations in light of their relatives’ diagnosis. These findings contribute to previous audience reception-type work highlighted in chapter three which has argued that audiences are ‘active’ - their interpretation of media information depends on the social context in which they are received (Morley, 1980) and the “*complexity of the reception process means that some messages are interpreted in entirely unexpected ways or rejected altogether*” (Miller et al., 1998: 211).

Secondly, this technology may not always be seen as a ‘gift’ or something that is ‘hoped for’ by families. Some families may in fact dread that their loved one has some form of awareness and thus has awareness of some degree of insight into their plight, disability and isolation. This

was highlighted by some of my interviewees⁵²: whilst some participants were positive and hopeful about the technology, others were much more ambivalent about the research. Thus, although some relatives did see the possibility of awareness as a good thing, others spoke about the worry that their relative might have always been aware, and the possibility that their relative may understand his/her plight. For these relatives - contrary to that reported by the newspapers – the possibility of awareness was a worse outcome. And although some participants were initially hopeful about the scans, for one participant this hope had given way to fear at the prospect of this technology and what it would/would not tell them. At the time of interviewing only one participant remained hopeful that this technology was going to help their relative (her relative was imminently about to have an fMRI scan).

Finally, journalists' over-optimistic representations of the technology failed to acknowledge and/or problematise many of the difficult challenges and hurdles faced by families, such as the probable prognosis of limited recovery. This is by no means unexpected – as mentioned above, media articles have been documented to over simplify. Families faced with a vegetative relative are, however, most likely to be aghast with a whole wealth of feelings and emotions: by rage and/or by love; by wanting to care and nurture and/or wanting a peaceful death; and by wishing for a recovery and/or by feeling that very partial recovery is almost harder than no recovery at all. This was clearly highlighted in my interviews with family members. Thus, families seem to live with the knowledge that 'recovering' their lost loved one is not an option and that they need to think of 'recovery', if it happens at all, in terms of small steps unlikely to go beyond a type of severe disability that remains invisible in media reports. They also have to deal with the emotional complexity of brain activity being detected, or not, and have often become acutely aware that there are no easy answers (*that's what the media does...makes you think there's answers out there that just aren't*). The interviewees are also operating in a world of disempowerment – struggling with what counts as evidence of consciousness (for example, whether or not clinicians take into account family observations); what consequences will follow from fMRI results (what options are available and who makes treatment decisions) and questions about the role of technological advances in general and the very definition of hope itself.

⁵² This was also illustrated during a 2006 court case, which saw a family applying for the discontinuation of all life sustaining treatment for a patient in a persistent VS. The application was initially rejected on the basis of a recent study reporting the positive effects of zolpidem on some patients reported to be in a VS. The family feared that were the patient to 'wake up' she might experience distress, sadness, or pain. However, these fears were dismissed and authorisation was given to administer three days of Zolpidem to the patient 'An NHS Trust v J' (2006), Family Division, High Court, UK.

Overall, whilst it is important to remember that my interviews do not allow unproblematic access to some external reality; these accounts are just as constructed as the newspaper accounts (Dixon-Woods, 2003), they do stand to show that for families, or at least my interviewees, the range of views and perspectives of the fMRI technology seems to be a long way from the simplistic excitement and optimism presented in newspapers' hopeful and excited stories of a miraculous new breakthrough. This resonates with previous work, including that of Dixon-Woods and colleagues who have argued that parents' in-depth interview accounts point to newspapers being selective and privileging certain types of representations of childhood cancer (Dixon-Woods, 2003). Rapp has also repeatedly written about this. For instance, in her ethnographic analysis of pregnant women undergoing an amniocentesis as a predictive genetic test for their foetus (Rapp, 2000), and also in her analysis of parents' views of children's brains in relation to the use of fMRI for children classified for special education services (Rapp, 2011).

Rather than presuming a one-answer positive response about the advent of new technologies such as fMRI, such narratives caution us to consider the needs, desires, and emotions of families who have a severely brain-injured relative. We must consider that as relatives of severely brain-injured patients grapple with the everyday realities, they have to face the question 'hope for whom' and 'hope for what?' As discussed in section 5.3.3, configuring the user of a technology as 'everybody' (i.e., assuming the technology will 'work' for everybody) (Oudshoorn et al., 2004) fails to acknowledge the sheer diversity of potential users and the fact that not all potential users' expectations will align with the capabilities of the technology i.e., they will not – as discussed in section 5.3.3 – all be 'ideal' users. Rather, than pushing these individuals aside, we need to remember, consider and incorporate the perspectives and views of such individuals when designing, promoting and using such technologies.

5.5 Concluding remarks

In this chapter I have shown how the UK newspapers excited framing of the Owen and colleagues' studies as a 'breakthrough' is problematic on a number of levels, including the fact that it has simplified the research and suggested that the technology 'works'. Further, by contrasting the news media's representations of the fMRI technology with interviews I conducted with family members I have also illustrated how the newspapers simplified family's responses to the technology and gave the impression that it is something that is always 'hoped

for'. Rather, families have much more nuanced reactions to Owen and colleagues research. Such responses remind us that this fMRI is not configured for *all* severely brain-injured patients – and, in fact, not *all* technologies are configured to *all* users - rather potential users are a diverse population of individuals with differing experiences – all of which will influence each users' views, hopes and expectations about the technology. It thus reminds us to remember the complex social, medical, emotional, and political world into which a novel neurotechnology enters.

Chapter 6: Managing expectations – the role of science press officers and the press release

6.1 Introduction

In the previous chapter I highlighted the gap between newspaper representations and the perspectives of family members' views about the use of fMRI for severely brain-injured patients. In this chapter I explore how and why this excitement was generated. To explore 'the how', I examine the role of the funding body and journal press releases, as well as the role of expert comments placed on the Science Media Centre's website in promoting Owen and colleagues' studies. To explore the 'why', I report on my interviews with science press officers, examining their broad role in writing press releases, as well as their views regarding the reporting of science and health research more generally. Finally, I conclude by discussing the implications of my findings and situating them in the broader academic literature.

6.2. Press releases and the Science Media Centre website

The Medical Research Council (MRC: funding body) press releases, which launched the publicity for each of the two Owen and colleagues' studies, portrayed the research in the language of breakthrough, emphasising originality (e.g. a '*new method*' that had '*never before been tried*' (MRC press release 2010)). The results were '*exciting*' (2006) and '*startling*', causing the researchers to be '*astonished*' (2010). The mood of excitement in these documents closely echoed that portrayed in the UK newspapers, which similarly described these studies in the rhetoric of breakthrough. Indeed, much of the coverage in the UK newspapers was largely based on reproducing chunks of the press release – an increasingly common practice of what is known as 'churnalism' (Davies, 2009; Williams & Clifford, 2009). Moreover, the press release in 2010 neglected to mention that three of the five patients who showed some sign of brain activity in the fMRI scanner (including the patient who was able to communicate 'yes' and 'no') showed behavioural indicators of awareness when re-examined at the bedside post-fMRI (i.e., had minimal awareness) - a point also absent from *all* newspaper articles. Such omissions may enact a present in which the technology has applicability to more patients than is thought to be the case.

As well as excitement about the studies, the two MRC press releases suggested patients' conscious awareness, as well as their potential for thought, or even communication and choice. For instance, the title of the 2006 press release read: '*Patient in vegetative state plays tennis in her head*'. The first line stated that '*...a patient in a vegetative state can communicate through her thoughts*'. The 2010 press release title was: '*Brain scan gives vegetative state patient the power to say yes and no*' (2010). Moreover, Owen commented in the 2010 MRC press release that the technology '*provided the patient with a way of communicating his thoughts to the outside world*'. Assumptions about the patients' consciousness were mirrored in the newspaper articles, as were some of the metaphors used to help describe this awareness. For example, the metaphor 'power', which was used in the title of the 2010 press release, was picked up by journalists from The Times, the Guardian and the Independent. And the word usage 'outside world' appeared in 14 of the 2010 articles – many of which also incorporated Owen's comment from the press release. This phrase also headlined in the Independent: '*Brain scanner enables man presumed to be in vegetative state to communicate with outside world*' (4 February 2010).

The MRC documents also promoted positive expectations about the future of the research, quoting the authors as stating that '*this technique may allow us to identify which patients have some level of awareness*' (2006); and '*in the future we hope to develop this technique to allow some patients to express their feelings and thoughts, control their environment and increase their quality of life*' (2010). These comments were later picked up in four 2006 and four 2010 news articles. Indeed, a more general examination of the sources of quotes in newspaper articles identified that just under half of the 51 articles - six in 2006 and 16 in 2010 – incorporated at least one authors' comment from one of the MRC press releases (this proportion would be much higher if commentary pieces were excluded – $n=22/32$). It is likely, then, that the language of breakthrough; the excitement; the metaphors; and the expectations, surrounding the UK newspaper reporting of the Owen and colleagues' studies in 2006 and 2010 can be attributed, at least in part, to the MRC press releases.

Science, the journal which published the original 2006 research, also released a press release in 2006. In contrast to the MRC press releases, this document was much more conservative: excitement was not outwardly conveyed; there was no mention about the expectations of the research; and the narrative was much more questioning about the awareness of the patient - even more so than the authors of the original paper: '*her brain responses closely matched those of healthy volunteers and perhaps show a deliberate effort to follow the instructions, according to the authors*' and '*In a related perspective, Lionel Naccache discusses whether this patient is actually conscious*' (my underline).

Finally, in both 2006 and 2010 the Science Media Centre posted a number of expert comments on their website in response to Owen and colleagues' studies. The posted comments mentioned a number of caveats related to the studies, for example, Dr Narender Ramnani commented *'this finding is based on a single case study...'* (2006) and Paul Matthews (Professor of neurosciences) cautioned: *'response to stimuli...does not provide evidence of a "decision" to respond...The authors did not image activity related to "decision"...merely the responses to command stimuli'* (2006). However, commentators still maintained that the studies' findings were *'remarkable'* (Dr Narender Ramnani, 2006) and a *'huge step'* which *'in the future...will be able to detect cases of other patients who are conscious....and be able to communicate with them'* (Professor Frith, 2010). In addition, Professor Firth also stated on the website that *'it is difficult to imagine a worse experience than to be a functioning mind trapped in a body over which you have absolutely no control'* – a comment which, as discussed in chapter five, was picked up by several journalists, and which is suggestive that patients able to respond in fMRI scans somehow have 'fully functioning minds' (the implications of which have been discussed in chapter five). Whilst there is no way of knowing how many journalists accessed the Science Media Centre website to read the comments, 11 articles incorporated an extract of at least one posted comment, the majority being news articles (n=9/32) and so it is likely that this website offered an important source of information – and possibly excitement - to journalists when reporting Owen and colleagues studies.

6.3 Science press officers

Almost as soon as I commenced my interviews with science press officers, it became clear that all participants were fully aware of the fact that science/health research can be sensationalised in newspaper reporting. The interviewees spoke about the different factors they believed were responsible for this. Some interviewees viewed journalists as the culprits, commenting that journalists' failure to research their story properly meant that they wrote their newspaper articles only incorporating one interpretation of a study:

Quite often journalists aren't seeking any further interpretation of a piece of work than the interpretation that's given in research, and possibly speaking to the researcher behind the research...and that's quite worrying (PO 3 university)

Other interviewees viewed the press release and scientists themselves as playing a role in such reporting:

You can have the best of intentions but a press release is not infallible...you are at the mercy of what a scientist tells you to a large extent (PO 3 university)

And finally, one interviewee did not point to one specific problem, but rather believed that each step of the dissemination of research process incrementally contributed:

A story can involve so many different people all along the chain and I don't think we'll ever pin down and know this is what makes every story go wrong...I think that there might be a bit of hype in the press release, it might just land on the desk of the wrong journalist that day, there might have been nothing else happening in the news, the scientist was a little bit keener in the interview than they should have been (PO 10 media centre)

Perhaps unsurprisingly no interviewee saw themselves or their occupational practices as being culpable. Least of all, participants viewed themselves as responsible for hyping research findings. Rather, they viewed it as their *obligation* to produce accurate, 'honest' press reports. In the sections below, I present findings from my interviews with science press officers, which offers some part of an explanation as to how technologies such as Owen and colleagues' fMRI studies are conveyed with excitement and positive expectations, whilst at the same time my participants spoke about their obligation to avoid hype when reporting such research.

6.3.1 The science press officer - seller versus communicator

Interviewees adopted a number of related reasons for justifying the necessity of science press offices and/or public relation departments in science institutions. Their reasoning often correlated to that found in the academic literature (discussed in chapter three) and related to three main points. First, discourses pre-dominantly focused on raising profiles of institutions and their researchers (*'good publicity does raise the profile of an organization or a university or a discipline'* (PO2 self employed)); *'putting their research institute on the map'* (PO 1 charity association); and the need to *'attract funding'*:

The overall overarching...reason I do my job, or kind of why my job is here, is to promote the research at the university...I'm raising the profile of research or the researcher (PO 6 university)

When they come to put in...a bid for some funding, the person who sits on the purse of the ear so seen may have read this and thought, “oh yeah that rings a bell”, they might not do it consciously, it may be self-conscious (PO1 charity association)

This desire to raise an institution’s profile also extends across national borders as institutions attempt to attract funding from international students:

A lot of universities have taken on an international press officer and they’re targeting it at places like Singapore and China because they want international students (PO 5 media centre)

Second, interviewees drew on issues relating to the public understanding of science approach to science communication. In this sense, the goal of the science press officer becomes to ensure science is communicated to the public accurately and that the diffusion of information about science is from the scientist to the public. This was particularly evident in the narratives of interviewees from the media centre, but nearly all participants referred to the GM crop and/or the MMR incident at one point or another as a rationale for the need for scientists and/or science press officers to be the ones communicating science to the public, and to thus ensure that media frenzies and ‘bad reporting’ are less likely to occur. For example, interviewee PO 4 commented that: *‘science and health’s always pretty much near the top of the news agenda, I think that’s why it needs to be scientists talking about it’*. In the same vein, interviewee PO 2 remarked:

There was some fairly sort of pivotal anti-science events...most notably things like animal rights activities and GM crops...it became rapidly very clear that you can’t just run away from it and say “oh we’re not going to talk to journalists so the whole thing will just go away” - when these issues flare up [you need] people both in the press office and the academics themselves who are able to be spokesmen

Third, though much less frequently, interviewees talked about the funding requirements placed on scientists and institutions to communicate their research to the public:

My cousin’s actually a neuroscientist and she was saying that...they have a greater remit now to get their information out to the public so it’s definitely high up on their need to do...actually not just her needs, it’s...any university that has a research element (PO1 charity association)

In this sense, participants spoke about the public having the right to know how public money which funds research is being spent. As discussed in chapter three, this ‘right to know’ is based around the idea the public should have the opportunity to benefit from any knowledge generated from public funds (Clegg Smith et al., 2010):

Part of [the research council’s] right to operate is dependant on the fact that we will communicate our outcomes to the public - we’re a publicly funded organisation...for the researchers we would say they have a responsibility to make their work as accessible as possible (PO4 research council)

You can’t just get away with saying “oh our people are terribly clever and they do terribly important research please give us money”, people want to know how their money’s been spent and what the results are (PO2 self employed).

Thus, overall my participants pre-dominantly viewed the necessity of science press officers as related to two dichotomous points: on the one hand, being responsible for raising the profile of an institution, and on the other hand, being responsible for accurately communicating science to the public.

Interviewees’ also adopted two similarly dichotomous outlooks when describing their views about the *role* of a science press officer. First, interviewees used a ‘selling’ narrative when describing their role. This was seen most strongly in the interview with participant PO 1 who adopted business terminology. This interviewee freely referred to the institution she worked for as her ‘client’ (*‘my client therefore ... is the [XX] Society’*), and spoke about the institution becoming a ‘brand name’ (*‘it’s about marketing and public relations and PR...I need to help the [XX] Society become a brand name’*). She stated that:

My client has the need to be seen as a figurehead in the UK and part of that is being a kind of brand name, so part of that is being in the public consciousness

Similarly using expressions from business, interviewee PO4 commented that *‘obviously you have a vested interest, you’re protecting your organisation’s reputation’*. Other interviewees also adopted a selling narrative, albeit with a lesser use of business language. Second, interviewees spoke at length about the benefits of science communication in terms of the public. In this way interviewees’ discussions centred on informing the public about science in an accurate and responsible way.

This narrative, which has been documented previously (Clegg Smith et al., 2010), was most visible in the discourses of those interviewees from the media centre, but was evident in all interviews. For instance, participant PO 10 stated that:

Its our job to manage that quite diplomatically...so that we get the right outcome basically for the public, that's why we're here - to make sure that ultimately the science gets covered in sort of, as accurate and responsible way as possible

These two different perspectives spoken about by my interviewees can be understood, at least in part, in terms of the different agendas of science press officers, and thus my interviewees, in their different institutions:

It sometimes depends on the institution and the angle you're coming at, for instance...general publicised research has a slightly different agenda to maybe someone who is publishing a product their trying to sell, and trying to get their name in lights (PO 9 journal)

Such an agenda came across strongly in the discussions I had with participants from the media centre, whose interviews focused almost solely on a public-centred science communication narrative (*'I mean we are the only press officers in the UK...I would argue...where the only thing we care about is accuracy'* (PO 10 media centre)). Interviewees PO 6 and 7's discussions also tended to focus more on the science communication angle of their job role, though to a much lesser degree. In contrast, my participant from industry (PO 8) spoke predominantly in terms of the selling aspect. However, in spite of this, and in spite of the fact that interviewee PO 10 from the media centre stated that: *'a lot of press officers don't see public understanding of science as their responsibility....'*, all my participants spoke throughout their interviews about the importance of both the selling and the science communication aspect of their role.

Such different goals in the same industry clearly highlights a tension that exists for science press officer trying to perform their role - trying to strike a balance between getting research into the public domain (selling) versus doing so in such a way that it informs the public in an accurate, 'honest' and responsible way. Similar tensions have been recently noted in relation to scientists who, too, must balance the motives of public engagement to secure funding alongside their more altruistic interest of informing the public (Clegg Smith et al., 2010). Science press officers are aware of this tension and it has been explicitly discussed in various guides written specifically for the industry. For instance, Stempra's guide to being a science press officer states that *"to help us*

communicate science responsibly, to walk the fine line between generating interest in a story and over-selling it” (my underline; (Stempira, 2009)). Indeed, many of my participants explicitly highlighted these tensions in their interviews. Participant PO 3 remarked:

We try and do a very honest job...so we try not to overstate something but obviously there is always a band between that, and knowing that in order for the media to be interested in something you need to know what the most compelling aspects of that research are

This is also borne out by PO 9, who commented:

You’re trying to portray an accurate overview of the thing that you’re trying to sell, you’re trying to not over hype it too much...and trying to make sure that the reputation of our publishing house is kept intact

Particularly interesting here is the use of the words ‘accurate’, ‘sell’ and ‘over hype’ in one sentence. Finally a participant from the media centre said:

If you get coverage like this from something you've put out you're a massively happy press officer because it's good publicity for your particular story...but in terms of the science...you tread that very fine line between helping people get what they need and actually helping the science get out there...the flip side is making it accurate and evidence-based enough but without making it too boring for the journalist (PO 10 media centre)

Moreover, participants from the media centre spoke about how the balance of the tension can sometimes be pushed or pulled in one direction. This is often caused, they said, by pressures from employers and/or from scientists themselves. For example, interviewee PO 10 remarked:

If you're a press officer and are part of an organisation where you probably have a couple of exciting stories...and you've got your boss breathing down your neck, and you're worried about this that, and the other, or maybe the scientist that you're dealing with is not really shy but actually really wants to get their name on it and they're putting pressure on you

It is important to consider such pressures, which may be faced by science press officers on a day-to-day basis as they carry out their role. Such pressures are often not considered in the wider literature, or by stakeholders commenting on this industry – comments which can often be

critical (Russell, 2008; Macilwain, 2010;), as was evident in a 2011 article in *Research Fortnight* which discussed the results of an analysis of the BBC's science coverage in 2009-2010 (Research Fortnight, 2011).

6.3.2 The press release and the avoidance of hype

When discussing their role, interviewees talked about a variety of strategies used to communicate science research to the public. The press release was, however, seen as the predominant method of communicating science research to the news media, *via the journalist*. My discussions with interviewees about the press release offered insight into how the 'seller *versus* accurate communicator' tension highlighted in the above section plays out whilst conducting their role. I illustrate this below.

All interviewee's spoke about writing press releases in terms of responsibilities. Participants believed incredibly strongly - in fact their interviews suggested almost an obligation – to refrain from hyping press releases:

I certainly feel that they [press officers] have an obligation to write press releases that do not hype the research because that just gets everyone into trouble then and creates false expectations...you've got to understand what it might turn into and therefore write the press release accordingly (PO 2 self employed)

We play quite a major role in how things are portrayed and making sure that things aren't over hyped (PO 9 journal)

Moreover, interviewees seemed to have a very clear sense of the possible impact hyping press releases could potentially have on individuals' lives in terms of hopes and expectations, and many interviewees spoke explicitly of this: '*the kind of press releases that we put out can affect people's lives... somebody who's affected by that disease will...think there's hope for them*' (PO 7 research council).

Interviewee PO 2, for example, made reference to the idea of 'desperation' and 'clinging to hope', and spoke about not 'running away' from the consequences of a press release:

People are very sick - or families of people who are very sick - are also desperate and will cling on to any hope, and so that's again why you've got to manage the situation, and if you do publicise it be prepared for that follow up, you can't just publicise it and then run away from it

In fact, interviewee PO 9 seems to understand that families will cling to *any* hope in difficult situations: *'it's not really fair on people who are already in emotional states and are clinging onto anything they can'*. And interviewee PO 3 spoke about their concerns that patients will contact them for information about research:

When you're dealing with stories about disease you have to be very mindful of the person who has that disease, or the family of the person who has that disease, and not raising their expectations that there's going to be a new treatment round the corner...I don't want a patient calling me and having...say "yes I know it says that...but actually...they're not going to be able to help"

Many interviewees went as far as describing the avoidance of hype as a priority over the 'selling' aspect of their role. However, this prioritisation was not universal – one interviewee spoke more in terms of balance. Speaking about one specific research study she said:

I think we have to be very careful that we don't provide unfounded hope...nevertheless it is different and it is a breakthrough, no one has ever done it before (PO 8 industry).

Further, whilst all participants spoke strongly about their responsibilities, some interviewees discussed how other science press officers did not share this obligation. For instance interviewee PO 6 viewed herself as *'more conservative than most when it comes to press releases...if anything I've been accused by academics for slightly understating things'*. Interviewee PO 1 commented that:

I can't necessarily say all other people involved in journalism take the same approach because I think one of the reasons why I got out of [my previous career] was because it was becoming infatuated with people who weren't so virtuous

An explanation of such comments can be found in the concept 'it's not me it is them', which has been reported previously by Peddie and colleagues in their exploration of public perceptions of stem cell research (Peddie et al., 2009); and also by myself and colleagues in our research exploring direct-to-consumer advertising of prescription medicines (Carter et al., 2010) (also see (Clegg Smith et al., 2010)). The comments closely align with a premise which was highlighted in an earlier comment from another interviewee, as well as being explored in the recent Nuffield Report on novel neurotechnologies (Nuffield Council on Bioethics, 2013). This premise argues

that each individual in the dissemination of science contributes a *'pinch of hype'* (page 219) i.e., each individual believes how they report a piece of research is reasonable (adding just a little exaggeration). At the same time, these individuals blame others for the hype seen in the newspapers. However, rather than there being any particular individual or profession to blame, it is the cumulative build up of each 'pinch of hype' which leads to the final media article. Alternatively, and more broadly, the concept 'it's not me it's them' may more cynically suggest a method by which individuals justify situations and their relative involvement in these, to other people i.e., an individual is aware of a situation they are themselves unhappy about but, for a wide variety of possible reasons, is unable to view themselves as being involved in such a situation and therefore justifies the situation as being caused by others.

Press releases were, in themselves, objectified as a possible route towards responsible, accurate and 'non-hyped' science dissemination to the public: *'if you're worried about a story and you're worried about it being hyped, you can say very clearly in black and white...'* (PO 10 media centre). The press release therefore gave participants *'a degree of control over how that research is reported'* (PO 3 university):

The main advantage [of a press release] is you're controlling the messaging...the more room there is for misinterpretation the more important it is that you actually put out a press release' (PO 6 university)

Although interviewee PO 7 did talk about the press release in terms of losing control:

You have less control over a story, when it gets out, you can write a beautifully worded nuanced press release, but a journalist could interpret that however they want

Press releases were also a good starting point, which allowed for responsible media coverage of a particular issue or piece of research: *'it gives them a signpost for what the researchers certainly think of their own work before it escalates or gets misconstrued and nobody has a starting point'* (interviewee PO 3); and participant PO 2 commented:

There's no doubt that [hype] does happen...but if you're starting point is a press release that is well written, that tells us as it is, that has been approved by the scientist in question, that you

know the various issues, the pit falls, and what might be hyped [and] what might not be hyped are discussed before hand, I think you are at least prepared

Interviewees spoke about various methods they adopted to avoid hyping press releases. First, participants discussed the paramount importance of portraying the research accurately. For instance, interviewee PO 9 stated that *'overall I think you're trying to portray an accurate overview of the thing that you're trying to sell'*, and interviewee PO 2 commented: *'I have to make sure that the integrity of the science is absolutely paramount'*. Many interviewees spoke of their reliance on scientists to ensure this accuracy: *'it's important that [the scientists have] signed off the final version so we're not putting out anything that's inaccurate'* (PO 3 university). Writing a press release accurately also included ensuring necessary caveats and/or qualifications were present. For instance, interviewee PO 2 stated: *'great to report progress...as long as you qualify it - that...there's still an awful lot to learn, it may not be appropriate for everybody etcetera'*; interviewee PO 6 commented: *'if I'm talking about a new therapy...I make it very clear who it's limited to, that it doesn't work for everyone'*; interviewee PO 9 remarked: *'I think we would always press release a controversial paper, if nothing else just to get the caveats out there'*; and interviewee PO 5 said that *'the limitations should be in the press release so that the journalist doesn't get the wrong view'*.

Second participants viewed relevant statistics and information about the research as necessary to be included in press releases. Interviewee PO 4 gives the example of including information about the sample size to indicate the reliability of the data: *'particularly for things like statistics you realise that you can't over-extrapolate or under-extrapolate'*. For some participants 'relevant information' to ensure accurate reporting also included information about the research funding body. Interestingly, this seems to align much more closely with the selling aspect of the role than that of communicating science - though participant PO 7 did not seem to view it as such. In his interview, he stated: *'we also try to include information obviously about where it's been published, because that validates that it's in a peer review journal'*.

Participants' third strategy became evident when I drew their attention to the use of the word 'breakthrough', which headlined in a press release I presented to them reporting the use DBS for minimally conscious patients. Interviewee PO 1 found the use of this word in this context acceptable (*'because it's not been used on the minimally conscious before so it's still valid in that context'*). Other interviewees also found it 'arguable'. In spite of this, as a general rule participants spoke about avoiding this word, and other similar words: *'we have a few buzz words which we really hate, "breakthrough", "missing link" things like that'* (PO 9 journal). Reasons for this were given in terms of, for example, not wanting the story to sound like the answer to everything:

[If] you talk about a breakthrough in a press release then that kind of word attracts hype...you've got to remember all this research is being built on previous research, eureka moments are very, very rare (PO 2 self employed)

Fourth, interviewees spoke of other techniques they used to avoid hype in terms of the scientists. Interviewee PO 3 spoke about evaluating her own scientists' work (*'I don't think we're thinking that we don't want our scientist's work to be evaluated, because that's science and that's a healthy thing'*), and interviewee PO 2 talked about having discussions with scientists about potentially worrying research: *'if I...feel that...there is a huge danger for it to be hyped then I will discuss this with the scientist'*.

Finally, interviewees PO 4 and PO 9 spoke about the necessity of being open and transparent in the press release:

I think over-hyping is often dampened down by just being really transparent about it because often the science isn't going to be there without any holes in it and without any caveats (PO 9 journal)

In circumstances where research has the potential to be misinterpreted this would involve holding press briefings. Interviewee PO 9 stated that her office *'do press briefings for a selection of papers - quite often they are ones which we think may be controversial and may need explaining slightly more'*. And interviewee PO 4 commented that for science deemed controversial:

[We] would give a press conference at the Science Media Centre just so that all the journalists can ask [the scientists] questions until they've addressed any ambiguities

As evident from my findings, then, interviewees' narratives clearly highlighted not only their obligations to refrain from hyping science and/or health research, but also their views about why hype is problematic, why the press release offers an avenue to avoid hype, and the methods adopted to ensure that this can be achieved.

6.3.3 Press releases and the journalist

It became very apparent from speaking to my participants that alongside their self-expressed responsibilities to write accurate and 'honest' press releases, nearly all interviewees (n=9) viewed press releases as documents written 'for' journalists, with interviewees catering to the journalist and typically placing the journalist at the forefront of their discussions (*I write releases for journalists'*

(PO 1 charity association); *'you have to remember the audience is the journalist'* (PO 10 media centre)). As one interviewee noted: *'basically just make it as easy as possible for the journalist to get the information that they need as quickly as possible'* (PO 4 research council). Interviewee PO 1 seemed all too acutely aware of the competitiveness involved in attracting journalists' attention: *'journalists will have hundreds of press releases a day sent from everybody so it would typically end up in their bin unless it's caught pretty quickly'*. And interviewee PO 3 commented that her office thinks *'quite carefully about which words come first in order to grab the journalist's attention because we know we're competing with a lot of other stories'*. This reliance on journalists was most clearly highlighted when interviewees' discussed how journalists' views seemed to act as the primary driving force in the production of specific guidance documents for their industry: *'we produced guidance about three years ago and we went out and asked some of the journalists what they wanted'* (interviewee PO 5). Interviewee PO 7 commented:

They got a guide to working for press officers and I edited that, and in the course of it I spoke to quite a few journalists, asked them what they wanted in a press release....we basically want to make it as easy as possible for the journalists to write up a story

Only interviewee PO 9 recognised the importance of a press release both catering for journalists and servicing authors and the public. For her, she thinks

We have to be aware of what the journalists want, we have to be awake to their needs ...but our main role is to act as a service for the authors and ultimately the public...so I think our role is more geared towards them, but we just have to bear the journalists in mind somewhere along the line

She does, however, describe how it is still important to speak to journalists about their preferences: *'I mean we try to keep quite a healthy dialogue with journalists about what they do and don't like'*.

Participants spoke about selecting stories for journalists on the basis of their 'newsworthiness': *'it would be decided [whether to press release] on its newsworthiness'* (PO 8 industry). Interviewee PO 7 talked about how press officers are educated about news values: *'I mean there is that set of news values that you're typically taught about'*, which, at least for my participants, were synonymous to those of a journalist. In fact, when speaking about 'newsworthiness' participants spoke using classic journalist narratives:

You look for...typical journalist components about what makes a story, is it something that's unpredictable? Is it something on a large scale? Is it something on a small scale? Is there an element of controversy? Does this overturn what was previously thought? (PO 4 research council)

There's a number of criteria that a journalist would apply...for one thing it has to be new...for a journalist...they have to be able to say "a study published today", so we put stuff out in advance so that they can do that (PO 3 university)

Most notably, participants spoke about the importance of a story containing what journalists call the 'so what' factor:

People talk a lot about the "so what" question. It's essentially, what does this mean to the general public, and if you can't answer that there's no point in publicising it (PO 5 media centre)

Essentially participants described this concept as the affect the 'story' has for the man on the street: *'how is this actually going to affect the man on the street? Does it have implications for someone who has this disease...?'* (PO 6 university). Interviewee PO 8 spoke about the importance of newsworthiness much more broadly, in what she called 'initiatives':

If you're creating an initiative then you have to create it so it is newsworthy rather than...getting to the day when you're trying to make news out of it and realise it isn't newsworthy, that's the trick!

This interviewee was my only participant from an industry organisation (recruitment in this area was extremely problematic), and so unfortunately it is difficult to comment whether the almost aggressive media/selling slant to this interviewee's comment is a reflection of herself *or* her employer. Though, it is worthy to note that overall interviewee PO 8's comments were most focused on the selling aspect of the science press officer role. Moreover, she was the only participant who made reference to the role of science press officers in the context of the communications industry more generally (*'and now it is very much, like all communications I think, much plainer English'*), and although this comment is fairly innocuous, it does highlight the possibility that some science press officers in industry may see themselves more as public relations champions with a much lesser role in science communication.

Finally, when talking about writing press releases, participants spoke in narratives often used by journalists: they spoke about the journalists' standard news pyramid (*'there's definitely a format which is the standard news pyramid'* (PO 3 university)); about a 'grabbing' headline; and about a first paragraph that sums up the 'who, what, when, where, and why' of the story:

There's a fairly easy schematic to look at if you're looking at any press release. You go for the inverted triangle...we work on the same principle [as journalists], so we expect to get anybody's attention in our first paragraph - always answering who, what, where, why and when, all those in the first thing -and then go into the methodology...afterwards (PO 4 research council)

When discussing how much detail should be placed in a press release, this too was contextualised in terms of journalists: *'we tend to write it so [the journalists have] got all the information in front of them'* (PO 7 research council). Interviewee PO 9 was the exception:

We have a strict format to our press releases in that they are actually a lot shorter than a lot of university press releases or funded press releases and they're only between 200 and 300 words, so it's very brief, almost like a note or a flagging up to journalists to say "read this research this is worth having a look at"

This comment, which was at odds with the other interviewees comments, along with the fact that this interviewee was the only participant who believed that catering for journalists was *not* the primary role of a press release (see above) raises the question of whether this interviewee's views were individual or were related to the institution in which she worked.

6.3.4 'Selling' accurate science information

It became evident from speaking to my interviewees that they had a specific method for managing the potential tension between the imperative to both accurately portray science to the public and to sell a 'story'. This method seemed to be implicit for the interviewees – a process they were unaware they were following. Interviewees seemed to talk about accuracy in terms of facts only. These facts, however, could be written in a language and style that adopts a selling slant. In fact, *'being sensationalist and accurate shouldn't be mutually exclusive'* (PO 4 research council):

If there's something that's engaging, or there's a pun that can be used well in it, it's in your interest to do that... we did a story a few weeks ago on flu where we called something a super-

antibody and it was right because it was the first antibody that had nailed every kind of flu that hurts people...what we kind of do is just say ‘can I say this can I not say this? Can I get away with saying this and it still being right?’ (PO 4 research council)

He may say ‘it’s amazing it’s astonishing it’s good they’ve done these things’, as long as he’s got the actual study accurate and what they have and haven’t found (PO 5 media centre)

In fact, interviewee PO 2 talks about how sometimes an article ‘*sounds sensational but actually when you read it properly it’s actually perfectly reasonable*’. This selling slant involves clear strategies. For instance, in terms of the informational content of the press release interviewee PO 7 stated that ‘*we will always try and include a quote from the relevant science funding headed division... it gives you that better chance of being named checked*’. Interviewee PO 6 also remarked that ‘*we do use external quotes....typically from funding bodies*’. Participants also viewed the use of patient quotes as acceptable – though this was rarely considered and had its limitations (‘*we do [put patient quotes in] but it’s not very often*’ (PO 7 research council)). In this sense the quotes were seen as a method to add human experience without compromising the science (i.e., to create a selling slant without affecting the accuracy of the data). For example, interviewee PO 4 stated that: ‘*we’d use them quite carefully but you can’t have them contradicting what the scientists say*’. Other interviewees similarly remarked:

I guess you should also give access, should that feel appropriate, to the patient’s family, if they felt that they wanted to do it, because you’d get human interest off the back of that (PO 8 industry)

We’d always be very careful because it adds a very human element to it...however, in this instance [the use of deep brain stimulation for a minimally conscious patient] I think it couldn’t be detached...its about finding a balance I guess (PO 9 science journal)

Finally, some comments from participants suggested that science press officers might shift the responsibility to report accurately onto journalists i.e., they admitted that the press release may be biased (‘*...if you want an impartial voice then you’re not going to get that from a press release*’ (PO 3 university) and it was the responsibility of the journalist to bring impartialness to the ‘story’. As participant PO 4 commented: ‘*it’s for [the journalists] to turn [it] into an article...by getting a more rounded version for the needs of their editors and their readers*’. This is also illustrated in some of the discussions I had with interviewee PO 3:

It's not really the press release it's more about why is the journalist not doing the further work needed to make sure that all these facts add up? (PO 3 university)

These comments highlight a contradiction in some of my interviewees' narratives between, on the one hand, speaking about the ways in which they reported science in an accurate and 'honest' fashion, and on the other hand, admitting that the press release may not be written as impartially as they had suggested, and that it is for the journalists to make it more 'rounded' and ensure the 'facts add up'. Such contradictions are not altogether unsurprising and have been noted previously by Billig in his research into individuals' dialogues about a variety of subjects such as racism, family and the monarchy. Billig argues that people's ideologies do not represent an 'individual opinion' and they are not uniform, rather they are dilemmatic – the very process of thinking about an ideology is a process of debate (between one-self and/or with others broader ideologies) and therefore people's ideologies contain contrary themes (Billig, 1991). He writes how people's prejudice beliefs are often constituted by a rhetoric of contradictory claims as they try to justify their ideology:

Prejudice' refers to psychologically irrational beliefs and speakers attempt to justify, and particularly to self-justify, their own rationality: therefore speakers try to make their discourse 'reasonable' by finding external reasons for discrimination (Billig, 1988: 91)

6.3.5 Views on newspaper and press release portrayal of fMRI studies

During my interviews I asked my participants to speak about their views on the reporting of the 2010 studies conducted by Owen and colleagues. To do this, I presented my participants with the 2010 MRC press release, followed by the 2010 Mirror article reporting the study. My findings from this aspect of the interview corroborate my findings above.

Participants had mixed views about the MRC press release. Some interviewees viewed the press release as competent and pretty fair (*I thought that press release was pretty fair* ' (PO 2 self employed)). Others spoke about the document lacking information and description – particularly in terms of explaining the nature of a vegetative state: *'my query would be around, perhaps in the first paragraph explaining a little bit more, what a vegetative state is'* (PO 8 industry); and *'there was actually very little detail in it...this doesn't even tell you what a vegetative state is'* (PO 7 research council). Several interviewees viewed the lack of limitations and caveats in the press release as painting a too positive picture of

the research: *'there's not many caveats in it, there is not much about the limitations here it's very much a positive story'* (PO 10 media centre); and:

They could have gone into a bit more detail about what it actually means and what it will mean for other patients and how likely this is to be successful in other patients' (PO 7 research council)

In contrast to these participants, one interviewee thought that the press release should have sold itself better. In this way, the 'interesting' parts should have been brought higher in the document, and the statistics made more powerful: *I would say, nearly one in five or something and then put 17% in brackets; I think I would have put that higher up as well. New England journal carries weight* and:

Its quite interesting that you've got this bit in here about "more importantly for the first time in five years decided the patient was a way of changing and educating his thoughts to the outside world". I would probably have used that a bit earlier as well (PO 8 industry)

In comparison to the different views regarding the MRC press release, participants generally viewed the Mirror newspaper article as well written: *I think this is quite good* (PO 10 media centre); *I'd be happy with that* (PO 2 self employed); and *'it does have caveats in there from your Doctor Laureys saying it is early stages...I would have [been] happy with that one'* (PO 4 research council). In fact, interviewee PO 5 was really positive about the article, commenting that it was a 'big deal'. And despite the mixed views about the press release, participants viewed the newspaper report as an accurate reflection of the release: *'it seems a pretty accurate reflection really'* (PO 2 self employed); *'overall I think his tone reflects the press release'* (PO 5 media centre); and *'from the press release, it's fine actually the way they've written it'* (PO 7 research council). Although some interviewee's did raise concerns about the misleading headline (which, as discussed in chapter three, are normally written by editors): *I know they put "speaks" in quotation marks, but that is still overselling'* (PO 7 research council); and:

It's pretty misleading, he's not speaking, I think I would say that speaking involves more than a yes no response for starters, and he actually isn't giving words...this is not the yes part of the brain and the no part of the brain (PO 3 university)

Only PO 9 voiced major concerns:

It's a shame that articles don't put success rates, or how small the sample was, or how many people out of how ever many it actually worked for, because it is important. If it's just one case study there's no way of knowing whether it's transferable into others and they're not highlighting that at all, it's almost a given that if this is happening here ...everyone's got a chance, and they don't outline the reasons why perhaps further research is needed or perhaps we should be cautious...I don't think that's highlighted enough which is really important because it's such a debilitating kind of thing to have...they should put things like that in there so people can have a more balanced view about how realistic this is (PO 9 journal)

These findings suggest that at least for some of the participants, they do try to avoid hype, and are critical of press releases that are written otherwise. However, criticism of the press release seemed to be related to the absence of limitations rather than to a concern about the language used to present the findings. Moreover, it was interesting that many of my participants were not nearly as critical of the newspaper article, which equally conveyed excitement. This seemed to be, to a degree, related to participants comparing the press release to the newspaper article: the belief was that the accuracy of the Mirror article was related to the press release rather than to the content of the newspaper article *per se* – because the article echoed the content of the press release it was a good piece of reporting. Thus, participants seemed to view the press release and the Mirror article with a specific 'vision'. To explore these points further, I presented my participants with a press release reporting another similar innovative technology – a case study of the use of DBS for a patient in a minimally conscious state. The title of this press release was three-fold:

Patient with Severe Traumatic Brain Injury in “Minimally Conscious State” Shows Functional Improvement After Deep Brain Stimulation

Breakthrough Findings in Nature May Offer Hope to Similar Patients, Says Research Team from NewYork-Presbyterian/Weill Cornell, Cleveland Clinic and JFK Johnson Rehabilitation Center for Head Injuries

World's First Successful Electrical Stimulation for Minimally Conscious Brain-Injured Patient

Despite such a title, participants' views about the framing of this press release were - although mixed - generally more positive than the MRC's reporting of the fMRI study. For instance, for interviewee PO 2, the use of the term 'breakthrough' in the headline was appropriate: *that's the*

typical wording to describe that something's new....because it's not been used on the minimally conscious before so it's still valid in that context'. In fact, for interviewee PO 4 an even stronger news hook was needed: *'...the benefit about saying that if the results were replicated it will change the standard of care for these patients - that would have been my hook*'. For other interviewees the use of the word 'breakthrough' was *'arguable*'.

It was a study that was one patient, and that is something to always to be aware of. But I mean I suppose that was clear from the press release...and I actually noticed they used the word "breakthrough" in their sub-heading, but it might actually be arguable in this case, because it does seem pretty dramatic - the changes that this is having on the patient (PO 7 research council)

This was because, for instance, the research emanated from a top university: *the researchers that have done this work are quite good, they're world leaders I know in New York, so it's probably a bit hyped but its...*' (PO 10 media centre). Though, it was important not to raise unfounded hope: *'I think we have to be very careful that we don't provide unfounded hope....nevertheless it is different and it is breakthrough*' (PO 8 industry).

The presence of caveats in the press release seemed sufficient enough to provide balance, making the press release acceptable:

What's good about this is that they are very careful to talk about "ok we've seen this in one patient but we don't know what the implications are more widely they need to do further research" so I think they strike a nice balance between the potential, but also what they don't yet know (PO 3 university)

It includes - particularly towards the end of the press release....a few caveats...so even though they are talking about this in positive terms, they are honest enough to say, "if this will carry on", so I thought that was quite interesting (PO 7 research council)

Only interviewees PO 3 and PO 9 commented on the position of caveats – albeit they interpreted this differently: *'it's nice that they put the caveat "if this is replicated in other people" quite high up*' (PO 3 university); and *'they don't seem to have many of those [caveats], until a lot further down the press release*' (PO 9 journal).

Drawing this together, my participants' views on the two pieces of reporting I presented to them seem to confirm my findings from the previous sections of this chapter - that science press officers have a certain 'vision' about whether an article is sensationalised. For my participants the question of whether a piece of reporting is 'hyped' is related to, at least in part, the accuracy of the facts and to the presence of caveats in the text. For my interviewees, the placement of caveats at the end of the article is reasonable because, as interviewee PO 10 remarked:

When I read everything...I always read the last bit first because that's where all the caveats and stuff generally are, I look at where it comes from...I generally don't read the headlines - I mean obviously you get drawn to it, but I don't pay attention to them, so when I look at that I guess my perspective is very different...

Interviewee PO 5 supported this: *'I would expect something a bit caveated in the last paragraph'*.

Moreover, for my interviewees, quotation marks symbolise 'non-fact' comment, and for them there is a clear separation between these 'non-fact quotes', as opposed to 'non-quoted fact' in the rest of the article. For example, interviewee PO 6 stated that:

If an academic wants to [elaborate on] some aspects of the research that's what a quote is for, so it is very clear that this is something that they feel but it's not stated as such in the paper' (PO 6 university)

This interviewee elsewhere remarked: *'we do use external quotes....typically from funding bodies....I mean it's just a quote...'*. These comments may contrast to an otherwise unassuming public who may not distinguish between quoted and un-quoted text. Indeed, Fiona Fox, director of the Science Media Centre picked up on this issue in one of her recommendations to the Leveson Inquiry in which she stated *"quotation marks should not be used to dress up overstatement"* (Fox, 2012). Finally, for my interviewees, writing style is not seen as a main factor in determining whether an article is hyped. As one of my participants remarked, science press officers are entitled to 'poetic license':

Its probably a bit hyped but its...its a really difficult one because my first instinct is that even if it is a bit hyped, does it really matter...but then when you start to get into it, then you think well actually what if I had a family member who was in this state and this is actually raising hope for them...I know enough about the background of these things to know that this is very unusual, a lot of what these guys do only works in a small number of patients etc. So it's difficult, I think it is

a little bit hyped but I, by far away it's not the worst one I've seen...I think there's a certain amount of poetic license in it...it's difficult where to draw the line - you have to be accurate and evidence based, but if this is generally the first time they've done this procedure and it has worked, then it's fascinating and it's a great story (PO 10 media centre)

6.4 Summary and discussion

This chapter has explored the role of science press officers and science press releases in perpetuating excitement about science and/or health research to the public, specifically in relation to the fMRI studies conducted by Owen and colleagues.

The mood of excitement portrayed in the newspapers about the two fMRI studies closely echoed that seen in the MRC press releases, suggesting that these documents had some role to play in generating this excitement. As discussed in chapter three, such findings have been repeatedly reported previously in broad studies which have explored the role of press releases in science research reporting (Miller et al., 1998; Woloshin & Schwartz, 2002; Kuriya et al., 2008; Woloshin et al., 2009). Similar findings have also been noted specifically in relation to innovative health technologies (Nerlich et al., 2002; Henderson & Kitzinger, 2007; Racine et al., 2007a).

There were also indications in the press release, as well as from some of my interviews with science press officers too, that the authors of the studies may have played a role in generating excitement about the research. Authors were quoted in the press release as finding the results '*exciting*' (2006) and being '*astonished*' (2010). Moreover, in my interviews with science press officers, some of my participants recognised that some scientists – including Owen himself - are particularly media savvy: *'I know Adrian Owen wouldn't have let it go out unless he was happy with it, and he's a very kind of robust spokesman'* (interviewee PO 2). Finally, though not discussed above, in my interviews with science press officers it became evident that writing a science press release is very much a joint endeavour between the scientist and the press officer - participants spoke about interviewing scientists prior to writing a press release and discussing drafts of the releases with the scientists, and that it is an institutional requirement - at least for all my participants - that a press release is approved by the scientist before it is released. This involvement of scientists themselves in generating excitement about their own research has also been noted previously (Nerlich & Clarke, 2003; Smart, 2003; Kitzinger, 2005; Henderson & Kitzinger, 2007; Rödder & Schäfer, 2010), as has the way in which scientists' and/or science press officers' use of metaphors have found their way into the public arena (Nerlich et al., 2002).

In contrast to the MRC press releases, the *Science* press release posted about the fMRI study in 2006 was much more conservative, and excitement was not outwardly conveyed. This is an important finding as it cautions us to be careful about generalising about all press releases being generators of excitement, and it highlights the importance of exploring the source of a press release when considering its content.

Finally, my findings suggest that via the posting of comments from other scientists on their website, the Science Media Centre may also have played a role in generating excitement about Owen and colleagues' studies. It is questionable whether the provision of these comments, which described the studies as '*remarkable*' and a '*huge step*', reflect the mission of this centre, which, as it appears on their website, is to provide '*accurate and evidence-based information about science...through the media*'. As discussed in chapter three, Joan Haran has previously critiqued the Science Media Centre for its pro-science goals, arguing that via its contribution to the setting of media agendas and to the framing of news stories, it has the potential to obfuscate the distinctions between science knowledge, scientific practice and science governance (Haran, 2011). Haran raises an interesting point that is relevant in this instance: although I would argue the Science Media Centre does to a degree play a role in ensuring science is portrayed in the newspapers in a (more) controlled fashion, we need to tread cautiously. First, the provision of 'balancing comments' by the Science Media Centre seems to encourage, rather than address, issues related to churnalism: journalists are spoon-fed 'counter-arguments' to the authors of a publication, rather than being encouraged to investigate a story independently. Interestingly, science press officers from the Science Media Centre do not necessarily view it this way: in their critique of the Science Media Centre, Williams and Gajevic note that one of their Science Media Centre interviewees stated that "*when churnalism does happen they're just churning the scientists' words, and not a pre-agreed 'line' from the SMC [Science Media Centre]*" (Williams & Gajevic, 2013: 514). Second, the Science Media Centre's strategy could also be considered a form of control by the centre over what they deem appropriate for journalists to include in their news articles (Williams & Gajevic, 2013) (also see (Henderson & Kitzinger, 2007)). As Haran has previously noted, the Science Media Centre and its "*media savvy*" scientists attempt to:

Impose closure on the messages transmitted by the media and to retain the authority to speak for – and about – their profession and its practices [...] is arguably at odds with the attempt to

restore public trust in science by engaging members of the public in informed debate (Haran, 2011: 255)

And third, whilst, the comments posted on the Science Media Centre's website were importantly sourced from external experts in the field, by trying to provide 'balanced' information via solely approaching scientists for their views about these fMRI studies, it has paved the way for just more scientists to be excited (even if slightly less so than the original authors) about the research, and provided information that could be considered scientist and/or technology-centred. Williams and Gajevic have also pointed out that "*the scientists quoted...do not exist in a promotional vacuum: many are experienced media operators, and all had the support of institutional press officers*" (Williams & Gajevic, 2013: 515). It could be further argued that, in this instance, the Science Media Centre had taken the view that a scientist's knowledge is the only (or only important) source of expertise (this adds to my previous point about control). Such information fails to address many of the social implications associated with the research. In terms of the fMRI studies, this would include some of those issues raised by my interviewees in the previous chapter - such issues which were not mentioned in the press releases, the Science Media Centre website, or in the majority of newspapers.

Whilst my findings point to the press releases as generating excitement about the two Owen and colleagues' studies, in contrast, my interviewees expressed responsibilities to avoid hyping. Such findings have been reported previously (for example, see (Henderson & Kitzinger, 2007)). They viewed themselves as almost *obligated* to produce accurate press reports that avoided hyping, and, in turn, avoided prompting false hope and expectations for the public, patients and families. What quickly became apparent during my interviews was that the reason my participants were able to hold these views whilst science press releases at the same time seemed to be hyped, was, at least in part, deeply rooted in how science press offices viewed their role in disseminating science. To summarize, for my participants, the role of the science press officer was two-fold (though different press officers prioritised each of these roles to varying degrees). First, it functioned to raise the profile of its institution to secure necessary funding. Second, it functioned to accurately communicate science from scientists to the public. These findings have been documented previously (Clegg Smith et al., 2010). However, this thesis develops this idea: this dichotomous role filtered into the writing of science press releases: on the one hand, press releases were viewed as a method of 'control' to ensure that science is communicated responsibly and accurately to the public. On the other hand participants catered press releases to the

journalist, with their primary goal being to sell the press release to the journalist. My interviewees negotiated such contradictory roles when writing press releases as follows: participants seemed to talk about the accurate dissemination of science research in terms of facts only i.e., ensuring the informational content of the press release was correct and that the research had been caveated and limitations mentioned. Their ‘science story’ could maintain this accuracy even though the facts of the story were written in a language and style that adopts a ‘selling slant’, by, for example, the language used; the use of quotes; and the introduction of a ‘human element’.

On the basis of the above findings I would like to make several points. First, in my discussions with science press officers about their role, some of their comments were almost identical to previously reported comments made by science journalists talking about their profession. I highlight three examples. First, my participants and journalists both share the need to write in a competitive environment. For instance, one journalist interviewed by Winsten stated that *“I’m in competition with literally hundreds of stories everyday, political and economic stories of compelling interest”* (Winsten, 1985: 9). In comparison, interviewee PO 1 remarked *‘journalists will have hundreds of press releases a day sent from everybody so it would typically end up in their bin unless it’s caught pretty quickly’*. Second, the pressure on science press officers to attract journalists’ attention seems to be analogous to the pressure on science journalists to attract the attention of their editors (*“..what your boss thinks your audience is...come[s] into play [when choosing a news story]”* (journalist)(Reed, 2001); *“most of all I have to gauge what my editor thinks”* (journalist)(Henderson & Kitzinger, 2007: 75). In this way both science journalists and press officers must search for news offering headlines that are interesting not only to the potential reader, but also to their editors / a journalist. Finally, journalists have spoken about the tensions in their role, on the one hand to sell a story, but on the other hand to refrain from overstepping ‘the boundary of truth’ (Winsten, 1985; Entwistle, 1995). My interviews identified similar tensions. For both science press officers and for journalists, individuals differed in where they struck this balance.

It is perhaps unsurprising that there are so many similarities between science press officers and journalists given the similarities of their roles. Although more research is required, these similarities may be evidence of something more deeply problematic in the science press officer industry: the close alignment they seemed to have with journalists – both relationally (my participants spoke of close relationships between themselves and journalists), as well as via the above similarities in their descriptions of their job role, suggest that perhaps science press officers are unaware of just how much their role constitutes a ‘selling’ or ‘journalistic’ aspect at the

expense of the ‘communication’. For interviewees who seem to pride themselves on their strong belief that one of the goals of their job was to accurately inform the public about science research - they were, in short, champions of accurate, ‘honest’, science communication - this point raises serious questions about the underlying assumptions of many of my participants about their role as science press officers, about the industry’s ethics and about the norms of its culture.

Second, the science communication role my participants see themselves in is reminiscent of the public understanding of science approach to educating the public about science. As I discussed in chapter three, the underlying assumption of this approach has been widely criticized (Gregory & Miller, 1998; Schäfer, 2011). Alternative proposals include the public engagement approach - an approach, which does not preference science knowledge but argues that knowledge should be produced as the result of public interactions – or engagements (Grants, 2003; Schäfer, 2009; Rödder, 2011). Whilst engagement strategies have now been embraced by a variety of institutions, including the UK research councils group⁵³ and the Wellcome Trust⁵⁴, Borhelt and others have previously argued that asymmetrical communication models are still the preferred mode by scientists and of science public relations practice (Borchelt, 2008; Clegg Smith et al., 2010). My interviews with science press officers support this: when discussing their role as a science communicator, all my participants viewed their own role as aiding scientists’ in their role in informing the public about science in a uni-directional manner (*‘it needs to be scientists talking about [science research] I think, if it’s going to be accurate and [they want to have] people understand the importance of science’*). Indeed, one interviewee expressed concern about some press officers’ lack of appreciation of this aspect of their role: *‘[some] press officers don’t see public understanding of science as their responsibility and again should we be doing something about that?’* (PO 10 media centre). Such inconsistencies between these views and the research exploring the ‘sender/receiver’ public understanding of science model raises questions about the underlying assumptions and ethics some science press officers may have about their role as aiding the public’s understanding of science.

Third, as I stated in chapter three, Nelkin argues that *“the tensions over science reporting have less to do with accuracy than with style”* (Nelkin, 1996: 1601). My participants’ beliefs that they accurately communicate science by reporting facts using language that adopts a selling style adds evidence

⁵³ <http://www.rcuk.ac.uk/per/Pages/Home.aspx>

⁵⁴ <http://www.wellcome.ac.uk/Funding/Public-engagement/>

to this. However, the style with which science can be reported is not in itself unproblematic. In 1985 Winsten argued that “*sometimes the tone of the story....misleads, even when each sentence is factually accurate*” (Winsten, 1985). More recently this point has been re-iterated by a group of prominent scholars in the science communication field who wrote that “*accuracy in reporting and the dissemination of high-quality evidence are not necessarily synonymous*” (Bubela et al., 2009: 516). These scholars continue:

Many academic articles, editorials and reports draw on findings about errors of omission and accuracy to recommend best practices and checklists for journalists. But...The most important issue may not necessarily be content, but rather how the research is framed (Bubela et al., 2009: 516)

Finally, my participants’ responses to the two press releases I presented to them during the interviews suggested that, for them, the inclusion/exclusion of necessary caveats and limitations seemed to be the over-riding determinant of whether a press release was viewed as ‘hyped’, rather than the language style in which the release was reported. Indeed, at the Leveson inquiry one of the points made by Fiona Fox, the director of the Science Media Centre, was that science reporting can be improved with more caveating, more limitations, more accuracy (Fox, 2012) - the influence of the style in which a news report is written, being completely absent from her discussion. Moreover, for my participants, the appropriateness of the reporting in the newspaper article presented to them seem to be related to how well it reflected the associated press release rather than its content *per se*. Both these facts point to a specific ‘vision’ that a science press officer has as to how she/he views hype. Such a vision is unlikely to be shared by others, such as scientists; stakeholders; the public; and/or by families ((Caulfield & Bubela, 2004); also see findings from interviews in previous chapter). For example, it is doubtful how many individuals reading a newspaper article read the last paragraph first, or clearly distinguish between an article’s content in and out of quotation marks – two techniques spoken about by my interviewees. The point is most clearly summed up by one of my press officer participants:

I don’t know if I’ve been in the job too long because I think had I been still in the middle of my neuroscience PhD would I look at that and go “Oh my God it’s hideous”. But I don’t look like that at that now

The same interviewee also remarked in relation to the Mirror’s reporting of Owen and colleagues’

2010 study:

When I see things like this...half of me thinks “Oh my God” and half of me thinks “I love it” because it’s half a page in the Mirror. Yes, it’s not going to make my Gran understand the complexities of neuroscience and psychology, but for me when it’s fighting with 20 other stories and they’ve got this in...it is a great story

6.5 Concluding Remarks

Overall, in this chapter I have argued that the scientists, the Science Media Centre and the associated MRC press releases were all likely to have played a role in generating excitement about the two studies conducted by Owen and colleagues in 2006 and 2010. My interviews with science press officers help to de-construct the role that this industry plays in such science/health reporting: science press officers view this reporting differently to how it is perhaps viewed by scholars, stakeholders and or the public – they have a specific ‘vision’ of what constitutes hype. I return to this point in more detail in the final discussion chapter.

Chapter 7: fMRI for severely brain-injured patients: ethical debates

7.1 Introduction

In the preceding two chapters I focused specifically on exploring how and why the excitement surrounding the UK newspapers' reporting of the two Owen and colleagues' studies was generated, as well as exploring the effect of this excitement on some family members. I also highlighted the gap that was evident between the newspapers excited portrayals of the technology and the more nuanced responses of family members to the research. In this chapter I explore how the ethical issues associated with these studies were portrayed in the press releases and UK newspapers. I compare this to the types of issues family members reported as concerning them about the technology and highlight key areas of difference. In addition, I also point to further differences between my findings and how academic scholars have discussed the associated ethical concerns of this technology.

7.2 Defining ethics

During the course of writing this thesis I found it increasingly difficult to neatly define the ethical issues associated with the fMRI research.

In a recent study by neuroethicists Racine and colleagues which explored the news media's portrayal of neuroscience, the authors defined 'ethical, legal and social issues' (considered to be issues relating to, for example, commercialization; discrimination; stigma; privacy and confidentiality; dignity and integrity; justice; and the meaning of research) separately from 'scientific medical issues' – classified as validity, reliability, safety issues, and side effects (Racine et al., 2010). Across the literature discussing fMRI for severely brain-injured patients, as well as from my empirical data, concerns regarding the use of this technology have ranged from issues associated with end-of-life decision-making and clinical decision-making; philosophical issues related to the meaning of consciousness; issues related to social justice, including access to the technology; and questions about the medical validity and clinical applicability of the research i.e., the technical limitations of the technology. If I were to adhere to Racine and colleagues categorization of ethical, legal, social *versus* scientific medical issues (which is a common categorization throughout similar studies) most of the issues relating to the use of fMRI would be

categorized as the former (i.e., as ethical, social legal concerns) with one exception - the technical limitations of the technology. However, I argue that the case of separating the technical limitations (and possibly other concerns not typically viewed as ethical, social or legal) away from other issues is not so straightforward. The reason for this is two-fold. First, the societal impact of technical limitations may themselves raise ethical and/or social concerns. For example, if a technology can only be applied usefully (i.e., is clinically valid) to a small proportion of the population, this may be viewed as a limitations, however, this also raises questions regarding the amount of resources society should invest into the technology (cost-benefit issues), as well as questions regarding obligations (should this technology be mandatory?). A similar point has been noted previously by Racine and colleagues (Racine et al., 2006a) who stated that *'scientific issues such as limitations, interpretation, and validity are double-headed, because they include both technical and social concerns'* (Racine et al., 2006a: 137). And second, in discussions with my interviewees about their experiences with the technology, the boundaries between 'ethical issues' and 'technical limitations of the technology' were blurred: for some of my interviewees the limitations of the technology factored in to serious concerns about its use.

Thus, whilst the distinction between ethical, social, legal *versus* scientific medical issues is useful, it is problematic so far as to (a) assume that the division between such issues is a neat one, and (b) acting to define what an 'ethical, social, legal' issue is. Because of this, in this chapter I very broadly consider that an ethical issue be defined as any concern that has been raised about the technology in the academic literature, the news media, and/or by my interviewees. I discuss some of the implications of this decision in my final discussion chapter.

7.3 Newspaper and press release reporting of ethical issues

There were three main ethical issues that featured in the press release and newspaper reporting of the research, and these included the studies' limitations, qualifications, and social justice concerns; end-of-life decision-making; and personhood. I discuss each of these in three broad divisions. First, I discuss how issues relating to the studies' limitations, qualifications, and social justice concerns were presented in the press releases and the newspapers. In the following two sections I discuss how issues relating to personhood and end-of-life decision-making were reported in the newspapers (the press releases did not discuss these two issues). Just over half of the news articles mentioned at least one of these two issues (n=28/51) with most of these mentions being related to end-of-life decision-making.

7.3.1 Reporting of limitations, qualifications, and social justice issues

As discussed in the previous chapter, three press releases were disseminated about the two Owen and colleagues' studies in 2006 and 2010 (MRC, 2006 and 2010; *Science*, 2006). Caveats about the research were scarce in these documents - in fact only the 2006 MRC press release mentioned a limitation of the research (*'if we don't see responses in a patient it does not necessarily mean that they are not aware'*), which was subsequently picked up by three journalists (n=3/17; 2006 articles only). There was no other reporting of limitations of the technology bar a commentary piece in 2010 by Ilora Finlay, Professor of Palliative Medicine:

The danger is that the patient is now abandoned until the next MRI...“yes”/”no” answers are different from complex communication. The doctors' "sensitive" question may arrive in the patients' brains with gross insensitivity, like a grenade exploding in their thought processes...[we] need much more than simple “yes”/”no” questions to assess what patients feel... (The Times, 4 February 2010)

Social justice issues were also neglected from the press releases and only one journalist, Mark Henderson who at the time was The Times science correspondent, reported that fMRI is *'an expensive and difficult procedure that can be done only infrequently'* (Times, 4 February 2010).

In terms of qualifications, the two press releases in 2006 *did not* make generalisations about the studies they were reporting: it is important to remember that the 2006 study only involved one patient. In fact, the press release disseminated by *Science* (2006) cautioned against generalising the results:

Both Naccache and Owen emphasize that it is important not to generalize from this single patient to most other vegetative-state patients'. "This is unlikely the case for all vegetative patients," Owen said

However, in some of the 2006 newspaper articles reporting the study, results were generalised. In the first line of four news articles reporting the study (n=4/10; excluding commentary pieces) journalists spoke of 'patients', plural, rather than 'the patient' or 'the woman'. For example, *'patients who are in a vegetative state may be able to hear...'* (The Times, 8 September 2006). And only

four news articles explicitly (n=4/10; excluding commentaries) stated that the study could *not* be generalised for all. Guest writer Dr Ed Walker, who helped treat victims of Hillsborough, made a similar point that *'the validity of this one-off experiment has been questioned'* (Independent, 12 September 2006; Belfast Telegraph, 16 September 2006), as did a commentary article appearing in The Guardian (*'it would be wrong to rush to conclusions generalising from just one case'* (11 September 2006)).

Generalisations were also present in images presented next to the 2006 articles. For instance, a brain scanner image in the Daily Mail showed a 'normal' and a 'persistent VS' brain with the generalising caption stating *'a patient in a persistent vegetative state shows a smaller reaction [to the healthy brain], but critically the same area'*. (Daily Mail (b), 8 September 2006). As discussed in chapter two, the processing of fMRI images is itself complicated, and fMRI images of 'normal' or 'healthy' brains are themselves an average of many individuals' brain scans. Generalising images in the newspapers may provide an over-simplified view of the technology to the public - most of whom are unaware of the nature of the intricate processing of fMRI images - and more importantly dichotomises the overwhelmingly complex differences amongst individual brain scans. Issues and implications related to this, and also related more broadly to brain images are beyond the scope of this thesis, but have been discussed extensively in the literature (Dumit, 2004; Joyce, 2008).

In 2010, the press release and all the UK newspaper articles highlighted the story of a patient who was able to wilfully modulate his brain activity to answer 'yes' and 'no'. Whilst the press releases mentioned that only a minority of the patients had responded to the fMRI task, articles rarely mentioned this fact (n=11/34), and failed to discuss the implications for 'non-responders' and their families. In the articles which did mention it, reference to this was generally found much lower down in the articles; in the press release it was higher up. And in both the press release and the newspaper articles, press officers and journalists drew attention to the minority of patients who responded or showed signs of awareness, rather than the majority of patients who did not: *'four [patients] were able to generate thoughts of tennis or their homes and create mind patterns that could be read by fMRP'* (Guardian, 4 February 2010). Though as the guest writer and philosopher John Harris said we must remember that *'even five people in every 54 who are still ghosts in their own bodily machine and who might be helped is a very significant number'* (Independent, 4 February 2010).

7.3.2 Personhood and consciousness

Issues relating to the nature of consciousness/awareness/personhood were not mentioned in the MRC press releases, but were referred to in the *Science* press release (2006; *'In a related Perspective, Lionel Naccache discusses whether this patient is actually conscious'*). Five 2006 news articles echoed this point – four of which quoted a comment by Paul Matthews (Professor of Neuroscience) which had been placed on the Science Media Centre's website stating that *'contrary to the claim of the authors, the observations do not establish either that the patient made a 'decision to co-operate' or that she had self-awareness'* (e.g. Daily Telegraph, September 8 2006). Comments questioning the association between brain activity and patient awareness, whilst welcomed, were typically placed at the end of articles, and were embedded in a predominant rhetoric of certainty about the capabilities of fMRI as a tool for the detection of awareness in vegetative patients. Commentary pieces provided a little more detail about some of the issues. For example, the Independent's Health Editor, Jeremy Laurance, referred to an editorial in *New England Journal of Medicine* which questioned the relationship between awareness and the research findings. The day later, in another piece, he highlighted that: *'Having awareness is not the same as having a biographical life with feelings, thoughts and memories. A lot more goes into forming the human personality than a mere set of neurons and synapses'* (Independent, 5 February, 2010). Similar points were made in guest pieces. For example, Sheila McLean (Emeritus Professor of Law and Ethics in Medicine), argued that:

While this research shows that there may be a level of consciousness in some cases, this does not necessarily imply that recovery is possible; merely that the ability to communicate at a relatively elementary level exists in some cases (Guardian, 5 February 2010)

And philosopher John Harris, wrote in the Independent:

Even...where there does seem to be communication, it is still difficult to have any idea what sort of consciousness it is that might be responding...To know whether or not there is really someone in there involves more than evidence of consciousness or communication. We communicate with animals and they are conscious, but most of them are not persons...What's special about people is their capacity for what is sometimes called a 'biographical life'...Someone with a biographical life is aware of himself or herself, has hopes, fears, memories: he or she is someone with a past and a future of which they are aware, who can experience happiness and misery, and who wants to choose between them... (4 February 2010)

Other discussions about the issues relating to consciousness and/or the complexities of defining this term were infrequent, and limited to comments similar to that seen in the Express, which noted simply that ‘*[the findings] raise a whole issue regarding consciousness and how we use this term*’ (8 September 2006).

7.3.3 Implications for end-of-life decision-making

Well over half of the news articles that mentioned at least one ethical issue referred to ethics solely in relation to issues relating to end-of-life decision-making (n=21/28; 23/28 in total made reference to this point). Two news articles were even angled to highlight this ethical issue to make the story newsworthy. For example, ‘*Breakthrough intensifies ethical dilemma over switching off life support*’ headlined in the Daily Mail ((b), 8 September 2006). Headlines are, of course, penned by editors and sub-editors and not written by journalists. However, journalists, too, drew attention to this particular ethical issue, and two journalists even incorporated comments from lobby groups concerned with end-of-life decision-making: the Daily Mail’s news article included a comment from Care not Killing ((b), 8 September 2006) and a commentary piece in The Sunday Times included a quote from Dignity in Dying (4 February 2010).

A closer look at many of the news articles revealed that discussions of the ethical issues related to end-of-life decision-making were limited. The Mirror’s journalist, for example, stated merely that ‘*it may later raise the issue of [the patients] being asked if they wished to die*’ (4 February 2010). Other journalists opted to use terminology such as ‘*Ethical dilemma*’ (headlined in Daily Mail, 8 September 2006) and ‘*controversy*’ (Guardian, 4 February 2010) with little regard to their meaning or implication. For example, readers of The Times read only that ‘*decisions to switch off life-support systems...could become even more fraught*’ (8 September 2006) and the Express printed simply that ‘*the discovery may fundamentally change the way decisions are taken to remove vital life support systems for such patients*’ (Express, 8 September 2006). Even the Daily Mail ((b), which headlined the issue, only provided a small discussion of why these dilemmas were ethically problematic:

The woman involved in the latest test results would not have her treatment withdrawn, because her condition is relatively mild on the case of PVS [persistent VS] and the possibility of recovery remains, however small. However more serious patients with no chance of recovery might still have the same responses to external stimuli as the woman yet find their treatment withdrawn (8 September 2006)

Some commentaries provided further discussion on the issue. For instance, in her article *The Ethical Dilemma of Vegetative States*, Professor of Law and Ethics in Medicine, Sheila McLean, discusses issues around whether patients in a vegetative state should be kept alive. Ilora Finlay, too, talks about end-of-life issues. For her:

Asking patients if they are in pain and need pain relief, and inquiring about other physical aspects of their situation, is a long way from knowing the extent to which they have capacity for complex decision-making and asking them whether they want to be kept alive

She cautions us that Owen and colleagues' research does not '*mean that we will have a short cut to difficult decisions about whether we carry on treating and caring, or whether we end life*'. Other guest writers used end-of-life decision-making as a news hook to re-enforce their personal views. For example, an opinion piece in the Sun by guest writer, Phyllis Bowman (a key figure in the founding of both the Society for the Protection of the Unborn child' and the 'Right to Life' lobbying group) declared '*I am Opposed to Euthanasia*' and used the '*tremendous*' findings for the fMRI research to underline her views (Sun, 4 February 2010). Similarly, Melanie Phillips in the Daily Mail used the research as a hook to reiterate her opposition to 'legalised killing' and to protest against '*doctors who want to play God*' (Daily Mail, 11 September 2006). Another report, under the headline '*We now know that patients in a vegetative state can hear and think*', recorded the personal experience of a journalist who had been in a coma for a month, and recovered without serious problems. On the basis of his experience he concluded by expressing concern about patients being allowed to die, stating that: '*if it [the fMRI research] leads to doctors becoming more cautious about condemning patients, I, for one, will be relieved*' (Daily Mail, 16 September 2006).

The mention of implications related to end-of-life decision-making in the news articles is interesting since the associated press releases did not draw attention to these issues. However, implications relating to this issue were mentioned in a comment posted on the Science Media Centre's website. The particular comment, posted in 2006, was written by Dr Narender Ramnani from Royal Holloway University. He ended his statement about the research stating '*given such patients might be conscious and capable of making their own decisions, is it acceptable for others to terminate their lives...*'. It is possible that the posting of such a comment on the Science Media Centre's website,

could have been a trigger, or could have played a role, in some journalists' inclusion of the issue of end-of-life decision-making in their news articles.

7.3.3.1 Legal issues

In spite of the fact that fMRI was sold to readers as a technology which carried implications for end-of-life decision-making, there were only a few mentions of current legal practices in this area, and these were nearly all in commentary articles. For example, an article in the Guardian discussed the withdrawal of life support in relation to the use of advanced directives/ living wills (11 September 2006); in the Daily Mail Melanie Philips stated that *'the law has allowed doctors to stop giving such patients food and fluids on the grounds that this permits them finally to die and thus end a 'living death''* (11 September 2006); and in her piece describing the vegetative state, Sarah Boseley, health Editor at the Guardian, wrote that *'with the consent of the family, doctors may go to court for an order allowing them to sedate the patient and withdraw nutritional support, allowing them to die'* (4 February 2010). Only one journalist mentioned the Mental Capacity Act (2005):

It raises huge questions over Labour's Mental Capacity Act which comes into force next year. The legislation lets patients draw up 'living wills' allowing doctors to withdraw treatment if they become incapacitated' (Daily Mail ((a), 8 September 2006)

And finally, a commentary piece in the Guardian by Sheila McLean offers the only other mention of the law:

The consequence of a diagnosis of permanent vegetative state is that it can be lawful to withdraw...ANH [artificial nutrition and hydration] with the result that the patient ultimately dies. In England and Wales (but not in Scotland) court approval is needed before ANH can be removed...The presumption seems to be that it is permissible not to continue with ANH because it is essentially futile (5 February 2010)

Despite the limited discussion of the legal practices relating to end-of-life decision-making, a significant proportion of articles made a reference to Tony Bland (n=7) and/or Terri Schiavo (n=8) - as discussed in chapter two, these were two highly publicised permanently vegetative patients who had their life support removed following landmark court decisions. The cases were used as a source of historical reference about such controversies. For instance, the Daily Mail's

journalist made reference to the ‘*legal battle over whether doctors were allowed to withdraw [Schiavo’s] feeding tube after 15 years*’ ((b), 8 September 2006); and the Independent’s journalist described Bland as ‘*a victim of the 1989 Hillsborough football stadium disaster, who spent three years in a VS before his feeding tubes were withdrawn and he died in 1992*’ (8 September 2006). In the Independent in 2010 (4 February) these references were deemed significant enough to have a separate section following the main article entitled *Prisoners in their own bodies*, which contained three paragraphs about, and images of, Schiavo, Bland, and Houben⁵⁵. The image of Tony Bland was significantly larger than the others and is shown in Figure 7.1.

Other newspapers featured different images: for example, Figure 7.1 shows the controversial image of Schiavo which featured in the Guardian. This image was promoted by Schiavo’s parents during their legal battle to try and keep her alive. It is a picture of her seemingly smiling at her mother (post injury). Her parents argued that this suggested Schiavo had some awareness. (Guardian, 8 September 2006). And the Daily Mail showed a photograph of a happy Schiavo pre-injury captioned with the stark statement ‘*her feeding tube was withdrawn after 15 years*’ (Daily Mail, 8 September 2006). The referral to Schiavo and Bland in these articles represents an example of media templating – “*events that attracted intense media interest at the time and which continue to carry powerful associations*” (Kitzinger, 2000: 61). Kitzinger argues that media templates:

Are routinely used to highlight one perspective with great clarity [and]...are instrumental in shaping narratives [and]....guiding public discussion not only about the past, but also the present and the future (Kitzinger, 2000: 61)

⁵⁵ Ron Houben had been diagnosed as being in a vegetative state for 23 years when, in 2009 his caregivers claimed that in fact he was conscious and could communicate (i.e., had locked-in syndrome). In 2010, the claim was rejected when communication could not be repeated with a different facilitator.



Figure 7.1: Picture of Tony Bland featured in various newspapers. Bland in the Independent, 4 February 2010 (top); image of Schiavo pre-injury printed in the Daily Mail, 8 September 2006 (bottom left); and controversial image of Terri Schiavo which featured in the Guardian, 8 September 2006 (bottom right).

References to Schiavo and Bland, then, seem to be (intentionally or unintentionally) more than just informative. Their presence is suggestive that fMRI may have been able to detect awareness in these patients. Indeed, a number of pro-life activists and commentators framed Owen and colleagues' studies in this light. The most notable of whom was Bobby Schindler, Schiavo's brother, who, in an interview with Rob Stein, commented: "*I wish this could have been used on my sister to see what could have been done to help her*" (*Beneath the 'vegetative state,' scientists find some alert minds*, Washington Post, 4 February 2010).

7.3.3.2 Informed consent

The issue of informed consent was picked up by only two journalists and in each case it was in relation to end-of-life decision-making. The Daily Mail's journalist, Julie Wheldon, for example, questioned '*is it acceptable for others to terminate their lives without the consent of these patients?*' ((b), 8 September 2006)). Sheila McLean also spoke about this issue in her commentary piece in the Guardian (5 February 2010) where she questioned whether using fMRI technology to ask if a patient wants to live or die could not technically be considered informed consent.

7.3.3.3 Summary

End-of-life decision-making was by far the most discussed ethical issue associated with the reporting of Owen and colleagues' studies. However, journalists' mention of this issue was often followed by a limited discussion – including little acknowledgement of the legal situation of such decisions. For example, journalists' descriptions seemed to imply that patients would either have or would not have decision-making capacity and that for those who did, they would want to be asked whether they wished to live or die. Further, they implied that if a patient did wish to end his/her life, they would be legally allowed to do so. However, whilst such patients have a right to refuse artificial nutrition and hydration, a recent court case which denied the right of a patient with locked in syndrome (Tony Nicklinson) to be euthanised at his request, suggests otherwise (Judiciary of England and Wales, 2012). Commentary pieces added a deeper discussion of the complexities of such issues, but were also ground to re-enforce pro-life views.

It is important to remember that it is likely that whilst some patients may be able to communicate, this does not mean they will have full decision-making capacity. And those

patients who do not respond in an fMRI are not necessarily completely unaware. As Benedict Carey, a science and medical journalist for the New York Times, explains:

The public is inclined to liken awareness to a lamp, either on or off. Brain-injured patients are either there or not there. For researchers, however, unconsciousness is less like a lamp than a bundle of old Christmas lights: some dark, others with lights blinking here and there, still others flickering...’ (An image of consciousness creates a stir, 10 September 2006).

7.4 Interviews with family members

7.4.1 Understanding the fMRI technology

Interviewees’ understanding of the fMRI technology and its limitations came primarily from hospital consultants and researchers. Rachel offers a good example of how her knowledge of fMRI as gained from the media (overly optimistic – it was going to ‘*prove everything*’) gave way to a more rounded knowledge following on from discussions with the clinicians. She vividly recalls how she first approached her relative’s consultant about the research:

When you discover it you think it’s this amazing thing that only you know about and then you forget that you’ve got these neurologists that have studied for like 40 years and they’re like “yes of course we know of fMRIs” and you’re like “oh well can we do it? Let’s go and have it done”, and do you know what the thing was, that’s not just where that ended because they said “look it’s not that simple, it’s not like there’s just one in every hospital”, and I’m like “oh why not? Why don’t we have these in every hospital?”, and then they’re like “we have been trying to get him one done”. And then they said “but it’s not that simple we haven’t been able to arrange it, there’s not any studies going on that they want him for”. I was like “studies? This is life you know, it’s his life, it should be on the NHS, what do you mean studies?”

For Laura and Eli, it was the consultant/researcher who first approached them about the research. Laura provides another good example of how her discussions with the clinicians gave rise to a good understanding of what the technology can offer:

The consultant...she sort of went on to explain a bit about what it involved...I can remember she said “I don’t want to raise your hopes because even though they’re starting to do this, it’ll be a long time before they can take that next step. They may find out information, perhaps little parts

of the brain are working, but they're a long way away from finding a way of actually using those skills to help the person involved"

Alison and Trudy did not discuss their meetings with the consultants directly, however both showed an understanding of the technology. For instance, this is an extract from Alison's interview as she talks about the difficulties regarding using the technology:

Someone in Andrew's condition, he had to have a shunt put in and he had to have a plate. Now all of those things are metal and you obviously can't put bits of metal through an MRI scanner so you have to try and find out what sort of metals they are. In Andrew's case the plate is titanium so that's fine, the shunt we never did find out properly - they couldn't tell us after ages of trying - so he had to have an x-ray, and in actual fact then the plate itself - although it's titanium and there's no danger - it casts a shadow so that you can't get the correct readings and things from the start, so somebody with a plate it could very well be that they're not suitable for this kind of research

Whilst all interviewees generally understood the drawbacks of fMRI, they engaged with them differently. This often reflected their distinct experiences with the technology, as well as their relative's diagnosis, patient care, recovery prospects, and length of time since diagnosis. Whilst speaking about her experiences with the technology, Alison described many of the difficulties she incurred. First she talked about the difficulties with any assessment:

There were so many things that have to be taken into consideration when they do these assessments...patients get very tired easily, get very distracted, there's all sorts of things why they might not be able to do something, they might just be asking them at the wrong time of day, they might have an underlying chest infection that hasn't been diagnosed yet...it brings up questions about how the diagnosis is actually made...

More specifically in terms of the fMRI technology, she spoke about the cost of the machines (*'maybe they need to have more scanning like this to be able to, to actually make a diagnosis and to be correct but then they're very expensive aren't they?'*); the time it takes to prepare access to the fMRI machine (*'I think these things don't happen overnight, you'd be left sort of waiting for weeks and months while all the protocols are sorted out'*); and the fact that this technology is still in the realms of research (*'but I'm still hoping that when he takes part in the research this time'*). In terms of getting to the fMRI machine, she talks

about the difficulties in moving Andrew to a facility that houses an fMRI machine - a point echoed by Rachel, who also felt that travelling to an fMRI machine would be '*distressing*':

They have to travel so far to get somewhere to do it, for Andrew it took two hours to get here and because he'd been up a long time - he can only tolerate sitting in his wheelchair for five or six hours - because the ambulance was delayed, he had a long journey so he was absolutely exhausted, and whereas you and I will have a good night's sleep and be fine the next day, not necessarily the case for a severely brain injured patient, so I guess they need a bit more facilities, it's the same everywhere isn't it? (Alison)

Alison also speaks about the difficulties of her relative having a scan:

Even moving someone in Andrew's condition, like the ambulance journey etcetera, can be traumatic in a way that you or I couldn't really understand. It's very, very tiring and if there is any awareness there it's all change, it's different, there are different people, different environment. Andrew doesn't react terribly well to being put flat on his back, his limbs will stiffen and you can see that's almost a sign of protest. He does get used to it but he can't move so he has to be moved from one bed to another, slid here, there and everywhere it's all, it can be traumatic

Finally this interviewee expressed a clear understanding of what this technology can really offer i.e., this technology cannot overcome brain damage, but rather has the potential to detect instances of awareness that have gone undetected during bedside examination. In reference to innovative mind-operated technologies she says:

All those kind of things would be absolutely wonderful, but I think you come back to the difference between the conditions and whether someone is truly in a persistent vegetative state or whether they're in a locked in syndrome

In spite of acknowledging so many drawbacks of this technology, and in spite of the fact that the initial set of her husband's scans provided disappointing results, Alison was still very positive about the research, and at the time of interviewing (two years since the first scans), her husband was having his second set of scans. As mentioned in chapter five, Alison felt that:

Ideally you would think that patients in these conditions could undergo this scanning once a year or something to see if there were any changes, and yes I accept that it can be a bit traumatic for them

Thus for Alison the drawbacks of the technology did not detract from her positive view of the research. This was also the case for other interviewees. For example, Eli was happy for her husband to take part in the research and although she did not speak much about the drawbacks of the use of the fMRI, when she did it was more as a passing / joking comment:

So he had the week there...but the first day he went to the MRI scanner he was sick...“don’t worry that won’t cost a million pounds we can clean it out” (laugh). But the next time the results of the tests were quite interesting

Trudy also knew many of the limitations of fMRI, however, again her view was nuanced: she was aware of the limitations of the technology, but she still viewed the research in a positive light. When talking about the journey to Cambridge she said *‘Tracey was exhausted...it was quite a pressure ...for her but...[the fMRI] was really quite good’*. And although she spoke about her daughter staying asleep through some of the tests, and being a little disappointed with the outcome of the scan, she maintained her positivity after discussions with the research team:

I was fortunate enough that although Tracey stayed asleep when they were showing photographs or they were flashing photographs of family members - she didn’t open her eyes once - in a way there was a bit of disappointment when we then saw the results, and for other people perhaps the results came as a disappointment if some of the things don’t come out as you want it, but as [the researcher] said to us you’ve got to be aware that this is where Tracey is now, at six months or a year...of being injured, but in two years time it may well show a different pattern

Like Alison, she thinks *‘[the fMRI] should still carry on, I know it’s expensive but...’*.

Whilst the above interviewees remained positive about the research in spite of its many limitations, for Laura, the technology’s drawbacks played a much greater role in her decision-making. As this interviewee tussled with the drawbacks of her daughter having an fMRI scan she said:

Do we want to put her through the upheaval of the movement when she has a routine and she's comfortable, and then there was also the problem of the fact that she goes into spasm and then she would need to be very completely still for the scans to work and obviously they couldn't sedate her because then that would be pointless, so there was so many different things that we had to think about

As discussed in chapter five, this interviewee was very concerned about how to deal with the possibility that the technology identifies that her daughter does have some awareness but this is all the technology is capable of doing (*'[what] if there is something there but there's not a damn thing that we can do to get to her to reach her'*). These concerns weighed heavily on her mind. Alison also felt:

That if you knew that your loved one could communicate...that would be great, then of course you would come to the situation of how do you accommodate that, the fact that you can do it in the scanner you can't have someone in an MRI scanner for the rest of their life

However, different to Laura, for Alison, it was something she thought about, but it did not detract from her overall positive view about the research - she felt it was just *'the next stage that they need to work on I suppose'*.

The drawbacks of the technology also factored strongly into Rachel's decision-making – or rather, took the decision-making out of her control. In her case, it was the technical limitations which prevented her husband from being eligible for a scan:

There's a lot of fMRI studies, isn't there, that you have to know the cause before you're accepted into their research programme, and 'cause they never knew the cause I think that was a big stopper

She also points out that he *'bad [metal] in so you couldn't put him in a machine anyway'*. Rachel also spoke about the fact that: *'it's not like something we can carry around with him...what if you do get in there and then you've got to take him away again...'* This was something Rachel found *'really hard'* to accept.

Overall, my discussions with family members suggested that participants had a good understanding of many of the drawbacks of the technology. They face the fact, ignored by much of the reporting, that, access to fMRI is currently not available outside certain studies (*'studies?*

This is life you know it's his life''') and that not all patients can be scanned (spasms and metal plates in the skull can make patients ineligible) and even transporting them to an fMRI location may present insurmountable challenges (Tovino, 2008). These drawbacks were spoken about implicitly in participants' narratives, featuring in descriptions of their experiences. However, each of the interviewees had very nuanced beliefs about the limitations of the research in terms of their views about the technology. In this sense, the limitations of the research meant something different to each of the interviewees, and influenced their views as well as their decision-making about whether to use the technology to different degrees.

7.4.2 End-of-life decision-making

7.4.2.1 Family members' views about end-of-life decision-making

End-of-life decisions seemed prominent in many of the interviewees' minds. Alison talks about how:

We tend to notify each other if there is something in the paper...when we do see something, yes, we'll avidly read it no matter what it is, whether it's research or someone else has been in this position and has applied to have end-of-life procedures

None of the participants felt they could actively apply to court to ask for their relative to die. However, they varied regarding how strong their views were and why they had such views. Trudy and Rachel were avidly against the idea of allowing their relative to die. For Rachel her views stemmed from a very pro-life narrative: *I don't think anyone should be switched off, but I've always been good like that...I'm very pro-life*. She talks about her concern that her husband's artificial nutrition and hydration would be withdrawn:

I was really fighting I got lawyers...because I was terrified they'd switch off his food and nutrition. The more you look into that that was panic, I looked into it properly and realised it's not that simple but you do panic...

Trudy was not as adamantly pro-life, rather her views about end-of-life decision-making were set in the context of her broader life ideology of *'never say never'*. Because of such views, Trudy finds it *'really heart wrenching when I read about cases where people who've stopped treating [their relative], really I find*

that absolutely horrendous to read'. Though she did acknowledge an understanding of others' decisions in light of their beliefs in clinicians who spoke of hopelessness for their relatives (a belief that she herself refused to accept):

At the beginning Tracey was very unaware, she certainly would not have wanted to stay alive like that...there didn't seem to be any quality of life at the beginning and if the hospital had said "up to six months you're not going to get anymore - that's it", if you had gone down that line and believed that then I sometimes I can see how people get to that position especially when everything is just so dreadful

At the time of interviewing, Trudy's daughter had made a steady improvement since her brain injury several years prior, and Rachel's narrative was filled with faith in her relative, and the recovery he had already made. It is difficult to tell if the views of these two participants regarding end-of-life decision-making would be different if they had lived through different experiences – for example, if their relatives had shown no signs of improvement. Such was the case for Laura, whose son had shown no sign of improvement from a VS since her brain injury nine years ago. For her, she was not against allowing someone to die, but it was something she herself could never go through: *'if the time came that the decision would have to be in play, I know I couldn't do it but ...'*. In spite of this she struggled with her experience and wished it would end:

I need her to be at peace because it's just an ongoing torture nightmare for all of us and it's a devastating impact on her brother...

I do not want Lavena to outlive me, because, you know, I'm her advocate, I'm her voice, I need to know that she's at peace

Alison's husband had also shown little (if any) sign of improvement from a VS following his brain injury three years prior. Like Laura she *'couldn't go to court and ask them to withdraw his feeding, I couldn't do that'*. She does, however, talk about having a do not resuscitate order for him:

Andrew is on a do not resuscitate order....I've, the family, my two sons, Andrew's dad we've all agreed that he really wouldn't want to live like this being completely helpless, what sort of quality of life can there...?

Similar to Alison, Eli also had a do not resuscitate order for her husband – again, such a decision was decided upon in consideration with other family members:

[The nurse] gave me what effectively was a do resuscitate form...and I sort of knew what she was asking me but she didn't say explicitly. It was just sort of, say "do you want to think about this? Are you happy with this?" So I talked to the girls over a couple of weeks...and I said "if Dad had another incident like he had before...and he survived, the chances are he would be in a worse state. Would you want that to happen? Or would you rather that he died? Do you want him to be resuscitated?" And they both pretty instantaneously said "no"

When her husband died, she felt *'it was a blessing because there was nothing there. There was no...he was there, but he was trapped, and even he was getting tired of it'*.

Participants' views about end-of-life decisions did not always correlate to their views about the withdrawal of artificial nutrition and hydration. Trudy and Laura were particularly opposed to this as a method of allowing someone to die:

You're talking about withdrawing food and water...it's absolutely terrible...I would take him to Switzerland if I could...I would, if it ever came to a horrible sort of decision...And if it came to a Judge deciding to withdraw [artificial nutrition and hydration] I would finish it myself, I'd put a pillow over his head. 'Cause I could not watch him...how do we live through the two to three weeks that it could take (Laura)

They wouldn't do that to an animal...our dog was ill...they didn't say to us "well actually take him home, withdraw food and drink, keep him sedated till he dies". Within five minutes he's at peace in my arms. It's inhumane as far as I'm concerned (Laura)

The whole thing about stopping the hydration, I think that's a horrendous thing...I think that is appalling...it's almost like a torture and I don't like that. You know if somebody is having to go then it's the whole controversial thing, then perhaps another source or another way, it shouldn't have been that, I don't like it at all (Trudy)

Trudy refers to an article in the Daily Mail (27th July 2011) by Nikki Kenward - previously locked-in as a result of **Guillian Barre Syndrome** - who spoke out strongly against withdrawing artificial nutrition and hydration in the case of 'M':

I thought actually it was an exceedingly good article, and the woman Nikki, who had been in this situation...she wrote...“would [‘M’]s family just take a bit of time to consider what happens inside the body when all of the water is refused and what happens to your kidneys”, and that just blew me away. That’s why I got the whole thing about it being torture and it is

In summary, none of the participants felt they could actively apply to court to ask for their relative to die. However, they varied regarding how strong their views were and why they had such views. Moreover, participants’ views about end-of-life decisions did not always correlate to their views about the withdrawal of artificial nutrition and hydration.

Interviewees not only spoke about their views regarding end-of-life decision-making, they also spoke about the complexities involved with making such decisions. Their narratives highlighted the difficulties involved in making such decisions, the greyness of the situation, and the tremendous emotional burden involved when thinking about such decisions. This vividly contrasted with the way these issues were described in the newspapers reporting the fMRI studies, which whilst mentioning that these types of decisions are fraught with difficulties, made no reference as to why. For instance, Trudy talked about how, although she made a decision to fight to keep her daughter alive, she must live with the knowledge that she would have chosen not to live in this condition:

We have been in a situation a few times - some just talking about it - we would never ever have done it, I’ll make that very clear. We had talked about it because it was something that if I was feeling really upset and I said “I know Tracey doesn’t want to live through this”...and you can get really quite emotional, and I can remember crying buckets, but I know if we had come to make that decision I couldn’t have done it...we’ve always said “never say never” and I that’s my little thing I hold on to

Alison provides another good example of such difficulties. This interviewee tells how *‘you can only act in what you think would be their best interest’*. But she struggles with this concept as she tries to make sense of what her husband’s best-interests would be, and whether what he might want now would differ from his wishes prior to the accident:

I mean we've kept Andrew alive for three years, is that right? You could turn it around that way can't you but I'm not god, I can't make him live, I can't make him well, so do I have the right to make him die? I don't know, do I think that he would want to die? Yes I really do, but as I said before that's how he would have felt when he was whole and healthy. He might feel differently now, if he has any sort of an understanding, it's an impossible situation because you can't tell, you just can't tell, all you can do is act in the best interest of the person that it's involved with, and according to your heart I think

Moreover, she tells us a story, which illustrates how one's views about what they think they would 'want' when considering end-of-life decisions can dramatically change when they actually experience it:

I got a phone call at 3 o'clock in the morning to say Andrew wasn't breathing properly and they'd called an ambulance so I shot down there, joined him in the ambulance, and I was so terrified that I was going to lose him that I was almost sick in the ambulance. We got to the A and E and they had to do an emergency tracheostomy...after about four days [he improved] so that was brilliant...but it showed me at that time I wasn't ready to let him go...So if it actually came to it that he was really really ill I can sit here and say "yes y'know I think it would be time for him to go now" - I don't really know - I might do everything I possibly could to keep him alive

Finally, several of the interviewees talked about the extra burden of the law when making end-of-life decisions. Alison, for example, recognised that, although you might want to act in the best interests of your relative, *'in this country you can't just do that you have to go to court'*. And Eli, for example, discusses how the court would not give her the right to make decisions about her relative's treatment options:

I had to go to the court of protection. I never got the right to decide his welfare. The judge would not give it. The question came back "Has there been an issue? Is there an issue?" And I said "well no"....And I'm thinking well, at the time when there might be a disagreement between me and the doctors and then I apply are you, the judge, going to be up at three in the morning to make the decision that I can have the right to decide my Andrew's future?

Whilst individuals with a relative in a permanent VS can apply to the courts to have artificial nutrition and hydration withdrawn (no cases have been denied), it is the clinicians who have the legal authority to decide about treatment options. And whilst clinicians have a duty to consider

the best interests of the patient – something a family will no doubt also want, sometimes perspectives may differ, in which case it is the clinicians' decision which has legal authority. This makes this area legally dubious and complex. For a more in depth view of family members experiences related to end-of-life decision-making, see for example, (Kitzinger & Kitzinger, 2013; Kitzinger & Kitzinger, 2014). Overall, these findings can contribute to the much broader social science and societal debates on end-of-life decision-making.

7.4.2.3 End-of-life decision-making and fMRI

Whilst family members' narratives about end-of-life decision-making were broad and complex, only three interviewees intersected these discussions with discussions about the fMRI technology, and only in a few instances. In these instances interviewees acknowledged the potential of using fMRI as a tool in such decision-making. For Eli, fMRI was seen as a technology that could (potentially) be used as a tool to ask questions to patients about whether they wanted to live or die. Eli, for example, felt that *'if there's one person whose machine is not switched off five years from now because they now know how to ask the questions...then that's a positive thing'*. However, she does note the difficulties with this concept:

I think if you can say that somebody is responding then that is a very positive thing...But if you then ask them "Do you want to stay like this?" and you got the answer "no", what would you do about it?...(Laugh) No body would ever dare ask that question. Because that is the big issue isn't it? And that's where euthanasia is...

Trudy and Rachel spoke about fMRI as a technology able to detect/not detect brain activity, which could in turn, be used legally as a decision-making tool in the courtroom. These interviewees disagreed about whether they felt this was a good or bad thing. Trudy who is very pro-life referred positively to the possibility of using fMRI as a method to detect awareness in the recent court case of minimally conscious 'M': *'the doctors are obviously saying that there is something, there is more in there, well has she therefore had an fMRI scan - can they see if there's stuff in there'*. This point is reminiscent of that put forward by other pro-life activists, which I briefly spoke about in section 7.3.3.1. In contrast, Rachel, who was concerned that such tests might prove against her relative making a recovery, was much more worried with the prospect of using fMRI scans in the courtroom:

These things can't be the be all and end all, they cannot base people's lives on these scans and these EEGs, they just can't...I think they're informational...they're very interesting and who knows what potential they have, but it's such a new study...I will be furious if they try to base cases on them

Overall, then, whilst the implications of fMRI in terms of end-of-life decision-making had been considered by these three interviewees, such considerations were not spoken about at length. In fact, such considerations constituted very little of these family members' narratives during the interview. Moreover, in no instances did any of the interviewees relate the use of this technology to their own end-of-life decision-making about their relative.

7.4.2.4 Concerns about the reporting of the Schiavo and Bland cases

As discussed in section 7.3.3.1, the cases of Schiavo and Bland were used as templates in a number of the newspaper articles. In this section I argued that their presence in these articles was not only suggestive that Schiavo and Bland may, too, have had some awareness, but that this awareness may have been detected if Schiavo and/or Bland had had an fMRI. Whilst some interviewees shared this view, family members prioritised a concern and expressed great compassion for the families of these two individuals, which they articulated clearly:

It's just the whole subject is so distressing...for the families that are actually making a decision on that, and also for the patient as well, you know, so within the context of it I don't know whether I would then find that encouraging to have that in the same time [as] when they're talking about "vegetative state is responding to commands". You then think "what if she was but they weren't even aware that she was, so therefore her life was ended when perhaps there was still more in there" (Trudy)

I think for anybody who was really struggling with that decision they would feel awful reading [the story about Terri Schiavo], and they're going to feel bad enough as it is anyhow, but to have someone come out so openly and say "that's wrong", that's not going to make them feel very good about themselves... it's a very difficult decision and I don't really think there is any right or wrong answer (Alison)

I think it...would upset the families of the two people greatly...I think they've made a very heroic decision, although it's not one that I would - well they probably haven't the courts have decided -

but I mean they've begged for it...To then have something like that thrown at them, to find it in the same article. Yeah it's kind of like "shouldn't have done that, was wrong"...I don't think the two should be put together...can you just imagine if I'd seen Lavena's name there. I'm seeing it from the family's point of view and how much guilt would you then feel (Laura)

Alison expressed how others fail to understand the complexities involved with such decision-making:

I dread to think, y'know, like if this was online so you have all the things afterwards - people commenting...I think the majority of people say "oh I wouldn't want to live like that"

This comparison highlights the large gap between the media representations of these court cases and the relatives' comments. The relatives' comments give us a unique 'lived' perspective of possible impact of the news media reporting.

7.4.3 Implications in terms of awareness and consciousness

Although most interviewees understood many of the drawbacks of fMRI in terms of applicability and social-justice concerns, the majority of them did not question the clinical validity of the technology. In this sense, as I discussed in chapter five, interviewees felt that the research participants who showed brain activity in the studies had awareness, and that fMRI technology was, in theory, capable of providing answers in terms of this. Maybe because of this, interviewees spoke little about how the demonstration of brain activity via an fMRI scan may be linked to the idea of 'consciousness', how you could define consciousness, or how this was related to personhood. Two interviewees spoke about their views on personhood separate to their discussions about fMRI. For both Trudy and Rachel the recent court case of minimally conscious 'M' gave them a chance to highlight the importance of realising that, following a brain injury, your relative as you knew them has now gone, but that you have a new and different person to love:

It's a horrendous thing to go through - you're always mourning the person you've lost, so in a way it's going to sound horrible but death would have been an easier option in the first place...because you mourn and you get over. In the very early stages you're mourning all the time for that lost [relative] but...how we dealt with it... I lost my daughter but I got another one, and I

don't know whether these people have...been able to cope with the fact that they've lost 'M' as she was, but actually have got another 'M' (Trudy)

I think the problem is, that family haven't been properly enough supported - their reasoning is that this is not how the woman would've wanted to live, but they're basing it on the woman before her accident...they haven't talked about how even somebody who has a car accident and gets up and walks away at the end of it [has] still suffered a brain injury, has personality changes...she's had that huge brain injury - do you not think she's suffered one or two personality changes? (Rachel)

In these comments these interviewees view the 'self' as something that is fluid and that can change over time. In so doing they question an often predominant view that a person is a never-changing entity and raise questions about identify and the 'self'.

7.4.4 Duty of care, dignity, and support

Some of the interviewees spoke at some length about their experiences in hospitals and the need for basic care and support, and access to facilities. Whilst these concerns did not detract from their views about research and for the possibilities that fMRI could hold, it did seem at times that these concerns weighed more heavily on their lives, and in a sense were either equally, or more important, to them than this new technology. Interviewees reported break downs in care for their relative due to a lack of staff expertise with *existing* equipment (e.g. the hoists used to move patients around) and failures to provide or repair it (e.g. obtaining and maintain appropriate wheelchairs). They were acutely aware of the context of care delivery, and thus sometimes questioned what fMRI could deliver in practice, even if the scientists were successful in their ambitions to develop its capability in ideal laboratory settings. Alison and Trudy stated:

Going into hospital...is the most awful experience...when you're going somewhere where they don't know how to operate the sling to get him from a chair to a bed, they just don't understand how to deal with them, and it is very, very distressing (Alison)

I can remember coming in [the hospital] one day - she's on the ward and - no kidding - bearing in mind Tracey can't move herself, her arm was through the thing like this [shows arm] and her head was scrunched between the metal bar, scrunched there and just laying there and I went ballistic,

you know I said “there’s a nurse sitting over there, can’t she see she’s stuck” It was dreadful, she’d always come back with bed sores (Trudy)

Alison felt incredibly distressed by such environments, which she felt took away her relative’s dignity:

I was getting really upset and she was getting very flustered and this poor gentlemen in the next bed was going “yeah, sort yourself out girl, you can see you’re upsetting her”...And finally a senior nurse came in and said “well we’ll just close everybody else’s curtains, it’s quite simple” but it’s just this, dignity is everything isn’t it, if you lose your dignity it’s very difficult, and for me to see Andrew without any dignity, it’s very hard, people need to be aware of that

Alison also expressed the need for some emotional support:

There just didn’t seem to be any support, any emotional support and that’s what you desperately need. And maybe in the early days you’re not ready to hear that, y’know, three years down the road you’re going to be pretty much in the same situation, so it’s not a case of holding out a hand and saying “there, there, everything will be alright”, it’s just a case of holding out a hand and saying “there, there”

The above comments require us to remember that the very basic care of patients who have a disorder of consciousness seems lacking. This raises questions more broadly about the introduction of expensive technologies into such a health-care setting, and how much such technologies can contribute to patient quality of life improvement when such basic health care is so poor and in need of improvement. This is a consistent finding in other research with families with severely brain-injured relatives – where the recruitment method meant they had no special interest in fMRI. These interviewees expressed cynicism about how fMRI would work in practice making comments such as: *“if she can’t even be given a call button that works for her I don’t really hold out much hope for the miracles offered by super-duper high powered science brain scanning”* (Kitzinger, personal communication, see also (Kitzinger & Kitzinger, 2013; Latchem & Kitzinger, 2012)).

7.5 Academic context of newspaper and press release reporting of ethical issues

In this section I contextualize my findings in a range of academic literature.

The press releases and UK newspapers, which reported the two Owen and colleagues' studies in 2006 and 2010, contained limited mention of the technical limitations and social justice issues related to the research. In contrast, in spite of no mention in the press releases, end-of-life decision-making was drawn upon as an ethical issue in many of the newspaper articles.

As discussed in chapters one and three, Racine and colleagues have previously conducted several quantitative-type studies which have explored how neuroscience is reported in the UK and US print media. In one study, they showed that 17 per cent of articles reporting fMRI research between 1991 and 2004 contained at least one scientific or medical issue (comparable to what I have defined as the 'technical limitations'). In the same study, 9 per cent of articles were shown to contain at least one ethical issue, legal or social issue (Racine et al., 2010); and in another study looking at news media reporting of research relating to neurostimulation research between 1995 and 2004, 16 per cent of articles contained at least one scientific/medical issue and 14 per cent of articles included ethical, social or legal content (Racine et al., 2007b). Racine and colleagues' reportedly poor representation of technical limitations is in agreement with my findings. In contrast, my findings report a higher level of ethical content (just over half of all articles; approximately 55 per cent) – mainly related to the ethical issue of end-of-life decision-making. A prominence of the reporting of ethical issues associated with innovative technologies more broadly has, however, been seen elsewhere: Racine has reported that 46.4 per cent of articles specifically reporting neuro-genetic testing contained an ethical, legal or social issue (Racine et al., 2010). Smart reported that 55 per cent of UK news articles reporting on the 'first draft' of the mapping of the human genome contained an ethical, social or legal issue (Smart, 2003), and Craig has shown that ethical content and language is prominent in the reporting of genetic testing (Craig, 2000). Moreover, in Racine and colleagues exploration of the print media's portrayal of a highly publicised specific research study reporting remote-controlled animal navigation involving brain-machine interfaces (Racine et al., 2007a), 74 per cent of the articles featured at least one ethical issue –predominantly animal rights concerns (60 per cent). One possible interpretation for this is that journalists seized on the 'animal rights issue' to make their story newsworthy. To corroborate this, similar to my findings, ethical issues were present in several headlines reporting this research (Racine et al., 2007a). The use of ethics to make a story newsworthy has also been reported in Miller's media analysis of the 'gay gene'. Miller noted that

“the gay gene story was predominantly framed by the assumption that the ethical implications were important”
(page 272) and:

A number of feature articles in the broadsheet press...used the ‘gay gene’ as a peg on which to hang discussion of the ethical, social, political and legal implications and progress of the Human Genome Project (Miller, 1995: 276)

The use of ethics to make a story newsworthy has also been considered by scholars analysing the framing of science reporting. As discussed in chapter three, the reporting of science in the media often takes the form of a specific frame. In the case of the reporting of Owen and colleagues’ studies, the typology of the framing would therefore be described as “ethics” (this is, of course, alongside the frame of “social progress/breakthrough” as described in chapter five). As scholars have shown, the framing of research in this way will likely influence public perceptions of this technology, and more research would need to be done to determine how this influence manifests.

To crudely gauge more generally the prevalence of journalists’ use of ‘ethics’ in headlines I performed two quick searches in the Nexis® database. The first was a search of the headlines of all UK newspapers in the Nexis® database since 1990 using the search term ethic* (* is the truncation operator of this database). The second was a similar search, though rather than searching headlines, I looked for articles where the word ‘ethic*’ appeared at least three times (this is because editors predominantly write headlines and journalists predominantly write articles). The results are displayed in Figure 7.2. Although my search did not provide the total number of newspapers being searched each year i.e., I could not identify the *proportion* of newspaper articles or headlines containing the word stem ‘ethic’, for both searches, the results clearly show a steady increase in the use of this word from 1990 until 2010. Moreover, in the past few years (2011 and 2012) there has been a much more sudden increase in the word’s usage.

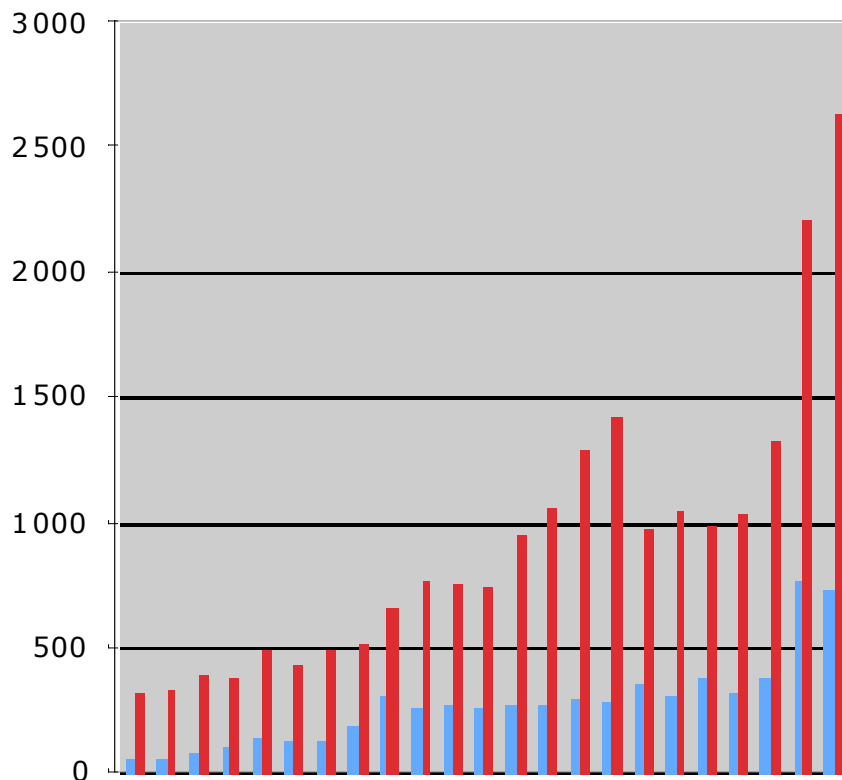


Figure 7.2: Bar graph showing the increased use of the word ‘ethics’ in news reporting from 1990 to 2010. Red bars indicate the number of articles containing the word stem ethic* three or more times. Blue bars represent the number of headlines containing the word stem ethic*

These findings offer some explanation as to why journalists reporting Owen and colleagues’ research may have considered any ethical issue – or the mention of the term ‘ethical’ - as something that is newsworthy and worth reporting. However, the findings cannot explain what triggered journalists to predominantly focus on end-of-life decision-making. One possible source could be the comment posted on the Science Media Centre website in response to the 2006 Owen and colleagues’ study. Another possible source is the editorial and/or perspective reported in the respective journals alongside the two Owen and colleagues’ studies, each of which raised concerns about end-of-life decision-making. Finally, the authors themselves may have had a role to play: in one of the newspaper articles Owen was quoted as saying that: *‘it may later raise the issue of [the patients] being asked if they wished to die’*. Whatever the source of this news angle, this focus on end-of-life decision-making by journalists has the potential to overshadow other relevant ethical issues, for example, issues related to: the medical limitations of the technology; the cost of the

technology; the inability for patients to consent to their own research participation; the accessibility of fMRI (it is not widely accessible); and the effect of this research on families and other potential users of the technology. This point has already been noted by Racine and colleagues in relation to the reporting of genomics in the news media (Racine et al., 2007a), who argued that such a predominance of one ethical issue means that many important and pressing other issues are left unattended, even if they are of great public interest (Racine et al., 2007a).

7.6 Summary and discussion

My findings from this chapter have shown that whilst the technical limitations and issues relating to access of the technology were only briefly mentioned in the press releases and newspapers, it was these issues which were most talked about by family members during their interviews. And, whilst many journalists predominantly discussed end-of-life decision-making as an ethical issue associated with Owen and colleagues' studies, my interviewees' discussions about this issue did not, in the main, intersect with their discussions about fMRI. Comparing these findings to the academic literature (discussed in chapter two) highlights how the scholarly literature is dominated with concerns related to the implications of the technology in terms of end-of-life decision-making, and philosophical discussions about consciousness – similar to that seen in the newspapers. Fewer scholarly papers have discussed various social justice concerns, including access and cost of the technology, and the limitations of the technology, and fewer still have cautioned not to promote families' hopes and expectations about a technology still in the investigational stages of development.

Drawing this together, the way in which newspapers reported Owen and colleagues' studies and the way in which my interviewees discussed the technology aligned to some degree with the types of ethical issues talked about in the academic literature. However, there were some key areas of difference. Primarily, in the academic literature, many issues are presented in an impersonal fashion; from a clinicians' and/or researchers' perspective; and are technology-centred i.e., mainly consider the issues related to the technology as determined by its ability to work, rather than how the drawbacks of this technology may affect the public and/or patients and their relatives. This is in contrast to the concerns spoken about by my interviewees. Such concerns were not defined by the participants as such, but rather were spoken about implicitly in participants' narratives, featuring in descriptions of their experiences. These descriptions give a much clearer sense of the

limitations/concerns of this technology from a users' perspective, and offer a more informative and enlightening understanding of the everyday realities of using this technology in the social world.

Secondly, interviewees raised new and important issues relating to the technology which were missing from both the academic literature, as well as from the press releases and newspapers. For example, the question of: whether to use the technology even if it is available (i.e., when to not use the technology). If we only consider those ethical issues seen as important by academic scholars or by newspapers, we are likely to miss other important user concerns. Indeed, scholars arguing for this particular technology to become obligatory (Bendsten, 2013; Brukamp, 2013) seem to have ignored (or have failed to consider) the user concerns raised by some of my interviewees. I discuss this in more detail in the discussion chapter.

Finally, my discussions with family members reminds us that we must be cautious when discussing the implications of a new technology: my interviews suggest that in contrast to how limitations are often spoken about in the academic literature and newspapers, there is no 'one size fits all' in terms of how (potential) users of fMRI understand and/or react to the technology. Participants viewed the limitations associated with fMRI very differently depending on their previous experiences relating to their relative and his/her injury - reminiscent of how family members' views and expectations about the technology were also deeply influenced by their experiences, as discussed in chapter five. In this sense, the harsh limitations of fMRI for one individual may be minor problems for another.

Wainwright and colleagues have reported similar findings and argued similar points to the above following their interviews with scientists about translational stem cell research. Whilst their focus is on the scientist as opposed to my focus on families, they also highlight how their interviews provide a more socially embedded account of some of the ethical implications of the research from the perspective of the scientist, compared to most accounts of the ethics of stem cell research, which are de-contextualised reviews of the ethical and legal literature. They argue that the scientists' accounts are *"very different from the 'narrow' philosophical accounts of bioethics because they do not situate themselves in a position of detached abstract rationality"*. They continue: talking to scientists *"allows us to provide a more grounded and detailed analysis of perspectives, processes and practices that are often erased or 'skated over' by purely philosophical analyses"* (Wainwright et al., 2006a: 745). Similarly, Buchman and colleagues - in their recent paper exploring fMRI in relation to mood disorders - argued that *"discussion about the ethics of potential clinical translation...must be informed by the attitudes and*

experiences of those who are implicated in the epistemological and ontological shifts these technologies imply” (Buchman et al., 2013: 68).

All of the above supports the idea that fully understand the ethical issues associated with fMRI for severely brain-injured patients, ethical discussion must not only include philosophical, ‘arm-chair-type’, ethical debates, but must also include sociological and/or empirical bioethical research of the ‘lived experience’. Such an argument has been repeatedly made more generally by many other social science scholars who have criticised the principled nature of reasoning which constitutes the foundations of much bioethical discussion, arguing that this type of ethical reasoning de-contextualises the process of ethical decision-making and in so doing it limits bioethics’ contributions to public debate and policy on new and emergent technologies (Fox, 1976; Hoffmaster, 1992; Haimes, 2002; Hedgecoe, 2004; Samuel & Brosnan, 2011; Williams & Wainwright, 2010). Hedgecoe, for example, argues that principle-centered bioethics ignores the role of social and cultural factors, resulting in *“a significant difference between ethics as presented in bioethics, and the way in which ethical reasoning takes place...as shown by an increasing number of sociological...studies”* (Hedgecoe, 2004: 121). And Petersen has commented that *“Bioethicists and those who are strongly influenced by bioethics’ ideas and principles have a trained incapacity to see the big picture shaping technological innovations”* (Petersen, 2011: 11). By offering empirical data the social sciences can thus conduct ‘sociology in bioethics’ to achieve a more ‘socially reflexive healthcare ethics’ (Wainwright et al., 2006a). Buchman and colleagues point to Kleinmann who stated that empirical sociological research *“can both inform the content of ethics analysis and act to shift the focus of ethical reflection toward the specific, lived moral experience within which costs and benefits take on their individual meaning”* (Kleinman, 1999; Buchman et al., 2013: 68).

In addition to the identified need for sociological research to help bring to light some of the ethical issues surrounding the use of fMRI, my findings from this chapter also provide evidence which contributes the concept of ‘perspective’ in ethics. The differences between the types of ethical issues discussed in the academic literature, and the concerns talked about by my interviewees relates to the idea that what is viewed or presented as ethical, or even as ethically significant, depends on who is partaking in the discussion about the research, or who is presenting the research i.e., ethical issues are ‘shaped’ by perspective. The notion of ‘ethical positions’ has been discussed previously by Cribb and colleagues (Cribb et al., 2008). Using their analysis of interviews with translational research scientists and clinicians, these authors examined

how roles – defined as norms structured by institutions and organisations of society – shape ethics. They argue that a number of (philosophical) bioethicists have developed lists of stem cell related ethical issues. These ethical issues are problems for everyone and for no one in particular, and the vantage point is, on the surface, analogous to that of the generalised citizen. However, they argue, not every individual is equally implicated in the same way in every kind of ethical issue. Rather, the normative structures produced by the institutions and organisations of the scientific and the clinical construct different ethical spaces and role positions (Cribb et al., 2008). Much like my findings, then, Cribb and colleagues view ethics as something that is ‘shaped’. However, my findings suggest that this ‘shaping’ is not limited to role position, but can (also) be shaped on an individual level by individual experience. Bowman has argued a similar point. Talking at a conference at Cumberland Lodge, UK, in 2012 Bowman analogised ethics to a theatre stage. She first argued that, depending on where a person sits in a theatre audience, their view of the stage will be different - in some cases even obscured (Bowman, 2012). She then asked us to imagine that the theatre stage represents ‘ethical issues’, and a seat in the theatre represents a person viewing those ethical issues. She concluded that each person’s view of ethics will always be slightly (or more so) different and/or obscured, with some parts of the stage sometimes hidden from view.

My discussions of Schiavo and Bland are an exemplar of my overall conclusion and neatly draw out the contrasts between academic, journalist and participant perspectives. For academics, Schiavo and Bland represent legal cases or precedents. For journalists, these individuals are templates for their articles, and at most, possibly a way to argue that these individuals may have had some undetected awareness. For family members, Schiavo and Bland were somebody’s relative, their son, their daughter or their family member.

7.7 Concluding remarks

In this chapter I have shown how Owen and colleagues’ research was presented in the news media as a technology associated with a number of ethical issues, the most notable of which were issues related to end-of-life decision-making. I have also shown how this issue featured heavily in the ethical scholarly literature focusing on this technology, alongside discussions of other issues related to, for example, clinical decision-making, and questions about consciousness. Moreover, I have shown how the concerns of family members about the technology varied to a degree from

those reported by the news media and the scholarly literature – being, rather, often related to the limitations of the technology’s capabilities and accessibility. In fact, a far cry from how this technology was often portrayed in the news media, some of these family members did not equate the advent of this technology with a necessity to use it. In light of this, I have argued two points. First, for the importance of sociological research in ethical discussion, and second, that what is viewed as an ‘ethical issue’, depends on perspective.

Chapter 8: Discussion

8.1 Introduction

This chapter summarises the findings of the thesis and draws on relevant sociological literatures and concepts to contextualise the work. In particular, I discuss how my findings contribute to the sociology of expectations literature. I also touch on other sociological concepts in media theory, the sociology of bioethics, and the public understanding of science. Moreover, I show how Haraway's concept of 'situated knowledges' acts as a useful framework to help understand my science press officer interviews. By linking Haraway's ideas to the sociology of expectations I make an original contribution to this arena of sociological research. Towards the end of the chapter, I discuss the implications of my findings, including how they relate to policy. I then discuss some of the limitations of the study. Finally I explore some areas for future research.

8.2. Sociology of expectations as a useful conceptual approach

The MRC press releases and the UK newspapers presented Owen and colleagues' studies using language and metaphors of 'breakthrough', excitement, hope, and future benefit, with limited mention of the studies' caveats. This section discusses these findings and links them to existing work on the sociology of expectations. Before doing so, however, I discuss how my findings can also act as a case study for some general concepts regarding health topics in the media, some of which were discussed in chapter three. Many of these concepts relate only to this specific aspect and these specific findings of my thesis, however, I discuss them briefly here because I believe it is important to situate my findings more broadly in the various academic work in this area, which cuts across medical sociology, media studies, the public understanding of science, and science and technology studies. I then move on to a more detailed discussion of the sociology of expectations, and discuss how this concept offers a useful framework in which to explore my findings more broadly. The sociology of expectations then becomes a key framework for the discussion of my findings throughout the rest of this chapter.

First, my newspaper analysis exemplifies Clive Seale's discussion of health media. Seale points to Sparks and Tulloch (Sparks & Tulloch, 2000) who argued:

There is no room for a drug that is good in some respects but bad in others. This tendency to generate dramatic effect through extrematised oppositions is an aspect of what some have called ‘tabloidisation’ (Sparks and Tulloch 2000) (Seale, 2003: 519)

This ‘tabloidisation’, or ‘sensationalism’ was evident in the newspaper reporting of Owen and colleagues’ studies. In addition, Seale discusses the various ways in which Western media try to grab public attention. Seale mentions Langer (1998) who presents examples of certain items (twitches) that become news because they disrupt expectations in an emotionally stimulating way (Langer, 1998). Owen and colleagues’ research lends itself to this idea: the expectation that a severely brain-injured patient may be aware or able to communicate is very likely to be a clear disruption to the average readers’ expectations. In line with this idea, journalists used words such as ‘shocked’ to describe clinicians’ reactions to the outcome of the research (*A man believed to be in a permanent vegetative state shocked doctors*’ (Mirror, 4 February 2010)).

Second, my newspaper analysis contributes to the notion of biomedicalisation. Clarke and colleagues describe biomedicalisation as the “*increasingly complex, multisided, multidirectional processes of medicalization*”⁵⁶...*through the new social forms of highly technoscientific biomedicine*” (Clarke et al., 2003: 161). One aspect of this biomedicalised turn particularly relevant to my findings is the transformation in how biomedical knowledges are produced, distributed and consumed. In particular, Clarke and colleagues quote Bauer (page 177), who stated that:

Evidence of the dominance of health news is an empirical indicator of the advent of a medicalized society...medicalization of science news is a correlate of these larger changes in society...anticipating breakthroughs on the health front, and mobilizing ever greater demand for medication and services (Bauer, 1998: 747, 744)

The reporting of fMRI for severely brain-injured patients is one such ‘empirical indicator’ of an increasingly biomedicalised society.

Third, my findings also resonate with literature written on the political economy of hope (Delvecchio Good et al., 1990; Brown, 2006). As already discussed in chapter three, this literature argues that hope is a form of capital sold on the basis of a continuing belief that, via research, the

⁵⁶ The processes through which aspects of life previously outside the jurisdiction of medicine come to be constructed as problems.

future holds the solutions to current health-care issues (Moreira & Palladino, 2005). In this sense society invests in future hope rather than the certainty of the here and now. Mulkay argues that such hope for the future is so widespread in discourses about health technologies in general, that it is now very often seen as natural and taken for granted by most people most of the time (Mulkay, 1993). My findings provide a case-study example for this literature, and of how hope acts as a major rhetoric running through news articles reporting on an innovative health technology.

Fourth, my press release analysis adds empirical findings to the ‘medialisation of science’ concept, which was also discussed briefly in chapter three and argues that there is an increasing orientation of science towards the news media in contemporary society. As my findings have shown, in the case of Owen and colleagues’ studies, both the scientists and the science press releases issued on their/their institutions behalf, played a role in informing the news media’s reporting of the research. Each, thus, act as an example of instances where scientists themselves and/or their institutions have been involved in the process of news media production. The medialisation of science has been shown to be epistemically determined, such that some areas of science, for example, healthcare research, are more prominently medialised than others (Schäfer, 2009). My findings contribute to the similar idea that medialisation of a particular area of science/healthcare research can also be influenced by scientists themselves. In particular, Owen was noted by my interviewees as being particularly ‘media savvy’, and most likely played a large role in publicizing his research. A recent news feature in *Nature* described Owen as being “*not afraid of publicity*” (page 179) and described Owen’s home page as a billboard of links to his television and radio appearances (Cyranoski, 2012). Indeed, Owen has had a multitude of media engagements in relation to his research. One notable instance is the recent BBC Panorama episode ‘*The Mind Reader: Unlocking My Voice*’, which focused exclusively on Owen and colleagues’ research (November 2012).

Beyond the above concepts, my findings empirically develop the sociology of expectations. This concept, discussed in some detail in chapter three, and which has increasingly become popular in contemporary sociological studies, states that the promises and expectations about innovative technologies, such as those raised in the reporting of Owen and colleagues’ studies, are put into circulation for a reason – they are performative and have an influence in present time (Brown et al., 2000; Michael, 2000; Brown, 2003; Hedgecoe & Martin, 2003; Borup et al., 2006). By

promoting promises and expectations, technologies such as fMRI for severe brain-injuries, become legitimized and justified, and the uncertainty inherent in their development is reduced. This concept cautions us not to view the generation of expectations and excitement about Owen and colleagues' studies simplistically as hype. But rather to view the promotion of Owen's vision - a future in which fMRI will help diagnose and communicate with patients bedside diagnosed as in a VS - as a means of enrolling support and resources, as well as enabling the establishment of networks and infrastructure, which will further enable the development of the fMRI technology. The use of 'breakthrough' and other similar metaphors to describe Owen and colleagues' research further serve to strengthen such expectations and reinforce such promises (Nerlich et al., 2002; Nerlich & Halliday, 2007).

From my newspaper and press release analysis alone I am unable to say for sure what performative role the promotion of Owen and colleagues' vision will have in establishing social, cultural or political norms. In order to determine this more work would be required to explore how fMRI plays out in society, for example, how and where it is funded and or adopted for clinical use/research, and how it is viewed by other actors - members of the public, investors, policy-makers, funding-bodies, scientists, and so forth. It is, however, worth mentioning several points. First, sociological research in the similar areas of MRI and PET suggests that the media reporting of these technologies has had an influence on their social standing (Joyce, 2008; Dumit, 2004). Second, although the nature of this work is still in the realms of experimental science, the widespread and excited reporting is likely to have played a role in the technology being deemed significant enough to commission a brain scan for the ex-prime-minister of Israel (Ariel Sharon), who had previously been in a vegetative state (2006-2013), to assess the nature of his diagnosis and prognosis. Third, though experimental, the use of fMRI for severely brain-injured patients has already been raised in the UK courts: in a recent case before the Family Division of the English High Court the official solicitor objected to the withdrawal of treatment from a patient bedside defined as being in a VS, of which one objection arose from the possibility that fMRI might indicate that the patient retained a degree of consciousness. Although this objection was eventually withdrawn, it stands to show the possible power of the media in news dissemination and also highlights the possibility of new socio-technical networks between industry, researchers and the law (Pickersgill, 2011a). And finally, following the reporting of this research, Owen was awarded a ten million dollar grant from the University of Western Ontario, London, Canada to continue and extend his work, and to make it cheaper, more portable and more reliable. Research

into the use of fMRI for severely brain-injured patients is now backed by a vast amount of financial support, and is advancing rapidly (Naci & Owen, 2013) and according to Owen and his fellow researchers, “*responsible integration of this technology into the clinical setting should....be a principal focus of future research*” (Peterson et al., 2013a: 12); my underline). From these above points an interesting picture emerges. Following the widespread and excited media coverage of Owen and colleagues’ studies, new social-technical networks are emerging in terms of funding opportunities, and – despite the fact that this technology is still very much in the realms of the research setting - in terms of clinical (Ariel Sharon) and legal application. This at least offers preliminary support for the arguments which substantiate the sociology of expectations.

In spite of the growing trend to analyse research through the sociology of expectations, there has been little discussion in this specific area about the views and beliefs; the pressures and the agendas; and the existing tensions of the individuals, and of the professions perpetuating such expectations. In particular, with relation to science press officers, Brown states that press releases are “*the productions of research communities seeking to raise the profile of their work as a means of persuading potential patrons of the benefits of investment or sceptical publics of future benefits*” (Brown, 2003: 14). In this specific instance, I would argue that Brown over-simplifies many important issues surrounding the production of science press releases, for instance, how science press officers understand the meaning of excitement and expectations, and how they engage with such ideas. In the following section I argue that my interviews with science press officers help addresses this absence, and that Haraway’s concept of ‘situated knowledges’ can contribute to existing work in this area.

8.3 ‘Situated knowledges’ and the sociology of expectations

This section discusses my analysis of the interviews I conducted with science press officers and links it to existing work on ‘situated knowledges’ and the sociology of expectations. To briefly summarise my findings from chapter six, I argued that science press officers, or at least my interviewees, have a specific ‘vision’ of what defines hype. Interviewees viewed ‘accuracy’ of reporting in terms of facts only. However, these facts can be written in a language and style that adopts a ‘selling slant’. This ‘selling slant’ can be accomplished via the use of specific informational content in the press release (for example, the naming the funding body), the use of quotes, and the introduction of the ‘human element’. In accordance with this, interviewees views about whether press releases were considered hyped tied heavily into the presence/absence of

caveats about the studies and the source of the research, rather than the writing style, or the use of 'breakthrough' language.

Very loosely borrowing from linguistic anthropology and conversation analysis, my findings seem to align closely with work conducted by Goodwin (Goodwin, 1994). Goodwin argues that the way individuals are trained in their profession affects the way those individuals view the world i.e., they interpret the world in an occupationally specific manner. Whilst the science press officer role does not strictly fulfil the criteria of a profession in sociological terms (for example, there is no specific course/exam which needs to be completed and no official membership), they do loosely represent a community characterised by, for instance, a particular expertise, language and tools (Fournier, 2000), and so I would argue this concept is useful here. Goodwin states:

Different professions...have the power to legitimately see, constitute and articulate alternative kinds of events. Professional vision is perspectival, lodged within specific social entities...[...]..such vision...is something accomplished through the competent deployment in a relevant setting of a complex of situated practices (Goodwin, 1994: 626)

This suggests that my interviewees' views of hype in relation to press releases must be seen as socially situated - related to the *"body of practices through which the objects of knowledge which animate the discourse of a profession are constructed and shaped"* (Goodwin, 1994: 605) (note one of my interviewee's comments *"I think had I been still in the middle of my neuroscience PhD would I look at that [the Mirror article reporting Owen and colleagues' research] and go "Oh my God it's hideous"*)

This was articulated by a journalist in Reed's analysis of scientists' and journalists' views on media reporting: *"everyone comes from their own kind of cultural position and there's no way you can say that you don't bring that with you"* (Reed, 2001: 287). Although strict adherence to the concept of professional vision would require more detailed ethnographic research exploring the nature of how science press officers go about their day-to-day work, their conversations, and their modes and methods of carrying out their role, professional vision, in its broadest sense, offers a useful framework in which to situate my findings.

Haraway's work on situated knowledges⁵⁷ offers another useful, but much more broadly understood sociological framework for my findings. Haraway – a firm feminist – rejects the traditional concept of objectivity, which views objectivity as external, disembodied, passive and stable, and which can be viewed from any specific place or context i.e., 'viewed from everywhere' to provide an absolute point of view on a given issue (Haraway, 1988). However, for Haraway, radical social constructionist arguments which completely reject objectivity and argue that all knowledge is theorized as "*power moves, not moves toward truth*" (page 576) are also problematic. These accounts are "*nowhere while claiming to be everywhere equally*" (page 584) i.e., they seem 'to lose too much'. Referring to the category of 'sex' Haraway argues that radical social constructionism loses "*...not just analytic power within a particular Western tradition but also the body itself as anything but a blank page for social inscriptions*" (page 591). Thus, relativism, she says:

Is the perfect mirror twin of totalization in the ideologies of objectivity; both make it impossible to see well, [they] are both "god? tricks" promising vision from everywhere and nowhere (page 584)

Haraway thus proposes an alternative view of objectivity, which she argues allows us to develop a better account of the world. In this account objectivity exists, however, the idea that we can somehow understand an external reality as it is, is actually a myth. All attempts to engage, visualise, explore and understand the 'outside' world are embodied, socially-mediated and partial and can only offer a particular perspective i.e., it is impossible to know and understand the world as it actually is, since all ways of collecting data (which we use to build knowledge) are socially-mediated. Knowledge claims can only be made in context: knowledge must be 'situated' (in a particular perspective):

I am arguing for politics and epistemologies of location, positioning, and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims...I am arguing for the view from a body, always a complex, contradictory, structuring, and structured body, versus the view from above, from nowhere, from simplicity. Only the god trick is forbidden (page 589)

⁵⁷ I am aware that much of Haraway's work is highly contested and discussed (for example, see Sismondo, S. (2009), *An Introduction to Science and Technology Studies*, Oxford, Wiley-Blackwell). It is not my intention to engage in such debates. Rather I wish to draw on Haraway's 'situated knowledges' as a useful concept which offers insight into my findings and a contribution to a sociology of expectations.

Knowledge is not objective because it correlates to the outside world, but rather because it *logically derives* from the tools, modes of understanding, and reasoning of a particular perspective. In short, “*only partial perspective promises objective vision*” (page 583). Moreover, for Haraway, there are no privileged positions of objective knowledge, but rather different positions of situated (limited) knowledge should be exchanged to allow greater understanding and comprehension of the particular object of enquiry.

In order to use Haraway’s concept to help explain my findings two points need to be considered. First, that the content of a science press release i.e., the way in which the research has been described in a press release, is a piece of knowledge; and second, that such knowledge is produced from the tools, modes of reasoning and modes of understanding of science press officers i.e., in line with their aims of translating science information from the scientist into a way that will be appealing to journalists. In light of these two points, according to Haraway, because the knowledge in a science press release has been logically derived from the modes of understanding of the industry – it adheres to the rules and aims of science press officers i.e., it contains accurate facts and caveats whilst at the same time is alluring to journalists - then, for science press officers, it is considered an objective piece of knowledge and is not hyped (obviously there is some variation between different press officers and their perspectives regarding hype, and this will no doubt reflect the variation between institutions, and their own beliefs and views). This objective knowledge, of course, is situated and cannot be considered a representation of reality, and it may therefore be viewed differently from another perspective. Thus, for other professions and/or individuals who have a different situated perspective, and use different modes of reasoning, tools and methods to produce knowledge, a science press release may, in fact, be viewed as hyped. For example, ethicists’ and/or (some) scientists’ modes of reasoning is that words and terms need to be chosen very carefully to avoid creating unrealistic expectations, and as such they will have a different perspective of what is objective knowledge – for these professions, what is seen as hyped will be different from that of a science press officer.

Haraway’s concept of situated knowledge is not only useful in helping us understand science press officers and their views and beliefs about hype, but can also contribute to the sociology of expectations. This is because, whilst there is much literature written about hype in the context of the sociology of expectations, this literature centres around who may produce hype and the possible effects of this hype. Little is written about what hype is, or exactly how hype is

generated. Haraway's concept provides us with this – it gives us insight into the relative nature of hype (what is defined as hype varies in perspective or 'situatedness'), as well as a mechanism of how hype may get created: just through applying their own aims and protocols, science press officers generate documents which are seen by others to be hyped, and it is this hype which has a performative function – they create interest in the research to help secure public support and funding. Thus, with an understanding of Haraway's situated knowledge in relation to my interviews with science press officers we have a more expanded account of the sociology of expectations.

To summarise, there is a division of labour in the dissemination of science to the public whereby a specific group of science communicators (science press officers) has been delegated the specific role of selling science.⁵⁸ The production of hype is increasingly the product of this particular, specialist group. But science press officers do not believe they are creating hype. This industry has its own sets of aims, understandings, methods, and rules which result in the creation of documents that, whilst to others who are not science press officers may appear to be hyped, do not appear hyped to press officers (for some professions it may be the opposite - these documents may not be 'hyped' enough, for example this may be the case for editors of newspapers – though research would need to be conducted to determine this). This is because, according to Haraway, science press officers believe they are doing exactly what they should be doing - communicating science to the public in a way that is attractive to journalists. This has not been acknowledged in detail previously by other sociology of expectations' scholars.

8.4 Expectations are not all powerful or created in a vacuum

My interviews showed that in some instances there is a disjunction between scientists' (i.e., Owen and colleagues) visions of the fMRI and how it will help families, versus families actual expectations, hopes and desires in terms of the technology i.e., Owen and colleagues imagined a particular future for the technology (it will allow us to communicate with vegetative and minimally conscious patients, increasing their well-being and the well-being of families) but such an imagined future does not always correlate with the views of families: some relatives' visions of this technology are ones that evoke a complex mix of anxiety, worry, fear, and guilt. This is unsurprising since expectations are not created in a vacuum, but are themselves socially-mediated

⁵⁸ Scientists, too, play a role in selling science. However, this is not considered the primary role of scientists.

(Wainwright et al., 2008)- expectations can only have influence if they are aligned with the expectations of their recipients, and as shown in chapter five, at least for (potential) users of the technology, this can only be when recipients are ‘ideal users’. Because a whole range of social, emotional and cultural factors determine when a (potential) user is an ‘ideal user’, such factors will affect whether or not promissory discourses will have influence. The tension here between the scientists’ and some families’ different imagined futures of this technology is not something new, but has been reported previously in other instances of biomedical innovations. Most notably, Blume’s analysis of the cochlear implant for the deaf provides a good example of a discrepancy between scientists’ expectations of the implant and its use versus potential user expectations of the technology (Blume, 1997). Drawing these findings into the work compiling the sociology of expectations these findings caution us not to view expectations as ‘all powerful’ but to consider them, too, as socially-mediated.

8.5 Sociology of expectations and the role of neuroethics

Above, I have argued that the sociology of expectations provides a useful framework with which to analyse the findings of this thesis. In this sense, my findings support that Owen and colleagues themselves, as well as their institution’s science press officers, have played an important role in promoting expectations and excitement about the fMRI studies. Creating a dominant narrative of expectations in the news media plays a vital role in helping to secure funding for the continuation of this research. I wish to now extend this further to argue that the ethical literature debating issues relating to Owen and colleagues’ research can also be considered in the framework of the sociology of expectations.

Owen and colleagues’ research was published in peer-reviewed science journals in 2006 (*Science*) and then again in 2010 (*New England Journal of Medicine*). In the accompanying editorials and subsequent UK news reports, authors and journalists highlighted that this research raises serious ethical issues, mainly in terms of detecting consciousness and end-of life decision-making. Shortly after the original publication a number of academic papers discussing the ethical issues associated with this technology began appearing in the literature. Since that time there has been a steady stream of papers published in relation to the fMRI technology and the associated ethical issues, mainly with relation to concerns about end-of-life decision-making, medical decision-making, and issues relating to consciousness (as discussed in chapters two and seven). I wish to argue that this

increasing trend of ethical papers may be, at least in part, related to the 'secure funding space' made possible by the dominant promotion of Owen and colleagues' vision/expectations about the research. This is because this 'secure funding space' is not just restricted to the networks and collaborations of scientists, clinicians, industry or any stakeholders directly involved in the progression of this research, but can also be 'inhabited' by other scholars, such as those from ethics, who can garner funding to study the ethics associated with the new innovative technology i.e., neuroethicists can apply for funding opportunities to explore the ethics of fMRI on the back of the expectations already attached to this technology via its promotion by the researchers. Such a point has been noted previously by others - both generally about neuroscience/neuroethics (Pickersgill, 2013), as well as more specifically in relation to the bioethics enterprise surrounding a particular health technology (Hedgecoe & Martin, 2003). Pickersgill articulated this as:

The potential of and excitement associated with neuroscience animate new normative debates and areas of research (e.g. neuroethics)...this assumed potentiality propels sociotechnical work between neuroscience ...and ethical discussions about its consequences. By capitalizing on the perceived novel nature of neurologic knowledge, this work further substantiates and legitimates interdisciplinary praxis, endeavours to mutate expertise and claims to novelty (Pickersgill, 2013: 328)

Pickersgill has also written about similar ideas in his discussions of neurolaw (Pickersgill, 2011a). Moreover, by publishing in the ethical arena associated with a specific technology neuroethicists can enact a vision of the technology as being associated with an abundance of ethical issues. Such literature thus has a performative role: this vision can act to garner additional funding opportunities to explore the ethical issues in more depth. As Pickersgill notes:

[Neuroethics] seek[s] to identify and manage the emerging and potential consequences of neuroscience, answering the 'host of new questions' ethicists claim scientific research raises...[some commentators] have questioned...the degree to which it constructs neuroscience as innovative and transformative in order to provide support for the neuroethical enterprise (Pickersgill, 2013: 328)

Hedgecoe, too, has spoken about this in his work on pharmacogenetics. For Hedgecoe:

Bioethics debate...play a central role in creating visions which can form the basis for the enrolment of social support from key groups of actors, mobilizing resources and translation into

practice...bioethical discourses should be seen as an integral part of the socio-technical processes...for emerging...technologies (Hedgecoe & Martin, 2003: 354)

Whilst debating ethical issues is by no means a bad thing – indeed raising and debating ethical issues associated with any new technology can only enhance our understanding - the way in which such issues are debated can be problematic. For instance, Hedgecoe argues that the bioethical discourse surrounding pharmacogenetics is often weak in terms of rigorous ethical debate; ethicists seem to unquestioningly accept the expectations of a technology perpetuated by the scientists; and ethicists engage in ethical debate, the boundaries of which have been laid down by scientists (Hedgecoe, 2010). In a similar vein, my findings also raise questions – though different questions - about bioethical discourse. For instance, it raises question about which ethical issues are drawn to attention. Whilst concerns related to end-of-life decision-making, medical decision-making, and the philosophical questions of consciousness are by far the most discussed in the literature, my interviewees pointed to other concerns, for example, questions revolved around ‘choice’ and the use of the technology, as well as around the impact of the technology’s limitations. Such issues are participant-led ‘ethics’, and represent the ‘ethics’ of the social world or the ‘lived experience’ of fMRI.

Many social science scholars have written and spoken about the distinction between bioethical literature and the ‘ethics’ of the social world i.e., the ‘lived experience’, especially when discussing health-care practice and decision-making (Fox, 1976). In his book reporting an ethnographic study of clinicians working in a psychiatric ward, Brodwin argued:

The ethnographic critique of bioethics relies on a categorical division between “moral talk” and “ethics”...moral talk is utilized by ordinary frontline practitioners...Ethics, by contrast, is the codified, reflective language of elite experts, located far from the scene of clinical action...Moral talk addresses everyday experience and gets expressed idiomatically in the midst of ongoing social life. Ethics is based on the human capacity for reasoning and gets expressed through formal systematic theory... (Brodwin, 2013: 14-15)

Here ‘moral talk’ can be considered as the ‘lived experience’. Brodwin rejects the distinction between ‘moral talk’ and ‘ethics’, arguing that, at least for the clinicians, bioethical regulation shapes daily work and:

Commentaries about right and wrong are coproduced by high-order mandates as well as the local context of practice. To set up a categorical division between abstract normative ethics and everyday moral talk obscures this reality (Brodwin, 2013: 16)

For Brodwin, the notion of everyday ethics, which views ethics as contextually situated in the close-in landscape of practice, provides a better conception. This may indeed be true, and is an important point of discussion for the growing number of scholars specifically exploring the nature of ethics and morality in the health-care field and beyond (see, for example, previous work by Edel and Edel (Edel & Edel, 2000)). However, for my findings, I would argue that the ‘ethics’ and ‘moral talk’ distinction is useful for categorisation - the majority of bioethical literature discussing the fMRI technology can be classified as ‘ethics’ and by contrast, my participants’ discussions more closely align with ‘moral talk’ (i.e., these discussions were more related to participants’ everyday experiences in social life – their ‘lived experience’).

The absence of discussions about moral talk from literature discussing the ethics of fMRI for severely brain-injured patients has several problematic consequences. First, it has a narrowing function i.e., what becomes constituted as ‘the ethical issues related to fMRI for severely brain-injured patients’ may in fact miss some of the wider issues that are important to families who are the (potential) users of the technology. For instance, my findings have shown how the use of fMRI has introduced new and novel ethical dilemmas for relatives, dilemmas otherwise absent from the ethical literature – a point previously noted by Williams and colleagues in their study of antenatal screening (Williams et al., 2005). On a related note, second, it delineates what counts as ‘ethical’ and so the ethical issues associated with a technology are viewed as related solely to ‘ethics’ as opposed to a more complex and complicated combination of both ‘ethics’ and ‘moral talk’. And finally, such a division runs the risk that policy and decision-making may be enacted only in consideration of such ethical debate as opposed to on the basis of a more rounded view of the technology/ethics/moral talk. To give an example, Bendsten (2013) has argued for a moral obligation to use this technology and, drawing on an extract I used earlier, Peterson and colleagues have argued that the “*responsible integration of this [fMRI] technology into the clinical setting should...be a principal focus of future research*” (Peterson et al., 2013a: 12). Whilst, as discussed in chapter seven, in an ‘ideal’ world (i.e., with arm-chair thinking) such ethical arguments may seem sound, the premises of such discussions fail to consider how this relates to the lived experience, i.e., how families react and cope with the idea and use of the technology (for instance, some families do not wish to access the technology because of the potential implications it brings).

Haraway's notion of 'situated knowledges' can be useful here in helping to explain the different notions of ethics/moral talk. The tools, modes of understandings and aims of ethicists (i.e., for example, but not limited to, philosophical debating) form the grounding of their debates about the 'ethics' of fMRI. These tools and modes of understanding will be different to that of social scientists, who require a more empirical, 'lived experience' approach to generate knowledge about ethics. Each discipline considers their knowledge objective. But knowledge is 'situated' and thus cannot be considered a representation of reality. Rather, each piece of knowledge can help contribute to a wider understanding of the fMRI technology.

One way in which scholars have tried to address the discrepancy between 'ethics' and 'moral talk'/the 'lived experience' is by conducting empirical bioethical research. Over the past few decades, this field of research, which uses social science methods to explore ethical issues, has been gaining increasing support from a variety of ethics scholars, as well as scholars from other disciplines. Such work, whilst still criticised on a number of grounds by scholars on both sides - philosophers *and* social scientists - does offer a potential avenue for research which can try to draw together these two concepts - or at least present a more socially embedded view of 'ethics'. In addition to empirical bioethics, there is a growing body of work from social science scholars who are exploring some of the 'moral talk' surrounding innovative health technologies (for example, see (Fox, 1976; Williams et al., 2005)). Such scholars object, or at least criticise the term 'empirical bioethics' because it implies that the discipline of 'ethics' is a superior form of knowledge/expertise to the knowledge generated by social scientists about ethical issues. Rather, they view themselves as conducting 'sociology in bioethics' (Williams & Wainwright, 2013). Moreover, some of these scholars are making increasing efforts to try and bring social scientists and ethicists together (virtually and physically) to try and tease out strategies and more coherent frameworks for working co-operatively⁵⁹ (see, for example, the Interdisciplinary and Empirical Bioethics network⁶⁰). Alongside the work conducted by empirical bioethicists and social science scholars in the ethics of health-care/science, there is a slow growing number of scholars concerned with the position of ethicists as 'experts' of health-care/science research decision-making.⁶¹ Unfortunately since empirical bioethics is still relatively new, and since there are still

⁵⁹ More broadly some scholars are trying to bring together clinicians, lawyers and other professions in an attempt to work together in understanding 'ethical issues in its broadest sense'. The LABTEC project which this thesis is part of is one example of such an initiative.

⁶⁰<http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PCCS/MESH/ieen/index.aspx>

⁶¹For example, a recent workshop on Bioethics expertise was held at Queen's University, Belfast (June 6-7th 2013).

few (but increasing) social science scholars working in the arena of innovative technologies/ethical issues, there is little research under this rubric to contribute to the ethical literature on fMRI for severely-brain injured patients (Samuel, 2013; Samuel & Kitzinger, 2013).

8.6 Implications of findings

In the above sections I have shown how the expectations promoted about the use of fMRI for severely brain-injured patients have a performative effect in that they create a secure space for further research - both scientific and ethical. In this section I discuss some of the implications of these expectations. Firstly, expectations promoted about the technology may have negative implications in terms of families. There are several ways this could occur. First, the promotion Owen and colleagues' expectations i.e., using fMRI in a clinical setting to determine awareness of patients severely brain-injured patients, presented interviewees with a heavy burden as they worried about the consequences of fMRI scanning for their relative. Some spoke about the guilt that would be attached if they found out that their relative had been aware whilst they thought otherwise. For others, the possibility of a negative fMRI result would 'steal their hope' of any sort of recovery.

Second, the promotion of expectations resulted in some interviewees being 'hopeful' about the technology. Hope itself should not necessarily be viewed as something bad or something we should avoid - in fact, hope is part of the fabric of human nature and is valuable in its own right; hope can also create a framework for innovation of health technologies (note: the 'political economy of hope' (Delvecchio Good et al., 1990)), and without hope there is a danger of adopting a position of therapeutic nihilism. Hope can, however, have negative consequences – especially if hope is unfounded ('false hope'). Such false hope can have the undesirable effect of generating disillusionment when technologies fail to materialise (Brown, 2003; Petersen & Sear, 2011). In addition, because the type of hope presented in the newspapers is future-orientated, time-dependent and linked to the outcome of the fMRI technology, it may be double-edged producing at the same time hope and anxiety, dependence and ambivalence, certainty and insecurity i.e., investing hope into a certain future may cause anxiety or insecurity that such a future may not be enacted (Rhodes et al., 2009). Jox and colleagues specifically caution us about the specific consequences of false hope in relation to fMRI for severely brain-injured patients

(Jox et al., 2012); and such concerns were borne out in one of my interviews. For this interviewee, because her initial hope for the research was technology-bound, linked to promissory discourses, and future orientated (Barnard, 1995; Rhodes et al., 2009), when she realised (after discussions with consultants) that such promises could not be met for her relative she described herself as feeling ‘*sunken*’ and ‘*down-hearted*’. The negative implications of false hope can be differentiated from other forms of non-goal orientated or time-bound hope which accept uncertainty and are not so bound by technological development. Such forms of hope encourage a focus on the present (Barnard, 1995; Rhodes et al., 2009).

Finally, the disjunction between the promoted expectations about the fMRI technology and those expectations of family members’ expectations of the fMRI technology cautions us not to necessarily prioritise expectation discourses about fMRI for severely brain-injured patients, but rather to also consider the desires and wishes of families in relation to this technology. Haraway’s perspective on ‘situated knowledges’ is useful again here: the expectation that fMRI will one day act as a tool for diagnosis and treatment of severely brain-injured patients is situated in the tools and protocols of the scientist/clinician. This vision offers no more or less insight or knowledge about this technology than the experiences of family members as the (potential) users of this technology.

Promoted expectation can also have an affect on policy. If families concerns about the technology (or ‘family-led’ ethical issues / ‘moral talk’) are over powered by promissory discourses, or by more ‘philosophical’ debates on ethical issues, they may not be taken into account during policy decision-making. This may lead to decisions about the technology being enacted on the basis of promissory discourses alone. Indeed, this point was alluded to by Peterson and colleagues in the *American Journal of Bioethics* (Peterson et al, 2013a) when they argued that:

Despite skepticism regarding the precise clinical and diagnostic application of fMRI, popular demand and legal precedence may undercut any preventative arguments advanced by the medical ethics community [regarding the ethically responsible integration of this technology into the clinical setting] (page 12)

This statement seems to suggest that the authors view ‘popular demand’ – often the result of promissory discourses⁶² - as an independent irresistible force indicating whether or not to integrate fMRI into the clinical setting (Samuel, 2013).

Besides the above implications on families and policy, the emergent rhetoric of expectations can have a number of other consequences. First, it can promote the idea of technological determinism i.e., that technology progresses just because it works, and is thus beyond the influence of various social, political and/or cultural aspects. This is a concern since technological determinism brings the future into the present – failing to take into account that the path of translation from bench to bedside is rarely this straightforward (Wainwright et al., 2006b; Martin et al., 2008a); rather, it often shifts back and forward between the science laboratory and the clinic to re-address any clinical, social or ethical concerns that may have arisen. As mentioned in chapter three, this concept has long been rejected by Science and Technology Studies scholars (indeed, this is the underlying assumption of the sociology of expectations!) (Timmermans & Berg, 2003).

Second, Brown has argued that the disparities between expectations and eventual realities “*have to be borne by someone, ultimately damaging reputations and trust*” (Brown, 2003: 6). For instance, this would mean that the promises that cannot be met in relation to fMRI may result for some (for example, some families who were initially excited about this technology) in a lost belief in research for severely brain-injured patients and a possible weakening of trust relations and reputations between scientists and, for example, families who have very different experiences of the technology. Disparities in expectations may also have implications in terms of misallocated resources as well as in the distortion of policy priorities. Thus, increased funding for fMRI based on promissory discourses rather than *solely* technical capability or potential to benefit could divert funds away from other more beneficial technologies, or even from basic care. For instance, several of my interviewees spoke about their concerns regarding the basic facilities and training that hospitals give their staff for caring for severely brain-injured patients. This point has broader implications for the healthcare of severely brain-injured patients and has been highlighted further by Latchem and Kitinger (Latchem & Kitinger, 2012). It has also been the focus of a recent report by the Royal College of Physicians (Royal College of Physicians, 2013).

⁶² Though not always, note for example, my earlier referral to Blume’s study of the cochlear implant.

Finally, the rhetoric of expectations can influence the publics' understanding of the use of fMRI for severely brain-injured patients (Nerlich & Halliday, 2007). Whilst it is not necessarily the news media's role to educate the public about this technology, the public does receive most of their information about science via the news media, and representations of this technology in terms of breakthrough is likely to impact on understanding and/or perspective (Gonon et al., 2011). As I mentioned in the introduction to this thesis, this is a point that has been re-iterated on many occasions by Illes, Racine and colleagues in their discussions about the news media's representations of neuroscience (Racine et al., 2005; Racine & Bell, 2008b; Illes et al., 2010) and is something that needs addressing. Indeed, Illes, Racine and colleagues have discussed and debated various ways to improve the publics' understanding of neuroscience (and to avoid the misunderstanding of neuroscience). Their recommendations include, for example, the promotion of multi-directional communication between scientists, the media, social scientists, the public and other stakeholders; more involvement of neuroscientists in public engagement; and the creation of funding opportunities for training in neuroscience education (Racine et al., 2005; Illes et al., 2010). Blakeslee and colleagues have also discussed various ways to aid neuroscience communication (Blakeslee et al., 2012).

One of the most fascinating aspects about my research findings derived from the interviews I conducted with science press officers. In terms of the sociology of expectations, it is interesting that there seems to be an entire industry – science press officers - that has been established to promote scientists' expectations about health technologies to ensure that these are the dominant visions perpetuated in society. As discussed in chapter three, the capabilities of science press officers to promote this particular vision of science has been documented previously by scholars who have explored staged media events by scientists and their press officers, for example, in relation to the Human Genome Project (Nerlich et al., 2002) and the hybrid embryo debate (Williams & Gajevic, 2013). Whilst general (i.e., non science/health) public relation strategies and departments are established promoters of a wide range of professions, their presence in the health and science arena is particularly interesting, or perhaps worrying, for two reasons. First, much of the research being promoted by these particular press officers is relevant to us in the deepest way - it is about research and possible outcomes of research related to our or our relatives' health and well-being. Second, science press officers, or at least my interviewees, do not view themselves as engaged in perpetuating expectations about science/health research - rather they view themselves as communicating science knowledge from the scientist to the public in an

‘honest’ accurate fashion. As pointed out in chapter six, this raises serious questions about the underlying cultural norms of science press officers.

My findings in relation to the Science Media Centre, too, raise some interesting questions. This centre seems all too aware of the importance of scientists communicating with the public (the primary role of the institution is to better manage this). Alongside this, my interviews with science press officers seem to suggest that this centre is also aware that scientists sometimes hype their own work to gain attention. However, some of the centre’s functions, for example, their ‘roundup and rapid reaction’ that posts expert scientist/clinician comments about specific research on their website, seem to be organised in such a way that does not take account of this (i.e., as touched upon in chapter six, posting comments is seen as a way to control hype that may come from journalists, but does not allow for questioning the position or beliefs of scientists/clinicians). Questions about the roundup and rapid reaction function of the Science Media Centre need to be asked on a fundamental level in terms of ‘power’, ‘knowledge’ and the control of science dissemination (as pointed out in chapter six, by rounding up comments for journalists it could be argued the centre is exerting a form of control – or even power – over the ‘knowledge’ disseminated for science dissemination), as well as in terms of promoting churnalism.

Also discussed in chapter six, rather than viewing the entirety of science knowledge as situated (Haraway, 1988) and seeking opinions about the research from scholars outside of science, the Science Media Centre plays a role, or at least this was the case for my findings, in sometimes promoting researcher/clinician opinions of science research as the dominant discourse, balancing information about new research solely with opinions from other scientists/clinicians. Although I am not suggesting the Science Media Centre should approach families for quotes about such research, I do believe that some strategy is needed to ensure a more balanced list of comments about science and/or health on the Science Media Centre’s website. Perhaps they could consider asking a social scientist conducting research in this area!

My findings from the science press officer interviews also have implications in terms of policy. The Nuffield Council on Bioethics recently launched its working paper on novel neurotechnologies. Part of the remit of the working party which produced this report was to explore communication of research and the media. In the section discussing this, concerns were raised about the over-optimistic portrayal of novel neurotechnologies in the news media, and the

potentially detrimental consequences of such presentations. Whilst incredibly informative, and in line with much of this thesis, the final part of this section stated a series of recommendations. These were summarised as:

We recommend that all actors working in professions involved in communicating the findings of research involving novel neurotechnologies have a responsibility to reflect upon how their representation of the current and future applications of novel neurotechnologies might impact on others and to remain circumspect about the promises of these applications (however exciting they may be to them professionally or personally) (Nuffield Council on Bioethics, 2013: 218)

The report lists a number of ways in which this can be achieved, for example to “*resist pressure to publish only positive...findings*”; “*to be transparent about the source of funding...especially if it has been conducted...with commercial interest*”; “*to be aware of the broader social, legal, and political implications...*”, and:

To reflect on the pressure that may be imposed by institutional and structural forces to add a “pinch of hype” and to consider the successive and cumulative effect of this... (Nuffield Council on Bioethics, 2013: 219)

The findings of my thesis suggest that by reducing such a reflective Nuffield report to such recommendations the working party has ‘missed the point’ so to speak, of what hype is. We cannot define the hype surrounding novel neurotechnologies singularly or unproblematically, since what is viewed as hype is itself situated. My discussions with science press officers seem to suggest that they are only too aware of the consequences of hype on patients, families, and members of the public, and participants spoke explicitly about this during their interviews. And whilst science press officers may only publish positive findings, and may – in the view of others – add a ‘pinch of hype’, science press officers do not envisage themselves as the generators of hype. Rather by following their protocols, by accurately reporting facts and caveats whilst making their press releases alluring to journalists, they view science press releases as objective knowledge. Because of this, asking science press officers to reflect further upon their work is unlikely to have much effect.

8.7 Limitations

This was a small (case) study only involving ten science press officers, 51 UK newspaper articles and six family members who have (had) a severely brain-injured relative. For this reason, this case study is limited in its generalizability and further research would be required to determine if my findings were supported more broadly amongst further interviewees and/or across other case studies of innovative health technologies which are still in the translational stages of development. Below I explore the limitations of this thesis in more detail.

First, in terms of the newspaper analysis, I am aware that I have based my analysis on a limited sample of data – 51 UK newspaper articles. Whilst I justified my sample size in the methods chapter, and whilst I argued that such a sample size was sufficient for the type of analysis I was aiming to achieve, If I had more time, a closer inspection and analysis of other forms of news media would have allowed for a more comprehensive, and possibly richer, data set. Social media is fast becoming an important outlet for not only information about science and health research, but also of views and beliefs about such research, An analysis of tweets, or a key word search in Google to identify blogs and other online publications would have allowed me to access such data. Broadcast media (television and radio) and magazines could have also potentially added richness to my data set.

Second, the interviews conducted for this thesis are not a lens into ‘reality’, but rather provide a constructed, or situated, perspective of the views and opinions of the interviewee. Moreover, the knowledge generated from the interview process would inevitably have differed if the interview had taken place in a different context. One likely mode in which the context can affect knowledge produced is in terms of self-presentation – a situation where respondents are keen to make a certain ‘impression’ on the interviewer, and answer questions accordingly. Another example is if there had been a different interviewer. For instance, the interviews I conducted with family members who had (had) a severely brain-injured relative were emotional, and it is likely that the nature of the interview – for example, how ‘open’ the family member had been about their feelings – would most certainly be influenced by who was interviewing them. As a novice interviewer I was aware that at times it was difficult for me to steer the topic of conversation in directions where I felt comfortable to handle emotionally and I am aware that this may have affected the interview, and in turn my data set.

Third, the recruitment problems I encountered when trying to organise the interviews with family members were by far the biggest limitation of this project. Whilst the six interviews I conducted offered invaluable insight into the experiences of families with relation to fMRI, I would like to have interviewed more family members, since saturation of this data set had not been met. In this way I could have gained more understanding of family members' views of the technology.

Fourth, at times in my thesis I discussed the possible roles of journalists' and scientists' in the generation of hype and in news dissemination. However, my analysis relied solely on the newspaper articles and on my interviews with science press offices. I did not interview scientists and journalists themselves (I discuss this further in section 8.8 'Future Research').

The fifth limitation concerns how I defined 'ethics' throughout the thesis. In chapter seven I highlighted how I had struggled with the difficulty of defining 'ethical issues' in relation to the use of fMRI for severely brain-injured patients. From examining the ethical literature on the subject, as well as conducting interviews it seemed, and indeed I later argued, that ethics is too narrowly defined in the ethical literature. After much deliberation I decided to define ethics for the purpose of this thesis as inclusive of any concern raised about this technology, since even if these concerns were not strictly 'ethical' as determined by definitions by other scholars (Racine et al., 2010), they often related back to ethical issues. Whilst this categorisation helped with the analysis of my data, it runs the risk of being too inclusive a definition. The inclusivity of 'morality' has been critiqued before by some anthropological scholars examining the nature of ethics/morality. Such scholars have argued that morality is often used as a *"convenient term for socially approved habits – this is too broad a term, including for example, religious practices, ritual, reciprocity, or kin relations"* (Zigon, 2008: 1).

8.8 Future research

In this final section I highlight a number of different avenues that this research could take, were the research project continued. First, I would broaden the study somewhat. I would like to conduct a further exploration of science press officers from different countries to determine any differences in protocols, views and opinions related to science in the news media. In addition, as discussed above, I would like to interview people who care for, or have (had) a severely brain-injured relative, but did not have experience of the fMRI technology. This would allow me to

gain a deeper understanding of families' views about the use of fMRI and to possibly highlight any broad differences in opinions depending on different experiences or social-cultural backgrounds. Future research could also explore families' views on other technologies that also relate to their relative's condition. I could then determine how these future findings relate to the findings of this thesis: that there is a disjunction between the expectations associated with a technology as portrayed in the news media, and with families' perceptions of the technology.

Focus groups with respondents of the public which explored their views and beliefs about the use of fMRI for severely brain-injured patients and what they perceive as its associated 'ethical' issues would provide another way to broaden this study. Such an analysis would not only add to work conducted in this thesis in terms of what is viewed as an 'ethical issue' (in terms of fMRI for severely brain-injured patients, ethical issues were represented differently in the literature, in the news media, and by family members – it would be interesting to explore the public's views on this in relation to the news media), but would also contribute to the growing amount of research exploring audience reception in media studies (Hughes & Kitzinger, 2008).

Conducting a similar case study of a different technology (for example DBS) would provide another, final, avenue of expanding this project. Such a study would allow me to compare and contrast the findings of the two case studies, drawing out any key similarities and/or differences in terms of the conceptual ideas already put forward during this thesis.

More widely, it would be interesting to conduct a number of interviews – or possibly focus groups - with both the scientists who took part in the fMRI research, with scientists more generally, with journalists, and with more science press officers, to explore their views of, and interactions required whilst, disseminating science for the news media. I would specifically want to interview these professions (particularly scientists and journalists) in relation to the writing of press releases to expand the work of this thesis. My interviews with science press officers provided a one-sided view about how press releases are prepared, and the types of scientist-journalist interactions involved. I would like to gain a closer idea of how scientists and journalists view such interactions in terms of their profession, their agendas and their expectations about their research. It would be particularly interesting to present scientists/journalists with the press releases issued by the MRC reporting Owen and colleagues' studies to gain more insight into their views with respect to this particular research, and as to offer an interesting comparison to my interviews with science press officers. In addition, conducting focus groups with scientists, journalists and science press officers to discuss their views on specific pieces of science research

reporting in general could provide more detail to my deconstruction of the concept of hype and to my use of Haraway's 'situated knowledges' as a concept to help understand the notion of hype.

I would also like to conduct a much closer exploration of the Science Media Centre, its role, its responsibilities, and the views and beliefs of individuals who work in the organisation. Some work in this area has already been started (Haran, 2011; Williams & Gajevic, 2013), however, I would argue that my thesis has raised many questions that need answering. I envisage that this could be achieved via an ethnographic-type approach, also drawing on my empirical bioethics background.

Finally, also drawing on my interest in empirical bioethics, it would be sociologically interesting to more broadly explore the nature of bioethics and/or neuroethics and/or expertise and ethics in terms of health technologies. Such work could involve gaining more empirical evidence for the ideas discussed earlier with relation to the sociology of expectations and ethics publishing, or could involve a closer analysis specifically focusing on the nature of ethics and how it should/could/is defined.

8.9 Concluding remarks and recommendations

This thesis has contributed to the sociology of expectations, sociology of bioethics, media theory and the public understanding of science by providing a case study of how and why the news media reported research involving a specific innovative neurotechnology. It has also developed the sociology of expectations by using Donna Haraway's 'situated knowledges' concept as a framework for understanding the nature of hype. This thesis has re-affirmed the importance of understanding that expectations promoted about technology may have a significant influence on (potential) users of a technology - but not necessarily, since expectations are not all-powerful and users views and beliefs are complex and plural. Finally, this thesis has provided empirical support for the importance of sociological research when considering issues related to innovative neurotechnologies. The implications of this thesis are very broadly two-fold. First, it reminds us of the importance of considering families and patients' perspectives on innovative research before heralding such technologies as 'breakthroughs' (news media); and also in policy and ethical debates before stating that such technologies "*should...be a principle focus of future research*" (Peterson et al., 2013a: 12). Second, it cautions us to problematise simplistic recommendations that aim to control the amount of hype in science news reporting (see, for example, the Nuffield Council of

Bioethics report discussed in section 8.6). Such recommendations need to be considered in light of the relative nature of hype (objectivity is ‘situated’) and the fact that individuals may differ in how they define responsible reporting and what constitutes hype. Rather, what is required is a much broader questioning of the entire framework of science reporting. The findings from this thesis support the following recommendations:

Recommendation 1: My research highlights the importance of social science dialogue in scholarly ethical and policy literature. A more substantiated effort needs to be made to consider the concerns of (potential) users of innovative technologies prior to policy decision-making.

Recommendation 2: My research underlines the need for policy-makers, clinicians, scientists, news disseminators and stakeholders to take into account a range of ethical, social and economic factors before making pronouncements about the role and ‘promise’ of interventions for patients with a severe brain injury. For example, the quality of basic care provided to this patient group, as well as other factors, such as support networks, should be considered alongside the possibilities of technological intervention, rather than being marginalised.

Recommendation 3: My thesis underlines the need for more questioning of the fundamental structures and agendas involved in disseminating science to the public:

- short-term, scientific press releases, especially those which report work with ambitions to bring ‘real world’ social benefits, should include comments from social science researchers with expertise in the area – not just scientists. The establishment of a database of social science experts to draw upon for quotations or expert commentary about science - similar to the scientist/clinician database created by the Science Media Centre - should be a priority (indeed this might usefully be developed by a body such as the Science Media Centre to complement their existing work⁶³).
- funding bodies could all agree on a new format for press releases that would routinely include a clear statement of limitations rather than simply putting the most positive spin possible on what has been achieved.

⁶³ I have spoken to the Science Media Centre about this and they ensure that they have social scientists on their database. If this is the case, the list of social scientists needs to be expanded on drawn upon more frequently.

- on a grand, long-term scale, there needs to be more questioning of the fundamental structures and agendas involved in disseminating science to the public.

This thesis has outlined a wide-ranging agenda for future research and I hope that both myself, and others, will contribute to research on clarifying these issues over the next decade or so.

Appendix 1: Interview guide – science press officers

INTRODUCTION

Who am I? Where am I from? And why are we doing this interview?

To briefly reintroduce myself, I'm Gabby Samuel and I'm funded by the Wellcome Trust to do a PhD looking at how neuroscience, particularly fMRI and DBS, is portrayed in the media. For me, what's interesting is there has been a push over the last decade or so for the public to be aware, and if possible understand, cutting-edge science to produce better (or more inclusive) decision-making. In turn, this involves scientists and journalists to work alongside each other.

POs, I think, act as a kind of bridge between the two to aid that process. So I'm interested in learning more about the experiences, views, and reflections of POs working in these positions to find out what they think are the main rewards or even challenges of doing this kind of work.

Explain structure of the interview: I have broken up the interview into 6 small sections: background, what your job involves, DBS & fMRI, dealing with scientists and journalists, and wider themes. Try and think of this as a conversation and hopefully each question will flow onto the next. And please feel free to elaborate or give any examples that you think will help me understand.

CONTEXT / BACKGROUND

Can you please tell me a little about yourself and how you came to take up this role?

What does your role involve (both officially and unofficially)?

Have you worked in science or the media before, and if so, in what capacity?

What makes a “good” PO?

DOING THE JOB

Do they see their role as intermediary or not? If not then how do they see their role?

I understand some universities offer media workshops to help familiarise scientists with speaking to journalists. Have you ever attended one of these workshops or been involved in running one?

Have you been trained up (either through formal courses, qualifications etc or mentored) to do this job?

If qualifications are relevant (journalism, English, science more generally) then how have these skills helped (or not) do the job?

Can you walk me through how you would find out, work up, and issue a press release? Please feel free to give an example if it's easier.

What are the main advantages of this approach? And what are the possible downsides?

Your job, I imagine, involves staying in close contact and abreast of cutting-edge science that's going on in the university. How do you do this? Is there some kind of network forum that's facilities this (webpages, regular seminars, etc)? Do you approach scientists for information or does it work the other way around (it could be a little of both – explain)?

EXAMPLE: DBS & fMRI MEDIA COVERAGE

Do you know what the techs are? Are there any immediate pros or cons that spring to mind that you would wish to flag up in a PR?

What did you like about the way these issues were reported? Were there any points of concern?

Happy/sad?

Happy with media content or not?

What is the most important thing about a press release? Accuracy, expectation, hope, discovery etc?

SCIENTISTS

Given the speed at which science develops, and the variety of disciplines with their own techniques, jargon, etc; how do you make sense of the information given to you? And how do you turn that into something understandable for non-technical audiences?

Is it necessary to get feedback from scientists once the PR has been written? What input does the scientist have to the PR? Can a scientist prevent a PR – for whatever reason – from going ahead?

How is the relationship between the S and PO –do they always agree or are there disagreements – could you give me an eg of this?

How would you describe the process of translating scientists' work for journalists? Do certain words, language, or content have to be changed? If so, what? (does **this also change the ethical responsibility in terms of writing.**) Do you identify with this or do they see it as a problem?

JOURNALISTS

What is it that journalists need when reading a press release?

You need to make the press release understandable to people – how do you do this? What are the most important things you need to consider when turning it into a press release? How do you chose what studies to make press releases – do you wait for scientists to provide the studies – are all turned into press releases? Do you need to select studies? And if so how?

How are PRs issued to journalists? Is it targeted (say only to people we like or know who will write a good story) in terms of dissemination?

What happens if a journalist misrepresents, or exaggerates, what was written in the PR? Is there are recourse (especially if there is reputational damage)? Is all publicity good publicity?

WIDER THEMES

Why has this role developed in recent decades?

You don't have to answer this, but if there were any potentially negative aspects of a new piece of research how would they be handled in the press release? Marginalised? Downplayed? Not mentioned at all?

Have you heard of the Science Media Centre? Have you worked with them before in any capacity? What do you think of their efforts to bring scientists and journalists together?

Is there anything else that you think is important, or wanted to say, that we haven't covered?

Thank you for taking part.

END OF INTERVIEW.

Appendix 2: Interview guide – family members

PREAMBLE

- 1) From King's College London/Brunel University
- 2) Looking at how the media reports of science
- 3) There are no right or wrong answers: want to know what you think
- 4) Recording; transcript kept safe; completely confidential
- 5) Stop me/ask questions any time

BACKGROUND

As I am sure you know, the media – newspapers, magazines, the internet etc – often report on new medical technologies that have been developed, or are now being used, such as fMRI for patients in a VS, but also fMRI for other purposes, GM crops, genetic testing, etc. In this study we want to find out how people - people like you – respond to these media reports –how do the reports make you feel/think, do they raise a lot of questions for you / are they re-assuring?

OK to get started?

WARM UP

1. I think the best way to start is to ask whether you remember if you knew anything about fMRI before you were told about it at the hospital?
 - a. Where did you know about it from? What was the context?
 - Media, leaflets, friends, TV
 - b. What were your initial impressions of it?
 - Were you excited / hopeful / anxious / worried / any images?
 - c. When you underwent an fMRI for the first time, what happened to these impressions? Were they confirmed? Did they change? If so, how and in what ways? Did the reality match your imagination?
2. Did you know about any other forms of treatment for the VS?
 - a. Where did you know about them from?
 - b. What were your initial impressions?
3. What have you been told about fMRI at the hospital?
 - Who told you? Were they supportive? Did you understand?
 - How did it make you feel?
 - Were you given any information to take home? If so, in what form? How did you find it? Was it easy to understand, answer your questions, etc.
 - Did they talk about pros and cons of it?
 - a. Did it differ from what you read in the media (if participants had read about it in the media)?

- How, why, did it bother you? Upset you? Did it re-assure you? Change your ideas?

b. What do you see as the pros/cons, potential and limits of fMRI?

5. Do you have any views re how coma/VS in general is represented in the media?

SHOWING THE PARTICIPANT NEWSPAPER ARTICLES

1. We are going to do an exercise now, which will involve talking about your impressions of one or two newspaper articles that I show you.

Show participant a newspaper article that is quite speculative and doesn't contain much information

Can you talk me through how this article makes you feel?

- Any comment about the journalist, the description, the layout?
- Does reading it make you think differently?

In light of what you are going through, and reading this – has this changed the way you feel?

- Made you angry / sad / happy?

How does what you have read compare with your experience

- Does it upset / re-assure you or are you indifferent
- Do you think it represents a true picture?
- Do you like / dislike anything in/about the article?

What do you think is the accuracy? / use / pros/cons, potential and limits compared to what you know about the technology?

Is there anything else you would have liked to know?

2. We are now going to do another exercise - I am going to show you media articles on the same topic as before, but that went into a little more detail about the study.

-How do these paragraphs make you feel?

-Do they raise any questions for you?

-Are you happy with what is portrayed here?

Do you think that the parents/families had an idea that the diagnosis might have been wrong? Do you think families would always be happy with this sort of result?

WRAP-UP

- Ask if the participant has any comments or questions he/she would like to ask. Also, ask the participant whether they wish to be sent the results of the study.

Is there anything else you would like to tell me about the area?

Feel free to come back anytime

- Thank them for their time etc

Appendix 3: Ethical approval

A3.1 Science press officer interviews

Give a brief description of participants and procedure (methods, tests used etc) in up to 150 words

This study aims to look at how journalists and press officers play a role in portraying the use of fMRI and deep brain stimulation (DBS) to study individuals with a DOC in the media.

Interviews will be conducted with journalists and press officers to provide a rich account of their beliefs, ideas and perspectives about the how the media and press officers report fMRI and DBS studies for individuals diagnosed with a DOC, as well as how they report neuroscience more generally. Interviews will be approximately 40-50 minutes and be held at a location convenient for the participants. Informed consent will be sort.

Name of Principal Investigator at Brunel University (please print): Gabrielle Samuel



Signature of Principal Investigator at Brunel University:

E-Mail Address: gabbysamuel@gmail.com

Date: 29 march 2011

This request for expedited review has been: (1) **Approved** (no additional ethics form is necessary)
(2) ~~Declined (full University ethics form is necessary)~~



Signature of Departmental Research Ethics Officer:

5 August 2011

Date: _____

A3.2 Interviews with family members

Give a brief description of participants and procedure (methods, tests used etc) in up to 150 words

This study aims to look at how the media plays a role in helping construct public opinions and beliefs about using fMRI to study individuals with a DOC.

Approximately six focus groups (of between 5-9 participants) will be convened to provide a rich account of the perspectives of the public as well as individuals with a relative/family member diagnosed with a DOC towards media reporting of fMRI studies of individuals diagnosed with a DOC. Interviews will be conducted with any potential participants who wish to take part in the research but who are uncomfortable with the focus group format.

Name of Principal Investigator at Brunel University (please print): Gabrielle Samuel



Signature of Principal Investigator at Brunel University:

E-Mail Address: gabbysamuel@gmail.com

Date: 29 march 2011

This request for expedited review has been: ☒ (1) Approved (no additional ethics form is necessary)
(2) Declined (full University ethics form is necessary)



Signature of Departmental Research Ethics Officer:

4 April 2011

Date: _____

Appendix 4: Participant information sheets

A4.1 Science press officers

INFORMATION SHEET FOR PARTICIPANTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Media reflections of the ethical issues surrounding experimental neuroscience: A case study of functional Magnetic Resonance Imaging (fMRI) for Disorders of Consciousness

We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What are the aims of the research and possible benefits?

The aim of the study is to look at how the media reports Functional Magnetic Resonance Imaging (fMRI) and Deep Brain Stimulation (DBS) studies on individuals diagnosed with a disorder of consciousness (DOC). fMRI is a form of scanner, which can scan the brain of individuals. Deep Brain Stimulation involves the implantation of electrodes in the brain for therapeutic purposes. DOC's refers to individuals either in a coma, a vegetative state or a minimally conscious state. *No prior knowledge about this subject is necessary.*

We hope that the findings of our research will contribute to a better understanding of media reporting of medical neuro-technologies. A copy of the results will be distributed to all participants who request one.

Who are we recruiting?

We are recruiting press officers and individuals involved in press departments who are 18 years old and over and who can speak English.

What will happen if you agree to take part in this study?

You will be invited to take part in an interview. This interview will take about 45mins - 1 hour, and will take place at a time and location convenient to you. In the interview we will talk about your opinions and beliefs about how the press reports fMRI and DBS for individuals diagnosed with a DOC. *No prior knowledge about this subject is necessary.*

Are there any risks to participating?

Most people enjoy talking about their personal values during interviews. However, if at any point during the discussion you feel uncomfortable, you are free to withdraw at no

consequence to yourself. Our aim is to provide all participants with safe, respectful and confidential opportunities to discuss their beliefs and opinions.

Will the information I provide be kept confidential?

All information that is collected from or about you during the course of the research will be kept strictly confidential, in accordance with the 1998 Data Protection Act. Only the principal researcher Gabrielle Samuel and collaborator, Prof Jenny Kitzinger, will know your identity.

Interviews will be recorded and transcribed. Transcription will take place through an external agency, who have signed a confidentiality agreement. The transcription will contain pseudonyms to ensure that it is not traceable to yourself.

What if I decide not to take part?

You are free to withdraw from the study at any time. A decision to withdraw will not affect the standard of care you receive. In addition to withdrawing yourself from the study, you may also withdraw any data/information you have already provided up until it is transcribed for use in the final report (one week post interview).

What do I do now?

If you decide to participate, or if you have any further questions, please contact Gabrielle Samuel. Before you participate you will be asked to sign the attached consent form.

E-mail: gabbysamuel@gmail.com

Telephone: 07775 445 380

What if something goes wrong?

If this study has harmed you in any way you can contact Brunel University, London using the details below for further advice and information:

Gabrielle Samuel, principal researcher: gabbysamuel@gmail.com. Telephone: 07775 445 380

Professor Steven Wainwright, Deputy Director of the Centre for Biomedicine & Society, Brunel University, London: steven.wainwright@brunel.ac.uk. Telephone: 07793 056 589.

Dr David Anderson Ford, Chair, Brunel University Research Ethics Committee: david.anderson-ford@brunel.ac.uk

A4.2 Family Members

INFORMATION SHEET FOR PARTICIPANTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Media reflections of the ethical issues surrounding experimental neuroscience: A case study of functional Magnetic Resonance Imaging (fMRI) for Disorders of Consciousness

We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What are the aims of the research and possible benefits?

The aim of the study is to look at people's beliefs and opinions about how the media reports Functional Magnetic Resonance Imaging (fMRI) studies on individuals diagnosed with a disorder of consciousness (DOC). fMRI is a form of scanner, which can scan the brain of individuals. DOC's refers to individuals either in a coma, a vegetative state or a minimally conscious state. *No prior knowledge about this subject is necessary.*

We hope that the findings of our research will contribute to a better understanding of how media reporting affects people's views and beliefs. A copy of the results will be distributed to all participants who request one.

Who are we recruiting?

We are recruiting individuals from the general public who are over 18 and who can speak English.

What will happen if you agree to take part in this study?

You will be invited to take part in an interview. This interview will take about 45mins - 1 hour, and will take place at a time and location convenient to you. In the interview we will talk about your opinions and beliefs about how the media reports fMRI for individuals diagnosed with a DOC. *No prior knowledge about this subject is necessary.*

Are there any risks to participating?

Most people enjoy talking about their personal values during interviews. However, if at any point during the discussion you feel uncomfortable, you are free to withdraw at no consequence to yourself. Our aim is to provide all participants with safe, respectful and confidential opportunities to discuss their beliefs and opinions.

Will the information I provide be kept confidential?

All information that is collected from or about you during the course of the research will be kept strictly confidential, in accordance with the 1998 Data Protection Act. Only the principal researcher Gabrielle Samuel and collaborator, Prof Jenny Kitzinger, will know your identity.

Interviews will be recorded and transcribed. Transcription will take place through an external agency, who have signed a confidentiality agreement. The transcription will contain pseudonyms to ensure that it is not traceable to yourself.

What if I decide not to take part?

You are free to withdraw from the study at any time. A decision to withdraw will not affect the standard of care you receive. In addition to withdrawing yourself from the study, you may also withdraw any data/information you have already provided up until it is transcribed for use in the final report [DATE TO BE INSERTED].

What do I do now?

If you decide to participate, or if you have any further questions, please contact Gabrielle Samuel. Before you participate you will be asked to sign the attached consent form.

E-mail: [INSERT BRUNEL EMAIL ADDRESS]

Telephone: [insert mobile number]

What if something goes wrong?

If this study has harmed you in any way you can contact Brunel University, London using the details below for further advice and information:

Gabrielle Samuel, principal researcher: [INSERT BRUNEL EMAIL ADDRESS].

Telephone: [insert mobile number]

Professor Steven Wainwright, Deputy Director of the Centre for Biomedicine & Society, Brunel University, London: steven.wainwright@brunel.ac.uk. Telephone: 07793 056 589.

Dr David Anderson Ford, Chair, Brunel University Research Ethics Committee: david.anderson-ford@brunel.ac.uk

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