Collaborations, Connections & Participation: An ethnographic study of dementia research in the UK

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This thesis examines the question: How is biomedical research in the field of dementia enacted? I address this question using ethnographic fieldwork, interviews and document analysis conducted between September 2010 and March 2014, which examine the relations involved in the emergence of a national dementia research agenda in the UK. Over the last decade in the UK 'dementia' has become characterised as *the* public health crisis of our time. The sense of crisis around the conditions covered by this umbrella term is exacerbated by a global trend toward increased longevity and acute awareness of the limitations of existing treatments. In 2011 the UK Department of Health, in collaboration with national research organisations, announced the launch of an integrated dementia research strategy. Taking a historical and emergent perspective on research into aging, neurodegenerative diseases and the concept of 'dementia', this examination demonstrates how the evolving research initiative marks a shift in the process of co-production which exists between science, policy and publics in the UK.

Using a detailed examination of linguistic and visual material from the perspective of science policy and practice, the thesis demonstrates how shifts in biotechnology make conditions described under the umbrella of 'dementias' differently visible. The scientific narratives which accompany this changing visibility, present dementias as a challenging target for social and scientific intervention. In response to this complexity, the research agenda focuses on the relationships and interactions between the multiple stakeholders involved. A rhetoric-based analysis demonstrates how researchers use such collaborations to try and remake the connections between aging, dementia, science and social responsibility. I argue that this process of breaking and remaking such connections is part of persuasive attempt to embed patients, participants and publics in the conduct of clinical research.

This ethnographic description demonstrates how this process of embedded engagement is not without challenge. Researchers feel increasingly exposed to public expectations and frustrations which exist beyond the control of the 'citadel' of science (Martin 1998). Thus through cyclical re-workings of narratives of success and failure, hope and possibility, researchers involved in the development of new interventions for dementia diagnosis and treatment attempt to balance the tension between the rhetoric of future potential products and their day-to-day experience of the scientific process. Thus the thesis demonstrates how the development of new interventions is a continual negotiation of uncertainties and anxieties for both researchers and their participants. The thesis contributes to a growing literature on the complexity of biomedical research and knowledge making.

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List of Acronyms

AD	Alzheimer's Disease
ARUK	Alzheimer's Research UK
BOLD	Blood Oxygenation Level-Dependent
CCG	Clinical Commissioning Group
DALY	Disability Adjusted Life Years
DeNDRoN	Dementias and Neurodegenerative Disease Research Network
DLB	Dementia with Lewy Bodies
DSM	Diagnostic Standards Manual
DSM-IV-TR	Revised fourth edition of the Diagnostic Standard Manual
EBM	Evidence Based Medicine
fMRI	Functional Magnetic Resonance Imaging
IADL	Instrumental Activities of Daily Living
ICH-GCP	International Council for the Harmonisation of Good Clinical Practice
ICD	International Classification of Disease
IRAS	Integrated Research Assessment System
MAGDR	Ministerial Advisory Group for Dementia Research
MRI	Magnetic Resonance Imaging
MRC	Medical Research Council
NHS	National Health Service
NHSE	National Health Service England
NICE	National Institute of Clinical Excellence
NINCDS – ADRDA	National Institute of Neurological and Communicative Diseases and Stroke / Alzheimer's disease and Related Disorders
NMR	Nuclear Magnetic Resonance
NMRC	Newcastle Magnetic Resonance Centre
PCT	Primary Care Trusts
PET	Positron Emission Tomography
QALY	Quality Adjusted Life Years
RAFT	Recruitment and Feasibility Tool
RCT	Randomised Control Trial
REC	Research Ethics Committee
R&D	Research & Development
RfPB	Research for Patient Benefit
SEM	Scanning Electron Microscopy
SPECT	Single Photon Emission Tomography
UKCRNP	UK Clinical Research Network Portfolio
UKNSC	UK National Screening Committee
VaD	Vascular Dementia
WHO	World Health Organisation

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Chapter 1 Introduction: Complexity in the study of biomedical research

Biomedical research into dementia is a rapidly growing phenomenon. Yet, little is known about the social and cultural relations that make this growth possible. How is biomedical research in dementia enacted? To answer this question I conducted an ethnographic study of the emergence of a dementia research community in the UK. By focusing on the relational nature of bioscience, my work emphasises the everyday interactional performances which make research happen. This work thus provides a novel contribution to the anthropological study of knowledge production and the understanding of social practices in the biosciences. One of the main challenges in the research was to capture and clearly articulate the complexity of the relations in biomedical research, whilst providing a systematic representation of the messy nature of the processes, scales and connections involved. In this introduction I outline why an approach focused on complexity is important I argue that ethnography is recognised as an important tool in capturing complexity and addressing the types of messy social relations apparent in the study of dementia research. By tracing the formation of relations, connections and interactions I attempt to capture this complexity at work. I argue for the need for a study of dementia which focuses explicitly on research and research relations. I end the chapter by providing an overview of the content of the thesis.

Anthropology of science and social studies of science and technology.

This thesis developed out of a broader interest in the relationship between concepts of mental health and emerging biotechnologies, such as neuroimaging. Developments in imaging have radically altered the trajectory of the field of neuroscience (Beaulieu 2001, 2002, Cohn 2004, 2008, Dumit 2004, Andreasen 1989). The potential to examine processes inside a living brain represents one of the most influential shifts in conceptualising, understanding, diagnosing and developing treatments related to brain functionality including a broad spectrum of mental illness, cognitive disorders, neurodegenerative diseases, learning disabilities and acquired brain injuries. Biotechnological developments, such as imaging have radically altered western biomedical models of brain anatomy, neuronal development, molecular and neurochemical processes and brain function. Biotechnologies in neuroscience play a pivotal role in the

development of new models and definitions of 'normal' brain structure, function, development and aging (Hogle 2007; Jones & Higgs 2010; Williams et al. 2012).

Social scientists have recognised and traced how biomedical research has had a fundamental impact on the role of the brain in representations of health, well-being, personhood and identity, particularly across Western European and Northern American societies (Rose 1991, 1996).[1] The development of knowledge about the brain has been driven by changing cultural understanding of the mind and the role of science (Jasanoff 2004). Conversely, natural scientists developing knowledge about the brain are continually re-evaluating and redefining the concept of 'mind', shaping how science proceeds and how knowledge about the brain and mental health is socially defined (Blakemore & Greenfield 1987, Herholz *et al* 2001). Therefore, this thesis is influenced by Jasanoff's (2004) theory of co-production. From this perspective, developments in the neurosciences are both a result of, and driving force for, shifting social perceptions of mind, brain and mental health.

My approach in this thesis has been influenced by the accumulation of research in the neurosciences as well as biotechnologies more broadly. In particular, this includes field such as new genetic and reproductive technologies (Franklin 2003, Franklin & Ragone 1998, Ginsburg & Rapp 2004, Strathern 1992a, Gibbon & Novas 2008). Social research in these fields demonstrates how biotechnologies can force deep critical reflection on the nature of personhood, culturally conceived 'natural' categories and what it fundamentally means to be human. My decision to focus upon dementia as a case study was prompted by the growing prominence of the syndrome in public and media discourse. As a disease related to ageing and the end of life, dementia concerns some of the most profound questions concerning human identity and personhood. At the same time, however, changing knowledge about the conditions which cause dementia are fundamentally changing how the syndrome is characterised in research and clinical practice. By reflecting on the medical background of causes of 'dementia', such as Alzheimer's disease, I demonstrate the important role of interaction and collaboration in

[1] In a critical analysis of the concept of the 'normative' brain Rose (2007) has discusses extensively how new neuroscientific biotechnologies and pharmaceuticals are linked with the construction of governance and state bio power in contemporary understanding of the 'self'.

scientific practice. Such relations, I argue, are central to understanding the complexity of the changing landscape of dementia research.

An ethnographic approach to complexity: developing an study of the UK dementia research agenda

Contemporary ethnographers haves developed a fascination with complexity, particularly in relation to developments in technoscience and biomedicine. For example, complexity is located in human and non-human networks (Latour 1987, 1999; Latour & Woolgar 1986), in hybridity (Harraway 1991), in the pervasive processes of definition and classification (Bowker & Star 2004, Martin 1992, 1998; Mol 2002), in multi-sitedeness and virtuality (Marcus & Fischer 1986, Marcus 1995, Rabinow *et al.* 2008, Wouters *et al.* 2008), and in the relations through which it is shaped and enacted (Mol & Law 2002, Strathern 1992a, 1992b, 1995a, 1995b).

What can a study of dementia neuroscience research contribute to this extensive body of literature? This study presents a unique and timely description of a period between 2010 and 2014 when the emergence of national dementia research agenda marked a fundamental shift in the public, political and scientific awareness of this group of conditions in the UK. My approach to the study of biomedical and biotechnological research in dementia neuroscience is focused on the interweaving social relations and scientific knowledge which formed the everyday processes of making this shift happen. As I became familiar with the field of dementia research in the UK it became clear that this was site of immense connectivity and complexity. The participants visible in the study, that is, clinicians, research scientists, research staff, publics, and industrial organisations were all integral to the processes taking place. These characters operate in a tangled web of relations, in which aims, goals and motivations overlap and connect them, whilst also becoming the cause for tension between them.

First, I wish to clarify my decision to use the term 'dementia' and 'dementias' when referring to conditions which cause the symptoms classed as dementia syndrome. Dementia is a concept which, as I go on to demonstrate, has historically undergone radical redefinition. Today we understand dementia not itself as a condition, but as a title for a range of symptoms including, but not limited to, memory loss, behavioural changes, difficulty with communication, and visual

processing, and problem solving. As I go on to discuss in the following chapter, these symptoms result from progressive damage to the brain caused by specific neurodegenerative disease processes. There are over one hundred conditions which can cause symptoms of dementia. Of these the most common forms, include: AD, Vascular Dementia (VaD), Dementia with Lewy Bodies (DLB), and Parkinson's disease dementia (PDD). These are the conditions most commonly referenced in this thesis. In both social and scientific research on dementias there is a tendency to focus on one specific disease pathology, and in particular on AD, as the most dominant disease group. However, the researchers and participants with whom I was involved were concerned with a range of dementia causing conditions. In addition, in the process of public engagement and the politicisation of dementia as a cause for social and political mobilisation, my participants almost inevitably talk about 'dementia', 'dementias' and 'dementia research', treating dementia as discrete object in discussion about research, policy, funding, and public awareness. As a result, throughout the thesis I use the term 'dementia' as it is used in this context, in the awareness that it conflates a wide range of conditions, and that it has become a politically-oriented concept beyond its current, formal, biological definition.

During the study, it became apparent, that the language and imagery used to represent dementia as a field of scientific, governmental and public concern were of vital importance to understand the kind of relations being formed, and how they were enacted. In particular, the concept of 'dementia' was framed by a peculiar combination of acute urgency and emergency. Through the use of the terms urgency and emergency I try to capture the development of dementia as both a site of a public health crisis, and an environment in which knowledge, opinions, relations and connections rapidly and continually evolved and intersected. A preliminary attempt at capturing the most salient issues and relationships in dementia research is illustrated in figure 1.

Implicit in this simple diagram are multiple, cross-cutting connections which it is the aim of this thesis to describe ethnographically. For example, when looking at how the members of a research group worked together on a dementia project, it was important to acknowledge the role of institutional affiliation, participation in local, national and international research and policy frameworks, and connections with wider national and transnational research networks. At the same time I was exploring where research data came from, how projects went about recruiting participants and how they disseminated or implemented their findings. Considering these basic

questions about how research happens, I draw attention to the overlaps and interactions between government organisations, health care institutions, and commercial groups. Through this process I bring into focus that research does not happen outside of social and cultural influence. Rather when exploring research the perceived emotions and anxieties of publics, patients, carers and researcher collide and influence with one another.

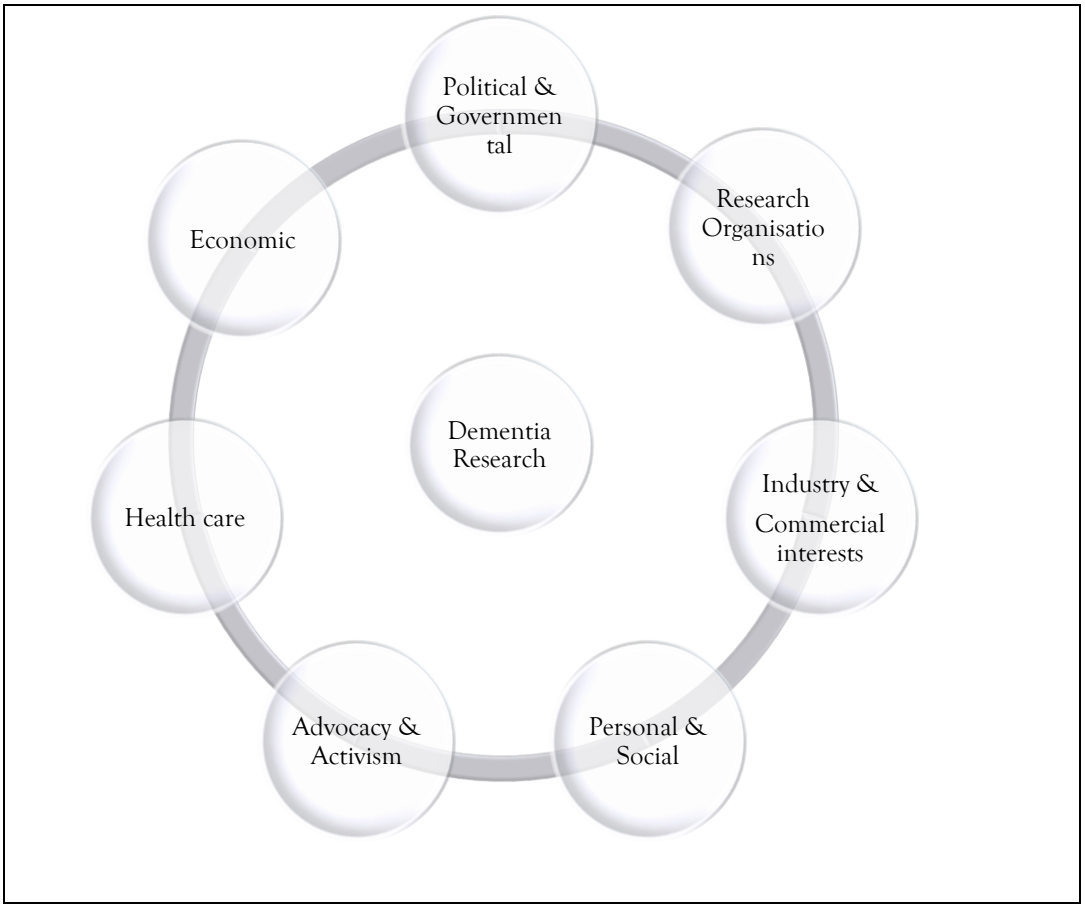


Figure 1: Key relationships emerging in a study of a dementia research community

Becoming aware of the nature of these complexities as my fieldwork developed, I found it increasingly unsatisfactory to conduct a study which separated or excluded the messiness of interconnections. Indeed, these aspect of dementia research became central to addressing the core question about the kinds of relations in which dementia research took place. As a result, this is a study which explores how those working in dementia research were aware of, subject to and involved in the messy, pluralistic and entangled processes which occur in making dementia as a disease, an object of research and, significantly, an item on the political agenda. In short, my work adds to a long tradition of social science scholarship which takes seriously the importance

of social relations in technoscience (Fischer 1996, 2007; Jasanoff 2004, 2005; Martin 1992, 1994, 1998; Nowotny, Scott & Gibbons 2001, 2003, 2005; Traweek 1988).

An ethnography of connections and relations.

Capturing the relations and connections at work in the development of the dementia research agenda is an important but challenging aspect of this study. Throughout the thesis I try to maintain a balance between providing clear and meaningful narratives, and ensuring they reflect the processes fundamental to the performance of dementia research. There is ample evidence from the anthropology of science and technology, that ethnography provides a uniquely valuable method for accessing and describing human interactions in the dispersed and entangled field of science and knowledge production (Marcus 1995, 1998; Knorr Cetina 1999, Konrad 2002). To develop this ethnographic approach, I immersed myself in the work and worlds of biomedical researchers in order to understand how they viewed their research practices. By attending research events I was able to observe how researchers experience, work with and make use of the connections between people, places and institutions. Being able to manage such relations is a fundamental part of scientific practice. Such relations were frequently nationally and even globally dispersed, but nonetheless shaped by researchers' local practices.

Becoming immersed in this way prompted reflections about how scientific knowledge is created, valued and validated. It caused me to consider how I, as an anthropologist, went about creating my own knowledge and understanding. By employing a grounded theory approach, I allowed the research to emerge from the data (Glaser & Strauss 1967). Observing how researchers constructed and talked about the challenges and aims of their work challenged my own perceptions of biomedical science. Whilst regulation and governance was extremely rigorous, knowledge practices and research development often proceeded in an open-ended and contested manner. The research processes I describe in this thesis, parallel those adopted by Nowotny, Scott and Gibbons (2001, 2003) in the development of the idea of mode II science. Whereas mode I science focuses on the idea of knowledge as discrete and contained within clear disciplinary boundaries, the Mode II approach is characterised by knowledge which is transdisciplinary and socially distributed; a temporary cohesion of ideas which are continually under scrutiny and subject to change (Nowotny, Scott and Gibbons 2001: 48). The characteristics

of Mode II science illustrate that far from being driven by transparency and certainty, scientific knowledge production is fraught by complexities which function at all scales. Strathern (1995a) demonstrates how ethnographic research traces relations as a means of accessing social order out of everyday complexity. However, by a systematic focus on the nature of relations, she shows how complexity is replicated and repeated across scales, escaping from and crossing between domains of social life. In this thesis, by analysing the relations between people, conceptual connections and rhetorical devices involved in the development of the UK dementia research agenda, I demonstrate the convergence and divergence of ideas and motivations which are shaping current practices in dementia science.

The study of complex relations in dementia research

In working in the field of contemporary dementia research, I am locating this study not only within anthropologies of science and science studies, but within the wider social and social scientific literature which addresses the conditions which cause dementia from a wide range of perspectives. From current biomedical descriptions, specific disease pathways affect the transmission of messages between neurons. Over time they cause over neuronal damage, resulting in the progressive symptoms of dementia. A person experiencing the effects of dementia will develop progressive cognitive impairment which affects global mental processing including everyday function, personality, and behaviour (Ballard et al. 2011; Blennow et al. 2006; Burns et al. 2002; Burns & Iliffe 2009). There are a wide range of critical approaches to the social study of dementia, particularly in the fields of social psychology and social gerontology. Within these approaches there is a large body of work around the themes of care, disability, personhood and social marginalisation (Baldwin 2008; Davis 2004; Dewing 2008; Cohen 2014; Innes et al. 2004; Innes 2009). In this work, questions are raised about the impact of the symptoms of dementia and a dementia diagnosis on the social relations within which life is experienced.

The examination of dementia diagnoses and the diagnostic processes is an area of particular interest for this thesis. The 'need' for timely and accurate diagnosis has received significant attention in the biomedical community (Hansen et al. 2008; Van Gorp & Vercruysse 2012; Chatterji 1998; Baldwin 2008). The characteristics of the conditions which cause dementia, and their interaction with the structures and biochemistry of the brain are seen to present a

physiological barrier to early diagnosis. The complexity of disease processes combine in the earliest stages of the disease with the brains capacity for plasticity. As a result, initial symptoms can be highly variable and fluctuating.

In both social and scientific studies of dementia, researchers have emphasised the stigmatisation involved in seeking help for, or receiving a diagnosis of dementia. This stigma, it is argued, is rooted in deeply embedded social fears (Garand et al. 2009; Vernooij-Dassen et al. 2005). From a functionalist perspective this fear is located around the loss of control of mind and body, leading to progressive restrictions on independence and self-determination (Higgs & Jones 2009). From an interactionist approach a dementia diagnosis affects not only the person involved, but their relationships with family, friends and colleagues. Dementias can therefore be seen as conditions which threatens inter-personal relationships such as those that exists within families, between life partners, and between the person and society (Innes 2009; Werner & Heinik 2008; Werner et al. 2012). This perspective is reflected in the current guidance provided by the NHS on the effect of receiving a diagnosis:

> Being diagnosed with dementia will have a big impact on your life. You and your family may worry about how long you can care for yourself, particularly if you live alone. People with dementia can remain independent for some time, but will need support from family and friends.
>
> Staying independent with dementia
> *http://www.nhs.uk/Conditions/Dementia/Pages/living-with.aspx*

Regardless of symptomatic experience, the very act of receiving the diagnostic label, is understood to have a detrimental impact upon the identity of the person (Goffman 1990). Thus social stigma is understood to be an important factor in compounding the process of social isolation and detachment experienced as a result of the symptoms of dementia itself.

One research response to the question of threatened identity and personhood in dementia treatment and care has been the development of a person-centred approach (Kitwood 1997, McLean 2007). Through experiencing the symptoms, stigmas and a lack of understanding about dementia, an individual's identity risks become sumbsumed by the condition itself. This loss of identity is compounded by the affect of these conditions on a persons capacity for interpersonal

communication. The increasing damage to a persons capacity to interact in accepted and expected ways can make it difficult to sustain the connections of empathy and relationality involved in compassionate care. The person-centred approach attempts to put the person back into the condition, stressing first and foremost ongoing respect for the humanity, history and identity of the individual, regardless of the impact of the condition on their ability to communicate these relations in a socially 'normative' manner. This approach has developed significant traction in the field of dementia care and care research. However, the achieveability of embedding this approach in to day-to-day care has come under question (Brooker 2004).

In contrast, a different response to the social implications of dementia diagnoses has been to questions the concept of dementia itself (Bond 1992). Vincent et al. (2008) challenge the role of diagnostic categories of dementia given that the biomedical understanding of these conditions remains uncertain and changeable. This leads the writers to ask to what extent diagnostic labels perform a social function, containing and explaining behaviour which is understood to be outside of the dominant social norm. In particular this perspective leads to questions about the value and role of early diagnosis given the lack of existing treatment efficacy. This argument reflects a wider shift in social science to question the social implications of the increasing biomedicalisation of aging dementia itself (Kauffman, Shim & Russ 2004).

However, in neurology, old-age psychiatry and within patient advocacy groups, failure to provide early and accurate differential diagnosis is understood to delay and impede a person and their family's access to the treatment and support systems which are currently available (Vernooij-Dassen et al. 2005). Whilst the exact causes and disease pathways involved remain contested, existing treatments such as cholinesterase inhibitors have been shown in randomised control studies to slow down the progress in Alzheimer's disease dementia (Singh & O'Brien 2009). A firm diagnosis which conforms to current National Institute of Clinical Excellence (NICE) criteria, therefore, represents a critical gateway to accessing care and treatment.

However, treatments such as that described above, do not work for all patients and their effectiveness tends to decrease over time. In effect dementias remain incurable. The lack of more effective treatments is interpreted by specialist clinicians as a key factor in the reluctance amongst many GP's to refer patients for specialist assessment as soon as dementia is suspected (Hansen et

al 2008). In contrast, GP's feel a responsibility to weigh the impact of diagnostic label against the possible benefits of existing and accessible treatment and support (Iliffe, Manthorpe & Eden 2003).

As the prevalence of dementia increases with age, people presenting with subjective memory complaints are often over the age of sixty-five. As a result, many live with a range of chronic and co-morbid disorders. This overlapping of conditions can complicate the process of receiving a firm diagnosis (Burns & Iliffe 2009). Without a firm diagnosis a person may have little or no access to support and no access to services, resources or treatments which can improve their quality of life. This is reflected in the language of patient advocacy groups such as the Alzheimer's Society, illustrated below:

> Many people with dementia face a wait of months and even years for a diagnosis and fewer than half ever receive one. This means hundreds of thousands of people are living in a state of limbo without access to treatment and support to live well. This government funding has the potential to reduce the wait for a diagnosis, give GPs the confidence to diagnose and reflects a commitment from the government to tackling dementia.
>
> "Government announces cash to cut dementia diagnosis times" 05 November 2012
>
> http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1385

Of the members of the public whom I spoke with at research events, a number described how their involvement with patient advocacy and disease research groups had resulted from searching for support which had not be available to them from main stream health care. Similarly, doctors and clinicians described sign-posting patients to advocacy groups as a primary source of help, local support networks and information for people with dementia and their families.

Why focus on research and research relations?

As I have briefly illustrated above, the personal and social impact of living with, being diagnosed with, or caring for, someone with dementia has received significant attention in current

literature, and from a wide range of perspectives. With some notable exceptions (Hedgecoe & Martin 2003; Lock 2001, 2013; Moreira & Bond 2008; Moreira, May & Bond 2009), relative little attention has been paid to the scientific practices and research infrastructures which play pivotal roles in redefining the nature of dementia itself. This thesis, therefore focuses on dementia researchers in the research process. This approach is motivated by the need for better understanding of the changing nature of biomedical research design, practice, infrastructure and governance, and how such changes are being managed by the researchers, clinicians and scientists working in this environment. The practices and processes of research have a direct impact upon how the nature of dementias are conceptualised, and how new treatment approaches are developed. Throughout the thesis, therefore, the core issues under scrutiny are the relations and connections through which the dementia research agenda is developed and enacted.

The public, although not the focus, are a critical part of the landscape of the research relations examined in this thesis. They appear as participants, advocates, fund-raisers and lobbyist, and as the imagined publics to which researchers and research group's appeal in the development of public engagement. In particular I look at the role of public patient involvement (PPI) and public engagement as these practices are framed by researchers as part of, albeit a challenging and at times unwelcome part, of the research process. I demonstrate how in governance and scientific and biomedical policy the public are framed as a resource required to make biomedical research feasible, sustainable and socially acceptable. There are important questions to be raised here regarding power relations and the enrolment of the public into the process of biomedicalisation. However, as I demonstrate at the start and the end of the thesis, these publics are not quiet, compliant and passive. Public participants play a key role in resisting, countering and even challenging the dominant narratives of science which I draw out of my observations of the dementia research community. The study of an increasingly public oriented future for scientific research has given rise to what Jasanoff has referred to as 'civic epistemologies'. I take this term to describe knowledge production which combines the complexity of emerging scientific practice with the plurality of social institutions and differently positioned actors (Fischer 2007, Jasanoff 2005).

The environment of drug development and clinical research in the UK National Health Service

In addressing the relations within which dementia research takes place I pay particular attention to the cross-cutting nature of the political, governmental, economic, scientific, academic, industrial and health care institutions involved in the research process. Throughout my research I was made aware of the concerns around the limited advances made in drug development for treatment of the disease processes involved in, and symptoms of, dementia over the last twenty years. In an open letter to the drug companies the British Association for Psychopharmacology expressed concern that a trend was emerging for the international pharmaceutical industry to withdraw investment from dementia research and development (R&D) because of its high cost and low success rate (British Association for Psychopharmacology 2010). The researchers and clinicians I worked with pinpointed a lack of investment in human, technical and financial resources for the failure to gain traction over the highly complex nature of the disease processes involved. I examine how these narratives of failure and the burdens of dementia are constructed and the kinds of relations implicated in that process.

As a result, I reflect upon the process of clinical trials and drug development as socially embedded processes. Staff involved with in-human trials (phases I – IV) are both personally and professionally committed to the research process. In particular, early career clinical researchers with whom I spoke saw the clinical research dimension of their work as a time consuming but necessary element of their long-term career development. In working with progressive diseases and their modification rather than cure, clinicians collaborating with clinical trials were never working towards the discharge of the patient, but sign-posting patients and their families or care givers towards the future treatment or care services they might require as their condition progressed. Under these circumstances clinicians such as old-age psychiatrists and gerontologists acquired a long-term interest in the progression of the patients' condition.

Decisions by clinicians to work with, or indeed as, researchers in clinical studies have to be understood in the highly complex web of relations involved in NHS in the UK. In chapters two and three I explore how these relations operate across a number of scales: local, national and transnational. For example, to work with NHS patients, staff and facilities, approval is required

from the regional ethics committee (REC). The research conducted follows protocols based on internationally agreed classifications of the disease and its phases. Due to the complex nature of capacity, the regulation of clinical trials for people with dementia is closely scrutinised, particularly in relation to the process of informed consent. Further economic, ethical and legal relations are implicated by funding agreements with pharmaceutical companies and national research organisations. A clinical trial will often involve multiple recruitment sites and engagement with other researchers and clinicians across the UK (see figure 2). Researchers have to manage inter-site hospital relations and the infra-structural requirements for the successful recruitment, testing and monitoring of the efficacy of any intervention. And throughout, the clinician and research team will have to engage with the immediacy of personal encounters as they struggle to work with patients who are experiencing the practical and emotional strain of a progressive chronic condition.

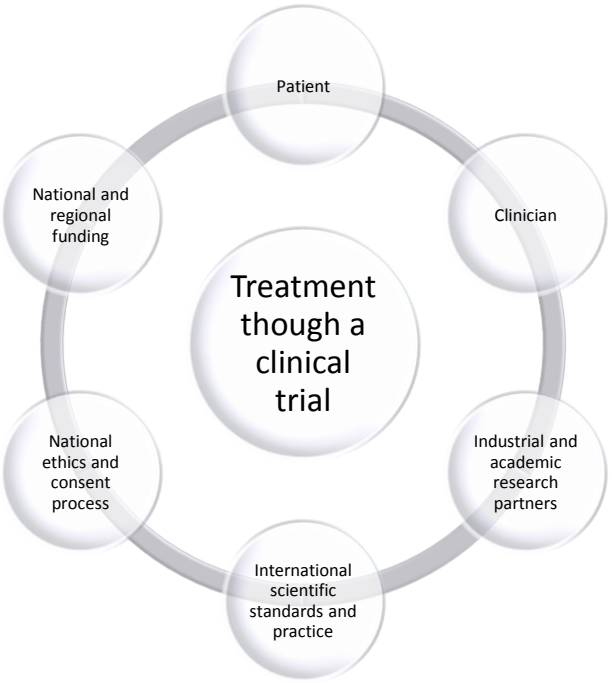


Figure 2: Relations within a clinical trial

In this introduction I have situated this thesis broadly as an ethnographic study of complex and shifting relations which are fundamental to the construction of the UK's national dementia research agenda. I have emphasised a focus on researchers and the research process, situated within wider social, cultural, political, economic and scientific relations. Such relations play a fundamental role in how dementia research is evolving, and social perceptions of dementia

conditions. By shifting focus from care or the products of research on to research relations and processes I represent the dynamic and creative culture of biomedical research which takes us beyond the well-worn triptych of science, politics and society.

An overview of the thesis.

This thesis has three broad sections. In the first section, comprising of chapters two and three, I provide a historical contextualisation of the study of dementia in the biosciences, and discuss the emergence of contemporary dementia research and the current research community on which this ethnography is based. In the second section, chapters four and five provide the core of the thesis, where I explore how language and rhetoric are used in research and research engagement to construct dementias as a specific problem for science and society. In the final section, chapters six and seven reflect on how the efforts to 're-make' dementias illustrate the ongoing evolution of the relationship between clinical research and society in the UK. I conclude in chapter eight by reflecting how the relations illustrated by the thesis can be characterised as transgressive and boundary crossing, managing and maintaining science which is in a perpetual state of tension and suspension. Below is an in-depth chapter overview.

The history and emergence of dementia research and a research community

In the first part of the thesis I provide an overview of 'dementias' as a concept which is neither 'natural' nor 'neutral', but historically situated in the continual evolution and interaction between social perception and biomedical practice. This overview is accompanied by a review of the theoretical and methodological approach taken in this case-study to examine the contemporary scientific practices and discourses by which dementias have become classified. This new visibility is part of a process of categorizing a group of conditions in a manner which makes them amenable to scientific study and intervention.

Chapter two explores the concept of dementia as a disease and an object of research as it has developed over time. I examine how the history of the disease concept is characterised through uncertain and stigmatised definitions which underpin its emergence as a problem disease for

science and society. In this history I examine the roles of standardisation, institutional relations and political economic infrastructures shaping dementia as a disease concept. I draw on the work of Fischer (2009) and Jasanoff (2004, 2005, 2011) to provide insight into how scientific knowledge and practices need to be understood as assemblages of technical, ethical, economic, legal, political, governmental and cultural relations. To understand these assemblages I begin by mapping examples of such relations as they have developed over time. I consider not just organisational and technical developments but the cultural dynamics of biomedical research into dementias. In doing this I employ Jasanoff's idea of science as an embedded civic epistemology, rather than a set of isolated technoscientific practices. Using this approach, I illustrate how the UK dementia research community is continuing to evolve under particular social and economic circumstances.

Chapter three delves further into the structure and working of the dementia research community. This dispersed site of research shaped the methodological conduct of my work. By examining the procedures needed to negotiate access and approval ethnographically, I highlight the organisational convolutions and relations involved in developing biomedical research. I describe how my failure to access the laboratory setting facilitated a different sort of research approach, one attuned to the importance of dispersed processes, practices and relationships which are integral to making dementia research happen. I argue that my experience of negotiating access revealed the key role played by language, imagery and classification in the exchanges between scientists, participants in science and the general public. I illustrate how the dispersed nature of the research community is realised across multiple real-world and virtual sites. Thus, working on contemporary science practice as a social scientist, I argue, both benefits from and challenges a classic understanding of ethnographic field work (c.f. also Prainsack et al. 2010, Prainsack & Wahlberg 2013).

The language and rhetoric of dementias as a problem for UK science and society

The second section of the thesis focuses in in-depth examination of the language and narratives around dementia which have developed amongst an emerging research community. These narratives act as a response to the historical under-resourcing highlighted in the earlier chapters, perceived by clinicians and neurologists to be bound up with key characteristics of

neurodegenerative conditions which result in the symptoms of dementia. I frame these narratives as persuasive rhetorical acts which form part of a wider effort in the dementia research community to change perceptions of 'dementia' to enable new momentum for scientific and social engagement.

Chapter four introduces the role of rhetoric in bringing dementia into focus as a contemporary problem. I analyse how the idea of dementia as 'burden' features in the language pathology, practice and policy of dementia science. Language is used by those working in dementia research to make links between dementia as a condition experienced by people in society, on the one hand, and dementia as an object of scientific research on the other. In this chapter, I outline the ways in which perceptions of dementia are seen to have a negative effect on scientific practice. The condition is often linked to the inevitability of ageing and therefore is likely to be seen as a research field in which success will be less 'heroic', as one dementia researcher put it. The chapter highlights how researchers seek to remedy the failure of dementia research to become a priority for research. I describe how researchers engage in a process of identifying and objectifying the impediments and barriers to successful research. Such impediments include: the complexity and lack of understanding about dementia causing pathologies; the difficulties of working with people with cognitive impairments; the stigmas of age and chronic disease; and the weaknesses in the UK research infrastructure.

In chapter five, I look at how these issues, classified as 'burdens' of dementia and dementia research, are externalised through a rhetoric of risk. Here my emphasis shifts onto how scientists capture public and political attention and construct dementia as a national crisis. By using a rhetoric-based approach to the language and imagery of dementia research, I demonstrate how stakeholders convey a scale of urgency and emergency in the 'dementia crisis'. Attempts to raise the profile of the disease oscillate between the intimacy of specific pathologies, to the gross scale of national statistics, probabilities and projections of future prevalence. The chapter concludes that these strategies of risk and crisis combine to form a dementia social movement akin to that observed in other disease movements, but one explicitly enmeshed with the needs and aims of biomedical research.

Remaking dementias and the relationship between clinical research and society in the UK: anxieties, tensions & suspension.

The final section of the thesis uses material gathered during public engagement events to demonstrate how dementia is being reshaped as a condition with a particular social and scientific future, as a researchable, treatable and manageable set of conditions. I explore how such engagements mark the ongoing evolution in the relationship between clinical research, national health care and society. I argue that this is a relationship of tensions in which different rhetorical devices are balanced against one another. I use examples of participant-researcher interaction to examine the anxieties and fault lines which emerge in this process, which becomes in a sense part of the self-perpetuating mechanism of biomedicine in which outcomes are permanently suspended.

Chapter six examines the strategies used within the research community to create a new kind of relationship between society and research science. The making of this relationship involves breaking existing stigmatised associations between dementia and age. Scientists are then involved in constructing a community of publics, patients and participants to support the dementia research agenda. I argue that this strategy is employed to strike a balance between the gravity of risk and the possibility of hope, innovation and the potential for future drug development. I suggest that scientists are working to naturalise the link between the problem of dementia and the solutions which biomedical science would like to offer. Essential to this link is the cultivation of trust in science, scientists and the research process. I conclude by reflecting on the limits of the rhetorical devices used, as they reveal internal anxieties about the nature of dementia research.

In chapter seven, I focus on how these anxieties are portrayed by researchers and how they manage expectations and limitations of their science, questioning the concept of a 'cure' and reflecting that research often proceeds down what, are in effect, blind alleys. Such reflections lead scientists to debate the nature of success and failure in dementia research. I describe how researchers talk about these anxieties with members of the public and how they share the difficulties they are facing. Using notions such as the time taken to undertake research, the complexity the disease and the rigours of the scientific process, scientists attempt to control and

direct public expectation. These discussions illustrate the tensions and contradictions which lie at the heart of the evolving dementia research agenda.

My conclusion steps back from interpersonal processes and micro-level communications of public-science engagement, returning to the original question posed by this study: Through what kinds of relations is dementia research enacted? Drawing on Nowotny, Scott and Gibbons (2001) description of transgressive institutions, I argue that the kinds of examples I have given in the thesis can be usefully thought of as transgressive relations. That is relations which cross, collapse and continually remake the boundaries between science and society. Such relations, play a vital role in maintaining suspension in the process of scientific knowledge production. I consider how connections made through institutions, technologies, practices and discourses play a vital role, conveying the potentiality of research innovation, in spite of the uncertain, complex nature of the scientific process. I conclude by asking about the implications of this process for the ongoing relationship between biomedical research and society.[2]

[2] Prior to starting the study I completed the University of Durham, Department of Anthropology's ethics review process. The Ethics Committee reviewed my research approach and confirmed that I had appropriately considered potential ethical concerns. Due to time constraints I decided not to continue with the NHS REC process, and worked with interstitial organisations who facilitated my contact with the researchers and the public who became involved in this project. As my project changed I updated the departmental ethics committee with the changes to my research approach.

Chapter 2 Dementia science in context

"So, let me ask you a question", my companion asked as we drove up the hill.

"What's the difference between Alzheimer's Disease and Dementia?" He had asked me what I was studying during my PhD, and I had explained in my usual, imprecise way that I was looking at the social impact of new technological developments in mental health research, how they might be changing how we thought about the brain and the mind. I described how I had come to focus on the use of medical imaging in the developing dementia research agenda. I paused cautiously to consider my answer,

"Well I'm a social scientist. I only have a lay understanding of the conditions which cause dementia. I've never been trained in the biosciences. But, as I understand it Alzheimer's Disease is one of the main subtypes of dementia. The largest proportion of people in the UK diagnosed with dementia are diagnosed with Alzheimer's Disease. That's the one we hear about most often. It has a specific disease pathway associated with the development of plaques and tangles in the brain. But there are many other types which I've heard researchers talk about during the project, vascular dementia or dementia with Lewy bodies for instance." He looked at me significantly unimpressed,

"So what's dementia then?"

I was torn. Do I talk about my uncertainty? How the meetings I had been attending, and the articles I had been reading over the last 18 months had consistently expressed concern about what we didn't yet know about dementia. How do I explain that the boundaries of the disease and the pathways of its development remain a topic of contestation by the experts themselves?

During my field work I became acutely aware of the complex and contested nature of dementias as a disease group. When people heard what I was researching I was frequently asked to give definitions or provide insight into the facts of 'dementia'. From my research I was aware that there were many potential routes I could take to an answer: I could talk about the historical

development of dementias as a category, the emergence of contemporary diagnostic definitions, general public awareness, and the role these factors all played in the development of the dementia research agenda I was observing in the making.

In this chapter I address the uncertain nature of dementia by contextualising this study within the current context of aging populations and changing health care systems. In particular, I explore how aging is a key risk factor in current social and biological perceptions of dementia. I then reflect on the historical and social networks which shape these perceptions. I present a brief outline of the history of the development of the idea of dementia from antiquity through to the first formal classifications of the disease. This account of contemporary neuropathology centres on the molecular definition of the disease pathway of a specific dementia causing condition attributed to Alois Alzheimer. AD was the first pathology specifically identified and named. As such it plays a predominant role in this history, and in public discourse it is frequently synonymous with the broader range of conditions which cause dementia. Following this account I explain how this history resonates with the concerns discussed by current dementia researchers.

Age, chronic disease and emergent technologies

People are living longer. This is a global trend, all-be-it one which is occurring highly unevenly. Disparities in access to and development of health care systems, in different settings combine with other socio-economic factors to limit life expectancy (Baer, Singer & Susser 2003). Changes in medical and technological developments such as vaccination, drug therapies, transplantation, and artificial implants have played a significant role in increasing life expectancy (Lock 1996, Lock & Nguyen 2010). In North America and Western Europe, increasing access to such biotechnologies enable people to survive acute illness, and live longer with chronic ill health, that is, with conditions for which there are no definitive cures and which require long term management.

In medical anthropology the spread of intensive therapeutic interventions has led to an increasing focus on the long term processes and relationships involved in the diagnosis, care, treatment, rehabilitation, technological intervention and research of chronic conditions (Cohn *et al.* 2013, Graffy *et al.* 2010). Areas of particular focus include chronic lung and heart diseases

(Hunt et al 2001, Goldsmith et al 2000), long term cancer treatments (Fergusen & Kaspar 2000, Fosket 2004, Lock 1998, Perusek 2012), diabetes, endocrine and metabolic disorders (Cohn 1992, 1995, 2000) and mental health conditions (Kleinman 1988, Martin 2009). Developments in biotechnologies which target the brain, such as neuroimaging and biomarker research, have led social scientists to consider how the burgeoning discipline of neuroscience may affect out social and biological understanding of mental and neurological health (Dumit 2004, Lock 2013, Moreira & Bond 2008, Rose 1996, 2007)

Chronic conditions, including neurological disorders, become more prevalent as people age. People over the age of sixty-five are increasingly likely to experience not one, but multiple chronic conditions (Schubert et al 2006). New health research provides hope to ameliorate the physical and mental deterioration, discomfort and uncertainty experienced by an increasing number of people who live into their eighth and ninth decades (WHO 2011). As I reflect in this thesis, aging populations raise challenging questions for national states and global institutions around the personal, ethical, legal, economic and governmental responsibility to facilitate long-term health care provision in later life.

In dementias specifically, progressive changes in the structure of brain tissue are associated with global deterioration in a person's cognitive state. This affects not only a person's ability to process, reason and recall, but can have devastating effects on those most personal of qualities which we associate with the self: mood, personality and behaviour. Thus, in dementias, biological and mental health care intertwine. A key element in our contemporary understanding of dementia is the role played by age. Age remains the primary known risk factor in the development of the most common dementia causing conditions, including AD, VaD and DLB (Holmes 2012). In the UK, epidemiologists currently estimate that one in twenty over the age of sixty-five will develop symptoms of dementia. This estimate rises to one in five of those over the age of eighty-five (O'Brien 2005). The link between aging and dementia means that a study on dementia research as a socially embedded process must address the current and changing social attitudes to age within this cultural context. On the one hand, ethnographic studies have suggested that across many cultures older members of societies are valued as powerful holders and arbitrators of accumulated experience, knowledge and understanding (Keith 1979). On the other hand,

social researchers have observed age to be associated with a loss of control over physical, mental and social well-being (Cohen 1994, Leibing & Cohen 2006, Whitehouse et al 2005).

From the moment of conception we age, develop and change, aging is implicit to human existence. Transitions over the life course are a feature of many classic ethnographic accounts from Malinowski (1961) to Evans-Pritchard (1971) and Turner (1974). Given the importance of aging, it is significant that until recently, old-age and later life received less ethnographic recognition than might be expected (Cohen 1994, Clarke 1967, Keith 1980). In the last two decades the field of anthropology of gerontology has become more coherent (Cohen 1994, Albert & Cattell 1994).

The aging of the human brain connected with increased risk of neurodegenerative disease connects the study of dementia research with anthropology's increasing attention to later life and the end of life. This is evident in the increasing number of social studies on the state of well-being and care in later life (Binstock, et al 2007, Johnson 2005, Kitwood 1997, McLean 2007). During my UK based fieldwork amongst dementia researchers, age was presented in a complex range of ways. It was a stigma and a challenge to be overcome; a vulnerability to be protected and the object of social action and the fight for rights and recognition. These different interpretations, as I show in subsequent chapters, have all been used to support and mobilise a national dementia research agenda. This is an agenda focused around four areas, the 'cause, cure, care and prevention' of conditions which cause dementia (Alzheimer's Society 2014). This agenda emphasises innovative treatments and technologies which many hope will hold the clue to slowing down, stopping or potentially curing dementia.

Cutting edge developments in the biosciences intersect with the most intimate points of human social life, from conception and birth to aging and death. From gene therapies to novel brain imaging technologies, developments in biomedicine are rapidly expanding and increasingly affect everyday experience. Through the dialogue between science and society, mediated by clinical encounters, governmental initiatives, media campaigns, industry and health activism, the language of biomedicine is becoming an increasingly familiar. This familiarity inevitably shapes how we currently understand and experience aging. This study is therefore located in a wider field of anthropological work in science and technology studies, which demonstrate how

emerging technologies reveal common aspects of life in a new light (Ginsberg & Rapp 2004, Lock 2001, Rapp 1999, 2001). In the rapidly expanding field of neuroscience such technologies interrogate our thoughts, feelings, behaviours and emotions, reconfiguring the boundaries of the 'normal' and 'abnormal', what constitutes well-being and ill health (Williams, Katz & Martin 2011). Such biomedical developments have the potential to incite both immense hope and deep seated social anxiety (Rose 2007).

However, there is relatively little social science research focused on the current development of biotechnologies specifically for people with, or at high risk of developing dementia (Lock 2013, Moreira & Bond 2008). This study therefore offers a timely opportunity to explore the hopes and anxieties involved in the cutting-edge developments in biomedical research into conditions which cause dementia. Conditions which cause dementia involve the uniquely intimate space of the human mind, and throw into relief the Cartesian mind and body duality which continue to underpin dominant western philosophies of science and medicine (Pickstone 2000). These diseases combine the changing physical body with complex, culturally specific perceptions of age and aging. In this thesis, through the ethnographic analysis of developments in dementia research practices and the political agenda which shapes them, I develop an understanding of the role of biotechnological research in the co-construction of knowledge about dementias and ageing in UK society.

Dementia: A brief historical perspective

Interest in and understanding of mental and behavioural changes associated with later life have a long and convoluted history. The development of a classification of dementia as a specific syndrome resulting from a particular group of disorders, which have distinct and identifiable disease pathways, is a relatively recent phenomenon. The stabilization of disease categories in the face of shifting and uncertain knowledge is a key feature of current dementia science. As Bowker and Star (1999) discuss, there is a continual tension between evolving knowledge and the construction of stable, workable categories. For instance, Sontag (1994) and Martin (1994) both argue in the context of the immune system and HIV that as a disease category and the biological systems in which they are thought to act become more concrete, so the disease becomes a tangible object for strategic scientific investigation and intervention. As Fischer (2009) describes it is useful to therefore to think of classifications of disease and developments in treatments and

technologies, as in a continual process of emergence. This is illustrated by the simple cycle in Figure 3: What we understand today as emergent soon becomes established and eventually historical as it is superseded by newer forms of knowledge. This process is central to my reading of dementia as a concept. Over time, the understanding of dementia has evolved from a set of behavioural observations, to be defined by an increasingly specific set of pathologies. These pathologies are themselves the site of current debate and reconfiguration, and are by no means fixed. To illustrate this processual approach to the concept of dementia I provide a brief overview of the historical influences which have shaped contemporary western[3] knowledge of these conditions to the present day.

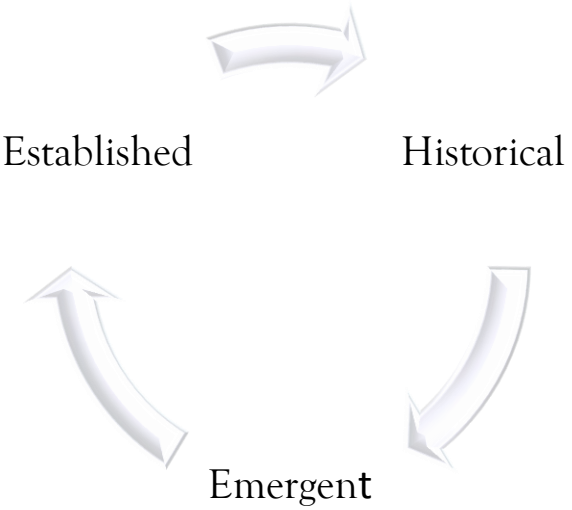


Figure 3: Continual process of emergence

I frame the history of conditions which cause dementia as a continual process of construction and contestation, what Jasanoff (2004) describes as a process of co-production. By using the term co-production I suggest that knowledge about dementia is shaped through the interaction of cultural beliefs, scientific and technological innovation, changing medical practice, infrastructure, government policy and public and patient interests.

[3] As my case study addresses specifically dementia neuroscience in the UK, this history is biased towards the influences pertinent to this Western biomedical context. Such an account acknowledges, albeit briefly, the non-western influences which are integral to this history of neuroscience, although there is not space to expand upon it here (c.f. Clarke, Dewhurst & Aminoff 1996, Finger 2000, Smith 2014).

Taking an embedded historical approach to conditions which cause dementia, I first locate them in the broader history of our beliefs about the mind, and the evolution of the contemporary biomedical model of the brain (Young 1970). There have been radical changes in our understanding of the human brain and mind, with the location of the mind 'wandering' between different organs of the body such as the heart, lungs and brain (Boller & Forbes 1998, Clarke, Dewhurst & Aminoff 1996: 2, Smith 2014). In relative terms, it is only recently in human history that the brain has been understood as the 'organ' of the mind. As a result, historical descriptions of dementia differ radically from the conditions we would recognise today. As a result, historical descriptions of dementia differ radically from conditions we would recognise today. However, Boller and Forbes (1998) persuasively argue that over time there has been a persistent preoccupation with the role of aging in changes of mental function. Finger (2000: 13-14) describes archaeological evidence from the Edwin Smith Surgical Papyrus of twenty-seventh century B.C.E Egypt which illustrate the cumulative effects of trauma and illness associated with the head and brain matter. Boller and Forbes suggest as early as 2000 B.C.E. such Egyptian archaeological evidence also associates aging with progressive impairment of memory and cognition (1998: 125). The historical shaping of dementia continues to be felt in contemporary perceptions of the condition.[4] This leads the authors to suggest that the observation of what today we call describe as the symptoms of dementia, are 'probably as old as mankind itself' (Boller & Forbes 1998: 125).

In the 'Golden Age' of fifth century B.C.E. Greece, during the rise of democracy and the concept of individual rationality, there is evidence in the work of Hippocrates that the brain begins to be located as 'the major controlling centre for the body' (Finger 2000: 29). However, it is important to note, this hypothesis was far from dominant, and throughout antiquity the location of the mind and soul were a matter of continuous debate (Smith 2014). In spite of contention around the nature of the brain itself, during this period, Plato, Horatius and Cicero are all described as recording observations which link aging in later life with cognitive degeneration (Boller & Forbes 1998). Moving toward the common era, Galen is credited with developing experimental methods

[4]Writers looking at the history of medicine caution against the over-interpretation of terminology, explicitly differentiating the evolution of a word from the evolution of a concept. Concepts must be viewed in context, and may not be directly comparable through time as knowledge and thinking change and evolve (Berrios 1987, 1995, Foucault 1973). With this in mind the evidence I focus on here is the broad association between observed descriptions of aging and of changes in behaviour. This does not assume equivalence between the ways in which cognition, mental functioning, the brain or dementia are conceptualised in their specific historical contexts.

to demonstrate what his predecessors Hippocrates and Aristotle had hypothesised, that the brain was the definitive organ of the mind (Finger 2000: 46). The work of Galen and later Celsus radically expanded the theory of localised brain function and produced the first attempts at systematic accounts of cognitive change. Aretaeus in the second century AD is recorded as making a specific differentiation between acute changes in behaviour, and those which followed a chronic course. This differentiation as linked to the first specific reference to a progressive course of, 'irreversible impairment of higher cognitive functions' (Boller & Forbes 1998: 127).

It is only in the late fourteenth century that the concept of dementia came into common usage in Western Europe (Berrios 1987). The first modern psychiatric definitions of dementia as a disease affecting cognition, are attributed to Esquirol and Pinel in France in the late eighteenth century (Berrios 1987, Boller & Forbes 1998). These early definitions of *dementia senilis* still lack what we would recognise as an empirical description or medical case history today. There is also no clear distinction between the neurological, biological, psychiatric or functional nature which we recognise in contemporary definitions of neurodegenerative conditions (Boller & Forbes 1998). Berrios also suggests that during this period the concept of dementia was not itself associated with a specific age group, nor limited to cognitive changes (1987: 829). Lock (2013) on the other hand, supports the idea that the association of later life with observable, chronic and irreversible changes in thought, memory and behaviour is a theme which has remained persistent across time, and continues to underpin popular perception of dementias. The historical evidence presented here suggests, that whilst complex and context specific, early definitions and associations of dementia do demonstrate an enduring association between aging and potential cognitive decline. This relationship would remain a topic of contention over the next two centuries, and continues to be an issue with complex social and scientific implications for contemporary dementia researchers.

An evolving pathology: pre-senile dementia and twentieth century neurophysiology, laboratory cellular imaging techniques

Between the seventeenth and eighteenth century there was renewed interest in and increasing acceptability of human dissection and pathology in medical science and teaching. Combined

with a shift in technological sophistication and increasingly anatomical definitions of disease concepts, the practice of pathology revolutionised understanding of the structures of human anatomy, including the brain (Duffin 2010: 32-33). The Edinburgh school of dissection in particular played a major role in furthering the social acceptability of human dissection and the legal procurement of human cadavers for research and teaching (Duffin 2010: 35). This was in part made possible by social, philosophical and religious shifts during the period, evidenced and reproduced in the work of Descartes and Willis, which constructed a separation between the material body and the concept of the immortal, rational soul (Clarke, Dewhurst & Aminoff 1996: 74-79, Grand & Feldman 2007). In this period, the understanding of neurological systems and the interaction of brain and body were experimentally mapped. This represented the first steps in neuro-anatomical approaches to brain function and solidified the identification of the brain as the seat of the mind and, in turn, the person (Finger 2001, Whitaker, Smith & Finger 2007).

In the nineteenth and twentieth centuries the concepts of senile dementia came under systematic scrutiny and observation by clinicians, undertaking research into the clinical and pathological features of dementia (Hodges 2006). These clinician-researchers systematically recorded psychiatric case histories on their wards. Intriguingly, these observations did not privilege old age, but focused on 'dementia like' neuropsychiatric cases involving younger people. These were people under the age of sixty-five years, the lower age threshold after which *dementia senilis* was believed to present. This interest in the anomaly of younger people presenting with *dementia senilis*-like symptoms led some clinicians and researchers to question what organic factors other than ageing might be involved in the development of these dementia disorders (Berrios 1990). This focus on the organic cause of mental disorders coincided with increasingly detailed documentation of the transmission of sexually transmitted illness throughout Europe (Boller & Forbes 1998). Diseases such as 'neurosyphillis', were strongly associated with chronic deterioration in mental health. The work of Alzheimer in Germany on dementia at the turn of the twentieth century, coincided with the increasing emphasis on identifying the organic causes of psychiatric disorders (Boller, Bick & Duyckaerts 2007).

In describing the work of ground-breaking neuropathologists such as Alzheimer, Nissl and Kraeplin, the medical historians Whitehouse, Maurer and Ballinger write

> [W]e are reminded of the difficult issues that were involved in defining the conceptual boundaries of this disease - issues that remain daunting despite the tremendous progress that has been made in the last few decades.
>
> (Whitehouse, Maurer & Ballinger 2000: 3-4).

Alzheimer's work presents an important moment in the evolution of the discipline of contemporary neuroscience. Whilst a practising psychiatry in the first decade of the 20th century, Alzheimer used new cell staining techniques developed by Bielschowski in 1903 for microscopy, to analyse the histopathology, orcell structures, of brain tissue from deceased patients (Förstl 2000: 72). This was the first time that staining had been used in neuro-anatomy and Alzheimer created images of the 'plaques' and' tangles' which are still referenced today in describing the pathology of AD. Combining this information with clinical observations, Alzheimer developed a combined clinical and laboratory base approach which marked a major shift in the practice of neuroscience (Maurer, Volk & Gerbaldo 2000: 6 - 9).

In the research which finally led to the identification of AD, Alzheimer emphasised that the pathology he was describing most likely represented only one subset of a larger range of neurodegenerative diseases. He stressed that the extent and nature of this subtype was not fully understood. Alzheimer therefore warned against the simple acceptance of a single and unquestionable classification. This risked, he felt, the false categorisation of a potentially much more complex range of conditions into a single undifferentiated syndrome. He wrote:

> [W]e must not be satisfied to force it [AD] into an existing group of well-known disease patterns. It is clear that there exist many more mental diseases than our textbooks indicate. In many such cases, a further histological examination must be affected to determine the characteristics of each single case. We must reach this stage in which the vast, well-known disease groups must be subdivided into many smaller groups, each one with its own clinical and anatomical characteristics.
>
> (Alzheimer quoted in Maurer, Volk & Gerbaldo 2000: 21).

The scientific, clinical and academic environments of key German universities, laboratories, hospitals at this time made possible rapid advances in the identification of neurodegenerative diseases. The relationship between Kraeplin and Alzheimer is of particular note. Kraeplin, Alzheimer's former mentor and later professional colleague, was a great supporter of his innovations in laboratory practice and cell staining techniques. In publications and presentations, it was Kraeplin, a 'classificatory optimist' (Förstl 2000: 74), and a senior figure in German neuroscience, who coined the term Alzheimer's disease. This was in the context of shifting relationships between competing senior scientists, laboratory groups and increasing access to international journals in multiple languages. Based in Munich, Alzheimer's and Kraeplin developed one of the largest and most influential groups of international neuroscientists at that time (Förstl 2000: 74). There was emerging professional consensus that AD was a specific disease category. Over the next decade AD became an increasingly common concept and a dominant theme in dementia research journals. As a result of these emerging social and scientific relations, and contrary to Alzheimer's instinct, across Europe AD became increasingly synonymous amongst lay people with all dementias. Significantly today, the usage of AD has also become a *lingua franca* or short hand for scientists when communicating in the public arena and working on the politics of raising awareness of dementia research. This legacy is apparent in the names of the dominant dementia research charities both globally, Alzheimer's Europe and Alzheimer's Society, and here in the UK, where Alzheimer's Society and Alzheimer's Research UK (ARUK) are the dominant dementia charities. Although both organisations deal with a much wider range of dementia causing conditions that AD, the decision to unify their work under the banner of the single and most common dementia pathology is of note.

Thus in the classification of conditions which cause dementia a paradox emerges: in the process seeking to define the concrete homogeneity of a disease category, there occura a proliferation of classifications (figure 4). Alzheimer, himself, emphasised that his findings marked the burgeoning complexity of a heterogeneous classification of dementias from observations of cases in which there was an earlier than usual age of onset and a specific pattern in cellular degeneration. However, rather than expanding outward, the prevailing research environment pulled inward, towards a single concrete classification which could become a focus for research. The success of the category of Alzheimer's disease speaks both to the social and political nature of the scientific relationships developed between neuroscientists in Europe during the early

twentieth century (Boller & Forbes 1998). In a world in which scientific reputation, publishing and research design were increasingly part of a growing and interconnected international scientific community, Alzheimer's cell images and case histories provided the foundation for the construction of a concrete disease entity. This movement toward the dominance of AD demonstrates the functional importance of having a named disease when it comes to the development research networks. Having a clear object of research attached to systematically diagnosed subjects, plays an important strategic role in the development of dementia studies. The expansion of research interest and infrastructure, in turn, enabled scientists and clinicians to map the complex heterogeneity which existed within this disease category, which undermine any simple homogeneous typology of disease.

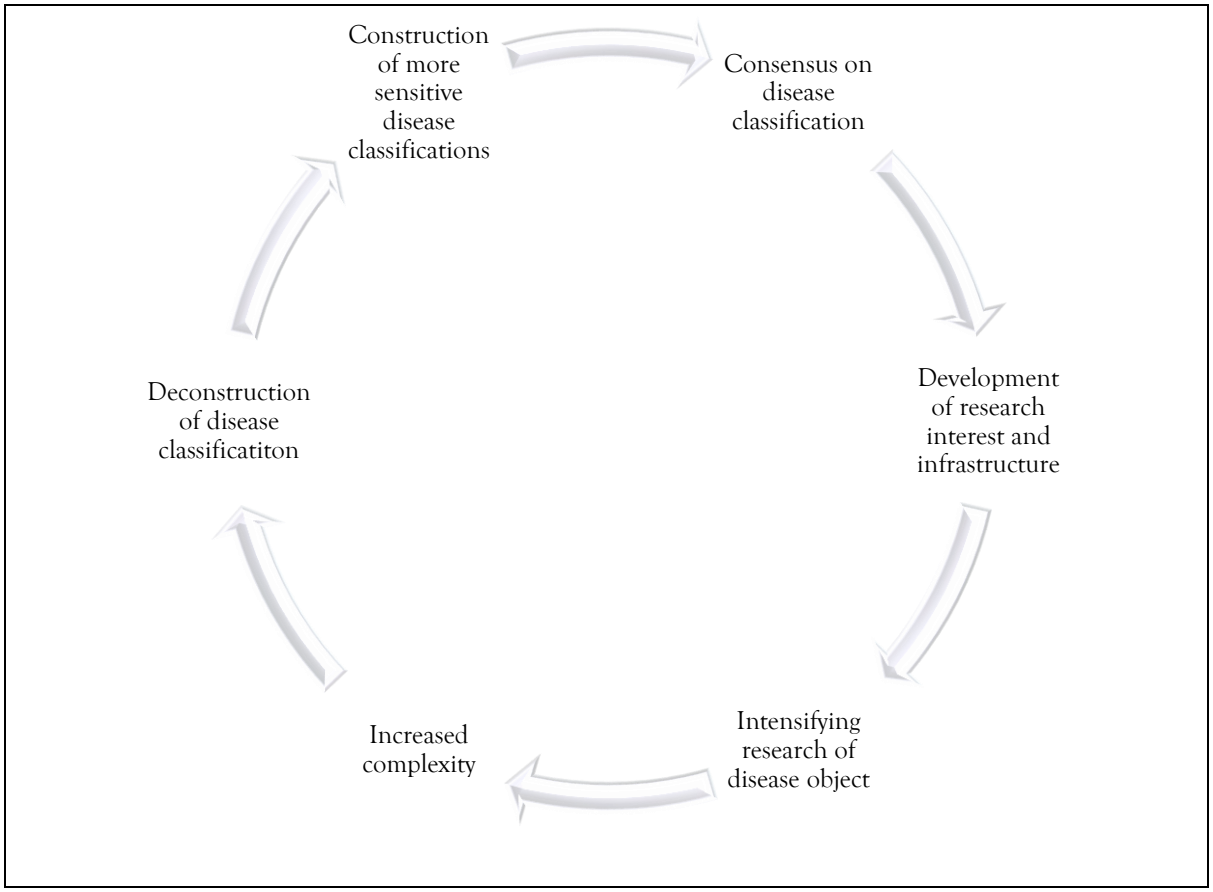


Figure 4: Cycle of proliferating classifications

As AD came into focus as an object, an organic disease which could be targeted by science, researcher's understanding of what dementias were, how they might be studied and treated was undergoing radical redefinition. As new tools and technologies emerged, knowledge expanded and the tension between a heterogeneous and homogeneous discourse about dementia was

perpetuated. As I go on to discuss later in this thesis, the boundaries between dementia subtypes and their variations continues to evolve as a matter for contention in the neuroscientific community (Dubois et al. 2010).

At the core of contemporary scientific epistemology is an ongoing tension between scientific certainty and the imperatives of replication, testing and falsification. Certainty is necessary in order to create the structures – conceptual, institutional, and relational – which enable research to take place. Within these structures the experimental process is used to render such knowledge as fragile, uncertain and contested. Science and technology can thus appear to produce homogenous and concrete explanation, what Latour refers to as a 'black-boxed' knowledge (Latour 1987). Inevitably, when we look more closely at any given concept within context, it is revealed to be a composite and pluralistic artefact, involving contributions from a diverse range of actors, combining distributed information which is continually disputed (Latour & Woolgar 1986). Social and historical studies of science demonstrate, therefore, that the development of science should be viewed not as isolated practices, but practices which take place within changing and complex social relations and specific cultural and historical contexts (Bowler 1989, 1990, Gould 1992, Latour & Woolgar 1986). In the section which follows I illustrate this tension with reference to the continued evolution of dementia disease classifications, and in particular the development of dementias within the Diagnostic Statistical Manual (DSM) and the International Classification of Disease (ICD). Both publications are used internationally as guidance for the formal diagnosis of conditions which cause dementia.

The Diagnostic Standard Manual and the International Classification of Disease

A specific interest in the collection of information on the instance of disease has been traced back to seventeenth century England and Europe (Greenwood 1948). As Foucault argued in his account of biopower, recording information about the health of populations has become an integral part of the operation of the modern nation state (Foucault 1990, 2002). In the United States in the mid-eighteenth century, a more complete and systematic collection of census information went hand in hand with the accumulation of information on verifiable incidents of a disease which could be classified by defined criteria (Strand 2011). Such data was developed to enable physicians to systematically identify the signs and symptoms of a particular disease. As in

the case of AD, observed symptomatic data could then be posthumously correlated with material evidence of the pathological changes caused by the condition. Consequently in 1855 the International Statistical Congress in Brussels developed the first versions of the International List of Causes of Death. This was based on the records developed by Farr and D'Espine (Greenwood 1948). The work of the Congress's 1893 committee, chaired by Bertillon, Chief of Statistical Services of the City of Paris, led to the development of the International Classification of Causes of Death list. Under the aegis of the World Health Organisation (WHO) in the US these early attempts at a systematic nomenclature eventually evolved into the International classification of Disease and Related Health Problems (ICD) (WHO 2014). The ICD was widely used in Europe to classify and diagnose mental health disorders but did not find favour in its home nation. Increasingly it was the DSM which became the commonly used system in the UK and US for categorising mental health conditions and diseases of the nervous system (Jetté et al 2010, WHO 2014).

The development of the DSM is linked to the development of the international scientific community in the early part of the twentieth century. Researchers and clinicians increasingly looked to forms of evidence from large scale samples which were conceptualised as more reliable and robust, allowing comparison across time and place. As the case of Alzheimer's work illustrates, the role of clinicians maintaining and exchanging patient records and case histories became central to this process. Clusters of cases were identified and 'written up' into accounts which could be readily exchanged amongst the wider neuroscientific community. This exchange took place through private communication and increasingly through publication in the expanding number of specialised biomedical journals. Better regulation, standardization and recording practices facilitated communication and provided the basis for discouraging potentially harmful practices from a newly professionalising medical community (Busch 2011)

The routes of this classificatory preference are to be found in the routine health screening of army recruits in the United States during and after the Second World War. This unique context provided an opportunity for physicians and psychiatrists to observe illness in a large and relatively controlled population (Blashfield, Flannigan & Riley 2010). Menninger, a US military physician working with service personnel and their records, developed the Medical 203 document, which provided procedures for the large scale statistical monitoring of psychiatric diseases and set

precedence for the further systematisation of disease categories (Houts 2000). Such efforts underpinned the American Psychiatric Association statistical record of the US hospital inpatient population. It was from these records that statistically significant mental disease groups were identified and classified. This data formed the basis for the Diagnostic and Statistical Manual of Mental Disorders, commonly called the DSM (Rogler 1996, Cooper 2005). For those working in the field of psychiatry, the DSM provided an officially recognised name, numerical code and description of the explicit mental and physiological criteria the patient had to display in order to fit the diagnostic category. The guide included a list of symptoms, their duration, and the common alternative conditions to be excluded, in order for a diagnosis to be considered firm.

The first edition, the DSM I, was released in 1952, and the second edition, DSM II, appeared in 1968. At this time, records suggest that the guidance was little used by practising psychiatrists (Cooper 2005). However, by the third edition (DSM III) which appeared around 1980, the resource is described as 'embedded in [US] mental health at every turn' (Cooper 2005: 1). By the 1980s, there was increasing professionalization and regulation of scientific and biomedical research. At the same time, there was rapid development of the transnational scientific community, with increasing connection to global pharmaceutical industries and markets. Cooper notes: 'research papers are couched in DSM terminology and pharmaceutical companies list the DSM diagnoses that their drugs treat' (Cooper 2005: 1). Within this context the DSM became the fundamental guide to the classification of mental health worldwide.[5]

From its inception the capacity of the DSM to define disease has come under challenge. Far from a neutral and purely empirical process, the DSM has been shown to be subject to commercial, political and cultural influences and interests (Rogler 1996).[6] Some of the categories of disease

[5] Although outside the scope of this particular history, it is important to note that this professionalization and regulation of medical and bio-scientific research occurred in the context of emerging ethical standards developed through a series of multi-national documents: the Nuremburg Code, 1947, the Universal Declaration of Human Rights, 1948, the Declaration of Helsinki, 1964, the International Covenant on Civil and Political Rights, 1966, the Belmont Report, 1979, and the 1996 International Conference on Harmonisation Good Clinical Practice(ICH-GCP). These 'milestones' were historic in the development of multi-national ethical framework, defining the acceptable limits of medical research with human subjects and in the role of voluntary participation and informed consent for research participation (Bhatt 2010).

[6] In the United States where health care is primarily privately funded, with relatively limited state support available, medical insurance policies, and the companies that supply them are the primary conduit for citizens to pay for to health care at the point of need. Insurance and pharmaceutical companies are significant part of the US economy. As a result, lobbyists have significant power in the political arena. In the area of research which informs the

described in earlier DSM manuals are today understood to be purely historical and cultural phenomena rather than legitimate diagnoses. In particular, the role of the DSM in legitimising the classification of homosexuality as a mental disorder has been critiqued. This classification is seen to have contributed to stigma and discriminatory legacy which continues to be experienced within lesbian, gay, bisexual and transgendered communities today (Jutel 2011). The evidence of such classifications demonstrate how each edition of the DSM should be thought of very much as products of their time and reflective of the dominant values of the cultures in which they are constructed. As a result changes in cultural understanding can have a profound impact on the kinds of social behaviour which are classified as evidence of a 'disorder' of the mind (Cooper 2005). In short, the use of rigid definitions and boundaries based on standardised statistical calculations, have the effect of constructing rather than describing disease realities. The utility of this construction is described by Berrios and Porter: 'Diagnostic categories are about creating something which can be acted upon with beneficial outcomes' (Berrios & Porter 1995: xvii). This process highlights the way in which diagnostic labels function as a tool of science as well as a means of social control and the exercise of biopower (Foucault 1990, Rose 1996, 2007). As societies themselves are subject to continual change, both the ICD and the DSM continue to be revised and rewritten in response to shifts in not only science, but also changing cultural, commercial and political interests. The shifting nature of disease categories once more highlights a paradox: changing evidence has the potential to both consolidate and compromise the bounded concept of disease categories, including those used to define conditions which cause dementia.

In my own study, dementia researchers and research projects often referred to the patients diagnosed using the classifications outlined in the textual revision of the fourth edition (DSM-IV-TR), released in 2000.[7] The category provided by DSM-IV-TR was often combined in research protocols with the ICD 10, released in 1994. For dementia, however, more important is the additional disease classification developed by the National Institute of Neurological Disorders and Stroke–Alzheimer Disease and Related Disorders (NINCDS–ADRDA), published in 1984. Whilst the DSM classification describes a 'probable diagnosis' of AD based on clinically observed

construction of the DSM health industries play a significant role. As a result, diagnostic practices and concepts demonstrate the interrelation of health care, health industry, economy, political structures and scientific practices.
[7]DSM V was published May 2013. Consequently the most recent amendments in the diagnostic criteria for dementias fall outside the limits of this thesis.

signs and symptoms; the NINCDS-ADRDA classification allows for a definitive diagnosis with the inclusion of imaging data. Additionally the NINCDS-ADRDA classification can be informed by histopathological evidence to specify the particular condition and the pathology involved in causing dementia.

At the time of the initial development of the NINCDS–ADRDA and the DSM IV, common access to information about the histopathology of the dementias was still limited to post-mortem analysis. With the advent of new technologies such as imaging and bio-marker tests, the capacity to observe disease processes *in vivo* has led to a fundamental change in the diagnostic categories of conditions which cause dementia. As Dubois et al. write:

> The NINCDS–ADRDA and the DSM-IV-TR criteria for Alzheimer's disease (AD) are the prevailing diagnostic standards in research; however, *they have now fallen behind the unprecedented growth of scientific knowledge*. Distinctive and reliable biomarkers of AD are now available through structural MRI, molecular neuroimaging with PET, and cerebrospinal fluid analyses. This progress provides the impetus for our proposal of revised diagnostic criteria for AD.
>
> Dubois et al. (2007: 734 (my emphasis))

As I discussed in the history of dementia, advances in research continually render existing diagnostic standards limited. Frequently throughout history the DSM has been found to be playing catch-up with evolving research knowledge. For instance although imaging technologies began to be developed in the 1970s, and used in dementia research since the 1990s they were not included in the 2000 DSM criteria.

Neuroscience: Heading toward 'The Decade of the Brain'[8]

Having considered the categories by which conditions causing dementia are defined, I now move on to discuss how the development of these new biotechnologies have changed biological and

[8]The idea of a 'decade of the brain' originated in the US between1990-1999 and was launched by President Bush (Abi-Rached 2008). However, the concept of a decade dedicated to the brain and brain science spread to many other organisational bodies, including the EU. The decade became a trope to capture and capitalise on the potential of advances in neuroscience to transform our understanding of our biology, psychology and sociality (European Commission 1992).

biochemical understanding of the brain and its process. Such changes reflect the continuing shifts which occur between knowledge and practice. Just as Alzheimer's use of cell staining techniques radically changed how researchers understand a range of dementia conditions in the early twentieth century, today new technologies of neuroscience are having a similar transformative impact on the fields of clinical research, clinical trials and health care practices. By tracking changes in research design, changes in inclusion and exclusion criteria for research, and infrastructural development of research facilities, it is possible to see this relationship evolving in practice. The criteria which are developed in the categorisation processes described above must change as new biological evidence becomes accepted by the majority of those who make up the dementia research community.

As Dubois et al. (2007) indicate a key development in the evolution of current dementia disease categories was the emergence of 'in vivo' brain imaging, particularly the development of Magnetic Resonance Imaging (MRI) (O'Brien 2005). The technique of MRI was first published by, and remains largely attributable to, Mansfield and Lauterbur in 1974 (Geva 2006). As with all major advances in science, however, there remains a degree of contention about the primary international contributors to the development of the technique (Filler 2009). The development of such imaging technologies in the 1980s required a synthesis of novel advances in a range of disciplines including engineering, medical physics and computer programming techniques and technologies. It was only during the later development of the technology that it became apparent the potential MRI would have in human biomedicine. As a result, the range of technologies used to create visualisations of living brain tissue structures and processes classed as neuroimaging are still considered a relatively young and emerging field in medical physics. The first MRI scan of human tissue of a live human subject took place in the UK in 1984. The synthesis of disciplinary techniques and willingness of key scientists to work across disciplinary boundaries enabled the development of equipment to image soft tissues in the living body, including the brain. Over the last 30 years new developments in this technological field have been rapid. New imaging approaches have resulted in multiple modalities being in use in health research and care today (Farah &Wolpe 2004). The most common of these, and the ones used by researchers in this study included MRI, functional MRI (fMRI), Photon Emission Tomography (PET), Scanning Photon Emission Computer Tomography (SPECT), used to image the brain in vivo, and

Scanning Electron Microscopy (SEM) used to image post-mortem brain tissue at very high resolution.

(F)MRI, MRI and PET are the most common imaging tools used in clinical practice. The techniques for most gross neuroimaging techniques are based on the measurement of variations in the oxygenation or metabolism of brain tissue. In structural imaging (MRI) the measurement of metabolism is correlated with tissue density in order to map the physical brain structure. The primary data produced by these methods are translated through mathematical algorithms to construct two dimensional or three dimensional visual representations. In fMRI metabolic changes are correlated with specific changes in activity when a controlled stimulus, such as a language processing task, is experienced. Thus fMRI can be used to map brain activity in action, over time, providing a four-dimensional representation. PET uses a radioactive isotope marker that is taken up by selected cells in the brain. The rate of uptake of the isotope provides a secondary measure of metabolism which is correlated with brain activity. Other technologies that are in common use in dementia research include: Scanning Photon Emission Computer Tomography (SPECT) which focuses on measuring variation in photon emission; Blood-Oxygenation-Level-Dependent (BOLD) (Jezzard & Clare 2001).[9] The large scale collection and comparison of such data enables researchers to construct an aggregate model of structures and processes which are understood to make up the 'average' living human brain. By extension, these processes then enable researchers to identify potentially abnormal structures or disease processes which correlate with disorders in physical and mental function. The collection of these data informs the construction of disease categories, becoming part of the process of diagnosis, and central to the development and practice of research and treatment.

As well as the gross scale of imaging the structure and function of the brain in techniques of MRI and PET, current advances in dementia research involve working at the cellular and molecular level. This is related to the development of SEM which allows the imaging of posthumous brain tissue at extremely high resolution. This technology allows researchers to visually examine disease processes at the cellular level which has been central to the accurate differentiation between

[9] Farah & Wolpe (2004) provide further overview of the main imaging technologies in common use in clinical practice and clinical neuroscientific research. For a fuller technical overview of the MRI and fMRI see also D'Esposito 2006, Durvernoy 1999, Gjedde 2001 and Glover 2001.

dementia conditions such as DLB and VaD. By identifying and trying to understanding the biochemical and bimolecular processes occurring at the cellular level, researchers are developing a new picture of how specific disease processes work, and how more refined treatment protocols could be developed to intervene more effectively and earlier in course of the condition (Lock 2013).

Unsurprisingly, in such a rapidly developing field there are vibrant debates in the imaging community about the relative value and efficacy of different techniques for particular patients and for particular conditions (Jackson & Purandare 2007). Within the dementia research literature, MRI, fMRI and PET dominate research into dementia condition diagnoses and treatments. Although these are widely accepted techniques, a number of writers have drawn attention to the lack of standardized protocols for interpreting data produced by these technologies (Jezzard & Buxton 2006). The absence of standard procedures there is concern about the over-interpretation of data produced by non-comparable processes (Andreasen 2001, Beaulieu 2002, Dumit 2004, Joyce 2005). Joyce (2005) suggests that the variable processing of data can lead to idiosyncratic inference and interpretation at various stages in the production of imaging data.

In this thesis scientific images and images of science play an important role in the evolution of dementia research in the UK both practically and rhetorically. I examine MRI and fMRI and SEM images are used by scientists not simply as evidence of their findings, but also, as a means of conveying their knowledge, interests and concerns beyond the scientific domain. This includes the use of imaging data in the fields of policy, patient recruitment, public awareness and research advocacy. This places the scientific image in both the scientific and political arenas. There is an extensive body of literature which examines the complex processes by which medical images are formed and the relations and connections they elicit (Burri & Dumit 2008, Cohn 2008, Dumit 2004, Joyce 2005, Prasad 2005). This literature amply demonstrates how images used in medicine and biomedical sciences have helped define and critique basic categories in scientific and biomedical discourse (Lynch 1985). Developments in scientific imaging have been shown to have the capacity to reshape, challenge and completely alter people's cosmologies of health and illness. Taking this approach I am locating scientific images as an important artefact through which people come to know the world, understand its working and conceptualise the role they play

within it. This has been demonstrated particularly in the construction of diagnostic categories and labels, which can have important implications for the identity, behaviour and social relations of the people which receive them (Kilshaw 2008, Greco 2012).[10]

Scientific images can thus play a vital role in fixing both social and medical realities. However, it is important to note that often such images become disconnected from the scientific mode of production. Portrayals of science in action have led social scientists to examine how biomedical images (including technical diagrams, illustrations of disease processes, medical images and images of science) are used in diverse locations, for a complex range of purposes and by a variety of differently positioned actors. For instance, such images play important roles not only in peer reviewed academic journals (Daston & Galison 1992), but also in public health campaigns (Löwy & Krige 2001, McCool et al. 2012). The reproduction of images in this case are clearly motivated by, and produced within, different contexts. However, one feature in the contemporary age of biomedicine is the abiding fascination with visualisations of the human body. Galison (1997) suggests that images provide unrestricted access to information with an incredible level of immediacy. Images, he argues move fluidly between domains, by-passing the technical, scientific and social complexities of their production (Daston & Galison 1992, Galison 1997). In short, images are forms of knowledge which are flexible, porous, and open to multiple uses and interpretations. Such interpretations therefore, can rapidly move the image away from its original signifier, in sometimes unexpected ways.[11]

The expansion and growing sophistication of biotechnologies, such as imaging, have shifted how scientific research groups are shaped and constructed. Increasingly dementia research groups will bring together researchers with a range of disciplinary specialisms. Therefore scientific images,

[10] The role of diagnostic categories in reshaping or challenging people's sense of identity has been drawn into particular relief in the case of emergent conditions which do not have accepted boundaries or classifications. The cases of chronic fatigue syndrome (CFS) known also as Myalgic Encephalopathy (ME) and Post Traumatic Stress Disorder (PTSD), are high profile examples where the contested nature of the conditions, crossing organic and psychiatric boundaries, have made them sites of potent political and personal conflict (Clarke & James 2003, Dumit 2005). This sort of identity making and contestation is also particularly apparent in the narratives of other neurodegenerative and chronic conditions, where the boundaries between being 'sick' and being 'well' fluctuate and blur (Monks & Frankenberg 1995, Marenderani, Locock & Powell 2012).

[11]Simultaneous developments in the digitisation of data and the incorporation of information communication technologies (ICT's) into the process of neuroimaging, facilitates the development of large scale and transnational data comparison. This has resulted in transnational scientific endeavours such as the Human Brain Project. For a more in depth examination of the role played by ICT's in the development of contemporary neuroscience see Beaulieu (2001, 2004).

such as neuroimaging, are not only a product of increasing trans-disciplinarity, but also an important tool for facilitating these kinds of transdisciplinary working relationships. As such medical imaging can be a powerful tool. Imagines provide a shared object and language within a research group, one which can operate across and beyond disciplinary boundaries. For instance, neuroimaging data constructed during an fMRI project to improve diagnostic accuracy between AD and VaD, would be used both within the specific project, and also presented to specialist audiences from different fields. These fields may include: clinical practice, disease pathology, biochemistry, statistical programming and digital modelling. Such images may then also be used in future research presentations, proposals and documents involved in the development of the research infrastructure. The same images also appear in patient documents to explain diagnostic processes and treatment options. Such images may appear again in material to recruit participants to clinical trials and in media content to raise awareness of dementia conditions at public engagement events. This is a far from an exhaustive list, but illustrates how an image may be used to facilitate the scientific process across different domains.

In the early 1990s the growing variation of modalities of data production, operating within different scientific communities, resulted in large quantities of data on an increasing number of neurological and neurodegenerative conditions. However, different approaches within research groups and specialisms, and variations between national scientific policies led to different imaging techniques becoming dominant in different localities. This is apparent in the use of technologies such as PET, particularly as they relate to availability, access to and control of the radioactive materials required. As a result, there exists a great variation, nationally and internationally on the types of data available for the comparison of particular conditions such as AD. This variation raised concerns among the scientific community worldwide (Beaulieu 2004). Some scientists considered the lack of systematisation, synthesis and collaborative sharing of data to be limiting the success of the field of dementia research. The perceived lack of coordination was understood to restrict the effective application of data to advance research and clinical practice. In response to this flaw in research structure, groups of senior scientists worked within their national systems of science policy, developed strategies to attempt to maximise the productivity of dementia research.

Beaulieu (2004) has compared the strategies which subsequently developed in North America and Western Europe. North America scientists focused on how infrastructure could be developed to take advantage of the burgeoning, geographically dispersed, data-rich digital research community. Capturing the popular imagination was considered crucial to the success of the enterprise. The US 'Decade of the Brain' was launched by President Bush in the 1990s. This led to initiatives such as the Human Brain Project (HBP). Such initiatives, following the precedent of the Human Genome Project (HGP), were designed to integrate data and increase research productivity and application. This was achieved by capitalising on national social and political enchantment with scientific understanding of the human condition, enlisting a sense of national pride to build public and political support (Beaulieu 2004).

In contrast, neuroscience researchers in Europe and the UK focused not on the coordination of data management systems, but on the networks of scientists, researchers and clinicians involved. UK and EU policy suggests that dementia neuroscience lacked the people with the appropriate range of clinical and technical research expertise to work across disciplines. Beaulieu argues that in these regions, the dominant issue was perceived to be a lack of sufficiently qualified cross-disciplinary scientific personnel required to take full advantage of and develop new technologies in this field (Beaulieu 2004). Simply put, UK and European dementia research policy, upon which this anthropological study is based, foregrounded the importance of technical expertise and relations. As a result, developments in the UK dementia research community have focused on initiatives to raise the profile of dementia neuroscience and to recruit high quality, young scientists from across a range of disciplines. This focus is apparent in the Medical Research Councils' (MRC) 2008 Strategic Report on Neurodegeneration: "When judged against other countries, a particular weakness in the UK is the relatively fragmented research effort, with small research teams" (MRC 2008: 5).

Dementia research in the context of the UK National Health Service: health economics, standards and regulations

Moving on from the state of contemporary dementia neuroscience, in order to understand the shape of dementias and dementia research in the UK it is necessary to locate research efforts

within the context of a national health service (NHS) and the wider national system of health and social welfare. Although shaky at its inception in 1948, Klein describes how the NHS developed into "a tax funded service that provides comprehensive, universal health care that is free at the point of delivery" (Klein 2010: v). This service was underpinned by an ethos of collectivism and public confidence in the structure of state planning. However, by the 1970s, economic and political climates were changing both globally and nationally. At this time, notions of health research and 'public' science were reshaped along increasingly market-oriented principles (de Chadarevian 2011).[12] Klein argues that the NHS quickly became a monolith of technocratic rationalism (2010: 46-75). As a result, in the early 1980s a parliamentary review of the NHS recommended greater investment in public health and health services research to increase productivity and rationalise expenditure (Black 1997). In 1991 this led to the UK becoming the first European country to officially integrate a national research and development program into the health system, heralding a new era in health research and health care (Klein 2010).

Over the last twenty years, across consecutive governments, the marketization of the NHS has continued, with patients reconfigured as 'consumers', and the language of choice and individualism entering every aspect of the health care relationship. However, the NHS has shown great resilience, existing throughout 'policy drama and organisational turbulence [...] in a cocoon of institutional and cultural continuity' (Klein 2010: v). Whilst public opinion is frequently frustrated by unequal or inconsistent quality and availability of care, the NHS remains 'a much loved, if also much criticised, national treasure' (Klein 2010: v). However, the commercialization and marketization of national health care, has accompanied a decline in public trust in the medical profession and by extension the biomedical research community. As a result, there is increasing demand for transparency and accountability within biomedical research. This

[12] De Chadarevian suggests that whilst the commercialisation of health research started in the UK, it was perfected in the United States, where the practice of patenting new developments had become central to the growth of emerging health-care markets. The UK research system continues to be criticised for failing to make effective use of patent law to control intellectual property developed through the national research infrastructure. As a result, measures have been put in place to ensure that all new project funding agreements address how intellectual property rights will be protected (de Chadarevian 2011). Klein (2010) suggests that one reason academic and clinical researchers have been, and remain reluctant to engage with the commercial research practices relates to the collective and paternalistic ethics and politics which underpin the history of the NHS. There remains a tension between with the logic of the market and the ethos which underpins the health service.

accountability is realised through complex processes of audit, regulation, and a responsive approach to the concerns of the 'patient /consumer'.

UK biomedical researchers, thus work within a complex set of structural, bureaucratic, ethical and regulatory frameworks. Alongside these frameworks, UK biomedical research sits within wider European and transnational structures such as the EU Clinical Trials Directives. These directives in turn sit within international ethical, commercial and scientific regulatory structures, for example, those provided by the WHO (ICH 2010). These multiple, and often competing frameworks, must be harmonised in order for research and experimentation to proceed. It should be noted that whilst the challenges of new modes of accountability are reshaping clinician / patient relations, they have not dis-assembled the long standing hierarchical power relations which largely persists.

As the field of biomedical research is vast, I begin by outlining the kinds of dementia research involved in this project, and situate these in the national context of funding and regulation. Black (1997) identifies four broad tiers of research supported within the NHS: Basic, clinical, health service and public health. In this project I looked at studies in two main areas of dementia research, basic and clinical. Basic research is laboratory based, focusing on the proof of principle in relation to understanding of dementia subtypes and their pathologies in relation to the ageing brain. This may involve human cell line and animal cell or subject studies.[13] Second, I considered clinical research, also known as applied research, which involves living human subject. Clinical or applied research is divided into two main areas: observational and interventional. Observational studies do not involve any physical intervention in the subject's treatment. Rather, they use diagnostic technologies (ranging from imaging to psychological tests) and patient records to understand and monitor the disease pathways of specific dementia subtypes in the individual or, within larger population groups. Interventional studies research the effect of technologies, medicines, therapies and practices on human participants. Hackshaw pinpoints four main targets for interventional research:

[13] I am particularly concerned with study implications of experimenting with human tissue. However, it is important to acknowledge the controls and regulations involved in animal based studies of dementia. The background and implications of such regulations are a considerable topic of interest, but beyond the scope of this thesis. For a discussion of the changes in control and regulation of animal based research see Brody (1998) and Blakemore et al (2012).

-to diagnose or detect disease

-to treat an existing disorder

-to prevent disease or early death

-to change behaviour, habits or other lifestyle factors

(Hackshaw 2009: 7)

Currently in dementia research one of the main targets for interventional studies are to develop methods of early identification, to slow the organic progression of the condition, maintaining or improving the cognitive capacity or quality of life of the recipient.

UK biomedical research is overseen by the National Institute of Health Research (NIHR) which is the core research arm of the NHS. The NIHR works alongside the discipline specific research councils. In the case of biomedical and biotechnological research, this includes the Medical Research Council (MRC), the Engineering and Physics Research Council (EPSRC), and increasingly the Economic and Social Research Council (ESRC). The councils fund and provide guidance and regulations for funded studies. Such guidance is both responsive and anticipates future directions and issues arising from research. As a result such organisational bodies are involved in shaping future research design and foci. The national research councils, such as the MRC, work alongside specific academic and industry research centres. It is through these centres that research projects are developed and conducted. In order to access human research subjects, data or tissue, an academic research group must have, or create links between, academic institutions and regional NHS facilities. Access to, and ethical approval for, research with a patient population is administrated by regional Research and Development (R&D) and Research Ethics Committees (REC).[14] These are organised and administered at the level of Primary Care Trusts (PCT), the regional umbrella organisation under which NHS services are collected and to a degree coordinated.[15]

[14]A more in-depth description of the structures and processes involved in NHS R&D and REC approval is given in chapter two.

[15] The PCT system of regional organisation was replaced by the Clinical Commissioning Group (CCG) in April 2013 (Great Britain, National Health Service England (NHSE) 2013). The CCG devolved commissioning power for regional NHS services from the top-down PCT structure to regional collectives of General Practitioners.

In the UK applied pharmaceutical and biotechnological research studies involve a tightly regulated and high cost research process. Industry plays a major role in providing finance and resources for projects which are based in the NHS. UK government policy increasingly emphasises the academic-commercial partnerships as the natural basis for biomedical research (Sheard et al 2006). Internationally the UK is also located within highly competitive transnational health markets. As a result biomedical research and industry is positioned by current government as a key resource in the UK economic recovery and future expansion (Great Britain, Department for Business, Innovation and Skills 2011). There is a significant branch of anthropological work focused on the global nature of biotechnological research.[16] Therefore, whilst throughout this thesis I make reference to the transnational and collaborative connections which shape national research practices, primarily I am focused upon how such relations are realised and enacted within the national scientific, social and political-economic networks.

In the last six decades, one of the main challenges for the NHS has been to respond to the shifting demographics of an ageing population. As a result, decisions on resource allocation and priorities determined by the Department of Health are moving away from the classic targets of infectious disease, toward chronic degenerative health conditions such as dementias (but also conditions such as arthritis, metabolic, endocrine, cardiovascular and cardiopulmonary conditions). As the NHS is increasingly called upon to help manage and treat such conditions, so it also confronts the anxieties, needs and expectations of an aging public. As a consequence, one of the core policy frameworks which dominate current NIHR and research council strategy is that of 'Research for Patient Benefit' (RfPB) (Great Britain, NIHR 2013, 2014). The RfPB initiative launched in 2006 is described by the NIHR as a 'response-mode programme' focused on research which can improve delivery of front-line health services in the short to medium term (Great Britain, NIHR 2008: 2).

With increasing emphasis on rapid response to outcomes and patients benefit, how do funders and policy makers identify and assess the value of biomedical research across a broad range of potential interventions? The principles of Evidence Based Medicine (EBM) are widely used to

[16] For an overview of the main debates on the practical, political and ethical issues related to the transnational nature of biotechnological development, in particular in pharmaceutical trials see in particular Lock & Nguyen 2010 and Ong & Collier 2008.

evaluate research and demonstrate the clear and quantifiable benefit of any treatment programme. As Timmermans and Berg note, the concept of EBM can have a variety of interpretations, such as a process of 'critical self-evaluation, the production of evidence through research and scientific review, and/or the ability to scrutinize presented evidence for its validity and clinical applicability' (Timmermans & Berg 2003: 3). The fundamental meaning of EBM for research is that any new intervention must 'be more effective than another or that it has a similar effect, but is safer, cheaper or more convenient to administer' (Hackman 2009: 8). Evidence of efficacy and utility must be demonstrated through 'proper statistical analysis' which provides robust and objective evidence' (Hackman 2009: 8). As such research must refer to national and transnational clinical standards and guidelines, which define how diagnostic and therapeutic strategies are objectively 'proven' to be better than their alternatives.

The internationally recognised 'gold standard' for assessing the efficacy of a clinical intervention is the Randomised Control Trial (RCT). The concept of controlled experimentation can be traced back to antiquity, but the structure we recognise today first emerges in the mid-eighteenth century in the work of James Lind on scurvy (Hacksaw 2009, Bhatt 2010). Controlled testing, involves comparing the outcomes of a group who receive the experimental intervention to groups which receive: no intervention, an alternate treatment or a placebo. However, the knowledge that one is receiving an experimental drug has been shown to have a psychological impact, which significantly biases the results of the trial. As a result, in 1943, the UK MRC designed and funded the first double-blind comparative trial of *patulin* to treat the common cold (Timmermans & Berg 2010). Blinding attempts to address bias through the alternate allocation of subjects to intervention or non-intervention group, where neither clinician nor subject knows which group the subject is assigned to. Although the concept of randomisation had been considered since 1928 (Hackshaw 2009), it was the 1948 testing of streptomycin for pulmonary tuberculosis, again under the auspices of the MRC, which marked the first recognised randomised trial. Here, participants were assigned random numbers to further minimise the potential for bias, by preventing any prediction of which treatment group a participant would be assigned to. The combination of randomised and double-blind protocols enabled complex data to be subjected to relatively simple statistical tests (Lesaffre & Verbeke 2005).[17] Clinical trials, like the disease

[17] Where variables were continuous this requires a t-test, where the variables are categorical a chi-squared test (Lesaffre & Verbeke 2005).

categories upon which they intervene, continue to evolve. However, from this point onward clinical trials acquired the key characteristics we associate them with today: meticulous design and implementation, systematic enrolment criteria and systematic data collection (Bhatt 2010). These principles of a systematisation and control remain the backbone of the authority claimed by the knowledge and products which result from the clinical trial process.

In the case of clinical drugs trials Lesaffre and Verbeke (2005) describe how a study will be divided into four phases illustrated in figure 5. The classic trial structure is reiterated in the ARUK 2013 research strategy illustrated in figure 6. This diagram also demonstrates how basic research and clinical research are particularly closely interlinked in dementia science. The need to improve understanding of the basic disease mechanisms involved in the specific conditions which cause dementia remains a high priority in the development of better drug targets and diagnostic tools for clinical trial.

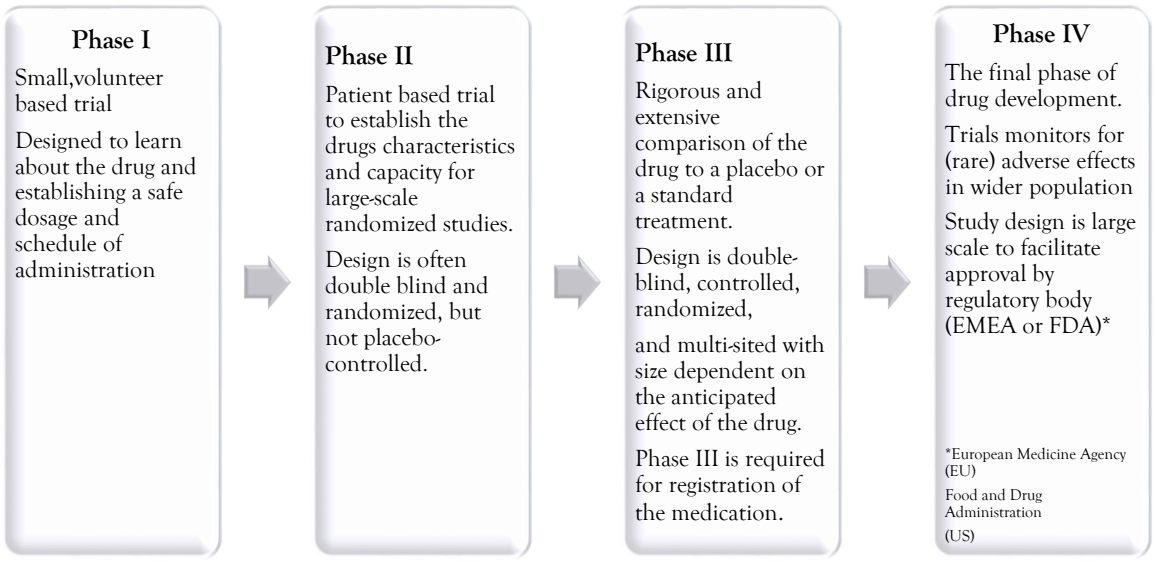


Figure **5:** Phases of the clinical trial.
Lesaffre &Verbeke (2005)

The inclusion and exclusion criteria for trials in dementia research employ the disease category continually developed thought DSM, ICD and NINCDS/ADRDA. These criteria enable researchers to define the 'right patient' to recruit for a specific trial (Dubois et al 2007). Developing a tightly controlled profile for recruitment allows researchers to select patients whose

response to the intervention can be considered comparable. As such phase I and II trials involve 'ideal' patients. These studies explore the response of a very specific disease pathway within that specific sub-sample of patients. Thus the RCT both creates and acts upon the 'ideal' research subject (Timmermans & Berg 2010). This is again illustrated by the ARUK research strategy illustration (figure 6).

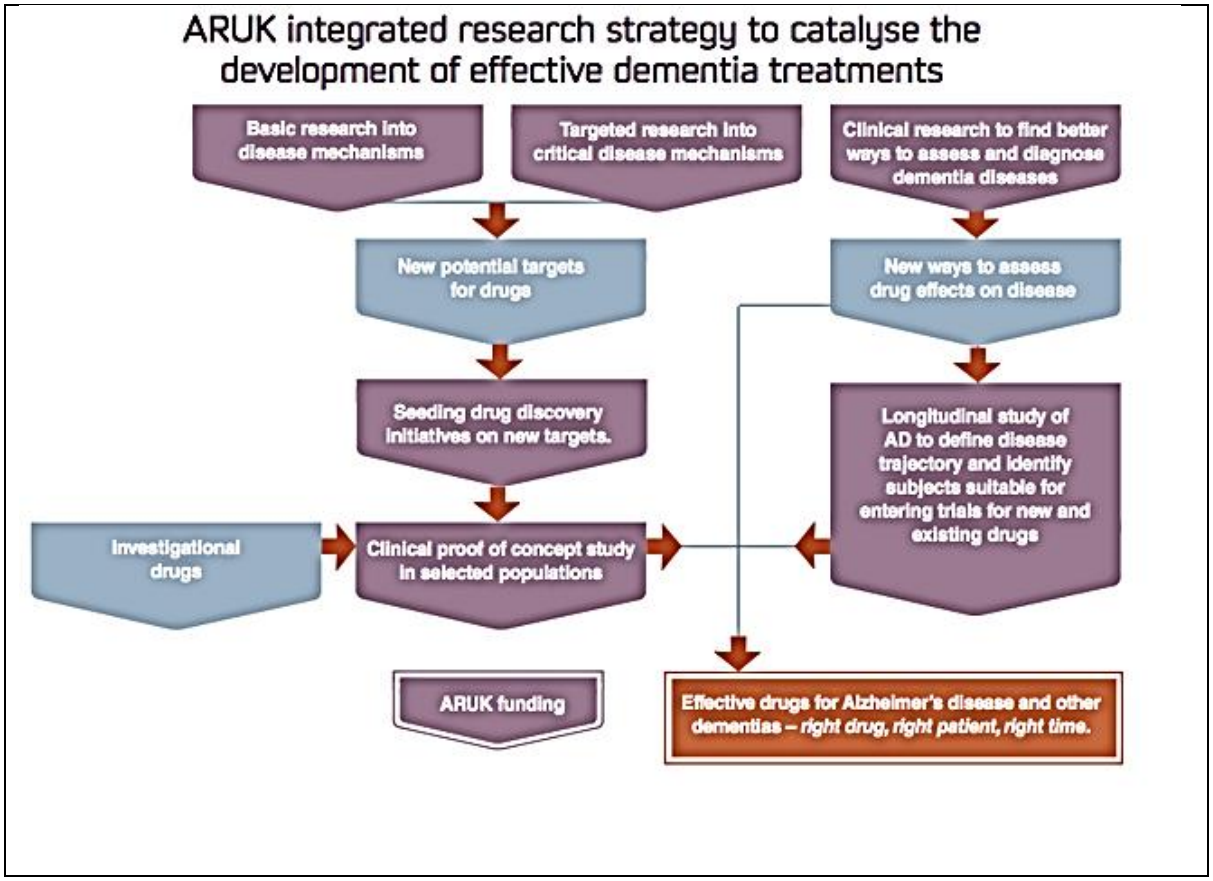


Figure 6: Diagram of the ARUK Dementia research strategy

This research approach has been dubbed 'right patient, right drug, right time' (Ashley-Webb 2013). This image illustrates the feedback which takes place between the changing categorisation of the condition, the types of treatment and diagnostic targets which are adopted, and the trial design. Thus the trial process, in working to protect the participant, and the quality of the data produced, continually modifies and increases the emerging complexity of the disease. This cycle between research and diagnosis perpetually reinforces the idea of a fixed and controlled set of categories, which are in actuality changing, fragmenting and being redefined (Bowker & Star 1999).

Although clinical research functions within these categories, a major concern for research is that, like other age related chronic illnesses; those affected with conditions which cause dementia are highly likely to have other co-morbid disorders. As a result researchers struggle with the very controlled limits of the RCT structure, in the content of a disease which render the recruitment of a 'pure sample' increasingly problematic. This was reflected at a discussion I observed at a meeting of clinicians, scientists and the public involved in the Alzheimer's Society Research Network:

> **Chair of meeting**: What I was going to ask you about was one of the debates about the sort of heterogeneity of AD, you know, the fact that there are a lot of different types of pathology in the brain. A lot of people particularly perhaps once they are past the age of 80 have vascular changes and other things going on, and it feels like there has been a debate with some people arguing that we should be doing initial trials on fewer, purer groups who have particular imaging or, you know biomarker changes, that we know have got AD but not much else. But on the other hand people would argue if we do that, then the trials aren't generalizable to anyone except people who meet those very tight criteria. Do you have any views on that?
>
> **Epidemiologist**: Yes, yeah I have pretty firm views on that, because it is true of other disease other than dementia as well. Clinical trials are a very pure form of experiment, and generally people who design trials want their trial population to be less… problematic, really (laughs), and so they ideally want them to have no other diseases, and therefore the very old people are excluded from trials, often just because, not because of age but because they often have co-morbidities, and so you end up testing a drug, any drug on a population that ultimately it won't be given to. Because when it's then put out wider, it is given to very old people that have got [other] conditions, and we've see the results of that with some drugs where they have been interacting with others, with other drugs. So yes, ok maybe we could focus on particular populations of particular forms of dementia, but I would say I wouldn't rule out the other co-morbidities at all. And I think yes it would be great if we could intervene earlier but, but we're then looking at following people up for a very long time, and we have to judge a really delicate

> balance of designing trials that don't have downsides where people need following up for 10 years. It is just not feasible to do this. And of course we're in a really tricky area and I don't think there is a simple solution

Creating a synthesis between recognised standards, demonstrating comparable efficacy across therapies, and trial protocols with results that can be replicated and compared across different nations has led to complex efforts to 'harmonise' clinical guidelines transnationally. Since 1990, the UK, along with Europe, the United States and Japan, participate in the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH 2010). The organisation provides bi-yearly updates, developed by representatives of regulatory agencies and the pharmaceutical industry, with the aim of constructing collective standards of practice in clinical trials. Regularly updated training in ICH guidelines for Good Clinical Practice (ICH-GCP) is a requirement for investigators conducting research within the UK NHS (NJRO 2014). Thus the structures of trial practice and therefore, the categories used to understand diseases are embedded in a wider transnational process of construction and debate.

The National Institute for Clinical Excellence (NICE) is the arm of the NHS tasked with providing national guidance on clinical, social care and public health guidelines and medicines practice (Great Britain, NIHR 2014a). In providing guidance on the use of newly available medicinal products, NICE uses an EBM approach. This approach is informed by the 'best available evidence' based on expert opinion and measures of efficacy, safety, patient need and cost-benefit (Great Britain, NIHR 2014b). Collapsing the complex benefits posed by an experimental treatment into a manageable and universally approved system of comparison has generated its own field of complex calculations and classifications of benefit. This system is used not only by those approving therapies for NHS use, it inevitable informs how researchers define and test the benefits of the treatments in development, and how the disease itself is objectified. EBM has thus spawned a wide range of secondary measures which are used to quantify the efficacy of interventions for complex dementia conditions (Katona et al 2007). For example, outcomes in dementia research can include multidimensional measures such as MRI evidence, behavioural symptoms, tests of cognition and global function, and activity of daily living functions (O'brien 2003: 94-95). Measures such as the instrumental activities of daily living scale (IADL) and Quality Adjusted Life Years (QALY) place a numerical score on the benefits a

treatment has the potential to provide. Such scores become powerful 'expert' evidence in the subsequent fiscal comparisons which form part of the NICE consultation process (Katona et al 2007). The NICE website emphasises that their reports are guidance and not legislature, giving individual physicians flexibility and ultimate responsibility for practice decisions (Great Britain, NICE 2004c; Moreira 2011). However, with clinical commissioning and budgeting responsibilities devolved to the local CCG in 2013, in an economic climate which asks the NHS to make efficiency savings of £20 billion, such guidance has significant authority (Nuffield Trust 2011). This is particularly true in cases such as existing treatments for dementia, which demonstrate how difficult it is to capture both efficacy and benefit (Moreira 2011). During public consultation on NICE guidelines, inevitably less quantifiable assessments of benefit and cost are brought into play, thus the development of such guidance can become political and highly contested (O'Brien 2006).

The successful development of scientific innovations, therefore, requires researchers not only to understand the potential for novel medical technologies, but also to be aware of the national and transnational methods by which the efficacy and value of such technologies will be measured. Thus when preparing their research design to include accepted, quantifiable means of assessing the quality and efficacy of scientific discoveries, scientists are already deeply engaged with the social and political-economic factors which shape the domain of clinical research.

The prioritisation of patient expressions of need was a source of concern for some of the researchers I spoke with during this project. On the one hand, they feared that the NHS was becoming a demand driven service which would become unsustainable in the current fiscal climate. On the other hand, researchers and clinicians were sceptical as to whether there currently exists enough knowledge about the aetiology of conditions which cause dementia to develop the products which might meet the increasing demand for effective, outcome-based interventions.

MRI techniques and technologies are a case in point. The potential of these technologies has fundamentally altered our understanding of neurodegenerative disease processes in the living brain. However, the costs of fitting and running MRI technology are substantial. Having personnel to run, analyse and interpret imaging data is a significant and ongoing cost. Today the

application of MRI diagnostics within the NHS has reached an unprecedented scale, becoming the largest growing field of imaging and radiodiagnostics (Great Britain, Audit Commission for Local Authorities in England and Wales, National Audit Office, 2011; Svenson & Steele 2013). Indeed, its applications have moved far beyond what was imagined in the early days of its funding and development. As I learned in my fieldwork, whilst clinicians and publics are enchanted by these technologies, clinical researchers and epidemiologists are increasingly wary of their potential over-application. This is particularly true in relation to proposals for a national dementia screening strategy.

A mode II study of dementia from a risk society perspective

Within the field of neuroscience the role of imaging technologies has altered the kinds of knowledge available to understand both the 'normal' aging processes of the human brain, and the processes involved in specific degenerative disease pathways (O'Brien 2005, Frisoni et al 2010). However, as understanding of neurology and knowledge about neurodegenerative conditions has developed, it has revealed the extent of what we do yet know about the biology of conditions which cause dementias. Indeed, the gap between what is known, but not yet understood would appear to be widening with each new discovery. As such, a core issue explored in this study is the relationship between perceived health risks, uncertainty and the accumulation of medical and scientific knowledge driven by public and political expectation as much as scientific curiosity.

My argument here comes close to that of Beck and Giddens about the nature of risk in contemporary society (Beck 1992, 1994, Giddens 2013). These writers argue that, rather than mitigating risk, emerging science and technologies have seen risk and uncertainty proliferate. As knowledge expands so the boundaries of knowledge grow. As a consequence society becomes increasingly concerned about the expanding realm of the unknown (Beck-Gernsheim 2000). This in turn feeds a sense of being at risk, not only at the level of the individual, but also at the level of public perception and awareness of the community. Dementia research provides an excellent example of the dynamics of a risk environment in practice, and the responses that emerge. As I go onto show in chapter three, public support for dementia research has become a lynch pin in efforts amongst the scientific community to prioritise dementia research at a national level.

Dementia researchers are aware of the huge pressure to deliver knowledge, and more importantly, treatments which fulfil the social contract between science and the public. This is a social contract that is built on the premise that more research will provide better outcomes for those with complex dementia syndromes.

This picture of contemporary experimental neuroscience fits with what has been described by Gibbons et al as the second mode of science: namely characterised as 'socially distributed, application-oriented, trans-disciplinary, and subject to multiple accountabilities' (Nowotny 2003: 179; cf also Gibbons et al 1994, Nowotny *et al* 2001, 2006). Nowotny suggests that those most inclined to involve themselves in mode II science are those least established and with most to gain (2003). In the case of dementia, research is on the one hand well established with a long and complex history. On the other hand dementia science is perceived amongst current researchers to be highly underfunded and under-resourced, having failed to achieve significant traction on the disease processes involved in dementia. Many of the techniques and technologies which are becoming increasingly central to the development of new dementia diagnostics and treatments remain relatively new and rapidly emerging. These characteristics are particularly apparent in the development of new imaging technologies and biomarkers (Lock 2013).

The emergent characteristics of dementia neuroscience which I have outlined above illustrate two key features upon which this thesis is focused. Firstly, I focus on the challenges and problems scientists and researchers experience in trying to address the complexities which surround dementia research. This complexity, I suggest, is rooted in the particular way dementia causing conditions continue to be highly plural, problematic and changing disease objects, which researchers struggle to define. Such struggles take place in an environment of clinical research which is enmeshed both biomedical, and social, political and economic relations, which themselves are continually evolving. I argue, therefore for a theoretical approach located in the theory of co-production, in which the dementia research community is examined as an example of civic-epistemology. By using this term I suggest that dementia science can useful be examined not as separate from, or outside of social relations. Rather this is a case study of dementia science as a process of knowledge production which takes place within social relations. Secondly I consider how dementia research is emerging as a very public site of science. Public engagement, I will show, is embedded in the emergence of the dementia research agenda, which is attempting

to addresses specific challenges attributed to dementia researcher by researchers and policy makers. This thesis, therefore, explores the dementia research agenda as a novel re-emergence of mode II science, and aims to understand the implications of this changing sense of relationality and community between science and society.

Chapter 3 The emergence of the 'field'

In this thesis I provide a novel qualitative understanding of the connections that are shaping contemporary dementia neuroscience practice and policy. Over the course of the study I have followed a grounded approach, that is, the project has evolved in response to constraints and possibilities as these presented themselves in the course of the research. In this chapter I describe the research process, participants, and methods. I reflect on how I moved from a simple and coherent concept of dementia research, to a study which had to confront the much more convoluted realities of science as it is embedded in social, political and economic relations. In particular, I look at the process of negotiating access to different groups in the research assemblage, including public and patient participants, academic and clinical researchers and research organisations. This overview illustrates how the process of gaining access shaped the kind of methods I was able to use to shed light on dementia research practice.

I then go on to consider the main problems and anxieties articulated by those who helped me develop this project and the issues of access which we all had to negotiate. These issues are important because they demonstrate a key methodological premise of the study, that is, how people make and break relations in research. Thus, on the one hand, scientists and their publics have overlapping aims and interests and could forge relations and make connections to facilitate advancement of their mutual goals. At the same time, competing interests or perspectives amongst the same groups could create friction and uncertainty which could lead to connections being reconfigured. In this regard, the relation between science and society is dispersed and fragmented rather than linear and clearly situated. What I observed were groups operating organically and rhizomatically, rather than in tree-like networks (Deleuze & Guattari 1997). I describe how the spreading of connections between scientists and publics led me to take an analytical approach based on linguistic and visual imagery and rhetoric as a strategy for observing the relations and collaborations that make up a 'research community'.

A turn of events: the national dementia research call

I conducted research between October 2010 and March 2014. By chance, my entry into the world of dementia research occurred at a time when the profile of dementias in UK medical,

scientific, governmental and 'public' was rising rapidly. In March 2012, I observed the media announcement by Prime Minister David Cameron, of the 'National Dementia Challenge'. This was outlined in a Department of Health press release as,

> (T)he Government's ambition to increase diagnosis rates, to raise awareness and understanding and to strengthen substantially our research efforts so we can help those living with dementia have a better quality of life.
>
> (Lansley, Department of Health, March 26, 2012)

For neuroscientists', psychiatrists, biomedical and clinical researchers specialising in the field, the pledge of investment in financial, human, technical and social resources at such a high level marked the culmination of more than twenty years debate and lobbying (Fox 1989, Keen 1993). These efforts were directed at the under-resourcing and under-representation of dementia disorders in the UK, and world health research agenda.

Key landmarks preceded Cameron's statement. One such landmark was reached at a Dementia research workshop I attended in January 2011. Presented by the UK's National Institute of Health Research (NIHR) and the Ministerial Action Group on Dementia Research (MAGDR), this event brought together a wide range of researchers: Clinical, biomedical, qualitative and quantitative. Also in attendance were senior National Health Service (NHS) and Department of Health (DH) officials who announced a 'call' for applied health research on dementias (Great Britain NIHR 2014a). Key speakers at this event were the UK's Chief Medical Officer and Director General of Research and Development Professor Dame Sally Davies who was also the chair of the UK Clinical Research Network (UKCRN), Paul Burstow Minister of State for Care Services, Alistair Burns, the National Clinical Director for Dementia in the Department of Health, himself a Professor and Honorary Consultant of Old Age Psychiatry. This was a formidable line-up of senior, clinically trained, politically active health policy-makers whose connections with the scientific community made them extremely powerful drivers of a dementia-specific research agenda.

Joining the political, clinical and scientific representatives were members of the UK's two main dementia advocacy groups: the Alzheimer's Society and the Alzheimer's Research Trust which, significantly, rebranded itself as Alzheimer's Research UK (ARUK) in 2010. The change of name suggested an intensification of efforts to market dementias, using the dominant brand of Alzheimer's, as a major public health concern for which public and political mobilisation was required. Barbara Woodward-Carlton, a representative for the Alzheimer's Society and member of the Quality Research in Dementia Group (later renamed the Research Network), was scheduled to give a presentation at the event. She represented the Society's 'lay' members, the patients, carers, and former carers who wished to be involved in 'actively shaping the research programme' (Alzheimer Society 2012). As the day progressed, key contributions were made by the chair of Neurosciences and Mental Health Board of the Medical Research Council (MRC), UK's leading governmental funder of clinical research and the Director of the Dementias and Neurodegenerative Research Network (DeNDRoN). This powerful assembly of advocates for dementia research serves as a useful example of the processes and relations that I had been following over the last year. The NIHR meeting acted as evidence of what had emerged as a highly active social-scientific movement which had developed around specific issue related to working on dementia.

During Woodward-Carlton's presentation the room became quiet, uncomfortably so. She described caring for her mother, who had dementia and had recently passed away. She did not hold back. This was her platform, and she had a clear point that she wanted to communicate. She explained her position with a graceful clarity to over 300 researchers and health care practitioners from across UK universities, NHS trusts, research networks, research centres, private research companies, and medical charities. She explained that the public experience of dementia research had stagnated. People who experience the impact of dementia, she argued, had not benefited from the knowledge that research had produced. She criticised the failure to disseminate or implement research findings beyond or even across the health and social care sector. In particular, she drew attention to the lack of research dissemination and research informed training amongst primary and acute services.

There followed a vacant pause, and then applause. When the question and answer session began, it was the tension that struck me, the feeling of discontinuity between Barbara's concerns and

the questions which followed. Researchers, who made up the majority of the audience, fell into a discussion which, I would come to recognise as reflecting their long standing and well-rehearsed frustrations: Why were researchers still failing to gain access to appropriate patient groups or data sets? Why was a national neurodegenerative disease register not up and running to facilitate research recruitment? Why were projects not being reviewed by subject appropriate panels?

Despite the applause Barbara had received, I could not but help noticing the absence of discussion about her concerns about the failure to implement existing research knowledge. Were her comments so incommensurate with scientists' wider research concerns? This led me to consider just what is the relationship between the public voices that are expressed at research meetings and the actual practices involved in the scientific process?

A complex field of multiple stake holders

This example acts as a useful reflection on the nature of the field site in which I was working. It demonstrated how multiple players, with diverse perspectives, interests and goals come together in the research process. Significantly, it draws attention to the way that beneath the superficial sharing of an agenda, there was a tension between the need to carry out more research and to use existing research for direct patient benefit (fPB). What response would result from such meetings? Often uneasy exchanges and competing perspectives revealed the explicit and implicit shaping of the logistics and the context of research, as it was understood by differently situated actors. It was this context which led me to adopt an analytical perspective in which laboratory and clinical practice needed to be understood in relation to the social entanglements though which the UK dementia research agenda was being shaped.

Undertaking ethnography at this interface resulted in an often chaotic sense of the field. Actors could be from a wide range of institutions, from diverse locations across the UK, with radically different statuses and power to influence and control the development of research. On occasions such as the NIHR meeting they shared physical space, however, they had competing ways of understanding and knowing dementia, and different ideas about how 'good' dementia research should look, and what it should do. This chaos provided a rich context in which to observe contemporary entanglements of science and society. Such research meetings and events became

a key site for my conduct of ethnographic research. These settings providing unique opportunities to observe how scientists viewed and responded to relations outside of, but critical to the funding, recruitment and dissemination of their work in hospitals and laboratories.

In the following sections, I introduce the main actors in the field including research institutions (NMR Centre), research infrastructure organisations (DenDRoN, NIHR, and UKCRN), government representatives (DH), the pharmaceutical industry, public and patient participants and patient advocacy groups (Alzheimer Society, Alzheimer Research UK).

Developing relations and addressing access: working inward and studying up

Whilst an awareness of multiple stakeholders is essential to this study, it is important to emphasise that throughout these networks are primarily explored from and understood within the clinical and scientific perspectives on dementia research. In other words, I focused on tracing the interaction of the social and the scientific primarily from the perspectives of researchers. I particularly look at how scientists and clinicians understood, framed and interacted with the growing visibility of, and interest in their work. In order to do this I had to examine not only researchers in isolation but researchers in their interactions with other stakeholders in the research process. However, locating and accessing clinical research in this context presented a major challenge in this study.

There were two main issues: defining a location and negotiating access. The entanglement between clinical research and publics which I found so intriguing made the idea of a site specific study a less than satisfactory way of proceeding. Yet, if I wasn't to focus on one location, how was I to define my site of study, and how would I negotiate access and conduct ethnographic field work?

The second issue revolved around access and power relations in the field. The project was scrutinised and approved by Durham University's Anthropology Department Ethics Committee. However, to work on NHS sites and with NHS staff required a second tier of approval. As many researchers have found, working with the NHS for non-NHS researchers is a notoriously challenging prospect (Simpson 2011, Lewis & Russell 2011). Gaining access involves a lengthy

administration process and the development of good ties with a regional NHS research and development group. This is particularly difficult for a non-clinically trained, qualitative researcher who has never worked in the field before. As has been discussed by anthropologists doing ethnographic studies within the NHS, working with medical and scientific professional groups such as neuroscientists carries its own peculiar set of challenges. As I explore below, these include restricted access, limited availability, and limited tolerance for the qualitative research approach and methodology.

Experts & elites

Understanding the particular challenge of working with elites was fundamental to the research I undertook. The issue of how to manage power relations in research encounters which involve elite and expert groups or what Nader referred to as 'studying up' has a long history in anthropology (Conti & O'Neil 2007, Konrad 2002, Nader 1972 also cf. Nugent & Shore 2002). When 'studying down' the power of the researcher, (both consciously and unconsciously, assumed and ascribed) is recognised as having an effect on interaction with participants, requiring the exercise of reflexivity and awareness. The often paternalistic assumptions which underpin this approach were challenged by ethnographers especially when they began to turn their gaze onto their own communities, and those groups which hold and exert power in the contemporary world.

In Science and Technology Studies (STS), where informants are often academic and clinical researchers and practitioners, with high levels of formal and technical knowledge, the practice of ethnography takes on particular characteristics. To access organisations, such as the NHS, which are hierarchical and have explicit definitions of expertise, the approach of the ethnographer has to be framed accordingly. This is particularly true where the researcher's own expertise (as an ethnographer) do not easily translate into the epistemic foundations upon which the definitions of the community are built. Traweek (1998) describes this as entering a culture of 'extreme objectivity', or more precisely one in which the ideals of research are based upon explicit ideas about the nature of knowledge and validity. I go on to demonstrate, that although this epistemic ground was certainly a challenge I encountered, in my interactions with members of the dementia

research community, participants were often highly aware of the importance of social relations in the process of research and knowledge making.

The researchers with whom I hoped to work were often highly pressurised and practicing under severe time constraints. They combined academic, clinical, and administrative workloads in addition to their role as principle investigators. This was particularly true for those identified as leaders in the development of the national dementia research agenda. The main strategies I adopted to manage this process are those described by STS scholars as a willingness toward acclimatisation and negotiation (Nader 1972, Knorr Cetina 1999, Boyer 2008). My own experience, like theirs was a perpetual process of adaptation.

I had prepared myself to use both participatory and more structured data collection practices such as semi-structured interviews. These would enable me to choose the most suitable tool for the context and the nature of the participants. For elites in particular, I believed that the semi-structured interview would be most beneficial, allowing as it does for a fixed time and location to fit the participant's schedule. Furthermore, a pre-emptive outline of questions would help them to contextualise what was expected in the meeting. Curiously, I found that during formal interviews, participants were often reticent in discussing any issue which they saw as falling outside their technical domain. They deferred to others, whose point of view on a particular issue they would describe as having greater validity than their 'opinion', which they didn't feel had a place in an interview.

My experience therefore echoes that described by Rabinow (1999) where informal rather than formal encounters as a participant-observer, yielded far richer and fuller conversations about how researchers understood the changing research environment. These settings included events such as research meetings, symposia and workshops. In these more informal settings the same participants who during interview stated they were unable to comment on a technological, clinical or economic issue, freely initiated discussions and raised their concerns about the wider issues of dementia research and how they might impact upon research work.[18] In this project,

[18] Participants in these informal contexts were always informed or reminded of my role as a researcher of these events and I received verbal consent to use our discussion to inform my project. As such I always adhered to the guidelines on maintained consent outlined by the ASA

such occasions captured the finer-grain of social interaction and negotiation that occurs in dementia research environment far more fully than the formalised interviews.

I found that to work with experts in this environment, I could not ignore the role played by non-scientific participants. In working across the public-science interface, I also increasingly encountered the 'expert-patient'. On the one hand the concept of the 'expert-patient' is a rhetoric construct developing within NHS and Department of Health policy making. On the other hand, expert-patients were those with dementia and those who cared for them who had acquired a very different kind of 'expert' knowledge about the research process. Thus, the role and identification of 'downstream' as well as 'upstream' expertise, and their potential to exert force or power are an important feature of this study (Evans & Collins 2002: 609, Kerr et al 2007). I use accounts of key episodes, such as the presentation made by Barbara Woodward-Carlton's at the NIHR meeting given at the start of this chapter, to represent these 'downstream' expert voices in action.

These episodes show participants vocally resisting the 'upstream' narratives about research presented by scientists and clinicians. In particular this is apparent in accounts of the uneasy negotiations which taking place between Public Patient Involvement groups and dementia researchers. This reflection on power relations situates my analysis of dementia research in the flow of day to day social relations. In reflecting on the multiple flows of power, my aim is not imply an equal control of power between researchers and other participants. Neither the expert-patient, nor the social-expert in the form of the anthropologist, can be said to stand on an equal footing with clinicians and scientists in the domain of clinical research.

DeNDRoN and the NMR Centre

Having been primed by accounts of STS research to encounter resistance in negotiating access to the laboratory context, I was surprised to find genuine interest and enthusiasm for my work amongst the scientists and clinicians I met. By making links with the North East branch of DeNDRoN, I developed good contacts with leading neuroscientists and medical imagers based in Newcastle. Initially, through contacts within DeNDRoN I was put in touch with the Newcastle Medical Resonance Centre (NMRC). My research into how DeNDRoN's administration of the Clinical Research Network Portfolio (UKCRN) demonstrated that the two Magnetic Resonance

Imaging (MRI) scanners and functional MRI (fMRI) techniques based at the NMRC, made it a crucial technological hub for a number of observational dementia projects. These studies explored the aetiology of specific dementia types and has a particular interest in the study of Dementia with Lewy Body (DLB). They also specialised in interventional phase III trials examining drug efficacy and diagnostic procedures.

I put together a proposal for research and put this to the senior management of the NMRC and in September 2010 met with one of the centre's directors. We discuss how a project examining dementia research might work, and how I might make contact with researchers in order to observe imaging practices in the context of dementia research. Whilst waiting for our meeting I looked around the corridors, like my own department I observed the conference posters which showed different aspects of their centres research. From the work I had already done, I recognised the names of some of the researchers involved. Unlike in my own discipline where single authors were common, I was struck by the long lists of authors involved in each project. This reflected the shape of research in this field which frequently required the collaboration of people from different technical specialties, a diverse support team, and the involvement of multiple senior researchers to enable a project to take place.

Other posters told the story of a fundraising project centred on a local man, Charlie Crowe, who was in the late stages of Alzheimer's disease (AD) (figure 7). Charlie sadly passed away in February 2010. A former Newcastle football player, images from Charlie's life and footballing career collected by him and his family became the focal point for a campaign to raise funds for a new multimillion pound MRI scanner to extend the centre's capacity as a leader in imaging research and diagnostics for dementia and metabolic syndromes.

I was shown around the centre's first floor and introduced to people from the many specialists involved in imaging research. In one room medical physicists, mathematicians and computer programmers worked alongside one another. In another room, I met men and women involved in neuroscience, old age psychiatry and psychology. In yet another office the administrative team negotiated issues such as funding, research governance and approval. I was made aware of how the directors of the centre were concerned about creating a sense of team identity.

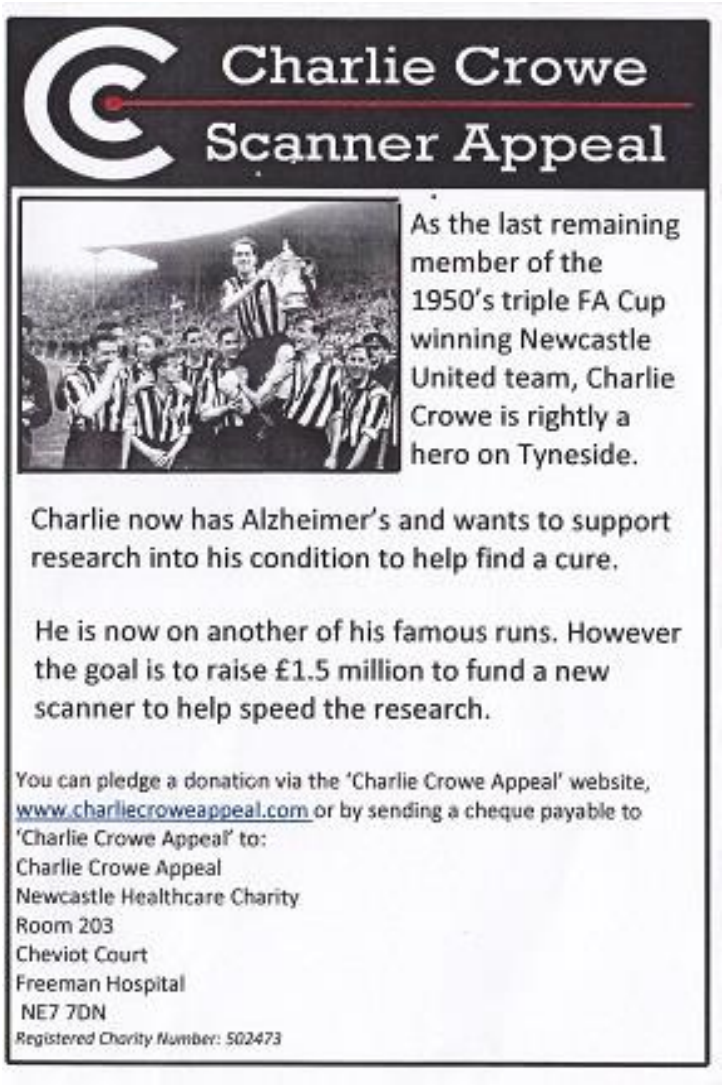


Figure 7: Advert for the Charlie Crowe Scanner Appeal

The director talked extensively about the process of attracting and recruiting internationally excellent scientists. He emphasised that for him the administrative team was a focal point for enabling research to actually take place, negotiating the complex layers of bureaucracy involved in working between regional NHS organisation, academic institutions and national funding bodies. The director of the NMRC talked about his role in ensuring the high scientific profile of the unit, working with both the local community, Newcastle University and regional NHS organisations. Maintaining the reputational capital of the centre was clearly important when furthering research activity both nationally and internationally.[19]

[19] The role of reputational capital in scientific communities has long been a concern in social studies of science (Merton 1968, Mulkay 1976).

Downstairs were the rooms for the clinical research team of nurses and imaging technicians who were involved in ensuring that research participants completed safety questionnaires and consent processes. They also prepared people for the scanning process itself. The director expressed his anxiety about this situation, explaining that he really wanted this office on the same floor as the others, to ensure that there was no sense of disparity between the different groups involved. However, this was not possible as the unit was starting to outgrow the original purpose built facility that he had helped designed.

Social relations in clinical research

Finally, I was introduced to the scanning suite itself. At the centre was an imposing, stark white machine with the iconic moulded, circular, polo-mint shaped entrance. A familiar low hissing, pumping noise filled the room, as the gas compressor continually fed helium to super-cool the coils forming the magnet bore. A bed where the participant would lie could be raised from sitting height to slide them into the machine. Surrounded by reinforced concrete to shield the magnet, the room was windowless and gently lit. The relative silence combined with the rhythmic hiss seemed to me both clinical and calm. Unexpectedly on the wall was projected an image of Newcastle football club. The director explained that by using a periscope mirror inside the scanner people could see out. This reduced their feeling of claustrophobia when they were fully inside the bore of the scanner. This, he said had been found particularly useful when working with people with dementia who might become easily disoriented and anxious. The slide show of images projected on the wall provided patients with familiar scenes, often related to the history and landscape peculiar to the city. The director described how earphone defenders were used to shield the patient from the loud noise made by the magnetic coils vibrating during different stages of the scan. These headphones were also connected to the scanning booth so that the technicians could engage participants in conversation during the scan. This helped to reassure anxious participants and helping them to remain as calm, comfortable and, importantly as still as possible. The technique of MRI requires that the subject remains still for the duration of each scan in order to collect effective data. It was clear from this initial encounter that this was not just a clinical and scientific environment but one in which social relations had to be forged and maintained.

The ways in which the social was an integral part of the scientific had been poignantly illustrated by the creative and considered use of visual imagery to help a person with dementia feel secure and calm whilst having a structural MRI. The social quite literally made the scientific possible. The use of such imagery, however, was not only directed at research participants but was a significant element in fund raising campaigns. Working with iconic regional figures, organisations and businesses, the NMRC employed such imagery as part of efforts to secure funding for a more powerful Tesla scanner to improve data acquisition in the diagnostic and research process. This induction to the research community alerted me yet further to the importance of such social interactions to the research process. In turn I was shown how these interactions were shaping scientific practice itself. In the environment in which I was working a participant could be framed simultaneously as an object of scientific scrutiny which needed to be contained, and as a person and subject whose particular needs researchers worked hard to understand and negotiate. As such it became apparent that the method of detailed ethnographic observations would be a valuable means of illustrating complex relations and dynamics at work.

Government, industry and the market in dementia research

The role of relations was further illustrated at research events where every effort was made to bring together different stakeholders. However, during eighteen months of fieldwork I never encountered an industry representative or member of the pharmaceutical industries. After the event, I became curious about this physical absence. As suggested in chapter one, Big Pharma is a principle sponsor of clinical trials and drug development. However researchers, echoing my experience, discussed commercial and industrial partners by their absence rather than their presence. For instance, the closure of R&D programmes into drug development for psychiatric and neurological diseases by three major pharmaceutical companies, GlaxoSmithKline, AstraZeneca and MSD, was a cause for great concern. This prompted the members of the British Pyschopharmacology Association (BPA) to write an open letter to the Minister of State for Universities and Science, Rt. Hon, David Willets, MP. This letter set out the biomedical, academic and economic impact such withdrawals would have. The representatives of the BPA closed their correspondence by emphasising the need for a combined political, scientific and medical response to prevent this trend of withdrawal from continuing (BPA 2010). Lack of progress and some significant failures in phase III drug development trials had led to a loss of

confidence in the prospect of effective and marketable treatments. The threatened a loss of industry investment led scientists to lobby politicians, who in turn put pressure on industry to support R&D in this area. However, increasing government pressure to develop academic - industrial relations to support research also presented scientists with a concern that they would lose control of the direction of pure research to a market-driven agenda. As they saw it, pushing research in non-scientific directions, and increasing the potential for earlier role out of minimally effective treatments would not be in patients' best interests. Thus, whilst not a principle focuses of this thesis, industry was an important presence in the developing research agenda. The curious role and narrative of industries 'absence' presented in this fieldwork could prompt an interesting direction for future investigation.

Negotiating access to NHS dementia research: capitulating to the hydra

By observing the lay-out of the NMR Centre I was observing how local, regional, national and international relations were experienced for researchers based at the centre. This left me excited about the potential of site specific project which could illustrate these relations across different scales. Now I had one final hurdle to cross, NHS research approval. NMR Centre researchers would be involved on projects recruiting through the NHS, and many of the staff involved would be NHS employees. As a result, I was required to apply for an NHS Research Passport, my project needed to go through the NHS R&D process and I needed approval from an NHS research ethics committee (REC). Having anticipated this I had already begun work to understand the research governance process. However, trying to apply this process to my project would prove a mammoth task, and one which I came to as a naive outsider. In spite of the encouragement of the head of the NMR Centre, plans which seemed so well set out soon unravelled.

As I started to complete the initial forms using the Integrated Research Assessment System (IRAS)[20] in November 2010 it became apparent that I would need to restructure my project to fit the terms of clinical research. I was baptised into a field of clinical research concepts based on radically different interpretations to those of qualitative research. In this context, participant observation or an interview needed to be redefined as an 'intervention' in the same sense as a

[20] IRAS is the online portal for the completion and submission of applications to NHS REC and R&D. Within the IRAS system all project documents such as the projects hypothesis, background, design, protocol, inclusion, exclusion criteria and consent documentation must be uploaded and demonstrated to meet the NHS framework for best practice.

project proposing the administration of a drug, clinical procedure or questionnaire. I would need to define when, where and how often the intervention would occur, how long it would last, how many people would be involved, and the cumulative amounts of time this would take. Conducting participant observation is a curious practice in even the most skilled hands. It involves an eye for detailed observation which might lead to 'thick description' (Geertz 2000). Such observation requires the detailed recording of events, settings and performances, over an extended period of time. In the terms of the R&D language of the 'intervention', I would have one period of participant observation. It would last approximately three hundred and sixty-five days, or a cumulative four thousand, three hundred and eighty hours (based on a twelve hour day). Following a grounded approach I would seek to engage with as wide a range of those involved in the research process as possible. The shape and size of that sample, would therefore only be determined over the course of the project.

To reconcile these ways of structuring research required me to reframe the study. Not only the language but my perception of the project had to adapt. I began thinking in terms of a limited range of interviews with discrete and defined pockets of observation. To develop an appropriate research protocol I needed to outline the recruitment of a 'population', 'inclusion' and 'exclusion' criteria, 'sampling' approach and allowance for 'bias'. As a result I would need to know who specifically would be prepared to let me observe their practices. I had the tacit consent and approval of the NMR Centre where researchers conducted their imaging work. However, each dementia research project was controlled by a research team which functioned independently from the NMR unit. I would therefore need agreement from the principle investigators on any project in order to configure my study within the format of the REC and R&D system. At this point three months had passed, and like fighting the mythical hydra, the number of organisations and the chain of individual gatekeepers I was in contact with were rapidly multiplying.

Whilst my research questions is focused on researchers and the relations involved in negotiating of the research process, I always had to acknowledge that research participants were an integral part of that process. Through the NHS and my departmental ethics approval process, I had to reflect that whilst working with scientists on projects which addressed dementia, to some extent I may encounter, observe and interact with people with dementia. Such patients due to the long-

term cognitive implications of their diagnosis would be defined as vulnerable. Although my primary intention remained to focus quite specifically on researchers and their collaborations, during the actual process of participant observation I would inevitably observe researchers observing patients – how could I do otherwise? A case in point was illustrated during my initial meeting at the NMRC, in which the director and I discussed observing technicians in the imaging booth during scans, conducting interviews with research nurses on the consent process, or with researchers about their analysis of participant data. In all these examples of observing the research process in action, members of the public recruited via the NHS would either be physically present or present in the form of their data. I therefore made a point of recognising the needs of these participants in the ethical documents I was producing. This would ensure that I would have clearance to engage with participants as part of the research process I was observing. A routine part of achieving clearance to work on NHS projects where there may be patient contact is a full criminal records check. By choosing an enhanced check I would have approval for any work which might include adults considered by to be vulnerable.

In addressing the *potential* presence of the public in research encounters, and its ethical implications for choosing the correct clearance, I found myself re-evaluating to what extent my presence could impact upon participant experience. Anthropologically it was important to recognise the impact my observations of scientists may have upon this group. From the experience that I had already had in the scanning suite, I had become aware that researchers were going to great efforts to imagine and engage research participants. Therefore, it was clear that a qualitative study of clinical research with human participants would benefit from a holistic approach which included the role of participants. Even if not interviewed directly, or the main focus of the study, participants were integral actors in the research process, and therefore inevitably would be 'present' in my data.

To recognise participants formally and engage with them directly, brought new levels of complexity to the clearance and access process. I explored how information sheets could be used to inform people of my presence and the aims and objectives of my project. Informed consent forms would signal agreement and awareness that scanning sessions would be observed and data generated from their involvement discussed. All this documentation was prepared in anticipation of going forward to a full ethics review panel. When I raised these issue with the

NMR Centre, I was advised against any attempt to actively include or inform research participants of my project. For me this was ethically highly problematic, as research participants would have no opportunity to actively engage with or dissent from being observed. Social science research ethics emphasise awareness and management of unequal power relations in research, particularly in the medical field (Leatherman & Goodman 2011). This supports the case for, at minimum, participants to be informed of the details and aims of the study I was undertaking. Paradoxically, the most recent version of the IRAS guidance recommends that potential public participants should be consulted in the research design and included where ever possible [IRAS 2009, INVOLVE 2012]. Yet, it seemed to be impossible for me to do just this. Sadly, the increasing complexity developing this project to fit the regulatory framework of the NHS, in conflict with how I understood the project, was beginning to render a laboratory study unfeasible in the time that I had to negotiate such challenges.

However, as a novice in the field, such knowledge was not available to me without trying to fulfil the research process requirements. In emergency discussion with my supervisor about the future of the project, I became aware that whilst I had totally failed to get access to my original field site I had spent the last eight months in an intensive study of the research process and reflexive discussion with neuroscience researchers about the process of ethical review. Indeed, this was an aspect of my original research design for which I had been given ethical approval for. Although I had not achieved my original goal of including laboratory observation, I had made contacts with, and achieved an insight into, the many organisations and structures involved in the process developing dementia research. Working around from the outside of this community had actually given me access to a perspective on research which I found would be echoed in many of my subsequent research encounters.

I gained a significant insight into a common challenge for researchers working with patients with dementia, and particularly those wishing to undertake qualitative work. This work also made it apparent that there are relatively few qualitative studies of participation in dementia research. Those studies which have been conducted are highly critical of the lack of balance between protecting potential participants and ensuring that those who want to and are able to take participate in clinical research have a forum to do so (Nuffield Council on Bioethics 2008). This

raises the question: to what extent is the goal of the ethical governance of research to ensure the protection of the participant, or the organisational integrity of research?

Dementia studies, in particular, have criticised the exclusory impact of rigid interpretations of cognitive capacity. The biomedical definition of capacity developed in the 2005 Mental Capacity Act has been challenged for lacking the flexibility to assess capacity for a person experiencing a fluctuating cognitive condition. A person in the early stages of dementia can experience discrete episodes of lost lucidity, disorientation and problems with word retrieval or word equivalence, which can undermine their perceived capacity. However, it has been suggested that reflexive and responsible engagement, with the support of a dedicated carer can enable a person in the early stages of dementia to communicate decisions about participation in a research study (Warner et al 2008). Crucially Warner et al (2008) describe how the patients they talked to, not only demonstrated capacity in this sense, they expressed an unequivocal desire to take part in and benefit from the process of research participation.

In making the decision to capitulate to the hydra of NHS approval and to refocus my study away from the laboratory, I found my experience was met with empathy from both clinical and social researchers. Many of those I subsequently met had gone through similarly drawn out processes with uncertain outcomes, and often multiple submissions and amendments to their projects. Interestingly, one researcher when hearing of my tribulations said that the more information they supplied to the RECs to pre-empt their queries, the more problems they seemed to create for themselves. As a result he recommended that in future I should never attempt REC approval alone but only as part of team that included NHS staff.

The collection and analysis of information which took place over course of my research into ethics was doubly instructive, it embedded me in the field, and reflected the nature and structure of NHS ethical processes themselves. Researchers, both clinical and care based, often described to me a feeling of their work being disconnected from the process of project approval. This was a theme frequently raised at research meetings, where the process was described as 'overly complex', 'prohibitive' without in actuality improving 'protection' for the participant. The traditional Randomised Control Trial (RCT) profile was not appropriate for the successful recruitment of people for dementia trials. This was particularly true for work in the less common dementias such as DLB, where limiting the population sample made the possibility of successful

recruitment levels almost unachievable. Some researchers suggested the prescriptive exclusion criteria of the RCT structure were entirely inappropriate for people over the age of 65 years, the most common age group for recruitment to dementia trials. In this age group not only was there a high likelihood of co-morbid disorders, but as a result, contra-indicated drug treatments which led to high exclusion rates and challenges to recruitment (Ferrucci et al 2004, McMurdo 2005, Ridda et al 2008).

DeNDRoN as a gatekeeping institution

The struggles that researchers experienced in designing trials demonstrated to me the fundamental importance of an organisation like DeNDRoN. At the national level DeNDRoN was responsible for the administration of a dementia disease register, which was seen as increasingly essential for the effective recruitment of participants to clinical studies. At the regional level DeNDRoN were key facilitators of NHS research approval processes with regional REC and R&D bodies. In particular, this organisation liaised between institutions and trust hospitals to address the problems arising in research design. Such work inevitably required operation across different regulatory regimes at different levels (local, regional and national). Through discussions with DeNDRoN staff about how dementia research worked, and how my study was to proceed, it became apparent that the DeNDRoN staff had become, in effect, the gatekeepers of dementia research in the UK. This gatekeeping role extended to include my own research. For my study, DeNDRoN enabled access not only to neuroscientists working on dementia, but also to public-patient involvement groups in the field. Through involvement with these organisations I also gained access to meetings and regional conferences where clinicians and researchers presented and debated the value, effectiveness and future directions of their research. Through these events I was able to conduct multiple sessions of participant observation which included: meeting, observing and talking with researchers from a variety of clinical disciplines, including: psychiatry, geriatrics, neuroscience, nursing, psychology, health and social care. In these encounters scientists and clinicians discussed how they viewed dementia research and how they defined the pressures and challenges they faced. The key senior clinicians, who were so integral to the development of the dementia research agenda and whose names appeared frequently on research articles and policy documents, became familiar faces at such events. Meeting early-career researchers presenting their work became an opportunity to arrange follow up interviews, and discuss what they thought was changing in the field at the laboratory level.

Throughout the course of my research three members of the DeNDRoN research team became key informants. These informants were involved in managing the research network, organising research events, and directly helping researchers operationalise their projects. It was in this process of looking outside of the laboratory, at the relations and collaborations formed around and between researchers and research units, that I identified my 'field site'. These scientific relations became my focus for over the course of the study.

Unexpected connections: the role of 'para-scientific' relations

The approach that I adopted generated a number of methodological challenges. I was not working with a discrete or stable locus such as a laboratory. Rather I had to travel between research settings and follow participants. Often, one research meeting or event would lead to an invite to another. It was through this snowballing process that the social and political connections which constitute the dementia research community began to emerge. Adopting this grounded approach allowed space for these connections, relations and events to happen and to inform my understanding of neurodegenerative disease for those who work and participate in clinical research. The strength of this methodology is that it traces practice, action, and relations as they are enacted (Traweek 1998, Wouters et al 2008). This methodological structure allowed me to observe the important organisational connections, such as those made with patient advocacy groups like Alzheimer's Society and ARUK, which researchers used in their efforts to engage beyond the laboratory. As I go on to argue, such relations might be thought of as activity that falls in the realm of the 'para-scientific', that is they run along-side science, facilitating political and scientific relations and interactions (Epstein 1996).

One consequence of this grounded approach was to demonstrate high degree of entanglement between dementia charities and the researchers and clinicians involved in developing a dementia research agenda. Whilst I had been aware of the importance of such organisations, I was unprepared for the very active overlap in the roles and goals of participants in these networks. By attending research meetings, conferences and public engagement events held by organisations such as Alzheimer's Society and ARUK I was able to observe at first-hand how scientists viewed the process of public-engagement and how this reflected their understanding of the role of the public in research. By looking at these organisations I was also able to talk to the organisers of patient groups and members of the public, including those directly experiencing the impact of

dementia. In these conversations I was able to get a sense of how lay participants' perceived clinical research and how they understood their role in the research process. In particular, I examine these perspectives when I explore how participant and researcher narratives of science can be seen to conflict and compete in chapter seven.

It became evident from my observation of Alzheimer's Society and ARUK, not only that they played an important role in representing the public in the public engagement of science. These organisations were key to the political manoeuvring taking place at the level of science policy. It is highly significant that leading researchers and clinicians who had high profile roles in public health policy often held key roles within these groups. Interviews with members of the Alzheimer's Society and participant observation at their meetings gave me access to the range of ways in which this interface actually worked. From raising public awareness of the different dementias, disseminating research information, raising funds, and encouraging research participation and the public patient involvement (PPI) movement, medical charities were powerful drivers of the research process. For instance, the idea of PPI has now become an enshrined tenant of research participation and is championed and made possible by such third sector organisations (INVOLVE 2012).

As I demonstrate in the next chapter, relationships between research, the third-sector, and government were commonplace, highly strategic and far from unproblematic. Rather, such relations were sites of constant negotiation, which could mobilise what Epstein describes as 'para-political power', being spaces which could both support and challenge biomedical authority (Epstein 1996). Third sector organisations such as patient advocacy groups are increasingly globally connected. Such organisations therefore become yet another example of how local practices are interlinked with non-local relations through the transnational exchange of research information, patient involvement practices and political agendas.

The virtual and visual in dementia research

To capture and reflect dispersed relations in my research approach I paid particular attention to how medical charities and research organisations use virtual space and visual imagery to communicate and build the relations which shape the dementia research process. Over the course of my research, it became apparent that websites were an important means of connecting

the dispersed and diverse range of people involved in research. For example, during the period of my fieldwork the websites of the NMRC, DeNDRoN, MRC, DH, ARUK, and Alzheimer's Society continually evolved to take advantage of existing and emergent types of virtual communication. The construction of virtual spaces and the use of hypermedia applications ('apps'), had the potential to increase the volume, speed and spread of research information disseminated to the public domain. As a result, analysis of hypermedia is, by necessity a key element of my research methodology, data and analysis. Observing the way virtual spaces are used within the dementia research community also throws light upon the ways in which researchers are trying to form relations with one another, and with public, political and commercial organisations. Such connections, therefore become an important means of understanding what Knorr-Cetina (1999) would describe as the 'epistemic culture' accessed through the 'material and symbolic' processes by which dementia science is being actively made (Wouters & Beaulieu 2006: 52).

In particular, I demonstrate how increasingly creative use of audio-visual content is key to understanding how connections which cross the boundaries between science and society are being constructed. Understanding how those connections are enacted in turn sheds light on the how the communities involve imagine both their selves and others involved in the research process. One example, which I examine in chapter six, considers the pervasive use of visual cell and brain imagery to make connections and appeal across boundaries, and between groups invested in the research process. For instance, images such as those in figure eight below, feature prominently on research organisation home-pages as a compelling and captivating gateway to the websites content. Carefully designed, produced and informed by media and marketing techniques, such content demonstrates an effort to bring dementia and dementia research to a wider audience with greater impact and immediacy.

Figure 8: MRI Images used on the NMRC Website

Describing how researchers and research organisations use images in virtual space, I trace the evolving relations between nationally dispersed groups of scientists and publics. The prolific use of virtual spaces both facilitates and construct the interface of science and society. Such spaces create virtual networks between 'real world' processes of research, diagnosis, participation and disease experience. The effort to ethnographically narrate this dispersed field of relations draws on the multi-sited approach described by Marcus (1995). However, what is of interest in this project is not the anthropological method of multi-sitedness per se, but how my informants operate within and across their own notions of multi-sitedness (Fischer 1995).

In the development of a dementia research identity I explore the use of visual imagery not only in virtual space; but also in conventional media such as leaflets, national television campaigns and promotional material produced by research and research interest groups. This material culture provides a further source of data to observe the social-scientific interface at work. In particular, the use of images demonstrates the importance of marketing and design logic in the development of research and patient organisations. For instance in the case of the Alzheimer's Society, marketing firms such as the Conran Design Group, were employed specifically to develop logos, interactive tools and media content of the Society. This work has developed a distinctive 'visual identity' and 'brand' for dementia research and advocacy (Gorman 2007). The importance of such strategies reflects both the increasingly visual nature of popular culture (Stafford 1994) and the importance of the marketization of identities in social-scientific relations (Burri & Dumit 2008: 297). In chapter five I explore the rhetorically persuasive role played by virtual and material culture to frame and reframe the nature of dementias as a topic of scientific, social, political and economic urgency.

Conclusion: on the thickness and thinness of ethnographic data

It is clear from the narrative I have given in this chapter that my project took a radically different approach to the one I had anticipated. Rather than a largely laboratory-based study which would trace collaboration from inside the clinical research project outwards; my study worked from the outside inward, looking at the dense research networks and support infrastructures in which individual researchers were located. This approach, in part, was a necessary result of being unable

to negotiate NHS access. However, it also facilitated a valuable grounded methodology which revealed important networks and relations in the research process (Clarke 2003). As a result, this thesis is based on a detailed analysis of the interaction, language and imagery which connects scientists, publics and the larger research and political infrastructure in which dementia research sits. This approach results in a classically 'thick' description and facilitated what Foskett (2004) describes as a 'thick analysis'. That is an analysis which draws on a wide range of data visual, linguistic and ethnographic, to pay specific attention to the contingencies, porous networks and changing relations as they emerge (Clarke 2003). Exploring this 'thickness' enables me to capture a snapshot of the complex scientific, social, political and economic relations at work in the contemporary field of dementia neuroscience as it is enacted.

In contrast to this 'thickness' there was also a sense of 'thinness' which had to be managed (cf Clifford & Marcus 1986, Marcus 1998). As a result, my case study reflects the kinds of distributed social networks explored by Nowotny, Scott and Gibbons (2001). The nature of the interactions I had with researchers and the meetings I took part in were inevitably partial and fragmented. My relationships, like the dispersed groups of researchers around me, were formed on the basis of professional rather than personal identities. Often these relations did not extend beyond the context of the dementia research agenda. As Lock, drawing on Strathern suggests, this constitutes an ethnography comprised of multiple 'partial connection' (Lock 2013: 19-21, Strathern 1991). These partial descriptions, therefore constitute both the foundation of the research as well as its limitation.

Chapter 4 The burden of dementia - a 'problem' for science and society?

'There is nothing good about dementia'

Comment made by a dementia Research Officer.

In the previous chapters I outlined the history and evolution of dementia as a shifting and contested disease concept, situated within multidisciplinary neuroscience and emergent biotechnologies. I then illustrated how these changes in dementia science relate to the apparatus of national and regional UK research regulations and internationally evolving research standards. In describing this as a dementia research community, I stressed the interaction between health, economics and national scientific strategy in shaping the state of dementia research. I then described how I identified dementia science as a site of research, developing a methodological approach based on grounded theory, which could access the social entanglements which characterise this field.

In this chapter, as the opening quotation illustrates, I consider why clinicians and researchers portray dementia as an especially problematic field for science and how they articulate their concerns. A usage that was particularly prominent in research discussions was that of *burden* to describe the total impact of dementia on science and society.[21] I suggest that the term *burden* has become an important metaphor, used by scientists to understand and work in the dementia field and moreover to gain rhetorical purchase in the wider society.

Rhetoric and rhetorical analysis in anthropology and science studies

Carrithers argues that rhetoric is of fundamental interest to anthropologists (2009). The art of persuasive communication, he argues, is evident in most human encounters; providing evidence

[21] Throughout the thesis I have treated certain concepts as native categories, that is, ones which are in common currency but which have specific uses, meanings and applications not entirely encompassed by technical and scientific definitions. In recognition of this I have italicised these terms.

of 'every-day micro-politics' at work (Carrithers 2005: 578). By incorporating rhetorical action into ethnographic analysis Carrithers suggests we are able to gain greater insight into culture as a dynamic process rather than a static blueprint. In my analysis, I suggest the rhetorical discourse surrounding dementia demonstrates the beliefs and ideas embedded in the disease concept as it is used by scientists.

Ethnographic approaches in science studies have often used language analysis to explore the co-production of biological science and social perceptions of illness or disease (Epstein 1996, Fee & Krieger 1993; Landesman, Ginzburg, & Weiss 1985; Singer 1994). In particular, a useful site for research has developed from paying attention to how scientists have communicated to audiences beyond specialist disciplinary field. As Martin (1991 & 1992) and Traweek (1988) have demonstrated, looking at science communication provides a valuable opportunity for observing the ways in which beliefs and assumptions are reinforced beyond the 'citadel' of science (Martin 1998). In the case of HIV, Martin demonstrates how the language used in public health campaigns and educational resources insight into social relations. She demonstrates that such relations are both shaped by and incorporated into accepted structures of scientific and medical knowledge (Martin 1994). Martin analyses the linguistic framework used to describe the cell structures and activity of human ova and sperm in American high school science text books. She argues that the framework used naturalises a culturally specific and gendered reading of reproductive processes (Martin 1991). In this argument the linguistic framing of the physical matter of human biology illustrates the pervasive power of science in the construction and maintenance of social relations and power inequalities in unexpected and insidious ways. Similarly, Sontag's comparison of the clinical and scientific language used to describe HIV and cancer, demonstrate how different disease processes are socially categorised, and acutely reflect local social beliefs (Sontag 1978 & 2002).

In the communication of disciplinary specific knowledge outside of their specialism or to wider non-scientific audiences, I found that dementia researchers use a shared language of *burden*. This is a term which used to communicate, translate and encapsulate the complex scientific and social issues which make dementia such a challenge for researchers. By demonstrating the flexible, shifting use of the notion of *burden* as rhetorically important, I illustrate how scientists locate these problems in the overlapping relations between science, government and society.

The language of *burden* in dementia research.

The first use of *burden* I look at is in the biological language of the physical pathology involved in dementias as found in neuroscientific articles. The articles used here were selected as they are co-authored by scientists who played a prominent role in research discussions I observed during my fieldwork in Newcastle, London and Birmingham. Often these authors were research leaders involved directly in the development of the dementia research agenda as it was become part of UK health policy.

In the first article I considered, the following claim was made:

> Progress is being made in the development of specific biomarkers for the diagnosis, and even prediction, of *AD including PET imaging and CSF tests for amyloid burden*. However, AD is still diagnosed after other dementing illnesses or other conditions associated with memory impairment have been excluded.
>
> ((My emphasis) Holmes 2012: 628)

Here *burden* refers to the volumetric measurement, or 'weight' of abnormal, insoluble amyloid protein present in the brain tissue of a person with AD. This material is measured in research and diagnostic tests using imaging technology (PET) and cerebro-spinal fluid tests where abnormal proteins are measure in the fluid extracted by needle from around the patient's lumber spine. The *burden* of dementia here is a physical and biological one, referring explicitly to the disease process whereby build-ups of abnormal or 'misfolded' proteins impede communication between neurons. Dementia researchers commonly identify the evolving amyloid *burden* as the first stage in the process that eventually leads to localised areas of neuronal death which cumulatively alter the patient's cognitive function. This image of pathology as a *burden* and as an impediment to communications is developed further in this example:

> A major feature of Alzheimer's disease is the *accumulation* in the brain of an amyloid-β peptide (Aβ), which *aggregates* to form oligomers, plaques, and cerebrovascular *deposits*. The putative key role of Aβ in the pathogenesis of Alzheimer's disease led to immunotherapeutic strategies that *aimed* to reduce levels of Aβ in the brain. *Active*

> immunisation of mice genetically modified to develop Aβ plaques as they age with full-length Aβ (Aβ42) resulted *in a reduction of plaque burden and improved cognitive function*.
>
> ((My emphasis) Holmes et al. 2008 :216)

A particular interest for the dementia researchers I was working with was the potential in recent developments in 'immunotherapuetic strategies'. This approach focuses on what is currently recognised as the key pathological process of AD, the 'amyloid cascade hypotheses'.[22] In this treatment process, drugs modify the immune system of the recipient to break down the insoluble Aβ deposits, which are understood to impede the communication between neurons, beginning the cascade of neurodegeneration which leads to cognitive impairment. Here the *burden* of plaque is compounded, as it is seen as a substance which is disordered and accumulating. The biological process is communicated using geological metaphors, such as the 'silting up' of neuronal networks, which conveys a slow but weighty and intransigent process. In contrast, the immune system, modified by treatment, is presented as flexible, active and responsive, breaking down protein barriers to improve cognitive functioning.

In the two former examples, it is the biological characteristics of the disease which are referred to as *burdening* the neurological system of the person with dementia. However, the linguistic framing of *burden* in scientific articles is extended to include person-oriented concerns in dementia research development:

> Biomarkers may enable more specific selection of appropriate populations, better targeting, identification of subjects at an earlier stage, and better assessment of treatment effects, but may also increase selection bias because of *different perceptions of burden by different population groups*. Similarly, *innovative approaches that might reduce burden and*

[22] The amyloid plaque cascade hypothesis remains the dominant theory of the disease process, or aetiology, in Alzheimer's disease. Put very crudely, research based on this approach starts from the premise that the 'mis-folding' of normal amyloid proteins initiate the disease process. These mis-folded proteins are insoluble and toxic. The abnormal lay down of insoluble amyloid-β peptide (Aβ) result in progressive interruption of chemical, electrical and vascular pathways in the brain which leads to progressive neuronal death. However, as I explore in chapter seven, the role played by Aβ is a highly debated topic. This was fuelled by the uncertain results of dementia 'vaccine' trials in the US. This has caused many to question at what stage Aβ becomes an active agent in the disease process. This fundamentally alters whether it should continue to be viewed as a primary therapeutic target (Chiti & Dobson 2006, Mulane & Dobson 2012).

> *minimize dropouts*, such as increasing the use of internet and digital technologies, *may be less acceptable in certain population groups and thus could also affect selection bias.*
>
> ((My emphasis) Vellas et al. 2013: 443)

In this extract, the *burden* described is one related to the challenge of current research processes and practices for participants. As I have reflected in previous chapters, clinical dementia research involves a highly complex research infrastructure. This infrastructure must unite the staff and technology required, with effective, supportive and sensitive practices which meet the specific needs of the participants involved. As I found through my contacts at the NMRC, assembling the specialist imaging technology and staff required to conduct and support this sort of research required the resources of larger centralised hospitals or clinics. As a result, participants may be required to routinely travel some distance to attend research sessions. Vellas et al (2013) argue that perceived and actual logistical issues can make the prospect of travel a barrier to long-term participation in research. Such barriers are doubly apparent for the person with dementia, experiencing the symptoms of disorientation involved with cognitive impairment, and also for the family members and carers who facilitate and support them during their visit. As a result, 'certain population groups' the researcher's argue, such as those including older people and those with cognitive problems, are more likely to see regular travel as a negative element of participating in research.[23] Thus, over time members of this study are more likely to 'drop-out' of a trial, creating the potential for poor retention rates, requiring higher overall recruitment. In addition, those who would be less negatively affected by travel, and therefore more likely to participate, are also likely bias the sample for secondary, not-controlled-for criteria.[24] This potential for bias threatens the fine scale control of the trial, with the potential for factors other than those being tested to influence the outcome of a study. The authors suggest that new ways of doing research could address such factors. By adopting utilising developments in ICT, researchers can ameliorate the *burden* travel presents for participants. Thus what begins as a *burden* for participants is

[23]Here population groups refer to the designation a group defined by a specific set of characteristics who are targeted by a specific research project: for example people with fronto-temporal dementia, over 65 years of age. This is the group within the wider population for whom the findings of the research design will be extrapolated to (Vellas et al 2013).

[24]What these secondary biasing characteristics might be, are not identified by the authors in this case. However, the implication is that as socio-economic background will impact factors such as carer support and access to private transport which might facilitate participation. To manage the potential for bias, it is standard practice to reimburse travel costs. However, limited access to familial or professional care and support is less easy to address, and remains a barrier to research participation for many people with dementia.

translated into a pressure on scientists and the practice of research. Research designs must be conscious of the changing ways research participation might create *burden*, and how this might be perceived by different categories of participants. Thus the *burden* is shifted, first to the participant and then back onto science. Researchers designing studies must anticipate, calculate and accommodate a varied and ever growing range of information which affect the populations they study.

This example demonstrates the wide-ranging potentially *burden*-some aspects of undertaking research: the regulatory structures, changing assessments of what constitutes ethical research, the practical realities for patient involvement in research participation, understanding the attitudes and behaviours of specific socio-economic groups, and how different aspects of the research process may be perceived by a variety of people. Researchers may attempt to calculate, model, or otherwise capture such variables to reduce their impact. Essentially, however, they are trying to imagine and represent the potential research participant. Indeed, they are even tasked to imagine how new technologies, such as increasingly accessible forms of virtual and tele-data collection, could be developed and creatively deployed to ameliorate perceived *burdens* in the research structure and thereby relieve the *burden* of dementia.

The *burdens* and barriers of dementias are not restricted to the disease pathology or the research process; they are also described by researchers in terms of their impact on the everyday lives of people with dementias and those that care for them.

> The impact of caring for a person with dementia arises from *a complex interplay of factors and is related to the risk of institutionalisation. Factors in carers that increase "the burden of care" are usually secondary to the caring role and include stress, vulnerability, deterioration in social networking, and economic issues*.
>
> ((My emphasis) Eccles *et al.* 1998: 806)

This extract reflects a set of fundamental concern for those involved in designing and operationalizing research projects involving people with dementia. Scientists and those working with them in the research design infrastructure have to imagine, research and consider how wider social and economic factors are impacted upon by a dementia condition. Critically, the dementia

research process relies on the support and involvement of a dedicated carers. Consequently, researchers must also consider how dementias affect the people involved in every-day social networks of support and care. By quoting 'the burden of care', the authors demonstrate how the concept of *burden* is also grounded in the social research literature on care. Thus, the *burdens* of dementia, and the dementia research process are fundamentally located in a relationship between researchers and research participants. In turn this relationship extends outwards to encompass the networks and needs of family, friends and professional carers who are implicated in the research process. Thus, like the cascading imagery used to describe AD pathology, the range of *burdens* created by dementias cascade outward. From the representation of changes in the localised neuronal activity of one person's brain into issues of social relations implicated in accounts of biomedical research design and development, the *burdens* of dementia spread and multiply.

The image of AD pathology, as something progressively building up, impeding and finally blocking neuronal connections, is mirrored by the description of the progressive degenerative impact on the social world of the person with the condition and their surrounding support network. Just as the individuals access to the social connections which locate them in the world become altered by the disease, so the disease affects their wider personal, social and economic ties, and in turn those of their carers. The *burden* of dementia is thus characterised as one of barriers and broken connections.

> Patients, families, and general practitioners may all be *reluctant to diagnose dementia because it is such a serious and largely unmodifiable disease that still carries a huge burden of stigma. Physicians may unconsciously hesitate to label a patient as such, and family members may gradually take over social roles from the patient, protecting him or her from difficulties in daily life, but also delaying the conscious recognition.*
>
> ((My emphasis) Burns & Iliffe: 405)

This quote reflects the disconnections which are linked to the social and cultural stigma with which dementia is described in both the social and scientific literature (Batsch & Mittelman 2012, Burn & Illife 2009, Herskovits 1995, Holmes 2012, Van Gorp & Vercruysse 2012). Just as the disease process is characterised as depositing unwanted, toxic, intransigent material in the

neuronal network, so a diagnosis of dementia threatens to deposit harmful labels and social barriers from which clinicians and family members may seek to protect the person with dementia. In particular, the very real, but also perceived associations of a dementia diagnosis are described as barriers to a person's independent social functioning.

This stigma is seen as inhibiting a person's capacity to recognise and accept their symptoms, diagnosis and wider impact of a dementia condition. Researchers recognise this challenge as understandable but unhelpful, leading to an unwillingness amongst UK GPs to give a diagnosis of dementia, or for a patient to receive it. This avoidance is widely characterised in scientific policy and literature as a major problem for dementia clinicians and researchers (Renshaw et al 2001, Turner 2004). For them, the *burden* of being diagnosed with a dementia becomes part of yet another cascading narrative of the barriers to effective research.

Clinicians and scientists described this diagnostic stigma as a two-fold *burden*. Firstly, due to the reluctance both amongst patients and GPs to a diagnosis, diagnosis often occurs later in the progression of the disease. As a consequence, patients who have the diagnosis required to be eligible for research inclusion, are less likely to meet all the inclusion controls, requirements of informed consent and the practical demands of participation.[25] Secondly, there is a concern that people further on in their disease progression are less likely to benefit from new therapies and treatments as their cognitive decline is too far advanced for them to retain a meaningful benefit in terms of cognitive function. By affecting the capacity for research into the earliest stages of disease aetiology, stigma is therefore understood to restrict efforts to develop diagnostic tools and drug and therapy targets. As a result, the social and medical stigma of dementia is seen to directly limit the potential for science to gain effective purchase on the impact of dementia, that is, to develop treatments which result in the recipient maintaining as much cognitive function as possible, for as long as possible.

[25] In the majority of trials on the UKCRN portfolio, during this study, a diagnosis of mild to moderate dementia, with a mini-mental-state score above 14 is required for a person to be included in a trial. As cognitive impairment increases over time, those who are diagnosed later in their disease process are less likely to meet this minimum requirement, being considered both unable to legally consent and less likely to reasonably tolerate the procedures they would undergo. However, Fisk and Wigley (2000) have argued for a more holistic approach to the definition of mental capacity should be considered. They argue that people respond differently to the progression of their dementia, and whilst they may possess a significant global cognitive deficit retain both the understanding, lucidity and willingness to engage with research if sensitively handled.

Researchers empathised with the fear, stigma and ground-shifting uncertainty, associated with receiving a dementia diagnosis. They recognised that people receiving early diagnoses and participating in research at this point in its development would be unlikely to benefit directly from its results. However, in viewing the disease as the primary target and prioritising future benefit over current uncertainty, diagnostic stigma was seen as a *burden* that must be overcome. Thus, the fear and uncertainty of diagnosis starts to be framed in research as a rejection by the patient of self-awareness and 'conscious recognition'. Failure to receive a diagnosis is described as negatively impacting upon a person's capacity to come to terms with, and receive support for, the changes in their health. Thus the decision 'not to know' is presented as a barrier when it comes to the patient planning their future life and care. It is described as delaying referral to specialist services which may be able to provide access to the existing and experimental pharmaceutical and cognitive therapies available, and which may maximise their changing cognitive capacity, and improve their overall quality of life.

This collection of extracts from dementia research papers represents a small, but pertinent, sample of the neuroscientific articles I read in the course of this study. Inevitably, given the diversity of the field in which I was working, this also represents a tiny amount of the work undertaken and published by researchers based in the UK. However, the regularity and diversity of the application of the concept of *burden* in describing neurodegenerative conditions is both striking and significant. Below is an analysis which illustrates the scale of the use of the concept of burden in dementia research papers.[26] This analysis is based on three high ranking journals on dementia and neuroscience research; Alzheimer's & Dementia, NeuroImage and Neuroscience, processed using the Science Direct database. These are the journals which the researchers I worked with frequently consulted and published in, and which I routinely consulted for research updates. In these journals, between 2000 and 2013, it is clear, even in this superficial analysis, that there has been a stark rise, not only in the volume of articles published on the theme of dementias, but significantly in the proportion of those articles where the terms dementia and *burden* coincide.

[26]A systematic examination of the ways in which 'burden' is used in these articles is beyond the scope of the project conducted here. However, the importance of rhetoric discussed here, would argue for further research to track such linguistic trends in dementia science.

Year of Publication	No. Articles including terms 'dementia' &'UK'	No. Articles including terms 'dementia', 'UK'&'burden'	Percentage of articles using the term 'burden'
2000	733	88	12.01
2001	666	86	12.91
2002	791	120	15.17
2003	897	136	15.16
2004	1416	261	18.43
2005	1277	220	17.23
2006	1346	228	16.94
2007	1399	313	22.37
2008	1695	341	20.12
2009	1819	394	21.66
2010	1793	424	23.65
2011	1908	454	23.79
2012	2320	585	25.22
2013	2674	737	27.56

Figure 9: Comparison of use of *burden* in dementia articles

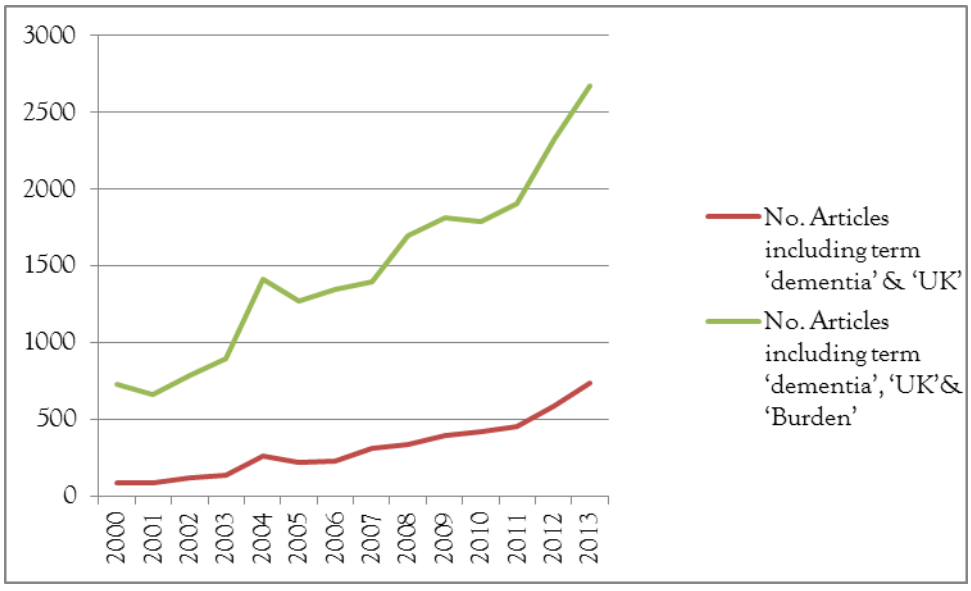


Figure 10: Illustration of rates of publication 2000-2014

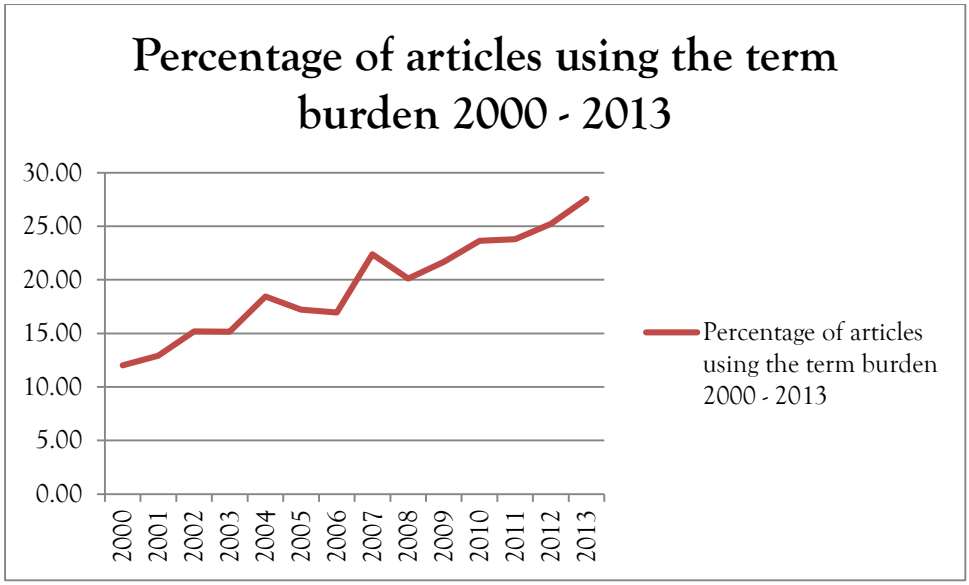


Figure 11: Illustration of increasing use of *burden* in dementia publications

The scale and pervasive use of the term *burden* in research articles suggests that the term has great utility, that is, it is useful to researchers when talking about dementia. It is a concept constantly moving between researchers' accounts of the social and scientific problem of dementia. *Burden* is used to activate different aspects of dementia: the pathology, the cognitive changes experienced by the person with dementia, the cost and demands placed on care givers, the stigma associated with the disease, the challenges posed to researchers and the wider social and economic costs attributed to changing rates of dementia diagnoses. In a single paper, *burden* might slide back and forth between the barriers dementia creates in the cognitive networks of the person, the social network in which the person resides, and in ethical, practical, organisational and scientific networks in which the researcher and their work exist.

Tracing the etymology of burden

Etymologically, *burden* originates from Indo-European roots, meaning child or something to be borne. This locates it within social, and particularly familial, connections. Middle-English *birde* or *burde* meant 'descent' or 'race'. This meaning is also retained in the contemporary use of the word *bairn*, meaning child, in several dialects in northern England, Ireland and Scotland. Later, the Germanic terms *byrthen, burthi* and *bürde*, combine the meaning with the more objective

concepts of a 'load' or 'weight'. This was further developed in Old English toward meanings of a charge, duty or responsibility. As Warnes' discusses extensively, the rhetorical and metaphorical power and versatility of the term *burden*, is more than two millennia in the making (Warnes 1993: 301-302). *Burden*, later took on a legal definition, as in 'the burden of proof', often applied to cases involving property where the 'actor' in a case took responsibility for proving their case (ibid: 303). These compound meanings resonate with the weight of problems and challenges which dementia scientists associated with working in this field.

Thinking about the language of *burden* in this way, also reflects how social value has become related to the concepts of labour, productivity and functionality in how scientists situate dementias in their work:

> Echoing the concerns of Standard and Poors, based on simple demographics, the *costs* of dementia are set to increase by 85% by 2030, with developing countries *bearing* an increasing *share* of the economic *burden*.
>
> ... the complexity and *cost* of trials in dementia, along with some high profile late phase 3 trial *failures*, means that there is a *withdrawal* [of pharmaceutical investment] from the field in many countries, with a wait for new basic insights to emerge.
>
> (Banerjee, S. 2012: 708)

In neuroscientific articles, *burden* often appeared alongside terms such as *loss*, *absence*, *failure* and *cost*. Again, such terms are attributed not only to the experience of the disease, but to the research infrastructure and pragmatic issues involved in developing scientific research in the field of dementia. The language adopted by scientists reflects wider political and economic concerns, which shape the environment in which research happens. In particular, the language of 'cost', featured notably in research talk. For example, the dementia *burden* is linked in research narratives to cost across a range of levels: the personal cost of dementia for those experiencing its effects, the financial and social cost to the UK, and the costs associated with the national and international health industry. The concepts of cost and value reflect the increasing neoliberalisation of the regulations and relationships which underpin the practice of biomedical

and biotechnological research. As Lave, Mirowski, and Randalls (2010) describe, the process of neoliberalisation has been enacted through a number of key changes in scientific practice:

> (T)he narrowing of research agendas to focus on the needs of commercial actors; an increasing reliance on market take-up to adjudicate intellectual disputes; and the intense fortification of intellectual property in an attempt to commercialize knowledge, impeding the production and dissemination of science. Taken together, these shifts suggest that the impact of neoliberal science policy and management extends far beyond the patent system into the methods, organization, and content of science.
>
> (Lave *et al* 2010: 659)

Indeed, the operationalization of health research, tied to pharmaceutical and bio-technological industry interests, are shown to have transformed how 'valid' objects of scientific knowledge and investigation are made and recognised (Abraham & Ballinger 2012). The neoliberal turn is characterised by increased emphasis on competition, growth, efficiency, speed, productivity and distribution, particularly as they relate to the field of drug development of and processing (Abraham & Ballinger 2012: 447-448). The rise of neoliberalism in the UK has been located in a political-economic shift of the 1980s. Abraham and Ballinger suggest: 'prior to this period there was a governmental and legislative expectation that the basic goal, and indeed the *raison d'etre* of pharmaceutical regulation was to protect public health over and above the commercial interests of pharmaceutical firms' (2012: 427). Subsequently, the certainty of this relationship was to come into question.

The tangled relationship between function, productivity and value in biomedical research can be seen in the way in which the *burdens* and 'costs' of dementia move between the practice of science and the description of pathology, to the social and personal experience of dementias described by clinicians and researchers. The loss of social ties is linked to a person's decreasing cognitive function, which in turn is related to their productive capacity – an inability to relate to the social world becomes tantamount to an inability to perform in it. As Rose (2007) argues, in the last fifty years we have moved from a society which relies on the productivity of physical bodies to a 'brain-economy' in which cognitive and intellectual capital play a significant role in sustaining national economic productivity.

Part of the 'neoliberal' regulatory framework which reflects this relationship between function, productivity and value can be identified in the development of secondary measures to assess efficacy. Such measures are required to quantify and give objective value to new biomedical interventions. This assessment of value exists in the context of the competition for limited national resources and a stake in the global market of biomedical research. For example, in epidemiology and health economics since the late 1980s, the term *burden* has been linked to quantified measures of disabling disease in the form of Disability Adjusted Life Years (DALY). The DALY measure aims to capture the impact of a disease by combining a measure of 'time lived with a disability' weighted by the degree to which it causes a person to loose 'functional capacity'. This calculation is combined with 'value choices' which adjust for expected changes in quality of life over the life-course, taking into account the expectations for time periods during which the disease is experienced, and 'years lost due to premature mortality' (Murray, 1994: 441, Lopez et al. 2006, Annand & Hanson 1996). This is a highly complex measure that aims to quantify the holistic impact of disease upon a person.

The DALY calculation of the *burden* of disease is highly influential in UK and international health policy. Thus, biomedical interventions aim to act upon the burden of disease by adding life years of a better quality or of higher value. This is constructed in the cost-benefit analysis of the QALY. Put bluntly, disease is the 'weight' or 'burden' which is alleviated by scientific intervention. Whereas science is value 'adding', disease is value 'losing'.

However, as many of the researchers I met pointed out there was concern that the *burden* of dementia could not be fully captured by these measures. This is borne out in the work of health economists, who suggest that conditions with high morbidity, such as cancers, cardiovascular disease and stroke, receive a disproportionate amount of funding in comparison to the *burden* calculated for neurological and mental health disorders, such as dementia. Based on WHO data, neurological and mental health conditions have the greatest, long term, disabling impact. Yet, neurological conditions receive comparatively less R&D funding, and the technologies developed to intervene in these conditions are far fewer (Ward et al. 2013).

As Annand and Hanson (1996) demonstrate, there is significant disagreement about how the highly complex assessment of disease *burden* should be calculated, and they are critical of current practices. For social theorists, the main issue is not only the uncertainty of these powerful measures of disease impact, but the very system of thought and belief which has led to the numerical capture and control over the value of 'life itself' (Agamben 1998, Rose 2007). Foucault (1973) identifies this turn as stemming from the birth of the concept of political economy in the eighteenth and nineteenth century writing of Adam Smith and David Ricardo (Cooper 2008: 5). The reshaping of value as 'a function of trade, exchange, and circulation' (Cooper 2008: 6) led to the person being conflated w(ith their labour and productivity. This shift in thought was interwoven with the changing structure and control of the nation state, and the post-enlightenment rise of science. In this context of power and control, the person, and the body were further separated. This separation enables the body, and the brain to become objects of scientific research and experimentation (Sharp 2000). As a result, the changing 'value' of the person over their life course became subject to the quantification of their biological, and increasingly, cognitive functionality (Rose 2007).

The association between human value and the biology of aging, returns us to the etymology of *burden*. Age and aging are a critical part of how the concept has developed and its current usage in everyday language, government policy and health economics and biomedical research. Warnes (1993) identifies five ways in which burden is used when talking about age and aging:

> ... the subjective or reflexive application of burden to being old; referents to an old person as well as an infant; its collective adjectival application to all old people in a society; the shift of the agent bearing the load from an individual or a single family to a collectivity; and the transfer of the weight of the load from an individual's emotions collectivity; and the transfer of the weight of the load from an individual's emotions, psychology and physical effort to monetary and fiscal charges.
>
> (Warnes 1993: 305)

Understanding the implicit link between physical and cognitive functionality, personal value and national economy sheds light on the disconnection described in the literature on the impact of receiving a diagnosis of a chronic, disabling condition (c.f. Beard & Fox 2008, Caddell & Clare

2011, Kleinman 1988, Lock 2004, Maynard 2006). This supports the need to understand the interconnection between the evolution of the life sciences and the social, political and economic context (Foucault 1973). Through this analysis of the fluid connections made using the term *burden*, I have illustrated how dementia science is continually embedded in social, political and economic context. The concept of *burden* connects the bodily substance of Aβ, economic standardising measure such as the DALY, the real world emotional and pragmatic impact of receiving a dementia diagnosis, and how this is understood by scientists to affect participation in the dementia research process. These facets combine to demonstrate how the concept of dementia *burden* is located not within scientific context, but within a dynamic social, historical and scientific framework. Unpicking the association of *burden* embeds the disease pathology in the cultural beliefs and perceptions that have evolved locally around aging, later life, changing perceptions of personal value, the aging demographic, and the neo-liberal political-economy.

Furthermore, the neuropathology of Aβ is not only a *burden* to brain function to be borne by the individual, and addressed by an abstract and uninvolved group of scientists. Rather the *burden* of dementia is represented as spreading and unfolding out from the individual, to the impact upon wider social relations in the shape of familial, community and professional carers who help support those living with the disease. Thus, the process of developing a dementia condition, continually intersects with personal relations and national health and social care practices, which locate the person in the wider political and economic dynamics at work in UK biomedicine. So, the language of a protein, visible only under a microscope, can be thought of as cascading outwards and somewhat chaotically to envelop the individual, the family and the community, all the way up to national and transnational levels of political economy. What I hope to have demonstrated here is how the language of dementia science itself, and the way science frames dementia are an area of study which requires a focus on relations and relationality between scientists and the community in which they practice and are located. I return later to the emerging criticisms of the use of *burden* as an appropriate discourse for narrating dementia, but now I turn to ethnographic examples which explore how the rhetorical *burden* of dementia are unpacked by researchers in their narration of the problems of dementia science.

Perceived problems in dementia science: barking up some wrong trees

At the end of two days of research meetings, the attendees of the Alzheimer's Society Research Network Meeting in 2011 came together for a final discussion. I sat at a table of women, who like me, were registered as 'friends of research', a group created by the Alzheimer's Society. Part of the Society's Research Network this group enables interested members of the public to attend national conferences alongside researchers and clinicians, who meet to present their work. A member of the audience, a retired neurologist and supporter of the Society was invited by the Chair of the meeting to start the discussion by raising a question. With dogged determination he began:

> Well I was concerned after I read in the Economist about the billions of dollars which had been spent on dementia trials in America [pause].I was concerned that the shortfall in performance of the research work ought to be taken more seriously than it seemed to be. It wasn't talked about. I am here discussing this in our own work, and it's making me wonder, moreover, whether, perhaps we've been barking up some wrong trees, with overemphasis on the amyloid cascade and so on. But I must say that [name of researcher]'s talk which I went to this afternoon did persuade me that the connections between the genes and the operation of amyloid in the brain, did seem to fill this gap. But anyway I thought it was a good thing to have something, some discussion about the way research is going now and how exactly it is performing…
>
> Question asked by retired researcher

The speaker was reflexive and questioning in his approach. He expressed concern that the 'shortfall' in research was not addressed as seriously as it should be, that the problem should and must be recognised within dementia science policy and practice. The object of anxiety is described as the 'performance' of research, but what this implies is a failure to create products of research, that is, to have reached a stage in an outcome-based science which had proved the efficacy of medical and biotechnological interventions. His concern was framed by anxiety about how global investment in research was being (mis-)directed. There are several themes emerging here. Dementia research is placed in the cost-benefit framework of biotechnological development

within the structure of NHS and pharmaceutical industry collaborations. The speaker questions this system of relations. Is the mechanism of collaboration and investment pushing research in the best scientific directions? Has this relationship taken research down the wrong path? This anxiety around practice and process is framed in the context of changing scientific knowledge. As new techniques, combining new technologies, such as genetics and imaging, change our understanding of dementia disease pathologies, the shape of existing theories are being radically and persuasively redefined. This process echoes the history of dementia science as a contested and evolving field of research described in chapter two. Dementias continue to be reshaped as knowledge, organisational structures and public patient involvement practices are co-produced. Thus, the speaker raises the question: does the collaborative market relationship between academic and commercial research, have the necessary reflexivity to change direction as new knowledge takes shape? Do the public-commercial relationships fundamental to contemporary research present challenges which become a potential block or *burden* to be managed by academic dementia researchers?

The panel I was attending consisted of two senior researchers and a senior clinical researcher. Each was a leader in their respective fields of epidemiology, metabolic research and neuroimaging for dementias. They were joined by the Society's media co-ordinator, standing in at the last minute for a researcher who was unable to attend. The neuroimaging specialist responded to the opening statement, and tentatively they each reached towards a critical understanding of the problems faced by dementia research:

> I think that is a very good context and I think that, you know, the reason we're here is that there haven't been any disease modifying drugs which have successfully come through clinical trials. Is that because there just aren't enough trials, and we need more investment in trials? Is it because the science hypotheses are wrong? Is it because we're designing the trials badly? Is it because we're doing the trials in the wrong groups of people? And I think those are all possible things that have been used a lot [to explain this failure].
>
> Comment from a leading clinical and research neuroscientist, specialising in neuroimaging.

During this debate the language of researchers continually moved back and forth between scientific practices and organisational structures. The hesitancy of the speaker conveys the uncertainty described by many research leaders. There was no one clearly identifiable cause for why dementia research was not as productive as desired, particularly in the area of disease modifying drugs (DMDs). The speaker suggests there are some useful targets in the research community which may be acted upon. For this speaker the prime target is the clinical trial. Addressing the clinical trial, the speaker emphasises the role of investment, the shape of the science being tested and the participant groups involved. By trying to recruiting the most suitable bodies and brains upon which research can act, science is engaged in actively defining the patient and research participant. This process illustrates how scientists view the problems within the scientific domain to be deeply interconnected with ideas about a public that somehow needs to be brought into the scientific citadel (Martin 1998).

The *burdens* of dementia research were a consistent theme in the talk of scientists and clinicians at research meetings such as the one described above. This was evidenced by research into the comparatively low levels of funding for neurodegenerative disease research, in comparison to other high impacting disease such as cancer. Over the course of the study it would become apparent that the sense of failure in dementia research to capture research initiatives and resources was historically embedded in the narratives of dementia neuroscience. Indeed, in 1983 Fox, writing about the evolution of a dementia research movement in the US, echoes many of the concerns UK researchers and clinicians were expressing at meetings some thirty years later. Combining extracts from policy documents produced between 2008 and 2012, with extracts from research meetings, I suggest, scientists are locating the *burdens* of dementia research in four broad fields:

- The complexity of dementias and the science which addresses them
- The impact of stigmas of dementia and the practice of dementia science
- Perceptions of progress and productivity in science.
- The implications of the collaborative relationships which dementia science requires (political, commercial, public).

These themes are expressed in the Medical Research Council's 'Strategic review of Neurodegeneration' (MRC 2008). This document was produced following a meeting in February 2008, of academic and industry scientists and clinicians from across the field of neuroscience and neurodegenerative disease. This meeting was chaired by Professor Christopher Kennard, Professor of Clinical Neurology, who in 2010 became head of the Nuffield Department of Clinical Neurosciences. The meeting was designed to inform the MRC's Neurosciences and Mental Health Board policy for funding research and training to meet 'the *human, societal and economic burden* of neurodegenerative diseases' (2008: 4, my emphasis). The conditions addressed included 'Alzheimer's disease and other dementias, Parkinson's disease, Huntingdon's disease, multiple sclerosis, motor neuron disease and prion disease' (ibid:4). However, the document makes specific reference to the clinical needs of the aging population, which of all the neurodegenerative conditions, places particular emphasis on dementias.[27] By combining extracts from this document, with comments made by researchers at meetings attended during the period of my study, I show how particular 'weaknesses' in the dementia research process have been identified, and how policy is trying to act upon them.

What follows is separated into two main analytical areas. The first section deals with efforts to change or redefine dementias as an object of research. This involves a changing understanding of the different dementias as a group of diseases, and resituating the diagnostic process involved in its identification. The second section addresses the relations in science, and how they may be acted upon to facilitate the flow of knowledge, people, resources and funding which are defined as a key feature of successful science.

Addressing the challenge of dementias and their diagnosis

> Effective intervention can only be achieved at early stage in at-risk populations, since after the point of diagnosis it may be too late. Without better pre-symptomatic markers it will remain challenging to perform clinical trials. Investment in this area is needed now, even if unlikely to pay off for many years.

[27] There is an underlying irony in that the dementia most often singled out as the catalyst for a focus on the impact of the aging population on health, Alzheimer's disease, is in fact, the most likely to occur in the younger old, that is, to be identified as 'early onset', below 65 years. This again reflects the not altogether straightforward relationship between aging and science.

Section 5.1 Key conclusions and recommendations.
MRC Strategic Review of Neurodegeneration(2008: 15)

> … [M]aybe it's all been too little, too late; that the process, the AD process has a self-fuelling, self-maintaining momentum. Now that, that's a worrying concept… giving treatments in the way that has been done for a decade or more, waiting for people to fulfil criteria. Add to that the recognition that the Alzheimer's process is detectable now with some imaging with some CSF markers, perhaps ten to fifteen years earlier than diagnosis.
>
> So, if you perhaps take those two things together that there is this long prodromal period with this anxiety that the disease process is self-fuelling, you then see that by the time we are intervening the disease has a 10 to 15 year head start on us.
>
> We wouldn't dream of putting effective therapies in for cancer say when people are at the palliative care, death bed stage. *It's too late*.
>
> So, if the process has been going that long, then that means early intervention. So, I think that's a really interesting thought.

Comment from Professor of Neurology
Alzheimer's Society Research Network Meeting (2011)

The conditions which cause dementia start long before outward signs of cognitive disturbance are experienced or observable in a person. This lag was identified by neurologists as a key issue in the apparent failure of existing treatment, and a significant barrier to effective research. Because the disease activity of dementias is active a decade or more before a person's cognitive changes are apparent, it is hard to diagnose in its earliest pre-symptomatic stages. Thus, there was potentially a whole range of disease activity researchers simply never had the opportunity to observe. As a result, scientists saw themselves, in contrast to researchers on cancers, only able to

join the battle once the war had already been lost. This required a way of seeing disease activity at the very start. However, as yet the precise nature of that start remains unknown. This has led to a focus on the development of the analytical techniques focused on proteins implicated in the earliest stages of the disease process. By identifying these in blood and CSF, researchers have the potential to develop a system of 'pre-symptomatic markers'. In the future, this may enable them to identify the disease in its early stages with a high degree of certainty. Moreover, it would enable clinicians to identify specific types of dementia. By intervening at this stage, with a treatment targeted at a specific disease processes, the recipient would have the best chance of retaining maximal cognitive function.

The narrative which was emerging in neurodegenerative disease research policy is one of potential prodromal diagnosis, that is, one taking place prior to significant neural damage. Furthermore, this was based on the development of biomarkers. This narrative potentially alters the shape and the conceptualisation of dementias. Rather than an intransigent *burdensome* tangle, or an elusive, undefined barrier, resistant to scientific intervention, dementia becomes a well-defined and identifiable target. In other words, dementia is made into an ideal site for the development and trial of a disease modifying, or even preventative and restorative treatments. As I go on to elaborate in chapters six and seven, research is often framed by the language of future potential. This future-orientation is reflected in the shape of the MRC strategy, which categorises its aims as medium term (one-five years) and long term (five-ten years). The benefits of these developments are aims and probabilities rather than concrete certainties, and are viewed as beneficial not only medically, but in the interests of entwined scientific and economic advantage.

> Further stratification of neurodegenerative disease syndromes and sub-phenotypic identification would benefit whole genome association strategies and enable future human trials to be undertaken more efficiently and cost effectively.
>
> Section 5.1 Key conclusions and recommendations.
> MRC Strategic Review of Neurodegeneration (2008: 15)

Whilst in policy discourse researchers describe working towards a clearly defined and targetable disease 'object', in scientific discussion dementia researchers retained the idea of dementia as a

more tangled and troublesome category. In reality, advances in research continually add to rather than subtract complexity to understanding these diseases. In the 2009 Report from the Ministerial Summit on Dementia Research, dementia was likened to obesity, as a 'wicked issue', 'difficult to define, have complex causes and solutions and consequently complex strategies for research' (Brayne quoted in the Report from the Ministerial Summit on Dementia Research 2009: 13). The causes of dementia are convoluted. As our understanding of genetics and bio-molecular biology have evolved, researchers have become aware that the interaction between biology and environment is far more complex than previously understood. Concrete 'upstream' risks interact with the less easily defined 'downstream' risks associated with environmental and behavioural factors which are entangled with socio-economic dynamics (Brayne quoted in the Report from the Ministerial Summit on Dementia Research 2009: 13-14).

As a result, a number of the projects I encountered at research meetings were focused on behavioural interventions. At the ARUK research meeting in May 2011, projects presented included the impact of lifestyle factors, framed by the title 'living well'. Such studies addressed issues such as diet, exercise, the role of social life, and the benefits of the supportive social infrastructure. Other projects at this event addressed the interaction of dementia with other chronic underlying heath conditions. This approach was echoed the 2009 Ministerial Report which identified the impact of co-morbid conditions such as diabetes, high cholesterol and hypertension in increasing dementia risk and the speed of disease progression (Report from the Ministerial Summit on Dementia Research 2009: 23). In addition research dissemination and public education policy placed increasing emphasis on the importance of diet, exercise and maintaining social relations in later life. This was demonstrated at a ARUK public engagement meeting in Newcastle, where presentations were based on the theme of 'Living Well'.

An important influence on this life-style based strategy was the increased understanding of the role of cerebrovascular elements in dementia subtypes, particularly Vascular Dementia (VaD), in which the accumulation of multiple microscopic infarcts is related to progressive cognitive decline. Clinicians and researchers also increasingly believed that single pathology dementias were unusual. It was more common for patients to have evidence of multiple, interacting dementia pathologies. At the Ministerial Summit, speaking on lay awareness of dementia, Professor Ian McKeith is paraphrased as saying:

> Another common misinterpretation is that dementia is always caused by Alzheimer's disease whereas in fact there are many different causes, including vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, Parkinson's disease dementia, Huntingdon's disease and many rarer causes. Mixed dementia (i.e. due to more than one disease process) is very often the true diagnosis. [28]
>
> (Ian Mckeith quoted in the Report from the Ministerial Summit on Dementia Research 2009: 13)

Researchers suggested, therefore, that the disease pathways which lead to dementia are not always as clearly defined, or distinctive as is first implied in the enthusiasm for the categorising potential of biomarkers. This complexity was true for dementias both as an object of science, and one suspended within the deeply social practices of diagnosis and recruitment. This suspension between scientific goals and social and ethical factors is reflected by the senior neurologist quoted earlier on the importance of early diagnosis. He completed his comments as follows:

> [I]t's very challenging, ethically, scientifically, logistically to intervene early, perhaps at the stage where people have the signs of the Alzheimer's process in the brain but are perfectly well with conventional tests.
>
> How do you track if a person has got better when they are already well? So there are things like that. So I think that's it really, that we have failed because we have got there too late. That is one thought…
>
> Comment from a Professor of Neurology
> Alzheimer's Society Research Conference 2011

[28] In spite of the recognition of mixed pathologies, the research meetings I attended tended to emphasise AD over other pathologies. This emphasis was perpetuated in media emphasis and the AD framework adopted by Alzheimer's Society and ARUK. As a result, it is unsurprising that AD continues to dominant the dementia research narrative. This was particularly of concern for those researchers who were trying to carve out a niche for emphasis on research into FTD, DLB and VaD.

The MRC Strategy Review (2008) emphasizes that early intervention is part of a longitudinal strategy which requires long term investment in both translational and basic science. The nature of the scientific process means that early diagnosis would have to precede effective treatment development. Thus, underlying the policy strategy, the prospect of early diagnosis comes with some highly problematic ethical and practical caveats. For the participants, early diagnosis with a deeply stigmatised and feared disease, without the prospect of treatment in one's lifetime, presents yet another aspect of what is to experience the *burden* of dementia.

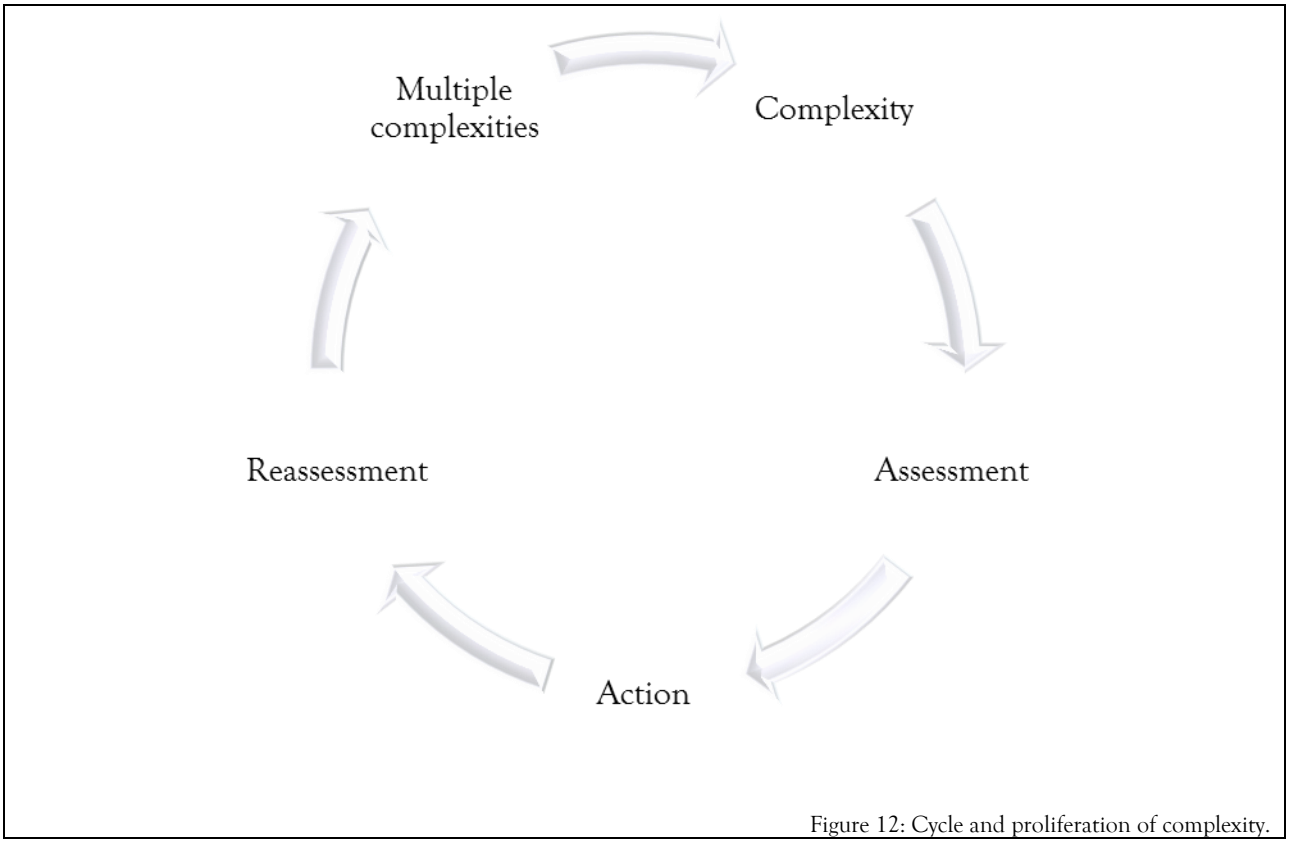


Figure 12: Cycle and proliferation of complexity.

The potential *burden* of early diagnoses for patients was of serious concern for scientific and clinical researchers. However, as in the Strategic Review discussed above suggests such *burdens* are presented as barriers to be overcome, rather than absolute blockages. Amongst some clinical and epidemiological researchers there was a sense that the response-led approach of research funding and policy based on the principles of progress, advancement and intervention might accelerate diagnostic and screening practices before the basic scientific understanding was fully in place. One concern was that this could lead to large numbers of people being diagnosed early but with relatively little support, or high numbers of false positive diagnoses leading to over treatment. On

balance, such researchers considered that such an approach would not be in patients' long-term interests and would be extremely challenging to manage in the existing NHS infrastructure.

Ashford *et al.* (2007) describe the tension between the proposition and the realisation of pre-symptomatic screening for dementias. On the one hand, early screening for dementia allows other common treatable conditions to be ruled out or addressed. For those found to be developing a condition which causes dementia, a diagnosis enables a person to make decisions about their personal and clinical care whilst they are able to access available treatments (Ashford et al 2007, Brayne 2007, UKNSC 2007). On the other hand, the knowledge required for effective and ethical screening is simply not yet developed; '[S]creening tests must be "cost-worthy", with the benefits of true-positive test results justifying the costs of testing and resolving false-positive cases, with due consideration for proper diagnostic evaluation and potential harms (Ashford et al 2007: 47). Brayne, Fox and Boustani (2007) point out that whilst some current cognitive tests are highly sensitive, and have good specificity in identifying subtypes of dementia pathologies, they are unable to effectively predict outcomes. In 2007 on the promise of new biotechnologies for identifying biomarkers they wrote:

> Despite the suggestion that biomarkers may be the promise for the future, no satisfactory biomarker is yet available for diagnosis, severity, progression, or prediction of response in dementia. Similarly, imaging has been suggested as a possible technique to localize and identify brain changes either globally or in specific regions. Neuroimaging improves the diagnostic accuracy of predicting cognitive decline. However, these tests are not appropriate for repeated screening and are costly and time consuming, limiting their applicability to primary care settings. Testing for genetic risk has the same problem as other biological or imaging measurement— an insufficiently close relationship to outcome.
>
> (Brayne, Fox & Boustani 2007: 2410)

At a European Neuroscience and Society Network meeting in 2012, Professor Brayne was one of the main voices advising caution in the implementation of early diagnostic screening for dementias. She cited the wide spread overtreatment resulting from the introduction of prostate screening in the US, as an illustration of the potential harm of implementing a screening process

prematurely (Brayne 2012). Brayne, Fox & Boustani writing about dementia screening in the US observe that any programme would need to be, 'clinically, socially, and ethically acceptable to health professionals and the public' (2007: 2410). One of the social issues surrounding the success of early diagnosis and screening is that concerns amongst the public around insurance disclosure would lead to a high refusal rate (Boustani et al 2006).[29] The UK National Screening Committee (UKNSC) in their 2009 review of screening for dementia, continues to reject the idea of systematic screening in primary health care (UKNSC 2009: 15). However, the general premise that early diagnosis should be encouraged was, and remains, a high profile part of the national dementia strategy (MRC 2008). Early diagnosis is presented as a strategic tool for research development, a utilitarian tool for the state to minimise the *burden* of disease for the individual and the nation, and a pragmatic tool for the patient to maximise their benefit from treatment and support. However, Brayne, Fox & Boustani carefully qualify this with the observation, that: 'the right to know is predicated on the assumption that better outcomes occur as a result of better informed choice' (2007: 2409). As I have demonstrated GP's reluctance to diagnose early would suggest that this is not an assumption which extends across UK health care research and practise.

The prospect of early diagnosis creates a pragmatic problem for clinical research. The problem of diagnosis is presented as a multi-scale issue: people choose not to engage early in the diagnostic process, they tend not to self-refer when early changes in cognition occur, GPs are reluctant to diagnose at an early stage, and clinicians are reluctant to put patients forward to clinical trials. Thus, early diagnosis was a concern of researchers who acknowledged the limitations of existing therapies, where even '(t)herapies in development do not offer strong prospects for effective cures' (MRC 2008: 4). The researchers I worked with, felt that to a degree patients, the public and clinicians had lost confidence and trust in the potential of clinical research. One research officer described in particular how clinicians had become 'research shy':

Me: What do you mean by research shy?

[29] Whilst this would differ the UK context where the health service is free at the point of need, the increasing role of private health care could lead to a similar response here. In addition, if people are diagnosed earlier and living longer, an early diagnosis has the potential to negatively impact on a persons' working life, mortgage agreements, critically illness and travel insurance.

Research Officer: Research shy? Just that they're [long sigh], that for whatever reason they haven't been involved in much research. You know, we have certain hotspots where people are really good. Here in [large city] you know, consultants are really good, really helpful. You present them with a project and chances are they'll say fine, yeah, no problem. You go elsewhere, and you can meet more, more difficult people. You know people who are just not as helpful, who have queries, maybe valid queries, maybe they don't like the study. In, like, a treatment study they might say 'no, I don't like the study, I don't like the protocol or the project. I'm not going to commit to it'. It may be they feel that their service at the present time is overburdened, that they have too many other things happening. You know, the nursing staff, the admin staff, they just wouldn't go for it, and you [pause], you just get a barrier. Yeah, you could have issues around consent and Caldecott approvals, or [pause]. You know, certain areas are very cautious about you looking at notes and things like that. Certain consultants are very, very frightened of you doing that, and so you have to make sure you have all sorts of permissions in place so that you can ease their minds, but yeah. Some places it's better than others

Me: Where do you think fear comes from?

Research Officer: I don't know I've never really [pause]. I think a lot of it is a concern that [pause]. I'm going to say protectiveness, but a certain [pause], just wanting to make sure that their patients are looked after. You know there patients are not all [pause], you know, that their patients are dealt with fairly, you know, there aren't any breaches in things like data protection , things like that. I mean, valid concerns, absolutely valid. But it maybe [pause]. I don't know whether it [pause] I don't know whether it goes back to medical school for some people. I mean I don't know [long pause].

Me: Some sort of reluctance in their training?

Research Officer: Yeah, I mean where it comes from [pause] I mean, difficult [long pause]. Could be the environments that they've been in, and maybe they've had negative experiences themselves. Maybe their opportunities to take part in research previously have resulted in …. I mean, you know, it's very difficult, it is hard work, and it can sometimes get a bit messy, and I mean maybe they're just not keen for that reason. I mean, I personally I find it, I mean particularly for old age psychiatrists, because they

have *so little* in their armoury, *just so little* that they can offer you know when you're dealing with dementia patients, that I just, I. My mind boggles a bit to think that somebody *wouldn't* want to, to try and increase their armoury by being involved in research and moving that process along.

Me: When resources are so limited?

Research Officer: I mean you've got *nothing*, and the only way you are going to be able to build on it is to do the randomised control trials, or otherwise you just can't, you are just going to keep prescribing the same things. The same people are just going to keep gradually declining, and end up in the nursing homes, and you, you're helpless. But where that shyness comes from, you'll have to ask them

Extract from an interview with a dementia research officer (2011)

In spite of having been involved in helping to develop many research trials, this participant found it very difficult to pinpoint any single issue responsible for the barrier to professional participation in the research process. Several ideas are tangled together. We see the idea of protecting the patient, from an uncertain and potentially harmful process. Repeatedly the interviewee cites the idea of the process being, hard, difficult and again *burdensome*. Yet, on the other hand, the limitations of existing treatments and the need for better scientific interventions, better products of science, very clearly, for this participant outweigh the complexity and anxiety which are understood to be part of the process.

Research involving cognitive impairment, aging and chronic disease

Part of this anxiety is tied up with the issue of research participation and informed consent for those experiencing progressive cognitive impairment. In 2005 the Mental Capacity Act had come into force. This created additional regulatory issues both ethical and practical. The MRC strategic review notes:

> It was not yet clear what ramifications enforcement of the Act would have on the feasibility to conduct research with those whose mental competence was in rapid decline, or already severely disabled, due to neurodegenerative disease.
>
> Section 4.3.5: New technologies, tools and infrastructure
> MRC Strategic Review of Neurodegeneration (2008: 13)

The regulation of clinical trials involving participants with progressive cognitive impairment is seen, again in the vernacular, as highly *burdensome* within the research community. As I outlined in my methodology, researchers described the regulatory paperwork involved in dementia science as highly complex, challenging to negotiate and time consuming. The clinical governance for research with human cell lines and tissues was also described as unacceptably *burdensome*. For researchers working with living subjects, there was a huge responsibility to protect potentially vulnerable patients. The need to protect and to demonstrate the transparency of the research process was seen to have resulted in a bureaucratic load. This was framed as impeding the involvement of a public who actively wanted to take part in research, and causing delays to and preventing the process of recruitment to research studies.

The tension between research protection and research discrimination was addressed by the 2008 Nuffield Council on Bioethics Working Party on ethical issues related to neurodegenerative conditions. The consultation paper produced from this meeting emphasises informed consent within the terms of the Mental Capacity Act, 2005, which required the support and formal consent of a 'carer'. Here 'carer' is defined as an 'unpaid person interested in the welfare of the person with dementia' (Nuffield Council on Bioethics 2008: 37). On the whole, within DeNDRoN, the participant-carer-clinician model of consent was seen as supportive, rather than detracting from the research process. The carer was always an integral part of the practical and emotional support system required for research participation to be successful. However, combined consent created a new set of *burdens* to be managed. Research teams had to be aware of minimising any additional pressure involvement might place on carers, who were already perceived as highly *burdened*. It also excluded from research, anyone who did not have a carer in the definition set out by the Act.

The Nuffield consultation paper cautioned that the ability of a person with a degenerative cognitive condition to make their own decision about research participation 'should not be underestimated' (Nuffield Council on Bioethics 2008: 35). At two research meetings I attended, a vocal sub-group of researchers and public participants raised the issue of the lack of trials in development for people with Down syndrome and dementia. Overly cautious and rigid approaches to consent and capacity were seen to be excluding people from research. This was in spite of a specific need for work in this area, as people with Down's are at particularly high risk of developing early onset dementias (Report from the Ministerial Summit on Dementia Research 2008: 17). Researchers and advocates at meetings suggested that work in this area was impeded by the inflexibility of this approach to capacity. This lack of flexibility did not take into account the case-by-case ability of people with complex degenerative cognitive conditions to understand and actively choose to participate in research. This created a further tangle for researchers who, on the one hand had to protect potentially vulnerable people from inappropriate or unethical research involvement, and on the other hand, wanted to ensure that all people had the opportunity to access the benefits of research.

As such, researchers described the need to to be familiar with the variability of dementia. Like other neurodegenerative diseases, patients could have 'good days and bad days'. DeNDRoN staff explained to me that being prepared to adapt to this variability was essential. This might involve in depth at-home discussions with the participant and their carer, finding out what time of day works best for them and being able to reschedule appointments at short notice. This understanding and flexibility was essential for successful relationships with participants, which meant better experiences of research, better retention rates and better data collection. Working with people with dementias in this way, researchers argued, required a much lengthier and negotiated approach to consent and involvement. This was in many ways, a more intricate and difficult process to achieve than rigid inclusion or exclusion of people based on a one off battery of cognitive tests.[30] Making research engagement available to all people with a dementia diagnosis required 'a skilled research workforce embedded in NHS clinical services' (Mckeith quoted in

[30] It should be noted, however, that research exclusion criteria did always have a cut off measure for cognitive capacity to consent, usually based on a minimum MMSE score of 14. However, conducting cognitive assessments on 'good days' rather than 'bad days', and taking a more sensitive and holistic approach to a person's cognitive capacity, enabled those who might simply have been rejected to make their choice to participate in research known.

the Report from the Ministerial Summit on Dementia Research 2008: 14). However, as the above extract from my interview with a research officer illustrates, for clinicians, there remained a 'fear' of facilitating research amongst such potentially vulnerable participants. A policy move to address this fear was to encourage research training early on in clinicians' careers, embedding research into the 'the culture and practices of the NHS' (Report from the Ministerial Summit on Dementia Research 2008: 24).

However, the culture and practice of the NHS in older patient services was described as already particularly *over-burdened*. The expanding population of people over 65 years of age, at increased risk of dementia along with, and often accompanied by, a range of chronic and complex health conditions were often described as a particular concern for clinical researchers. Combined with the challenges of regulation and the wider culture of 'fear' around research, clinicians, the gatekeepers to research recruitment, continued to feel actively 'dis-incentivised' from participating in research. This was an ongoing concern raised at the 2011 DeNDRoN North-East conference, where concern was raised about the lack of new clinicians coming forward to act as Principle Investigators (PI's) to lead in research.

The disincentives to engage with dementia research were not limited to practical, medical and regulatory concerns. The problems of dementia science were also located by research leaders in the historical and social legacy of the disease. Researchers suggested that working in the field of old age, had long failed to inspire the interest of the general public, the government and researchers themselves. One phrase used to describe this was that it was not a 'sexy' field of science. When asked to expand on this, researchers described the lack of discovery and innovation in the field. This was linked to a lack of resources and overall investment. Regulations were high, the patient population was medically and ethically complex, pharmaceutical companies were downgrading investment in the field. This was evidentially not an environment inspiring new researchers and clinicians to specialise in dementia science. In what would become a familiar comparison with cancer research, dementia researcher failure was compared unfavourably to the 'breakthrough' science and investment in oncological research. In short, work on dementia was not currently curative or disease modifying. It was therefore very much in the field of chronic disease with the emphasis on developing effective ways to managing symptoms. Along with the need for more basic science, this was viewed as having less imminent

opportunity for translatable success. This contrasted very much with the increasingly high profile discourse of a 'cure' for dementia which was embedded in the rhetoric of future prospects, and the radical changing infrastructure of the dementia research community

Challenges in research organisation and infrastructure

The strategies developed to address challenges to successful practice in dementia science and the talk of researchers, repeatedly returned to a cycle of complexity and stigma which needed to be met by collaboration to facilitate progress. However, increasing collaboration multiplies the potential complexity which has to be managed. I suggest that in trying to manage this cycle, the dementia research agenda increasingly stressed an evolving relationship between scientists, publics and patients. This demonstrates a fundamental theme in my research, that is, how the relationship between science and the social are becoming increasingly entangled. As the discussion below illustrates, enrolling differently positioned actors in the research process is part of an internal strategy of dementia science.

> We don't link well enough, and this is not me saying that, this is industry. We don't harness academia well enough. Academia just gets on with its own business and trials, the businesses of running trials is being left to the pharmaceutical industry, and that may be a mistake for many reasons. And partly that is because trials, and the process goes from a concept, to a proof of concept, to phase II where you see whether your drug is not only safe but that it has some effect. Then you go into this hugely expensive Phase III, where you have thousands of people on current phase III trials, sometimes 4000 across sometimes 60 countries, and you need to have more effective, more efficient studies, because you can't do anything without big trials. So we need to make our trials more effective, go earlier, and we have to have the courage to see when something is not working either. We invest a lot in trials, and then we don't want to believe our own results. So the results show this is not working, but we've got too much invested so we have to carry on
>
> Comment from Clinical Neurologist
> Alzheimer's Society Research Conference 2011

This comment, again displays a mixed set of feelings about the idea of developing the research community. Coming from a professor of clinical neurology this comment reflects the necessity and value of creating links across academia and industry and across nations to address the perceived weaknesses in current UK research. The language of efficiency and effect are very much the language of neoliberal economic foundations. However, this comment also reflects caution and unease. The economic nature of this necessary relationship means that 'harnessing' academia could lead it to be driven in directions which are not necessarily considered by academic and clinical research to be of scientific or patient benefit. This suggests academia needs to have the 'courage' to put on the brakes when data shows that something is not working, and not pushing it forward because 'investment' is too far down the line. This reflects the ambivalence as well as the enthusiasm for forging new types of links in the research community. On the one hand, they are necessary, on the other, they do not come without ties and obligations which need to be reflexively understood and considered.

Concerns about academic and industrial connections, were just one aspect of a more general concern about the nature and structure of relations in the dementia research community. A core concern of senior scientists was the lack of appropriate researchers and research skills. Research leaders perceived that there were too few new scientists with the complex collaborative and multidisciplinary skills required by dementia science. As I demonstrated in chapter two, cutting edge research into dementias increasingly required people who were able to work across skill boundaries in computing, medical physics, genetics, biochemistry and clinical domains. Those who possessed the range of skills required were at the top of their scientific fields. But the legacy of a lack of career opportunity and investment into dementias meant that these researchers were lost to other 'more developed' areas of science. Thus, another cycle occurs, in which lack of progress is related to a failure to accumulate people and skills, which in turn limits progress. The failure to attract researchers to dementia science was described in MRC Strategic Review a lack of 'human capacity' (2008: 11).

The lack of 'human capacity' in dementia science, researchers argued, led to research groups being simply too small, and project funding periods too short, for groups to successfully coordinate the 'critical mass' of skills with the necessary continuity to make an 'impact on the

complex disease pathways implicated in neurodegeneration' (MRC 2008: 11-12). However, achieving a coherent and successful interdisciplinary research team was described at the NMR Centre as a fickle and challenging endeavour. As I discussed in chapter two, this required not only selecting people with the right combination of technical skills, but ensuring recruitment took into account the right personalities, and a common group identity in order to forge a successful team. This idea featured again in the MRC Review, 'simply putting people together in the same building would not, in itself create the most productive environment, and the most successful examples of interdisciplinary working were led by individuals with the drive to create this environment' (2008: 12). This relied upon what the director of the NMR Centre described to me as 'research leaders'. These were senior clinicians and researchers who had the skills, the understanding and the contacts to engineer, facilitate and coordinate, 'world class research'. This was both a technical, political and social role which enabled leaders to have influence across multiple disciplinary and social boundaries. This suggests an element of tacit knowledge and experience, beyond technical, scientific or clinical skill (c.f. Polanyi 1967). 'Research leaders' must have both the formal and informal understanding of relationships in the science infrastructure. A combination of people management skills as well as scientific reputation allows 'research leaders' to cross domains, in a way that would be unimaginable for a less experienced researcher. MRC Strategic Review described this as a need for '[H]igh quality group leaders', who would 'naturally attract further talent into their departments to maintain research momentum' (MRC 2008: 11). This principle was succinctly described by a politician at the NIHR meeting in London in 2011, 'quality attracts quality'.

The challenges or barriers to successful research which these leaders must overcome, were identified at every level in the research process. From the scientists in the shared building, to national and international research structures. Infrastructural weaknesses at the national level, between researchers and NHS institutions were of particular concern. DeNDRoN was presented by the MRC as a critical boundary organisation which could coordinate and mediate between sites and between different levels in the community. This was part of a wider process of embedding research in both the clinical domain and at the clinical/public interface and key to addressing the *burden* of dementia research (MRC 2008: 14). To effect this requires training, education and awareness in the dementia field, not only for lay participants and the public, but for clinicians and basic researchers alike. If 'research leaders' were required to create the pathway,

research scientists and clinicians on the ground had be exposed to the concept of transdisciplinary collaboration early on, to develop the trust, confidence and awareness to move across boundaries with greater ease.

Building the relationships of science meant not just improving the flow of actors across boundaries; it also required the flow of resources such as technology and data. This was particularly important for the most expensive areas of contemporary dementia science, such as the use of Positron Emission Tomography (PET) and stem cell work. To build a successful and robust research community it was essential to attract the financial and technological resources which could make this work possible (MRC 2009: 12). These 'big science' techniques again required a constructive relationship between industry and academia. Another 'resource' which needed to flow was data. Gathering cohorts for phase III trials required many participants. Facilitating and 'harmonising' multi-site, international collaborations was necessary to meet the data needs of complex late stage pharmaceutical and technological developments. Integration at the transnational level across academic and industrial sites, and the national level, across the NHS, would ensure the development of science which could translate from 'bench to bedside' (Report from the Ministerial Summit on Dementia Research 2009: 13). Thus DeNDRoN at the national level and INTERDEM at the European level, were key facilitators of flow of technical resources and methodological knowledge (Ibid: 18-19). The primary means of addressing barrier and *burdens* in research were by creating connectivity and flows.

The *burdens* of dementia research

In the extracts from policy reports and research meetings reported above there is a pervasive sense that dementia research is seen by researchers as a major problem area of science. As I have shown, there are many facets to this problem, which exist both as part of the construction of dementias as objects of research, and perceived 'weaknesses' in the existing structure and processes of UK neurodegenerative disease science. The efforts by researchers to understand these weaknesses show them to be acting in often overlapping capacities as scientists, clinicians, advocates and policy maker. Such efforts have led to a focus on two critical areas in this field of science:

redefining the disease as an object of research and developing the research community to act upon it.

In the rhetoric underpinning dementia research, science is often portrayed as acting through flows: flows of people, knowledge, technology, funding, public and political support, participants and data. The narratives which develop suggest that these flows are impeded by barriers such as the stigma and complexity of the disease, the circumstances of the participants involved in research, and the organisational weaknesses that fail to make research possible. Such complexities demonstrate the entanglement of social and scientific challenges faced by researchers. Rather than being separate issues, researchers talk about the *burdens* of dementia in ways that capture the connectivity and complexity of these themes. For example, a lack of researchers working in the field would inevitably impact on the capacity to produce novel and successful experimentation, which would, in turn, affect research investment, confidence and the success of patient recruitment into trials.

The idea of research failure or weakness implicit in these concerns was recurrent throughout my fieldwork. For example, in the Ministerial Summit on Dementias Research, the question: 'What are the barriers to effective research on cure?' was answered by a round table group, who in clustering their concerns identified both stigmatised perception and regulation as principle areas for action:

> - Public and professional attitudes
>
> A significant *barrier* was considered to be the attitudes and *stigma* attached to dementia, not only in relation to the wider public, but critically among many individuals in the health and social care environment.
>
> - Regulatory Delays
>
> The research environment in the UK was seen to be '*regulatory heavy*', potentially *stifling* research development and innovation'.
>
> Report from the Ministerial Summit on Dementia Research 2009: 27.

The language used here characterise the barriers to progress in dementia research as systemic rather than isolated flaws. Like the language of Alzheimer's pathology, the *burdens* and tangled relationships of dementia dominated research talk. Here, *burden* is used to capture an inhibiting effect on the flow of knowledge, materials and investment around the research community. The content and rhetoric of scientific talk make an implicit connection between the social, scientific and biological problems of conditions which cause dementia. In particular, the biological themes of disease complexity, diagnostic limitation, cognitive degeneration, aging and chronic disease, are closely associated with the intractability of the social and organisational issues present for researchers. Thus, where research teams were 'fragmented', dementia diseases were 'sporadic' (MRC 2008). This demonstrates how the language of dementia and dementia science in policy constantly echo one another and draw attention to entanglement between cultural, social, biological and scientific ways of making sense of this group of conditions.

When scientists describe dementia as a *burden*, I suggest, it is both part of the reality of dementia research as it is perceived, and at the same time part of a rhetorical process which serves to identify dementia research as a critical, imminent and uniquely problematic issue within biomedicine. In the process of prioritising dementia as a problem for research, it is made into a distinctly political and social problem, particularly relating to funding and participant recruitment. The language of dementia research also reflects Rabinow's notion of biosociality, by demonstrating how the scientific framing of a condition is enmeshed in evolving forms of social interaction and identification (Rabinow 1996). Key in this regard are the way in which social attitudes to a disease associated with age and aging are embedded in and reproduce the social and economic structures which dominate UK society. The language which structures scientific knowledge and infrastructure in dementia research also reflects the challenging characteristics of long-term, chronic conditions which are less easily subject to scientific intervention. As such the *burdens* of dementia research illustrate issues in the social conceptualisation of physical and mental change over the life course and how science might intervene most appropriately and effectively around the co-produced category of dementia (Jasanoff 2004). The analysis in this chapter of the way *burden* is used has also illustrated the mutuality of government, public and scientist.

In the next chapter, I turn from the language of *burden* to the imagery of risk. Risk imagery, I suggest, is being used to capture, externalise and address the problems described by dementia

scientists reported in this chapter. Specifically, I show how the scale and shape of the dementia risk are being developed to communicate research concerns to a wider audience. I pay particular attention to the way scientists, clinicians and advocates use language and imagery to create powerful rhetorics to convey both the scale of the 'crisis', and also suggest a sense of the proximity of the risk. This chapter will set the scene for the responses developed by scientists in their appeal to 'the public' and a process in which the dementia research agenda is becoming the site of a very public science.

Chapter 5 The rhetoric of risk: the construction of a persuasive crisis.

Following the Ministerial Dementia Summit in 2009, a cross-parliamentary group, the Ministerial Action Group on Dementia Research was formed (MAGDR). The group's aims were 'to increase the volume, quality and impact of dementia research' (Great Britain, Department of Health, Ministerial Advisory Group on Dementia Research 2011). In order to achieve these goals MAGDR formed five sub-groups, chaired by leading clinicians who also held key organisational roles in government, academic and third sector organisations. The five sub groups were asked to focus on: the identification of priority topics for the research into care, cause, cure and prevention of dementia; guiding and securing funding; facilitating research; translating research into treatment and, finally, communication. The communication sub-group was designed specifically to identify:

> ...ways of raising public awareness of, and support for, dementia research and increasing public engagement in dementia research, via recruitment to trials and other studies.
>
> (Great Britain, Department of Health, Ministerial Advisory Group on Dementia Research 2009)

This sub-group was chaired by members of the UK's two main dementia charities: Rebecca Wood Chief Executive of ARUK, a specialist in charity management and strategy in the non-governmental (NGO) sector, and Clive Ballard Director of Research for the Alzheimer's Society and Professor of Old Age Psychiatry.[31] In the Department of Health's Dementia Information Portal, the implementation of a 'dementia strategy' is described as 'Improving public and professional awareness and understanding of dementia':

> Public and professional awareness and understanding of dementia needs to be improved and the stigma associated with it addressed. This objective should

[31] Clive Ballard would step down from this role in early 2014, to focus on the development of a research group at UCL dedicated to the study of conditions related to age.

> inform people of the benefits of timely diagnosis and care, promote the prevention of dementia and reduce social exclusion and discrimination. It should encourage behaviour change in terms of individuals seeking help and in the way professionals deliver services.
>
> (Great Britain, Department of Health, Dementia news information and conversations, 2011)

What these strategies describe is a process in which public engagement is placed at the heart of an evolving dementia research community. As in other areas of biomedical advance, public engagement and communication are expected to play prominent roles across UK science policy. This is reflected in the MRC's Strategic Plan 2009-2014 entitled 'Research Changes Lives' (MRC 2009). This document identifies as one of its four strategic priorities the need for enhanced communication between 'scientists, the public and policy makers' in order to address public uncertainty and demonstrate accessibility, accountability and transparency (MRC 2009: 29). In identifying the future direction of research communication, the document pinpoints the importance of evidence-based research in the wider realm of decision-making:

> The challenge is to show the public that the funding we receive is well spent. We aim to make the MRC's work more accessible to the public and policy-makers, demonstrating the value of our research and highlighting our achievements both nationally and internationally.
>
> • We will encourage and support more transparency in MRC decision-making.
> • We will improve MRC accountability by maintaining and enhancing the mechanisms we use for public involvement.
> • We aim to improve understanding of and *stimulate support for medical research among the parliamentary and policy-making communities*.
> • We will support the *continuing need for evidence-based policy and decision-making*.
>
> ((my emphasis) MRC 2009: 29)

The primary motivation for this approach to public engagement is one of fiscal accountability to the tax payer. However, underlying this fiscal accountability are more complex issues of creating

and maintaining trust, reputation and defining 'good' knowledge within both national and transnational contexts. The importance of scientific knowledge is presented not only as it impacts upon political decision-making on science, but on how evidence-based scientific knowledge should inform political decision-making more broadly. Thus, as the above quote illustrates, scientific accountability involves more than a simple economic connection between social, governmental and scientific organisations. The process of developing science depends on maintaining and strengthening relationships with public bodies, and the publics which they are influenced by. This requires scientists to translate and disseminate not only pure science but an understanding of the role and importance of research outside of the citadel. Without this activity it is unlikely that dementia science would become a national priority.

In this chapter, I look at how scientists communicate the risks posed by dementia, and how this becomes part of the process of creating connections and relations with the public. This dialogue, beyond the scientific domain, in turn, shapes public and professional understandings of dementia conditions, and the changing nature of dementia science.

'The impending storm': dementia & the language of urgency and emergency

In the Headline Report eighteen months into the MAGDR project, the chair of the advisory group, Paul Burstow wrote:

> *Dementia costs* UK plc £23 billion a year. And this is just the economic cost; the *real social cost*, for the 820,000 people living with the condition and the many others whose lives it touches, is incalculable
>
> Dementia continues to pose many challenges - to scientists, policy-makers, and above all to those living with the condition and their carers. Left unaddressed, these costs will continue to grow. *Leading scientists are already warning that the NHS will struggle to cope if the prevalence of dementia continues to rise as predicted.*

((My emphasis) Burstow quoted in Great Britain, Department of Health, Ministerial Advisory Group on Dementia Research, 2011)

Such policy and media reports illustrate an increasingly familiar epidemiological prediction of a growing number of people living with some form of dementia. Lock reflects upon how such powerful predictions, originating in the complex and long term calculations conducted in research become rapidly dislocated from the original statistical science which produced them (Lock 2013). Such calculations and numerical representations are reductive in that they take on a meme like quality, in order that they can be continually condensed. As such they become eminently reproducible slogans. This is reflected in the 2013 '1 in 3' campaign in the UK. Here, complex calculations are translated into the punchy and powerful slogan which predicts that by 2020 one in three people in the UK will be living with some form of dementia. Such formulations are intended to capture a sense of urgency and crisis.

Bakhtin suggests that the language used to articulate our experience of the world not only represents but creates our reality (Cresswell & Baerveldt 2011). By taking a realist approach conversation and dialogue become a primary focus for analysis. So when listening to clinicians and researchers discuss the future of UK's dementia research agenda at the joint NIHR and MAGDR meeting, it was notable that they talked of '*reactive* approaches to public health', and described the dementia research field as '*blowing up*'. The delegate's choice of expression was not merely indicative of, but actually part of the evolving shape of UK dementia research. They characterised the sense of enthusiasm and urgency, the explosive groundswell of public, scientific, commercial, academic and governmental attention driving an agenda committed to the diagnosis, treatment and care of people with dementia in the UK. Yet at the same time these phrases capture and communicate a tangible anxiety which underpin clinical research into neurodegenerative conditions.

During January 2012, a spate of articles and media reports described the threat of dementia using the language of environmental disaster, likening the dementia risk to a 'tidal wave' approaching an aging population and threatening to overwhelm national resilience. In the face of such a catastrophe, scientific solutions are presented as the best hope of stemming the 'tide'. Repeatedly, researchers at meetings would described the disparity between research funding in dementia

science in comparison with other illnesses which dominated public health expenditure. Again this is reflected by Paul Burstow who writes:

> Dementia costs the UK twice as much as cancer, three times as much as heart disease and four times as much as stroke - yet dementia research funding has not gone as far as these.
>
> (Burstow in DH, 2011)

The risk and costs of dementia are a fundamental part of how these conditions are discussed. By looking at trends in the language and imagery chosen by researchers and research organisations to convey dementia risk, I demonstrate how they create a sense of scale and crisis at a national level. The framing used to describe the risks associated with dementia relate to the condition's characteristics as chronic, progressive and, as yet, a poorly controlled group of diseases associated with aging. I consider how this dementia imagery compares with that used in two other key health research awareness campaigns: cancer and AIDS/HIV. I show how this comparison sheds further light on the particular way dementias are perceived. Cancer and AIDS/HIV research are examples where researcher advocacy has been used to create powerful health research campaigns, and strong disease and hence, biosocial identities. I show how the dementia research advocacy movement shares many similar characteristics, yet has developed its own distinctive use of metaphors in order to capture the disease entity. I then go on to show the different ways in which the scales dementia risk are being created. These scalar representations are used to construct the threat of dementia both as a large scale risk, and an immediate and personal crisis. This movement between scales demonstrates how the rhetoric of dementia research awareness is attempting to act on an 'imagined' public in increasingly sophisticated ways.

Dementia as flood

The 'Later Life' conference was organised for researchers and practitioners working in the field of gerontology. Opening the conference, Clive Ballard, Professor of Old Age Psychiatry and former head of research for the Alzheimer's Society, described the growth in the prevalence of dementia disorders in the UK. He referred to fellow scientists and clinicians who had likened increasing dementia rates to an impending wave; a 'grey tsunami', threatening to overwhelm the UK's health and social care services.

He then qualified his use of the term 'tsunami', considering it in poor taste and depersonalising, an unsuitable way of describing the experience of people with dementia. But, he referenced it none-the-less, as he felt it fitted closely with the picture of personal, economic and social crisis he had derived from his experience as a clinician. Ballard reflected on the capacity of current health and social care services to treat and support older people with complex health needs, especially the long and severe cognitive decline associated with dementia conditions. He effectively combined personal stories with epidemiological forecasts of dementia diagnosis rates in the UK over the next decade. Appropriate or not, the imagery lingered; a great wave was heading destructively and inexorably in the UK's direction.

Ballard's reference to the 'grey tsunami' refers to a relatively small but significant move amongst researchers internationally.

> Rising tide of late-life dementia is both a triumph of public health and an opportunity
>
> (Larsen & Langen 2008: 431)

> The Impending Storm: Addressing the Health Needs of Aging Populations
>
> *The perfect storm is brewing.* The proportion of the world's population age 60 and older is projected to grow from 11% to 22% between the years 2000 and 2050, an absolute increase from 605 million to 2 billion people. Health systems across the globe are ill prepared to meet the needs of aging populations. The challenges are many. Underinvestment in prevention contributes to the *rising burden of chronic illness*.
>
> (Bierman 2012:1)

> Will healthcare be drowned by the grey tsunami or sunk by the demographic iceberg?
>
> The devastating impact of population aging in the decades to come is becoming *like the proverbial weather: everyone is talking about it but no one is doing anything about it*. Predicted increases in demand for health and social care from 2010 to 2030 for people aged 65 and over in England and Wales include:
>
> - people with diabetes: up by over 45%
> - people with arthritis, coronary heart disease, stroke: each up by over 50%
> - people with dementia (moderate or severe cognitive impairment): up by over 80% to 1.96 million
> - people with moderate or severe need for social care: up by 90%
>
> (Mander 2014: 8-10)

Articles with titles such as those above, were part of a significant move which introduced the language of tides, storms, waves, and tsunami's to discussions of the risk posed by growing rates of dementias. Such language often relate dementia to its potential to overwhelm individual, familial, and community resilience and threatening the very foundations of the national health and social care infrastructure. As I discussed in chapter four, this threat relates to the identification in health economics of dementias as one of the most debilitating chronic conditions prevalent in the United Kingdom. Like heart disease, stroke, cancer and diabetes, dementia risk has been associated with age and lifestyle, and treatments currently involve long-term management, rather than curative intervention. Combined with the personalisation of health and social care (HSC), which marks a strategic reassessment of the role and structure of state involvement in the funding and organisation of long term care, the threat of dementia is characterised as a 'perfect storm' threatening UK society. Writing in the British Medical Journal (BMJ) Chief Executive of the Carers Federation is quoted as raising concerns about the restructuring of funding in HSC:

> "Things are almost developing to the point of a 'perfect storm' for retraction of voluntary sector monies," she said. "Across the country, funding of voluntary sector organisations had fallen by 40%"
>
> (White 2011: 342)

These examples give the risk of dementia watery characteristics, and imply force of nature outside of human control. Interestingly, Ballard criticises the use of natural disaster imagery that he himself is using. Later in this chapter I examine criticism of the rhetorical shifts in researchers' language when describing dementia. In this section, however, I focus on these emotive metaphors of tide and flood, and how they are used to characterise the challenge of dementia as a particular type of crisis. By using the language of watery natural disaster, dementias are located in a particular role in society. In the face of some impending storm, society and science may attempt to predict and prepare for the dementia deluge. It cannot, however, be prevented but must be 'weathered' by means of a complex and coordinated scientific, social and political response.

By rhetorically linking dementia with the destructive force of nature and natural disaster, research leaders such as Ballard affirm and construct the importance and scale of the dementia issue. A

risk of this magnitude would surely require a powerful coordinated response, and scientific and clinical research quickly rushes to fill the void that opens before the impending 'tsunami'. The description of the scale of the dementia as a natural disaster can be linked to a process which has been taking place over the last decade in which significant chronic public health issues such as cancer and heart disease have increasingly adopted the language of the epidemic (Weiss 1997, Mandell & Green 2011, Zeilig 2013). The 'perfect storm', reflects the implications of this language. Like a storm, the epidemic is an unstoppable and uncontrollable force of nature, during which a 'natural' contagion rages out of control, challenging the best efforts of biomedicine in a heroic struggle.

The language of the epidemic captures a sense of urgency and uncontrolled crisis. Whilst chronic conditions such as dementias, cancers, or heart disease do not involve contagious agents, increasingly in both science policy and media, the language and rhetoric of the epidemic is pervasive (Lock 2013). This rhetorical move conveys the considerable health challenge of chronic disease, that is, to convey the sheer numbers of people affected and the cost of the long-term treatment and care.

Root metaphors of disease play a key role in the social study of biology and biomedicine (Gaines & Davis-Floyd 2004: 100). Analysis of discourse and rhetoric in the biomedical encounter has become increasingly important in the shift from mechanisation of the body and the patient-as-object, towards the more humanistic conversation-oriented practitioner-patient relationship (Floyd & St John 1998, Kleinman 1988). With increasing emphasis on 'Mode II' science in science policy, the idea of relationality in biomedicine can be seen to extend to the research practice and policy and the shaping of disease construction and perception. Social research into disease experience and scientific discourse around the conditions HIV/AIDS and cancer have informed my interpretation of the scientific and public discourse emerging around dementia conditions (cf Sontag 1978, Martin 1994, Landesman, Ginzburg &Weiss 1985). In an analysis of the metaphors used in the description of cancers, for example, Sontag observes how both patients and clinicians describe the disease activity and process as 'animalistic'. In her account, she notes that the word cancer is linked to the Greek *karkinos* and Latin *cancer*, meaning crab. Sontag also describes how cancer cells are referred to as 'spreading', 'invading', 'attacking', and 'eating' (Sontag 1978: 10). In contrast, in the case of AIDS/HIV, researchers have identified how

scientific and lay descriptions tend to represent the condition as systemic and fluid, and capable of boundary crossing. Such language, as used by clinicians, patients and reflected in medical policy, convey connotations of pollution, deviance and decay, reflecting an implicit connection between the infectious agent and the social stigma associated with sexual and drug-taking practices implicated in the spread of HIV (Martin 1994, Sontag 1978, Epstein 1995, 1996, 2008). Such linguistic practices, which cross the boundary between public and scientific discourse reproduce underlying social attitudes and values in powerful ways.

What then of the representations of dementia? The use of the watery images of tides and storms to represent dementia demonstrates two very different rhetorical modes. On the one hand, the storm, flood and tsunami present nature out of control, violent and threatening, crossing boundaries with destructive potential. On the other hand, the movement of the tides suggests a more rhythmic or cyclical process driven by nature, a process which is predictable, yet inexorable. These competing metaphors reflect a tension which exists in the scientific representation of dementias which I explore here in more detail.

The storms of dementia are spoken of in research on a number of levels: in the pathology of dementia conditions, progressive neural death overwhelms the capacity of the cognitive function of the brain. As I explored in the previous chapter, scientists' and clinicians' are also acutely aware of the complex and destructive burden dementia places upon a person's ability to function neurologically and consequently the impact of their condition on their personal and social worlds. Likewise, the activity of the storm or flood of dementia resonates with the expanding, invasive burdens which flow out from the pathology of the disease to engulf families, communities and nations, personally, socially and economically. Biomedical research is thus, in this metaphor set up to compete against the violence of a natural force. Framed as mobilising resistance to the encroaching effects of the disease processes, science is responsive to the threat of the storm, protecting society from and attempting to ameliorate the damage it inevitably leaves in its wake. The imagery of dementia is portrayed as a space of violence or conflict and the role of research is one of active protector. This is reflected in the description of pharmaceutical, behavioural and life-style interventions as 'neuro-protective' (Jain 2000).

Whilst the rhetoric of the tide shares some of the stormy connotations, it suggests a slightly different relationship between the nature of the disease and the role of science. Part of this rhetorical shift towards tides suggests the connection between dementia and ageing, and wider themes surrounding progressive, chronic, neurodegenerative conditions. On the one hand, age continues to be identified as the principle risk factor in the main dementia conditions, AD, VaD, DLB, and FTD. These affect approximately 5% of people over 65. This rate increases to 20% for those over 80 years of age (O'Brien 2005 &2006).[32] Such epidemiological estimates, like the tides are expected to rise. In this metaphorical context, the disease process of dementia is associated with the unstoppable fact of aging. The research process has had to, in many ways, learn to adapt to and accommodate the realities of living with dementia. 'Defeating dementia' has required a research process which reflects greater understanding that participants are subject to a process of ebb and flow, good days and bad days, and a slow but inevitable disease progression. The responsive role of researcher in this context has a different orientation from that of heroic protector described above. The response is adaptive, reflexive in its preparation of long-term defences. This is reflected in the continuing emphasis amongst researchers on the gradual process of scientific discovery, and the continuing need for basic and observational research to understand the nature and processes involved in different dementia pathologies. This is not nature under scientific control, but science preparing long-term means of defending the boundaries of society against the more unforgiving and unrelenting processes of nature. Thus, the tide imagery also suggests an underlying anxiety for dementia research. If age is the primary risk factor in the most common dementia conditions, to what extent can science successfully act upon them?

The processes of aging, however, are increasingly not beyond scientific attention and intervention. Research into cellular aging is a rapidly evolving field of science and a core focus in the MRC strategy (MRC 2008). As a result, whilst researchers may appear to be working with the current 'tide', research has already demonstrated its potential to intervene in the aging processes and perhaps reverse its natural course. This is recognised in the achievement of extended life expectancy itself (Kitwood quoted in AlumNews 2010). However, as the MAGDR

[32] It is important to emphasise that whilst age is a primary risk factor, it is not an isolated one. Like many chronic conditions, in dementia increasing age is understood to part of a complex picture of multiple interacting risk factors including genetic and bio-psycho-social factors which vary between people. However, under emphasis on the factor of age has been shown to be as damaging as overemphasis in the movement to increase rates of diagnosis, treatment and research.

report states, 'the tide is turning' (Great Britain, Department of Health, Ministerial Advisory Group on Dementia Research 2009: 1). Advances in fields such as metabolic aging, cellular degeneration, and stem cell research are seen to have novel potential to inform future intervention in degenerative conditions such as age related dementias. This 'war on aging', allows research to maintain its heroic and mobilising role in the construction of a fight against dementia, even in the face of the tide of an aging demographic and an intractable disease (Lock 2013, Moreira & Bond 2008, Vincent, Bond & Tulle 2007).

There are similarities in the representations of dementia and cancer as battlegrounds and conflicts in which the researcher joins the patient and the public in a common fight. However, there are interesting differences in the lines along which these battle lines are drawn, and how the combatants are represented. Whilst people living in remission with cancer, or HIV controlled by medication, may be described as 'survivors' who are 'beating' their conditions, in dementias there are no survivors. Prior to my period of research, representations of the image of the person diagnosed with dementia in science policy, engagement and advocacy tended to be highly passive. The person themselves was indeed often absent from the discourse taking place. It was extremely uncommon for the voice of a person with dementia to be heard directly. This was reflected in the dementia awareness campaigns at that time, which often presented the dementia through the voice of a proxy: a family member, a professional carer or a practitioner. This portrayal of dementia patients, as I return to later, has undergone a rapid shift since 2010. This decade has promoted the direct voice of the person with dementia more than ever before, albeit accompanied by family members in the background. However, up until this point, the person with dementia had been represented in a distinctly passive position relative to both the disease and the science involved.

In spite of these attempts to remodel dementia engagement to emphasise an active relationship between patient-practitioner and patient-researcher, metaphors of 'greying', fading and dissolving continue to dominate dementia engagement practices. The Department of Health early dementia diagnosis leaflet and television campaign, created in association with the Alzheimer Society reflects the persistence of these associations. Narrated by a woman describing her father's changing conditions, she describes her awareness that something was not 'quite right'. With his

changing cognition, the image of the father slowly dissolves from the screen becoming washed out, grey and translucent:

"This is my dad." "He'd started to forget things. It couldn't just have been old age." "I tried to ignore the signs but it was getting worse."

Figure 13: National television campaign "This is my Dad" - Fading
Great Britain, Department of Health. (2012)
http://www.nhs.uk/dementia/Pages/dementia.aspx?WT.mc_id=91103

As the daughter encourages her father to seek help from his GP, eventually receiving a diagnosis of early dementia and treatment for his condition, his image eventually gradually returns to full potency and their relationship is sustained (figure 14). This representation of dementia as blocking or breaking connections, becoming a barrier to social relations and functionality, resonates with the discussion of the language of the disease, and the problems identified in research practice discussed in the previous chapter. The accumulation of abnormal disease pathology blocking neuronal connections, leading to a progressive loss of cognitive function is mirrored in both the language and imagery used in the narrative of this advert. Again what dementia unmakes, the social ties which fade away, are, albeit temporarily, remade through the biomedical engagement.

The risk of the untreated progression of dementia leading to the untimely dissolution of the person and their social ties, is linked to the rhetoric of loss and social death which tended to dominate dementia narratives in the twentieth century (Hughes 2011, Leibling & Cohen 2006). The concept of fading is linked to the discourse of the 'greying' of society. Using the image of the loss of hair pigmentation in later life, 'greying' has become extended to convey the changing demographic balance of age, and often carries connotations of a loss of social value and potency in later life (Kitwood 1997, Mclean 2007). In response, attempts have been made to remobilise the 'grey' concept as a political and economic identity (Hazan 1994, Higgs 1995).

"He was diagnosed with the early stages of dementia"

"Spotting the signs early meant we could get the right treatment and support."

"And I'd have the Dad I know and love for a little longer."

Figure 14: National television campaign "This is my Dad" - Returning (Great Britain, Department of Health, 2012) http://www.nhs.uk/dementia/Pages/dementia.aspx?WT.mc_id=91103

In spite of the active inference of the 'grey' movement as a political or economic force, defining older people as an underrepresented group, emphasises the sense of social disempowerment associated with later life. This narrative came under intense scrutiny in the eighties and nineties, as researchers began to address the contribution of disease rhetoric to the overall stigmatisation of conditions such as dementias (c.f. Bond, Coleman & Peace 1993, Kitwood 1997, Mclean 2007). In dementia narratives, the image of the 'quiet death' or the 'death of the self', although challenged vociferously remains stubbornly persistent, continuing to appear in both social and scientific representation (Sweeting & Gilhooly 1997). At the Alzheimer's disease International Conference, for example, a number of presentations focused on how internationally, the depiction of dementia in the media, fiction and reproduce rather than address the disease stigma (ADI 2012). Such stigma, it is suggested, has an ongoing impact, not only on the public but also on practitioner perceptions of dementia, which continue to affect willingness to engage with screening and early diagnosis of a dementia condition (Cartz Piver et al 2013).

As I discussed at the start of this section, Clive Ballard simultaneous uses, yet criticises the concept of the dementia 'tsunami' to illustrate the struggle taking place to capture and enter into a discourse about dementia. This dual reading of the metaphors reveals dementia science as a site of continually emerging and socially reflexive questioning which is rapidly reshaping its practices. Science policy and engagement must capture interest across science, government and the general public. Thus researchers and advocates continually try to find ways to communicate their needs and concerns, in areas such as achieving funding, making an early diagnosis, or

successful recruitment to randomised control trials. Key to these endeavours is the process of imagining the character and interests of the 'public' and how the priorities of science might be made persuasive to them.

However, as Sontag reflects upon in *Illness as Metaphor (1978)*, whilst rhetorics are eminently powerful at communicating and disseminating social and biomedical characteristics of a disease, they also engage people in inadvertent and unwanted ways. People diagnosed with a condition such as dementia, can find themselves subject to labelling which they find unhelpful or damaging to their sense of self and identity. With the increasing power of patient advocacy groups, the rhetorics quickly become open to public critique. I experienced this at an Alzheimer's Society research event where the use and connotations of words such as 'carer' and 'challenge' commonly used by practitioners, were debated by family members of those who had the condition. Some participants felt empowered and recognised for the hard work involved in 'caring', and their contribution as a 'carer'. Others, disagreed, they felt the title diminished the personal and familial content of their relationship as 'husband' and 'wife', which could and should never be reduced to that of 'carer' which, for them, carried an entirely different set of expectations and responsibilities. For them, all kin should care but not all 'carers' are kin. This tension reflects an ongoing debate about the recognition – moral, economic and practical – of family members who are also carers for a relative with a chronic and long-term condition. It also illustrates the way that the language emerging at the interface of biomedical and pubic engagement with chronic conditions such as dementia, can carry conflicting implications. For example, one woman at the Alzheimer's Society meeting in Birmingham in September of 2011, in a state of some distress, spoke of how being labelled as a 'carer' fundamentally threatened and undermined what she understood as the very nature of her relationship with her husband.

In spite of these attempts to change how the problems of dementia are captured, metaphors of water and disconnection continue to dominate discourse used in science policy, engagement and advocacy. As I have discussed in the previous chapters, the precise causes and disease processes involved in dementia pathologies are highly complex and the understanding of their aetiologies is evolving rapidly. Thus, the mobile and fluid imagery of water acts as a useful means of engaging with a disease which is seen to be of imminent risk, and yet in a state of perpetual emergence. Having described the imagery used to convey the urgency of the threat of dementia, in the second

part of this chapter, I turn to the different techniques used by the main dementia research charities to capture and communicate the scale of risk to the public.

Scales of risk

Raising the public profile of dementia was seen as a fundamental means of mobilising and maintaining political and economic will to support a dedicated dementia research agenda. This agenda would enable solutions to be found to the problems posed by dementias and the need to develop more effective research-led solutions. In a society where multiple health concerns compete for public attention and are typically presented in terms of crisis and risk, how can dementia research enrol the public to its cause? In this section I reflect on the creative use of scalar imagery in public awareness campaigns to help raise funds and encourage early diagnosis and participation in research. The scales created appeal on the one hand to large-scale risk and use epidemiological-type data and predictions. On the other hand, great effort is made to also make that risk intimate and personal. The strategic movement between the global and the personal were central to efforts to enrol the public in the dementia research movement. Here I use extracts from documents, research meetings and health promotion materials to explore how these scales were created and used by those involved in constructing the dementia research agenda. In particular I use extracts from an ARUK animation which powerfully visualises these scales.

One approach used to capture the urgency of dementia was to set the condition in relation to other key health crises. Comparisons of relative prevalence, cost, funding and research into other conditions, in particular cancer, became a familiar part of the rhetoric taking place at research meetings, in policy documents and public engagement materials. Drawing on epidemiological and health economists' calculations of the 'cost' of disease, this clip from the ARUK animation, captures a financial and visual comparison between dementia, cancer and heart disease (figure 16). Where cancer is a tower block, dementia is a skyscraper. Cancer and heart disease play a particularly prominent role in the public awareness of health. Diseases such as cancers are highly recognised and understood to seriously impact upon the person diagnosed with the condition. They also have a history of highly successful public engagement, awareness and fundraising campaigns (Rowe et al 2010).

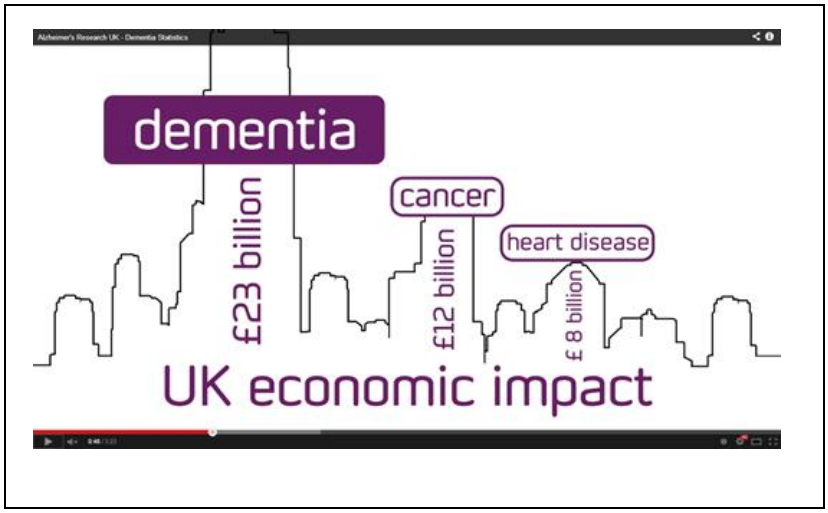


Figure 15: -Statistics of scale for dementia
Alzheimer's Research UK
http://www.youtube.com/watch?v=PrVooMwg0LU&feature=youtu.be

By setting up this comparison ARUK creates a scale of relative risk, suggesting that dementia should share this profile in the public imagination and that these conditions have a 'cost' which must be recognised. This 'cost' is then related to the relative funding of research in these areas, linking back to research scientists' descriptions of a legacy of underfunding for their field of research. Like the image of people with dementia discussed earlier, dementia was seen to have been faded out into the background in terms of investment and interest. As shown in chapter two, scientists in this field have long felt that theirs is a 'cinderella subject' which never quite gets to go to the research ball.

During the animation, different scales of text are used to highlight the comparative underfunding of dementia relative to its counterparts. This is in spite of the towering cost of dementia care demonstrated in the previous slides. Whilst the solitary dementia scientist shrinks into the background, the grey-coloured cancer scientists are present in number, dominating the screen and, by inference, national research funding. The simplicity of the animation captures a sense of the competition for resources between conditions. By highlighting the risks and costs of dementia to the UK economy, the resource emphasises the importance of directing a greater proportion of resources to meet the relatively cost of tackling dementia. The comparison between dementia and cancer research was a familiar one at the research events I attended. At a meeting organised by ARUK to encourage public engagement, four senior clinical researchers working on dementia debated the 'good news and bad news' about research:

Figure 16: Comparing scales of funding and resources
Alzheimer's Research UK - Dementia Statistics
http://www.youtube.com/watch?v=PrVooMwg0LU&feature=youtu.be

David: So unlike cancer for example where we know possibly what the problem is, the uncontrolled division of cells, and we understand a lot more about the mechanisms that drive it. We still have a much poorer understanding of what drives those pathologies that are associated with AD which can be clearly more complex. I don't know whether any of our other [pause] Roger [pause] do you want to say something? I had you filed away under good news but um (laughter).

Roger: If we just think back to the early 1960s, those of you who were alive in the 1960s, it was a time of great optimism. It was the time that we went to space and

> it looked as if science could do almost anything. And at that time the US president set a target to beat cancer by 1970, we all thought *wonderful* we'll have done it by 1970. And actually it didn't happen, and this brings us to Jim's point, it took 50 years of really *hard* work to understand the biology of cancers, and now we're getting developments coming thick and fast. But we had that time of *decade after decade* of investment and research before we could do it.
>
> David: Ok so that's one thing, 50 years and *12 times the budget* to, you know, required to produce the affects that we need. So I'm also going to articulate a question that has already been asked by someone else this afternoon which is all the emphasis that we have heard today, as this is the theme of the meeting on prevention, on treatment of the disease, on understanding, we have heard, about seven years on the research of care. And yet for people on the front line, and I'm including professional carers as well as family carers, there are real, real issues. Why is it that research into care for people with dementia seems to be such a Cinderella subject in relation to all this hot stuff around molecular biology and so on?
>
> Extract from a ARUK Meeting 2012

The comparison here between dementia and cancer research raises several interrelated themes: complexity, time, funding and success. The inference is that the growing effectiveness of cancer treatments are due to better understanding of the basic underlying biology involved. This is in contrast with dementia, where it is suggested the biology of the disease is more complex and less clearly understood. This lack of clarity is not only due to the complexity of the disease but the legacy of underfunding. The 'successes' of cancer research are due to an intensive long-term programme of research investment which has been lacking in dementia science. There is also the implication that the type of science is related to the measures of 'success'. The first researcher asks why 'hot' bio-molecular science is prioritised over research into care? Care research, whilst addressing the 'real' needs of people and care-givers living everyday with dementia, is perceived to be left out in the cold when it comes to public and political attention. This raises an interesting issue about how researchers see themselves as viewed by the public when it comes to their attempts to counter risk. Biotechnological interventions are understood to have greater social and scientific value or 'impact', when compared to research on lifestyle and caring practices which

manage rather than resolve the problems of dementia. This bias is further reproduced in the ARUK animation in which the underfunding of research is represented by a white-coated figure gazing into a microscope, an image which suggests that dementia research success will lie in the realm of the laboratory. This also reflects dementia researchers' own concerns about competing in the national health research market and begins to illustrate their anxieties about success and progress. Is research better represented as striving for a heroic response to the storm, or should it be a builder of more long-term tidal defences?

Having established dementia on a level with competing risk between conditions, research engagement goes on to create a sense of scale. Clearly, every health concern must have its rhetoric of catastrophe in order to claim a place in the public's attention and on the national funding agenda. In dementia, the catastrophe is often communicated in numbers, the figure most often repeated being that currently 820, 000 people are living with a form of dementia. Although numbers can be a powerful means of representing scale, research engagement and its use of media is going a step further in illustrating how abstract numbers relate to more tangible and familiar concepts. One method used to achieve this is relating numbers to images of space and place. Thus, the ARUK uses its animation to illustrate that this number of people is more than the population of some of the UK's major cities, including the capitals of Wales and Northern Ireland (figure 17). Perception of the scale of dementia is shifted to a new realm with the suggestion that the number of people in the UK with dementia would be equivalent to the nation's third largest city. All the while a contemplative rhythmic sound track plays in the background of the animation. This sound track, at once sorrowful yet rising in tone, intimates hope and possibility and is similar to a Cancer Research UK (CRUK) advertisement released in the same year. This advert makes a similar appeal for support and awareness. However, there the similarities end, and it becomes clear the ARUK and CRUK have adopted very different 'brand identities'. The CRUK edits together the images of an invading black stain, which retreats with images of research and a description of success in research – once again a white-coated scientist peers down the microscope, representing the archetype of clinical research. This narrative sits in direct contrast to ARUK's animation which explicitly focuses on the relative scale, impact, and support required for research into dementia.

Constructing the image of the risks and costs of dementia, could simply be read as realising the very real epidemiological gravity of the situation. However, this doesn't pay attention to the level of skill and attention paid to creating the scale of dementia in ever more creative and tangible ways.

Figure 17: Relating scale of dementia to space and place
Alzheimer's Research UK
http://www.youtube.com/watch?v=PrVooMwg0LU&feature=youtu.be

This is reflected in the ARUK's most recent campaign to coincide with the 2014 World Cup. Described as raising awareness of the scale of dementia as a global problem, the organisation used its daily Facebook feed to post the flags of the matches taking place. Each nation is given its World Cup statistics and ranking, followed by the number of people estimated to be living with dementia. Using such a high-profile and popular sporting event which has been shown to cross

many social divides in term of public interest, is yet another example of a dementia research organisation working hard to find creative and timely ways to locate the disease at the very heart of national awareness. [33]

Figure 18: The dementia World Cup
16th June 2014
https://www.facebook.com/photo.php?fbid=783754491642746&set=a.191296384221896.46948.185521991466002&type=1&theater

Time is another reoccurring feature of the attempt to convey the scale of the dementia problem and the urgency of the crisis. In one advert, the rhythm of music accompanies an image of a ticking clock, followed by the caption: 'Every 3.2 minutes in the UK someone develops dementia'. How this has been calculated is unclear, but it creates a very real sense of the immediacy of the threat posed by the disease. The reference to an abstract 'someone' suggests

[33]In the comments a writer notes that the numbers of people with dementia seen in blue in the first slide aren't very easy to read for her husband due the impact dementia on visual processing. ARUK immediately responds, thanking the commentator, and true to their word, the following day the offending colour has been made higher contrast and more visible.

that anyone might find themselves dealing with the impact of dementia diagnosis at any time. Thus the scale of the dementia risk is both imminent and pervasive.

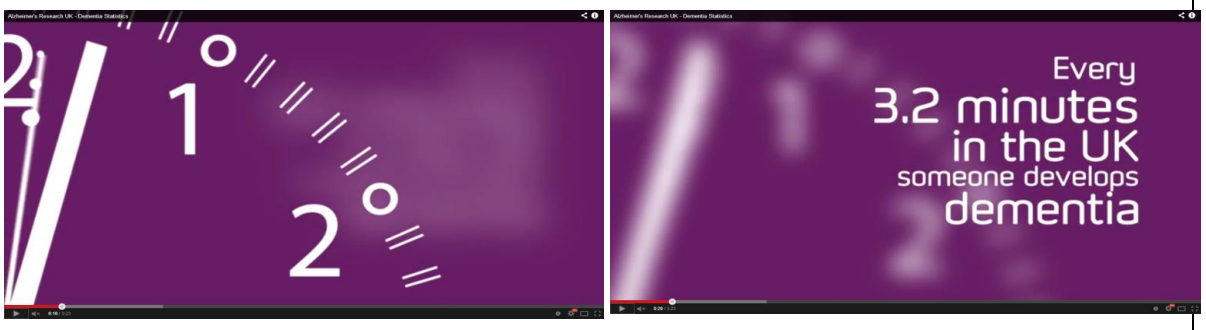


Figure 19: Relating risk of dementia to the passage of time
Alzheimer's Research UK - Dementia Statistics
http://www.youtube.com/watch?v=PrVooMwg0LU&feature=youtu.be

Sharing the burden in a community of risk

The use of the techniques such as the World Cup and the comparison of dementia rates to the populations of different cities, appeals to culturally embedded senses of space, place and identity. The threat of dementia is not remote, it is within one's local town, it is 'here'. Thus, research and disease engagement takes the 'inchoate' and intangible 'public', and constructs a defined notion of locality and community (Fernandez 1986, Carrithers 2008, 2009). Dementia, its risk and its threat, are then located within these communities, the disease is given place and identity within society. This is part of a distinct process in research engagement which makes dementias not only a range of conditions which threaten society on a grand scale, but a threat of the most local, personal and intimate kind. This is reflected in the changing dementia rhetoric which moves dementia research from using the register of national and social responsibility to using that of representations which appeal to the idea of the risk to the person, the individual and in particular, the family. This is reflected in the Department of Health national television campaign who's images I referred to earlier. I now look at the script in more details:

> This is my dad.
> He'd started to forget things. It couldn't just have been old age. I tried to ignore the signs but it was getting worse. I was afraid I was losing him. I was worried

about bringing it up. But he agreed to see the doctor. He was diagnosed with the early stages of dementia.

Spotting the signs early meant we could get the right treatment and support. And I'd have the dad I know and love for a little longer.

If you're worried about someone's memory, talk to them about visiting their doctor.

Transcript of 'this is my dad', National television campaign
(Great Britain, Department of Health, 2012)
http://www.nhs.uk/dementia/Pages/dementia.aspx?WT.mc_id=91103

The simplicity of the emphasis 'this is my dad', takes dementia from the national scale of risk, to the intimacy of the bond of a primary kin relationships. The language of 'forgetting', 'loss' and 'worry' are combined with the fading image of the father, to suggest how dementia presents a threat to that relationship. The final line 'I'd have the dad I know and love for a little longer' appeals to emotive cultural values associated with primary kin relations in the UK (Strathern 1992a). Again the narrative emphasises that biomedicine holds the potential to sustain these valuable social ties, which the onset of dementia threatens to disrupt and dissolve.

The personalisation of the risk of dementia, and the need for research and awareness was evident at research meetings. One neurologist opened a meeting by commenting that because of his age, he was now in a higher risk group for developing one of the dementias. This was said in part jokingly, but at the same time he conveyed that his interest in achieving effective treatment had taken on a new dimension and urgency. Researchers also referred to their own experience as carers as well as practitioners. This long quote from a gerontologist reflects the emotive role of kinship in experiencing dementia. She also questions why dementia advocacy, in comparison to other disease movements such as autism awareness, seems less able to engage with those diagnosed with the condition and their families and carers.[34]

Well actually I was at [pause] yesterday I was attending an international meeting on autism which is quite irrelevant to what I am doing today, and I was surprised

[34] The gerontologist is a non-native speaker. As a result there are a number of non-standard phrases. I have transcribed the discussion verbatim, because her comment showed her struggling emotionally and intellectually with the difficulties faced by both scientists and members of the public in the face of conditions which cause dementia.

at who was attending the meeting, it was attended by service users, by families and professionals, and these service users, autism and Asperger's, were obviously there, but also these families brought their children who were very vocal, and I was quite impressed actually with the strength of their interest, and in all fairness when I was thinking about these people and the cases that were raised in the 1960s, that with all the advances, with all the services which had been developed, and people were still unhappy about the services that were available and the service providers …. If only 1% of what you've got in dementia, and I think we've just got to keep pushing for, and I don't think there are many service users here in this room, yes? We are all professionals, or we have somebody who we care for, or we are worried as well about our own memories. But I think that we need to engage with the service users, and there is a lot of what we could hear, what we can learn from them.

First of all I would like to stress that people with dementia know exactly what is happening to them, there is personality, there is wishes which have to be heard. The Mental Capacity Act (2005) actually allows for their wishes to be heard even when they are declared mentally incapable. But even people with severe dementia know what they are saying, they have got lucid moments. When my mother –in-law smiles at me and says 'you're a lovely girl', I know she really means what she says, when she says to her son 'I love you' I know how touched he is. So I can understand, you know, why people disengage because we know that people with dementia seem to disappear, but they are not, they know exactly what is happening to them, and we need to get the community to know that, to know exactly what people in the field of mental health learn, how to listen to their needs. So I think you know there are some fields like cancer, but there are some other fields where not a lot of investment has been put, but great achievements have been made.

Amongst researchers narration of their involvement in, and concern for, a more effective dementia research agenda, there was a great willingness to share personal experiences caring for and kinship ties with people experiencing dementia. During public presentations or when I

discussed perceptions of the issues in dementia research with professional researchers, clinicians and advocates, it was not uncommon for them to express their concerns in terms of their kin relations. They were expressing an understanding of not just the politics or the science of dementia, but a personal understanding of the impact of the disease. Even in talking about dementia research, the condition could be made to cross the boundaries of the scientific, the social and the personal. Contrasting with the pathology of dementia which is seen as breaking connections, there was a conscious effort within the research community to make connections. Great effort was put into making dementia escape purely biomedical accounts and cross metaphorical boundaries.

The stigma of dementia was constructed as the prime barrier to the effective connection of publics and scientists with dementia research. As discussed in previous chapters, the intensity of this stigma is located in complex beliefs including: the inevitability of age-linked neurodegenerative conditions, the personal and social devastation of these syndromes and the lack of treatments currently available. This stigma is seen as one reason dementia discussion into the background. This has been reflected in the early phases of dementia awareness campaigns in which the voice of people with dementia were often represented by those involved in their care or treatment. The reluctance to include people with dementia in campaigns has been linked to concerns about protecting vulnerable people from a kind of instrumentalisation. The reluctance was particularly apparent given that up to the 2000s people tended to be diagnosed later in the progress of their condition, when their capacity to give independent informed consent had already severely deteriorated. Advocacy inclusion was made even more sensitive in the context of marketing campaigns where the boundaries between social, medical and commercial interests are blurred. The movement towards first person representations of dementia is therefore located in the more recent shift interrelated biomedical and social ideas about dementia. Increased rates of early diagnosis have combined with refined understanding of capacity to consent, signalled by a shift from a paternalistic and protective NHS to a relational patient-centred discourse. Changes in disability politics which pushed for improved understanding and inclusion practices also impacted this shift (Barnes, Mercer & Shakespeare 1999, Shakespeare 2006). These factors are in turn related to the increasing availability, permeation and normalisation of media, and particularly social media, as a tool of personal and social identity making. As such, social media become a core tool in crossing political-biomedical-commercial boundaries. Thus, whilst the

representations of carers and practitioners remain intensely valuable in the dementia movement, a critical part of de-stigmatising and bringing dementia out of the shadows has been the growing inclusion of people with dementia themselves. In recent campaigns we see the image and hear the voice of people diagnosed with dementia in highly polished marketing campaigns which maximise the scale and impact of dementia awareness campaigns. These factors are illustrated by in the 'Mind Over Matter' exhibition. In this event people who wanted to donate their brain to dementia research, after their death were asked volunteer to be photographed and to describe their motivations for participating in dementia research. This included people who remained cognitively healthy, and people who went on to develop dementia in their lifetime.

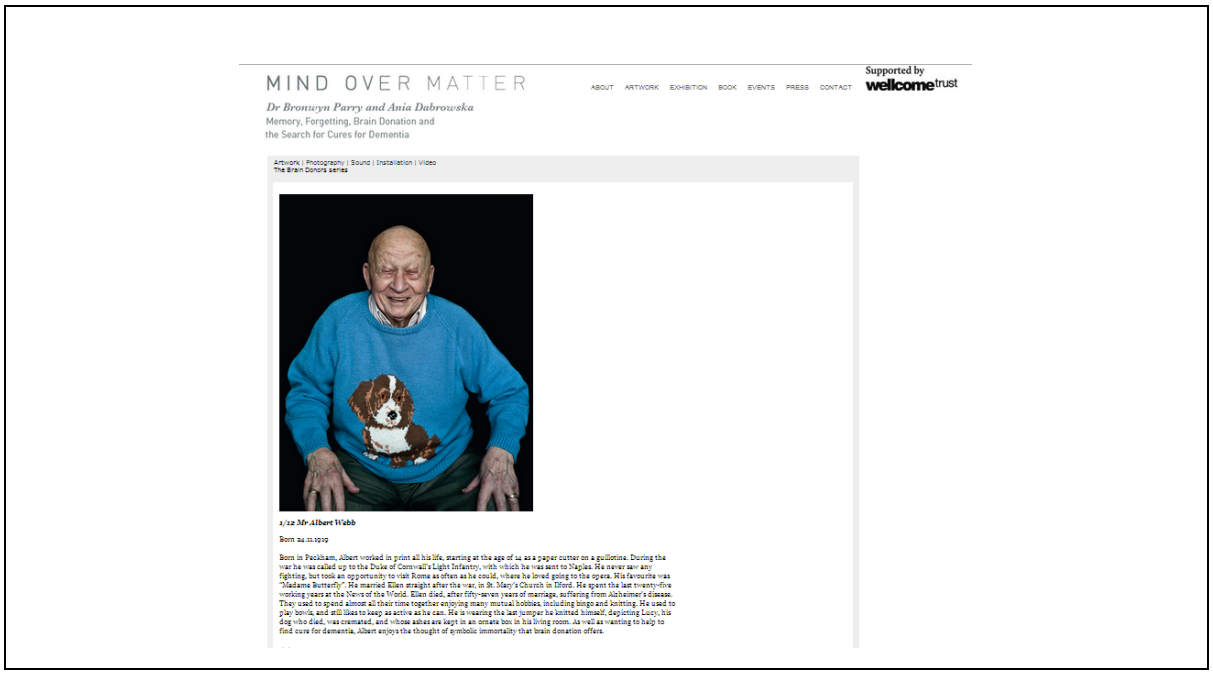


Figure 20: Mind Over Matter
'Memory, Forgetting, Brain Donation and the Search for Cures for Dementia' (Parry & Dabrowska 2011).
http://www.mindovermatterproject.co.uk/donors.html

Sponsored by the Wellcome Trust, this event aimed to challenge the boundaries surrounding both dementia and the protective anonymity of organ donation in the UK. The simple and elegant portraits of participants in the 'Brains for dementia' scheme are accompanied by biographies of the participant's lives. These biographies describe the participant's individual motivations for becoming involved in dementia research through brain donation.

During the same period, in 2011, the Alzheimer's Society launched a series of films and adverts, in collaboration with the NHS and the organisation 'Social Care'. These adverts are linked to

the Alzheimer's Society website, and through key social media websites to the Alzheimer's Society's dedicated channel on the 'YouTube' website. The Society has a dedicated You Tube channel, which acts as a repository for an array of audio-visual content developed and disseminated by the Society. In the 'I have dementia' campaign, the scene begins with the camera drawing in close to focus on the face of a woman. Standing alone, at the centre of the frame the woman introduces herself and says "I have dementia". Focusing on her voice, the woman gives a first-person description of dementia. This stands in marked contrast to the more familiar collective representations of person and carer used in dementia advocacy media. The camera slowly moves away from the figure, who is shown standing isolated on a grey background, accompanied only by her moving shadow.

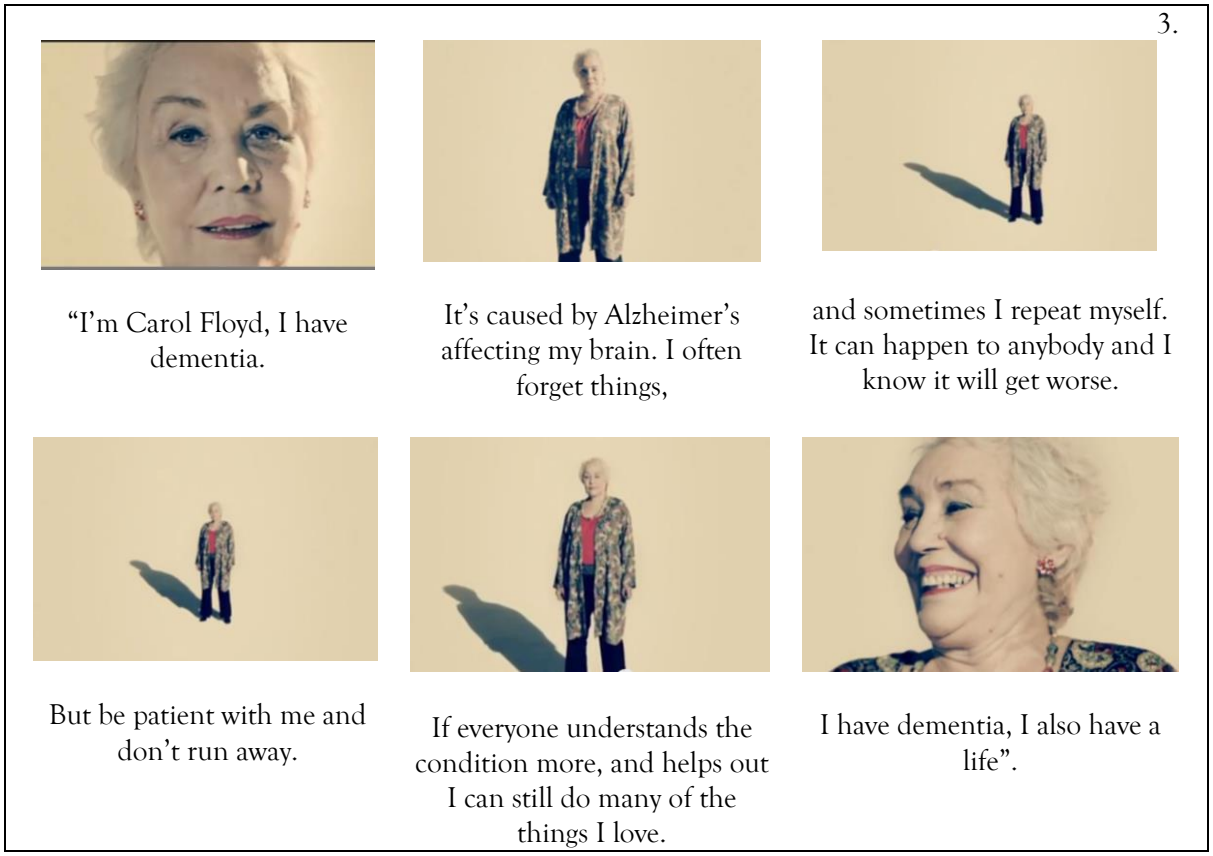


Figure 21: "I have dementia I also have a life" Campaign, Alzheimer's Society (2013)
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2092

Gently the camera tracks back to the face of the woman who says, 'I have dementia, but I also have a life'. After watching this advert, the website provides an immediate link to an accompanying film 'the making of the advert'. The crew describe the advert's intended message.

Ira: The only thing you focus on in this commercial is the person.

Jackie: It gets across the message that people generally back off because they don't understand dementia so we wanted to just mimic that with the camera move.

Ira: You maybe start by shying away from them but you end up as you understand the condition more and then more move back in and appreciate it more. I think.

Jackie: By stripping everything around them away you become less judgmental, so you don't judge so much who they are by their environment

The making of the advert: "I have dementia I also have a life" (Alzheimer's Society 2013) http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2092&pageNumber=2

The distancing motion of the camera is used to illustrate the perceived stigma, lack of understanding and fear which leads to social withdrawal from open discussion and recognition of dementia. The visual rhetoric attempts to persuasively re-engage the audience with the personal identity and life of the participant, albeit accompanied by the moving shadow of dementia. This reflects the personhood and person-centred-care approach which has gained increasing prominence in gerontological studies since the late 1990s (Kitwood 1997, Dewing 2008).

The growing visibility of UK organisations focusing on disease advocacy and research engagement is part of a wider global trend (Epstein 2008). Hypermedia, that is, forms of media which utilise multiple, interconnected modes of virtual and 'real world' communication technologies, play an increasingly sophisticated role in locating and connecting disease awareness in the public domain (Diebert 2013, c.f. Wellman & Haythornthwaite 2008). It is debatable to what extent these are precisely 'new' forms of communication (Wilson & Peterson 2002). Here, the aspect of hypermedia I wish to highlight is its role in creating connections between the public and clinical trials. Hypermedia provides novel means of bridging the domains of science, government and public. For instance, through the ARUK website, I can connect directly with people experiencing dementia from my living room; take a virtual tour of a laboratory; see which research studies are now recruiting; view step by step the discussions taking place about dementia research at the G8 Summit and so forth. Hypermedia provides a constantly developing tool in

the process of making campaigns for dementia awareness and research engagement. Such techniques enable dementia research to permeate the social, scientific and political landscape in new and unexpected ways.

Along with these powerful communication technologies, a central technique has been the use of high profile political, media and arts figures to spread awareness and develop the profile of dementia research. One prominent figure in this move is the author Sir Terry Pratchett, who has been diagnosed with posterior-cortical atrophy. He described his thoughts on dementia and dementia research in a blog for the ARUK website:

> If there is indeed an emerging sense – finally – that we've stopped pussy footing around dementia and can now bear to utter its name, we nevertheless find a cloud of unknowing persists. People read, watch and hear more about it than ever before. They know it's out there. They know it will claim more of us as we continue to age. They fear it.
>
> 'Sir Terry Pratchett – Dementia blog, what's the point of it all', ARUK (2013) http://www.dementiablog.org/terry-pratchett-on-dementia/

Celebrity involvement has become a key way in ensuring the public 'know it's [dementia] out there'. Singers, actors, presenters and politicians, who often describe their involvement within the context of familial care can caring relationships, have become an integral part of the process of conveying both the scale and intimacy of the dementia crisis. The celebrity voice has the power to reach across social boundaries, to engage through media which permeate our everyday lives. Their prominent role within the global economy also enables them to access and cross political and economic boundaries as lobbyists, fundraisers and advocates. Celebrities thus become powerful tools or conduits for both the dissemination and construction of dementia awareness on a global scale. This is a scale which the majority of scientists, carers, patients or advocates have neither ready nor independent access to. The celebrity aura with its grounding in fashion and popular culture provides a very particular kind of access to the public imagination when popularising dementia awareness. Their familiarity, their pervasive and recognisable presence in our lives and our homes, also imbues their role with a sense of proximity and intimacy. Our familiarity with them, and their descriptions of personal and familial experiences of are brought

together to reinforce the familiarity and immediacy of dementia as a political cause. Such narratives play an important role in locating dementia conditions within our sense of community.

The recent Dementia Friends campaign, developed by the Alzheimer's Society and Public Health England, demonstrates the massive scale and complexity of the media strategies being developed in dementia awareness. The Friends campaign aims to increase local awareness of the issues and impact of living with dementia, so that people with dementia-related conditions can receive greater support within their communities. Anne, a retired nurse and a person diagnosed with early-stage dementia, fronts the campaign. We see her speaking about her diagnosis and asking for support for the Friends organisation. At this point, a sequence of images are shown of singers, actors, authors and presenters singing the Beatles' 1967 song, 'A little help with my friends'. Televised during prime-time viewing on national channels and through YouTube, the advert has embedded interactive features. Using the 'red button' on a remote control, the film can be stopped at any point. Clicking on different faces opens up short clips of one of the celebrities or Anne herself describing their involvement in the advert, their experiences of dementia and their involvement in the Dementia Friend's movement. The advert concludes with Anne saying:

"Click here to become a Dementia Friend and find out how you can find ways of helping people like me"

Figure 22: "I get by with a little help with my friend". Public Health England (2014) http://www.youtube.com/watch?v=LfrnWrpPq54

This advert brings together multiple techniques: the first person representation of dementia, media and hypermedia communication, and celebrity advocacy. This demonstrates the

increasingly creative efforts collaborations between government and third-sector organisations to bring awareness of dementia into the public arena.

Creating research responsibility

Having consider the techniques and rhetoric used to create the scale and intimacy of the dementia crisis in the UK, in conclusion to this chapter, I consider in what ways the idea of community is being used in strategic development of dementia research. The strategy of bringing dementia awareness and support into everyday life and creating the sense of a dementia-aware society are visible in the narratives created around public participation in dementia research. Importantly, this participation includes the public not only as supporters, advocates or fundraisers for dementia research, but as potential recruits into research, tissue donation and clinical trials. Being part of an aware community 'at risk' from dementia, engages the public to be part of the solution. Increasingly, engagement with dementia emphasises that the solution to this crisis lies in biomedical research and its promise for future treatments. At a research engagement meeting, during a discussion of research needs and aims, one neurologist emphasised that research requires not only funding, but people to be prepared to participate as research subjects. Research requires not only people who are known to have a neurodegenerative condition causing dementia, but also healthy participants to help researchers understand the processes of 'normal' aging, as well as dementia pathologies. The neurologist made this appeal to the audience of scientists and public participants:

> We clearly need people living with dementia to agree to donate their brains, but we also need people, and this is where *you can help*.
>
> Quote from a neurologist at the Alzheimer Society Research Network Meeting 2012.

As a result the dementia research community is continually being extended. As the above quote suggests, even without a family history or experience of dementia, healthy members of the 'public' are all potential participants. UK citizens are thus framed as experiencing the social and economic impact of living in an aging society, and becoming increasingly tied into the dementia research network. Increasingly at risk from developing a dementia condition, the rhetoric implies

that the public are both invested in, and share responsibility for, working towards a solution. With the simple use of a personal pronoun, 'publics' are no longer an inchoate and intangible 'other' somehow to be accessed or acted upon by science. The public is made into participants, and critically those participants are personalised. As with the portrayal of people living with dementia in the media, research participants are being continually made into 'I', 'we', 'you' and 'me' (Carrithers 2008).

The personalisation of dementia research participants is reflected in a DeNDRoN engagement poster. A young woman in a white coat bends attentively over a coloured petri dish, pipette in hand, microscope at the ready, surrounded by the immaculate, brightly lit white surfaces and walls of the laboratory. Whilst she concentrates on an archetypal act of science the title announces:

Figure 23: Our brains Campaign, ARUK
Observed during a research meeting.

Here the brain comes to represents more than simply its physical matter. It is made into a representation of the skill and potential of the scientific community. The 'public', as supporters, funders, research participants and tissue donors, are framed as essential collaborators and combatants in defeating dementia. The rhetoric harnesses the idea of communal responsibility and the critical co-dependence of science and society. The 'labour' of research participation becomes part of the exchange relationship between science and society (Thorpe & Gregory 2010).

Chapter 6 Making and breaking connections in dementia research.

In the previous chapter I focused on strategies used to communicate the perceived crisis of dementia. Using examples from some of the prominent dementia research and engagement campaigns, I argued that rhetorical language and imagery are used to create mobile and fluid scales of risk in a concerted effort to place dementia and its clinical research at the centre of the public imagination. This is achieved by moving between the macro-scale, using population levels of predicted numbers of the growth in dementia diagnoses which bombard the observer by the sheer scale of the number of people at risk, and at the intimate scale of personal, familial and community experience. The intimate scale draws on familiar social signifiers such as locality, sport and celebrity. I ended by showing how the language and imagery of community are extending into the narrative of dementia research. Increasingly, engagement practices are being used to frame public involvement in clinical research as a relationship. This is a relationship which has mobilised a mutual social and scientific investment in, and responsibility to, the collective battle against dementia.

In this chapter I look at the rhetoric of research and engagement practices which are providing momentum for the restructuring of social and scientific perceptions of, and relations with, dementia and clinical research in the UK. In the first half of this chapter I discuss how research is challenging connections between age and dementias. I link challenge to research which is attempting to reshape social perceptions of age and aging more broadly. I look at how this is taking place in developing the market identity of older people, constructing them as valued actors in the development and consumption of goods. I then look at how this model of public involvement has been extended to clinical research, through the development of Public, Patient Involvement (PPI) initiative, considering the implications for clinicians and researchers. This demonstrates the close strategic relationship between researchers, clinicians, advocacy groups and government in the UK.

Whilst the storms and scales of the previous chapter are highly effective at conveying the urgency of the research agenda; risk can be itself a problematic strategy. Risk rhetoric has the potential to reinforce old stigmas and create new ones. The emergence of a new type of research community

has led researchers and advocates to employ a number of strategies to frame social relations with biomedical research. In the second half of this chapter I look at how highly sophisticated and creative engagement practices use a variety of social imagery to construct the public's relationship with dementia research. I focus on three examples, research participation as: a gift, as an act of altruism and/or as a social contract. What results is a balancing act between risk and hope, fear and trust. The narrative of dementia research is characterise by perpetual attempts to balance one rhetorical push with that of another. These competing rhetorics create an interface at which the dementia researcher community is evolving to be resilient, flexible and responsive. However, these relationships are not without their limits. This chapter concludes with a discussion of the limits of rhetoric, introducing how a research community remains a site of anxiety and contradiction for scientists in the field.

Breaking connections: Restructuring relations with dementia

In developing public awareness and involvement in dementia, research and advocacy groups have become very aware of the stigmas associated with dementia. As explored in chapter two, these associations are long in the making and are deeply embedded in social and historical perceptions of what dementias are and what they do. Stigma was perceived within policy as a core barrier to be overcome. Attempts to understand and counteract stigma have resulted in a process whereby some connections have been made increasingly visible in order to break them. The two associations I found were most often addressed in research policy and practices are two of the now familiar interconnected themes in this thesis: changing perceptions of age and aging, and changing perceptions of dementia as a group of conditions. In this section I look in more depth at the research initiatives which have attempted to challenge and restructure these core themes.

This is not normal aging

> 'Dementia affects over 750,000 people in the UK. It is not a disease in its own right and it *is not a natural part of ageing*. It is an umbrella term that describes a large group of symptoms that are caused by diseases that affect the brain, such as Alzheimer's disease.'

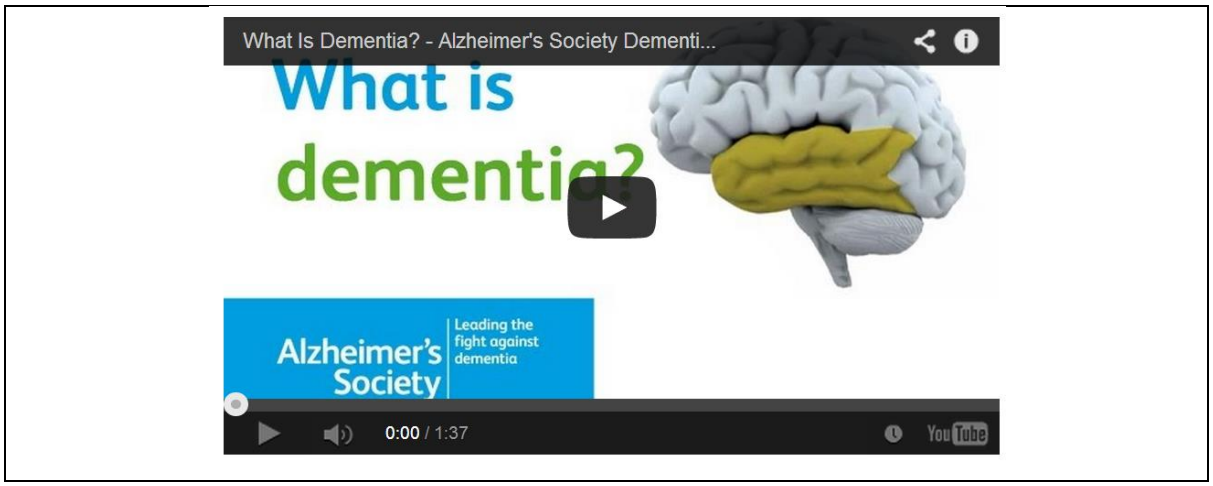


Figure 24: "What is Dementia?"
(Alzheimer's Society 2011)
https://www.youtube.com/watch?v=2mRbQCDeJAc

Conceptualising dementia as 'not normal aging', is an important part of the process of restructuring the association between dementia and age, and reshaping how the public and non-specialist clinicians engage with these conditions. In an Alzheimer's Society information film accessible via their website and streamed through YouTube, Anne Colbert, the Society's Acting Research Communications Officer, describes the key facts about dementias. She emphasises both that dementia is not a disease in and of its own right, and that at the same time it is not a 'natural' part of the aging process either. This is a key statement which was repeatedly emphasised in the public awareness material from the main dementia charities and at public engagement and research events. It performs a number of key functions. It embodies the disease process as an external invader; 'it' is not natural, it should not be there. Corbett emphasises that whilst 'dementia' is caused by a range of different disease processes, and is not, in itself, a disease category, the pathologies that cause the symptoms of dementia are tangible, and can be targeted by scientific research and intervention. This demonstrates the shifting tension which exists between defining and categorising dementia as a disease concept which can be used in raising awareness and promoting research on the one hand and, on the other, capturing the identity of this group of disorders. Corbett's description highlights the diffuse complexity which makes the contemporary use of the term 'dementia' biomedically unsatisfactory.

This dissatisfaction is linked to a second function of the phrase 'this is not normal aging'. The strong association between age and the most common forms of dementias is inescapable but

problematic. Researchers are concerned that if 'dementia' is seen as an inevitable consequence of aging, it becomes naturalised and unassailable. As has been discussed already, such an approach has the potential to further stigmatise these conditions, increasing reluctance to receive or give diagnoses, and to marginalise dementias a valid focus for research. However, the principle narrative of the imminent crisis is that of the increased scale of prevalence due to an aging population. Thus the 'war on dementia', can also be seen to take place at the level of a rhetorical struggle between the need to 'de-naturalise' dementias and reconstruct the disease entity, and simultaneously 'normalise' these conditions, to make them a higher profile and accepted field for research support and recruitment. This tension is suggested in the image work taking place in the following Alzheimer's Society 'infographic':

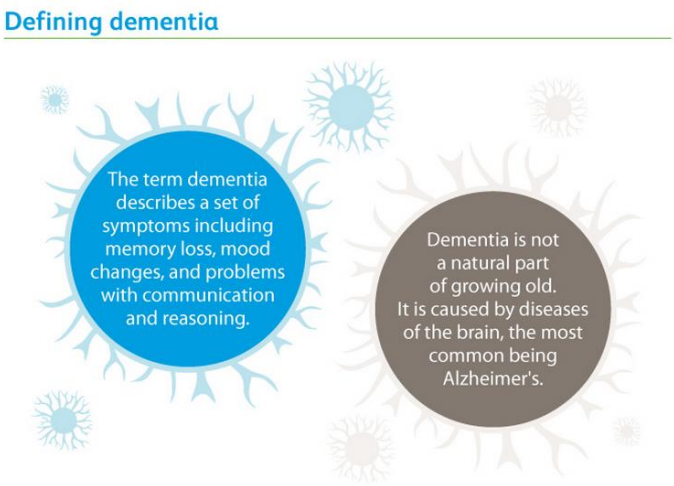


Figure 25: "Defining Dementia"
Alzheimer's Society http://www.alzheimers.org.uk/infographic

In 'defining dementia', the text emphasises again that dementia itself is not a disease. The text is enclosed in and surrounded by unspecified cell-like structures. The different coloured cells might stand for the biomolecular structures involved in healthy brain activity, or the 'unnatural' cell structures which mark the pathogenisis of disease, blocking and damaging neural connections.

These attempts to break the negative association between age and dementias are part of a process of creating biomedically 'good' and pragmatically 'useful' definitions of dementia conditions. This is part of an intensive effort by researchers in tandem with what Epstein has described as para-political advocacy organisations, to 'rewrite the story of dementia' (Epstein 2008). These efforts generate a vast array of images, narratives and metaphors, which sometimes work in synergy and sometimes conflict. This reflects the underpinning uncertainties and contradictions which feature in researchers' discussions about the future of dementia care and treatment.

Changing Age

In reconfiguring dementias as disease entities, the connection with age remains a thorny issue. How can research reshape this association without further stigmatising age or undermining the importance of it as a significant factor in the increasing prevalence of this group of conditions? How can age be made a positive tool in the research endeavour? This complex challenge has led to a particularly interesting, collective research response in the North-East. The Changing Age campaign launched in 2010 was developed by Newcastle University and marks a collaboration between local government councils across the North-East. The university committed itself, across disciplines and departments, to becoming a 'world-leading centre of for aging research' (University of Newcastle 2012). The Chair of the North-East Councils described their involvement:

> We are proud to support this Charter and to play our part in achieving its aims in every community we serve. Whilst we recognise that there will be challenges, there will also be opportunities to be grasped as councils take forward their increasingly important role in supporting everyone, regardless of age, to live healthy, safe, active and positive lives.
>
> Counsellor Paul Watson Chair, Association of the North-East Councils
> (University of Newcastle 2012). North East Charter for Changing Age.
> https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141891/charter-for-changing-age.pdf

The Charter emphasizes the idea of community, and the importance of the relationship between people in the region and the work of local researchers at the university. The Institute of Health and Aging was a dominant partner in this collective. As the title states, the campaign is a bold attempt at social engineering; to change perceptions and associations with age. At the heart of this initiative is a challenge to the association of aging, and more specifically old age as a social and personal 'burden'. This is reflected in this quote from Professor Tom Kirkwood, Director of the Institute for Ageing and Health at Newcastle University:

> Too often, public and political debate has focused on population ageing as a negative issue, a 'burden' to be managed. The campaign we are launching today seeks to change this, recognising the tremendously positive contributions that an ageing population has on society, and encouraging a profound change in attitudes to ageing, informed by facts and not by outdated misconceptions.
>
> Professor Tom Kirkwood quoted in AlumNews (2010)
> http://www.ncl.ac.uk/alumni/news/page.htm?an-ageing-population-isn-t-a-burden-newcastle-university-calls-for-profound-change-in-attitudes

The breaking of the association between aging and burdens, and the reframing of age as 'tremendously positive' and full of 'opportunities' ties this initiative to the wider rhetoric of the politics of aging. As the main image used to present the Charter emphasises, an explicit attempt is made to draw a connection between the politics of age and the politics of race:

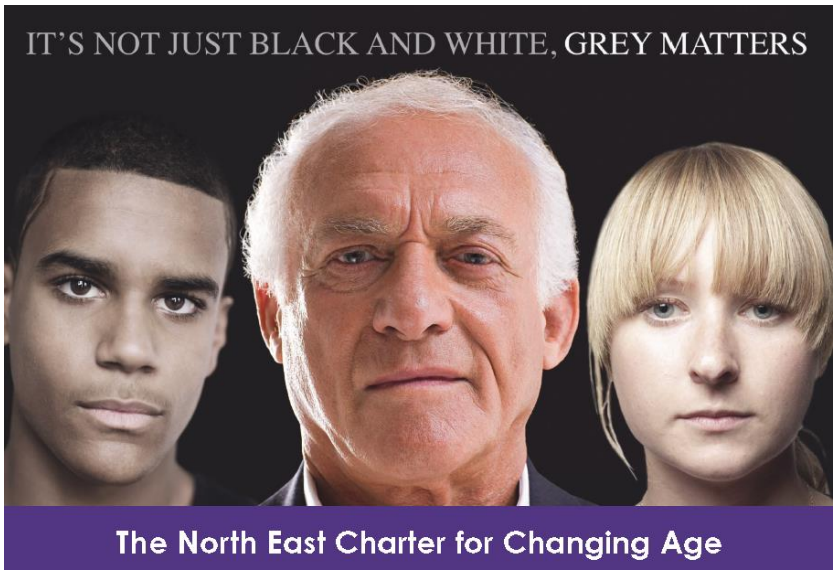


Figure 26: The North East Charter for Changing Age.
Campaign leaflet provided at the Later Life Conference, London (2013)

The inference is that, just as the acceptance of racial diversity and tolerance are signifiers of a 'modern' and 'moral' democratic society, so age should hold an equivalent moral and political status. By making this explicit, the Charter attempts to challenge the deeply embedded negative associations of age which are often perpetuated in everyday public and political discourse. This initiative strives to tackle the casual dismissal of aging issues, and places them at the forefront of

the social and political agenda. Interestingly, science is placed outside this issue, capable of acting upon, but not itself implicated in, the reification of social relations with age.

Biomedicine and science have played an important role in increasing quality of health over the life-course, and thus, the extension of the human life-span. Increasing longevity is hailed as 'one of humanity's greatest achievements' (quoted in AlumNews 2010). This creates both a positive perspective on age and contributes to the heroic identity of biomedical research. As the Charter states: '(I)llness and death have been postponed through centuries of scientific research, ingenuity and perseverance' (2012). The emphasis is on life as valuable, and therefore more life is more valuable. Aging is thus framed as a cumulatively positive process, a resource to be valued, rather than a value stripping, degenerative 'burden'.

The economics of later life

Part of the value of aging is located in its economic value and the potential created by longer lives. Extending the life-span is framed very clearly in the Charter in terms of the neoliberal economy, as an 'economic good':

> Longevity has made, and continues to make, an enormously positive contribution to our economy. Older people are contributors and consumers of products and services, adding substantially to economic growth
>
> The North East Charter for Changing Age (University of Newcastle, 2012) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/141891/charter-for-changing-age.pdf

At the Later Life Conference I attended in London in January 2013, the main emphasis of speakers was on research into the development of better provision and delivery of services, goods and infrastructural resources for older people. These services address not only the provision of health care, but assisted living technologies, legal and financial services, and 'life-style' products targeted at people over the age of sixty-five years. Thus, the needs of a growing older population are framed as having the potential to expand and grow the national economy. One presentation from a researcher working with the Rowntree Foundation on equity release, acknowledged the

need for a dramatic restructuring of the pension system. This is supported by the Charter which suggests that the age demographic and nature of later life has changed to such a degree that age-based exclusory practices which restrict access to work, education and social activities need to be radically reformed. Exclusion is seen as wasting the mental capacity of a growing sector of society.

By attempting to break the association between aging and burden, this research inspired initiative tries to shape later life as a positive time of national social and economic potential. This is demonstrated in the headline: 'great changes=great opportunities' (North-east Charter for Changing Age, 2012). This is in extreme contrast to the rhetoric of storms and tidal waves discussed in the previous chapter. Here research is riding the storm, turning the challenge of aging to the benefit of the nation. As a result, the attempt to make people over the age of sixty-five and research priority takes place within a community which defines value in terms of and individual's capacity for consumption and productivity. As extracts from the promotional material provided at the Later Life conference and the Changing Age for Business programme demonstrate (see figures 27 and 28), it is clear that a particular type of old age is being marketed, one which is active, healthy and prosperous.

The aim of the images above are to challenge the assumption that old age means 'passivity and dependence' (Kirkwood quoted in AlumNews, 2010). However, such images may bare little resemblance to the lifestyle experienced by large sections of UK society across their life course, and the reality for many older people. For many over the age of sixty-five, subsisting on a state pension, living with long-term, chronic conditions such as dementia which require high levels of costly personal care and support, the reality of old age and its challenges cannot be ignored.[35] This may explain why the 'burden' of old age, remains such an intransigent image; aging can be hard. Indeed, on one level it is the burden experienced by older people that leads to growth in the market in health and social care, which is being used to construct their value. Rather than a shift in social attitudes to old age, this movement can be read as a revolution in which aging reproduces rather than alters the dominant socio-political and economic framework.

[35] The basic average state pension was calculated as £118 per week in 2011-2012, rising to £124 in 2012-2013 (Great Britain, Department of Work & Pensions 2012: 4)

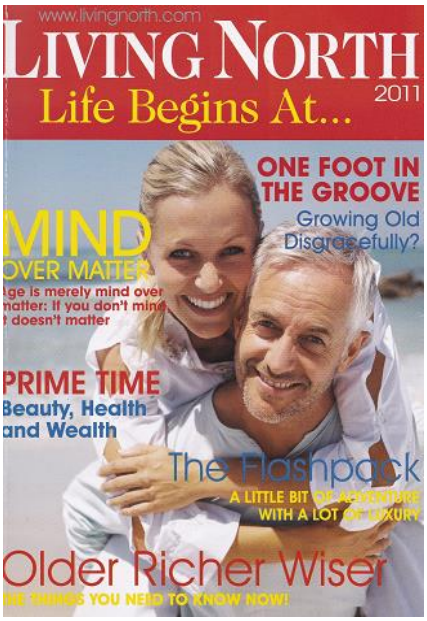


Figure 27: Living North (2011)
Part of the promotional material handed out at the Later Life Conference, London, January 31 2013

Figure 28: "Changing Age for Business"
Later Life Conference, London, January 31 2013

However, it could also be argued that the Charter is making pragmatic use of the dominant political economic framework in order to effect social change. Are researchers simply making best use of the strategic and rhetorical connections available to address a critical and urgent issues of social need? Furthermore, we might ask, given the entanglement of the market in society,

whether a market-oriented approach does not indeed present the best means of acquiring the momentum needed to effect social change for older people who currently experience marginalisation?

> It's a very difficult environment at the moment. There are huge cuts taking place across social care, but at the same time we're very aware of the aging population, it really is a perfect storm. There is minimal marketing focus aimed at the over fifties, and very little understanding of what the over fifties want and need. Ideally we would want to resist the notion of grouping, and emphasise the individual. But we have to work with functional definitions. Newcastle has taken on the role of getting aging and dementia research recognised worldwide. In 2009 we received the Queen's Award, that project was really a result of more than thirty-year's work. Now we want to build a societal theme around aging by pooling our research resources. The Campus for Aging and Vitality combines research with retail. It helps develop business start-ups, and provides access to research for new businesses. My vision for that is that this becomes the new Silicon Valley for aging. The engine that drives that research is the Charter for Changing Age. We aim to break down the barriers around age inclusion by getting companies involved in marketing to the changing demographic, overturning marketing prejudice. Newcastle University has excellent ties and access to older people's groups. Particularly there is a need for research into home living and enabling people to maintain a positive quality of life. There is a great need for collaboration in this space; ensuring researchers and business are in communication. The Institute of Aging and Health and VOICE North [Valuing Our Intellectual Capital and Experience] have been very important organisations. Medicine is core to this, but then again the pharmaceutical companies and the life sciences organisations are central to this also.
>
> Extract from field notes taken during a contribution by a researcher at a roundtable discussion on Changing Age for Business
> Later Life conference, 31st January 2013

As the field note above suggests, for researchers, the move to 'change age' should not be simply critiqued as a cynical or naïve exploitation of old age. Those working within the research systems are aware of this potential reading, and they are prepared to engage with it. As a result, during discussions, researchers often went to lengths to emphasize the sincerity and earnestness of their efforts to change how older people are involved in society and in the structure of research by using the prevailing political-economic framework. By breaking the connection of the 'burden' of age, new connections are forged which value the knowledge older people. By working with older people, researchers benefit from their knowledge and understanding to improve product designs. Although at times this narrative runs close to the boundary of representing older people as a resource for more effective marketing rather than knowledge collaborators in the process of design.

An example of how this engagement of older people has been effective can be seen in the 'The Bench' research project. A case-study from this project was used by researchers to demonstrate how public participation and inclusion could effectively be integrated alongside collaborative connections across research, business, design and manufacturing (see figure 29). The case-study was cleverly chosen as it showed how a simple, common place object such as a bench, could be problematic for older people in unexpected ways. The involvement of members of older people through VOICE North, provided essential knowledge for the design of improved public seating, not only for older people, but as a basic design improvement for wider society. One researcher involved in this project described the design process, and how it informed design and manufacture:

> Participants described that some materials such as stainless steel, were cold and uncomfortable to sit on, particularly when joint pain and mobility were issues. Slick shiny surfaces, such as plastic, favoured for aesthetic, durability and cleaning purposes were hard to grip. This made it difficult for a person to use their arms to help themselves to lower and raise themselves out of seats. The height of seating was often low, and the proportion of seats shallow. Many seats now are designed without backs or arms. This required a person to sit unsupported and made public seating difficult to get into or out of. For those with vision or cognition problems the low contrast colour of commonly used materials made seating

> difficult to see and frightening to negotiate. Seating was also not designed for sitting, but for keeping people moving. In order to feel comfortable and safe moving about public spaces participants reported they needed to be able to take a break, but existing seating provided little relief. There was also nowhere to safely place a bag of shopping or a walking aid in clear sight, and this could be a source of anxiety as a stick, for instance, might fall over, be difficult to retrieve from the ground, be forgotten or stolen. It was also common for seating to have no flat surfaces to lean on or place a drink. For a person using a walking aid, or requiring both hands to safely lower themselves into a seat, this made it practically impossible to engage in the simple act of sitting on a bench to have a cup of tea.
>
> The design combines ergonomic features with aesthetic design and looks little different from seating one can find anywhere in public spaces in the UK. However listening closely to the feedback of participants, the backs are higher and seats curved to facilitate comfort and movement. Seating spaces were clearly demarcated by arms, which had high contrast rubber moulded handles designed for high visibility and grip. These made seats more usable, provided effective support for sitting or standing. The handle design also allowed belongings to be placed securely in front of a person. This was an example of good inclusive design, not just for older people, but generally advantageous.

Extract from my field notes at the Later Life Conference, London 31st January 2013.

The researchers emphasised that the benefit of 'The Bench' project was not limited to those involved in the project who might find the seat better for them. The emphasis is on the benefits of this knowledge exchange for all society. In emphasising the knowledge of older people it does not isolate them as a special group, but acknowledges them as collaborators in the making of an age-friendly environment. This collaboration extends to the companies in the North East who became involved in a range of design-project, to benefit from insightful designs and their market potential. This inclusive role in research and design has been particularly successful in the field of built-environment and technologies of assistance.

Figure 29: The bench case study.
Changing Age for Business. Later Life conference, 31st January 2013

Remaking connections: Imagining 'publics', 'participants' and 'collaborators'

When developing technologies of assistance, design can directly incorporate feedback from members of the public, to produce goods, services and materials which have direct benefits for people's lives. This strategy appears to reinforce the response-mode of research, that is, the For Patient Benefit model which dominates the NIHR. However, how far is it possible for this model to be extended into clinical research, and how is this shaping the relationship between research and the public? This question was partially answered in a discussion of Public and Patient Involvement (PPI) with a research manager at a research meeting:

Research Manager: As partners and collaborators they've been really effective. This year we've had the first real push with the dementia themed call. PPI has helped researchers; it's helped them make successful grant applications. Having them involved as co-applicants or through steering groups has definitely been useful.

Me: Why do you think that involvement has been effective?

Research Manager: How has it been effective? Well I don't know. If you want proof, well we can't really say what difference it's actually made. At the least it's not doing any harm. For researchers and scientists I think it depends. Initially I think there was a delay in how it was perceived. At first it was seen as another 'tick-box' criteria. But I think that depends on the researcher and their relationship with the research network. Some totally do believe in it. One or two people I've spoken with have told me it's really changed how they think about their studies. But, then, being a PPI coordinator you're talking to the converted. Other researchers just really don't think it's very helpful. But it's difficult for the researchers. They have to avoid just instrumentalising the participants, just getting their data so they can publish. The pressure to recruit can overwhelm you.

But there has been a change in researchers, in their perspective, in their work and in the law. When I started running studies, patient participation wasn't all that common. I was surprised by the high-level focus. I was surprised to see it time and time again. It's the last bullet point of the whole executive summary. As long as that drive continues, PPI will be part of it. If it attracts a sufficient amount of business and studies [pregnant pause].

Me: You sound like you might feel a bit cynical about it?

Research Manager: I was cynical. I thought it was a political stunt. But then it's been retained. It's making a difference to research proposals and it's making a difference to their success. PPI is a time consuming process. It takes up a lot of

resources, but I would say it's worth it. At a local level there's no doubt it has helped. It's offering people an opportunity to be part of the processes, and lots of people are taking that opportunity.

I mean it is a political agenda. It is a cynical way of keeping people engaged. But PPI, I really enjoy it and I believe volunteers believe in it. They get something out of it.

I run training sessions on getting feedback. I'm always surprised by how many people come back. I think first and foremost it's a very positive thing. At the same time I do see it as a sophisticated marketing approach. But that's not really a problem; I mean it's all a social good. My thought process is that at some level, we need to be offering something at some level. But I think some researchers are embarrassed by the process. I think half of people struggle with the approach.

I mean, from the perspective of the volunteer, the public, they are on a mission. What they are going through is life-changing. They are constantly trying to make sense of it, to turn a negative into a positive by talking with and teaching others. They come out of it with something a bit more positive. It's kind of the personal benefit of a tragedy that can't be escaped.

I jump at the chance to talk, to interview, to do questionnaires. People need to talk, to rationalise and get things off their chest.

Me: Would you want to take part in a trial?

Research Manager: In trials? I think it depends on the situation. Taking part in the trial … there's the whole placebo effect. I guess I don't want to think about it. I wouldn't want to think about a situation of degeneration and death; I mean there's such a lack of understanding about dementia and mental health. I have a friend, he was a clinician who developed MCI (mild cognitive impairment), his wife is now his carer. I was talking to him on the phone and he sounded fine.

> You know he was high-achieving, really career-driven. But then a couple of times we met and he was really struggling. It was incredible, it was so real.
>
> Extract from an interview with a research manager 2011

This dual view of public involvement was further evidenced in government health policy literature:

> Direct involvement of the public in research, both as research participants and more actively in the processes of planning and commissioning of research and in the effective translation of its message … Such messages should utilise new media/social networking and professional communications expertise and be carefully targeted.
>
> Ministerial Advisory Group on Dementia Research: Headline Report June 2011: 9-10.

The work of PPI attempts to find new ways of forging connections and relationships between 'publics' and researchers. PPI is, broadly speaking, about making and sustaining the connections which give members of the public and patients a stake in an emerging dementia research agenda. As the above interview with a research manager illustrates, these connections can be viewed in a variety of ways. These reveal the multiple ways in which scientists imagine the 'public' and understand their role in, and relationship with, science.

On the one hand, PPI marks a change in the practice of science at the legal and bureaucratic level of the state. As has already been discussed in the UK context, PPI has been enshrined in clinical research through the gatekeeping role of the NHS R&D and REC processes. The REC application requires researchers to substantively demonstrate how they have, or intend to, include public and patient participants in the planning and development of research protocols. Perhaps, just as importantly, if public participants were not included, a researcher may be asked to explain and justify why this is the case. The REC process thus becomes impossible to negotiate without acknowledging the role of the 'public'. The necessity of this process fuels the greater

interdependence between researchers and interstitial groups such as DeNDRoN, and parapolitical organisations such as the Alzheimer's Society and Alzheimer's Research UK who often broker access to existing public and patient groups.

PPI has also become increasingly integral to the high priority concern around the process of recruitment for clinical research. Engaging with PPI in project development, facilitated registration on the UK's Clinical Research Network Portfolio (UKCRNP) which records every NHS approved clinical project. Being part of the UKCRN Portfolio facilitated access to the Recruitment and Feasibility Tools (RAFT) developed by DeNDRoN to identify potential problems in a project and address them early on (Great Britain, Department of Health, Ministerial Advisory Group on Dementia Research 2011). DeNDRoN could then support researchers negotiating access to tissue samples and aid in the process of recruitment, through the newly developed and growing neurodegenerative disease register. The regional groups at DeNDRoN were working hard to strengthen ties with local PCTs, through which clinicians were encouraged to ask patients to join the register early in the process of diagnosis with dementia. The register enabled researchers to access patient data and contact information for people with a specific form of dementia who had already had an opportunity to consider research involvement and expressed a willingness to participate. Access to the UKCRN was possible through the Alzheimer's Society website. The advocacy charity thereby became a means of enabling an interested person to become a potential research participant, or collaborate in PPI in future research projects. As this description shows the combination of changes in research legislature with the development in the research infrastructure and collaboration with patient advocacy groups created a highly entangled set of strategic connections to facilitate access to people and data. PPI can therefore, on one level, be viewed as a tool of research, a means of negotiating existing research bureaucracies, achieving recruitment needs and accessing tissue and bodies for research. In this sense, PPI is a political and strategic act carried out in order to maximise the scientific-good and in which the public, although engaged, remain secondary to the primary goal of extending the scientific agenda around dementia. However, for some, PPI was a further unwelcome extension of bureaucracy into research practice. It was seen as a time- and resource- consuming political act which detracted from the actual process of research, conflicting with the skills and demands of researchers.

For other researchers, the presence of lay people in decision-making panels on project funding and research priorities was more than a passive distraction. Their contribution had the potential to actively threaten the integrity of the scientific process. Following the 'deficit model', some researchers felt public participants lacked the knowledge about science to give an informed opinion about research design, particular in relation to basic science (cf Bucchi & Neresini 2007, 2010). PPI groups were understood by its detractors to be primarily interested in outcome-based research and principally the development of treatment which would directly benefit recipients. In this framework, the public are perceived by researchers to be acting as 'future users' and 'consumers' of the products of research (Lezaun & Soneryd 2007, Mohr 2011, Thorpe & Gregory 2011). For some researchers, this approach generated anxiety that PPI had the potential to drive science in directions which might not benefit the wider dementia research agenda. The concern is that limited scientific understanding is not simply a deficit but actually a question of whether publics reason in the same way as scientists. Does the reasoning of public and patient participants fail to embrace to the same objectives as the scientific agenda? However, constructing the public as consumers of clinical research aligns more closely with the response-mode science apparent in the Changing Age for Businesses model. Here, the involvement of patients and the public becomes part of the process of marketing research to the public. In short, PPI creates a market for science that the user can invest in.

In this section I have described the tension that exists when PPI is incorporated into attempts to extend knowledge about dementias. Critics see PPI as driven by the commercialisation of science and therefore a threat to scientific integrity. Advocates do not see PPI in terms of producers and consumers, but as a way of enlisting collaborators or 'co-applicants' into clinical trials. The role of publics and patients is presented as making the science both more successful and more socially robust, thereby becoming both a scientific and social 'good'. This presents a scientific understanding of public involvement which contains what Irwin describes as 'tensions, shifts in emphasis and partial contradictions' (Irwin 2006: 301). In the next sections, I explore how the quest for public involvement draws on rhetorics of gift exchange and mutual interest in an attempt to give the public a sense of integration in the dementia research community. In contrast to rhetorics around risk and adverse events described in the previous chapter, this approach to ageing and dementia effects a kind of normalisation of dementia. Dementia becomes a manageable and targetable condition one that medicine and research can act upon it - part of

everyday life in a re-configured version of what it is to age well in contemporary society. This is achieved through an engagement process which attempts to form new kinds of social contracts between science and society.

Dementia engagement and science as a social good.

In attempts to embed and normalise dementia and dementia research within UK society, what I observed was not simply researchers having to spend more time engaging publics and participants but also experimenting with different styles and media of communication in order to create new forms of intimacy between scientists and their publics. In this section I describe: 1.) the pervasive and everyday nature of such engagement strategies, 2.) how engagement images are used to capture ideas of hope, potential and community and 3.) how this has become the basis for thinking about science as a social good in contemporary society. I then conclude by suggesting that, whilst rhetorics are immensely powerful and useful in this social-scientific contract, they are continually under tension in dementia research from the anxieties which result from this relationship.

The pervasive and everyday nature of engagement strategies

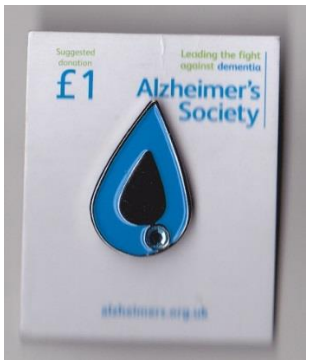


Figure 30: Alzheimer's Society pin

On a Friday afternoon I went to my local bank to conduct a transaction. By the cashier was an Alzheimer's Society campaign stand. For the donation of a pound you could be supporting research to help understand the 'cause, cure, care and prevention of dementias'. I gave a pound and in return I received the small blue and silver, tear-shaped pin pictured above. Later I would visit the cash machine outside a Tesco store, which announced the organisation's commitment to the Alzheimer's Society, and how I could use my transaction to donate money to help support the future of dementia research.

Having donated to the Society I became the recipient of regular postal updates on their research and their on-going campaigns. These told me not only how to support the Society, but how the financial donations might be used within the research process. Explicit links were continually

made between support for dementia awareness and support for research into conditions which caused dementia. In regional events such as The Alzheimer's Roadshow, the Alzheimer's Society and Tesco collaborated to bring regional researchers together with local people and 'potential recruits', to explain and discuss the development, findings and potential applications of their research.

Figure 31: Alzheimer's Society fundraising for clinical trials

As part of my ethnographic engagement with the dementia research community I also earlier that week, 'liked' the Alzheimer's Society and ARUK on Facebook. As a result most days my 'wall' provided regular updated posts on campaigns and fundraising events, research developments, or the opportunity to listen to podcasts of people's experiences of dementia. I listened to a celebrity ambassador describe her experience of the mood swings and personality changes which accompanied her mother's development of fronto-temporal dementia. Creating such daily pockets of dementia awareness result in what Amit and Rapport have called, 'mundane daily opportunities for consociation' (2002: 4-5). In other words, there is a pervasive and low-level exposure to the national dementia strategy whose evolution I have described in the earlier parts

of this thesis. Encounters in one's local bank, on public transport or in the supermarket, are part of a highly coordinated strategy to respond to what the Prime-Minister's office has described as 'the dementia challenge', that is, part of a programme which aims to make the UK a 'dementia friendly society' and a world leader in research.

Brains are good to think with: connections of potential, hope and futurity

In their efforts to bring the public into the research network by means of the everyday, researchers used an intriguing degree of creativity. 'Lion's Face' a nationally performed opera was based on the experiences of researchers and people with dementia (figure 32).

Figure 32: Promotional banner for the Lion's Face opera Northern Stage (May 2010).

During its performance at the Northern Stage, DeNDRoN North-East helped to coordinate an exhibition in the café of MRI and cellular brain images (figure 33). A 2010 funds and awareness-raising project around brain injury associated with Bristol University's Clinical Research Imaging Centre, invited people to, quite literally, knit their own neurons for an exhibition. At each of these events, what is clear that centre stage is the increasingly iconic and readily available image of human brain matter.

Having talked with researchers about their use of imaging techniques in the laboratory, I was intrigued at how these highly complex and sometimes contested forms of imaging were being used to facilitate researcher-public interactions. In a crude play on Lévi-Strauss' (1964) famous dictum, we might ask why are 'brains are good to think with'? By this, I do not only mean that we think with our brains, but that the image of the brain functions metaphorically and metonymically in dementia engagement. It becomes a way of representing patient and research

communities, as well as enabling them to talk to and connect with one another. In short, as Joyce observes through an exploration of brain MRI, the brain is a powerful, fluid and pervasive symbol which brings these communities together (Joyce 2005).

Figure 33: DeNDRoN "Brain Arcane" Exhibition.
Northern Stage (May 2010).

The use of readily recognisable images of the brain draws attention to the innovative potential and authority of contemporary biosciences and biomedicine. Such neuro-images signify the capacity of science to exteriorise that most complex of organs, the brain. This is an organ which, as I examined in the second chapter, has become increasingly associated with the nature of being human, and the makeup of the person. The image of the brain is associated with intelligence, personhood, and the not-yet understood potential of the brain/mind. The complexity of the brain is also part of the stigma and fear related to dementia conditions, which are portrayed as an ultimate threat to the personal, social and biological lives of those affected. Like biological images of the gamete or the dividing embryo, images of the brain, uncoupled from the body and made visible by science, carry this message (cf Franklin & Roberts 2006, Franklin & Ragone 1998). In this case of dementia research engagement, whether such images are scientific, animated, stylised or even knitted, these associations connect different worlds in order to fashion a research community.

This image-work aligns varied representations of the brain with the immense possibility of cutting-edge science. Indeed, such is the power and intrigue captured by these representations

that a successful strategy for recruiting people to trials has involved offering participants a copy of their brain scan to take home. The power of the image is linked back to the power of the appearance of objectivity which is contained by the visual in scientific communication, the idea that 'seeing is believing' (Daston & Galison 1992, Delahanty 2010). Thus, during a presentation to the Alzheimer's Society's 'Friends of Research', a researcher gave an account of the benefits of structured behavioural interventions for people with early stage dementia. She focused on the interventions and their effect on the quality of life and on the cognitive scores such as participants MMSE. At the heart of her presentation were a series of functional brain scan images. In the presentation the researcher paused:

> Well I don't understand the science, you'd have to ask the medical physics people on the team, but this shows us that for a number of people brain activation improved following people's participation in the trial, which shows us good evidence that the intervention worked.

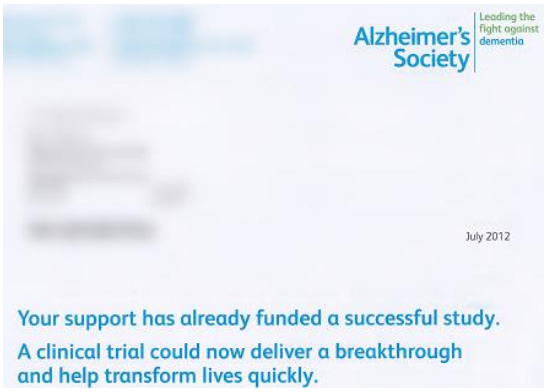
Both the researcher and the audience were required to have faith that the brain images supported the behavioural and patient-reported data the researcher described. The images were presented as confirmation that there had been an empirical and observable change in brain activity which confirmed what the people who took part in the trial reported and demonstrated in their behaviour: lower depression, higher levels of functionality, and improved scores on cognitive tests. She herself was not a specialist in brain imaging and therefore could not give a detailed interpretation of what the images showed. However, the bright blue, yellow and red shapes on the scans, were used to support the inferences she made from the measures she felt comfortable explaining. The images were not therefore, in this context data, rather they had become a means for the researcher to bridge the complexity of neurobiology and neural-plasticity and brain functionality in a talk to a non-specialist audience. The researcher did not need to explain how the image demonstrated changes in function, or how benefit was calculated across the group. What the images achieved was to reinforce and make concrete the core message: The intervention was validated by an objective and technological eye, and therefore had potential as a therapeutic strategy for people with early stage conditions causing dementia symptoms.

What is pertinent here is the extent to which brain images seem to capture the imagination of scientists, funders and 'publics' alike, and become a shared totem in 'defeating dementia'. They feature in photographic and brain image data exhibitions, in operatic events celebrating dementia research, in working with local dementia patients and regional 'heroes' to raise funds for new imaging equipment. Sometimes poignant, sometimes flamboyant, the visual element of brain-imaging and memory lent themselves to creative cultural representations which could permeate across social domains, forging relationships with the public as potential future research participants.

Thus images of the brain, become what Star describes as a boundary object (Star 1989, 2011). Boundary objects do not merely denote objects which are open to plural interpretations and flexible associations, although these are essential traits. Rather, such images enable researchers and publics to co-ordinate their efforts, even though they are working with different kinds of knowledge interests in and understandings of dementias. The knowledge being negotiated might be between differently situated participants in the research process, a patient with direct and specific experience of the impact of dementia on their life, a researcher concerned with recruitment and retention rates, or a policy maker trying to define priorities for future science. Brain images can therefore be seen to mediate complex collaboration networks in dementia science. Such images have different meaning and utility for different actors at different levels and across different contexts.

A key aspect of this capacity for multi-layered, multi-scale definitions is that it can contain the idea of the future potential of research. The future capacity of science is a key part of the public engagement rhetorics which surround dementia research. This is reflected in the Alzheimer's Society material in figure 34. Here the images of blue and white pill capsules, the colours favoured by the society, are used as a representation of this future 'treatment'. What that treatment may be, and in what manner it could be physically delivered to the patient are unknown. The image of the 'pill' here, like images of the brain, is again used to cross boundaries, having the creative productivity of the self-evident yet undefined concept (Star 1989, 2010).

2012



2012

2014

Figure 34: Marketing a cure: the 'pill' as a representation of hope.

The image of the pill neither asks nor requires explanation, rather it collapses multiple associations for the multiple stakeholders involved in research. The pill condenses patient and public hope for treatments along with the need for research to find economic, governmental, scientific and public support. Without this support it would not be possible to continue the work which will make the realisation and implementation of a future of treatment possible. In these examples we see the crucial use of tentative auxiliary verbs 'could' and 'might'. Such pervasive hedging, and subjunctive language denies certainty whilst promising possibility. Yet, the message conveyed in these examples reinforces the certainty that science, like hope, will always be needed. Thus science strengthens itself as an inescapable and unending necessity. Like the approaches of Bloch (1986) and Miyazaki (2004), the method of hope here is an essential part of the rhetoric of scientific engagement. Hope captures potential in action whilst suspending the need to realise a certain outcome. The significant difference here is that hope, potentiality and community are being enrolled in, and made to work within a framework of neo-liberal values.

These examples demonstrate how public engagement becomes part of a process of reshaping, not only the researcher, but also re-positioning the public in relation to clinical research. This move reflects a shift in governance and what constitutes a responsible science and, moreover, a responsible, scientifically-engaged citizen.

The rhetorics of brain donation and research participation: altruism and gifting

Enrolling the public in a dementia research culture is not simply a case of bombarding society with an indiscriminate, ever-increasing volume of images of dementia and its research. Here, I examine the social framing of the promotion of dementia research participation. Using the example of brain donation for dementia research, I reflect upon the idea of participation as an altruistic act of gifting, or what Simpson refers to as 'corporeal charity' (Simpson 2004). In the discourse of research participation as gifting, participation becomes an extended moral act underpinning a generalised exchange. This is an exchange which takes place between the participant and wider society, and in which the scientist is located as the caretaker or broker of the transaction. I argue that this framing of the research exchange locates clinical trials in a novel social contract between state, market and society.

The framework of the gift in tissue and organ donation and human participation in research, is dominant in post-war European biomedical research policy (Titmuss 1997, Waldby & Mitchell 2006). This rhetorical framing is based on the principle that research participation, like other kinds of tissue donation, must be free from coercion, manipulation and monetary gain. The individual makes a free and informed choice to donate their time and their body. In other words, it is a gift freely given. However, as extensive discussions of human organ and tissue donation have demonstrated (Waldby & Mitchell 2006, Waldby 2014), such 'gifts' are complex, socially layered artefacts and events. In Mauss' terms these layers form the 'spirit' of the gift (*hau*), which evoke unspoken ties and promises of future reciprocation (Mauss 2002). In the donation of parts of the human body, both living and posthumously, these ties and the expectations they form develop within distinctive cultural traditions (Simpson 2004). As I discuss below, where the gift involved is from the human body, for example a human brain pledged for Alzheimer's research, the layers of complexity become even deeper as concepts of biology, personhood, and identity interact with notions of exchange and value.

In Miyazaki's analysis of Fijian gift giving, he does not focus on the 'spirit' of the gift or the ties it creates. Rather Miyazaki is interested in the state of atemporal suspension created by the narrative of the gift. He uses the concept of hope to capture the anticipation but not the certainty of future reciprocity. Hope, Miyazaki argues, can usefully be seen as 'a common operative in all knowledge formation' (Miyazaki 2004: 9). As I discussed in relation to role of boundary objects in dementia science, the gift of research participation is not reciprocated by actualised results and treatments, but a future of hopeful possibilities. I argue, that the way in which scientific engagement and collaborative knowledge work in dementia research has developed relies heavily on this fluid and dynamic suspension. This suspension is evoked by the idea of participation as a gift given by the patient given to and valued by science and society. This notion of participation as a gift predicated on the suspension and future hope is articulated in my interview with the research manager (see pages 173-175), who suggests that participation in dementia research turns 'a negative into a positive'. Whilst there may be limited benefit for the participant themselves, the opportunity to contribute to potential future research and treatment development creates 'personal benefit of a tragedy that can't be escaped'.

The Brains for Dementia Research initiative illustrates how the posthumous donation of the human brain carries complex ties of gifting and suspended expectation:

> **Why do people donate?**
> Dementia can overwhelm peoples' lives
> For many, signing up to become a brain donor can help reduce the helplessness they feel in the face of this condition.
> People often want to take this step as a personal and practical contribution towards research that will uncover new ways to treat and prevent dementias.

Extract from the Brains for Dementia Research leaflet, provided at a DeNDRoN PPI Meeting (2012)

At this point, I want to briefly return to the 'Mind over Matter' Exhibition in 2011, which worked with the Brains for Dementia Research campaign, donors and the Wellcome Trust to

examine and make public what it means to donate a brain. The organisers have produced a website, in which participants describe why they made the decision to donate their brain. These appear alongside the participant's photographs, names, narratives, dates of birth and where appropriate the date of their death.

'As well as wanting to help to find a cure for dementia, Albert enjoys the thought of symbolic immortality that brain donation offers'
Mr Albert Webb

'Beryl and Erick decided to donate their brains to CFAS because both of her sisters suffered from dementia and they wanted to do something to help in finding a cure for it'
Mrs Beryl Foreman

'Conscience is the only reason she decided to become a brain donor'
Mrs Betty Munns

'She and her husband decided to become brain Donors simply to help "other folk'
Mrs Brenda Buck

'He would like his brain to be used to discover cures for diseases such as Alzheimer's because he thinks, that "losing memory, not knowing where you are, not knowing who you are, is a terrible thing". He would like to be remembered for trying to do his best for the human race'.
Mr Eddie Holden

Mind Over Matter: Memory, Forgetting, Brain Donation and the Search for Cures for Dementia (Parry & Dabrowska 2011).
http://www.mindovermatterproject.co.uk/donors.html

The participants' explanations, and in turn the message conveyed by the project, combine the sense of hope and possibility with pragmatism and the suggestion of wider social responsibility. There is pragmatism in the idea that there is an immediate reward in the sense of an increased sense of personal and moral value. The idea that bad deaths can be made good is woven into evolving biotechnologies and has become part of a cultural cosmology in which science offers the

possibility of escaping the inescapable (Simpson 2001). Our classic image of being diagnosed with dementia has become so frightening and the grieving process so painful and prolonged that dementia has indeed become an archetype of the 'bad death'. Research participation, and in this case brain donation is seen pragmatically as an opportunity to turn something bad, in to something good and to find value and usefulness in a disease which threatens to erase a person's sense of social value. This need to 'do something', frames research participation, not only as an outward, focused act of altruism for a society of strangers, but also a personal and familial act of resistance. As the following Facebook post from the Alzheimer's Society suggests, whilst dementia engagement and research involvement cannot resist the disease, it offers the 'opportunity' to suspend the devaluing nature of the condition.

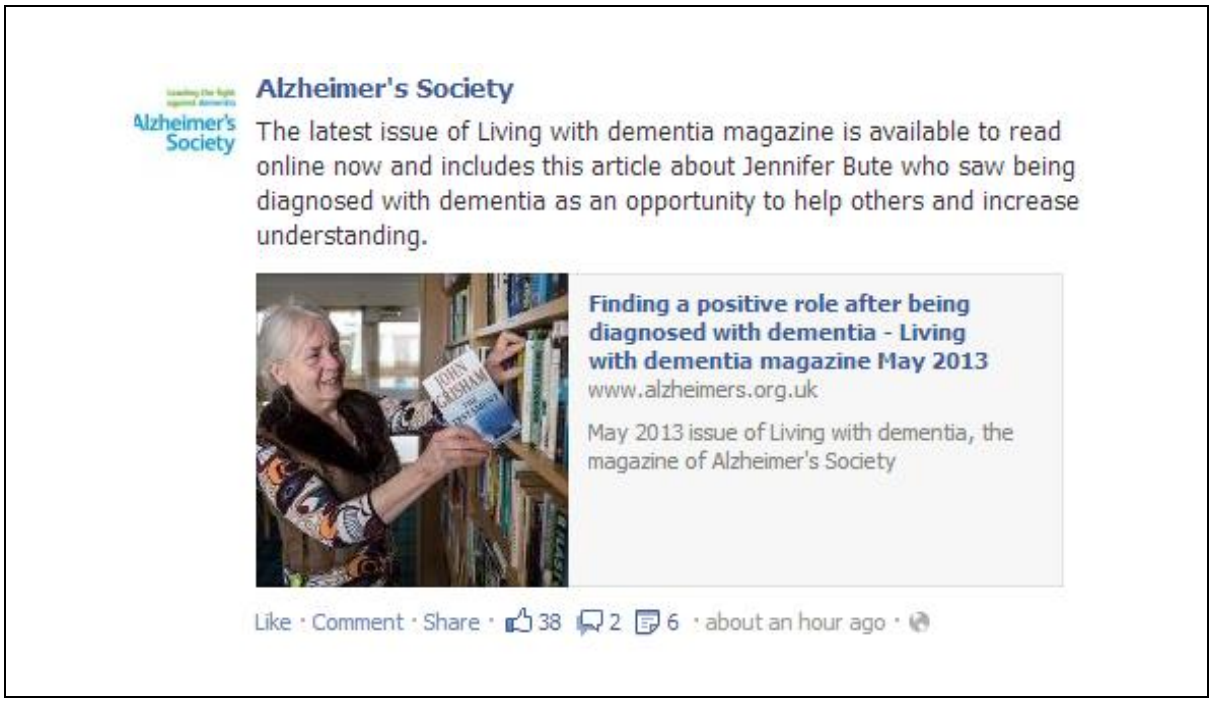
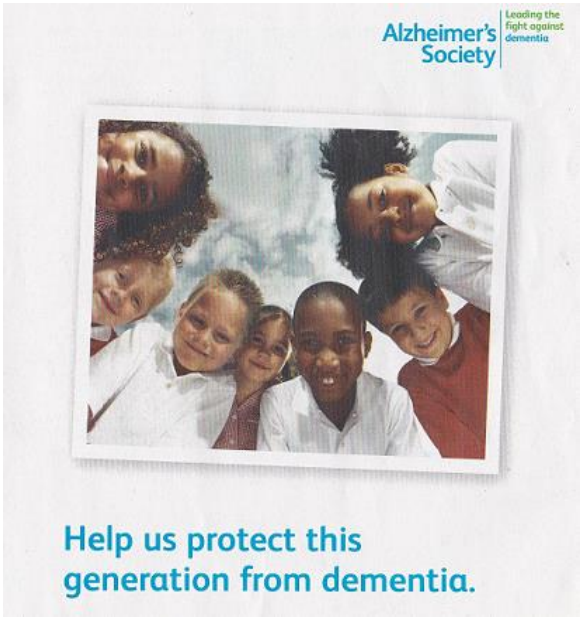


Figure 35: Social media framing research engagement as altruism.

The value that is gained from participation in research is located in the potential for the benefits of future knowledge to improve the lives of "other folk". The idea of the benefit to an anonymous unknown 'other' is central to the official ethos of organ and tissue donation. Brain donation is an act of altruistic social good. However, at the same time references to the potential that this act may help future friends and family, mobilises the idea of a personal, posthumous legacy. This is evident in narratives which use the participant's kinship ties, and specifically future kin (for

example, the grandchildren they don't yet have) to encourage engagement with the research supported by the Alzheimer's Society.



Help us protect this generation from dementia.

"Please help us make sure dementia doesn't exist when they grow-up
Help us fund research into a cure for tomorrow and provide the best care for people with dementia today
We must protect future generations from this devastating condition"

Figure 36: Mobilising kinship and futurity to support dementia research.

If in Miyazaki's example of Fijian gift-giving, the ritual process is oriented to evoke the 'hope of God's blessing' (2004: 8), dementia engagement in the UK evokes the blessings of science to improve the quality of our later life, and future lives. These shared hopes connect UK science and scientists to emerging notions of civil society. As defined by Cohen and Arato civil society is 'a sphere of social interaction between the economy and the state, composed above all of the intimate sphere (especially the family), the sphere of associations (especially voluntary associations), social movements and forms of public communication' (1994: ix). In the context of the current decentralisation of the welfare state, Powell argues that, 'virtue and welfare' have become defined by 'individual agency and personal responsibility' (2013:32, cf Powell 2007). A logical corollary of this view is that in the interplay between state and society 'citizens contend for power through society in the pursuit of civic virtue' (Powell 2013: 6). What I observed in the development of public engagement strategies were scientists and advocates contending for power and resources, using the language and rhetoric of civil society to enrol the public into a community of research

Viewing the rhetoric of dementia engagement through the analytical framework of hope and the gift, two further rhetorical themes emerge: a state of perpetual suspension and possibility, and an ongoing movement between the individual and society. In this dynamic context, the scientist or the researcher becomes the caretaker of donated time, tissue, bodies and resources and the facilitator of public involvement in science.

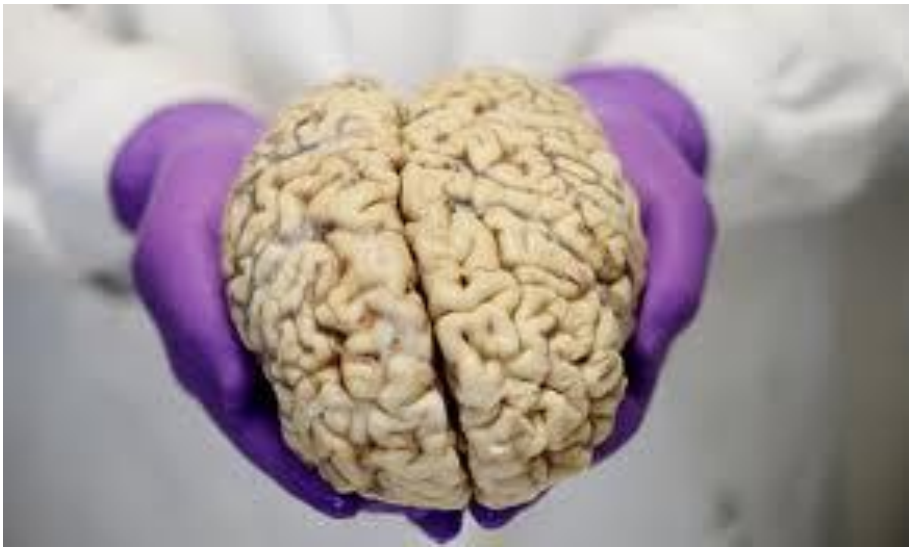


Figure 37: 'Our brains in their hands' campaign.

A fragile, exposed human brain, is held carefully in the sterile, purple gloved hands of an anonymous white coated scientist. The headline 'Our brains are in their hands'. What message does this convey? Science has its hands on our brains? It can cross the boundaries of the body? It has powerful access to our sense of self, our personhood, and our biology? The brain becomes a manageable artefact, a public artefact upon which science can act. The scientist is taking responsibility to protect this fragile object, and we are bound to them in our hope and trust.

Extract from field notes at the DeNDRoN North East Research Network Event (2012)

As the image above suggests, a central part of the relationship between researcher and participant is a sense of trust and belief in the role played by researchers and the messages which convey the

idea of science as a social good. These messages play heavily on the idea that a 'cure' for dementia must exist, even if it is locate in the future. Science merely requires the time, resources and ongoing public support and involvement in order for it to be found. Therefore, as part of a cyclical logic, clinical research participation becomes integral to both the rights and duties of the modern citizen. The impact of public-scientific engagement thus crosses the formal boundaries implicit in the idea of a public understanding of science. Dementia research both uses and has become permeated by novel forms of social interaction. This kind of engagement entangles people in shared notions of hope, responsibility and trust in dementia research: as citizen, as scientist and as participant.

The limits of rhetoric

In this chapter, I have explored some of the rhetorical strategies in dementia research, engagement and awareness campaigns. I have shown how such campaigns are part of the process of remaking negative perceptions of the association of dementia with 'normal age' for which research has a limited medical capacity to intervene. Both research and non-research contexts are used to consolidate a sense of collectivism and collaboration between the scientific community and the general public. This approach uses a range of rhetorical moves which connect research and research participation with the idea of civil society and uses a dynamic framework of hope, potential and trust. Dementia research is thus suspended in a state of continual emergence and possibility.

To conclude, I want to reflect on the limits of rhetoric in the campaign for a socially embedded dementia research agenda. Far from a campaign delivered *fait a compli*, this process of research engagement is constantly changing and adapting. As the growing network of connections between researchers and their publics expand, there is greater potential for information to flow against the grain of power, that is, not from scientists to the public, but from the public commenting upon the work of science. It is therefore useful to think of civil society as a 'communicative space' located between 'competing forces' in which each group, researcher, public participant, policy maker, and industry representative tries to bend 'the other' toward their particular interests (Powell 2013: 5). This encounter makes for a reflexive negotiation between science and society. The ARUK advert illustrated in figure 37, suggests that we should

place ‘our brain in their hands’, but equally, it would seem, we should be aware of the extent that their hands need our brains.

Drawing on Miyazaki’s development of the concept of hope I have suggested that suspension plays an important rhetorical role in sustaining the value of science in-spite of uncertain results and complex processes. However, this places the social-scientific relationship under continual tension. This tension runs between hope and trust in the scientific process and expectations for science to create tangible products. This is a tension which is not always easy for scientists to manage and negotiate. With the increasingly public nature of dementia science, and research participation championed as a ‘social good’, public responses to science cannot be wholly hidden and ignored. As a result, there are limits to the power of rhetoric to engineer social response and action in relation to science. In the chapter that follows I examine the constant process of pull and push, persuasion and dissuasion taking place in the relationship between dementia science and the UK public. I explore ethnographically examples of when these contradictions and anxieties bubbled to the surface. In this volatile and emerging context, I demonstrate how researchers use the fluidity of scientific potential to play with the image of science, allowing them to sustain the boundaries of their scientific authority, whilst attempting to use the notion of a social-scientific community.

Chapter 7 Anxieties, contradictions & expectations in dementia research

In the previous chapter I discussed the communicative strategies developed between research and research advocacy groups. I argued that these strategies aimed to consolidate the relationship between the wider public and dementia researchers in the UK. This work formed part of a structured research agenda which aimed to de-stigmatise dementias, increase rates of early diagnosis, and encourage participation of both patients and healthy participants in research into dementia causing conditions. As a result of these foci, the public have become an increasingly integral part of the dementia research agenda, and opportunities for research engagement, education and awareness have multiplied at an impressive rate. I observed this at many of the meetings and events I attended and researchers described both the benefits and pressures this approach to science created for them. In this chapter, I use ethnographic examples to examine the tensions scientists' describe in their work. These encounters I have described as anxious conversations. They demonstrate the degree to which experimental health research involves a relationship between social, political and scientific domains which is not always clear.

Having described these conversations I then go on to discuss three main themes around scientific anxiety in dementia research: how to define good science? how to manage the issues raised by scientific complexity? and how to work with public expectations? I describe how scientists' responses to these moments of anxiety and conflict lead to cyclical arguments which defend the boundaries of scientific authority but then go on to argue for their need for increased fluidity and porosity. Using the work of Fischer (2009) and Schechner (1998, 2002, 2011), I demonstrate how these arguments constitute a sort of scientific play. In this play, objects of scientific contention are created and destroyed only to be recreated. This leads me to recall, Barbara Woodwood Calton's question with which I began in chapter one: in dementia research between 2010 and 2015, what, if anything has changed?

A 'poison chalice': Anxious conversations about research

> The hotel conference room is strikingly familiar, a large open space, deeply carpeted with matching cushioned chairs. It is hot and humid in June 2011, as more than fifty researchers, clinicians, policy makers, and lay participants meet

in the north-east of England to discuss the state of dementia research and hear presentations from current projects and research initiatives. The success of the regional network was praised by a senior neuroscientist: 'You are officially the most active research community in the NHS in this area'.

There was much enthusiastic talk from both researchers and clinicians of the 'collective group identity' connecting researchers and publics, enabling trials to start 'on-time and to target' improving the 'quality and quantity' in research.

As the meeting progressed, discussions were littered with comments which painted a slightly different picture of how researchers and clinicians felt about developments in dementia research.

When describing the direction taken to develop the burgeoning national dementia strategy, a direction which was to achieve a significant profile in the national health funding priorities and public domain, a senior clinician and policy maker commented: 'well we weren't going to get *anything done* unless we focused on *something*'. A simmering sense of uncertainty lies below the appearance and performance of collective confidence.

Extract from field notes at the
Joint Meeting of Regional Association of Old Age Psychiatrists and DeNDRoN

The development of priorities for a national dementia research agenda combined political and scientific priorities, as well as being driven by the pragmatic necessity to create and capture public interest. Such interest provided the momentum necessary to ensure long-term investment in the field. At the meeting described above, the development of the dementia commissioning pack was a hot topic of discussion. As the UK prepared in 2013/14 to move from a primary care trust model to localised clinical commissioning groups, this commissioning pack was designed to help general practitioners decide how to prioritise dementia-based services in their area. For the first time, dementias had dedicated guidance, in the same way as, for instance, cardiac rehabilitation services. This guidance demonstrated the success of research organisations and patient groups in

raising the political profile of dementia so that it was recognised as a national health and research priority. The pack aimed to combine 'clinical, financial and commercial' information (Department of Health, July 2011) with evidence-based specifications of services, creating a 'tool-kit' for commissioners. The pack aimed to deliver a clearly defined and locally specialised range of services whilst maintaining a nationwide patient-centred approach. At the same time, the pack had to reflect strict guidelines for fiscal efficiency and value for money, as the impact of the financial crisis of 2008 continued to be felt (Nuffield Trust 2011). A stark balance was being struck between the understanding, empowering and empathetic language of person-centred treatments and carer support, and the financial imperatives of cost-benefit analysis. This illustrates the difficult balance being negotiated by clinically-informed researchers, policy-makers and practitioners in the NHS managing the clinical, political and economic environment of the time. In spite of the plurality being negotiated, the period from 2010 to 2014 marked a significant success for dementia research. Over the course of this period, pledges of government funding increased dramatically, political and public support was at an unprecedented high, and more research was being conducted in this field than ever before. Why then, at the meetings and events I attended and the interviews I undertook, was the pervading atmosphere one of tension, uncertainty and anxiety? Why, rather than focusing on the achievements and successes of the commissioning pack, did a clinician comment, with a tone of resigned frustration, 'well, at *least* it's a *start'*, suggesting a degree of pessimism about the approach being taken.

What this comment revealed was that there was a sense that beneath the benefits, gains and the positive progress achieved and acknowledged amongst clinicians and scientists there was a sense of caution. It was not clear what had in fact be achieved so far, what was possible, what had been promised, and what precisely, were the public and politicians expectations for dementia research? Such comments gave the conference an air of ambivalence. At times it felt like a performance in which unravelling threads revealed doubts about the seemingly optimistic project of changing the social, clinical and scientific attitudes toward research in the field of dementia. Achieving a dedicated dementia research funding stream as a national research priority had been long in the making, but by 2010-2011 it was beginning to be realised in terms of real funding and resource allocation. As a consequence, therefore, the success of dementia research was no longer a dreamed of impossibility, the imminent future of drug and therapeutic strategies was a growing concern. This was acutely recognised by one research leader:

> "It's like a *poison chalice*, we have the support, we have to *do* something with it *now*, or we *risk* putting back the course of dementia research by decades…"

At the same time as I was becoming aware of researcher anxieties, I was also seeing increasing evidence of the frustration voiced by public attendees at research events, as recorded in my journal:

> During the day, I got to know some of the different participants sat around my table. One of these was a PhD researcher, Diane. With her supervisor she was working on an early stage project to look at the impact of new hospital discharge protocols. These were designed to streamline treatment and discharge rates, reduce the length of hospital stays in order for people with dementia to return to home with appropriate support as quickly as possible. This was based on the evidence that longer in-patient stays tended to positively correlate with the progression of their dementia condition. Diane was at the stage of processing the data they had collected and presenting their early findings which were largely positive. People with rapid discharge and at-home support were reported to experience a less rapid decline in their symptoms. This was Diane's first conference presentation and her supervisor was in the audience. We shared stories about our nervousness, fear of exposure and uncertainty about how our work would be received by our peers.
>
> Her paper came after lunch, by which stage much coffee and sugar had been consumed to bolster the flagging group. Everything seemed to be going well, her results were clearly presented and tempered by the familiar researcher's caution that I used myself: 'the evidence suggested', it 'might be possible', and there 'were good indications'. There developed a tense atmosphere in the room, in particular a gentleman sat in the front row, he shifted impatiently in his seat, noticeably ill at ease even in such a large space.

When questions were invited he was quick to stand up and address Diane, "This would seem like a really important finding. When will it be put into practice in hospitals?"

Diane's response was carefully worded, "well this is an early phase of a much bigger study, I've been particularly looking at the discharge process but this has to be looked at more in-depth in the wider treatment process and would have to be tested amongst a larger group".

The questioner's agitation grew, "you keep saying this, 'when', 'if' 'possibly'". Gesturing frantically to the lady sat next to him he said "what about people, like my wife, who need these changes now?"

Diane was clearly anxious, the room was still, as she tried to explain again her work was only part of the picture and it was 'early days'.

"That's all very well, all you researchers keep saying that, but when are you actually going to do something?"

At this point the chair, a senior clinician and national policy advisor stepped in, very assertively protecting the researcher, "I think we have to keep in mind what we mean by basic research, research doesn't just translate into a change in practice overnight, there are many, many stages that a complex trial like this will have to go through before we start to think about the process of implementation. Have we got any more questions?' and with that this particular discussion was definitively closed.

Extract from field notes,
Joint Meeting of Regional Association of Old Age Psychiatrists and DeNDRoN.

These two examples capture a pattern repeated at many of the research events I attended over eighteen months of fieldwork. These meetings were often day long, involving presentations on

multiple projects. Huge amounts of effort and information were put into the process of knowledge exchange, communication and engagement. The languages of caution and uncertainty continually bubbled beneath these exchanges making for rather anxious conversations. These conversations were punctuated by moments of acutely uncomfortable conflict, as the one described above, in which divergent perceptions of what constituted successful or 'good' research were brought into focus.

It is thus apparent that whilst strategic, collaborative and entangled, the community which I have been attempting to trace is far from unified and harmonious. Yet, this is not a thesis about a manipulative science, separate from, and acting upon a naïve and passive public. In other words, it is not a simple power relationship of experts over lay-participants. Research images and public engagement events were designed to influence and persuade, but in drawing the public into an emerging research community, individual researcher's strategies were increasingly subject to direct criticism. As such, research meetings often felt like rollercoasters of hope, confidence and potential at one moment and risks and despair at another. Such discussions about research between lay people and scientists, demonstrated the fundamentally different frameworks being used by different actors in dementia research to judge the development and success of a research agenda that they themselves were actively shaping.

By necessity to have any hope of achieving the desired outcome of progress in dementia treatment, research and patient organisations had used the public and political domain to create dementia as a visible and viable object of national research and investment. A bargain had been struck; research had made itself and its lack of resources prominent, with the promise that adequate financing, infrastructure and support would enable it to deliver improved diagnostics, treatments and care. As such, positive and outcome-based action was expected and had to be seen to be being taken.

Public participants, including patients and carers such as Tom and Barbara introduced in earlier chapters, expressed that, for them, the priority was the efficient implementation of existing research knowledge so that people currently living with dementia could benefit as much as possible. This prompted researchers involved in engagement to ask a range of questions about their dialogue with public and political stakeholders. Given the scale and diversity of potential

problems presented by clinical trials on dementia syndromes, what were the best areas to focus resources on? What were the limits of what was yet not known about the different dementia sub-types and their interaction? Do the public and policy makers understand the structure of research science and the challenges of this particular group of conditions? These questions suggest two slightly different foci. Researchers are anxious about how the 'response-led', fPB, research environment, could create unrealistic pressure on them for the immediate development and implementation of new interventions. For them, such interventions are still suspended in the future, either through lack of knowledge or the convolutions inherent in the research process. For public participants, it is not future knowledge but an anxiety about why existing knowledge is so difficult to implement. How can research 'know' something, but be unable to effect direct and immediate change in health care practices? This tension between different perceptions and temporalities of knowledge was often the tipping point in the public-science relationship. Yet, how were researchers managing the anxieties that came with working with this tension? To what extent would their stakeholders tolerate the time required to develop treatments or technologies to the level of phase III clinical trial, that is, one capable of yielding usable drugs and interventions?

In discussing these issues with scientists, I found the conversations often returned to the nature of the complexities of scientific research. Bureaucratic regulation, the meticulous processes underpinning science, the challenges of collaboration and indeed the additional pressure of needing to communicate effectively with the public, were all part of the 'organized disorganization' of research (Hagstrom 1964). The strategies necessary to develop the identity, funding, recruitment, infrastructure and support for UK dementia research, demonstrate a growing entanglement between science, state and society. In short, researchers in rising to the 'dementia challenge' were acutely aware of what they perceived as the fundamental gap between the rhetoric of hopeful potential knowledge (which made a project financially, logistically and organisationally viable in today's UK health research structure) and the reality of what could be achieved in terms of tangible patient outcomes.

In the next section of this chapter I discuss four recurrent themes illustrated by these anxious conversations about research and public engagement: defining good science, contesting causation, temporality in research and the management of expectations.

Defining good knowledge, good science, and successful research

As I explored in the opening chapter of this thesis, the question of what constitutes 'good' knowledge about dementia, is rooted in a long historical process and continually emerges as scientific methods and technologies evolve. In this process, changing social perceptions of cognitive degeneration and aging combine with the emergence of collaborations between clinical, laboratory and biotechnological approaches. The evolution of dementia research within the context of new techniques in neuroimaging and bio-molecular chemistry continue to reshape, redefine and re-categorise dementia pathologies. This processes has made dementias increasingly amenable to complex statistical analysis, and we have more data about these conditions than ever before. At the same time, the model of the clinical trial has become the pre-eminent discourse of objective, quantifiable success. The observable, measurable and replicable model which moves from basic 'proof of concept' to implementation creates a form of knowledge which is presented as tightly controlled and subject to rigorous testing.

At its height, the model of clinical research has been realised in the form of the randomised control trial, the 'gold standard' of biomedicine (cf Timmermans & Berg 2010, Moreira & Wills 2010, Simpson and Sariola 2012). In RCTs, particularly ones which deal with changes in cognition and behaviour, the benefits of research are demonstrated through numerical assessments developed in the field of health economics, such as the QALY/DALY discussed in chapter two. In the UK, and across the globe, these developments in science and technology have taken place within the context of the political economy of nation states. These relations are in turn embedded in global market relations. For the researchers I worked with, 'good knowledge' was the result of 'good science', that is, knowledge produced by an internationally recognised, systematic, rigorously tested and accountable process. However, the international dimension introduces a further layer of complexity to the world in which researchers were working. This was illustrated at the NIHR meeting where the development of 'good' and 'better' dementia research was variously defined as robustly evidence-based, peer-reviewed, collaborative and efficient, fPB (for patient benefit), and 'on target and to time'. As the discussion above illustrates, there is no simple correlation between 'good science' and success; for whom is it successful for and in what ways? If we take as a starting point a definition of 'success' as the achievement of an

externally agreed and recognised objective, we might also ask, given the range of targets that researchers were aiming for, how did researchers themselves evaluate the 'success' of their science (Oxford English Dictionary 1991)?

I have demonstrated, therefore, that the nature of successful science is often a political and economic question as much as it is a scientific one. Even scientifically, for the researchers I was working with at the time of this study, knowledge about dementia causing pathologies was, and continues to be, in a rapid state of flux. As researchers come to know and understand more about dementia, there continue to be fundamental questions and issues at the level of basic science, classification and scientific discovery. As such, 'good' research was changing, modifying and adapting to new knowledge about dementias.

Dementia researchers, therefore, were never working with simply defined disease objects, but as parts of a highly complex assemblage. Consequently, everyday discussions of success or failure between researchers were based on the concrete experience of specific tests or findings within a particular project. This was often linked to how this result would contribute to, or impact upon other parts of the project, and how publishable the result might be. 'Goodness' in basic science or early stages of clinical research therefore, does not map neatly on to the conceptualisations of 'success' which are held, or believed to be held, by different actors in the research process. For those hoping to benefit from science, the 'good' was perceived to be located in how the finding or product of the process could be used to add 'value'. This 'value' might be at the personal level of the health of the individual, or at the national level influencing public health. It might also be at the level of the global market for the saleable products of health research. Whilst researchers are aware of these competing definitions, 'good science' was located in the accumulation of findings (positive or negative) achieved through 'good science', that is, science which is robust and processual.

To illustrate these variable readings of what it is to be successful in science, let us begin with a model account of successful drug development. Drug X has been identified as having the potential for reducing Y, a therapeutic target implicated in the early stages of the development of the pathologies which result in AD. Proof of concept and animal-phase testing has demonstrated that the drug effectively achieves the reduction of Y in brain tissue. Phase I-III

testing in humans confirms the safety of the drug for humans and demonstrates its efficacy, that is, that the drug reduces disease progression in a significant number of participants. The drug is approved for human use by the European Medicines Agency (EMA), and the UK NICE assessment suggests that the treatment has greater 'benefit' than 'cost' and is suitable for wide-scale use. Drug X becomes the recommended first-line treatment for early stage dementia. Consultants and patients have confidence in the findings. People with early stage cognitive changes come forward for early diagnoses and are widely prescribed the treatment. As a result many users of the drug benefit from a slowing of the deterioration in cognition. The drug is successfully marketed and produces a national economic benefit. The researchers involved are able to publish successful results, and develop their reputation and careers.

This example is a dramatic over-simplification. However, even as a hypothetical ideal of success, patients who are users of the drug may still evaluate success rather differently. For instance, not all users may respond to the drug as expected and the benefits of that response may change over time. Some recipients will have negative side effects which reduce or even override their sense of its benefit. It may be that local health policy makes the therapy more accessible in some regions than others. Specific consultants may have their own understanding or experience of the benefits of this or other similar therapies. These experiences may make them more, or indeed less, likely to make it available to their patients. In addition, those experiencing early memory changes, and their primary physicians, may, from prior experience, not have confidence in the diagnostic and treatment processes itself. As a result, of such factors the potential user may never have access to, or knowledge of the availability of the therapy. This brief thought experiment fashioned from my experience with researchers, illustrates how multiple factors beyond the laboratory - individual biology, local policy, physician and patient knowledge and experience - all have the potential to change one perception of a research intervention as 'successful' into one that is a failure.

In reality, most clinical trials will never reach this translational stage of development. Cummings et al (2014) in their analysis of American-based clinical trials for drug-development in Alzheimer's disease, between 2002 and 2012, suggests that 99.6% of trials failed to reach the point of regulatory review. In addition, relatively few potential 'agents' are entering phase I, suggesting that the number of new pharmaceutical treatments remains small compared to other fields of

research. Where a drug does successfully proceed to 'human-phase' testing and wider implementation, the process is agonisingly slow, estimated to take around ten to fifteen years. Initially, the drug will be available only to the specific range of patients or carers involved in that trial. Implementing that treatment across everyday clinical practice is in itself a difficult process. It requires changing the knowledge and perceptions of a range of medical practitioners and indeed the general public. Thus, making science perform 'successfully' does not stop at the laboratory door. It engages with local beliefs and attitudes in clinical, political and societal domains.

Crucially the dementia research that I was observing was not at this stage of development. The majority of the work being discussed by research leaders during the public engagement events that I observed was very clearly observational or basic science and not about interventional treatments. This is not to say that such treatments would not be developed but that scientists were trying to understand the pathologies which cause different types of dementia, and identify the best potential therapeutic targets for intervention. Nonetheless, this was a long way from providing credible treatments for the large numbers experiencing dementia.

The vaccine and the cascade: contesting causation.

Having established the difficulty of determining what is successful research, in this section I want to reflect on a specific case study of how researchers tried to develop a dementia vaccine. Let me begin with an extract from my field notes:

> Following the main speakers at an ARUK research event we were invited to look around the postgraduate posters on current dementia research projects. David, an early career researcher was presenting a poster on his work on molecular imaging in dementia research. I asked him about the possibilities of a cure for dementia and he described to me the current work being conducted on the bapineuzumab dementia vaccine. In lay terms he enthusiastically laid out for me how the vaccine aimed to use the body's own immune system to systematically break down the beta-amyloid plaques. Aβ was a dominant target for many in the neuroscientific community, believed to be a principle factor in the causal sequence that leads to

the neuronal and cognitive degeneration associated with dementia, a process which had become known as the 'amyloid plaque cascade hypothesis'. I had heard about the idea of the vaccine through articles and the media, but I explained I didn't really understand what made it a vaccine. He gleefully took me through the process, most of which I failed to follow, of how the body's own system could be switched on to target the particular proteins involved, in something akin to the way classic vaccines use the introduction of small amounts of the disease causing material to stimulate the body's immune system to recognise and build antigens to prevent future infection.

'So what happened?' I asked;

'Well, it worked', he answered, pausing wryly, 'a trial in the States showed that it really effectively broke down the amyloid plaques, cleared them from the affected areas.'

'There was just one problem' he smiles. I waited for the punch line 'It just didn't halt the neuronal degeneration'

'Oh' I said confused,

'Yeah, the neuronal and cognitive changes kept happening. That's the interesting thing, we've always thought the plaque preceded the degeneration, but, now, well there's lots of debate, it means that potentially we'll have to completely change our understanding of the disease pathway. There's older researchers who are really committed to the cascade hypothesis, they'll keep going down that route. And then there are people like my supervisor who thinks, hold on, if the plaques aren't causal then there's something else in the disease process which we just don't understand yet.'

'So the trial didn't work then?' I asked.

'Well that depends what you mean by 'work'' he answered.

Extract from field notes on a discussion with an early career researcher

Contrast this view of the failed vaccine trial with that of the head of research at the Alzheimer's Society:

We have seen a lot of, particularly as the big pharma companies are doing less, we're seeing less new drugs coming through, we're seeing less clinical trials in smaller biotech companies, we are much more desperate for individual drugs to work. And I think we have seen a few examples of failed trials where really they should never have moved past phase II, the evidence just wasn't strong enough, but they have been so desperate to take them on that… Perhaps they need to be taking stronger advice at that stage. And also there are mechanisms for looking at data in trials, sort of part way through, and canning the trial early if it's not working. Very few companies do that, but actually if it saves people participating unnecessarily, plus it saves money, we should be doing a lot more of that.

Clive Ballard during a discussion at the Alzheimer's Society Research Network, 2011

In the first instance, the failure is in hypotheses, whereas in the second example it is in the way that the market has driven the research agenda beyond what the evidence can support. In the third example we can see how research failure is transformed into a potential opportunity for hope and future success:

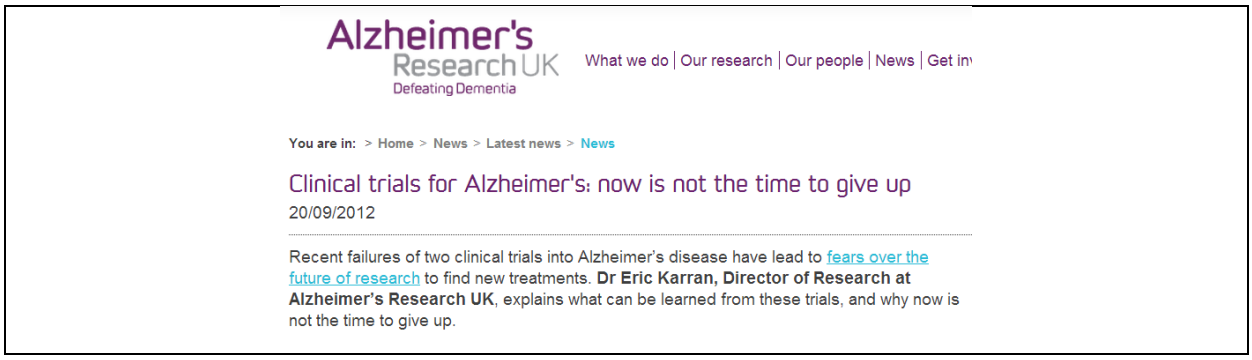


Figure 38: Re-narrating the failure of clinical trials (ARUK 2012) http://www.alzheimersresearchuk.org/clinical-trials-for-alzheimers-now-is-not-the-time-to-give-up-2/

The recent failure of two phase 3 clinical trials for Alzheimer's drugs is a blow to the field. Like three previous drugs that also failed in trials, these two antibodies – bapineuzumab and solanezumab – worked by targeting a protein called amyloid, which builds up in the brains of people with Alzheimer's. These findings

will also provoke pharmaceutical companies to question whether they can continue to invest in clinical research for such a challenging disease. But now is not the time to give up, and these perceived failures could in fact hold the key to future success...

With bapineuzumab, understanding why the drug failed will be crucial to developing treatments with a better chance of reaching their goals. For solanezumab, early reports suggest that there may have been some benefits for patients with mild Alzheimer's disease – adding weight to an emerging theory that drugs targeting amyloid would need to be given early to be successful. If we can find a reliable and inexpensive method of identifying people on the cusp of amyloid build-up, but who have not yet developed symptoms, then drugs that target amyloid could have a good chance of bringing real benefit. Meanwhile, work on treatments that attack different features of the disease must also continue.

Erik Karran (ARUK 2012)

Here the failure is placed on the timing of drug interventions and the challenge of getting access to participants early enough in the disease process. The views of the head of ARUK are summed up in an item on their blog in 2013. A trial which fails to produce desired outcomes, may still point to additional knowledge which may influence future success. As a result, this questions the nature of failure in science itself.

Figure 39: When is a failed clinical trial not a failure (ARUK 2013)
http://www.dementiablog.org/failed-dementia-trial/

At the start of my research in 2010, the potential of disease modifying immunotherapies for dementia causing conditions, described popularly as a 'dementia vaccine', were gathering great momentum and hope was growing within the research community, as well as amongst patient advocacy groups. The image of a vaccine drew on the great public health 'successes' of the childhood vaccination campaigns of the twentieth century, which successfully controlled or, in some cases, eradicated some of the infectious diseases which led to high rates of infant and childhood morality (Rusnock 2008). However, the failure of the 2012 trials brought great anxiety and uncertainty. A significant amount of industry investment had been dedicated to this research pathway, yet how would industry respond to such prominent and late stage failures? To what extent did this finding challenge the Aβ hypothesis upon which much dementia research was based?

As both the early career researcher and the head of research for the ARUK reflected, such failure whilst in many ways 'devastating', could not, and should not, be confused with failure in the everyday sense of the word. In the classic Popperian manner, hypotheses can and do fail, and, for scientists this is part and parcel of 'good science' (Latour & Woolgar 1986). Failure and falsification prevent ineffective research from progressing, and thus create the opportunity for more effective approaches to emerge. In particular, for David, the early career research introduced above, this was an exciting time. The failure of these trials had opened up the possibility for new avenues of research and new questions to be considered in a way that had been less possible when the Aβ cascade hypothesis had been so dominant. Yet, if one was a scientist intellectually and personally committed to further research on the cascade hypothesis, the outcome of these trials could be seriously disturbing. For those who were sceptical of this hypothesis, the trial's failure strengthened the argument for an independent research agenda rather than one driven by the logic of the market. Thus, for researchers, success and innovation required space for and acceptance of, the possibility of failure in ways that may not be fully appreciated by the public.

Participation and expectation

Given that research in the field of dementia is still, in many ways, in its early stages, researchers often had to engage in a delicate balancing act between the persuasive rhetoric of their potential success, and intimations of caution and potential failure. Researchers relied on promoting the

possibility of new and more effective treatments, whilst at the same time recognising, as one researcher put it:

> The impossibility of predicting the outcomes of the scientific developments. When people say "we're relying on luck then?" I tell them "There's a lot of luck in science".

In one breath, researchers emphasised their commitment to developing and translating new interventions into practice, whilst in the next, they stressed that this did not necessarily mean new effective treatments would be found in this decade or, indeed, in the next. Enrolling the public in the research agenda was, therefore, a balancing act. This balance was brought into particular focus in the process of recruiting participants who had dementia. I was to find this when I found myself in an anxious conversation with a group of nurses involved in the recruitment and consent process for clinical research:

> **Clinical trials nurse 1**: The inclusion and exclusion criteria are really strict. They [the research projects] have to make sure that they get the right kind of patient for the right trial. But we're seeing more and more people coming forward who are interested in participation.
>
> **Me**: Does that mean many people won't get on to a trial?
>
> **Clinical trials nurse 1**: No the majority won't be suitable, especially with older people where lots of them might have pacemakers or be on a lot of medication and things like that.
>
> **Me**: How do people respond to that?
>
> **Clinical trials nurse 1**: What do you mean?
>
> **Me**: If they're [people with dementia] being encouraged to get involved and then find they can't take part in a trial. Does that cause any difficulties?
>
> **Clinical trials nurse 2**: I mean it's a very carefully run process. We're very careful to make sure people don't have any false expectations, that we don't give them any false hope. We spend a lot of time with them explaining how it works. We make sure they know right from the start that there is every chance they probably

> won't be suitable, and we make sure they're OK with that. It's a process we've worked really hard to get right, and there are always new trials which they might be able to get involved with in the future.

At the start of the conversation the tone was enthusiastic and open, we were discussing a process which they experienced as positive and of mutual value. The coordinators of North-East PPI groups saw the genuine benefits participants described and experienced in becoming part of the extended research community. These benefits were presented to me as not just participation on a clinical trial, but also as highly socially supportive. Public research events, such as the one I was attending, enabled people experiencing dementia and their carers to meet, not only with researchers and clinicians, but also with one another. A special session was held during one event for PPI members to come together and discuss how the initiative was performing, and what other sorts of events or sessions members would like to see happen. During this session participants expressed that they got pleasure from their involvement, and were always interested to hear about the new developments in research. There was also discussion of the forthcoming visit to the regional Brain Bank, where participants were going to be given a tour of the facility and discuss the brain donation process.

As at so many events, these conversations were positive and hopeful, and I was left in no doubt that the PPI members I met felt genuine benefit from their involvement. However, in my conversation with the research nurses, as soon as I asked my question, the atmosphere became decidedly frosty. I was suddenly conscious of having crossed the line from an appropriate inquiry to more sensitive territory. The conversation was quickly brought to a conclusion as the nurses physically turned towards one another and away from me to discuss another aspect of the work in which they were involved.

In broaching the potential for disappointment I had, unintentionally, challenged the discourse of hope and positivity. As in the case with Tom at the start of this chapter, public participants could and did express their disappointment or frustration with the research process. In this instance, however, I was left in no doubt that questions about negative responses were not appropriate in this context. In the sense developed by Goffman, I had threatened the front stage performance everyone was participating in (1956). This threat had the potential, however slight, to damage the greater social performance taking place. My identity 'within' the research

community, at this moment, was spoiled and I was politely, but firmly shut out of causing any further harm.

The anxiety expressed by researchers was linked not only to how the public responded to them, it was also linked to how they imagined the public were likely to respond. Whilst some members of the public vocalised their frustration, others were more tolerant of what they understood to be the very difficult problem of dementia research:

> What I was thinking about was, if all this research was easy then the drug-companies would have done it, because it's a very big market. I think that I started off looking at the question as a businessman and saying to myself 'Yeah, that's right. Why are we failing?' But I don't think that the researchers should beat themselves up too much, certainly not people researching for the Alzheimer's Society, because 'blue-sky' research is equally as important as practical, focused research. So, perhaps the number of successes that have been had, are only an indication of the fact that the easy bit have been done and you're now looking at the difficult bits.
>
> Comment from the floor during the debate 'Why has dementia research failed'
> Alzheimer's Society Research Network (2011)

This comment suggests that the reflexive anxiety of researchers was not purely a response to external public pressure, but also part of an internal struggle to make sense of the competing scientific, political, social, economic logics within which their work is suspended.

'Science takes time, I think the public understand that'

From this interaction, and from those with other researchers and at public events, the issue of expectation in the dementia research process was a tangible source of anxiety, and one which needed to be managed. I discussed this with Steven, a research co-ordinator working in another regional dementia research network. He initially responded that, 'science takes time; I think the public understand that'. His experience, he said, was that the public were very aware of how complex and difficult the problem of dementia is. However, as we talked he described several

high profile failures in drug trials he had been aware of, and the 'erosion' of the amyloid hypothesis in the case of AD. He also mentioned that he was aware of trials where negative findings had been supressed, and covered by confidentiality clauses which prevented those involved in disseminating the information. So I asked again, how he felt public participants in the research process dealt with such problems, given the high level of expectation evolving around the dementia research agenda:

> We were running a study, but at the time people were like, "we just don't understand why this isn't already available." So I think people do get a bit pissed-off with the researchers when there is some kind of a consultation process. The science is not immediate, that's the thing.

Researcher's experience of public understanding of and response to dementia science was not monolithic but plural and mutable. Whilst researchers felt the public appreciated the complexity of the process involved in scientific research, this did not preclude them expressing their frustration about the time it takes to achieve translational results.

This movement between hope and frustration was well illustrated by a discussion around what one clinician saw as a lack of research on dementia for people with Down's syndrome:

> **Practitioner:** What I want to ask is that nothing has been said about people with down-syndrome and down-syndrome dementia. I have worked with a lot of people who have down-syndrome with the onset of dementia and it is a problem.
>
> **Researcher 1:** I heard it in the news last week about people with down-syndrome getting dementia. And in fact as you probably know downs syndrome is a chromosomal disorder and on this chromosome is the gene for APP that is the gene for the production of amyloid. So Down's patients [sic patients with downs syndrome] get a lot of amyloid and eventually when they get older they get also tangles, and this is one of the reasons it was believed that amyloid was one of the causes of the Tau pathology that we see in Alzheimer's patients. But for people like me who work in the field this is nothing new at all, we know that people with Down's get dementia much sooner than other Alzheimer patients, so I was really astonished when this came as a new thing.
>
> **Researcher** 2: I don't think that is the point though. The point that is being made is not about the cause, but this is again going back to what I said before, we have known now for more than thirty years that people with Down's syndrome are at

increased risk of developing dementia, yet there is still virtually nothing in terms of targeted interventions or particular services for this very, very vulnerable group.

Researcher 3: Can I just make a point about diagnosing people with down-syndrome with dementia, and there's the Down's Syndrome dementia scale that was adapted for people with down-syndrome and I think that that was one of the major achievements, because many of the people with down syndrome were inappropriately diagnosed with dementia for behavioural problems. Down south as far as I know, especially in Cambridgeshire, there is a lot of work being done with elderly people with down-syndrome. So there are cases where something has been done.

Practitioner: I just want to know, I mean with all this obviously wonderful research going on, how does that get fed into strategic development across health and social care? Because I don't think you can see either in isolation, it's about good quality care wherever it is delivered for people who have a dementia and their carers. And how does this happen? Because carers and people will still say to me, 'You are still disjointed, we still go to the clinic, we still see the psycho-geriatrician, but actually you're not listening to things about care?' How do you feed those things, those disappointments into the social care system?

Thus, researchers themselves expressed this dual tolerance and frustration about temporality in clinical research. On the one hand, things were being done and there was better understanding of the diagnostic process for people with Down's syndrome dementia than ever before. However, the increased risk for this group has been known for more than thirty years and yet there remained no effective interventions and few specialised services available. One gerontologist described this frustration what she saw as a perpetual cycle of knowledge:

If we go by pharmacology, we go into another cycle: The same people who told us some seven, eight, ten years ago not to use neuralgic medication, now are at the front line of recommending the same drugs that they have banned us from using ten years ago. This is in the new policies, even from the Alzheimer's Society.

So I think that we literally could 'find' as professionals, what we have been preaching some ten years, twenty years ago. Being in this field for more than twenty-five, thirty years now, it seems every 7 to 10 years that we discover the same cycle again and we go down the same routes.

> I think it is the time just to look outside the circle, outside the box and think about individually targeted care. Each of us, maybe will have tangles and plaques, maybe we will have identical tangles and plaques in the same brain areas as your people with Alzheimer's have, but that clinical pathology of how we present with those tangles and plaques could be very different, because each of us is very different.
>
> Local gerontologist speaking at an ARUK Meeting 2011

New information might emerge and then seemed to become lost in the wider research process, only to resurface in new research. Implementation may only occur after many turns of the research cycle, by which time 'good knowledge' may have fundamentally altered. As scientific research constantly develops, 'old' knowledge can become 'new', and past failures be reshaped as current successes. Such narratives of time and complexity suffuse scientists' anxieties and public frustrations. These concerns are nicely summed up in the following DeNDRoN poster. On a simple black background is centred a translucent black and white image of the human brain. The brain is composed of a mass intertwined ghostly white tangles representing neuronal networks. The title announces:

Use your brain to help untangle dementia

The image used plays on the tangles of Tau proteins which are thought to be central to the progression of Alzheimer 's disease. At the same time, the rhetoric hints at the complexity of the disease and the science required to understand and address it. It captures the non-linear, lengthy, messy process which is the reality of science, particularly in the relatively 'young' field of dementia research. At the same time, the poster addresses 'you' the viewer, as someone who might experience directly or indirectly the effects of a dementia. 'You' become a potential collaborator in the research process whether as a supporter, participant in a clinical trial, or as a person pledging donation of their brain after their death.

Conclusion: clinical research at play - managing the borderlines of science

In this chapter I have been describing how researchers make sense of what is perceived by many as the 'poison chalice' of the growing success of the dementia research community. The attention and accountability which come with substantial funding and a high profile research agenda have created a particular environment. This environment is one which is hopeful and full of potential, yet anxious and reflexive about when that potential might be realised, and what form it will take. What Konrad describes as the 'radically deterritorialised' nature of the modern scientific process is particularly apparent in researcher's encounters with public participants (Konrad 2002). These exchanges highlight the interaction of different perceptions about what constitutes successful dementia research. These boundaries between success and failure, expectation and actuality are managed by narratives which perform in cycles. These cycles create hope and potential, only to deconstruct them with reference to challenges of the complexities of research.

To conclude I want to reflect briefly on how the cyclical process of the production of knowledge in clinical research is reflected in the rhetorics of research policy more broadly. Following Fischer, I argue that the cyclical framework enables researchers to manage the plurality involved in the structure of contemporary socially engaged clinical science.

22 STRATEGIC AIM TWO
Research to people: Bringing the benefits of excellent research to all sections of society
24 Translation of research
To bring the health impacts of fundamental research to people more quickly.
25 Regulation, ethics, governance and working with decision-makers
To uphold and guide ethical research practice and the highest standards of research governance, to enhance the regulatory process by providing innovative approaches.
27 Communication
To enhance communication with scientists, the public, policymakers and partners.
28 STRATEGIC AIM THREE
Going global: Accelerating progress in international health research
30 Partnerships and shaping the agenda
To provide international leadership in partnerships which enhance the competitiveness of the UK knowledge and health base.
31 Global health

FOREWORD

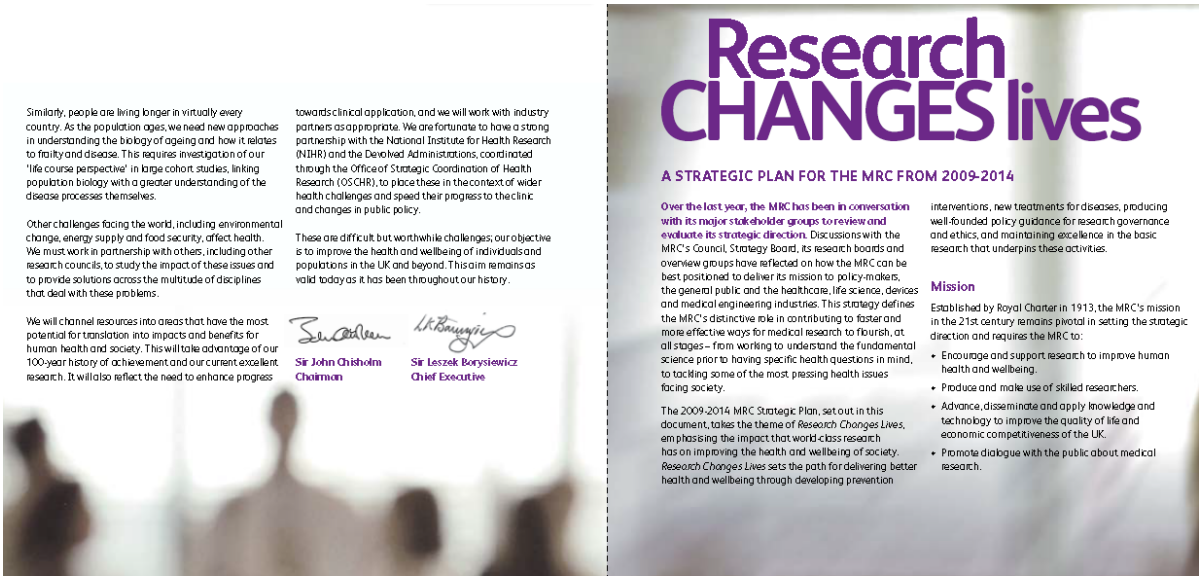
MRC researchers are global leaders in their fields of science, as the 28 Nobel Prizes over our 95-year history indicate. Always at the international forefront, the MRC addresses the most difficult scientific and health challenges of the day. Now, as we approach our centenary in 2013, we must not be complacent. We must remain driven by the needs of populations, individuals and patients and the desire of scientists to strive for new discoveries to improve human health through prevention and treatment.

To achieve this goal, we must build on our strong history and continue to recognise the importance of taking on fundamental problems by supporting basic science. This not only delivers discoveries but provides the basis for translation of research into patient benefit. We must ensure that scientists supported by the MRC have confidence that, even in difficult economic circumstances, science of the highest quality and excellence can and will be supported and sustained, as it takes many years before discoveries achieve their potential in patient care.

Building for the future requires the development of careers and opportunities for young scientists – the future of the UK biomedical enterprise. We will also invest in infrastructure to support our scientists and trainees ensuring that they continue to have access to the best and newest technologies and facilities to maintain excellence in a competitive world. Further, we will aim to create the right enabling environment to undertake the highest quality research, to produce and evaluate the optimal outputs and outcomes, and to communicate the impact to all parts of society.

Throughout the history of the MRC, the problems and the nature of scientific discovery and translation have not stayed the same. The MRC must respond quickly to a changing world. New infections continue to emerge and, despite major advances in their control, remain a major cause of mortality worldwide. Non-communicable diseases – diabetes, cancer, cardiovascular disease and mental disorders – account for a large proportion of the burden of disease in low- and middle-income countries.

Figure 40: MRC 2009-2014 Strategic Review



Similarly, people are living longer in virtually every country. As the population ages, we need new approaches in understanding the biology of ageing and how it relates to frailty and disease. This requires investigation of our 'life course perspective' in large cohort studies, linking population biology with a greater understanding of the disease processes themselves.

Other challenges facing the world, including environmental change, energy supply and food security, affect health. We must work in partnership with others, including other research councils, to study the impact of these issues and to provide solutions across the multitude of disciplines that deal with these problems.

We will channel resources into areas that have the most potential for translation into impacts and benefits for human health and society. This will take advantage of our 100-year history of achievement and our current excellent research. It will also reflect the need to enhance progress towards clinical application, and we will work with industry partners as appropriate. We are fortunate to have a strong partnership with the National Institute for Health Research (NIHR) and the Devolved Administrations, coordinated through the Office of Strategic Coordination of Health Research (OSCHR), to place these in the context of wider health challenges and speed their progress to the clinic and changes in public policy.

These are difficult but worthwhile challenges; our objective is to improve the health and wellbeing of individuals and populations in the UK and beyond. This aim remains as valid today as it has been throughout our history.

Sir John Chisholm
Chairman

Sir Leszek Borysiewicz
Chief Executive

Research CHANGES lives

A STRATEGIC PLAN FOR THE MRC FROM 2009-2014

Over the last year, the MRC has been in conversation with its major stakeholder groups to review and evaluate its strategic direction. Discussions with the MRC's Council, Strategy Board, its research boards and overview groups have reflected on how the MRC can be best positioned to deliver its mission to policy-makers, the general public and the healthcare, life science, devices and medical engineering industries. This strategy defines the MRC's distinctive role in contributing to faster and more effective ways for medical research to flourish, at all stages – from working to understand the fundamental science prior to having specific health questions in mind, to tackling some of the most pressing health issues facing society.

The 2009-2014 MRC Strategic Plan, set out in this document, takes the theme of *Research Changes Lives*, emphasising the impact that world-class research has on improving the health and wellbeing of society. *Research Changes Lives* sets the path for delivering better health and wellbeing through developing prevention interventions, new treatments for diseases, producing well-founded policy guidance for research governance and ethics, and maintaining excellence in the basic research that underpins these activities.

Mission

Established by Royal Charter in 1913, the MRC's mission in the 21st century remains pivotal in setting the strategic direction and requires the MRC to:

- Encourage and support research to improve human health and wellbeing.
- Produce and make use of skilled researchers.
- Advance, disseminate and apply knowledge and technology to improve the quality of life and economic competitiveness of the UK.
- Promote dialogue with the public about medical research.

Figure 41: 'Research Changes Lives'
MRC scientific goals 2009-2014

In the foreword to the MRC 2009-2014 Strategic Review shown above, the plural aims and identities of contemporary clinical science become visible (2009: 2-3). Written by Sir John Chisholm, Chairman and Sir Leszek Borysiewicz, Chief Executive MRC, the document sets out what is expected from researchers working in UK science during this period. Whilst the document never discusses the fears of failures explored above, the patterns in rhetoric reflect the cyclical arguments which dominate the anxious conversations I have been discussing.

In particular, the writers reflect the different temporalities within which research functions. The document emphasises the need for the early career support to ensure the best opportunities to attract 'young' scientific talent, to work with the best and newest technologies. At the same time, the document places particular emphasises on 'the biology of ageing and how it relates to frailty and disease' (MRC 2009: 3) Researchers are asked build for the 'future' whilst drawing on an internationally prestigious scientific past, to build on an enduring legacy whilst meeting continually changing problems. This comment is emblematic of what began with in the opening chapter of this thesis, that a movement between the historical and the emergent, fundamental to the shape of scientific knowledge at any one time.

Researchers are tasked with responding to the needs of publics and populations and to communicate with all parts of society, whilst at the same time ensuring that research remains driven by 'scientific excellence'. The writers suggest that 'we must remain driven by the needs of

populations, individuals and patients and the desire of scientists to strive for new discoveries to improve human health through prevention and treatment' (MRC 2009: 3). There is at once a sense of public-scientific mutuality here, and also a clear potential for the 'needs' of the public to be incompatible with the 'desires' of the scientist. This is seen again in this discussion of basic science:

> This not only delivers discoveries but provides the basis for translation of research into patient benefit. We must ensure that scientists supported by the MRC have confidence that, even in difficult economic circumstances, science of the highest quality and excellence can and will be supported and sustained, as it takes many years before discoveries achieve their potential in patient care.
>
> MRC 2009-2014 Strategic Review (2009: 2)

Thus scientists are required to 'respond quickly' and 'deliver discoveries', whilst acknowledging that results may be many years away. I would suggest that this pattern has emerged as a consequence of an increasing interaction between mode I and mode II science. It is made visible through intensifying methods of public engagement and an increasing involvement of 'publics' and 'patients' in the research process.

The narratives of research I have identified repeat these cycles. Researchers emphasise the positive developments and successes of the dementia movement, whilst at the same time regretting the failures which are often linked to underinvestment in the field. For research to continue it can never be truly successful or have a distinct end-point. Nor can research be truly flawed or it risks support being withdrawn. In this world failures can be read as successes, and future successes may not be achievable without prior failure to guide them. Fischer likens such tensions and contradictions to the mobius strip or the ouroborus, the snake eating its tale; they twist and turn and resist efforts to pin them down (Fischer 2013: 191-192).

This constant game of the creation and destruction in the realm of dementia science echoes the kind of process described in Schechner's theory of performance (1998, 2004). In order to make the social performance 'real', that is, to fully embody the role being portrayed, the actor must be at once themselves and the character they are creating. The tension and persuasiveness of the

performance lies in the skill of the performer to maintain a balance between acting the role and becoming the role. Researchers in science practice and engagement are similarly maintaining the equilibrium between multiple roles. Suspended between a transparent, trustworthy and authoritative role, capable of imminent scientific success; which is, at the same time, presented as underfunded, underdeveloped and vulnerable to complexity, risk and failure, researchers are, what Schechner informed by Turner (1974, 1982), describes as existing in the subjunctive, the 'as if' (Schechner 1989, 2004:19). Like the 'mights' and 'coulds' of scientific discourse, research is neither truly one thing, nor the other; neither completely capable of success, nor completely open to failure. As such, the audience, the participants, funders and politicians, are caught up in an unfolding scientific drama. This suggests that it is useful for science to maintain itself in a state of rhetorical suspension (Bloch 1986, Miyasaki 2004).

This cyclical structure enables the researcher to move between different orders of knowledge, that of: the researcher, the clinician, the local infrastructure, the national political-economy, and global scientific-market relations. I have used exchanges with public participants to illustrate occasions when this rhetoric appears to have reached its limits. As I have shown, this has resulted in very tense and anxious moments in which definitions of success and value were questioned both by public participants and by researchers themselves. Whilst these challenges create anxiety they do not break the chiastic-cycle of discussion. They may stretch it, push at the boundaries, but such is the flexibility of the discourse, the mutability of concepts such as 'success', that they can be reabsorbed and provide momentum for the next twist and turn in shaping contemporary dementia science. Managing these moments of tension result in the reflective and creative social dramas from which the community of dementia research is being formed. However, in the next turn of the cycle, public participants cannot be pushed out or ignored, indeed, they themselves have become part of the cycle which is increasingly shaping biomedical research in the UK.

In the concluding chapter of this thesis I return to the framework of my original question, how is biomedical research enacted in dementia science, and what types of relations are implicated in this process. Finally, I reflect on the implications these relations have for shape of biomedical research in UK society.

Chapter 8 Conclusion: tension and suspension in a community of research

The principal aim of this thesis has been to describe the relations involved in the emergence of a dementia research community in the UK. The account I have given demonstrates how collaborative scientific, biomedical, political and public networks are collectively mobilised around the concept of dementia as a national crisis. Biomedical researchers are working hard to define themselves as the authoritative source of knowledge for an effective solution. However, I have shown that the concept of collaborations does not imply a unified community. Rather this ethnography demonstrates relations characterised by implicit fractures and tensions. Such fractures are particularly apparent in the way dementias and the research process itself is understood to exist and to function. I suggest therefore, that the role of such relations in dementia research is to maintain a state of suspension in the scientific process. By using the term maintained suspension I refer to the processes and practices by which research is kept open-ended and incomplete. This incompleteness creates space to respond to criticism of the failures of existing science, whilst sustaining trust and hope in the potential of future science.

In this conclusion, following Beck (1992, 1994) and Fischer (1999, 2005, 2007) I build on this argument, demonstrating how research knowledge is kept in a state of perpetual suspension, the end point continually shifting as the bases for that knowledge continues to evolve. Drawing on the work of Nowotny, Scott and Gibbons (2001) I argue that the relations which I describe as maintaining suspension in dementia research can be thought of as 'transgressive'. By using the concept of transgressive relations I argue that these are relations which make partial connections across scales (Strathern 1991, 1995a). Through institutions, technologies and discourses, such relations form and mediate between and across the boundaries of scientific practice. At these boundaries, interstitial research organisations and patient advocacy groups employ rhetorical imagery and language which both construct and blur the boundaries between dementia science and the roles of dementia and science in society. The role played by the public within science is shaped by these practices of blurring. This study thus presents a timely case-study of the strategic connections between contemporary science and society. I raise questions about the important future of this relationship, are they relations of collaboration or persuasion? This study supports the need for a dynamic and contextual approach to understanding

contemporary scientific practice and knowledge making and building on existing work which scrutinises the evolving relationship between dementia science and society.

Transgressive relations: boundary crossing in the interplay between science and society

The narratives, discourses and rhetorics of contemporary dementia science that I have presented in this thesis act as a snapshot of a scientific moment. In this moment the shape of knowledge about the diseases that cause dementia is rapidly changing and unfolding. This unfolding is marked by tensions evident in discourses that both validate and contest the role of age and aging in representations of dementia as a condition and as a social crisis. Furthermore, the boundaries and definitions of the conditions which cause dementia are both asserted and questioned. Dementias must be at once made concrete and stable objects for investigation and at the same time collapsed as incomplete and inadequate models of understanding.

This ethnographic study can, therefore, be described as an example of techno-scientific knowledge production made under the conditions of what Beck (1992) describes as the 'risk society'. In taking this approach, I am understanding knowledge formation as a process shaped by the increasing blurring of institutional and organisational boundaries, which lead to and emerge from conditions of 'intellectual and social volatility' (Nowotny, Scott & Gibbons 2001: 30). The pluralistic and ambivalent discourses that surround contemporary narratives of dementia in research reflect broader changes in the co-evolution of science and society. In this environment, knowledge-making processes are explicitly open ended and continual, rather than leading toward discrete or defined end points of knowledge. This process reflects what Nowotny, Scott and Gibbons describe as 'the production of the New in an open-ended process of moving towards a plurality of unknown futures' (2001:36).

Nowtony et al. (2005) argue that alongside this environment of uncertainty and plurality there has been a loss of public trust in science and scientific authority. Implicit in this change in the relationship between science and society are the increasingly blurred boundaries between science and industry that occur in large scale biomedical and biotechnological innovation (Nowotny

2005). Although important, the mistrust of this relationship is visible throughout my account of dementia research. Here relations with industry are viewed as fundamental to the research process, but are also a source of deep anxiety around who controls access to resources and information and to what ends. Such relations are perceived by both academic and clinical researchers to have the potential to compromise the autonomy and independence of scientific practice. As a consequence, there are ever increasing demands for scrutiny, transparency, accountability and public involvement in scientific, policy, funding and decision-making.

In this ethnography, these demands are realised in a particular way. Public engagement is understood by research leaders and policy makers as key to their strategy for managing the tensions, anxieties and competing expectations which emerge in the increasingly diffuse and interconnected landscape in which biomedical research takes place. In the cases I have described here, public involvement is part of the process of ensuring the social acceptability and success of an agenda which focuses clinical research on early diagnosis and early clinical intervention. As a result, the research process I have described is one of multiple and cross-cutting connections between researchers, academic institutions, and national and regional NHS research infrastructures (NIHR, MRC, UKCRNP, DeNDRoN,), and key elements of the patient and disease advocacy community (Alzheimer's Society, ARUK).

These connections are visible in the relationships formed by key scientific and clinical research leaders in the formation of, and involvement with, dementia advocacy and charity groups. As such, patient advocacy groups are shown to be a critical site for creating connections between potential recruits and clinical trials. In this relationship, biomedical research is identified as *the* fundamental tool for changing how we live with dementia. As such, patient advocacy groups can be understood to be what Epstein (1996) describes as para-political organisations. Such organisations conduct key boundary work, with senior scientists holding posts across social, scientific and political domains during their careers. To play on Epstein's concept, such organisations might, therefore, also be usefully thought of as para-scientific. By this I recognise the process of co-production at work (Jasanoff 2004, 2005, 2007). 'Para'-work not only flows from science to politics, but can also be see to affect the directions in which research practice and policy evolves. In bringing together experts and public / patient participants, such para

organisations are both a result of, and a driver for the further development of mode II science (Nowotny, Scott & Gibson 2001).

Throughout the thesis I have drawn attention to examples of relationality mediated by digital and virtual tools. Such domains of engagement play a critical role in the development and maintenance of these boundary crossing networks. For instance,: The Alzheimer's Society website provides links to the DeNDRoN groups in England, Wales, Northern Ireland and Scotland. Through the society's website a lay visitor can, at the click of a button, access the Clinical Research Network Study Portal (UKCRNP). The UKCRNP enables a visitor to view disease specific research taking place in their local region. The visitor can select a particular project and find out its aims, objectives, inclusion and exclusion criteria. The language of the UKCRNP is clearly biomedical and there are important questions to be asked about the availability and accessibility of such technological interfaces across different demographics. However, what is of particular interest here is the practice of facilitating connectivity itself, however partial or mediated that process might be. The developing virtual nature of evolving biomedical research networks marks an important shift in the evolutions of research accessibility for society. In just three clicks of a button, a member of the public can send an e-mail to the academic or clinician who is designated as a study's primary investigator. In three clicks a member of the public can start the process to see if they are eligible to participate in a clinical study for dementia. Such connectivity can be viewed as an example of what Nowotny, Scott and Gibbons (2001) describe as 'transgressive' technologies. That is, digital tools for research expansion are rapidly creating the potential for connectivity and collaborations which are 'eroding the boundaries between different forms of rationality' (Nowotny, Scott & Gibbons 2001: 32).

Dementia research has continued to be resilient in the competing market of disease movements, with a growing profile in the national health agenda between 2010 and 2014. The current scale and intensity of marketing and media campaigns for dementia awareness is unprecedented. The integration and potential of new forms of hypermedia and mainstream media are being used to full advantage to connect this field of research to national awareness. As I explored in chapter five, despite the often radically different situated knowledge involved (Starr 1988, 2010, Starr & Griesemer 1989, Starr & Bowker 1999), scientific images and images of science in such media further erodes the boundaries between researchers and public participants. Such images become

a tool for mediating between scientific practice and scientific engagement. The scientific images such as MRI, fMRI, PET and SEM used in public engagement suggests to relate concrete practices in the laboratory, to the much more open ended and future oriented goal of knowledge production which will affect real-world treatment practices. This is particularly true in the use of images of science, where generic images of the scientist at work are used to connect what happens today in the laboratory to the potential for a 'cure' for dementia tomorrow. This process of relating the concrete present to the intangible future, resonates with what Nowotny, Scott and Gibbons (2001) describe as a fundamental tension in social relations with science and technology more broadly:

> Science and technology are valued for their capacity to create new knowledge and deliver an apparently endless stream of new products, but they are also an equally limitless source of new desires and wishes - which can only be satisfied by 'more' science and technology. In this sense science and technology dominate in a double sense - by delivering 'real', or tangible, results; and by creating insatiable images.
>
> (Nowotny, Scott & Gibbons 2001: 31)

Images of scientific practice and the brain, are used to convey the potentiality of research innovation, in spite of the uncertain nature of the scientific process and complex shape that any future intervention for dementia might take.

Engaging, persuading and collaborating

What does this description of a science characterised by transgressive relations mean for science and society? By recognising that public and patient engagement has become folded into the policy strategy for successful biomedical research how should it be viewed? Is it a tool for creating transparent engagement and better science, or a tool for persuading people to become involved in clinical research?

The idea that public engagement in science is a pragmatic strategy and a tool for making willing and compliant subjects is well described in the existing literature (Callon 1999, Callon et al 2009, Caron-Flinterman, Broerse & Bunders 2005). This approach situates public engagement firmly in a Foucauldian framework of power relations within which society becomes complicit in the

reification of the hegemony of biomedical authority to define the value of the person (Foucault 1990, 1992, 1997; Rabinow 1996, Rabinow & Rose 2006, Rose 1991, 1996, 2007). Arnstein (1969) for example argued that 'engagement', particularly when supported by the state, demonstrate relatively limited levels of equity and exchange. Thus, the reality of engagement can, at worst, be viewed as what Epstein termed 'recruitmentology' (2008). In this framework, engagement maintains the appearance of social responsibility, whilst unilaterally supporting the aims of the scientific establishment. The practice fulfils the letter of ethical governance without necessitating a response to the needs or concerns generated by patient-public perspectives (c.f. Callon et al 2009).

Whilst the examples I have presented provide evidence for this imbalance of power, they also hint at the limits of this argument. I show at both the start and the end of the thesis three distinct examples where participants' voice their concerns about the aims and goals of dementia research, and the failure of research to translate into realisable products to improve the experience of people with dementia. It can be argued that these countering discourses are raised and quickly submerged by the narrative that researchers cannot simply override the complexity of the scientific process, rather dementia research is uniquely complex, under-resourced and takes time.

However, these moments of engagement do demonstrate that public engagement is not as controlled or controllable as an instrumentalisation approach would, at first, imply. Whilst dementia research charities undoubtedly bring powerful clinical and scientific influences into the process of patient advocacy and research agenda, they inevitably bring the public into the research processes. In doing so, they create new avenues and expectations for the public to exert pressure on how science is scrutinised, funded, approved, and conducted. As such, public engagement, being formed of many cross-cutting relations, cannot be wholly contained within the power structures of biomedical research. Exchanges between researchers and participants increasingly take place in the public domain and via virtual and social media. These exchanges are open to immediate scrutiny and comment by a range of actors. Interactions are recorded in perpetuity, and can be rapidly re-disseminated or re-used by an uncontrolled range of 'others', for their own independent aims or agendas. It therefore becomes increasingly difficult for scientists not to engage with or respond to these small challenges to the authority of biomedicine. The anxiety of researchers during these conversations in which the rehearsed narratives of

dementia science are resisted and challenged, suggest that public engagement is far from a perfectly controlled scientific tool. Rather, as Nowotny puts it, public engagement has become part of a dialogic environment of contemporary science:

> '[A]n increasingly vociferous civil society is questioning the authenticity of the public nature of science. In the demand for greater lay participation, science as an institution comes under pressure to be more accountable to citizens and less closely linked to the interests of politics, the state, and the market'.
>
> Nowotny (2005:3)

As I have demonstrated here, public engagement, has become increasingly important in shaping how scientists construct and re-tell the story of dementia research. Echoing the processes of co-evolution (Nowotny, Scott & Gibbons 2001) and the co-production of science and society (Jasanoff 2011), the process of public engagement, has the capacity to influence processes in science by constitutionally altering the shape of society. Thus, access to, and participation in, clinical research for dementia is increasingly reframed as both a social 'right' and a moral responsibility (Harris 2005). The combination of biomedical, public health and national economic agendas, with public engagement and political activism suggest clinical research is moving toward science as a form of 'social good', and participation as a normative social duty. By mobilising the moral and social responsibility to participate in the development of new medical treatments and biotechnological developments, research participation becomes embedded in the idea of social contract. However, the different organisational groups involved in this contract - clinical researcher, laboratory researcher, advocate groups and patient groups - retain distinct identities whilst coming together to work on the collective theme of dementia research. Such groups can have very different perspectives on, and interests in, dementia research. The resulting dialogues are made up of plural agendas and competing rhetorics. Competition becomes particularly apparent when researchers and participants seek to define 'good' science.

Thus the case of transgressive relations I describe in dementia research, can be seen to create a complex network of connections. These are connections which are not clean and linear, but messy and incomplete. To adapt to and influence the changing environment of clinical research,

stakeholders in the dementia research community both collaborate and compete. Their interests coalesce and diverge in dynamic, transitory and fragmented ways. Whilst engaged in collaboration and dialogue, researchers and public participants are driven by independent interests which can also bring them into social conflict. Collaborations and collective ties are used to mobilise social and moral rhetorics. As a result, the notion of 'good' science which emerges in dementia research is used to exert persuasive pressure in a range directions, leading to competing definitions of the aims, outcomes, products and processes of the science involved. Thus, this study of dementia science is indicative of the tensions, anxieties and uncertainties of contemporary biomedical research. This uncertainty, I argued is highly challenging to negotiate, but provides a key space for the rhetoric of hope and futurity which provide the momentum for the perpetual cycle of science.

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