

**The Role of Instruments for Screening Cognitive Function
and Alzheimer's disease: A Sociological Exploration**

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Abstract

This qualitative ethnographic study examines how cognitive screening tools are used in clinical practice in the process of articulating a classification of Alzheimer's disease (AD). An exploration of how these low-technological tools constitute AD is important because of their central role in detecting initial cognitive decline in the 'ageing population'. The study draws upon fieldwork undertaken across a secondary healthcare memory service and a major teaching hospital in the UK. Focusing on the everyday practices and interactions between clinicians, patients and these technologies, the study shows how these tools were made provisional, and yet emerged as central mediators for producing knowledge about AD. I explore the uncertainties associated with measures of cognitive decline and consider how these were navigated and managed through the making of the tools as provisional devices. I continue by showing how the tools emerged as central mediators for negotiating how classification *proceeded* in medical practice: producing and reproducing professional hierarchies and identities. I also investigate how uncertainty was mobilised by clinicians to constitute the boundaries of classification; fuelled by the possibility that patients may go on to develop AD. Finally, I demonstrate how the adoption of the tools in the wider policy terrain translated into everyday clinical practice; increased efforts to quantify cognitive decline at earlier stages, produced uncertainty around patient futures. I reflect on how the making of these tools as provisional devices, relied upon and resulted in the portability of these devices and, in turn, constituted AD. Portability highlights the temporal and spatial aspects of classification processes involved in diagnosis/prognosis, as well as patient and professional identities and autonomy. I conclude by considering the implications of these findings for the diagnosis and management of patients with cognitive decline and AD locally in the clinic, and with respect to managing the 'ageing population'.

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Abbreviations

ACE 111	Addenbrooke's Cognitive Examination Version Three
AMTS	Abbreviated Mental Test Score
AMU	Acute Medial Unit
CST	Cognitive screening tool
CT	Computerised Tomography
GP	General Practitioner
MCI	Mild Cognitive Impairment
MDT	Multi-disciplinary Team
MoCA	Montreal Cognitive Assessment
MRI	Magnetic Resonance Imaging
CQUIN	Commissioning for Quality and Innovation Framework
REC	Research Ethics Committee
STS	Science and Technology Studies

Chapter One

Introduction

In 1906, Alois Alzheimer described the ‘peculiar case’ of Auguste D; a case that represents the first known patient to be described with what is now termed Alzheimer’s disease (AD) (see Alzheimer’s Society, 2015d). AD is used to label individuals with symptoms of cognitive decline (memory loss being a significant factor of AD), not attributable to normal ageing processes¹ (Ibid.). Alzheimer’s disease is a progressive disease and is also the most common form of dementia; dementia is the end stage of accumulated pathology (Alzheimer’s Society, 2015d). The World Health Organisation (2015) defines dementia² as,

“A syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement...the impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.”

Dementia of the Alzheimer’s disease type is however, a complex condition to diagnose and treat, as there are no known causes of the condition, and a definitive diagnosis can only be made at post-mortem examination (Hardy, 2006). Furthermore, symptoms associated with AD are difficult to determine from the presentations of normal ageing (Gubrium, 1986). Age however, is known to be the greatest risk factor for developing the condition (Alzheimer’s Society, 2015d) and subsequently, with the advent of an

¹ The term was initially used to describe decline in cognitive function in individuals below the age of 65. However, there is now a categorical distinction between early onset (30-65 years) AD and late onset AD (over the age of 65) (Alzheimer’s Society, 2015d). This thesis focuses attention on the process of diagnosing Alzheimer’s disease in individual’s aged 65 and over.

² The World Health Organisation does not provide a definition of AD more specifically

‘ageing population’, social policy (see Department of Health 2012 ‘The Prime Minister’s Challenge on Dementia’), and medical research and practice in the UK (see Alzheimer’s Research UK, 2015b and Medical Research Councils Neurosciences Mental Health Board, 2013) has firmly cemented the disease as a site for critical attention.

Expansion of AD in the ‘ageing population’

The ‘ageing population’ pertains to an increase in individuals over the age of 65 (see Rajah, 2009). According to the Alzheimer’s Society (2015c), there are currently estimated to be 850,000 people with dementia in the UK, of which approximately 67% have been diagnosed with dementia of the Alzheimer’s disease type. In accordance with the ‘ageing population’, this figure is set to exceed one million by the year 2025 (Ibid.). The expected increase in prevalence of the disease, presents a set of unique challenges for healthcare practitioners, family members and patients. These challenges range from increased pressure on primary care GP services and memory services in terms of referral rates, to the challenges facing family members in terms of care, at a time when the NHS is undergoing significant economic and political change³. Financially, the cost of dementia overall to the UK economy is estimated to reach £26 billion per annum (Alzheimer’s Society, 2015b)⁴.

³ The Health and Social Care Act introduced by the Coalition government in 2012 marks one of the most significant changes to the structure of the NHS in its 65-year history. Primary care trusts have been replaced with Clinical Commissioning Groups, which control the financing of local services; commissioning has become a process of competitive tendering to both voluntary and private sectors (See Department of Health, 2015; Kings Fund, 2015). The Alzheimer’s Society raised its own concerns with regards to the implementation of the bill, particularly in relation to the role of GPs as commissioners. The Alzheimer’s Society argues that there is a lack of awareness and understanding of dementia amongst GPs. As the role of GPs widens to become part of the commissioning process, the consequences of this lack of knowledge could mean that the needs of patients and their carers are not met. The organisation recommends that GPs increase their understanding of dementia for both their clinical and commissioning capacity to meet the challenges associated with the expected growth in the number of people predicted to develop dementia (see ‘Contribution to the Health and Social Care Bill Listening Exercise’, Alzheimer’s Society, 2011).

⁴ Organisations such as the Alzheimer’s Society only provide statistics for those living with dementia, they do not specify between types of dementia in their statistical estimations.

In order to manage the growth of AD specifically, and dementia overall in line with the advent of an ‘ageing population’, medical and scientific research and healthcare policy has responded accordingly. Alzheimer’s Research UK in its ‘defeat dementia campaign’ sets out to increase research investment by £100 million over the course of five years (Alzheimer’s Research UK, 2015c). These funds will be utilised to drive research output and increase the number of researchers within the organisation by 50% by 2020; encourage international collaboration and open access of intellectual property and regulation, and translate research into treatment in order to improve the quality of life for those living with dementia.

In healthcare policy, reports such as ‘Dementia UK: The full report’, by Kings College London and the London School of Economics (2007), outlines the impact and economic costs of dementia in the UK. It sets out the aim in policy to make dementia a national challenge, whilst focussing on the structure of health and social care more generally. More recently, the ‘Prime Minister’s Challenge on Dementia’ published in 2012, highlights the potential impact of the ‘ageing population’ on the role of healthcare practitioners, care workers, allied health professionals, non-governmental organisations (NGO’s), and non-profit organisations (Department of Health, 2012a, 2015b). The second phase of the Prime Minister’s ‘dementia challenge’ (2015-2020) which is currently being implemented, sets out to further improve dementia care and support for patients, families and carers. It also aims to advance innovation in research into dementia and other neurodegenerative diseases (Department of Health, 2015b). Setting out to equip the population with knowledge and resources to manage this ‘ageing population’ is considered crucial by the Prime Minister (PM) to ensure quality clinical practice, and health and social care. At a clinical level, this equates to ensuring more accurate and earlier diagnosis, prognosis and treatment of AD, and dementia more broadly.

As well as being a national concern, dementia is also a global concern. The G8 dementia summit held in London, UK in 2013 set out the aim to ‘develop co-ordinated global action on dementia’. Discussions focussed on,

‘improving life and care for people affected by dementia and their carers, preventing and delaying dementia, and social adaptation to global ageing and dementia’ (see ‘The Dementia Challenge, G8 Summit’, Department of Health, 2013). During the summit, plans were unveiled to significantly increase the amount spent on dementia research to follow the ‘global envoys’ on HIV and AIDS and on Climate Change’ (Department of Health, 2013). Investment in social and healthcare resources and technological and intellectual resources to manage the growth of AD in the ageing population, is subsequently the focus of debate in the UK and globally.

Diagnosing Alzheimer’s disease

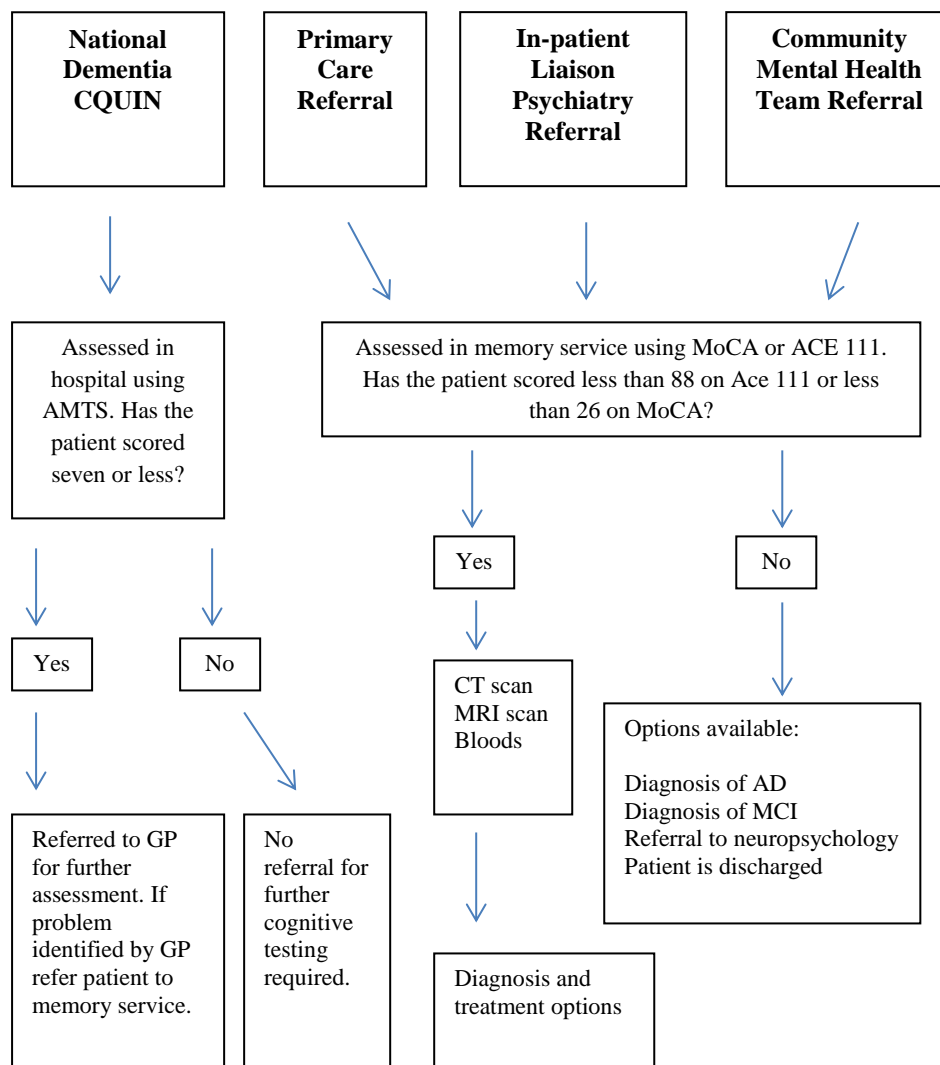
In terms of diagnosing the disease, medical and scientific research and healthcare policy in the UK, is currently being driven towards efforts to detect the condition in its earliest stages. According to the Alzheimer’s Society (2015c), approximately only 44% of individuals in the UK living with the symptoms of AD have received a formal diagnosis. As a result, developing methods, which promote diagnosis rates overall, and efforts to find a cause, cure and treatment for the disease at earlier stages, drives both medical research and healthcare policy (see Dubois *et al.*, 2007; Department of Health, 2012, 2015; Zetterberg, 2011). Biomarker technologies in particular, which aim to detect the earliest stages of AD, are the focus of current research developments worldwide (see Dubois *et al.*, 2007; Alzheimer’s Research UK, 2015b). In healthcare policy, initiatives such as the National Dementia Commissioning for Quality and Innovation Framework (CQUIN) in secondary healthcare, and the Enhanced Service Specification for Facilitating Timely Diagnosis and Support for People with Dementia 2015/16’ in primary care, aim to financially award NHS services for increasing referral and subsequent diagnosis rates in the clinic⁵ (NHS England, 2015a, 2015b).

⁵ Introducing targets to detect dementia in clinical practice has been met with controversy amongst practising GPs (see Brunet, 2014).

Despite current research programmes and healthcare policy initiatives, which aim to increase diagnosis rates overall, and early diagnosis more specifically, the act of diagnosing the disease in the clinic remains uncertain. As I will explore in more detail in Chapter Two, the disease category of AD and its nosological framework are complex, which makes diagnosing the disease difficult.

The following diagram depicts the number of pathways through which patients are assessed and referred to specialist old-age psychiatric memory service.⁶

Pathways into Specialist Old-Age Psychiatric Memory Service



⁶ This diagram refers only to the memory service included in this research and I am therefore not suggesting that this represents the case of all memory services across the UK.

In the clinic, instruments for screening cognitive function⁷ are the tools used to detect the initial stages of cognitive decline associated with AD. These low-technological tools assess and review levels of cognitive function associated with diseases such as AD (Ismail *et al.*, 2010). The tools used in the memory service, and of pertinence to this research, are the Montreal Cognitive Assessment (MoCA) and the Addenbrooke's Cognitive Examination 111 (ACE 111). These tools are open access and their reliability and validity in clinical practice has been well researched (see Nasreddine *et al.*, 2005; Mathuranath *et al.*, 2005; Mioshi *et al.*, 2006; Ismail *et al.*, 2010; Newman and Feldman, 2011). Cognitive screening tools have however, been criticised for their cultural insensitivity and with insensitivity to factors including age, education and socioeconomic status known to affect patients' scores (see Crum *et al.*, 1993; Parker and Philip, 2004). The tools also enact particular representations of class since a number of questions on the ACE 111, for example, require patients to understand the meaning of words including 'marsupial' and 'nautical'; categorising only those individuals who have specific levels of academic, educational attainment. The MoCA and the ACE 111 are also culturally specific, requiring individuals to recall previous UK Prime Ministers and US Presidents. The ACE 111 is also a time consuming test requiring high levels of concentration; difficult to maintain if the patient is struggling to answer the questions. As one clinician exclaimed during an observation of a team meeting, 'it's no wonder he [the patient] fell asleep, do you know how long it [the ACE 111] takes?' These tools have therefore been subject to criticism both across psychological and psychiatric research and as shown in the above quote, more tacitly amongst clinicians in the memory service, as this thesis will go on to demonstrate.

An additional tool of pertinence to this research is the AMTS as adopted in frameworks which govern diagnosis rates in secondary healthcare including the National Dementia CQUIN. The Department of Health introduced the National Dementia CQUIN In an effort to standardise screening practices

⁷ The terms 'instruments for screening cognitive function' and 'cognitive screening tools' are used interchangeably throughout this thesis.

and improve the identification of dementia in acute hospital settings. The initiative aims to identify patients with dementia and assess levels of cognitive function to prompt relevant referral and follow up after leaving hospital (Department of Health, 2012). The framework was developed in response to widespread concern regarding the care of people with dementia in general hospital, including length of stay and inaccuracy of clinical coding (see Department of Health, 2012 report ‘Using the Commissioning for Quality and Innovation (CQUIN) payment framework guidance on new national goals for 2012-2013’). In brief, the framework relies on the use of a particular instrument for screening cognitive function; the Abbreviated Mental Test (AMT) to identify those who may have pathological cognitive decline associated with Alzheimer’s disease and overall dementia⁸. The AMTS is a brief 10-item scale for the detection of pathological cognitive decline. Introduced in 1972 by Hodkinson, this screening test was developed by geriatricians to be used routinely within secondary care hospital settings (Woodford and George, 2007).

The AMTS, MoCA and ACE 111 are used alongside diagnostic technologies including Magnetic Resonance Imaging (MRI) and/or Computerised Tomography (CT) scans, and blood tests to rule out pathologies associated with other diseases such as cancer. Instruments for screening cognitive function play a central role in detecting *initial* cognitive decline. They are therefore important devices for navigating the complex terrain of diagnosing AD during initial consultations in the clinic, and navigating the challenges associated with an ageing population, as healthcare services are dealing with an increasing number of diagnostic referrals.

Whilst these tools are low-technological, and complex; time consuming, culturally insensitive, and enact particular representations of class, they are pervasive technologies across healthcare for detecting the initial stages of

⁸ Patients aged 75 and over admitted to an Acute Medical Unit (AMU) are assessed using an AMTS and referred to primary care for further testing if they score 7 or less/10.

cognitive decline. Given their low-technological and seemingly mundane status, the sociological significance of these tools is perhaps questionable, particularly when comparing them with the central focus in Science and Technology Studies (STS), on technological innovation for producing knowledge about disease. However, whilst these low-technological tools may appear to lack the sophistication associated with innovative technologies, which dominate the critical attention of STS, as I show throughout this thesis, these tools are in fact far from mundane. These tools remain the only technologies for assessing cognitive decline in initial consultations, and therefore play important roles in producing the *realities* of cognitive decline that could be associated with AD. They are important devices in the organisation of the memory service; they emerge as central mediators for producing knowledge about AD, and for negotiating the uncertainties inherent to diagnosing the disease, particularly since there remains no cure and there is a lack of treatment options available.

I explore the role of these low-technological tools in everyday clinical practice yet, I also critically examine the ways in which these technologies and diagnosis overall, are governed in initiatives such as the National Dementia Commissioning for Quality and Innovation (CQUIN) Framework aiming to increase diagnosis rates and detect cognitive impairment at earlier stages. Subsequently, it is important to distinguish between technologies of governance such as the CQUIN and the tools used in everyday clinical practice. In doing so, I demonstrate the practices involved as the CQUIN is adopted in everyday clinical practice and elucidate the ways in which these technologies of governance are approached and performed by healthcare practitioners involved in the diagnosis process (c.f. Latimer, 2000). These technologies of governance differ from everyday technologies in clinical practice and have the potential to reaffirm the role of medicine as ‘spectacle’ (Ibid.). Medicine as ‘spectacle’ has the potential to shift the ways in which the patient is approached in the hospital setting, the role of the professional, the tacit working practices of clinicians, the ways in which cognitive screening tools are negotiated and articulated, and subsequently the diagnosis process. As a result, I examine both the everyday role of

cognitive screening tools in the memory service alongside the frameworks through which diagnosis is governed: the CQUIN as a technology of governance is critically analysed. As this thesis demonstrates more broadly, the sociological significance of these technologies emerges as their operation in practice as a whole is investigated: bridging current understandings regarding age, diagnosis, and medical practice. Overall, I deploy the analytical gaze to that which is ‘taken for granted’ (Woolgar and Neyland, 2013).

It is timely to explore how clinicians navigate and negotiate the complexity associated with diagnosing AD locally in the clinic, and with respect to managing the ageing population more broadly. To do so, I investigate both the role of these cognitive screening tools in the clinic, and as adopted in initiatives such as the National Dementia CQUIN. I elucidate how the tools are used by clinicians to make sense of diagnosis in the clinic, and for family members and patients struggling to cope with increasing demands. In what follows, I will briefly outline the ways in which AD as a complex disease category has been explored within medical sociology, STS, philosophy and ageing literatures, which I develop in more detail in Chapter Two.

Previous Research

Alzheimer’s disease has previously been the subject of academic attention in sociology, philosophy, anthropology and STS; each discussion drawing on different methods and frameworks to critically examine the emergence of AD from its inception in 1906. Overall, the majority of these studies can be categorised as approaching two distinctive yet interrelated aspects of the condition. First, a number of studies investigate the experiences of individuals with a diagnosis of dementia in terms of how care and caregiving practices are approached and performed (Post, 1995; Kitwood, 1997; Wilkinson, 2002; Adams and Gardiner, 2005). Concern for preservation of personhood and ‘self’ in approaches towards care, drive the core interests of authors such as Post (1995) and Kitwood (1997). Yet, in

response to the claim that a more person-centred structure of care fails to recognise the role of carers and family members, a more ‘relationship-centred’ approach has since been suggested (Adams and Gardiner, 2005). This approach takes into consideration the experiences of individuals with dementia, informal carer(s), and one or more health and social care perspectives (Adams and Gardiner, 2005). It highlights the extent to which the experiences of the dementia patient are integrated with that of their carer, and was developed in response to the *absence* of the carer in previous discussions on care practices (Ibid.). Focussing attention on the experiences of individuals with a diagnosis in relation to preservation of ‘self’, corresponds with literature across medical sociology and ageing studies. Research in these areas has explored the embodied identity and lived experiences of individuals with a diagnosis of dementia (see Twigg, 2010; Twigg and Buse, 2013), and in turn, the (re)emergence of senility, which shapes the ways in which individuals experience the ageing process as a discursive construct between unsuccessful and successful ageing processes (see Gilleard and Higgs, 2010, 2013; Higgs and Gilleard, 2014).

Second, a proliferation of studies in philosophy, medical sociology and STS, critically examines AD as a diagnostic category. Scholars writing in the tradition of social constructivism, discuss the case of Alzheimer’s in relation to a series of ‘historical moments’ interpreted in specific ways which have shaped current understandings of the disease (Gaines and Whitehouse, 2006). It is argued that the disease is a socio-historical and a socio-cultural construction of which the difficulty in determining normal from pathological ageing processes has been a key factor of analysis (Gubrium, 1986; Lock, 2005; Gaines and Whitehouse, 2006). Linked to the idea that AD is a socially constructed disease criterion, the expansion of the category to incorporate the earliest stages of the disease (Mild Cognitive Impairment), intersects across wider debates around the medicalisation and biomedicalisation of ageing, and the difficulty in determining early stages of AD from ‘normal’ ageing processes (Estes and Binney, 1989; Kaufman *et al.*, 2004; Whitehouse and Moody, 2006; Moreira, May and Bond, 2009).

The emergence of AD as a public health priority and its expansion as a diagnostic category to incorporate MCI has also been extensively discussed by Peters and Katz (2015). Peters and Katz (2013) not only highlight the economic, political and social processes through which the category of AD emerged and has since been reconfigured to incorporate labels such as MCI, their work captures the ways in which ageing as a set of processes is being managed and (re)constructed more broadly. In the special issue of *Dementia* titled 'Voices from the Field: Expert Reflections on Mild Cognitive Impairment', Peters and Katz (2015) draw on data from interviews with leading scientists and researchers to explore MCI as a diagnostic classification. The authors found that these experts 'produced as many questions as they did answers' particularly around the meaning of MCI and its validity as a diagnostic category (pp. 285). The authors thus highlight the need to approach MCI with both care and caution for understanding how the label relates to ideas around the ageing brain. Developing the crux of arguments made in the field of social studies of ageing (see Gilleard and Higgs, 2010, 2013; Higgs and Gilleard, 2014), as chronological age becomes less of a marker by which successful ageing is constructed (given the increasing ageing population), other standards or markers enact ideas around what it means to age successfully, of which memory loss has become a significant factor: 'cognitive health has joined physical health as a key indicator of successful ageing' (Peters and Katz, 2015: 285). Peters and Katz (2013) summarise the crux of their arguments in the following question, 'how can we disentangle the public or 'neuro' culture of the ageing brain and our anxieties about growing older from the sciences that aim to identify risk, assess cognitive status, and treat and care for people with dementia'?

There remains a substantial degree of uncertainty around what MCI is, and what it actually means, despite the fact that the label has gained traction within scientific research, medical practice and public health, to describe and/or explain the earliest stages of cognitive decline. Expectations for maintaining, improving or enhancing the ageing brain have led to the notion

that MCI as a predictor of brain ill-health has an important role to play when negotiating the ‘successes’ of the ageing process.

Focus of attention on the earliest stages of the disease within current medical and scientific development, has also been criticised as the proliferation of technological innovation such as biomarker technologies in research, has reignited debates around the prevailing biomedical model for managing AD. First, it has been argued that this model fails to recognise the socio-cultural dimensions of diagnosis, and second, that it fails to privilege care as a viable alternative for managing the disease, particularly when it is difficult to categorise overall (Chaufan, Hollister and Fox, 2012; Cuijpers, Lente, Boenink and Moors, 2014; Cuijpers and Lente, 2014). Lock (2013) is especially critical of increased efforts in biomedicine to prevent AD and detect cognitive decline at earlier stages. Lock (2013) maps the shift in Alzheimer’s research from focusing on reversing the symptoms of the condition to preventing its onset. This shift is grounded on the conception that prevention strategies will lead to an improved understanding of AD’s aetiology. Yet, as Lock shows throughout her work, uncertainty with regards the aetiology of AD prevails, despite increased attention on disease prevention in research and policy.

Lock (2013) highlights the dilemmas emergent from, and embedded in, efforts to prevent Alzheimer’s disease through early detection of pre-symptomatic changes in the brain in healthy individuals. In doing so, Lock engages with ideas around biomedical uncertainty regarding complex neurological disorders such as Alzheimer’s disease of which there is no known cause or cure, despite increasing financial investment in medical and scientific research. As Lock (2013) contends, AD ‘is the most commonly diagnosed subcategory of dementia [and] proves to be an elusive phenomenon’ (pp. 11). Lock focusses on the uncertainties associated with attempting to detect AD as scientists remain committed to understanding the disease within biomedical and neurogenetic frameworks.

In doing so, Lock (2013) argues that there are inherent ‘uncertainties associated with predicting the future by means of biomarker testing’, which produces anxieties for patients (pp. 98). Lock subsequently investigates how individuals make sense of genetic risk demonstrating that despite the dominance of biomedical narratives regarding risk and disease progression, selfhood and care dominates patients’ concerns. Deconstructing the uncertainties and ambiguities inherent to diagnosing AD, efforts to detect AD at earlier stages, and the prevailing biomedical and neurogenetic lens through which AD is positioned, is the crux of Lock’s work.

Taken together, focus of attention on AD in previous research, shows how the emergence of the disease category, and expansion of interest in the disease, has triggered critical debates in two distinctive ways. First, in relation to the experiences of individuals with a diagnosis in terms of identity, self and material practices of care, and second, in relation to the diagnostic categorisation of AD as a socio-historical construction bound temporally, spatially and historically. Whilst the contribution of existing themes found in previous literatures is indisputable, they can be subjected to criticism. Despite the theme of complexity being at the centre of debates around the disease category of AD and its social, cultural and historical construction, the processes through which this complexity is navigated and managed in everyday, routine practice requires further in-depth exploration. Furthermore, the technologies, which play a central role in detecting initial cognitive decline associated with AD, is an under researched area within medical sociology, STS and ageing literatures. Whilst low-technological cognitive screening tools which pervade clinical practice have been subjected to rigorous studies testing their reliability and validity in the fields of psychiatry and psychology (see Jitapunkul *et al.*, 1991; Ihl *et al.*, 1992, Tombaugh and McIntyre, 1992; Crum *et al.*, 2003; Claes *et al.*, 2004; Davey and Jamieson, 2004; Parker and Phillip, 2004; Mitchell, 2008; Nieuwenhuis-Mark, 2010; Marioni *et al.*, 2011), their role in the clinic from a sociological perspective has yet to be explored. Furthermore, whilst studies with an STS perspective such as Moreira (2010), considers how memory loss emerges and is managed in UK memory clinics, an

investigation of the role of these particular technologies used in this process, remains an interesting area for exploration in sociological research.

Focussing on cognitive screening tools is fruitful for elucidating both how a diagnosis of AD is made sense of in the clinic, and on the potential impact that the ageing population might have on existing practice. In addition, an investigation into how these technologies operate in the clinic for bridging current understandings around age, diagnosis and medical practice, is important since there has been no substantial sociological attention given to how complexity is resolved, how discursive constructs around age and AD are handled in the clinic, and whether the expansion of the disease in an 'ageing population' has shifted and (re)configured current practice. Whilst ageing studies have investigated the re-emergence of senility and the ageing process as a constructed success or failure (see Gilleard and Higgs, 2010, 2013), given that age is a risk factor for developing AD, the effects of these discursive entanglements on the diagnosis process, would be an interesting dimension for exploration; absent from previous literature.

Additionally, although the experiences of *patients* diagnosed with dementia overall, and AD more specifically, occupies a dominant position in recent sociological literature (see Twigg, 2010; Twigg and Buse, 2013), research which takes into account the perspectives of professionals, particularly in the decision making *process* remains to be explored in-depth. Clinicians are, as highlighted at the beginning of this chapter, under increasing pressure to refer individuals for assessment, and to prepare the diagnostic pathway for patients in an 'ageing population' and changing healthcare environment. Reflecting on instruments for screening cognitive function embedded in healthcare practice and exploring that which goes unnoticed, is also productive when there is a plethora of studies in STS on *innovation* and its myriad of uncertainties.

Research Outline

A study which investigates how AD is classified through the use of cognitive screening tools enables a closer look at the world(s) of AD within and outside the confines of the clinic which thus far, has have gone relatively unnoticed in debates regarding AD and diagnosis. This research develops an ethnographic approach to explore how Alzheimer's disease is diagnosed in everyday clinical practice. At the intersections of medical sociology and STS, I investigate the process of diagnosis by centring cognitive screening tools as agentic devices for producing knowledge about cognitive decline, and analysing their operation in practice. Attending to the role of these technologies within complex socio-material practices and socio-technical environments (Berg, 1996; Mol, 1998, 2002a, 2002b; Latimer *et al.*, 2006; Latimer, 2013), enables a more nuanced perspective of what occurs 'on the ground'; beyond the taken for granted status of these pervasive technologies since they play a central role in the medical decision making process (c.f. Woolgar and Neyland, 2013). In effect, I turn the complexities of an AD diagnosis into matters of the everyday and I investigate how clinicians⁹ navigate the practices of classification in the clinic, identifying how AD is made up or 'done' (Garfinkel, 1967; Latimer, 2013). AD as a complex interplay of practices, which 'make up' diagnosis is worthwhile for exploration particularly when considering the extent to which diagnosis is a social *process* and AD is a nosologically complex and evolving phenomenon. This has the potential to shape debates around current diagnostic practice within the context of the 'ageing population', and the healthcare challenges it poses. In the following section of the chapter, I shall explain my aims and objectives for the thesis and outline the remaining seven chapters.

Current study

I explored both the role of cognitive screening tools in the clinic in everyday, routine practice, and their role as adopted in the National

⁹ I use this term to refer to a wide range of clinical staff and not simply medical doctors.

Dementia CQUIN. As I will discuss in more detail in Chapter Four, the current study was situated within a secondary healthcare UK memory service and a large teaching hospital trust in a metropolitan city. I conducted an ethnographically inspired study working with two memory clinic teams within the memory service across two different geographical areas of the city, an elderly medicine department within the teaching hospital and informatics department of a teaching hospital trust. I observed fourteen hours' worth of team meetings and consultations, and interviewed twenty-one healthcare professionals and two information managers. Whilst I observed clinicians from two memory clinic teams within one memory service this is not a comparative study. I set out to capture the interests of the memory service more broadly, rather than exploring the subtleties of difference between approach and practice across teams. Furthermore, I did not have access to observe memory nurses across both teams and as such a comparative study would have been imbalanced. The overarching concern of this thesis was to explore professional practice regarding the use of cognitive screening tools overall, as opposed to drawing attention to differences in practice and protocol across the two teams. Throughout my thesis, I explore the interactions across healthcare practice however, I do not focus solely on the patient-professional dyad in isolation, rather; this interaction is only a part of the whole and not the whole itself. The interaction between professionals and patients is only one aspect of the diagnostic process. With this in mind, I critically analyse both the micro processes of the clinic, and the adoption of the tools at a macro level in the wider policy terrain for managing the ageing population.

My primary focus for this research is on how clinicians use cognitive screening tools to navigate complexity in the diagnostic decision-making process. By recognising the constitutive role of medical technologies in healthcare (Berg, 1996; Mol, 1998, 2002a), I am interested in how the tools establish interactions, and mediate working practices across the situated contexts in which AD is 'done' (Garfinkel, 1967). Exploring how these tools produce and reproduce hierarchies, I also describe and analyse how clinicians approach these tools, explore who adjudicates on their use, where

they are adopted and by whom, across the spatiality and temporality of the decision-making process. Overall, this means I illuminate the multiple ways in which complexity is made sense of for producing knowledge about disease both within the arena of the clinic and the wider policy terrain. I am particularly interested in the use of cognitive screening tools within moments of performance and interaction (Goffman, 1959; Garfinkel, 1967; Mol, 1998; 2002a).

In line with my ethnographic approach, I do not ascribe AD a pre-defined ontological status and I abandon *a priori* knowledge, regarding disease classification. As I demonstrate in Chapter Two and Chapter Three, I hope to contribute to the literature on constitution or enactment of disease in practice through technologies in the clinic (Berg, 1996; Mol, 1998, 2002a; Latimer, 2013), risk and complexity in healthcare (Estes and Binney, 1989; Rose, 1998; Conrad, 2005), professional organisation literature (Latimer, 2000; Latimer, 2004) and the ageing process (Gilleard and Higgs, 2010, 2011, 2013; Higgs and Gilleard, 2014). However, I extend this literature in a number of significant ways adding to existing understandings of ageing, diagnosis and medical practice. First, I extend previous literature by demonstrating the power of mundane technologies as agents in the process of diagnosis. Second, I explore how the tools produce and reproduce professional power relations (hierarchies and identities) within a complex distribution of practice on a micro level. I also investigate the wider distributions of power with respect to the ageing population, through initiatives such as the National dementia CQUIN. In doing so, I highlight the temporalities of classification for producing knowledge about cognitive decline and AD. Third, I extend existing literature on ageing and risk, by exploring how the tools are implicitly involved in the construction of particular discursive representations and expectations of age and ageing, which has important implications for how diagnosis is approached in the clinic. Overall, I demonstrate how AD is a site for critical attention by intertwining social (senility, ageing, classification boundaries, risk), medical (the growth of scientific knowledge, screening, MCI), and political (case

finding, early diagnosis, increasing diagnosis rates, policy frameworks, screening) developments.

Aims and Structure of the Thesis

In this thesis, I shall answer one main research question guided by three sub-questions in order to critically examine the role of instruments for screening cognitive function in constituting cognitive decline and AD, within and beyond the confines of the clinic. My overarching research question asks, how do instruments for screening cognitive function constitute Alzheimer's disease at various sites of clinical and policy practice?

The following three sub-questions guide my empirical chapters –

How do clinicians use instruments for screening cognitive function to navigate and manage the uncertainties associated with measures of cognitive decline and articulate a formal classification of AD?

How do clinicians use instruments for screening cognitive function to negotiate the boundaries of classification in the organisation of clinical practice towards the production of AD diagnosis?

How do increased efforts to detect cognitive decline as laid out in the National Dementia CQUIN translate into clinical practice in the process of classifying AD?

In the following chapter, I will explore the clinical history of AD before continuing by engaging with key debates in medical sociology, STS, anthropology and philosophy. Debates within these literatures of relevance to this thesis, investigate AD as a socially, culturally and historically constructed phenomenon from its inception in 1906, to its establishment as a clinical diagnostic category in 1984, revised in 2011. I therefore identify opportunities to build on in current research as highlighted in this chapter,

and extend current debates particularly around how technologies operate in practice within a complex diagnostic process.

In Chapter Three, I outline the theoretical foundations of the thesis. I draw predominantly on an approach that demonstrates the constitutive role of medical technologies (Berg, 1996; Mol, 1998, 2002a), and adopt ethnomethodological sensibilities (Garfinkel, 1967) for exploring everyday healthcare practice. I do not however, remain wholly committed to these perspectives and I engage in theoretical pluralism or conceptual scaffolding (Goffman, 1959), by drawing on a wide range of concepts and ideas from a number of different perspectives bearing in mind that: ‘scaffolds, after all, are to build other things with, and should be erected with an eye to taking them down’ (pp. 246). Following this, Chapter Four comprises an outline of the practicalities and methods of my research in terms of gaining NHS ethical approval, the fieldwork process, data analysis, and my approach to ethnography, including a broad overview of the theoretical positions on which my *methodology* is grounded.

Chapters Five to Seven outline and present the key findings of my data. I begin analysis in Chapter Five by investigating the role of cognitive screening tools in the clinician-patient interaction. I demonstrate that within the organisation of the memory service, the tools are approached and performed as provisional devices by clinicians, for navigating and managing the complexities associated with measures of cognitive decline. The articulation work in the clinic is performed in order to navigate and manage three core elements of uncertainty associated with measures of cognitive decline. However, at the same time that I demonstrate what I describe as the ‘making of provisionality’, through the mediation and manipulation practices in the clinic, the tools also emerge as central mediators for producing knowledge about AD, within a complex distribution of medical practice. Within the organisation of the memory service, approaching and therefore *performing* the tools as provisional devices renders them portable as they shift across different settings. In doing so, they produce and reproduce professional hierarchies, confirming the idea that medical

technologies are implicitly involved in maintaining power relations in healthcare (Berg, 1996). However, as they shift across different spaces, the tools also align with what is socially and culturally significant for negotiating classification, and memory nurses are able to craft a unique space for responsibility within the MDT. The final section of the chapter demonstrates an important feature of the co-production of cognitive decline: the informal or ad hoc practices of the clinic are balanced alongside the formal quantified element of the technologies. I investigate how this co-production renders the tools portable for proceeding with classification. Overall, the chapter is grounded in a broader discussion around negotiating uncertainty, and professional and patient identities and hierarchies.

In Chapter Six, I explore how clinicians use cognitive screening tools to constitute the boundaries of classification, performed in response to the enactment of risk and complexity in the clinic. I demonstrate that uncertainty is mobilised by clinicians where patients are kept on for review, which is fuelled more broadly by the possibility that patients may go on to develop AD. This is driven by a borderline score on a cognitive screening tool, and patients are deferred to psychology. The space for deferral (Latimer, 2013) is simultaneously constituted through efforts to manage risk, and the expectations around the field of psychology in terms of specialist expertise and experience for resolving the borderlines. This deferral space is performed as both a technological and organisational endeavour. Overall, given the lack of diagnostic certainty around AD and treatment options for the disease, the space for deferral mobilises action and performs hope; uncertainty is utilised and valued. In the second section of the chapter, I extend the theme of risk and risk thinking, to demonstrate a further example of the borderlines of classification: the label MCI. Whilst MCI ‘depends on the language of risk’ (Webster, 2002: 447), it also depends on the extent to which the label constitutes particular discursive constructs around ageing, and the ageing process as a success or failure. The expansion of the disease to incorporate MCI is therefore involved in the construction of expectations around age, ageing and AD; it impacts how clinicians constitute the boundaries of the disease and label normal ageing,

MCI and AD. In this sense, the tools both enact risk through a borderline score mobilised by clinicians, but also *produce* risk and uncertainty for patients faced with a borderline condition.

In Chapter Seven, I extend this theme of risk, and explore how instruments for screening cognitive function are adopted in policy frameworks such as the National Dementia CQUIN, where I analyse how the framework translates into everyday clinical practice. The CQUIN is constitutive of wider networks of power in the organisation of healthcare, which is demonstrated by its aim to govern clinical practice (Rose, 1998). However, I extend this body of literature by reflecting on the extent to which the CQUIN shifts the temporalities of classification as it enacts the patient pathway. I engage with literature on the sociology of expectations, which demonstrates that the realisation of future(s) depends on particular representations of temporality in the present, which shifts as the CQUIN is translated in practice. I highlight the ways in which the CQUIN shifts how patients conceive the nature of diagnosis in the clinic, as it is implicitly involved in constructing patients' expectations around a future with AD, which produces as opposed to resolves the uncertainties in the clinic. It also reifies the linearity of the patient pathway, producing particular uncertainties and challenges around the practicalities of healthcare, including resource allocation for managing the ageing population. I conclude this thesis by arguing that the conceptual framework of portability developed throughout this thesis, is necessary for handling complexity in the context of the clinic, and in relation to managing the 'ageing population' more broadly. I also discuss the implications of these findings for current diagnosis and management of patients with cognitive decline and AD.

Taken together, the chapters aim to reveal the situated ontologies and technical capabilities of the tools (Woolgar and Neyland, 2013) within the routine, everyday procedures in which AD is 'done' (Garkinkel, 1967). I provide 'thick descriptions' of situated encounters, which attend to the social, cultural and political arenas of AD. I document professionals' approaches towards the tools and diagnosis more broadly, which has

important implications for how AD and ageing are conceptualised; technologies adopted and configured, and ideas surrounding normality (Canguilhem, 2008). The complex distribution of medicine in which these technologies and AD resides, provides the context in which diagnosing AD is explored. This shapes a particular understanding of ageing and AD dementia in the clinic, and within contemporary society, for a disease often metaphorically conceived as a ‘fate worse than death’ (Zeilig, 2013).

Chapter Two

Framing the Clinical History of AD

In Chapter Two, I map the emergence of Alzheimer's disease (AD) as a diagnostic disease category from its inception in 1906, by drawing on key debates within clinical literatures and medical sociology, Science and Technology Studies (STS), and ageing literatures. From the inception of Alzheimer's disease in 1906, to its emergence as a clinical disease criterion in 1984 (revised in 2011), medical and scientific researchers have sought to determine AD's nosology¹⁰. As yet, there is no cure for, or cause of, the disease and a definitive diagnosis remains at post-mortem examination. With this in mind, the emergence of AD as a disease category has also been explored by sociologists, STS scholars, philosophers and anthropologists. Within these literatures, scholars have drawn attention to AD's social and cultural framing and construction.

In what follows, I will begin by providing a short clinical history of the disease, where I demonstrate the continued efforts to categorically define AD, and determine cause, treatment and cure for the disease. I continue by showing how AD as a socially, culturally and historically constructed disease category has been approached across social sciences literatures. In doing so, I frame the chapter within a wider discussion on diagnosis as both category and process (Rosenberg, 2002, 2003, 2006; Jutel, 2009), reflecting on Jutel's (2009) claim that diagnoses are the 'classification tools of medicine' (pp. 278). Of pertinence to this chapter, diagnoses within medical practice play important roles within the institution of medicine and have therefore been a point of interest across social science literatures in terms of the social and historical framing of disease, and of debates around the authority of medicine in terms of medicalisation and biomedicalisation. Within these broader themes across medical sociology and STS, I

¹⁰ Nosology refers to the classification of disease (Oxford Medical Dictionary, 2009). Difficulties in classification occur when a disease has a contested or unknown pathogenesis or aetiology.

investigate the case of Alzheimer's disease, and the *categorisation* of the disease, to highlight the emergence of AD as both a public health priority, and a label, which continues to be difficult to frame, manage and therefore categorise in practice. Finally, this chapter draws this body of literature together to address the opportunities for research, which analyses the *processes* through which a diagnosis of AD is negotiated at both the clinic, institutional and policy level in an 'ageing population'.

A Brief Clinical History

For over a century, AD has been regarded as a clinicopathological¹¹ disorder, and a discussion of the cause and nosology of the disease has pervaded scientific and biomedical research (see Hardy, 2006; Giaccone *et al.*, 2011). The term initially arose in 1906 due to the work of Alois Alzheimer (arguably cases of the disease had emerged prior to this time but had remained nameless) (see Hardy, 2006; Uchihara, 2007)¹². Neurologically, the disorder is characterised by the observation of amyloid plaques (miliary foci) and neurofibrillary tangles (fibrils) in the brain (see Hardy, 2006; Uchihara, 2007; Giaccone *et al.*, 2011). These 'tangles' were made observable using tissue silver-staining methods (pioneered by Santiago Ramón y Cajal and Camillo Golgi in 1906), which meant that they could be visualised at autopsy (See Uchihara, 2007). In 1910, Kraepelin, a senior colleague of Alzheimer's, suggested labelling these findings as constitutive of a specific disease entity: Alzheimer's disease (Hardy, 2006; Uchihara, 2007; Giaccone *et al.*, 2011)¹³. At the time of Kraepelin's description, a clinical diagnosis of the disease could only be achieved at autopsy, yet even given the advance in research of diagnostic techniques during the past century, this also remains the most accurate method of diagnosis today (Ibid.).

As a consequence of Kraepelin's naming of the disease, AD was used to

¹¹ Clinicopathological pertains to signs and symptoms associated with disease.

¹² Hardy (2006) stresses that Alzheimer was not the first to describe or observe a number of clinical features of the disease. In fact, Hardy (2006) argues that Emil Redlich in 1898 first described the pathological plaques present in the brain at autopsy.

¹³ Kraepelin's description of AD led to the clinicopathological separation between the disease and other causes of presenile dementia such as Pick's disease (Hardy, 2006).

describe individuals with ‘presenile (classically, less than 65 years) onset age’ (Hardy, 2006: 3). ‘Senile dementia’ at that time was describable as being solely constitutive of hardening of the arteries in the brain (Ibid.). In 1968 however, Blessed, Tomlinson and Roth (1968) discovered that the majority of individuals with ‘senile dementia’ were no different from individuals with Alzheimer’s disease in the formation of pathological tangles and plaques present in the brain. This work led to the nosological separation between senile dementia and Alzheimer’s disease; senile dementia was abandoned as a term and AD was thus transformed from ‘a rare neurological curiosity to a major research priority’ (Hardy, 2006: 3).

In response to Blessed, Tomlinson and Roth’s (1968) case for the nosological separation between senile dementia and Alzheimer’s disease, Gaines and Whitehouse (2006: 61) argue from a philosophical perspective, that their research at that time, did not engage with the fact that individuals with symptoms of dementia did not always present the pathological formation of neurofibrillary tangles and plaques in the brain at autopsy (See Ballenger (2000) for a detailed discussion of this). This lack of correlation between observable pathology and signs and symptoms of AD, remains a point of contention in research and clinical practice. What Gaines and Whitehouse (2006) go on to contend however, is that despite this lack of complete correlation between dementia and findings at autopsy, the cases that *did* correlate perhaps empowered Blessed, Tomlinson and Roth and subsequent researchers, to further the objectification of the pathologies of the brain to ensure the disease appeared ‘real’ in research. Concurrently, the disease became ‘amenable’ to the efforts in biomedical science expanding the disease further, whilst its aetiology remained unclear (see Ballenger, 2000; Hardy, 2006; Uchihara, 2007).

From Blessed, Tomlinson and Roth’s work onwards, research into determining the cause of the disease, and in developing innovative measures for diagnosis, dominated clinical and scientific research. In the late 1970’s, research centred on developing an understanding of the biological mechanisms pertaining to a clinical diagnosis of AD (Hardy, 2006).

Investigations of individuals' brains and recognising that memory loss in particular was associated with the disease, led to the development of the 'cholinergic hypothesis of Alzheimer's disease' in the mid-1970's (see Bartus *et al.*, 1982; Francis *et al.*, 1999). The 'cholinergic hypothesis' proposes that Alzheimer's disease is caused by the degeneration of cholinergic neurons in a number of areas in the brain, which contribute to the decline in cognitive function particularly memory loss, in individuals with suspected Alzheimer's disease (Francis *et al.*, 1999). The cholinergic hypothesis is also the basis for pharmacological treatment for the disease; cholinesterase inhibitors such as Aricept aim to protect the cholinergic neurons lost in the early stages of the disease (Ibid.).

Alongside the occurrence of the 'cholinergic hypothesis', instruments for cognitive screening including the Montreal Cognitive Assessment (MoCA) in 1966, and the Mini-mental state examination, (MMSE) in 1975 were developed (see Folstein, 1975 and Nasreddine, 2005) (a detailed overview of the cognitive screening tools used in clinical practice, and of pertinence to this thesis, are detailed in Appendix A). Cognitive screening tools assess and review levels of cognitive function and are a means of detecting early signs of cognitive impairment (Ismail *et al.*, 2010). Non-invasive imaging of the brain such as Computerised Tomography (CT scans of the head), Single Photon Emission Computed Tomography, and Nuclear Magnetic Resonance Imaging was also developed from the 1970's onwards allowing for what was argued at the time, a superior understanding of neuroanatomy; a 'powerful diagnostic tool' (Khachaturian, 1985: 1100). Molecular genetics then began to dominate the 1980's through into the 1990's. In 1991, genetic linkage to late onset Alzheimer's disease and chromosome 19 markers were identified (see Roses, 2006).

Mapping the developments in research, which have attempted to determine the cause of the disease, a formal definition of AD in psychiatry as a clinical diagnosis emerged in 1984. The 1984 AD criteria and the Diagnostic and Statistical Manual for Mental Disorders fourth edition (DSM IV) state that AD is a clinical diagnosis made after the individual develops dementia

(Kimchi *et al.*, 2012): ‘clinical dementia is the end product of accumulated pathology’ (pp. 16). However, the developments in research from the 1960’s onwards, referred to by STS scholars Moreira, May and Bond (2009) as the ‘bioclinical collective’¹⁴ of AD (which led to the 1984 criteria) was, ‘built upon shifting foundations’ for two distinctive reasons (pp. 669). First, in the early 1980’s the cholinergic hypothesis was challenged; its translation into ‘safe pharmacology’ was questioned extensively by medical researchers. Second, molecular genetics, dominated the 1980’s through into the 1990’s, to which end the bioclinical collective of AD focussed attention on the genetic model of AD, leading to the development of the ‘amyloid cascade hypothesis’ (Hardy and Higgins, 1992). However, competing theories emerged, which challenged the foundations of this hypothesis and suggested alternative *biological* indicators for the pathological deterioration present in the brain (see Lovestone and Reynolds, 1997 and Nunomura *et al.*, 2006).

Despite these ‘shifting foundations’, the 1984 criteria reinforced a clinical diagnosis of AD, integrating research, therapeutic investigation, and clinical practice (see Moreira, May and Bond, 2009). In 2011, the National Institute on Aging and the Alzheimer’s Association work group on diagnostic guidelines for Alzheimer’s disease revised the 1984 criteria (Kimchi *et al.*, 2012). The 2011 criteria differ significantly from the 1984 criteria by describing new clinical criteria for the disease including the concept of mild cognitive impairment (MCI) (Ibid.). MCI was introduced as a diagnostic criterion for those at risk of developing the disease (Giaccone *et al.*, 2012). The criteria also incorporates the use of biomarkers to begin to understand the disease before it reaches the threshold of dementia (Budson and Solomon, 2012; Kimchi, *et al.*, 2012). Focus from herein as Zetterberg (2011) claims, has shifted towards developing innovative biomarker technologies to diagnose the disease in its earliest stages. More recent

¹⁴ The ‘bioclinical collective’ as described by Moreira, May and Bond (2009) aims to, ‘capture the extended, heterogeneous, distributed character of the production of evidence that is required by the contemporary intersections between laboratory and the clinic’ (pp. 686).

efforts in medical and scientific research include, developing stem cell techniques to study AD in the laboratory for pioneering treatment options, and developing clinical trials to *test* new dementia treatments (Alzheimer's Research UK, 2015b). As yet however, there are no definitive tests that may positively confirm a diagnosis of AD, and samples of tissue taken at autopsy remains the only accurate method of diagnosis (Hardy, 2006). In particular, the connection between observable pathological deterioration at autopsy and behavioural symptoms associated with a decline in cognitive impairment that could be associated with ageing generally (normal ageing) is ambiguous (Gubrium, 1986). This makes diagnosing the disease in the clinic difficult. As a result, the search for the cause of Alzheimer's disease continues but in an arena of medical uncertainty. In what follows, I will frame the case of AD within sociological, philosophical, anthropological, and STS academic literatures, which address the disease as a social, cultural, and historical category.

The case of AD: A socio-cultural and historical construction

As the clinical history of the disease demonstrates, the category of AD remains a significant source of uncertainty within medical and scientific research. Prior to discussing the specific case of AD in relation to its emergence as a socially and culturally constructed disease category, I will first outline the key points of interest in the well-established literatures of medical sociology and STS, which elucidate diagnosis as both process and category in the institution of medicine (Blaxter, 1978; Bowker and Star, 2000; Rosenberg, 2002, 2003, 2006; Jutel, 2009). As Blaxter (1979) first described, diagnosis is, 'the thing that the physician does: the conclusion reached, or the act of coming to that conclusion' (pp. 9). Diagnosis therefore involves both the emergence of pre-existing categories, and the collective judgements upon which these categories are labelled as specific disease entities. As Jutel (2001) contends, diagnosis is both material practice and yet dependent on its social framing.

Rosenberg (2002) further argues that diagnoses play important roles in the institution of medicine adopting increasingly, economic, political, cultural, organisational, and professional roles within medicine. At both an individual and institutional level, diagnosis provides a gateway to service provision and renewed status of the 'self' (Rosenberg, 2003) and as Nettleton (2006) argues; permission to be ill can be granted through diagnosis. Rosenberg (2003) continues by stressing that this paves a way for considering the relationship between disease categories and bureaucracy of healthcare, where disease categories appear as 'integrating mechanisms' impacting on a number of decisions within practice (pp. 499). For Rosenberg (2003), 'the awarding of diagnoses is one way of managing individual pain and social deviance, yet one that will remain endlessly contested at both the individual and social system levels' (pp. 502). At a local level in the clinic, Jutel (2009: 279) concurs with Rosenberg (2003), suggesting that diagnosis is both interpretive and relational; diagnosis sorts the 'real from the imagined', and yet is also a space of contestation and negotiation between professionals and patients, during interactions in the clinic. In this sense, diagnosis as a system of classification is performative with powerful effects and consequences for patients, clinicians and the organisation of healthcare practice. In terms of categorisation, Bowker and Star (2000) argue from an STS perspective, that agreeing about the kinds of conditions that lead to a *legitimate* diagnostic status, has important practical implications within healthcare from public planning of healthcare, to collecting health data.

Scholars such as Bowker and Star (2000) subsequently address the performative aspect of disease classifications. They question the significance of diagnostic classifications socially and culturally, whilst also demonstrating their spatiality and temporality. "A classification is a spatial, temporal, or spatio-temporal segmentation of the world. A 'classification system' is a set of boxes (metaphorical or literal) into which things can be put to then do some kind of work" (Bowker and Star, 2000: 10). In turn, the authors demonstrate how methods of classification, in particular that of medical classifications, emerge and are constructed as, 'workable

epidemiological tools' developed and constituted within medical organisations (Bowker and Star, 2000: 72). They also reveal that cross-culturally, disease categories have remained ambiguous, and classification and treatment pathways differ greatly. Therefore, despite a number of conditions configured as *contested* disease categories (see Nettleton, 2006), perhaps all standard medical classifications could be said to be in some part uncertain or 'configurationally complex' given what Bowker and Star (2000) describe as the messiness of disease (pp. 172). It is therefore well established in medical sociology and STS, that diagnosis is a socially and culturally configured process with powerful and productive consequences in the clinic and the institution of healthcare. Entangled in diagnosis, as category and process, are the negotiations, which lead to the construction of the boundaries of disease, of which constituting the normal from the pathological is a key process. The shifting boundaries of disease and therefore emergence of new disease entities (Brown, 1995; Jutel, 2009) are driven by the authority of medicine at *both* individual and institutional levels (Estes and Binney, 1989; Armstrong, 1995; Conrad, 1992, 2005; Aronowitz, 2001; Kaufman *et al.*, 2004; Dowrick, 2009).

The emergence of Alzheimer's disease can be framed across these key debates in medical sociology and STS, and although there has been an extensive body of literature, which draws on these theoretical sensibilities for understanding AD as category, and its expansion in an ageing population, particular *dynamics* of this process are missing. First, the process of, or *judgements* involved in applying the label AD requires further research. Second, the role of medical technologies as agents for navigating this process, in an arena of medical uncertainty, and for making sense of diagnosis in the organisation of healthcare, requires further exploration. Third, the social and cultural elements of diagnosis and relations between age, ageing and AD merits further attention. Investigating these dynamics would be fruitful for considering the nuances of the process of diagnosis made visible through particular technologies in the routines of everyday practice, but also in relation to the role diagnosis plays in an ageing population at both individual and social system levels.

Overall, a disease category is not only clinically or biologically produced but is historically, socially and culturally produced, as demonstrated by scholars including Rosenberg (2003), Mol (1998) and Fujimura (1996). Rosenberg (2003: 496) notes that in order to discern the ‘what’ of disease the ‘when’ and ‘where’ should be brought into consideration; disease is bound in time and space and is ‘necessarily historical’. In Mol’s (1998) investigation of the work of Barbara Smith¹⁵ who studied the social production of the prevalence of black lung disease in miners, she reifies Smith’s argument that black lung disease was socially produced. To do this, Mol demonstrates that the constant change in definition of the disease corresponded with political shifts in the coal mining industry. Similarly, Fujimura (1996: 255) in her work on cancer and the emergence of the ‘right tools for the job’ for diagnosis, argues that disease is situated within time and place, and negotiation of interpretation and meaning is crucial to its construction. Disease categories are therefore active participants in the institution of clinical and medical practice, and are social actors: ‘specific disease categories are omnipresent...indisputable social actors, real inasmuch as we have believed in them and acted individually and collectively on those beliefs’ (Rosenberg, 2002: 240). Focusing specifically on the case of AD, I frame its categorical construction, socially, culturally and historically.

¹⁵ As Mol (1998) states, Smith’s article ‘Black Lung: The Social Production of Disease’ (1981) was published in the *International Journal of Health Services* but has had little citation elsewhere.

Developing the work of Rosenberg (2003), Gaines and Whitehouse (2006) adopt a social constructionist approach in order to discuss the disease category of AD in relation to a series of ‘historical moments’, interpreted in ways, which have shaped current understandings of the disease. They demonstrate that the development of AD is ultimately a social process, constructed culturally and historically, particularly the focus on cognitive impairment and memory loss in the 1970’s, and the discrepancy around the cholinergic hypothesis as previously outlined. Prior to the work of Gaines and Whitehouse, Gubrium (1986) makes the case that the disease became a reality within a specific framework of empirical codes and structures of which difficulty in distinguishing normal from pathological cognition forms a key point for analysis: this will be discussed further in the chapter.

As argued by Brown (1995), analysing the social construction of disease overall, requires due attention to the historical construction of disease entities. In recognition of Brown’s (2009) claims, sociologist Annemarie Jutel (2009) maps and locates the emergence of AD as a socially constructed phenomenon born out of both scientific discovery *and* the interprofessional relationships between Pick and Alzheimer. As Jutel explains, research into AD’s nosology took place within two competing neuropathological schools: one in Munich with the work of Alzheimer and Kraepelin, and the other in Prague with the work of Fischer and Pick. Alzheimer focussed his attention on neurofibrillary tangles whereas Fischer described senile plaques: both of which are present in AD and Pick’s disease¹⁶. As Jutel (2009) argues, as consequence of the competition between each site of research, it was not until Kraepelin assigned Alzheimer’s name to a diagnosis of presenile dementia, that disagreement between the sites of research regarding what constituted each disease, was resolved, and the label AD assigned (Ibid.). The politicisation of these institutions led to the categorical distinction between Picks disease and the labelling of Alzheimer’s disease.

¹⁶ Pick’s disease is also referred to as Frontotemporal Dementia, which is one of the more uncommon types of dementia. Symptoms of Frontotemporal Dementia particularly in the later stages of the disease are similar to that of AD, which makes diagnosis difficult (see Alzheimer’s Society, 2015d).

A further significant moment in the history of the categorisation of AD and the labelling process was the nosological abandonment of senile dementia. Writing from an anthropological perspective, Lock (2005) argues that a number of social and cultural practices led to the term senile being eradicated in 1976. The category of senile dementia carried with it problematic connotations closely associated with ‘madness and moral disapprobation’ which was concealed within psychiatric hospitals (Lock, 2005: 203). This is where it remained until the 1970’s, when in 1976 the term senile was eradicated (Ibid.). Arguably, this transformation of senility into an ‘outmoded concept’ was in part due to its representation of a broader ‘gerontophobia’ existing within the population (Lock, 2005: 204). In turn, anthropologist Lawrence Cohen (1998) contends, families and patients feeling burdened by the disease began advocating for the *medicalisation* of senility. Fox (1989) also highlights the role of the family as a form of lay social movements driving to stabilise and define AD to generate research and promote diagnostic status. Coupled with Blessed, Tomlinson and Roth’s (1968) work, the eradication of the term ‘senile’, transformed Alzheimer’s disease from ‘a rare neurological curiosity to a major research priority’ (Hardy, 2006: 3) and led to its clinical categorisation in 1984. Despite the discrepancies associated with categorising AD however, anthropologists such as Lock (2005) claim that due to the role of families affected by the condition, and the efforts of clinicians to categorise the disease as legitimate, the conceptualisation or discourse of AD that is available in the clinic to the public is that it is a, ‘distinct, universal, biological entity’ (Lock, 2005: 205).

Constructing the normal from the pathological

Entangled in diagnosis as both category and process, lies the task of constructing the boundaries between the normal and the pathological across individual, institutional and social systems levels (Aronowitz, 2001). Constructing the normal from the pathological within the process of diagnosing AD is complex however, as the following section will demonstrate. It is well established that the nosology of AD has been debated

by scientists and medical researchers, and between social science scholars. Linked to its contested nosology however, is the difficulty in determining what are perceived to be normal from pathological ageing processes. Gubrium (1986), writing from a sociological perspective, contends that with the drive individually and institutionally to categorically 'explain' AD, there is inherent difficulty in determining normal from pathological ageing processes, despite its emergence as a discrete diagnostic entity in 1984. Gubrium's arguments are taken from in-depth analysis of visual, oral and written descriptions of the disease. The author demonstrates that everyday experiences of living with AD (behaviours associated with the disease) shape the demand for diagnostic explanation and treatment solutions for the disease, despite research and healthcare practice recognising that there is no known cause or cure. As Gubrium (1986) explains overall, the diversity of symptoms associated with AD, makes correlating symptoms with pathological changes in the brain inherently difficult. "How is pathology revealed in the neuritic markers of the brain of elderly persons, described as "there" when ageing is likewise describable" (Gubrium, 1986: 50)? Gubrium argues that focussing on the quantitative difference between normal and pathological ageing processes objectified in the brain, does not make a clinical diagnosis easier to which end, categorising behaviours associated with pathological ageing is inherently problematic.

More recently, as outlined briefly in Chapter One, the expansion of the disease category to account for the earliest stages of the disease, further complicates determining normal from pathological ageing processes, as the following section will demonstrate. Specialists and clinicians are increasingly faced with the challenge of how to identify when normal ageing processes begin to become pathological degenerations (Mendelzweig, 2009). The expansion of AD to incorporate the earliest stages of the disease reflects more broadly the continual (re)construction of the boundary between normal and pathological cognitive decline. The revisions to the 1984 diagnostic criteria in 2011 to incorporate Mild Cognitive Impairment highlight this effectively. As Whitehouse (2004) argues, MCI as a label makes it difficult for clinicians to demarcate normal

from pathological cognitive impairment (ageing processes). The purpose of the term MCI used by clinicians (prior to its incorporation as a diagnostic criterion) was to give a label to the origins of cognitive impairment associated with ageing more generally. However, the crux of the author's arguments here is that at what point does memory impairment begin to be manifested as MCI and then develop on to AD? Whitehouse (2004) also raises important questions around the construction of cognitive impairment as normal or pathological. Labelling the origins of cognitive impairment associated with normal ageing as potentially pathological, encourages critical discussion regarding the point at which any form of memory loss begins to become pathological deterioration (Ibid.). The construction of normalcy and pathology therefore underpins the difficulties in attempting to categorise Alzheimer's disease in research and practice, particularly as there is no definitive cause or cure.

Writing from a philosophical perspective, Whitehouse and Moody (2006) also question the value of the label MCI, and the ethical dilemmas it poses when new knowledge around more innovative techniques in research such as neuroimaging and genetics, blur the boundaries of the disease further (Ritchie and Lovestone, 2002; Whitehouse, 2003; Whitehouse and Moody, 2006). From an STS perspective, Moreira, May and Bond (2009) also explore the inherent uncertainty associated with the emergence of MCI, in line with the current 'search' for a category or biomarker to ground the earliest stages of the disease. The authors investigate the ways in which uncertainty is reframed in 'new diagnostic conventions' in terms of how organisations and clinicians begin to objectively know MCI. The difficulty in determining the 'normal' and the pathological from a range of different perspectives in healthcare, adds to the construction of the disease as a contested disease nosology. The revised diagnostic criteria for the disease also has the potential to shape individuals' experiences of the disease as the treatment options for those diagnosed, can only be administered at later stages of the disease; when a clinical diagnosis of dementia is made (Kimchi *et al.*, 2012). The implications of this shifting construction of normalcy and pathology in relation to the ageing process for individuals, wider public

health policy, and health and social care, is worth considering given the increasing number of individuals diagnosed with the disease.

The debated construction of normalcy and pathology, which underpins the categorisation of AD, can also be framed within broader literatures, which address the authority of medicine within the rise of medicalisation or biomedicalisation. As attested by scholars including Jutel (2009), medicalisation does not solely refer to diagnosis (see for example Apple, 1995). However, for the purposes of investigating AD, the construction of normalcy and pathology through which diagnoses emerge, intersects across broader conceptualisations and theories as to the expansion of disease categories which in turn reflects the processes of medicalisation and biomedicalisation. The following section will review literatures on medicalisation and subsequent biomedicalisation of society, which has important implications for how age and the ageing process are managed. Jutel (2009) discerns that disease is legitimised if the cultural considerations of normalcy and pathology allow for this. Yet, Armstrong (1995) writing prior to Jutel, contends that the construction of normalcy and pathology is also bound in temporality.

Armstrong in 'The Rise of Surveillance Medicine' considers the effect of focusing on healthy populations and targeting those 'at risk' of disease, and the changing construction of normalcy and pathology. Armstrong provides a socio-historical analysis of this construction beginning by discussing Foucault's description of the changes or new 'spatialisations' of illness, which he argues dominated the end of the 19th century into the 20th century. Armstrong stresses that medical focus has shifted beyond this 'tertiary spatialisation' of the hospital and sole concern of those who are 'ill' to concern for all members of the population who have the potential to 'become ill'. The author argues this is a primary feature of surveillance medicine; the problematisation of normality. To begin to understand this shift in medical practice the relationship between sign, symptom and pathology should be carefully considered. As Armstrong (1995) stresses, the space in which pain is considered shifted allowing for a renewed

understanding of the surface and depth of symptoms and signs. Armstrong (1995: 396) proceeds by arguing that the tertiary spatialisation of illness is characterised by the 'locus of illness in the context of healthcare activity'. The increased proliferation of acknowledging well bodies as 'at risk' is the predominant feature of the construction of this problematisation or 'medicalisation of society' (See Conrad, 1992, 2005; Clarke *et al.*, 2003). According to Conrad (1992), the emergence of medicalisation in social science literature began in the 1970's. Whilst arguing that the construction of normalcy and pathology was discussed prior to this in the realm of psychiatry, the term itself was not used until the 1970's. Since the 1970's, the term has been well placed in medical sociological literature. It is however, a concept that is perpetually changing (Conrad, 2005) with the development of biotechnological advances in healthcare, arguably shifting medicalisation toward biomedicalisation (Clarke *et al.*, 2003).

As Armstrong (1995) contends, medicalisation (as a form of social control) focusing on healthy populations (targeting those who are 'at risk' of disease), dominated the 20th Century. According to Armstrong this began with the increased surveillance of the 'unformed mind of the child' where physical and psychological development had the potential to become problematic and consequently open to intervention. Conrad (2005) however, argues that specific changes in medical organisation and knowledge now drive a shift in traditional notions of medicalisation. Medicalisation primarily focussed on the role of the medical professions categorising an increasing number of symptoms as pathological leading to the emergence of new disease categories (Conrad, 2005). This renewed focus on healthy populations has implications at a policy level, which is manifested by the uptake of resources aimed at identifying, managing, and potentially treating, those who may be 'at risk' of developing specific diseases. This is significant considering the ageing population and with the recent scientific endeavours, which attempt to identify Alzheimer's disease in its earliest stages; ensuring the disease is managed effectively.

Emergence of medicalisation and biomedicalisation

Clarke *et al.*, (2003) develop the ideas around medicalisation and argue that the 21st Century is dominated by ‘biomedicalisation’. Briefly, biomedicalisation is describable as the transformation of medicalisation, taking into account emerging technoscientific processes with the potential and indeed ability, to alter individuals’ experiences of ‘illness’ in a myriad of complex ways (Ibid). Medicalisation and indeed biomedicalisation have however been critiqued with the emergence of pharmaceuticalisation as a concept (Williams *et al.*, 2011). The authors stress that pharmaceuticalisation differs from the overall concept of medicalisation in a number of ways. Whilst the authors identify that pharmaceuticalisation is a necessary development of medicalisation, and also recognise the importance of the pharmaceutical industry for medicalisation, they argue the concepts differ. Pharmaceuticalisation extends beyond the initial focus and identification of ‘at risk’ individuals which dominates the concept of medicalisation, and is useful for critically engaging with the economic interest in commercialisation of pharmaceuticals and subsequent potential to construct new disease categories (Williams *et al.*, 2011: 711. Whilst focussing on medicalisation or biomedicalisation is not the primary focus of this review given the existence of extensive literature on the topic, it is important to illustrate the ways in which these theories can be used to demonstrate the shifting boundaries between the normal and the pathological. Moreover, to demonstrate the extent to which the ageing process is increasingly subject to the processes of biomedicalisation in particular.

As Estes and Binney (1989) note, the political and economic emphasis with regards to the commercialisation of pharmaceuticals, reflects what they term the ‘biomedicalisation of ageing’ (see Estes and Binney, 1989). Since Estes and Binney’s (1989) publication of ‘The Biomedicalisation of Aging: Dangers and Dilemmas,’ Kaufman *et al.*, (2004) have developed their arguments by iterating that biomedical sciences, shape the knowledge and expectations of the aged body and consequently medical intervention. Estes

and Binney (1989) identify the biomedicalisation of ageing in two distinctive ways. First, they argue that ageing is socially constructed and yet predominantly regarded as a medical problem, and second they argue the prevailing biomedical model for ‘managing’ ageing, has the potential to (re)shape medical and scientific research. With reference to the authors’ first point, the idea that ageing is a social construction corresponds with Gilleard and Higgs (2013) later claims regarding the eradication and subsequent revival of the term ‘senile’.

Despite the nosological abandonment of the term senile in 1976, Gilleard and Higgs (2013) stress that more recently there has been a revival or ‘re-emergence’ of the discursive construction of senility and the fear of old age. Their claims are compounded by the notion that ageing is predominantly managed through medical means, leading to the growing medicalisation of ageing, and therefore emerging narratives associated with successful ageing processes. This has the potential to reconfigure normality and well-being; or the projection of the third and fourth stages of ageing (Gilleard and Higg, 2013: 368). The re-emergence of senility therefore contributes to the conceptualisation of what Gilleard and Higgs (2010, 2013) term is the fourth stage of ageing. The paradox of this promotion is that it lends itself to the dichotomies between successful and unsuccessful, and healthy and diseased (Gilleard and Higgs, 2013). In relation to AD dementia within this body of literature, previous literature has also drawn attention to the increased surveillance of older individuals particularly those with dementia (see Kenner, 2008)¹⁷.

With reference to Estes and Binney’s second point and the extent to which the biomedical model (re)shapes medical and scientific research, dementia as a UK national challenge or public health priority, has signalled an interest

¹⁷ A number of studies published in the *Sociology of Health and Illness* special issue (2010), frame ageing through a science and technology studies lens critically examining ageing and dementia within particular biomedical, social, cultural, and technological arenas (Joyce and Loe, 2010; Mykytyn, 2010; Fishman, Settersten Jr and Flatt, 2010; Marshall, 2010; Kaufman, 2010; Brooks, 2010; Kinnunen, 2010; Brittain, Corner, Robinson and Bond, 2010; Wigg, 2010; Copelton, 2010; Loe, 2010; Neven, 2010).

in the development of innovative diagnostic techniques aimed at initiating early diagnosis to challenge the increasing ageing population (Dubois *et al.*, 2007). Diagnostic innovations for Alzheimer's disease such as MRI scans (Alzheimer's Research UK, 2012¹), combinatorial biomarkers including blood testing (Alzheimer's Research UK, 2012²) and novel biomarkers of damage to DNA and 'telomere dysfunction (chitinase activity, N-acetylglucosaminidase activity, stathmin, and EF-1alpha)' in cerebrospinal fluid (CSF) (Watabe-Rudolph *et al.*, 2012: 569) are examples of the increase in biomarker technologies aimed at identifying early stages of AD. This corresponds with Estes and Binney's (1989) claim that the increasing power and relevance of the biomedical model, has the power to shape research around the aetiology of disease and its biological constructions. As Kaufman *et al.*, (2004) stress, developments in biomedicine effect how we conceive the nature of 'growing old' primarily as a process amenable to the efforts in medicine to ensure a successful ageing process. Indeed, "medical interventions are reshaping norms of aging and standard clinical practice" (Kaufman *et al.*, 2004: 732). Therefore the increased number of biotechnologies, biomarkers and diagnostic imaging introduced to attempt to alleviate the challenging process of differentiating between mild Alzheimer's disease, mild cognitive impairment and non-AD dementias (Foster, 2007; Bloudek *et al.* 2011), ensure that normal ageing processes are reshaped (Kaufman *et al.*, 2004).

Constructing the classification 'box'

Underpinning this literature on the biomedicalisation of ageing in particular, is the idea that managing disease is predominantly the task of medical, biological and clinical classification frameworks. Within medical sociology, Rosenberg (2006) draws on STS scholars Bowker and Star (2000)¹⁸ and claims that for those conditions that are difficult to frame within medical, biological and clinical frameworks, the process of claiming legitimacy for symptoms is difficult, and makes the act of diagnosis complex. Focussing

¹⁸ STS scholars such as Bowker and Star (2000) express their concern that classification 'boxes' at times fail to consider context.

on Bowker and Star's (2000: 72) acknowledgment that methods of classification are 'workable epidemiological tools' developed within medical organisations, Rosenberg (2006) stresses the contested 'biological reductionism' of ADHD. The author argues that classification in practice, focuses primarily on biological intervention aimed at 'treating' this contested, arguably *contextual* behavioural disorder, whilst ignoring a number of social factors, which influence the condition. As Rosenberg (2006) elucidates, disease is legitimated upon presentation of clinical characteristics, which produce a discrete disease entity: to gain legitimacy, disease must be at once 'specific and somatic' (pp. 411). In doing so however, this effaces the perhaps equally important behavioural or emotional symptoms that may accompany clinical characteristics, which subsequently renders the boundaries of disease complex and contested (Ibid.). As Rosenberg (2006) explains, "the terms *hyperactive* or *attention deficit* are context-dependent by definition, reflections of specific institutional realities and cultural needs" (pp. 419 emphasis in original).

Jutel (2011) rightly points out that metaphorical boxing of classification therefore fails to consider the myriad of practices, voices, principles, interests and values which produce disease and henceforth its classification 'box'. In turn the voices, which 'make up' coding frameworks for classification, mean that classification is endlessly contested; there will always be differing interests, values and practices. As Rosenberg (2006) concludes, this will remain the case as long as we call upon medicine to be involved in constructing the normal from the pathological fuelling the 'guerrilla war' between disease and deviance, to provide one example (pp. 422). Privileging the medical or biomedical model for managing disease, has important implications for diagnosis and the process by which clinicians are able to determine boundaries that separate one disorder from another (Dowrick, 2009). This is likely to be a particularly difficult task for AD given the complexity concerning its nosology, and the difficulties determining normal from pathological ageing processes: determining these boundaries is much the role of medical technologies.

The role of medical technologies

Technologies play an integral role in classifying disease; as has been well established in STS, technologies are not just physical artefacts but also systems and tools of diagnosis more broadly. Within sociological examinations of medical technologies, studies range from exploring the more mundane or ‘taken for granted’ devices for measuring the body such as the medical record (Berg, 1996), to the more sophisticated technologies used in genetic testing (see, Cunningham-Burley and Kerr, 1999; Kerr and Cunningham-Burley, 2000; Webster, 2002). In relation to the more innovative technologies in healthcare, with continuing advancement in research and practice for creating new disease states and categories, this raises important sociological questions. Whilst technological change succeeds with ‘putting a name to it’ (Jutel, 2011), it simultaneously raises new challenges for patients and clinicians in terms of making sense of disease and diagnosis, and (paradoxically) increasing uncertainty (see Webster 2002; Cox and Webster, 2012). Therefore, as the expansion of disease grows as previously discussed, more sophisticated and accurate *screening* technologies are developed to detect pathology, or risk of pathology, at earlier stages and to target diagnosis, treatment and monitoring options effectively.

For AD, there has been no official screening programme implemented despite efforts to detect the disease in its earliest stages. The UK National Screening Committee has rejected AD as suitable for adoption in a formalised screening programme (UK NSC, 2015). In January 2015, the UK NSC reviewed screening for overall dementia and concluded that screening should not be recommended (UK NSC, 2015). The UK NSC concludes that there is a lack of evidence that a screening programme would be beneficial in terms of treatment, and the tools currently used in the diagnosis process including instruments for screening cognitive function are not deemed specific or sensitive enough for the purposes of a formal programme (Ibid.). In particular there is a lack of treatment available to prevent or slow down disease progression if identified early and finally whilst current tests

for dementia have the potential to identify individuals with MCI, only a small minority of individuals would go on to develop dementia which has implications for well-being (UK NSC, 2015). However, despite ruling against a formal screening programme for AD, cognitive screening tools used to detect initial decline are being adopted in frameworks such as the National Dementia CQUIN, which assesses all individuals over the age of 75 on entering Acute Medical Units in secondary healthcare. I outline the aims of the National Dementia CQUIN in Chapter Seven.

As I will discuss in more detail in Chapter Three, the focus of attention in this research is therefore on mundane practice and flexibility of tools, categories and devices in co-producing disease as Berg and Mol (1998) stress. Thinking about handling of disease in practice (Mol, 2002a) is particularly important if the disease itself is contested or can appear ‘invisible’ in clinical practice with no known cause or cure. This raises the question around how clinicians begin to make sense of diagnosis according to knowledge practices, which recognise the contested categorisation and nosology of the disease. Considering the matrix of health, technologies and ageing (Joyce & Loe, 2010) in practice and policy, specialists and clinicians are increasingly faced with the challenge of how to identify when normal ageing processes begin to become pathological degenerations (Mendelzweig, 2009).

Managing AD and care

So far, I have sketched key debates within medical sociology and STS, which investigates AD as a contested disease category. There is a further body of literature however, which attends to the experiences of individuals post-diagnosis in terms of care. Sociological scholars including Twigg (2010) and Twigg and Buse (2013) for example, have framed the experiences of individuals with a diagnosis of dementia overall, in debates around the embodiment of identity regarding clothing and dress. A further body of literature has also explored care as a material practice for those with an established diagnosis. The work of Tom Kitwood (1993) who developed

the psychosocial model for dementia in the 1980's, was pioneering in the sense it criticised the biomedical model of dementia, as it focused attention on the personhood of individuals. As such, Kitwood centred attention away from the concerns of professionals to the needs of patients, and his approach became the foundation on which debates regarding the relative lack of attention towards care as opposed to cure in dementia health policy, have since emerged (Ibid.).

A further body of literature also critiques the prevailing biomedical model of AD. In STS, Moreira, May and Bond, (2009) consider the extent to which privileging diagnosis as a means for managing AD (of which the 1984 criteria is a predominant driver), pitches cure against care; care as a viable alternative for managing AD is relatively neglected in research and policy (see Chaufan, Hollister and Fox, 2012: 792). In particular, in terms of increased efforts to detect AD in its earliest stages, Kimchi *et al.*, (2012) argue that whilst the revised criteria for the disease and the recognition of pre-dementia states in research, allows for a renewed consideration of how the disease can be managed, the provision of care and subsequent treatment for those with *pre-clinical* dementia is unclear; particularly, if symptoms fail to be demarcated from normal ageing.

Moreover, from a sociological, philosophical and bioethical perspective, a number of studies have explored how individuals' experiences of a diagnosis, are shaped by the stigma associated with the disease and notions of the diminished 'self' upon diagnosis (Post, 1995). Writing from a bioethical position, Whitehouse, Frisoni and Post (2004) emphasise the importance of disclosing a diagnosis of dementia in clinical practice, contending that to deny the truth from patients given the recognised stigma surrounding the disease, "underestimates the remarkable human capacity to deal creatively and resiliently with the implications of serious diagnoses" (Whitehouse, Frisoni and Post, 2004: 126). From a sociological and philosophical perspective, Davis (2004) also challenges the biomedical positioning of dementia by elucidating the 'societal structures' that underpin dementia, which means that practices of care, in terms of preserving the self,

may be performed differently (pp. 377). In relation to care, the pioneering work of Kitwood (1997) further stresses the importance of acknowledging and accepting the subjective experiences of the person with dementia. Kitwood states that the experiences of patients with dementia should inform both research and policy. The notion of 'dementia care' has subsequently dominated literature within the social sciences: issues such as preservation of autonomy in care (Wilkinson, 2002) and recognising interdependencies of care giving to ensure maximum quality care (Adams and Gardner, 2005) have featured particularly prominently. Preservation of autonomy in care has also been discussed in relation to the act of disclosing a diagnosis of dementia in clinical practice (Pinner, 2000; Post, 2004). Writing as a practising psychiatrist, Pinner (2000) argues that given the prevalence and importance of early intervention and prevention strategies for the disease, the disclosure of a dementia diagnosis is crucial.

Conclusion

In this chapter, I have framed the case of Alzheimer's disease in terms of its diagnostic category within sociology, STS, philosophy, and anthropological debates, which across their disciplinary trajectories, debate the social, cultural and historical construction of AD as disease category. The chapter begins with a short clinical-history of the disease in order to demonstrate that within medical and scientific research, the nosological framework of the disease has been debated. I also mapped the technological developments since AD's inception in 1906, attempting to determine cause, cure and treatment for the disease. Following this, I attended to the social science academic debates, which highlight the case of AD as a socially constructed disease criterion. In doing so, I discussed the wider bodies of literature in sociology and STS, through which the case of AD can be framed. It is well established in sociology and STS that diagnosis is a social process, classifications are 'workable' tools in this process, and technologies play key roles within healthcare practice.

A review of this social science literature has shown the extent to which AD has emerged as a critical site of attention within medical sociology and STS, particularly in terms of its categorisation and the experiences of individuals post-diagnosis. As postulated by Jutel (2009), analysing the social framings or forces through which a clinical diagnosis of disease is produced, generates an informed understanding of the ‘fluidity and fallibility’ of diagnosis (pp. 294). In doing so, diagnosis, ‘bind[s] the biological, the technological, the social, the political and the lived’ (Jutel, 2009: 294). Having explored the extent to which AD can be framed within, or has been framed within these social, political and technological arenas within medical sociology and STS, including debates on normalcy and pathology, and the authoritative role of medicine, it is clear that AD as a disease category has received worthwhile attention. However, the claims or debates drawn on from medical sociology in particular, explore the categorisation of AD as opposed to the *processes* of diagnosis. The process of diagnosis involves the particular judgements involved in assigning an AD category, which encompasses navigating complexity; negotiating the boundaries between normal and pathological; negotiating the discursive construct between successful and unsuccessful ageing processes, and negotiating the challenges facing the institution of healthcare in terms of increasing referral rates. Furthermore, the literatures reviewed are underpinned by a social constructivism paradigm, which as I demonstrate in Chapter Three, I develop to critically analyse how disease and diagnoses are handled in *practice* using particular technologies for making sense of complexity. The disease is more than that which is describable and able to be placed in time and space, it is ‘handled’ in practice performing realities of the disease not yet assumed, reaching far beyond the original manifestation of the disease (Mol, 1998, 2002a).

In Chapter Three, I map the theoretical frameworks on which this thesis is grounded. I attend to the constitutive role of medical technologies adopting an approach which foregrounds practice, for negotiating complexity towards a classification of AD. At the intersections of medical sociology and STS, I centre cognitive screening tools as actors in navigating identities and

hierarchies; discursive constructs of ageing, and risk and uncertainty, both within the clinic and through wider networks of political power with respect to the ageing population. I therefore show the ways in which clinicians perform, organise, classify, approach and *resolve* the complexity of categorising AD through the role of cognitive screening tools. In doing so, I further develop the STS focussed perspective, that classifying disease is a temporal and spatial process; embedded in a set of work practices and organisational routines (Bowker and Star, 2000). I argue that classifications are constitutions, enactments both productive and performative of the disease they attempt to ‘pin down’ (Mol, 2002b) socially agreed and made up between ‘debates’ and ‘negotiations’ in healthcare practice (Latimer, 2013: 195).

Chapter Three

Theoretical Foundations

In the following chapter, I will introduce some of the broader theoretical literatures and particular concepts that I draw upon to frame my analysis. As Chapter Two revealed, there remains a level of uncertainty in the medical arena about the nosology of Alzheimer's disease, and efforts to determine a cause and cure for the disease dominate medical and scientific research. Following a brief clinical history of the disease, I continued by framing the case of AD within sociology, STS, philosophy and anthropological literatures. Within these literatures, AD figures in two distinctive ways. First, AD is analysed as a contested socially, culturally and historically constructed disease criterion, and second, the experiences of individuals post-diagnosis are debated, particularly in terms of care as both material resource and social practice. Overall, I located the case of AD in broader literatures, which critically engage with diagnosis as category and process, classification and categorisation of disease, the construction of normalcy and pathology, and drivers of medicalisation and biomedicalisation. As shown, there has been relatively little attention given to *how* a classification of AD is accomplished and handled in routine, everyday practices in the clinic, and with respect to managing the 'ageing population' more broadly. Subsequently, it was found that there is relatively little known about how *complexity* which is entangled in a categorisation of AD is navigated in clinical practice, through the use of available technologies which are pervasive across healthcare practice.

By focussing on cognitive screening tools as agents within this classification process, I develop the theoretical orientation of scholars including Berg (1996) and Mol (1998, 2002a), who illustrate the constitutive role of technologies, and the multiple ontologies of disease in practice. I therefore investigate the ways in which cognitive screening tools, given their role in detecting initial cognitive decline, might be 'central mediators' (Timmermans and Buchbinder, 2013: 108) in the (re)production of social

worlds, by focusing attention on everyday practices and interactions in healthcare. In doing so, I extend the theoretical paradigms of previous research which tend to adopt a social constructivist approach for analysing the disease category of AD as outlined in Chapter Two, by providing an in-depth exploration of the ways in which complexity is handled in *practice beyond* reducing analysis of technologies to social factors. The overall theoretical concern of my thesis is to show the complex social, technical and political networks through which AD is constituted, and emphasise the co-production of classification across situated occasions.

To explore the role of cognitive screening tools in practice, I focus on an ethnomethodological tradition of work especially the work of Goffman and Mol to deepen my analysis of the constitution and performance of disease and technologies in practice. I concentrate on these writers' explanations of how uncertainty and complexity is negotiated, and identities and hierarchies are configured, in the everyday routine practices of the clinic. However, whilst I draw on ethnomethodological sensibilities to explore the everyday situated occasions in which classification is produced (Garfinkel, 1967), the arguments I make across the empirical chapters adopt a range of perspectives and concepts from different paradigms. Therefore, my theoretical position and approach is multiple: the complexity of the theoretical steering underpinning my research is a reflection of the complexity of AD, which this research seeks to explore. Handling of AD cannot be achieved by reducing analysis to one particular paradigm or indeed for it to be 'pinned down' (Mol and Law, 2002: 21). Overall, I focus on complexity; performance of technologies in practice (Berg, 1996; Mol, 1998, 2002a, 2002b); interactions; identity-work (Goffman, 1959); hierarchies; power relations in the temporal and spatial arena of the clinic (Latimer *et al.*, 2006; Latimer, 2013), and organisation of healthcare overall. I investigate what is 'taken for granted' when diagnosing AD, in order to understand and theorise the wider processes and complexities of handling an increasing number of individuals predicted to develop AD in the 'ageing population'.

Mundane technologies and foregrounding practice

Analysing the role of low-technological tools in healthcare represents divergence from the focus in STS, which predominantly analyses the *innovation* of medical technologies with which to measure pathology. I subsequently adopt a theoretical approach, which investigates the mundane with respect to medical technologies, which as part of my overall ethnographic approach, means I investigate that which has been largely ignored or taken for granted “‘givens’ that ‘grounded’ our social experience” (Timmermans and Berg, 2013: 108). Previous examples, which critically analyse mundane technologies in healthcare, include Berg’s (1996) analysis of the medical record in shaping healthcare practice and the modern patient. I develop the work of scholars such as Berg (1996) and the constitutive role of technologies in practice, to explore how they *mediate* particular situated occasions and socio-material environments for producing knowledge about disease.

Exploring the role of cognitive screening tools in practice requires an investigation of their role in an arena of medical complexity. As highlighted in Chapter Two, and which will I elucidate more thoroughly as the thesis progresses, diagnosing AD is complex. Not simply because there is no one definitive method for diagnosing the disease whilst a person is living, and detecting normalcy from pathology is difficult (Gubrium, 1986; Hardy, 2006) but because of the wider social and cultural discursive accounts of ageing and AD that exist in the general population with the potential to disrupt the classification process. Furthermore, the process of diagnosis is likely to be rendered further complex as healthcare practice handles an increasing number of cases for diagnosis in the ageing population. Throughout my thesis, I highlight the ways in which the entangled complexities associated with AD are dealt with. In order to navigate and make sense of complexity, there is the endless work of constitution and enactment through practices of coordination in healthcare, of analysing relations in socio-material practices, which the technologies perform and produce in healthcare. Opening up complexities for discussion is fruitful

since complexity in healthcare is ‘not only an intellectual challenge but also an often urgent practical task’ (Mol, 2002b: 249). The idea that the challenges and complexities facing healthcare are likely to be as much of a practical as an intellectual dynamic, underpins much of my analysis with respect to the ageing population in terms of referral rates and allocation of resources.

In order to demonstrate how AD and cognitive decline are constituted, and complexity navigated and resolved, I foreground practice. In particular, I draw on Mol (1998, 2002a, 2002b) to speak with and through my data, centring the role of mundane technologies for constituting AD in practice. Adopting this approach to practice, I demonstrate that the realities of cognitive decline and AD are situated, emergent and multiple; performed through medical technologies (Mol, 1998, 1999, 2002a). As Mol (1999) describes, the reality of disease is ‘done and enacted rather than observed...reality is manipulated by means of various tools in the course of a diversity of practices’ (pp. 77). Describing Mol’s (1998, 2002a) work further, in her analysis of lower-limb atherosclerosis in a Dutch hospital, she shows that the ordinariness of atherosclerosis becomes more than a singular object or reality reified by particular perspectives across healthcare, but *comes into existence* through the practices in which it is ‘handled’. The author describes a number of locations in which the disease ‘appears’, contending that clinicians are often faced with the challenge of navigating these appearances (or realities) in order to make sense of disease and begin to consider what happens next for practice and patient. Mol therefore postulates the extent to which and at what *points*, these multiple realities interfere and relate to each other; describing not the ontological ordering of disease but the *ontologies* that are continually being (re)negotiated across sociomaterial practice(s). Mol (1998, 2002a) moves away from regarding ‘knowledge’ as something with which to refer to and instead claims that it is something to be continually ‘manipulated’ which leads her to question ‘how are objects handled in practice?’ As Mol (1998: 162) questions however, ‘what difference does it make to say that medical practice performs bodies and diseases locally, and that its ontology is multiple?’ For Mol (1998), the

social analyst needs to re-think the opposing schools of thought on medicine, one that positions it either as a ‘source of salvation’ and the other as a ‘monstrous beast’ (pp. 162). As the author explains, exploring medicine from the ‘inside’ will enable access to the multiplicity of performances of disease in healthcare which are entangled, ‘go this way, that way, the other’ by engaging with clinicians and patients on the ground (Mol, 1998: 162). Importantly this dialogue ‘inside’ medicine can begin to cast light not on which aspect or composite part of disease in practice is more ‘real’ but which is most important; considering the effects and consequences of this for healthcare practice and the diagnosis process overall (Ibid.).

Across Mol’s (1998, 1999, 2002a, 2002b) work, she demonstrates that realities of disease are multiple and performed in particular socio-material practices. Extending the social constructivist approach for understanding disease in healthcare, Mol (2002) makes a clear case for considering the performativity of enactment or constitution of disease as opposed to its *construction*, explaining that construction implies the ability of an object to be brought ‘gradually into being’ to the point of stabilisation (pp. 42). Whereas, enactment implies that, “if an object is real this is because it is part of a practice. It is reality *enacted*” (Mol, 2002a: 44 emphasis in original). Although I develop this further in Chapter Four, Mol’s attention to enactment of practice represents a theoretical shift from construction to practice, highlighting the power of practice for constituting disease realities. As Law (2004) contends, discussing ‘constitution’ or ‘enactment’ requires the researcher to attend to the ‘continuing practice of crafting’ (pp. 56). Production of disease therefore depends upon this continuing crafting of practices with people, technologies, techniques and materials particularly for a disease that may not already be ‘bedded down in sedimented practices’ (Law, 2004: 56).

Yet in this thesis I demonstrate the myriad of ways in which clinicians *value* uncertainty *because* there is no closure for the disease. This represents a shift away from Mol since unlike atherosclerosis, there remains little if any

certainty as to what AD *is* amongst, clinicians, scientists, public health and patients.

Cognitive Screening tools shift between different actors, and across different spaces and temporalities. Yet, at the same time, I also demonstrate that the inherent characteristics of the tools do not hold some intrinsic similarity as they are made portable; they are not constituted or constructed the same across different spaces and times. In fact I show how the tools are (re)made and continually (re)shaped by clinicians since they recognise, utilise and *value* the uncertainties associated with measures of cognitive decline for the purpose of classification. I acknowledge however, that in demonstrating the ways in which these tools shift and translate in practice, these tools could be conceptualised as boundary-objects, or indeed immutable mobiles. However, developing the theory of portability, I make a conceptual shift away from these theories; reflected in my overall commitment to practice and ontology.

Boundary-objects as theorised by Bowker and Star (2000), are ‘plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites’ (pp. 297). In this sense these objects act as devices which cross different cultures and social groups; flexible or ‘multi-interpretable’ with the ability to be reconfigured across different spaces and cultures, and between different actors. There is little doubt that cognitive screening tools could also be theorised and understood in this way as they are differently interpreted by different actors and in different settings; treated as a crossing point between particular arenas. Yet by adopting the term portability, I am not referring to different and multiple interpretations of the tools but multiple *versions* or ontologies of the tools as they are made in practice; practices make these tools ‘work’. I demonstrate that the portability of the tools is not always fluid and does not always cleave at neat points where producing AD through the use of these tools is complex and messy: difference matters since AD is complex. The theory of boundary-objects

effaces the nuances of practice and the difficulties involved in trying to make these tools ‘work’.

I also acknowledge that Latour’s description of immutable mobiles could also be applied to conceptualise the role of these tools in healthcare. According to the theory of immutable mobiles, objects are ‘made to be easily transportable without changing the inherent characteristics of those things’. Latour (1986) argues further that in order to convince someone of something ‘you have to invent objects which have the properties of being mobile but also immutable, presentable, readable and combinable with one another’ (pp. 6). Whilst I show the mobility of cognitive screening tools, I argue that these tools *can* be modified across different spaces and times in order to make sense of complexity: emergent through particular sets of practices. Their role shifts in order to account for uncertainty and yet, as I will show throughout this thesis, this work is largely invisible; reconfiguring the relations that make these tools ‘work’. By drawing on my own theoretical position of portability, I show that the tools are brought into being, thereby rejecting the notion that these tools have any inherent characteristics which shifts or stays rigid.

Clinician-patient Interaction

Employing Mol’s approach to practice, I investigate the role of cognitive screening tools and the constitution of AD in situated interactions with clinicians and patients, in order to demonstrate how AD is constituted and complexity resolved. According to Woolgar and Lezaun (2013), adopting the terms enactment or constitution implies that objects for analysis are not meaningful because of the contexts in which they operate rather, as the authors describe, they are ‘realised’ through *interactions* in a particular situated occasion or ‘set of circumstances’ (pp. 324). The important theoretical point made here, is that by employing the term enactment, this echoes the theoretical position of ethnomethodologists and the idea that interactions *in action* produce particular realities (Garfinkel, 1967). As a

result, similar to the claims of ethnomethodology (Garfinkel, 1967), Mol attends to the situated performances in which disease is enacted.

I analyse the role of cognitive screening tools within interactions between clinicians and patients in situated occasions, to highlight the invisibilities and intricacies of everyday practice. Furthermore, since I foreground practice, I approach the role and therefore *values* of cognitive screening tools as emergent, grappled with, and negotiated in the clinic. Throughout my empirical chapters, there is a theoretical commitment to practice both in terms of producing knowledge about disease enacted and constituted, and in terms of the articulation of values associated with the tools used within the clinic (Dussauge, Helgesson, Lee and Woolgar, 2015). Observing cognitive screening tools in practice, involves theorising on the *interactions* between technologies, clinicians and patients that relates to identity-work, hierarchies, and power relations, to understand how clinicians and technologies operate in the clinic.

Whilst Mol's approach to enactment and performance is therefore is not unlike that of actor-network theory, her work differs subtly. Particularly in 'The Body Multiple', she argues that whilst disease is enacted in a number of different ways in the hospital setting, this multiplicity rarely leads to difference or chaotic practice (Mol, 2002a). For Mol (2002a), it is exactly this multiplicity and flow of relations, which makes the treatment for atherosclerosis function in the hospital setting. Overall, in order to begin to make sense of how complexity and multiplicity of AD is resolved, I adopt Mol's approach and investigate situated interactions between clinicians, patients and technologies. Within the realm of STS, researchers are increasingly 'exploring the fluidity, ambivalence and multiplicity of ontologies with contrasting realities produced across a number of practices, *emergent through action and interaction*' (Mol, 2012: 380 emphasis added).

Investigating how the tools are articulated during observations of consultations, the work of Goffman (1959) is also helpful. Perhaps to draw on Goffman is however, 'rather an unusual place for the sociology of

technology' (Pinch 2010: 410). Yet, as Pinch (2010) emphasises, Goffman in his work on 'Encounters' (1961), and 'Presentation of Self in Everyday Life' (1959), explicitly analyses the role of mundane technologies and materials in the interaction order. As Pinch analyses Goffman's (1961) work, he argues that there lies a 'hidden sociology of technology' where 'the *staging* of the interaction, the *mediation* of the interaction, and its *performance* depend crucially on the detailed material and technological arrangements in place' (pp. 414 emphasis in original). Whilst Goffman did not necessarily pursue the role of technologies in establishing social order, his work on the situated occasion of 'surgery', demonstrates just this; the interactions observed, align with 'material arrangements, tools, and technologies' (Pinch, 2010: 416). Pinch further extends his arguments to Goffman's theory on the 'Presentation of Self in Daily Life' and the performances of front stage and back stage practices, which as I will go on to describe, are of particular relevance to this thesis. Pinch (2010) argues that when shifting between front stage and back stage arenas, these spaces are 'bounded and connected' and therefore materiality matters (pp. 417). This bounded space permits participants to alter their behaviour and therefore the materiality of the setting, or the architecture of the different stages and is something Goffman closely analyses. According to Pinch, Goffman adopts material and technological staging to demonstrate how interactions are performed, despite as Pinch suggests, his work being an 'unusual place' to begin exploring the role of technologies for achieving social order in interactions.

For Pinch (2010), 'we need to combine the attention to technological artefacts, which is the strength of approaches such as actor-network theory and social construction of technology, with more traditional sociological approaches like Goffman's, which attend to the interaction order and the meanings through which materiality and technology facilitate' (pp. 424). In line with Pinch, I adopt the more traditional sociological approach of Goffman, to explore how AD is constituted in interactions with technologies, materials and actors in the clinic; I draw on Goffman (1959) to explore mundane technologies in 'situated microcosms of social interaction'

(see Pinch, 2010: 419). Overall, my theoretical position draws on Mol (1998, 2002a) to help inform an understanding of the multiple ontologies of disease, and its enactment through technologies, which are mundane and framed in interactive encounters (Goffman, 1959).

Identity-work

Goffman's (1959) work is also useful for investigating how the use of cognitive screening tools reflects particular background expectations in the clinic. As demonstrated in Chapter Two, there is a body of literature, which frames the experiences of individuals with a diagnosis of AD or dementia more broadly, in terms of self and identity. I therefore investigate the role of shared expectations around the self and AD that inform social interaction and its performances. Firstly, I turn to Goffman's analysis of drama in the everyday practices of institutions, where actions derive from 'a command of an idiom, a command that is exercised from moment to moment with little calculation or forethought' (Goffman, 1959: 74). As Goffman (1959) explains in his work on the presentation of self, actors perform the self. Goffman's dramaturgy metaphor is useful for considering how modes of presentation are employed and utilised by actors in the everyday, which has broader means for the ceremony of social context. The dramaturgy metaphor sets out how the performance of actors in interactions, is shaped by the settings, and the audience to which the actor performs (Goffman, 1959). As 'performers', individuals' incorporate particular societal ideals (norms in any given situation) and present in ways, which are appropriate according to societal standards and expectations: this is described by Goffman as the ceremony of everyday life. The front stage setting for this performance, embraces these societal ideals, and the actor performs characteristics in keeping with these ideals. The backstage regions of performance however, are the more 'truthful' performance of the self, which is not revealed front stage. As such, in the process of establishing social identity, the background work in settings or the mundane presentations, is driven by concern for self and identity and the emergence of what Mead (2009) first conceptualised as the 'generalised other'. These are the ideals

held by individuals in a particular society where actors, envisaging what is expected of them, adopt the perspective of the 'generalised other'. Broadly speaking, Goffman provides an insight into the conduct and strategies of individuals who attempt to uphold normative assumptions regarding appearance and conduct through actions, and behaviours in particular situations: the presentation of self. Furthermore as Goffman contends, what may seem mundane or ineffectual is revealing of this ceremony of everyday life, particularly in relation to the preservation or presentation of self and the interaction order. This involves a 'definition of the situation which involves not so much a real agreement as to what exists but rather a real agreement as to whose claims concerning what issues will be temporarily honoured' (Goffman, 1959: 21).

The work of Goffman (1959) is valuable for exploring interactions in settings in order to investigate the normative, everyday assumptions (Scott, 2009) of the clinic and operation of technologies. Furthermore, when applying the dramaturgy metaphor as a conceptual framework written in my empirical chapters, the backstage and frontstage interactions (Goffman, 1959) emerge as central components for the *performing* of technologies and *performativity* of AD. This argument is found in further commentaries, which attempt to grasp the meaning of performances within *technoscientific* arenas and cultures (see Law and Singleton, 2000). Similarly, I recognise the value of exploring taken for granted utterances and gestures revealed in the performance of technologies in interactions, which I relate more broadly to patient identity-work (Goffman, 1959). To accomplish order in the clinic, clinicians work to, or account for, the identity of patients in response to the complexities that AD produces, or what Mead (2009) describes as the 'generalised other'. As I have outlined in Chapter Two, there exists particular discursive constructs around ageing with respect to its constructed successes and failures, which I will analyse to highlight the impact that these constructions might have on the interactions in the clinic, and therefore the classification process overall. Furthermore, given that temporality is a key point of analysis in this thesis, I analyse the extent to which the self in Mead's (1982) terms, performed in interactions as argued

by Goffman (1959), is temporal. Rather than it being a static or structured entity, it is a moment *in time* with a ‘biographical history’ and is therefore temporal ‘it is a dynamic and open-ended flow of events’ (Flaherty and Fine, 2001: 157). Drawing heavily on Goffman to frame the clinician-patient interaction, I also draw on Mol when demonstrating how technologies perform in practice since Mol (2002a) claims that ‘objects are framed as parts of events that occur and plays that are staged’ (pp. 44). What is most interesting and relevant for this thesis is that Mol actively distinguishes her work from the dramaturgical perspective of Goffman and the *presentation* of self by emphasising the ‘two-way traffic’ between enactment and reality or the ‘performativity of enactment’ (Law, 2004: 56). Across my empirical chapters, I adopt Goffman’s approach to explore self and identity in situated encounters, and draw on Mol to extend this by demonstrating how self and identity are subsequently performed, *emergent* through interaction.

The space of the clinic, risk and power

Another aspect of this thesis is to analyse the importance of space within socio-material practices. By focussing attention on the clinician-patient interaction, and the wider role of cognitive screening tools through the implementation of the CQUIN, I investigate the clinic as a particular space for constituting and performing knowledge about AD. The clinic itself emerges as a site, which enacts particular social, cultural and political affective concerns (Atkinson, 1995; Latimer, 2000; Mol, 2002a). The work of Latimer (2013) in particular, is developed throughout my thesis for considering how the clinic affects the role of technologies in the medical decision making process. As Latimer (2013) argues in her work on the revival of ‘medical dominance’ for diagnosing dysmorphology, the clinic is an important, some might argue privileged, site for knowledge production particularly for navigating uncertainty around classification. I develop Latimer’s claims to draw attention to how AD is accomplished in practice, by locating the role of *mundane* technologies in the clinic and elucidating the extent to which this space is atemporal/temporal or bounded/unbounded

within the organisation of healthcare. Since classification, as critically analysed by STS scholars including Bowker and Star (2000), is temporal and spatial. Drawing on Latimer's work, I am also able to investigate the effects and accomplishments of broader theories of medicine, such as medicalisation and biomedicalisation, on a local level in the clinic. I will return to this point later in the chapter. Furthermore, I consider the role of technologies and to an extent materials (Latimer, 2004), in the decision making process where I am able to treat space, materials and technologies as important factors in the diagnosis process.

Another intention of this study is to postulate how complexity is handled in relation to the emergence of risk. This is accomplished in two distinctive yet interrelated ways. First, Rose (1998) is helpful for framing my analysis of the National Dementia Commissioning for Quality and Innovation Framework (QUIN) as a clinical, governance initiative and the extent to which the 'lure of the number' (Rose, 1998: 18), shifts the content of work in everyday clinical practice; developing the notion that clinical governance initiatives, such as the CQUIN, enacts risk. Risk is therefore constituted through the CQUIN as it drives classification of AD to earlier stages. Second, I show the extent to which the enactment of risk might shift the boundaries of the disease, where I engage with the notion of an 'at risk' label, and the role of technologies involved in this process. In doing so, I frame my analysis within biomedicalisation theory and its affects in the clinic showing how the expansion of AD to incorporate MCI in particular, might drive the problematisation of ageing. This relates further to the theoretical underpinnings of ageing literatures and the particular discursive entanglements of the third and fourth stages of ageing (see Gilleard and Higgs, 2010, 2013). How this is negotiated in the clinic, adds a further dimension to understandings regarding age and the relationship between age, ageing and AD, since age is the greatest risk factor for developing AD.

A further dynamic of this research, is to develop the broad theories associated with authority in medicine, to demonstrate the intricacies of power and the division of labour in the memory service and hospital setting.

I take heed of Mol's (1998, 2002a) approach towards knowledge and power relations, by elucidating how they are enacted simultaneously in situated moments alongside materials and technologies. I analyse the production of hierarchies in MDT work and ordering relations (Latimer, 2004), and the extent to which the distribution of knowledge across technologies, materials and actors is *shared* when making decisions about diagnosis. Overall, an investigation of power in my own thesis is about demonstrating clinicians' relations with the tools: who uses the tools, who adjudicates on their use, and who makes diagnostic decisions based on the operation of the tools in the clinic for resolving complexity and producing knowledge about AD. The work of Latimer (2004) and the position of the MDT in these debates is fruitful for analysis since the memory service is built increasingly on an MDT approach due to the current demands on the service (increasing delegation of tasks to non-specialists (Nancarrow and Borthwick, 2005)). Across the division of labour in the memory service and hospital setting, I reflect on how clinicians make medical-decisions, which, are made up of interactions over time, and where mundane or tacit knowledge practices play significant roles (Berg and Mol, 1998).

At the same time however, I also explore 'the broader distribution of power in society' (Harris, 2005: 175). I take heed of the critique around ANT theory and Mol in particular, with regards to their reluctance to address power (see Harbers, 2005). At the same time that I analyse power in relations, which are enacted in practice, I also draw attention to broader social and political networks of power within the complex distribution of medicine in which AD resides. This corresponds with Munro (1999) and his observation that "contrary to imagining power...as running through structures...power is theorised as exercised in the networks that cut transversally across structures (pp. 431). In other words, I try to explore how broad theoretical literatures such as risk and therefore medicalisation and biomedicalisation, shape the role of technologies both on a wider policy scale, and also within the clinic more locally. The broader political arena in which AD exists, dominant ways of managing AD, reflected in healthcare policy initiatives such as the CQUIN which promotes early diagnosis. This

has the potential to implicate the perception and expectations around AD and diagnosis on a local level in the clinic. If difference is valued, and enactments could always be otherwise, ‘there is not much space for describing how decisions reach closure, how facts become relatively final, and how professionals are held accountable’ (Jenson and Winthereik, 2005: 267). Therefore, whilst I attend to the intricacies of the political in everyday diagnostic practice, I also pay due attention to the role of management in healthcare. I consider who uses the technologies, who adjudicates on their use, who makes final decisions, and therefore who is accountable in the medical decision making process. Here, accountability is of particular pertinence to analysing the CQUIN as a measure of clinical governance, as it shifts professional boundaries and responsibilities. I develop the work of Mol and extend it to look at *both* the wider networks of political power in which current diagnosis is occurring (ageing population), and also the hierarchies, identities and structures of medical dominance, which lead to diagnostic resolve.

Temporalities of classification

A further aim of this research is to analyse the temporalities of classification given that the expansion of AD to include the earliest stages of the disease is promoted in initiatives such as the CQUIN, and an increase in referral rates is shifting the temporal orderings of the clinic. I frame my analysis of the temporalities of classification within my investigation of how the CQUIN, which draws these dimensions of time together, is approached in everyday clinical practice. The CQUIN attempts to manage the increasing number of individuals projected to develop AD in the ageing population. Here, Rose (1998) is particularly useful for theorising on the CQUIN as a clinical governance initiative, which may have an impact on professional identities, autonomies and responsibilities. In order to show how the CQUIN translates into everyday clinical practice, I draw on the sociology of expectations literature (see Brown, Rappert and Webster, 2000; Brown and Michael, 2003; Borup *et al.*, 2006; Selin, 2006). In doing so, I illustrate how the classification process is made up of different kinds and perceptions of time

and temporality, for navigating complexity and managing patient expectations around a future with AD. The CQUIN as a process for enabling patients and clinicians to prepare for the patient pathway, is a particular version of cognitive decline but one through which points of difference and contention in practice emerge, which cannot be easily sorted. I show how the socio-technical environments, and situated occasions for classifying AD, are temporal and bounded. By looking to the sociology of expectations literature, I also further elucidate how the CQUIN is entangled in, and implicitly involved in, constructing expectations around the future of AD both in the clinic and in terms of resource allocation. The political power of the CQUIN might shift the temporal orderings of classification, and the articulation of the tools in everyday practice because of the changing structure of healthcare, and complex distribution of labour in which AD resides. The spatiality and *temporality* of classification is therefore centrally located as a theoretical underpinning of this thesis.

Summary

In this chapter, I have drawn attention to the key theoretical positions, which underpin and inform my overall approach. In order to address the problematic of this research as highlighted in Chapter One, and to demonstrate the complexity of attempting to classify AD, I identify a number of theories, which I see as especially useful to my research. These include, the theories of Goffman (1959), Mol (1998, 2002a, 2002b) and Latimer (2013) for producing knowledge about cognitive decline and AD in situated occasions by focussing on cognitive screening tools. Woven throughout my empirical chapters, I adopt these theoretical perspectives to make sense of diagnosing AD. Overall, however, my approach to exploring the role of technologies in healthcare privileges and foregrounds practice in situated occasions across social, technical *and* political arenas in routine everyday practice (Goffman, 1959; Garfinkel, 1967; Mol, 1998, 2002a). As demonstrated in Chapter Two, a categorisation of AD is complex in relation to its nosological framework to which literatures within philosophy, anthropology, STS and medical sociology have responded accordingly.

However, the *process* of diagnosis accomplished in the clinic through the use of available technologies and their operation in practice, has not as yet been the primary focus in the literature. The practices of the clinic and the articulations and negotiations, which take place, are important for considering how to make sense of complexity and difference or the multiplicity of disease realities. This is therefore a study of how AD is 'done' and enacted (Garfinkel, 1967; Mol, 1998, 1999, 2002a).

More specifically, driven by an interest in the complex distribution of medicine in which diagnosing AD occurs, I capture the hierarchies, identities, responsibilities, interactions, and power-relations entangled with the operation of these technologies. I subsequently identify the dynamics of articulation work and how this hierarchical work (re)shapes the role of the tools in particular spaces (patients' homes and the MDT). This involves focusing on the articulation of the tools across time and space in the intricacies of the clinic. Furthermore, extending the micro claims of ethnomethodology, I also attend to the wider distribution of power across the memory service by developing broad literatures on risk. Therefore, I consider how the political dimensions of power are performed; analysing how the tools have the capacity to produce and (re)produce hierarchies and responsibilities in the memory service and hospital setting, but recognising that the wider arena of an ageing population enacted in the CQUIN needs to be accounted for. Grasping life in the clinic is partly a process of emerging dimensions of power that are both intricate and networked but also constraining. As a result, I ground the everyday practices of the clinic in a broader political arena to capture how moments of multiplicity hang together, difference is resolved, and actors held accountable. Overall, I foreground practice by analysing situated encounters which are at once, social and technical, and also political.

Chapter Four

Method and Methodology

In the following chapter, I discuss the research methods on which this study was grounded. I explain my research design including how I gained entry to the field, the fieldwork process, the data collected, how the data were analysed, and the limitations of my study. I begin by briefly outlining my overall approach which foregrounds practice, where I extend the lens of constitution and enactment of disease embedded in my theoretical approach, to the research design itself. I developed the notion that research methods have productive and performative consequences, and constitute multiple realities (Law and Urry, 2003). I adopted a qualitative approach drawing on ethnographic methods, in order to explore how AD was ‘brought into being’ and made within a particular set of healthcare practices (Woolgar and Lezaun, 2013: 323). In order to access the field prior to data collection, I proceeded with the NHS ethical review process, and I engaged with what Caine *et al.*, (2009) describe as ‘preliminary fieldwork’. I describe how data were collected within two memory clinic teams in a memory service, an elderly medicine department, and an informatics department in a large NHS teaching hospital trust in the UK. Overall, I drew on the concerns of ‘situational analyses’ (Clarke, 2003) in order to make visible and ‘better grasp the complexities of social life’ (pp. 572).

Approaching the research iteratively, is also a matter of reflexivity (Desmond, 2008), and I critically engage with the extent to which my role as a researcher was shaped by particular complex social and cultural relations. I continue by drawing attention to the limitations of my study and my claim to doing ethnography more broadly. As Hammersley and Atkinson (2007) note, “there is an important sense in which all research is a practical activity requiring the exercise of judgement in context; it is not a matter of following methodological rules, nor can all the problems be anticipated, or for that matter resolved”. As demonstrated in Chapter Three, the complexity of the theoretical steering of this thesis was a reflection of

the complexity of diagnosing AD, and therefore my research design attempted to order and make sense of the disorderliness of practice. Overall, I was interested in exploring the role of medical technologies in healthcare for producing knowledge about disease (Berg, 1996; Mol, 1998, 2002a) and investigating identities, hierarchies and responsibilities in which AD is seen to be ‘done’ (Garfinkel, 1967).

Approach: Foregrounding Practice

My overarching research question asks:

How do instruments for screening cognitive function constitute Alzheimer’s disease at various sites of clinical and policy practice?

The following three sub-questions guide my empirical chapters –

How do clinicians use instruments for screening cognitive function to navigate and manage the uncertainties associated with measures of cognitive decline and articulate a formal classification of AD?

How do clinicians use instruments for screening cognitive function to negotiate the boundaries of classification in the organisation of clinical practice towards the production of AD diagnosis?

How do increased efforts to detect cognitive decline as laid out in the National Dementia CQUIN translate into clinical practice in the process of classifying AD?

I investigated the role of mundane technologies in the process of classifying AD in order to highlight the social issues left ‘hidden’ in current diagnostic practice. As outlined in Chapter Three, my overarching theoretical approach, foregrounded practice and the multiplicity of disease which was constituted across particular situated occasions. By examining the multiplicity and complexity of classification and exploring medicine from the ‘inside’, I

attempted to make sense of the socio-technical settings through which AD is made (Mol, 1998: 163). I analysed how negotiations of practices, actions and interactions emerged as ‘central social processes’ in the production of classification and diagnosis (Clarke, 2003) where ‘nonhuman entities achieve a delegated agency within socio-technical networks’ (Hess, 2001: 2). Adopting this approach, I therefore considered AD aside from socially constructed categorical distinctions, which dominates previous literatures as noted in Chapters Two and Three, and assumes ‘closure [of AD] has been achieved’ (Law, 2004: 56). Rather, I attended to the constitutive versions and enactments of AD in practice through the use of technologies, thereby giving AD ‘a complex present, too, a present in which their identities are fragile and may differ between sites’ (Mol, 2002a: 43) beyond its historical construction.

I considered AD not as a single reality ‘out there’ for investigation, but as a production between interrelated elements of practice (Mol, 1998, 2002a). Opening up and interfering with current diagnostic practice to examine AD ‘in the making’ (Latimer *et al.*, 2006: 614) was useful for reflecting on how healthcare practice was dealing with, and responding to, the increased number of referrals to specialist memory services in the projected ‘ageing population’. To address my research questions, I therefore explored the myriad of ways in which complexity was navigated and sorted in healthcare. In terms of the first research sub-question, the aim was to highlight the processes through which the uncertainties associated with diagnosing AD, were navigated in the clinician-patient interaction across the division of labour in the memory service. With reference to the second sub-question, in order to investigate the ways in which the boundaries of the disease were constituted, I attended to the role technologies played in enacting risk and complexity within the organisation of the multi-disciplinary team (MDT). This meant I was interested in how clinicians dealt with further complexity as both a technological and an organisational occasion, producing and reproducing professional hierarchies. In order to answer the third sub-question, and the translation of the National Dementia Commissioning for Quality and Innovation Framework (CQUIN) in clinical practice, this meant

investigating how clinicians approached, negotiated, interpreted, and made sense of this initiative in practice. I therefore highlighted what shifted in terms of the ways in which clinicians were already making sense of complexity in practice as mapped through the first two sub-questions. Overall, I was interested in both moments of interaction, and accounts of clinicians and information managers.

In order to answer the research questions and attend to the ‘hows of social interaction’ (Holstein and Gubrium, 2008: 377 emphasis in original), I drew on the claims of ethnomethodology, which assumes that social practice is constitutive; it does not exist independently from the world under investigation (Holstein and Gubrium, 2008). The approach attends to matters of the everyday and as a result, this study attempted to ‘grasp’ the complexity and diversity of the situated world of classifying AD in the quest for social order (Garfinkel, 1967; Clarke, 2003: 572). Therefore attending to the ‘hows’ of social reality necessarily required a discussion of the ‘discursive resources’ from which multiplicities of disease were produced (Holstein and Gubrium, 2008). Discourse is, ‘composed of ideas, attitudes, courses of action, beliefs and practices that systematically construct the subjects and the worlds of which they speak’ (Lessa, 2006: 285). Herein, I framed the actions of clinicians in discursive practices, which through the use of the tests, were reflected in the interactions of the clinic and beyond. These practices (re)constituted the power, roles and identities of patients and clinicians, and were therefore implicitly involved in (re)producing power relations within the organisation of the service. My aim was to ‘sensitively illuminate’ (Pinder *et al.*, 2005: 765) power relations in terms of how the tools were approached, who adjudicated on their use, who had the expertise and skills to do so, and how this shaped the process of classification. I did not want to ‘proffer simple solutions to complex problems, possibly reproducing the very power structures it [my research] needs to challenge in doing so’ (Pinder *et al.*, 2005: 765).

At this point, I reiterate that despite the fact that I drew on the sensibilities of ethnomethodology for exploring situated occasions of interaction, I also

extended the culturally interpretive mode of analysis on which ethnomethodology is grounded by framing my analysis overall, within the work of Mol. The ‘socio-ontological’ and constructivist practice approach of Mol, moves from representation to performativity, and from epistemological to ontological concerns abandoning *a priori* assumptions about the reality of disease (Van heur, Leydesdorff and Wyatt, 2012). As Van heur, Leydesdorff and Wyatt (2012: 355) claim, “the language of ontology is used to assert long-standing commitments to situated, ethnographic research methods and to signify the centrality of tools in constituting socio-technical relations” (emphasis added). My research design subsequently reflected my overall approach to practice and I developed the concerns of Law and Urry (2003) who contend that research methods ‘do not simply describe the world as it is, but also enact it’ and I provided an empirical argument about ontology as opposed to epistemology (pp. 1). What is interesting regarding Law and Urry’s (2003) work, and which was particularly important for this thesis, is that the terms enactment or constitution embed the notion that there is no longer a single reality ‘out there’ to explore. What is known is no longer a single reality but instead is being ‘made’ at different locales and within different spaces (Ibid.). Multiplicity is produced in what Law and Urry (2003) consider are contested socio-material relations and practices (pp. 6 emphasis added). As Law and Urry (2004) stress, “to suggest that while the ‘real’ is indeed ‘real’, it is also made, and that it is made within relations” (pp. 395 emphasis added).

Research Design

The following research design grounded these conceptual claims. Through observation work and the accounts of professionals, I highlighted what shifted, was made useful, and was made visible, in the process of classification. I adopted a qualitative approach and drew on ethnographic methods: I interviewed professionals regarding their work practices, and subsequently observed the interactions between professionals, patients and the tests. The purpose of this observation work *in situ* (Holstein and

Gubrium, 2008) was to investigate the face-to-face interactions in the clinic. I drew on an ethnographic approach because as Law (2004) argues, ethnographic methods reject the traditional methods models in an attempt to explore the uneven process of producing knowledge in research, ‘it [ethnography] looks beyond the official accounts of method (which are often clean and reassuring) to try to understand the often ragged ways in which knowledge is produced in research’ (pp. 18). Although I focused on the multiple truths or versions of AD which the ‘ethnographer discovers’ as described by Denzin (2000: XV), I did not exclusively adhere to the principles of ethnography or any other discipline or tradition. In particular, I did not claim to be wholly ethnographic in approach, instead adopting a qualitative approach, which drew on ethnographic methods, as there were limitations to my sample and data collected. This will be discussed further in the chapter.

Site for research

As ethnography implies an open-ended approach to the research design (Maxwell, 2012), this research design responded to and emerged from empirical work. I gathered data for my research in a memory service and a large NHS teaching hospital trust. To begin data collection, I underwent a lengthy preparation process necessary for gaining access to privileged environments. Initially, I planned to conduct research across two memory services within adjacent cities, and also carry out participant observations of clinicians in hospital wards across two large NHS teaching hospitals. In order to gain access to each of these sites (selected in part for the large number of individuals from a variety of social and ethnic backgrounds), I applied for NHS ethical approval. NHS ethical approval involves an in-depth assessment where a study is granted or declined clearance by an independent panel of medical and non-medical experts. Applying an open-ended approach to the research design however, meant that in order to gain ethical approval, I immersed myself in the intricacies of the field since securing access to the field begins prior to negotiating the bureaucracies of the ethical landscape. Securing access ethnographically (Wolcott, 1990) is

accomplished through extensive interaction work between potential gatekeepers or experts within the field, and engaging with literature to prepare for formal review. Subsequently, fieldwork is not marked by those who adjudicate on ethicality of the study, but emerges from the interactions and instances that precede this official access to the field (Hammersley and Atkinson, 2007). Furthermore, the epistemological assumption of ethnography is to abandon *a priori* assumptions of the ways in which knowledge is acquired (Maxwell, 2012). As such, ethnographic fieldwork begins by exploring what Malinowski (1922, 1967) terms ‘foreshadowed problems’.

The role of ethnography in the social sciences has been subject to considerable debate, and in order to ground its complexity, has been defined broadly as a method of participant observation in the field (Denzin, 1997). Yet, given that ethnography is not consigned to the methods for data collection, the definition of ethnography is contested (Hammersley and Atkinson, 2007). Solely grounding ethnography in methods for data collection such as participant observation and semi-structured interviews, does not take into consideration the work that necessarily has to occur prior to entry into the field. I therefore drew on the assumptions of Caine et al., (2009) who refer to the stages of research that occur prior to formal access to the field. In the following section, I will outline the work I undertook prior to formal ethical review, in recognition of the fact that making connections within the field, the role of gatekeepers, and understanding the intricacies of the culture of the field, is crucial for ethical review. In accordance with my theoretical approach more broadly, I both rejected the pre-existence of AD ‘out there’ to be explored (Law and Lien, 2012: 366), and ignored *a priori* assumptions about the field gathered during preliminary fieldwork.

Preliminary fieldwork and NHS ethics

Throughout my thesis, I adopted pseudonyms for each of the research sites. Carlton Hospital was an in-patient and out-patient elderly assessment unit based in a large psychiatric hospital. As I will explain further in the chapter, I was unable to carry out my research in this site despite having ethical approval confirmed. Nunmill Hospital and Ridge NHS Centre were both out-patient and in-patient elderly psychiatric services with specialist memory clinic facilities. Holmwood Hospital was a large teaching hospital. Gaining access to these sites was a carefully considered process, as I will highlight throughout the chapter.

My study began with a discussion with my doctoral supervisors who suggested I contact a colleague and previous Dean of a medical school. This colleague was named as my Clinical Supervisor and overarching gatekeeper to the sub-sites. At this point, plans for my research were tentative, vague and particularly ambitious principally about how I wanted the study to proceed. During the meeting with the clinical supervisor, we discussed how best to proceed with the Research Ethics Committee (REC) application. This included formulating an inclusion and exclusion criteria for patient participation, discussing how I would proceed with ensuring patients had capacity to consent to research, and deciding on a process for recruitment in out-patient clinics and Acute Medical Unit in-patient wards. I heeded his advice concerning meeting clinicians within these sites to discuss my project further, and accepted his recommendations. Following this meeting, the Clinical Supervisor arranged for me to discuss my research project with Consultant Psychiatrist 1, the lead clinician for a memory clinic within the memory service. It was during this meeting that concerns about the practicalities of my work were raised. The cognitive test that I wanted to investigate had recently become subject to copyright and the Trust was no longer paying for its use. Consultant Psychiatrist 1 expressed her enthusiasm for the project but advised that I revise my investigation to ensure the service would not be implicated. Furthermore she suggested I explore the

reliability and validity of other tools within the service such as the Montreal Cognitive Assessment (MoCA) and Addenbrooke's Cognitive Examination (ACE) 111. The meeting was overwhelming as I realised how little I knew about old-age psychiatry or medicine in general. Furthermore, it demonstrated the extent to which the researcher has to negotiate the agendas of both themselves and of those on whom their research depends. Consultant Psychiatrist 1's suggestions with regards to assessing the reliability and validity of tools within the service, did not align with my own aims and objectives for the research. Whilst the reliability and validity of these tools has been researched within the field of psychiatry and psychology in terms of sensitivity and specificity, it was not the task of this research to further develop this body of literature.

Having met with my doctoral supervisors and revised my research aims to ensure the service would not be implicated in regard to copyright, I once again approached Consultant Psychiatrist 1 and she agreed to support the study. In addition, Consultant Psychiatrist 1 also organised a meeting with a consultant psychiatrist in Carlton Hospital (I will explain further in the chapter how I did not go on to include this site within my research). I pitched my research to the consultant psychiatrist in this site and she agreed to support the study. I gained access to the elderly healthcare department at Holmwood Hospital through the Clinical Supervisor. The Clinical Supervisor also put me in contact with Information Manager 1 based in Holmwood Hospital as part the teaching hospital Trust. I met with Information Manager 1 who advised on who I would need to contact and the kinds of documents I may be able to access upon ethical approval. Following initial meetings, email exchanges, and telephone calls with consultant psychiatrists, geriatricians, information managers and memory nurses, and further contact with the Clinical Supervisor, I developed key contacts within each of the sites. This helped me to map out the specifics of data collection, which proved essential to gaining ethical approval.

NHS ethics and claim to ethnography

A number of individuals, including professionals and students, who had been successful in the ethical review process, recommended that it would be beneficial to recruit someone within each site of study and a clinical supervisor to champion my study. I was made aware by previous doctoral candidates that the NHS REC looks favourably on researchers who are able to demonstrate this support, and therefore the Clinical Supervisor was assigned this role. Consultant Psychiatrist 1 and Information Manager 1 became my gatekeepers throughout the duration of my study. Coyne (2010) describes the ways in which gatekeepers are able to effectively maximise recruitment opportunities, hone the research design, and embed the researcher within the setting because as Johnson (1990) contends, they have access to privileged knowledge systems. This work is fundamental for the scaffolding of a research project particularly when conducting research in a hospital setting (Coyne, 2010). For the purposes of navigating the NHS ethics application, the role of the gatekeeper is also essential for diminishing the possibility of rejection or rebuttal; the gatekeeper role is deemed to possess more power than the researcher in navigating the ethics terrain (Reed, 2007). As an individual with no medical background or specific alliances with the sites for investigation, I discerned that the sponsorship of each of these individuals would ease the transition from stranger to researcher (c.f. Coyne, 2010).

I prepared the NHS REC documents for submission during the preliminary fieldwork stage. My vague, at times naïve, thoughts and ideas regarding the research design, were reshaped through discussions with key contacts in the field. Within the extensive research protocol, I provided an account of the data that would be collected; where this would be collected and how; the number of hours expected to be in each site; how participants would be approached, and how many would be recruited. The application process was a laborious task and it has been argued more generally that the rigorous, prescriptive stipulations of the process hinder the art of engaging in iterative qualitative research (Bosk and De Vries, 2004; Dingwall, 2006). Following

receipt of my initial application, I was invited to attend a REC meeting (December 2013) where I was asked a number of questions about my study by both medical and non-medical members of the committee. The meeting lasted for approximately twenty minutes. During the meeting, the committee queried a number of points. First, they queried why I had stated I wanted consent forms to be signed and posted to myself; they questioned how this would work as the forms are usually signed in the presence of the researcher. Second, the committee queried the timescale of the research, which they deemed to be an adventurous commitment for successful completion within three years. In response to these points, I confirmed I would not ask for consent forms to be posted and that I would ensure my research was finished in the given timescale since my funding is a three year contract without the possibility of financial extension. Third, the REC queried the patient information sheet, which they suggested was unclear, as I had implied that if non-English speakers can read the information sheet they could then consent to participate in the study. They suggested that I amend the inclusion and exclusion criteria to ensure that patients did not misunderstand. At the end of the meeting I was also given space to ask any questions. I asked whether the inclusion and exclusion criteria for assessing capacity to consent to research, which I had discussed extensively with my academic supervisors and my clinical supervisor, would be practical; members stated that they had no queries or discrepancies about this aspect of my research.

Overall, the committee was particularly responsive towards the fact that I was investigating the best use of current practice as opposed to developing a new technology for implementation. The committee spoke encouragingly about the importance of research, which explores how current technologies are used. In this sense the committee conveyed a sociological imagination that I was not anticipating. Despite its laborious and at times bureaucratic nature, recognised by clinical researchers (see Ashcroft, Newson and Benn, 2005 and Shaw, Boynton and Greenhalgh, 2005) and social science researchers (see Reed, 2007 and Richardson and McMullan, 2007) alike, the ethics committee was unquestionably helpful and supportive of my research

ideas, and looked favourably on the project. As a result, my research was approved pending the completion of minor amendments and following resubmission I was granted full ethical approval in January 2014. My experience chimes with Hedgecoe's (2008) claims that the REC and its members primarily see their role as facilitating and supportive of social research. It has been argued however, (see Murphy and Dingwall, 2007; Reed, 2007) that the process of NHS ethics may complicate the practice of doing ethnography in medical settings, of which there is a considerable history (see Bosk, 1979; Strong, 1979; Atkinson, 1995; Berg, 1996, 1997, 1998; Mol, 1998, 2002a, 2002b; Latimer, 2000, 2013).

As ethnography involves the researcher participating in the area of study for an extended period of time (Hammersley and Atkinson, 2007) subsequently, I question whether gathering detailed snapshots of the field (as is the case with this research), constrained my claim to doing ethnography. In order to investigate this, I focus on the role of the REC and the ethics application process overall. Although I have attempted to apply an ethics in practice approach to my research (Guilleman and Gilham, 2004), which goes beyond formal ethics applications and approval, the question remains as to whether this formality and the research design approved by the REC, constrained my claim to ethnography overall. I reflect on the existence of committee ontology or ontologies, which I claim did not reflect the broad ontological assumptions of this research that embraced multiplicity, and constitution of disease in practice. The REC requires researchers across clinical and social science practice to detail each stage of the research process including specifying research methods; outlining the recruitment strategy; providing an inclusion and exclusion criteria list for assessing suitability for participation; detailing ethical considerations including potential risk of harm to participants, and finally, detailing the benefits of the study. Subsequently I provided an inclusion and exclusion criteria list to assess participant suitability for study; outlined in detail the sites for study; stated what I would be focussing on during observations of team meetings and consultations, and rigorously outlined how I would be seeking informed consent from participants. As stipulated earlier in the chapter, the

formulation of the research design was a collaborative endeavour with clinical ‘experts’ and gatekeepers, which was key to successfully negotiating the REC process, and ensuring a transparent research design that would safeguard the interests of participants. Commitment to transparency however, which was reflective of a broadly realist perspective and therefore constituted a particular version of AD ‘out there’ for exploration. The emphasis of my research however, was on demonstrating how in practice AD became to be made ‘real’ appropriating the lexis of ontology in the terms ‘constitution’ or ‘enactment’. In a phenomenological sense then, ‘rather than there being a world of concrete objects which a theory cuts this way and that,... the cake is constituted in the very act of cutting it’ (Garfinkel, 1972: 5). Conceptually, this was in stark contrast to the role of the NHS REC, which embraces essentialism and realism, and the importance of *a priori* knowledge to ensure transparency in research.

The REC dictated the population for recruitment, the settings for investigation and a version of pathological cognitive decline only evident in those with the capacity to consent to research. The committee reduced the ‘plurality of worlds’ for exploring how instruments for screening cognitive function constitute AD, and projected particular normative concerns regarding AD in practice on my research. Overall, the REC projects a powerful set of practices upon research. It has the ability to constitute the sites and practices the researcher engages with in fundamental ways. Although this is primarily evidenced in the necessity to detail each stage of the research process, it extends beyond what the researcher will be doing and who will be included in the study, to considering the ontological and epistemological assumptions the researcher has to embed in the research practice in order to ensure ‘ethical’ practice. The NHS ethics review process is essentially an enactment or reification of the (bio)medical model (Hedgecoe, 2008), which itself has the potential to impose on the research design. With respect to my own work, it imposed on the overall constitution of AD by dictating the particular sites and settings for investigation, and therefore versions of the disease for exploration.

Subsequently, I questioned how these competing epistemologies and ontologies could be navigated to ensure that I upheld the key concerns of the STS scholars that have influenced my research and my claim to ethical practice; in particular the ability of my work to be wholly ethnographic in approach. As such, I adopted a reflexive, flexible approach to my research, wherein I stipulated that the claims I made are reflective of a specific, particular world of AD rather than making broad, general assumptions. Furthermore perhaps the constraints or norms of the REC embedded in what became the research design should not be of sole concern but instead the analysis of the norms embedded in the practices that came out of this design should be of primary significance (c.f. Mol, 2012). Therefore, I adopted ethnographic methods in recognition of the fact that I could not claim to be wholly ethnographic in approach.

Fieldwork: Ethnographic Methods

Following confirmation of ethical approval, I contacted each of the gatekeepers within the proposed sites for research. To clarify, it was at this point that my connections with Carlton Hospital were not taken up. Despite having agreed to my study, for organisational reasons, the gatekeepers deemed that my work was going to be too onerous a task for clinicians and patients. As such, fieldwork began with Holmwood Hospital, Nunmill Hospital and Ridge NHS Centre. Following an email exchange with Consultant Psychiatrist 1 at Nunmill Hospital, she invited me to attend a Multi-disciplinary Team (MDT) meeting. Here I presented my research and gathered the contacts of those who would like further information about the research, and to be contacted for possible participation. With regards to participant observation of consultations, it was agreed that I would contact clinicians separately with criteria for inclusion and exclusion, and they would then contact me with relevant appointments to observe week by week. The research protocol I produced for the ethics committee was formulaic and included a list of exactly what it was I wanted to observe or would be of interest to me. Yet, I also entered the field with flexible research interests

and concerns in order to guide initial consultations. I observed team meetings, hospital wards, offices, and consultation rooms, where AD gets 'done' (Garfinkel, 1967). The majority of my fieldwork however, was conducted via observation in two teams in the memory service. As I will explain in the final sections of this chapter, I could not observe memory nurses in the second memory clinic team, as I did not have ethical approval to carry out observations in patients' homes.

Observations of team meetings and clinical encounters were focussed and selective, which reflected the microcosm of the cultural actions of the clinic as opposed to portraying a whole cultural system (Wolcott, 1990). Therefore despite the small sample of observation data I had, I maintain that I have provided the level of 'thick descriptions' (Geertz, 1973) and cultural interpretation (Wolcott, 1990), in clinical encounters to reveal the 'situated rationality of action' (Murphy and Dingwall, 2007: 2224). Limiting my observation focus to two teams in one memory service also allowed me to formulate well-thought through, rich and deep insights into the social life of the setting in line with my theoretical sensibilities as outlined in Chapter Three. In what follows, I briefly describe the nature of the three locations in the memory service setting where I carried out observations and interviews.

Memory Service

The memory service is an NHS governed institution and is accredited by the National Memory Services National Accreditation Programme, through the Royal College of Psychiatrists. This programme aims to expand the number of memory services for accreditation to increase performance management and improve clinical services for diagnosing dementia, in line with the PM's Challenge on Dementia as outlined in Chapter One (see Royal College of Psychiatrists, 2015).

Nunmill Hospital

The memory service is governed by a partnership foundation trust and the memory service operated within three memory clinic teams covering three

localities of the city. The memory service was based at Nunmill Hospital. The service overall, aims to assess, diagnose and treat individuals predominantly over the age of 65 experiencing early dementia and provide support for those who are subsequently diagnosed. I observed appointments in Nunmill Hospital and Ridge NHS Centre. In Nunmill the memory clinics were held in a building adjacent to the main hospital site. The building was not only used for memory service but for all mental health services, which fall under the responsibility of the community mental health service. Arriving at the centre, individuals are greeted by a small waiting area with a reception desk facing the seating. The room is generally quiet with only a couple of rows of seats. There are a number of information leaflets scattered around and posters on the walls with information about various mental health services available across the city. Aside from the posters, the walls are relatively drab, broadly representative of a generic GP surgery or healthcare centre. Nothing about the waiting area sets it apart as a specialist service. Adjacent to the reception desk is a security-coded door which leads to a number of consultation rooms each containing a desk, computer, three chairs, a set of scales and other generic medical equipment such as a stethoscope. The rooms are numbered (e.g. Consultation Room 1) and are used by a number of clinical professionals working across the service. Clinical professionals come and go through the building throughout the day; they are not assigned a specific consultation room.

Ridge NHS Centre

The second site was located in a suburb on the outer areas of the city serving the north locality of the city. Memory clinics were held in Ridge NHS centre. On arriving at Ridge, individuals are greeted with a large waiting area and a reception to the left. The room is generally bustling with clinical professionals walking through the waiting area and around the building more generally. Despite the fact that their work is scattered across the city, Ridge is also where a number of the professionals' offices are located. Those working behind the reception area add to the hustle and bustle of the waiting room as they converse openly with each other and engage with

individuals waiting for appointments. Along the corridor from the waiting room are the offices of clinical professionals (serving as consultation rooms); a number of generic consultation rooms; a bathroom, and a room dedicated to staff meetings. Whilst a number of professionals pass through this space, consultants, registrars and junior doctors are those primarily occupying this space, as memory nurses in Ridge do not carry out appointments in clinic but rather in patients' homes.

Holmwood Hospital

The third site, from which interviews with geriatricians and information managers were conducted, was located in the centre of the large metropolitan city. This NHS teaching hospital trust was therefore not part of the partnership foundation trust through which Nunmill Hospital and Ridge NHS Centre were governed.

Data collection

I will start by outlining how I collected data in Nunmill Hospital and Ridge NHS centre. I spent approximately six months collecting the data for my research. I carried out seven observations of consultations, two observations of team meetings and twenty-three interviews with professionals. Combining these methods, I attended to the operation of cognitive screening tools in practice and thus the interactions between the clinicians and the tests (Goffman, 1959; Mol, 2002). Whilst observation alone can reveal this spatiality of regions central to how AD is 'done' (Garfinkel, 1967), I supplemented the rich in-depth data from these selective observations with interviews, to explore the situated actions of clinicians (Murphy and Dingwall, 2007), the rationality behind why and how they located themselves, and the tools in practice. Carrying out observations also meant that I could elucidate the 'inevitable slippages between what people said they thought and did, and what they 'actually' thought and did (Pinder *et al.*, 2005: 764). Observations are situated occasions of clinical work and represent the fluidity of relations between humans and materials for supplement through interview. These methods enabled me to consider the

frontstage and backstage practices, which make up AD as outlined in Chapter Three. In traditional ethnographic standards for ‘doing ethnography’, participant observation allows the researcher to be placed both ‘inside’, through participation and ‘outside’, through observation of the social world under exploration (Spradley, 1980).

Selecting observations, as a method for gathering data, was not extensively and exclusively adopted in this research for a number of practical reasons. In part, the small number of observations carried out, reflects my overall focus on the particularity of setting; namely consultations where cognitive screening tools were used with patients. I selected observations to reveal the ‘artful practices’ (Garkinkel, 1967: 11) of the everyday work of clinicians set with the task of classifying AD, supplemented by the accounts of professionals during interview. The arguments drawn from my observations in this thesis, stemmed from extensive fieldnotes written before, during and after the observation event. However, whilst I immersed myself in the routine procedures of the consultations, I did not immerse myself wholly in the routine procedures of the clinic overall (see Garforth and Kerr, 2010). I did not sit and observe the waiting area, or how professionals occupied themselves between consultations, or what they conversed about in the staff quarters and so on, because of my ethical review constraints. Although immersing myself into the culture of each setting informally would have allowed me to capture truly what was taken-for-granted, I had to confine this to what was taken for granted in the moments I was present in the team. I could not develop more than a ‘peripheral membership role’ in the field (Angrosino and Rosenberg, 2011: 468) and nor could I claim to have become ‘one of them’ (Wind, 2008: 87). My fieldwork was a specific formulation of negotiated interactions and despite the importance assigned to carrying out observations, doing fieldwork is ‘so much more than being there’ (Wind, 2008: 86).

Observations of consultations were arranged with clinicians in Nunmill Hospital. Consultant Psychiatrist 1 subsequently put me in contact with Consultant Psychiatrist 2 in Ridge NHS Centre, and again I met with the

team, outlined my research, gathered a list of professionals who would like to be contacted with further information, and similarly to Nunmill, I arranged consultations with individual clinicians. I had stipulated in my protocol for ethical review that I would include only those who had the capacity to consent to research, and this was the responsibility of the clinician to identify. As a result, I could not sit in the waiting rooms and wait for clinicians to inform me of a suitable case, particularly given that clinicians rarely spent more than a morning or afternoon in any one site. If there was cause for concern regarding capacity to consent when I arrived at the clinic and met the patient, I did not observe the appointments. I arranged to observe the team meetings where I provided a 'cover story' (Bosk, 1979: 194) when questioned about my presence in the team, 'I am a PhD student in sociology interested in how clinicians use instruments for screening cognitive function in the process of diagnosing AD'. This was met with enthusiasm across each of the teams and made contacting professionals for both observation of consultation and interviews less daunting.

Access to the sites for observation was opportunistic. I waited on professionals who would email me with a list of potential observation dates and times; it was crucial that patients met the criteria for inclusion. In the majority of cases, I was asked to arrive approximately fifteen minutes prior to the start of the appointment to discuss with clinicians how I would be seeking consent from the patient. However, primarily this time was spent with the clinician who talked me through the patients' medical notes and explained why they had been referred and what the appointment might entail. From the initial consultation I observed, I engaged in a process of reflexivity, continually moving back and forth from the field with revised thematic criteria, focus points and questions (c.f. Duneier, 1999). Following the six months of observation and interview work, I reached the point of data saturation both practically and conceptually. I began to make clear links between sets of data. Although data could have been supplemented with further rich and useful information, this may have led to an overload of unnecessary data to organise. In retrospect, I feared my presence was

perhaps too onerous for a number of clinicians who at times felt pressured by my presence because they had misconstrued the nature of my work, as I will go on to discuss when I turn to the limitations of my research.

Fieldnotes

During the observations of consultations and team meetings, and once I had gained consent from patients and practitioners, I carried a notepad and made fieldnotes. During the brief and de-brief or less formal encounters, I relied on memory and created notes immediately following fieldwork. This was because I felt that writing extensive notes during conversations (particularly if this was a first encounter with a clinician) would add to professionals' curiosity as to what and why I was writing. Consultations were an appropriate more formal environment to construct fieldnotes. Whilst this approach to data collection has the potential to be construed as ad hoc and less rigorous than other forms of data collection, the notes I made during consultations were well-recorded, detailed and illuminating (Atkinson, 1995). The fieldnotes gathered, contained exhaustive information of particular moments; briefing with the clinicians prior to consultation, consultation, de-brief following the consultation and the team meetings. They described interactions, relations, discourses, verbal practices, non-verbal practices, space of the setting and personal reflections. Fieldnotes are not, and should not be read as, a comprehensive, exhaustive record of the setting; the researcher necessarily draws on tacit knowledge systems that cannot be contained in the written notes (Hammersley and Atkinson, 2007). As such, I relied on my memory to 'recontextualise' the observable events (Hammersley and Atkinson, 2007: 147).

I transcribed the fieldnotes as soon as possible following fieldwork because I opted not to use an audio-recorder; I feared that it would disrupt the order of the setting perhaps already compromised by my presence. This meant that I might have missed key events that I could have captured on the recorder. However, my overarching concern was that the presence of a recorder would be an intrusion on what was already a particularly sensitive

consultation. As Memory Nurse 6 explained when waiting for a patient to arrive prior to observation, *'the patient needs to be as relaxed as possible, they may be coming into this clinic worried what's going to happen and the family member might be too'*.

Conducting interviews

Semi-structured interviews were carried out with twenty-one healthcare professionals and two information managers. The views and perspectives of patients undergoing testing for cognitive decline and the process of diagnosis, is of undeniable value and yet is a significantly under researched area of study. An increasing number of scholars highlight the benefits of involving dementia patients in research (Bond and Corner, 2001) but recognise that doing so poses ethical and practical issues, such as how to gain informed consent and assessing capacity to consent to research (Sherratt and Soteriou, 2007). The aim of this study was to explore how cognitive screening tools were used to classify AD, and henceforth constitute the disease in clinical practice, given the lack of attention towards the process of diagnosing AD within Sociology and Science and Technology Studies (STS). Whilst the accounts of patients would provide an interesting and important component for this endeavour, I attended to situated occasions to pursue an exploration of professionals' interactions with the tests in healthcare practice, and how they made sense of the complexities associated with categorising AD more broadly. Furthermore, ensuring that patients included in the study had the capacity to consent to research, meant that gaining ethical approval would have proved challenging particularly, as I was also constrained by the three year timeframe to carry out doctoral research. I drew on both observations and interviews for my fieldwork.

The majority of my fieldwork however, was in fact taken from interviews with clinical professionals. Interviews with clinical professionals were used both to confirm the observational data (often I wanted to clarify moments of uncertainty in the clinic) and as a method to simultaneously probe for

information and generate unexpected data. There were a number of instances however, where clinicians consented to observation but did not consent to a follow-up interview. Semi-structured interviews more generally, are also a particularly useful method of data collection for research within the healthcare setting. According to Holloway and Wheeler (2013), semi-structured interviews are not dissimilar from the practitioner-patient encounter rendering them particularly effective at capturing the reflections and perspectives of clinicians. Furthermore, following discussions with a number of practising clinicians, it was made clear that the semi-structured interview method would be familiar to a number of clinicians. In accordance with my theoretical approach more broadly however, neither the accounts of clinicians nor the observations of interactions were ‘gold standard’ of an enactment or constitution of AD (Law, 2004). Rather, they participated in the enactment or constitution of realities: I attended to matters of ‘praxiography’ as opposed to epistemology where methods do not presume the nature of AD (c.f. Mol, 1998, 2002a).

Whilst the formal methods adopted in this research such as interviews and observations were assemblages of the interactions and relations between the ‘fluxes of the real’, I did not take these accounts at face value. Instead I attended to their situatedness, which allowed me to engage with the continued enactment or continuing crafting of social life (Mol, 2002a). As such, I engaged with a context driven fieldwork, which encompassed both the unscripted and scripted accounts of professionals, particularly as ethnography adopts a multiple methods approach (Hammersley and Atkinson, 2007). Semi-structured interviews were also carried out with geriatricians in the large teaching hospital Trust (I did not observe these clinicians because of ethical approval constraints) and information managers who provided both non-clinical and clinical perspectives on the implementation of the National Dementia Commissioning for Quality and Innovation Framework (CQUIN). Their perspective on how both the instruments and the data generated were used was an important dimension for this research. Both geriatricians and information managers interviewed were sampled purposively from within the memory clinic teams, where I

gathered a wide-range of clinical professionals from across the hierarchy of the teams. Whilst empirically, this meant my research had limited generalisability I have generated theories, which could be generalised across other sites of practice.

The majority of my field data was taken from interviews with professionals across psychiatry, psychology, gerontology and informatics. I drew extensively on interviews with professionals where I shifted back and forth between these formal ‘accounts’ or multiple versions of truth. However, I approached data with caution, recognising the identity enactments and justifications of actions through which these accounts were ‘made’. I further recognised that within these actions emerged a particular version of truth and yet at the same time, I did not claim that participants’ voices ‘[spoke] for themselves’ (Atkinson and Delamont, 2006: 166). Since I drew on ethnomethodological sensibilities, interview ‘accounts’ were not taken at face value rather they created ‘the realities they purport to describe’ (Atkinson and Delamont, 2006: 167). Since the data I had was predominantly drawn from interviews with professionals, there were moments across my thesis where the versions of truth emerging from interview accounts were difficult to supplement, confirm or refute through the more informal practices emergent during observation.

I did not exclusively attach importance to professionals’ ‘accounts’ (Garfinkel, 1967) however, in terms of what they accounted for, and said they did during interview. I was also interested in their actions during observations and how these interactions ‘fitted’ alongside more formal interview accounts; the ‘slippage’ between formal accounts and informal practices (Horlick-Jones, 2005). Observing consultations and team meetings, I drew extensively on Goffman (1959) to demonstrate the front stage and back stage performances and mediation practices with regards to the use of cognitive screening tools. I therefore approached the data as negotiations of roles and identities across the spatiality of interaction (Goffman, 1959). Observing both the front-stage consultations and the back-stage team meetings and de-briefing with professionals, I viewed individuals as situated

beings whose interactions with humans, materials, objects and technologies, were embedded with social and cultural meanings. For those moments where I was able to carry out observations alongside interviews, I was able to verify and/or refute professionals' claims. The kinds of thoughts and actions professionals reveal to an interviewer, are bound in the context and situation itself which emerges during observation (Garfinkel, 1967; Goffman, 1983). I recognised the multiple and situated versions of reality produced in the field and 'revealed' in accounts.

Drawing on both interviews and observations, I mirrored Walford's (2009: 118) claim that doing ethnography requires multiple methods of data collection. However, this is not a question of truth or untruth with respect to the kinds of knowledge produced by such methods. Instead, by drawing on both interviews and observations, reflects the efforts made to comprehend interactions which are contextually constructed and shaped by the power relations between researcher and researched. The thoughts and actions emergent during interaction or revealed to the interviewer, and the situatedness of these actions are dependent upon the situation itself (Garfinkel 1967; Goffman 1983). I therefore explained action both at the individual level and drew on context-driven fieldwork.

The interviews were carried out throughout the six-month fieldwork period across Nunmill Hospital, Ridge NHS Centre, and Holmwood Hospital as part of the large teaching hospital Trust. I was given an allotted time for interview set aside from the routine working practice of professionals, and the location of the interviews meant enabled me to capture the context of their professional practice. The interviews were semi-structured, audio-recorded and ranged from thirty minutes, to one hour thirty minutes in length. I created interview schedules but approached them as guides, which allowed me to develop points, reflect on questions and refine where necessary. As demonstrated in Appendix K, these were flexible interview guides as not all the questions may have been asked. The questions focussed on professional practice in terms of experiences, lives, opinions and interactions within the organisation. Professionals were informed and asked

to consent to the interview being audio-recorded for transcription; informed that they could refuse to answer questions and stop audio-recording if necessary, and withdraw from the interview at any point throughout its duration. The professionals were sincere and often candid about their role and the use of cognitive screening tools, drawing on and reflecting on specific patient cases to elaborate specific points. Although they were particularly candid in these responses however, there were a number of times where professionals pretended to place their hands over the recorder or asked me not to include what they had said in my thesis. Overall, professionals were eager to participate and were particularly open. In what follows, I outline my role as researcher within the field and how this was shaped, approached and perceived by professionals. I reflect on the reasons for their candid accounts of their experiences and approaches towards the tools and their role in the organisation, which in part, I consider to be reflective of the subject under investigation.

The role of the researcher and student researchers

Amit (2000) reflects that negotiation and reflexivity within the research process will influence the experiences told; the situations will define the method, and the way the method is approached. During both observations and interviews, clinicians were engaged with my research and generally supportive of my role. However as there is a 'delicate relationship' between the ethnographic researcher in the clinical space and access to this space (Long *et al.*, 2008: 71 emphasis added), gatekeepers were crucial to this engagement and support. When I approached clinicians for interview, or I was asked about my presence when carrying out observation work, disclosing my affiliation with the gatekeepers provided me with the authority to be present in the team and also to approach participants for inclusion in the project (see Atkinson, 1995). I consider that without these gatekeepers, access to participants would have been enormously time consuming and laborious. Moreover, whilst my observations of the settings were minimal, it was important that I established relationships with professionals in order to claim the rights of the observer in the shifting

positions of insider and outsider research status (Hammersley and Atkinson, 2007). It is to this last point that I turn when considering my role as a student researcher in the acquisition of data and access to the field.

The concept of participant observation in traditional ethnographic standards of ‘doing ethnography’ positions the researcher as both ‘insider’, through participation and ‘outsider’, through observation of the social world under exploration (Spradley, 1980). The extent to which these positions are fixed is however, a matter of contention, experienced differently by participants and the researcher (Desmond, 2007; Hammersley and Atkinson, 2007; Angrosino and Rosenberg, 2011). Given the existence of pre-determined ‘roles’ within the clinical setting (patient, health worker, relative/visitor (Wind, 2008)), it is perhaps only appropriate for researchers to assume the role of researcher or student in these settings, thus failing to participate *per se* in the roles under investigation. Subsequently I drew on the concerns of Woolgar and Neyland (2013) in their ethnographic work on exploring the role of mundane technologies. For Woolgar and Neyland, (2013) they describe their task, ‘to document and reflect upon the experiences of moving back and forth across cultural divides and perceptual boundaries, of being simultaneously an insider and outsider and of moving between the two’ (pp. 15). The degree of participation however, will differ in accordance with the settings to be researched and the characteristics of the researcher themselves. Furthermore, I am aware that my level of participation in the field constrained my ability to be wholly ethnographic. Whilst Consultant Psychiatrist 1 sponsored my study, my role as researcher in the field was ultimately as ‘outsider’.

What contributed to my approval in the field despite not being fully immersed in the field was that clinicians were willing to engage with the topic, which they felt was worthy of study. Moreover, the merit of qualitative research is that individuals feel able to talk about their lives and experiences with someone who is a relative stranger, and I reflected on my role and access as one of reflexivity. Whilst negotiating access to clinical settings may be relatively unproblematic as Wind (2008) suggests, the

complexities of holding this position of access is inherently difficult. Undoubtedly professionals working in these settings are constantly undergoing their own negotiations with the patients themselves that leaves little scope for the role of the researcher. It was therefore important that I made myself known as a researcher and built rapport with the professionals working in the field (Goodson and Vassar, 2011). There were moments however, particularly during the observations of team meetings when professionals misconstrued exactly what it was I was doing and referred to me as a psychology student or social worker.

In relation to the interviews carried out with professionals, as a student researcher, interviewing elites could have been a challenging process particularly when I did not have a claim in the profession overall (Harvey, 2010). As Harvey (2010) contends, it is essential that junior researchers be better organised, persistent and flexible than those interviewing lay people. For Harvey, it is crucial to be aware that the lack of experience of junior researchers and establishment within the field of study, may hinder the recruitment process. As such, I remained flexible with regards to arranging interviews; acknowledging that clinicians' schedules could potentially change and therefore I may be required to alter my working practices. The gatekeepers also aided the process of recruitment as my affiliations with these professionals allowed me to access individuals perhaps more easily than if I had approached the field blind.

Data analysis

In line with the philosophical and theoretical orientations of this research, a 'reflexive interaction' process guided the data analysis process (Altheide, 1987:65). Analysis of data is an on-going process, which begins in the field and continues in transcription and coding (Ibid). Ethnographic analysis adopts an iterative process in which themes arise during data collection or 'field work' (Thorn, 2000) where the researcher codes and categorises data to 'interpret thematic categorisations, search for inconsistencies and contradictions and generate conclusions about what is happening and why'

(pp. 68). Themes were identified both at a ‘manifest level’ (observable within the data), and at the ‘latent level’ (that which is underlying the phenomena and not directly observable) (Boyatzis, 1998). Thematic analysis in this research did not impose strict analytical frameworks on the data but was sensitive to the emergence of themes, inferences and nuances in the data. I also carried out situational analysis, which renovates the framing of actions central to a grounded theory approach, and considers the ‘key elements and conditions that characterise the situation of concern’ (pp. 554). As such, the complexity of resolving and constituting AD was framed within what Geertz (1973) describes as ‘thick descriptions’ of social worlds, arenas and negotiations (Clarke, 2003: 558).

Clarke (2003) claims that grounded theory does not take into account the ‘sea of discourses’ (pp. 559) that represents the post-modern era. Subsequently, influenced in part by the concerns of grounded theory, Clarke draws attention to ‘inchoate social features of a situation’ to make them more ‘visible’ (pp. 572). As Clarke suggests, the situational analysis approach can be utilised to analyse or map a variety of data including observations, interviews and documents. As such, throughout my fieldwork, the material from interviews and observations were compiled to establish moments of intersection and also disconnection. The ‘fractional objects’ of reality (Mol, 2002a) emerged through the cross checking of data materials, revealing the thick descriptions and subsequently interpretations of data (Geertz, 1973). Furthermore, I sought a method of ‘social inversion’ (Clarke, 2003: 572) where I attempted to reveal the invisibilities of situation. This was in accordance with my overall approach, which foregrounded practice and as a method overall, which allows social scientists to explore that, which has been largely ignored or taken for granted (Timmermans and Berg, 2003).

This is not to suggest however, that themes emergent in the literature review were not considered to make sense of the data. During fieldwork, I adopted an inductive, reflexive approach and developed themes, categories and interpretations to illuminate the areas of inquiry of pertinence to my

research, which also aided the focus of my empirical chapters. As such, my findings were coherently sorted and grounded in theory. In terms of the tools used for analysis, I attempted to manage and make sense of my data through NVivo9: qualitative data management software. However, I decided against persevering with this software as I found that it became increasingly time consuming when attempting to order my data. As such, I decided to begin analysis manually, which allowed me to manage and make sense of my data without becoming overwhelmed by quantity and scope (Seidel, 1992). In the thesis, I provided quotes from both observations and interviews, and attempted to keep as much detail as possible to avoid further fragmentation of accounts and instances. During transcription I transcribed *verbatim* and I deleted some of the more ‘distracting’ aspects of the data such as pauses (Atkinson, 1995: 12).

Limitations of ethnography

I do not claim to have produced a wholly ethnographic study but I adopted the theoretical orientations of this approach and drew on ethnographic methods including participant observation. Subsequently, it is important to consider the limitations of ethnography regardless of the extent to which this research can claim to be wholly ethnographic in approach. According to Hammersley and Atkinson (2007), there are five dominant ethical issues to consider when drawing on ethnographic sensibilities. Whilst these are not solely constitutive of ethnography and can be applied more broadly to other social science methods or methodological frameworks, ethnography gives these issues a ‘distinctive accent’ (pp. 207). The authors categorise them under five headings: informed consent, privacy, harm, exploitation, and consequences for future research (pp. 207). More generally, as Bosk (2001) claims, ethnography has the potential to become a moral and ethical problem for a number of reasons. We knowingly encourage the types of data which will yield rich data such as discrepancies, do not completely disclose the interests of the research, and exploit participants who may get ‘little or nothing in return’ (Hammersley and Atkinson, 2007: 217).

In relation to the issue of informed consent, as Hammersley and Atkinson (2007) contend, because the researcher actively builds and facilitates rapport with participants, it could be the case that participants ‘forget’ that the research is taking place (pp. 210). Furthermore, and particularly in relation to my research, regardless of the fact that the study was overt in nature, I did not disclose every detail about the research to the participants. First, when attempting to navigate initial access to the field, I did not have all the components of my research mapped out because of the reflexivity regarding fieldwork in ethnography more broadly. Second, whilst I provided enough information for participants to understand the basics of my study and ensure it was relevant for professionals working in the medical sector, there were a number of occasions where despite providing numerous information sheets, clinicians asked if I was a psychology student or a social worker. On reflection, since I did not provide every detail of my study this could have confused participants and yet concurrently, providing reams of information could be regarded as intrusive subsequently affecting the behaviours of participants (Hammersley and Atkinson, 2007).

Furthering this discussion on informed consent, whilst studies including Atkinson’s (1981; 1984) which examines teaching of medical students at the bedside in hospitals, did not seek consent from the patients or students present, this exclusivity would have been ethically problematic for my research. As a non-medical student entering a medical field, I had to gain consent from each person within the consultation room. Whilst the control ethnographers have over the research process is minimal (Hammersley and Atkinson, 2007), given that it is difficult to ensure every person within the observation arena can be fully informed, this was something I had to overcome having stipulated to the REC that I would only include those with the capacity to consent to research. It was also important to recognise that clinicians were attempting to fit my role into their own pre-existing frames of practice. Subsequently, I had clear criteria of who or what to observe: I observed encounters with patients, professionals and family members/carers, and observed professionals in team meetings. These closed environments meant that some control was exerted over the encounters and ensured that

patients met a specific set of criteria for inclusion to avoid exploiting them if they did not have capacity to consent to research.

Another problem arising from my study concerns anonymity. Whilst I replaced names with the professions of participants and ordered them numerically; replaced the names of research settings with pseudonyms; omitted details that could be traceable to the participant, and altered traceable attributes of participants, there were no guarantees that this was enough to preserve anonymity. Attempting to do so however, overcomes the distinction between private and public and trust between researcher and researched (Hammersley and Atkinson, 2007). Yet despite my attempts to conceal the identities of those participating in my research given the relatively localised and specific site for study, there was the possibility that those within the field may uncover these identities laid down in permanent text for public exposure. Whilst I have tried to overcome this as best as possible, it remains a feature of ethnography overall which researchers are continually navigating.

Perhaps another limitation of my study was the fact that I was anxious throughout my observation work that clinicians would perceive my role as one of judgement. This anxiety was born in part out of the fact that during analysis, I became aware that I might release details that could be perceived by professionals as a criticism of how they approached the tools and diagnosis more broadly. Moreover during my fieldwork, professionals themselves expressed their anxieties during observations and private conversations that I would be informing them that they were incorrectly administering the tests. As Trainee Psychiatrist 2 said to his patient during observation, prior to carrying out the test, *'this is where Julia is going to watch to see if I do it [the test] right'*. In order to overcome this, I clearly stated in the participant information sheet and clarified with clinicians prior to observations, that I would not be making judgements about existing practice. As I will demonstrate in the following empirical chapters, I clarify further that my aim was to uncover the complexities that clinicians were faced with when classifying AD; examining how they navigated social,

cultural, political and technical arenas through the use of the tools and within the organisation of the team. My intention was not to provide a privileged account of what should or should not be happening, or judge or render professional work open for criticism; healthcare organisations and particularly the memory service were under a great deal of pressure to perform. It was my intention therefore to provide a detailed, analytical account of the relationships, interactions, accounts, approaches and labour associated with classification which did not require me to pass judgement on these situated occasions. I have endeavoured to provide a critical yet accurate portrayal of how diagnosis and AD is 'done' across the settings (Garfinkel, 1967).

As is the case with all qualitative research, carrying out the fieldwork for this research required flexibility, patience and investment in time. Appointments were cancelled at the last minute, at times clinicians forgot I would be attending observations or interviews, interviews were rearranged when professionals were required elsewhere, and so on. In accordance with these practical difficulties I faced however, there are a number of limitations of ethnography more broadly which require elaboration. A further practical limitation of my study was that whilst I gained ethical approval for two further sites for investigation, I did not access these sites since they claimed my work would be too onerous due to increasing clinical demands on the service. As such my sample is particularly small yet also rich and in-depth in accordance with my theoretical allegiance to 'thick description' (Geertz, 1973). Furthermore, whilst I observed consultants, registrars and junior doctors across both teams, I could only observe memory nurses in one of the teams as they carried out the majority of nurse appointments in patients' homes, for which I did not have ethical approval. Nor could I observe patients undergoing cognitive assessment associated with the CQUIN in a hospital ward as whilst I had ethical approval to do so, following contact with a number of individuals including consultant geriatricians and senior nurses, it was deemed too onerous for me to be present on an AMU, and capacity to consent could not be guaranteed. As such I avoided making

general claims regarding my observations but treated them instead as moments in time.

Whilst the claims in this thesis were broadly representative of one specific team in an organisation, it remained difficult to discuss these situations in relation to making universal claims about the NHS more broadly. However, given the fact that the memory service and the large teaching hospital Trust are NHS institutions, their practices will be similar to other NHS institutions in spite of locality of variation. For example, the National Dementia CQUIN is a universal framework implemented across all NHS hospitals in the UK. I argue that each of these sites constituted a situated example of the use of cognitive screening tools in the process of diagnosing AD in the UK, and my analysis answered broad questions about how technologies are used in the process of classifying AD in clinical practice. Whilst perhaps my research overall, has limited external reliability, validity and representativeness, my theoretical sensibilities meant that there was no absolute reality that could be found in some pre-existent state across time and space. As Hammersley and Atkinson (2007: 234) note, whilst ethnography is unable to provide a solution for queries regarding generalisability, perhaps nor can any other form of social research. Drawing on ethnographic methods including observations, my research was highly interpretive; some of the text is not objectively reported but created and manipulated. However, whilst ethnography 'plays a complex and shifting role' (pp. 2) as an approach to doing research, it does not mean that the researcher cannot offer useful insights into and applications of particular forms of social life. Perhaps appreciating the limitations of ethnography as an approach (as with all social science research methodological sensibilities), and recognising its situated findings, should be of central concern to the ethnographer in the field.

Summary

In this chapter I have briefly outlined how my overall theoretical approach to practice, informed my research design. For Timmermans and Berg (2003),

an approach which foregrounds practice allows the analyst to observe the subtle effects and implications of technological implementation in everyday practice. With this in mind, I have reviewed my research design, the reasoning behind my decisions, and how my decisions were informed. As a result, my research design aimed to reflect not simply the ‘high hopes or dire warnings’ of cognitive screening tools, but intervene in the invisibility of current diagnostic practice in which these tools are situated, implemented and remain pervasive (Timmermans and Berg, 2003: 97). I opened up current diagnostic practice but at the same time abandoned preconceived ideas about technologies, techniques and professionals. As I have outlined, I embedded performative sensibilities in my research design, I asked what kinds of tools cognitive screening tools are, what they do, how they produce multiplicity in situated occasions, and resolve complexity. Furthermore, I described the ways in which I drew on the concerns of situational analysis (Clarke, 2003) to deal with the complexities of healthcare practice before continuing to engage with the limitations of my study which ranged from issues regarding informed consent, to my claim to ethnography overall. I highlighted how the accomplishment of ethnographic fieldwork relies on a complex and detailed relationship between theory and negotiation of knowledge construction *a priori*, which may have been constrained by the NHS REC.

In the following three empirical chapters, I shall tell the story of how cognitive decline and Alzheimer’s disease are classified in clinical practice. Across these analysis chapters, I investigate the role of cognitive screening tools within complex socio-material practices, and explore the interactions between clinicians, patients and technologies in clinical practice. I attend to the ways in which clinicians make sense of diagnosis in the clinic and with respect to managing the ‘ageing population’ more broadly, demonstrating how cognitive screening tools, mundane and taken for granted, are ‘brought to life’ (Berg, 1996: 501).

Chapter Five

Navigating Uncertainty in the Clinic

The following three chapters outline the key findings of my study. By attending to the everyday work of professionals, I explore the constitutive role of instruments for screening cognitive function in the process of classifying Alzheimer's disease (AD). I explore the role of these technologies in the clinician-patient interaction and demonstrate the myriad of ways in which clinicians are able to approach and perform the tools as provisional devices. In doing so, producing and reproducing patient identities and professional hierarchies, to navigate and manage uncertainty (Chapter Five). I also investigate how the boundaries of classification are constituted through the mobilisation of uncertainty for the production of AD (Chapter Six); and analyse the adoption of the tools in the wider policy arena for detecting the disease in its earliest stages (Chapter Seven). I argue that initiatives such as the National Dementia CQUIN, shifts the temporalities of classification when translated into clinical practice, producing further uncertainties particularly around patient futures, as it attempts to reify the patient 'pathway'.

In Chapter Five, I show how clinicians negotiate cognitive screening tools and articulate their provisionality in response to the uncertainties associated with measures of cognitive decline. This articulation work points to the fact that the value(s) associated with these tools are not 'stable and predefined' but 'grappled with, articulated, and made in concrete practices' (Dussauge, Helgesson, Lee and Woolgar, 2015: 1). This STS approach to the notion of values, grounds my empirical chapters since this thesis does not attempt to deconstruct whether the tools have intrinsic value for producing knowledge about cognitive decline. Rather, it elucidates how their values are constituted in socio-technical arenas for dealing with complexity and for making sense of classification. Overall, in relation to what I argue is the making of the tools as provisional devices, possible because of their low-technological and mundane status, I introduce the concept of portability

across the three empirical chapters. I define portability as a set of practices, which ensures the movement of cognitive screening tools across different actors and settings, and across time and space. This portability, which is articulated across the sites of study, is necessary for two distinctive reasons. First, it is necessary for navigating and managing the uncertainties and complexities associated with diagnosing AD in the everyday, routine clinic. Second, it is necessary for managing AD in terms of resource allocation and service provision in the wider healthcare setting. The making of the tools as provisional and therefore portable devices is not completely unbounded however, and throughout my empirical chapters and particularly in my discussion, I reflect on when portability occurs, where it occurs, on whose proviso, and when it does not, across different settings and temporalities.

In this chapter, I capture how clinicians use cognitive screening tools to navigate and manage the uncertainties associated with measures of cognitive decline. Tracing interview accounts and observations in the memory service, I demonstrate how uncertainty is manifested threefold. First, in the absence of a definitive method for diagnosing AD, second, in the ambiguities associated with the tools themselves, and third, in the ways in which patients conceive the meaning of diagnosis overall. I argue that the tools are articulated as partial and therefore provisional devices, for navigating and managing this uncertainty, and I emphasise how the tools are subsequently made portable for making sense of classification. In the context of the memory service, an increasing number of tasks are being delegated to memory nurses and Occupational Therapists (OTs), including the use of instruments for screening cognitive function in initial consultations. I therefore illustrate that performing the tools as provisional devices, is practised differently across the professional hierarchy, reproducing the power relations within the memory service. Whilst all clinicians observed, engage with mediation and manipulation practices, professionals occupying positions higher up the professional hierarchy, are afforded the responsibility of privileging clinical judgement to manage uncertainty (c.f. Bosk, 1979). Mapping these two distinctive strands of provisionality, I suggest that despite the tools producing and reproducing professional

hierarchies, the making of provisionality through mediation and manipulation practices also carves out a unique space for memory nurses. As the tools are made portable into patients' homes, memory nurses assign significance to what is socially and culturally significant in this space. The final section of this chapter, highlights clinicians' commitment towards objectivity, and the quantified element of the tools across the memory service, which drives how classification proceeds within a complex distribution of medical practice. These practices, as well as aligning with my arguments in Chapters Six and Seven, play a key role in understanding how the constitutive role of cognitive screening tools, drives the medical decision-making process in an arena of uncertainty. The power of the mundane is revealed, necessary for navigating and mobilising the networks of practices involved in what Berg (1992, 1996) describes as medical decision-making processes. More broadly, this chapter is grounded in theoretical literatures on patient identities and professional hierarchies (Goffman, 1959; Latimer, 2000, 2004; Nancarrow and Borthwick, 2005).

Organisation of the memory service

Despite the ambiguities, which emerge as both cause and consequence of AD as a nosologically contested disease however, clinicians in the memory service overall, were committed to finding a diagnosis for patients, family members and carers in this arena of complexity and difficulty. There was a commitment towards getting diagnosis 'right' for a disease which remains in part highly stigmatised, fuelled more broadly by archaic approaches towards mental health and ageing more generally. Across the memory service, instruments for screening cognitive function were administered with individuals who had been referred either from primary care, in-patient liaison psychiatry, or through the community mental health team. The memory service consisted of a wide-ranging number of professionals working in the field of psychiatry including consultant psychiatrists, specialty doctors, registrars, junior doctors, memory nurses, and occupational therapists. On entry into the memory service pathway, a record of the individual's referral was sent to the team and either allocated through

the central system, or discussed and assigned to the appropriate professional in the multi-disciplinary team meetings (MDTs), depending on the individual's care trajectory. For initial appointments where cognitive function is assessed using instruments for screening cognitive function, memory nurses were expected to carry out the majority of the appointments either in the patient's home or in clinic. The diagnostic appointments were the responsibility of the medics within the team. In the clinic, a family member and or carer usually accompanied individuals. The standard procedure for appointments is that the clinician asks the patient whether they know why they have been referred to the memory service and a full clinical history is taken prior to formalised testing for cognitive decline. Depending on the information gleaned from the appointment, which in the case of this research lasted no longer than 1 hour, clinicians explained to individuals that they will either be referred for further diagnostic testing or in the case of consultants, speciality doctors, trainee doctors and registrars, a diagnosis was made during the appointment. Completion of a diagnostic appointment depended on the need for, or prior completion of, blood tests, Computerised Tomography (CT) or Magnetic Resonance Imaging (MRI) scans. The cognitive testing made up (at the most) 25 minutes of the clinical encounter unless the patient was having difficulty understanding or answering the questions. At this point, the clinician could allocate more time depending on overall caseload.

The organisation of the memory service reflects an increasingly complex distribution of medical practice: a multi-disciplinary approach to healthcare. Pressures on workforce boundaries due to increased demand on the memory service, have led to a delegation of tasks previously only performed by expert professionals (c.f. Nancarrow and Borthwick, 2005): the administration of cognitive screening tools. The structure of the memory service in terms of delegation of tasks is important for analysing how the tools are used to navigate uncertainty, who adjudicates on their use, and for what purpose, within the MDT. Consultant Psychiatrist 2 explained the complex distribution of the service when asked about the history of the cognitive screening tools in current practice,

‘One of the reasons that we chose the Addenbrookes was that, about oh my goodness how many years ago now (I work with Mark who’s one of our clinical psychologists here) when we wanted to look at changing the memory service from being very medically led, so doctors did all the initial assessments, to when we knew there was going to be this big increase in cases, we would go for a multi-disciplinary team approach.’

To provide some context, the Addenbrooke’s Cognitive Examination that Consultant Psychiatrist 2 refers to, is a 30 question cognitive screening test used primarily for initial appointments across the memory service (see Appendix A). There was only one instance where I observed the Montreal Cognitive Examination (MoCA) being used for initial appointments and this was during an observation with Consultant Psychiatrist 4. When asked during de-brief why the MoCA was used instead of the ACE 111, Consultant Psychiatrist 4 explained that he deemed the tool to be *‘quicker’* to use than the ACE 111 and that the *‘clear history’* was considered to be *‘the most important tool’*. At the same time, Trainee Psychiatrist 1 explained during an observation that the reason for using an ACE 111 as opposed to a MoCA reflects the severity of the case; the MoCA is used for *‘moderate to severe cases’* and for patients *‘struggling with hearing and attention span’*.

The uptake of the ACE 111 in the memory service, reflects the shift in organisation of the service overall, (as Consultant Psychiatrist 2 described) and is therefore representative of the potential consequences of demand on healthcare provision (Nancarrow and Borthwick, 2005). As a result, the ‘big increase of cases’ the ‘professional turf’ (Nancarrow and Borthwick, 2005: 899) in which, cognitive screening tools are administered, has become occupied by the traditionally lesser-valued or invisible roles of those whose expertise does not reside in the medical domain, such as memory nurses and OTs (c.f. Latimer, 2000; Allen, 2014). In what follows, I frame the investigation of the role of cognitive screening tools within this reconfiguration of the service. Memory nurses were increasingly required to

carry out initial appointments with patients, prior to involvement with professionals occupying positions higher up the professional hierarchy.

The ‘making of provisionality’

Cognitive decline and Alzheimer’s disease are ‘categories in the making’ (Latimer *et al.*, 2006: 614) continually (re)negotiated, navigated, and produced through the use of cognitive screening tools, and other diagnostic techniques across the professional hierarchy. The process of classification therefore relied on the articulation of the tools in the clinician-patient interaction, to respond to the uncertainties associated with measures of cognitive decline. First, tracing interview transcripts, I highlight the ways in which clinicians approached these tools across the professional hierarchy. In initial consultations across the memory service, the use of the tools was dependent on the clinical history of the patient; patient narrative of symptoms; family member and or carer narratives of symptoms; further diagnostic testing, and practising of clinical judgement. Articulating cognitive decline also relied on the ‘traditional clinical skill’ of attending to sign, symptom and pathology (Latimer *et al.*, 2006: 614). The test was administered with the patient after the clinician had completed the clinical work. During conversations with clinicians including memory nurses and consultant psychiatrists, they described the relationship between the cognitive screening tools, clinical history, and functioning of the patient. When asked about the placement of the tests during consultation, Memory Nurse 4 explained,

‘Yeah well it’s basically about the person themselves, so you’re asking literally about their well-being, how they are physically, how they are socially ‘cause that’s a big important task. It’s not just a case of doing that memory test, it’s all about what are they doing on a day to day basis, how are they getting up on a morning, how are they functioning, how do they get washed and dressed, how do they have their breakfast, are they going out regularly, how are they getting their meals, do they get the shopping brought in, do they

have visitors you know it's everything basically so I tend to do, ask all those questions, and then do the memory test.'

This was further demonstrated by Memory Nurse 3,

'I actually do my holistic assessment, I'll start gathering my information and once I've gathered my information I then start to do my cognitive testing and that's kind of the 80/20 rule there'll always be a percentage where that it won't be like that but for the, in terms of how I like to do my assessment that's kind of what I do. So I'll go in, do the holistic assessment, when I've done that bit then I'll say, 'and now do you mind if I ask you some memory questions' and, and I usually do it then.'

As both memory nurses illustrated, clinicians gathered the evidence for classification by attending first to the functioning of the patient and the extent to which the patient deviated from their normal or standard everyday routine. The ability of the patient to function or perform on a '*day to day basis*' was privileged, the '*80/20 rule*'. This partiality was also confirmed by Memory Nurse 6 who explained during interview that they '*would value the cognitive tool from between 20 to probably 40%. I would say that the other information was more important*'. During an observation of a consultation with Trainee Psychiatrist 3, having discussed with the patient what the appointment would entail, she explained that '*I just want to get a picture of what's happening before objective testing*.' In this instance, the clinician felt it was important to reiterate the significance of the clinical work prior to objective testing because the appointment began with the patient asking a number of questions about CT scans and cognitive testing. The authority of the technology is as yet partial and incomplete, positioned alongside what was socially and clinically important (c.f. Latimer, 2000). This was also confirmed across the professional hierarchy as the following extracts from interviews with Consultant Psychiatrists 1 and 2 highlighted.

As Consultant Psychiatrist 1 clarified,

‘Right, I suppose as a psychiatrist our clinical history is an assessment and that is probably the main stay of what we do, so that’s the bit that we give the major focus of when it comes to our differential diagnosis and formulation. The ACE 111 and MoCA are tools to support our clinical history and clinical acumen.’

In addition, as Consultant Psychiatrist 2 illustrated during interview,

‘I use, I guess the first tool I would always say is that I use my clinical interview skills, so that would be my first thing is that I would always take a comprehensive history from the patient ‘cause that gives you loads of information without any formalised screening tool. I would then supplement that information if depending on what I found. If somebody’s mild to moderate impairment in my own mind as I’m doing this assessment, I would preferably, the first time I meet them, use the Addenbrooke’s cognitive examination version 111, so that would be my preferred tool.’

For Consultant Psychiatrists 1 and 2, their clinical work constituted the technique or ‘*tool*’ to privilege in the routine clinical encounter. As such, the cognitive screening tools were presented as devices, which ‘*supplement*’ the clinical work, confirmed by Consultant Psychiatrist 1 as ‘*the main stay of what we do*’ thus constructing and confirming professional identity aside from the use of the technology in the clinic. The idea that these ‘formalised’ tools were used as aides or conceptual support tools, suggests that the process of classification was not confined to any one technique or indeed formal technology. Interview transcripts were replete with further examples, and the partiality of the tools was a frequent topic of discussion across the professional hierarchy. During an observation with Memory Nurse 6 he reassured the patient following completion of the test, ‘*not to worry because the test only plays one part*’. Clinicians further attested their partiality in formal interview accounts stressing that the tools in the clinic were ‘*not the*

be all and end all'. This partiality does not mean however, that the tools were downgraded or became redundant in the process of classifying AD as Memory Nurse 1 explained, *'they are a really important part...and I do definitely value them, but they are only part of our assessment as Nurses'*. I will return to the role of memory nurses further in the chapter. The classification 'box' to adopt the metaphor used by Bowker and Star (2000) and developed by Jutel (2009), was thereby not solely constructed or constituted through the use of cognitive screening tools; the utility of the tools was compounded by the clinical work that preceded their use.

Developing this notion of partiality so far accounted for by clinicians, I suggest that uncertainty associated with diagnosing AD overall, had direct implications for the articulation of cognitive screening tools in the clinic. The status and role of the tools was entangled with the uncertainties and complexities associated with measures and the process of measuring, cognitive decline. As outlined in Chapter Two, AD is difficult to categorise, and there is no one technique or technology with which to definitively confirm a diagnosis in the clinic. Moreover, the uncertainties associated with measures of cognitive decline extend beyond the difficulty in clinically or biologically framing the disease. A diagnosis of AD and the process of diagnosing, produce discursive accounts of mental health, which tended to be articulated in the clinic. Together this formed a repertoire of uncertainties, with the potential to disrupt the process of classification, and it became the task of clinicians to navigate these uncertainties through the use of cognitive screening tools. During interview, Clinical Psychologist 3 highlighted the complexity associated with diagnosing AD overall, as she explained when asked to reflect on the role of the tools in the clinical encounter,

'There's always a danger that if you attach too much importance to just one aspect of the diagnostic process, that you might have missed something and it is often a process of exclusion rather than confirmation in terms of the diagnostic process for dementia so I think it's dangerous if we attach too much importance to the tests.'

Clinical Psychologist 3 raised a number of key points. First, conceiving the tools as partial or incomplete systems to metaphorically ‘box’ AD (Bowker and Star, 2000: 10) reflected the uncertainty associated with categorising AD more broadly. For clinicians to make sense of the extent to which producing knowledge about cognitive decline and AD is a process of exclusion rather than confirmation, for Clinical Psychologist 3 it was much to do with not privileging any technique or technology. The tools were used only to determine what AD was not as opposed to what AD is ‘out there’ (c.f. Jutel, 2011). This was also articulated during observations of team meetings where the significance of the tools was entangled in in-depth discussions between clinicians describing patient functioning, clinical history and mental health history. There was a collective agreement amongst clinicians, that the tools only played a small part of what was essentially the ‘*bigger picture*’; clinicians avoided placing privileged emphasis on the tests (Observation Team Meeting Nunmill Hospital). Yet, at the same time, the tools also performed a sense of responsibility particularly for memory nurses, and whilst the tools partiality was collectively iterated across the memory service, there were also tensions around the extent to which the tools were increasingly being used to formalise work practices. Memory Nurse 7 framed the tools as devices for legitimising work practices as she described during interview,

‘Well I think they play a part of it and I suppose we seem to need to have measurements of things now don’t we to sort of see how people are doing so there’s – it, it’s interesting I think to see how someone’s functioning when they are doing something like this and then to compare. For me I think the biggest importance is about how somebody’s actually functioning day to day with things that they need to function with; I wouldn’t personally put too much reliance on the using things such as the Montreal Cognitive Assessment (MoCA) but I suppose it plays some role in building the bigger picture.’

Memory Nurse 7 confirmed that within the space of the clinic, individual function was regarded as a technique in itself in the process of classification. Arguably, this work which focused on *'functioning day to day'*, was encompassing of the more informal practices of clinicians; difficult to formally measure by any technological device. According to Memory Nurse 7, increasing methods for measuring *'how people are doing'* using technologies such as cognitive screening tools are emerging more generally. This produced tensions around formally measuring and tracking patients' progress and thereby legitimising work practices, and simultaneously accounting for the invisibility of the clinical work through, which the tools were mediated. Furthermore, as Memory Nurse 7 explained, in recognising these motivations, it was simultaneously important not to privilege these tools for considering AD as a broader *'picture'* of components or adding *'a piece to the puzzle'* (Interview Memory Nurse 1) because *'you wouldn't sit a maths exam and not do a maths exam would you really or say somebody was blind and they got given an eye test - you need to do something'* (Interview Memory Nurse 1). At the same time that the tools were expressed as partial devices, they were also important devices for legitimating work practices, which resonated particularly with memory nurses.

In my analysis thus far, I have focussed predominantly on the accounts of clinicians. In what follows, I develop my analysis by exploring how the partiality of the tools was constituted during the clinic-patient interaction. My analysis of the articulation of the tools and their emergent values is entangled overall with my claim to foregrounding practice. I show that the value(s) of the tools and the expectations around their performance for detecting cognitive decline are not intrinsic or pre-defined properties but were 'made' within the arena of the clinician-patient interaction (c.f. Dussauge, Helgesson, Lee and Woolgar (2015). Through the actions of clinicians, the tools were negotiated between professionals across the hierarchy in the MDT, and across different settings, in response to the uncertainties associated with measures of cognitive decline. Analysing the clinician-patient interaction, I found that clinicians valued individual particularities *in situ* and yet despite the tools emerging as provisional

devices, I do not suggest that they were redundant in the classification process. In fact, the practices of the clinic brought them ‘to life’ (Berg, 1996: 501); in turn, shaping how cognitive decline and AD were measured. Prior to exploring the intricacies of the clinician-patient interaction, the following extract from an interview with Trainee Psychiatrist 1 confirmed that the process of classifying AD overall is complex,

‘Yeah I think sometimes it’s the unknown you know. I think when people have cancer they have an x-ray, they have a CT you know, they have blood tests and so on and this is, dementia’s a much greyer subject for people ‘cause people present in such a different number of ways and I think that the people who are in that grey area of having cognitive decline but still functioning reasonably well, probably got under the radar and then it’s not until people are very, very demented...if you ask somebody about dementia they think of the very old demented person in a care home don’t they, so yeah I think the fact that you can’t identify it and say right I’m living and I’m functioning with dementia I’m ok, I’m still having a reasonable quality of life, does sort of cloud it for people.’

Trainee Psychiatrist 1 began by comparing AD to diseases such as cancer for which visual imaging technologies such as MRI (Magnetic Resonance Imaging) and CT (Computerised Tomography) can (in the majority of cases) be used to confirm the presence of disease . Visual imaging techniques ‘clear[ing] the ‘fuzziness of reality’’ (Gross, 2012: 106). What is different about AD however is that the ‘fuzziness’ (Gross, 2012: 106) of the disease, is neither metaphorically nor literally made clear through the use of visualisation techniques such as a CT scan. For Gross (2012), visual imaging technologies are perceived to be more objective and accurate methods for producing knowledge about the problem than the individual particularities of patients. Yet as Trainee Psychiatrist 1 confirmed, AD is ‘greyer’, in that it is uncertain and difficult to produce a classification of AD through the available technologies. The experiences of patients and individual particularities (Dodier, 1998), *‘people present in such different*

ways’ therefore made the practising of these technologies inherently difficult. It also directly impacted the experiences of patients and the ways in which they conceived a diagnosis overall, *‘if you ask somebody about dementia they think of the very old demented person in a care home’* which I will discuss further in this chapter. However, aside from the complexity associated with definitively diagnosing AD using any particular technology, I also observed that the testing process produced anxieties for patients, emergent in the space of the clinic. As I observed during consultations, this was recognised by clinicians and subsequently performed in the clinic,

“During previous observations of consultations, I had been invited into the room to wait for the patient with the clinician but the memory nurse was running late and so I was shown to the consultation room where I waited for the clinician to arrive. The room consisted of three chairs and a desk with a computer: two of the chairs were adjacent to the table with the computer and one in the corner of the room. On arrival, I asked the clinician where would be most appropriate for me to sit (usually it is clear which seat I should occupy). The memory nurse suggested that I move the chair in the corner so that I would not be sitting behind the patient, explaining that the patient needs to be as relaxed as possible and *‘it is likely that the patient and the family member will be coming into the clinic worried about a diagnosis’* (Observation Memory Nurse 6).”

Memory Nurse 6 spoke candidly about the anxiety both patients and family members felt about the consultation process and the possibility of diagnosis, which was a frequent note of observation throughout the memory service. Staging this within the practices through which cognitive decline is measured more generally, this anxiety was representative of what I conceive of as both a ‘culture of testing’ in relation to the use of cognitive screening tools, and also the existence of negative discursive constructs around mental health more broadly. In the case of Memory Nurse 6, navigating this discourse was about ensuring the patient was as relaxed as possible because

as he attested during follow-up interview, *'there's a huge psychological dimension to a potential diagnosis...it can have all kinds of different responses'*. Anticipating these responses was much of the work of clinicians, and the ways in which they approached and mediated their use of the tools.

Anticipating 'all kinds of responses': A culture of testing

Seen through the lens of a 'culture of testing', this anticipation work led clinicians to undertake what I conceive of as practical mediation and manipulation practices in order to navigate this 'culture of testing', which had the potential to impact how patients conceived the nature of diagnosis overall. Grounding this anticipation work further, the 'culture of testing' had the potential to impact patient self and identity of which the technologies were important mediators for navigating and preserving the presentation, and thereby performance, of self (Goffman, 1959; Mol, 2002a). In the ceremony of the clinic and observable across the memory service, clinicians engaged with front stage and backstage mediation and manipulation practices (Goffman, 1959) of the cognitive screening tools in order to protect patient identity. This mediation and manipulation work occurred 'front stage' in markedly practical ways, and was driven by the performance of clinicians backstage in two distinctive ways (c.f. Goffman, 1959). First, the process had the ability to compromise patient identity born out of a wider perception about mental health which existed in the wider population, and second, because clinicians recognised the ambiguity of the tests and themselves as users of the tests. Engaging first with mediation practices, initially, clinicians reassured patients that the tests were not markers of intelligence. As I witnessed during a consultation with Memory Nurse 6, he talked through the test with the patient continually reassuring them throughout,

“During the consultation, Memory Nurse 6 asked the patient a series of questions about previous medical history, symptoms, changes in lifestyle, behaviour, and mood. When asking these questions, Memory Nurse 6 paused for a moment and apologised, *'I'm sorry*

about all these questions some of them are quite personal'. This was marked by silence from the patient, and the clinician, wanting to elaborate on this further, reassured the patient about how important it was to ask all the questions because the test figures as only *'part of the assessment and it does not matter if you got 0 or 100'*. The patient appeared visibly anxious however, glancing to the family member sat beside him. Memory Nurse 6 asked if it would be ok to carry out a test to *'look at how their memory is working'*. The patient agreed but still appeared anxious and responding to this, Memory Nurse 6 told them to just *'do your best'*. The test began and the clinician explained to the patient that he would miss out the writing tasks because of their lack of education, which the patient appeared visibly relieved to have confirmed. The family member also remarked here that the patient could barely write their signature, which had always been the case. The clinician pulled out the test from the draw in the desk, all the while explaining to the patient that although the patient has a poor level of education, this is *'not an intelligence test and they see lots of intelligent people who can't read or write very well'* telling the patient that he could tell he *'is an intelligent man'* from the history taken: the patient nods and smiles and the test began."

Throughout the appointment, Memory Nurse 6 performed reassurance practices to protect both the patient and the family member from the vulnerabilities of the consultation as I will go on to illustrate. From the beginning, the clinician attentively responded to the anxieties of both the patient and family member about what the consultation would entail. This is suggestive of the extent to which the clinician-patient interaction, and the narration of the tests by clinicians, was continually performed to protect the patient's identity (Goffman, 1959). First, Memory Nurse 6 clarified and made explicit that the test does not signify a marker of intelligence. In doing so, they actively positioned the performance of the patient in relation to being able to just *'do their best'* regardless of intelligence. Furthermore, intelligence was categorised beyond traditional accomplishments of literary

attainment in order to protect patient identity; the idea that poor education equated to lack of intelligence. This was demonstrated during the observation as follows, *'we see lots of intelligent people who can't read or write very well and I can tell you are an intelligent man from the history you gave'*. Responding to this, Memory Nurse 6 actively manipulated the test, *'because of your lack of education I will miss out the writing tasks'* which was again, accomplished for the protection of the patient's identity. These performances however, were also illustrative of the extent to which, the active doing of the test, served to accomplish or affirm the culture of testing. A lack of education signified failure at being able to carry out a number of the tasks. This will be discussed in more detail later in the chapter.

The carefully choreographed narration of the test and the reassurance practices were in the main, performed to reassure the patient and had a direct impact on their behaviour in the clinic; initially looking confused and anxious, to engaging and interacting with the clinician, telling jokes and smiling throughout. Memory Nurse 6 reflected on his approach to the tools during a de-brief conversation where he explained why he felt it was necessary to narrate the test in this way,

“I suppose it's also a generation thing about the idea of exams and things like that - a cognitive test isn't an exam. As soon as you use the word test it - it, it - a clinical test is easier I'm going to do a blood test I'm going to do a blood pressure people can cope with that but if you sort of say we're going to do a cognitive mental test with you, people think back to the 11+, they think back to education, they think of 'oh am I going to suddenly be asked to write something? I'm illiterate or I'm dyslexic and going to feel stupid' so it's about sort of saying I'm trying to understand how your brain is working. And I usually - and I say everyone will be different, I, I always say *'I don't mind if you get zero on this I've already seen enough to know that things are fine'*, even if things perhaps aren't fine and there are problems, the fact I had that conversation with the person to reassure.”

Memory Nurse 6 maintained that there was a discursive culture of testing which exists outside of the clinical encounter that emerged in the clinic which the tools had the ability to reproduce, and in turn shape how patients approached the cognitive screening tests. Memory Nurse 6 claimed that the use of the word *'test'* conjured notions about education and henceforth intelligence, which was integral to the patient's identity. For Memory Nurse 6, narrating the test as a device to *'understand how your brain is working'*, protected the identity of the patient. Furthermore, the clinician also underplayed the importance of patient performance, by masking the reality of the clinical work that preceded the test, *'I don't mind if you get zero on this'* and *'I've already seen enough to know that things are fine even if perhaps things aren't fine and there are problems'*. The patient was reassured that things were *'fine'* and that the significance of them scoring poorly on the tests was irrelevant because of the clinical work that had preceded the test. The efforts of the clinician extended beyond the doing of the test itself, and into how they narrated the significance of the clinical work done prior to the formal testing; performed in the interests of the patient. This culture of testing discourse was illustrated similarly during an observation of a consultation with Trainee Psychiatrist 3. However, tensions also emerged in the clinic, which reflected the extent to which dementia and diagnosis overall, were negatively perceived across the general population. I found that the culture of testing was further troubled by negative discursive constructs around AD and mental health as the following observation notes suggest,

“Trainee psychiatrist 3 asked the patient about losing her car keys or house keys, and whether she had ever left the gas on without realising. At this point, the patient interrupted visibly frustrated by the questions raising her voice saying, *'I know who the Prime Minister is as well and where he lives!'*”

“When trainee psychiatrist 3 scored the test at the end of the appointment, both the family member and the patient suggested that

this was the point at which the clinician would confirm whether they're *'doolally'* at which point both the patient and the family member laughed.”

Arguably, from the perspective of the patient, the test, which asks the patient to name the PM, was considered integral to classification. This did not simply reflect the emergence of a discourse of testing however; rather following completion of the test, the test constituted and enacted particular representations and discursive accounts of AD and mental health more broadly, hence the reference to being *'doolally'*. This negative discourse around the perception of AD and mental health was a frequent note of observation across clinic appointments, and which I found particularly uncomfortable to witness as a researcher. Throughout observations, I reflected on the extent to which both patients and family members were attempting to protect themselves against potentially undermining interactions seen here with reference to *'doolally'*, thereby highlighting the vulnerabilities of the diagnostic procedure. This was demonstrated similarly during an observation with Speciality Doctor 1. From the beginning of the appointment, the patient made a concerted effort to explain that memory loss is a normal part of growing older, recalling everything that they could remember from their childhood to prove and protect against the kinds of questions that would be asked, and therefore the testing process overall.

There were therefore numerous occasions where the test constituted negative discursive accounts of mental health and AD observed across the memory service. During the same observation with Specialty Doctor 1, the clinician asked the patient about family mental health history. An important observation I made from reflecting on my field notes, was that at this point both the patient and the family member claimed that the patient's Mother had memory loss, saying she'd, *'lost it – she didn't even know her own husband in her own house!'* Reference to having *'lost it'* was also witnessed during an observation with Trainee Psychiatrist 2, where the family member asked the clinician if the patient had *'lost the plot'*. Furthermore, expressed during an observation with Consultant Psychiatrist 4, when the patient was

asked about the history of dementia or Alzheimer's disease in the family, the family member replied with, *'his [the patient] sister has dementia towards the end of her life; she was saying all sorts of silly things'*. Following the cognitive screening test, the patient also said that he felt a *'bit barmy'* and on the way out thanked the clinician for *'not laughing'*. Together, these discursive constructs around AD and mental health resonated across observations of consultations and had important implications for how clinicians approached cognitive screening tools. This is a theme I develop further in Chapter Six.

Developing the theme around the 'culture of testing' and protecting patient identity, at the same time that clinicians were actively aware of the anxieties produced by the initial appointment, this was at times contradicted in the act of accomplishing the test in the clinic. There were moments where clinicians (re)affirmed the role of these tools as critical examiners or 'tests' of cognitive decline and in doing so, produced the very culture of testing that clinicians sought to avoid. This was observed during a consultation with Specialty Doctor 1,

“The clinician asked the patient whether it would be ok if she asked him to do a test to assess his memory – called it a memory test. She stated that *'not everyone gets everything right and there's no right or wrong answer.'* Later in the appointment, the clinician stated that *'some questions are very easy'* before asking the patient *"how are your maths skills"*? Having correctly answered the maths section the clinicians stated that *'they managed to get them all right – 'well they're [maths skills] clearly better than mine.'*”

Specialty Doctor 1 narrated the active doing of the test in relation to patient performance and skill, *'not everyone gets everything right and there's no right or wrong answer'*. She then actively contradicted this when asking the patient about their 'maths skills' and informing the patient of their positive performance, *'you managed to get them all right'*. In doing so, the tools emerged as critical examiners of cognitive performance, contradicting the

reassurance practices that the clinicians tried to deploy. Despite the projection that there was *'no right or wrong answer'* to the questions on the test, Specialty Doctor 1 made every effort to ensure that the patient was assured that their performance was not wholly negative. Following the testing the clinician explained, "*You didn't do badly and you got a few right. There was always going to be the expectation that you wouldn't do too well as you're reporting having memory difficulties.*" *'You did get a lot of things right'*". Yet both Memory Nurse 6 and Specialty Doctor 1, were compelled to draw attention to and protect, the performance aspect of the test and in turn the patient's identity, *'this is not an intelligence test'* and *'there's no right or wrong answer'*. These reassurance practices were articulated in the majority of observations observed. For example, clinicians would praise patients *'well done'* who had correctly answered questions, and at the same time informed patients that they had answered incorrectly *'I'm sorry Jean that's incorrect'* (Observation Trainee Psychiatrist 2). As I observed during the consultation with Trainee Psychiatrist 2 however, I reflected on the extent to which his particular reassurance practices were entangled in his own frustration that the patient was failing to correctly answer the majority of the questions.

The testing process and the degrees of care work involved in protecting patient identity have thus far been witnessed as narration practices performed throughout the duration of the appointment. Subsequently, the tools emerged as value-laden components rather than *'dead, disconnected, without any relevance'* (Berg, 1996: 501). Therefore, agreeing with Berg (1996) that the interrelation and interaction between actors and the tools overall, was necessary for making medical practice work in the clinic, this occurred not simply for accomplishing professional roles in the organisation of the memory service. It also occurred in order to negotiate the myriad of complexities emergent in the clinic, which had the potential to reconfigure patient identities. The active doing of the tests signified a shift towards considering the tools as enactments or constitutions of the culture of testing which did not simply present (Goffman, 1959), but produced and performed identities through the work of clinicians (Mol, 2002a). Extending this

analysis further, it also signified the extent to which this performativity was not simply enacted by the technologies but was influenced more broadly by the conditions in which these technologies were adopted; presenting moments of tension between discursive constructs around age, ageing and AD. I develop this point for analysis in Chapter Six.

Manipulation work: managing the ‘problem’

The mediation work occurring in the clinic witnessed thus far, went beyond matters of discourse in terms of how clinicians narrated the tests, towards practical manipulation work to ensure cognitive decline became a ‘manageable problem’ for both practitioner and patient (Berg, 1996: 504). Drawing on Berg (1996) who argues that the medical record serves to ‘transform[ing] a patient’s problem into a manageable problem’, I extend his analysis in two distinctive ways. First, I argue that the tools emerged as important components for medical decision making for both clinicians and patients in the organisation of healthcare. Second, this work led to the complete (re)constitution of the technology rather than a transformation of representations of the technology as Berg (1996) describes. Through the mediation and manipulation practices witnessed, the tools were (re)constituted as provisional devices inscribed with ad hoc procedures from one interaction to the next, for the purpose of transforming and making sense of complexity. Clinicians manipulated the tests in a number of practical ways including changing the order of the tests and actively omitting sections of the tests. The following observation of a consultation with Trainee Psychiatrist 3, highlighted this active manipulation work,

“Trainee Psychiatrist 3 asked the patient to name as many of the animals on the test, at which point the clinicians tried to reassure the patient that they *‘can go back to it if need be’*. I reflected here whether the clinician was pre-empting that the patient might find this task particularly difficult. My feelings were confirmed when the clinician asked the patient to point to the *‘marsupial’* and the patient having glanced at both their family member and myself in confusion,

asked the clinician *'what is a marsupial?'* Instead of answering, the clinician exclaimed that *'a lot of people don't know what that is so we'll leave it'*. The family member interrupted at this point (perhaps to protect the patient from what might be an embarrassing situation) and exclaimed that, *'this is quite a hard question'* and the clinician agreed. In order to protect the patient further, the family member turned to the patient and explained the meaning of marsupial.”

It is clear from the observation that the inherent characteristics of the test (c.f. Latour, 1986) at times underwent significant manipulation and mediation work. I have postulated thus far that in the interpretive repertoire of the clinic, clinicians were able to approach and perform the tools as provisional devices in response to the ways in which patients conceived the nature of testing. Here however, this provisionality involved a very different set of uncertainties around the ambiguities of the tool, and the normativity of the questions written in the test. The tools overall, require patients to have a particular understanding and comprehension of language and vocabulary since the test classifies and boxes a specific group of individuals (Bowker and Star, 2000): only those who are able to engage with the vocabulary and language of the tests. Perhaps the manipulation work performed by clinicians was therefore entangled with negotiating the ‘bounds’ of the tools constructed overall, without due attention to what is ‘socially [and culturally] agreed’ (Jutel, 2011: 202). Furthermore linking back to my previous claims, perhaps this mediation and manipulation work was performed in response to the vulnerabilities that the diagnostic procedure brings forth. As a result, the clinician omitted the question from the test and the tool was reconstituted to take into account the patient who happened to ‘fall between the cracks’. Memory Nurse 6 explained the necessity of this manipulation work in the clinic both during a de-brief following observation of the consultation and during interview,

“I asked why the patient had conducted the test in this particular way and he responded by explaining that, *'I didn't abide wholly with the way Addenbrooke's wishes the test to be carried out because I want*

to make the patient as relaxed as possible and give them the best chance possible.’ The clinician also explained that the reason they didn’t ask the patient to draw a clock straight away was because they wanted to see *‘how they did it.’* The clinician further suggested that the patient’s lack of education would play a part in how they would score the test and feedback to the memory team. They acknowledged that other clinicians *‘will do this differently.’*”

When asked why he felt this manipulation work was necessary during interview,

‘I want the person to do as well as possible and I’ll do anything to facilitate that and possibly I’m corrupting the test and maybe I should be just sort of parrot fashion saying what day of the week it is what month it is please repeat this but I - I suppose - I want the person to do as well as possible.’

For Memory Nurse 6, the active manipulation of the tests was accomplished in the interests of the patient to maximise patient performance and *‘give them the best chance’*. As a result, the tools emerged as value-laden components of the classification process. Arguably, this manipulation work also reflects how the test performed patient identity; the inability of the patient to carry out some of the tasks actively drove the clinician to omit sections of the test. For Memory Nurse 6 this work however, compromised the formality of the tools, *‘corrupting the test’*. Furthermore, he went on to question whether he should be conducting the test *‘sort of parrot fashion’* but acknowledged that in doing so, would be failing to account for the complexity of classifying, and its effects and consequences for the patient, *‘want the person to do as well as possible’*. I also suggest that the manipulation work observed in the clinic was further performed in order to navigate and manage the ambiguity of the tools; clinicians were actively aware both of the limitations of the tools, and themselves as users. I observed a consultation with Trainee Psychiatrist 1, where the clinician actively recognised and subsequently navigated and managed this ambiguity,

“As Trainee Psychiatrist 1 began the test she asked the patient to repeat three words ‘lemon, key, ball.’ The patient repeated the words ‘lemon’ and ‘key’ but struggled to repeat the word ‘ball’. Having struggled to repeat the word ‘ball’ and as the patient began to look increasingly frustrated, Trainee psychiatrist 1 interrupted at this point and explained *‘I will give that point to you because of my accent. It could either be bull or ball with my accent’*. The patient, seemingly relieved, laughed and Trainee Psychiatrist 1 wrote a scribbled note in the margin of the test. The clinician carried on with the test and asked the patient to *‘subtract seven from 100’*. The patient repeated the question a number of times looking to the family member for assistance but did not understand what the clinician was asking them. At this point the family member interjected to tell the clinician that the patient does not know what the word ‘subtract’ means and asked Trainee Psychiatrist 1 to *‘say takeaway instead of subtract.’*”

During a de-brief with the trainee psychiatrist following my observation of the consultation, they expressed their concern at how the language on the form had negatively impacted on the patient’s score; manifested in the patient’s inability to understand the words *‘subtract’* and *‘nautical’*. *“I think if I’d asked, ‘what would you find in the sea?’ they’d have got it but obviously I have to follow the form.”* Yet despite Trainee Psychiatrist 1’s manipulation or mediation of the test, this only extended in practice so far since she recognised that she was required to *‘follow the form.’* This notion of ‘following the form’ however, was not shared across all professionals in the memory service, *‘I didn’t abide wholly with the way Addenbrooke’s wishes the test to be carried out’* (Memory Nurse 6). During an interview with Memory Nurse 7, she raised her concerns as to the ways in which clinicians carried out the tests, and the ambiguities and uncertainties inherent to the process. As she explained,

‘The one [instruction] where you’re to read out lots of letters and every time they [patients] hear the letter ‘A’ they’ve to tap on something, I find that always a little bit difficult ‘cause you’re trying to read and concentrate and you’re also trying to see if they’re tapping in the appropriate places and sometimes I think, ooh did they do it or did they not kind of thing you know. So I do wonder about the accuracy of that and I think, I just wonder between us all, how I think some of us might be kinder than others at you know, just if something’s not dead on accurate but is acceptable, I think from what I’ve heard some colleagues say they wouldn’t score it and maybe I would or *vice versa*.’

Memory Nurse 7 highlighted a number of issues of pertinence to considering the ambiguities and uncertainties associated with these technologies more broadly. The tool more generally, is difficult to perform wholly accurately because of the nuances and idiosyncrasies of practice across the memory service. Whilst this is an argument that could be made about other medical technologies elsewhere in healthcare, what is interesting about the use of cognitive screening tools is that from observing their use in practice, they had the ability to be made provisional during interactions, and therefore their nuances accounted for between professionals. Ambiguity in this sense as attested by Memory Nurse 7, led to portability of the tools between colleagues for the organisation of the memory service as they ‘*wonder between [them] all*’.

So far, I have sketched the ways in which clinicians articulated cognitive screening tools to navigate and manage uncertainties associated with measures of cognitive decline in the clinic. In the following section, I develop the theme of uncertainty and extend my analysis, to investigate the extent to which there were specific *dimensions* of provisionality, which were performed differently across the professional hierarchy. I develop the claims made by Berg (1996) that through the informal or ad hoc practices witnessed this, ‘form[s] a crucial site in the sociotechnical organisation of medical work’ (pp. 501 emphasis added). As I have suggested, whilst

mediation and manipulation practices were afforded the responsibility of all clinicians (despite the majority of whom were memory nurses), the art of clinical judgement, in the clinic, which rendered the tools further provisional, was predominantly the responsibility of consultants. I therefore argue that the tools produced and reproduced professional hierarchies, thereby confirming the differing roles and responsibilities of consultants and nurses, despite the tools being articulated as provisional devices by *all* clinicians. In the following analysis, I explore the practising and at times privileging of clinical judgement in order to account for the uncertainties observed thus far.

Practising clinical judgement

In this study, clinical judgement was used to navigate uncertainty, which added a further strand to the socio-technical system in which cognitive screening tools operated overall. To provide some context, whilst elsewhere in medicine the impact of new developments in bioscience has brought particular types of uncertainty associated with greater understanding of complex biologies, in Alzheimer's disease this has yet to occur. Instead, as demonstrated, uncertainty was located in the meaning and use of standardised tools, such that clinical judgement remained of vital importance as the following analysis illustrates. If as Donna Haraway (1987) suggests, (although this has been critiqued see Latimer *et al.*, 2006; Latimer, 2013), the progression of molecular science would render clinical judgment unnecessary, considering the relative lack of technoscience and molecular science for AD in everyday practice, the clinic, and with it clinical judgement, perhaps remains essential to the process of formal classification. This is important to consider, given the overall arena of uncertainty in which classifying AD resides.

Clinical judgement in practice is employed to manage medical uncertainty across healthcare (Fox, 1957, 1980, 2000). According to Fox (1957), the concept of uncertainty in relation to the acquisition of medical knowledge is because of medicines inherent unknowns, and the increase of medical

information, which has the potential to redefine disease classification and categorisation. In terms of the role of technologies within this arena of uncertainty, for Atkinson (1984), the act of practising clinical judgement, is in order to reach a level of certainty that medical technologies have failed to achieve; ‘medical knowledge and practice are inherently ‘uncertain’, while the ‘certainty’ of dogmatism and personal judgment are response to that on the part of the clinician’ (pp. 954). The negotiation, communication, and messiness of classifying AD within the clinic (c.f. Bowker and Star, 2000) ‘observed and interpreted within the ordinary, practical activities of diagnostic and related work’ requires the practising and at times privileging of clinical judgement (Latimer *et al.*, 2006: 607). The ‘gaze’ of clinical judgement or expertise (Foucault, 1973) therefore, suggests a particular disciplined method of observing through which the clinic emerges as a site for knowledge production (Latimer *et al.*, 2006). As a result, in the clinics for classifying AD, with the active manipulation of the tests given their particular ‘situational exigencies’ (Berg, 1996: 515) and recognised ambiguities, the practising of clinical judgement or negotiating ‘individual particularities’ (Dodier, 1998: 55) played a key role in the constitution of Alzheimer’s disease: *‘the ACE 111 and MoCA are tools to support our clinical history and clinical acumen’* (Consultant Psychiatrist 1). Furthermore, as measuring cognitive decline has so far been demonstrated as a social process as well as a clinical one, both clinical judgment and the situated nature of the clinic, helped to inform how the tools could be used for navigating uncertainty as Consultant Psychiatrist 2 explained,

‘Clinical judgement is crucial but then there are false positives but that - I think that comes more with experience as well when you become a consultant as well. You - you get a feel just from speaking to the patient you get you’re getting so before you’ve even started that cognitive assessment you sort of have an idea in your mind as to what you might be expecting and hopefully the score can formalise that. So clinical judgement is important setting things in context is very important as well.’

This was demonstrated similarly by Consultant Psychiatrist 1,

‘I think it’s because as you learn to hone your diagnostic and clinical skills you take, you pick up on more of the subtleties of the history, the subtleties of other sort of presenting features and so you’re less reliant on a sort of raw quantitative data the emphasis on more of the qualitative aspects that you get from the history.’

According to Consultant Psychiatrist 2, navigating the uncertainties or ambiguities associated with the practising of cognitive screening tests, such as the occurrence of *‘false positives’*, required the experience and expertise acquired as a consultant. As such, exercising clinical expertise occurred alongside navigating inherent uncertainty and ambiguity regarding the classification process (Latimer *et al.*, 2006). Furthermore, the privileging of clinical judgement or gaze, a particular form of medical perception (c.f. Latimer *et al.*, 2006), was exercised through initial conversation with the patient; consultants were able to *‘get a feel just from speaking to the patient’* about the possibility of a classification. This corresponds with the idea that the higher up the professional hierarchy within the memory service, the more likely clinicians were to utilise professional experience and expertise in relation to clinical judgement. As Consultant Psychiatrist 1 illustrated, with the honing of *‘diagnostic and clinical skills’*, this also shaped how clinicians approached the quantified outcome of the tests, which I will go on to discuss further in the chapter.

Therefore it is not the case that these tools have intrinsic value *per se* but rather for consultants, it is that their value emerged from being able to draw on their expertise and experience, which allowed them to take into account *‘context’*, and employ clinical judgement when making decisions in the clinic. Medics and consultants in particular, practised their clinical judgement or *‘clinical acumen’* (Consultant Psychiatrist 1), which reflected the acquirement of skills over time, related to expertise and experience. Therefore clinical judgement in *‘clinical problem solving processes’* was given legitimacy to those clinicians occupying positions higher up the

professional hierarchy, which was evidenced across the memory service (c.f. Bosk, 1979). Whilst there was a collective agreement about the partiality of the tools, the instances where clinical judgement was privileged, demonstrates that provisionality was performed differently across the hierarchy. In doing so, this confirmed the power relations within the service; the professional hierarchy was produced and reproduced precisely because of these different practices. Tracing my fieldnotes, this was further evidenced during an observation with Consultant Psychiatrist 4. During debrief following the observation, the clinician turned to me once the patient had left the room to say *'actually clinically I could have given a diagnosis; I just know that I could give a diagnosis from the history which the test confirmed.'* Despite the clinician having given the patient their score of '15/30' and referring the patient for a CT scan, the clinician maintained that clinically they could have given a diagnosis. This was a frequent note of observation across appointments with professionals higher up the professional hierarchy, particularly consultants.

Shifting the classification space: patients' homes

As I have previously suggested however, practising cognitive screening tools in initial appointments was predominantly the task of memory nurses and OTs, reflecting an MDT approach to healthcare. Therefore whilst approaching and performing the tools as provisional devices enabled consultants to exercise clinical judgement, simultaneously memory nurses were able to carve out a unique space for their role in the service. The practice of classification was troubled when the space of the clinic produced tensions around the meaning of classification and the testing process, which were difficult to navigate. Despite the clinic emerging as an important space for knowledge production (Latimer *et al.*, 2006), its performative architecture in this study, had important implications for how patients conceived the nature of testing and diagnosis overall. It is at this point where I formally introduce the concept of portability. In this manner, the sociotechnical arena in which these tools were used shifted, and also shifted the ways in which clinicians interacted with patients, the tools and cultural

materials. In the following section I introduce patients' homes as important spaces for navigating the clinic and its myriad of discursive affects.

As evidenced in Nunmill Hospital and Ridge NHS Centre, the tools were transported into patients' homes thereby extending the context of their use. Extending the space in which these tools were used by clinicians (i.e. extending the space of the clinician-patient interaction) was significant for classification, as it allowed clinicians to further mediate and manipulate the tests in order to 'sort' the social and cultural practices enacted in the clinic. Subsequently, this guided how clinicians approached and administered the tests. Similarly to the processes of the clinic, clinicians (predominantly memory nurses) engaged in front stage and backstage work (Goffman, 1959) when performing the tests. Much of this work relied on the 'situational exigencies' (Berg, 1998: 515) of patients' homes where nurses carried out tasks 'backstage', to navigate the ambiguities associated with the tests. In the analysis that follows, I consider space and materials as important for analysing the social rather than treating them as 'second class citizens' (Law, 1991: 6). Therefore, as I will go on to illustrate, the home of a patient emerges as an important space for extending the care with which clinicians approached the classification process, necessary for directing an 'immediate course of action' (Berg, 1997: 129).

At this point, I reiterate that I did not have access to observe the consultation process in patients' homes. In the following analysis, I therefore draw predominantly on the accounts of memory nurses and supplement them with observations of MDTs, where nurse work was transported for collective discussion. From the outset, memory nurses drew attention to the discursive nature of the clinic. When asked to explain the reason for carrying out initial consultations in a patient's home, Memory Nurse 6 suggested that it '*avoid[s] any white coat syndrome*' in order to be able to secure as much information as possible for a classification, striving for a '*truer picture*' of the condition. Similarly as Memory Nurse 2 explained when asked about the advantages of carrying out initial assessments in the home,

“You get to see way more - you can see people will sit there if they come to a doctors or they come to the hospital and they get dressed, it’s smart you’ve got a bit of that white coat syndrome haven’t you, where they sit up straight and answer the questions and everything’s fine and lots of people (especially wives and husbands) just mop up what’s going wrong what the other half can’t do; they mop it up and just do it, so you don’t always get to see what’s happening really. In their home, people are more relaxed as well and I think you get a bit of a truer feel of what’s going on and people are much - they know where they are and, they feel more comfortable, they might be having a cup of tea or a biscuit, and they can show you round the home and you can see for yourself what it is they can and can’t do. Any problems you can then think, *‘oh I need to get that put in, we need to get this, we need to get that’* and they tend to do (in my view), I think that they do better with the cognitive testing when they’re relaxed and in their own home. So it might take longer, and we might not see as many people in a day, but I think the whole assessment is better is more patient centered I’d say. I’ve no proof of that other than my own thinking.”

For Memory Nurse 2, the home is a space for accumulating evidence, getting a *‘truer feel of what’s going on’* because she is able to *‘visualise’* the problems that may not manifest themselves in the clinic. Similarly to Memory Nurse 6, she explained that this may in part be due to what she considered is a *‘white coat syndrome’*. This was further confirmed by Memory Nurse 4, *‘at clinic sometimes they can put on a little bit of a front’*. Arguably, what both memory nurses alluded to was the presentation of self in the clinic (Goffman, 1959) manifested in the actions of the patient to, *‘sit up straight’* and *‘get dressed - its smart’*. This space of the home served as an extension of the mediation work observed during initial consultations; the space of the home was considered integral to the process of approaching the classification process with care for protecting patient identity. Subsequently, for Memory Nurse 2, the clinic had the potential to mask or ignore what was happening *‘backstage’* (Goffman, 1959) in a home

consultation. This ‘backstage’ work or embodiment of identity backstage, was revealed through observation of the mundane or perceived normality and routine to patients’ lives. In order to reveal ‘*what’s happening*’ for Memory Nurse 2, it was about normalisation of routine ‘*they might be having a cup of tea or a biscuit and they can show you around the home*’ through which they could make decisions about, and proceed with, facilitating the appropriate course of action (c.f. Berg, 1992), “*any problems you can then think ‘oh I need to get that put in, we need to get this, we need to get that’*”.

As Memory Nurse 3 also attested she ‘*want[s] people to do their best*’ adding that ‘*people all function at their best in their own homes it’s where their strengths are; if they were coming to a clinic they’ve already got themselves stressed trying to find the place*’. This was confirmed by Consultant Psychiatrist 1 who explained when asked during interview, about the possibility of an inaccurate cognitive screening outcome, ‘*we feel that our patients are much more comfortable in their home environment and you are much more likely to get a more accurate assessment both from history and their functioning on tests*’. The ‘*strength*’ of patients, or ensuring they were ‘*relaxed*’ was performed in the home beyond the medical domination of the clinic. As a result, the ambiguities of the technologies were navigated, and formalised efforts to protect patient identity was performed within this space. Clinicians were able to manage the ways in which patients conceived the nature of the testing process overall, outside of the performative architecture of the clinic. For Memory Nurse 3, this subsequently produced a more accurate version of the technology for the process of classification.

This was confirmed by Memory Nurse 4 during interview, ‘*I like home initials although occasionally I do them in a clinic but I do prefer to do them at home because I think you’re seeing people more relaxed, you’re seeing what’s about in the house, you’re seeing how they’re functioning at home*’ and OT 2, ‘*sometimes we get sent out just to see ‘cause a lot of the things, a lot of the assessment that’s done, particularly if it’s something new in the service, might be done at clinic so people are not seen in their home*

situation.’ What was seen or made visible within this space, was captured by both memory nurses and OTs; the space of patients’ homes was significant for producing knowledge about decline, and for constituting what OT 1 described as *‘taken for granted’*. Yet, not all initial appointments took place in the home environment. As a result, it was the task of OTs in particular, to be *‘sent out’* to see patients within this space (Interview OT 2). Tensions arose however, since the overall role of cognitive screening tools in this space was a point of contention for OTs. As OT 1 explained, cognitive screening tools were privileged over being sent out to see because, *‘we have the professional backup of the tests now it’s not hopefully gut reaction... so practice wise, I think things are less subjective and more objective these days which can only be a good thing’*. Despite both OTs and memory nurses collectively attesting the importance of the home environment, tensions also arose, as OTs suggested that formal assessment within these spaces was important for *legitimizing* their work practices. Being able to *‘justify’*, or *‘be accountable’* for OT 1 and OT 2, required increased use of testing through formal assessment. For OT 2, increased justification of their work through the use of the tools overall, allows for *‘professional backup’*; their practice could be formally identified and legitimated (c.f. Latimer, 2000). This was valued by OT 2 because as she explained, relying on *‘gut reaction’* downgrades (Latimer, 2000) their work in the process of classification; the tools then serve as agents to strengthen clinical reasoning (see Berg, 1998).

It was also within the home space that memory nurses in particular, were able to attach significance to cultural materials not available in the clinic. As Latimer (2004) argues, cultural materials order relations; legitimising practice and producing professional hierarchies. In this sense, materials *‘make relations, both conceptual and lived, manifest’* and are *‘symbols of significance’* (pp. 759). I develop Latimer’s claims by demonstrating that by attaching meaning to materials this rendered the tools further provisional but in doing so, created a unique space for the role of memory nurses in the MDT. Attaching symbolic meaning to materials, seen in the previous section by Memory Nurse 2 as *‘having a cup of tea or a biscuit, and they*

can show you around the home and you can see for yourself what it is they can and can't do', cognitive decline was further enacted as a social and cultural, as well as a medical and clinical problem. Memory Nurse 7 also described the importance of the home for navigating uncertainty manifested in the complexity of a false positive or false negative result on a cognitive screening test,

‘If you do a home visit that can tell you an awful lot of things ‘cause you can obviously check out with the environment as well what’s happening. You know I’ve always sort of said if you can get into somebody’s fridge it tells you an awful lot really ‘cause you know there’s sort of things maybe out of date or even empty, if there’s no food available so it’s always it’s sort of gathering a whole collateral of evidence to be used.’

Aligning the evidence towards medical decision-making in the space of patients’ homes required that nurses in particular, ascribed significance to what was both socially and culturally important. First, Memory Nurse 7 shifted the measurement of cognitive decline from the technology onto the cultural materials for example, the fridge. The cultural material, the fridge and its contents, were aligned alongside formal measures for detecting cognitive decline because as she argued, the setting enacted particular conceptualisations of cognitive function. The home symbolised particular socio-cultural preoccupations about how older people should be managing their household, functioning day to day, and thus experiencing cognitive function observable within this space (c.f. Bourdieu, 1992). For Memory Nurse 7, gathering the evidence in the context of a patient’s home required interpretation of the patient’s ‘social situation’ (Latimer, 2000: 69) utilised to confirm or refute the results from cognitive screening tests. What is interesting is that in the space of the home, the work of memory nurses could not be immediately reclaimed by those higher up the professional hierarchy (c.f. Latimer, 2004). At which point, memory nurses played a key role in constructing the initial test, for taking forward into the MDT meeting.

Patients' homes enabled particular social and cultural practices that emerged in the clinic to be sorted backstage. Memory nurses, and to a certain extent OTs, were therefore able to attach importance to what was socially and culturally significant for navigating uncertainty in this space. The shifting context, in which these tools were accomplished, is therefore suggestive of their overall portability across particular spaces. However, the question remains as to how the information gathered from these tools was used to proceed with the classification process. In what follows, I analyse the role of the tools within the MDT; the informal or ad hoc practices inscribed in the tools were brought into this space for collective discussion. In doing so, I demonstrate that the practices inherent to the making of the tools as provisional devices, were performed and collectively resolved across the hierarchy. Regardless of specialism across the service, the tools will always be partial devices within the wider arena of uncertainty, and simultaneously, the MDT further produced and reproduced professional hierarchies and power relations for negotiating complexity.

The role of the MDT

MDT meetings reflected portability on a micro level; the work performed by clinicians was brought into this arena for collective discussion. The meetings served as platforms for the mobilisation of evidence: the interpretation of cognitive screening tests, CT scans and MRI scans, presentation of clinical history and patient symptoms, towards formal classification of disease (c.f. Latimer *et al.*, 2006). In particular, the manipulation and mediation work, performed in the clinic, was navigated and discussed, clinical judgement was practised and privileged, and professional hierarchy was subsequently maintained. I found that clinical judgement was practised in particular, to negotiate and manage the ambiguities associated with the tools as shown in the following observation of a team meeting at Nunmill Hospital,

“The consultant steering the meeting turned to Trainee Psychiatrist 2 and asked him ‘*who’s next?*’ Trainee Psychiatrist 2 started

presenting a GP referral; a patient who had a cognitive screening test completed. The trainee psychiatrist outlined the results from the patient's assessment including their score from the MoCA, but also explained that the patient had difficulty completing the test; he paused at this point and exclaimed that this was perhaps not due to lack of cognitive function but actually '*negotiating the practicalities of the test*' itself. He outlined how the patient found it difficult to '*see*' the animals on the test because of visual difficulties. Here, I reflected on the extent to which Trainee Psychiatrist 2 recognised the limitations of the test and the potential it had to affect the performance of the patient. He completed his presentation by explaining to the consultant that he was unsure whether the test signified lack of cognition and a collective discussion about the results from the test ensued between colleagues."

Similarly to memory nurses, as I will go on to illustrate, trainee psychiatrists were also required to discuss all initial appointments with the team. In the case of the observation of this team meeting, Trainee Psychiatrist 2, presenting the findings of the consultation, recognised the ambiguities associated with the tests and testing, or '*the practicalities of the test*' itself. This manifested itself in the patient having difficulty visualising the content of the test. Subsequently, Trainee Psychiatrist 2 actively employed their clinical judgment or perception to stress that, '*performance of the patient but may not be due to a definitive lack of cognition*'. This had parallels with a meeting at Ridge NHS Centre,

'Memory Nurse 1 presented a GP referral: the patient had made an appointment with their GP because they were concerned about their memory and having completed an AMTS, they scored 7/10. Following a brief description of the AMTS, the clinician proceeded by discussing the physical health of the patient, living arrangements and living conditions. The memory nurse highlighted that the patient had poor language skills and '*as a result of their poor English they were difficult to assess*'. The clinician carried out a MoCA instead of

an ACE 111 as the ACE 111 was seen as too arduous. Here, the clinician explained to the registrar steering the meeting that they had to administer the test three times and she had to ask the son to '*act as interpreter*'. At this point, the clinician reflected on whether they thought the poor score was due to the patient's lack of English but explained that when the son interpreted the test for the patient, the patient still scored similarly. The registrar steering the meeting asked how the patient performed on the visual-spatial aspect of the test; the patient had scored particularly badly. The memory nurse and registrar engaged in an in-depth discussion about the family support for the patient, medical history and the need for further testing including a CT scan and diagnostic appointment. Importantly, the clinician stated that the family was not unduly worried about the low scoring on the MoCA and '*were not particularly interested in a diagnosis.*'"

Here, assembling the evidence meant recognising the ambiguities of the test through mediation work, and privileging of individual or clinical judgement and perception. Memory nurse 1 recognised the ambiguity associated with cognitive testing, '*as a result of their poor English they were difficult to assess*' and mediated this by asking the family member to '*act as interpreter*'. Despite the limitations of the cognitive test score, the patient was referred for further diagnostic testing. The final interpretation of the test towards medical decision-making (Berg, 1996) however, relied on those higher up the professional hierarchy concurring with the work of the memory nurse. Although the memory nurse could not be certain that the score was attributable to the beginning of the dementia process, the registrar decided that further clarification was required through additional diagnostic technologies that could help to align the evidence (c.f. Latimer *et al.*, 2006). This observation serves to reflect how practising of clinical judgement sustained professional hierarchy and power relationships in the clinic, and concurrently that uncertainty became a collective endeavour within the MDT (c.f. Bosk, 1979; Cox and Webster, 2012). Whilst the score itself did not represent a classification for either the nurse or the registrar, and both

actors recognised the importance of context and judgement, it was the registrar who adjudicated on the following classification process. As Consultant Psychiatrist 2 demonstrated during interview, this extended beyond the clinician-patient interaction into the multi-disciplinary team meetings, *'I don't necessarily discuss that patient in full detail in an MDT'*. The memory nurses were given the task of carrying out the initial consultations with patients, and the medics (other than the junior doctors who were also subjected to the checking process) acted as interpreters in the MDT.

At this point, I reiterate that despite the division of labour within the service, where adjudicating on diagnosis required the work of consultants, medics and psychologists, the definition of what constituted cognitive decline was constructed through the interactions between medics and nurses observed during the MDT. This interaction work relied on both the expert adjudicators (consultants) and the work of memory nurses to construct patient context, in relation to the role of cognitive screening tools. The work done in clinics and the home was brought into the memory service for discussion, which drove medical decision-making (Latimer, 2000: 69) and the management of uncertainty observed in the clinic. When asked about the diagnosis process across the memory service, Memory Nurse 1 explained,

‘In terms of the actual diagnosis, once the nurse has gained all the information that they need it would then be taken back to the MDT and discussed so it would be kind of like a team discussion about whether any further diagnostic testing is needed it's never a decision that you'd make on your own.’

For Memory Nurse 1, the *'information'* acquired in the consultation was articulated and rendered meaningful within the interactions of the memory team at the MDT. Despite the fact that nurses were not afforded the responsibility of interpreting the cognitive screening tests, for Memory Nurse 1 this did not represent a downgrading of professional expertise and skill (c.f. Davies, 1995; Rafferty, 1996) because she contends it would

'never [be] a decision you'd make on your own'. As a result, this revealed the epistemic division of labour in the service necessary for enabling the process of classification to proceed. Furthermore, as highlighted at the beginning of the chapter, collating the information with regards to patient function and thus individual particularities during the clinician-patient interaction was interpreted and made meaningful by those higher up the professional hierarchy. As such, the role of the MDT was essential for assembling the evidence despite being implicated by uncertainty and complexity. Arguably, there was a shared responsibility of uncertainty within this diverse network of actors (c.f. Cox and Webster, 2012). Therefore, whilst memory nurses were able to carve out a unique space for work in response to managing the uncertainties produced by the clinic, professionals higher up the professional hierarchy subsequently adjudicated on this work within the space of the MDT as the following observation extracts highlight. During a team meeting at Nunmill Hospital, the work carried out by memory nurses was translated by medics within the team,

“A memory nurse presented the case of a patient whose family member expressed concern that the patient *'hasn't got out of bed since Christmas'*. The nurse read through the referral letter to the clinicians present in the MDT, which included information concerning cognitive assessment tests, medication, blood tests and x-rays. However, the consultant did not draw particular attention to these factors and expressed their concern that the patient hadn't left their bed in approximately six to eight weeks. The consultant decided that this was enough information to warrant her going to see the patient in their home to *'see what's going on.'*”

When presenting information from a referral, Memory Nurse 1 enacted the ‘problem’ (Berg, 1996) in relation to the social situation or context of the patient, having *'not got out of bed since Christmas'*. Arguably, this points to what Rose (1998) contends are the increased efforts in healthcare to calculate risk in psychiatry, which has the potential to transform the ‘act of diagnosis’ towards focussing on the management of the everyday (pp. 185).

Despite engaging with the medical information for the patient such as blood tests and CT scans, it was context that affected the consultant's decision. The consultant transformed what the nurse found to be significant into a clinical problem, suggesting she arranges to go and see the patient in their home. Furthermore, the observation of the team meeting pointed to the ceremonial order of the MDT (Strong, 1979; Latimer, 2000), which produced and reproduced power relations within the service because the consultant adjudicated on the subsequent stages of the patient's classification process. This decision however, relied on the construction of cognitive decline manifested in the everyday, and therefore the role of memory nurses. In this instance it was the context of the nurse work that informed and was transformed as evidence in the classification process because of the division of responsibility rather than subordination within the service more broadly (c.f. Latimer, 2000). This was further illustrated during a conversation with Consultant Psychiatrist 4 when asked about the importance they ascribed to the multi-disciplinary aspect of the team,

‘Yes it is important because the nurses always present their initial assessments and they're always discussed and the good thing is that we'll have different views on the problems for example we have OTs and (although at the moment we don't have a psychologist but ideally we should have one) there are nurses support workers, OTs, medics so they get like from different views and social workers and you know from different perspectives I think the problems looked at from different perspective and the patient will get a better kind of support at the end.’

For Consultant Psychiatrist 4, the network of actors in its different ‘*views*’ and ‘*perspectives*’ connected to ‘*support*’ the patient in the classification process. In turn, he also recognised that when making decisions in the clinic (Berg, 1996), the work of memory nurses was effectively translated to account for the ‘problems’. The interactions in the MDT led to a ‘*shared understanding of the patients' needs*’ (Consultant Psychiatrist 1) to get ‘*a kind of better support at the end*’ (Consultant Psychiatrist 4). Consultant

Psychiatrist 4 reflected on the importance of a diverse range of clinicians solving the problem. Yet, what this also highlighted is the extent to which professional hierarchies were sustained since expert consultants reclaimed the work of memory nurses. Nurse work required justification within the team, *'nurses always present their initial assessments'*; their work was both translated, and yet also reclaimed by those with the expertise to handle it.

Balancing act and valuing the quantified outcome

The question remains as to how clinicians across the memory service approached the quantified outcome of cognitive screening tools when informal and ad hoc practices were performed in situated occasions. The work of Berg (1992) is helpful for framing the following analysis. With respect to resolving medical decisions, Berg (1992: 169) contends that problem solving in medical practice 'could be seen to be utter chaos' and questions what kinds of 'frames of reference' clinicians use to 'clean up' or prevent this chaos or messiness. Practising routine across clinical practice is one method Berg (1992) describes to organise this complexity, and for clinicians to order their different world(s). In order to make sense of uncertainty and classification, the characterisation of disease relies on the processes of routine. The routine performance of memory clinics and the clinical work of practitioners entailing the gathering of clinical history, patient narrative, medical history and psychiatric history, were routinely performed which 'facilitate[ed] medical action' (pp. 170). As demonstrated in my research, the decision making process for classifying AD was constitutive of what Berg (1992: 170) describes as 'locally situated routines' and which meant that clinicians were able to recognise and account for the complexity and uncertainty around diagnosing AD. According to Berg (1992), these routines overall, are performed with a 'certain 'automatism': habitually, without explicitly reflecting on or legitimating the actions involved' (pp. 170).

However, exploring the significance of the quantified outcome of the test, I extend Berg's arguments. Whilst clinicians accounted for locally situated

routines in order to prevent the ‘chaos’ that Berg (1992) describes, this was balanced alongside privileging the quantified outcome of the tools. The routines for AD were continually shifting and actively reflected on by clinicians because of the continually emerging complexities associated with classifying AD as this chapter has demonstrated. Rather than routines therefore, I suggest that the provisionality and therefore portability of the tools across the organisation of healthcare, allowed clinicians to make sense of ‘chaos’ and proceed with classification.

Initially, I describe the ways in which clinicians approached the quantified outcome for making decisions about proceeding with classification. I explore what Berg (1992) describes as the ‘reconstruction’ of data; evidenced in the ‘downgrading’ of data obtained from cognitive screening tests, which added a further dimension to the making of provisionality. Across the memory service, the possibility of uncertainty, manifested in false positive and false negative results, drove clinicians to actively mediate the results from cognitive screening tests if the patient was deemed to lack education or be highly intelligent: if a patient did not ‘fit’ their previous clinical work. This was evidenced during an interview with Consultant Psychiatrist 2 when asked about the possibility of false positive and false negative results,

‘So if I get somebody where they’re mismatched with how they’ve scored compared to how they’re functioning that would make me think what have I missed here. The other population is the very bright so I have lots of people in my patch that are retired old-age psychiatrists, psychologists, lecturers at the University, Professors and of course they have massive cerebral reserve I’ve even had people who’ve made some of these tools that then come to see me so it’s kind of being mindful of that.’

As Consultant Psychiatrist 2 explained, lack of correlation between the quantified element of the test and the clinical work had much to do with being ‘*mindful*’ of the extent to which patients had the skills to perform the

tests anyway. Those with the *'cerebral reserve'* to perform particularly well on the tests, could mask the true picture of cognition.

This was further demonstrated in the following extract taken from an observation with Trainee Psychiatrist 1,

“The clinician discussed with me the score from the test and expressed that were *'very surprised at the score, I thought they would do much better as the patient was quite sharp and remembered all their medication, life history, events...'*”. Trainee Psychiatrist 1 legitimated their *'surprise'* at this low score by adding that *'the patient's literacy and numeracy is poor and they could have scored higher as they couldn't possibly do some of the tasks'* all the while talking through the form with me to demonstrate this.”

Trainee Psychiatrist 1 subsequently fitted the data to their clinical work in recognition of the fact that the patient could not fulfil all the necessary tasks; legitimating their *'surprise'* at the score (c.f. Berg, 1992). Furthermore, when asked about the possibility of false positive or false negative diagnoses and the role of cognitive screening tools, Trainee Psychiatrist 1 explained,

‘You can get false positives and you can get false negatives but the the only way that you can overcome that because although these are objective measures of cognitive function, you're gonna have your inter-rater bias, you're gonna have all these confounding factors that will affect it, so the only way that you can account for that is to try and put it into a clinical context and it keeps coming back to that. But if you've got somebody who scores a little you know, I've had patients who have scored slightly lower than I expected them to 'cause they were really high functioning...it's just about putting it into that clinical context and assuming, never assume it's completely right.’

First, Trainee Psychiatrist 1 expressed what was consistent across the memory service, the element of surprise concerning the quantified element of the test and the clinical work that preceded it. In this instance, Trainee Psychiatrist 1 sorted this complexity by attending to the patient's inability to complete literacy and numeracy tasks. During the observation, she actively manipulated the tests by omitting sections of the tests. What this excerpt also suggests, is that the clinic was both resistant to statistical reduction in the sense that Trainee Psychiatrist 1 recognised that to make sense of the quantified outcome it had to be placed in *'that clinical context'*. However, whilst the clinic was 'resistant to statistical or biological reduction' (Latimer *et al.*, 2006: 571), the quantified element of the tools was important for proceeding with classification as I will go on to demonstrate.

Despite adopting the concerns of Berg's (1992: 159) theory of reconstruction in the routine practices of the clinic however, the modification of data to support the 'transformation' he proposes, was a complex networked process for the classification of Alzheimer's disease. As demonstrated, clinicians were at times surprised at the results and outcome of the tests, in accordance with both the clinical work that preceded the test, and their clinical judgement. Yet although the clinical work and clinical judgement, were at times privileged, this occurred alongside the numerous moments where clinicians used or mediated the tools to *'supplement'* *'correct'* or *'guide'* their clinical work. The raw scores were embedded in the clinical framework, making up just one aspect of the *'diagnostic picture'* (Interview Consultant Psychiatrist 2). As Consultant Psychiatrist 1 explained when asked about the value they ascribed to the tests as detectors of cognitive decline, *'detecting not all, quantifying partially'*. Therefore, as the final section of this chapter demonstrates, fitting the data to the clinical work was a process of continual adjustment both within and outside the confines of the clinic. A balancing act therefore ensued which shifted across the professional hierarchy, as I demonstrate in the following analysis.

It is perhaps 'self-evident' that commitment to standards in medicine and use of protocol, *'we're supposed to be doing them consistently and asking*

them in a consistent way so really if you're following the absolute proper guidelines for the test then I guess everybody should be able to do it', did not wholly constrain the practices of the clinic, *'everybody's different aren't they no matter how standardised you try to do something'* (Interview Memory Nurse 1) (c.f. Latimer *et al.*, 2006: 623). What I will go on to illustrate however, is that despite the clinic and its practices resisting reduction to statistics as evidenced in the work of Latimer *et al.*, (2006) and Latimer (2013), I extend these claims by drawing attention to the general commitment to objectivity and measurement across the memory service, which was necessary for the organisation of what was essentially a complex distribution of medicine. Clinicians navigated valuing both objectivity and order, and the practices of the clinic, until the tools emerged as portable or black-boxed (Latour, 1987) devices necessary for organising where AD was 'done' (Garfinkel, 1967). The making of AD, thus rested on the provisionality of the tools, and their role as central mediators for organising AD in the memory service.

First, I will attend to what Dodier (1998) describes as the co-existence of systematic protocols of medicine and individual particularities when utilising the tests in the clinic. Similarly to the work in the clinic this was achieved in order to navigate and in turn manage the uncertainty associated with measures of cognitive decline. During the clinician-patient interaction, this amounted to, *'follow[ing] the form'* whilst at the same time recognising 'individual particularities', *"there is that quote, 'when you've seen one person with Alzheimer's you've seen one person' because everybody is so different and you can't compare two people"* (Memory Nurse 4). As witnessed across the memory service, there was a commitment to both protocol and judgement. The fact that clinicians were *'supposed to be doing them consistently and asking them in a consistent way'* but equally, that performing the test required interaction with the patient *in situ* which shaped the tool, *'skills come in how you administer, and how you engage with people when you're administering it really'* (Extract taken from a conversation with Memory Nurse 1). This extract reflects what Dodier (1998) claims are 'internal tensions in action' between adhering to protocol

and interacting with the patient and the test *in situ*; related to the ways in which clinicians navigated the uncertainties associated with measures of cognitive decline (pp. 55). Together with the work done in the clinic and patients' homes, clinicians also mediated the quantified data in terms of narrating the results within the space of the MDT, as the following extract from an interview with Memory Nurse 6 highlighted,

“In this case [patient example] 46 out of 100 and I would say something like, *‘but I felt that their cognitive ability was better than the test suggested and I also felt that the test was negatively influenced by the fact that this patient wasn't very literate so the literacy things couldn't be done, or maybe if they've got eyesight problems or maybe they've got verbal problems’*, which is obviously a deficit but that has influenced the overall score giving a worse score than it is.”

As Memory Nurse 6 explained, navigating the score required recognition of the ambiguities and practices which, *‘influenced the overall score giving a worse score than it is’*, or the ‘shadows’ of clinical practice (Latour, 1986: 18), and accomplished this in the MDT meetings, *“I would say something like, ‘but I felt that their cognitive ability was better than the test suggested’”*. Whilst Memory Nurse 6 was committed to the score, its value was negotiated by accounting for ‘situational exigencies’ (Berg, 1996: 515) in response to the complexities that shaped and manipulated the outcome on the tests. The score was handled with care accounting for their role *in situ*. Therefore, the formal tests or *‘follow[ing] the form’*, was at times ‘superseded’ by what Berg (1996: 515) describes as ‘ad hoc’ or ‘informal’ procedures.

Although I have demonstrated the accomplishment of the tools within locally situated routines, the (re)construction of data to fit the clinical work also occurred outside the confines of the clinic in response to the complexities associated with the ambiguities of the tools. Therefore the mediation work of the data was not confined to the clinic (tacit and

embedded in the culture of the memory service), which demonstrated how the overall diagnosis process extends biomedical and medical spaces (Street and Coleman, 2012). Within the corridors and offices of the memory service, scores were continually debated and discussed by memory nurses backstage (Goffman, 1959). Memory Nurse 2 explained this informal practice and commitment to the score as a classification system in itself,

“I mean today I did just exactly that [checked test score] there was someone was drawing you know the cube drawing and I wasn’t quite sure what I would have given that the score is 0, 1 or 2 and I just asked a colleague ‘*what would you give in this instance*’? And she said well I’d have done this, that, and the other and I thought ok, and I took that on board and made my judgement from that sort of thing. So we do, we often say, you know, ‘*what do you think about this*’, and it’s not unusual.”

Similarly as Memory Nurse 7 also explained,

‘I’ve just done it now because sometimes when you look at how someone’s responded to one of the elements on the tests, it you can have a little bit of self-doubt as to when you’re judging it.’

Outside the confines of the clinic, memory nurses navigated the materiality of the tests and its outcomes, through interactions and conversations with colleagues in order to sort the ambiguity and uncertainty embedded in the tests. For Memory Nurse 2, this routine communication with colleagues (re)ordered the uncertainties emergent in the clinic, and the informal, ad hoc practising of the tools reconfigured their ‘life-as-usual character’ (Garfinkel, 1967: 37). The tools were shaped by and became active agents through this backstage work of memory nurses, which was not practised uniformly by those higher up the professional hierarchy. This suggests that clinicians across the hierarchy had differing routines for approaching the quantified outcome of the tools and resolving uncertainty. However, furthering this observation as Memory Nurse 7 explained, this ad hoc work also extended

into commitment to best practice where 'self-doubt' drove communication backstage. Furthermore, the quantified element was important for organising AD, which was highlighted by Trainee Psychiatrist 1 during interview,

'It [the score] just gives it gives you something 'cause you know doctors rotate through jobs all the time it does give you something objective to put down on a bit of paper other than your subjective view of the patient so that other physicians and doctors can look at that and get something out of it...what these tools do is as I say is allow that transference of information between practitioners and monitoring of progressions which is important for thinking about pharmacological intervention and things like that so it is important yeah.'

And further illustrated by Memory Nurse 2 when asked to reflect on the extent of the inter-collaboration and communication in the service,

'If somebody said to you they've got 22/100, you'd think oohh we all - the team would know where that person was it means the same thing to everybody I think.'

This network of communication within the MDT, enabled the tests to emerge as agents in the classification process where '*knowing what everything means*' amounted in part to the score on the memory test. What is significant about this extract is that the quantified outcome of the tool was important for proceeding with classification. This commitment to objectivity at times over the subjectivities inherent to medical practice (Fox, 1980) was valued within the work practices of the memory service, '*doctors rotate through jobs all the time it does give you something objective to put down on a bit of paper*'. As a result, the tools became 'portable' with the, 'transference of information between practitioners and monitoring of progressions' inherently valued. The portability of the tools reflected and introduced in this chapter will be extended in the analysis of Chapters Six

and Seven. This is not to suggest that clinicians held intrinsic value to the quantification of cognitive decline, but within the organisation of the memory service and the constraints of the clinic and clinical work, the raw score was valued and the tests became ‘black boxed’ (Latour, 1987). In doing, so the multiplicity of practices as outlined in this chapter were subsumed within the broader commitment to portability where the informal or ad hoc practices of the clinic for proceeding with classification, “no longer needs to be considered, those things whose contents have become a matter of indifference” (Callon and Latour 1981:285).

Despite the mediation work to ‘fit’ the data to the clinical work, within what Berg (1992) describes as locally situated routines, in order to make sense of classification in the memory service, it was the numerical score overall, which was valued. There was a stronger commitment within and across the service towards diagnosis in an organisation that was under increased pressure to make AD known in the clinic. The quantified outcome was reified as an objective set of truths for organising within the service, reflecting the complex distribution of medicine: rotation of registrars. More broadly however, whilst cognitive function as ‘amorphous, heterogeneous experience’ was transformed into a ‘calculable problem’ (Lakoff, 2007: 58) the locality of the clinic and the role of these tools *in situ*, was not disposed or made useless. Overall, as the provisionality and subsequent portability of the tools was made within the clinician-patient interaction and across the MDT, uncertainty associated with measures of cognitive decline were navigated and managed, and classification proceeded within a complex distribution of medical practice.

Summary

In this chapter, I captured how uncertainties associated with measures of cognitive decline were navigated and handled by clinicians in the clinician-patient interaction and across the MDT. Through the making of the tools as provisional devices, clinicians were able to navigate the difficulty in determining a definitive diagnosis of AD, the ambiguities associated with

the technologies, and the ways in which patients conceived the nature of a diagnosis overall. This provisionality, which was constituted in the clinician-patient interaction, was accomplished in three significant ways. First, during the clinician-patient interaction, clinicians mediated and manipulated the tools where the practices of the clinic were able to ‘bring [the tools] to life’ (Berg, 1996: 501). Through these mediation and manipulation practices manifested in reassurance practices in the narration of the tests to actively omitting sections of the tests, clinicians were able to (re)constitute the tools to deal with the complexities emergent in the clinic. Extending this analysis further, I demonstrated how clinical judgement was subsequently privileged, which highlighted the production and reproduction of professional hierarchies, and subsequently the hierarchical dimensions of provisionality in the arena of the memory service.

As a result, the second stage of provisionality was witnessed and the portability of the tools became manifest. In response to the performative architecture of the clinic, which produced particular anxieties around the testing process linked to negative accounts of mental health, which tended to be articulated in the clinic, the tools were transported into the space of patients’ homes. Developing the claims of Latimer (2004), I argued that it was in this space that memory nurses’ assigned significance to what was socially and culturally significant for producing knowledge about cognitive decline. Yet, what this pointed to more broadly, was the ability of the tools to produce and reproduce professional hierarchies, and configure and mediate particular relations between clinicians across the memory service (c.f. Berg, 1996). I demonstrated that whilst memory nurses were able to carve out a unique space within patients’ homes, consultants reclaimed the work of memory nurses in the MDT. Overall however, the work of memory nurses was significant because of the distribution of medicine across the service; they were routinely called upon to carry out the tests and therefore were explicitly involved in the making of provisionality. Overall, the provisionality of cognitive screening tools was a multi-disciplinary task, which became an important resource for navigating the uncertainties associated with cognitive decline.

The third way in which provisionality was performed across the service was through the reconstitution of the quantified element of the tools, for navigating and managing uncertainty. However, whilst I drew on the claim that overall the clinic resists reduction to statistics (Latimer *et al.*, 2006: 571), I also demonstrated the commitment to objectivity for proceeding with classification in the memory service and the medical decision making process. As a result, there emerged a balancing act: valuing the informal and ad hoc practices of the clinic, alongside the ‘black-boxed’ (Latour, 1987) quantified element of the tools. Through this ‘black boxed’ (Latour, 1987) tool, clinicians were able to proceed with classification in a complex structure of medical practice. I highlighted that whilst the quantified outcome of the tools was further mediated, clinicians also valued the quantified outcome of the tools.

Furthermore, I extended Berg’s (1992) claims that the medical decision making process involves locally situated routines for resolving or preventing ‘chaos’. I demonstrated that it was the portable outcome of the tools and the continual negotiation of routine to respond to emergent complexities that was important for making sense of the messiness of healthcare practice. Moreover, since I agreed that AD and cognitive decline are ‘categories in the making’ (Latimer *et al.*, 2006: 614), the making of the tools in locally situated routines does not end in the arena of the clinician-patient interaction or the MDT. They are continually being made provisional and continually constructed in the corridors and offices of the clinics and during interactions with patients. Developing Berg (1996), I argue overall that the practices of provisionality did not mean that the formal work (despite being continually superseded) ‘stand[s] ‘powerless’ in the face of the contingent and interactionally achieved nature of the social’ (pp. 515). This chapter therefore illustrated the interrelation and co-production between the informal and ad hoc practices of the clinic, and the quantified outcome of the tools.

In the following chapter, I describe and analyse how clinicians use cognitive screening tools to constitute the boundaries of classification in the organisation of the memory service. In constituting the boundaries of disease, risk and uncertainty are mobilised in two distinctive ways. First, a borderline score on a cognitive screening tool drives clinicians to keep patients on for review, and second, it drives the categorical distinction between MCI and AD. Yet, despite the enactment of risk in the clinic, the expansion of the disease produces discursive constructs and contradictions around the ageing process and the meaning of AD overall, which impacts how clinicians proceed with classification.

Chapter Six

Constituting the Boundaries of Classification

In Chapter Five, I captured how clinicians articulated cognitive screening tools to navigate and manage the uncertainties associated with measures of cognitive decline. I demonstrated that in the clinician-patient interaction, clinicians mediated and manipulated the tools to deal with uncertainty, which manifested threefold. First, in relation to the social and cultural discourses around mental health and AD emergent in the clinic, second, with regards to the ambiguities associated with the tools, and third, in relation to the complexity associated with categorising AD more broadly. Together these formed a repertoire of uncertainties navigated through mediation and manipulation practices performed in the clinic, which constituted the making of the tools as provisional devices *in situ*. As I demonstrated, given this provisionality, the tools were rendered portable to further account for the uncertainties produced by the arena of the clinic. The tools subsequently shifted between different settings and across different actors. I therefore concurred with previous literatures including the work of Berg (1996), by arguing that the tools both produced and reproduced the power relations within the organisation of the memory service. Given the complex division of labour in the memory service, however, and as the tools could be transported into patients' homes, memory nurses were able to carve out a unique space for professional practice. They attached significance to what was socially and culturally significant for constituting cognitive decline. In order to proceed with classification however, this work was collated in the MDT for adjudication by consultants.

In the final section of the chapter, I captured how clinicians proceeded with classification; balancing the formal practice of the tools and their quantified outcome, alongside the informal practices witnessed in the clinician-patient interaction. In doing so, I developed the work of Berg (1992) arguing that whilst clinicians reconstructed the data to 'fit' their clinic work, for AD, the locally situated routines Berg describes were more complex than originally

assumed, as they continually underwent adjustment by clinicians to navigate and manage emergent complexities. This occurred both within the clinic and in the corridors and offices of the memory service: producing and reproducing the professional hierarchy. Overall, the portability of the tools as they shifted across a complex distribution of medical practice, enabled the classification process to proceed beyond recursive routines performed ‘habitually’ (Berg, 1992: 170).

In the following chapter, I explore how clinicians approach and use cognitive screening tools to negotiate the boundaries of classification in the organisation of the memory service. I argue that the enactment of risk and complexity in the clinic which blurs the boundaries of AD, creates a space where patients are kept on for review (Latimer, 2013); there is the possibility that patients may go on to develop the disease. I therefore argue that the imprecise and uncertainty in the clinic is mobilised, utilised and valued by clinicians (c.f. Latimer, *et al.*, 2006, Latimer, 2013). The uncertainty, which drives this space for review and deferral¹⁹, can be characterised twofold. First, the patient may be deemed complex or risky due to physical or mental health concerns complicating the classification process, and second, the ‘messy’ patient narratives and results from cognitive screening tests do not necessarily fit neatly into a pre-defined AD category (Manning, 2000). I thus illustrate that cognitive screening tools play an important role in mediating and constituting the boundaries of AD. To demonstrate this, I focus on the significance of the borderline score, which is mobilised by clinicians for keeping patients on and creating a space for deferral, where the score is made portable across to neuropsychology.

Subsequently, a borderline score also drives clinicians’ employment of the label Mild Cognitive Impairment (MCI), where I argue that constituting the boundaries of classification has the potential to ‘problematise’ ageing. The ‘diagnostic creep of Alzheimer’s’ to include MCI (Beard, 2012: 12) has

¹⁹ I use the term ‘deferral’ to draw attention to both the theory of Latimer’s work on deferral processes in the clinic, and to denote those patients who are referred to neuropsychology, reflecting the theoretical or conceptual position of the chapter overall.

repercussions for the ways in which patients conceive diagnosis and ageing overall, and shifts the ways in which clinicians approach the tools and therefore the boundaries of AD constituted. The process of keeping patients on in the service is also entangled with efforts to offer those patients who are negatively affected by the possibility of a diagnosis, care-into-the-future. Extending my arguments in Chapter Five, keeping patients on in the service is not simply performed in response to the enactment of risk, but is also performed to account for those patients who may be negatively affected by the classification process and diagnosis overall.

This chapter is grounded in broader themes including risk in terms of the shifting boundaries of disease, and develops the conceptual framework of portability in two distinctive ways. First, it demonstrates the tools manoeuvrability across the fields of psychology and psychiatry and second, it highlights the movement of patients across time and space, necessary for navigating complexity, and producing knowledge about the boundaries of disease. Since the tools are enacted as provisional devices, this drives the space for deferral, constructed on particular expectations about the field of psychology for negotiating the borderlines of AD and sorting complexity. It is the perceived partiality and enacted provisionality of the tools that renders them portable as they shift from the field of psychiatry to psychology.

Navigating risks and complexity

In the first section of this chapter, I explore how the boundaries of AD are negotiated and handled across the fields of psychiatry and psychology. In doing so, I demonstrate the mobilisation of uncertainty and explore the processes which drive clinicians to keep patients on for review. Classification overall, requires compromise (Hedgecoe, 2003) particularly in relation to formally classifying Alzheimer's disease, which in itself is ambiguous and nosologically contested (Gaines and Whitehouse, 2006; Hardy, 2006). As demonstrated in Chapter Five, a categorisation of AD was difficult and involved a process of exclusion as opposed to confirmation confirmed by Consultant Psychiatrist 1 during interview, that a diagnosis is

'by definition a probable diagnosis' which as she further iterated, was a way of *'hedging your bets'*. If a categorisation of AD is therefore only ever probable, what happens to the decision making process (see Blaxter, 1978) when complexity becomes too much to sort in the clinics of psychiatry, blurring the boundaries of the condition? This is a particularly pertinent question if what is being made known is uncertain in itself, which makes determining 'tidy boundaries' as described by Cox and Webster (2012: 400) inherently difficult.

In what follows, prior to the creation of a space for review or deferral (Latimer, 2013) to psychology, I show how the enactment of complexity characterised by a risky patient, was initially sorted within the hierarchy of psychiatry. Within the clinics of psychiatry, the everyday practice(s) of clinicians as they interacted with the tools was complicated by the emergence of complexity and risk. On a micro level, the characterisation of a risky patient occurred within the clinic in two distinctive ways. First, this characterisation was based on those who had unrelated physical or mental health issues, and second, on those who scored either particularly well or particularly poorly on the cognitive screening test. This represented what clinicians conceived of as a 'borderline score', which may not reflect the patient narrative or results from other diagnostic assessments including Magnetic Resonance Imaging (MRI) or Computerised Tomography (CT) scans. Extending my analysis in Chapter Five, where I demonstrated the extent to which cognitive screening tools produced and reproduced professional hierarchies, this complexity was first 'sorted' within the hierarchy of the psychiatry team. During an interview with Consultant Psychiatrist 1, they explained how complexity was sorted across the hierarchy,

'If it's a straightforward referral with no particular issues or risks identified, then they're often allocated to one of the memory services nurses to do the initial assessment. If there's any complexity, if there's any physical co-morbidity, if there's any mental health concerns about depression for example, and also if there's been any

imaging that's been done prior to the referral, those are the patients which tend to be seen by one of the medical members of the team for assessment.'

This was illustrated further by Consultant Psychiatrist 3,

'If there's mental health issues as well, so somebody's presented to the GP, they're anxious, they're depressed and they've got memory problems, that can be a bit more difficult for a memory nurse to disentangle. They might come straight to a doctor to say to do that initial assessment but they want to try and rule out if there's an acute mental health illness that needs treating first of all, before we go down the road of a memory assessment.'

For each of the two consultant psychiatrists, patient risk and complexity was enacted in the clinic through the production of medical or mental health concerns. As they explained, navigating this complexity, which compromises the boundaries of routine, required the expertise of those occupying positions higher up the professional hierarchy. For Consultant Psychiatrist 3, disentangling the heterogeneity of patient symptoms '*they're anxious, they're depressed and they've got memory problems*' required navigation work, to '*rule out*' the possibility of other conditions. Whilst the possibility of mental or physical health concerns would be noted in the GP referral notes, this was also assessed in the clinic. During each observation of a consultation, the patient was asked directly about their mental health history; '*I'm going to ask you about your mood and mental health now*' (the patient nodded), the clinician asked, '*do you feel depressed*' (Observation Speciality Doctor 1). On a further occasion, '*I'm sorry but the next couple of questions are going to be quite dodgy questions, do you ever feel depressed?*' (Observation Memory Nurse 6). Negotiating co-existing mental health concerns, framed by Memory Nurse 6 as '*dodgy questions*', and related predominantly to depression, was a frequent topic of discussion in each of the consultations observed. I reflected during observation that a number of patients at this point of the consultation were quick to dismiss the questions,

which is perhaps suggestive of the discursive constructs around mental health that remain in existence in the general population. Resolving these characteristics of a risky patient also depended on the division of labour within the memory service. As Consultant Psychiatrist 3 explained during interview,

‘So the moments where it may come straight to a medic is if it’s urgent or if there are potentially risks. So if they’re wandering or family are under a great deal of strain, so if it needs memory nurse the waiting list is a couple of months. Whereas me, I can arrange to do a home visit which is a bit quicker.’

Demonstrated in Chapter Five, memory nurses were allocated the majority of initial consultations with patients thereby suggesting that a lack of risk and uncertainty was assumed to arise in the clinic. However, with the increasing pressures on the memory service in terms of referral rates for initial appointments, those occupying positions higher up the professional hierarchy in the memory service were becoming involved in these more routine appointments. As Consultant Psychiatrist 3 recounted, this was particularly the case if the pressure on the family was becoming difficult to manage. Therefore it was at times necessary for consultants to navigate and sort uncertainty, potential ‘*risks*’, because of the increased demand on memory nurses. However, the notion of a complex or risky patient did not end here. The enactment of risk and complexity in the clinic, at times led to a borderline score on a cognitive screening tool. A borderline score subsequently became a vehicle through which uncertainty was mobilised and indeed valued, leading to the creation of a space for deferral; a borderline score was significant for keeping patients on in the service (c.f. Latimer, 2013). This space for deferral also enacted a sense of hope for clinicians. Given that there remains no cause or cure for AD, this space was utilised to create value out of uncertainty; emerging as a space for hope for clinicians, that mobilised action rather than closed down uncertainty. Prior to demonstrating how a borderline score which institutes risk and complexity, was handled by clinicians in the medical decision making

process, the following extract summarises how the score overall, was handled across the professional hierarchy. Exploring how clinicians routinely negotiated the quantified outcome in the space of the MDT is important for considering the work that shifts when negotiating a borderline score in the division of labour in the memory service.

During an interview with Memory Nurse 3 she described how the score was negotiated in the MDT,

“Well it [the score] will be discussed at the next MDT with that consultant team and the MDT outcomes in terms of scores it might be that medically a doctor might say ‘*what was the total score*’? And then they’ll they maybe say ‘*what happened to the sub scores*’? And it might become a numbers game. And then somebody might depending on what else is happening and what other conversations it might be ‘*can I have a look to see how they did on the visual aspect*’?”

From the outset, this extract reflects the hierarchical work produced by the quantified outcome on the test. The ‘*numbers game*’ was played by professionals occupying positions higher up the professional hierarchy. In doing so, it also rendered the work of nurses visible in initial consultations, ‘*can I have a look to see how they did on the visual aspect*’? This translation work serves to sustain the professional hierarchy in the service and its ceremonial order (Strong, 1979); the work of nurses remained subject to scrutiny by those higher up the professional hierarchy. I also witnessed the ‘*numbers game*’ that Memory Nurse 3 described during observations of team meetings, the registrar or consultant steering the meeting would directly ask the memory nurse or trainee psychiatrist presenting for the ‘*overall score*’ which would then be orchestrated by the more senior colleagues in the decision-making process. This is suggestive of a collective and collaborative approach to making sense of the quantified element of the tools, and yet when risk and complexity were enacted in the clinic, this had the potential to reconfigure the quantified outcome of the tools and so create

what I conceive of as a borderline score. Clinicians managed and made sense of the risks associated with the score, as it was mobilised to create a space for deferral into the field of psychology. In doing so, the borderline score reproduced and also reconfigured the power relations within the memory service, to negotiate the boundaries of AD and proceed with the classification process.

Risk and the space for deferral

I ground my analysis of a borderline score on the theme of risk. On a macro level, there is widespread agreement that the post-modern era is characterised by attempts to quantify risk, turning the ‘incalculable calculable’ (Beck, 1992). Yet for the purposes of this chapter, I frame the ‘dramatic shift’ of risk in the arena of medical practice, at a local level within the clinic (see Almeling and Gadarian, 2014: 482). I draw on the claims of Armstrong (1995) who contends that the shift in risk thinking is represented by a move from ‘hospital medicine’ where individuals were treated according to manifest pathologies, to ‘surveillance medicine’ and the monitoring of those who are deemed to be ‘at risk’ of potential pathology.

Grounding this chapter in risk therefore ignites debates around the boundaries and categorical distinctions between health and disease. The boundaries of disease become blurred as risk emerges as a mechanism through which bodies are constructed as having the potential to become ill (Ibid.); normality becomes ‘problematized’ (Armstrong, 1995: 482). Commentators have drawn attention to how people experience medical risk (see Edwards, *et al.*, 2008; McBride *et al.*, 2010), with scholars such as Armstrong (1995), Novas and Rose (2000), Rose (2007b, 2009) and Clarke *et al.*, (2010), theorising on the role of risk in the constitution of self and daily life, described as ‘somatic citizenship’. As societies become increasingly biomedicalised and thus technoscientific and ‘risky’, this encourages individuals to identify and inscribe themselves through increasingly technoscientific means (Clarke *et al.*, 2003). The ‘self’ in all its regimes and responsibilities, is reconfigured as individuals construct

themselves as ‘enterprising’ and autonomous individuals for deciding their own life course. Whilst the notion of somatic citizenship is not the primary focus of the following analysis, the concept is important for developing the claims I make further in the chapter around the consequences of the problematisation of ageing. Discursive constructs around the ‘successes’ of ageing, encapsulate the idea that we are autonomous individuals responsible for how we grow old, and therefore the extent to which we are ‘at risk’ of developing diseases associated with old-age such as AD.

Aside from concerns about the experiences of risk and the healthy population, commentators have also drawn attention to the convergence of the boundary between risk and chronic disease: the experience of being at risk, and the disease itself (Aronowitz, 2009). In terms of medical knowledge, medical science, and medical technology, commentaries on risk and uncertainty in health also claim that medical science emerges as a site for uncertainty and risk (Webster, 2002); medical technology and knowledge advancement means we are less able to tolerate clinical uncertainties (Fox, 1980; Crawford, 2004), and risk and uncertainty drives societal responses to, and experiences of, contested illnesses (Hayden and Sachs, 1998; May, 2000; Nettleton *et al.*, 2004, 2005; Nettleton, 2006).

Notwithstanding the idea that innovative technoscience enacts risk and shifts the boundaries of disease, this chapter troubles dominant constructions of risk, by exploring the power of low-technological tools for constituting the boundaries of AD. As demonstrated, cognitive screening tools as mundane technologies, were utilised to constitute the boundaries of AD; built in part around the expectations associated with the technologies in the field of psychology. In the latter part of the chapter, I also show how the problematisation of ageing, shifted how clinicians approached and therefore constituted the boundaries of AD, and employed the label MCI. Keeping patients on for review was not simply a matter of making sense of risk and the extent to which patients may go on to develop AD, but also about making sense of the contradictions around risk, age, the process of ageing and AD. The enactment of risk and the expansion of AD, have the potential

to problematise normality, which as I demonstrate, had important implications for the ways in which clinicians approached classification practices.

Initially, I illustrate the ways in which risk as enacted in the clinic, was mobilised by clinicians to create a space for deferral to neuropsychology (Latimer, 2013). What Latimer (2013: 103) describes as the ‘imprecise’ or uncertainty in the clinic, was driven more broadly by the emergence of increasing levels of risk. Rather than disposing with a borderline score and therefore uncertainty, the clinic emerged and was ‘equipped’ to manage uncertainty; transformed into a ‘space that actually thrives on the imprecise’ (Latimer, 2013: 103). As argued by Latimer, the space of deferral returns the act of decision making to the clinic and thus reaffirms the role of the clinic as a critical site for knowledge production. I extend Latimer’s claims towards the end of the chapter, as this space of deferral for AD, was both created and performed ambivalently, as I illustrate by drawing particular attention to the label MCI. The space for deferral was driven by the mobilisation of uncertainty as well as discursive constructs around ageing and dementia, which played important roles in constituting this space, and therefore the decisions clinicians made about keeping patients on in the memory service. The space for deferral was utilised by clinicians to make sense of uncertainty.

Across the memory service, uncertainty was a key characteristic of clinic appointments and team meetings as I addressed in Chapter Five. What I found particularly interesting from observing both consultations and team meetings, was that this uncertainty was utilised, mobilised *and valued* by clinicians as I witnessed during in-depth, collective discussions in team meetings, to ad hoc conversations during de-briefing consultations, and in the offices of the memory service as clinicians debated the ambiguities of the tools. This mobilisation of uncertainty was further witnessed when constituting the boundaries of classification; uncertainty and complexity were not disposed but utilised by clinicians as the following extract from an interview with Memory Nurse 1 highlighted,

‘Looking at the cognitive test I think the cut off for the ACE 111 (I’d have to look it up to know exactly) but I think it’s kind of mid 70s so if somebody’s scoring over the mid-70s out of 100 on the test, you’d be thinking is this a known dementia or is this just a normal ageing process? Sometimes only time will tell on that, sometimes you just have to go back in 12 months and see if there has been any deterioration really.’

As Memory Nurse 1 explained, the ‘*cut off*’ on the ACE 111 was a device through which the clinician could navigate and continue the classification process (Blaxter, 1978). For Memory Nurse 1, a patient scoring 70 or above on the ACE 111, did not constitute a classification of dementia but nor did it constitute processes of normal ageing; borderline in the memory service as I will show throughout this chapter, does not always have the ability to categorise symptoms as pathological (Jutel, 2009). In recognition of this, Memory Nurse 1 attested the importance for keeping patients on, ‘*sometimes you just have to go back in 12 months and see if there has been any deterioration*’. Furthermore, the tools emerged as agents of risk (Armstrong, 1995). As Memory Nurse 1 suggested, there was a possibility that patients may travel beyond the borderline, towards diagnostic closure. Arguably, this monitoring procedure serves as an extension of surveillance and the medical gaze (Foucault, 1973; Armstrong, 1995) towards those who have the potential to develop AD. This notion of keeping patients on in time resonated across the memory service, linked overall to the myriad of ways in which clinicians approached the classification process with care, as demonstrated in Chapter Five. Similarly to Memory Nurse 1, Consultant Psychiatrist 2 explained the significance of the ‘cut off’ score on the test and ascribed particular value to the role of neuropsychology when deferring patients, ‘*if they’re right on the cut off and they’re really distressed do I refer them to neuropsychology for some in-depth testing just to see actually no, this is the start of an Alzheimer’s dementia?*’ Memory Nurse 1 also reflected on the possibility that a high performing patient, who had the potential to alter the course of the tests, may require review over time for

diagnosis, in recognition of the ambiguity associated with the testing process. Importantly, these extracts point to the temporality of the classification process; clinicians took their time with diagnosis particularly when faced with deploying the label MCI. This is a point I develop further in the chapter.

As an agent of risk therefore, a borderline score prompted deferral to the field of psychology; there was a chance that patients could go on to develop AD. This space of deferral ensured patients were subsequently ‘kept on’ (Latimer, 2013) in the memory service for further investigation. I argue that this space of deferral was constructed both around the mobilisation of risk, and also around psychiatrists’ expectations regarding the field of psychology, the technologies adopted in this field, and their expertise and experience. As highlighted by Consultant Psychiatrist 1 during interview when explaining the reason for deferring patients to neuropsychology,

‘I suppose if you’ve got, so patients who’ve got, where their working diagnosis is uncertain, if they if they score unexpectedly well or poorly on a test which doesn’t mirror the history, that would potentially be a reason for sort of referring on for neuropsychological testing by our psychology colleagues.’

Consultant Psychiatrist 1 recognised that the score from the cognitive screening test may not correlate with the history as narrated by the patient. This was a point made by a number of clinicians during interview, and particularly during observations of team meetings, there were instances where clinicians would exclaim that the patient had *‘given a really good history but their test score was poor’* (Observation Team Meeting Ridge NHS Centre). As I have deduced from the interview excerpt, Consultant Psychiatrist 1 subsequently treated the quantified score as a ‘material-semiotic device’ inseparable from the practices of the clinic (Verran, 2012: 112). Rather than dismissing the situational exigencies and individual particularities (Berg, 1996; Dodier, 1998) which may have shaped the patient scoring *‘unexpectedly well or poorly’*, Consultant Psychiatrist 2

explained how these factors promoted clinicians to defer patients to psychology for further testing. However, this reflected a point of disjuncture from Chapter Five. Rather than the clinician mediating the data to fit the clinical work, on presentation of a borderline score, clinicians ‘stepped out’ of their already complex routines and deferred the borderline score to psychology for further clarification, in order to resolve the complexity associated with a borderline score (c.f. Berg, 1992). The space for deferral therefore mobilised risk and yet at the same time, was constructed around the expectations of the tools adopted in both psychiatry and psychology. There were instances where the tools used in psychiatry were not perceived to be adequately sophisticated for resolving complexity. This was confirmed by Memory Nurse 3 as she explained during interview,

‘But also with the cognitive testing there’s always those people that are in you know like the grey zone isn’t there. Sort of it’s usually if they’re getting in their 80’s [score result] and then from that it might be it might determine more neuropsychological testing it might generate another referral to psychology for further testing.’

The borderlines of classification were manifested practically in a borderline score or what Memory Nurse 3 described as the ‘grey zone’, navigated by clinicians towards deferral to neuropsychology. Here, the technology was significant for deciding how to proceed with the classification process. The ambiguity of testing, which was subjected to extraneous factors such as patient ‘distress’ or ‘functional impairment’, justified the need for the increased use of testing. Therefore when the boundaries of AD became increasingly blurred, it was further testing in psychology that was utilised to sort this complexity. The use of further testing or further technological intervention in psychology had a more enhanced role when negotiating the boundaries of classification; presumed to create added certainty. As Consultant Psychiatrist 4 further illustrated, at times, cognitive screening tools used in psychiatry were ‘enough in most cases...[but] sometimes you need some more sensitive tests and more specific tests then you need you know stronger evidence to show that there is problem with the cognitive

functioning'. The expectation was that this *'in-depth'* or *'further testing'* would order the uncertainty in the clinic. Many other practitioners expressed a similar sentiment across the memory service. There were also instances during observations where clinicians would stress to patients at the beginning of the appointment, that if there were any discrepancies about the results from the tests or *'confusion'*, they could defer patients to psychology for more *'specialist'* testing. From my own experiences of being present during observations, this is suggestive of a further caring approach to the consultation: clinicians recognised the uncertainties emergent in the clinic and the possibility of unexpected results and attempted to navigate this early in the appointment. Similarly to Memory Nurse 3, Consultant Psychiatrist 2 also recognised the importance of deferring to neuropsychology although she was careful to iterate that she had a *'low threshold for referring them [patients] for neuropsychological testing' if 'they're very distressed or there's function[al] impairment.'*

The crux of the analysis in this chapter is that uncertainty emerged as an enabling feature, which was further evidenced by Memory Nurse 1 who illustrated during interview, *'if we have somebody where the diagnosis is uncertain the test the cognitive tests and scan are giving, painting quite an unusual picture we'll often send them to psychology for neuropsychological testing'*. For Memory Nurse 1, the uncertainty of a diagnosis or *'painting'* of an, *'unusual picture'* was sorted through deferral to neuropsychology; the clinic emerged and was *'equipped'*, to manage this uncertainty. Echoing Consultant Psychiatrist 4, Memory Nurse 3 expected the tools used in psychology to more accurately distinguish and categorise Alzheimer's disease (or help distinguish one disorder from another (Dowrick, 2009)) through the increased number of tools they have in the field, *'I think psychologists have a much more sort of cognitive tools in their tool bag than perhaps nurses do'*. From the psychologists' perspective however, it was the more sophisticated or comprehensive tests used in the field, which were valued for the ways in which patients made sense of their deferral. The space of deferral and passing over the score into psychology, was important for reifying to patients that clinicians *'don't take diagnosis lightly...based*

on a sixth sense...it does give a really good platform for having those conversations' (Conversation Clinical Psychologist 3). I reflect here on the dynamics of care work embedded in consultations for *'having those conversations.'* At the same time that clinicians were actively engaged in practices which attempted to care for the patient in terms of protecting and preserving identities in the clinic, the tools were also key agents for enabling clinicians to take responsibility for diagnosis in a caring manner; confirming that they did not take *'diagnosis lightly'*. The space of deferral when referring patients to psychology was therefore constructed both on the idea that patients may go on to develop AD, but also on the expectations of the technologies used in psychiatry and psychology.

Entangled in the management of risk therefore, were the expectations associated with the field of psychology, which emerged in spite of the fact that clinicians approached and performed the tools as provisional devices in routine practice. This developed further than technological expectation however, into the expectations around the specialist expertise and skill of psychologists, which resonated across accounts with psychiatrists. Both psychiatrists and psychologists expressed the importance of specialist expertise and experience for further sorting complexity and moving beyond the borderline. As a result, the space for deferral is suggestive of the division of labour within the memory service, and concurrently, the expectations of technologies and the field of psychology, for making sense of complexity and mobilising uncertainty.

MDT: Professional roles and expectations

Keeping patients on for review to neuropsychology reflects psychiatrists' expectations about the expertise and skill base of psychologists; their ability to adjudicate on, interpret and use, both instruments for screening cognitive function, and more sophisticated neuropsychological assessments such as the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS). Psychiatrists legitimated the role and identity of psychologists in terms of 'expertise derived from job specialisation' (Sanders and Harrison,

2008: 295), purifying the field of psychology (c.f. Latour, 1993). As Consultant Psychiatrist 4 explained when asked during interview to reflect on the process of deferring patients to neuropsychology,

‘When you need detailed assessment of the cognitive domains - specific cognitive domains - then again those neuro-psychometric testing come in handy and they are not very easy to just you know conduct them you need specific training you need specific skills and the psychologists have that skills and training.’

According to Consultant Psychiatrist 4 the ‘expertise’ (Sanders and Harrison, 2008) of psychologists within the complex network of the memory service, served to sort the uncertainty and diversity that emerged in the clinic. Whilst scholars including Larson (1990) depict this space as a ‘battlefield wherein different kinds of experts fight for pre-eminence’ (pp. 35), deferral to psychology was particularly important for negotiating complexity and constructing the normal from the pathological. Psychiatrists legitimated the professional role of psychologists by referring to their expertise with regards to their ‘job specialisation’ (Sanders and Harrison, 2008: 295), *‘you need specific training you need specific skills and the psychologists have that skills and training’*. Concurrently however, psychologists were also increasingly aware of the limitations of these technologies and approached them with caution. During a conversation following a formal interview with Clinical Psychologist 1, he explained how the expertise and skill of psychologists was performed not by approaching and using the tools without question, but performed in recognition of the limitations of the tests. As he clarified,

Clinical psychologist 1: ‘I think that in the right hands those tools are very good at detecting the difference between normal ageing and pathological processes; however, in the wrong hands they’re quite dangerous. So I think that’s why a lot of the training I do is about what does this number that you got out of it mean and what

tolerances type 1 and type 2 errors associated with this age group and this this measure’.

JS: Could you elaborate on what you mean by the ‘right hands’?

Clinical psychologist 1: So I suppose what I mean by that is somebody who sees the value of doing testing but doesn’t treat it as - a somebody who’s aware of the sort of limits of the test. Does that make sense? So it doesn’t mean it’s any particular profession it means that, that person is going to place value on the results but know the limit of what those test results can tell you and also take into account all the other things so a lot of the people in the memory service are very skilled in doing this as lot of people who work in the wider Trust are very unskilled.’

Clinical psychologist 1 acknowledged that the purpose of these technologies for determining the normal from the pathological could only be realised when placed in the *‘right hands’*: those who are *‘aware’* of the limitations. As Clinical Psychologist 3 illustrated, failing to recognise these limitations produced uncertainty and complexity, *‘type 1 and type 2 errors’*, *‘dangerous’* for classification overall. Furthermore, extending the claims I made in Chapter Five, in relation to the quantified outcome on the tests, Clinical Psychologist 1 valued both the objective, standardised and quantified element of the test in terms of the ability to ‘train’ individuals to uniformly carry out and interpret the tests (a standardised array of tools could be drawn upon (Porter, 1996)) but also accepted the importance of practising professional judgement, *‘somebody who’s aware of the sort of limits of the test’*. This points to a claim that those with specialist expertise are the actors who have the authority to adjudicate on the use of the tools, and their inherent value in the classification process. This was evidenced further by Clinical Psychologist 3 who illustrated during interview,

‘Sometimes with these tools you can kind of come across as a real expert and they allow you a certain language and jargon to use if you

want to, if you choose to do that, that can kind of definitely feed in to that kind of expert position. And often the psychometrics and the statistics of it is a language that other members of the team don't necessarily speak. So people take it at face value then: yeah 'we're not going to argue with the psychologists because they clearly know what they're talking about' and don't quite understand when we go into percentiles and things like that yes. But that sounds a bit too negative and critical now because there is a place for it.'

Across the memory service, the professional expert model 'implies a covenant based on trust that the expert will act in the patient's best interest' (Timmermans and Mauck, 2005: 23). As Clinical Psychologist 3 clarified however, this covenant of trust was compromised, if psychologists exercised their professional autonomy when using the tools without recognising the limitations of doing so. Despite psychiatrists emphasising and constructing expectations around the expertise and skills of their colleagues within psychology, this may not be productive for the decision-making process overall. Reflecting on observations of both consultations and team meetings, clinicians, particularly those occupying positions higher up the professional hierarchy, continually iterated that memory nurses in particular should '*be careful*' about using the tools and drawing definitive conclusions from the results. Subsequently, the process of deferral rested not solely on the materiality of the tools, but reflected more broadly the professional hierarchy within the service; related to expertise and skill to exercise caution.

Entangled in the constitution of the space of deferral and portability of the tools to psychology, was the negotiation of the everyday, organisational life of the MDT for constituting the boundaries of disease and creating this space for deferral. As I demonstrated in Chapter Five, the MDT in the memory service was an arena for collectively agreeing about the role of cognitive screening tools, and was demonstrable of the division of labour in the memory service. When negotiating the borderlines of classification therefore, and the deferral space to psychology, how did psychologists navigate their role, and how were decisions made about moving beyond the

borderlines in the MDT? In what follows, I explore the distribution of the medical-decision making process across the MDT (c.f. Orlikowski, 2007) where negotiating the boundaries of classification was performed. As argued by Øvretveit (1993), multi-disciplinary working encourages, and offers opportunities for, collectively sharing different views and perspectives. It is therefore a space, which facilitates an independent and autonomous method for ‘doing’ healthcare (see Saferstein, 1992; Housley, 2000). Drawing on the claims of Latimer (2004) however, the question remains as to how risk and complexity were resolved in such a collaborative space? ‘When no single narrative, or actor, is explicitly invested with authority over others, how exactly do matters get settled’ (Latimer, 2004: 758)?

In what follows, I capture how cognitive screening tools and the discussion of a borderline score, were central conduits for instituting interactions, debates and negotiations between professionals within the space of the MDT. However, I demonstrate that when negotiating a borderline score, both consultants and psychologists retained their professional power by adjudicating on how the borderlines were constituted for proceeding with classification, and also interpreting or call[ing] to account the work of memory nurses (Latimer, 2004: 770). Whilst I demonstrate that ‘all members play a part’ (Latimer, 2004: 768), I extend this analysis by arguing that psychologists played an integral role in calling every actor (including consultants (somewhat unexpectedly)) into account in the MDT. Prior to the enactment of risk and deferring decisions to psychology, the process of calling clinicians to account (Latimer, 2004) was observable in routine MDT meetings as I noted whilst observing a team meeting at Nunmill Hospital,

‘The consultant psychiatrist was sat at the head of the table around which sat each member of the team. I noticed that rather than the consultant sitting with each patient’s notes, each clinician had their own pile of patient notes stacked in front of them. The consultant started the meeting by beginning with GP referrals. She asked which

clinician would like to begin and a memory nurse responded. Giving the name of the patient referred to the memory service to the consultant, the consultant entered this into the computer database, and the patient's information was displayed on the wall at the opposite end of the table for all clinicians to see. From herein, patient referrals, results from initial appointments and then diagnostic appointments were discussed, with the consultant steering the meeting, *'who's assessed patient x'*, *'are you checking their living arrangement OT 1'*, *'can you talk me through what you're doing about their falls...'*, *'could you talk me through the main problems you see from the assessment'*. Memory nurses often turned to consultants to ask *'what should be done next?'* with collaboration between memory nurses and OTs, *'I've been to see patient x in their home and do you think they'd benefit from a stairlift/memory board?'*

As I reflected during the observation, the consultant occupied a central position in sustaining the power relations in the service, which concurred with the claims of Latimer (2004). The consultant occupied the head of the table, steered the meeting, was responsible for the majority of the decision making, and called memory nurses and OTs to account, *'can you talk me through what you're doing about their falls...'*, *'could you talk me through the main problems you see from the assessment'*. This is suggestive of the division of labour in the service. However, what I also witnessed across the memory service was that clinicians occupying lower tiered positions in the hierarchy, also called each other into account as I found when observing a team meeting at Nunmill Hospital,

'A memory nurse presented the case of a patient experiencing memory problems. The memory nurse continued by questioning whether the patient's partner, who she had met in the initial consultation, was also experiencing memory problems. At this point, an OT interrupted to say that she disagreed having also met the couple in the last couple of weeks: 'from my own observations I don't think the partner is experiencing memory problems at all'. In

the end, the memory nurse responsible overall for the patient, explained that she hadn't seen the couple for '*so long*' she was perhaps missing key factors of decline and asked the OT to stay at the end of the meeting to discuss this further. I reflected at this point on whether this accounting practice would have occurred if it had been the OT disagreeing with the consultant.'

Although consultants continually called those occupying positions further down the professional hierarchy into account when negotiating evidence in the MDT, clinicians in these lower tiered positions also accomplished this accounting practice amongst one another, observable in the team meeting. Therefore whilst professional hierarchies were maintained, this was articulated across and within the hierarchy at simultaneous moments; seen here in the discussion between the memory nurse and the OT given their shared patient responsibilities. The following section therefore, addresses the role of psychologists within the MDT for negotiating risk. Whilst I demonstrate that the MDT accomplished and (re)accomplished professional hierarchy, this shifted when negotiating borderlines, and with the involvement of psychologists. When psychologists entered the space of the MDT, they played a privileged role in interpreting the cognitive screening tools used in psychiatry. As Memory Nurse 2 explained when asked about the significance of the cognitive screening scores during interview,

'We would discuss it [results from cognitive screening tests] at the MDT and we'd go through it and we have a psychologist there most of the time and he kind of picks up on things that we probably wouldn't and the medics obviously clearly see things from their angle and they know what they're looking for. If there's something out of the ordinary, then that gets picked up and discussed and we can decide where it's to go, if it's a borderline score then we look at what else we've come up with; the behaviours and how they're functioning and things like that then it might be about where do they go. So it all helps to build a picture of where the best place to meet their needs is going to be made and it could be that it just goes to a

medic and will go for a CT scan and will go for diagnosis but it could be that it goes to psychology for further testing. Or it could be we don't know what's going on here but if there's no huge risks we'll go back in six months' time and we'll see somebody again and we can compare if there's been no change we'll see what's happening and we'll bring it back then. If there's anything outstanding I just say (well or unusual) we'd pick up on that and run with that and see where we go with that.'

The interpretation of the tests was handled in the clinic as a multi-disciplinary team task. However, as Memory Nurse 2 attested, the psychologists served as the actors with the ability to navigate the complexities of the tests and their outcomes, *'he kind of picks up on things that we probably wouldn't'*. As Memory Nurse 2 noted, the technologies and their outcomes were managed and approached differently across the professional hierarchy because of the diverse *'angle[s]'* of expertise. This is of course interesting because memory nurses were afforded the responsibility of carrying out the majority of initial appointments, but recognised the limitations of their profession in being able to interpret the outcomes of the tests. Arguably, such a claim represents a form of disciplinary power (Foucault, 1973), controlling rather than coercing how *'something out of the ordinary'* was approached and organised. Clinicians utilised this hierarchical power (Foucault, 1973) to mobilise the actions of clinicians to *'build a picture'* of what was essentially a complex classification process. Within the team, the psychologist held the privileged position of interpreting and making sense of the technologies, and their inherent ambiguities and uncertainties. This privileged position was grounded more broadly in the hopes and expectations held by psychiatrists of the field of psychology as previously attested. The possibility of the uncertain or the unknown, *'or it could be we don't know, what's going on here?'* served to drive the deferral of patients to neuropsychology. Subsequently, the professional hierarchy of the memory service was sustained. The interactions between clinicians mobilised and facilitated how clinicians approached classification within the organisation of the memory

service. As such, the patient was not disposed but ordered and managed within the team, of which psychologists played an important role. The mediating and thus enabling feature of the borderline score (enacting complexity) also extended into legitimating the need for increased use of diagnostic technologies (Latimer, 2013), '*CT scan, psychology for further testing*' in order to fix a diagnosis.

At this point, I contend that at times, a borderline score did not necessarily lead to deferral in the sense that the patient was 'passed over' to psychology. Rather, in the team meeting, the psychologist adjudicated on the uncertainty produced by the test without necessarily taking over the patient in terms of caseload. The following extract suggests how moving beyond the borderlines occurred through the responsibility of psychologists when present in the MDT. As Memory Nurse 3 explained during interview,

"Psychologists at the team meeting usually take a more pro-active role in '*actually can I have a look at it Joan?*' They actually take it off me and then they sort of sift through and I - and maybe because they're more knowledgeable about it, they can sort of glean a bit '*oh I think they're leaning towards an Alzheimer's type presentation*' without actually giving a diagnosis but they may - they may sort of help to inform in terms of the - cos the next appointment is for a diagnosis so it might be and then of course you've got your bloods and then the next part you would have a CT scan so it will it will be sort of aided in formulating a diagnosis and that's usually it's usually the psychologist that would contribute that."

What is interesting is that here, the technology itself served as a central conduit for reaffirming the power relations in the service and calling to account or calling to interpretation (Latimer, 2004) the work of memory nurses '*can I have a look at that Joan?*' As such, the clinical psychologist had the expertise to interpret the cognitive screening tools used by clinicians in psychiatry. Despite the psychologist in the MDT meeting only able to speculate on the results from cognitive screening, '*oh I think they're leaning*

towards an Alzheimer's type presentation... without actually giving a diagnosis', this speculation work sustained the professional hierarchy and reflected their expert role. This was confirmed by the actions of the psychologist, in their physical handling of the test. For Memory Nurse 3, the test was also a valuable component for classification because psychologists had the expertise to handle it, *'maybe because they're more knowledgeable about it'* constructing a space for deferral in the MDT and for professional boundaries, necessary for the constitution of AD. The psychologist in the MDT held the privileged position for calling all clinicians into account. Nevertheless, observed during a consultation with Trainee Psychiatrist 3, it was not always the case that the borderlines of classification were deferred to, and therefore resolved by, psychology. Observing the consultation with Trainee Psychiatrist 3, I noted the importance of the role of the patient in determining how the boundaries of classification were resolved,

“The patient arrived at the appointment having previously had a CT scan prior to cognitive testing. One of the first questions the patient asked the clinician was to explain the result from their CT scan stating they *'know about brain shrinkage'* questioning whether *'there is any medication I can take for it'*? The clinician however, steered the consultation back to the cognitive screening test and did not answer. Following the cognitive screening test, the clinician gave the patient their score of 80/100 and explained that they had taken this score with the rest of the history as discussed at the beginning of the appointment. The clinician described what the score meant and suggested that it showed the *'start of the cognitive process.'* The clinician explained this further by saying that the patient has a *'bit of cognitive impairment but it is borderline with the cognitive testing'*. I noted at this point that the clinician did not explain the use of the term *borderline* and the patient did not press for this information. The clinician explained that taking everything into consideration from the history, what the patient and family member was telling them, the CT scan and the cognitive testing score, that it showed the start of the Alzheimer's type process. The clinician talked through

the results from the CT scan, which she had not been able to do at the beginning of the appointment, and explained that the results meant they could rule out other physical pathologies including cancer. The clinician reassured the patient that this was very positive, particularly when compared with the results from the cognitive screening test.”

Here, the significance of a CT scan and the information gathered from the cognitive screening tool produced a borderline case. The boundaries of the disease were effectively constituted as Trainee Psychiatrist 3 aligned the *‘borderline’ score, (80/100) with the clinical evidence, history, CT scan’* concluding that together this demonstrated the *‘start of the cognitive process’*. During the observation, I reflected on whether the use of the term *borderline*, for the patient was perhaps ambiguous. However, despite this possible ambiguity, the patient played a significant role in organising the process of moving beyond the *borderline score*. It was clear from the beginning that the patient was interested about a diagnosis, she continually asked questions about the results from the CT scan and therefore brought cognitive decline into a material, visual space and engaged in *‘brain talk’* (Gross, 2012: 107) for constituting diagnostic resolve. This *‘brain talk’* is a specific form of objectification of disease which in this case allowed the patient to consider the *‘what next’* in the classification process (Blaxter, 1978). However, for the clinician, the scan was used only as a prop to exclude the possibility of more visible diseases such as cancer. Subsequently, reaching diagnostic closure, the *borderline score* on the cognitive screening test, became significant for the medical decision making process. In the clinician-patient interaction, it was the patient that drove the clinician to push forward with diagnostic closure and move beyond the *borderlines*. This was further evidenced during the de-brief conversation with Trainee Psychiatrist 3 following the consultation where she elaborated on the significance of a *borderline score*,

“The clinician discusses with me the *borderline nature* of the diagnosis and goes on to explain how they have taken into

consideration the history of the patient, and the CT scan results, to come to a diagnosis. The clinician ascribes a particular meaning to the concept of borderline stating that, *'had the patient not seemed to want a diagnosis, I could have left it for about a year and asked the patient to come back for a review'*".

At times, the decision-making process in terms of what was 'done' or enacted with the borderline score, was performed at the discretion of the patient. Despite recognising that the patient could be kept on for review over time, the patient was an active participant in their diagnosis, *'had the patient not seemed to want a diagnosis'*, and steered the classification process in the clinic. The score drove diagnostic closure as opposed to keeping patients on in the traditional sense of 'review' to measure and manage cognitive decline (c.f. Latimer, 2013). Furthermore, the power relations in the clinic were exercised and mobilised towards diagnostic closure, and the patient emerged not as a docile subject (Foucault, 1973), but as an active participant in accomplishing classificatory boundaries. Whilst the patient's risk of developing AD over time, could have led to them being kept on in the service or even deferred to psychology, the appointment reflected the extent to which the patient sought legitimacy for symptoms (c.f. Nettleton, 2006) and the clinician responded accordingly. In what follows, I introduce a further dynamic of the boundaries of classification: the expansion of AD to incorporate the label MCI. I investigate the enactment of risk, which prompted clinicians to use and also resist this label in practice.

Categorical distinction between MCI and AD

In the first section of this chapter, I have demonstrated how a borderline score was mobilised to create a space for deferral in terms of keeping patients on for review, and deferring patients to the field of psychology. In this space, psychiatrists argued that psychologists, have the expertise and experience and even the 'right tools for the job' (c.f. Clarke and Fujimura, 1992), to successfully negotiate the boundaries of classification. Recognising that patients may go on to develop AD and therefore

mobilising risk, was also entangled in the expectations around the field of psychology, in terms of the technologies available, and their expertise and experience. As a result, I have captured the ways in which the space for deferral was created through the enactment of risk in the clinic driven by a borderline score, but I also illustrated that this space was constructed around the organisation of the memory service overall. Drawing on Latimer (2004), the space of the MDT was an important platform for negotiating classification, where I argued that psychologists were privileged actors within this space, for adjudicating on areas of uncertainty and complexity. Uncertainty and risk however, are also entangled with the classificatory struggle between normal and pathological ageing processes, crafted within and outside the confines of the clinic (Foucault, 1973; Canguilhem, 1978; Rose, 2001). In the following section, I subsequently investigate the category MCI as an extension of the borderlines concept, and explore the contradictions around AD, MCI and ageing, which impacted how clinicians employed the term beyond efforts to manage risk. I illustrate the processes through which clinicians utilised a borderline score to work towards labelling patients with MCI: putting a name to the evidence available (c.f. Jutel, 2011). MCI is however, a contested category in the memory service.

The expansion of the disease category to incorporate MCI is linked more broadly to efforts to increase early diagnosis rates for AD. For Alzheimer's disease, there has been increased interest in the earliest stages of the disease as it is anticipated that this will prevent the continuation of the dementia process, and for which treatment options will be most beneficial (Dubois *et al.*, 2007). Yet, with the expansion of the disease category to incorporate the earliest stages of the disease including MCI, some commentators have argued that these categories, which serve to support the work of clinicians and scientific researchers (Moreira, May and Bond, 2009), actually 'reveal increasing ambiguity rather than clarity' (Gaines and Whitehouse, 2006: 62).

First, I consider how MCI as an extension of the borderlines concept, is grounded more broadly in 'risk' which led to further complexity regarding the categorisation of AD, and constituting the boundaries of the disease in

the memory service. MCI represents and constitutes those ‘at risk’ of developing AD. As a result, it emerged as a vehicle for the management of diversity in the clinic, which was both resisted and accepted by clinicians. Broadly speaking, the advancement of high-tech medicine creates categories of ‘pre-symptomatic’ patients; there is a possibility that patients will go on to develop disease which creates a space for new forms of risk and ambiguity to emerge (Webster, 2002: 447). This uncertainty and ambiguity however, cannot be wholly attributed to the advancement of high-tech medicine in the clinic towards the production of new categories, given that diagnosis for AD relies on cognitive screening tools; low-technological and mundane tools. As a result, exploring how risk was enacted in the clinic requires, as demonstrated in the first section of this chapter, attending to the role of cognitive screening tools and the significance of the borderline score, which produced risk. Subsequently, the label of MCI ‘depend[s] on the language of risk’ (Webster, 2002: 447) both in terms of the possibility that patients may go on to develop AD, and with regards the uncertainty and ambiguity associated with the nosology of the disease overall.

Moreover, the expansion of AD to include categories such as MCI, represents what some commentators may argue is the ‘medicalisation of ageing’ or the ‘biomedicalisation of ageing’ however, I argue that clinicians were not simply passive respondents to the ‘engine’ of medicalisation. Whilst the expansion of the AD category raises questions around the medicalisation of normality, I explore the consequences of this problematisation, particularly in relation to ageing since as Rose (2007a) argues, ‘the theme of medicalisation, implying the extension of medical authority beyond a legitimate boundary, is not much help in understanding how, why or with what consequences these mutations have occurred’ (pp. 701 emphasis added). The expansion of AD to incorporate MCI, was implicit in constituting or constructing the ‘impossible expectations’ (Aronowitz, 2009: 436) around what it means to age, which shaped how clinicians negotiated the boundaries of cognitive decline and employed the label MCI. I therefore explore what prompted clinicians to label patients with MCI, and negotiate the boundaries between MCI and AD, or the

‘borders of normality’ (Rose, 2009: 77). I highlight the renewed conditions of normality where clinicians, employing the label MCI, were implicitly engaged in the construction of patients’ expectations around both a diagnosis of AD, and the ageing process, which in turn implicated how clinicians approached diagnosis in the clinic.

Initially, a borderline score on a cognitive screening tool prompted how clinicians used the label MCI. In particular, the uncertainty that arose when aligning evidence in the clinic (of which the borderline score was one component), drove the constitution of MCI in both the clinics of psychiatry and psychology. Traced from interview accounts and fieldnotes, the term MCI was predominantly used to describe a particular set of symptoms as Clinical Psychologist 3 explained, MCI is *‘a description of a presentation or certain symptoms that people present that aren’t quite in that kind of clinical diagnostic criteria of being able to call it a dementia’*. Categorising MCI from clinical dementia, was therefore determined by the presentation of a borderline score as Memory Nurse 2 attested during conversation,

‘Well I suppose when we use these tests, if somebody’s functioning wise is not too impaired, hasn’t changed that much and they get a borderline score, then you would say it’s probably a mild cognitive impairment. If they score quite low but they’re still functioning, and there’s no vascular things nothing to show on the brain scan, it’d be mild cognitive impairment but at that stage we would continue to monitor because people do tend to go on to develop a dementia and have problems trying to access things and support themselves so we would try and kind of advocate for people like that.’

As Memory Nurse 2 highlighted, a borderline score was used to navigate categorisation of MCI. If there was a lack of correlation between what was made visual through the use of brain scans and the borderline score, then a classification of MCI was produced. However, as Memory Nurse 2 clarified, this was far from a simple process, related to how the tests were interpreted by different professionals within the hierarchy of the service. A lack of

correlation between functioning and performance on the tests (representing the ambiguities associated with the tests more broadly as discussed in Chapter Five) drove the utility of the borderline score. The borderline score became and was transformed as useful (Latimer, 2013) if there was lack of correlation between patient narrative and performance on the test, which led to formal categorisation of MCI. Again, the tools acted as surveillance devices attempting to calculate the 'risk' of patients who may go on to develop AD (Foucault, 1973; Armstrong, 1995). Their position as surveillance devices through the borderline score allowed clinicians to '*monitor*' patients and keep them on within the service. Arguably, in a Foucauldian sense the clinical 'gaze' extended to include those with a borderline score who may be at risk of developing AD. The power of this particular gaze, interweaved within the networks of the organisation, produced how MCI and subsequently memory loss was approached. Yet, tensions arose since clinicians across the memory service did not uniformly approach MCI as a discrete category. As the following extract from an interview with Clinical Psychologist 1 illustrated, the bounds of AD categorisation, and thus the emergence of MCI, were 'socially agreed' (Jutel, 2011: 202), and therefore the label was contested across the service. There were a number of clinicians, who resisted MCI as a categorical label as Clinical Psychologist 1 explained,

'But we're getting more and more of that I think as people are more aware of memory and having bad memory and people think there's something wrong about that. Whereas I think in the past, so if you asked my older colleagues, one chap who recently died unfortunately, but he would, I remember a conversation with him where he was saying MCI is just a label for someone that we've always known about and is just an invention of the PhD industry of America.'

Clinical Psychologist 1's account suggests that the label MCI is broadly representative of what Conrad (2005) describes as the 'engine of medicalisation'. According to commentators including Conrad (2005),

medicalisation refers to the increasing construction of new medical categories such as Post Traumatic Stress Disorder (PTSD) and hyperactivity, for management within medical or biomedical domains. As Clinical Psychologist 1 clarified, the bounds of AD overall are socially constituted; fuelled by growing concerns within the general population about memory decline. This is driven more generally, by political and economic agendas focusing on the early detection and diagnosis of AD, to ‘manage’ the ‘risky’ ageing population. MCI as a discursive moment (Foucault, 1973) produces the current truth about memory loss *as ‘something to worry about’*. Herein, discourse constitutes a categorical distinction between memory loss, *‘having a bad memory’*, and pathological decline produced by the increasingly complex systems of knowledge production available to (re)configure normality; individuals *‘we’ve always known about’*. In this sense and broadly speaking, MCI has reconfigured normative assumptions regarding cognitive decline.

The question remains as to what extent this label was subsequently useful for sorting risk in the clinic, and whether clinicians approached the borderlines of MCI unequivocally. Although MCI configures patients as ‘at risk’, the following extract from an interview with Memory Nurse 2 showed that a classification of MCI overall, does not definitively confirm progression to AD dementia. Therefore in the clinics across the memory service, the label did not wholly ‘sort’ the risk as produced in the clinic which was a sentiment echoed by a number of clinicians. Overall, MCI enacted risk and was resisted by clinicians; they were reluctant to label individuals because of the lack of certainty associated with its progression to AD dementia. When asked to discuss the value they ascribed to the term MCI, Memory Nurse 2 contended,

‘Well personally no. I just kind of think you’re - either you’ve got a dementia or you haven’t you’ve either got memory problems that are ageing or not and at the moment if it’s not dementia it’s an ageing process ‘cause it might not turn into a dementia we know they normally do so no personally I don’t think it’s that meaningful.

People can come back and see us whenever they want but they don't need to be told they've got MCI but that's my personal view and I could be completely wrong.'

Despite recognising that the label MCI ensured patients were kept within the service, Memory Nurse 2 demonstrated ambivalence towards the label as a discrete category, which was a frequent point of observation across the memory service. Whilst it could be used to ensure patients were kept within the service, clinicians frequently noted that in doing so this was unproductive for patients in terms of disease progression and treatment options. As this extract highlighted, the label MCI is in effect redundant given that more generally, it serves little purpose in defining what Memory Nurse 2 considered to be normal ageing processes. Furthermore, despite the label MCI enabling patients to be kept within the service for review, this was resisted by Memory Nurse 2 and did not necessarily require a formal label for patients to make use of the service. The label MCI overall, is therefore performative, producing effects and consequences, which produced further uncertainty and risk; there is no definitive moment at which an individual will develop AD and this remains uncertain. A paradox thus occurred: in order to keep patients on for classification, a label need not be applied because of the ambiguity associated with its employment. A label was not required for surveillance and MCI had powerful consequences in the memory clinics; producing and constituting further uncertainty (Rose, 2001). As Clinical Psychologist 3 explained, *'although a number of people with MCI convert in having dementia, a large proportion of people that fits that kind of label of MCI do not convert to dementia. Now it's about kind of how we deal with that how much do we pathologise it or not'*. As Clinical Psychologist 3 illustrated during interview, the discrepancy between MCI and progression to AD, makes the labelling process difficult. Furthermore, MCI had important implications for the responsibilities of clinicians.

A diagnosis more generally, is used to mobilise action: resource allocation and treatment options (Jutel, 2009) however, what the following extract from Consultant Psychiatrist 3 highlighted, is that MCI may not have

productive consequences for continuing the diagnosis process beyond the clinic. For Consultant Psychiatrist 3 an ‘ideal diagnosis’ or formal label, is used to drive management and treatment of the condition for patients and family members (c.f. Jutel, 2009) but as he explained, with the label of MCI this was difficult to practise,

‘A diagnosis is given to either help the patient to understand what’s going on, deal with it and plan ahead for the future and to get treatment that would normally be the reasons why we give somebody a diagnosis so you know what you’re dealing with and you plan ahead and can get some treatment. With MCI is such a heterogeneous category, that some of these people may just have age related cognitive decline. Some of them maybe a bit physical health problems or medication issues so it may be just something that’s static as 1 in 10 will go on to progress to dementia each year, so 1 in five you’d expect half of them to go on to progress to dementia but you can’t say which will and which patients won’t. So essentially you’re giving someone a diagnosis but saying to somebody, I don’t know if this’ll get worse. It may become dementia or not, there’s no specific treatment that we can suggest other than healthy lifestyle which you would have given them anyway even if it wasn’t MCI.’

Consultant Psychiatrist 3 raised a number of important issues. Navigating the borderlines of classification manifested in the label MCI was complex and uncertain, as MCI regardless of context of use, does not have the ability to determine progression to AD. In essence, risk and uncertainty is not sorted through formal categorisation and surveillance continues. For Consultant Psychiatrist 3, it was this uncertainty, which also impinged on professional identity within the clinician-patient interaction (Goffman, 1959). As he explained, upon diagnosis, the work of the clinician is to provide possible treatment and to enable patients to ‘*plan ahead*’. Both professional identity and patient identity were therefore compromised when employing the label MCI. There is little certainty in this label for clinicians in terms of proceeding with the process of diagnosis, and little certainty for

patients in terms of prognosis. Furthermore, out of necessity regarding lack of treatment and knowledge regarding progression, Consultant Psychiatrist 3 exercised a form of pastoral power; governing the patient with MCI (Foucault, 1977). Power relations between the clinician and patient were enacted in the clinic when faced with navigating uncertainty and risk. The patient was implicitly disciplined to maintain a *'healthy lifestyle'* to ensure somatic citizenship (Rose, 2001) in the face of increasing risk and uncertainty regarding MCI. Memory Nurse 4 echoed this point during interview and suggested that the label MCI is useful for patients in that, *'it gives them [patients] that push to right, I'm gonna keep going...carry on with my knitting and the crosswords...I think it just helps people to get on, it's like if we all have a little fright you know... you think oh right, I'll cut down on this, I'll do a bit more exercise and it spurs you on a little bit, the same is for MCI.'* Herein, the label MCI is useful for governing the patient's own sense of self in terms of healthy or unhealthy lifestyles; to keep their brain engaged with activities such as crosswords. This was illustrated similarly during a number of observations and interviews. During an interview with Memory Nurse 7, she explained that often those patients who completed crosswords or puzzles would *'seem to fair very well when they're completing a lot of these tests and see it quite often as a challenge they quite enjoy doing'*. Throughout an observation of a team meeting at Ridge NHS Centre, the clinician suggested that the patient liked *'to do puzzles and crosswords and actually I think they see the cognitive test as a 'bit of a challenge' so I thought they would probably do quite well.'* Arguably these observations correspond with what Beard (2012) claims is the *'heightened sense of value imposed on brains, mind and sentience in western societies'* which demonstrates how processes of medicalisation have led to what he describes as *'existential angst'* in individuals with the potential to develop AD (pp. 13). The label MCI therefore, produces particular contradictions around age, ageing and AD, which had important implications for its use in practice, as the following analysis contends.

Contradictions and expectations: age and MCI

Here, I extend my analysis of the label MCI and the management of risk, where I consider the contradictions around the distinction between AD and MCI. I found overall, from carrying out my research in the memory service, that distinguishing ageing processes from MCI was a complex and entangled process of accounting for risk, and also negotiating the negative discursive constructs around what it means to age and age successfully.

As Consultant Psychiatrist 3 explained during interview,

‘Mild cognitive impairment is ill-defined. There’s no clear borderline between dementia or MCI and ageing and sometimes the temptation is we want a diagnosis, MCI is an easy diagnosis, it’s not quite dementia. But, so a lot of people do get a diagnosis of MCI that may just have normal age related cognitive decline. It’s more a formal diagnosis rather than just saying it’s just your age which families, patients, GPs if they’re worried to come to the GP and they come back ‘oh this just seems to be your age’; so even though it’s possibly an arbitrary distinction between early MCI and age related cognitive decline I think you might veer towards calling it MCI, it’s that distinction.’

As Consultant Psychiatrist 3 illustrated, the bounds of classification with respect to distinguishing ageing from MCI and then from dementia, was complex and uncertain. What Consultant Psychiatrist 3 recognised however, is that classification is performative. Despite there being little certainty associated with its employment as a label, the effects and consequences of using it as a discrete category, is what prompted clinicians to label patients with MCI. As Consultant Psychiatrist 3 explained, clinicians were driven at times to formally categorise patients with MCI as a ‘*formal diagnosis*’ to discursively distinguish MCI from processes of ageing. Herein, the ‘monster’ of old-age (Canguilhem, 2008) was tamed; there emerged a categorical

distinction between pathology and ageing, therefore reconfiguring ‘normal’ ageing processes. However, it was Consultant Psychiatrist 3’s reference to MCI as an, ‘*easy diagnosis*’ which I found particularly interesting. Rather than it being a label for managing risk or the ‘at risk’ label, it problematises ageing, since patients who were worried about their memory, sought diagnostic answers and for which MCI was therefore useful. Here MCI was perceived to be less threatening compared to dementia, which drove its employment as a label. Paradoxically, as I will go on to show, such actions by clinicians reinforced the constructed distinction between successful and unsuccessful ageing processes, as a consequence of efforts to medicalise later life (Estes and Binney, 1989).

Furthermore, the label MCI illustrated a semantic shift between MCI and dementia more broadly; clinicians utilised the label MCI as a way of categorising pathology without employing the label dementia, ‘*I think the temptation for some people is they use it [MCI] ‘cause they don’t want to say you’ve got dementia and then people miss out on an early diagnosis*’ (Conversation Consultant Psychiatrist 2). At times clinicians sought to distinguish between AD and MCI to avoid ‘ascribing the associated spoiled identity’ of AD (c.f. Goffman, 1963). This was evidenced further during an interview with Memory Nurse 1 when she was asked to reflect on the usefulness of MCI as a label,

‘I think it might be quite intimidating for people. I guess from my perspective when we know what it is, you know we think it sounds relatively benign compared to Alzheimer’s disease but I bet if you gave somebody that diagnosis, they wouldn’t like it really but if you could explain to them what it is then that’s probably, I do think it is a useful diagnosis definitely.’

Memory Nurse 1 highlighted a number of important points. First, she recognised that MCI as a discrete category may have important consequences for patients. Second, Memory Nurse 1 recognised that semantically, the label MCI enacts different consequences for patients than

the label AD. She noted that a diagnosis of MCI was at times useful for patients since its label had more ‘benign’ consequences than perhaps Alzheimer’s disease. As a result, this impacted how clinicians approached the labelling process, as Consultant Psychiatrist 2 attested; some clinicians may not ‘*want to say you’ve got dementia*’. In turn, the label MCI employed by clinicians, may not map onto how patients conceive the meaning of the label and *vice versa*, which had the potential to make the diagnostic process further complex and uncertain. Arguably, this corresponds with Aronowitz’s (2009) claims that the experience of risk and disease overall, converge; to what extent does MCI put a ‘veneer of optimism onto the expanded groups identity’ (Aronowitz, 2009: 436) and thereby create impossible expectations around what it means to age and also develop AD? The contradictions between MCI, AD and ageing had important implications for constituting the boundaries of AD through the label MCI since, a diagnostic label and classification of MCI, was driven by cultural expressions in the memory service of what, or who, should be regarded as normal or pathological (Rose, 2001; Canguilhem, 2008). These cultural expressions were implicit in constructing patients’ expectations around ageing, MCI and therefore AD. As I reflected when observing consultations and carrying out interviews across the memory service, these expectations were constituted in terms of particular expectations of decline related to decline in standards of activities of daily living, and of performance of cognitive function related to age and ageing more generally. During an interview with Consultant Psychiatrist 2, she explained,

‘So I think in the older old age ‘appropriate cognitive decline’ as I call it, or normal ageing, is much easier sometimes to explain than MCI and often I probably wouldn’t say to somebody in their 90’s, they’ve got MCI, if they’re independent in all activities of daily living with short term memory loss...If somebody was 70 with MCI, I would be much more likely to - I wouldn’t give them the option not to come back for follow-up.’

For Consultant Psychiatrist 2, *'appropriate cognitive decline'* was dependent on age. Thus she configured 'normal ageing' in relation to performing activities of daily living and remaining an independent and therefore, responsible somatic citizen (Rose, 2001) which drove how she classified individuals with MCI. As a result, the employment of the label was reconfigured across particular age groups, which highlighted the significance of age as a factor when constituting the boundaries of classification. What I found particularly interesting during observations of consultations, was that patients and clinicians overall, were less concerned about increasing age and the risk of AD: the older the patient the more normal the symptoms. Herein a contradiction emerged; whilst the ageing population was a significant risk factor for developing AD, this was contradicted by clinicians and patients within the clinic, as I reflected during observations of consultations.

“The consultant asked the patient about previous mental health history and family mental health history, at which point the family member in the consultation stated that the patient’s sister had been diagnosed with AD before she died. The clinician asked the patient, *'what age was your sister diagnosed with AD'*? The patient replied, *'in her 80's'*. The clinician seemed relieved at this point and exclaimed *'oh it wasn't early AD then, that's ok'*. I made a note at this point reflecting on my surprised at this contradiction around increasing age and the normalisation of AD. I reflected on whether this would affect how the patient from herein, conceived the relationship between ageing and AD (Observation Consultation, Consultant Psychiatrist 4).”

“The consultant asked the patient about memory loss and the types of symptoms they were experiencing at which point the family member interrupted, *'she is 80, I just put it down to old-age'* to which the clinician did not respond (Observation Trainee Psychiatrist 2)”.

From these observations, it would appear that older age was mobilised by both clinicians and patients as an important component for *normalising* memory decline in the older population. I reflected during the observation with Trainee Psychiatrist 2 on the opportunity that the clinician had to mediate the family member's response since I noted throughout this appointment that both the patient and the family member were visibly anxious, both attempting to normalise the types of symptoms the patient was describing. Age overall, therefore played an important role in constructing or driving the borderlines of classification.

Borderline and the 'Third and Fourth Stages of Ageing'

In the final section of this chapter I develop the notion that, 'to classify is human' (Bowker and Star, 1999: 1); classification in practice shapes and performs how we live (Hacking, 1996). As such, not only were clinicians faced with navigating how normalcy and pathology in medicine classifies AD but they also navigated the discursive entanglements of normalcy regarding the ageing process: how patients conceived the nature of growing old. Such classificatory struggles were enacted and performed both within and outside the clinic. In the clinic, professionals mobilised social and cultural practices and discourses related to how dementia and ageing were conceived within the general population. This was particularly important for a nosologically contested disease such as AD, where uncertainty is a dominant feature of classification.

In what follows, I extend my analysis of how the boundaries of classification were constituted and diagnosis resolved. As discussed in Chapter Five, clinicians did not solely utilise the score of cognitive screening tests to navigate or 'sort' a classification (Bowker and Star, 2000) moving back and forth between different forms of evidence. As a result, whilst I have demonstrated the role of cognitive screening tools as central mediators in the constitution of boundaries and diagnostic closure, I extend this focus by attending to the emergence of particular social and cultural

discourses, around ageing and dementia, which impacted how diagnosis was approached and performed. In the clinics of the memory service, ageing was discursively constructed by patients, which had the potential to drive the classification process as Trainee Psychiatrist 2 described when asked about the nature of the borderline score,

‘There’s a real danger of just sort of pinging everybody off for a CT head particularly the ones who are actually maybe have slightly less cognitive impairment, and the maybe more higher functioning, and a little bit more affluent. They’re quite intelligent and they push for it but you really sometimes need to be quite firm, but reassuring with them, that it’s a normal age related cognitive decline and there’s nothing really kind of acute going on’.

For Trainee Psychiatrist 2, there was the possibility that a borderline score enacted what was constructed across the memory service as, *‘normal age related cognitive decline’*, which was at times, resisted by patients. Categorising patients as *‘quite intelligent’* for Trainee Psychiatrist 2, enabled patients to request further evidence to confirm, clarify and make sense of their experiences. As a result, the discursive boundaries between ageing and cognitive decline were constituted; patients were reluctant to ground their experiences in *‘normal age related cognitive decline’*. Here, the patient emerged as an active participant in the process of navigating the boundaries of classification and sought legitimacy for their symptoms (c.f. Nettleton, 2006). Moreover, the following extract from an interview with Clinical Psychologist 1 illustrated that whilst recognising that diagnosis overall, is a discursive and arbitrary distinction between normal and pathological ageing processes (particularly because things could always be otherwise), this may not be useful for the patient.

“I will usually spend an amount of time talking with them about trying to help them understand and make sense of, *‘ok we’re saying there’s nothing wrong but you’ve felt there was so why is that’* and so sometimes that’ll be saying to someone, *‘look the scores you’re*

getting are not in the clinical range but maybe there's some maybe there's a little bit of a drop off in this compared to where you were you might have been and that may just be ageing and you may just be noticing normal ageing.”

As Clinical Psychologist 1 explained, during the clinician-patient interaction, navigating the discursive boundaries between normalcy and pathology was reflected not merely in the production of a diagnosis but also the discourses, which constructed how ageing and cognitive decline were approached. In this instance, reassuring the patient that *'there's nothing wrong'* required navigating how the patient conceived the nature of growing old without cognitive decline. As Rowe and Kahn (1997) contend, successful ageing is constructed and equated with physical functioning, low risk of disease, and engagement in society in the continuing acquirement of Bourdieu's notion of social and cultural capital. Broadly speaking, normality and the monster (c.f. Canguilhem, 2008) are reconfigured in relation to how ageing is perceived and classified more broadly; there is an intense classificatory struggle between how ageing is constructed as a success or failure, marked by decline in cognitive function. Yet in the memory clinics, attributing cognitive decline to pathology was what legitimated patient symptoms beyond that of 'normal' ageing which reinforced the claim that positive or successful ageing is built on a discursive oxymoronic notion that to age successfully is to resist ageing (c.f. Torres & Hammarström 2006). The antithesis of such a claim however, is that increasingly, individuals embrace a cultural notion of ageing that is defined by the choice to grow old gracefully; recognising and actively engaging with ageing and all it encompasses (see Fairhurst, 1998; Hurd Clarke, 2002).

Subsequently, clinicians were faced with navigating how patients conceived and approached the boundaries of classification and diagnostic closure. This was reflected in how patients perceived dementia as successfully or unsuccessfully ageing: the extent to which a diagnosis represented an endemic fear of ageing (Gulette, 1998). Across the memory service there were instances where diagnosis represented a discursive shift from the third

stage of ageing into the ‘black hole’ of the fourth stage of ageing (c.f. Laslet, 1991; Twigg, 2006; Gilleard and Higgs, 2010). Clinicians working in the fields of psychology and psychiatry across the memory service recognised that there were ‘powerful assumptions’ (Gilleard and Higgs, 2013: 369) about ageing and AD that resided in the population, which had the potential to infiltrate the practices of the clinic and the clinician-patient interaction (Goffman, 1959). Clinicians across the memory service recognised the extent to which patients performed or accomplished the boundaries between normalcy and pathology, which was driven by assumptions more broadly as to what a diagnosis of dementia might represent. In particular, this shaped how the body with dementia and ‘self’ was perceived, presented and in turn constituted (Goffman, 1959). During an interview, when asked about the consequences of an ageing population, Consultant Psychiatrist 1 explained,

‘The consequences for patients are obviously that more of them will either personally experience a dementing illness or know someone that has. There is still an awful lot of stigma in the population generally and amongst individuals as to the nature of it [AD dementia], a lot of fear. A lot of our patients will have had you know family members who historically would have had dementia when they’d have had a very potentially, very negative experience of what it was like in the age of institutional care and lack of any cholinesterase inhibitors or other treatments. So there’s still a reticence I think for people to come forward.’

Consultant Psychiatrist 1 suggested that whilst diagnosis rates may increase given the ageing population, this may not be a simple process involving patients actively seeking diagnostic answers for their symptoms. There has been an assumption thus far in my analysis, that patients are active agents in the classification process, willingly referring themselves for testing and potential diagnosis. Yet, as Consultant Psychiatrist 1 explains, this did not always appear to be the case. At times, patients were unwilling to present with symptoms, in part because of the assumptions about dementia, which remained in existence across the population. Consultant Psychiatrist 1 coded

these assumptions in relation to archaic approaches towards mental health generally and care, the '*age of institutional care*' which produces and enacts '*fear*' of stepping into the 'community of otherness' (Gilleard and Higgs, 2013: 368); a state of becoming which lacks agency, choice and autonomy.

As Consultant Psychiatrist 1 suggested, the '*nature of it*' is uncertain and classification is bound in historical assumptions about what it means to develop the condition. The fear of the 'senile other' or the symbolism of senility (Isaacs, Livingston, and Neville, 1972) (related to dementia and old age more broadly) had the potential to drive the extent to which patients '*come forward*' for potential classification. The fear of the unknown, and the uncertainty associated with AD dementia more broadly, therefore had the potential to compound the assumptions of the 'social imaginary' of the fourth stage of ageing (Gilleard and Higgs, 2010, 2013); to push forward with diagnostic resolve, required acknowledgment of what testing cognition means for patients. In navigating this discourse however, there were a number of moments where clinicians actively resisted the ways in which dementia was discursively represented by patients. When discussing how patients approached diagnosis, Clinical Psychologist 1 explained,

“I think people don't understand it and I think people think about it in terms of being mental I saw a chap before you came in and he said '*am I mental?*'? You know and of course that's not what I'm looking at ever really so I think there's a lack of there's just a general lack of understanding I think, people's experiences of dementia is usually of their older relatives who were treated quite poorly.”

For Clinical Psychologist 1, dementia as a classification overall, is misunderstood and misrepresented, driven by archaic approaches towards mental health '*am I mental?*' and historic depictions of old age, reinforcing the symbolic power of the state of 'senility' (Gilleard and Higgs, 2013: 373). This reflects what Gilleard and Higgs (2013) contend is the re-emergence of senility. Patients have experienced relatives metaphorically passing through into this fourth state and subsequently fear the 'community of otherness'

that this represents (Gilleard and Higgs, 2013: 368). For those patients who do *'come forward'*, these powerful assumptions are brought into the clinic, which has the potential to affect the practices of classification. As Consultant Psychiatrist 1 described when asked about how these assumptions may affect the clinician-patient interaction,

“There can be a tendency to minimise symptoms - that’s either conscious or a subconscious one- because of the fear you know, *'you’re going to put me in a home, you’re going to send me off to some institution somewhere or other'*, so that’s definitely a factor.”

As Consultant Psychiatrist 1 suggested, the patient has the potential to drive the consultation, *'minimise symptoms'*, since perhaps a diagnosis represents an imaginary of being, restrained from exercising agency and therefore making choices specifically about care (c.f. Gilleard and Higgs, 2010, 2013). Although Consultant Psychiatrist 1 contended that such assumptions encapsulate historical representations of care and institutionalisation, care homes remain a space or *'void'* (although less distinctive as an institution), *'every bit as terrifying as the workhouse and its infirmaries'* (Gilleard and Higgs, 2010: 126). It is the irreversibility of the process both practically and conceptually speaking (entering the care home and the *'black hole'* of the imaginary of the fourth stage of ageing) that signified for Consultant Psychiatrist 1, why patients were often reticent to divulge their symptoms, *'you’re going to send me off'*, *'beyond any chance of return'* (Gilleard and Higgs, 2010: 125). Tracing observation fieldnotes, there were moments where I observed patients and family members actively attempting to minimise or normalise symptoms and make light out of what was clearly an incredibly anxiety inducing process. Throughout appointments, patients would continually stress how much they could remember about their life, and patients would recite rhymes or poems when asked about their memory to grasp onto their ability to remember; inextricably linked to their identities and selves. As a researcher present during these moments of interaction, I found this particularly difficult to observe, and which I made a clear point for reflection in my fieldnotes. The negative discursive constructs around

ageing and AD dementia, affected diagnostic resolve particularly for those patients caught in the borderlines between normal ageing, MCI and AD.

For Clinical Psychologist 1 however, whilst recognising that patients may approach the meaning of diagnosis with preconceived ideas about ageing and dementia, he challenged these assumptions in an attempt to (re)affirm and (re)construct the agency of individuals diagnosed with dementia. As he explained,

‘I think psychologically people find it very difficult to value the experiences of someone with dementia as much as they would value the experience of somebody who’s a top athlete. Ok so but who’s to say that this next moment of this person with dementia’s life is of any less value than the next moment of Cristiano Ronaldo’s life? You know and it’s that sort of it’s that I think where greater value is placed on certain people’s lives and experiences whereas, yes you may have dementia but that doesn’t mean that you don’t enjoy playing with a doll let’s say even though you’re 90. Or that you don’t enjoy having your hand massaged or held - you may not enjoy or be able to write a novel like you did when you were 50 but that’s not - do you know what I mean?’

For Clinical Psychologist 1, due to a broader commitment to fitting a classification, the experiences of individuals with dementia are often neglected. As a result, the discursive distinction between unsuccessful and successful ageing processes, and henceforth the discursive dichotomy between the third and fourth stages of ageing (Gilleard and Higgs, 2011) requires due attention for how it might impact the management of individuals with dementia. Perhaps what Clinical Psychologist 1 is also pointing to, is the idea that ageing and in this case, dementia, can in some sense be performed. Despite Schwaiger (2006) drawing attention to the performance and perception of old-age more broadly, as Clinical Psychologist 1 contended, *‘playing with a doll’* for individuals with dementia could (re)perform how ageing and henceforth dementia is

conceived more generally since ‘ageist perceptions of older people can be changed over time by the ways in which people perform age’ (Schwaiger, 2006: 31). In constituting the boundaries of classification and working towards diagnostic closure, requires not simply the role of techniques, technologies and professionals but recognising and actively engaging with expectations around AD, dementia and ageing and the ways in which they are discursively constructed in the general population more broadly. In the following chapter, I extend this theme of expectation. I demonstrate that navigating expectations of a future with AD in the clinic, was constrained by particular representations of the future constituted by the National Dementia Commissioning for Quality and Innovation Framework (CQUIN), which aims to detect AD at earlier stages to manage the risks associated with the growing ageing population.

Summary

In this chapter, I have attempted to capture the points at which complexity and uncertainty became difficult to resolve in the clinics of psychiatry, and for which making decisions regarding diagnosis was therefore increasingly problematic. I explored the dynamics of clinical practice, which shaped how the borderlines of AD were conceived, constituted and performed. As a result of increased complexity in the clinic, which was manifested in complex patients and borderline scores on cognitive screening tests, the boundaries of classification became increasingly blurred and thus difficult to constitute. I illustrated the extent to which cognitive screening technologies were central mediators in both producing this complexity, and also driving how clinicians responded to this complexity through attempts to sort uncertainty in the field of psychology.

I began this chapter by identifying the enactment of risk and uncertainty in the clinic that constituted the boundaries of classification. The production of a borderline score, which enacted risk and complexity, was mobilised by clinicians across the memory service (c.f. Latimer, 2013) driven by the possibility that *in time* patients may go on to develop AD. Drawing on the

work of Latimer (2013), I showed that the creation of a space for deferral and keeping patients on within the service was driven by the mobilisation of uncertainty. However, I developed Latimer's claims to argue that this space was performed ambivalently, particularly when employing the term MCI. Troubling dominant constructions of risk, I captured the role of the mundane for shifting and thereby constituting the boundaries of classification demonstrating the expectations around the field of psychology for resolving complexity. On presentation of a borderline score, psychologists in the MDT emerged as important actors for sorting the complexity and moving patients on beyond the borderlines. The space for deferral was built on both the technologies available in psychiatry and psychology and the expertise and experience of psychologists; perceived to sort the ambiguities associated with a borderline score. The space for deferral was therefore an MDT occasion. I developed the claims of Latimer (2004), to highlight that the MDT retained its hierarchical power as psychologists held a position of privilege during the MDT, for negotiating complexity. In doing so, constituting the boundaries of classification was at once a technological endeavour for mobilising risk, and an endeavour, which reaffirmed professional responsibilities and hierarchies.

The second section of the chapter explored the boundaries of classification through the employment of the label MCI. I extended the idea that the borderlines of classification were instituted by risk and uncertainty (Rose, 2001; Webster, 2002) by analysing the contradictions in the memory service around age, ageing and AD. Clinicians approached the term MCI ambivalently; they recognised that the problematisation of ageing and keeping patients on for review, constructed particular expectations around the ageing process which as I observed in the memory service, was difficult to navigate in the clinic. I therefore considered the consequences of the role of broader networks of power such as the problematisation of normality (Armstrong, 1995; Conrad, 2005), accomplished in the intricacies of the memory service. Constituting the borderlines through the label MCI, involved managing the expectations of patients in terms of the constructed successes or failures of the ageing process (Gilleard and Higgs, 2010, 2013).

Clinicians mobilised a borderline score within the powerful yet productive hierarchy of the service, acknowledging that MCI is a contested label, and that it has the potential to constitute discursive entanglements of ageing and dementia represented in the wider population. Overall, within this chapter I have demonstrated the ways in which uncertainty was mobilised and valued by clinicians through the space of deferral. In order to make sense of uncertainty, the space for deferral performed a sense of hope for clinicians; uncertainty was not disposed but emerged as an enabling feature of the classification process because of the lack of diagnostic resolve.

In Chapter Seven, I extend the theme of risk by exploring how increased efforts to detect AD in its earliest stages, translates into everyday clinical practice. I analyse the extent to which, the CQUIN as a particular enactment of the future with AD, shifts the temporality of classification as mapped across Chapters Five and Six necessary for navigating and managing uncertainty and complexity.

Chapter Seven

The Dementia CQUIN: Time, Futures and Expectations

In Chapter Seven, I develop the theme of risk introduced in Chapter Six. I extend my analysis of the management of uncertainty by investigating the role of clinical governance initiatives such as the National Dementia Commissioning for Quality and Innovation Framework (CQUIN), which attempts to improve diagnosis rates for Alzheimer's disease (AD) in secondary healthcare. I explore the CQUIN as a device, which aims to improve diagnosis rates and therefore manage the risks associated with the ageing population, through the promotion of early diagnosis. Overall, this chapter captures how the CQUIN translates into everyday clinical practice, and investigates the extent to which it has the potential to shift the current classification practices mapped in Chapters Five and Six. I begin the chapter by framing the CQUIN as a clinical governance initiative, which I argue has the ability to constrain clinical autonomy in the hospital setting (Rose, 1998); recognised by information managers and clinicians in my study. I continue, by exploring the extent to which the CQUIN alters the content of work in the hospital setting, where I describe the points at which the framework shifts the way clinicians approach cognitive decline, and consider the impact that increasing referrals might have on memory service practice.

Given the uncertainties associated with current practice for diagnosing AD, described throughout this thesis, the CQUIN attempts to manage uncertainty by controlling diagnosis rates. This according to Nelis (2000) is 'likely to prompt action which anticipates specific futures' (pp. 210). The majority of this chapter therefore, extends the body of literature on risk and clinical governance, by demonstrating that as the CQUIN attempts to calculate risk and therefore manage uncertainty, it performs and enacts a particular construction of the *future* with AD. In doing so, it shapes how the patient pathway is performed. Rather than predicting what the future might bring in

terms of the CQUIN, I explore how its principles are performed in the present through an investigation of its translation in everyday clinical practice. Therefore, drawing on the analytical perspective of the sociology of expectations (see Brown, Rappert and Webster, 2000; Michael, 2000; Brown and Michael, 2003; Borup *et al.*, 2006; Selin, 2006)²⁰, I question the extent to which the ‘future is mobilised in real time to marshal resources, coordinate activities and manage uncertainty’ (Brown and Michael, 2003: 2). The future depends on particular representations of time in the present, which has important implications for managing and navigating uncertainty and the patient pathway for AD.

As I will go on to highlight, the implications of the CQUIN’s particular enactment of a future with AD, in everyday practice, manifest in two distinctive yet interrelated ways. First, it impacts the patient pathway post-diagnosis in terms of resource allocation, and second, it affects patients’ expectations around a future with AD, producing uncertainties with respect to the meaning of diagnosis overall. This is an argument I have made throughout my thesis. In Chapters Five and Six I captured the mechanisms for managing uncertainty in the clinic, related to particular representations of time and therefore realisation of futures, which were constituted in the clinic. In Chapter Five, I showed how clinicians mediated and manipulated cognitive screening tools to deal with the uncertainties around measures for cognitive decline. This included navigating how patients understood their future selves and the meaning of diagnosis more broadly. In Chapter Six, I demonstrated that when constituting the boundaries of classification, clinicians often retained patients into the future for possible classification. This was driven in part by the *expectations* patients themselves held about their future selves, and the ageing process overall. With this in mind, the hopeful discourse around early diagnosis, which the CQUIN institutes, is designed to help patients to prepare for their future. In the final section of

²⁰ As I will discuss further in Chapter Eight, whilst the analytical perspective of the sociology of expectations is predominantly concerned with emerging innovation, I apply the principles of this analytical standpoint to exploring the myriad of ways in which the CQUIN as a more mundane technology, might shift the temporalities of classification in terms of the futures of an ageing population.

the chapter, I argue that this hopeful discourse may in fact construct patients' expectations about a future with AD and produce particular uncertainties for them in the present. Overall, I focus my analysis on how the CQUIN and promotion of early diagnosis is translated, interpreted and negotiated across the hospital and memory service settings. I highlight the affects and consequences for clinicians, patients and family members, and cast light on the anticipations and anxieties the future of an ageing population with AD produces (c.f. Adams *et al.*, 2009).

Risk, uncertainty and clinical governance

According to Hacking (1999) risk thinking, or the characteristics of risk, is the art of making the *future* calculable in the present and as demonstrated in Chapter Six, risk attempts to 'discipline uncertainty' (Rose, 1998: 180). According to Aronowitz (2009), 'the *risk* of disease is some statistical probability that ill health might happen' (pp. 419 emphasis in original). Therefore the projected numbers of individuals, who have the potential to develop AD, has led to the governance of referral and diagnosis rates through the implementation of the National Dementia CQUIN. This further corresponds with what Rose (2009) argues, that 'numbers legitimate, and make demands' rendering a 'space governable yet contestable' (pp.78). In relation to the National Dementia CQUIN's role in calculating and managing the future risks associated with the growing ageing population, two overarching aims are apparent. The first aim of the CQUIN is to increase awareness and the quality of care in hospital for those already diagnosed with dementia. The second aim is to increase assessment, referral, and subsequent diagnosis rates for AD, by detecting cognitive decline associated with the disease at earlier stages. The second aim is therefore entangled with attempts to manage the number of individuals who might go on to develop AD since age is the greatest risk factor for the disease. It is this second aim, which I analyse within this chapter where I demonstrate that the governance of a specific group of individuals through initiatives such as the CQUIN is a point of contention across healthcare practice as I will demonstrate throughout this chapter.

The implementation of governance initiatives in healthcare corresponds with the overall focus in healthcare practice on the management or eradication of uncertainty which has been demonstrated throughout history (see Fox, 1959; Atkinson, 1984). Commentators such as Hillman *et al.*, (2013) have argued however, that more recent measures for managing risk and uncertainty in healthcare, are target and performance driven where ‘measurement become[s] a central risk technique’ (pp. 945). Shifting from efforts simply to manage or eradicate risk, towards the monitoring and regulation of healthcare practice through performance measures and target setting is marked by efforts to improve the *quality* of healthcare (see Checkland *et al.*, 2004). As a result, examples of clinical governance initiatives for dementia include the Quality and Outcomes Framework (QOF)²¹ in primary healthcare and CQUIN in secondary healthcare.

Commissioning for Quality and Innovation Frameworks are pay-for-performance schemes introduced by the Department of Health in 2009. They enable commissioners to reward excellence and quality healthcare, by connecting the finances of healthcare providers, such as NHS Trusts, to the achievement of target driven, and performance-managed, quality improvement goals (see NHS Improving Quality, 2015). The National Dementia CQUIN introduced in 2012, focuses attention on efforts to standardise screening practices for cognitive decline, to identify patients with dementia in Acute Medical Units (AMU) in hospital settings. As previously stated, the CQUIN has two overarching aims and the 2015/2016 guidance for the National Dementia CQUIN extends the aims of previous CQUINs by aiming to support and improve the communication between healthcare providers, general practice and the community, for both new and existing patients (see Commissioning for Quality and Innovation (CQUIN) Guidance, 2015/16). The rationale behind the CQUIN is that the number of

²¹ GP Quality and Outcomes Framework subset 2014-15 dementia data ‘supports the Prime Minister’s Dementia Challenge, within which aims (sic) there is an ambition to improve the national diagnosis rate of dementia.’ GP Practices are financially rewarded for achieving a monthly target of dementia diagnoses (see ‘Quality Outcomes Framework (QOF) Recorded Dementia Diagnoses 2015’ pp.4).

individuals set to develop overall dementia, is predicted to increase which is likely to cost the UK economy £26.3 billion per annum (Alzheimer's Society, 2015).

The National Dementia CQUIN has three stages. As a pay-for-performance scheme, the initiative provides financial payment to each NHS Trust that achieves a quota of 90% of patients reaching each of its three stages²². At Stage 1, 90% of individuals admitted to AMU are asked the 'awareness question'. The patient, family member or professional carer is asked, 'have you/has the patient been more forgetful in the past 12 months to the extent that it has significantly affected your/their daily life.' This question must be completed within 72 hours of admission. If the answer is yes to this question, the patient is moved to Stage 2. To receive payment, 90% of patients from Stage 1 need to be referred to Stage 2, which includes giving patients an Abbreviated Mental Test Score (AMTS) to complete, to determine the presence of dementia. If the patient scores below 7/10 on the AMTS they are moved to Stage 3. Again to receive payment, 90% of patients from Stage 2 have to be referred to Stage 3, which includes referral to specialist diagnostic assessment, for example GP, memory clinic or old-age psychiatry liaison team. Payment is received if 90% compliance has been achieved in each of these three stages (see diagram 'Dementia CQUIN: FAIR (Find, Assess and Investigate, Refer' page 8 Using the Commissioning for Quality and Innovation (CQUIN) payment framework, 2012).

Pay-for-performance schemes, in particular CQUINs, have received criticism from health policy and health economics commentators. Maynard and Bloor (2010) writing in the British Medical Journal, argue that the NHS should proceed cautiously when implementing performance measurement initiatives. They argue that as a result of initiatives such as CQUINs, which aim to improve a particular area of practice, this may lead to a deterioration of outcomes in other areas of healthcare practice. Furthermore, Kristenson, McDonald and Sutton (2013), question the design characteristics of pay-for-

²² Unlike Quality and Outcomes Frameworks, the CQUIN is aimed at rewarding hospital trusts rather than the clinical team.

performance schemes, and the extent to which they reflect local needs and priorities. More broadly, an increasingly systematic and calculating form of risk governance is therefore being witnessed within the NHS, which Brown and Calnan (2010) refer to as the 'dark side' of healthcare. Patient safety and quality of care are open to surveillance through target setting practices to avoid the (re)occurrence of prolific healthcare disasters (see Brown and Calnan, 2010). As a result, in response to what Ling (2000) describes as 'real medical failures' healthcare practice is being 'drawn back into attempts to establish protocols and rules' of which commissioning initiatives are one example (pp. 261).

Furthermore, social sciences commentators have challenged this shift towards standardised clinical governance regimes, suggesting that these regimes produce a technocratic, reductionist approach to healthcare, which has the potential to constrain professional autonomy (Abbott, 1988, Armstrong, 1977; Berg *et al.*, 2000). According to Hillman *et al.*, (2010), healthcare has 'fallen victim to a wider societal trend to attempt to eradicate uncertainties through reasoned calculation,' (pp. 951), alongside the rise of bureaucracy more broadly, the 'risk management of everything' and the emerging 'bureaucratic patient' (see Rosenberg, 2002, 2003, 2009; Power, 2004; Kerr, 2008). In what follows, I investigate the extent to which the CQUIN, as a device for enacting future risk management, translates into everyday clinical practice by initially addressing whether it constrains the practising of clinical autonomy in the hospital setting.

It has been well established by sociological scholars including Rose (1998), that calculating risk and uncertainty about the future of healthcare practice, also has the potential to weaken the autonomy of clinicians. In my study, efforts to calculate risk through the CQUIN shifted the content of work and approach of clinicians for measuring cognitive decline, where clinical autonomy was 'de-emphasised' in favour of transparency and order (pp. 189). Tracing interview transcripts with information managers and the lead

clinician for the CQUIN²³, these actors *recognised* the possibility that clinicians may regard the CQUIN as a bureaucratic initiative in what is already, an overly bureaucratised healthcare service. They were collectively concerned that the CQUIN might be viewed as a ‘*paper based exercise*’ (Information Manager 1) given that, ‘*there is [already] so much paperwork*’ (Information Manager 2), which as the lead clinician reflected, ‘*it’s hard, it’s paperwork, it’s pieces of paper*’. Arguably, these accounts are suggestive of the extent to which the CQUIN more generally, has the potential to generate a focus in clinical practice overall, ‘upon paperwork rather than practice’ (Kerr, 2008: 9) driven more broadly by the ‘lure of the number’ (Rose, 1998: 187). Exploring the accounts of clinicians, this was confirmed by Trainee Psychiatrist 1, who argued that the culture of healthcare practice is shifting towards a more target driven approach. As she explained during interview,

‘I think at some point there’ll be some kind of government target that everybody who presents with x, y or z, needs to have this formal assessment documented and needs to have maybe like a yearly cognitive assessment or something like that. I think it’s going to become much more rigid, which is kind of frustrating because I think clinicians should be left alone to treat people, patients how they feel is appropriate, and as they’ve been trained to do.’

As Trainee Psychiatrist 1 illustrated, clinical autonomy overall, is likely to be compromised with a more target driven approach to healthcare. As she highlighted, this is perhaps going to have implications for the way that classification is currently practised, and how the tacit knowledge systems of clinicians, are valued more generally. As I will go on to elucidate, information managers also *recognised* the likelihood of this shift in the culture of healthcare practice. At the same time however, as the following interview extract demonstrates, the lead clinician for the CQUIN argued that in fact it was transparency of performance and ‘lure of the number’ (Rose,

²³ The lead clinician for the CQUIN was a practising geriatrician who oversaw its implementation in the clinical setting.

1998), that prompted improvement in practice for this particular healthcare site,

“I feel very strongly that people don’t get patted on the back enough, don’t get told when they’re doing well but they’re told when they’re doing badly and that happens a lot in the health service...I do try and let people know that also data is extremely powerful, ‘cause if you send a spreadsheet around and you’ve got wards in the same specialty, and everybody else is hitting 98% and they’re green, and you’re amber, and you’re green, people will start to think – *‘hang on a second, why are my mates in the same specialty hitting that, what am I doing wrong?’* So it helps drive up standards and improve performance really. So yeah I do encourage us sharing the data. I think it helps sustain it, and I think it helps improve it, and at the end of the day it’s a very worthwhile thing to do really.”

The CQUIN as a performance management initiative offers opportunities for surveillance and accountability. According to the lead clinician, the data was shared within the organisation, and clinicians were made aware of their own performance for documentation. This increased transparency within the team, and the CQUIN as a surveillance device, thus reflected a discourse of performativity. As a performance management framework, it encourages clinicians to be accountable; transparency of practice necessarily lends itself to performance improvement because of comparability across sites, which as the lead clinician argued, *‘drive[s] up standards’*. Discussing exclusively the role of consultants and junior doctors here, for the lead clinician, the CQUIN performed how these actors approached their professional roles and identities *‘they’re green and you’re amber’* serving as a performance of Othering within the organisation, which was described similarly by Information Manager 1, *‘improves performance’*. In this particular hospital site, the ‘objectivity effect’ (Rose, 1998: 189) of the CQUIN, for Information Manager 1, served to perform the professional hierarchy, which is an extension of the claims I made in Chapters Five and Six.

As the accounts from information managers and the lead clinician so far suggest, they recognised that practising the CQUIN may be resisted by clinicians. In what follows, I address the extent to which information managers and the lead clinician actively look beyond the CQUIN in terms of the ‘lure of the number’ (Rose, 1998: 187). Instead, these actors promote and thereby anticipate, the CQUIN as an initiative for reifying the patient pathway *beyond* performance management and target setting practices. Therefore I extend Rose’s (1998) claim that quantification is privileged for calculating and managing risk, by demonstrating that the CQUIN overall, is constitutive of a particular representation of the *future* grounded in anticipation of the reified patient pathway²⁴. Across interview accounts and observations, I argue that the future enacted by the CQUIN, ‘is now, on the cutting edge of the present’ (Flaherty and Fine, 2001: 155) and as a result, my overall analytical focus is grounded in the sociology of expectations.

The future of the patient pathway

STS literature in recent years has begun to develop an area of work, which investigates the temporal orderings within the development of technoscientific research and practice (see Brown, Rappert and Webster, 2000; Brown and Michael, 2003; Selin, 2008). In particular, commentators developing the analytical standpoint of the sociology of expectations have begun to develop an area of work, which seeks to explore the future as constituted in the present. The key analytical move of the sociology of expectations shifts the focus of critique from looking into the future, to looking at the future; the future is constituted in accordance with particular representations of temporality in the present. ‘...*looking at* how the future as a temporal abstraction is constructed and managed, by whom and under what conditions’ (Brown, Rappert and Webster, 2000: 4 emphasis in original). Despite the sociology of expectations analysing *innovation* in technoscience, I capture how the analytical themes raised by this approach, can be applied to the role of more mundane technologies and initiatives in

²⁴ Referring to the patient pathway here, I am describing the process whereby clinicians detect initial cognitive decline, refer patients for diagnosis, carry out diagnostic assessments, prescribe treatment and care options.

healthcare with regards to the CQUIN. Managing the future of AD, as a particular temporal abstraction, is important for considering how this might shift the representations of time embedded in current classification practices, and thereby reflecting on the translation of the framework in everyday, routine practice.

As the following analysis shows, the two information managers included in my study and the lead clinician, were able to anticipate the future patient pathway through the implementation of the CQUIN, which had the potential to act as a ‘powerful agent on our present’ (Brown, Rappert and Webster, 2010: 9). From the perspective of clinicians, this manifested in two significant ways. First, the CQUIN shifted the organisation of healthcare and second, the CQUIN produced particular uncertainties for clinicians in the hospital setting. Prior to analysing these implications, Information managers and the lead clinician, collectively agreed that the CQUIN should be performed *beyond* a framework for quantifying and calculating risk,

‘I guess it, you know, the data is the data and that’s it; you can make it flat or three dimensional depending on what you want it to tell you. So I don’t think people relate to numbers as much as they relate to a story.’

As I have shown in Chapters Five and Six, emphasising the quantified outcome of cognitive screening tools, was balanced alongside valuing the more ad hoc or informal practices through which the tools were mediated. As witnessed during observations of consultations and team meetings in the memory service however, clinicians at times *emphasised* the significance of the quantified outcome for negotiating the boundaries of classification, and for *proceeding* with classification in a complex distribution of medical practice. The account of Information Manager 1 serves to highlight a further dimension of this balancing act. It was her use of the word ‘*story*’ which is interesting, since a story denotes a narrative with a past, present and future: the construction of cognitive decline across time. Similarly to the practices of the memory service, according to Information Manager 1, the numerical

data produced by the CQUIN was not emphasised above the narrative embedded within the outcome of the technology; overall, it was used to narrate the patient's journey, which clinicians and information managers found useful in this particular study. Furthermore, the data could only be used to tell part of the story of the patient journey, as Consultant Psychiatrist 1 explained during interview when asked about the consequences of an ageing population, *'there's gonna be increasing needs for this group [ageing population] and increasingly complex needs as time goes on'*. Beyond the theme of risk, the data from the CQUIN overall, enacts the future in terms of patients' *'needs'* over time as it frames the patient pathway. As I will go on to capture, it was this dimension of the CQUIN that the information managers included in this study, found useful for ensuring clinicians complied with the framework, beyond its role as a paper based exercise for calculating risk. As the following extract from an interview with Information Manager 2 highlighted,

'People aren't always that aware of the relevance of it [CQUIN] and because there is so much paperwork, sometimes they don't - you know if you're new into a role, you don't actually understand that the paperwork is for the patient care and if they support each other... and so I think there's got to be that whole awareness of it and education of it to get people to comply with it really.'

Here, Information Manager 2 clarified that she is aware that the CQUIN may be seen to be unproductive in terms of adding an extra bureaucratic layer to clinical practice. Reflecting on observations of both consultations and team meetings in the memory service, there were numerous moments where clinicians remarked that referrals were increasing and they had little time to complete their weekly patient load. Particularly during weekly MDT meetings, clinicians would express their concern about the increasing allocation of referrals, and the impact this might have on time spent with each patient. The culture of current specialist, diagnostic services for dementia overall, were subsequently already facing a culture of 'paperwork rather than practice' (Kerr, 2008: 9). What is interesting about Information

Manager 2's claims is that to navigate this culture of bureaucracy, they stressed the importance of anticipating the value of the CQUIN as a device for managing patient care. According to Information Manager 2, this meant that clinicians were more likely to comply with the principles of the CQUIN; they were able to anticipate its role beyond a target driven initiative. As Information Manager 1 further illustrated during an interview,

“You know those numbers are telling you a story about patients who are going through a journey in the hospital. So I often used to have difficult discussions with the team because they would say, ‘*ah yeah we’ve hit 90%*’ and I would say, ‘*but has that last patient been referred?*’ and they’d say ‘*no*’ and I’d say, ‘*go talk to the dementia lead about it; let’s get them referred*’ because actually it’s not about the performance, it’s about making sure that if you think about the value that the CQUIN is meant to be giving, then the performance should emerge from the correct clinical practice rather than *vice versa*.”

There are two important points to draw from this interview excerpt. First, the account of Information Manager 1 concurs with previous literatures that the CQUIN represents efforts to quantify and calculate risk driven by a commitment to objectivity (Rose, 1998). Arguably, the account also highlighted the extent to which commissioning initiatives overall, place trust in numbers (Porter, 1996). Given the increased attention in healthcare policy to formalise, measure and hold clinicians accountable for their work through initiatives such as the CQUIN, this arguably represents *distrust* of clinicians to effectively detect cognitive decline in the hospital setting. What is also interesting about this excerpt is that as clinicians successfully hit the 90% target, often it was the *information manager* that had to prompt the extra referrals beyond the target of 90%. Despite Information Manager 1's claims however, I reflect here on whether current practice and prompting clinicians to achieve 100% referrals, was a consequence of clinicians expending an increasing amount of time implementing the CQUIN, and therefore may not necessarily have *had time* to go above and beyond the quota of 90%.

The second point to draw from Information Manager 1's account is that she described the CQUIN as a framework for anticipating and thereby reifying the patient pathway. Information Manager 1 was keen to demonstrate that the CQUIN served a purpose beyond performance measurement to considering its role for the future of the patient pathway, their *'journey in the hospital'*. The uniformity of procedure (Berg, 1997a) by achieving or performing the target of '90%' became more than a simple 'accountability' procedure (Kerr, 2008: 9): the numbers *'are telling you a story'*. Anticipating the patient journey prompted the performance of the CQUIN and the narrative of the data was valued (c.f. Berg, 1997a). This was confirmed by Information Manager 2, *'it's not just about the numbers and how we do that, it's about the whole package of care really so it's the more 'touchy feely' aspect to the CQUIN'*. As Information Manager 1 further elaborated during interview, constructing this *'package of care'*, had important implications for the future of the patient pathway,

'So actually that early identification of somebody suffering from possible dementia has a lot of value to play and actually a lot of value to play in healthcare in general because actually diagnosing that earlier might allow us therefore to prevent admissions for that patient later on in that pathway. So I guess for me it's an opportunity to improve patient experience.'

Here, early identification of cognitive decline more generally, prevents (re)admission to secondary healthcare, and therefore manages any possible disruption to the reified patient pathway. This is because, the CQUIN overall encourages earlier detection of pathology before *'it's too late...to manage what is likely to be a very difficult point of time in their lives'* (Interview Information Manager 1). In doing so, the CQUIN actively anticipates and mobilises the patient's journey in terms of the patient pathway to *'improve care'* as argued by the lead clinician during interview. The "real time" activities of these actors were performed in response to the uncertainties around the current patient pathway for dementia: from the

hospital setting and through into memory service at earlier stages (Brown, Rappert and Webster, 2000: 4).

Yet, as I have captured in Chapters Five and Six, this patient journey is not necessarily a linear process, as clinicians shift back and forth between different techniques, technologies and professionals across healthcare, to account for the emergent complexities enacted in the clinic. Increasing referrals were subsequently met with reticence particularly by professionals working in specialist memory services. Furthermore, this '*whole package of care*' that Information Manager 2 described, is suggestive of the more tangible and practical applications of the CQUIN along the '*patient journey*' as Information Manager 1 illustrated. Yet, preparing for this '*package of care*', implies a very different set of care practices than those captured in Chapters Five and Six, where I analysed the informal, ad hoc or carefully choreographed diagnostic appointments in order to manage uncertainty. As a result, despite Information Manager 1 emphasising the '*touchy feely*' aspect of this package of care, paradoxically this produced uncertainties, which the CQUIN and early diagnosis overall, claims to resolve. I will develop this point further in the chapter.

So far, I have briefly sketched the accounts of information managers, framed within a broader analytical perspective, which demonstrated the extent to which the CQUIN enacted and anticipated specific futures around the patient pathway. This was seen by the two information managers and the lead clinicians to aid the performance of the CQUIN and minimise disruption to autonomy. The question remains however, as to how this approach was translated into clinical practice by clinicians, and whether anticipations about the future as projected by information managers were, 'object[s] of creation rather than fully set' (Selin, 2008: 1880). Selin makes an important claim that informs the following section: the extent to which creating particular futures had important implications for both patients and clinicians despite the CQUIN enacting these futures as 'fully set' (pp. 1880).

Shifting time and moments of uncertainty

Drawing on interview transcripts and observation notes, in what follows, I argue that the CQUIN emerged not simply as a device for calculating risk; rather, in anticipation of the patient pathway, it shifted the temporal orderings of current classification practice. In doing so, it had important implications for the content of work in the hospital setting, and for patients facing assessment as the ‘future influence[ed] the present’? (Mead, 1936: 301). According to Mead (1936) in his writings on time, the future is constituted in both the past and the present since the future is ‘already being made’ (pp. 301). Mead’s writings refer predominantly to notions of temporality in interactions. The self is a temporal moment inscribed across time, a point I will develop further in the chapter. Approaching the future by adopting this analytical framework, I analyse time and temporality not simply as ‘facet[s] of nature’ (Flaherty and Fine, 2001), neutral and value free, but as analytical devices in themselves, which in my own study, had important implications for diagnostic assessment, classification practices, and the everyday work of clinicians.

The promissory claims of the CQUIN have been presented thus far in terms of its ability to enable clinicians to prepare for the patient pathway or the ‘*patients journey*’ in the hospital setting, into specialist memory services, aside from debates around professional autonomy and the value of tacit working practices. This was confirmed by the accounts of information managers and the lead clinician. The ways in which these promissory claims were *realised* in clinical practice had important implications however, for classification practice in the hospital setting, in two distinctive ways. First, it implicated the ways in which a number of clinicians approached cognitive assessment and second, it implicated the organisation of healthcare practice. In terms of being able to explore the CQUIN in practice, the CQUIN was difficult to observe. Despite having ethical approval to observe the framework on hospital wards, the nature of it, and its demands on AMU, meant that clinicians were reluctant to allow me to carry out observations. They were concerned that my presence on the ward would disrupt working

practice. As a result, the accounts I have of the CQUIN from those working in the hospital setting, were taken from semi-structured interviews.

In order to explore how clinicians approached the CQUIN in the hospital setting, a significant component of this process was performing the AMTS for those patients referred to Stage Two of the CQUIN. The AMTS (see Appendix A), is a 10-question tool to assess decline in cognitive function: a result of seven or less would warrant referral for diagnostic assessment. Prior to the implementation of the CQUIN, it was used routinely across the hospital setting; its adoption in the CQUIN has simply standardised its use for assessing cognitive decline. Tensions arose however, between those actors implementing the CQUIN, and clinicians practising the CQUIN, with regards to the usefulness of the AMTS in practice. For the lead clinician, the AMTS prompts the successful performance of the CQUIN since it fits neatly into the current pressures and demands on clinical practice. The simplicity of this tool is what connected different actors across space and time in order to ‘create ‘direction’’ for assessing cognitive decline and preparing the patient pathway (Brown, Rappert and Webster, 2000: 4). As the lead clinician explained during interview,

‘I think as a quick screening or quick assessment test the AMTS is a very good one; I’m a huge fan of it. It’s had its critics and it has its limitations of that there’s no doubt but the beauty of it is, that it takes a matter of a couple of minutes to do. It doesn’t require anybody to draw anything on a piece of paper, it doesn’t require like the Mini-mental state examination, somebody to fold a piece of paper, it is a series of questions that can be answered quickly, can be done at the bedside, by just about anybody who’s trained.’

For the lead clinician, the *‘beauty’* of the AMTS is the fact that it is a simple, portable test which can be transported or transferable across healthcare sites, *‘at the bedside’* by those who have been adequately trained. The test reduces the time it takes to assess cognitive function in AMU, and mobilises action across settings because of its simplicity and portability. In terms of

mobilising action across settings, this is a point I will return to further in the chapter. However, whilst the lead clinician referred to the concept of portability here during interview, this produced a very different dimension of portability than that which was witnessed during observations across Chapters Five and Six. According to the lead clinician, the simplicity of the AMTS enables it to shift effortlessly between different actors and in different spaces.

Performing this portability however, without due regard for the informal and ad hoc care practices observed in the clinics of the memory service, had important implications for clinicians in the organisation of the hospital setting. There was a collective concern across the hospital setting, that the adoption of the AMTS despite its portability, negatively affected the point in time at which cognitive decline was assessed, managed and documented. This had implications for patients who were being assessed, and the organisation of the hospital setting overall. Developing the claims made by Mol, Moser and Pols (2010), I am not suggesting that the AMTS ‘work[ed] or fail[ed]’ rather, by shifting the point in time at which cognitive function was assessed, a variety of affects emerged which were at times ‘surprising’ for patients and clinicians alike (pp. 14). In the hospital setting, this ‘surprise’ or what I argue were the unintended consequences of the CQUIN, were difficult to navigate as the following extract from an interview with Registrar Geriatrician 1 illustrated,

“I think it’s [AMTS] a really blunt screening tool I preferred it when I could use my discretion I think it’s really obvious when you are talking to a patient who’s got cognitive impairment that may not have been picked up recently and I think that these things are better done if they’re more targeted and that you just that you pick this stuff up. I think also the other side of that is just by screening everybody, there are some people who find it really offensive that you’re asking them these questions and when I do to those people who I know are going to score 10/10 because they’ve given me a really good story of why they’re in hospital and absolutely

everything, you know there's no cognitive impairment, it's then really embarrassing and I do like say, *'I'm really sorry David Cameron makes me ask you these questions'*. But having said that, although I think that I would prefer to use my clinical judgment, I'm a geriatrician and I recognise that there are a lot of other specialties out there who would not have the skills and expertise that I have and will be less good at picking these things up: wouldn't recognise it, wouldn't be interested in doing it. So perhaps the screening tool is more appropriate for them, but then how could you say these groups of people can use the screening tool but geriatricians you don't have to do it, you can use your judgment. So I can see why they've done it as a screening tool."

Echoing the point I made at the beginning of the chapter, arguably the observations of Registrar Geriatrician 1 serve initially to highlight how the CQUIN both constrained professional autonomy or discretion²⁵, and also reflected disciplinary objectivity as opposed to mechanical objectivity (Porter, 1996). The tacit knowledge systems of geriatricians were privileged and insight was applied through 'learned experience amongst peers' (see Berg *et al.*, 2000). In the case of the registrar, this led to disdain for 'standard or standardised solutions' to what was essentially a complex, or what should be a 'targeted' task (Berg *et al.*, 2000: 784). However, the account of Registrar Geriatrician 1 also highlighted the *expectations* that clinicians held of these technologies. Registrar Geriatrician 1 drew attention to the difficulties associated with using the AMTS and characterised it as a *'blunt'* tool. The tool made it difficult to exercise discretion and judgement, necessary for negotiating the ways in which patients might conceive the assessment process. The CQUIN more generally, shifts the point in time at which clinicians assess cognitive function to earlier stages, which in this instance, had direct implications for how patients conceived and therefore perceived the testing process. For a number of patients who might *'find it*

²⁵ The effect of this framework on professional autonomy however, is likely to differ across specialties particularly where specialisation in medicine (in this case elderly medicine) is traditionally associated with exercising greater professional autonomy (Nancarrow and Borthwick, 2005).

offensive’ to be assessed, the AMTS produced particular uncertainties in the hospital setting as found in my research. Drawing parallels with the claims I made in Chapters Five and Six, navigating how patients conceived the possibility of a diagnosis was difficult when the CQUIN governed the use of the AMTS for use at specific moments in time. Arguably, in this sense, the interpretive repertoire of the clinic and the making of provisionality had the potential to be constrained through the CQUIN. Drawing on Mol, Moser and Pols (2010) is helpful here, since the observations made in Chapter Five, illustrated the ways in which clinicians were able to treat the tools as provisional and temporary, aware of situational exigencies and individual particularities and therefore clinicians were able to engage in ‘care work’ (pp. 15).

The sentiments of Registrar Geriatrician 1 however, were not necessarily shared across the hospital setting as the following extract from an interview with Consultant Geriatrician 1 highlighted, *‘It [AMTS] doesn’t tell you the cause, it doesn’t tell you whether it’s acute or chronic, but it helps identify patients. So I guess what I’m saying is, the ones that are really confused it’s obvious but there’s a group of people we think are absolutely fine, but actually it’s not until you do the AMTS that you start to pick up the subtle problems.’* According to Consultant Geriatrician 1, the technology had the ability to enact, and render visible, the subtlety of symptoms. Yet, as the CQUIN extends the boundaries of practice to those less obvious cases, and the point in time at which cognitive function is assessed to those who might be in the earliest stages or asymptomatic, for Registrar Geriatrician 1, this had the potential to *produce* uncertainty for those patients who may be *‘offended’*.

Extending the theme of time and the temporal orderings of the content of work in the hospital setting, the CQUIN also had the potential to shift the current structure and practice of AMU, particularly for junior doctors. It shifted the priorities of junior doctors and the point *in time* at which cognitive function was assessed and documented. As the following extract from an interview with Consultant Geriatrician 1 confirmed, the CQUIN as

a medical accomplishment, therefore produced and reproduced professional hierarchies,

‘It’s [CQUIN] predominantly medical so the nurses often have a role in prompting it. They have, they’ve now just moved to an electronic patient screen that they update and one of the things is the dementia CQUIN so they will often prompt us if it hasn’t been done. But it’s a medical, for us it’s a medical responsibility to do it; junior doctor senior doctor and then it’s our medical responsibility to pass it on to the GP or liaise directly without liaison psychiatry. So the multi-professional communication would be nurse to doctor we would communicate doctor to nurse if we’ve identified problems.’

The responsibility of the CQUIN as Consultant Geriatrician 1 described is primarily a ‘*medical*’ accomplishment, which served to sustain the professional hierarchy in the hospital setting. This supports my argument that such tools had the ability to produce and reproduce the division of labour in healthcare. Whilst still maintaining ‘*multi-professional communication*’, those higher up the professional hierarchy were able to check or confirm the work of nurses, as communication was ‘*nurse to doctor*’. However, despite this division of labour as demonstrated throughout this thesis, the process of assessing and subsequently diagnosing AD through the use of cognitive screening tools was a collective and collaborative network of practices. The hierarchy of the CQUIN however, had the potential to shift this collaboration and produce moments of chaotic practice since the framework predominantly relied on the role of junior doctors in AMU. Trainee Psychiatrist 1 highlighted the ways in which the arena of the AMU meant that junior doctors were not *making time* for the CQUIN since the immediacy of defining and presenting problems in this space, meant assessment was put off to do *in time*. This produced particular uncertainties around how the CQUIN was dealt with in clinical practice and the content of work on the ground. As Trainee Psychiatrist 1 described,

'One of the things that we did find when we audited the CQUIN tool at the - in the acute medical unit, is that the people who are undertaking these cognitive assessments are junior doctors. They're foundation year one so they've just started, or foundation year 2 maybe an SHO that'll have been in for about three years. So that initial assessment would be by a junior doctor and they're done at - you know like, being a junior a doctor on a hospital ward is frantic; it's just so so busy. You don't eat or drink for 14 hours and it's just, it's really busy so you almost at the time you kind of like, I don't actually care about this patients' dementia which is chronic long term, I don't need to solve that, what I do need to solve is that this lady's oxygen's level is in her boots, her blood pressure's dropping you know that kind of stuff. So the kind of more, the kind of dementia picture really takes a back seat in the acute setting. So I think that they've got a long way to go at trying to educate younger doctors as they're coming in on the importance of using these short acute admissions for identifying these. Obviously all patients have their consultants who'll see them in ward reviews, and particularly elderly consultants - they're always looking out for stuff like this but it would be really useful for junior doctors to have a bit more training on why it is important to sort of flag it up. You know even if it's three in the morning, have a little think about it: if the daughters saying, *'oh she's not been herself, you know she's been a bit more forgetful for the last six months'* that is important. That needs to be documented.'

Healthcare practice is fragmented and disordered (Atkinson, 1995) particularly for junior doctors. For junior doctors attempting to establish themselves within the hospital team (c.f. Kerr, 2008) the pressures and practices of AMU made the accomplishment of the CQUIN difficult. As Trainee Psychiatrist 1 explained, in AMU it was generally the responsibility of junior doctors to carry out the CQUIN, who in the early stages of their career, are facing huge demands and demands on time in particular. To accomplish the CQUIN in the current temporal orderings of AMU was

therefore difficult, to which end the *'dementia picture really takes a back seat.'* The priority for junior doctors in these conditions was to attend to what was immediately the problem, *'this lady's oxygen is in her boots, her blood pressure's dropping'*. As Trainee Psychiatrist 1 iterated however, documenting the CQUIN was important for the purpose of anticipating and preparing for the patient pathway: in terms of what was both immediately present in time and that, which may be important over time. Therefore different temporal orderings co-existed in the space of AMU, which led to moments of uncertainty particularly for junior doctors. For junior doctors concerned with what was *immediately* the problem in a pressurised healthcare service, meant that the CQUIN was put off to do *in the future* at which point the reified patient pathway was affected. The CQUIN in its quest to establish order for the future of the patient pathway had the potential to shift current approaches to cognitive function in practice.

The difficulties faced by junior doctors when practising the CQUIN are reflective of the conditions in which the framework overall is implemented, and the increasing pressures on the healthcare service. I reflect here on the elusiveness of the CQUIN in my own research in terms of the difficulty in recruiting participants. I consider that the difficulty I found following the CQUIN through practice, parallels with, the current conditions in which the CQUIN is operating in terms of the demands on the service, and as I will go on to demonstrate, demands on healthcare resources. As the following accounts and observations across the memory service illustrate, reifying the patient pathway through the CQUIN was difficult given the practical challenges currently facing the NHS.

Mobilising resources along the pathway

According to the implementers of the CQUIN including information managers, the CQUIN since it encourages assessment and therefore referral rates, institutes a particular future care pathway. The CQUIN is useful for describing the journey of the patient and also to *prescribe* in terms of referring patients from hospital to primary care (c.f. Pinder *et al.*, 2005).

Drawing on Pinder *et al.*, (2005) the CQUIN is a ‘mobilising metaphor’, which drives ‘*structure to doing something about it [dementia] once they’re [the patient] left hospital, which we didn’t really have before*’ (Conversation Consultant Geriatrician 1). At the same time that Consultant Geriatrician 1 argued that the CQUIN formalises current working practices, there were points at which this structure was difficult to maintain. As Consultant Geriatrician 1 explained,

‘My hesitancy is we can identify, and we can recommend some follow-up, but does that turn into someone carrying out the follow-up and the patient actually going; and ‘cause a lot of the challenges in the NHS are communications across transitions of care.’

What Consultant Geriatrician 1 described as ‘*communications across transitions of care*’ produced particular uncertainties around referral and follow-up practices. Reflecting on my own observations of consultations and team meetings, the CQUIN was marked relatively by its absence in terms of communicating the source of referrals to the memory service. Arguably, practising the CQUIN was made further complex as Information Manager 1 explained, ‘*patients move around the organisation*’ leading to ‘*messy*’ rather than ‘*streamlined*’ practice (Interview Information Manager 1). Unlike the practices observed in Chapter Six, the portability of patients across healthcare sites instituted by the CQUIN, produced complexity as opposed to resolving complexity. As the following extract will confirm, the follow-up practices driven by the CQUIN, raised further uncertainties in terms of care options and resource allocation, which effected the decisions made by clinicians in terms of referrals. As Registrar Geriatrician 1 illustrated,

‘You have to look at the bigger picture. So you’re picking them up and referring them back to the GP; I know that in (location) there’s a four month wait to be seen in memory services, so actually you can highlight this to the GP, and relatives and carers, that there may be an issue and be followed up, but actually then they’re waiting a long

time for that follow-up. So actually if the memory services are struggling to see the volume of patients that we're referring, you then ask the question you know the bigger picture: what kind of care are we offering these patients in terms of diagnosis and treatment? And that then leads you on I suppose to say, well actually what treatment is there? Yes there are four drugs out there, but they're drugs and they're not completely effective. What other then - you think about more holistically, what other social care do we give to these patients? And I think that that's been in decline recently as well. So it's a very, it's a small bit isn't it in doing an AMTS, and just cos you identify, what on earth does that lead to? And that - what that leads to is like the bigger picture, and actually perhaps that's what we need to be improving, is that bigger picture of improving assessment, diagnosis, treatment and like care and support in the community; that needs to be there and I think that's a really big issue.'

Developing the theme, upon which this chapter is grounded, the future patient pathway instituted by the CQUIN, is developed in the present in order to 'marshal resources [and] coordinate activities' (Brown, Rappert and Webster, 2000: 4). However, translating this in practice was difficult because of the practical challenges facing the organisation of healthcare; the *conditions* of its implementation. As the CQUIN increases identification and referral rates more broadly, Registrar Geriatrician 1 expressed their concern that '*the bigger picture*' in terms of treatment and care were not advancing at the pace of initiatives, which promote diagnosis more generally. This therefore created particular uncertainties around patient futures in the hospital setting, which paradoxically, the CQUIN was expected to handle and sort.

Furthermore, the CQUIN may well increase the speed of referrals but at the same time, this produced particular challenges within the *memory service* facing demands on resources and time. The increased number of referrals was a frequent note of observation across the memory service. They had the

potential to slow down the time it took for referral to specialist memory clinic already a point of concern for clinicians as I noted during a conversation preceding an observation with Trainee Psychiatrist 3, *‘The clinician explained to me that the patient had previously had a CT scan following reports of memory loss in 2013. The clinician noted here that ‘as you can see, the time it’s taken for referral had been quite a lengthy process.’* Increasing referrals also had the potential to disrupt the reified patient pathway or what Registrar Geriatrician 1 described as *‘care and support in the community’*. Overall, Registrar Geriatrician 1 confirmed the uncertain relationship between diagnosis and prognosis which was at the centre of concerns around efforts to diagnose AD overall, as this thesis has argued. The process of referral for preparing the patient pathway was also a point of contention as the CQUIN moved into the memory service. Here, I witnessed how clinicians across the memory service interacted with the CQUIN, and observed these particular uncertainties negotiated in practice. I observed a team meeting with Ridge NHS Centre where (rather unexpectedly), the CQUIN appeared in a discussion regarding referral practices,

‘A memory nurse presented a new referral from the GP. The clinician began by stating that the patient’s physical health is a *‘major concern’* going on to detail the patient’s medical history. The memory nurse explained that during a home visit they tried to administer the ACE 111 but the patient had fallen asleep (scored 32/84). The memory nurse suggested that although she wanted to carry out a scan she did not think it would be beneficial for the patient as he is *‘near end of life’*. The nurse exclaimed that the patient’s memory decline is *‘almost the least of the patient’s worries’* going on to questions, *‘it’s a wonder why people get referrals’*. A memory nurse interjected at this point, *‘it’s because of the CQUIN’*”.

During the team meeting, the ambivalence towards formal initiatives such as the CQUIN became clear. As suggested above, the memory nurse became concerned for the health of the patient more broadly, and the

inappropriateness or irresponsibility of carrying out the tests with the patient who was *'near end of life'*. What I reflected on during this observation was that despite information managers and geriatricians arguing that the CQUIN is useful for structuring the patient pathway, increasing referral rates had the ability to produce particular anxieties for clinicians and patients. This anxiety was initially manifest as patients referred to memory service from the CQUIN, were then subject to extensive technological testing through the use of ACE 111 when in fact dementia was the *'least of their worries'*. The CQUIN then shifted the point at which the patient in this instance was referred from the GP. Here, the CQUIN appeared fleetingly yet significantly drawing attention to the lack of care associated with diagnostic referral: without due regard for the *conditions* in which the framework was being implemented in terms of the organisation of practice, and the individual particularities of patients as mapped in Chapters Five and Six. Tracing further observation notes, I also found that, tensions arose between the availability of resource allocation and treatment options. The conditions in which the CQUIN was being implemented reflected the lack of resources available, particularly for treatment options. The conditions in which it was being implemented could have led to its *absence* in observations of the memory service; its inability to produce action beyond initial referral was a point of contention across the memory service in particular.

Marshalling or mobilising resources through the CQUIN and therefore constituting a future with AD through “‘real time’ activities”, (Brown, Rappert and Webster, 2000: 4) was difficult when the availability and accessibility of treatment options *in particular* was a cause for concern. As I have clarified throughout this thesis, clinicians continually worked to negotiate classification in an arena of medical uncertainty; treatment options in the service were limited and there is no cure for the disease to which end clinicians shifted back and forth between techniques, technologies and professionals. During an observation of a team meeting at Nunmill Hospital, I witnessed the tensions within the NHS overall, with regards to the resources available for AD, and therefore the conditions in which frameworks such as the CQUIN were being implemented overall,

“The specialty doctor presented the case of a patient who having been given a diagnosis of AD, was finding it difficult to swallow the tablet capsules of Galantamine. The speciality doctor explained to the consultant that instead of prescribing the capsule form of the treatment, she has ordered the medication in liquid form. At this point, the consultant gasped and exclaimed, *‘do you know how much a bottle of that costs - over £2000 per bottle!’* The specialty doctor looked taken aback and the consultant went on to say, *‘no, I’m sorry you’re going to have to withdraw that order – we’ve been told specifically not to order that in.’* The consultant reasoned that they knew about this only because they were invited to attend a medicines management meeting. A discussion ensued between the clinicians about the trusts reluctance to prescribe liquid forms of the treatment because of demand on services, and yet a number of older patients were finding it incredibly difficult to take the capsule form. As the consultant exclaimed, *‘we’re torn really.’*”

This observation is suggestive of the practical challenges currently facing the NHS in terms of resources. Clinicians were faced with having to navigate the uncertainty around a lack of resources and the financial burden of the NHS trust, which affected patients and their treatment options. It also affected the ways in which clinicians were able to account for individual patient needs; a concern, which resonated with all clinicians across the memory service. The following extract from an interview with Consultant Psychiatrist 3, highlighted further the uncertainties associated with classifying AD particularly at earlier stages, given the demands on the memory service overall. As they explained,

‘I think referral numbers from what I understand are going up, and are likely to continue going up. As well, the resources with the economy, the resources are going down as well, particularly with social care as well. So it’s going to mean a lot more demand on the one, the service. And as you mentioned earlier on it’s the fact that publicity as well from the government, publicity about dementia

pushing early diagnosis as well and pressure on the hospitals as well; the CQUIN screening for dementia to refer people to clinic. So I think it's going to be a lot more input or demand on services, a lot more emphasis on diagnosis, but then less support afterwards with social care budgets being reduced. Other agencies having to make cut backs, so we're going to end up with a lot of people being diagnosed with dementia, with MCI and then not much to do with them afterwards. So it's a concern.'

For Consultant Psychiatrist 3, diagnosis in the classification process is privileged, '*a lot more emphasis on diagnosis*', overall, in the context of the implementation of the CQUIN. Early diagnosis is privileged both within the clinic, and more broadly in terms of social resources. As demonstrated in my study, patients and clinicians were necessarily affected by this privilege in the memory service. The patient pathway *beyond* diagnosis was a particular concern for Consultant Psychiatrist 3, because of the practical challenges facing the service in terms of resource allocation. As the CQUIN and commitment to early diagnosis drives referral rates more generally, this disrupted the reified patient pathway across the memory service because of the limited resources available in terms of treatment and care. This was a frequent topic of discussion across the memory service since it was this group of actors directly involved with referrals and therefore practising diagnosis.

So far, I have sketched the difficulties and uncertainties that emerged in everyday practice when attempting to prepare for the future of the patient pathway. As demonstrated, the CQUIN shifted the ways in which clinicians approached cognitive assessment, and also reflected the tension around the practical challenges facing the NHS, in terms of availability of treatment and resources. The conditions, in which the CQUIN is being implemented more generally, produced tensions around the availability of resources in terms of both care and treatment. Entangled in the uncertainty of the conditions of healthcare practice, I reflect on the extent to which this implicated my own observations of the CQUIN; elusive because of the

complexities that already exist in healthcare which clinicians were continually navigating. The following section, based on interview accounts and supplemented by observations from within the memory service, captures how a broader commitment to early diagnosis translated into clinical practice. Whilst the first section has demonstrated the future reified in the patient pathway, in the final section of the chapter I critically analyse how the CQUIN constitutes a further dimension of the future as it shifts a classification of AD towards earlier stages.

Shifting classification *in time* and early diagnosis

Developing the notion of the future as a discourse with effects in the present (Selin, 2008) and the temporality of classification, I analyse how commitments to early diagnosis through initiatives such as the CQUIN, were approached, interpreted and negotiated in everyday clinical practice. According to scholars Flaherty and Fine (2001), we have a ‘profound interest in knowing the future, but try as we might, it always seems to surprise us’ (pp. 155). As I demonstrate, the CQUIN and its commitment to early diagnosis, as it reified the patient pathway, produced complexities and uncertainties for both patients and clinicians.

According to Golumb *et al.*, (2004), ‘explosion of interest [in AD] reflects a shift in dementia research away from established disease and toward early diagnosis’ (pp. 353). As illustrated in Chapter Six, efforts to expand the disease to incorporate the label Mild Cognitive Impairment (MCI), is a direct example of attempts to diagnose AD in its earliest stages. Early diagnosis of AD reflects a commitment in policy and practice, to calculating and formally measuring, the number of individuals set to develop the disease and therefore categorised as ‘at risk’. The expansion of the disease to incorporate asymptomatic cases, the at risk status, and early diagnosis, reflects the aim in medicine to manage the threat of disease through population screening programmes using highly sophisticated and innovative technologies to detect potential pathology. With the case of AD however, as I demonstrated in Chapter Two, the matter of screening is a point of

contention within clinical practice; a screening programme for Alzheimer's disease to formalise risk calculation, has not been recommended (UK National Screening Committee, 2015). As Wilson and Junger (1968) explicate, adequate knowledge of the disease is required in order for screening practices to be implemented, perhaps why there are no formative population based measures to identify those who may be at risk of developing Alzheimer's disease. Instead initiatives such as the GP QOF and the National Dementia CQUIN are implemented to identify and case find a number of individuals perceived to be at risk of AD. In terms of the CQUIN, this includes a group of individuals over the age of 75 admitted to AMU.

Aside from the theme of risk, which has been adequately addressed in this thesis, the objective of the following section is to critically analyse how clinicians approached early diagnosis. In doing so, I illustrate that despite its hopeful discourse, early diagnosis through the CQUIN and more generally, shifted the temporality of classification, which produced particular uncertainties for both clinicians and patients. Part of this analysis included analysing whether the constituent futures of AD as performed in Chapters Five and Six could, 'carry on' through this promotion of early diagnosis (Law and Singleton, 2000: 775). Clinicians, patients and family members were affected by the principles of early diagnosis: anticipation, 'the present is governed, at almost every scale, as if the future is what matters most', emerged as an affective condition (Adams *et al.*, 2009: 248). In Chapters Five and Six, cognitive screening tools in the memory service, were co-constituted around two interrelated representations of temporality and futures *in the present* for managing uncertainty. First, during the clinician-patient interaction, clinicians mediated and manipulated the tools to protect patient identity, built around the ways in which patients conceived the nature of testing and diagnosis overall. Second, I demonstrated the ways in which clinicians kept patients on *into the future* driven by the possibility that they may go on to develop AD and which I linked to the mediation and manipulation practices witnessed in Chapter Five. In part, this process of keeping patients on was also driven by patients' expectations around a

future with AD. I investigate how this navigation work shifted with efforts to increase early diagnosis rates.

To this end, I extend my analysis of the CQUIN, by drawing on Michael's (2000) claims about positive and negative futures. The kinds of futures rhetorically enacted by the CQUIN, and commitment to early diagnosis more broadly downplay the role that the CQUIN has, in constructing particular expectations about a future with AD. As I will elucidate further, early diagnosis overall, produced uncertainty for patients and uncertainty around resource allocation given the practical challenges facing the NHS in terms of treatment options and care. I concur with Michael (2000) that, 'the sorts of futures attached to a given project are...often contested' (pp. 30). In this sense, stressing of the good associated with the CQUIN and early diagnosis more broadly, was implicit in 'downplaying' the more 'tangential' consequences of promoting early diagnosis for AD, which is uncertain and complex (pp. 30). Although Michael (2000) discusses technoscientific developments and the future, the themes raised can be similarly applied to the more mundane practices of the CQUIN, since as I show, it was implicit in constructing both patients' and clinicians' *expectations* about a future with AD. Overall, by problematising or pathologising later onset AD, and promoting early diagnosis, policy makers and therefore clinicians implicitly engage in the construction and constitution of patient expectations around what a future with AD might bring. The construction around patient expectations in this chapter is related to the reified patient *pathway* that the CQUIN and with it early diagnosis institute as demonstrated in the first section of this chapter. Early diagnosis as it shifted the temporal orderings of everyday classification practices, produced particular uncertainties in terms of resource allocation, care and treatment.

Efforts to increase diagnosis rates and diagnose AD in its earliest stages have been criticised publicly by clinical professionals. In response to the lack of a screening initiative for AD, healthcare professionals have questioned whether the current rhetoric around early diagnosis and case finding, is in fact a screening method that lacks robust evidence (see

McCartney and Brunet, 2014). As a practising GP, Brunet (2014) also questions the effects that the increased governance of healthcare professionals may have on the GP-patient interaction. This process is further complicated again by the introduction of the National Dementia CQUIN. Tracing interview accounts and observation notes, clinicians and patients, practised ‘wilful resistance’ to early diagnosis and the kinds of temporal orderings this constituted (Michael, 2000: 32). At one level, there was the notion that ‘in the face of the fear of such a devastating condition [AD], and with such a possibility [early diagnosis], who could resist this hope; (Rose, 2009: 78) and yet at the same time, the hopeful discourse around AD was contested. Prior to analysing the perspectives of clinicians, I am not suggesting that all healthcare professionals responsible for promoting early diagnosis necessarily *endorsed* its principles. As the following extract from Clinical Psychologist 1 highlighted,

“The prevailing sort of narrative is still: if we can’t give them medicine then what’s the point. If we can’t cure it what’s the point. There is still a lot - still around - certainly I’ve sat in commissioning meetings with GP commissioners saying, ‘*remind me again what’s the point of early diagnosis*’? So you know these are people who are in positions of responsibility, with a lot of experience of training, who are still very unsure about it all.”

As Clinical Psychologist 1 explained, during commissioning meetings, early diagnosis was a point of contention. The uncertainty around early diagnosis lies with the fact that for commissioners, as there are no definitive treatment or cure options for the disease, this made the discussion of early diagnosis futile. This points more broadly to the uncertain relationship between diagnosis and prognosis suggested in this thesis. The interesting point to draw from this extract, is that even those who have the responsibility to make decisions regarding whether or not to privilege early diagnosis and to consider how best to anticipate future diagnostic decisions, were ‘*unsure*’ of what was best for who, and why. Drawing on Aronowitz (2009: 423) here, as the CQUIN overall, aims to detect AD in its earliest stages, this does not

necessarily mean that it ‘change[s] patients’ ultimate prognosis’ (pp. 423). This was an argument iterated by a number of clinicians across the memory service. However, early diagnosis was also approached *ambivalently* in terms of making decisions about *who* early diagnosis was best for and why. The following extract from an interview with Clinical Psychologist 3, illustrated moments of uncertainty and complexity addressed throughout this thesis, which directly impacted how clinicians approached early diagnosis. Despite the fact that there is no known cause or cure for AD, what Clinical Psychologist 3 suggested, is that promoting early diagnosis, managed *clinicians’* anxieties about the lack of diagnostic certainty whilst a person is living. As Clinical Psychologist 3 illustrated,

‘The current kind of situation where we haven’t, there isn’t an end point so, and so, I wanted to say - I mean sometimes people talk about kind of anti-task behaviour in order to contain the anxiety in clinicians and whether how much of this activity [early diagnosis] is more to do with kind of clinicians’ kind of helplessness that actually really and truly we only can find out certainly post-mortem. Also there is not a cure actually yes we can support people through their illness and through their journey but we can’t offer an awful lot in terms of certainty to people so in what way are we trying to contain our own kind of levels of anxiety within this by feeling that we’re doing something useful?’

Clinical Psychologist 3 raised a particularly important point here. As she highlighted, promoting early diagnosis through initiatives such as the CQUIN, enabled clinicians to manage their own anxieties about diagnosis overall. Beyond analysing the mechanisms of early diagnosis through the lens of risk, it was this uncertainty around a definitive diagnosis for AD that drove the promotion of early diagnosis because there is no cure. In this sense then a paradox emerged. A lack of certainty about the future of AD in terms of cure and definitive diagnosis drove clinicians to manage their own professional anxieties by promoting early diagnosis. However, in doing so, this had important implications for *patients* as early diagnosis was implicitly

involved in constructing patients' expectations about a future with AD. Tracing interview and observation notes, the CQUIN produced particular uncertainties around patient futures as it shifted the point in time at which classification was practised. This therefore raised the debate about early or timely diagnosis as Consultant Psychiatrist 3 explained,

'So early diagnosis would be picking it up at the earliest possible stage; so somebody may not realise they've got a problem, the relative may not realise they've got much of a problem, but they might not be scoring as well as the rest of the population on testing. If you looked in more detail you may pick up that they've got an MCI, or a very early dementia, so that would be an early diagnosis would be picking up before the person has noticed a problem, or before any family member, or before it's causing any problems. Timely would be if there's been a problem identified by a family member, or by someone else, and they're concerned enough. Timely would be that they had access to services, that they can get it quickly, so that when they go to the GP is not just their age or having to wait 6 months for an assessment. Timely would be once they've identified a problem, they can get into services, get an assessment, get a diagnosis as smoothly and as quickly as possible. So timely would be when it's caused a problem and they want to know a diagnosis but not trying to screen. Essentially screening is designed for asymptomatic people, and if they're asymptomatic why are you screening for something that you can't prevent, you can't really treat? There's screening for things that you can't do anything about seems not just pointless, but harmful.'

According to Consultant Psychiatrist 3, the distinction between early and timely diagnosis had distinctive consequences when applying each approach in practice. The debate between early and timely diagnosis²⁶ was a frequent topic of discussion during interviews particularly when discussing the

²⁶ Notions of both early and timely diagnosis have been the focus of attention in recent clinical academic literatures investigating how clinicians (predominantly GPs) respond and practise timely diagnosis and early intervention initiatives (see Dhedi, Swinglehurst and Russell, 2014; Robinson, 2015).

CQUIN with clinicians. For Consultant Psychiatrist 3, early identification in the memory service was difficult to practise because of the complexity associated with the disease overall, which cannot be treated or prevented. Unlike Clinical Psychologist 3, Consultant Psychiatrist 3 resisted early diagnosis, referencing ‘timely diagnosis’ as an effective alternative. Timely diagnosis represents a more careful and considered approach to measurement of cognitive decline. It follows the *process* from diagnosis, treatment, to prognosis. The expectations that Consultant Psychiatrist 3 shared here about early and timely diagnosis were built around the availability of treatment and cure, and the ways in which clinicians conceived the nature of diagnosis overall.

Closing off futures?

I focus attention from herein on the ‘*harmful*’ *effects* and *affective* consequences of early diagnosis for patients that I frame within a broader discussion around patient futures. Developing the debate between early and timely diagnosis, Trainee Psychiatrist 1 during interview, highlighted a number of important points for analysis,

‘I also think there’s a real danger with early diagnosis of - there’s a difference between early diagnosis and timely diagnosis, a huge difference. So not everybody wants a diagnosis: I had a case recently, a still on-going case that I’m seeing next week, of a gentleman in his early 70’s used to be very, very high functioning, ran his own law firm and he came in; he had really good cognitive decline. I’ve given them a diagnosis of dementia and him and his wife are just devastated. You know absolutely devastated. He’s fit and healthy in every other way and yes that’s good for them to know about the you know and they did want a diagnosis, but after you given them that diagnosis in the clinic they then go home and then they sit and they think. They’re you know they’re literally devastated by it and you wonder you know in this case actually maybe with a kind of a couple of years of not knowing that he definitely had dementia, it might

have been good for them 'cause he's very frustrated now. He's lashing out verbally at his wife 'cause he's so frustrated and worried about the future, and maybe that's not always the best thing. But they want you know, this couple did want it and sometimes I think people think they want a diagnosis because we want to know what's causing the memory loss and they want treatment 'cause early treatment is really important you know 1/3 to 2/3's of people do respond to the medicines that we have and to slow down the progression of forgetfulness, but not everybody wants that diagnosis.'

For a number of clinicians, early diagnosis is useful for allowing patients to plan for their future and make decisions regarding future care, '*early diagnosis is so important so that you can allow people to make decisions about their future themselves*' (Consultant Psychiatrist 2). In a number of instances this was echoed during observations of team meetings where clinicians would stress the importance of making decisions about their future whilst '*they still had capacity*' (Observation MDT Nunmill Hospital). I reflected here on the extent to which clinicians actively wanted patients to be able to prepare for their future, whilst at the same time recognised that diagnosis may not necessarily be sought after by patients and family members. I develop this point further towards the final sections of the chapter. To what extent might early diagnosis therefore have the potential to close off futures in terms of anxiety and anticipation as to what the future with AD might bring? This extract from Trainee Psychiatrist 1 served to highlight these tensions. As she explained, classification and diagnosis should be handled with care given that the *anticipation* associated with diagnosis had important and at times adverse implications for patients and family members. In this case, for the patient 'the future is what matters most' (Adams *et al.*, 2009: 248), '*he's so frustrated and worried about the future*'. According to Trainee Psychiatrist 1, the patient was '*very high functioning*' and was therefore subsequently affected by the interests of diagnosis, which served to compound a theme raised in Chapters Five and Six, regarding the construction of a successful ageing process.

Trainee Psychiatrist 1 also expressed feelings of ambivalence about early diagnosis; she recognised that there may be times where patients are unsure about ‘want[ing] a diagnosis’ (c.f. Mol, 2008). Furthermore, alongside the increased focus on diagnosis overall however, the autonomy of those *reticent* towards diagnosis had the potential to be constrained. Whilst Trainee Psychiatrist 1 intimated that the consequences of diagnostic classification might engender fear about the future, to what extent might this fear be driven by constructions of self, identity and the aged body specifically related to what Trainee Psychiatrist 1 conceived as a ‘*very high functioning patient*’? Trainee psychiatrist 1’s acknowledgment that ‘*a few years not knowing*’ might be useful, echoed an argument I made in Chapter Six. Clinicians were able to take their time with diagnosis, which was constrained by efforts to increase early diagnosis rates in an ageing population. This was a point that was similarly stressed during an interview with Consultant Psychiatrist 3 when describing the CQUIN overall,

‘It’s [CQUIN] a case it seems of questionable value to me. Not just because of the demand for the service but because of the worry that it causes for patients and the lack of benefit.’

Consultant Psychiatrist 3 recognised that the patient is potentially affected by the interests of the CQUIN, ‘*worry it causes for patients*’: and anticipated the consequences of knowing. In doing so, clinicians were implicitly involved in constructing patients’ expectations around diagnosis, AD, and what the future might bring. This shifted how classification was approached in practice and the lives of patients in the present; eloquently described previously by Trainee Psychiatrist 1. Reifying the patient pathway through formal initiatives such as the CQUIN shifted the temporal orderings and constitutions of diagnosis in the present, which as I have suggested, had the potential to impact patient futures. The conditions, in which the future was constructed, produced uncertainties for both patients and clinicians in the organisation of healthcare facing current demands on both resources and time. This had important implications for resolving or dealing with the

complexities entangled in classifying in AD, and therefore making sense of AD overall.

Translating early diagnosis through initiatives such as the CQUIN was subsequently approached ambivalently across the memory service. Clinicians encouraged early diagnosis since it enabled patients in the memory service to prepare for their future and raise awareness about AD, and yet they also recognised that shifting the *temporality* of classification produced particular uncertainties and anxieties for patients. This ambivalence was highlighted most fruitfully by Clinical Psychologist 1 during interview,

‘I mean for me in one way it’s [early diagnosis] great. I think - well there’s a couple of ways in which it’s great. One way which from a patient care point of view, is that if we know early what’s going on, people have a chance to make sense of their experiences to plan and change things accordingly. For the systems around that person to adapt, both family and societal statutory and voluntary and so on and so all of that’s good. And I think you know for me, it’s the science of sort of cognitive assessment is fascinating. So I really enjoy it: reading and researching and seeing patients and working with them. So I, the downside of it all is that I think that’s something that people feel we can measure and value, and it’s something that doctors and psychologists can get involved with and label as an activity that they’re doing. They’re much the stuff about making the life of people with dementia worthwhile and improving their experience; it falls into the sort of much lower valued bracket of ‘care’, which as a society we undervalue. And so I think to a certain extent, there’s sort of a little bit of a conspiracy - not a sort of conscious one - but or a collision of motivations, that’s created this. So we can set a target for it; we can measure it; we can get doctors and nurses and psychologists to do it; we can say that it’s a difficult and complex thing that we can sell. So it’s, the Trust has an investment in them as a health economy within the health economy as a provider of

services to support that, and people's jobs depend on it, and so on: it's an industry... it's much harder to describe, it's much harder to price, it's much harder to value...to do person-centered dementia care that actually improves people's lives.'

More generally, early diagnosis, enables patients to prepare for a future with AD or '*make sense*' of their diagnosis. However, the notion of early diagnosis also has a commitment to the overall healthcare economy. The culture of practising early diagnosis is therefore entangled in efforts to improve diagnosis rates through formal measurement targets, which contribute to this healthcare economy. As a result, the experiences of patients, and care practices or what Information Manager 2 described as the '*touchy feely*' aspect of initiatives promoting early diagnosis, are undervalued in these discussions, which could lead to a '*collision of motivations*'. This created a repertoire of uncertainty in clinical practice and arguably corresponds with Latimer's (2000) claim, that the 'purity' of the clinic and clinical work does not necessarily value the role of 'social work' in medicine (pp. 122). The lack of value associated with such work is perpetuated by the increasing demands to rationalise, legitimise and measure clinical work through what she contends is a 'narrow definition' of 'evidence and efficacy' (Latimer, 2000: 22). For clinicians they were concerned that early diagnosis enacts a promissory abstraction about the future, embedded in the wider institution of the healthcare economy as '*industry*'.

This excerpt further illustrates the claims I made at the beginning of the chapter, that with the expansion of AD to incorporate the earliest stages of the disease, this reflected the broader commitment in medicine to calculate risk. More generally, this has important implications for those areas of practice that are difficult to quantify and measure. Moreover, the extract corresponds with Aronowitz (2009) who iterates when discussing the converged experience of risk and disease, 'it is, of course, difficult to measure consequences such as fear, disturbance to peace of mind, and the work of patienthood and to balance these effects against the health benefits

of new knowledge and practices...’ (Aronowitz, 2009: 439). Measuring fear and anxiety in the memory service was inherently difficult and yet as demonstrated, were the *affects* produced by the hopeful discourse around early diagnosis, as it constructed patients’ expectations around a future with AD. This fearful anticipation of AD was witnessed across the memory service.

Observed across team meetings and interactions between patients and clinicians, clinicians recognised the fear associated with the label AD (see Beard and Neary, 2012) and the possibility of a future with AD. In observations of consultations, patients would thank the clinician for not laughing or apologising for how ‘*stupid*’ they thought they were. Patients often expressed anxiety with regards a diagnostic label in relation to how they conceived AD overall, as mapped in Chapters Five and Six. Subsequently, as policy initiatives such as the CQUIN actively *promote* diagnosis they become implicitly engaged in (re)constructing this fear and anxiety for patients as the following analysis will demonstrate. I observed a team meeting at Nunmill Hospital where I noted that clinicians recognised the fear associated with AD,

‘A Memory Nurse presented the case of a patient who refused to attend an initial appointment for cognitive testing and also refused to attend a scan appointment. The consultant steering the meeting, explained that there *‘isn’t much that can be done as the patient has the capacity to make these decisions’*. A memory nurse interrupted at this point and exclaimed that this was a regular occurrence suggesting there is still a lot of negativity around the meaning of memory loss and its associations with dementia, which as she explained, *‘a lot of patients are fearful of and reject the terms’*.

Managing this fear and anxiety and the rejection of a dementia label, was an important aspect of clinicians’ work as demonstrated in Chapter Five. However, as early diagnosis reifies the patient pathway and emphasises the importance of diagnosis, this produced further anxieties which clinicians

found difficult to navigate. Tensions arose around promoting early diagnosis and maintaining the individual at the centre of medical decision-making. Whilst the CQUIN and early diagnosis more generally, creates populations of individuals at increased risk of developing AD, the implications for clinical practice in terms of the diagnosis process are important to consider. This was confirmed during interview with Clinical Psychologist 2

‘I wonder about the balance. What happens to all those people who have a diagnosis, and if there is such a value placed on them having a diagnosis, do we then lose the - do we then lose sight of the individual at the centre of it; what it means for them to have that diagnosis, how they want that to be?’

This quote from Clinical Psychologist 2 effectively illustrated the approach taken by all clinicians across the sites under investigation, that by privileging diagnosis, this had important implications for patient futures. What is interesting about this excerpt is that it relates to the points I made in Chapter Five. As shown, in order to manage uncertainty and the ways in which patients conceived the nature of the testing process overall, clinicians would approach and perform the tools with provisionality which meant that at times, clinicians would keep patients on for review as demonstrated in Chapter Six. However, what Clinical Psychologist 2 described here, is a shift from this provisionality for the protection of patient self and identity, towards a method of diagnosis, which may not take into consideration patients’ *expectations* around diagnosis. As Flaherty and Fine (2001) contend ‘looking forwards to goals or purposes of one kind or another, the self, constructs a line of action in the present by anticipating and thereby bringing into being, just those events which seem to call for an intended response’ (pp. 157). In this sense, the patient self ‘*how they want to be*’ is likely to have an impact on a future with AD in the present. Furthermore, for Clinical Psychologist 2 we must take care of diagnosis, it should be about ‘*balance*’ between navigating resources and privileging diagnosis. As she explained, the value associated with diagnosis and assessment may not map onto the ways in which *patients* conceive the nature of diagnosis. As a

result, for Clinical Psychologist 2, privileging diagnosis, at times fails overall, to locate the individual at the centre of its concerns. The sentiments of Clinical Psychologist 2 were illustrated across the memory service and confirmed by Clinical Psychologist 3 who argued that early diagnosis produced particular anxieties for patients about future care practices.

‘It’s a really difficult balance to strike here isn’t it because early diagnosis absolutely is very important, and good media coverage; and the general population becoming much more aware of the symptoms of dementia; and of dementia as such in terms of kind of dementia friendly societies and communities it’s hugely important. I would definitely subscribe to that, but the other side, the flip side of that coin is that you can potentially create huge anxiety in the worried well or in what is not necessarily a process that needs to be pathologised. So I don’t know whether I’m clear of what I’m trying to say, because there’s a great danger with pathologising it because with pathology comes great anxiety. With pathology also comes a whole biomedical kind of culture and system of something that perhaps isn’t best addressed in a biomedical environment but more in a community kind of environment’

The hopeful discourse around diagnosing AD is that ‘earlier is almost always better’ (Lebowitz, 2004: 350) which is promoted through popular culture and media discourse. Paradoxically, as Beard (2012) argues however, ‘contemporary public perceptions and media portrayals of Alzheimer’s are almost exclusively pejorative’ (pp. 12). This has the potential to produce particular uncertainties around patient futures in the present or the ‘*worried well*’. In part, this is entangled with the fact that despite the uncertainties associated with diagnosing AD which are recognised in practice and policy, managing the disease remains within a biomedical framework. In terms of what Clinical Psychologist 3 described as ‘*anxiety*’ for patients, the overarching biomedical model for managing AD is therefore implicit in constructing patients’ expectations around a

future with AD as the following extract from an interview with Consultant Psychiatrist 1 clarified,

‘It’s very difficult isn’t it because we don’t have a cure because there’s a limited number of things we can actually offer to people: are we just giving them more years of anxiety? And you know sort of this sort of ‘Sword of Damocles’ isn’t it hanging over you sort of. I think it is going back to the cancer analogy in some ways, it not the same as cancer because cancer’s got potentially curative treatments etc. I suppose the converse argument is though that we know that the state of treatments is poor within Alzheimer’s dementia or dementia generally; Alzheimer’s and Lewy body being the only ones that actually got any treatments. And it’s only I think by increasing our population, and our awareness, and a profile of it both locally and sort of nationally and globally, that potentially we’re going to have more interest from pharma and other companies and doing the research that will therefore hopefully leads to sort of population benefits in the long run. So yes it’s a double edged sword.’

For Consultant Psychiatrist 1, classification is ‘*difficult*’ and this excerpt made it clear that to diagnose without a ‘*cure*’ requires handling with care because it has the ability to increase ‘*anxiety*’ in those diagnosed; rendering ‘hope and fear’ (Adams *et al.*, 2009: 248) key components in the driving of classification. As Consultant Psychiatrist 1 explained, diagnosis therefore represents the ‘*Sword of Damocles*’ embodiment of foreboding regards diagnosis; an affective state. The future of AD is uncertain in terms of cure and treatment, which created the space of ambivalence confirmed by Clinical Psychologists 1 and 3. It also had the potential to prolong the anxieties felt by patients as it shifted the point in time at which cognitive function was assessed. Whilst keeping patients on into the future was predominantly valued across the memory service as demonstrated in Chapter Six, clinicians also recognised that not all patients actively sought a diagnosis. I also witnessed the ‘*double edged sword*’ described by

Consultant Psychiatrist 1, during an observation of a team meeting at Ridge NHS Centre,

“A memory nurse presented the case of a patient who they described as ‘*cognitively deteriorating*’ in terms of loss of memory and loss of physical functioning. The memory nurse explained that the patient and the patient’s family were keen to know whether they could discuss treatment options. The registrar steering the meeting interrupted at the points and suggested this would be like ‘*clutching at straws*’ and the memory nurse agreed since the cognitive screening test was ‘*very low*.”

Throughout this thesis, it has become clear that the complexities associated with diagnosing AD overall, were constituted both in the act of diagnosis and the lack of treatment and curative options post-diagnosis. Negotiating the complexity in the MDT, clinicians were therefore faced with the knowledge that for some cases, providing treatment would be like ‘*clutching at straws*’. Reflecting on my observation here, I am not suggesting that clinicians were making such decisions with ease, rather it was clear from observations and conversations with clinicians, that as described during a team meeting at Nunmill Hospital they felt ‘*torn*’: on the one hand seeking to diagnose patients, and at the same recognising the lack of options in terms of treatment and care. When patients were referred at earlier stages, this presented further challenges for both clinicians and patients particularly around the availability of treatment at earlier stages. However, whilst I have suggested thus far that clinicians and patients were affected by the temporalities of early diagnosis, there was also a collective agreement in the memory service, that clinicians did not want patients to reach a point where they *could not* exercise autonomy or agency. I observed a team meeting at Nunmill Hospital where these tensions were apparent,

“The consultant psychiatrist presented the final case of the meeting. She explained that the patient has a lack of insight in relation to their dementia diagnosis and looking to colleagues for support here, she

contended this was problematic because it meant that *'patients are waiting until a 'crisis point', 'wanting to cross the bridge when they come to it instead of dealing with the situation straight away.'*"

This observation reflected what was broadly the case across the memory service, that despite the anxieties that the promotion of early diagnosis produced for individuals, clinicians were concerned that patients were *unwilling* to mobilise for the future and instead were waiting for a *'crisis point'*. Conflicting representations of temporality therefore emerged: according to the consultant in the team meeting, by waiting for a crisis point, the timeframe in which both patients and clinicians had to make clinical decisions was narrowed. At the same time, and as demonstrated throughout this chapter, clinicians recognised that promoting early diagnosis through efforts to calculate risk, had important implications for patients in the present. The CQUIN and promotion of early diagnosis more broadly, institute particular representations of temporality and of the future, which had important implications for clinical practice and around patients' expectations regarding what a future with AD might bring; shifting the process of classification in the present. Subsequently, the temporal orderings of early diagnosis and its affective consequences correspond with Mead's conceptualisation of the future, 'there you have the future, the conclusion of the act, implied in what is now going on but which is not yet achieved, coming in to set up the conditions in terms of which stimuli shall arise' (Mead, 1936: 156).

Summary

In this chapter, I have captured how efforts to increase diagnosis rates at earlier stages through initiatives such as the Dementia CQUIN, translated in everyday clinical practice. Despite not having the opportunity to follow the CQUIN through hospital practice, its effects have been observed in the intricacies of memory service practice, since it is explicitly involved in reifying the patient pathway across practices of care. I began the

chapter by exploring the extent to which the CQUIN, as a method of clinical governance for calculating risk, was approached by information managers and the lead clinician for the CQUIN. I recognised the opportunity I had to analyse the CQUIN in terms of the ways in which it might shift professional identities and autonomies in healthcare practice, as it created a focus on paperwork rather than practice. However, what is interesting about my own analysis from tracing interview accounts with information managers and the lead clinician, is that they were overtly aware that the CQUIN might simply be viewed and therefore practised as a simple paper based exercise. In doing so, they actively engaged with, and responded to this, by projecting the CQUIN beyond its role a performance measure, to its role in preparing and anticipating the future patient pathway for patients. Drawing on the analytical standpoint of the sociology of expectations, I have attempted to demonstrate that through the “‘real time’ activities” (Brown, Rappert and Webster, 2000: 4) of information managers and the lead clinician for the CQUIN, the CQUIN reifies the patient pathway in an attempt to manage the uncertainties associated with identifying AD in the hospital setting. Whilst information managers and the lead clinician for the CQUIN contended that the CQUIN sorts the complexities associated with the patient pathway, this was however, a point of contention across the hospital setting and memory service.

Analysing the CQUIN in terms of the future and therefore as a particular temporal abstraction, troubled dominant constructions around risk and calculating futures, since the CQUIN had direct implications for representations of time *in the present* for patients and clinicians alike. Translating the CQUIN in practice, *produced* rather than managed uncertainties for both the organisation of healthcare and patients in the clinic. As the initiative was implicitly involved in shifting the representations of temporality in the present, this had important implications for the content of work in hospital, and the point at which cognitive decline was assessed and approached. It implicated the ways in which registrars and junior doctors approached and assessed cognitive function in the hospital setting, and directly impacted memory service practice in terms of

increasing referral rates. This point has been demonstrated in my study despite the fact that the CQUIN as a specific initiative for increasing referrals was relatively elusive in discussions in the memory service. Therefore attempting to reify the patient pathway, the CQUIN produced further uncertainties. What is interesting is that more generally, the initiative is pitched as a mobiliser of resources. However, within the current organisation of the healthcare service facing huge demands on both finances and time, this was difficult to practise. As the CQUIN prepares to mobilise resources by privileging diagnosis, this affected and reproduced the uncertainties it is expected to sort for both clinicians in terms of professional responsibilities, and patients in terms of a future with AD, since care as a viable alternative for managing AD overall, is missing. This had important implications for how diagnosis was approached, assessed and dealt with in the clinic, further impacted by the urgency to detect the disease at earlier stages.

In the second section of the chapter, I explored how the CQUIN institutes a further dynamic and dimension of time in relation to early diagnosis. For a number of clinicians in the service, the CQUIN and commitment to early diagnosis overall, was implicitly involved in constructing the expectations around patient futures, which had important implications for how patients and clinicians responded to diagnosis. As I demonstrated in Chapters Five and Six, clinicians performed cognitive screening tools with provisionality. They practised mediation and manipulation work to navigate and manage the uncertainties associated with measures of cognitive decline. In Chapter Five, I demonstrated that this was much to do with navigating how patients conceived the nature of testing linked to discursive constructs around mental health and AD overall. In Chapter Six, I demonstrated how clinicians kept patients on into the future, driven in part by the expectations patients held about a future with AD. This provisionality had the potential to be constrained by the CQUIN and promotion of early diagnosis more broadly. Clinicians therefore, were continually navigating what they recognised as the uncertainties produced by this shifting temporality of classification, both on a local level in the clinic, and in relation to managing the ageing

population. Tensions arose however, as clinicians were also acutely aware of the importance of enabling patients to prepare for their future through early diagnosis: ambivalence was collectively observed across healthcare practice. There was also a collective concern amongst clinicians, that the material resources post-diagnosis, were failing to meet the needs of patients since AD overall, cannot be treated or cured. The shifting temporalities instituted by the CQUIN and early diagnosis more broadly, shifted current practice, which had important implications for patient futures, and the future of the reified patient pathway.

Throughout this thesis, I have attempted to capture the intricacies of power relations as performed within the everyday practices of the memory service, to make sense of the complexities associated with diagnosing AD. This included drawing attention to professional hierarchies and responsibilities, and the role of the MDT for negotiating the medical decision making process. Thus far, the networks of practice and clinicians in their different approaches, views, and perspectives across particular settings and points in time, interrelated and intersected for the purpose of making the tools and diagnosis work (c.f. Mol, 1998, 2002a). Yet, as I identified in the second section of this chapter, the wider political networks of power, which drive initiatives such as the CQUIN, produced particular uncertainties in everyday practice, for both patients and clinicians. One dimension of this, was confirming the uncertain relationship between diagnosis and prognosis, and the second dimension involved the ways in which clinicians struggled against feelings of ambivalence about early diagnosis. Developing the claims of Michael (2000), and the idea that with futures are entangled both positive and negative futures, the concerns raised by clinicians in terms of patient anxieties, were often invisible or tangential within the overall, promotion of early diagnosis. Yet, as I demonstrated, everyday practice was constrained by the introduction of the CQUIN and early diagnosis more broadly. This reflected the broader distributions of political power through which cognitive screening tools and AD were being managed and governed overall, which had important implications for the *futures* of AD realised in the present. Combined with constraint to clinical autonomy, clinicians in the

memory service and hospital setting were facing the very challenges that they set out to negotiate in everyday clinical practice. The points of analysis I made in this chapter however, have been made for the purpose of further discussion, rather than conclusive arguments, since I had limited observation data to follow the CQUIN through healthcare practice.

Chapter Eight

Discussion

In the preceding chapters, I explored the constitutive role of instruments for screening cognitive function, as they were used to navigate and manage the uncertainties associated with Alzheimer's disease (AD), a disease, which is difficult to categorise and therefore diagnose. As Chapter Two illustrated, categorising AD is a complex process reflected in the attempts within medical and scientific arenas, to determine the boundaries, cause of, and cure for the disease. Concurrently, Science and Technology Studies (STS), medical sociology, philosophy and anthropology literatures, have shown how these processes are informed by, and express AD's socially, culturally, and historically constructed categorisation from its inception in 1906. In Chapter Two, I highlighted how AD could be framed within, and intersected across, key debates around diagnosis as a social process (see Blaxter, 1978; Rosenberg, 2002, 2003; Jutel, 2009); disease categorisation and classification (see Gubrium, 1986; Bowker and Star, 2000; Gaines and Whitehouse, 2006; Rosenberg, 2006); the construction of normalcy and pathology (see Gubrium, 1986; Aronowitz, 2001; Whitehouse, 2004; Whitehouse and Moody, 2006; Mendelzweig, 2009; Moreira, May and Bond, 2009); and wider debates around medicalisation and biomedicalisation (see Estes and Binney, 1989; Conrad, 1992; Armstrong, 1995; Clarke *et al.*, 2003; Kaufman *et al.*, 2004; Conrad, 2005). Despite AD being central to a number of these wider sociological and STS debates, the ways in which an AD classification is accomplished in the clinic through the use of available technologies, is an under researched area in previous literatures. Cognitive screening tools are low-technological and yet pervasive devices in healthcare, since their introduction in the 1960's. Their sociological significance until now however, has been relatively overlooked, particularly when compared to the innovative technologies, which dominate interest in STS. As I have demonstrated in this thesis, the operation of, and interaction with these tools in practice, as a *whole* is important for understanding how uncertainty is negotiated, and therefore knowledge about

AD produced, in a complex division of labour in healthcare. Complexity arises both in terms of the difficulties associated with classifying AD, and of the challenges posed by the ageing population. These tools, which inform initial consultations, therefore perform central roles in mediating and helping to define and manage cognitive decline. As a result, I analysed the role of the tools in the clinic, and their adoption in the National Dementia Commissioning for Quality and Innovation Framework (CQUIN). A policy framework, which aims to control and thereby increase referral and diagnosis rates for AD, in order to manage the proliferation of individuals anticipated to develop the disease.

Observing initial consultations and therefore drawing on ‘thick descriptions’ (Geertz, 1973) of clinician-patient interactions, I began my analysis in Chapter Five by investigating the ways in which clinicians navigated and managed three core areas of uncertainty. First, in relation to the difficulty associated with diagnosing AD overall, second, in relation to the ambiguities associated with the tools and third, in relation to the ways in which patients conceived the nature of diagnosis overall. I described how clinicians handled these uncertainties within the situated and socio-material culture of the clinic, through mediation and manipulation practices. The role of the tools and their constituent values were negotiated and enacted across the memory service, as all professionals across the clinical hierarchy were engaged with approaching and thereby performing the tools as provisional devices. I referred to this as the ‘making of provisionality’, stressing that this does not denote a normative downgrading of the tools in the clinician-patient interaction. Rather, their provisionality, was made across the service, and was important for rendering the tools manoeuvrable and mobile across particular settings. Broadly speaking, as they shifted across different settings from patients’ homes to the MDT, they served to sustain the power relations within the memory service, whilst at the same time crafting a unique space for the role of memory nurses. Given the increased delegation of tasks to memory nurses including initial consultations, memory nurses attached social and cultural significance to the classification process in practice. However, as their work was transported into the multi-disciplinary team

(MDT) meetings, their work was transformed and reclaimed by professionals occupying positions higher up the professional hierarchy, confirming that the tools produced and reproduced professional hierarchies. I therefore concurred with Berg (1996) that the tools mediated professional hierarchies for the organisation of healthcare. Developing Berg's (1996) work however, I suggested that rather than the clinician-patient interaction and the MDT encouraging different representations of the tools, in fact the tools were (re)constituted in these spaces.

In addition, I also captured the ways in which clinicians balanced the informal or ad hoc practices engineered into the tools, and the quantified outcome on the tests. In doing so, particular dynamics of provisionality were witnessed across the hierarchy of the memory service. Extending Berg's (1992) claims that routines are important for managing the potential 'chaos' of ad hoc practice, I showed how these routines were continually shifting and open for negotiation. As a result, the quantified outcome was both reconstructed to fit the clinical work to account for individual particularities and situational exigencies in and beyond the confines of the clinic, and yet at the same time, valued as a 'black boxed' device (see Latour, 1987). Herein, the portability of the tools rather than routines of practice became crucial for proceeding with classification. It was the portability of the numerical outcome across a complex distribution of medicine that was significant in the memory service. Within the performative architecture of the clinician-patient interaction, the tools were, in Berg's (1996: 501) terms, brought to 'life'. Yet simultaneously, the formal quantifiable outcome was necessary for bridging the complexities of the distribution of medicine, and for enacting the tools as central mediators for proceeding with classification. A moment of co-production therefore occurred, whereby the formal quantified outcome and the informal practices of the clinic, aligned for proceeding with classification since the formal does not 'stand 'powerless' in the face of the contingent and interactionally achieved nature of the social' (Berg, 1996: 515). For AD in particular, it was the *portability* of this formal work performed in the hierarchy of the memory service, which enabled the

classification process to proceed and for clinicians to make sense of complexity.

In Chapter Six, I illustrated how cognitive screening tools were used to constitute the boundaries of classification across the memory service as clinicians *mobilised and valued* – rather than closed down - the uncertainties associated with diagnosing AD. Clinicians exploited the borderline score on a cognitive screening tool, as a way of keeping patients on for review, as the enactment of risk played out in the clinic. Creating a space for deferral and utilising uncertainty (to develop the work of Latimer (2013)) was fuelled by the possibility that patients may go on to develop AD. The clinic was an important space for producing knowledge about uncertainty. Rather than disposing of uncertainty, it was actively valued by clinicians, which in part led to this space for deferral. In the face of hopelessness about diagnosis and treatment options, and fuelled by the production of a borderline score, this space enabled clinicians to keep patients on for review. I continued analysis of the *portability* of this borderline score as a means through which the boundaries of professional groups could be bridged, as neuropsychology was called on to sort the uncertainty embedded in a borderline score. This space for deferral was therefore articulated as a privileged space for neuropsychology, and moving beyond the numerical borderlines, became both a technological and organisational endeavour. The expectation held by psychiatrists was that psychologists have a well developed and sophisticated, technological ‘tool box’ to draw on, and expertise and experience, to adjudicate on the significance of a borderline score. This expectation was *projected* on to this group of actors by psychiatrists but also emerged in MDT meetings. Psychologists were able to legitimately call all actors into account (Latimer, 2004) for the negotiation of the borderline.

In addition, a borderline score was also mobilised when making decisions about employing the label Mild Cognitive Impairment (MCI). However, this extended beyond attempts to formalise or calculate risk. Here, key themes within the literatures on medicalisation and biomedicalisation (Armstrong, 1995, Conrad, 2005) were helpful to support my argument that

the problematisation of ageing itself, was implicitly involved in the construction of discursive accounts of ageing and AD. This affected the extent to which both clinicians and patients approached the term MCI and the constitution of the boundaries of the disease across the organisation of healthcare. Across this chapter, I suggested that whilst the space of deferral was constituted primarily on the risks associated with developing AD on presentation of a borderline score, it was also built on the expectations that clinicians held about the field of psychiatry. In essence, a further moment of co-production occurred for negotiating complexity in the clinic: entangled with risk were the expectations around the field of psychology, which aligned for proceeding with classification and moving beyond the borderlines. The moment of diagnosis witnessed in this chapter however, also highlighted the agency of the patient, the art of discretion in the clinic, and the ways in which clinicians approached diagnosis with care in light of individual particularities, and with respect to keeping patients on in the service.

I extended the theme of risk and expectation in Chapter Seven by focussing on the ways in which clinical governance initiatives such as the National Dementia CQUIN, translate into everyday clinical practice. Employing the term translation, I captured the interactions, negotiations, interpretations and points of contention, at which the principles of the CQUIN were negotiated and handled in practice. In the UK, the increasing ageing population drives initiatives such as the CQUIN, for monitoring and increasing referral and early diagnosis rates for AD, and dementia more broadly. I showed how this initiative could be used to highlight shifting professional boundaries, identities, hierarchies and autonomies; a theme developed in much of the medical sociology and organisation studies literatures. I developed my analysis however, by demonstrating that the CQUIN enacts a particular representation of a *future* with AD as it reifies the patient pathway, which produced as opposed to resolved the uncertainties it is expected to manage. The CQUIN thus affected and shifted the temporalities of the content of work in the hospital setting, and the classification process to earlier stages,

and therefore the point *in time* at which cognitive decline was assessed, approached and therefore managed. This had important implications for both the organisation of healthcare and for patients' expectations around a future with AD. The CQUIN implicitly constructed patients' expectations around a future with AD as it reified the patient 'pathway'.

More broadly, my thesis contributes to the analysis of the practice of medical technologies, and the multiple constitutions of AD across socio-technical arenas (Berg, 1996; Mol, 1998; 2002a) where key aspects of medicine including uncertainty, risk, medicalisation and biomedicalisation are to be found. It also extends this literature in three ways. Firstly, it draws attention to the role of mundane technologies used to detect the initial stages of cognitive decline through which diagnostic decisions are negotiated. The role of low-technological, mundane technologies in this process is an under researched area of previous literatures, particularly those exploring the social framing of the disease category, and the consequences of medicalisation and biomedicalisation. Yet, these mundane tools play a central role in detecting cognitive decline in the ageing population. The role of the mundane in terms of analysing medical technologies in healthcare is also a dynamic under researched in STS literatures, which tend to focus attention on innovative, disruptive diagnostic technologies for example, MRI scanning (see Joyce, 2008) within socio-technical environments for producing knowledge about disease. The power of the mundane is revealed across this thesis.

Secondly, this thesis demonstrated both the everyday and routine role of the tools in the intricacies and networks of the clinic, and yet it also demonstrated how their adoption on a macro scale implicated the locality of the clinic: the power of the political within the arena of classifying AD was addressed. Thirdly, it confirmed that the relationship between medical technologies, diagnosis and prognosis is a process of continual and embedded routine and repetition across healthcare. However, in the locality of the clinic, as complexities emerged which were unanticipated and disruptive, and because of the complex distribution of medical practice,

these routines were continually shifting. Furthermore, on a macro level in an ageing population, where organisations are faced with handling an increasing number of individuals with AD, reifying the patient pathway through the CQUIN more generally, does not necessarily lead to closure for a disease that is difficult to cure and treat.

The overall aim of this thesis was to investigate how uncertainty and complexity were managed for making sense of classification and producing knowledge about AD. The conceptual framework underpinning this thesis has been developed as a way of understanding how to manage and resolve uncertainty. Therefore, embedded within these three broad developments is a key concept established from my findings, which extends what is known about age, diagnosis and medical practice generally, and with reference to AD more specifically. Across my thesis, I developed the conceptual framework of portability through which I mapped and demonstrated the spatiality and temporalities of classifying AD across professional hierarchies: portability became necessary for making sense of complexity. I use the term ‘portability’ in this chapter, to illustrate how the multiplicity of AD hangs together, and for demonstrating how complexity was resolved. However, I also highlight that the multiple enactments of AD built around this portability concept, did not always cleave at neat points, which was impacted in part by the wider structures of political power, shifting current practice. These included initiatives such as the National Dementia CQUIN, which aims to increase referral and diagnosis rates in order to manage the ageing population.

Through the conceptual framework of portability, I captured how cognitive decline was constituted across socio-technical and political arenas, and socio-material practices. As I clarified, the concept of portability was not unbounded and atemporal, but was, temporal, spatial, hierarchical and at times chaotic. The *ontologies* of AD were therefore constituted in spaces, which were temporal and bounded, which had important implications for managing diagnosis in terms of the ageing population. The emergence of portability, I initially attributed to the ways in which the technologies were

articulated in the interactive processes, and space of the clinic. The concept of portability was born out of the myriad of ways in which clinicians were able to approach and perform the tools as provisional devices in the interpretive repertoire of the clinic. The *values* of the technologies were *constituted* which reflects the arguments made by Dussauge, Helgesson, Lee and Woolgar (2015) that technologies do not hold *intrinsic* value but are made in practice: seen in this thesis in the clinic through the lens of provisionality.

The mediation and manipulation practices witnessed in the clinic could also broadly represent what Mol, Moser and Pols (2010) describe as ‘care work’, performed in order to navigate and manage uncertainty (pp. 15). Clinicians across the memory service adapted their narration of the tests and the technologies *in situ* (for example, changing the questions on the tests), in order to cope with the uncertainties produced by measures of cognitive decline. This was shown to include the discursive constructs around ageing, AD and mental health more broadly, the difficulty for clinicians to determine a definitive diagnosis, and the ambiguities associated with the technologies overall. With reference to the discursive constructs around age, AD and mental health, the technologies were also implicitly involved in protecting patient identity through the actions of clinicians. Patient identity was constructed within the initial consultation, where the presentation and performance of self, shifted how the clinicians used and approached the tools. As a result, this thesis has contributed to understandings regarding patient selves and identities constructed and potentially *disrupted* by the testing process and diagnosis process overall. As I captured in the clinic, patient identities were constituted around negative discursive constructs around AD, ageing and mental health, that remain in existence in the general population. The work of Goffman (1969) was useful for framing this aspect of my analysis and the mediation and manipulation practices witnessed, in recognition of these discursive constructs for re(constructing) patient identity.

Portability was also an important concept for considering how matters were resolved when the informal or ad hoc practices through which the tools operated were valued in practice. Despite agreeing with Berg (1992: 169) that locally situated routines are important for ordering ‘chaos’, I developed his argument by suggesting that the routines for classifying AD were perpetually shifting and actively reflected on by clinicians, within and beyond the confines of the clinic *because* of the continually emerging moments of complexity. Therefore at the same time that routines were important (i.e. reconstructing the data to fit the clinical work) for negotiating complexity *in situ*, it was the *portability* of the quantified outcome of the tools rather than routine, that brought social order to these informal practices in the memory service. In turn, the complexities constitutive of the clinic were transformed into manageable problems for both patient and clinician through the articulation of the technologies in the clinic (Berg, 1996). This therefore accomplished the provisionality of the tools in the clinician-patient interaction. The tools were given meaning through the actions of clinicians; (re)constituted and entangled in the social and clinical work of the clinic. Overall, the interpretive repertoire of the clinic enabled clinicians to approach and thereby perform these tools as provisional devices in response to the uncertainty in which AD is entangled more broadly.

The enactment of provisionality however, was multiple and textured; layered through points in time and across different settings and actors. At the same time that it was ‘made’ through the navigation of uncertainty produced in the clinic, it was also seen through the lens of the dominance of the clinic (not necessarily a point unique to the study of AD) (c.f. Latimer, 2013). Across medicine, clinical judgement remained an important method for navigating uncertainty as it was practised in response to a level of uncertainty that the technologies had failed to achieve (Atkinson, 1984). Practising clinical judgement across the memory service was therefore integral to the performance of the technologies. I argued that clinical judgement added a further dimension to the making of the tools as provisional devices, afforded the responsibility of those actors occupying

positions higher up the professional hierarchy including consultants (c.f. Latimer, 2013). Therefore, I demonstrated the *dynamics* of provisionality and the dominance of the clinic: memory nurses practised provisionality through mediation and manipulation practices, and consultants approached provisionality by privileging clinical judgement given their expertise and experience. Developing this point further however, it was the performative architecture of the clinic that encouraged a further dynamic for the making of provisionality, and where the first *practical* moment of portability was witnessed. The interesting point here is that the making of the tools as provisional devices shifted across the professional hierarchy: consultants exercised clinical judgement in the clinic (Bosk, 1979), and memory nurses often attached significance to what was culturally and socially significant (Latimer, 2000; Latimer, 2004). The collective line of agreement however, across the memory service was that these technologies required this level of mediation, to navigate and resolve the complexities unique to AD. Clinicians recognised the situated occasions and individual particularities for classifying AD, and the dynamics of this mediation work were observable across the professional hierarchy.

There is much to be said for the space of the clinic and within it clinical judgement for constructing the medical-decision making process (Berg, 1996; Latimer, 2013). Yet, in the process of diagnosing AD, the space of the clinic was at times a barrier to both the performance of the technologies, and therefore the management of uncertainty. The discourse of the clinic made the practising of the tools difficult, and the mediation and manipulation practices complex. The space, context and conditions of the clinic, impacted the articulation of the technologies for dealing with uncertainty. The clinic was imbued with negativity around what it means to be diagnosed, described by a number of professionals as '*white coat syndrome*'. The role performance of the clinic in this sense, affected how cognitive decline was assessed further affecting patient identity. Agreeing with Latimer (2004) that clinicians (particularly memory nurses) attached significance to what was socially and culturally significant, I introduced patients' homes as a unique space for navigating uncertainty. As the tools were transported into

this space, clinicians (the majority of whom were memory nurses) were able to exercise further provisionality. Within this space, knowledge was distributed across both the tools *and* the materials in patients' homes. Moreover, as only the memory nurse and the patient occupied this space, the work of memory nurses could not be *immediately* called into account or transformed by those higher up the professional hierarchy (c.f. Latimer, 2004). This is not to suggest however, that the tools did not simultaneously produce and reproduce professional hierarchies. Within MDT occasions, the significance of the work of memory nurses was then transformed by consultants in order to proceed with classification. The tacit knowledge systems and the practising of clinical judgement worked alongside what was culturally and socially significant in the classification process and the mediated performance of cognitive screening tools. At this point, I reiterate that despite the making of the tools as provisional devices, I am not suggesting that this equated to the downgrading of the technologies. This is a normative assumption and suggests that these tools hold intrinsic value, which users fail to recognise. Rather, we need to see the value of these tools not in terms of their putative design and purpose, but how their role as articulated and *made* in the clinic renders them *important* tools in the classification process. This is further suggestive of the co-production between formal and informal practices observed in the clinic.

Throughout my thesis, I have demonstrated the ways in which clinicians were continually finding value in uncertainty, which was highlighted most significantly when there was discrepancy over the boundaries of disease. In order to deal with complexity, the technologies played an important role in the interpretive repertoire of the clinic. Diagnosing Alzheimer's disease however, particularly in terms of determining 'tidy boundaries' (Cox and Webster 2012: 400) for the disease is complex, which rests partly on the performance of cognitive screening tools. Subsequently, it is fruitful therefore to elucidate the ways in which clinicians approached the *risks* enacted by a borderline score on a cognitive screening tool. Risk was dealt with in two significant ways in the memory service. First, risk was mobilised by clinicians for keeping patients on for deferral, and second,

through the expansion of the disease to incorporate the label MCI. MCI was however, a point of contention across the memory service. Overall, I developed Latimer's (2013) arguments, that uncertainty was utilised and mobilised within this space of deferral. However, entangled with risk for constituting the boundaries of classification were the *expectations* around the field of psychology in terms of the technologies used, and specialist expertise and experience. At the same time that a borderline score mobilised uncertainty it also became portable across professions. As a result, both the expectations around the expertise and experience of psychologists along with the technologies in this field played an enhanced role in constituting the boundaries of disease. Constituting the boundaries of AD reflected the complex distribution of labour across the service, and the ambiguities associated with cognitive screening tools. My analysis also demonstrated the co-production of the boundaries of AD built around risk, expectation, and the division of labour in the memory service. Here I concurred with Lock (2013) and argued that uncertainty dominates understandings of, and approaches towards, MCI in particular. Yet I also demonstrated that clinicians were continually crafting meaning out of uncertainty; keeping patients on in the service in order to make sense of diagnosis in everyday practice. I showed how this uncertainty and lack of clarity had important implications for professional practice; uncertainty mobilised work in the service and had value in itself.

Mobilising and subsequently valuing uncertainty for the space of deferral required psychiatrists in particular, to demonstrate willingness to adapt to new and emergent hierarchical structures. It became the role of psychologists to reclaim the work of psychiatrists, and make decisions about moving beyond the borderlines. In my study of the memory service, psychiatrists projected their expectations about the expertise and technological skill set of psychologists onto this field, and psychologists performed this privileged position in the MDT *legitimately* calling all actors into account (Latimer, 2004) in order to make decisions about constituting the boundaries of classification. Overall, this demonstrated that on these occasions medical technologies had the ability to produce and reproduce the

intricacies of hierarchical work in healthcare. A key aim of this thesis overall, was to elucidate the initial processes of classification and the role of technologies for navigating the complexities entangled in this process. There were only a couple of occasions where clinicians performed diagnostic decisions during initial consultations. The diagnostic appointment that I did observe, the patient played an important role when clinicians were faced with making decisions about keeping patients on for review or making a diagnosis. What I emphasise here is that the borderlines of classification were not solely enacted by the technologies; clinicians accounted for individual particularities *in situ* which again reflected the co-production of the tools in practice.

Despite the portability of the tools across professional boundaries, this space of deferral however, was not unequivocally constituted across the memory service particularly when making decisions about the label MCI – the space remained ambiguous. I argued that the label MCI enacts the ‘language of risk’ (Webster, 2002: 447) and yet at the same time, was a point of contention across the memory service. It is tempting to make conclusive arguments that the label MCI and the expansion of AD overall, is a consequence of medicalisation and biomedicalisation processes infiltrating the practices of the clinic. At one level, I concurred that the label MCI constituted the effects of biomedicalisation, and argued that it demonstrated increased efforts to detect or problematise cognitive function. I also highlighted that the problematisation of ageing led to discrepancy across the memory service about the development of MCI to AD. I extended this framing however, by exploring the *consequences* of the ‘problematization of normality’ (Armstrong, 1995: 482) contending that clinicians were not simply passive respondents to medicalisation. They actively recognised the consequences of efforts to problematise normality since as I have shown across this thesis, negative discursive constructs particularly around the successes or merits of ageing, impacted how patients conceived the classification process. As I demonstrated in Chapter Seven, this problematisation produced uncertainties and anxieties around a future with AD.

At times, the label MCI was employed to enable clinicians to label pathology *without* having to employ the label AD. The extent to which this affected the meaning of AD and the ways, in which patients conceived the label AD, was a point for further discussion. Perhaps the expansion of AD to incorporate MCI or those high functioning patients with MCI, had the potential to construct what Aronwitz (2009: 436) describes as ‘impossible expectations’ around AD since some individuals will simply be unable to perform these expectations as high functioning individuals and therefore ‘live well’ with AD. AD is therefore entangled in negative discursive constructs around the expectations of what it means to age, and a future with an AD diagnosis. This drove a number of clinicians to label patients with MCI, which as a result problematised ageing. Subsequently, there were moments across the memory service where clinicians were implicitly involved in constructing patients’ expectations around what it meant to age as either a success or failure (Gilleard and Higgs, 2013). The expansion of AD thus shifted not only the meaning of AD but also the meaning of ageing. Resolving the boundaries of classification and moving beyond the borderlines was therefore a social, technical and cultural process, which reflected the extent to which age and ageing overall, are dynamic, discursive processes. Constituting the boundaries of AD also highlighted the contradictions present around age and ageing, for employing the label MCI. The status and therefore meaning of MCI was a matter of contention across the service, and a number of factors were attributed to its resolve. I concurred with Peters and Katz (2015) that the anxieties around the ageing process are entangled with the ways in which ageing is constructed as a success or failure of which memory loss is a significant factor. This was particularly the case when discussing early diagnosis with clinicians and the emergence and popularity of MCI. Yet, I also showed that MCI was performed ambivalently by clinicians. At the same time that clinicians expressed their concern that the label would produce further uncertainties and anxieties for patients, it also enabled clinicians to keep patients on in the service; mobilising uncertainty within a complex distribution of medical practice.

What my analysis pointed to more broadly was a further moment of co-production of cognitive decline; constituted through efforts to manage and make sense of risk, and also account for patients' expectations around age, ageing and AD as marked successes or failures (Gilleard and Higgs, 2010, 2013; Higgs and Gilleard, 2014).

Within my analysis overall, and the moments of provisionality and portability witnessed thus far, were particular dimensions of time important for accomplishing cognitive decline, and making sense of classification. The distribution of knowledge across space was therefore temporal and the different temporal orderings for classifying AD was an important point to highlight, which I will discuss in the remainder of the chapter. It is well established particularly in the field of STS that classification is a temporal process (Bowker and Star, 2000). Although Mol (2002a) speaks of reality as moving *too fast* to be explained by the orders of institutions and societies, this effaces the realities of classification which are made and unmade in particular conditions and through actions in practice - at what point and *who decides* whether things speed up, slow down and shift *in time*? The multiple moments of temporality, which interrelated and intertwined across the classification process, in this thesis did not always meet or cleave at neat points, producing further uncertainties around the classification process. This had important implications for patients and for the practicalities of healthcare more broadly. I therefore addressed the concept of time at different points throughout this thesis for negotiating how classification was resolved.

Throughout my thesis, the different kinds of temporal orderings through which complexity was resolved and navigated have been an important theme. I have drawn on literatures including Mead (1936) and Adams *et al.*, (2009), to demonstrate the shifting dimensions of time and its effects on clinical practice in the present: from clinicians exercising their agency in taking their time with patients particularly in the home environment, to the time at which clinicians deferred patients to neuropsychology, to clinicians keeping patients on into the future. Concurrently, MCI also represented a

further dynamic of temporality: the expansion of the disease pushed the boundaries of AD to detect the condition at earlier stages. Time was therefore a key driver of how the classification process was accomplished. Yet, this localised temporality was bound by a different delocalised temporality, as I argued in my analysis of the National Dementia CQUIN. As initiatives for increasing diagnosis rates were implemented in practice, they necessarily worked to *speed up* the time it took for diagnostic assessment, and the point *in time* at which cognitive decline was assessed and therefore problematised.

To address the issue of time, I drew extensively on the sociology of expectations literature particularly in Chapter Seven (see Brown, Rappert and Webster, 2000; Michael, 2000; Brown and Michael, 2003; Borup *et al.*, 2006; Selin, 2006). I explored how initiatives which govern the use of cognitive screening tools for managing increasing diagnosis rates, created particular temporal orderings and anticipations around the future, which in turn had important implications for everyday clinical practice. The sociology of expectations literature was of use here inasmuch as this particular analytical perspective could help us explore the role of everyday, *mundane* technologies overlooked in this body of literature. Therefore, I troubled the dominant construction of this literature, which illustrated the innovation of technoscience by analysing the ‘real time activities’ (Brown, Rappert and Webster, 2000: 4) of the mundane performed in the present, for the realisation of particular *futures*. In doing so, I therefore tracked moments of tension produced by the CQUIN. I investigated the CQUIN as a device, which shifted the temporalities and spatialities of classification inherent to resolving or dealing with complexity.

It would be tempting to have grounded my discussion of the CQUIN, within debates around risk, calculation of risk, and clinical governance, and the effects of this on professional roles, responsibilities and autonomies (see Rose, 1998; Nancarrow and Borthwick, 2005). However, more importantly for negotiating complexity and constituting AD, the CQUIN and its commitment to early diagnosis, shifted the content of work in everyday

practice, and the current temporal orderings of classification. This was demonstrated in a number of ways including the time at which clinicians approached patients, the ways in which the immediacy of problems were addressed in Acute Medical Units (AMU), and the ways in which clinicians in the memory service, approached cognitive decline as the CQUIN moved across transitions of care. The CQUIN as a tool for reifying the linearity of the patient pathway was implicitly involved in shifting the temporalities of classification in the present, and in constructing patients' and clinicians' expectations around a future with AD. This was a particularly important point given that in order to protect patient identity through mediation and manipulation practices, clinicians were also involved in preserving how patients conceived their *future* selves built around particular discursive representations of what a future with AD might bring. As a result, efforts to detect AD in its earliest stages shifted and produced further anxieties for patients in particular.

At this point, I reiterate that the version of cognitive decline or AD that was enacted in the hospital setting did not easily translate with the cognitive decline that was articulated in the everyday practices of the memory service. Addressing what I considered was the issue of power at play here, the structure of healthcare, and with it wider networks of political power, were manifest as they produced two distinctive yet interrelated sets of concerns. First, it produced particular discursive constructs around age, ageing and AD, which manifested in the clinic; the CQUIN had the ability to construct patients' expectations around what a future with a diagnosis might bring. This produced uncertainties and anxieties in terms of living with a diagnosis of AD, and on a practical level in terms of the lack of resource allocation with regards to treatment and care. Second, the CQUIN also constructed *clinicians'* expectations around a future with AD since it privileged diagnosis as a dynamic for managing AD, and reaffirmed the uncertain relationship between diagnosis and prognosis. Although this is not necessarily a point unique to AD, clinicians attested that because of the difficulty in determining a treatment or cure for AD, care as an alternative and viable option for managing the disease, is often overlooked within the

prevailing (bio)medical model. Echoing Lock (2013), despite the prevailing (bio)medical model through which AD is positioned, care was often at the core of both clinicians' and patients' concerns as demonstrated throughout my thesis. As highlighted, the interactive processes in the clinic, which shape classification, were replaced by a linear and temporal sequence (observation, to identification, to referral, to diagnosis). The CQUIN interrupted the temporalities of everyday clinical practice and the *nuances* of this linear process.

On a practical note, the portability of the tools enabled an increasing number of individuals to flow through healthcare practice. However, this produced further complexities that the tools were expected to resolve: from navigating uncertainties produced by the clinic and the problematisation of ageing (Gilleard and Higgs, 2010, 2013), to the lack of closure the process produced in terms of treatment and care. The on-going negotiations of expectations around a diagnosis with AD flow between actors across professions, and across materials and space, within the temporalities of navigating AD. Yet, these on-going negotiations were constrained as the CQUIN was deployed in clinical settings. Overall, I argued that the CQUIN therefore constrained the making of provisionality in the clinic and the 'tinkering practices' described by Mol, Moser and Pols (2010) for negotiating complexity and creating value out of uncertainty. The mundane and low-technological nature of these technologies rendered them easily adoptable and portable within frameworks such as the CQUIN, and yet as demonstrated throughout this thesis, the tools depend on mediation, manipulation and what Mol, Moser and Pols (2010) contend is 'care work' (pp.15). Furthermore, the political rhetoric of the ageing population through which initiatives such as the CQUIN emerged, raise urgent and disquieting questions for professionals and patients about whether earlier is necessarily better (Lebowitz, 2004). Resolving this tension between the tools as adopted in the wider policy terrain, and their translation into everyday clinical practice, required an exploration of the conditions in which these tools are used. Cognitive screening tools connect relations between actors, and across

materials, technologies, space and time, which as I have addressed was important for handling and making sense of uncertainty around diagnosis.

By exploring the micro practices of the clinic and the role of cognitive screening tools as adopted in the wider policy arena, I have also been able to extend Mol's (1998, 2002a) theoretical sensibilities in three significant ways. First, I captured how clinicians were *accountable* for diagnostic decisions when constituting the boundaries of the disease, and when implementing governance frameworks such as the CQUIN in practice. Second, I showed the points at which multiplicity *does not* cleave at neat points. Third, I demonstrated how complexity was resolved through hierarchical relations. Throughout my thesis as I drew on Mol to speak with and through my data, I concurred that the lack of closure around AD or what Mol (2002a) describes as the 'permanent possibility' of 'doubt', was 'tamed' within moments of co-existence and co-production (pp. 164). Yet, I extended Mol's claims by capturing moments of chaotic practice and uncertainty, which *could not* be easily tamed, *fuelled* by the lack of closure around AD. What Mol describes as this 'permanent possibility of doubt' does at times, lead to chaotic practice, which was most fruitfully observed within my analysis of the CQUIN. As a wider structure of power, the CQUIN was implicitly involved in the construction of expectations around patient futures, built around powerful discursive constructs around ageing and AD. The CQUIN also produced tension around the *process* of diagnosis within the organisation of the hospital and memory service, and on a practical level, ignited debates around the challenges of resource allocation for managing AD. This had important implications for both patients and clinical practice more broadly. I have also extended Mol's work by demonstrating that unlike atherosclerosis, where Mol effectively demonstrates what atherosclerosis is, Alzheimer's disease remains elusive. Whilst AD appears to be 'everywhere' it is also 'nowhere' (c.f. Lock, 2013): there is no agreement amongst healthcare practitioners, policymakers, patients or family members about what AD *is*.

What I have alluded to across this thesis and emphasised when analysing the National Dementia CQUIN, is that for a disease such as AD, managing treatment and care options is a restricted process. This thesis therefore confirmed the relationship between diagnosis, prognosis and medical technologies, and yet at the same time, raised particular questions around the reified patient pathway. As a descriptive and prescriptive endeavour (Pinder *et al.*, 2005) the patient pathway was also temporal, hierarchical, discursive and fluid. Cognitive screening tools as provisional and portable tools encouraged a renewed focus on the reification and linearity of the patient pathway. The reified patient pathway embedded the linearity of the process of referral, to diagnosis, to prognosis, to disposal. However, for a disease such as Alzheimer's disease which is difficult to categorise; for which there is no known cause or treatment, and for which the problematisation of cognitive function produces powerful affects, closure by reifying the patient pathway was a complex process. A governance initiative, which constrains, or has the ability, to constrain the nuances of practice for AD, produces rather than sorts the complexities it sets out to challenge. Furthermore, in the arena of the 'ageing population', the technologies are used to allocate resources in terms of diagnosis and referrals; there is the *expectation* that closure is possible which was difficult to fulfil. Clinical professionals challenged this 'closure'; they recognised that for a disease such as AD, the patient pathway is built around complex networks of social, technical and political arenas in which AD exists.

Across this thesis, and woven throughout my analysis, I have also highlighted that articulating a classification of cognitive decline and AD is *affectively* charged. In the interpretive repertoire of the clinic, I demonstrated the ways in which clinicians managed the emotions of the clinician-patient interaction, where clinicians approached and performed the tools *with care* to negotiate the vulnerabilities of the diagnostic encounter. In doing so, clinicians were able to protect patient identity, and the anxiety felt by both patients and family members about the possibility of a diagnosis. I extended this argument in Chapter Six, by illustrating that whilst clinicians were able to keep patients on into the future, driven by risk,

this was also performed in order to account for, and thereby legitimate, the symptoms that patients were presenting, rather than disposing them as processes of ageing. These practices of care I linked to the negative discursive constructs which remain in existence across the general population with regards to what it means to age, and the expectations entangled in a diagnosis of AD. As a result, across this thesis I have drawn attention to processes of care over time through the actions of clinicians. To which end, a particularly significant aspect of my analysis could include encouraging auditors and healthcare policy actors, of the uncertainties and anxieties and therefore *dangers*, of proxy measures for calculating risk and diagnosis, through initiatives such as the Dementia CQUIN. It is crucial that these initiatives do not overshadow or constrain the locality of practice performed in the clinic, and embedded in a more person-centered approach to diagnosis, for making patients and family members feel *cared* for, and for making sense of what is essentially an uncertain and anxiety provoking diagnostic journey.

Conclusion

The intention of my thesis was not to propose specific policies for improving clinical practice, or proposing best practice in terms of the ways in which cognitive screening tools are adopted and governed more generally. Rather, I hope my arguments will elucidate what it is that cognitive screening tools accomplished for producing knowledge about AD. Given that AD is complex to diagnose in clinical practice, both in terms of its contested categorisation, and the negative discursive constructs around ageing and AD, much of the role of these tools was dedicated to making sense of complexity for both professionals and patients. Clinical practice is however, beginning to witness the challenges posed by the ageing population. As a result, analysing the conditions in which these tools operate, and highlighting what is currently valued in practice, is integral for understanding what then might shift, be lost or improved, and the effects of this for clinical practice. Many of the dilemmas produced by the uncertain relationship between diagnosis and prognosis can be mapped across other

disease categories and yet for AD, managing the *expectations* embedded in this process produces particular uncertainties for a disease that has no known cause or cure. The nuances of the patient pathway, and the uncertainties produced by attempts to reify what is essentially a temporal, fluid, provisional and situated diagnostic process for cognitive decline, have been made manifest within this study.

This study, at the intersections of medical sociology and STS, also has broader appeal for considering the intersections between technologies, expectations and ageing, and the hierarchical and political structures through which diagnosis is accomplished. AD and cognitive decline are categories 'made' through the use of mundane cognitive screening tools for navigating complexity. Yet at the same time, as the politics of an ageing population govern the use of these tools, the provisionality and portability witnessed in the clinic has the potential to be constrained. The relationship between the micro everyday practices of the clinic within a shifting organisation of healthcare deserves attention when the challenges posed by the ageing population have direct implications for how diagnosis is performed, and therefore AD made sense of, for patients, family members and clinicians.

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Appendices

Appendix A: Summary of Assessment Tools Available

Summary of the assessment tools available

The table below outlines the assessment tools that are currently available. It also details how they are used and current validity evidence that supports them. Please note that while the table provides the evidence base, this toolkit is also based on recommendations from experts in the advisory group and known practicalities and feasibilities of use of the tools in clinical settings.

Scale	Overview of scale	Duration of application	Cut-off point for dementia	Reference
Abbreviated mental test score (AMTS)	A 10-item scale, validated in wards but used in UK primary care.	<5 minutes	6-8/10	Hodkinson HM: Age Ageing 1972; 1:233–238 Jitapunkul S, Pillay I, Ebrahim S. Age Ageing 1991; 20: 332-36.
6-item cognitive impairment test (6CIT)	Three orientation items, count backwards from 20, months of the year in reverse, learn an address. Validated in primary care.	<5 minutes	8/24	Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Med Care 2002;40(9):771-781. Brooke P, Bullock R.. Int J Geriatr Psychiatry 1999; 14: 936-40.
Mini-cog	3-item word memory and clock drawing. Validated in primary care. Low sensitivity.	2-4 minutes	5/8	Borson S, et al. J Am Geriatr Soc 2005; 53:871–874. Buschke H, Kuslansky G, Katz M, Stewart WF, Sliwinski MJ, Eckholdt HM, et al.. Neurology 1999; 52: 231-38.
General practitioner assessment of cognition (GPCOG)	Developed for primary care and includes a carers' interview.	5 minutes		Brodsky et al. American geriatric society. 2002;50:530–4.

Scale	Overview of scale	Duration of application	Cut-off point for dementia	Reference
Montreal cognitive assessment scale (MoCA)	Tasks are executive function and attention, with some language, memory and visuospatial skills. Validated in many conditions incl MCI, Alzheimer's disease and Parkinson's disease dementia.	10 minutes	26/30	Nasreddine ZS, et al. J Am Geriatr Soc 2005;53:695-9 Smith T, Gildeh N, Holmes C. Can J Psychiatry 2007; 52: 329-32. Dalrymple-Alford JC, et al. Neurology 2010; 75: 1717-
Addenbrookes cognitive examination-III (ACE)	Based on the ACE-R which is the well-validated version with very similar characteristics.	10-20 minutes	82-88/100	Int J Geriatr Psychiatry. 2012 Jul;27(7):659-69. doi: 10.1002/gps.2771. Epub 2011 Nov 8.
Mini mental state examination (MMSE)	This 11-item measure of cognitive functioning and its change, is extensively studied and has good validity. Less good for Lewy body dementia and fronto-temporal dementia due to its focus on memory. Cutpoint not valid in different cultures and in particularly highly or uneducated participants.	≤10 minutes	24/30	FolsteinMF, FolsteinSE, McHughPR.1975.J PsychiatrRes12 (3):189-198. Tombaugh TN, McIntyre NJ.J Am Geriatr Soc 1992; 40: 922-935. Nilsson FM. Acta Psychiat Scand 2007; 116: 156-157.

Source: Helping you to assess cognition: A practical toolkit for clinicians pp. 16-17 (see Alzheimer's Society, 2015b).

Appendix B: Information Sheet for NHS Staff (Observation and Interview)

Participant Information Sheet (NHS Staff Observation and Interview)

Study Title: Screening for Cognitive Function in Clinical Practice

You are being invited to take part in a research study. Before deciding whether you would like to participate, it is important for you to understand why the research is being carried out and what it involves. This sheet outlines the purpose and implications of the study and provides more detailed information about its conduct. I am willing to answer anything which is unclear or needs clarification. Please take time to decide whether you want to participate. You will be able to keep this sheet and a signed consent form. If you would like to participate, please contact me by telephone, by email, by letter, or in person. Thank you for reading this.

This is not a clinical study. The purpose of this study is to explore the use of instruments for screening cognitive function across healthcare practice. Specifically, the objectives are to explore the use in practice of instruments for screening cognitive function by clinicians in aiding a diagnosis of Alzheimer's disease; better understanding the disease and loss of cognitive function; considering the implications of the tests and their results for patient care, healthcare service delivery and overall clinical practice.

I would like your consent to be present as a researcher in the clinic or hospital ward as part of your medical team. If you agree, I would like your consent to observe staff team meetings and/or the use in practice of these instruments in out-patient clinics, acute medical services in hospital or joint elderly assessment services in hospital. Observing staff team meetings involves the researcher being present whilst the results of screening tests will be discussed. This will be only one aspect of the meeting and anything discussed which is not relevant to the research will not be noted. Observing clinical practices of cognitive screening processes involves the researcher

being present during consultations where instruments for screening cognitive function will be used with patients who have not had a formal diagnosis of Alzheimer's disease. I will not be providing nor interfering with prevention, diagnosis, or treatment. These events will not be audio-recorded, but notes will be taken. You will have to provide informed consent for each stage; the presence of the researcher in the clinic as part of your medical team; observation of team meetings; observation of consultation and interview. You can withdraw from the study at any time without explanation, and information which might identify you will be removed as far as possible.

After this, you may be approached for an interview which will last between 30 minutes and 1 hour. If you agree, your interview will be audio-recorded for transcription purposes. You will have to provide informed consent, information which might identify you will be removed as far as possible, and you can withdraw from the interview at any time without explanation. When the research study stops, you will receive a summary of the study's findings on request so you can check that where you are quoted, it is both accurate and anonymous. The data collected will be published in a PhD thesis approved by the University of Leeds and potentially through academic publications such as books, book chapters, and peer-reviewed journal articles.

All information collected during the study will be kept strictly confidential. The research location and identities of everyone taking part in the study will be subjected to anonymisation. Any information which may identify you will be removed. Electronic or manual data collected (audio recordings, transcripts, typed-up field notes) will be either stored in a locked filing cabinet on the University of Leeds security-controlled premises or on an encrypted, password-protected USB device, both of which will only be accessible by the researcher. Audio recordings and manual copies of field notes will be destroyed after use in accordance with the University of Leeds regulations. A manual copy of your contact details will be kept in case you need to be

contacted for a second interview and so you can receive a copy of the study's findings, but these will be shredded after the PhD thesis is completed. Please note that you have the right to check the accuracy of data held.

The project has been reviewed and given favourable opinion by the Yorkshire & The Humber - Leeds West Research Ethics Committee and is being funded by the Economic and Social Research Council (ESRC).

If you would like to request more information about the study or register an interest in participating, please contact me using the details provided below:

Julia Swallow
School of Sociology and Social Policy
University of Leeds
LS2 9JT
0113 343 0112
J.E.Swallow@leeds.ac.uk

Appendix C: Information Sheet for NHS Staff (Interview)

Participant Information Sheet (NHS Staff) – Interview

Study Title: Screening for Cognitive Function in Clinical Practice

You are being invited to take part in a research study. Before deciding whether you would like to participate, it is important for you to understand why the research is being carried out and what it involves. This sheet outlines the purpose and implications of the study and provides more detailed information about its conduct. I am willing to answer anything which is unclear or needs clarification. Please take time to decide whether you want to participate. You will be able to keep this sheet and a signed consent form. If you would like to participate, please contact me by telephone, by email, by letter, or in person. Thank you for reading this.

This is not a clinical study. The purpose of this study is to explore the use of instruments for screening cognitive function across healthcare practice. Specifically, the objectives are to explore the use in practice of instruments for screening cognitive function by clinicians in aiding a diagnosis of Alzheimer's disease; better understanding the disease and loss of cognitive; considering the implications of the tests and their results for patient care, healthcare service delivery and overall clinical practice. One aspect of this will be to explore the implementation of the Dementia Commissioning for Quality and Innovation Framework (Dementia CQUIN), using the Abbreviated Mental Test (AMT) dictates healthcare service delivery and patient care for NHS trusts.

Your Role in the Project

You have been approached as a participant in this project owing to your work as an information manager. As an information manager analysing, interpreting and presenting health data and information relating to the implementation of the Dementia CQUIN, you have the expertise to provide

insight into how this data is used to dictate resource management and healthcare service delivery.

The Content of the Interview

What you are being asked to consent to is an informal interview where you will be asked about your work as an information manager. Broadly, the interview will cover your reflections on how the Dementia CQUIN is implemented to allow retrieval of data; your professional relationship with clinicians who implement the CQUIN in practice using the AMT; your reflections on the role of the Dementia CQUIN in managing resources and healthcare service delivery in the Trust, and your reflections on the efficacy of the framework overall. Please feel free to elaborate on any answer or area which you think is particularly relevant or important. The interview will take approximately thirty-sixty minutes and will be recorded on an audiotape and later transcribed for analysis.

If you agree, your interview will be audio-recorded for transcription purposes. You will have to provide informed consent, information which might identify you will be removed as far as possible, and you can withdraw from the interview at any time without explanation. When the research study stops, you will receive a summary of the study's findings on request so you can check that where you are quoted, it is both accurate and anonymous. The data collected will be published in a PhD thesis approved by the University of Leeds and potentially through academic publications such as books, book chapters, and peer-reviewed journal articles.

All information collected during the study will be kept strictly confidential. The research location and identities of everyone taking part in the study will be subjected to anonymisation. Any information, which may identify you will be removed. Electronic or manual data collected (audio recordings, transcripts, typed-up field notes) will be either stored in a locked filing cabinet on the University of Leeds security-controlled premises or on an encrypted, password-protected

USB device, both of which will only be accessible by the researcher. Audio recordings and manual copies of field notes will be destroyed after use in accordance with the University of Leeds regulations. A manual copy of your contact details will be kept in case you need to be contacted for a second interview and so you can receive a copy of the study's findings, but these will be shredded after the PhD thesis is completed. Please note that you have the right to check the accuracy of data held.

The project has been reviewed and given favourable opinion by the Yorkshire & The Humber - Leeds West Research Ethics Committee and is being funded by the Economic and Social Research Council (ESRC).

If you would like to request more information about the study or register an interest in participating, please contact me using the details provided below:

Julia Swallow
School of Sociology and Social Policy
University of Leeds
LS2 9JT
07896 815 788 J.E.Swallow@leeds.ac.uk

Appendix D: Information Sheet for Relative and/or Carer

Information for Patients' Relatives and/or Carer

What is the aim of the project?

This research is for a PhD at the University of Leeds, which is looking at how memory is assessed in clinical practice. The observer wants to look at how this is accomplished in patient appointments.

Why have you been asked?

You have been asked and invited by the researcher because you are a relative and/or carer of a patient who has been identified by their healthcare practitioner as someone appropriate to the project and you may be accompanying them. You will be given time to read and think about whether you would like the researcher present during the appointment.

The observations

The observer will take notes and will not participate in the session. She will not have access to your relative's clinical records and they will not be identified; the term 'patient' will be used in notes

Observations will last for the duration of the patient appointment. The observer will not in any sense be judging the practices she is observing, but in the unlikely event that unsafe practice is brought to her attention she will follow appropriate Codes of Practice.

What will you and your relative/ individual you are caring for have to do?

He or she, and if you are accompanying, will attend the appointment or be present at the time of consultation as normal. You will be asked to sign a form indicating your consent to the observation.

Can they decline or withdraw from the observation?

You or your relative/individual you are caring for can refuse to have the observer at the appointment and they or you can ask her to leave at any point during it with no disadvantage to yourself or to the patient.

What data or information will be collected and what use will be made of it?

The data is being collected for the PhD and only the observer and her supervisor will have access to the information.

The results of the project, including direct quotations may be used in the PhD thesis and may be published in journals but individuals will not be identifiable.

What if I have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact:

Observer: Julia Swallow School of Sociology and Social Policy University of Leeds J.E.Swallow@leeds.ac.uk

Supervisor: Professor Anne Kerr School of Sociology and Social Policy University of Leeds e.a.kerr@leeds.ac.uk

The project has been reviewed and given favourable opinion by the Yorkshire & The Humber - Leeds West Research Ethics Committee.

Thank you for taking the time to read this sheet

Appendix E: Information Sheet for Patients

Information for Patients

What is the aim of the project?

This research is for a PhD at the University of Leeds, which is looking at how healthcare professionals assess memory. The observer wants to look at how this is accomplished in patient appointments.

Why have you been asked?

You are being invited to participate because your healthcare practitioner has identified you as someone appropriate to the project. You will be given time to read and think about whether you would like to take part.

The observations

The observer will take notes and will not participate in the session. She will not have access to your clinical records and you will not be identified; the term 'patient' will be used in notes.

Observations will last for the duration of the patient appointment. The observer will not in any sense be judging the practices she is observing, but in the unlikely event that unsafe practice is brought to her attention she will follow appropriate Codes of Practice.

What will you have to do?

Participate in the appointment as you would normally. You will be asked to sign a form indicating your consent to the observation.

Can I decline or withdraw from the observation?

You can refuse to have the observer present during your appointment and you can ask her to leave at any point during it with no disadvantage to yourself.

What data or information will be collected and what use will be made of it?

The data is being collected for the PhD and only the observer and her supervisor will have access to the information.

The results of the project, including direct quotations may be used in the PhD thesis and may be published in journals but individuals will not be identifiable.

What if I have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact:

Observer: Julia Swallow School of Sociology and Social Policy University of Leeds J.E.Swallow@leeds.ac.uk

Supervisor: Professor Anne Kerr School of Sociology and Social Policy University of Leeds e.a.kerr@leeds.ac.uk

The project has been reviewed and given favourable opinion by the Yorkshire & The Humber - Leeds West Research Ethics Committee.

Thank you for taking the time to read this sheet

Appendix F: Consent Form for NHS Staff (Observation of Consultation)

Consent Form – Observation of Consultation (NHS Staff)

Study Title: Screening for Cognitive Function in Clinical Practice

Name of Researcher: Julia Swallow

Please initial box

1. I have read and understood the information sheet Version 2.0 for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I agree to participate in a later interview, if this is necessary, which will be audio-recorded and will be anonymised.
4. I acknowledge that my data may be used in the PhD thesis and academic/other publications but any data used will be made anonymous.
5. I consent to the researcher being present and taking notes during consultations where instruments for screening cognitive function will be used to assess patients' memory NB: this will also require consent from the patient(s).
6. I acknowledge that I can request a summary of the study and its findings.

I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person Taking

Date

Signature

Consent

Appendix G: Consent Form for NHS Staff (Observation MDT)

Consent Form – Observation of Team Meetings (NHS Staff)

Study Title: Screening for Cognitive Function in Clinical Practice

Name of Researcher: Julia Swallow

Please initial box

1. I have read and understood the information sheet dated..... (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I acknowledge that my data may be used in the PhD thesis and academic/other publications but any data used will be made anonymous.
4. I consent to the researcher being present and taking notes during staff team meetings where clinical professionals will discuss the results of screening tests NB: Patients' personal or clinical information will not be noted by the researcher.
5. I acknowledge that I can request a summary of the study and its findings.

I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person Taking

Date

Signature

Appendix H: Consent Form for NHS Staff (Interview)

Consent Form for Participants (NHS Staff) – Interviews

Study Title: Screening for Cognitive Function in Clinical Practice

Name of Researcher: Julia Swallow

Please initial box

1. I have read and understood the information sheet Version 2.0 for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. My participation in the project is entirely voluntary.
3. I am free to withdraw from the project at any time without any disadvantage.
4. There are no foreseeable risks or harm associated with participation in this project.
5. The results of the project may be published but every attempt will be made to preserve my anonymity.

I agree to take part in this project.

_____	_____	
Name of Participant	Date	Signature
_____	_____	
Name of Person Taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher (original).

Appendix I: Consent Form for Relative and/or Carer

Consent Form for Family Member and/or Carer

Study Title: Exploring how Memory is tested in Clinical Practice

Name of Researcher: Julia Swallow

Please initial box

1. I have read and understood the information sheet Version 2.0_for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I consent to the researcher sitting in and taking notes during the medical appointment. Consent will also be taken from the patient and healthcare professional.
3. I understand that my consent is voluntary.
4. I can withdraw this consent at any point during the consultation and it will not affect the medical care of the patient.
5. I understand that the researcher will be taking notes during the observation on the actions of the patient and professional but there will be no data collected on my actions as the carer/family member.

I agree to take part in the above study

Name of Participant

Name of Person Taking consent

Date

Date

Signature

Signature

Appendix J: Consent Form for Patients

Consent for Participants (Patients)

Study Title: Exploring how Memory is tested in Clinical Practice

Name of Researcher: Julia Swallow

Please initial box

1. I have read and understood the information sheet Version 2.0 for the study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that I am free to ask the researcher to leave the appointment at any time without giving any reason, without my medical care or legal rights being affected.
4. I understand that the relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I acknowledge that my data may be used in the PhD thesis and academic/other publications but any data used will be made anonymous.
6. I consent to the researcher sitting in and taking notes during the medical appointment. Consent will also be taken from the healthcare professional.

7. I acknowledge that I can ask for a summary of the study and its findings.

I agree to take part in the above study

_____	_____	
Name of Participant	Date	Signature

_____	_____	
Name of Person Taking	Date	Signature

Consent

Appendix K: Interview Schedule for Clinical Professionals (memory service)

Interview Schedule Memory Clinics

General Information

Practice Background

- How long have you been working as [insert profession]?
- How long have you been part of the department here?

Daily Role:

- Could you talk me through your main responsibilities and tasks?

Professional Practice – Individual Consultations

These questions are focused on your individual use of instruments for screening cognitive function in practice.

Referrals

- Could you talk me through how patients are referred to you for assessment?
- Where are the majority of patients referred from?

Consultation

- Could you talk me through the types of instruments you routinely use to assess cognitive function?
- Do they each have a specific purpose?
 - If so, what is the purpose of each tool?
 - How do you decide to use which tool with patients and why?
- How much attention do you pay to loss of memory?

- Could you talk me through what other kinds of assessments you perform with the patient in the consultation?
 - Is this standardized for each patient?
- At what point during the consultation do you administer these instruments for screening cognitive function with patients?

- Could you talk me through what happens during the remainder of the consultation when the patient has completed the cognitive assessment test?
- At what point do you consider further diagnostic testing is required?
- Is this based purely on the patient's performance on the test?
- Could you talk me through what kinds of further diagnostic testing may be used and why?

- Could you talk me through a scenario where a patient has scored positively on the cognitive assessment test?
 - What happens next?
- Could you talk me through a scenario where a patient has scored negatively on a cognitive assessment test?
 - What happens next?

- Could you reflect on how important your clinical judgment is when using these tests with patients?
- Could you talk me through the possibility that false positive, false-negative results may occur in the consultation?
 - How could you overcome this?

The Instruments in Practice and AD

I would now like to discuss your approach towards these instruments and the outcome of these instruments for practice, patients and understanding AD.

- Could you briefly talk me through the history of the use of these instruments in clinical practice generally?
- How much do you value these screening tools as indicators of pathological cognitive decline?
- How important do you think they are in detecting cognitive decline in your area of healthcare?
- Do you think these instruments impact on a broader understanding of cognitive impairment associated with diseases such as Alzheimer's disease?
 - If so, could you talk me through this?
 - If not, could you talk me through what you think the overall purpose of these instruments is in clinical practice?
- Could you reflect on whether your use of these instruments has altered since you have been practicing?
 - If so, could you please talk me through what is different about your previous use of these tests and how you practice them now?
 - Why do you think this is?
 - If not, could you please talk me through how your use of these tests has remained the same?
 -
- Could you reflect on whether you think these instruments are used similarly across healthcare practice?
 - If so, what do you think leads to this similarity in practice?
 - If not, what do you think influences clinicians to use these tests in certain ways?
 - Do you think that the different ways in which clinicians administer these tests impacts further diagnostic testing?
- Has the uptake of these tests by clinicians in your area of practice altered in the time you have been practicing?

- If so, could you talk me through the extent to which clinicians used these tests when you first started practicing compared to now?
- If not, could you reflect on why you think their use by clinicians has not changed since you started practicing?
- Do you think that the way you use these tests in consultations will differ between settings and clinicians?
 - If so, could you talk me through how you think their use may differ from hospitals to memory clinics to out-patient clinics?
 - If not, do you think their standardized use is valuable to clinical practice in terms of diagnosis, patient care and treatment?
- Could you talk me through what happens to the results of these tests?
- Could you talk me through how the results from the tests determine further diagnostic testing, patient care, treatment and wider healthcare service delivery?
- Could you please outline what you consider to be 'normal' ageing processes?
- Do the results from these tests influence your understanding of Alzheimer's disease?
 - If so, could you outline exactly how your understanding of the disease changes in accordance with the use of these tests?
 - If not, could you outline to what extent you think the purpose of these tests is to navigate the difficulties in conceptualizing Alzheimer's disease?
- How important do you think these tests are in determining healthcare service delivery, patient care and treatment?
- Could you please talk me through how these tests are used to determine pharmacological treatment for AD?

Focus on early screening and diagnosis in relation to an ‘ageing population’

I would now like to move onto discuss the recent attention in both policy and practice on the early identification of AD in accordance with what is being projected as an ‘ageing population’.

- What does the concept of an ‘ageing population’ mean to you as a practicing [insert profession]?
- What do you think the consequences of an ageing population are for patients and your profession?
- Do you think the ways in which you practice and use these instruments has altered in accordance with this focus on an ‘ageing population’?
 - If so, could you talk me through how your practicing of these tests has changed?
 - If not, do you think this idea of an ‘ageing population’ has yet to feed into what happens in consultations?
- Do you think your perception of cognitive impairment has altered with the increased focus on the ageing population and early detection of Alzheimer’s disease?
- Can you reflect on the incorporation of Mild Cognitive Impairment as a diagnostic criterion in relation to your administration of these tests?
- Has this label affected your understanding of cognitive impairment?
- Do you think it is a useful label in determining normal from pathological cognitive impairment?
 - If so, could you talk me through how and why?
 - If not, could you talk me through why this label may not be helpful?
- Could you please reflect on whether Mild Cognitive Impairment has impacted your administration of these tests?

Implementation of the National Dementia CQUIN- Memory Clinic/Out-Patient Staff

- Are there any patients who attend your clinics who have been referred to you from the implementation of the National Dementia CQUIN in hospital?
- If so, approximately what percentage?
- Could you reflect on what you think about a standardized screening programme using instruments for screening cognitive function?
- Do you think these instruments should be used to screen for initial cognitive decline?
- Could you reflect on whether you think the National Dementia CQUIN may impact your use of these instruments?
 - If so, could you talk me through what you think this impact may be?

Implementation of the National Dementia CQUIN- Hospital Staff

- Could you reflect on whether your use of these instruments has altered in accordance with the implementation of the Dementia CQUIN?
- What do you think the impact of the CQUIN has had on diagnosis rates?
- Do you consider the Abbreviated Mental Test to be valuable in the process of screening for initial cognitive decline?
- Could you reflect on what you think about a standardized screening programme using instruments for screening cognitive function?
- Do you think neuropsychological instruments should be used to screen for initial cognitive decline?

Inter-Professional Communication/Collaboration

- How much communication is there between different professionals using these instruments?
- Has this altered at all since you have been practicing?
- Are the results of these tests discussed routinely with fellow practitioners?
- What do you think the impact of this may be for a patient's diagnosis, care and treatment?
- How important do you consider inter-professional communication/collaboration is in relation to the use of these instruments?
 - Who is it important for and why?

Changing landscape of screening, diagnosis and intervention

- Do you think that current focus in policy on early assessment has altered the way you use these instruments?
- Could you reflect on what you think of the increased focus in policy on identifying AD in its earliest stages?
- Do you think instruments for screening cognitive function have an important role to play here?
- Could you talk me through what you understand as biomarker technologies in detecting early signs of Alzheimer's disease?
- What do you think the future of instruments for screening cognitive function is in relation to other medical technologies such as biomarkers?
- Could you reflect on how you think these instruments may be valued by clinicians if biomarkers technologies become routine practice?

Closing

- Is there anyone in particular you think would be useful for me to interview?
- Are there any other comments you would like to make regards your use of these instruments which we have not already covered?
- Are there any comments or questions you would like to ask about the research?

End

