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Social and Ethical Challenges in Dementia Diagnosis: A Case Study of Dementia Policies in England and Wales

Master's thesis

In M.Sc. Health Sciences, Faculty Life Sciences

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Matriculation No. 2224830

Location and Date of Submission:

Cardiff, 17th November 2016

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Acknowledgements

I would like to thank my supervisor at HAW Hamburg, Prof Dr Christine Färber, for the regular communication and helpful input from Germany via e-mail and phone.

I would also like to thank my supervisors at WISERD: Dr Alexandra Hillman for the regular communication in person or via e-mail, I am grateful for valuable peer reviews and suggestions on this thesis; Dr Martin O'Neill and Dr Eva Elliott for interesting insights into academic work during my time at WISERD and for helpful peer reviews and advice.

Thank you all for making the cooperation between HAW Hamburg and WISERD possible.

This Master's thesis included secondary data that came from a post-doctoral fellowship study exploring the ethical aspects of dementia diagnosis funded by the Wellcome Trust (WT091772).

Special thanks to my interview partners who offered their expertise and time and to the researchers who sent me their research papers upon request.

I would further like to express my gratitude to my family, friends and fellow students for their support, especially my parents, Dr Margrit Schüssler and Dr Friedemann Schüssler, and my siblings, Axel, Ina, Nora, Christoph, Teresa and Gabriele, as well as my friends in Cardiff who were willing to do a final proofread of parts of this thesis.

Table of Contents

Abstract

Background and Purpose: Dementia has become a major global health issue due to the burden on patients, carers and on health and social care systems. The approach of early dementia diagnosis being financially incentivised in England and Wales has been met by controversy. This case study allows an overall picture of the developments in dementia policies (2009-2016) and a reflection of the policies' impact on the services and patients. Social and ethical challenges in dementia diagnosis are explored from three perspectives: policy/services, research and clinical practice.

Methods: Policy documents and expert interviews were combined. Policy documents showed developments and achievements related to dementia diagnosis. Experts in dementia policies/services reflected on practical challenges and strategic concerns that have informed dementia policy. Clinicians from a memory clinic reflected on their approach to diagnosis and the policies' impact on clinical practice. Researchers offered their expertise regarding diagnostic technologies, discussed the value of an early diagnosis and a potential screening programme for patients and families. The data was analysed by using Mayring's Qualitative Content Analysis.

Results: Social and ethical challenges arise in the current approach of dementia diagnosis. Ethical issues include among others the lack of understanding of MCI and early dementia, the potential for misdiagnosis and overdiagnosis, the lack of effective treatment and prevention strategies, patients' feelings of disorientation and increased fear around dementia, and the impact of stigmatisation on people's lives. Social issues include pressures on the social and health care system and the resulting lack of specialist services and post-diagnostic support.

Conclusion: The benefits of knowing about one's MCI and early dementia might not confidently outweigh potential harms as yet. Awareness raising without incentivising dementia diagnosis might be sufficient in motivating people to receive an assessment. Timely diagnosis instead of early diagnosis seems to be the more appropriate option.

Keywords: mild cognitive impairment, dementia policies, ethical issues, social issues, dementia

Abbreviations

Alzheimer's Disease	AD
Alzheimer's Disease International	ADI
Apolipoprotein E	APOE
Clinical Commissioning Groups	CCGs
Commissioning for Quality and Innovation	CQUIN
Confidence Interval	CI
Dementia with Lewy bodies	DLB
Department of Health	DoH
General practitioners	GPs
Global Burden of Disease	GBD
Hazard Ratio	HR
Mild Cognitive Impairment	MCI
Mini Mental State Examination	MMSE
National Institute for Health and Clinical Excellence	NICE
Quality and Outcomes Framework	QOF
Relative Risk	RR
World Health Organization	WHO

List of Tables

List of Figures

Chapter 1: Introduction to the Study

1.1 Introduction

Due to the internationally ageing population and the subsequent significant impact of dementia on individuals and families as well as on health and social care systems, dementia has become a major global health issue (Robinson 2015). It was recommended in 2012 by Alzheimer's Disease International (ADI) that every country should have a national plan for how to tackle Alzheimer's Disease (AD) and other dementias. This plan should among others include raising awareness among the public, families and health professionals to achieve a better understanding of dementia and to improve healthcare practices and attitudes. Moreover, policies should be developed that would improve care and services for people with dementia. A research agenda should aim to identify changes in prevalence and incidence of dementia and new and more effective treatments (Wortmann 2012). Although various new therapies are being examined in different phases of clinical trials no current treatment can cure or change the progression of dementia (ADI/World Health Organization (WHO) 2012). The lack of a cure shifted the focus increasingly to ways to reduce the risk of developing dementia in the first place (Robinson 2015).

Evidence has demonstrated that the disease might be preventable. It is seen as likely that brain pathology begins decades before the onset of clinical dementia. Researchers working in the field of dementia have been hopeful that illuminating the molecular pathways considered to be a "prodromal" phase of the disease may prove beneficial to identifying preventions or cures. This means studying those who are not yet symptomatic but for whom there are pathological changes associated with AD that are thought to occur 20 years or more before the unalterable symptomatic stages of the disease are reached. In the past decade, technologies were developed enabling researchers to learn about pre-symptomatic dementia and led to a variety of research findings that make the prevention of AD seem a more reachable target for the future attempting to intervene in the molecular changes associated with AD to prevent future dementia (ADI 2014; Lock 2013). Moreover, there is emerging evidence that tackling developmental risk factors and experiences in early life, cardiovascular risk factors, lifestyle, and psychological aspects can be beneficial. Large longitudinal cohort studies showed a decline in the prevalence of dementia internationally which was linked to public health interventions. All these findings might have led to greater attention given to earlier diagnosis and intervention (see ADI 2014; see Matthews et al. 2016; see Robinson 2015).

Recognizing the above outlined potential, the issue of under-diagnosis was highlighted in the National Dementia Strategy for England (2009) and the National Dementia Vision for Wales (2011) both promoting an early diagnosis. There has been a lack of clarity about what an early diagnosis means and which disease stage it refers to. A diagnosis can either be given at the stage of early dementia when daily living is already limited or the stage before the clinical diagnosis of dementia defined as mild cognitive impairment (MCI). Thus, the expression 'timely diagnosis' was seen as more adequate than 'early diagnosis' as it implies a more person-centred concept and does not associate the diagnosis to any particular disease stage. 'Timely' means at the right time for the person in their individual circumstances whereas 'early' is understood in the chronological sense (see Dhedhi et al. 2014).

Some evidence suggests that a diagnosis would improve quality of life, help patients and carers manage the situation, plan for their future and appreciate the positive things in their lives (Derksen et al. 2006). The UK National Screening Committee was called upon to evaluate whether it would be beneficial to introduce a population based screening programme for dementia. They base their decision on internationally acknowledged criteria and a thorough process of reviewing evidence (Public Health England 2014a). The criteria comprise epidemiological knowledge of the disease, evidence and validation of the tests being used for screening and appropriate treatment available (Alzheimer's Research UK 2015). After reviewing Wilson and Jungner's report from 1968 on screening criteria, the WHO (2008), among others, emphasised the importance of having scientific evidence of the effectiveness of a screening programme, quality assurances that would avoid potential risks, and a guarantee of confidentiality, informed choice and respect for autonomy. The UK National Screening Committee considers population based screening as not suitable to increase the diagnosis rates for dementia (National Screening Committee 2015). Instead, in England, case-finding in high risk groups was introduced including people over 75 years of age and those with learning disabilities, Parkinson's disease and high vascular risk. This approach means incentivising a proactive memory assessment of patients in both primary care and acute hospital settings, for those who may not report any symptoms (Robinson 2015). In Wales, a similar approach was chosen that included rewarding general practitioners (GPs) within the Quality and Outcomes Framework (QOF) for dementia diagnosis (see QOF 2015).

The introduction of case-finding has been followed by significant controversy. It was argued that the case-finding approach is in fact a way to carry out population screening, masking it as something else since it was not possible to show the necessary evidence for benefits to gain permission as a screening programme (McCartney 2014). The

recommendation against screening upheld over the years should remind policy makers that the case-finding approach contradicts best evidence. Instead of testing patients for dementia who were accessing healthcare for other reasons, who may subsequently lack the opportunity to fully consent to assessment for memory problems, it was argued that focus should instead be given to those who seek a diagnosis for their problems with memory or cognition and better ongoing care and support for those with a diagnosis. Furthermore, it is argued that resources invested in early diagnosis could be better used for dementia services and research (Barer 2014; Kmietowicz 2015; McCartney 2013).

Some studies suggest that the assessment process preceding diagnostic disclosure was perceived to be more stressful than receiving the diagnosis as it can uncover and make the patient more aware of their cognitive deficits and limitations (Derksen et al. 2006; Connell/Gallant 1996). Another study discusses the potential of a diagnosis to cause harm (Gillon 1985); Draper et al. (2010) found that people with MCI and early dementia have a raised suicide risk, commonly accompanied by comorbid depression (Draper et al. 2010). A diagnosis could also induce negative feelings such as fears of other people finding out, being socially embarrassed, not being heard and being dependent in the long term (Husband 2000). Moreover, the potential of overdiagnosis of dementia was highlighted in some literature along with the negative consequences of misdiagnosis that can cause misery for the patient and their family. Spence (2012) has argued that instead of reaching those people with dementia without a diagnosis, recent policy initiatives are more likely to draw people who worry about their health, but do not have dementia to the memory clinic (Spence 2012). The emphasised benefits of receiving an early diagnosis are seen as lacking in evidence, leaving the patient to worry about future deterioration without effective treatment (Barer 2014).

In 2014, surprise was expressed by some regarding the attention given to potential overdiagnosis since not even half of those suffering from dementia received a diagnosis at that time. Moreover, instead of emphasising misdiagnosis as a reason against the case-finding approach for identifying those with dementia, an accurate diagnosis should be promoted by improved education and cooperation of primary and secondary care. The financial incentive offered to GPs for the referral of patients who are thought to be at higher risk of dementia to specialist services was justified by its voluntary feature and the additional work load that would need to be accepted by clinicians (Burns 2014).

In a Government response of a consultation on the GP contract 2013/14 it states that the Department stays committed to implementing case-finding for people with dementia and emphasises the difference between this approach and dementia screening on the basis that dementia is a symptomatic condition as opposed to screening programmes that tend

to be used for symptom-less conditions, such as breast cancer (Department of Health (DoH) 2013a).

This Master's thesis recognizes the need to further critically examine the cost-effectiveness and possible benefits and risks for patients in the approach of incentivising dementia diagnosis in England and Wales.

1.2 Research Question

The following research question and secondary questions will be addressed:

What are the social and ethical challenges facing clinicians in regards to early/timely diagnosis of dementia and how have these been framed by wider policy in England and Wales?

1. What plans, strategies and achievements have been identified in Welsh and English policy documents that relate to the early/timely diagnosis of dementia over time (2009 to 2016)?

2. What social and ethical challenges do experts in dementia policies/services, experts in dementia research and memory clinic staff address in regards to early detection of dementia?

1.3 Source of Data and Purpose of the Study

This study draws on primary and secondary data taken from an ethnographic research project that involved expert interviews with researchers interested in dementia and with clinical staff from a UK based memory clinic (the original study was funded as part of a Wellcome Trust post-doctoral fellowship award: WT091772), a document analysis of policies related to early/timely diagnosis in England and Wales and primary data comprising of interviews with experts in dementia policies/services.

The combination of qualitative data allows an overall picture of the developments in dementia policies in these countries from 2009 to 2016 and a reflection of the policies' impact on dementia services and patients. Moreover, related social and ethical challenges in dementia diagnosis can be explored from three different perspectives: policy/services, research and clinical practice.

1.4 Outline of the Study

This study comprises six chapters. Following the current introduction, Chapter 2 will expand on essential background information building a basis for the following chapters. Firstly, a comprehensive medical description and examination of the respective conceptual challenges is provided to establish a greater understanding of dementia, particularly AD and MCI. This is followed by outlining the current possibilities in the assessment of dementia and the availability of treatment. The most current epidemiological evidence on changes in prevalence and incidence of dementia internationally and in England and Wales is described and critically assessed. Subsequently, the potential to reduce the risk of developing dementia and the attention this approach currently receives in the UK is addressed. Finally, the economic impact of dementia and evidence of the consequences for the patient and their families' quality of life are considered.

Chapter 3 describes the methodological approach of this study, including the development of the research question, the research design and data collection, data analysis and the associated limitations. Chapter 4 presents the results that are derived from the data and address the perspectives of policy makers, those working in third sector organisations, researchers and memory clinic staff regarding the social and ethical challenges in dementia diagnosis in England and Wales. These findings will subsequently be discussed in chapter 5. Chapter 6 summarises the core issues and concludes by outlining recommendations for dementia diagnosis.

Chapter 2: Background for Dementia Diagnosis in England and Wales

AD and other dementias strongly affect people who suffer from the disease and their families and place a significant burden on health and social care systems (Robinson 2015). This chapter shall demonstrate the current evidence relating to dementia which illustrates why this public health issue needs to be tackled and what background evidence needs to be considered in making decisions about how to approach it.

2.1 Causes of Dementia

The term 'dementia' refers to a progressive or chronic malfunction of cortical and subcortical function that leads to complex decline in cognition. As well as this decline in cognition, changes to mood, personality, and behaviour can be experienced (Ritchie/Lovestone 2002). The most common cause of dementia is AD. More rarely, AD can occur before the age of 65. 65 is not a clinical cut-off but is instead an artificial cut-off point based on the traditional age of retirement. Alzheimer's for those aged under 65 is referred to as early onset AD (Alzheimer's Society 2015a). Structures called 'tangles' consisting of hyperphosphorylated tau protein and 'plaques' built by proteins composed of amyloid beta while the disease is progressing are thought to be responsible for the decrease of connections between nerve cells. Ultimately, the amyloid plaques and the tangles lead to oxidative stress, inflammation and the death of these cells and therefore loss of brain tissue (Alzheimer's Society 2014a; ADI 2014). Another recognized reason for the brain damage occurring in AD is ischaemia which might result from cerebral atherosclerosis, small vessel disease and cerebral amyloid angiopathy (ADI 2014). Beyond the changes that occur at the molecular level, the aetiology of AD has been explained through recourse to various other potential modifiers to cognition, including: brain trauma, education, and lifestyle (Lock 2013).

Patterns of genetic inheritance are different for the two forms of AD. Young onset AD sometimes affects several generations tending to accumulate within families. Mutations in one of three genes – two presenilin genes (PSEN-1 and PSEN-2) and the amyloid precursor protein gene – occur very rarely, but are the cause in some of these cases. People affected usually develop AD in their 30s or 40s. In comparison, inheritance of late onset AD is based on a more complex pattern. The effect of a small number of genes identified to influence the likelihood of developing this form of AD are subtle, variations can decrease or increase the person's risk, but are not known to directly trigger AD. The gene called apolipoprotein E (APOE) is known to have the greatest impact on the risk and is located on chromosome 19. Two forms of this gene – the E4 and E3 allele – are

associated with a higher risk of AD, the APOE E2 on the other hand is mildly protective (Alzheimer's Society 2012).

Apart from genetics, a close family member with dementia – even though less predictable than for early onset AD – and age are the best known risk factors for later onset AD (Alzheimer's Society 2012; Ritchie/Lovestone 2002). Age may not influence the symptoms experienced, the needs of younger people, however, are often different, therefore the support has to be adequately adapted (Alzheimer's Society 2015a).

Vascular dementia is the second most common cause of dementia and is due to impaired blood vessels and therefore decreased blood supply to the brain. As age is the greatest risk factor for vascular dementia, this type of dementia rarely affects people aged less than 65. Apart from age as a risk factor that cannot be controlled, genetics play a small role in developing this form of dementia. Some alterable risk factors have more impact, however: Someone who has suffered from a stroke, heart disease or diabetes is about twice as likely to get vascular dementia. Other possible risk factors are sleep apnoea and a history of depression. It is argued that a combination of prescribed medicines and a lifestyle that is considered to be healthy is associated with a decrease in the risk of dementia. Mostly, the patient with vascular dementia already takes tablets to control underlying diseases, for example, through reducing blood pressure, preventing blood clots and lower cholesterol. This arguably implies that health systems should provide regular checks on weight, blood pressure and cholesterol from the age of 40 and that individuals should be responsible for taking regular physical activity, not smoking, eating a healthy balanced diet and drinking alcohol merely in moderation (Alzheimer's Society 2014b).

A less common form of dementia includes dementia with Lewy bodies (DLB) accounting for about 10-15% of all cases of dementia. This form shares symptoms with both Parkinson's disease and AD. Lewy bodies are abnormal protein deposits (alpha-synuclein) that show in brain nerve cells. It is not fully clear why they show and what their contribution to dementia is. They are, however, associated with low levels of essential chemicals – mostly dopamine and acetylcholine – responsible for carrying messages between nerve cells. A decrease in connections between these cells leads to their death. Depending on where these protein deposits are located in the brain the person will show different symptoms. Difficulties with movement are generally associated with Lewy bodies at the brain base which are characteristic for Parkinson's Disease. If, on the other hand, they are found in the outer layers of the brain, this leads to cognitive symptoms which are typical for DLB. Both problems with mental abilities and movement can appear simultaneously. Eventually, dementia is developed by one third of people with Parkinson's disease, movement problems are shown in two thirds of people with DLB. That means the

clinical presentation of both Parkinson's disease and DLB dementia show more similarities the more the condition progresses (Alzheimer's Society 2016a).

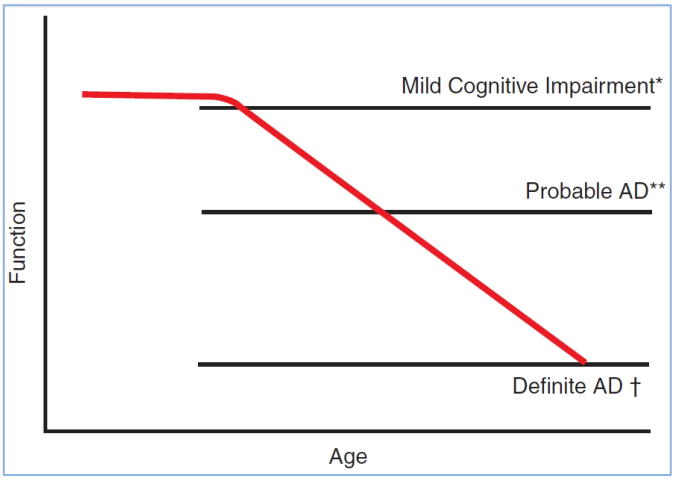
Frontotemporal dementia is another less common form of dementia and gets its name from the lobes of the brain that are affected which are responsible for problem-solving, planning, behaviour and the control of emotions and speech. People affected show typical difficulties with language and changes in behaviour and personality. Although generally less common in elderly people it is the third most common cause of dementia in people under the age of 65 years – most often between 45 and 65 – affecting women and men almost the same. The factors that lead to frontotemporal dementia are not known, but it is assumed that a mixture of lifestyle, medical and genetic aspects are the cause. 10-15% of people affected by this type of dementia have several close family members in different generations suffering from this disease (Alzheimer's Society 2016b).

It is known today that specific neuropathologies leading to dementia appear in various forms. Histopathological studies have shown that cases with characteristics of more than one form of dementia are more common than distinct dementia syndromes (see Ritchie/Lovestone 2002). Mixed dementia, for example, occurs when both vascular disease and AD are thought to be the cause, i.e. blood vessel problems coexist with abnormal protein deposits of AD. Moreover, brain changes due to AD also appear together with Lewy bodies and in some cases a person shows a mixture of vascular dementia, AD and dementia with Lewy bodies (Alzheimer's Association 2016). Before the stage of dementia sets in, a stage known as MCI has been acknowledged which is explained in more detail in the following sub-chapter.

2.2 Mild Cognitive Impairment

In 2011 new diagnostic guidelines for AD were released that recognised a continuum that includes two phases prior to the dementia phase (Jack et al. 2011). Figure 1 shows how the cognitive function of a person moves through these phases and declines as AD is developed which can be very subtle in the beginning.

Figure 1: Hypothetical Change in Function as an Individual develops Alzheimer's Disease

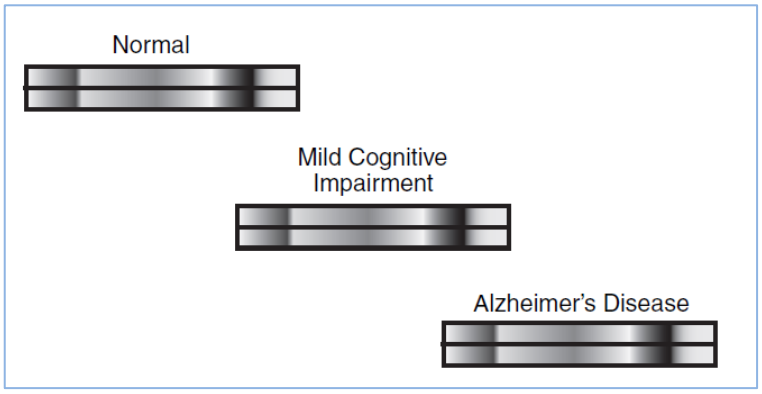


Petersen 2004

The individual would therefore move from an asymptomatic, preclinical phase to a symptomatic, pre-dementia phase, also known as MCI before receiving a diagnosis of probable AD. At present, AD is a diagnosis by exclusion which means that a definite diagnosis is only possible post-mortem (Bender 2003; Lock 2013). The concept of MCI attempts to identify individuals earlier during the decline of cognition which then would make it possible to intervene at this earlier point, if drug treatments become available (Petersen 2004).

The following diagram demonstrates the overlap in the boundary between normal ageing, MCI and AD.

Figure 2: Cognitive Continuum showing the Overlap in the Boundary between Normal Ageing, Mild Cognitive Impairment and Alzheimer's Disease



Petersen 2004

For dementia diagnosis, the subtle differences and overlap between these phases pose a challenge to distinguish between normal ageing and MCI as well as between MCI and very early dementia (Petersen 2004).

The Alzheimer's Society (2015b) defines MCI as 'a condition in which someone has minor problems with cognition'. Since the difficulties do not present a major problem with regard to daily life the patients do not have dementia, however, affected people show measurable deficits in cognition. Compared to a healthy person of the same age and educational background, their issues are worse than would be expected. Most commonly, a patient with MCI experiences a memory impairment, other cognitive domains on the other hand are relatively intact (Petersen 2004). The first symptom in patients with MCI that indicates a likely progression to AD tends to be impaired episodic memory, i.e. the ability to learn and keep new information. However, a change could also be observed in language, executive function (reasoning, planning, problem-solving), attention and visuospatial skills (Winblad et al. 2004; Albert et al. 2011).

Therefore clinically, MCI shows a heterogeneous nature: the impairment can be amnestic, single non-memory domain or involving various cognitive domains. These clinical presentations could be due to degenerative, vascular, metabolic, traumatic, psychiatric or possibly other reasons (Winblad et al. 2004). That means, when patients with MCI are observed over time, some develop forms of dementia (5-10% every year), others stay the same or for some, their cognitive function may even improve (40-70%) (Le Couteur et al. 2013). If possible explanations are narrowed down to dementia, it cannot be diagnosed reliably by the physician if it is due to AD, Lewy body, subcortical, or cerebrovascular disease (Winblad et al. 2004; Whitehouse et al. 2004). Moreover, some patients showing the pathophysiology that is characteristic for AD might not experience symptoms during their lifetime. It is then essential to better identify the biomarker and/or cognitive features that offer the best information about progression from the asymptomatic to the clinical stages of MCI and AD. If the association between the development of the disease and the pathophysiological process of AD can be clarified, it is thought to be ideal to treat patients in these pre-symptomatic stages before significant cognitive impairment, as it is done similarly for cancer treatment and cardiac disease (Sperling 2011).

2.3 Assessment Process and Possibilities for Drug Treatment

Memory clinics are acknowledged as the best service through which to carry out assessments and reach diagnoses of dementia. Research, alongside clinical practice, and providing subjects for dementia based clinical trials is a central part of memory clinics'

purpose. They present the first site where new knowledge in dementia is transferred into the clinical domain (see DoH 2012).

In the UK, memory clinics first appeared in the mid 1980's with the aim to offer the best available expertise for people with memory problems at the earliest possible stage and therefore raising the amount of people who had the opportunity to receive specialised support outside mental institutions. Early diagnosis and treatment aimed to prevent deterioration, diseases other than dementia should be identified and treated, new therapeutic agents should be evaluated and people worried about their memory who did not show abnormal deficits should receive reassurance (Jolley/Moniz-Cook 2009). Most clinics are embedded within mental health services. The UK is distinct internationally in having an acknowledged specialty of old age psychiatry and a system within the NHS that secures specialist services for older people experiencing mental health problems nationwide (Jolley/Moniz-Cook 2009; Jolley et al. 2006). The UK memory clinics have significantly contributed to the development of neuropsychological and medical approaches to patients and families, conducting research in biology, pharmacology and neuropsychology to a large extent, and promoted understanding of aetiology, characteristics and natural history of dementias. In comparison, the development of population based services that actively promote health and well-being has been relatively neglected (Jolley/Moniz-Cook 2009).

There is no single diagnostic test for dementia (DoH 2014a). During an assessment for dementia a history is taken which includes talking to the patient and a person who knows them well to find out when and how the symptoms appeared and what effect they have on the patient's life. Their own medical history and their family member's is examined alongside a review of current medication. A physical examination is useful in case there is the suspicion of a stroke or Parkinson's disease. Blood and urine samples are taken to potentially identify other conditions as a cause for the symptoms (Alzheimer's Society 2014c).

A patient's cognition should be examined when they are not experiencing depression or are acutely unwell due to delirium. Cognitive testing comprises the examination of reasoning, recall, abstract thinking, verbal and visuospatial skills. To examine cognitive abilities there are various tests that can require a few minutes or up to 90 minutes. For instance, there is the Mini Mental State Examination (MMSE), Montreal Cognitive Assessment, Abbreviated Mental Test Score, and Addenbrooke's cognitive examination. Furthermore, a mental state examination should be carried out and the patient's functioning overall needs to be looked at. According to the National Institute for Health and Clinical Excellence (NICE) a brain scan is recommended as necessary for the

assessment. It can exclude normal pressure hydrocephalus and brain tumours or detect vascular damage. However, although a scan might help underpin a dementia diagnosis, the disease cannot be excluded by a normal result (DoH 2014a).

To identify MCI in a patient the clinician needs to find an aetiological diagnosis in each distinct case to direct appropriate therapy due to its heterogeneous nature, for example for vascular brain disease, depression or vitamin deficiency (Werner/Korczyn 2008). Apart from the reports by the individual patient and/or an informant about the degree of their decline, it is important to determine cognitive decline objectively. This is done by cognitive testing where typical scores for patients with MCI are 1 to 1.5 standard deviations below the mean for their peers of the same education and age on culturally suitable normative data. These ranges are meant to be understood as guiding principles and not as cut-off scores (Albert et al. 2011).

Successes in dementia research, for example, in genetics or in diagnostic technologies, such as developments in imaging, have made diagnosis more uncertain due to the similarities between AD and other dementias. Moreover, there is no biomarker that would make a clear distinction between normal ageing and AD. The uncertainty applies even to the neuropathological features, tangles and plaques, that cannot be linked to the severity of cognitive impairment confidently (Whitehouse et al. 2004). After all, clinical judgement is the essential component for a diagnosis of dementia or the information of MCI, even though functional measures and cognitive tests are useful in the assessment (Petersen 2004).

Four drugs can nowadays be prescribed that can slow down the rate of deterioration and alleviate symptoms for some time, but commonly go along with side effects, and do not benefit all patients (Lock 2013). Medication available to treat AD include acetylcholinesterase inhibitors and NMDA receptor antagonists which can temporarily stabilise or ease symptoms of AD and are recommended for people with either mild-to-moderate or severe AD (Alzheimer’s Society 2014d). This means the drugs merely offer symptomatic benefits and are not effective against disease progression. It is therefore not surprising that the attempt to use cholinesterase inhibitors to treat MCI as if it were the beginning of AD were unsuccessful. This might change if therapies are developed that are disease-modifying (Werner/Korczyn 2008).

2.4 Epidemiology of Dementia

2.4.1 Mortality, Prevalence and Incidence

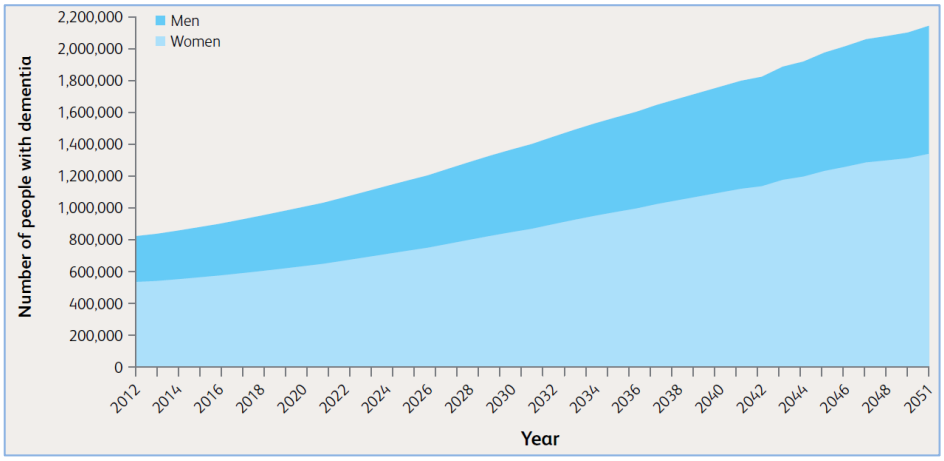
In England and Wales, the Office for National Statistics found that AD and other dementias were the leading cause of death for women and the second leading cause of death after ischaemic heart diseases for men in 2015 (Office for National Statistics 2015). In the UK, there are 60,000 deaths that are directly attributable to dementia every year (Alzheimer's Society 2014e).

Given that age is the primary risk factor for dementia, the group mainly affected by the condition is older people. Demographic transition means that life expectancy from age 60 continues to rise everywhere in the world and mortality rates are decreasing. This leads to an epidemiologic transition with an increase in chronic diseases made worse by certain behaviours and lifestyles including diets high in salt, fat and sugar, tobacco use and little physical activity, especially in middle income countries (Ritchie/Lovestone 2002; ADI 2015). The reduced mortality amongst other conditions that will affect future generations will mean extended survival for people as they age. This set of circumstances will lead to an increased lifetime risk of dementia onset (Alzheimer's Society 2014f).

As can be expected, recently published reports have suggested considerable increases of dementia cases internationally in the next decades, especially among the oldest old and countries that are experiencing demographic transition (ADI/WHO 2012). Worldwide it is said that 46.8 million people were living with dementia in 2015. Every 20 years this number is estimated to almost double resulting in 131.5 million in 2050 (ADI 2015). Estimations that assume that life expectancy will not experience an improvement in the future and consider only the onset of dementia in people aged 60 or older yield that one out of every three people born in 2015 will suffer from dementia during their life (Office of Health Economics 2015).

In the UK there are about 850,000 people with dementia today (Alzheimer's Society 2014e). Figure 3 shows the projected increases in the amount of people suffering from dementia in the UK from 2012 to 2051 based on constant age-specific prevalence and distinguishing between men and women.

Figure 3: Projected Increases in the Number of People with Dementia in the UK (2012–2051), assuming Constant Age-Specific Prevalence, by Gender



Alzheimer's Society 2014f

If age-specific prevalence remains the same and increases are only influenced by demographic ageing, by 2025, it is said there will be about 1 million and by 2051 there will be about 2 million. When calculated from the year 2013 this equals an increase of 40% and 157%, respectively (Alzheimer's Society 2014f). Women are more likely to be affected by dementia which is unexplained at present (Ritchie/Lovestone 2002). One possible explanation is the fact that women have longer lives than men and, as mentioned above, age is the most significant known risk factor for dementia (Public Health England 2016). An exception to this is vascular dementia which is slightly more likely to occur in men (Alzheimer's Society 2014f). Moreover, it is estimated that at least 42,000 younger people suffer from dementia in the UK which equals more than 5% of all individuals with dementia (Alzheimer's Society 2015a).

It is likely that due to the various definitional criteria and differences in sampling and assessment methods, findings concerning the prevalence of MCI are contradictory and few. Predictions excluding other MCI subtypes and only considering prevalence rates of AD and the likelihood of conversion from MCI to AD yielded an increase of MCI prevalence from 1% at age 60 to 42% at age 85 (Werner/Korczyn 2008). Other estimations reveal that among people aged over 65 between 5% and 20% have MCI (Alzheimer's Society 2015b).

For the interpretation of such estimations, it should be kept in mind that other factors besides an actual increase in incidence might influence the figures. Promoted early detection and diagnosis to increase diagnosis rates and a shift in the diagnostic boundary could lead to testing and referring individuals to specialist services who would not have experienced this before, now being identified to have ever milder stages of dementia (see Matthews et al. 2016). Furthermore, it is noted that the above outlined predictions should

be considered a ‘worst case scenario’ rather than inevitable results. Evidence suggested that rates of prevalence and incidence among the risk group of older people is decreasing in high-income countries such as the UK (Alzheimer’s Society 2014f).

A study published by Matthews et al. (2016) focuses on the direct comparison of dementia incidence across time in various areas in England and Wales. The researchers were consciously consistent in their choice of diagnostic criteria to avoid a respective impact on dementia incidence. Incidence is considered a more reliable comparator measure across geography and time compared to prevalence since the latter is the product of both mortality and incidence (Matthews et al. 2016). This is problematic due to the two indicators potentially developing in different directions. For example, a decrease in incidence may take place while the duration of survival with dementia increases, cancelling out the other indicator’s impact on prevalence (ADI 2015).

The results of the study show that incidence rates in England and Wales have in fact decreased over the last twenty years in the areas examined. Women’s rates are declining less strongly compared to men’s; the reduction is thus driven by a decrease in incidence among men at all ages. In the UK, it is suggested that there are just under 210,000 incident cases of dementia per year, 135,000 in women and 74,000 in men. This means a far smaller rise than it was suggested based on extrapolation of the estimates reported earlier. Taking account of a reduction of age-specific incidence of dementia (when using steady diagnostic criteria), it can be argued that despite the ageing population, the estimated numbers of people developing dementia in any year has stayed relatively stable (Matthews et al. 2016).

Based on the study findings it is possible to assume that there is a change in population brain health across generations. Moreover, there is an adverse effect on brain health by risk factors linked to disadvantage. This means that the positive development might be limited to those countries that have significantly invested in population health throughout the lives of those now in older ages (Matthews et al. 2016). Improvements in public health might have the potential to greatly lessen or even prevent the predicted increases in dementia prevalence in the next decades. This will be examined closer in the next sub-chapter.

2.4.2 Risk Reduction

Apart from non-modifiable risk factors such as age, gender and genetics, studies have focused on modifiable risk factors and protective factors for dementia and cognitive impairment (ADI 2014). Health behaviours, such as physical activity, diet, smoking and

alcohol habits are not only strongly associated with each other, but also with the metabolic syndrome that includes the following conditions: abdominal obesity; diabetes and prediabetes; high blood pressure; and high cholesterol. Recognising that for most people with dementia there is a mixture of pathologies that underlay the presenting symptoms, vascular risk factors are suggested as a precursor to vascular dementia and AD. It was argued that there might be an association between atherosclerosis and AD based on mutual aetiologic and pathophysiological processes (ADI/WHO 2012).

A systematic review underpins the role of vascular risk factors and suggests that, among the included factors, type 2 diabetes mellitus and hypertension showed the highest level of evidence in the association with dementia, particularly when they were examined in mid-life (Duron/Hanon 2008). In the context of diabetes, studies have mostly found that the disease is linked to an increased risk of dementia, but is stronger associated with vascular dementia than with AD. It was also shown that there is an association between diabetes and MCI (ADI 2014). For instance, based on a quantitative meta-analysis, participants with diabetes had higher risk for MCI (relative risk (RR) 1.21, 95% confidence interval (CI) 1.02 to 1.45), vascular dementia (RR 2.48, CI 2.08 to 2.96), AD (RR 1.46, CI 1.20 to 1.77) and any dementia (RR 1.51, CI 1.31 to 1.74) than those participants without diabetes (Cheng et al. 2012). Moreover, the association between the risk of stroke and hypertension and therefore of dementia following a stroke is seen as established. Dementia is more common among those individuals having experienced a stroke than those who have not (Tzourio et al. 2014). For example, Ivan et al. (2004) focused on dementia after a stroke while using a case-control design in their study and found that 19.3% of cases and 11% of controls developed dementia. A stroke at baseline doubled the risk of developing dementia (HR 2.0, 95% CI 1.5 to 3.1). Adjusting for education, age, sex, and exposure to individual risk factors for stroke did not lessen the risk (HR 2.4, CI 1.6 to 3.7).

In the context of obesity and overweight, Whitmer et al. (2005) found that in middle age the conditions are linked to an increased risk of future dementia in old age regardless of frequent comorbidities and sociodemographic factors. People who were overweight (body mass index 25.0 to 29.9) had a 35% increased risk of dementia (hazard ratio (HR) 1.35, 95% CI 1.14 to 1.60) and people who were obese (body mass index ≥ 30) had a 74% greater risk of dementia (HR 1.74, CI 1.34 to 2.26) in comparison to participants of normal weight (body mass index 18.6 to 24.9).

In the context of later stages, Wysocki et al. (2012) found in their study that there was a significantly faster decline in the MMSE scores of participants with hypertension and questionable dementia (baseline dementia status was defined beforehand) compared to

those with questionable dementia who did not have increased blood pressure. On the other hand, there was no significantly faster decline found between those with and without hypertension and frank dementia or intact cognition. Controlling or preventing hypertension was therefore seen as potentially helpful in decreasing the rate of cognitive decline in individuals who are cognitively vulnerable.

Apart from cardiovascular factors, the role of psychological factors were examined. A systematic review, published in 2006, suggests a history of depression as an independent risk factor for AD (overall OR 2.02, 95% CI 1.80 to 2.26) (Ownby et al. 2006). Another systematic review focused on the role of late-life depression for dementia and found a significant risk for all-cause dementia (OR 1.85, 95% CI 1.67 to 2.04), vascular dementia (2.52, CI 1.77 to 3.59) and AD (OR 1.65, CI 1.42 to 1.92) (Diniz et al. 2013). In comparison to the research on depression, anxiety as a potential risk factor was researched by few studies. For example, the Caerphilly prospective study linked anxiety to a raised risk of incident dementia at follow up (OR 2.89, 95% CI 1.27 to 6.54). However, the association was shown not to be statistically significant after adjusting fully for general health and vascular risk factors (Gallacher et al. 2009). Another study found no significant relationship between dementia and either anxiety disorders (HR 0.92, 95% CI 0.58 to 1.45) or anxiety symptoms (HR 1.05, CI 0.77 to 1.43) (De Bruijn et al. 2014).

A study by Brayne et al. (2006) focused on severe cognitive impairment and dementia in the phase before death and the role of social class and higher education as proxies for lifestyles and healthy exposures. They found that the prevalence of both conditions increases steeply with age in that period. The risk of dementia or severe cognitive impairment was shown to be approximately 60% by the time a person who is 90 years old dies. It was shown that individuals with higher social class and higher education were at significantly lower risk of dying with cognitive impairment or dementia. It was, however, shown that the decrease regarding dementia for higher education and social class was merely 7% and 2%, respectively. Regarding cognitive impairment the reduction had a value of 10% and 7%, respectively. Both factors together resulted in a decrease of 10% for cognitive impairment and 7% for dementia. The researchers concluded that the inequalities in social advantage and healthy lifestyles noticeable at particular ages seem to diminish the longer the life expectancy is (Brayne et al. 2006).

Based on the large reduction in mortality due to stroke and heart disease over the past 50 years, linked to public health interventions altering risk factors, and given the available evidence in the context of dementia there were calls to approach dementia the same way (see Smith/Yaffe 2014). Research on primary prevention has, however, received relatively little funding which is seen to be disproportionate considering its impact on society. Based

on these considerations, the Blackfriars Consensus on promoting brain health in the UK was published by public health practitioners, policy makers, community and voluntary representatives, and researchers. They agreed that there is a potential to include dementia risk reduction in current efforts to prevent non-communicable diseases (NCDs). This is backed by the notion, as described above, that there are common causal explanations for dementia and other NCDs and despite this, the current prevention strategies and NCD policies lacked consideration of the potential for health promotion and for risk reduction in relation to dementia. Moreover, a clear approach to known risk factors such as alcohol and head injury received little attention (Public Health England 2014b).

In midlife, one or more of seven risk factors including smoking, low fruit and vegetable consumption, diabetes, obesity, binge drinking, high blood pressure, and raised cholesterol are commonly found in individuals (Public Health England 2016). A 'brain ageing' risk assessment tool was developed by Public Health England for clinicians and individuals, the effectiveness of various marketing approaches in promoting positive alteration of lifestyle-related risk factors was tested and dementia prevention as one of the main outcomes was included in programmes improving health such as NHS Health Checks (DoH 2014b). The NHS Health Check is meant for adults in England aged between 40 and 74 and comprises a dementia component which seeks to raise awareness of dementia particularly among individuals aged 65 to 74 by giving them information about their risk and the availability of memory clinics. It is attempted to widen this approach to target 40 to 65 year old patients (Public Health England 2016; DoH 2013b).

The recognition of the potential benefits of a public health approach has given more attention to environmental and social factors, for example, high education, reductions in poverty, decreased exposures to toxins and improved community support (Lock 2013). Although some decision makers recognize the importance of these factors, policies in the UK, nonetheless, seem to consistently emphasise healthy lifestyles. It should be kept in mind that a focus on altering health behaviours through interventions on the individual level – while still an important part in tackling health inequalities – do not fully consider the influence of the economic and social environments on people's health over time (Katikireddi et al. 2013). Upstream determinants, for example education, are mentioned as potentially playing a part in decreasing health inequalities (Eikemo/Mackenbach 2012). In comparison, downstream interventions, such as campaigns relying mostly on media, are suggested to most likely result in intervention-generated inequalities. That means those groups that are most urgently in need of being positively affected by preventive interventions are least likely to benefit (Lorenc et al. 2012). It is suggested that policy

makers focusing on tackling health inequalities should take into account the potentially adverse effects that respective campaigns can have. There is also more research needed on identifying the most effective approach in terms of upstream interventions (Katikireddi et al. 2013).

2.5 Impact and Cost of Dementia

Compared to all chronic diseases, dementia is considered one of the diseases significantly contributing to disability and dependence (ADI 2013). Moreover, people with dementia have to cope with feelings of marginalisation and isolation due to the stigma attached to the disease (Wortmann 2012). Stigma has been differently defined, for example Goffman describes stigma as a behaviour, reputation, or attribute which is socially discrediting in some way. Other people are led to mentally classify the person in a rejected, undesirable stereotype instead of in a normal, accepted one (see Goffman 1963).

The concept of stigma has been further developed to consider different interrelated types of stigma, namely public stigma, self-stigma and stigma by association. While public stigma relates to the reactions of lay individuals towards a stigmatised group or person, self-stigma means the internalisation of public ideas resulting in harms to the person's self-esteem and self-efficacy. Stigma by association is based on beliefs and emotions of those staying in the stigmatised person's surrounding environment such as professionals and family members (ADI 2012; Corrigan/Rao 2012).

The progressing decrease in quality of life and the likelihood of a premature death can be named as two of the most significant impacts of dementia (Alzheimer's Research UK 2014a). The quality of life of those living with the condition as well as their carers or families can be considerably affected. The person with dementia experiences deteriorating cognitive function that, over the years, limits their ability to live on their own and might decrease life expectancy. Their carers, commonly a partner or an adult child, frequently experience major demands on their energy and time which can impact on their own health, well-being and employment (Alzheimer's Society 2014f). Unsurprisingly, people suffering from dementia report a lower quality of life compared to those over 65 years and the whole population. This reported quality of life increasingly deteriorates as the severity of the disease progresses leading to a loss of cognitive and physical function (Alzheimer's Research UK 2014a).

The Global Burden of Disease (GBD) estimates are directive to assess the impact of dementia and be able to compare it to other health issues. The impact is hereby called

‘burden’ and interpreted in terms of related mortality and disability. Disability adjusted life years are the main indicator and consist of the sum of Years of Life Lost and Years Lived with Disability, therefore considering the effect of dementia on both quantity and quality of life. According to the findings from the Global Burden of Disease estimates, dementia is among the first 10 most burdensome conditions among the group of older people internationally. When compared to other conditions, its impact results mainly from years lived with disability instead of years of life lost due to premature mortality. The GBD estimates by the Institute for Health Metrics and Evaluation in 2010, however, indicated a smaller health loss attributed to dementia than the previous estimates by the WHO in 2004. Its rank order relative to other significant conditions moved from place 5 to 9. Mostly, this is due to alterations in disability weights rather than in the estimates of disease occurrence (ADI 2015).

Moreover, the EQ-5D can be used to measure health related quality of life of patients and carers. Quality of life is assessed considering five aspects: self-care, mobility, pain or discomfort, usual activities, and depression or anxiety. Given the rates by the respondents for each dimension (‘no problems’, ‘some problems’ or ‘extreme problems’) the assigned health state is transformed into a single summary index ranging up to a value of 1 equalling full health (Alzheimer’s Research UK 2014a). A study by Mesterton et al. (2010) examining the impact of dementia in terms of decreased quality of life gathered data on the EQ-5D scores of 233 Swedish patients with AD and those of their carers. The results were stratified by disease severity: Highest scores for the patient were measured for mild Alzheimer’s (0.64) and lowest for those with severe disease (0.24; $p<0.01$). The same pattern was observed for the carers (Mild AD: 0.80; Moderate AD: 0.77; Severe AD: 0.75), although this turned out to be not statistically significant.

Apart from the impact on patients and carers, the financial implications of dementia need to be considered. Studies in mainly high-income countries, including the UK, on the cost of dementia have shown the major economic burden that dementia is associated with, namely through direct costs, i.e. health and social care, and indirect costs, i.e. families and friends’ unpaid care. People affected by dementia have to carry the costs of health and social care and at the same time can experience a decrease or lack of income. Emerging evidence suggests similar developments for middle-income countries (see ADI/WHO 2012).

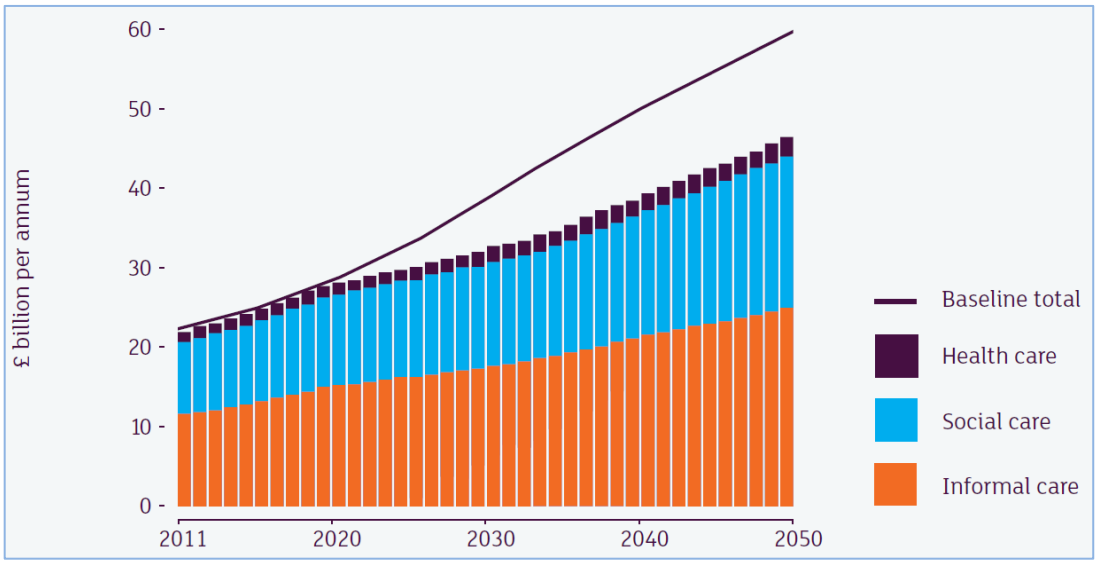
Worldwide, estimations suggest dementia costs were $818 billion in 2015 (ADI 2015). In the UK; a study found that the costs for social and health care in relation to dementia almost equal the combined costs of heart disease, stroke and cancer (ADI 2015). Based on numbers of the year 2006, dementia cost £23 at that time. Social care expenditure (£9

billion) was greater than the health care costs (£1.2 billion) and productivity losses cost £29 million. The largest cost, however, was the time spent by informal carers with a value of £12.4 billion (Alzheimer's Research UK 2014a).

£26 billion of combined health and care costs as well as the contribution made by informal carers were spent in the UK in 2015. By 2025 it is estimated dementia will cost the UK economy £32.5 billion and by 2050 it could rise to £59.4 billion. Efforts to prevent dementia would therefore not only prevent human suffering, but would have a positive effect on the economy (Smith/Yaffe 2014).

A report from Alzheimer's Research UK (2014b) showed among others that in the theoretical case of an intervention delaying dementia this would result in major cost savings. The following diagram illustrates the decrease from the baseline cost for health, social and informal care in a scenario where the onset of dementia is prevented for another 2 years in 2020.

Figure 4: Projections of Cost of by Year and Type of Cost for an Intervention that Delays Onset by 2 years from 2020 (£ billion)



Alzheimer's Research UK 2014b

If dementia onset was postponed in 2020 for 2 years, in 2030 the cost for the economy would drop from £38.1 billion to £32.2 billion. In 2050, this means that £46.5 billion would be payed instead of the estimated £59.4 billion. If dementia was delayed by 5 years – not displayed in this graph – in 2020, in 2030 there would be a decrease in cost from £38.1 billion to £24 billion and in 2050 from £59.4 billion to £38.2 billion. This analysis did not take cost of treatment provision into account, but is seen as a representation of the financial impact of a later onset of the disease alongside the additional advantages for people's wellbeing and quality of life (Alzheimer's Research UK 2014b).

Chapter 3: Methodology

This chapter illustrates the methodology used to answer the research questions. The research design and data collection will be described. Subsequently, the analytical approach to the data will be illustrated and finally the limitations of the chosen approach will be evaluated.

3.1 Research Approach

The presented work is a case study which focuses on policies, particularly looking at early diagnosis of dementia, in Wales and England from 2009 until 2016 and related social and ethical challenges. Both primary and secondary data were used to achieve this purpose. The primary data gathered by the researcher comprises guideline-based expert interviews with people working in dementia policy and service provision in Wales and UK policy documents specifically related to dementia. The secondary data comprises expert interviews with clinical practitioners involved in assessing and diagnosing those with dementia and those working in dementia research. This was pre-existing data generated as part of a previous ethnographic research project on the ethics of dementia diagnosis funded by the Wellcome Trust (WT091772).

The identified policy documents provide information about the ways the policy makers in Wales and England decided to deal with the upcoming challenge of the ageing population, increasing dementia cases and about intermediate achievements. The interviews with experts (across policy, practice and research) shall examine potential issues related to the chosen approach in more detail. Four experts involved in dementia policies/services were interviewed by the author and provide insight into the practical challenges and strategic concerns that have informed dementia policy in the Welsh context and on the approach taken to increase diagnosis rates in both England and Wales. The secondary data includes interviews with seven experts in dementia research and twelve interviews with clinicians working in a memory clinic. The former are particularly interested in new diagnostic technologies, early detection, prevention and post-diagnostic support. They illustrate developments in research that are framing dementia policies and express their expert opinion on the push towards early diagnosis. Memory clinic staff on the other hand explore how they approach early diagnosis and the impact that dementia policies have had on clinical practice, illuminating challenges in everyday social practices compared to official ambitions that are found within the policy framework.

This research approach enables the researcher to compare and contrast three different perspectives on the issues related to the early diagnosis of dementia, highlighting different

interpretations of various social and ethical challenges. Words and sentiments displayed in the policy documents are considered in the context of the wider networks of action that dementia policies sit within, i.e. dementia services, biomedical science, politics and the public. All data are examined for their points of emphasis and possible inconsistencies in the framing of the diagnosis of dementia and what the consequences of these might be for patients and their families as well as for the health care system more widely.

Thus, the analysis of the identified documents and interview data aims to answer the following research question and secondary questions:

What are the social and ethical challenges facing clinicians in regards to early/timely diagnosis of dementia and how have these been framed by wider policy in England and Wales?

1. What plans, strategies and achievements have been identified in Welsh and English policy documents that relate to the early/timely diagnosis of dementia over time (2009 to 2016)?

2. What social and ethical challenges do experts in dementia policies/services, experts in dementia research and memory clinic staff address in regards to early detection of dementia?

3.2 Qualitative Document Analysis

3.2.1 Definition and Purpose of Documents

Documents are ‘social facts’ which are manufactured, shared, and utilized in socially organised ways. The data needs assessment and interpretation to create meaning, understanding and empirical knowledge (Bowen 2009). Rules are forming their construction, they display a specific structure and are embedded in a discourse. Their existence in the world is therefore based on organized, collective action (Prior 2003).

Documents can give insight into past events and background information which can help researchers understand the historical foundations of particular issues and demonstrate the conditions that influence the assessed phenomena. In this case, policy documents display information about dementia policies in the past years (from 2009 to 2016) including their priorities and the reasoning behind chosen approaches to tackle problems such as under-diagnosis and the stigmatisation of dementia. This helps contextualising the information received through the gathered interviews. Moreover, documents can be used to track development and change in published periodic reports. Subtle differences

can potentially hint to major developments in a project. For this study, documents were identified that presented intermediate achievements in reports published in 2012, 2013 and 2016 and respective shifts in focus. Theoretically, it is possible to assess final reports to receive an impression of an organisation or program's achievements over time, however, as dementia diagnosis and other issues in dementia policies seem to be an on-going issue no final reports have been published (see Bowen 2009). The analysis of the chosen policy documents is limited to the content as a resource. It is reflected for this study, however, that policy narratives are connected to action, therefore impacting on how dementia diagnosis is approached in England and Wales and what this means for patients and clinical practice (see Prior 2003).

3.2.2 Identification of Documents

Utilising the UK government website (www.gov.uk), publically available documents were identified by using the search term 'dementia' since this displayed all relevant policy documents. Documents from the following organisations were included: DoH, Cabinet Office, Public Health England, and NHS England. Those organisations provided the following relevant document types: Policy paper, impact assessment, letter, press release, and speech.

Only documents related to dementia policies in the UK were included when dated from 2009 – coinciding with the introduction of the national dementia strategy – to 2016 shortly after the completion of the original ethnographic research project that generated the data for secondary analysis as part of this study. This timeframe also helps capture the current picture. The search focused primarily on documents of organisations concerned with the design, implementation, and evaluation of dementia policies. The documents were required to cover the topic 'early/timely diagnosis'.

The following documents have been chosen for analysis:

Table 1: Identified Policy Documents

Department of Health	**Public Health England**	**NHS England**	**Cabinet Office**
Living well with dementia: A National Dementia Strategy (2009)	Recommendation against national dementia screening (2015)	Enhanced Service Specification. Facilitating timely diagnosis and support for people with dementia 2015/16	Prime Minister's speech to the Dementia 2012 conference

Living well with dementia: A National Dementia Strategy. Implementation Plan (2009)	PM launches next phase of Britain's fight against dementia (2015)		
National Dementia Vision for Wales (2011)			
Prime Minister's Challenge on Dementia (2012)			
Dementia. A state of the Nation Report on Dementia Care and Support in England (2013)			
Delivering major improvements in dementia care and research by 2015: Annual report of progress (2013)			
Letter to PM: Progress on the Prime Minister's Challenge on Dementia: Year Two (2014)			
Prime Minister's Challenge on Dementia 2020 (2015)			
Prime Minister's Challenge on Dementia 2020 Implementation Plan (2016)			

To identify essential background literature the reference lists of the included documents as well as a free web search with the search engine Google and Google Scholar were used for manual searches.

3.3 Expert Interviews

3.3.1 Definition and Purpose of Expert Interviews

As a method of inquiry, the expert interview is used widely as a means for exploration. An ‘expert’ is a person who possesses knowledge of a social phenomenon which the researcher shows an interest in while the expert interview is a particular method used to gather data about this phenomenon providing the opportunity to resort to the knowledge of specific actors who are essential for the area of interest (Bogner et al. 2009).

The experts chosen for this study provide distinct knowledge regarding processes and contexts related to their particular professional sphere of activity and act as representatives for a number of actors. The expert interviews received from the ethnographic research project deliver the perspective of those working in dementia research and clinical practice, while the newly gathered, original interviews focus on the perspective of those involved in dementia policies/services. This enables the researcher to receive practical, everyday knowledge from three different and relevant perspectives regarding the issues and concerns related to dementia policies. The desired insights on policies cannot be acquired from policy documents alone. Interpretive knowledge is based on subjective experiences and these experiences provide different views on dementia diagnosis that are dependent on the position and role of the expert concerned. However, all these positions are interrelated, illustrating patterns as well as inconsistencies and resulting in an overall picture of social and ethical challenges in dementia diagnosis (see Bogner et al. 2009; see Flick 2014).

A shared area of interest or expertise between the interviewer and interviewee can be advantageous in motivating a potential expert to take part in an interview – having curiosity about the topic and an interest in sharing their opinion with an external expert – and can make further explanations unnecessary. These experts, as was mostly the case in this study, might have an implicit understanding for the political and/or scientific importance of their field of activities and be used to being in the public eye. Moreover, the choice to carry out expert interviews is advantageous due to its practicality by gaining thorough data with little effort in terms of economic and time resources (see Bogner et al. 2009).

3.3.2 Primary Data

3.3.2.1 Access to the Field

The networks of three contact persons at Cardiff University were accessed and eventually led to contact details, mostly e-mail, of a number of potential interview partners. The e-mail subsequently sent to them contained information about the proposed research that this thesis would entail and the requirements for their participation as experts: They were informed that it would need 1 hour maximum and in case of time constraints less time would be feasible. A requirement was the knowledge of strategy or policy related to dementia diagnosis and services in Wales due to their involvement in dementia policies or services either at the current time or in the past. After receiving rejections, one on the basis of their perceived lack of expertise and another due to the restrictive rules of their organisation, I was referred to other people, and successfully interviewed four experts. This number of interviewees was seen as appropriate as the aim of these interviews was to supplement the policy documents, providing a more nuanced, contextual account of the reasoning behind particular policy aims and decisions related to early/timely diagnosis.

An information sheet and a consent form were sent to each interviewee via e-mail. The former explained in more detail the purpose of the study, the reason why they had been invited, what happens if they took part, disadvantages, risks and benefits of their participation, and what would happen to the results of the study. The consent form made sure that they understood the information, had their questions answered, emphasised the participatory nature of their commitment with freedom to withdraw at any time without giving a reason, and informed them about the recording of the interview and their strict anonymity.

An interview guideline was developed beforehand and reviewed by Professor Dr Christine Färber at HAW Hamburg and the research fellows Dr Alexandra Hillman and Dr Martin O'Neill at Cardiff University. Its aim was to help keep the conversation in the desired subject area and to not miss any important aspects of their experience and insight, while leaving enough room to adapt. It was considered beforehand that the gathered data would come from people involved in dementia policies or services in the Welsh context. This might limit their statements in some cases to be of relevance only to Wales, however, the phrasing of the questions purposefully covered both England and Wales granted that their expertise would be sufficient. This was mostly the case since the identified policies are partly relevant for Wales or England only or for the whole of the UK and therefore the two countries have significant similarities. This will be considered in the analysis and the presentation of results.

Following the interviews, the audiorecordings were fully transcribed and anonymised. If any names were mentioned, they were replaced with pseudonyms to ensure data protection. Since the aim of the expert interviews was to establish both the experts' knowledge of policy aims and their perceptions of them, the transcription was done word for word to ensure an accurate record of the content of their reponses, however, words such as 'yeah', 'right' and utterances such as 'uhm' were removed for purposes of clarity and dialect was transformed into standard language. The result is a cohesive text representing the original grammatical structure and wording (see Mayring 2014).

All the documents can be viewed in full in the appendix.

3.3.2.2 Reflection of Interview Processes

The first interviewee seemed very motivated and took the time to travel to Cardiff University where the interview took place. During the interview a very comfortable and talkative attitude was shown, directing the interview most of the time and answering several questions without having to be asked for specific topics or to elaborate. The interview lasted for one hour and all questions were covered.

The second interview was carried out in an area outside Cardiff where the expert's office was located. The interviewee seemed quite nervous and reluctant to go into depth. It took place in an open space where people did not linger, but walked past regularly which led to distractions including a very short break to let people finish their conversation nearby and leave. During the interview the questions were adapted to have an emphasis less on policies and more on the expert's specific work in dementia services. Asking for elaboration was necessary several times. In the end the interviewee felt the need to apologise for a perceived lack of knowledge. The interview lasted for 24 minutes.

The third interview took also place in another area outside Cardiff where the office of the interviewee was located. A question from their side led to providing information on the previous interview partners. As the expert was familiar with the first interviewee's work this led to cutting down statements on respective topics assuming it was heard in the first expert interview. Furthermore, it was perceived as distracting that before the start the interviewee stated there was a colleagues' event taking place soon on short notice. After a few minutes of talking someone interrupted urging them to come to the event. This led to worries about taking up too much time while simultaneously trying to get enough information. The interviewee did not seem to wish to talk about specific topics spontaneously, but strictly adhered to my questions. Thus, the interview was fully

structured by the previously prepared interview guideline. In the end, the interview lasted for 36 minutes and offered valuable information.

The fourth interview was conducted in an office in Cardiff, the interview situation was perceived as relaxed. The interviewee had been involved in dementia policies before the current job and had to state, as a response to two questions, that due to the time passed their knowledge was not perceived as sufficient for certain topics. Considering the previously conducted interviews, the questions were sometimes adapted to achieve more depth and spot potential consensus or inconsistencies. The interview lasted for 32 minutes.

3.3.3 Secondary Data

The secondary qualitative data consisted of expert interviews carried out between 2012 and 2015, undertaken as part of an ethnographic study of memory clinics focusing on earlier referral and diagnosis of dementia.

Ethnography is a qualitative approach that involves the examination of learned and shared patterns of beliefs, values, language and behaviours of a culture-sharing group over an extended period of time (see Creswell 2013). The ethnographic research approach stems from nineteenth-century Western anthropology where pre-industrial cultures were observed and was first perceived as an addition to ‘ethnology’. Ethnology focused on the comparison and historical analysis of non-Western societies and cultures. Over the years, the term ‘ethnology’ experienced a loss in popularity due to anthropologists carrying out their own fieldwork calling their approach ‘ethnography’ instead. Up till now its meaning has been exposed to various interpretations and re-contextualizations to allow dealing with specific circumstances (Hammersley/Atkinson 1995).

The research project included observations, for many the defining feature of ethnography, in two memory clinics in major teaching hospitals in England and Wales (see Savage 2000). Additionally, patients from each memory clinic and a family member, a carer or a friend were interviewed to examine their experiences and views in the context of dementia diagnosis. Memory clinic staff were interviewed to examine their reasoning behind giving information to their patients. Experts in dementia research reflected on new diagnostic technologies, the impact these might have upon the information available to patients and relatives and what this information might mean (see School of Medicine 2016).

These interviews facilitated a conversation within the limitations of the interview, giving more flexibility towards the interviewee’s talk compared to standardized interviews (see Hammersley/Atkinson 1995). Even though such interviews as the most common in

ethnographic research can appear as casual conversations, an implicit research agenda is underlying them, i.e. accessing the expert's knowledge for the purpose of the research question (see Fetterman 2010).

As described before, the interviews with memory clinic staff and experts in dementia research were chosen to be included in the current case study. The interviews with patient and carers as well as the conducted observations were not considered appropriate to answer this study's research questions. On the other hand, the expertise of memory clinic staff and researchers interested in dementia presents two different perspectives to what is described and justified in the policy documents and explained by experts in dementia policies/services. This choice therefore enables the researcher to fulfil this study's purpose to examine social and ethical challenges in dementia diagnosis from the perspective of policy/services, research and clinical practice.

3.4 Qualitative Content Analysis

To explore social and ethical challenges in regards to early/timely diagnosis of dementia and the related wider policy framework in England and Wales, the primary and secondary data were analysed using Mayring's qualitative content analysis. This approach aims to preserve the strengths of quantitative content analysis and while taking this background into account to create techniques of systematic, qualitatively oriented text analysis. A set of systematic and transparent procedures is characteristic for this approach and facilitates the analysis and interpretation of data in relation to the research question (see Mayring 2002).

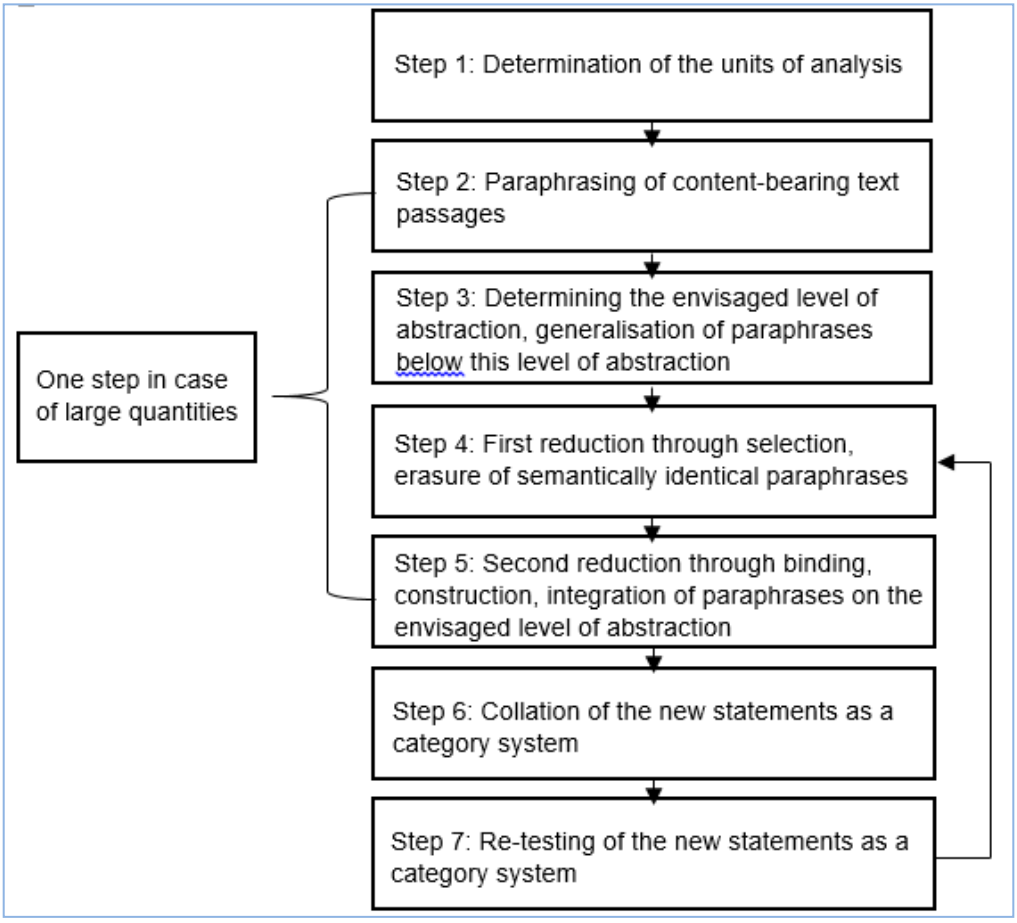
Many quantitative content analyses have not given enough attention to consistently take into account that the data relates to a specific context of communication. In qualitative content analysis it has to be made explicit to which part of the communication process the conclusions from the analysis relate to, the data is therefore always interpreted within its context, i.e. its effect and origin. This is particularly helpful for the analysis of the gathered data for this study since issues around dementia diagnosis are embedded in various contextual aspects related to policy, research and clinical practice (see Mayring 2014).

The main principal of this approach is a category system developed on the data employing a theory-guided procedure (Mayring 2002; Mayring 2014). This means categories were derived while moving between the data and the research question. The interviews with memory clinic staff and researchers working in the field of dementia were analysed while keeping the focus on social and ethical challenges that clinicians encounter in regards to early/timely diagnosis of dementia. When reading the gathered

policy documents and interviewed experts in dementia policies/services, information related to a policy framework in England and Wales and respective practical challenges and strategic concerns were examined. The categories that developed from this process were constantly checked and revised, if necessary. Approaching the data in this way makes a reconstruction or repetition of analysis and therefore the evaluation of reliability and comparability of findings possible (Mayring 2002; Mayring 2014).

Three fundamental forms of interpreting can be differentiated: Summary, Explication and Structuration. The appropriate technique is chosen taking the research question and the data into account. In this case, it was seen as useful to summarize and explicate the material. The summary procedure aims to reduce the material to its essential content by becoming progressively abstract which leads to a manageable overview of the original material (see Mayring 2010). The following figure describes the various steps to take in the summary procedure.

Figure 5: Step-by-step Model of Summarizing Content Analysis



Mayring 2014

Figure 5 shows that first of all units of analysis needs to be defined. This includes decisions regarding the approach towards the material, defining conditions for encoding

and which passages and in what sequence. In the case of this research, the approach was to keep processes of coding open-ended, with the categories inductively derived from the data. The text passages were therefore seen as content-bearing when they explicitly or implicitly display information regarding the research question of social and ethical challenges in dementia diagnosis. There was no restriction towards the minimum or maximum portion of text. The collected data was progressively dissected by moving from one text passage to the following (Mayring 2014).

The next step, as described in Figure 5, would be to paraphrase important passages and their subsequent generalisation below a determined abstraction level. However, since the volume of data was too large, it required bringing together several analysis steps (Mayring 2014). This means content-bearing text passages taken from the expert interviews or policy documents were directly generalised to the defined level of abstraction, yielding statements specifically addressing the policy or research context in which dementia diagnosis is embedded in England and Wales and potential social and ethical challenges. Simultaneously, repetitive or insignificant generalisations were removed and similar ones (bundling) and several statements about one topic (construction/integration) were merged. The statements resulting from this process formed the aforementioned category system (Mayring 2010).

Explication as the second form of interpreting used for this study includes the display of additional data on specific text components, for example terms or sentences. By doing so, the text passage was elucidated and interpreted in order to achieve an understanding. In this case, a broad contextual analysis was carried out, therefore the explanation does not have to be limited to the textual context allowing additional material to be taken (Mayring 2014).d

A qualitative software analysis package, NVivo10, was chosen as a tool to facilitate the data analysis and organise the data more effectively.

3.5 Discussion of Methodology

After providing a justification for the methodological choices made, including the decision to combine a secondary analysis with the conduction of expert interviews, it is also important to reflect on the methodological limitations to this approach.

Some might argue that there are challenges in terms of re-using qualitative research data since a secondary analyst has a distance to the production of primary data and to the contexts of data production. This distance and partial knowledge might limit secondary analysis. However, a successful secondary analysis is dependent on its objectives and as

long as the analytical approach is appropriate, the results should not be poorer compared to the primary analysis (Irwin/Winterton 2011). Moreover, some necessary information, for example, about the respondents' attributes was found in the data. Even though the distance was not perceived as limiting, getting an impression of the data might have required more time than would have been necessary in the case of collecting the data themselves.

The interviews with experts in dementia policies or services delivered practical and interpretive knowledge of dementia diagnosis mainly in the Welsh context, but they also at times referred to respective policies in England. Furthermore, the interviews with experts in dementia research and with memory clinic staff delivered information on dementia policies and services in England as well as Wales. However, the identified policy documents provided more information on the approach to early diagnosis and especially to intermediate achievements in England than in Wales. This limitation regarding information on early/timely diagnosis in the Welsh context needs to be acknowledged, but was perceived to be outweighed by the other chosen data sources.

The identification of interview partners was challenging at first, but this was facilitated by the supervisors of this Master's thesis. Some of the originally identified experts referred me to other apparently more knowledgeable people. This did not prevent the second interviewee working at the Alzheimer's Society from lacking confidence in talking explicitly about dementia policies. However, their insights regarding dementia services were helpful as it was possible to ascertain from their responses some of the experiences of patients affected by MCI or early to late stage dementia who are utilising services. Another interview with a person involved in the post-diagnostic support services could have led to more substantiated data, but was not the original goal of the conducted expert interviews.

Furthermore, a prior testing of the interview guideline in addition to the review carried out by the responsible supervisors might have been beneficial to prevent occasional unclear formulations. However, this was not perceived as disrupting for the interview process.

Chapter 4: Results

This chapter sets out the main findings from the primary and secondary data chosen for this study. The data has been analysed and grouped into thematic categories to illuminate social and ethical issues relating to dementia diagnosis that are embedded in policy frameworks in Wales and England.

Accounts across dementia policy/services, research and clinical practice in the context of early/timely diagnosis were brought together and compared, demonstrating respective variations in the interpretation of the identified challenges in dementia diagnosis. An overall picture is formed illuminating patterns and inconsistencies in the framing of the diagnosis of dementia. Specifically, the development and achievements of dementia policies in England and Wales are described based on the identified documents, the interviewed experts in dementia policies/services are able to offer more depth describing some of the justifications for decisions and offering their reflections on strategic concerns, for example, in terms of cost-effectiveness. Memory clinic staff provide a detailed description of their approach to dementia diagnosis and how this affects the patient and their family. Moreover, their ideal position at the frontline of dementia services provides important insight into the impact policy decisions have had on services, including concerns such as the available resources. Researchers working in the field of dementia offer expertise regarding diagnostic technologies and their limitations and discuss the value of a dementia diagnosis for patients and families and the pros and cons of a potential screening programme.

Various themes were identified from the data. Firstly, individual attributes of all interviewed experts give an impression of their experience and/or field of interest to enable the reader to understand their accounts accordingly. In the second sub-chapter, the way dementia diagnosis is organised and developed in England and Wales over the years from 2009 onwards is described. This is followed by identified ethical issues that include those faced by clinicians in the decision making of diagnostic disclosure, the kinds of uncertainties encountered in assessing and communicating to patients who are identified as having MCI and the reactions of patients to an MCI diagnosis. Moreover, the perception of treatment and prevention strategies and the risk identification for AD are described. This chapter ends in addressing the issue of stigmatisation.

The next sub-chapter comprises social issues in dementia diagnosis which describe the achievements of dementia policies relating to raised diagnosis rates in England and Wales followed by highlighting the impact this development has had on dementia services. This chapter ends in describing the vision of greater joint working between sectors.

4.1 Respondents' Attributes

The attributes of the interviewed experts in dementia policies/services are shown in Table 2, including their institution where they are currently engaged and, if applicable, where they were engaged in the past as well as their professional role.

Table 2: Institution and Professional Role of Experts in Dementia Policies/Services

Respondent ID[1]	Institution	Professional Role
PE1	Previous: Welsh Government; Current: NHS England	Leading position in Mental Health Promotion
PE2	Alzheimer's Society	Dementia Support Worker
PE3	Public Health Wales	Leading position for improvement programme (one priority: dementia)
PE4	Previous: Welsh Government; Current: Third Sector	Previous: Commissioning services for older people; Current: Chief Executive

The first interviewee was originally involved in social work. From managing social work teams over commissioning services for local authorities, leading strategy in Public Heath eventually a position for Mental Health Promotion within the Welsh Government was taken, although currently seconded to a leading position from the National Health Service for Wales also focused on mental health.

The second interviewee started as a volunteer for the Alzheimer's Society and subsequently took the role of a Dementia Support Worker.

The third interviewee was personally affected by dementia while caring for a family member suffering from the disease. This sparked the motivation and interest to work in mental health. The current position requires leading an improvement programme with one of the main issues being dementia care improvement, including memory assessment services.

Finally, the fourth interviewee is currently the Chief Executive of a third sector organisation and was chosen as an expert due to her previous role at the Welsh Government related to older people's needs. In the past, similar positions revolving around older people's wellbeing were taken.

1) For reasons of focus on the three relevant perspectives of policy, research and clinical practice on social and ethical challenges in dementia diagnosis, respondent IDs were kept instead of pseudonyms

The secondary data included interviews with memory clinic staff which focussed on reflections on their professional practice and specifically their approach to diagnosis. The professional roles of those who took part in interviews are displayed in Table 3.

Table 3: Professional Role of Experts within two Memory Clinics

Respondent ID	Professional Role
S1	Research Nurse
S2	Geriatrician
S3	Psychiatric Nurse
S4	Research Nurse
S5	Specialist Nurse
S6	Specialist Nurse
S7	Speech Therapist/Psychologist
S8	Clinical Psychologist – post diagnosis support group
S9	GP (Temporary placement)
S10	Assistant Psychologist (Temporary post qualification placement)
S11	Assistant Psychologist (Temporary post qualification placement)
S12	Old Age Psychiatrist (Semi-retired, 1 day/week)
S13	Neurologist Registrar (Temporary placement)

Interviews with experts in dementia research were also utilised as a secondary data set. Their areas of interest are set out in Table 4.

Table 4: Research Interests of Experts in Dementia Research

Respondent ID	Research Interest
RE1	AD neurochemistry, genetics, inflammation
RE2	Prevention of AD
RE3	Biomarkers for drug treatment
RE4	Biomarkers for diagnostic technologies and drug treatment
RE5	Prevention of AD
RE6	Post-diagnostic support
RE7	Biomarkers for drug treatment

4.2 Early or Timely Dementia Diagnosis in England and Wales

According to the interviewed expert from the Welsh Government (PE1), policies in relation to dementia focus on the whole pathway, i.e. how to reduce the risk of developing dementia, early diagnosis, issues related to the middle to late stages of dementia and end of life care. The overall priority is perceived to be early diagnosis of dementia and intervention. In Wales, for example, this is promoted through 1000 Lives Improvement, an initiative run in collaboration with NHS organisations in order to improve the care and quality of life for people with dementia and their carers. Furthermore, considerable attention is given to living well with dementia and the economic costs in relation to the middle and later stages of dementia. The reduction of risk of developing dementia on the other hand should, according to the interviewed expert, receive more attention amongst policy makers. For the development of policies, the involvement of health and social care sector, the third sector, academics and the public is mentioned. The role of the public is described in more detail in the following extract:

> *[…] when you engage in a public consultation the people who are likely to engage with you are people who have an interest in the subject that you're discussing, so they will tend to be carers or people with the condition […]. I think quite often with dementia we sometimes don't think as much about service users as we do perhaps when we're talking about schizophrenia or bipolar disorder with depression and anxiety because of the issues in relation to mental capacity and the person's capacity to engage, but of course for a long period of a person living with dementia they are fully capable of engaging and we've actually in the last few years been seeing some very very robust voices of people with dementia coming forward to talk about their experience.* (Expert in dementia policies/services, Welsh Government)

It is further stated that the accounts of a person with dementia and their carers, which could be a family member, a friend or a neighbour, regarding the timing of a diagnosis and their experience of receiving a diagnosis is taken into account.

The National Dementia Strategy for England published in 2009 revolves around raising awareness and understanding, early diagnosis and support and the development of services to promote living well with dementia. Early diagnosis of good quality and intervention for all is stated as the second objective and one of the priority objectives. In more detail, this meant that all individuals with dementia should be able to access a care pathway that would offer a competent and fast specialist assessment leading to the sensitive communication of an accurate diagnosis and appropriate post-diagnostic treatment, care and support. The ambition was motivated by the observed under-diagnosis of dementia; in 2009 only one-third of people were given a diagnosis at any time

in their illness. Often they were diagnosed when they had already reached crisis point that could potentially have been prevented if earlier action would have been taken (DoH 2009a).

The National Dementia Vision for Wales published in 2011 addresses the need for early diagnosis and timely interventions. Its other main themes are the improvement of service provision, training for health professionals, and access to support, information and advocacy services (Welsh Assembly Government 2011). According to the expert from Public Health Wales, Wales was *"behind the curve*" in terms of identification and diagnosis of dementia compared to England. Even though some achievements were made, there was a strong need to educate and raise awareness. Issues that were specifically mentioned in the strategy for Wales were the consequences of dementia for rural communities and the role of the Welsh language. The latter is seen as important for those who are affected by the disease and go on to only be able to express themselves in their first language Welsh (Welsh Assembly Government 2011). The second expert from the Welsh Government elaborates on this issue further:

> *[…] everybody who speaks Welsh can also speak English, but not everybody who speaks English and lives and works in Wales can speak Welsh. Therefore if somebody has some form of dementia and their first language is Welsh and they are in receipt of care either at home or in hospital and they are far more comfortable or completely only converse in Welsh, then the people who are providing their care whether they are care workers or nurses or clinicians will have an immediate barrier if they are not able to speak in Welsh as well […].* (Expert in dementia policies/services, Welsh Government)

The person with dementia would therefore potentially not receive appropriate care if the care is provided by health professionals who are not able to speak in Welsh and no family members are there to support the conversation.

In England, there has been a lack of clarity about where and by whom dementia diagnoses should be carried out, whether this be in Primary Care Trusts which were replaced later in 2013 by Clinical Commissioning Groups (CCGs) following the Health and Social Care Act in 2012 (DoH 2009a; NHS England 2014). GPs, geriatric medicine, old age psychiatric community teams and neurology services were all said to be possible points of contacts where a diagnosis of dementia could be made. Based on a consultation process by the DoH it was considered ideal to have clinicians with specialist skills being responsible for making dementia diagnoses (DoH 2009a). The government explained this decision by stating:

> *With a disorder as common as dementia it is tempting to assume that this should be*

> *completed by primary care. However, this is in effect the status quo which has delivered the low levels of activity […]. A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources.* (National Dementia Strategy, 2009)

Instead, their role was said to include determining patients with dementia symptoms, excluding other explanations than dementia and – if applicable – referring the patient on to a specialist service. Various options such as old age psychiatrists, GPs with a specialist interest, neurologists, and/or geriatricians could form this specialist service. It was meant to facilitate the care pathway by locating responsibility and ensuring referral, easy communication and transparent performance monitoring (DoH 2009a).

In 2012, the Prime Minister's Challenge on Dementia was published recognising the seemingly prevailing issue of under-diagnosis (DoH 2012). In his speech to the Dementia 2012 conference, David Cameron states:

> *Can you imagine if these were cancer diagnosis rates? There would be a national outcry. And dementia should be treated in just the same way…because just like most other diseases, it makes a real difference if you spot it early. You can help people live independently for longer, even put the brakes on their decline.* (Cabinet Office, 2012)

To illustrate the urgency of promoting an increase in diagnosis rates, he equates dementia with cancer. Even though difficulties in diagnosing dementia due to the complexity of the disease are acknowledged, he emphasises the importance of raising the rate, considering the variations in dementia diagnosis across the country. In East Riding the diagnosis rate was at 29% compared to 57% in Sheffield at that time. Thus, financial incentives for hospitals – £54m accessed at the Dementia Commissioning for Quality and Innovation (CQUIN) – were introduced to carry out risk assessments for every patient aged over 75 years and promote referral to specialist services (Cabinet Office 2012; NHS England 2015a). From April 2013 the quality of dementia care was included as well and receiving CQUIN payments was made dependent on giving support to carers conforming to the guidelines of the NICE/Social Care Institute for Clinical Excellence (DoH 2012).

Furthermore, it was seen as an opportunity that patients aged over 75 years who have the biggest risk of having dementia visit their GP once (about 97%) or several times in a year (DoH 2012). In 2013 an Enhanced Service was introduced to be carried out by GPs rewarding those practices that adopt a *"pro-active, case finding approach"* (DoH 2013b) to examining the memory for signs of early dementia of patients with chronic neurological

conditions, Down's syndrome aged 40 or over, learning disabilities aged 50 or over and over 60s with cardiovascular risk factors or diseases such as diabetes (DoH 2013c; NHS England 2015a). One year later, in April 2014, a new Dementia Directed Enhanced Service was published which has broadened the focus to offer patients who have received a diagnosis of dementia an appointment to form a care plan. This plan emphasises their physical, social and mental needs and includes signposting to support services in their area and referral (DoH 2014b).

In Wales, the QOF first came into force in 2004 and is responsible for rewarding practices for quality in clinical practice. Every year, it is agreed on a list of indicators updated in accordance with NICE guidance. All practices took part in 2012/13, although it is not obligatory. Changes were made in 2015/16 enabling GPs to give more time to the care for those patients who have complex care needs, specifically referring to the frail elderly. In the context of dementia, practices receive points for establishing and maintaining a record of patients with dementia and for the percentage of those whose care has been checked in a face-to-face conversation in the last 15 months (NHS Wales 2015; Welsh Government 2015).

According to the expert from the Welsh Government the approach of financially incentivising dementia diagnosis is not equivalent to a screening programme and explains it as follows:

> *[…] it's not a screening service because it's not about screening everybody over a particular age, screening is the wrong work, but it is about doing diagnostic work where people are indicated as potentially having a disorder, okay different from screening.* (Expert in dementia policies/services, Welsh Government)

The approach of having incentives to increase diagnosis rates is therefore chosen over systematically screening the population for dementia. Social and ethical challenges related to this decision and potential future developments will be reflected upon in more detail in the following sub-chapters.

4.3 Ethical Issues in Dementia Diagnosis

4.3.1 Decisions in Clinical Practice regarding Diagnostic Disclosure

Diagnostic disclosure can be seen as a path that starts at the baseline level of a patient's awareness and ends at the highest amount of useful and bearable information for the patient (Whitehouse et al. 2004). In this context, the clinician's decision to disclose or withhold information as one ethical consideration within dementia diagnosis should be examined.

There is a general consensus among the interviewed memory clinic staff that the question is not if you should disclose a diagnosis, but how and when. This is underpinned by the principle of respect for autonomy which according to Beauchamp/Childress (2009: p.103) means acknowledging the patient's *"right to hold view, to make choices and to take actions based on their personal values and beliefs"*. According to an old age psychiatrist *"truthful information"* and *"as much information as you can"* (S12) should be given to the patient.

Decisions that need to be considered for diagnostic disclosure is explained by a geriatrician in the extract below:

> *Yes I think it depends on the circumstances of the patient. I think it would depend I suppose how much impaired the patient is. You know how much he is going to be able to take in. I think how you feel that the information you're going to give is going to have you know. What sort impact it's going to have in sort of, I don't know his mood or what sort of reaction he's going to have to that. Is it going to be accepted readily or is there no impact of how he feels about things? Or is it going to have a bit of really a devastating impact on how he feels about it?* (Geriatrician, memory clinic staff)

The process leading up to diagnostic disclosure requires experience to be able to choose the right time and the amount of information that is appropriate which is dependent on the individual patient. Firstly, the patient's degree of impairment needs to be considered in deciding how much information is appropriate. Commonly, cognitive problems in the patient are perceived by the family instead of the patient who is either less aware of them or even lacks insight completely. This might lead to patients not being interested in having an assessment and they might show resistance at first (see Gordon/Goldstein 2001). Moreover, it adds to the challenge that memory clinic staff are often confronted with, when the family member wishes to withhold a diagnosis of AD from the patient. This is firstly associated to the stigma attached to the label of AD as the geriatrician points out:

> *[…] if you've got stomach cancer you'd expect to know and nobody would sort of think of hiding it from you. I think we have to change the mentality. It's been a bit of taboo sort of mental health, under the mental health umbrella. So it's just your mind is going and it's really you're mad sort of thing.* (Geriatrician, memory clinic staff)

Another reason for wanting to hide the diagnosis from the patient is a *"protective mechanism"* (S1) where family members wish to avoid upsetting the patient. This is considered for diagnostic disclosure by memory clinic staff and in some cases it is accepted to not use the term 'AD', but instead use euphemisms such as *"significant memory problems"*, described as *"more than what is expected for your age group"*,

"progressive" and in need of *"some monitoring and perhaps some treatment […] to slow down the progression"* to still give them information about what is happening (S2). Furthermore, when the term 'AD' has been used, it is accepted to subsequently use euphemisms in case the patient has forgotten about it and it would repeatedly provoke a negative reaction (S4). According to staff it is, however, *"very rare that a diagnosis is withheld at the request of a relative and if it is, it's because we've given a lot of thought to it"* (S5). This applies to cases, for example, where the patient had multiple previous experience with caring for a person with AD and it was considered detrimental to use the term 'AD'. This decision requires the patient not asking directly for the diagnosis, because then it would be the staff's *"duty to tell"* (S7). This is linked to the strategy to achieve a stronger position in favour of disclosing a diagnosis of AD, namely through having pre-diagnostic conversations with the patient (S8). Here the patient is told by the clinician that memory problems might be found that are worse than could be expected for their age group. They are then asked to choose whether they would want to be told why they have these problems. An affirmation by the patient supports diagnostic disclosure based on the moral argument of the *"right to know"* (S3; S6; S11; S13) in the later discussion with their family.

If this conversation, however, has not taken place the memory clinic staff has specific counterarguments to convince the patient's family of the benefits of telling. A specialist nurse explains one of them:

> *We explain well, you know, how would you feel if you… you liken it to cancer. If you had cancer, would you expect to be told? And it's usually well yes, you wouldn't expect your relative to be told but not you and, you know, it's very much like that, that it's your mother, father, sister's right to be told their diagnosis […].* (Specialist Nurse, memory clinic staff)

Therefore, at first they contrast AD with cancer and challenge the patient to think about the appropriateness of withholding a diagnosis of cancer which they would usually deny. Other arguments are described by the interviewed GP who is temporarily placed at the memory clinic in the following extract:

> *So you then have to go into well, you know, I think this is important because they probably know they've got a problem but they're not really sure and they're worried about expressing it to you, perhaps if they know that there's an illness and this is the reason for it, it'll be easier for them to deal with, blah di blah. And usually I can win them round and I can say – the other thing I usually use, I say I'd be uncomfortable to give tablets to somebody who doesn't know what they're getting tablets for. By the end of my little spiel with them and if I'm really struggling, they really don't want to know, tell*

them, then I usually would you – or to think about it, would you want to know if you were in that scenario? And that usually wins them round a little bit more. (GP, memory clinic staff)

The argument is brought forward that the patient might be relieved to have an explanation for their experienced issues. The staff members' duty to tell is mentioned in the context of prescribed medication since it is seen as necessary that the patient knows what they are taking the drug treatment for. Moreover, it is emphasised that the adverse effect of diagnostic disclosure that the family member expects is not reflected in reality, as described by the specialist nurse:

And you know, we acknowledge that a lot of it is fear for the relatives. The relatives know what's the matter, they've got this preconceived idea about how the patient is going to respond and not actually understanding that for the vast majority of patients, their lack of insight protects them from taking on board the implications of the diagnosis. (Specialist nurse, memory clinic staff)

Despite potential conflicts, the presence of family members is considered helpful for diagnostic disclosure. This becomes clear when memory clinic staff reflect on the difficulties of giving information to a patient who has come by themselves, with a neighbour or a supervisor from work. Family might not live nearby, so the patient is generally less aware of their problems (S5; S6). This means the support usually received by these family members is missing and giving information is described as *"tricky"* (S6) which likely refers to the lack of support.

Moreover, the presence of a family member is seen as important in case the patient says no to receiving information on their condition. This is explained by the old age psychiatrist as follows:

Do you want that information; do you want to know what all that information is?' And I've had patients say to me, 'No, I don't want to know, you keep that to yourself.' 'Do you want your family...?' 'Oh, you can tell them, but don't tell me. Don't tell me; I'd worry about it.' (Old age psychiatrist, memory clinic staff)

The patient may therefore go on to allow the clinician to tell their family instead of themselves. This should, however, be done in any case according to the interviewed geriatrician:

Some patients really they don't want to know. Although they are just in complete denial that really I think it is […] in subsequent interviews that probably you come round sort of to discuss the diagnosis openly again with the patient. But at the beginning some patients wouldn't accept it really. Wouldn't accept there is anything wrong. But the

> *carer or the spouse or whoever is there with them they should be aware of what the likely diagnosis is yes.* (Geriatrician, memory clinic staff)

If the patient is in complete denial and expresses their wish not to be told, the carer or spouse should be made aware of the probable diagnosis as the patient's attitude might change over time and they may come to accept it eventually.

Furthermore, it needs to be considered when relatives give information that suggests that the diagnosis could put a patient in a vulnerable position of *"being exploited in some way"* (S3) by carers and/or relatives. This is, however, perceived to be very rarely the case.

The approach to diagnosis is structured similarly by all memory clinic staff responsible for giving a diagnosis. To get an impression of the patient's awareness of their problems they will be asked at the beginning of an interview what they wish to achieve by the appointment where the patient might mention the potential discovery of AD. Moreover, the assessment process and its focus on various causes is explained to them which delivers grounds for the patient's consent to proceed (S8). The results of the assessment are communicated by pointing out the patient's strengths as well as problems. These problems should then be examined more closely with the aim to prevent them getting worse (S7). At a later stage, following the assessment, the patient is asked for their opinion on the cause which gives the clinician the chance to refer back to the pre-diagnostic conversation regarding their expectations of the appointment (S7; S8). Common patients' reactions are described in the following by the GP temporarily placed at the memory clinic:

> *[…] actually most people clam up, even if they think they don't want to say the words, they wait for me to say it, so they'll say well yeah, well I'm worried, and they never say it. And then you kind of say well I'm worried there's something more serious going on like a dementia, does that surprise you to hear that? And they'll usually say no, I've kind of been thinking about it. And then I'll say this is probably an Alzheimer's kind of dementia, have you heard of Alzheimer's?* (GP, memory clinic staff)

If not done before, this situation provides the clinician with the opportunity to explain differences between types of dementia. As implied before, depending on, for example, whether the patient has referred themselves and are in the early stages of the condition, or if they are in the later stages of their dementia, they would display greater or lesser awareness of their problems and the possibility of AD. The GP further states that the same questions can come up when talking to family members as it was important to realise what their concerns are. If the patient shows insight, the carer still adds information, if, however, the patient lacks awareness, the carer might deliver the main

information. In the context for the interview, it is considered best to separate patient and carer. Assuming the clinician is not confident in a diagnosis yet, before further assessment this uncertainty needed to be communicated since there is *"nothing worse than backtracking in this kind of scenario"* (S9). In the example below, another explanation of how the diagnosis is given is described by a speech therapist/psychologist:

> *And then maybe saying well you know, it is possible that Alzheimer's disease could be causing the problems you're having. So kind of, you know, always gauging how they're reacting, and not actually saying, I suppose, straight in your face well actually, this is Alzheimer's disease 'cause we don't know, you know.* (Speech therapist/psychologist, memory clinic staff)

As mentioned in Chapter 2, the clinician is still obliged to define a diagnosis of AD as possible or probable since only autopsy can give a confident diagnosis (see Lock 2013). The ethical issue of uncertainty, especially in earlier disease stages, i.e. MCI, is examined in more detail in the following sub-chapter.

4.3.2 Uncertainties in the Stage of Mild Cognitive Impairment

According to the interviewed dementia policy/services experts there are various benefits of an early identification of MCI. The patient would receive support, information and advice and by one of the experts it is even said to enable the patient to make lifestyle changes to potentially reduce the risk for the development of dementia:

> *[…] the earlier the better. Allowing people to monitor themselves and do things to delay the onset, in their diet, in their lifestyle, in the use of tools to stimulate their memory, whatever games and things. I think we should encourage it.* (Expert in dementia policies/services, Public Health Wales)

Another benefit referred to the situation in which the patient's cognitive impairment would progress to dementia, but they had the chance to plan ahead and complete the *"bucket list"*:

> *[…] you can you can do the things that you won't be able to do now and I think that's sometimes forgotten because sometimes people, we're talking about reasonable good disposable incomes, they can go on holidays and have experiences whilst they still able to do that, those things are important particularly if you're a couple.* (Expert in dementia policies/services, Welsh government)

Moreover, the impact of possible negative emotional reactions are said to possible be attenuated by psychological interventions (PE1) and emotional and practical support could

be received by interventions such as peer support or befriending services decreasing isolation and preventing crisis (DoH 2015). Memory clinic staff mention a *"memory strategies group"* that is most useful for people with MCI in which they learn how to cope with memory problems that affect them at times, for example by using a diary (S11). Potential benefits of an early diagnosis opposed to one at a later stage are also reflected by the interviewed expert from the Alzheimer's Society:

> *Basically putting things in place for the future, getting accurate and proper information on their diagnosis, not feeling alone, feeling supported, that there's somebody that they can ring if they've got problems or if they need help with things we got advocacy service as well, just feeling that they've got a level of support to cope with things as they go on with their journey. […] because if we reach people when they are in crisis, if they haven't got things like power of attorney and got that sorted, then things can get messy.* (Expert in dementia services, Alzheimer's Society)

Lasting power of attorney legally enables another adult to make specific decisions for the person with dementia who is not able to do them themselves, regarding finances, health and welfare (Alzheimer's Society 2016c).

However, the move towards diagnosis of ever milder stages of dementia enabling the patients and families to embrace these benefits also leads to more uncertainty than already given in dementia diagnosis. Difficulties regarding the distinction between MCI and early AD are encountered, as described by a specialist nurse in the following extract:

> *But often it can be quite subjective as well. You know, just sitting in the meeting yesterday, you know, there were some patients with a Mocker or mini mental, or whatever it was, of 22 and the doctor was saying it was Alzheimer's, and then there were other patients with the same Mocker that they were saying it was mild cognitive impairment. And it is a very grey area, isn't it?* (Specialist Nurse, memory clinic staff)

The interviewed geriatrician states that a formal questionnaire such as the tests described in Chapter 2 can provide information about the impact of the experienced problems with cognition on everyday functioning. The test will result in a number, a score that can act as a point of reference for the evaluation of the patient's condition in the future. A good clinical history is nonetheless seen as imperative for making the distinction between these two disease stages.

However, as implied in the above quote, there is the potential for a lack of clarity when interpreting these scores. Whatever the clinical information available, it seems diagnosis remains a clinical judgement.

A specialist nurse emphasises the importance of monitoring patients to specify the patient's stage of disease in the future which, according to an expert in dementia research, made it possible to see that some people with a diagnosis of dementia remained the same over *"five to six years"* (RE1). For instance, doubts arose when a patient was taking Aricept and reported no deterioration of their health status. It was considered that this development might not be due to the drug treatment, but simply due to a misdiagnosis of AD (S6).

In the above scenario the person might have had MCI which poses an increased risk of AD but cannot deliver a straightforward prognosis of the patient's health status. The increased risk that might or might not yield a change in the patient's life needs to be explained (see Whitehouse et al. 2004). Even though the potential progression can only be left open, the clinician might have a *"gut instinct"* (S3) for the patient's future health status. For instance, a specialist nurse describes the situation when the clinician conducting the assessment does not have results from a brain scan and cognitive test that would support a future deterioration of the patient. Nevertheless, details in the history suggest that the patient will experience progressive problems which may cause them to return for another assessment at some point.

Adding to the uncertainties, a patient's individual attributes can confound the test results. For instance, a patient being illiterate is given as a potential cause for bad scores. The interviewed old age psychiatrist was assuming mild cognitive problems, but could not define them based on the testing:

> *How can you put it across to those people? You're almost saying to them, 'There's something wrong with you, but I don't know what it is,' and I find that difficult.* (Old age psychiatrist, memory clinic staff)

A neurologist registrar describes MCI as a *"very poorly defined group"* (S13) since the daily functioning that is not yet impacted by an impairment in one or more cognitive domains required different demands from individuals.

Given the outlined complexity, the effectiveness of tests was examined in the context of screening for dementia on the population level. The results regarding false positives and negatives resulted in the recommendation against it (see Public Health England 2015a). A research expert describes this difficulty with the current testing tools:

> *What's going to happen is, you're going to get a lot of false positives. A false positive isn't a trivial event here. You wouldn't say to someone, oh I think you've got, I'm not sure if you've got cancer or not. Oh okay, let's say you've got cancer. Which is the danger we have really with our inaccurate tools really. Because we're using clinical*

> *tools, we haven't got a process that says, this is […]. The blood tests and CSFs and scans still don't really help us for sure. It's really only over time that you can be sure.* (Researcher for AD neurochemistry, genetics and inflammation)

As a further example, the research expert goes on to describe a situation in which a person with a false diagnosis of AD who was actually suffering from a depression and an infection went on to sell their home and give their money to their family based on the expectation of a premature death, only to eventually realise the mistake.

The uncertainty of the label of MCI or dementia given to the patient also seems to affect the way information is provided. This is explained by an assistant psychologist who says that the nature of the diagnoses were difficult to put in written form. The *"clinical accountability and responsibility"* (S10) would potentially result in legal consequences, if written information turned out to be false. Despite this, memory clinic staff express the ambition to provide written information which then needs to be accepted by the patient themselves and not only by the family member (S10; S12).

Considering this issue in relation to the current approach to raise diagnosis rates, the experts from the Welsh Government and Public Health Wales acknowledge incentives in dementia diagnosis in England and Wales pose the risk of false positives (PE1 and PE3). In contrast to the research expert's opinion quoted above, however, confidence is put in the development of diagnostic technologies. False positives should be ruled out by applying the *"battery of assessment tools"* available and becoming *"much more sophisticated"*, including for example brain scans (PE1).

4.3.3 Patients' Reactions to Mild Cognitive Impairment

Despite the uncertainty, a clinical psychologist states that patients and their families who are confronted with the information of MCI often react with relief, especially if they have come to the memory clinic expecting the worst (like a brain tumour, or indeed expecting AD or another dementia). Instead, they are taken seriously, receive an answer that might explain their problems and they do not feel the need to blame themselves, *"'it's not me just going mad'"* (S8). Moreover, the clinicians delivering the information are described by an assistant psychologist as competent in the way they explain it:

> *When the doctor's delivered that diagnosis they really good at explaining, you know, this is a category that sometimes people fall into, sometimes they get better, sometimes they stay the same, sometimes they get worse, and yeah not knowing what's around the corner I suppose, but knowing that there's that open communication*

that they can have contact with the team at any time is more reassuring for them. (Assistant Psychologist, memory clinic staff)

It is reflected that no patient has been seen to react with distraught and are rather comforted by the information. Some patients are said to express disappointment over the decrease in their cognitive abilities, but can accept it due to the deterioration not being as bad as they thought (S11).

In contrast, the interviewed expert in dementia services did mention negative feelings as a reaction to MCI linked to the experienced uncertainty:

Yes I think people can feel a bit lost, left and not have a definite answer, they kind of feel from my experience with people is […], if they had a diagnosis then it would something they could then deal with, but they kind of feel a bit, with the MCI, they're not sure where that's going to lead. (Expert in dementia services, Alzheimer's Society)

A research expert in AD prevention embraces timely diagnosis, but expresses strong doubt against making an early diagnosis, particularly giving someone a label of MCI due to AD who is, for example, still in employment, describing this as being *"of no value whatsoever"* (RE2). Another research expert in AD prevention adds that due to individual circumstances, the benefit of being able to plan ahead actually is not as straightforward as it seems:

And even the planning consequences are quite difficult because although one can define a prognosis in a general sense, helping people make decisions about, "How much longer should I work? What should I do about my retirement planning?" all those sort of things really become very difficult because there is such variation between individuals. (Researcher for AD prevention)

Thus, difficulties can arise due to the uncertainties regarding the prognosis for those with MCI or indeed with early AD.

Moreover, due to conceptual issues of MCI and therefore a lack of knowledge regarding response to treatment, prognosis, and the underlying path of physiology, difficulties in creating a care pathway for MCI was mentioned by the researcher interested in AD neurochemistry, genetics and inflammation. The way these difficulties are dealt with is described in the following extract:

What we do with them is we phone them up every six months to see if they've declined and, at the same time, we're taking all the resources that could be treating people in nursing homes and in the community who've got dementia, making their lives a little bit better. But instead what we're doing is phoning up a bunch of people […] and we've

> *just been distracted from looking after people with, dare I say, a genuine illness.* (Researcher for AD neurochemistry, genetics and inflammation)

Available resources are therefore seen as being used inefficiently.

Next to false positives and negatives, drug treatment played an essential role in the decision against systematically screening at-risk individuals for early signs of dementia in England and Wales (see Public Health England 2015a). This is illustrated in more depth in the following sub-chapter, complemented by the examination of possible prevention strategies.

4.3.4 Perceptions of Treatment and Prevention Strategies

There is not enough evidence that the available treatment would slow down the progression or even prevent the illness in the early stages of dementia (see Public Health England 2015a). In England's National Dementia Strategy the benefits of an early diagnosis are stated as follows: appropriate treatment, information, care and support. In comparison, the National Dementia Vision for Wales puts the focus on appropriate information, support and care as beneficial outcomes of an early diagnosis. Treatment which is subsequently mentioned once in the policy paper should be received at the right time and in the right place (see DoH 2009a; see Welsh Assembly Government 2011). It is unclear, however, how treatment is defined in the Welsh policy paper, i.e. whether it is meant in the medical sense or 'treatment' simply refers to the previously stated benefits of information, support and care.

The interviewed policy experts from the Welsh Government explain that appropriate treatment for someone with an early diagnosis is seen as much broader than merely medication. Depending on the individual it included verbal and written information, social care to sort, for example, financial and care affairs, making advance statements about their wishes regarding care and treatment as well as psychological interventions to deal with grief, loss, anxiety, fear and depression which could occur in *"a person with dementia in these early stages"* (PE1; PE4).

The negligible role of drug treatment when deciding to disclose information about MCI comes out in some of the interviews with experts in dementia research. In their view, benefits of an early diagnosis includes the opportunity to plan ahead and offer support for carers, but also to do related research, rule out other aetiologies and *"rationalise"* (RE2) cardiovascular health and improve cognitive activity. When a patient gains knowledge about their health status, this can provide the opportunity to consider *"life priorities"* (RE4). In this sense, they are similar to the benefits mentioned by the policy experts.

According to the researcher interested in AD neurochemistry, genetics, and inflammation, patients with MCI have awareness for their memory problems, feel already worried and therefore wish to receive an explanation to ease their concerns. This is described in more detail in the following extract:

> *So people want to know what's happening and they want to know even if we haven't got a treatment yet. They want to know what they've got and what the prognosis is. I think if you had a memory loss where you can't remember from one second to the next what's going on, you want to know what's going on. You want some information. Even if we haven't got treatment for it yet.* (Researcher for AD neurochemistry, genetics and inflammation)

The relief that patients might feel when offered an explanation therefore outweighs the lack of treatment to offer.

Moreover, treatment is not seen as a necessary requirement for giving a diagnosis, such as it is done for Huntington Disease. In this case it is said a precise diagnosis could be made, but there were no interventions, the benefit from knowing was the opportunity to adapt your life accordingly (RE5).

Apart from being motivated to seek advice due to the patient and their families' concerns, memory clinic staff mentioned that patients generally have high expectations regarding treatment. The interviewed neurologist registrar describes this in the context of MCI in the extract below:

> *See these public health campaigns to me; I've seen the adverts on television. To me they seem to be implying that if you turn up in clinic with a memory problem you'll get a pill that will make it better and public health messages are very difficult things in themselves but I think that that's not the right message but I think that that is the message that people take from them.* (Neurologist registrar, memory clinic staff)

It is described by memory clinic staff that often the patient's daughter or son access information on the internet before the first assessment (S3), or patients read about it in the newspaper and address the topic themselves (S5). If these expectations are not met in explanations by the memory clinic staff, doubts can arise in the patient regarding the usefulness of seeking a diagnosis in the first place. Drug treatment then is used as *"leverage"* (S3), stating that the drug treatment might be helpful for the patient and the opportunity will be looked into in order to prevent the patient rejecting the service and having no support in the future. Nonetheless, a research nurse noticed over the previous years that hopes for drug treatment are persisting *"however much we try and bring them down to earth"* for the *"miracle cure"* (S4). The topic of drug treatment is present enough in

the media to make people with very early dementia or people *"who actually haven't even got dementia"* (S5) ask for the drug Aricept since they believe it would prevent the disease developing. It needed to be explained that such a treatment has limited efficacy that is also dependent on people receiving them at the right time and not too early to maximise the benefit (S6). On the other hand, a speech therapist/psychologist has not only experienced people who would *"fight tooth and nail"* to receive the drug treatment, but patients who are very accepting of the fact that the specific treatment for AD is not appropriate for them since they do not want to take anything that would not benefit them (S7). If patients do not have AD but vascular dementia it is said to pose an additional challenge to explain to a lay person that there is the option to control respective risk factors, but not to give drug treatment which instead is meant for AD (S11).

In contrast to the high expectations that patients and their families have of available drug treatment, evidence for strategies to prevent dementia by reducing individual risk is described to be lacking. Thus, these potential strategies seem to receive less attention, as described by a researcher in AD neurochemistry, genetics, and inflammation:

> *We've got lots of strategies haven't we, I suppose, but then they are all - I mean to be honest they're out there it's just that people haven't really properly characterised the risk. So we know some of the environmental potential risk factors we can modify, it's just a question of how big a change does that make. What you really want is a tablet isn't it, it solves all the problems.* (Researcher for AD neurochemistry, genetics and inflammation)

However, looking for a cure is seen as unrealistic since by the time a person has memory problems their brain cells have already been affected (RE4).

Some of the interviewed experts including research and policy experts describe in more detail the role of a healthy lifestyle in preventing dementia. The researcher interested in biomarkers for AD drug treatment acknowledges the lack of direct evidence, but suggests that indirect effects of lifestyle on dementia are based on strong plausibility. For example, lifestyle is associated with some morbidities that are known to affect dementia. Moreover, direct effects are nonetheless perceived as likely. However, due to small sample sizes and inaccurate measurements in studies they are not proven yet and therefore reductions in risk cannot be quantifiable.

A research expert in biomarkers for diagnostic technologies and drug treatment and the expert from the Welsh Government both mention the previous studies showing a decrease in dementia prevalence or incidence. The policy expert relates the improvement to better control of vascular risk factors, with people being made more aware of the

importance of being physically active, a healthy diet, and reducing their alcohol intake. Furthermore, achievements in the management of conditions from the care provider's side are mentioned as a reason for the decrease in incidence. The need for more awareness for the potential to develop dementia from birth is also emphasised, as described in the extract below:

> *[…] actually when we're talking about many of the aspects around dementia it's across the age spectrum, so actually from birth we're laying down the pathway that will impact on our potential for developing a dementia, but particularly in adulthood, middle age that's when you can make lifestyle choices that are most likely to have the greatest impact in terms of reducing your risk.* (Expert in dementia policies/services, Welsh Government)

This challenges the perception that dementia is only relevant to retired people above a certain age range (PE1). The expert in dementia research confirms these statements:

> *But if you've actually got memory problems, then the earlier you adopt these changes, the better. So if you've got someone who's quite significantly demented by the time they get to see the doctor – and that does still happen unfortunately, but increasingly less so – then I think there's less point in doing it. It becomes impractical and it probably won't yield much. These lifestyle changes are really for the future, I think, rather than the present.* (Researcher for biomarkers for diagnostic technologies and drug treatment)

Missing out on this opportunity at the optimum time of middle age, the research expert associates little benefit to lifestyle changes later on. This reasoning was, however, neglected when another expert in dementia research considered the question for meaningful advice for people who already have MCI. According to this researcher, involved in biomarkers for AD drug treatment, the advice of a healthy lifestyle would nonetheless be justified even though an earlier adoption would have been ideal. MCI is then seen as a useful motivational factor to change their lifestyle for the better, considering possible benefits:

> *But whether it will help you use what you've got and enjoy the bit that remains, it absolutely will. So why would you not do that? You know, stimulate intellectual life. I think it's a great idea.* (Researcher for biomarkers for AD drug treatment)

Additionally, a study is mentioned whose early results indicate *"some sort of impact"* (RE7) of lifestyle alterations even if the disease has already started developing. The question of whether crosswords or sudokus, for example, influence the rate of pathology remains unanswered (RE3).

The difficulty in giving helpful advice to patients with MCI seems therefore to be linked to the lack of detail and consensus in the evidence on risk reduction, essentially leaving room for uncertainty. There seems to be a variety of ideas regarding prevention, some useful and some less well established. Studies with large sample sizes would help establish better quality evidence and shape more informed messages for patients and families.

The researcher in AD prevention concludes more reliable sources are needed to enable individuals to understand which aspects of their lifestyle may be important in the prevention of AD, which are promising and which are less likely to help (RE5).

4.3.5 Risk Identification for Alzheimer's Disease

The interviewed experts in dementia research considered the possibility of potentially identifying people's risk to develop AD when they are still asymptomatic or when they have MCI.

Before any serious symptoms appear, biomarkers could potentially be picked up in the disease process showing the person's higher risk of developing a dementia due to AD (RE4). At the moment there is a *"huge gap difference"* (RE7) between what is done in research contexts and clinical practice. For a research project, the diagnostic paradigm would need to be as accurate as possible to reach more precision regarding the cohorts of people who likely display AD pathology (RE4). The differences between research and clinical practice are not seen as necessary to be adapted as the resulting information would not lead to drug treatment (RE7), as underpinned by the researcher for AD prevention:

> *[…] in the case of Alzheimer's disease where we have nothing to offer that we are confident would be helpful, the consequences of making a diagnosis early are in general quite limited […].* (Researcher for Prevention of AD)

In this context, it was mentioned that the research, for instance, on genetic biomarkers seemed to make faster progress than on possible drug treatments which *"haven't moved at all really for 10-15 years"* (RE1). Drug treatment is here seen as a requirement for the patient to receive knowledge about their risk to develop AD. The researcher interested in biomarkers for diagnostic technologies and drug treatment explains it firstly by the cost that would need to be paid for carrying out sophisticated testing methods which would only be justified by *"a really good payoff to the NHS, as well as for the person who's got the problems"* (RE4). Secondly, the capacity to accept all patients who might be in need of this testing would not be there.

In the case of MCI, the information of a certain risk to develop AD based on measured indicators would merely result in telling them to control possible risk factors. However, they would receive this advice when receiving information about their cognitive impairment in any case (RE4).

A research expert in AD neurochemistry, genetics, and inflammation expresses doubts regarding the available tests such as amyloid brain scans or cerebrospinal fluid measures, in more detail elaborated in the following extract:

> *I'd like to move the boundaries a little bit further earlier if we could, if it could be safe in doing that. But at the moment I don't think we're there yet, I don't think any of the tests, the amyloid scans etc. are really making me feel comfortable enough to make earlier than we are at the moment to be honest.* (Researcher for AD neurochemistry, genetics, inflammation)

This attempt to identify risk in asymptomatic stages is assumed to be difficult based on the current challenges that exist in predicting the risk of people with MCI going on to develop AD in the future (S10). Moreover, pathology and symptoms do not seem to always be connected. A situation is described when the Mini Mental State Examination, the CT scans and blood tests do not deliver indication that the person has AD, nonetheless, the history would show that it is likely the case. If the point of diagnosis is set a few years back, it would make it even more difficult to diagnose accurately due to the lack of opportunity to question the patient regarding possible symptoms (S9).

The research experts therefore consider it to be ethically problematic that the accuracy of a risk prediction would be limited, nonetheless, the individual would have to live with this uncertain knowledge. On the other hand, it is seen as beneficial to have the early chance to change their lifestyle and control risk factors such as high blood pressure (RE4; RE7). Essentially, as stated by a research expert and a staff member from the memory clinic, it needed to be taken into account that wanting to know would depend on the individual. The impact of information on a person's life and how they would be able to cope with it is seen as unpredictable (RE4; S11).

According to the research expert in biomarkers for diagnostic technologies and drug treatment, the move towards earlier phases of AD in the drug development, either MCI or the asymptomatic phase, stems from current drug treatments only being able to alter the symptoms due to brain cell death and not being able to prevent the pathological change either by slowing it down or preventing it. However, it is also suggested that AD is not a *"meaningful concept"* (RE5) and differences in patients' experiences with AD are not understood sufficiently. Instead, there is no *"one-size-fits all intervention"* (RE2), but an

individual would have a unique mixture of pathologies, for example, DLB and AD affecting their brain health. It is perceived as established that there are multiple factors playing a role in the disease process. That would mean that diverse underlying causes would have to be identified and tackled in advance as a way to prevent dementia (RE4) and various treatments would be necessary (RE5). Just like preventing a stroke or myocardial infarctions, a patient would ideally be treated for causal mechanism in the asymptomatic phase. An incremental progress is assumed regarding the findings on pathologies and the development of helpful interventions *"at different levels of the parallel"* (RE3). One of the interviewed researchers points out the necessary requirements for this approach:

> *So it's not a matter of doing a trial for Alzheimer's disease. It's doing a trial for this pathology which is one of several within Alzheimer's disease. And so you can anticipate a need for a large number of trials. […] But there will be this diversification of pathologies and therefore research enterprise around each of those pathologies, which is really underlying my thought that we do need just a new trials infrastructure because the number of trials required is going to explode.* (Researcher for biomarkers for drug treatment)

Furthermore, it is stated that biomarkers could be useful to identify risk groups in the future instead of focusing on individuals (RE1). For instance, identifying individuals would begin at the baseline level and would include taking a history and doing a blood or urine test. If this would result in a positive result, then the identified patients would receive more expensive and specific tests (RE2). A single screening test is perceived as insufficient, a much more specific indicator would require repeated measurement, thus patients taking part in frequent and regular testing to detect changes (RE3).

Although there is little confidence expressed to find a single biomarker that would become acceptable for screening, of all the possibilities the expert in AD neurochemistry, genetics and inflammation would choose brain imaging as the diagnostic technology since essentially dementia is linked to atrophy. There would be limitations as in some cases brain atrophy suggests an AD diagnosis, but the patient might not be cognitively impaired (RE1). Another argument for brain imaging as the method to choose, brought forward by the researcher interested in AD prevention, relates to the possibility of standardisation and relatively easy conduction compared to performance measures and cognitive testing. Moreover, other biomarkers such as the assessment of cerebrospinal fluid might be difficult to carry out on a large scale. This approach, as well as blood tests, are also seen as relatively imprecise (RE5). Considering the current possibilities for testing with regard to the diagnosis of dementia, the most accurate approach remained therefore a clinical diagnosis, in need of the patient's own account (RE1).

4.3.6 Overcoming Stigmatisation

The interviewed expert from the Welsh Government describes how stigmatising ideas of dementia can pose challenges in regard to promoting living well with dementia. People with dementia can be *"very isolated"* (PE1) due to the stigma attached to the condition and to discriminatory, unsupportive communities which can make continuing to live in their own home difficult.

The first barrier to overcome with regard to stigma relates to receiving a timely diagnosis which might be when the patient wants that information or the relative thinks it is necessary. In this regard, the belief in the usefulness of a diagnosis is essential, however, the idea that knowing is pointless due to the lack of a cure still prevails in parts of the population (S3) and also among GPs ignoring the benefit of planning ahead and adjusting to the new situation. The expert from the Welsh Government attempts to explain GPs' attitude by assuming they would not want patients having to cope with a label of dementia due to the stigma unless *"they absolutely have to"* (PE1).

After receiving a diagnosis, support in the community is highlighted as the basis for providing services and facilitating independent living for people suffering from dementia. A strategy introduced by the Alzheimer's Society attempts to build up support in the community and promotes so-called dementia friendly communities which is described as a way to *"normalise things, wanting to make it visible, not wanting to hide it and wanting to communicate a much better understanding"* (PE1). Respective progress has been observed in this regard. In 2013, over 50 cities, villages and towns were involved in the programme to become dementia friendly, two years later there were 82 communities across England which exceeded the ambition to reach 20 cities by 2015. Another project that trains people to become Dementia Friends Champions reached 2247 people in 2013 who would run information sessions within their communities. Moreover, 21 schools received an education programme which evaluated various approaches to teaching children and young people about dementia and a nationwide campaign was carried out to raise awareness and motivate people to pay their GP a visit if they had any concerns (DoH 2013b). The experts in dementia policies mentioned increased media attention on dementia over the previous years and therefore more general awareness for AD and other forms of dementia (PE1; PE3; PE4).

The benefit of such a development is reflected by the expert from the Welsh Government:

> *I do think people's attitudes to it are changing quite rapidly and the media portrayal of dementia has changed. We're seeing lots of drama, lots of news articles around it, which means that some of those things are bringing it much more into the light and*

> *people are reflecting on it which I think then makes the whole issue around early diagnosis easier […].* (Expert in dementia policies/services, Welsh Government)

The disease is not talked about in hushed voices any longer (S5) and as implied in Chapter 4.3.1, people coming to a memory clinic already have the thought that it might be AD. In contrast, a diagnosis of AD 20 years ago where diagnostic disclosure was based on less knowledge held by the patient, the diagnosis would have come more as a shock (S6+S7). Although there are still individuals who would not want to know, there are patients coming in and saying straightforwardly: *"Actually I'm worried I might have that Alzheimer's Disease"* (RE6). Just as it is talked about motor neurone disease or depression, people would talk about dementia. Increasing awareness also led to GPs recognising signs of dementia more effectively and referring patients on to specialist services (S8). Without this awareness, it is mentioned that the access to services for people with dementia might also be negatively affected. In organisations that are in fact responsible to support and promote independence, for example day hospitals, the belief *"whatever you say to the person is not going to be remembered, so what's the point in telling them"* poses ethical challenges. Instead, *"equity of service"* should be the standard, considering that a day hospital taking care of older people will certainly encounter some individuals with a cognitive impairment or dementia (S3). A speech therapist/psychologist addresses another consequence of people with dementia being viewed differently by health professionals:

> *[…] if you get a diagnosis of Alzheimer's disease in the very early stages, and you end up then, you know, subsequently a few months later being diagnosed with cancer, would that diagnosis in your medical notes affect the way judgements are made about your treatment? So there's all of those things as well.* (Speech therapist/psychologist, memory clinic staff)

An expert in dementia research describes a similar situation in which a surgeon might consider the dementia of their patient as a reason not to carry out an operation based on the belief they would not be able to cope afterwards (RE1).

Despite achievements in tackling stigma and raising awareness for dementia, the policy expert from Public Health Wales mentions increased fear of dementia without specifying reasons:

> *At the minute I think it's become the thing that people most fear, it used to be cancer, now people will fear the loss of their own memories, the onset of Alzheimer's or other kinds of dementia.* (Expert in dementia policies/services, Public Health Wales)

In the future, dementia policies are seen to make dementia *"everybody's business […] and normalise rather than stigmatise cognitive impairment"* (PE3). The interviewed old age psychiatrist sees the medicalisation of AD as a useful approach to reduce the stigma. AD should therefore be perceived as a disease just like heart failure (S12). A change was therefore seen as necessary in the way dementia and memory clinics are viewed:

> *Well, I'm fairly convinced that we need to de-stigmatise dementia. We need to re-think it, re-conceptualise it in terms of brain health. And we need to take away the idea of the inevitability of dementia and replace it as an outcome that we can prevent, that we can do something about. And from that basis we can then recruit society to help us in this enterprise. […] we have to have places where people out of the goodness of their hearts take the risk to come and help us in the genuine hope of us in ten, fifteen, twenty years' time having if you like, genuine answers, effective answers, to each of these small pathologies […].* (Researcher for biomarkers for drug treatment)

This means that a change in perception of dementia by destigmatising the condition would potentially make it possible to acquire patients without symptoms yet for studies relying on society's good will to eventually receive answers of how to deal with various dementia pathologies.

A so-called *"brain health clinic"* should be seen as responsible to examine different cognitive domains *"without any stigma attached"* (RE3) in the way it is done when measuring someone's blood pressure. However, unlike blood pressure it is acknowledged there is so far no equivalent effective treatment for dementia.

Furthermore, one of the experts in dementia policies believes in the role of raised awareness for potential risk reduction in reducing stigma:

> *I think we've done some good work from a Public Health perspective around lifestyle issues which I think actually will help to reduce some of the stigma associated with things.* (Expert in dementia policies/services, Public Health Wales)

The belief that dementia is preventable is seen as a solution to the stigma that surrounds dementia facilitating living well with dementia and – from the perspective of a researcher interested in biomarkers for drug treatment – to increase the willingness in the population to participate in related research. However, it is not reflected that there could be other consequences linked to this approach. For instance, the group of patients and their carers could understand the messages in a similar way drug treatment was apparently perceived based on campaign messages. That means it could potentially result in unrealistic hopes towards preventing the disease while not considering that the evidence base for such interventions is not yet fully convincing.

4.4 Social Issues in Dementia Diagnosis

4.4.1 Increased Diagnosis Rates in England and Wales

The investment in prevention, early intervention and support from the community was considered cost-effective due to the resulting decrease in admissions to long-term institutional care over 10 years (DoH 2009b). According to the interviewed expert from the Welsh Government diagnosing people at an early stage of dementia was informative for commissioning services at the local level. Due to the lead in time, services could be planned in advance instead of having to deal with the needs of a large amount of people with more severe dementia abruptly.

In 2012, David Cameron describes the approach of personal budgets at the Dementia conference to deal with increased diagnosis rates, as follows:

> *[…] for those who get their care at home, we're rolling out personal budgets and direct payments that put people in the driving seat. I know from experience how incredibly frustrating it is when some distant official is telling you the kind of care package you need, where you should go and how it should be spent. You think - hang on a minute - this is my family, my home, my life. I know best what I need. If it's a different care agency people want - so be it. If it's a specialised kind of therapy - they should choose it. We're ending the nightmare of one-size-fits-all - and this is happening quite fast.* (Cabinet Office, 2012)

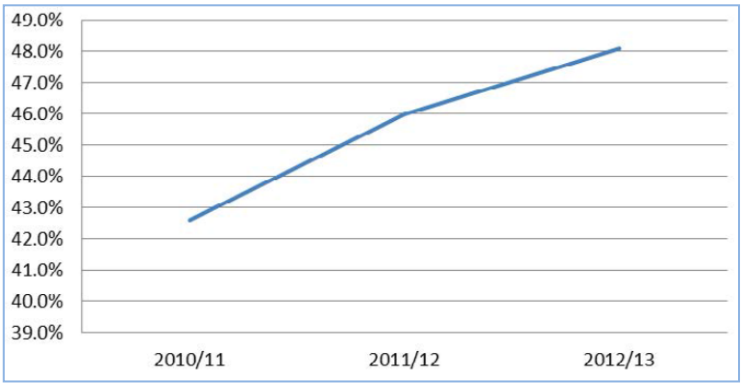
The government argues that this shift in policy – giving patients and carers more control through their own budgets to spend for their care – would be supportive in maintaining health, wellbeing and independence, preventing deterioration of the patients and their family's situation and simultaneously leading to a decrease in the burden on public services (see Cabinet Office 2012). The interviewed expert from the Welsh Government elaborates on this point of view:

> *[…] there might still be steps that people can take themselves or their family or other services to maintain health and wellbeing, to maintain independence and to reduce a core on other public services, so ultimately if you like prevention is better than cure, there may be no cure but prevention and early action might be good and is likely to be good for everybody. And certainly as much control as you can possibly give to the individual and their family, as opposed to the providers and services creates a better balance.* (Expert in dementia policies/services, Welsh government)

In the context of personal budgets, a council decides on the appropriate amount of money that is given to an individual entitled to receive publicly funded social care to meet their needs (Alzheimer's Society 2011).

The impact of incentivising clinicians to carry out more dementia related assessments and therefore increasing diagnosis rates to achieve benefits for the patient and their family seems to create new challenges. In England, the amount of individuals receiving an assessment by a memory clinic has increased four-fold from 2010/11 to 2013, as illustrated in the following diagram (see DoH 2013c).

Figure 6: Increase in Dementia Diagnosis, England



DoH 2013c

Almost half of these people diagnosed with dementia over the past year were in the early stages of the illness (DoH 2013c). As a result of the CQUIN reward for hospitals in England there were 4,000 referrals a month in 2013. In the first quarter 71% of patients admitted to the hospital were examined for potential dementia. 86% thereafter received further assessment. Eventually, of all those cases registered as potentially having dementia 87% were taken over by specialist services (DoH 2013b; DoH 2013c). Nonetheless, less than half of people with dementia were given a formal diagnosis and there were prevailing variations in diagnosis rates across England (worst performance: 31%; best performance: 75%). The aim was set to increase the diagnosis rate to two-thirds of people having a diagnosis with the following support by 2015. This meant that more than 160,000 people would additionally receive a diagnosis in that year compared to 2011/12. CCGs were meant to pursue the planning and commissioning to achieve their local aim (see DoH 2013b).

In the new Challenge on Dementia for England published in 2015 the development is praised regarding the consistent increase in the number of individuals getting a diagnosis of dementia. 59% of people with dementia were said to receive a diagnosis. Moreover, the raised awareness for the potential advantages of receiving a diagnosis by the population

and health professionals is mentioned. Various models of diagnosis were accessed by individuals at all phases of dementia, for instance they received a diagnosis in primary care in drop-in clinics without having to be referred from a GP (see DoH 2015).

For Wales, information on diagnosis rates were published by the Alzheimer's Society and other organisations. According to this data 36% of people with dementia received a diagnosis in 2011. This rose to 43.4% in 2015 (Alzheimer's Society 2015c; Tesco et al. 2011).

In the Prime Minister's Challenge on Dementia (2015) it is stated that there was a variety of challenges that needed to be addressed. Information on dementia prevalence at local and national level should be improved which then enables CCGs to limit the consisting differences in diagnosis rates and waiting times for an assessment across England. The aim was to have the initial assessment in an average period of 6 weeks. Moreover, diagnosing people of Black, Asian and Minority Ethnic origin and other groups should be promoted since according to the existing evidence diagnosis rates are especially low within these communities (see DoH 2015; see Public Health England 2015b). However, instead of having the main focus on early diagnosis there were other priorities identified: Improved post-diagnostic support for the patient and their carer is mentioned; longer independent living in their home; better waiting times for a diagnosis across England; continuity of care provided by their GP; and the possibility of advanced care planning for all patients at the best time for them. Although acknowledging previous improvements, the document emphasises the need to improve support and care (see DoH 2016).

This slight shift of focus likely stems from the experienced impact of raised diagnosis rates on dementia services which is described in more detail in the next sub-chapter.

4.4.2 Impact of Increased Diagnosis Rates on Dementia Services

The impact of increased diagnosis rates for dementia comes out clearly in the interviews with the memory clinic staff. They described a *"massive change"* (S1) and a lack of resources in terms of personnel and time in the memory clinic as is illustrated in the following quote by a research nurse:

> *How could we see all these patients? It just wasn't sustainable or even possible, physically possible. So we had to stop the follow ups. They had the clinics, the follow up clinics had to stop. All our clinics are devoted to new diagnoses you know, GP referrals. And I know as a research nurse I have been on the periphery of that. But I know the nurses they found that immensely tough because like I've just described to you, the relationships you build up. And it's not just with the patients it's with the whole*

family. And these people rely on you. You're their contact you know. And so the plan was yeah, stop the clinics but everyone has to be contacted. Everyone has to be told, if you have any problems you need to ring us. So of course the phone was constantly ringing […]. (Research Nurse, memory clinic staff)

The political push towards early diagnosis and intervention put pressure on the memory clinic and led to a different approach to see patients, shifting the focus from follow-ups to new early referrals instead. At that time the referrals were perceived as too many for the amount of services available.

Although this increase of responsibilities for the specialist service seems to be acknowledged by all memory clinic staff, a research nurse points out that the necessary resources in terms of staff have not increased:

Well no there's definitely been a change, certainly when I started there was […] I'm not even sure how many people used to get referred, I think we're into over 100 immense now to the team and yet the staffing I don't think has actually necessarily gone along with that. (Research nurse, memory clinic staff)

Memory clinic staff acknowledge the change in terms of increased diagnosis rates as a necessity to avoid situations when patients' dementia has progressed and reached crisis point, but also critically address the amount of money that would be needed for dementia care. The lack of resources does not apply merely to memory clinics, but essentially to the care and support the patients receive post diagnosis, as explained in more detail by a specialist nurse:

[…] they used to put monitoring visits in for the very early people, where things are perhaps starting to get a little bit difficult but maybe somebody once a week, who would pick up on changes. Now, you know, you've got to be at a critical or substantial level of risk to get a care package of any description. So there's this big gap. So you've got early diagnosis but you've got be a lot worse to get help now, than several years ago. (Specialist nurse, memory clinic staff)

The expert from the Welsh Government expresses understanding regarding GPs' doubts towards an early diagnosis when the respective support services are not available:

[…] so if I'm a GP I ask myself what is the benefit of having a diagnosis, if the support services aren't there, I'm not going to see much benefit, and I therefore think, the part of the problem with the GPs is that we have not paid enough attention to resourcing the support services, so if a GP was to give a diagnosis, but nowhere to refer onto. So I think our policies have been a bit chicken and egg. Lot of emphasis on the diagnosis

> *and not enough emphasis on these support services that go along with that to help the take up of the diagnosis.* (Expert in dementia policies/services, Public Health Wales)

Moreover, the approach of QOF points is considered as ineffective in regards to increasing diagnosis rates in Wales (PE3). A research expert in AD neurochemistry, genetics, and inflammation describes the decision of a GP to refers *"basically […] all of his patients"* (RE1) to memory clinics to raise the income into his practice due to the QOF points he receives for it. As a consequence, it is said that services were faced with a large number of people who did not seem particularly worried regarding their memory.

In the Prime Minister's Challenge on Dementia (2012) not only choice of care, but the quality of care is recognized as in need of further improvement. Health and social care services are said to face difficulties due to the increasing amount of individuals with dementia accessing their services and therefore require further attention and intervention. Otherwise, not every individual would receive the treatment and support that they want and need. David Cameron stated in his speech that health reforms would put *"more power into the hands of clinicians"*, for instance to prevent people with dementia being admitted to the hospital since a stay might accelerate that person's decline (see Cabinet Office 2012). GPs and other clinicians who regularly interact with people with dementia and their carers were given the primary responsibility for commissioning health care that needs to fit their patients' lives and needs (DoH 2012). This approach is, however, subject to controversy, in more detail addressed in Chapter 5.

Training and support as mentioned by a research expert is seen as essential if more responsibilities are to be taken over by primary care, *"simpler things"* could be done for secondary care colleagues and *"then it leaves more time for them to do the complex stuff"* (RE6). A research nurse underpins this approach as well, but implies interpersonal challenges:

> *Yes they're their largest client group aren't they elderly people? You know and spotting it early as well and have the confidence to address that goes such a long way on such a personal human level. To address things like that and make sure that you are going down the correct pathway to facilitate that diagnosis. And for that person to receive the help they need.* (Research nurse, memory clinic staff)

A specialist nurse considers the time it takes from noticing initial problems in a patient to giving a diagnosis. It would take time for commonly a relative to notice these issues and get a GP appointment, the GP might do tests to exclude other reasons and additionally the patient would have to wait for an appointment in the memory clinic. For instance, in

2013 the average time period from the point of referral to assessment was 5.2 weeks and another 8.4 weeks from that point in time to getting a diagnosis (see DoH 2013c).

The conclusion is drawn that having a nurse from specialist services one afternoon a week to do pre-screenings would decrease the diagnostic process by several months (S5). A research expert interested in biomarkers for diagnostic technologies and drug treatment takes this one step further and would see expertise for dementia diagnosis equally in primary care provided by GP specialists and specialist services. Having GP specialists would save resources, *"as long as the quality and standard of the diagnostic procedures don't deteriorate because they're being done in a rushed ten-minute consultation in a primary care setting"* (RE4). Apart from GPs not necessarily feeling competent to take up this responsibility, secondary care specialists might feel their role is taken over (RE6). The role of secondary care specialists is, however, seen as vital in the future by the interviewed old age psychiatrist. This is due to the attempted moves to re-define dementia at the pre-clinical stage of the disease which would make the early detection and treatment much more specialised and could not be carried out by GPs. Nonetheless, it is seen as necessary for GPs to partly cover the care for the resulting follow-ups and offering respective services (such as cognitive behavioural therapy) in a similar way to the primary care management of diabetes or asthma (S12).

Moreover, it is stated that the policy push towards early diagnosis did not actually reach out to those people with dementia in need of a diagnosis, but instead filled the clinics up with the *"worried well"* (RE2). Media coverage might therefore increase the worries in those people who are anxious about their health already (S12). It is reflected, however, that the amount of people coming to the service needing a different service is small compared to the individuals who are deemed to be in the early or moderate stages of dementia. Thus, patients were consistently added to the current ones (S4). This perception is challenged by a neurologist registrar, as described in the extract below:

> *So we used to see lots of, well I think I saw quite a few interesting people come through that clinic and I'm not putting myself up but I think that when you approach it in the light of what is wrong with this person? Rather than is this Alzheimer's or not? You're focus shifts.* (Neurologist registrar, memory clinic staff)

In an exemplary scenario a patient is at first associated with Vitamin B12 deficiency since symptoms seemed to be similar to those memory clinic staff might commonly see in patients, but it turned out to be a rare neurological disease. This seems to imply that the focus on AD and other dementias in a memory clinic might promote a respective diagnosis rather than acknowledging the potential for other diseases.

A GP patient survey carried out during the period the interviews with memory clinic staff took place showed that a raised proportion (7% increase from March 2012 to March 2013) of those suffering from dementia stated they did not have sufficient support from organisations and services in their area in coping with their disease (DoH 2013c).

The role of false positives is considered by the policy expert from the Welsh Government, as in more detail described in the following extract:

> *The big challenge then is that we are ensuring that the right people are getting seen in a timely manner and if there are false positives, then that's not delaying because of the volume going in, people who do have a dementia getting a timely diagnosis, so the more pressure there is on memory assessment service the slower and the less timely the diagnosis will be, just because of the ability and the capacity to meet the demand and yes there is a risk of that.* (Expert in dementia policies/services, Welsh Government)

Nonetheless, the expert from Public Health Wales does not see the potential false positives as the major issue, since ideally these people would receive support. However, it is further stated that support services would have to be available in the first place and providing these should be seen as a priority (PE3). Unwanted consequences of a diagnosis such as the emotional response or the stigma attached to the label are here disregarded.

Taking the impact on dementia services with the current approach of case-finding into account, the consequences of a systematic screening of the population are considered. As mentioned before in Chapter 4.3.2, screening people systematically would result in *"lots of false positives"* (RE1). According to the interviewed researcher, this would also lead to increasing lack of resources and pressure on an underfunded NHS that would currently be unable to deal with the resulting number of patients with an actual diagnosis.

The expert in dementia services from the Alzheimer's Society points out the difficulties encountered when wanting to provide support to people with MCI:

> *In terms of the support that they receive, yes it would be, we do support people with MCI or any type of brain related injury, we can support them, but you wouldn't be able to provide information then of specific types of dementia and how you can deal with that, those specialities, if you like. So it would be more general support, because you wouldn't know if that person would go on to develop dementia, if there's no diagnosis, then we can't give the support that we ordinarily give.* (Expert in dementia services, Alzheimer's Society)

Instead of the usual support that people with a diagnosis of dementia received, i.e. information on their disease, people with MCI would receive psychological support, if necessary (PE2). In this context, the expert from the Welsh Government points out:

> *[…] we have a lack of access to psychological therapies generally, I think that's particularly the case in older people's mental health services which means it's particularly the case for people with a cognitive impairment or an emerging cognitive impairment. So we've got a long way to go to address those issues.* (Expert in dementia policies/services, Welsh Government)

It is problematic that the role of psychological therapies is seen as essential here, the access to such a service, however, is perceived as limited, especially for older people with a cognitive impairment.

Furthermore, insufficient provision of services is mentioned in regards to support for carers, i.e. respite care support to enable them have breaks. A need to train doctors and nurses *"much more thoroughly"* (PE3) about issues related to supporting patients with a cognitive impairment is expressed. Specifically, people with learning disabilities were yet to receive appropriate services which needed to be created and evaluated (PE4).

One of the interviewed researchers state that the policy recommendations were not implemented equally in all areas, in more detail described in the extract below:

> *And it was quite clear that the way it's implemented is very patchy in different parts of the country, and also that different service providers' interpretation of what they should be doing varied even for what I thought were quite simple and straightforward recommendations. They were interpreted differently in different places.* (Researcher for biomarkers for diagnostic technologies and drug treatment)

Based on this observation, the provision of services might therefore turn out to be different for service-users in various areas.

Acknowledging variations between locations possibly based on resources and incentives, the expert from the Welsh Government partly contradicts the perception of the general lack of support services. The following extract demonstrates this observation:

> *[…] so they might be a range of support that meets one person or one family's needs in one locality, but somebody in the same locality just may not be able to enter those, you know have different sets of doors to go through, they maybe find those doors are closed. So I think there is support, it is sometimes, it is patchy, geographically patchy, but also when some of that inconsistency can relate to us all being individuals and needing and wanting things in different ways.* (Expert in dementia policies, Welsh Government)

Thus, one patient might seem to receive appropriate support from the voluntary sector, the Alzheimer's Society, for example, from the medical side, their GP, or from family and friends. In the same location this might be perceived as inappropriate by someone else for individual reasons.

4.4.3 Vision of Greater Joint Working between Sectors

In the National Dementia Strategy published in 2009 the government expressed that social care, health commissioners and providers as well as independent and third sector organisations and people with dementia and their carers need to plan and work together to achieve the identified priority objectives. Moreover, the perceived importance of a comprehensive change of how health and social care and organisations of other sectors deliver their work is addressed to improve the outcomes and experiences for people with dementia and their families (DoH 2009a).

The National Dementia Vision for Wales underpins the need of all services to work together in an integrated manner facilitating services to meet the individual needs of those experiencing dementia (Welsh Assembly Government 2011). In 2013, this requirement to achieve the stated aims was highlighted once more in the Annual Report of Progress by the DoH. It is mentioned that support, care and attempts to improve research were sometimes delayed, duplicated or fragmented not only on the local and national but international level. Without joined up care with the main focus on the individual patient and their family it is stated that there was a risk of poorer quality of care and inefficiency regarding the way public resources are delivered. An extended variety of services, including, for example, transport, housing, welfare and leisure, needed to be recognized. More efforts were necessary to make integrated support and care the standard and to guarantee broad dissemination of the learning process (DoH 2013b).

According to the Prime Minister's Challenge on Dementia published in 2015 not only greater joint working between social care and health to deliver local care was necessary, but services in specialist centres that would meet the needs of patient with various conditions. This was especially important for individuals with dementia who suffer from co-morbidities. Future models of integrated services should broaden the role of primary care to comprise therapists, nurses and other professionals based in the community (DoH 2015).

From the policy perspective, the extent of direct support by social services that would lead to sustained quality of life at people's homes is seen as increasingly limited. Instead, indirect support, i.e. through supporting carers and funding the third sector, is seen as

helpful (PE3). Collaboration and support between various dementia services are said to be necessary since the NHS was not able to carry out all necessary services. Instead the third sector or local authorities would have to step in (PE1). Two of the interviewed experts in dementia policies see the third sector as vital for patients and their family in the context of dementia support:

> *The third sector got an enormous capacity to be able to support people with information, meeting other people with similar issues, helping people with transport if they lose the ability to drive their car, you know I think the third sector has got an enormous contribution to make for the development of that kind of dementia friendly communities. So third sector is, I think, a real asset to us and we need to use them better from the NHS perspective. The Social Services and Wellbeing Act that's coming will help this.* (Expert in dementia policies/services, Public Health Wales)

The third sector is perceived as helpful in providing information and opportunities to keep socially and cognitively active to potentially promote quality of life and slow down the progression of their dementia (PE1).

There are, however, also challenges to this approach which, among others, will be addressed in the following sub-chapter which discusses this study's results.

Chapter 5: Discussion

The question of whether to screen for dementia or not will be the subject of on-going controversy within policy and academic circles for the foreseeable future. In this study, social and ethical challenges in dementia diagnosis, specifically in the current context of incentivising dementia diagnosis, were explored. The results highlight that the current approach of case-finding or QOF points to raise diagnosis rates, whether seen as screening or not, goes hand in hand with social and ethical issues that need to be considered in terms of the impact that policy decisions have on the patients' lives and clinical practice. For instance, the decision to pro-actively ask patients who visit primary care or hospitals for other reasons if they have experienced problems with their memory in the previous year is likely to lead to some of them being assessed and having expectations regarding treatment and support. What benefits and harms this process yields is not a simple question to answer, but the preconditions in which dementia is approached, assessed and diagnosed, and its related consequences, need to be considered carefully.

Memory clinic staff agreed that the need for diagnostic disclosure is self-evident based on the principle of respect for autonomy. However, based on the aforementioned definition of diagnostic disclosure by Whitehouse et al., it begins with the patient's degree of awareness and ends with an amount of bearable and useful information (see Whitehouse et al. 2004). In this respect, the issue of informed consent before an assessment needs to be examined. It is clear that there is a lack of knowledge regarding the aetiology of early dementia and especially MCI as the potential pre-dementia stage of the disease. After an assessment the patient with MCI receives the information that *"sometimes they get better, sometimes they stay the same, sometimes they get worse, and yeah not knowing what's around the corner"* (S11). The validity of a patient's agreement to an assessment can be questioned since the information on dementia and MCI is lacking. The patient cannot be fully aware of the uncertainties that surround the early stages of dementia due to the current testing possibilities and conceptual issues and what this might mean for their present and future lives.

It did not come out clearly to what depth these uncertainties are discussed before the initial assessment, but pre-diagnostic conversations seemed to mainly cover the patient's expectations, the possibility of finding memory problems worse than could be expected for their age and different causes of dementia. This study therefore supports one of the reasons behind the decision not to screen, namely the lack of knowledge regarding dementia and its early stages as it leads to difficulties for clinicians both clinically and ethically. It could on the one hand be argued that it would be unethical to withhold an offer

to test and potentially remove uncertainty-induced anxiety by disclosing information about MCI. However, the patient needs to be able to consciously decide against obtaining information that leads to other kinds of uncertainty. Remarks regarding the complexity of the disease, including the gaps in knowledge in the early stages, might be necessary in pre-diagnostic conversations.

In the case of a clinical diagnosis of dementia, studies revealed that the vast majority of those with mild dementia would want to receive complete information (see Pinner/Bouman 2003). However, there are others who do not wish to know and their preferences should be respected equally. A routine disclosure of a diagnosis is therefore not recommended, but clinicans need to understand what the individual patient wishes for and act accordingly (Marzanski 2000). A practical challenge arises when considering how to figure out the paitent's opinion without revealing any unpleasant information to those who would prefer not to know about it (Gillon 1985). However, even after agreeing to an assessment, according to Andorno (2003) there is no strict duty to disclose, but it is even called the responsibility of the clinician to choose the right amount of information that a patient likely wants and is able to cope with at the time. Memory clinic staff describe how they observe patients' awareness of the disease and their attitudes towards it during the assessment process and adapt the diagnostic disclosure to the individual's likely preferences. An additional challenge to this, described as occurring quite frequently, is the wish by family members to not disclose a diagnosis of AD to the patient. Apart from the paternalistic desire to keep patients from knowing the negative implications of their condition, Pinner and Bouman (2003) also mention as a possible reason that they might want to avoid having to cope with the patient's knowledge and possible negative reactions. This stands in contrast to the family member's wish to know if it were them. The duty to disclose is then used by memory clinic staff as an argument against the family member's request, particularly when drug treatment is involved or when the patient explicitly requests the information. Only in rare cases is it explicitly agreed to keep the diagnosis from the patient. Based on the potentially negative effect on the patient's emotional state, the principle of non-maleficience is chosen over the right to know. Information is then given using euphemisms, such as 'memory problems', instead of the term 'AD'.

The reactions to MCI are mainly described as positive, characterised by acceptance and relief. On the other hand, a dementia support worker during their interview delineated a picture of people feeling lost due to the uncertainty linked to MCI. This issue of uncertainty was described by the interviewed researchers in the context of risk identification for AD in people in an assumed asymptomatic stage of the disease. It was described as ethically problematic to disclose a person's risk of AD due to the limited accuracy of the identified

biomarkers to predict the future of individuals, subsequently letting them live with this uncertain knowledge. The reason why this is not perceived as problematic for people in the stage of MCI is based on their wish to know since they already experience symptoms of their cognitive impairment. However, even if a patient expresses their wish to know what is wrong and initially feels relieved due to the previous concern for worse explanations, feelings of disorientation can still be experienced at a later point. As one expert in dementia research highlighted, there is uncertainty regarding, for example, future planning which is supposed to be one of the strong benefits of an early diagnosis. This uncertainty is due to the heterogeneous nature of MCI, as described in Chapter 2.2, and the fact that not all of the patients with MCI, but 5-10% will develop some forms of dementia (see Le Couteur et al. 2013). Thus, the low prognositic significance of MCI could ultimately have similar effects on the patient as limited knowledge of individual risk in an even earlier stage.

It could be argued that knowledge of individual risk for a patient with MCI, if accurate, could hypothetically at least increase the prognostic significance. However, if there is no clinical benefit for the patient and therefore for the NHS, the costs for this approach is not seen as justified by the experts in dementia research. In the case of MCI, the information provided to a patient regarding their risk of developing AD based on measured indicators would merely result in telling them to control possible risk factors which would be done in any case without, for example, having to examine cerebrospinal fluid or do an amyloid scan.

For those people who are already experiencing symptoms, testing for dementia seems to be challenging. Based on numbers provided by the National Screening Committee the calculated specificity is 87.10%. If the age group of over 65s would be tested it would result in 18 people having a positive test result, while only 6 of them would in fact have dementia (see National Screening Committee 2015). When questioning the experts involved in dementia policies this issue seems to be recognized for the current approach of incentivising dementia diagnosis, but is immediately counterbalanced by other arguments. The risk of false positives is seemingly outweighed by the future improvement in testing possibilities, for example brain imaging.

Less confidence is expressed by those involved in the development of more sophisticated diagnostic technologies. Currently, a scan might strengthen a diagnosis of dementia as in some cases brain atrophy would suggest an AD diagnosis. However, the patient might still not be cognitively impaired. On the other hand, a normal result would not be sufficient to exclude dementia (see DoH 2014a). The issue of symptoms and pathology not necessarily being connected is especially problematic for an early or the envisaged pre-

clinical diagnosis. Moreover, studies have demonstrated that characteristics of more than one type of dementia are more common than distinct dementia syndromes. The more sophisticated diagnostic technologies tend to not lessen the uncertainty, but actually increase it due to the similarities between AD, other dementias and Parkinson's disease or the overlap between MCI and AD (see Ritchie/Lovestone 2002; see Whitehouse et al. 2004).

Moreover, in this context, the issue of overdiagnosis needs to be reflected on. The situation is described in which a GP is driven by the financial incentive of QOF points and therefore refers all of his patients to specialist services. In a published article of the British Medical Journal, a GP underpins this potential of overdiagnosis for other reasons. It was implied that the priority of increasing diagnosis rates and the criticism that CCGs had to face if they did not meet the targets led to raising numbers regardless of the situation and therefore to overdiagnosis. The diagnosis rate for his own practice was said to be 126.7% which he explained by overdiagnosis or highly inaccurate figures (see Brunet 2014). Related to this, one of the interviewed clinicians addresses their own and other staff's subconscious focus in the memory clinic in terms of diagnosis. Instead of asking in more general terms for the cause of the patient's problems, they tend to ask the question if they were dealing with AD or not.

Memory clinic staff described difficulties in distinguishing between MCI and AD and the role of subjectivity in clinical judgement. Additionally, every individual patient has different cognitive capacity which makes it difficult to equally examine them for an impairment in one or more cognitive domains. The testing is also perceived as challenging when a patient, for example, is illiterate. Despite confounded test results, the clinican assumes mild cognitive problems based on the history, but no clear information could be offered to the patient in this case. The only approach that is perceived to make a diagnosis more certain at the moment is taking the patient's history and monitoring them over time. In terms of a potential population based screening, the interviewed experts in dementia research state that even if confidence in biomarkers increased in the future, it would only be possible if it would not be a one-off test, but comprised a repeated measurement, for instance, the use of regular imaging.

The different perceptions of policy makers and those involved in diagnostic technologies might be explained by the phenomenon referred to as 'distance lends enchantment' which illustrates that the more a person retreats from those researchers who actually actively carry out the studies the less they see what is going on in the study and the uncertainty and skill that goes along with it. When the person reads a second hand report this would simplify the study further resulting in the understanding of a 'quasi-logical certainty'. Thus,

the understanding for the large complexity of the research is lacking and they feel more certain of the research while the actual researchers are more aware of the studies' pitfalls (see Collins 1997). This could even be applied to the increases of dementia cases where predictions are meant to be considered a 'worst case scenario' rather than inevitable results (see Alzheimer's Society 2014f). As pointed out by Lock (2013), even though the accuracy in assessing AD cases is not given, the portrayal of the increase of cases and the upcoming challenge in the media and publications is made with confidence. This might be true for particular areas of the globe, but there are studies contradicting the huge increases of dementia cases in the UK (see Matthews 2016). Nonetheless, this portrayal seems to be a significant argument for the policy push towards early diagnosis. In the context of false positives, simply trusting the development of more sophisticated diagnostic technologies in the future to minimise the risk seems insufficient as a solution given that incentivising dementia diagnosis is currently taking place.

It is recognized by one expert in dementia policies that the policies have been *"a bit chicken and egg"* (PE3). The current approach is justified, however, by stating that instead of focusing on the issue of false positives, critique was rather appropriate for the subsequent lack of support services for those with a diagnosis, whether right or wrong. The lack of support services is seen as stemming from the neglect in resourcing them and the simultaneous strong emphasis on early diagnosis. Burns (2014), as mentioned in the second chapter of this study, sees misdiagnosis not as a reason against the introduction of case-finding, but instead improved education and cooperation of primary and secondary care should work against this risk. Again, based on the findings of this study, the mentioned need for education, training and extension of support services requires more attention, but it should not be a reason to downplay the very current risk of limited accuracy in dementia diagnosis.

The person with a false positive diagnosis would have to cope with downstream consequences, for instance as found by Derksen (2006) due to the impact on their partnership and their social relationships or, as demonstrated in Chapter 4, due to the stigma associated with the disease. Health professionals could potentially view the person with a dementia diagnosis differently, essentially affecting decisions regarding their drug treatment for other conditions such as cancer or carrying out an operation. In this context, achievements mentioned in the policy documents mainly referred to public stigma including dementia friendly communities, building up support in the community and increased media attention. It is also described that GPs are more aware of the benefits of referring patients on for a diagnosis despite their past attitude to keeping the stigmatising label away from patients due to the lack of interventions. Raised awareness of people was

generally described as helpful in facilitating diagnosis, continuous living in the patient's own home and even to potentially risk stratify patients without symptoms yet for an intervention in the future relying on society's good will. Self-stigma and stigma by association, although not explicitly mentioned, received attention by being challenged through reducing public stigma. Moreover, according to Corrigan/Rao (2012) self-stigma can be tackled by promoting personal empowerment which is addressed in the data in the form of giving patients among others the option to know about their condition, seek information and support, specifically peer support or befriending services, and therefore develop control.

However, tackling stigma of dementia and raising awareness generally should be viewed as a continuous challenge. This is underpinned by the statement of one of the experts in dementia policies referring to Wales having a strong need to educate and raise awareness as the country was lagging behind England. Moreover, dementia was referred to as the disease replacing cancer in terms of the fear that it provokes in people. Apart from increased fear as one unwanted consequence of raised awareness, the patients and their families seemed to receive a certain image of available drug treatment. As confirmed by Whitehouse et al. (2004) patients' hopes tend to focus on biological fixes based on created anticipations of cures for AD. The high hopes lead to difficulties for memory clinic staff explaining their realistic use and benefits. Drug treatments that are meant for early mild-to-moderate or severe AD and so far only treat symptoms and do not affect disease progression cannot be viewed as a reason for early diagnosis since patients with MCI or early dementia would not necessarily be eligible. Although this is not made explicit in, for example, the National Dementia Strategy in 2009, it is reflected by the interviewed policy makers who see the mentioned benefit of treatment as beyond medication and including planning ahead and receiving support. Not only are there, however, possible uncertainties in planning ahead, the support for people with MCI and early dementia carries with it significant challenges.

There seems to be a general lack of support services due to the neglect to resource them, but the support that is available for patients with MCI seems to be especially problematic. Memory clinic staff mentioned a support group that enables patients with MCI to learn how to cope with memory issues. Apart from that, the expert involved in support services states that their team would usually provide necessary information to service users, but as MCI is not a diagnosis, but a risk condition, there is not much to offer apart from sending them to services responsible for psychological support. An expert in dementia policies stated that people *"in these early stages"* – it is not clear if the expert refers to the stage of MCI or early dementia – can potentially react with grief, loss, anxiety, fear and depression.

However, it is also stated that psychological support is lacking for people with an emerging cognitive impairment. Werner and Korczyn (2008) suggest the expansion of services to include support groups specifically for people with MCI and the availability of information regarding the risk condition and its development as well as – in accordance with some of the interviewed experts – regarding secondary prevention, i.e. changes in lifestyle, such as nutrition and physical activity.

One expert in dementia policies/services mentions the possible benefit of lifestyle changes as a reason for telling patients of their cognitive impairment. Among the interviewed researchers the opinion was expressed that a change of health behaviours at an already symptomatic stage would likely not yield improvements in terms of preventing deterioration. Nonetheless, it is seen as justified to give the advice of a healthy lifestyle to someone with a cognitive impairment since it could benefit the patient generally and evidence might still emerge. However, there is a need for more evidence that lifestyle alterations are effective in the stage of MCI.

The population is described by one of the experts in dementia policies/services as not being aware of the potential to alter the risk of developing the disease from birth and particularly in adulthood and middle-age. A widespread view was said to be that dementia was only relevant for retired people of older age. However, as described in chapter 2, recent epidemiological studies showed that there has been a decrease in incidence of dementia over the past 20 years and this is likely linked to public health interventions (see Matthews et al. 2016). Cardiovascular risk factors in mid-life are found to be associated with a higher risk of dementia (see Duron/Hanon 2008). Moreover, a history of depression is suggested as an independent risk factor (see Ownby et al. 2006). Apart from individual-level interventions, social and economic factors need to be considered in the decision how to promote brain health among the population. In this respect, efforts should focus on identifying the most effective way to deal with health inequalities (see Katikireddi et al. 2013).

It should be reflected that promoting the perception of dementia being preventable could not only potentially decrease stigma among the population, but also result in unrealistic expectations. This was observed in the context of the available drug treatment which patients and their families had increasingly heard of, but that at the same time believed to be a simple answer to avoid or slow down the disease. In reality, drug treatment is not yet able to prevent the disease or to confidently slow down the disease. It is only able to alleviate symptoms temporarily – although not in all patients – and can go along with side effects (see Lock 2013; see National Screening Committee 2015). In regards to risk reduction, not only are there risk factors, such as obesity, diabetes and hypertension, that

could be controlled, but there are non-modifiable risk factors such as age, gender and genetics. A simplification of the reality of being able to prevent it by leading a healthy lifestyle might lead to self-blaming by a person with dementia and ultimately even potentially increase stigma around the condition.

Furthermore, it should be noted that some decisions of the government regarding the management of services that is supposed to meet the patients' needs in a more effective way yield its own challenges. First of all, to achieve the aims illustrated in the two strategies for Wales and England, the Department of Health and the experts involved in dementia policies all expressed the need for joint working between health and social care. On the government website it says that a patient might need services provided by various health and social care professionals. This can, however, result in people experiencing fragmented health and social care services and difficulties in accessing them. These services might also lack focus on the patient or their carers' needs. Integrated care is seen as the solution and would mean combining all the different aspects of care with the benefits of reducing confusion, delay, repetition, gaps and duplication in delivering services, as well as patients getting lost in the system (see NHS England 2015b). There are, however, barriers to this goal of joint working and especially joint planning. Professional issues might arise, such as competitive values and ideologies, competition for domains, and variations in specialisms, skills and expertise. Moreover, there might be structural issues, for example, gaps in services; financial issues, including differences in funding mechanisms; and procedural issues, such as differences in planning and budgetary cycles (see Leathard 2003).

Improving service provision is also linked to expectations regarding the involvement of the third sector and the responsibilities attempted to be given to patients and carers through personal budgets. For the partnership working between the NHS and the third sector, there are barriers such as pressures on resources and different organisational priorities. Moreover, differences in regulatory and legislative restrictions can present challenges (see Addicott 2013). In the context of personal budgets, it was shown that it is less likely for older people to associate personal budgets with positive changes and more likely for them to state that personal budgets did not change some outcomes, such as the perception of greater control, improved relationships with friends and family and feelings of safety (Centre for Disability Research 2011). Despite potential benefits to individuals with dementia and their carers, the system was found to not be appropriate for the needs of people with dementia and their carers. For instance, as dementia is a condition that progresses patients' needs would change over time and the system was required to take this into account. Moreover, it was perceived by some people with dementia and carers as

unduly complex and stressful to deal with financial arrangements in addition to their already difficult situation. It was suggested that besides direct payments as an option, a managed budget should be offered or those with dementia and their carers should be included in an open discussion around care planning (Alzheimer's Society 2011).

Furthermore, as mentioned in Chapter 4, due to the health reforms in 2012, GPs and those clinicians in regular contact with people with dementia and their carers received the primary responsibilities to commission services that should meet their needs. This approach was, however, also recognized as potentially leading to conflicts of interest. For instance, in 2014/15 41% of governing body members for the CCGs were GPs who were in the position to decide about local health services and at the same time would have received payment by their CCG for the provision of these services. In the Health and Social Care Act it was made a requirement that CCGs prepared to manage conflicts of interest to avoid limitations to their integrity in the decision making. Moreover, transparency for how they work was said to be essential (National Audit Office 2015).

Chapter 6: Recommendations and Conclusions

There is a continuous need to raise awareness for dementia which at the moment is not only done by promoting increased media coverage and dementia friendly communities, but by pro-actively asking patients in primary care and hospitals for any concerns regarding their memory. The latter might be beneficial to reach those who genuinely lack awareness and are in need of an assessment, but as demonstrated by this study it can also increase uncertainties, fear and unrealistic expectations of treatment in some individuals and lead to a significant capacity issue for dementia services.

In accordance with the National Screeening Committee's recommendation it should be reflected if better understanding of the conditions and evidence is necessary to enable the patient to make an informed decision before an assessment. Awareness raising without incentivising dementia diagnosis might be sufficient in driving people to the clinic since knowledge of treatment and decreased stigma in terms of people addressing the topic themselves was said to be increasingly noticeable. This might also relieve services and decrease the risk of false positives and overdiagnosis. Even though the risk of misdiagnosis is acknowledged, it is justified by some by putting the blame on the lack of sophisticated diagnostic technologies, of education among health professionals, of cooperation between primary and secondary care and of support services. Until this gap is filled, however, patients could potentially suffer due to false diagnoses, uncertainties, unavailable support. In this context, there should also be a separation between the diagnostic technologies used in research and the ones used in clinical practice as long as sophisticated technologies continue not to yield a good payoff for the patient and the NHS in terms of drug treatment and costs.

It seems right to offer patients and their families and carers the opportunity to plan ahead and receive support and information, but that is if they by themselves wish to do so. Instead of promoting an early diagnosis, the current limitations of benefits of an early diagnosis should be acknowledged. Timely diagnosis, that means a person with memory concerns, a close friend or a family member or a professional notice a problem and subsequently address it, seems to be the more appropriate option.

Moreover, a healthy lifestyle should be promoted during peoples' lives and as early as possible. The potential for risk reduction by not only controlling lifestyle factors, cardiovascular risk factors, and psychological aspects, but also by improving the social and economic environment among the population should continue to be promoted. In this context, the Blackfriars Consensus on promoting brain health in the UK is a first step towards this goal.

Until early diagnosis in conjunction with disease-modifying treatment would form a preventive strategy, the benefits of knowing about one's MCI and early dementia might therefore not confidently outweigh potential harms as yet.

References

Addicott, R. (2013): Working together to deliver the Mandate. Strengthening partnerships between the NHS and the voluntary sector.

Albert, M.S.; DeKosky, S.T.; Dickson, D.; Dubois, B.; Feldman, H.H.; Fox, N.C.; Gamst, A.; Holtzman, D.M.; Jagust, W.J; Petersen, R.C.; Snyder, P.J; Carrillo, M.C.; Thies, B.; Phelps, C.H. (2011): The diagnosis of mild cognitive impairment due to Alzheimer's disease: Recommendations from the National Institute on Aging and Alzheimer's Association workgroup. Alzheimer's & Dementia 7: 1-10.

Alzheimer's Association (2016): Mixed dementia. <www.alz.org/dementia/mixed-dementia-symptoms.asp> Accessed on 10th July 2016.

Alzheimer's Disease International (2012): World Alzheimer Report 2012. Overcoming the stigma of dementia.

Alzheimer's Disease International (2013): World Alzheimer Report 2013. Journey of Caring. An analysis of long-term care for dementia.

Alzheimer's Disease International (2014): World Alzheimer Report 2014. Dementia and Risk Reduction. An Analysis of Protective and Modifiable Factors.

Alzheimer's Disease International (2015): World Alzheimer Report 2015. The Global Impact of Dementia. An analysis of prevalence, incidence, cost and trends.

Alzheimer's Disease International; World Health Organization (2012): Dementia. A public health priority.

Alzheimer's Research UK (2014a): Lewis, F.; Karlsberg Schaffer, S.; Sussex, J.; O'Neill, P.; Cockcroft, L.: The Trajectory of Dementia in the UK – Making a Difference.

Alzheimer's Research UK (2014b): Defeat Dementia. The evidence and a vision for action.

Alzheimer's Research UK (2015): Population screening and Targeted Case Finding Policy Statement.

Alzheimer's Society (2011): Getting personal? Making personal budgets work for people with dementia.

Alzheimer's Society (2012): Genetics of dementia.

Alzheimer's Society (2014a): What is Alzheimer's Disease?

Alzheimer's Society (2014b): What is vascular dementia?

Alzheimer's Society (2014c): Assessment and diagnosis.

Alzheimer's Society (2014d): Drug treatments for Alzheimer's Disease.

Alzheimer's Society (2014e): Dementia 2014 report statistics.

Alzheimer's Society (2014f): Dementia UK. Update.

Alzheimer's Society (2015a): What is young-onset dementia?

Alzheimer's Society (2015b): What is mild cognitive impairment (MCI)?

Alzheimer's Society (2015c): Wales Dementia Diagnosis. Progress on improving diagnosis of dementia 2014-2015.

Alzheimer's Society (2016a): What is dementia with Lewy bodies (DLB)?

Alzheimer's Society (2016b): What is frontotemporal dementia (FTD)?

Alzheimer's Society (2016c): Lasting Power of Attorney.

Andorno, R. (2003): The right not to know: an autonomy based approach. J Med Ethics, 30: 435-440.

Barer, D. (2014): Dementiagate: spend the money on dementia services and research. British Medical Journal.

Beauchamp, T.L.; Childress, J.F. (2009): Principles of biomedical ethics. New York/Oxford: Oxford University Press.

Bender, M. (2003): Explorations in Dementia. Theoretical and Research Studies into the Experience of Remediable and Enduring Cognitive Losses.

Bogner, A.; Littig, B.; Menz, W. (2009): Interviewing Experts.

Bowen, G.A. (2009): Document Analysis as a Qualitative Research Method. Qualitative Research Journal 9, 2: 27-40.

Brayne, C.; Gao, L.; Dewey, M.; Matthews, F.E. (2006): Dementia before death in ageing societies – the promise of prevention and the reality. PLoS Medicine 3, 10: 1922-1930.

Brunet, M. (2014): Targets for dementia diagnoses will lead to overdiagnosis. British Medical Journal.

Burns, A. (2014): Achieving quality of care in dementia by appropriate and timely diagnosis.

Cabinet Office (2012): Speech Transcript: Prime Minister's speech to the Dementia 2012 conference.

Centre for Disability Research (2011): Older people and personal budgets: A re-analysis of data from the National Personal Budget Survey 2011.

Cheng, G.; Huang, C.; Deng, H.; Wang, H. (2012): Diabetes as a risk factor for dementia and mild cognitive impairment: a meta-analysis of longitudinal studies. Internal Medicine Journal: 484-491.

Collins, H. (1997): Expertise: Between the Scylla of Certainty and the New Age of Charybdis. Accountability in Research 5: 127-135.

Connell, C.M.; Gallant, M.P. (1996). Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. Journal of the American Geriatric Society 44: 1003-1009.

Corrigan, P.W.; Rao, D. (2012): On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change. Canadian Journal of Psychiatry 57, 8: 464-469.

Creswell, J.W. (2013): Qualitative Inquiry & Research Design. Choosing Among Five Approaches. Thousand Oaks/London/New Delhi/Singapore: SAGE Publications.

De Bruijn, R.F.; Direk, N.; Mirza, S.S.; Hofman, A.; Koudstaal, P.J.; Tiemeier, H.; Ikram, M.A. (2014): Anxiety Is Not Associated with the Risk of Dementia or Cognitive Decline: The Rotterdam Study. The American Journal of Geriatric Psychiatry: 1382-1390.

Department of Health (2009a): Living well with Dementia: A National Dementia Strategy.

Department of Health (2009b): Living well with Dementia: A National Dementia Strategy Implementation Plan.

Department of Health (2012): Prime Minister's Challenge on Dementia. Delivering major improvements in dementia care and research by 2015.

Department of Health (2013a): Consultation on GP contract 2013/14: Government response.

Department of Health (2013b): The Prime Minister's Challenge on Dementia. Delivering major improvements in dementia care and research by 2015: Annual report of progress.

Department of Health (2013c): Dementia. A state of the nation report on dementia care and support in England.

Department of Health (2014a): Dementia Revealed. What Primary Care Needs to Know.

Department of Health (2014b): Progress on the Prime Minister's Challenge on Dementia: Year Two.

Department of Health (2015): Prime Minister's Challenge on Dementia 2020.

Department of Health (2016): Prime Minister's Challenge on Dementia 2020. Implementation Plan.

Derksen, E.; Vernooij-Dassen, M.; Gillissen, F.; Olde Rikkert, M.; Scheltens, P. (2006): Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis. Ageing & Mental Health 10, 5: 525-531.

Dhedhi, S.A.; Swinglehurst, D.; Russell, J. (2014): 'Timely' diagnosis of dementia: what does it mean? A narrative analysis of GP's accounts. British Medical Journal open: 1-9.

Diniz, B.S.; Butters, M.A.; Albert, S.M.; Dew, M.A.; Reynolds, C.F. (2013): Late-life depression and risk of vascular dementia and Alzheimer's disease: systematic review and meta-analysis of community-based cohort studies. The British Journal of Psychiatry 202, 5: 329-335.

Draper, B.; Peisah, C.; Snowdon, J.; Brodaty, H. (2010): Early dementia diagnosis and the risk of suicide and euthanasia. Alzheimer's & Dementia 6: 75-82.

Duron, E.; Hanon, O. (2008): Vascular risk factors, cognitive decline, and dementia. Vascular Health and Risk Management 4, 2: 363-381.

Eikemo, T.A.; Mackenbach, J.P. (2012): The potential for reduction of health inequalities in Europe. Erasmus MC.

Fetterman, D.M. (2010): Ethnography: Step-by-Step. Thousand Oaks/New Delhi/London/Far East Square: SAGE Publications.

Flick, U. (2014): An Introduction to Qualitative Research. SAGE Publications Ltd.

Gallacher, J.; Bayer, A.; Fish, M.; Pickering, J.; Pedro, S.; Dunstan, F.; Ebrahim, S.; Ben-Shlomo, Y. (2009): Does Anxiety Affect Risk of Dementia? Findings From the Caerphilly Prospective Study. Psychosomatic medicine 71, 6: 659-666.

Gillon, R. (1985): Telling the truth and medical ethics. British Medical Journal 291: 1556-1557.

Goffman, E. (1963): Stigma: Notes on the Management of Spoiled Identity. New Jersey: Prentice-Hall.

Gordon, M.; Goldstein, D. (2001): Alzheimer's disease. To tell or not to tell. Canadian Family Physician 47: 1803-1809.

Hammersley, M.; Atkinson, P. (1995): Ethnography. Principles in Practice. London/New York: Routledge.

Husband, H.J. (2000). Diagnostic disclosure in dementia: An opportunity for intervention? International Journal of Geriatric Psychiatry 15: 544-547.

Irwin, S.; Winterton, M. (2011): Debates in Qualitative Secondary Analysis. Critical Reflections. A Timescapes Working Paper.

Ivan, C.S.; Seshadri, S.; Beiser, A.; Au, R.; Kase, C.S.; Kelly-Hayes, M.; Wolf, P.A. (2004): Dementia After Stroke The Framingham Study. American Heart Association 35: 1264-1269.

Jack, C.R. Jr; Albert, M.S.; Knopman, D.S.; McKhann, G.S.; Sperling, R.A.; Carrillo, M.C.; Thies, B.; Phelps, C.H (2011): Introduction to the recommendations from the National Institute on Aging and the Alzheimer's Association workgroup on diagnostic guidelines for Alzheimer's disease. Alzheimer's & Dementia: 1-6.

Jolley, D.; Benbow, S.M.; Grizzell, M. (2006): Memory clinics. Postgraduate Medical Journal 82: 199-206.

Jolley, D.; Moniz-Cook, E. (2009): Memory clinics in context. Indian Journal of Psychiatry 51, 1: 70-76.

Katikireddi, S.V.; Higgins, M.; Smith, K.E.; Williams, G. (2013): Health inequalities: the need to move beyond bad behaviours. Journal of Epidemiology & Community Health.

Kmietowicz, Z. (2015): Evidence to back dementia screening is still lacking, committee says.

Le Couteur, D.G.; Doust, J.; Creasey, H.; Brayne, C. (2013): Political drive to screen for pre-dementia: not evidence based and ignores the harms of diagnosis. British Medical Journal: 1-6.

Leathard, A. (2003): Interprofessional Collaboration. From Policy to Practice in Health and Social Care.

Lock, M. (2013): The Alzheimer Conundrum: Entanglements of Dementia and Aging. New Jersey/Oxfordshire: Princeton University Press.

Lorenc, T.; Petticrew, M.; Welch, V.; Tugwell, P. (2012): What types of interventions generate inequalities? Evidence from systematic reviews. Journal of Epidemiology & Community Health 67: 190-193.

Marzanski, M. (2000): Would you like to know what is wrong with you? On telling the truth to patients with dementia.

Matthews, F.E.; Stephan, B.C.M; Robinson, L.; Jagger, C.; Barnes, L.E.; Arthur, A.; Brayne, C. (2016): A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. Nature Communications: 1-8.

Mayring, P. (2002): Einführung in die qualitative Sozialforschung. Weinheim/Basel: Beltz Verlag.

Mayring, P. (2010): Qualitative Inhaltsanalyse. Grundlagen und Techniken. Beltz Verlag.

Mayring, P. (2014): Qualitative content analysis: theoretical foundation, basic procedures and software solution. Klagenfurt.

McCartney, M. (2013): Would doctors routinely asking older patients about their memory improve dementia outcomes? No. British Medical Journal.

McCartney, M. (2014): “Case finding” in dementia is simply screening with no evidence of benefit. British Medical Journal.

Mesterton, J.; Wimo, A.; Langworth, S.; Winblad, B.; and Jönsson, L. (2010) Cross Sectional Observational Study on the Societal Costs of Alzheimers Disease. Current Alzheimer Research 7, 4: 358-367.

National Audit Office (2015): Managing conflicts of interest in NHS clinical commissioning groups.

National Screening Committee (2015): UK NSC dementia screening recommendation.

NHS England (2014): Understanding the new NHS. A guide for everyone working and training within the NHS.

NHS England (2015a): Enhanced Service Specification. Facilitating timely diagnosis and support for people with dementia 2015/16.

NHS England (2015b): Delivering better integrated care. <www.gov.uk/guidance/enabling-integrated-care-in-the-nhs> Accessed on 26th October 2016.

NHS Wales (2015): QOF. <www.gpone.wales.nhs.uk/qof> Accessed on 25th September 2016.

Office for National Statistics (2015): Deaths Registered in England and Wales (Series DR), 2015.

Office of Health Economics (2015): Lewis, F.: Estimation of future cases of dementia from those born in 2015.

Ownby, R.L.; Crocco, E.; Acevedo, A.; John, V.; Loewenstein, D. (2006): Depression and Risk for Alzheimer Disease. Archives of General Psychiatry 63: 530-538.

Petersen, R.C. (2004): Mild cognitive impairment as a diagnostic entity. Journal of Internal Medicine 256: 183-194.

Pinner, G.; Bouman, W.P. (2003): Attitudes of Patients with Mild Dementia and their Carers towards Disclosure of the Diagnosis.

Prior, L. (2003): Using Documents in Social Research. London/Thousand Oaks/New Delhi: SAGE Publications.

Public Health England (2014a): Evidence and recommendations: NHS population screening. <www.gov.uk/guidance/evidence-and-recommendations-nhs-population-screening> Accessed on 13th September 2016.

Public Health England (2014b): Blackfriars Consensus on promoting brain health: Reducing risks for dementia in the population.

Public Health England (2015a): Recommendation against national dementia screening (2015). <www.gov.uk/government/news/recommendation-against-national-dementia-screening> Accessed on 19th September 2016.

Public Health England (2015b): PM launches next phase of Britain's fight against dementia. <www.gov.uk/government/news/pm-launches-next-phase-of-britains-fight-against-dementia> Accessed on 8th October 2016.

Public Health England (2016): Health matters: midlife approaches to reduce dementia risk. <www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk> Accessed on 10th August 2016.

Ritchie, K; Lovestone, S. (2002): The dementias. The Lancet 360: 1759-1766.

Robinson, L. (2015): Dementia: timely diagnosis and early intervention. British Medical Journal: 1-6.

Savage, J. (2000): Ethnography and health care. British Medical Journal 321: 1400-1402.

School of Medicine (2016): Ethics in Practice. <medicine.cf.ac.uk/primary-care-public-health/research/healthy-ageing/current- projects/ethics-practice> Accessed on 24th February 2016.

Smith, A.D.; Yaffe, K. (2014): Letter: Dementia (Including Alzheimer's Disease) can be Prevented: Statement Supported by International Experts. Journal of Alzheimer's Disease 38: 699-703.

Spence, D. (2012): Bad medicine: dementia. British Medical Journal.

Sperling, R.A.; Aisen, P.S.; Beckett, L.A.; Bennett, D.A.; Craft, S.; Fagan, A.M.; Iwatsubo, T.; Jack, C.R.; Kaye, J.; Montine, T.J.; Park, D.C.; Reiman, E.M.; Rowe, C.C.; Siemers, E.; Stern, Y.; Yaffe, K.; Carrillo, M.C.; Thies, B.; Morrison-Bogorad, M.; Wagster, M.V.; Phelps, C.H. (2011): Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup. Alzheimer's & Dementia: 1-13.

Tesco; Alzheimer's Society; Alzheimer Scotland (2011): Mapping the Dementia Gap.

Tzourio, C.; Laurent, S.; Debette, S. (2014): Is Hypertension Associated With an Accelerated Aging of the Brain? American Heart Association 63: 894-903.

Welsh Assembly Government (2011): National Dementia Vision for Wales. Dementia Supportive Communities.

Welsh Government (2015): Quality And Outcomes Framework Guidance for the GMS Contract Wales 2015/16.

Werner, P.; Korczyn, A.D. (2008): Mild cognitive impairment: Conceptual, assessment, ethical, and social issues. Dove Medical Press Limited 3, 3: 413-420.

Whitehouse, P.; Frisoni, G.B.; Post, S. (2004): Breaking the diagnosis of dementia. The Lance Neurology 3: 124-128.

Whitmer, R.A.; Gunderson, E.P.; Barrett-Connor, E.; Quesenberry, C.P.; Yaffe, K. (2005): Obesity in middle age and future risk of dementia: a 27 year longitudinal population based study.

Winblad, B.; Palmer, K.; Kivipelto, M; Jelic, V.; Fratiglioni, L.; Wahlund, L.-O.; Nordberg, A.; Bäckman, L.; Albert, M.; Almkvist, O.; Arai, H.; Basun, H.; Blennow, K.; De Leon, M.; Decarli, C.; Erkinjuntti, T.; Giacobini, E.; Graff, C.; Hardy, J.; Jack, C.; Jorm, A.; Ritchie, K.; Van Duijn, C.; Visser, P.; Petersen, R.C. (2004): Mild cognitive impairment – beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. Journal of Internal Medicine 256: 240-246.

World Health Organization (2008): Revisiting Wilson and Jungner in the genomic age: a review of screening criteria over the past 40 years.

Wortmann, M. (2012): Dementia: a global health priority – highlights from an ADI and World Health Organization report. British Medical Journal.

Wysocki, M.; Luo, X.; Schmeidler, J.; Dahlman, K.; Lesser, G.T.; Grossman, H.; Haroutunian, V.; Schnaider Beeri, M. (2012): Hypertension is Associated With Cognitive Decline in Elderly People at High Risk for Dementia. The American Journal of Geriatric Psychiatry 20, 2: 179-187.

Statutory Declaration

I hereby declare that I wrote this thesis without any assistance and used only the aids listed. Any material taken from other works, either as a quote or idea have been indicated under ‘References’.

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Location / Date Signature: Alexandra Schüssler