

**THE UNIVERSITY OF HULL**

An investigation into the perceived value of an early dementia diagnosis from the  
perspective of General Practitioners and members of the lay public

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## Abstract

The following studies investigate possible factors underlying the variance in dementia diagnosis rates between Hull, East Riding and Sheffield PCT. The first study utilised qualitative approaches to explore the perceived importance of an early dementia diagnosis by GPs practicing in Hull and East Riding PCT. Although GPs were committed to early diagnosis, they identified key barriers including lack of time, inadequate cognitive assessments, limited access to specialists and negative perceptions of treatment efficiency. GP views did not differ significantly between the two areas, but access to post-diagnostic services was reported to be significantly more limited within East Riding. The perceived inadequacy and difficulty accessing such services often resulted in scepticism regarding the value of a diagnosis. It was therefore concluded that in order for GP perceptions to improve the benefits of diagnosis need to increase, mainly regarding post-diagnosis services. The second study used questionnaire data to explore and compare knowledge and perceptions of dementia in the general public of Hull and Sheffield. Although dementia knowledge was poor across both groups, this was particularly evident from the Hull group, which could act as an underlying factor behind their lower diagnosis rates. Poor dementia knowledge was particularly evident regarding at risk groups, identifying the full range of dementia symptoms and differentiating dementia from normal ageing. The present studies highlight the need for improved availability and adequacy of patient services and increased public education of dementia and also offer valuable insights in to potential methods of improving local dementia diagnosis rates.

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**An investigation into the perceived value of an early dementia diagnosis from the  
perspective of General Practitioners and members of the lay public**

**1. General introduction**

Dementia is described as a degenerative brain disorder causing progressive cognitive and behavioural deterioration (Budson & Kowall, 2014). The disease is characterised by loss of memory, language deterioration, impaired judgement and changes in mood and personality (Green, 2005). There are several subtypes of dementia including; Alzheimer's disease (the most common cause of dementia), vascular dementia, dementia with Lewy bodies and fronto-temporal dementia (Alzheimer's Society, 2013). Findings suggest that the incidence of dementia doubles every five years from the age of sixty-five through to ninety years of age (Bachman et al., 1993). Worldwide there are a total of 4.6 million new cases of dementia each year, which equates to one new diagnosis every seven seconds (Ferri et al., 2005). Recent figures indicate that there are currently 800,000 people with dementia living in the UK, a figure that is set to double over the next forty years to a staggering 1,700,000 in 2051 (Alzheimer's Society, 2013). These alarming statistics pose great problems to the UK economy as each year the total costs of dementia are estimated to be around £23 billion. To put this in to perspective this is double the cost of cancer, three times that of heart disease and four times that of stroke.

Due to the growing problem of dementia, researchers, politicians, medics and other related professionals have come together in an attempt to radically transform the way we deal with cases of dementia. In 2009, the Department of Health issued the 'National Dementia Strategy', which outlined a five-year plan to dramatically improve the service provided to dementia patients and their caregivers. The strategy focused on three main

themes including raising public awareness, aiding early diagnosis and improving information and support services. However, despite the push for early diagnosis, figures from 2012 illustrate that only 44.7% of people with dementia living in the UK hold a diagnosis (Alzheimer's Society, 2014).

An early diagnosis of dementia can be highly beneficial to both patients and their caregivers for a multitude of reasons. Firstly, an early diagnosis allows many dementia patients access to pharmacological treatments. However, access to medication is slightly more complex for individuals presenting with Lewy body dementia. Prescribing medication to improve cognitive function and reduce hallucinations may worsen the Parkinsonian like symptoms (Alzheimer's Society, 2013). However, medications to improve the Parkinson's symptoms may adversely worsen cognitive function and hallucinations. It is therefore recommended that non-pharmacological treatments are used before medications are prescribed. Patients with other subtypes of dementia are treated with cholinesterase inhibitors. Although meta-analytic reviews have cast doubt over the effectiveness of cholinesterase inhibitors, including donepezil, rivastigmine and galantamine (Kaduszkiewicz, Zimmermann, Beck-Bornholdt & van den Bussche, 2005), there remain many studies which illustrate the positive effects that treatment can have upon cognitive function (Birks, Melzer & Beppu, 1999; Wilcock, Lilienfeld & Gaens, 2000). Studies have presented evidence of improved memory function, reduced anxiety and greater participation in a range of daily activities (Royan, 1998). Furthermore, cholinesterase inhibitor medications have been shown to help the symptoms of Alzheimer's disease by restoring function (McGeown, Shanks & Venneri, 2008) and have the potential to slow the rate of atrophy (Venneri, McGeown & Shanks, 2005).



An early diagnosis also grants patients and caregivers access to non-pharmacological therapies. There are an increasing number of such therapies available for dementia patients including cognitive behavioural therapy, reality orientation, validation therapy and reminiscence therapy (Douglas, James & Ballard, 2004). Alternative therapies also include art therapy, music therapy, light therapy and aromatherapy. There is now a growing body of evidence suggesting that such therapies can produce small to moderate effects, such as increased cognitive function and improved quality of life (Spector et al., 2003). A recent review of twenty-eight evaluations of psychosocial interventions found that therapies (including behavioural therapy, cognitive stimulation and physical activity) did produce positive effects (Vernooiji et al., 2010) such as reduction of behavioural symptoms (Livingston, Johnston, Katona & Lyketsos, 2005), improved physical condition (Heyn, Abreu & Ottenbacher, 2004) and reduced depressive symptoms (Livingston, Johnston, Katona & Lyketsos, 2005). Community based occupational therapy was also found to provide positive benefits such as improved daily functioning and the reduction of caregiver stress, even twelve weeks post treatment (Graff et al., 2006). Findings indicate that these effective outcomes are most frequently observed when multidimensional approaches are utilised and when therapies are modified specifically to the needs of the patient and caregiver (Gormley, 2000; O'Connor, Ames, Gardner & King, 2009; Vernooiji-Dassen et al., 2010). Psychosocial interventions have also been found to produce positive outcomes for dementia caregivers by reducing caregiver burnout (Milne & Stone, 1996) and minimising the risk of psychological morbidity, which, in turn, potentially delays the institutionalization of the patient (Brodaty, Green & Koschera, 2003; Mittelman et al., 1993).

Additionally, an early diagnosis can provide a diagnostic answer, increasing the time within which the patient and family can come to terms with the diagnosis and receive

important information (Green, 2005; Iliffe, Manthorpe & Eden, 2003). From a more practical perspective, an early diagnosis enables patients to make legal and financial plans while they are still capable of making informed decisions (Green, 2005; Iliffe, Manthorpe & Eden, 2003; McCurry & Terry, 1997; Wood et al., 2003). It also allows for increased time to plan for future care management, again potentially delaying institutionalisation (Green, 2005; Iliffe, Manthorpe & Eden, 2003).

### *1.1 Dementia diagnosis in primary care*

When concerns arise over an individual's memory, patients and concerned family members commonly seek medical help from their General Practitioner (Brodaty, Howarth, Mant & Kurrle, 1994; Downs, 1996). Although GP diagnostic procedures vary (Boise et al., 1999), there are three key stages involved in making a diagnosis of dementia. The initial phase at which the symptoms are first noticed is referred to as the 'trigger phase' (Buntinx et al., 2011). Although memory problems are the most commonly associated symptom of dementia, the triggers that are most frequently reported include the increasing difficulty in conducting tasks of everyday living, behavioural problems and cognitive disturbances (De Lepeleire et al., 1994). During this phase many barriers are faced, such as failure to recognise the symptoms of dementia, failure to attribute them to a serious condition and reluctance from patients and caregivers to seek medical help (Boise, Morgan, Kaye & Camiciolo 1999; Hamilton-West, Milne, Chenery & Tilbrook, 2010; Rimmer et al., 2005; Schelp et al., 2008; Werner, 2003; Werner, 2008). The patient's family plays a vital role throughout the trigger phase by ensuring that the suspected case of dementia is brought to the attention of a GP (Boise et al., 1999).

However, identifying dementia poses problems for GPs practicing in primary care settings as the disease has no classic presentation (Iliffe & Drennan, 2001). For example, approximately one in three patients displaying dementia symptoms also exhibit symptoms of depression, bereavement, anxiety-disorder and alcohol misuse (Iliffe & Drennan, 2001). Furthermore, the symptoms of dementia can differ significantly depending on the type of dementia present in the patient. Alzheimer's disease is a progressive disease that develops gradually over time with memory loss being one of the first symptoms to occur (Alzheimer's Society, 2014). Vascular dementia (caused by reduced blood flow to the brain), however, presents a sudden or stepwise deterioration with key symptoms including reduced memory, language and visuospatial skills. Personality may also be affected. Lewy body dementia (caused by protein deposits in nerve cells) on the other hand, accounting for only 10% of all dementia cases can present a very different array of symptoms (Alzheimer's Society, 2014). Symptoms can include Parkinsonian like symptoms, paranoid delusions, auditory and visual hallucinations, falls and symptoms of depression (Iliffe & Drennan, 2001).

The next phase described by Buntinx and colleagues (2011), is the 'disease oriented diagnosis' phase. NICE guidelines list four crucial elements in the diagnosis including history taking, cognitive examination, physical examination and review of medication ([www.guidance.nice.org.uk](http://www.guidance.nice.org.uk)). The physical examination involves a dementia blood screen that investigates routine haematology, biochemistry tests, thyroid function, serum vitamin B12 and folate levels to allow the GP to rule out other health related conditions that may be causing the decline in memory. A common example of this would be infections, which are highly associated with temporary memory deficits. Regarding cognitive examinations, NICE guidelines specify that the examination of patients should include the assessment of language, attention, concentration, executive function, orientation and short-term and long-

term memory. Examples of the recommended standardised cognitive instruments include the Mini Mental State Examination (MMSE, Folstein et al., 1975) and the General Practitioner Assessment of Cognition (GPCOG, Brodaty et al., 2002). Cognitive screening allows the GP to obtain a score, which will indicate whether the patient's performance is within the range of normal limits. If their score is below a recommended cut-off point, this may indicate that the patient should be referred to a specialist for further assessments. Additional clinical and brain imaging tests may be required during this phase to exclude treatable conditions such as depression (Buntinx et al., 2011).

The final step in the diagnostic process is referred to as the 'care-oriented diagnosis' phase (Buntinx et al., 2011). This stage is comprised of the assessment of patient and caregiver needs, which includes conducting the appropriate assessments and making the necessary referrals to support services. The GP is then required to monitor the patient and assess their treatment needs. However, many barriers to dementia care are believed to occur during this phase. For example, patients and caregivers frequently report that GPs regularly provide insufficient dementia related information (Haley, Clair & Saulsberry, 1992; Holroyd, Turnbull & Wolf, 2002), a lack of support after the diagnosis has been made (Laakkonen et al., 2008) and poor referrals to support services (Haley, Clair & Saulsberry, 1992).

Practitioners and the primary care team play a central role in the diagnosis and management of dementia (Downs, 1996). However, dementia can be extremely difficult to diagnose and manage and therefore poses great challenges in primary care settings (Iliffe & Drennan, 2001). Dementia is regularly missed, under-diagnosed and undocumented in primary care (Boustani et al., 2005; Iliffe, O'Connor et al., 1988; Valcour et al., 2000; Iliffe, Walters & Rait, 2000). A UK study observed that only half of the expected number of

dementia patients is entered on to the dementia register (Connolly et al., 2011). This under-diagnosis was found to vary with practice characteristics (e.g. number of GPs per practice), socio-economic deprivation and between each Primary Care Trust. Reasons for the experienced difficulty in diagnosing dementia in primary care settings will now be discussed in detail. Although there are many common barriers to diagnosis presented in the literature, these can be broken down in to three key categories including GP factors, service factors and factors associated with patients and their associated caregivers.

### *1.2 General Practitioner factors affecting an early diagnosis of dementia*

When concerns arise over an individual's memory, patients and worried family members will commonly seek help from their General Practitioner (Brodaty, Howarth, Mant & Kurrle, 1994; Downs, 1996). As a result Practitioners are referred to as the gateway to receiving a diagnosis of dementia (Downs, 1996). They are responsible for making referrals to specialist services for more thorough assessments and support services. The important role that Practitioners play when diagnosing dementia cannot be disputed, however, their practice remains variable (Boise, 1999). The last decade has witnessed a boom in research, using both qualitative and quantitative methods, in an attempt to understand the barriers faced by GPs when attempting to make an early diagnosis of dementia. The key barriers voiced by GPs affecting their ability to make an early diagnosis of dementia will now be presented.

Firstly, GPs claim to have a lack of sufficient medical training specific to dementia (Cahill et al., 2008; Greenwood et al., 2010; Iliffe & Wilcock, 2005; Renshaw, Scurfield, Cloke & Orrell, 2001). One study found that only 47.6% of 1005 GPs asked practicing throughout

the UK claimed that they had adequate training to effectively diagnose and manage dementia (Renshaw, Scurfield, Cloke & Orrell, 2001). Furthermore, in a study of three hundred Irish practitioners, 90% claimed that they had not received any training specific to dementia and 83% 'expressed a desire for this' (Cahill et al, 2006). Findings also indicate that GPs lack confidence when attempting to make a diagnosis of dementia (Cahill et al., 2006; Cahill et al., 2008; Turner et al., 2004), expressing uncertainty of the correct diagnosis and experience fear of misdiagnosing a patient (Cahill et al., 2008; Hout, Vernooji-Dassen, Bakker, Blom & Grol, 2000; Illife, Manthorpe & Eden, 2003; Phillips et al., 2012). This uncertainty partly reflects the difficulty faced when attempting to differentiate symptoms of dementia from symptoms of typical ageing (Cahill et al., 2006).

Furthermore, studies demonstrate that Practitioners exhibit minimal agreement on which screening instruments they should utilise during the diagnostic process (Illife, Manthorpe & Eden, 2003) and a large proportion of GP's claim that the diagnostic procedure that they follow differs from that of 'recommended practice' (Downs, Cook, Rae & Collins, 2000). One study found that only 43.9% of 1005 GPs asked use specific tests and protocols in the diagnostic procedure (Renshaw, Scurfield, Cloke & Orrell, 2001). Practitioners additionally express concerns over gaining the ethical consent necessary from the patient in order to conduct the appropriate assessments (Illife, Manthorpe & Eden, 2003). GPs also report feelings of embarrassment when conducting such assessments (Hout, Vernooji-Dassen, Bakker, Blom & Grol, 2000), asking very basic questions such as 'who is the queen'. Cognitive tests were also perceived to be threatening for patients by harshly exposing their cognitive ability (Woods, Moniz-Cook et al. 2003).

Research also indicates that even when a diagnosis has been confirmed, Practitioners have neither the time nor knowledge to refer patients and their caregivers to the appropriate support (Hinton, 2007). Poor GP knowledge of local support services has been frequently presented in the literature (Turner et al., 2004). In a recent study assessing GPs' awareness of local dementia support services, over two thirds (sample size of 137) were able to name day care services but less than half of the GP sample was able to identify memory clinics or caregiver support groups (Pentzek, Fuchs, Abholz & Wollny, 2011). It is therefore essential that improvements are made in the availability, accessibility and adequacy of support services. However, it is of equal importance that these improvements are met with increased GP awareness of appropriate support services available for dementia patients and caregivers.

Finally, a major barrier affecting GPs when attempting to make an early dementia diagnosis is their attitudes regarding the importance of an early diagnosis (Bradford, 2009). There is now a growing body of evidence documenting GP scepticism regarding the benefits of an early diagnosis (Bradford et al., 2009; Milne, 2000; Renshaw, Scurfield, Cloke & Orrell, 2001; Milne, Woolford, Mason & Hatzidimitriadou, 2010). It has therefore been suggested that GP attitudes may act as a barrier to receiving a diagnosis (Bradford et al., 2009). For example, a study of GP attitudes in East Kent presented findings that only 40% of participating GPs were positive in their attitudes concerning the benefits of an early diagnosis (Milne, 2000). This is not a unique finding as subsequent research investigating GP views found that just over 50% of GPs practicing throughout England and Wales believed an early diagnosis of dementia to be beneficial (Renshaw, Scurfield, Cloke & Orrell, 2001). Practitioner responses included 'dementia is untreatable so why diagnose?' and 'early

diagnosis will lead to wasteful plans and miseries'. In subsequent studies, GPs have argued that if the symptoms of dementia are not causing the patient problems, they should wait until the situation worsens (Illife & Wilcock, 2005). Practitioners claimed that in many cases they felt like they had no choice but to wait for things to deteriorate before they were able to effectively distinguish between normal ageing and dementia.

Further evidence of negative attitudes regarding dementia is provided by a study asking 182 Practitioners to rate their agreement to five dementia related statements using a magnitude estimate scale (Milne, Woolford, Mason & Hatzidimitriadou, 2000). One third of GP's asked disagreed that an early diagnosis of dementia held major benefits and one quarter of the sample did not believe that it was important to actively look for the early warning signs of dementia in older adults. Two thirds of GPs even believed that there are negative consequences associated with an early diagnosis. The study explored these views in further detail by examining the relationships between GP beliefs. Analysis revealed a positive correlation between actively looking for early warning signs of dementia and the belief that there are appropriate support services available. Practicing early diagnosis was also significantly correlated with the belief that failing to make an early diagnosis could lead to negative consequences. The perceptions presented by GPs were arguable partly reliant on their perceptions regarding the positive and negative consequences associated with a diagnosis.

Practitioners acknowledge multiple hazards associated with a diagnosis of dementia. A study investigating GP attitudes in East Kent found that roughly two-thirds of the sample of 182 GPs believed there to be negative consequences associated with an early diagnosis (Milne, Woolford & Hatzidimitriadou, 2000). Many GP's expressed concerns about giving



somebody a label of dementia (Illife, Manthorpe & Eden, 2003; Phillips et al., 2012), which could activate stigmatization and potentially affect the patients relationships with close friends and family (Illife, Manthorpe & Eden, 2003; Cahill et al., 2008). Additionally, GPs report concerns of the psychological impact that a diagnosis could have upon a patient, creating great anxiety and in severe cases leading to the onset of depressive symptoms (Illife, Manthorpe & Eden, 2003; Hansen, Hughes, Routley & Robinson, 2008; Milne, Woolford, Mason & Hatzidimitriadou, 2010). Furthermore, GPs express fears regarding the consequences of making an incorrect diagnosis, which could be extremely damaging to both the patient and family (Illife, Manthorpe & Eden, 2003). An early diagnosis may also raise expectations about long-term outcomes and the medical help which is available to patients (Milne, Woolford, Mason & Hatzidimitriadou, 2010).

Practitioners also exhibit significant scepticism regarding the efficacy of the dementia medications that are currently available to patients (Cahill et al., 2008; Hansen, Hughes, Routley & Robinson, 2008; Olafsdottir, Foldevi & Marcussion, 2001) with GPs expressing little agreement as to whether the anti-cholinesterase medications are more effective when used in the early treatment compared to the later stages of the disease (Illife, Manthorpe & Eden, 2003). Research showed that only 55% of 153 GPs asked believed that the available medications warrant an active search for patients with dementia (Olafsdottir, Foldevi & Marcusson, 2001). The most frequently listed reasons for providing drug treatments were if the patient were in the early stages of the disease and if the GP felt that the treatment had the potential to significantly affect the disease course. The main reasons cited by GPs for not providing drug treatments were occurrences where the patient or caregiver refused treatment, or when the GP believed that the disease had progressed too far to provide any significant benefit. Additional factors included the cost of medication,

side effects of medication and the perception that treatment could prolong a patient's poor quality of life (Olafsdottir, Foldevi & Marcusson, 2001).

Despite these perceived hazards associated with a diagnosis of dementia, Practitioners acknowledge that a diagnosis of dementia can bring many benefits. Practitioners claim that an early diagnosis can be beneficial as it may reduce patient anxiety and confusion regarding the cause of the problems and allows other medical causes to be ruled out (Wackerbarth & Johnson, 2002; Illife, Manthorpe & Eden, 2003; Milne, Woolford, Mason & Hatzidimitriadou, 2010). It also grants patients earlier access to medical treatments that are proposed to be most effective when taken in the early stages of the disease (Milne, Woolford, Mason & Hatzidimitriadou, 2010; Wackerbarth & Johnson, 2002). In addition, a diagnosis can provide patients and family members' access to the appropriate support services which can in turn reduce stress and delay admission to care (Milne, Woolford, Mason & Hatzidimitriadou, 2010).

GPs also believe that a diagnosis can provide many practical benefits, such as increased time to organise support and plan for the future (Illife, Manthorpe & Eden, 2003). This additional time allows for legal arrangements to be made in advance and grants patient and caregivers access to support services. Furthermore, it allows the patient and family the opportunity to come to terms with the diagnosis and by diagnosing early, it decreases likelihood of reaching a crisis point. A diagnosis could also provide patients and their family with detailed information so that they are able to anticipate future problems and formulate long-term plans (Milne, Woolford, Mason & Hatzidimitriadou, 2010).

### *1.2.1 Factors predicting variation in GP knowledge and attitudes of dementia*

Multiple attempts have been made to identify correlates and predictors of variation in GP knowledge and attitudes regarding dementia. However mixed results have been obtained and a clear consensus is yet to be established. Factors repeatedly presented include age of the GP (Fortinsky, Zlateva, Delaney & Kleppinger, 2009; Rubin, Glasser & Werckle, 1987), number of years in practice (Ahmad, 2010) and geographical location of practice (Bond et al., 2005; Cahill et al., 2008).

Several documented findings now exist within the literature suggesting that GP knowledge and attitudes regarding dementia diagnosis can be significantly affected by the age of the Practitioner (Fortinsky, Zlateva, Delaney & Keplinger, 2009; Kaduszkiewicz, Bachmann, & van den Bussche, 2008; Werner, 2007). Kaduszkiewicz (2008) and colleagues investigated whether attitudes regarding dementia differed between GPs and dementia specialists. Although no significant differences were identified between groups, the study did demonstrate that younger GPs were more positive regarding the need for an early diagnosis. This perhaps demonstrates a recent shift in attitudes in favour of an early diagnosis, and could potentially result from more recent training. Younger GPs have also been found to be more open and willing to use computer software to aid in the diagnosis and management of dementia patients (Fortinsky, Zlateva, Delaney & Keplinger, 2009). In addition to GP attitudes, knowledge of dementia has been found to vary with Practitioner age. Werner (2007) investigated dementia knowledge in a sample of 395 GPs practicing in Israel and found that older Practitioners demonstrated less knowledge of the symptoms typically associated with dementia. This is consistent with previous findings that older GPs perform worse when asked to recall causes of dementia, compared to younger GPs (Rubin,

Glasser & Werckle, 1987). However, the study conversely found that although older GPs demonstrated less specific dementia knowledge, they claimed to be more comfortable when making a diagnosis of dementia. This could result from older GPs having increased experience and familiarity with patients.

It is worth taking the time here to reflect on whether GP age directly affects GP attitudes and knowledge, as opposed to the number of years in practice and the time at which they received their medical training. Although one could dispute this theory, much of the evidence investigating variation in GP knowledge as a result from the number of years in training mimics the results described associated with age differences.

For example, a large sample of 1,011 GPs practicing across England were divided into two groups; those who graduated pre-1990 and post-1990. Each group was given a short dementia knowledge quiz and questionnaire concerning their attitudes towards early diagnosis. Analysis indicated that GPs graduating before 1990 exhibited greater pessimism about the importance of actively looking for the early signs of dementia and about the benefits of making an early diagnosis, in comparison with GPs graduating post-1990. The GPs who graduated pre-1990 also appeared significantly more likely to believe that dementia management could be a drain on resources with little positive outcome. However, confidence in diagnosing dementia, providing related advice and managing dementia related symptoms was significantly greater in those who graduated before 1990, perhaps reflecting their experience in managing patients with dementia.

However, the paradox in these findings is that the GPs who felt most confident at diagnosis and managing cases of dementia (pre-1990) were least convinced by the benefits and more likely to believe that dementia management is a drain on resources. This paradox

could result from changes in training post-1990. GPs graduating post-1990 were more positive about early diagnosis, perhaps reflecting their up to date knowledge of the new dementia medications. Therefore, that older GPs may benefit from additional training in the modern dementia treatments, to improve their attitudes towards the potential benefits of an early diagnosis and younger GPs on diagnostic procedures and management to improve comfort in making a diagnosis.

Finally, GP attitudes and practice has found to be significantly affected by geographical location, both within and across countries. This was illustrated by a multinational study investigating GP views regarding dementia screening across the UK, France, Spain, Germany and Italy (Bond *et al.*, 2005). Results showed that physicians practicing in Italy were twice as likely to support routine dementia screening for people aged sixty-five years and above compared to France, Germany and the UK. Research indicates that not only do GP views on dementia vary with location but so do medical prescriptions for dementia and referrals to support services (Fortinsky, Zlateva, Delaney & Kleppinger, 2009). When GPs practicing in Connecticut and Maine were asked to identify the main barriers they faced when diagnosing dementia similar barriers were reported, including lack of time during patient appointments, lack of support and lack of awareness of support services, but at different frequencies depending on the location of practice. Regarding the support services available for dementia patients and their family/ caregivers, significant differences were again observed between the numbers of referrals to home health agencies, adult day care programmes and support groups, again depending on location of practice. Furthermore, research has shown that GPs who practice in rural areas

experience greater difficulty when attempting to access diagnostic services compared to more urban areas (Cahill et al., 2008).

### *1.2.2 The evolution of GP views on dementia diagnosis*

It is clear that valid attempts have been made to improve dementia diagnosis in primary care, such as the Evidenced Based Interventions in Dementia trial (EVIDEM-ED trial, Iliffe et al., 2012), which was an educational intervention for GPs aimed at improving dementia diagnosis and practice. However, it is not so clear whether such educational interventions and increased awareness of dementia have led to a significant improvement in how GPs view the importance of an early diagnosis of dementia and the benefits that it can bring. To date, there has been minimal research addressing this point and examining how Practitioner views have evolved over time. There was, however, one study that compared attitudes towards the importance of an early diagnosis of dementia in GPs practicing in East Kent over a four-year period (1997-2001). This study appears to be relatively unique amongst the literature by comparing GP views over time in the same area and utilising identical testing stimuli. The study presented very promising findings, indicating an increase in positive attitudes towards an early diagnosis of dementia, an increase in positive views regarding the perceived benefits associated with an early diagnosis and an increase in the number of Practitioners reporting adequate support services. The findings from the study suggested that this shift in GP attitudes resulted from the introduction of new dementia medications (Milne, Hamilton-West & Hatzidimitriadou, 2010).

### *1.3 Service factors affecting an early diagnosis of dementia*

The second key set of barriers affecting an early diagnosis of dementia relates to service factors; these refer to the lack of resources within primary care settings (Bradford et al., 2009). Primary care is said to be underequipped to support the needs of patients and caregivers and unable to deliver the continuity of care necessary (Iliffe et al., 2003). The lack of GP time to fully assess an individual with dementia in a typical patient visit is commonly cited within the literature (Bradford, Kunik et al., 2009; Boise et al., 1999; Brodaty, Howarth, Mant & Kurrle, 1994; Cahill et al., 2008; Greenwood, Mackenzie, Habibi, Atkins & Jones, 2010; Hinton, Franz et al., 2007; Iliffe, Manthorpe & Eden, 2003; Olatsdottir, Foldevi & Marcusson, 2001; Turner, Iliffe et al., 2004; Milne, Woolford & Hatzidimitriadou, 2000). Although GPs in small practices may have a degree of flexibility over patient appointment scheduling, Practitioners in larger practices report very little control over appointments (Hinton 2007). Time limitations can be particularly problematic when trying to make a diagnosis of dementia because it is a lengthy process requiring longitudinal observation due to its complexity (Hansen, Hughes, Routley & Robinson, 2008). Longer examinations are also necessary as GP's frequently involve the caregivers in the assessment process in order to acquire details of the patient's history and aid in the decision making process for treatment plans (Hinton, 2007). In addition, it is reported that the increasing patient caseloads and associated paperwork further add to the time pressures experienced (Hinton, 2007). These time constraints pose potential threats to an early diagnosis as they can potentially impact the GPs ability to undertake thorough assessments and limit the time to discuss with patients and family the needs of the individuals and the support available for them.

Primary care is also said to lack the specialist support and communication necessary to aid practitioners throughout the diagnosis (van Hout, Vernooij-Dassen et al., 2000; Hinton et al., 2007; Teel, 2004). The literature documents repeated difficulties faced by GPs when attempting to access and communicate with medical specialists for supplementary help and support (Cahill et al., 2008; Hinton et al., 2007; Olafsdottir, Foldevi & Marcusson, 2001; Teel, 2004; Turner et al., 2004). When Practitioners suspect dementia, they will commonly refer the patient to Neurologists and Psychiatrists in order to confirm the diagnosis. However, evidence suggests that GPs experience limited availability of such specialists (Boise et al., 1999; van Hout, Vernooij-Dassen et al., 2000; Hinton, Franz et al., 2007; Teel, 2004). As a result, patients regularly become victim to long waiting lists for specialist medical help. Furthermore, when patients eventually do see a specialist, it has been noted that poor feedback is provided from the specialists for the GP to be able to further manage patient care (Hinton, 2007). Work by Olafsdottir and colleagues (2001) showed that only 43% of the 153 GPs asked were satisfied with the coordination between primary care and specialist services such as memory clinics. Practitioners express the need for an improvement in the adequacy and availability of specialist services and an increased contribution from specialists such as Social Workers and Psychiatrists (Milne, Woolford, Mason & Hatzidimitriadou, 2010).

Research indicates that practitioners also show disagreement as to whether dementia diagnosis and management should occur in primary care settings as opposed to secondary care. In a study of 127 GPs practicing in north London and central Scotland, a third of GPs believed that dementia is best diagnosed within specialist domains as opposed to primary care settings (Turner et al., 2004). A third of GPs also felt that managing



dementia in primary care was often more frustrating than rewarding. In addition, evidence suggests that some practitioners believe that primary care has very little to offer dementia patients as their referrals are often unhelpful and the patients' problems are mainly social in nature (Wolff, Woods & Reid, 1995; Renshaw, Scurfield, Cloke & Orrell, 2001).

In order to improve primary care and improve the suitability to diagnose and manage dementia GPs express the need for multidisciplinary teams to coordinate dementia care (Hinton et al., 2007). The research by Olafsdottir and colleagues (2001) showed that 43% of GPs felt that dementia care coordinators should be introduced in order to organize primary care, secondary care and post-diagnostic services for patients and their associated caregivers.

An additional service issue is the lack of routine dementia screening in primary care (Boise et al., 1999). It is argued that cognitive screening should be implemented into the routine care of older adults in order to detect dementia in the early stages, especially for individuals who are at high risk of developing the disease (Ashford et al., 2006). However, few studies have evaluated the effectiveness of implementing such a screening program within primary care settings. A study conducted in 2005 addressed this issue by investigating the feasibility and utility of implementing a dementia screening program for individuals over the age of 65 years attending primary care services in Indianapolis (Boustani et al., 2005). Of the 3,340 individuals who were screened, 13% screened positive for possible dementia but only 47% of these had dementia. Although the program was able to identify previously unidentified cases of dementia, introducing such a program faced many barriers. Such barriers related to the significant use of primary care resources, including the considerable cost, use of human resources and GP time. The authors concluded that

primary care services are currently unprepared for the introduction of dementia screening programs. Although the costs of establishing such a program may be high, the study highlighted that the economic costs are also significantly high when dementia patients remain undiagnosed. The debate remains controversial regarding the cost-effectiveness of dementia screening, however, it is argued that screening programs should only be introduced in to primary care services if they have the appropriate human resources and facilities for diagnosis and treatment (Brayne, Fox & Boustani, 2007).

The lack of accurate screening tools to detect dementia is an additional barrier which is commonly cited within the literature (Bond, Stave, Sganga, O'Connell & Stanley, 2005; Downs, Cook, Rae & Collins, 2000) along with the limited access to cognitive assessment tools (Hansen, 2004). As previously noted, in order to diagnose dementia, NICE guidelines ([www.guidance.nice.org.uk](http://www.guidance.nice.org.uk)) specify several standardised cognitive testing instruments for use including the Mini Mental State Examination (MMSE, Folstein et al., 1975), the 6-item Cognitive Impairment Test (6-CIT, Brooke & Bullock, 1999) and the General Practitioner Assessment of Cognition (GPCOG, Brodaty et al., 2002). However, it is argued that the use of screening assessments alone has insufficient specificity and sensitivity to establish a valid diagnosis of dementia (Boustani, 2005). Furthermore, the cognitive assessments utilised can often be extremely distressing for patients (Manthorpe et al., 2013). Patients can find the assessments particularly threatening as they can harshly expose their cognitive deficits (Woods, Moniz-Cook et al., 2003).

One of the most traditionally utilised cognitive screening tools for dementia used in general practice is the MMSE (Harvan & Cotter, 2006; Milne et al., 2008; Moorhouse, 2009; White et al., 2002). However, researchers have long argued that the MMSE is limited in its ability to detect dementia in the early stages of the disease (Lomholt & Jürgensen, 1998;

Wind et al., 1997). Studies have demonstrated that the assessment tool can seriously underestimate cognitive deficits in psychiatric populations (Faustman, Moses, & Csernansky, 1990) and produce considerably high false positive rates (White et al., 2002). This high false positive rate is believed to result from findings that lower scores on the MMSE are significantly associated with increased age and lower levels of education (Bassuk & Murphy, 2003). It is therefore argued that the MMSE is not the most effective assessment tool for use in primary care (Moorhouse, 2009). Instead, recent reviews of available cognitive assessment tools suggest the use of the General Practitioner Assessment of Cognition (GPCOG, Brodaty et al., 2002), the Mini-Cognitive Assessment Instrument (Mini-Cog, Borson, Scanlan, Brush, Vitaliano & Dokmak, 2000) and the Memory Impairment Screen (MIS, Buschke et al., 1999) for use in primary care settings. All three tests were found to offer a valuable alternative to the MMSE as they were simple to administer and minimally affected by age, gender and ethnicity (Milne et al., 2008).

The debate surrounding the cost-effectiveness of cholinesterase inhibitor medication for the treatment of dementia constitutes an additional service issue. It has long been questioned whether dementia medications are cost-effective. However, there is now a growing body of research which suggests that cholinesterase inhibitors do provide cost effective benefits for patients with mild to moderate dementia (Getsios, Blume, Ishak & Maclaine, 2010; Ikeda, Yamada & Ikegami, 2001; Jones, McCrone & Guihaume, 2004; Neumann et al., 1999; O'Brien et al., 1999; Trinh, Hoblyn, Mohanty & Yaffe, 2003). A longitudinal study found that over a ten year period, patients (with mild to moderate dementia) who were treated with donepezil reduced medical costs by an average of £2,300 per patient compared to untreated patients (Getsios, Blume, Ishak & Maclaine, 2010). This reduction in cost increased to £4,700 when unpaid caregiver time was taken into account.

Reduced costs were also present for patients with severe dementia; however, these costs were noticeably less (£1,600 reduction in healthcare cost and £3,750 reduction in societal costs). The evaluation of additional dementia medications such as memantine treatment significantly reduced medical costs, increased years of independence and delayed institutionalisation of the patient (François, Sintonen, Sulkava & Rive, 2004; Jones, McCrone & Guihaume, 2004). Despite the promising findings, additional research is necessary which provides controlled, longitudinal data to support these preliminary findings (Neumann et al., 1999; O'Brien et al., 1999). Furthermore, it is important to conduct research that compares the benefits between different dementia medications, investigates treatment use in terms of disease progression and evaluated the quality of beneficial outcomes systematically (Loverman et al., 2006).

A further service factor associated with dementia diagnosis relates to the availability and adequacy of local support services. Firstly, it is acknowledged that the cooperation between primary care and local community services is limited and in need of improvement in order to help patients through the transition (Olafsdottir, Foldevi & Marcusson, 2001). GPs indicate that it can be extremely difficult to access, organise and coordinate the appropriate community support services for patients and caregivers (Turner et al., 2004; Olafsdottir, Foldevi & Marcusson, 2001; Hout, Vernooji-Dassen, Bakker, Blom & Grol, 2000; Hinton et al., 2007). Olafsdottir and colleagues (2001) found that only 24% of GPs asked were happy with the degree of cooperation between themselves and community support services. Furthermore, GPs have expressed the opinion that local support services are underequipped to fully support the need of patients and their families (Iliffe & Wilcock, 2005; Iliffe, Manthorpe & Eden, 2003; Renshaw, Scurfield, Cloke & Orrell, 2001). These post diagnostic services can also be extremely difficult for patients and carers to access,

especially for those residing in rural locations (Szymczynska, Innes, Mason & Stark, 2011).

GPs stress the need for an increase in the number of services primarily aimed to support the needs of the caregivers (e.g. counselling services), (Milne, Woolford, Mason & Hatzidimitriadou, 2010).

#### *1.4 Patient and caregiver factors affecting an early diagnosis of dementia*

The third main category of barriers to an early diagnosis relates to patients and their associated caregivers. A common barrier to receiving a diagnosis of dementia is believed to be the delay between the onset of dementia symptoms and the recognition of a problem by the patient or family (Knopman, Donohue & Gutterman, 2000). One study contained evidence of reports of delays of up to 2.25-years from the point where caregivers first noticed the onset of symptoms to the formal recognition of a problem (Knopman, Donohue & Gutterman, 2000). A further time lag is then reported, occurring between the identification of the problem and the time when individuals actively seek medical help. This subsequent time lag has been recorded to be between 0.82 and 1.31-years. This is not a unique finding, as 30-month delays have also been recorded from symptom recognition to time of diagnosis (Boise, Morgan, Kaye & Camicioli, 1999). Although many factors may contribute to these delays in help seeking behaviours, one known factor is believed to be public awareness and understanding of dementia (Boise, Morgan, Kaye & Camicioli, 1999; Bradford et al., 2009; Katsuno, 2005; Knopman, Donohue & Gutterman, 2000).

Studies reveal that the general public often have significant gaps in their knowledge of dementia (McManus & Devine, 2011; Schelp et al, 2008). This is particularly important as research suggests that people who have better knowledge of dementia and the associated

symptoms are more likely to seek help in the early stages of the disease (Werner, 2003). In particular studies have shown that the public can exhibit poor awareness of the key symptoms, causes, treatment and long term outcomes of the disease (Arai, Arai & Zarit, 2008; Roberts & Connell, 2000; Steckenrider, 1993). The public also show great difficulty effectively distinguishing between normal aging and the symptoms of dementia (Corner & Bond, 2004; Werner, 2008), perhaps because the public still maintain perceptions that memory problems are a normal part of the ageing process (Corner & Bond, 2004; Werner 2004a). As a result, the symptoms of dementia are commonly ignored until a crisis point is reached (Corcoran, 2009; Iliffe, 1997).

Even when symptoms are finally recognised by patients, attempts are regularly made to cover up and deny the symptoms and diagnosis (Aminzadeh, Byszewski, Molnar & Eisner, 2007). This is consistent with the finding that the public frequently exhibit reluctance to seek medical help in cases of dementia (Boise, Morgan, Kaye & Camiciolo 1999; Hamilton-West, Milne, Chenery & Tilbrook, 2010; Rimmer et al, 2005; Schelp et al., 2008; Werner, 2003; Werner, 2008). Substantial time lags are recorded from the onset of dementia symptoms to the time of help seeking (Boise, Morgan, Kaye & Camicioli, 1999; Haley et al., 1992; Knopman, Donohue & Gutterman, 2000). It is reported that the majority of dementia patients only seek medical help when the dementia has developed in to the late stages where little can be done (Banerjee & Chan, 2008; Milne, 2000). This reluctance to seek help could be linked to the frequently noted stigma associated with dementia (Iliffe, Manthorpe & Eden, 2003; Mackenzie, 2006; Morgan, Semchuk, Stewart & D'Arcy, 2002; Vernooji-Dassen et al., 2005) and the finding that the general public can hold very negative perceptions of dementia (McManus & Devine, 2011).

Additionally, many studies report patients' refusal to undergo cognitive examinations (Hansen, Hughes, Routley & Robinson, 2008). A study of primary care patients showed that almost half of the patients who scored above threshold for cognitive impairment refused diagnostic evaluation. Patients were more likely to refuse examination if they were older or if they were unaware of the cognitive symptoms exhibited (Boustani et al., 2006). Patients expressed concerns regarding the loss of their current employment position, losing health insurance and their driving licence (Boustani et al., 2008).

#### *1.4.1 Public knowledge of dementia*

Whilst there is an abundance of research regarding the barriers to dementia diagnosis, little attention has been paid to the general public's knowledge of dementia (Werner, 2003). A basic knowledge of the signs and symptoms of dementia is essential in order to allow individuals to identify suspected cases of dementia in the early stages. If individuals lack this knowledge then the symptoms of dementia could be missed or ignored, therefore delaying and preventing an early diagnosis. Previous research investigating other diseases such as cancer has shown that knowledge of disease symptoms can aid an early diagnosis, therefore potentially improving the benefits of treatment (Yardley, Glover & Allen-Mersh, 2000). However, our knowledge regarding the way in which individuals think about dementia and react to dementia symptoms is limited. The few studies that have focused on this particular area are limited by their small and often non-representative sample sizes (Arai, Arai & Zarit, 2008). In addition, much of the research has been conducted by multinational countries, leading to large variability in the findings. It is therefore essential that further research is conducted in this area to identify the level of knowledge and awareness of dementia in the general public and determine what

educational health interventions are required to aid the early detection of dementia symptoms, promote early help seeking and to assist an early diagnosis.

Research suggests that there is variability in the general public's perception of what dementia actually is. The Northern Ireland Life and Times (NILT) found that a total of 94% of respondents identified dementia as a disease of the brain (McManus & Devine, 2011). However, 54% inaccurately claimed that dementia was a mental illness, 28% thought dementia was a natural part of ageing and 58% thought dementia was just another term for Alzheimer's disease. So although it is clear that some awareness of dementia is present, we can see from the results that there is a degree of confusion and variability in the public's knowledge and beliefs.

Previous research indicates that the general public do possess a degree of basic awareness of dementia. A US study measured public knowledge of dementia, including knowledge of symptoms, aetiology and misconceptions and found that the majority of participants scored moderately high on the easy/general index of the Alzheimer's disease Awareness Test (ADAT) (Steckenrider, 1993). The ADAT is a 17-item test, which assesses both general and complex understanding of dementia. An example of a general item includes asking whether memory loss is a primary symptom of AD. Complex items test more detailed and sophisticated knowledge such as whether older men are more likely to develop AD than older women. Results demonstrated that individuals exhibited a basic knowledge of the less scientific concepts surrounding dementia, many of which were believed to be publicized heavily by the media. However, very few participants were able to show understanding of the more complex issues including the disease aspects. Factors found to be associated with higher levels of dementia knowledge included increased age,



education, caregiver relationship with patient and knowing somebody who had suffered from dementia.

#### *1.4.2 Knowledge of the causes of dementia and at risk groups*

Although there may be a basic level of dementia awareness in the general public, it has been repeatedly found that gaps in dementia knowledge exist. As previously mentioned, these gaps tend to refer to the biomedical aspects of dementia, such as the causes of the disease (Steckenrider, 1993). A large-scale study conducted in Japan using 2500 participants evidenced poor public awareness of the biomedical causes of dementia (Arai, Arai & Zarit, 2008). For example, only 46% of the participant sample was able to correctly identify that some subtypes of dementia can be caused by cerebrovascular disease. Furthermore, only 10.6% believed that some types of dementia are hereditary and only 10.2% accurately identified that dementia could shorten a person's life expectancy. However, participants performed better when asked simpler, more general questions about dementia. In total, 70.4% of participants correctly identified that the risk of dementia increases with age and 73.2% correctly stated that dementia is a disease of the brain. These results support Steckenrider's (1993) prior finding that the public possesses a basic knowledge of dementia but lack specific knowledge on disease aspects.

Although this is an international study, inadequate knowledge of the biomedical causes of dementia has also been presented in a recent study conducted in Britain (Hudson, Pollux, Mistry & Hobson, 2012). Findings indicated that 75% of a sample of 312 participants residing in Lincolnshire lacked knowledge that hypertension or hypercholesterolemia could increase one's disposition to dementia. Again, evidence was found that the public lack awareness that AD can shorten a person's life expectancy as only 42.9% of the sample

correctly identified that after the onset of AD symptoms, the average life expectancy of the patient is approximately six to twelve-years.

However, an Australian study presented higher levels of awareness as 80% of a sample of 2,000 participants, aged eighteen years and over, accurately identified that old age, brain disease and strokes were causal factors of dementia (Low & Anstey, 2009). However, similar to previous research, only 34.4% were able to correctly identify heart disease as a risk factor. A more worrying finding was that a significant proportion of the sample falsely believed laziness (31.8%) and weakness of character (22.1%) to be causal factors of dementia. Not only do these results show the existence of gaps in knowledge regarding the causes and risk factors of developing dementia but they additionally show that the public hold inaccurate and negative perceptions of the disease. The study also found that over 70% of the participant sample believed that it was possible to reduce the risks of dementia. Frequently suggested activities included physical and mental exercise and healthy eating.

Research has additionally explored the general public's awareness of populations who may be particularly at risk of developing dementia. One study asked the members of the general public whether dementia only affects individuals who are aged sixty-years and over (Goddard, 2012). Encouragingly, 100% of respondents correctly identified that it was not just people who are over the age of sixty who are at risk of developing dementia. In addition, 92% of participants with previous contact of dementia and 87% without contact disagreed that everybody will develop Alzheimer's disease if they live long enough. When participants were tested on their beliefs about hereditary risk factors of dementia and asked

'if your mother gets Alzheimer's, would you definitely get Alzheimer's disease' 79% without contact and 69% with disagreed with the statement.

Although there is little research which addresses this point directly, the public belief that dementia could be hereditary is a consistent finding. The public hold misconceptions that dementia is genetic and believe that most cases of dementia are caused by hereditary factors (Roberts & Connell, 2000). Individuals believe that people are at higher risk of developing dementia if a family member also has the disease (Yeo, Horan, Jones & Pendleton, 2007). This false belief has been found to cause significant threat and worry within the general public, especially in females and individuals of a young age (Roberts & Connell, 2000). It is important that we address this misconception through health education in order to increase public awareness and reduce unnecessary fears.

#### *1.4.3 Identifying the symptoms of dementia*

In order to receive an early diagnosis, knowledge of dementia is crucial but it is also of great importance that individuals are able to accurately and efficiently identify the symptoms of dementia in the early stages of the disease. Individuals with higher levels of knowledge and awareness of AD symptoms have been found to be significantly more likely to seek medical help (Werner, 2003). However, research indicates that symptoms of dementia are repeatedly missed and ignored (Phillips et al., 2012). One suggested explanation for this is because people face great difficulty when attempting to distinguish between the symptoms of Alzheimer's disease and symptoms of normal ageing (Bond et al., 2005). This difficulty has frequently been cited in the literature for both members of the public and medical professionals (Iliffe & Wilcock, 2005; Knopman, Donohue & Guterman,

2000). The failure to distinguish between the two could be a partial consequence of the repeated finding that people perceive memory problems to be a natural and inevitable part of the ageing process (Corner & Bond, 2004; Werner, 2004a). Interviews with dementia patients have highlighted that patients also attribute memory problems to external factors such as physical complaints and overload (Werner, 2004a).

One factor affecting confidence in distinguishing dementia from normal ageing is believed to be previous contact with dementia patients. One study showed that 87% of participants with previous contact with dementia patients claimed to understand the difference between normal signs of ageing and symptoms of dementia compared to only 21% of participants without contact (Godard, 2012). The significantly higher percentage of people with previous contact of dementia patients is perhaps not surprising, as they would have received increased exposure and experience of the symptoms.

One study empirically assessed the public's ability to identify the symptoms of dementia by asking them to rate a list of fifteen symptoms using a likert scale, ranging from 'definitely not' a symptom of AD to 'definitely' a symptom of AD (Werner, 2003). The list of symptoms was comprised of eleven AD symptoms and four depressive and psychological disorder symptoms. Encouragingly, participants were able to accurately identify a large proportion of the correct AD symptoms. Examples of frequently selected AD symptoms included 'inability to remember simple words' (60.7%), 'having difficulties completing everyday tasks' (65.1%), 'having judgement problems' (62.4%) and 'having difficulty performing simple maths calculations' (62.3%). 'Inability to recognise the way home' was recorded to be the most frequently recognised symptom of AD (94.7%), whereas difficulty

remembering where personal items were (e.g. glasses and keys) was identified to be a symptom of AD in less than half of the participant sample (47.4%).

Although the study evidenced that members of the general public may be able to accurately identify common symptoms of AD, it simultaneously highlighted that the percentage of the public that are able to do this is not as high as one would hope. For example, memory loss is arguably the most common symptom of AD; however the two symptoms relating to memory loss (including difficulty remembering where personal items are kept and inability to remember the name of an actor or public figure) were selected as symptoms by less than 60% of the sample. Furthermore, a significant proportion of participants falsely rated numerous non-AD symptoms as AD symptoms, such as social isolation, sleep problems, stress and lack of appetite (selected by 40%, 34%, 37% and 33% of the sample respectively).

Further evidence that the public hold high levels of awareness regarding the cognitive symptoms of dementia comes from a Japanese study (Arai, Arai & Zarit, 2008). Again, a high majority of the participant sample correctly identified the correct dementia symptoms including 'reduction in cognitive abilities, including understanding, judgement and memory loss' (70.9%), 'become unable to perform familiar tasks' (97.3%) and 'become unable to recognise time, place and persons' (95.7%). The results did however support previous findings that the public possess limited knowledge regarding the more biological aspects surrounding the disease. For example, only 10.2% of the sample correctly identified that dementia can shorten life expectancy after onset and only 37.4% believed that some types of dementia are treatable.

The discussed studies are international so issues surrounding the transferability of results need to be highlighted. However, Hudson and Colleagues (2012) additionally found that members of the British public exhibit reasonably high levels of awareness regarding the cognitive symptoms associated with dementia. Over 80% of participants were able to correctly falsify that people with AD remember recent events better than things that happened in the past, indicating their awareness that it is typically short-term memory which is affected in dementia. Furthermore, over 80% of participants correctly identified that the statement 'if trouble with memory and confused thinking appears suddenly, it's likely to be due to AD' as false, thus showing that the majority of participants do not believe that AD has a sudden onset. However, only 56.8% of participants demonstrated knowledge of impaired ability to handle money and paying bills to be an early symptom of dementia.

The results from the discussed studies are relatively promising; however, some studies have presented significantly lower levels of public knowledge regarding the cognitive symptoms of dementia. For example, in a study from Brazil, only 41% of participants believed memory impairment to be a characteristic of dementia (Schelp et al., 2008). These differences are likely to result from the different methodologies utilised and regional differences in dementia knowledge. The study subsequently presented another very interesting finding. Participants were asked to identify the symptoms which they associate with normal ageing. In total, 56% listed behavioural and mood changes and 23.3% memory problems. Participants were then asked to complete the same task, but this time listing the symptoms that they associate with dementia. This time, 41% of participants listed memory and 32% listed behaviour problems as symptoms. Although we are able to detect variation in the percentage of participants listing memory impairment and behaviour/mood changes

in dementia and normal ageing, we are also able to see a great overlap. The observation that a significant proportion of participants would attribute the symptoms to both conditions further illustrates how people regularly confuse the symptoms and finds it difficult to differentiate dementia from normal ageing.

The literature also suggests that the public lack knowledge regarding the links between AD and depression. For example, Hudson and colleagues (2012) found that 52.5% of participants identified that symptoms of severe depression can be mistaken for AD and only 58.2% were aware that people with AD are prone to depression (Hudson, Pollux, Mistry & Hobson, 2012). Furthermore, the public lack awareness of the psychological and behavioural changes that are common in the disease. Studies show that as few as 32.9% of sample of 73 individuals were aware of behavioural changes in dementia (Schelp et al., 2008).

There are several factors to consider when reading the evidence presented regarding public knowledge of the symptoms of dementia. Firstly, the vast majority of studies concentrate solely on public knowledge on the symptoms of Alzheimer's disease as opposed to the additional subtypes of dementia such as vascular or frontal lobe. This is problematic because the different subtypes of dementia can present a considerably different array of symptoms. Although Alzheimer's disease represents the most common form of dementia it is also important to study public knowledge of the other dementia subtypes in order to understand how to develop interventions aimed at informing the public of common dementia symptoms to promote early help seeking.

#### *1.1.4 Public knowledge of treatments for dementia*

To date, there has been little research specifically investigating public perceptions regarding the efficacy of dementia medications. However, survey data suggests that members of the public do exhibit awareness that treatments are available. Evidencing this is the NILT Survey finding that 75% of respondents believe that pharmacological treatments are available for patients with dementia (McManus & Devine, 2011). Only a minority of respondents (6%) falsely believed that dementia could be cured by medications, thus indicating that the public hold relatively accurate perceptions of the limitations of dementia medications and are aware of the long term outcomes. This finding has been replicated in a recent British study, which indicated high levels of public awareness that AD cannot be cured (Hudson, Pollux, Mistry & Hobson, 2012). A large proportion of the British participants (76.8%) also demonstrated their knowledge that prescription drugs are not available that can prevent the onset of AD.

However, even though awareness of available treatments is high, the same cannot be said for public perceptions concerning the effectiveness of the available treatments. One study found that 30% of caregivers and 24% of the general public claimed that they did not believe the medications to be effective at reducing dementia symptoms. Conversely, despite this negative perception a high proportion of participants still believed that delaying medication could have adverse consequences as medications may harness the potential to delay the progress of the disease (Bond et al, 2005). The general public have also been shown to display a tendency to favour non-pharmacological therapies such as social engagement or attendance at support groups, compared to pharmacological medications. Werner (2003) claimed that this result was concerning because there appears to be a clear



divide between the favoured treatments of dementia by the general public and health professionals. A possible reason for this discrepancy was linked with the negative public perception of the harmful side effects of medications (Werner, 2004c). Werner (2004b) presented findings that over 70% of the public recommended engagement in a support group and engagement in social activities, compared to only 44.5% who recommended pharmacological treatment.

Public beliefs about medication efficacy are extremely important as they have been found to be highly associated with help seeking behaviours (Werner, 2004b). However, evidence suggests that members of the public claim that they are provided with insufficient information regarding the treatments and care options for dementia (Bond et al, 2005). It is therefore essential that developments are made in order to provide patients and carers with additional information and guidance on the treatments and care packages that are available for them. It is also important that advances in dementia medications are accompanied by research in to public understanding and awareness of these treatments (Werner, 2004b).

The way in which the general public perceive dementia patients, living with the disease and long-term outcomes is another extremely important area to research. The stigma associated with dementia has been frequently cited in the literature (Mackenzie, 2006; Morgan, Semchuk, Stewart & D'Arcy, 2002; Vernooji-Dassen et al, 2005). In a study investigating dementia stigma 1,560 French participants completed ten questions assessing perceptions of dementia. Shame, loss of self-esteem and fear of exclusion were highly reported. Stigmatization was found to be highest in participants who were health professionals but lowest in older people (aged seventy-five and over) (Piver et al., 2012).

This stigma has also been shown to be particularly prevalent in certain ethnic groups. For example, in a study of dementia knowledge in Korean immigrants, only 25.7% of a sample of two hundred and nine participants correctly identified that the statement 'AD is a form of insanity' was false (Lee, Lee & Diwan, 2010).

Research indicates that both positive and negative perceptions of dementia patients exist within the general public. Results from the NILT survey evidenced this point by presenting respondents with a list of words and asking them to select the most appropriate words to describe a patient with dementia (McManus & Devine, 2011). The most frequently selected words included confused (90%) frightened (62%) and lost (58%). Positive descriptive words were selected significantly less, for example happy (7%), gentle (6%), kind (4%) and fun (3%). Despite this finding, the general public report positive emotional reactions towards dementia patients, with compassion, concern and desire to help being listed as the most frequently reported emotions. However, a significant proportion of participants also experienced fear (32.8%), uneasiness (50%), embarrassment (23.5%) and discouragement (32%) (Werner & Davidson, 2004). Emotional reactions to dementia patients have been found to be affected by previous contact with dementia patients (Knesebeck, Angermeyer, Ludecke & Kofahl, 2013). People who have previous contact or who have cared for a dementia patient show less negative reactions such as fear and anger and instead react more pro-socially (such as pity, sympathy and desire to help). Individuals who exhibited negative reactions were more likely to disagree that dementia patients have a high quality of life, were less willing to care for a family member with dementia at home and showed higher levels of scepticism regarding the benefits of an early diagnosis.

Furthermore, the public exhibit fears and anxieties of developing dementia themselves, expressing concerns of losing independence, identity and dignity (Corner & Bond, 2004). They also experience fear of caring for a person with dementia. The national survey conducted by the Alzheimer's Association of 1,020 American adults found that almost half of the sample (49%) claimed to be equally afraid of taking care of a loved one with AD as they were of developing the condition themselves. Similarly, a total of 73% of respondents believed that you have to care for dementia patients as if they were your child and 34% said that it would be better for the dementia patient and their family if they were cared for in a residential unit or care home facility (McManus & Devine, 2011). In addition, 46% of respondents believed that when a person becomes diagnosed with dementia they are no longer treated like a human being. A total of 75% of respondents believed that once a person develops dementia, the person that you knew disappears and a further 27% would agree that when people have advanced dementia; their life is not worth living (McManus & Devine, 2011).

These results highlight that negative beliefs about dementia exist within the general public. It is therefore important to address this issue in order to encourage help seeking. Again, this should be targeted through educational health interventions that are aimed at highlighting the benefits of an early diagnosis, emphasizing the support and care services available to dementia patients and their family and reducing stigmatization.

Research indicates that the public exhibit openness to dementia screening (Wilker, Blendon & Benson, 2013). In total, 67% reported they are 'somewhat' or 'very likely' to undergo early medical assessments if it becomes available. Interest and willingness was higher in those who were worried about developing dementia, those who have an

immediate blood relative with AD and participants who have previously cared for a patient with AD. Older respondents were also found to be more open to receive early medical tests.

When individuals do experience concerns about developing the disease, research indicates that they commonly seek help from informal sources such as family members, friends and neighbours as opposed to formal help networks (Goddard, 2012). A study investigating possible predictors of seeking help from social and help networks, found that people were more likely to seek help if they had parents with AD, they were better informed of AD, they were more concerned about developing the disease and if other people had reported noticing changes in the patient's memory (Hodgson & Cutler, 2004). Furthermore, people were more likely to actively look for information sources if they had parents with AD, they had higher levels of education, they were female and they expressed stronger fears about developing the disease.

Looking forward, findings suggest that educational interventions should be aimed at preventing inaccurate illness representations and increasing dementia knowledge in order to avoid the misattribution of dementia symptoms to other causes (Hamilton-West, Milne, Chenery & Tilbrook, 2010; Hurt, Burns, Brown & Barrowclough, 2011) and preventing people from thinking that memory impairment is an inevitable part of aging (Werner, 2008).

There is now a growing body of evidence that documents members of the public reluctance to seek medical help in cases of dementia (Boise, Morgan, Kaye & Camiciolo 1999; Rimmer et al., 2005; Schelp et al., 2008; Werner, 2003; Werner, 2008; Hamilton-West, Milne, Chenery & Tilbrook, 2010). A study analysing views of the public, caregivers and Physicians across five European countries (including France, Italy, Poland, Germany and the UK) found an average delay of forty-seven-weeks from first recognising the symptoms to

consulting their GP (Bond et al., 2005). This delay in seeking help was reported to be of most concern in the UK, with an average of thirty-two-months compared to other European countries such as Germany who only had an average delay of only ten-months. The underlying factors associated with this delay have been identified as poor awareness of the symptoms of Alzheimer's disease, failure to recognise the severity of the symptoms and the misinterpretation that the symptoms were being elicited by other co-morbidities. There are also psychological factors that are believed to prevent people from seeking help, such as denial and fear. In total, over 50% of the general public asked strongly agreed that fear prevented people from consulting with GPs regarding Alzheimer's disease.

One study investigated help seeking behaviours in older adults who suffered from subjective memory complaints (SMC) and found that help seeking behaviours were not associated with degree of cognitive impairment, but were associated with personal beliefs about memory (Hurt, Burns, Brown & Barrowclough, 2012). It was found that the individuals who actively sought medical help believed that their memory complaint could be attributed to a medical cause and therefore could potentially be treated by medication. However, the older adults who did not seek help were more likely to believe that their memory complaint was being elicited by social factors and therefore were less likely to be treatable. This finding is in keeping with previous literature suggesting that people are more likely to seek medical help if they identify the symptoms as severe and view them as a permanent change, as opposed to a short term complaint (Hamilton-West, Milne, Chenery & Tilbrook, 2010). People are less likely to seek help if they attribute the observed symptoms to psychological issues such as depression. Beliefs regarding the outcomes of dementia also play a key role in help seeking because some people see little benefit of

seeking medical help because there is little that can be done and no available cure (Corner & Bond, 2004).

#### *1.4.5 Factors affecting public knowledge of dementia*

Not only is it important to investigate levels of dementia knowledge in the general public but it is also important to understand why this variability in knowledge occurs. For the purpose of this review it is important to consider the limitations to the transferability of findings from international studies which utilise ethnically diverse populations as there is substantial evidence to suggest that knowledge of AD varies considerably between ethnicities (Ayalon & Arean, 2004; Connell, Roberts & McLaughlin, 2007; Mahoney et al., 2005; Purandee, Luthra & Burns, 2007; Roberts et al., 2003). For example, research showed significantly different levels of dementia knowledge between South Asian and Caucasian older adults residing in Manchester (Purandare, Luthra, Swarbrick & Burns, 2007). Both groups' performance on the Dementia Knowledge Questionnaire (DKQ) was similar relating to questions about the aetiology and symptoms of dementia. However, south Asian participants performed significantly worse on questions regarding general knowledge, epidemiology, change in personality and the speech and reasoning deficits that are associated with dementia. These lower levels of dementia knowledge in the south Asian group is of particular importance as it highlights that levels of dementia knowledge can differ between ethnic groups, even within the same geographical location. It could also be indicative as to why only 3% of patients receiving cholinesterase inhibitor medication for Alzheimer's disease are from ethnic minorities (Purandare, Swarbrick, Fischer & Burns, 2006).

Significantly different levels of dementia general knowledge have been similarly documented between Whites and African American participants (Roberts et al., 2003) and between Black, Hispanic and White participants (Connell, Roberts & McLaughlin, 2007). Particularly striking evidence of ethnic variation in dementia knowledge came from a study of four ethnic groups of older adults recruited from primary care practices in San Francisco. Anglo, African American, Asian and Latino participants aged fifty-five years old and over were asked to complete a short survey consisting of seventeen true or false questions relating to Alzheimer's disease (Ayalon & Arean, 2004). Anglo participants exhibited a significantly greater knowledge of dementia in comparison to the other ethnic groups. However, it is important here to take a close look at the results of the study to really emphasize the problem of poor knowledge in dementia. When asked if Alzheimer's disease is contagious, only 46.7% of Asian and 48.6% of Latino participants were able to correctly identify the statement as false (compared with 84.3% Anglo). Only 16% of Asian and 24% of Latino participants believed that the statement 'Alzheimer's disease is a normal part of ageing, like gray hair or wrinkles' was false (compared with 65.5% of Anglo participants). This is a particularly worrying finding because if people believe dementia to be a natural part of ageing they may be less likely to seek help. With regard to the prognosis of dementia, only 16.7% of Asian and 37.8% of Latinos thought that Alzheimer's disease could be fatal (compared with 41.6% of Anglo participants). In addition, only 20% of Asian and 13.5% of Latino (compared with 71.8% Anglo) identified that it was incorrect that the majority of people that suffer from Alzheimer's disease live in institutions like asylums. These low levels of knowledge are likely to severely affect access to a diagnosis and subsequent support.

However, the findings of a recent study questioned previous evidence of ethnic differences in AD knowledge. The study compared AD knowledge and beliefs across white, Latino and black participants (Ayalon, 2013). Although significant differences in knowledge were observed on seven out of thirteen test items, only four items showed significant differences when age, gender, education and having a family member with AD were controlled for.

Age is an additional factor that has been reported to contribute to the variation in dementia knowledge in the general public. Increasing age has been found to be negatively correlated with dementia knowledge about the warning signs and symptoms of dementia (Werner, 2003) and perceptions of risk of developing dementia (Price, Price, Shanahan & Desmond, 1986; Werner, 2002). Not only do young and middle aged adults outperform older adults when tested on their knowledge of typical and atypical ageing, but they also exhibit significantly more stereotypical views of memory and cognitive decline in normal ageing (Hawley, Cherry, Su, Chui & Jazwinski, 2006). However, few studies to date have looked in detail at the important effect that age has on knowledge and attitudes towards dementia. This is therefore an important area for future research and one that will be addressed within this study. Level of education has also been repeatedly found to be positively correlated with knowledge, awareness and beliefs regarding dementia (Steckenrider, 1993) and fewer misconceptions about AD (Edwards, Cherry & Peterson, 2000). Throughout the following study the degree to which education influences dementia knowledge will be examined.



### *1.5 Present studies*

Despite the recent push for the early diagnosis of dementia, statistics indicate that only 48% of individuals living in England with dementia receive a formal diagnosis (Alzheimer's Society, 2014). This figure falls even lower within many areas of Yorkshire, including Hull (44.71%) and East Riding of Yorkshire (38.50%). Figures from 2011 (Alzheimer's Society, 2014) showed that when ranking the local health areas within the UK on their dementia diagnosis rates (1= highest UK ranking, 176=lowest UK ranking) Hull was ranked 175 and East Riding was ranked 110. Therefore, it is clear that measures need to be taken to increase these low diagnosis rates, especially considering that the incidence of dementia is estimated to double over the next forty years (Alzheimer's Society, 2013). In order for diagnosis rates to improve, it is important to understand the factors which are currently delaying a timely diagnosis. The previously literature suggests that GP factors, service factors and patient/caregiver factors all contribute to a delayed diagnosis (Bradford et al., 2009). However, it important to investigate these barriers faced in more detail to understand which are the most prominent factors currently being faced within the Yorkshire area and how the local health authorities can address these issues.

The present research therefore investigates the potential barriers to an early diagnosis of dementia within the Hull and surrounding East Riding of Yorkshire using two key approaches. Firstly, Study One utilises qualitative methods to conduct face-to-face interviews investigate GP attitudes regarding the importance of an early diagnosis and the barriers that they face when making a diagnosis. Study Two will then collect quantitative data examining perceptions and basic knowledge of dementia in the general public in order to identify potential factors which may delay help seeking, thus preventing an early diagnosis. Together, these studies will provide an insight in to the potential barriers to an

early diagnosis of dementia within the Yorkshire area, both before and after medical help is sought by patients. Findings can inform future interventions aimed at promoting early help seeking and improving both primary and secondary care dementia services.

### *1.6 Aims and rationale of Study One*

It is now commonly accepted within the literature that GP attitudes regarding the importance of an early diagnosis of dementia can act as a barrier in the diagnostic procedure (Bradford et al., 2009). Although previous research has investigated Practitioner views, gaps in the research still remain. To date, the literature is comprised of international studies (e.g. Bond et al., 2005; Olafsdottir, Foldevi & Marcusson, 2001), studies utilising a cross sectional sample of GPs from across the UK (Renshaw, Scurfield, Cloke & Orrell, 2001) and studies which have been conducted in specific areas such as Ireland (Cahill et al., 2006; 2008), east Kent (Milne, Hamilton-West & Hatzidimitriadou, 2005; Milne, Woolford, Mason & Hatzidimitriadou, 2000) and London (Iliffe & Wilcock, 2005). Although the research provide insightful findings, it is difficult to generalise the results as evidence suggests that GP views and practices are likely to vary significantly as a result of geographical location (Fortinsky, Zlateva, Delaney & Kleppinger, 2009). Further research is therefore necessary to understand the factors affecting GP perceptions of the value of a diagnosis and the barriers faced within the Yorkshire area.

A second key issue with the previous literature is that the vast majority of studies utilise postal surveys and questionnaires but few use face-to-face interviews, taking a true qualitative approach. The advantage of conducting interviews is to gain a much richer understanding of the experiences and perspectives of practitioners. The questions are open

ended rather than forced questions that may cause biased results. An additional key advantage of using interviews as opposed to surveys is that the questions can be revised throughout the interview process and additional questions can be added to ensure that GP perceptions and any issues raised are explored fully (Charmaz, 2014).

To address these issues, Study One explores GP attitudes towards dementia diagnosis within the Hull and surrounding East Yorkshire area. The first aim of the study is to determine GPs perceived value of a diagnosis and potential factors underlying these perceptions. The second aim is to identify the barriers faced by GPs when attempting to make a diagnosis and identify how these barriers could be addressed. The sample will be comprised of GPs practicing in Hull PCT and GPs practicing in East Riding of Yorkshire PCT. The study will therefore also compare the attitudes and perceptions between both areas in order to identify whether large differences exist which could contribute the variance in diagnostic rates between the two areas. Findings will inform future interventions to address these barriers, in an aid to improve dementia diagnostic rates in the local area. This research is particularly important if we are to prepare primary care services for the ever-increasing number of patients developing dementia.

## **Method**

Semi-structured interviews were conducted with GPs to investigate attitudes towards the importance of an early diagnosis of dementia and the factors that influence these views.

## 2.1 Participants

In total, eight GPs were recruited to complete the semi-structured interview. The sampling frame consisted of all licensed GP practicing in the Hull and East Riding PCT's as of September 2012. This list of practicing GPs was obtained via the NHS services website ([www.nhs.uk/Service-Search/GP](http://www.nhs.uk/Service-Search/GP)). Recruitment consisted of five phases where twenty GPs were randomly selected off of the register and sent a participant recruitment pack. There was an interval of two weeks between each recruitment phase until enough participants had consented to complete the study. Participants were recruited via postal invite, seeking their participation for the interview. Each postal recruitment pack included a cover letter, an information sheet and a response sheet. A follow up letter was mailed out four weeks after to non-respondents to encourage participation. In total recruitment packs were sent out to a total of one hundred GPs and a positive response rate of 8.82% was obtained. The sample was divided in to two equal sized groups of GPs practicing under Hull PCT and East Riding PCT. The demographic information for both participant groups is presented in Table 1. An independent samples t-test revealed that there were no significant differences between the ages of GPs in the Hull group ( $M = 42.5, SE = 4.63$ ) compared to the East Riding group ( $M = 48.0, SE = 3.92$ ),  $t(6) = .91, p = .4$ . Furthermore, there were no significant differences between the number of years in practice between the Hull ( $M = 13.25, SE = 4.44$ ) and East Riding group ( $M = 16.25, SE = 3.71$ ),  $t(6) = .52, p = .62$ . Gender was also split evenly across groups.

GPs were to be excluded from the study if they had previously participated in dementia research investigating attitudes towards diagnosis or if they had received specialised dementia training in the past. However no participants met these criteria. All

GPs provided informed consent to participate in the study and were aware that they were able to withdraw from the research at any time without any adverse consequences. They were also informed that, once transcribed, parts of their interview may be included in the final study report which would be used for scientific purposes only and would remain completely anonymous. Furthermore, any information provided within the interview which could potentially later identify the GP, was removed from the transcriptions. All participants were reminded that they could choose not to respond to specific questions if they felt uncomfortable providing an answer. Once the interview had been completed, GPs were fully debriefed on the aims of the research project. Ethical approval for this study was obtained from the Departmental Ethical Committee at the University of Hull.

Table 1

*Demographic information of GPs in the Hull and East Riding participant group.*

Participant	Age (years)	Gender	Years in practice	PCT
GP.01	40-49	Male	21-25	East Riding
GP.02	50-59	Female	11-15	East Riding
GP.03	50-59	Male	21-25	East Riding
GP.04	30-39	Female	6-10	East Riding
GP.05	40-49	Male	11-15	Hull
GP.06	30-39	Female	6-10	Hull
GP.07	50-59	Male	21-25	Hull
GP.08	30-39	Female	0-5	Hull

## *2.2 Materials*

The semi-structured interview was comprised of 23 open-ended questions (Appendix A). Seven of the questions were designed to gather basic procedural information regarding the diagnosis process followed in primary care; the remaining 16 questions explored GP perceptions regarding the value of an early diagnosis of dementia and the barriers that they face when making this diagnosis. These questions were based around four key topics including: (1) perceived importance of an early diagnosis, (2) barriers faced throughout the diagnostic procedure, (3) perceived effectiveness of pharmacological and non-pharmacological treatments, and (4) attitudes towards specialist services and support services for dementia patients and their caregivers. These topics were derived from key findings presented throughout the literature. A set of possible prompts were provided for questions that could be used by the researcher when participants needed encouragement to provide further information. However, these prompts were only used as a flexible guide for the researcher as opposed to a set structure to follow. Each interview was recorded with the use of a voice-recording device and later transcribed, with the use of QSR NVivo 8 computer assisted qualitative analysis software.

## *2.3 Procedure*

The face-to-face interviews took place in the GPs' practice or at the Centre for Health and Clinical Neuroscience at the University of Hull, at a time specified by the Practitioner. The interviews were conducted by the principle researcher on the project and lasted between 30-40 minutes. Before each interview, participants were asked to read the information sheet informing them of the study and were given the opportunity to ask any

questions and sign a consent form agreeing to take part in the study. Participants were also given the opportunity to read the questions on the interview before the official interview commenced. They were then required to sign a consent form explaining their rights as a participant. The researcher was sat opposite the GP, with the voice-recording device placed in the middle to maximise sound quality. Once the interview was complete the participants were fully debriefed on the aims and background to the study. Interviews were later transcribed on to Microsoft Word and edited to remove confidential information. All transcripts were then imported to NVivo 8 for analysis. The interviews were then analysed using grounded theory analysis techniques.

### *2.3.1 Background to grounded theory analysis*

Grounded theory is rooted in Sociology. The theory has been theoretically developed from Pragmatism and Symbolic Interactionism (Cobin & Strauss, 1990). The primary aim of grounded theory is to develop an explanatory theory of social processes which are observed in the environments in which they occur (Glasser & Strauss, 19967). The theory then allows a degree of predictability regarding the specific conditions which may be necessary to elicit particular experiences/feelings (Cobin & Stauss, 1990). It examines the “six C’s” of social processes that include the causes, conditions, consequences, contexts, contingencies and covariance’s (Strauss & Corbin, 1998).

Grounded theory is similar to other methods of qualitative analysis in that it utilizes the same sources, including interviews for example (Straus & Cobin, 1994). It can be used alongside or in support of quantitative research and to represent the perspectives of the participants studied. However, grounded theory places a very strong emphasis on the

development and emergence of a theory from the data and places an important emphasis on the verification of the theory, not only through follow up research, but via continuous verification conducted through the course of the study.

Qualitative analysis was used in the present study in order to gain a deeper level of understanding of GP attitudes. An advantage of using qualitative methods to study this area, is that it allows rich and exploratory data to be gathered. Open-ended questions were employed during the interviews, allowing participants to answer in their own words, as opposed to asking them to choose between fixed responses. Qualitative techniques allow us to gain the individual experiences of GPs and the difficulties that they face when attempting to make a diagnosis of dementia.

Grounded theory analysis was selected for this study as an effective method to qualitatively examine interview transcriptions. This method was selected for numerous reasons. Firstly, it allows for a theory to develop directly from the data using a constant comparison method and incorporates the full range of participant experiences. This is important for the present study to allow us to develop a theory regarding the influences underlying GP attitudes. Furthermore, grounded theory opposes testing theories from the literature. The researcher is advised to collect data prior to exploring pre-existing research in order to prevent old theories being imposed on to new data. This was considered a strong advantage as ensured that conclusions made were reliable, fit the data accurately and reflected GP views specific to this region. Finally, the explanatory theory produced can help to inform future interventions (Starks & Trinidad, 2007) which will be of great benefit when attempting to increase the local dementia diagnosis rates.

Grounded theory was also thought to be particularly appropriate for this study as one of its key principles is that phenomena is continuously changing and evolving (Corbin &



Strauss, 1990). Therefore, all developed theories should incorporate the process of change in to them. Theories developed by grounded theory analysis should identify how the studied population adapts to the changing environment. These principles are essential in order to understand GP views regarding the perceived importance of an early diagnosis. As new health policies and new treatment options are continuously being produced for dementia care and management, it is of vital importance that the developed theory captures the interaction between GP views and their evolving environment.

To further understand the basic principles of this theory, a brief history will now be presented along with the methodological guidelines used to analyse the data set. Glaser and Strauss (1967) developed grounded theory analysis in the 1960's. The sociologists both conducted research exploring dying in hospital environments. In particular, they studied when and how professionals and patients knew that they were dying and how they managed and dealt with the news (Charmaz, 2006). Whilst conducting their analysis, they developed methodological and systematic methods for studying the process of dying and other areas of social sciences.

Perhaps why grounded theory became so popular was due to its systematic approach to qualitative research. Their book *The Discovery of Grounded Theory* (Glaser & Straus, 1967) questioned previous beliefs that qualitative research was unsystematic and subjective. The book aimed to highlight the rationale and importance for developing theories that are grounded and use constant comparisons within the data through process of the study (Straus & Cobin, 1994). It also aimed to explain the logic and guidelines of using grounded theory and legitimize qualitative research.

Grounded theory is a methodology used for developing theory that is in data, systematically gathered and analysed (Straus & Cobin, 1994). An essential feature of

Grounded theory is comparative analysis, meaning that theories evolve by continuously comparing and analysing the data throughout the collection period (Straus, 1967). Since its introduction a number of guidelines and procedures have evolved to enhance the effectiveness of the methodology. Although originally developed for research in Sociology, grounded theory has been increasingly used in Psychology (Straus & Cobin, 1994).

### *2.3.2 Guidelines for using grounded theory*

For the purposes of this study, the grounded theory guidelines followed are taken from Charmaz (2006) in her book titled *Constructing Grounded Theory*. These were chosen as they provide a clear and systematic step-by-step guide of grounded theory analysis. They maintain the classic principles of grounded theory whilst also accommodating new developments of the theory.

During the coding phase, the researcher followed the guidelines presented in *Constructing Grounded Theory* (Charmaz, 2006). The following five key stages were utilized throughout the analysis process: 1) Initial coding, 2) Focused coding, 3) Axial coding, 3) Theoretical coding, 4) Memo writing, 5) Theoretical sampling, saturating and sorting.

Firstly, during initial coding, line-by-line coding was utilized. Line-by-line coding is particularly appropriate for the analysis of interviews and narrative data (Charmaz, 2008). Throughout this phase, each line of a participant interview is provided with a code defining and summarising what is happening in the text. See Appendix B for examples of line by line codes produced during this initial phase of analysis. This process forces the researcher to heavily interact with the data; engaging in close reading, questioning and comparison. This coding process occurs simultaneously to data collection. The codes search for potential

meanings behind the data and themes and processes are identified. The codes should additionally indicate the boundaries and conditions necessary for the process to occur. In vivo codes are also using during this phase which represent direct statements. These are useful in discovering meanings in the text. The researcher then must identify the most prominent codes and the ones that occur most regularly throughout the data. Charmaz (2006) describes coding as the crucial link between the collection of data and the emergence of a theory. The codes illustrate how data is sorted, selected and analytically accounted for. Charmaz described grounded theory coding as the bones of an analysis. The theoretical integration will then assemble the bones collected into a full skeleton of analysis.

Secondly, during focused coding, the researcher produces codes which are more selective and directive than codes produced by line-by-line coding (Glaser, 1978). See Appendix C for an example of the focused codes produced. The codes are then tested against the data by using them to sort through and organise large volumes of the data. These focused codes allowed the researcher to categorise the data analytically and systematically. By comparing the focused codes with the actual data, the focused codes are become well defined and developed. The researcher must then evaluate the focused codes produced to establish which codes best explain the data. The researcher looks for the codes that are said to carry 'analytic momentum' (Charmaz, 2006), meaning that they carry the weight of the analysis. The focused codes selected are then developed in to theoretical categories.

Thirdly, during axial coding categories were compared and connected to the emergent subcategories. Categories are compared to subcategories in order to identify the links between each one and to illustrate how the researcher has interpreted the data. This process allows the data to be restructured to give coherence to the emerging analysis.

During the initial phases of coding, the data becomes somewhat fragmented but axial coding allows the researcher to sort the data and bring it back to one coherent whole (Straus & Cobin, 1998). During axial coding the researcher asks questions such as why, where, when, who and how. The guidelines set by Strauss and Corbin were followed (1998) in an attempt to identify the conditions necessary for processes and events to occur, the actions that participants take and the subsequent consequences of these actions.

Theoretical coding then uses the codes identified by the researcher during focused coding. During this process, Glasser (1978) claimed that the researcher should explore how each code relates to each other and how they can be integrated in to a logical theory. It allows the researcher to paint a picture of how factors affect each other, providing a clearer understanding of causes, effects and relationships. It also allows for specific conditions to be determined which elicit a particular phenomenon. However, during this phase, the researcher remains objective trying not to force previous theoretical frameworks on the data. During this phase, the researcher avoids identifying topics instead of actions and processes, avoids coding out of process and avoids using codes to summarise rather than analyse the data.

Memo writing is then described as the vital step between data collection and drafting the report. In their book, Bryant and Charmaz (2007) said that “if data is the building blocks of the developing theory, memos are the mortar”. Memos allow the researcher to keep track of their thoughts and ideas about the data. During this process the researcher is advised to regularly take the time to stop and analyse their ideas about the codes that are emerging thorough the data. Thought should be particularly paid to the connections made between codes, your research questions and possible implications. The perceived benefits of this process are that it immerses the researcher in the data and

increases the level of abstraction about the ideas (Charmaz, 2006). When producing each memo, the researcher followed the memo writing guidelines listed in Charmaz 2008. These guidelines consisted of eight key instructions: 1) each memo to be given a title to allow for easy sorting and organisation; 2) memos should be produced throughout the research process; 3) each code should be clearly defined by properties presented within the data; 4) identify the conditions which are necessary in order for the code to emerge; 5) all codes and categories must be repeatedly compared and contrasted with other codes and categories; 6) when writing the memo, include the data from which it has been derived; 7) the consequences of the code or category need to be established; 8) the researcher should aim to identify any existing gaps presented in the data. See Appendix D for an example of a written memo produced during the analysis phase.

Finally, theoretical sampling is undertaken with the aim of developing any emergent categories. The properties of the categories should be identified during this phase and the researcher should aim to saturate the properties of each category. Theoretical sampling also allows the relationships between categories to be identified and explained. Variation within categories and gaps within that category should additionally be identified throughout this process. Theoretical sampling differs from other types of sampling methods as it does not sample data in order to address an initial research question. Instead, theoretical sampling allows the researcher to collect data which will help develop and define the categories that have emerged throughout data collections. The researcher is unable to know what concepts will need to be sampled before analysis of the data commences. In order to do this, the researcher gathers more information, which highlights and defines the boundaries and relevance of the emergent categories. Theoretical sampling has the advantage that weak categories can be identified and attended to. If categories are not clearly defined or the

relationships between them remain unclear the researcher can address this when collecting further data. If needed, the researcher may also return to previous participants for more information. This process also allows the researcher to empirically evaluate logical inferences regarding the relationships between categories.

Data collection was completed once theoretical saturation occurred. This refers to the point in time where theoretical sampling reveals no further information about the emerging themes (Charmaz, 2006). This does not simply mean that themes are consistently repeated throughout data collection. Instead, theoretical saturation refers to the stage when gathering new data fails to uncover any novel property or theoretical information regarding the identified theoretical categories.

## **Results**

Using grounded theory analysis five key theoretical categories emerged during the course of the interviews. These are presented in Table 2.

Table 2

*Key categories underlying GP perceptions regarding the importance of dementia diagnosis.*

Categories	Subcategories
Increased dementia awareness	Increased public awareness
	Increased GP awareness
Perceived importance of an early diagnosis	Hope of benefits
	Fear of hazards
Perceived value of available treatments	Pharmacological treatments
	Psychosocial and support services
Perceived barriers to diagnosis	GP limitations
	Service limitations
	Patient factors
Need for service improvement	Dissatisfaction with current service
	Views that the service could improve

*2.4.1 Increased dementia awareness*

The first key theme to emerge throughout the interviews was a significant increase in dementia awareness. Specifically, GPs noted a significant increase in the general public's awareness of dementia, which in turn had led to increased reporting and an increase in patient requests to be screened for dementia. This increase was evident from both patients and concerned friends and family members alike. GP.2 claimed that patients *"are becoming a bit more switched on"* and as a result primary care has witnessed *"a surge in the number of requests to be screened for dementia"*. Patients were said to be coming forward asking to be assessed for dementia, even after making minor memory errors such as forgetting their keys. GP.7 stated that *"they are just so terrified that they will present it"* where as they might not have before. GPs mostly viewed this increase in awareness in a positive light. Participants believed that people were seeking medical help at an earlier stage than before, meaning that GPs were able to identify dementia in the early stages of the disease. GP.7

stated that *“people are probably coming forward sooner than they would “and as a result “we possibly are catching people earlier”.*

There were several factors which emerged underlying this increase in awareness. Firstly, GPs claimed that there has been a dramatic increase in dementia related advertising and publicity. GPs expressed that this publicity was having positive effects as it was raising awareness and encouraging people to seek medical help at an early stage. Dementia charities in particular were listed as the driving force behind this publicity.

*“People are actually quite aware of dementia. There’s quite a lot of publicity out there for them and so people quite often say ‘I’m quite worried that I might have dementia’ which is encouraging when people self present to us” GP.1*

Secondly, GPs also believed that the increase in dementia awareness had resulted from the increase in treatment options. GPs were in agreement that the public have become more aware that there are potentially beneficial medications available and therefore patients are incentivised to seek help. The increase in treatment options also incentivised GPs to be more proactive about confirming a diagnosis in order to grant patients access to such treatments. It was noted by GP.1 that pharmaceutical companies may have additionally contributed to this increased awareness as they came very close to directly advertising their products to the public, even though they are not allowed to do by law.



*“Awareness has increased on the back of the introduction of medication that slows progress, so now we’ve got a treatment, whereas before there was no treatment, so there was no need to diagnose with no treatment” GP.6*

Although GPs felt that the increase in dementia awareness had led to positive outcomes, they also felt that it had resulted in numerous negative consequences. This was particularly evident with GP.7 who described her frustration to particular newspaper sources which, in her opinion, provided false impressions of the efficiency of dementia treatments and therefore unfairly raised patients’ hopes and expectations.

*“...that gives patients the impression that if they come forward they can get access to medications which will be highly beneficial and allow them to maintain a long standing independence. That’s a very false impression to give which unfairly raises expectations” GP.7*

*“...You know, someone cures dementia in a mouse and all of a sudden ‘there’s a cure for dementia’ and you just want to say we’re really not there yet you know” GP.7*

Additionally, although the increase in publicity had led to increased reports of suspected dementia cases, GPs voiced concerns that this was problematic for primary care service as they are not currently ready to facilitate the increased number of requests to be screened.

*“...there’s a lot of sort of talk in the media about this explosion of dementia patients. I think this explosion is already happening and I think we are not yet equipped for it”*

*GP.2*

GPs were aware that the situation was only likely to worsen, claiming that *“it’s going to be a bigger problem in the future”* (GP.2) as the dementia incidence rates increase. This increase was believed to be a partial result of the *“baby boom”* where a large number of people were born after the end of World War Two, meaning that the number of people developing dementia will increase dramatically over the next twenty years (GP.6). Another perceived reason for the increasing incidence of dementia was because people are generally living longer.

In addition, GPs also reported that they themselves had experienced an increase in their awareness of dementia. They claimed to be more aware of the available treatments and the importance of acting early when presented with cases of suspected dementia. However, although GPs felt that they needed to be more active in diagnosing dementia, they were unsure of the correct procedure to follow.

*“I think now there is greater awareness that we need to do something, even though at the moment it’s sort of, so ‘what do we do next’ like situation” GP.1*

#### *2.4.2 Perceived importance of an early diagnosis*

The second major theme to emerge throughout the interview process was GP perceptions regarding the value of an early diagnosis. It was clear throughout the

interviews that GPs showed firm agreement in the belief that *“there are pros and cons for early diagnosis”* and *“there’s barriers and there’s dangers”* which need to be considered when making a diagnosis. Generally, the participant sample was very positive about the value of an early diagnosis of dementia. However, this belief rested heavily on individuals’ perceptions of the effectiveness of dementia treatment.

Perceived benefits of a diagnosis fell in to three key categories, including GP service factors, patient factors and caregiver factors. GPs believe that a diagnosis is important as they felt it was their duty to make a diagnosis, claiming *“because there are treatments available then you have a duty to diagnose”* (GP.4). GPs also stated that a diagnosis was important as they claimed that *“we need to be open with people”* (GP. 1). GP.1 stated that every patient would say yes to being informed if a problem with their health was identified. From a health care service perspective an early diagnosis is also beneficial because it avoids acute admission to hospitals. He further added that by acting in advance, it is possible to relieve the pressures placed on secondary care by preventing patients from reaching a crisis point.

GPs stated that an early diagnosis was important for patients, firstly, to grant patients access to potentially beneficial medications. Multiple GPs believed that access to such medications has the potential to slow the rate of the disease progression and alleviate some of the symptoms experienced.

*“I think that, erm, if you have got any condition that is potentially treatable and it’s important and it’s going to affect people in a substantial way, then I think, yeah, it’s very important indeed” GP.1*

Secondly, GPs felt that a diagnosis is extremely valuable to patients as it provides many practical benefits such as time for future care planning, financial planning and conducting legal arrangements such as power of attorney. A benefit of diagnosing dementia in the early stages was that patients are able to make these practical arrangements whilst they still have the mental capacity to make informed decisions. These practical benefits associated with a diagnosis are heavily cited within the literature (Illife, Manthorpe & Eden, 2003; Milne, Woolford, Mason & Hatzidimitriadou, 2010). These benefits were strongly endorsed by participants and some claimed that these practical benefits even outweighed the benefits elicited by medication.

*“I think, more than the Aricept and everything else is so that people can sort out their advanced care, so they can get their power of attorney and things while there’s still little doubt whether they still have the capacity ... I think that’s not what the media’s all about but... probably more important than getting access to the drugs and things is making those decisions while you are still in a position to make those decisions”*

GP.7

Thirdly, an early diagnosis can also be beneficial for both patients and their caregivers, giving them time to come to terms with the diagnosis, gain closure and gain and understanding of what is causing the symptoms. GPs expressed that people can become frustrated when they do not know the cause of the problem and feel like health professionals are not taking their concerns seriously. This finding supports previous research that knowledge of the diagnosis is beneficial for reducing patient and caregiver

anxiety caused by uncertainty of the cause of the symptoms (Wackerbarth & Johnson, 2002; Illife, Manthorpe & Eden, 2003; Milne, Woolford, Mason & Hatzidimitriadou, 2010).

*“... I think it is important that the carers know because, erm, I think people can become very frustrated that nobody is taking any notice of what they are saying, and I think if you give somebody a diagnosis, even if it’s not a nice diagnosis, at least they feel that they have got some sort of closure. At least they know what’s going on now. People hate the unknown” GP.1*

GPs also believed that an early diagnosis was beneficial for the caregivers and family members of the patient. GPs acknowledged the strain placed upon caregivers and showed enthusiasm to support them in order to reduce negative outcomes such as stress and psychological burnout. GPs also showed concern regarding the health of the carers, believing that due to the strain of caring, they regularly neglect their own health. GP.7 stressed the need for future research which evaluated potential methods to improve the life of carers because it was said that *“the NHS rely on these people”* to provide care to patients before hospitalization. This can significantly cut costs for secondary care.

*“Carers too face a difficult time, which is why it is essential that we do what we can to help the patient so we can also relieve caregiver stress” GP.1*

*“dementia has a big knock on effect on carers and you find the health deteriorates”*  
GP.2

Although GPs saw many benefits of an early diagnosis, no GPs in the sample supported the introduction of blanket dementia screening for populations particularly at risk of developing dementia. GPs claimed that it would be too time-intensive and expensive. In addition, they failed to see the benefit of introducing such a system on the grounds that there is currently no adequate evidence to suggest that it would be advantageous. These negative attitudes towards blanket screening are not surprising given that there is currently little evidence in the literature supporting the introduction of dementia screening, due to the fact that primary care is currently under-equipped to facilitate such a program (Boustani et al., 2005).

However, GP.7 did suggest that it might be feasible to introduce dementia screening in to the current chronic disease management procedure. So for example you could introduce a tick box question "*are you suffering from any memory problems*" when people with chronic diseases attend routine appointments. It was also suggested that instead of blanket screening, GPs should be encouraged to be more proactive in actively looking for the early warning signs in patients particularly at risk. They should also be encouraged to take memory complaints more seriously as it was claimed, "*a lot of the time concerns just get dropped*" (GP.7). So although GPs were against blanket screening, the sample was open to ideas regarding the improvement of the current screening process.

As discussed the majority of the GP sample were extremely positive about the advantages of an early diagnosis. However, several major concerns were raised which questioned these benefits. For example, GP.7 claimed that there seems to be a big push for GPs to diagnose dementia in the early stages but felt there is "*a gap in the research showing the benefits of early diagnosis in terms of quality added life years*". They also stated "*I don't*

*think necessarily the treatment warrants the drive for an early diagnosis*". Instead they felt that the diagnosis was more beneficial in terms of the additional time to make important decisions while the patient still maintains the capacity to do so.

GPs also suggested that there are numerous hazards associated with the point at which the GP is required to disclose the diagnosis. One hazard listed was the psychological impact that a diagnosis can have upon a patient and their family. GPs believed that by disclosing a diagnosis of dementia, *"you just create worry"* and *"increase anxiety"* for your patients. GPs fear of patients' psychological reaction to a diagnosis is common in the literature as it can increase anxiety and risks leading to depression in severe cases (Illife, Manthorpe & Eden, 2003; Hansen, Hughes, Routley & Robinson, 2008; Milne, Woolford, Mason & Hatzidimitriadou, 2010). However, despite Practitioners' views, the research suggests that patients want to know their diagnosis and once the initial reaction has subsided, they are able to use coping mechanisms to adjust (Lee, Roen & Thornton, 2013). Patients report being happy to have received to the diagnosis as it helped them to understand the causes of their behaviour and helped them come to terms with their condition.

GP.2 expressed that it comes as *"such a blow to people"* and they fear giving the diagnosis as they claimed, *"some patients don't like to be diagnosed with dementia"*. Other GPs in the sample agreed with these claims and suggested that the disclosure of a diagnosis would particularly impact patients whose insight remains intact. In comparison, patients in the late stages of the disease are unlikely to remember that you told them the diagnosis at all. GP.1 added that a particular hazard of a diagnosis of dementia is that there is little hope associated with the disease in relation to the long-term outcomes. This issue was repeatedly voiced and GP.3 stated *"What you can do about it is in some ways minimal"*.

*“... a diagnosis can regularly be hazardous because a lot of the time, you know, it’s a terminal diagnosis, in the same way if you tell somebody that they’ve got cancer for example, at least cancer you have sort of got a hope that you might get better, whereas dementia is like, this is the path, ends up in a not very nice way, and to have to live with that sometimes for three or four years while you are still functioning, and live with that and know that that’s coming in not necessarily a good thing” GP.7*

The stigma and labelling of dementia was also commonly reported as a hazard of a diagnosis with GP.6 claiming that the *“positives [of diagnosis] are outweighed by the stigma of dementia”*. GP.5 added that the labelling of dementia could sometimes be unhelpful as it can lead to patient denial of treatment. Previous research indicates that dementia stigma can significantly affect the patients’ relationships with friends and family (Illife, Manthorpe & Eden, 2003; Cahill et al, 2008) and caregivers of the patient can also experience significant stigmatization (Werner, Goldstein & Buchblinder, 2010).

Another potential hazard of a diagnosis is the lack of adequate support for the patient and family throughout the process. When asked how beneficial an early diagnosis of dementia is, GP.5 stated *“it’s really a question of how much support goes with it”*. It was repeatedly voiced by many GPs that a diagnosis could be unbeneficial if it is not accompanied by the adequate care and support.

*“There seems to be a big push for it (diagnosis) but my concern is, once you’ve made all the diagnosis, is there more care and support because without the social care and support it’s a bit of a waste of time” GP.4*



GP.8 voiced *“if [a diagnosis] benefits the patients...we are able to offer more support to them, that’s fine but... at the moment we are struggling to even support the patients who are newly diagnosed”*. They described the system as *“oversaturated”* as increasing amounts of patients were now being diagnosed but the overwhelming fear was clearly stated *“we can’t just diagnose it and then leave it”*.

The interviews did however highlight that GPs views were slowly evolving towards a positive view of early diagnosis. This shift in attitudes was commonly linked to the increase in treatment options available for dementia. This is consistent with previous research suggesting that GP attitudes are becoming more positive regarding the value of an early diagnosis (Milne, Hamilton-West & Hatzidimitriadou, 2010). The study showed that positive GP views resulted from the availability of potentially beneficial treatment options. This is consistent with the findings of the current study.

*“GPs approach to dementia is certainly evolving. I think that, erm, I think before it was thought of as a condition that you couldn’t do much about and therefore there wasn’t much point of diagnosing it”* GP.4

A second factor underlying the gradual shift in GP attitudes was the reduced costs of dementia medications. Commonly prescribed dementia medications such as Aricept have recently come off their patent, meaning that other drug companies now have permission to produce these drugs in bulk, causing the price of such treatments to decrease dramatically. GP.1 claimed *“It’s not going to cost hundreds of thousands of pounds to treat them anymore”*.

*“...it’s absolutely plummeted to the floor, and that might actually make a difference to peoples medication because it used to be about fifty or sixty pounds a month to prescribe but it’s now about a pound a month to prescribe” GP.1*

Another reason for the shift in GP attitudes was thought to result from the introduction of new financial incentives. The Quality and Outcomes Framework (QOF) was introduced in 2004 as part of a new voluntary contract for GPs. Its aim was to improve primary care services by rewarding Practitioners for good practice. The QOF illustrates the quality of service at each surgery using a points system ([www.nice.org.uk](http://www.nice.org.uk)). These points are then exchanged for financial rewards. So for example, GPs are able to earn QOF points for 1) establishing and maintaining a register of patients diagnosed with dementia, 2) reviewing care through face to face appointments within twelve months of receiving a diagnosis, and 3) completing a patient blood screen within six months of being placed on to the practices dementia register ([www.nhsemployers.org](http://www.nhsemployers.org)). Although many GPs claimed that the QOF system was a great incentive to improve dementia management in primary care, some GPs did not show complete agreement with the system.

*“...even though I don’t terribly approve of the financial incentives for doing things in general practice, I do think that the emphasis on dementia for quality points, will actually make people more aware of it, even if it is just for financial reasons. It’s a carrot that will probably work” GP.1*

Finally, GPs claimed that they are now less reluctant to refer suspected cases of dementia on to the consultant. GP.8 explained that in previous years she showed hesitation

referring patients whose performance was borderline on cognitive assessments. However, she claimed that consultants were now increasingly supportive to GPs and encouraged them to refer every patient that they suspect.

#### *2.4.3 Perceived value of available treatments*

Another major theme to emerge was the perceived efficacy of treatments for dementia, including both pharmacological and non-pharmacological treatment options. This largely determined GPs' perceptions of the value of an early diagnosis. GPs exhibited significant uncertainty regarding the efficiency of available medications and were uncertain of the long-term effects and potential side effects. This was partly because they were unaware of the evidence supporting the newer medications available and because the quantity of patients going on to such treatments is still relatively low. GPs did however exhibit the desire and interest to learn more about these treatments and the potential benefits.

GP's perceptions of the effectiveness of dementia medications were seemingly complex. Many GPs shared the belief that medication provides the potential to slow down the progression of the disease and believed that patients who receive treatment do not seem to deteriorate as rapidly as those who do not. However, some GPs noted that medication could often be more effective for some patients compared to others. It was clear that medications are limited in that they cannot improve the patient's condition and certainly cannot provide a cure. Treatment was however, viewed to provide an additional benefit of aiding behavioural management in particular, especially for patients who are becoming violent towards the people around them.

Although a large proportion of the sample believed in the benefits of medication, when asked if they believed pharmacological treatments to be effective, two GPs in particular exhibited significant scepticism.

*“I haven’t really seen an increase in the number of people staying at the coping stage of dementia because of medication though. I certainly haven’t seen anyone improve. It’s something that we can offer but I don’t think it’s a huge benefit” GP.7*

*“I don’t think that’s effective at all basically. We do tend to have patients who come back and say it’s not doing any good at all and... you know, it’s not going to cure it or anything. There might be a delay but it will take a long time so it’s quite difficult for patients to appreciate that kind of change” GP.8*

With regard to the stage at which patients should be given medications, GPs were in firm agreement that patients who were in the late stages of the disease were unlikely to benefit from treatment because the disease had progressed too far. The majority of the sample was also in agreement that dementia medications were more effective the earlier they were administered in the disease course. However, a minority of the participants were unconvinced that the effectiveness of medications warranted the drive for an early diagnosis. This is not a unique finding as previous qualitative research has also documented poor agreement that medication is more effective when administered in the early stages (Iliffe, Manthorpe & Eden, 2003).

*“I think that treatments help delay it, but ... I’m not sure if you start them really early if it would delay that progress significantly at the beginning” GP.4*

Not only did GPs attitudes regarding the effectiveness of medications affect the perceived value of a diagnosis but so did the effectiveness of non-pharmacological treatments. Psychosocial treatments were highly valued by GPs, even though some argued that we were lacking the facilities for such treatments. Psychosocial treatments were respected and valued in terms of their efficiency, especially when used in the later stages of the disease. Benefits of such treatments included improved quality of life, improving memory in the early stages of the disease and preventing patients and caregivers from reaching a crisis point. They were also believed to provide a useful information service and provide people with important advice on practical matters such as legal arrangements.

*“I think that psychosocial treatments are of vital importance... I think that in terms of medicine you are really very limited in what you can do. They may be very helpful in terms of improving memory, especially in the early stages but also they are about quality of life for people and for families. So, having support, meeting other people in the situation, I think those things really contribute and make a difference to people”.*

GP.3

One GP, who was particularly enthusiastic about the benefits of psychosocial treatments, stated that they were also beneficial for addressing the more behavioural issues associated with dementia. They explained that there is a pressure from residential homes to “sedate the problem away” when patients do exhibit such behaviours (GP.7). However,

psychosocial treatments offer an alternative to sedation as they have the potential to reduce or alleviate the behavioural symptoms without the use of medication.

Psychosocial treatments were not only recognised as beneficial for patients but they were also believed to be greatly beneficial for carers and family members.

*“I think having access to someone to talk to is very helpful for the relatives and having somewhere where they can go and explain how hard it is to live with someone with dementia, who doesn’t know who you are. I think that is very, very helpful” GP.7*

The common view, however, was that although psychosocial treatments were extremely beneficial, there is a clear shortage of them and the services in which they offer. Cognitive stimulation therapy was one example given that was believed to improve long-term outcomes but was unavailable in the area. GPs claimed that the services available are largely dependent on location. GP.6 claimed that *“there is a great divide between Hull and East Riding”*, mainly because *“Hull has got vast amounts of money and Clinical Psychologists and they’ve got a vast range of services”*. In comparison, services within East Riding were described as very limited. GP 6 further added that *“it’s a postcode lottery”* regarding the services available to patients. The GP was also reluctant to refer across PCT boundaries for fear of causing problems. Although it was noted that the Alzheimer’s Society offers many services such as memory cafes, it was stated, *“there’s very little in the way of psychological support in East Riding”*. This view is supported by previous literature showing that post-diagnostic services are significantly more limited in more rural locations (Szymczynska,

Innes, Mason & Stark, 2011). Patients and carers can also be more reluctant to attend such services due to travel difficulties.

GPs noted that they lacked awareness of the available support groups in the local area. Although they expressed a desire for this knowledge, they claimed that they had not got the time to check and it was not their responsibility. Instead referrals to support groups were said to be the duty of social workers. This is consistent with previous literature that found that GP awareness of local dementia services was relatively limited with less than 50% of GPs being able to name patient support groups (Pentzek, Fuch, Abholz & Wollny, 2011).

A further problem voiced by GP.7 was that there *“there isn’t much that’s actually fun”* for the patient. The GP acknowledged that the support services still provided a break for carers but was concerned that it didn’t provide many benefits for the patient. As a result GPs claimed that patients were often reluctant to use these services, even though the carers wanted them too. Additionally, GP.5 said that although dementia charities were proactive in increasing services *“it doesn’t seem very much if it’s only an hour or two every week”*. GP.2 suggested that these services should be made more accessible to patients particularly in the later stages of the disease. A qualitative study examining patient perceptions of dementia services similarly highlight the limitations of such services, also stating that there is a clear need for age appropriate services to attract younger patients who are reluctant to use them (Beattie, Daker-White, Gilliard & Means, 2004).

It was also suggested that more home-based services should be introduced, such as having someone visit the patient at home, even if it was just for a chat. The perceived benefit of this was to potentially reduce loneliness and decrease the risks of the patient developing depression, which could significantly worsen the situation. GP.2 stated that

there is currently a nursing service offering home care in the local area to both patients and carers. They claimed that it was very effective as the nurses regularly detected if a patient or carer's health was deteriorating significantly. But again this service is oversubscribed. GP.7 also claimed that research in to the effectiveness of intensive support programs is needed.

*"I would like to see research about what can improve the life of carers of people with dementia because that is a thing that people rely on quite a lot. Like the NHS rely on these people. If there was actually evidence showing intensive carer support or intensive home support was beneficial and saves money in terms of delays residential care and was actually supported, I think that would be more beneficial than things like Aricept" GP.7*

#### 2.4.4 Perceived barriers to diagnosis

The majority of the GP sample was in agreement that they were confident in their ability to make a diagnosis of dementia. GPs made claims such as *"I feel confident in making a diagnosis of memory impairment"*, *"I know what I would do and I think I know what my role is expected to be"*, and *"dementia, if it's there, is fairly obvious"* (GP.2). This is contradictory to previous findings suggesting that GPs lack confidence when attempting to diagnose dementia (Cahill et al., 2006; Cahill et al., 2008; Turner et al., 2004). Early warning signs that GPs looked for in normal patient visits included confusion, forgotten appointments, complying with regular medication and reports of roaming. However, GP.1 in particular did express a lack of confidence when attempting to diagnose dementia.



“It’s a lack of fundamental knowledge to make a confident diagnosis and know how to differentiate it between other things”. GP.1

However, despite this confidence exhibited by the majority of the participant sample, key issues emerged throughout the interviews which acted as barriers to an early diagnosis. These included fear of misdiagnosis, difficulties differentiating dementia from other conditions, conflict during the diagnostic process and problems regarding cognitive testing.

Firstly, the fear of misdiagnosing a patient was an issue voiced by each participant in the sample. Research has repeatedly shown that such fears can frequently lead to missed or delayed diagnosis (Iliffe, Manthorpe & Eden, 2003; Iliffe & Wilcock, 2005, Milne, Woolford, Mason & Hatzidimitriadou, 2000). GP fears includes failing to diagnose a patient and informing someone that you suspect that they might have dementia when in fact they do not, but have scored poorly on the test. Participants feared that making a misdiagnosis could result in the failure to diagnose a treatable condition. GPs described cases where they had made misdiagnosis and were worried about the consequences that it had upon the patient. For example, GP.4 described a case where they had suspected that a patient may have dementia so they referred them on to a dementia consultant for additional assessments. However, the consultant concluded that the problems experienced by the patient were likely to result from normal ageing. The GP expressed fears that they had *“created a lot of anxiety in the patient, unnecessarily”*.

*“GPs are very wary, because although consultants say this is dementia or not, the patient is with the GP for life, and we have to pick up the pieces if we say it’s this and it turns out not to be” GP.6*

GPs also found making a diagnosis difficult when they were required to differentiate dementia from other conditions. It was repeatedly noted that GPs found it especially difficult to differentiate between dementia and normal ageing, particularly in the early stages of the disease. GP.8 claimed that it is particularly tricky to differentiate age related memory problems from dementia. They gave the example of the older adult patients who they regularly visit in nursing homes. Although they can complete their daily activities satisfactory, there are certain times when their capabilities vary and the only thing you are able to do is monitor them over time to determine whether these problems are age related or point to early stage dementia.

It was also said to be difficult when patients experienced psychological conditions such as depression, which commonly elicit memory problems. Additionally, GPs stated that depression and dementia often coexist, which can make cases particularly complex to diagnose. GPs were often in agreement that in cases of uncertainty they would trial out a course of antidepressants to determine whether the patient’s condition improved or not. In order to help GPs differentiate dementia from other conditions, Practitioners focused on factors such as pattern of impairment, degree of progression and pre-existing conditions.

GPs claimed that an additional barrier to dementia diagnosis is the repeated conflict throughout the process, which challenged GP confidence and knowledge of what actions to take next. It was explained that many patients fail to recognise their symptoms and exhibit both lack of insight and denial. Denial is commonly identified in dementia causing many

barriers to diagnosis (Teel, 2004). Denial was found to be a root of three key problems, including help seeking, assessments and medication use. GP.3 stated that patients “*are certainly not going to take tablets if they think there is nothing the matter with them*”. GP.2 stated that an additional problem is that “*it’s quite hard to try to convince patients to go for the assessment*” (GP.2) and counselling them in to doing so was reported to be quite tricky (GP.8)

*“I think the main barriers are often the individual attitudes themselves, whether there is an element of denial... whether their ready to accept there is a problem”* GP.5

Further conflict can arise between the patient and caregivers. This can be particularly problematic when patients are not aware that they have a problem and have been made to come in by a family member. GP.5 said that patients can often feel “*tricked*” in these cases by their family. It can also cause conflict when the family of the patient contacts the GP privately to ask if they will assess the patient, but then the GP is placed in to a difficult position as they are asked not to inform the patient of who has reported them and why. GP.4 said that they feared “*landing the person in it*” who has consulted them in concern for their family member.

GP.1 reported that “*patients are less cooperative than the carers*” throughout the diagnosis process. This was thought to be a result of the patient’s lack of insight. It was also suggested that carers are more proactive “*because the burden tends to fall on them*” to ensure the patient’s case is managed adequately. During these cases of denial, GPs lack the confidence and knowledge of how to move the case forward.

A further area of conflict was the withdrawal of anti dementia medications. This tended to occur between the GP and the family of the patient. GPs described cases where patients were on the medication long-term and they were no longer observing any significant effect. Family members were however extremely against withdrawing medication as it removed any hope of the patient's condition ever improving and they feared that the condition would only worsen if they were to come off the treatment.

*"What we find difficult is quite often people remain on medication long term, where our impression is that it's not really doing much good anymore and that ideally they shouldn't be on it, but that step to remove it is hard. Medication is started with great hope and expectation so it can be quite difficult. You can be in the situation where people say well I really don't want that to be stopped because what if things get worse again and so you can get a bit stuck with people remaining on treatment long term" GP.3*

*"We often end up in the situation where ... patients are on the drugs which aren't making a huge amount of difference but there is a very strong relative pressure not to withdraw it. That's usually the issues that we face. Even in the terminal decline stages of dementia, erm, you are saying 'look, it's obvious it's not helping' but relatives say 'no, they need to stay on it'. That's what we tend to get more of an issue with. The relatives pin an awful lot of hope on the medication" GP.7*

An overwhelming barrier in the diagnostic process was cognitive screening for dementia. A repeated issue was uncertainty regarding the appropriate screening tools to

utilise during the diagnosis process. Not only did GPs express an uncertainty of which tests to use but also a lack of ready access to tests, leading GPs to rely on Internet searches to access them. Furthermore, GPs expressed that they receive very little feedback from secondary care to inform them whether they have used the necessary screening tools. GPs tended to repeatedly use tests that they were familiar with. The most commonly reported test used was the MMSE, despite their knowledge of the test's failures. Other tests used included the GPCOG (Brodaty *et al.*, 2002) and the Addenbrooke's Cognitive Examination (Mathuranath, Nestor, Berrios, Rakowicz & Hodges, 2000). The choice of test was often reliant on what they had been taught to use throughout their medical training. GP.2 also voiced that they felt undertrained to administer such tests in the appropriate manner. This led one GP to state that it was "*the blind leading the blind*". GPs expressed a need for clarity regarding the adequate tests to use and better assess to screening tools in primary care.

*"... It's simply GPs not being aware enough of what screening tool to use. There's just no clarity. If they simply said use the GPCOG and here is the printed out copy for you, that's it. Instead I just Google it or cut it out of Wikipedia" GP.1*

*"I have no idea whether they are the correct ones but they came up most popular on a Google search" GP.1*

*"...when I said hands up what screening tool do you use, everybody used a different one. It's almost comic in effect" GP.1*

Another issue was the concern that the screening tools lack sensitivity and therefore fail to detect cognitive impairment in high-functioning patients. Not only can this delay the chances of an early diagnosis but also leaves the GP unsure of what procedure they should follow next. GP.6 claimed that patients have to score very poorly before they meet the criteria for cognitive impairment. One particular case where this issue is evident is where patients are highly intelligent and therefore perform well on the tests even when they are in the early stages of the disease. These results are reflective of previous studies not only illustrating a lack of effective assessment tools but also a lack of clear guidelines to support the GP (Boise, Camicioli, Morgan, Rose & Congleton, 1999; Downs, Cook, Rae & Collins, 2000).

GPs highlighted that patients often lacked the ability to complete the tests and express their true cognitive ability. GP.5 claimed, *“stress and anxiety itself can influence performance”* on the tests, therefore cognitive testing may not be an accurate reflection of the patient’s ability. Patients were said to experience anxiety and embarrassment when they are unable to answer simple questions and looked to other people to answer it for them. Furthermore, GP.2 found cognitive tests particularly problematic when patients suffered from physical conditions, which affect their ability to complete the written parts of the cognitive examinations. For example patients who have suffered from a stroke or have arthritis in their hand may find this particularly problematic and the tests do not accommodate for such issues. It was also noted that *“some patients can’t understand the instructions”* of the tests which can add to the confusion.

Perhaps the most prominent barriers identified throughout the interview process were service limitations. This consisted of three key limitations including lack of GP time, unsatisfactory waiting lists to see dementia consultants and lack of GP training. Time

appeared to be the most commonly listed limitation affecting GPs ability to diagnose and manage cases of dementia. This issue was reported by all GPs in the sample and is heavily supported by the previous literature (Boise et al., 1999; Cahill et al, 2008; Hinton et al, 2007; Greenwood, Mackenzie, Habibi, Atkins & Jones, 2010; Hansen, Hughes, Routley & Robinson, 2008; Hout, Vernooji-Dassen, Bakker, Blom & Grol, 2000; Turner et al, 2004; Milne, Woolford & Hatzidimitriadou, 2000). Lack of time significantly affected GP ability to conduct thorough cognitive examinations. This in turn influenced which screening tool the GP would utilise during patient assessments. One GP felt that the Addenbrooke's cognitive examination was the most accurate and sensitive screening tool to detect dementia, but they were deterred from using it in primary care, as it is too time intensive (GP.2). The GP therefore used the MMSE, even though they were unsatisfied with the tests sensitivity. GPs voiced the need for the development of shorter screening tools.

*“Once you pick up any diagnosis that requires any form of monitoring or investigation, you then have to put the time in ... and time is what we are shortest of in general practice” GP.1*

Diagnosing dementia was described as a lengthy process which was difficult to fit in to a normal patient visit (Bradford et al., 2009; Boise et al., 1999; Hinton et al., 2007). GP.5 argued that there are shortcuts that you can take during the diagnosis process, including the use of shorter cognitive screening tools. However, they were reluctant to take such shortcuts as they preferred to use the MMSE in order to gain a full measure of patient cognitive ability which also allowed an accurate baseline measure to be attained which GPs can employ throughout the course of the disease to monitor cognitive decline.

*“quite simply it’s a lack of time... it’s not like sticking a stethoscope on a chest and saying yeah there’s a murmur or checking a pulse and saying yes you are regular”*

GP.1

To address these time constraints a common suggestion was to train other health care professionals to administer the tests. The most common suggestion was that practice nurses should be trained to administer cognitive tests to relieve the pressure placed on Practitioners.

The second service limitation was the lack of GP training. This finding is repeatedly identified throughout the literature (Cahill et al, 2008; Greenwood et al., 2010; Iliffe & Wilcock, 2005; Renshaw, Scurfield, Cloke & Orrell, 2001). GP.4 claimed that they had received limited dementia training during their time in medical school. Although he received educational input on the biological aspects of dementia, very little training was given regarding dementia itself and how to manage it. Furthermore, multiple GPs claimed that they had received very little training regarding the treatments of dementia. GPs all expressed a desire for additional dementia related information and training, further supporting previous findings that GPs desired dementia related training. It was suggested that they should receive *“refresher training or maybe focused training like the protected time of learning”* that they receive each week (GP.2). However, GPs stated that the limited refresher training they had received was extremely beneficial. GP.1 claimed that there is a limited amount of teaching in terms of regular meetings and update meeting for GPs, but generally ones that are commonly sponsored by pharmaceutical companies *“often have their own slant on it”*. GPs also expressed a desire for more information detailing the



current dementia services available in the area because the GPs felt that they had little time to search for these services themselves.

Despite this apparent lack of training, GP.1 claimed that they are overloaded with information that is sent through the post. However, due to time constraints they fail to get the time to get through it, providing no benefit. GP.1 suggested that a potential solution to this problem would be to integrate all information into one website which was regularly updated with new treatments and guidelines.

*“Instead of having one hundred/two hundred websites each for different conditions, you could actually coordinate them all through one channel”* GP.1

The third service limitation identified was the current length of waiting lists to see a dementia consultant. When asked to identify the main barrier to diagnosing dementia, GP.2 responded, *“the main barrier is the barrier for quick referral and quick assessment”*. This seemed to be echoed throughout the majority of the GP sample.

*“I would say referral times are the biggest barrier to diagnosis then...waiting to be seen by the clinician and having to wait to initiate management is a big problem”*  
(GP.8)

It was claimed that secondary care was *“struggling under the weight of referrals”* and as a result it has become *“an overloaded service that you cannot access”* (GP.2). GP responses did however significantly differ when asked to estimate the average time it takes

to be referred to a consultant. Some GPs claimed that the waiting list was four to six weeks; whereas GP.8 said that patients can be waiting up to six months. The long waiting lists can sometimes result in patients feeling like they have no option but to pay for private health care (GP.2). The GP claimed that this is *“really disheartening when you’ve got a lot of media coverage encouraging people to come in”* and seek medical help. However, it is interesting to note that one GP in the sample (GP.4) disagreed with the sample at whole, expressing no concerns with the length of the current waiting lists. The reasons underlying this difference of opinion were not established so future research may benefit from collecting quantitative data from a large sample of GPs investigating Practitioner views regarding waiting lists more thoroughly.

*“I think it’s not that long a wait. I think a couple of month’s maybe and neurology up to three months. It doesn’t seem too excessive compared to some of the other waits for things”* (GP. 4)

The waiting lists were also said to be problematic after the GP tells a patient that they suspect that they have dementia and then they are left with no support for months until they can go for further diagnostic assessment. The patient is therefore left extremely anxious and unsupported. GPs were in agreement that the current waiting lists are unsatisfactory.

GP.3 noted that long waiting lists are particularly problematic when you are relying on a patient with a possible memory deficit to remember when their appointment is. The GP claimed, *“the chances of them forgetting their appointment is quite high”* so then

patients end up back on the very end of a long waiting list. The reason for the difference in waiting time was dependent on where the GP referred the patient to and in which primary care trust this was in. GPs in East Riding tended to report lower waiting times compared to GPs who referred people to the memory clinics under the Hull PCT.

#### *2.4.5 Need for service improvement*

GPs expressed the opinion that they were not satisfied with the service offered in primary care for dementia. GP.1 said *“I think most of us would say hand on heart would say the service is inadequate... both within primary and secondary care services”*. Multiple GPs suggested that one way to improve the service is through *“very close coordination between primary and secondary care services”*. GP.5 added that information should be shared more effectively between the two. It is also important that communication is improved to allow GPs to better manage patients’ cases after they have received their diagnosis.

Furthermore, GP.2 described the necessity of addressing the current *“bottleneck”* described when referring patients for further specialist assessments. GPs expressed that they wanted to offer their patients a quicker system, which is currently unavailable. GPs also wanted to be better informed of support services available for patients and caregivers in the local area because due to time constraints they were unable to keep updated with current service options.

In order for primary care services to be improved GPs also wanted clearer information and more accessible procedures, to follow during the diagnostic process. GP.1 stated, *“it’s a total lack of a clear and systematic pathway which tells you where to go next”*. Although the GP admitted that there *“are probably some excellent guidelines available”* it

was claimed that they do not have the time to find them. Differences were however identified between the resources available at individual practices. GP.8 explained that their surgery uses a specific dementia template, which comprises a set of tick box questions and advice to direct GPs directing the GP on exactly what procedure he or she should follow. However, it was clear that other surgeries lacked such resources that could be of extreme benefit. Surgeries could therefore develop such guidelines for their own practice or guidelines could be shared within each PCT to allow for consistency across the board.

Finally, GPs indicated that they felt under a significant amount of pressure due to the NHS's increasing expectations and demands placed upon GPs. In order for GPs to become more proactive in dementia diagnosis, they claimed that they needed to feel better supported. They also claimed that there is a significant lack of resources in primary care and these *"resources are getting less rather than more"*. Therefore if the system is to be improved GPs need to feel better supported and be allocated adequate resources such as time, improved dementia guidelines and easier access to specialist dementia consultants. A suggested method to relieve some of the pressure placed on GPs was to train practice nurses to take on the responsibility of conducting the cognitive assessments for dementia. It was also suggested that each practice could employ a trained professional to run a frequent clinic based at the surgery so GPs could channel their patients through them. This was thought to be extremely beneficial as it may reduce patient reluctance to agree to further assessments. GP.2 claimed that they used a similar idea with practice based counselling and patients were extremely happy with the service and to go somewhere familiar.

*“Primary care is expected to absorb everything really, without necessarily the resource to go with it... I think it’s just an expectation that GPs and support staff will do even more, in the same amount of time and it’s not going to happen” GP.5*

## **Discussion**

The present study was the first of its kind to qualitatively examine GP attitudes towards dementia diagnosis and management within the Yorkshire area. The majority of research in this field employs quantitative techniques, predominantly consisting of survey data (Cahill et al., 2008; Milne, Hamilton-West & Hatzidimitriadou, 2005; Oloafsdottir, Foldevi & Marcusson, 2001; Renshaw, Scurfield, Cloke & Orrell, 2001). However, such techniques are limited in their ability to gain a deep insight in to Practitioners true perceptions of the inadequacies and problems faced within the system. The findings from this study therefore provide a deeper explanation of the difficulties experienced when attempting to diagnose dementia in primary care. It also offers a range of methods, suggested by GPs, which could be implemented in order to improve the service currently offered to dementia patients.

The first key finding to emerge throughout the interview process was the increase in dementia awareness from the perspective of practitioners and members of the general public. GPs felt that they were under increasing pressure to diagnose and refer patients with suspected dementia to memory clinics as early in the disease stages as possible.

Practitioners also felt that members of the public were becoming increasingly fearful of dementia as a result of the increased publicity. As a result they were reporting to their GP unnecessarily after any small incident of a slip in memory e.g. misplaced personal items such

as keys. However, on whole, the increase in awareness was seen in a positive light as it increased the probability of an early diagnosis.

The second key finding to emerge from the interviews was that practitioners, on whole, exhibited considerable positivity regarding the necessity to diagnose dementia in the early stages of the disease. This perception was underpinned by feelings that it was their duty as a GP to confirm the diagnosis and a view that patients and their family members have a right to be informed. The three key benefits of a diagnosis that drove practitioner positivity included access to pharmacological treatment, access to psychosocial treatment and community support services, and time to make practical decisions while the patient still maintains the capacity to do so.

It also became very evident that GP views were slowly evolving to become more positive regarding the benefits an early diagnosis can elicit. This was consistent with Milne's (2005) finding that GPs are becoming more committed to diagnosing dementia in the early stages. The study concluded that this shift in attitudes was due to better accessibility of specialists, improved services and the stronger emphasis placed on the value of early diagnosis. The present study, however, suggests that the recent improvement in attitudes results from the new medical incentives offered by the QOF and the dramatic reduction in dementia medication costs. As Milne's (2005) results compares attitudes from 2001-2004, it is perhaps not surprising that factors influencing GP views have changed. It does however suggest that if dementia services continued to improve, so would GP attitudes. This is of particular importance in this study, as GPs expressed significant dissatisfaction with the local services specialist and community support services available for dementia patients. Therefore, one way of improving the views of GPs in the area could be to focus on the

improvement of services which can better support the needs of the patient and their family post diagnosis.

Furthermore, throughout the interviews it emerged that although GPs were now more incentivised to prescribe medications in the early disease stages, this shift in views had not resulted from the belief that medications are more effective the earlier that they are taken. GPs expressed a desire for research, which could inform them of the effectiveness of treatment, particularly regarding the long-term outcomes of treatment and what disease stage medications are most effective. Firstly, this suggests that GPs could be better informed of the previous research indicating the effectiveness of dementia medications (Birks, Melzer & Beppu, 1999; Wilcock, Lilienfeld & Gaens, 2000). Secondly, it supports repeated claims in the literature that additional research is needed to determine the quality of treatment outcomes, compare the efficiency of different medications and determine the long-term outcomes of treatment (Loverman et al., 2006).

Despite the increased positivity exhibited by Practitioners, two factors emerged through the course of the interviews which were repeatedly found to underlie GP attitudes regarding the benefits of an early diagnosis. The first factor was the lack of availability of specialist and community support services. GPs feared that although diagnosing patients was important, there is currently a significant lack of care and support to accompany the increasing rates of diagnosed patients. Therefore without this support, GPs were sceptical of the value of a diagnosis, claiming that it can be a waste of time. They described instances where they had referred patients on to specialists but were concerned that they 1) are faced with long waiting lists, 2) may forget about the appointment and then return to the back of the waiting list, 3) receive no support whilst waiting to be seen. GPs expressed

significant concern of the psychological impact that a diagnosis may have upon the patient and the stigma associated with gaining a label of dementia.

The second factor underlying GP attitudes towards the benefits of an early diagnosis was the perceived efficiency of pharmacological interventions. Although the majority of practitioners believed that medication helped to slow down the progression of the disease and alleviate the symptoms experienced, some GPs demonstrated significant hesitation about treatment options. Firstly, it was stated that drug treatments are only effective on a proportion of patients. Furthermore, GPs were unsure whether prescribing medication to patients in the very early disease stages had any real benefits compared to later in the disease course. Although there was a degree of variation in Practitioner attitudes concerning the benefits of early diagnosis, all GPs in the sample exhibited a dedicated commitment to their duty to diagnose patients as early as possible. However, many barriers are experienced throughout the diagnosis process despite their efforts.

Mirroring previous research, the participant sample felt that they were faced with many barriers when attempting to make an early diagnosis. Firstly, GPs claimed to have a lack of training specific to dementia (Greenwood et al., 2010; Iliffe & Wilcock, 2005, Renshaw, Scurfield, Cloke & Orrell, 2001) and insufficient time within a normal patient visit to fully assess a patient with dementia (Boise et al., 1999; Hinton et al., 2007; Greenwood et al., 2010; Turner et al, 2004). They also claimed that when investigating an individual's cognitive capacity, the current assessment tools (namely the MMSE) were too time intensive and lacked sensitivity. Practitioners wanted better clarification on the recommended tests to be utilised and wanted clearer guidelines to direct them through the diagnosis process. Some GPs were even forced to rely on internet searches to identify and download popular assessment tools and to interpret patient's results.



Practitioners also experienced other previously reported barriers including fear of misdiagnosing a patient (Cahill et al., 2008; Hout et al., 2000; Phillips et al., 2012) and difficulties differentiating dementia from normal ageing (Cahill et al., 2006; Cahill et al., 2008). Conflict also emerged to be a very large barrier faced at several stages during the diagnostic process. For example, GPs reinstated previous claims that patients frequently exhibit both denial and decreased insight of cognitive ability that can prevent them from help seeking (Teel, 2004), agreeing to further assessments (Hansen, Hughes, Routley & Robinson, 2008) and agreeing to take medication. Furthermore, once patients are placed on medication, additional conflict arises when attempting to withdraw treatment when it is no longer beneficial.

In review of the current diagnostic services offered to patients, Practitioners were in firm agreement that the service is inadequate. The sample, therefore, put forward three suggested methods of improvement including 1) improved GP training, 2) improved specialist and community support services, 3) Improved cognitive screening procedures. Firstly, in support of previous findings (Cahill et al., 2008; Greenwood et al., 2010; Iliffe & Wilcock, 2005), Practitioners claimed to have insufficient training specific to dementia and expressed a desire for improved dementia guidelines and regular refresher training. The topics that GPs particularly required more information on included the efficiency of new dementia treatments, the long term outcomes of pharmacological treatment and the recommended cognitive screening tests to be utilised. There is now growing evidence to suggest that educational interventions for Practitioners may provide significant benefits. For example, Downs and colleagues (2006) evaluated the benefits of a GP training intervention that employed electronic tutorials, decision support software and educational workshops. Both decision support software and educational workshops improved

Practitioners detection of dementia. The finding that decision support software was beneficial is particularly relevant to our finding that GPs claiming to have dementia templates guiding them through the diagnosis procedure were particularly confident when making a diagnosis. Conversely, GPs in the sample who claimed to lack confidence in diagnosing suspected cases of dementia also claimed to have a lack of systematic guidelines to support them.

Secondly, Practitioners wanted to see a dramatic improvement in availability of specialist and community support services. In particular, many stressed the need for the introduction of local home-based support services for patients. Such services are not only beneficial for patients, but home based services have also been found to relieve caregiver stress and aid in the management of patients daily behavioural problems (Corcoran & Gitlin, 1992). Practitioners were also in the agreement that the quality of patient support services was in need of improvement because patients regularly refuse to attend (Brodaty, Thomson, Thompson & Fine, 2005).

However, it is also important to note that although GPs have been said to be the ones responsible for making referrals to specialist and support services (Downs, 1996), our research supported previous findings that GPs exhibit limited awareness of available support services (Fortinsky, 1998). Therefore, future educational interventions for GPs should inform them of the local services for patients or provide easy to access materials that detail all available support that the patient is eligible for. In accordance with previous research, (Hinton et al., 2007), GPs suggested the need for multidisciplinary teams and better coordination between primary and secondary care services. Few studies have evaluated the benefits of implementing multidisciplinary teams but the small scale studies

which have presented positive results. For example, when a partnership program was developed between primary care and a dementia community support service, both GPs and caregivers reported better patient management and high satisfaction with the partnership (Fortinsky, Unson & Garcia, 2002).

Finally, GPs suggested that improvements in the cognitive screening of suspected dementia patients were needed. The sample repeatedly suggested that practice nurses could be trained to administer dementia assessments in order to relieve the pressures placed upon Practitioners. Dennis and colleagues (1998) evaluated this idea by asking community psychiatric nurses to administer semi-structural interviews on patients referred to Leicester University Memory Clinic. By comparing nurse reports with the official diagnosis made by the clinic, results indicated that nurses can be trained to accurately identify cases of dementia. A more recent study conducted in Manchester similarly documented nurses ability to accurately identify patients with cognitive impairment (Page, Hope, Bee & Burns, 2008). Findings from the present study also suggest that dementia screening could be implemented in to the primary care's Chronic Disease Management, where patients with serious conditions such as heart disease and stroke are regularly monitored. Practitioners suggested that some of these populations may be particularly at risk of developing dementia and it would therefore be beneficial when monitoring such patients to include a memory check with appointments as standard.

As a final note, it is important to address variability in the views expressed by the sample of GPs. Both GPs practicing in Hull PCT and East Riding of Yorkshire PCT showed strong agreement in their attitudes towards key themes such as the value of an early diagnosis, the effectiveness of available treatment options, adequacy of patient support

services and common barriers to diagnosis experienced within primary care. This is perhaps not a surprising finding as the dementia diagnosis rates observed in Hull (44.71%) and East Riding (38.50%) are relatively similar. However, one area where GP views did diverge slightly related to the availability and adequacy of local services currently available for patients. Although both groups felt that the availability of such services could be improved, GPs practicing in East Riding PCT appeared to experience greater difficulty in accessing such services. For example, GPs in Hull claimed that referral times to see dementia consultants ranged from six to eight weeks compared to GPs in East Riding who described cases where patients were required to wait three to four months for further assessment. Furthermore, GPs in East Riding claimed that they had very limited access to psychosocial and support services and felt disadvantaged at what appeared to be a postcode lottery for patients. These findings are not surprising as previous research documents greater difficulty accessing post diagnostic in rural areas (Cahill et al., 2008; Szymczynska, Innes, Mason & Stark, 2011).

### *2.5.1 Limitations and directions for future research*

Before discussing the implications of the present study, we will first examine the limitations of our analysis. Firstly, the aim of the study was to investigate the attitudes of GPs towards the importance of an early diagnosis of dementia. However, when interpreting the results it is important to question the possibility that the GP participant sample utilised may present a biased view. For example, although participant invitations were sent out to a large sample of GPs practicing in the Hull and East Riding PCT, only a minor agreed to participate. We therefore have to consider whether the study only appealed to particular

GPs. For example, is the participant sample comprised only of GPs who hold a special interest in dementia diagnosis or perhaps have personal experience of dementia? If so, this could lead to biased results.

Furthermore, the findings presented are only applicable to practitioners within the Hull and East Riding area as research shows that GP practices vary with geographical location (Cahill et al., 2008). In order to gain a wider perspective on GP attitudes it would be important to interview a cross section of GPs from across the UK to determine whether the results presented in this study are reflective of those of a larger sample. Initially a larger sample of GPs was planned for the study. However, it is important to note that after conducting eight interviews saturation had occurred, meaning that no new information was emerging from the interviews. Therefore it was inadvisable to continue GP recruitment for the study.

Furthermore, although GP attitudes were compared between GPs in Hull PCT compared to East Riding PCT, it was difficult to identify whether any significant underlying differences existed. To compliment the qualitative data it would have been advantageous to collect quantitative data from a large sample of GPs, rating their attitudes on a number of different constructs such as the perceived value of an early diagnosis and the perceived benefit of treatment option. This would have allowed us to determine with more confidence whether there were any significant differences in attitudes. Further research would be needed to confirm whether the results found are reflective of GPs located throughout the UK.

A further potential limitation of the study is that it became evident that social desirability may have influenced GP responses. GPs were made aware that the data would contribute to a report that could be published in a scientific journal in the future. GPs were

informed that all data would remain anonymous at all times and would be not traceable to the GP or the practice. However, on two occasions, one GP made extremely strong comments concerning social issues and governmental policy regarding dementia, which they then asked to be retracted from the interview transcript. Although the retraction of such comments did not directly affect the overall results of the interviews, it does indicate that GPs may have reserved their true feelings at times.

The present study highlights that GPs are committed to diagnosing dementia in the early stages, even if they have low expectations about the perceived outcomes. GPs did however claim that limited dementia training affected their ability to diagnose and manage cases of dementia. To address this issue, it is recommended that future research develops and evaluates the impact of educational interventions for Practitioners. Examples of such interventions include the well-known EDIDEM-ED trial that aims to improve dementia diagnosis and management within primary care settings (Iliffe et al., 2012).

Smaller scale interventions have also recently been developed and evaluated which produced positive effects. Lathren and colleagues (2013) evaluated the effectiveness of a one day GP training program focusing on screening, diagnosis, case management and coordination with support services. Results of such training included increased GP confidence in dementia care competency six-months after training. GPs also claimed to be able to provide patients with better information regarding the disease and support services available to them. Further research and implementation of such interventions are crucial in order to aid the improvement of current dementia diagnostic rates.

Future research should concentrate on collecting quantitative data investigating GP attitudes between different Clinical Commissioning Groups (CCGs). Research within a particular area and CCG will allow key barriers of dementia diagnosis to be identified and

potential methods to increase the diagnostic rate within that region. To develop the findings of this current study it would be interesting to compare GP attitudes with regions what have the highest dementia diagnostic rates in the UK.

### *2.5.2 Conclusion*

To conclude, the results of Study One indicate that GPs are committed to diagnosing dementia but the perceived value of a diagnosis rests heavily on the perceived effectiveness of pharmacological treatment and the level of support that accompanies the diagnosis. The main factors affecting GPs perceptions included poor access to specialist services and inadequacies of psychosocial and support services. This was particularly evident in East Riding PCT, where services were reported to be more limited. Although GPs listed many benefits of a diagnosis, the most valued was time to make arrangements for the future and access to specialist and support services. Therefore, it is not surprising that that many of the GPs in the sample exhibited scepticism of the value of a diagnosis when it was felt that the current services were inadequate and oversubscribed. GPs felt that this situation was likely to get worse as the incidence for dementia increases.

Although GPs identified factors which could be improved within primary care itself such as GP training and improved dementia guidelines, they feared that making a diagnosis could be hazardous to a patient when they are faced with long waiting lists to see a specialist and are provided with no support. This concern made GPs question the benefit that making a diagnosis would have. Therefore, it is of vital importance that improvements are made to specialist and community support services not only to accommodate for the increasing incidence rates of dementia patients but also to incentivise GPs to make a

diagnosis in the early stages of the disease. This study provides an in-depth exploration of GP attitudes regarding the benefits of an early diagnosis of dementia and offers valuable suggestions on how dementia could be better diagnosed and managed within primary care settings.

Although these findings will be of great benefit in informing future interventions aimed at improving the dementia diagnosis process, a subset of barriers to diagnosis emerged which need to be address separately. These barriers relate to the general public and include public confusion regarding the symptoms of dementia, public refusal to seek help and public stigmatisation of dementia. These issues need to be investigated and addressed if local dementia diagnosis rates are to increase. Even if dementia services improve, an early diagnosis is still partly reliant on individuals' ability to recognise the symptoms of dementia and actively seek help in the early disease stages. Study Two therefore explores perceptions and general knowledge of dementia in the general public. This will allow barriers to an early diagnosis to be highlighted that occur before the point of seeking medical help.

## **Study 2**

### *3.1 Aims and hypothesis of Study Two*

From the research conducted to date, it is hard to gain a clear picture of the general public's level of understanding of dementia. This is largely because of the variability in results obtained, variation in participants used and the differing methodologies utilized. Although the data collected is useful, it is hard to draw clear conclusions and make



generalizations to the population at whole. Furthermore, few studies measured important demographic information, including education and income that could affect participant's knowledge of dementia (Anderson, Day, Beard, Reid & Wu, 2009). Studies are also said to use convenience sampling of specific groups, which could fail to accurately represent general public knowledge of dementia at large. It is therefore advisable that we treat these studies with some degree of caution and use their findings to inform us of how dementia knowledge can vary, especially between different geographical locations. In order to gain a deeper insight in to the public's awareness of dementia, it could be of great benefit to study individual locations and populations to develop educational interventions that are tailored to address specific areas of poor dementia knowledge.

Therefore, the aim of Study Two is to explore levels of basic dementia knowledge and perceptions of the disease in the general public of Hull. The second aim of the study is to compare the evidenced knowledge and perceptions of dementia evidenced by the general public of Hull to the general public of Sheffield which is an area in Yorkshire that presents significantly higher dementia diagnosis rates. Statistics indicate that the percentage of dementia patients that have received a diagnosis in Sheffield is 68.08% compared to only 44.7% in Hull (Alzheimer's Society, 2013). The study aims to determine whether levels of dementia awareness in these two populations differ significantly. This could offer valuable evidence to help explain the variance in diagnostic rates between the two locations. In addition, the study will analyse the effect of age and education on knowledge of dementia. The study will inform the literature of necessary directions for future educational interventions for the general public and highlight particular populations that should be targeted specifically. Information regarding gaps in dementia knowledge

amongst the general public of Hull and Sheffield can be of direct benefit in order to address the poor local dementia diagnostic rates.

It is hypothesized that significant differences will be observed in the levels of dementia knowledge exhibited between participants residing in Hull and Sheffield. It is expected that participants in Hull will have significantly lower levels of dementia awareness, therefore partially accounting for the lower diagnostic rates observed in Hull. In addition, hypothesis two states that there will be a significant effect of age and education on dementia knowledge and beliefs regarding help seeking behaviours.

## **Method**

### *3.2.1 Participants*

The participant sample consisted of 230 of the general public aged eighteen-years and over, recruited from Hull and Sheffield city centre. The Hull and Sheffield group consisted of 115 participants each. For the purposes of analysis, participants were divided in to three age groups; young adults (18-38 years old), middle aged adults (39-59 years), and older adults (60-80 years). The Hull group consisted of 50 young adults, 30 middle aged and 35 older adults and the Sheffield group consisted of 55 young adults, 37 middle aged and 23 older adults. In addition, education level was recorded for participants educated below degree level and at degree level and above. Within the Hull participant group, sixty participants (52.17%) were educated below degree level and 55 (47.83%) participants were educated at degree level and above. In the Sheffield participant group, 47 participants (40.87%) were educated below degree level and 68 (59.13%) were educated above degree level. Gender differences between groups were minimal (Hull: males = 63, females = 52).

Sheffield: males = 62, females = 53). Participants were excluded from taking part in the study if they were healthcare professionals or working in a dementia related industry. However, no participants met these criteria. All participants provided informed consent prior to completing the survey which had received ethical approval from the University of Hull's Ethics Committee.

### *3.2.2 Materials*

The survey consisted of 36 questions, 26 of which were multiple-choice (Appendix E). The remaining ten questions were open-ended questions exploring personal beliefs about dementia. The questions were designed to investigate the basic knowledge of dementia, including the disease prevalence, symptoms, populations particularly at risk of developing dementia and attitudes towards help-seeking. The answers that are assumed to be correct were taken from multiple dementia fact sheets provided by the Alzheimer's Society including: What is dementia (2013), Am I at risk of developing dementia (2013), Rarer causes of dementia (2013), Drug treatments for Alzheimer's disease(2013) and Dementia 2013 infographic (2013)'. Although no questions were taken directly from existing instruments, the questions were designed to reflect the key questions assessed in the previous literature investigating public knowledge of dementia (Bailey, 2000; Connell, Roberts & McLaughlin, 2007; Punandare, Luthra, Swarbrick & Burns, 2007; Roberts et al, 2003; Wikler, Blendon & Benson, 2013). For the vast majority of the multiple choice questions, yes/no/don't know responses or true/false responses were utilised. This response was selected over likert rating scales to coincide with the previous literature and make comparison between the results and past research possible. The questionnaire was

designed in order to avoid using the existing instruments which are much shorter and therefore do not tap all of the key areas of dementia knowledge. Furthermore, many existing instruments investigate knowledge of Alzheimer's disease rather than dementia more generally and therefore fail to assess knowledge of the other subtypes of dementia. The present questionnaire additionally recorded demographic participant information such as age, gender and education in order to identify any underlying differences in dementia knowledge.

### *3.2.3 Procedure*

During April and May 2013, surveys were conducted in Hull city centre and Sheffield city centre to investigate public awareness of dementia. Participants were recruited from city centre locations and informed of the study. Verbal consent was attained from all consenting participants. Participants were read aloud each question by the researcher and instructed to take as much time as needed to answer each question. Participants were given the opportunity to hear the questions again or read the questions themselves. Each survey was completed in approximately ten to fifteen minutes. After completion of the survey, participants were debriefed on the aims of the research and were provided with a dementia information sheet (Appendix F). The information sheet provided basic information regarding the associated signs and symptoms of the early stages of dementia. The information used was attained from the Alzheimer's Society. The information sheet also listed the contact details of the named researchers on the project to allow participants to make contact if they had any further questions or queries about the research.

## Results

Pearson's chi-square analysis was conducted to determine whether differences in dementia knowledge exist between the Hull and Sheffield participant groups. The data was additionally analysed to determine whether participant responses were significantly associated with demographic information such as age group and education level. Pearson's chi-square analysis revealed no significant differences in frequency between the Hull and Sheffield participant group in terms of age group,  $\chi^2 (2, n = 230) = 3.45, p = .18, phi = .18$  or education level,  $\chi^2 (1, n = 230) = 2.95, p = .09, phi = .18$ .

### 3.3.1 General knowledge of dementia

Dementia is defined as a set of symptoms including memory loss, mood change and problems with communication and reasoning ('What is dementia' factsheet, Alzheimer's Society, 2013). Alzheimer's disease, however, is a disease of the brain, which causes the onset of dementia symptoms. To investigate each participant's ability to differentiate between these two terms, they were provided with the statement 'Alzheimer's and dementia mean the same thing' (Appendix E – item A3) and were given three multiple choice answers including 'yes', 'no' and 'don't know'. Pearson's chi-square analysis revealed a significant difference in responses between the Hull and Sheffield participant groups,  $\chi^2 (2, n = 230) = 7.89, p < .02, phi = .02$ . Although only 12.2% of participants in Hull and 15.7% in Sheffield believed that the two terms had the same definition, only 2.6% of participants in Hull were able to correctly identify that the statement was incorrect, compared to 12.2% in Sheffield. The majority of participant responses lay in the 'don't know' category, which was selected by 81.7% of participants in Hull and 75.7% in Sheffield. No significant associations

were detected between participant response and age group,  $\chi^2 (4, n = 230) = 7.45, p = .11, phi = .18$ , or between response and education level,  $\chi^2 (2, n = 230) = 3.94, p = .14, phi = .13$ .

According to recent statistics, one in three people over the age of sixty-five will go on to develop dementia ('Dementia 2013 infographic' factsheet, Alzheimer's Society, 2013). With the aim of assessing public knowledge regarding the high prevalence rates of dementia, participants were asked to estimate the proportion of people over the age of sixty-five years who will develop dementia (Appendix B – item A4). Participants were provided with multiple-choice answers including '1 in 3' (the correct answer), '1 in 5', '1 in 8' and '1 in 10' people. There were no observed differences between responses of the Hull and Sheffield group,  $\chi^2 (3, n = 230) = 4.61, p = .10, phi = .14$ . Interestingly, no participants in either group provided the correct answer. The most frequently selected answer was '1 in 8', which was selected by 41.1% of participants in the Hull group and 51.3% of participants in the Sheffield group, with the second most popular answer being '1 in 10'. Responses indicate that both groups underestimated the proportion of people over 65 who are likely to develop dementia. No association was identified between participant response and age group,  $\chi^2 (4, n = 230) = 1.66, p = .8, phi = .09$  or participant response and education level,  $\chi^2 (2, n = 230) = 2.78, p = .25, phi = .11$ .

Evidence of the underestimation of dementia prevalence was additionally observed when participants were required to estimate the number of people with dementia living in the UK (Appendix E – item A5). Possible answers included 220,000, 420,000, 620,000 and 820,000; the latter of the four being correct ('Dementia 2013 infographic' factsheet, Alzheimer's Society, 2013). Pearson's Chi-Square analysis revealed a significant difference between the responses given by the Hull and Sheffield group,  $\chi^2 (3, n = 230) = 10.77, p < .01$ ,

$\phi = .22$ . Only 3.5 % of participants in the Hull group correctly identified that there are 820,000 people currently living in the UK with dementia compared to 9.6% in Sheffield. From examining incorrect responses we can see that 12.2% of participants in Hull selected 220,000 compared to only 2.3% in Sheffield. However, the percentage of participants selecting 420,000 (41.7% Hull, 40% Sheffield) and 620,000 was (42.6% Hull, 47.8% Sheffield) was similar in both groups. No significant associations were identified between participant response and age group,  $\chi^2 (6, n = 230) = 9.66, p = .14, \phi = .21$ , or between participant response and education level,  $\chi^2 (3, n = 230) = 3.34, p = .34, \phi = .12$ .

### 3.3.2 Causes of dementia and at risk groups

The questionnaire aimed to examine the general public's knowledge of groups who may be particularly at risk of developing dementia. In order to do this, participants were provided with the statement 'dementia only affects people over 65' and were required to answer using 'true', 'false' or 'don't know' responses (Appendix E – item A7). Pearson's Chi-Square analysis identified a significant difference between the responses of the Hull and Sheffield groups,  $\chi^2 (2, n = 230) = 5.97, p < .05, \phi = .16$ . Participants in the Hull group (39.1%) were significantly more likely to respond 'true' compared to participants in the Sheffield group (31.3%). There was no significant association between responses of the three age groups,  $\chi^2 (4, n = 230) = 6.73, p < .15, \phi = .17$ . However, from looking at the proportion of people incorrectly stating that dementia only affects people over sixty-five, a trend was evident that a higher proportion of older adults (43.3%) believed that the statement was true compared to the proportion of young (33.3%) or middle aged adults (31.3%). Furthermore, a significant association was identified between participant response

and education level,  $\chi^2 (2, n = 230) = 10.37, p < .01, phi = .21$ . The proportion of participants who falsely believed that dementia only affects individuals over the age of sixty-five were higher in the group who were educated below degree level (41.1%) compared to degree level or above (30.1%).

As previously discussed, the literature suggests that the public lack awareness of the biomedical causes of dementia (Steckenrider 1993; Arai, Arai & Zarit, 2008). To explore this finding further, participants were asked to identify which medical conditions could make an individual more susceptible to developing dementia. The questionnaire asked participants to select the populations who are particularly at risk and were given multiple choice answers including Down’s syndrome, stroke victims, heart problems, Parkinson’s disease, Huntington’s disease, depressed and ‘none of the above’ (Appendix E – item A8). In fact, all of the responses presented have been named as risk factors for dementia (‘Rarer causes of dementia’ factsheet, Alzheimer’s Society, 2013). However ‘none of the above’ was also given as a response to prevent participants from being forced in to giving a random answer. Participant responses are presented in Table 3.

Table 3

Percentage of participants selecting populations at risk of developing dementia

	Area (% of responses)			Age groups (% of responses)			Education level (% of responses)			
	Hull	Sheffield	$\chi^2$	Young	Middle aged	Older adults	$\chi^2$	No degree	degree	$\chi^2$
Down syndrome	0.9	1.7	0.34	1.0	1.5	1.7	0.2	0.0	2.4	2.64
Stroke	35.7	35.7	0.0	28.6	43.3	39.7	4.4	28.0	42.3	5.06*
Heart	7.8	14.8	2.78	8.6	16.4	10.3	2.58	6.5	15.4	4.53*
Parkinson’s	18.3	33.0	6.59*	29.5	23.9	20.7	1.68	15.9	34.1	10.02**
Huntington’s	6.1	10.4	1.43	8.6	9.0	6.9	0.2	7.5	8.9	0.16
Depression	11.3	21.7	4.54*	18.1	23.9	5.2	8.24*	14.0	18.7	0.91
None of the above	34.8	25.2	2.51	37.1	14.9	34.5	10.63*	43.9	17.9	18.48**

\* $p < 0.05$ ; \*\* $p < 0.005$



The two populations most frequently selected by participants included 'stroke' and 'none of the above'. Pearson's Chi-Square analysis revealed that participants in the Sheffield group were significantly more likely than the Hull group to correctly identify 'Parkinson's disease' and 'depression' as at risk groups. In addition, education level was associated with the proportion of participants selecting 'stroke', 'heart' and 'Parkinson's'. In all cases participants were significantly more likely to correctly identify the group at increased risk of developing dementia if they were educated at degree level or above. However, people educated below degree were significantly more likely to respond 'none of the above' in comparison to individuals educated at degree level or above.

It is also believed that females have a higher risk of developing dementia than males. It is estimated that two thirds of people with dementia are women ('Dementia 2013 infographic' factsheet, Alzheimer's Society, 2013). Participants were therefore presented with the statement 'dementia is more common in women than men' (Appendix E– item A6). There was no significant difference in the proportion of 'true', 'false' and 'don't know' responses between the two groups,  $\chi^2 (2, n = 230) = 4.12, p < .13, phi = .13$ . The proportion of participants who correctly identified the statement to be true was low in both groups, with only 7.8% of correct answers in Hull and 16.5% in Sheffield. The number of participants falsifying the statement was similar in both groups, with 49.6% in Hull 46.5% in Sheffield. However, high frequencies of 'don't know' responses were recorded in both groups (Hull: 42.6%, Sheffield: 40%). Participant responses were not significantly associated with age,  $\chi^2 (4, n = 230) = 4.97, p = .29, phi = .15$ , or education level,  $\chi^2 (2, n = 230) = .88, p = .65, phi = .06$ .

### 3.3.3 Identifying the symptoms of dementia

An additional aim of the study was to investigate public awareness of the signs and symptoms of dementia. The questionnaire asked participants whether they were able to list the symptoms of dementia (Appendix E – item A2). Encouragingly, 94.8% of participants in Hull and 96.5% of participants in Sheffield responded ‘yes’. There was no difference in responses between the Hull and Sheffield group,  $\chi^2(1, n = 230) = .42, p = .52, \phi = -.04$ , between participants of different age groups,  $\chi^2(2, n = 230) = 4.0, p = .14, \phi = .13$ , or between participants of different education levels,  $\chi^2(2, n = 230) = 2.32, p = .13, \phi = -.1$ . Participants were then tested on this ability by asking them to list as many symptoms of dementia as possible. Table 4 shows the full list of symptoms described.

Table 4

#### Percentage of participants selecting descriptive terms to describe a dementia patient

Symptom	Area (% of responses)			Age groups (% of responses)				Education level (% of responses)		
	Hull	Sheffield	$\chi^2$	Young	Middle aged	Older adults	$\chi^2$	No degree	degree	$\chi^2$
Memory loss	77.4	86.1	2.9	75.2	79.1	96.6	11.81**	75.7	87.0	4.89**
Forgetfulness	63.5	72.2	2.0	67.6	67.2	69.0	.05	70.1	65.9	.47
Confusion	55.7	52.2	.28	32.5	77.6	60.3	30.85**	32.7	72.4	36.2**
Hand tremor	14.8	11.3	.61	12.4	19.4	6.9	4.36	20.6	6.5	9.97**
Communication difficulties	9.6	14.8	1.46	3.8	23.9	13.8	15.6**	6.5	17.1	5.94*
Depression	7.8	10.4	.47	1.0	23.9	6.9	26.38**	0.9	16.3	16.2**
Forgetting names	6.1	12.2	2.57	12.4	9.0	3.4	3.6	10.3	8.1	.32
Difficulties with daily activities	6.1	12.2	2.57	9.5	9.0	8.6	.04	5.6	12.2	3.0
Wandering	5.2	13.0	4.25*	9.5	11.9	5.2	1.75	1.9	15.4	12.72**
Incontinence	3.5	6.1	.86	1.9	3.0	12.1	9.15*	7.5	2.4	3.19
Mood swings	2.6	6.1	1.67	1.0	11.9	1.7	13.16**	.0	8.1	9.1**
Live in the past	1.7	6.1	2.89	1.9	7.5	3.4	3.41	0.9	6.5	4.72*
Aggression	3.5	2.6	.15	2.9	3.0	3.4	.05	2.8	3.3	.04
Forgetting who they are	4.3	.0	5.11*	2.9	3.0	.0	1.73	0.9	3.3	1.45
Seeing people who are not there	4.3	.0	5.11*	4.8	.0	.0	6.09*	3.7	0.8	2.3
Forgetting where they are	3.5	.0	4.07*	.0	4.5	1.7	4.8	.0	3.3	3.54
Motor problems	.0	3.5	4.07*	.0	.0	6.9	12.07**	1.9	1.6	.02
Paranoia	.0	2.6	3.04	.0	4.5	.0	7.4*	.0	2.4	2.64
Hearing voices	2.6	.0	3.04	2.9	.0	.0	3.62	2.8	.0	3.49
Headaches	1.7	.0	2.02	1.9	.0	.0	2.4	1.9	.0	2.32
Difficulties swallowing	0.9	1.7	.34	.0	3.0	1.7	2.94	.0	2.4	2.64
Maths problems	0.9	.0	1.0	1.0	.0	.0	1.2	.0	0.8	.87
Loss of sight	0.9	.0	1.0	1.0	.0	.0	1.2	0.9	.0	1.16

\* $p < 0.05$ ; \*\* $p < 0.005$

'Memory loss', 'forgetfulness' and 'confusion' were the most frequently listed symptoms. A higher proportion of older adults (96.6%) listed 'memory loss' as a symptom of dementia compared to young (72.5%) and middle aged adults (79.1%). Analysis also revealed a significant association between participants listing 'confusion' as a symptom of dementia and age group. Only 32.5% of young adults listed 'confusion', compared to 77.6% of middle aged and 60.3% of older adults. Education level was additionally found to be associated with the proportion of participants listing 'confusion'. Only 32.7% of people educated below degree level compared to 72.4% educated at degree level or above thought 'confusion' was a symptom.

'Wandering' was also correctly listed as a symptom of dementia, but significantly more frequently by participants in Sheffield (13%) compared to Hull (5.2%). The proportion of participants giving this response was significantly associated with education level. Only 1.9% of participants educated below degree level listed 'wandering' compared to 15.4% of participants educated at degree level or above.

In addition, participant responses were significantly associated with education level for the following symptoms; 'depression', 'mood swings' and 'living in the past', all of which were listed as a symptom significantly more frequently by participants educated at degree level or above. Education was also significantly associated with the number of people falsely listing 'hand tremor' as a symptom of dementia. However, in this case participants educated below degree level were more likely to report the symptom. In total, 20.6% of people educated below degree level falsely perceived 'hand tremor' to be a symptom of dementia, compared to only 6.5% of participants educated at degree level or above.

To further examine public knowledge of dementia symptoms, participants were then presented with a list of ten symptoms, five symptoms of dementia and five symptoms that are not typically associated with dementia (Appendix E – item A9). Participants were required to accurately identify the five correct symptoms from the list which included; ‘anxiety and depression’, ‘decline in the ability to talk, read and write’, ‘forgetting names of friends and everyday objects’, ‘sudden changes in mood and personality’ and ‘struggling to remember events from a long time ago’. Participant responses are presented in Table 5.

Table 5

*Percentage of participants claiming the symptoms to be those of dementia*

Symptom	Area (% of responses)			Age groups (% of responses)				Education level (% of responses)		
	Hull	Sheffield	$\chi^2$	Young	Middle aged	Older adults	$\chi^2$	No degree	degree	$\chi^2$
Anxiety and depression	20.9	19.1	.11	14.3	26.9	20.0	4.3	11.2	27.6	9.65**
Struggling to remember recent events	81.7	87.7	1.65	80.0	89.6	87.9	3.49	81.3	87.8	1.87
Seizures	8.7	5.2	1.08	10.5	9.0	.0	6.37*	12.1	2.4	8.34**
Decline in the ability to talk, read and write	39.1	40.0	.02	29.5	35.8	62.1	17.1**	31.8	46.3	5.08**
Auditory hallucinations	6.1	7.0	.07	3.8	11.9	5.2	4.67	3.7	8.9	2.54
Forgetting names of friends and everyday objects	86.1	86.1	.0	87.6	86.6	82.8	.76	78.5	92.7	9.6*
Headaches	20.9	19.1	.03	22.9	17.9	15.5	1.44	24.3	15.4	2.85
Sudden changes in mood or personality	13.0	16.5	.55	8.6	31.3	6.9	20.67**	4.7	23.6	16.23**
Struggling to remember events from a long time ago	48.7	45.2	.28	56.2	25.4	55.2	17.7*	54.2	40.7	4.22*
Vertigo	2.6	0.9	1.02	2.9	0	1.7	1.95	3.7	.0	4.68**

\* $p < 0.05$ ; \*\* $p < 0.005$

Analysis revealed no significant differences in participants’ ability to identify the correct symptoms of dementia between the Hull and Sheffield group. However, several important associations were identified between response and education. Participants were significantly more likely to accurately select ‘anxiety and depression’ if they were educated at degree level or above. Only 11.2% of people educated below degree level correctly identified the symptom compared to 26.7% of participants educated at degree level. Similarly, participants educated at degree level were significantly more likely to select

‘forgetting names of friends or everyday objects’ as a symptom of dementia. Only 78.5% of participants educated below degree level identified the symptom compared to 92.7% of people educated at degree level. This pattern of results was also found with the proportion of participants correctly identifying ‘sudden changes in mood or personality’. The number of participants to correctly identify the symptom was found to be significantly associated with education level, with only 4.7% of participants below degree level correctly identifying the symptom compared to 23.6% of participants educated at degree level.

Furthermore, as the literature suggests, confusion can regularly occur when attempting to differentiate dementia symptoms from symptoms of typical ageing because individuals frequently perceive memory loss as an inevitable part of the ageing process (Boise, Morgan & Kaye, 1999; Bond et al., 2005; Ortiz & Fitten, 2000; Wilkinson, Sganga, Stave & O’Connell, 2005). The questionnaire was designed to explore these findings by investigating public perceptions of memory loss and empirically assessing whether members of the public can effectively differentiate between the symptoms of dementia and typical ageing. Firstly, participants were asked whether they regarded memory loss in old age to be a serious medical condition (Appendix E – item B1). Multiple-choice answers included ‘yes’, ‘no’ and ‘don’t know’ responses. Using Pearson’s Chi-Square analysis a significant difference was observed between the beliefs of the two participant groups,  $\chi^2 (2, n = 230) = 19.92, p < .01, phi = .29$ . Only 13.9% of participants in Hull believed memory loss in old age to be a serious condition, in comparison to 40% of participants in Sheffield. When data was collapsed across areas, analysis showed that age group had a significant association with participant response,  $\chi^2 (4, n = 230) = 28.04, p < .01, phi = .35$  (Figure 1). Participants in the older adult group (12.1%) were less likely than participants in the middle aged (37.3%) or

young adult group (28.6%) to believe memory loss in old age to be a serious medical condition. There was also a significant association between participant response and education level,  $\chi^2 (2, n = 230) = 12.45, p < .01, phi = .23$ . In total, 36.6% of people studying at degree level believed memory loss to be a serious condition, compared to 15.9% of people studying below degree level.

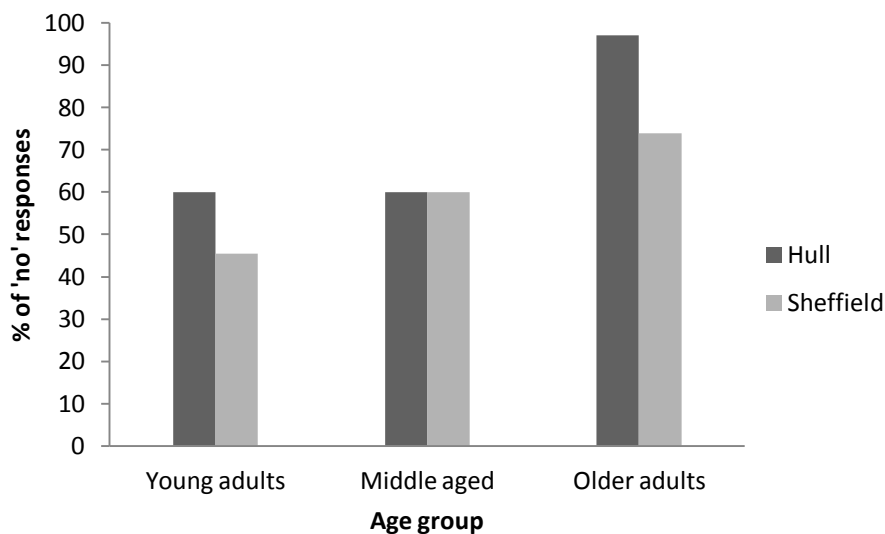


Figure 1. Proportion of participants who believed that memory loss in ageing was not a serious medical condition

When participants were asked whether they believed dementia to be a natural part of the ageing process, a significant difference was observed between the proportion of 'yes', 'no' and 'don't know' responses of the two participant groups,  $\chi^2 (2, n = 230) = 10.82, p < .004, phi = 0.22$  (Appendix E– item A1). Participants in Hull were more likely to respond 'yes' (36.5%) compared to the Sheffield group (27%). Chi-Square analysis revealed no significant association between participant response and age group,  $\chi^2 (2, n = 230) = .89, p = .61, phi = .03$ . However, an important trend was observed between the different age groups. In total, 41% of young adults responded 'yes', compared to 22.4% of middle-aged adults and 25.9%

of older adults. This difference indicates that young participants are more likely to believe dementia to be a normal part of the ageing process. Furthermore, subsequent analysis revealed a significant association between participant response and education level,  $\chi^2 (2, n = 230) = 14.25, p < .001, phi = 0.25$ . In total, 41.1% of people not educated at degree level believed dementia to be a natural part of ageing compared to only 23.6% educated at degree level.

The questionnaire also asked participants whether they expected their memory to decline significantly in old age (Appendix E – item B7). No significant differences were identified between the Hull and Sheffield group,  $\chi^2 (2, n = 230) = 2.21, p = .33, phi = .1$ . Similar responses were observed across groups as 56.5% of participants in the Hull group and 47% of participants in the Sheffield group believed that their memory would decline. Collapsing data across groups revealed a significant association between response and age group  $\chi^2 (4, n = 230) = 27.61, p < .001, phi = 0.35$ . From the results it is evident that participants in the older adult group were less likely to expect their memory to decline with ageing, as only 39.7% of older participants responded ‘yes’, compared to 52.2% of middle-aged adults and 58.1% of young adults. Education level was not associated with participant response,  $\chi^2 (2, n = 230) = 4.89, p < .09, phi = 0.15$ .

In order to further examine the public’s ability to distinguish dementia from ageing, participants were asked what factors would lead them to suspect that memory loss was being caused by something more serious than normal ageing (Appendix E– item A14). The factors are listed in Table 6.

Table 6

*Factors which would lead participants to believe that memory problems were caused by something more serious than normal ageing.*

Factor	Area (% of Responses)			Age Groups (% of Responses)			x <sup>2</sup>	Education (% of Responses)		
	Hull	Sheffield	x <sup>2</sup>	Young	Middle aged	Older adults		No Degree	Degree	x <sup>2</sup>
Severity of memory problem	53.9	65.2	3.05	54.3	67.2	60.3	2.84	60.7	58.5	0.12
Frequency of memory problem	50.4	62.6	3.47	64.8	52.2	46.6	5.75	46.7	65.0	7.81**
Degree to which daily life effected	47.0	53.9	1.11	56.2	44.8	46.6	2.6	57.0	44.7	3.46
Behaviour out of character	27.0	21.7	0.85	10.5	34.3	37.9	20.40**	17.8	30.1	4.72*
Rate of symptom onset	5.2	12.2	3.51	2.9	14.9	12.1	8.61*	3.7	13.0	6.19*

\* $p < 0.05$ ; \*\* $p < 0.005$

There were no observed differences between the responses provided by the Hull and Sheffield participants groups. However, analysis revealed that education was significantly associated with the proportion of participants answering 'frequency of memory problems',  $x^2 (1, n = 230) = 7.81, p < .01, phi = .18$  'rate of symptom onset',  $x^2 (1, n = 230) = 6.19, p < .01, phi = .16$  and whether the 'behaviour was out of character',  $x^2 (1, n = 230) = 4.72, p < .01, phi = .14$ . All three associations showed that the proportion of participants providing these responses were higher in individuals who were educated at degree level or above.

The questionnaire then provided participants with a list of eight symptoms, consisting of four symptoms of dementia and four symptoms of typical ageing (Appendix E–item A13). The participants' task was to correctly identify the symptoms of dementia. The correct symptoms of dementia included 'loss of interest in social activities', 'unable to operate even simple new appliances', 'repeats self and loses thread of what others are saying' and 'becomes dependent on others for activities of daily living'. Table 7 presents participant responses.



Table 7

*Participant responses when asked to distinguish symptoms of dementia and normal ageing.*

Symptom	Area (% of responses)		$\chi^2$	Age groups (% of responses)			$\chi^2$	Education level (% of responses)		$\chi^2$
	Hull	Sheffield		Young	Middle aged	Older adults		No degree	degree	
Occasional word finding difficulties	40.9	36.5	.46	40.0	43.3	31.	2.11	34.6	42.3	1.43
Occasionally calling people by the wrong names	40.9	30.4	2.73	36.2	29.9	41.4	1.83	37.4	34.1	.26
Loss of interest in social activities	9.6	12.2	.4	6.7	19.4	8.6	7.25*	9.3	12.2	.48
Complains of memory problems but is able to detail incidents of forgetfulness	50.4	53.0	.16	64.8	43.3	37.9	13.48**	62.6	42.3	9.48**
Unable to operate even simple new appliances	34.8	43.5	1.86	31.4	58.2	31.0	14.45**	16.8	58.5	41.8**
Repeating self and losing thread of what others are saying	53.9	58.3	.44	54.3	65.7	48.3	4.07	49.5	61.8	3.49
May have to pause in familiar territory to find their way	51.3	47.8	.28	61.9	44.8	32.8	13.56**	48.6	50.4	.08
Become dependent on others for activities of daily living	73.0	80.0	1.55	66.7	80.6	89.7	11.86**	72.0	80.5	2.32

\* $p < 0.05$ ; \*\* $p < 0.005$

Analysis revealed no significant differences in participants' ability to distinguish symptoms of dementia from typical ageing between the Hull and Sheffield group. 'Becomes dependent on others for activities of daily living' was the most frequently selected symptom of dementia reported by the two participant groups, with 73% of participants in the Hull group and 80% of participants in the Sheffield group identifying it as a symptom of dementia. Participants who were educated below degree level were found to be less likely to successfully select 'unable to operate even simple new appliances' as a correct symptom of dementia compared to participants educated at degree level,  $\chi^2 (1, n = 230) = 41.8, p < .01, phi = .45$ . 'Loss of interest in social activities' was the least selected symptom, with only 9.6% of participants in the Hull group and 12.2% of participants in the Sheffield group accurately identifying it as a symptom of dementia.

However, 'complains of memory problems but is able to detail incidents of forgetfulness' was falsely perceived to be a symptom of dementia by a large proportion of

participants. The proportion of participants selecting this as a symptom of dementia was significantly associated with age group,  $\chi^2 (2, n = 230) = 13.48, p < .01, phi = .24$ . It was apparent that young adults were more likely to believe this to be a dementia symptom (64.8%) compared to middle-aged adults (43.3%) and older adults (37.9%). Education level was also a significantly associated factor,  $\chi^2 (1, n = 230) = 9.48, p < .01, phi = -.2$ . In total, 62.6% of participants educated below degree level falsely identified this as a symptom of dementia compared to only 42.3% of participants educated at degree level or above.

### *3.3.4 The perceived importance of an early diagnosis of dementia*

In order to investigate public beliefs about the benefit of an early diagnosis, participants were asked if they believed the early diagnosis of dementia to be important (Appendix E– item B6). Results indicated that there was a significant difference between the beliefs of the two groups,  $\chi^2 (2, n = 230) = 10.93, p < .01, phi = .22$ . Only 60.9% of participants in Hull believed that an early diagnosis was important in comparison to 79.1% of participants in Sheffield. Participant responses were significantly associated with age group,  $\chi^2 (4, n = 230) = 98.09, p < .01, phi = .65$ . The Phi value indicates that age group had a large effect on participant response. Only 37.9% of older adults believed an early diagnosis to be important compared to 74.6% of middle-aged adults and 84.8% of young adults. This indicates that older adults were significantly less likely to believe an early diagnosis to be important compared to the younger age groups (Figure 2). Collapsing data across areas highlighted a significant association between participant response and education level,  $\chi^2 (2, n = 230) = 33.03, p < .001, phi = .38$ . A total of 85.4% of participants studying at degree level

believed an early diagnosis of dementia to be important compared to only 52.3% without a degree.

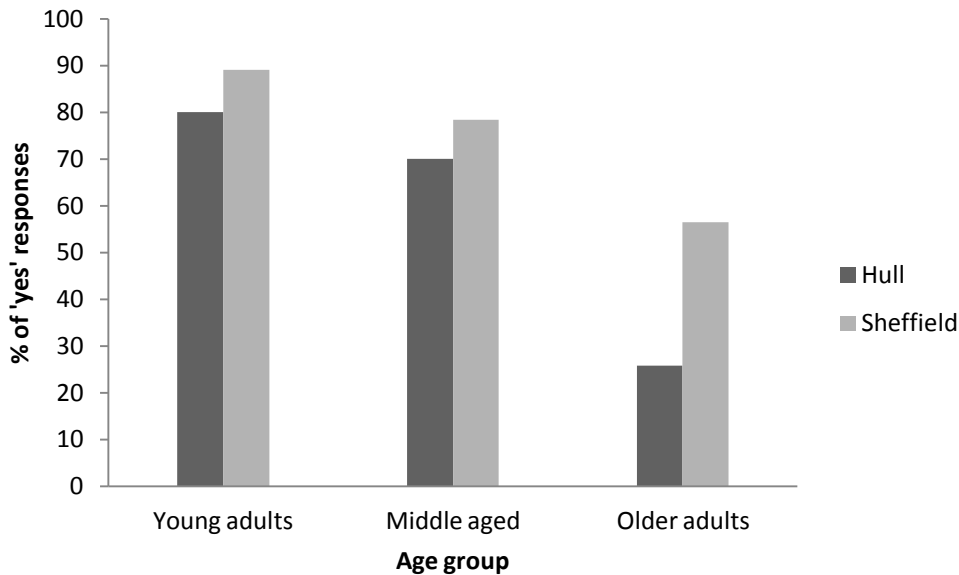


Figure 2. Proportion of participants who believed an early diagnosis of dementia to be important

The questionnaire then invited participants to list the benefits that they associated with an early diagnosis. Table 8 shows the full list of benefits described.

Table 8

*Participants perceived value of an early dementia diagnosis*

Factor	Area (% of Responses)			Age Groups (% of Responses)			Education (% of Responses)			
	Hull	Sheffield	x <sup>2</sup>	Young	Middle aged	Older adults	x <sup>2</sup>	No degree	degree	x <sup>2</sup>
Treatment	68.7	85.2	8.85**	76.2	74.6	81.0	0.78	72.9	80.5	1.86
Support	73.9	74.8	0.02	72.4	80.6	70.7	1.99	72.9	75.6	0.22
Care	53.0	48.7	0.44	47.6	58.2	48.3	2.04	52.3	49.6	0.17
Finance	18.3	29.5	4.03*	27.6	22.4	19.0	1.66	20.6	26.8	1.24
Comforted by knowledge	18.4	16.5	0.14	15.2	20.9	17.5	0.91	15.1	19.5	0.77
Quality time together	0.0	3.5	4.07*	3.8	0.0	0.0	4.85	0.0	3.3	3.54
Time to come to terms with diagnosis	36.5	33.9	0.17	36.2	32.8	36.2	0.24	34.6	35.8	0.04

\*p<0.05; \*\*p<0.005

Access to treatment, support and care were the three most frequently perceived benefits of an early diagnosis. Significant group differences were observed between the Hull and Sheffield group in the proportion of people selecting 'treatment',  $\chi^2 (1, n = 230) = 8.85, p < .01, phi = .2$ , 'finance'  $\chi^2 (1, n = 230) = 4.04, p = .04, phi = .13$  and 'extended quality of time together',  $\chi^2 (1, n = 230) = 4.07, p = .04, phi = .13$ . In all cases, the proportion of participants listing these benefits was significantly higher in the Sheffield group compared to the Hull group.

The questionnaire additionally explored public perceptions regarding the efficacy of dementia medications (Appendix E – item A11). Analysis revealed that there was no significant group difference in the proportion of 'true', 'false' and 'don't know' responses when presented with the statement 'dementia can be treated with medication',  $\chi^2 (2, n = 230) = 4.89, p = .09, phi = .15$ . In total, 55.7% of participants in the Hull group and 69.6% of participants in the Sheffield group responded 'yes'. When data was collapsed across groups, a significant association between age group and participant response was detected,  $\chi^2 (4, n = 230) = 10.63, p = .03, phi = .2$ . Participants in the older adult group (50%) were less likely to believe that dementia could be treated by medication compared to young (55.7%) or middle aged adults (65.7%). Furthermore, there was an additional significant association between education level and beliefs regarding medication,  $\chi^2 (2, n = 230) = 10.23, p = .01, phi = .21$ . Only 53.3% of people educated below degree level believed that dementia could be treated by medication, compared to 70.7% of people educated at degree level or above.

Participants were then presented with the statement 'dementia can be cured if detected in the early stages' and were given 'true', 'false' and 'don't know' multiple choice answers (Appendix E– item A12). Pearson's Chi-Square analysis revealed that there was no

significant difference between the proportion of participants in Hull and Sheffield who believed that 'dementia could be cured',  $\chi^2 (2, n = 230) = 3.51, p = .17, \phi = .12$ . Overall, the percentage of people who believed that dementia could be cured in both groups was minimal (Hull: 7.8%, Sheffield: 5.2%). However, a significant association was observed between participant response and age group,  $\chi^2 (4, n = 230) = 10.43, p = .03, \phi = .21$ . Young adults (9.5%) were more likely to believe that dementia could be cured, in comparison to middle-aged adults (4.5%) and older adults (3.4%). Additionally, education level was associated with participant response, with 8.4% of people educated below degree level and 4.9% of participants educated at degree level responding 'true',  $\chi^2 (2, n = 230) = 19.73, p < .001, \phi = .29$ .

In order to examine public perceptions regarding living with dementia, participants were presented with the statement 'nothing could be done to help people live well with dementia' and asked to select a 'true', 'false' or 'don't know' response (Appendix E– item B5). Analysis revealed no significant differences in the responses between participants in the Hull and Sheffield group,  $\chi^2 (2, n = 230) = .1, p = .95, \phi = .02$ . In total, 13.9% of participants in the Hull group and 14.8% of participants in the Sheffield group responded 'true' indicating that they believed that nothing could be done to help people live well with dementia. Further analysis detected a significant association between response and age group,  $\chi^2 (4, n = 230) = 42.57, p < .001, \phi = .43$ . The Phi value of .43 is indicative that this association has a moderate effect. The results indicate that the proportion of older adults (32.8%) responding true was significantly higher than the young (5.7%) or middle aged adults group (7.5%). This suggests that older adults are more likely to believe that nothing can be done to help people live well with dementia compared to younger age groups.

Education level was also associated with participant response,  $\chi^2 (2, n = 230) = 12.52, p = .002, \phi = .23$ . Over double the percentage of people with a degree (36.6%) falsified the statement, indicating that they believed that something can be done to help people live well with dementia, compared to participants without a degree (15.9%).

When participants were asked whether they believed there to be a stigma attached to dementia, there was no significant differences in the proportion of 'yes', 'no' and 'don't know' responses obtained in the Hull and Sheffield group,  $\chi^2 (2, n = 230) = 1.03, p = .56, \phi = .07$ . A comparable proportion of participants in both groups believed there to be a stigma attached to dementia, with 61.7% of Hull participants and 67.8% of Sheffield participants answering 'yes'. No significant associations were observed between participant response and age group,  $\chi^2 (4, n = 230) = 3.38, p = .5, \phi = .12$ , or education level,  $\chi^2 (2, n = 230) = .13, p = .12, \phi = .02$ .

The questionnaire additionally required participants to list the words that they would use to describe a person with dementia (Appendix B– item B4). Table 9 shows the full list of words described.

Table 9

*Participant's descriptions of a patient with dementia*

Symptom	Area (% of responses)			Age groups (% of responses)				Education level (% of responses)		
	Hull	Sheffield	$\chi^2$	Young	Middle aged	Older adults	$\chi^2$	No degree	degree	$\chi^2$
Forgetful	59.1	71.3	3.76	59.0	79.1	60.3	8.07*	57.0	72.4	5.94*
Confused	59.1	64.3	.66	46.7	77.6	70.7	19.21**	57.9	65.0	1.2
Scared	36.5	46.1	2.17	36.2	43.3	48.3	2.4	37.4	44.7	1.27
Frustrated	26.1	42.6	6.96*	18.1	56.7	37.9	27.5**	23.4	43.9	10.7**
Frightened	37.4	39.1	.07	34.3	34.3	50.0	4.53	35.5	40.7	.64
Angry	27.0	30.4	.34	20.0	44.8	25.9	12.58**	16.8	39.0	13.79**
Aggressive	16.5	12.2	.88	10.5	19.4	15.5	2.74	12.1	16.3	.79
Old	14.8	7.8	2.78	20.0	6.0	1.7	15.23**	20.6	3.5	17.1**
Lost	3.5	12.2	6.03*	8.6	4.5	10.3	1.63	9.3	6.5	.64
Lonely	4.3	10.4	3.11	6.7	13.4	1.7	6.38*	0.9	13.0	12.19**
Frail	2.6	5.2	1.04	1.0	4.5	8.6	5.92	5.6	2.4	1.53
Mental	3.5	.9	1.84	4.8	.0	.0	6.09*	4.7	.0	5.88*
Tormented	.0	2.6	3.04	.0	.0	5.2	9.01	1.9	.8	.5
Insane	3.5	.0	4.07*	3.8	.0	.0	4.85	3.7	.0	4.68*
Unpredictable	0.9	.0	1.0	.0	1.5	.0	2.44	.0	.8	.87
Weak	2.6	.9	1.02	3.8	.0	.0	4.85*	2.8	.8	1.33
Lifeless	.0	.9	1.0	.0	1.5	.0	2.44	.9	.0	1.16
Pale	0.9	.0	1.0	2.0	.0	.0	1.2	.9	.0	1.16
Shell of older self	.0	0.9	1.0	.0	.0	1.7	2.98	.0	.8	.87
Vacant	.0	1.7	2.02	.0	3.0	.0	4.91	.0	1.6	.19
Slow	.0	.9	1.0	2.0	.0	.0	1.2	.9	.0	1.16
Emotional	3.5	.9	1.84	2.9	3.0	.0	1.73	.9	3.3	1.45

\* $p < 0.05$ ; \*\* $p < 0.005$ 

Words most frequently used to describe a patient with dementia included 'forgetful', 'confused', 'scared', 'frustrated' and 'angry'. Group differences were minimal between the Hull and Sheffield group in the words they used to describe a patient. Participants from Sheffield were, however, significantly more likely to describe a patient as 'frustrated',  $\chi^2 (1, n = 230) = 6.96, p < .01, phi = .17$  and 'lost',  $\chi^2 (1, n = 230) = 6.03, p = .01, phi = .16$ . Conversely, the Hull group was significantly more likely to describe a patient as 'insane',  $\chi^2 (1, n = 230) = 4.07, p = .04, phi = -.13$ . Education was significantly associated with the proportion of participants describing a patient as 'forgetful',  $\chi^2 (1, n = 230) = 5.94, p = .02, phi = .16$  'frustrated',  $\chi^2 (1, n = 230) = 10.7, p < .01, phi = .22$  'angry'  $\chi^2 (1, n = 230) = 13.79, p < .01, phi = .25$  and 'lonely',  $\chi^2 (1, n = 230) = 12.19, p < .01, phi = .23$ , all of which were reported significantly higher by participants educated at degree level or above. Education was also associated with the proportion of participants using the terms 'mental',  $\chi^2 (1, n =$

230) = 5.88,  $p = .02$ ,  $\phi = .16$  and 'insane',  $\chi^2 (1, n = 230) = 4.68$ ,  $p = .03$ ,  $\phi = -.14$ . In both cases, participants educated below degree level used the terms frequently more than participants educated above degree level. Analysis additionally revealed that age was significantly associated with many descriptions, including 'forgetful',  $\chi^2 (2, n = 230) = 8.07$ ,  $p = .02$ ,  $\phi = .19$  'confused',  $\chi^2 (2, n = 230) = 19.21$ ,  $p < .01$ ,  $\phi = .29$  'frustrated',  $\chi^2 (2, n = 230) = 27.5$ ,  $p < .01$ ,  $\phi = .35$  'angry',  $\chi^2 (2, n = 230) = 12.58$ ,  $p < .01$ ,  $\phi = .23$  and 'lonely',  $\chi^2 (2, n = 230) = 6.38$ ,  $p = .04$ ,  $\phi = .17$ . For these examples, middle aged adults were significantly more likely to provide these descriptive terms in comparison to young or older adults.

### 3.3.5 Attitudes towards help seeking

In order to examine public help seeking behaviours, participants were asked if they would delay voicing concerns to friends and family if they suspected that they themselves might have dementia (Appendix E– item B9). No significant difference was established between the responses of the Hull and Sheffield participant group,  $\chi^2 (1, n = 230) = .02$ ,  $p = .89$ ,  $\phi = -.01$ . In total, 60.9% of Hull participants and 60% of Sheffield participants responded 'yes' indicating that they would delay voicing their concerns. No significant associations were identified between response and age group,  $\chi^2 (2, n = 230) = 3.11$ ,  $p = .21$ ,  $\phi = -.12$  or response and education,  $\chi^2 (1, n = 230) = .98$ ,  $p = .32$ ,  $\phi = -.07$ . Participants were then asked to list the reasons why they would delay voicing these concerns. The full list of reasons described are listed in Table 10 'Uncertainty of the symptoms', 'embarrassment' and 'fear of worrying family members' were the most frequently reported preventative factors for help seeking.



Table 10

*Participants perceived factors underlying decision to delay help seeking*

	Area (% of responses)			Age groups (% of responses)				Education level (% of responses)		
	Hull	Sheffield	x <sup>2</sup>	Young	Middle aged	Older adults	x <sup>2</sup>	No degree	degree	x <sup>2</sup>
Uncertainty	19.1	22.6	.42	20.0	26.9	15.5	2.51	20.6	21.1	.01
Embarrassment	32.2	41.7	2.26	44.8	38.8	20.7	9.43	36.4	37.4	.02
Worry family	40.9	48.7	1.42	42.9	47.8	44.8	.4	39.3	49.6	2.48
No benefit	2.6	1.7	.2	3.8	.0	1.7	2.87	2.8	1.6	.37
Ability undermined	7.8	6.1	.27	7.6	6.0	6.9	.17	6.5	7.3	.05
No cure	9.6	7.8	.22	7.6	11.9	6.9	1.28	7.5	9.8	.37

\* $p < 0.05$ ; \*\* $p < 0.005$

The questionnaire additionally asked participants whom they would consult if they suspected that they had dementia (Appendix E– item B10). Multiple-choice answers were provided including ‘family member’, ‘GP’, ‘friend/neighbour’, ‘nurse/social worker’ and ‘support group’. Both groups displayed large favourability towards consulting a GP for advice, with 70.4% of Hull participants and 58.3% of Sheffield participants selecting this answer. The second most popular response was to consult a family member. However, over double the proportion of older adults selected this answer in comparison to young or middle aged adults. See Table 11.

Table 11

*Who participants would consult if they suspected they may have dementia*

	Area (% of responses)			Age groups (% of responses)			Education level (% of responses)			
	Hull	Sheffield	$\chi^2$	Young aged	Middle aged	Older adults	$\chi^2$	No degree	degree	$\chi^2$
General Practitioner	70.4	58.3	3.72	68.6	64.2	56.9	2.22	63.6	65.0	.06
Family member	19.1	23.5	.65	10.3	20.9	41.4	21.29**	21.5	21.1	.04
Friend/neighbour	3.5	6.1	.86	2.9	10.4	1.7	6.67*	4.7	4.9	.01
Nurse/social worker	4.3	12.2	4.65*	14.3	6.0	0	10.72**	6.5	9.8	.78
Support group	3.5	0	4.07*	3.8	0	0	4.85	3.7	0	4.68*

*p*<0.05; \*\**p*<0.005

Participants were also asked whether they would want their diagnosis disclosed to them if their doctor confirmed that they had dementia (Appendix E– item B13). There was no significant difference in responses between the Hull and Sheffield participant group,  $\chi^2 (1, n = 230) = 2.78, p = .1, phi = -.11$ . A high number of participants claimed that they would want their diagnosis disclosed, with 85.2% of participants in Hull and 92.2% in Sheffield. Pearson’s Chi-Square analysis revealed no significant differences between participant responses and age group,  $\chi^2 (2, n=230) = 2.87, p = .24, phi = -.11$ , educational level,  $\chi^2 (1, n = 230) = 2.66, p = .10, phi = -.11$  or gender,  $\chi^2 (1, n = 230) = .61, p = .43, phi = -.05$ .

In order to establish what people would do if they suspected dementia in a family member, participants were asked whether they would feel comfortable telling somebody that you were concerned about their memory (Appendix E– item B12). There was no significant difference in responses between the Hull and Sheffield participant groups,  $\chi^2 (2, n = 230) = .62, p = .74, phi = .05$ . Interestingly, a high volume of participants claimed that they

would not feel comfortable telling someone that they were concerned about their memory, with 76.5% of participants in Hull and 72.2% of participants in Sheffield sharing this belief. Collapsing data across groups revealed a significant association between participant responses and age group,  $\chi^2 (4, n = 230) = 27.56, p < .01, \phi = .35$ . In total, 83.8% of young adults claimed that they would not feel comfortable discussing their concerns, compared to 68.7% of middle aged adults and 63.8% of old aged adults. This finding is indicative that younger adults would feel less confident when telling somebody that they were concerned about their memory, but this confidence seems to improve with age. A significant association was also revealed between participant response and educational level,  $\chi^2 (2, n = 230) = p = .02, \phi = .19$ . Overall, 81.3% of participants educated below degree level did not feel confident discussing memory concerns, compared to only 68.3% educated at degree level or above. No association was identified between participant response and gender,  $\chi^2 (2, n = 230) = 2.53, p = .28, \phi = .11$ .

The questionnaire also aimed to examine public views of the adequacy of the current levels of dementia awareness. Participants were asked 'have you heard more about dementia in the news or other media over the last five years?' (Appendix E– item B9). Analysis revealed a significant difference between the Hull and Sheffield group,  $\chi^2 (2, n = 230) = 13.81, p = .001, \phi = .25$ . Double the number of people in Sheffield (45.2%) claimed to have heard more about dementia in the media than Hull (22.6%). No associations were found between responses and age group,  $\chi^2 (4, n = 230) = 2.16, p = .71, \phi = .10$  or response and education,  $\chi^2 (2, n = 230) = 1.25, p = .54, \phi = .07$ .

Participants were also asked whether they believed there to be enough public awareness regarding the key facts of dementia (Appendix E– item B14). Chi-Square analysis

revealed no significant differences in responses between the Hull and Sheffield group,  $\chi^2 (2, n = 230) = .69, p = .41, phi = -.06$ . Both groups showed agreement for the lack of public awareness of dementia (Hull: 96.5% and Sheffield: 98.3%). Participant responses were not significantly associated with age,  $\chi^2 (4, n = 230) = 3.80, p = .15, phi = .13$ , or educational level,  $\chi^2 (1, n = 230) = 1.01, p = .32, phi = -.07$ .

Participants were additionally asked if they knew where to find information about dementia (Appendix E– item B15). No significant difference in responses were obtained from the Hull and Sheffield group,  $\chi^2 (2, n = 230) = .88, p = .35, phi = -.06$ . In total, 89.6% of participants from the Hull group and 93% of participants from the Sheffield group claimed that they would know where to look for dementia related information. There was no significant associations between participant responses and age,  $\chi^2 (2, n = 230) = 2.57, p = .28, phi = .11$ , or education,  $\chi^2 (1, n = 230) = 1.60, p = .21, phi = -.08$ . Participants were also asked to list the places that they would look for information. The sources of information listed by participants are provided below in Table 12.

Table 12

*Participants' favoured sources of dementia related information*

Factor	Area (% of Responses)		$\chi^2$	Age Groups (% of Responses)			$\chi^2$	Education (% of Responses)		$\chi^2$
	Hull	Sheffield		Young	Middle aged	Older adults		No Degree	Degree	
Internet	73.9	80	1.2	92.4	82.1	43.1	52.57**	70.1	82.9	5.31*
Doctor	29.6	30.4	.02	6.7	32.8	69.0	69.41**	38.3	22.8	6.59*
NHS	7.0	7.0	.0	3.8	16.4	1.7	13.33**	5.6	8.1	.56
Alzheimer's Society	7.8	15.7	3.4	11.4	20.9	1.7	11.05*	3.7	18.7	12.36**
Family	3.5	.0	4.07*	3.8	0	0	4.85*	3.7	.0	4.68*
Books	3.5	1.7	.69	.0	0	10.3	18.27**	2.8	2.4	.03

\* $p < 0.05$ ; \*\* $p < 0.005$

The most frequently listed source of information was the 'Internet', which was favoured by 73.9% of participants from Hull and 80% of participants from Sheffield. The

second most frequently used source of information was found to be the 'GP'. Age was significantly associated with the proportion of people selecting the 'Internet'  $\chi^2 (2, n = 230) = 52.57, p < .01, \phi = .48$  and the 'GP'  $\chi^2 (2, n = 230) = 69.41, p < .01, \phi = .55$ . When looking at the number of participants listing Internet as the source of information, only 43.1% of older adults reported using the internet, compared to 92.4% of young adults and 82.1% of middle-aged adults. Conversely, the percentage of older adults (69%) selecting the doctor was significantly higher than the young (6.7%) or middle aged groups (32.8%).

## Discussion

The aim of this study was to explore levels of basic knowledge and perceptions of dementia in the general public of Hull and Sheffield. A questionnaire was administered to participants, allowing levels of dementia knowledge to be investigated and compared between the two participant groups. The study additionally drew comparisons between participants of different age groups and different education levels, with the aim of identifying potential factors which may affect knowledge of dementia. The rationale behind utilising members of the public from Hull and Sheffield was to investigate whether differing levels of knowledge could contribute to the large variance in dementia diagnostic rates between the two regions.

The study identified that large variability in knowledge and perceptions of dementia existed between the two groups and also varied with age and educational level. However, the study additionally highlighted that significant gaps in dementia knowledge occurred within the sample on whole, indicating a need for public education on dementia. The key areas in which individuals particularly demonstrated a lack of dementia awareness will now

be discussed in relation to the potential effects this may have upon help seeking behaviours and local diagnosis rates.

Firstly, participants in both groups drastically underestimated the high incidence rates of dementia. Statistics indicate that there are currently 820,000 people living with dementia in the UK (Alzheimer's Society, 2013). However, only 3.5% of participants in Hull and 9.6% of participants in Sheffield were able to identify this as the correct answer. The most commonly selected answers included 420,000 and 620,000, indicating that both groups significantly underestimated the dementia prevalence rates. The underestimation of dementia prevalence was additionally observed when participants were asked to identify the proportion of people over the age of sixty-five who would develop dementia. The correct answer is that '1 in 3' people over the age of sixty-five will go on to develop the disease ('Dementia 2013 infographic' factsheet, Alzheimer's Society, 2013); however, not a single participant from either group was able to identify this as the correct answer. The most frequently selected answer was '1 in 8' people, selected by over 40% of Hull participants and 50% of Sheffield participants. Taken together the results suggest that the general public of both Hull and Sheffield lack sufficient awareness regarding the high incidence rates of dementia.

Secondly, the study showed that both groups lacked adequate knowledge of the causes and the populations who are at particular risk of developing the disease. In total, approximately a third of participants (39% of participants from Hull and 31.3% of participants from Sheffield) believed that dementia only affect people over the age of 65 years. Individuals were more likely to hold this belief if they were educated below degree level. The statistics observed are distinctly lower than Goddard's (2012) finding that 100%

of participants were able to correctly identify that dementia does not only affect people over 60 years of age. Furthermore, few participants were able to correctly identify that dementia is more common in women than in men (Hull: 7.8%, Sheffield: 16.5%).

Participants also showed a significant lack of awareness regarding the medical conditions, which make a person more susceptible to develop dementia. The most frequently identified risk factor was 'stroke'; however this was only identified by 35.7% of each participant group. When presented with a list of risk factors (including stroke, heart disease, Parkinson's disease, Huntington's disease and depression), over a quarter of participants in each group claimed that none of the listed populations were at increased risk. Similar to previous literature (Arai, Arai & Zarit, 2008; Hudson, Pollux, Ministry & Hobson, 2012; Low & Anstey, 2009), few participants were able to accurately identify heart disease as a risk factor for dementia (Hull: 7.8%, Sheffield: 14.8%). However, participants educated above degree level were significantly more likely to identify at risk groups to include 'stroke', 'heart problems' and 'Parkinson's disease'. Taken together, these results suggest that there is currently a poor level of public awareness of risk factors for dementia. Cohorts at high risk may therefore be unaware and unlikely to watch out for possible early warning signs of dementia. Educational interventions should aim to promote public education and improve awareness of dementia symptoms, particularly amongst at risk groups.

Other important findings of the study relate to the public's ability to identify the common symptoms of dementia. Public knowledge of dementia symptoms is of critical importance because individuals possessing higher levels of awareness regarding the symptoms of dementia are significantly more likely to actively seek medical help (Werner,

2003). Encouragingly, the present study documents findings that 94.8% of participants in the Hull group and 96.5% of participants in the Sheffield group believed that they were aware of the symptoms associated with dementia. Memory loss, forgetfulness and confusion were the three most frequently reported symptoms. However, other important symptoms such as 'forgetting people's names', 'difficulties with daily living' and 'mood swings' were only listed by a small minority of the sample. Furthermore, other common symptoms of dementia such as poor problem solving and impaired reasoning and judgement' were not listed by any of the sample. Participants were also provided with a list of symptoms, consisting of dementia symptoms and a selection of other commonly reported symptoms that are not typically associated with the disease (e.g. headaches). Although group differences were minimal, education had a significant effect on knowledge, as participants educated at degree level were more likely to correctly identify 'anxiety and depression', 'forgetting peoples names' and 'changes in mood and personality' as symptoms of dementia.

Participants were able to demonstrate high levels of awareness regarding the common symptoms of dementia (such as memory loss and confusion), but exhibited poor awareness of the more complex cognitive symptoms and the associated neuropsychiatric symptoms (such as anxiety, depression, mood swings and changes in personality). A lack of awareness of the neuropsychiatric symptoms is particularly problematic as they are highly associated with specific subtypes of dementia (e.g. Lewy body dementia and fronto-temporal dementia). This finding indicates that the public lack awareness of the full array of dementia symptoms, particularly the less common ones associated with the rare causes of the disease. This issue needs to be met with public education to improve awareness of the



full range of symptoms that can typically be exhibited by a patient, allowing individuals to spot the early disease warning signs and seek medical help.

In addition to poor recognition of the full array of symptoms associated with dementia, the study also presented strong evidence that the public hold very inaccurate perceptions of memory loss in ageing. Not only did they fail to view memory loss as a serious matter but a large proportion of participants also expected that their own memory would decline significantly as they age. In addition, this study supports previous findings that people perceive memory problems to be a natural part of the ageing process (Corner & Bond, 2004; Werner, 2008). The majority of participants from both groups failed to identify that memory loss in ageing is a serious medical condition. Interestingly, participants in the Sheffield group were approximately three times more likely than the Hull group to consider memory loss in old age to be a serious condition (Hull: 13.9%, Sheffield 40%). Older adults were found to be significantly less likely to believe memory loss in ageing to be a serious condition, compared to the both young and middle-aged adults. Participants educated at degree level were twice as likely to view memory loss as serious. A large proportion of participants (57% in Hull and 47% in Sheffield) also stated that they expected their memory to decline with ageing. However, older adults were significantly less likely to expect their memory to decline in comparison to younger age groups. One could argue that that this is because they are the age group who hold more accurate representations regarding the extent of memory loss due to ageing.

Furthermore, results support previous claims that people perceive memory problems to be a normal part of the ageing process (Corner & Bond, 2004; Werner, 2004). Participants in the Hull group (36.5%) were significantly more likely to believe that dementia

was a natural part of ageing compared to the Sheffield group (27%). Striking differences were also observed between participants of different age groups and different education levels. Firstly, younger adults (41%) were more likely to hold this belief compared to the middle aged (22%) and older adult group (26%). Secondly, 41% of people educated below degree level believed dementia to be a natural part of ageing in comparison to only 24% of participants educated at degree level or above.

When asked what factors may lead an individual to suspect that memory problems were being caused by something more serious than typical ageing, the most frequently listed answers included the frequency of the memory problems (Hull: 50.4% Sheffield: 62.6%), the severity of the memory problems (Hull: 53.9%, Sheffield: 65.2%) and the degree to which the symptoms affect daily living (Hull: 47.5%, Sheffield: 53.9%). Other factors included how out of character the behaviour was for that individual (Hull: 27, Sheffield: 21.7%) and the rate of onset of the symptoms (Hull: 5.2%, Sheffield: 12.2%). Participants educated at degree level were more likely to list 'frequency of memory problems', 'rate of symptom onset' and whether the 'behaviour was out of character'. Taken together the results point towards a vital need for public education, informing individuals that memory loss in ageing is a serious condition and not part of the natural ageing process. If the public continue failing to view memory loss in ageing as a serious condition, one could argue that they will be prevented from seeking medical help in the early stages. As the Hull group displayed significantly lower levels of awareness regarding memory loss, it could a) be a factor underlying the lower diagnosis rates observed compared to Sheffield and b) suggest that educational interventions are of particular importance in this area.

In order to empirically examine the public's ability to effectively distinguish dementia from typical ageing, participants were asked to correctly identify the symptoms of dementia from a list containing symptoms of normal ageing. 'Becomes dependent on others for daily living' was the most commonly selected symptom of dementia. However, only a small proportion of participants associated 'loss of interest in social activities' and 'unable to operate even simple new appliances' with dementia. Instead, a large number of participants from both groups misidentified symptoms of ageing to be symptoms of dementia, including; 'complains of memory problems but able to detail incidents of forgetfulness' 'pauses in familiar territory to find their way' and 'occasionally calling people by the wrong names'. Participants' poor performance on this task highlights public confusion regarding the differentiation between dementia and ageing. This difficulty when attempting to distinguish between dementia and typical ageing has been frequently documented in the literature (Bond, 2005; Iliffe & Wilcock, 2005, Knopman, Donohue & Gutterman, 2000).

A positive finding was that the majority of participants perceive an early diagnosis of dementia to be important, however, participants in the Sheffield group were significantly more likely to view it as important (Hull: 60.9%), Sheffield: 79.1%). Age was found to have a large effect, as young and middle aged adults were twice as likely to believe an early diagnosis to be important compared to older adults. This is particularly interesting because the older adults are at increased risk of developing dementia and yet only 38% of the older adult groups claimed that an early diagnosis was important. If the public fail to see the importance of a diagnosis, they may be prevented from seeking medical help. Education level also affected participant belief, with people educated above degree level significantly

more likely to agree that an early diagnosis was important (Above degree level: 85.4%, below degree level: 52.3%).

When participants were asked to explain the reasons why they believed an early diagnosis was important the most frequently listed answers included access to available treatments, access to support services and time to plan the patients' short-term and long-term care plans. Other perceived benefits of an early diagnosis included time for financial planning, time to come to terms with the diagnosis, comforted by knowledge of the diagnosis and time to spend quality time together. The advantages described are consistent with the advantages heavily cited within the literature (Ashton et al., 2006; Iliffe, Manthorpe & Eden, 2003; ; Milne, 2010; Milne & Wilkinson, 2002; Milne, Woolford & Hatzidimitriadou, 2010; Woods & Pratt, 2005), indicating that both groups hold accurate perceptions of the benefits of a diagnosis, which may in turn encourage people to seek help when they suspect dementia.

Although access to available medications was one of the most frequently reported benefits of an early diagnosis, only 55.7% of participants in Hull compared to 69.6% of participants in Sheffield believed that dementia could be treated with medication. These statistics are only marginally smaller than the NILT survey findings that 75% of a sample of the general public believed there to be pharmacological treatments available (MacManus & Devine, 2011). Older adults were significantly less likely to believe that dementia could be treated with medication than the younger age groups. As previously mentioned, the older adult participant group were less likely to believe in the importance of an early diagnosis. These findings are complimentary as if older adults lack awareness of the treatment for dementia, they may not see the value of an early diagnosis. Education was also found to

affect participant beliefs regarding medication, with participants educated at higher levels were more likely to exhibit awareness of the available treatments.

Participants did however show high levels of awareness that dementia could not be cured by medications, even if detected in the early stages (Hull: 92.2%, Sheffield: 94.8%). Again this result is compatible to the NILT survey finding that only 6% of the participant sample believed that dementia could be cured (MacManus & Devine, 2011). So although the public demonstrated awareness of the limitations of pharmacological treatments, future educational interventions should aim to increase public knowledge of the availability and efficiency of current dementia medications prescribed. Older adults in particular should be targeted to improve their awareness of treatments, with the aim of improving their opinion of the importance of diagnosis.

Only a minority of participants believed that nothing could be done to help people live well with dementia. However, yet again, older adults held the most negative perceptions, as they were significantly more likely to believe that nothing can be done to help people live well with dementia compared to the other age groups. Again this corresponds to the finding that older people are less likely to see an early diagnosis of dementia as important. If older adults believe that nothing can be done to help them live well with dementia, they see limited benefit of pursuing a diagnosis.

Worryingly, both groups demonstrated that negative attitudes of dementia still exist within the general public. For example, the majority of participants in both groups believed that there is still a stigma attached to dementia (Hull: 61.7%, Sheffield: 67.8%). This is not surprising given the growing body of evidence documenting the stigma associated with dementia (Mackenzie, 2006; Morgan, Semchuk, Stewart & D'Arcy, 2002; Vernooji-Dassen et

al., 2005). When asked to list words to describe a patient with dementia, no positive words reported by participants in the Hull or Sheffield group. The most frequently reported descriptions included forgetful, confused, scared, frustrated, frightened and aggressive. These findings replicate those of McManus and Devine (2011) who found that the public use mostly negative words to describe a patient with dementia (such as confused, frightened and lost) with only a small minority using positive description. The present study, however, observed a more concerning finding that a minority of participants used extremely negative terms such as 'mental' and 'insane' to describe a patient. This further supports claims that the stigmatisation of dementia patients still occurs within the general public. Such responses were significantly affected by educational level as participants educated below degree level were significantly more likely to describe a patient as 'angry', 'old', 'mental' or 'insane' compared to participants with a higher education level.

When attitudes towards help seeking were investigated, both groups claimed that they would delay voicing concerns to family and friends if they suspected that they themselves might have dementia (over 70% of participants in both groups). What's more, the majority of participants in both groups claimed that they would not feel comfortable telling somebody that they were concerned about their memory (Hull: 77%, Sheffield: 72%). However, if the public delay voicing concerns this could lead to delays in help seeking and ultimately a delay in a diagnosis. The most frequently documented preventative factors for voicing concerns included uncertainty that the symptoms were associated with dementia, embarrassment, and fear of worrying the family. In cases where they were concerned about their memory, the public demonstrated favourability to seek help from their GP, followed by a family member. This is consistent with recent findings that the majority of

people seek help from their GP, their spouse or their children in cases of MCI (Werner, Heinik, Givon, Segel-Karpas & Kitai, 2014).

Finally, the results revealed that the public demonstrated firm agreement in the need for increased dementia awareness. In total, 96.5% of participants in the Hull and 98.3% in the Sheffield group claimed that there is a lack of public awareness regarding dementia. Interestingly, when asked whether they had heard more about dementia in the media over the last five years, double the percentage of Sheffield participants (45.2%) claimed to have heard more compared to the Hull group (22.6%). This is an extremely important finding because awareness of dementia has been linked to help seeking behaviours (Werner, 2003). Therefore, if the general public have not witnessed this boom in dementia related publicity in the recent years, it could potentially explain why the area possesses a lower diagnosis rate.

The vast majority of participants in both groups claimed that they would know whether to look for information on dementia. The most commonly reported source of information was the Internet. Results showed that older adults were significantly less likely to use the Internet compared to young or middle-aged adults, but instead were more likely to consult their GP or doctors practice for information. Additional sources included NHS, Alzheimer's Society, family and books. This information may be useful when attempting to design educational interventions aimed at different age groups.

### *3.4.1 Limitations of the study and directions for future research*

It is acknowledged that there are several limitations of the present study. The first limitation of this study is the use of opportunistic voluntary participant sampling. This method was employed because it was fast and meant that a large number of participants were easily available. However, it is acknowledged that this is a weak sampling method as the sample may not be representative of the entire population and this, therefore, limits the ability to generalise the present findings. For example, although there were no significant differences between the age groups in the Hull and Sheffield group; there is a large difference in the number of young adults that are utilised in the study compared to middle-aged and older adults. When participant groups were collapsed, there are only 58 older adults and 37 middle-aged adults compared to 105 young adults. Data collection took place on weekdays between 9:00 a.m. and 15:00 p.m. in city centre locations and as a result student populations were easily accessible. Therefore it was much easier to recruit younger adults. However, the distribution of ages in the participant sample does not reflect the population at large, meaning that we should be careful when generalising the results. Future research should aim to avoid the use of opportunistic voluntary sampling to avoid such issues.

Another limitation, is that there is a significant association between age group and education,  $\chi^2(2, n=230) = 8.63, p = .01, \phi = .19$ . In total, 43.9% of younger adults were educated at degree level compared to 36.6% of middle-aged adults and 19.5% of older adults. Perhaps this would be expected as data collection took place in busy cities heavily populated with university students. However, as a result, differences observed in the study could be a partial consequence of differences in education level, as opposed to age group.



Having said this, it would be extremely difficult to match participants on their age and education for public surveys. This survey should provide the base of our knowledge on public awareness of dementia, in which we need to build upon. If research was to extend on the present findings, additional demographic information of the sample should be studied. For example, the present research did not account for participant race in the analysis which is a factor found to be underlie variance in dementia knowledge (Ayalon, 2013).

One suggestion for future research is to explore the underlying factors of dementia awareness more thoroughly and accurately. The questionnaire utilised in this study measured 'true', 'false' and 'don't know' responses to a set of statements. However, many of these items measured personal beliefs about dementia, such as whether they believe that there is a stigma associated with dementia. For items such as these, there is no right or wrong answer. Future research may consider designing a questionnaire based purely on dementia facts. A total correct score could then be calculated for each participant. This could make it much easier to directly compare the effect of variables such as age, education, gender and ethnicity on participants' knowledge of dementia. In addition, it would be interesting to collect qualitative data, investigating public perceptions of dementia. This would provide a more thorough understanding of public views and the reasons why people may delay seeking medical help when they suspect dementia.

Further research also needs to examine the effectiveness of educational interventions aimed at the public to increase dementia awareness. The literature contains large scale research projects which examine the effectiveness of educational interventions aimed at GPs. An example of such a project includes the EVID-EM trial, which aimed to increase recognition and response to dementia in primary care settings (Iliffe, 2010). The

trial includes educational interventions aimed at both general practice and practice nursing and provides associated educational resources to further support development needs. However, little research has focused on public interventions to improve dementia awareness. One study looked at the effectiveness of interactive voice response telephone systems to receive public calls regarding concerns of dementia and presented encouraging findings (Mundt, Kaplan & Gresit, 2001). Public education is not only important to help people identify the symptoms of dementia and seek help at an early stage but it is also important in order to reduce dementia stigma and public perceptions on how well people can live with dementia.

#### *3.4.2 Conclusion*

Study Two provides useful insights regarding gaps in basic knowledge of dementia and perceptions of the disease held within the general public of Hull and Sheffield. The primary aim of this study was to determine whether differences in dementia knowledge existed between the two locations. In accordance to our hypothesis, the Hull group exhibited significantly lower levels of dementia knowledge on multiple areas that were assessed. These key areas included knowledge of causal factors and at risk groups, awareness of symptoms typically associated with dementia and the ability to distinguish dementia from typical ageing. The perceptions of dementia exhibited by the Hull group also appeared to be more negative than those of the Sheffield group. For example the Hull group were less likely to believe memory loss in ageing to be a serious medical condition and less likely to believe an early diagnosis to be valuable. They also used significantly more negative terms to describe a dementia, including pale, weak, unpredictable, insane, mental,

old and aggressive. Such descriptions imply that dementia stigma may be particularly evident in Hull, perhaps where dementia awareness is not as high as other regions.

It is possible that the lower levels of dementia knowledge and increased negative perceptions observed in the Hull group could result from a lack of public education regarding the disease. This explanation is supported by the finding that only 22.6% of the Hull group claimed to have heard more about dementia in the last five years compared to 45% in the Sheffield group. The lower levels of dementia knowledge observed in Hull could therefore contribute to the lower diagnostic rates.

Although the Sheffield group exhibited significantly more dementia awareness than the Hull group, performance by both groups was suboptimal. Large gaps in dementia knowledge were evident in both participant groups. Both groups drastically underestimated the prevalence of dementia and showed a lack of awareness of populations at risk of developing the disease. Although groups were able to identify the common disease symptoms (e.g. memory loss) there was a clear lack of awareness of the less common symptoms such as problem solving and impaired reasoning. A lack of awareness was also presented for the neuropsychiatric symptoms that are highly associated with the rarer causes of dementia. Although both groups were able to list memory loss as a symptom of dementia, they failed to view memory loss as a serious medical condition and instead considered it to be a normal part of the ageing process. Furthermore, the majority of both groups believed there to be a stigma associated with dementia. Over 70% of both groups also claimed that they would delay seeking medical help if they suspected that they or a family member had dementia. This was led by uncertainty of the disease symptoms, embarrassment and fear of worrying family close relatives.

The major implication of the present research is that public educational interventions are of vital importance to improve dementia knowledge within the general public. Such interventions should focus on increasing public knowledge of the full range of dementia symptoms and improving knowledge of groups which may be particularly at risk of developing the disease. Increasing dementia awareness within the general public is of particular importance as dementia knowledge is documented to be positively correlated with help seeking behaviours (Werner, 2003). Educational interventions should also aim to address the finding that the general public claim that they would delay seeking medical help if they suspected dementia. This issue could partly be address through increased awareness of the benefits associated with an early diagnosis. The present research also highlights that populations in particular need of such interventions include older adult groups and individuals educated below degree level, where dementia awareness was found to be particularly low. To conclude, the present findings should be integrated in to future educational interventions that aim to increase local dementia diagnosis rates by improving the publics' ability to recognise dementia in the early stages of the disease and seek medical help as soon as possible.

### **General Discussion**

A systematic review of the literature exploring dementia diagnosis in primary care suggested that there are three key barriers when attempting to confirm a diagnosis in the early stages. These include provider factors (relating to General Practitioners), system factors and factors relating to patients and their associated caregivers (Bradford et al., 2009). With this in mind, the present studies investigated barriers specific to Hull, East Riding and Sheffield PCT, which could contribute to the poor dementia diagnosis rates

observed within these areas. GP attitudes were investigated towards the importance of a dementia diagnosis along with the perceived barriers affecting their ability to diagnose a patient in the early stages of the disease. Public knowledge and perceptions of dementia were also examined within Hull and Sheffield in order to identify whether poor knowledge of the disease aspects could act as a barrier to help seeking.

In accordance with previous research, GPs expressed that provider factors affecting their ability to confirm a diagnosis included lack of training specific to dementia (Boise et al., 1999; Cahill et al., 2008; Iliffe & Wilcock, 2005), limited knowledge and accessibility of accurate cognitive screening tools (Hansen, 2004) and negative attitudes regarding the benefits of an early diagnosis (Bradford et al., 2009; Milne, 2000; Renshaw, Cloke & Orrell, 2001). In particular, GPs expressed significant scepticism regarding the benefits of administering pharmacological treatments early in the disease. Even though Practitioners were in agreement that a diagnosis provided many practical benefits (such as increased time for financial planning and legal arrangements), many were concerned that a diagnosis could be hazardous for a patient as there is currently a lack of secondary care and community support services to fully support the patient's needs.

As well as GP barriers, system barriers also played a major role in preventing the early diagnosis of dementia. Such barriers mainly resulted from poor availability of essential resources. The studies were consistent with previous findings that lack of time in a typical patient visit (Olafsdottir, Foldevi & Marcusson, 2001; Turner et al., 2004) and poor availability of specialist services (Turner et al., 2004) severely affect the GPs ability to make a diagnosis. The sample claimed that making a diagnosis was a lengthy process and they felt that they had insufficient time to conduct the adequate cognitive tests, collect a detailed

medical history of the patient and to fully understand and address the needs of patient and family. GPs expressed genuine concerns for the psychological well being of a patient when informing the patient that they suspect dementia, knowing that they will then be faced with a waiting list of up to four months to see a consultant. Practitioners then felt let down by the service offered to dementia patients within secondary care. Patients would regularly forget their appointments and be placed back at the start of the waiting lists. Secondary care was also said to discharge patients without thorough examination, ignoring the concerns of the GP. Even when a diagnosis is made, the GP then feared that there was inadequate community support to accompany it. These concerns were increasingly presented by GPs in East Riding PCT, where resources were reported to be particularly scarce. It was repeatedly claimed that post-diagnostic services, particularly those located within East Riding, needed drastic improvement as they currently provide inadequate cognitive or psychological benefits for patients or caregivers.

Delays in diagnosis were also regularly attributed to patient and caregiver factors. GPs claimed that conflict from the patient and their family acted as a strong barrier to the delivery of an early diagnosis and the subsequent quality of their care and management. In agreement with existing research, GPs claimed that the public lack awareness of the common symptoms of dementia and therefore fail to seek medical help until the disease has progressed significantly and a crisis point is reached (Iliffe et al., 2005; Teel, 2004). Patients were also said to regularly deny their memory problems, which cause additional delays to help seeking (van Hout, Vernooji-Dassen, Bakker, Blom & Grol, 2000).

Results from the study of public knowledge were consistent with the views presented by the GP sample as dementia knowledge and perceptions were found to be

suboptimal within the general public of both Hull and Sheffield. Confirming previous findings, large gaps in dementia knowledge existed surrounding the symptoms of dementia (Werner, 2003) and causes and groups at high risk of developing the disease (Arai, Arai & Zarit, 2008; Steckenrider, 1993). Negative perceptions of dementia were also evident from both groups. Over 60% of participants in both groups believed that there was a stigma attached to dementia. Furthermore, when asked to describe a patient with dementia, some descriptions included 'old', 'aggressive', 'mental', 'insane', 'weak' and 'pale'. These results strongly support the growing body of evidence documenting dementia stigma in the general public (Mackenzie, 2006; Vernooji-Dassen et al., 2005). GPs from Study One feared the impact that this stigma would have on a patient once they have been given a label of dementia. Poor awareness of dementia and negative attitudes of the disease were particularly evident within the Hull group, which could act as a contributing factor to their lower diagnosis rates compared to Sheffield.

The present studies are the first of their kind to explore factors underlying poor dementia diagnosis rates within the county of Yorkshire. The results are therefore of particular relevance for future attempts to improve the diagnostic service. Hull and East Riding PCT currently hold a diagnosis rate of 44.7% and 38.5% respectively (Alzheimer's Society, 2013). With the incidence of dementia predicted to double over the next forty years, it is essential that the findings from this study are utilised to develop new methods to address the growing problem of dementia in this area. Suggested methods will now be discussed to address the provider, service and patient barriers experienced within this area.

Firstly, in order to improve the diagnosis service provided by the GP, several suggestions were presented. GPs stated the need for increased education specific to

dementia, either through the 'protected time for learning scheme' or through educational resources which were organised in a clear manner and could be accessed via a single website. The need for education on how to differentiate dementia from normal ageing, which cognitive tests should be utilised and information regarding the benefits of administering pharmacological treatment in the early disease stages was repeatedly stressed. Clear and systematic diagnostic guidelines were also requested which could guide GPs through the diagnosis process. Interesting, some Practitioners claimed that their practice already had such guidelines in place, suggesting that useful resources were not being shared between practices or across PCT boundaries.

Interventions to improve the service offered by Practitioners should also be informed by research investigating patient experiences though the diagnosis process and opinions on how the GP could have improved the way in which they managed their case. Previous research has documented cases where patients reported the GPs failure to provide adequate information about the disease (Holroyd, Turnbull & Wolf, 2002). Some patients even claimed that the GP exhibited uncertainty, reluctance to confirm the diagnosis and deliberately withheld important information (Teel & Carson, 2003). This repeatedly led to a patient's mistrust of the Practitioner. Such experiences could be extremely informative when designing education interventions for medical professionals in order to create a more patient-centred approach.

Secondly, GPs recommended several methods for improving the service offered to patients on whole. It was proposed that practice nurses could be trained to administer cognitive tests. This would alleviate the time pressures placed on GPs and could also be used in the development of a local dementia-screening program for patients at particular



risk. Screening could also be introduced for patients who are part of the 'chronic disease management' using a single tick-box question of whether they currently suffer from any memory complaints. It was additionally suggested that dementia consultants could offer a dementia clinic at local practices once a month to reduce the bottleneck of patients remaining on waiting lists. Finally, in accordance to previous research (Iliffe et al., 2005), GPs stated that there needs to be a vast improvement in the integration of primary, secondary and community based support services. This could be achieved by the introduction of dementia case managers.

The present findings demonstrated that GPs highly valued post-diagnostic services but some felt that local services, specific to this area, were oversubscribed and failed to provide significant psychological or cognitive benefit to the patient. Suggested methods of improvement included 1) improving the availability of such services, 2) introduce more home based services for patients in the later stages of the disease and 3) to make services more cognitively and psychologically beneficial and fun for patients and caregivers to encourage them to attend. Future research should also take patient and caregiver views on what aspects they find beneficial from such services. For example, research exploring patient experiences of local support groups found that such services provided many benefits to the patient (Mason, 2005). Patients greatly valued social interaction and sharing experiences with people in a similar situation as themselves. This had the added benefit that it was based in a welcoming and accepting environment where communication was facilitated for those experiencing communication difficulties. The service was described as an 'anchor' as it was a continual form of support. It gave members the chance to learn more about their condition and discuss potential coping mechanisms. Such views should be

taken into account when developing and improving post-diagnosis services to ensure that they meet the needs of the patient and caregiver.

One method to measure performance and monitor improvement of both provider and service factors is to introduce pre-existing and validated quality indicators, which measure the quality of dementia management. For example, Perry and Colleagues developed and validated a set of twenty-three quality indicators, which measured factors such as collaboration between GPs and practice nurses, referrals and the assessment of patient and caregiver needs (Perry et al., 2010). This would be beneficial, as it would allow differences in the quality of dementia management between PCTs to be quantitatively determined and reasons for these differences in quality to be clearly identified.

Thirdly, the barriers to diagnosis elicited by patients and caregivers need to be met with large-scale public education strategies. The general public need to become well informed of the symptoms of dementia to allow them to identify the disease in the early stages and seek medical help at a time where it will be most beneficial. Educational interventions should aim to increase public awareness of the populations at particular risk of developing the disease and the benefits of receiving an early diagnosis. Although GPs claimed that public awareness was on the increase, they stressed the need for media sources to be accurate with their information and not over emphasize the effectiveness of current drug treatments.

Interventions should also aim to make the public more accepting of patients currently suffering from the disease as previous research indicates that patients experience stigma, social isolation and feelings that they have to hide their memory problems from others (Katsuno, 2005). They also fear public reactions when informing others of their

diagnosis. They stressed the need for public education to reduce negative perceptions, such as the disease being contagious or that patients are crazy. Findings from Study Two compliment these findings as the general public exhibited reluctance to discuss memory problems with others if they were concerned about their own or someone else's memory. Educational interventions are therefore essential in order to encourage help seeking behaviours and decrease stigmatisation for patients who are currently suffering from the disease.

After reviewing the present studies, considerable evidence exists suggesting that factors such as GP perceptions of the importance of an early diagnosis and public knowledge of dementia could both play an important role in determining the local diagnosis rates. The area of particular focus was Hull, which current holds a diagnosis rate of 44.7% (Alzheimer's Society, 2014). Interestingly, Study One demonstrated that although GP views were similar in both groups, GPs practicing in East Riding PCT expressed greater fears that a diagnosis would have little benefit due to the limited availability of local specialist and support services, compared to GPs in Hull PCT. East Riding PCT currently only holds a diagnosis rate of 38.5%. This lower diagnosis rate could therefore be a partial result of the poor access to dementia related services. Furthermore, when we compared dementia knowledge between members of the public of Hull and Sheffield, we found significantly less dementia awareness in Hull. Therefore, knowledge of dementia could contribute to Sheffield's significantly higher diagnostic rate of 68.08%.

The studies present numerous suggested methods for improving local diagnosis rates both from a primary care and public perspective. They also contain important and detailed information that can be utilised in the development of educational interventions

aimed at medical professionals and the general public. Such interventions and improvements to the primary care service are crucial in order to accommodate the ever-increasing incidence of dementia.

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## Appendix A

### GP Interview: Investigating GP attitudes towards dementia diagnosis in primary care.

I am now going to ask you a series of questions. In your answers, please provide as much information as possible.

**1) Have you noticed an increase in the number of patients with dementia throughout your time in practice?**

**2) Do you feel confident when making a diagnosis of dementia?**

-Particular areas most comfortable with/ lack confidence

**3) Do you consider the early diagnosis of dementia to be important?**

-Can you think of any benefits? / Can you provide any more information on the benefits?

-Can you think of any hazards? / Can you provide any more information on the hazards?

-Have your beliefs about the benefits and hazards changed at all?

**4) Do you think that screening for dementia should take place in Primary Care settings?**

-Advantages

-Disadvantages

-What about in populations particularly at risk

**5) Do you ever spot warning signs of dementia? Can you tell me about when and how?**

-Can you provide case examples?

-What do you look for?

-Reactive or proactive

**6) \*If something leads you to suspect that a person has dementia, could you tell me about what you would do next?**

**7) Do you use any screening tests when diagnosing dementia? Can you tell me anything about why or why not?**

-Benefits/ limitations

- Availability

-Informant

**8) Do you feel that there are any barriers when diagnosing dementia?**

**9) \*Could you tell me a bit about how you differentiate memory problems caused by dementia from memory problems caused by normal aging?**

-Previous cases

-How might you go about the process of differentiating between the two?

**10) Do you experience difficulties when differentiating patients who have memory concerns due to psychological factors (e.g. depression), from patients with real cases of dementia?**

-How might you go about the process of differentiating between the two?

-Previous cases

**11) Have you attempted to differentiate between different types of dementia?**

-Why? If not, why not?

**12) What are your feelings about disclosing a diagnosis of dementia?**

- Difficulties faced

-Times it works better than others

**13) If a colleague was new to diagnosing dementia what advice might you give them?**

**14) How effective do you think pharmacological treatments for dementia are? What are the benefits and drawbacks of such treatments?**

- Experience from patients
- What do you usually prescribe and why?
- Acetylcholinesterase inhibitor medication?

**15) How effective do you think the psychosocial treatments for dementia are? What are the benefits and drawbacks of such treatments?**

- Patient experience
- Availability?

**16) Do you think that the current interventions (social or pharmacological) warrant a drive for early diagnosis?**

**17) Has your approach to dementia diagnosis changed over time? How and why?**

**18) Could dementia diagnosis be improved in Primary Care?**

- If so, how?

**19) Can you tell me about any training you've received or any information you've been provided with about diagnosing dementia?**

- What information or training has been provided? Please provide details
- Who or what organisation provided the info/training?
- Applicable to everyday practice?

**20) Can you tell me about any training you've received or any information you've been provided with about dementia treatment?**

- What information or training has been provided? Please provide details
- Who or what organisation provided the info/training?

**21) Could you summarise for me the most important points about dementia diagnosis for you.**

**22) Have you any suggestions for future topics of research relating to the diagnosis of dementia?**

**23) If you were studying dementia diagnosis as I am, are there any other questions that you would ask?**

## Appendix B

Initial Coding: Line-by-line coding	
<p>Excerpt from interview transcription 3</p> <p><i>So I have had a patient recently that I suspected definitely has dementia, they have also been denying things, so is very reluctant to come in and finally did come in and we made a referral, but his wife was told that it would be months... over 4 months until they could be seen and so she's made the difficult decision of arranging a private appointment just because she felt that there was no option really and so that's one of the biggest barriers. This is really disheartening when you've got a lot of media coverage encourage people to come in. Also, in education for GPs in terms of recognising and picking up on early signs of dementia and then when you refer you face what seems to be a good service when you get there, and I am sure they are really struggling under the weight of referrals, but is now an overloaded service that you cannot access. So, people give up and you know the chance of them forgetting their appointment is quite high anyway, so then you are back at the beginning of the weighting list if you forget because you've got a memory problem</i></p>	<p>Dealing with patient denial and reluctance to seek help</p> <p>Unsatisfied with long referral waiting lists for specialist help.</p> <p>Feeling of lack of options for patients Feeling disheartened</p> <p>Positive views on the quality of service</p> <p>Perceived inaccessibility of secondary care services.</p> <p>Facing the same process from the beginning</p>

## Appendix C

Focused Coding	
<p>Excerpt from interview transcription 5</p> <p><i>I think the main barriers (to a diagnosis of dementia) are often the individual attitudes themselves, whether there is an element of denial, whether they are ready to accept there is a problem. Erm, I think, erm, so in a sense there's an element of insight and then there's the element of compliance and accepting, erm, that they are going to go through the process, and actually one of the more positive things has been the change in the NICE guidelines on prescribing medication because for most people the thought that there might be some medication, to at least keep them where they are and stop things deteriorating, erm, is something that we can offer as a way of encouraging them to have the tests and see whether we can improve things. Erm, generally speaking it's not the carers. Most carers choose to, erm, get involved, erm, because the burden tends to fall on them. Probably, yeah, I think the support is probably sufficient in terms of diagnostically and recommendations for treatment, for it not be as much of an impediment as it previously was. It seemed to be a long, drawn out process before, without any significant outcome other than maybe the label. So, it's really what goes with the diagnosis.</i></p>	<p>Battling with patient denial</p> <p>Perceived benefits of medications</p> <p>Evolving views regarding the perceived importance of a diagnosis</p>

## Appendix D

### **Early Memo**

**Title:** Feared lack of support for patients

Feared lack of support for patients refers to the level of support offered to both patients and their caregivers during and after the disclosure of the diagnosis has occurred. Support is made up of contributions from primary care, secondary care and community support services. Support appears to refer to services which can help the individual come to terms with the diagnosis, receive help with daily activities.

The participant exhibits increasing compassion for both patients and caregivers, acknowledging how difficult the disclosure of a diagnosis can be. Fear of a lack of support is repeatedly presented. The conditions that have led to this fear have not been stated. However, the participant fears that patients will just be “pushed from pillar to post”.

The feared lack of support seemed to predict other key themes which emerged throughout the interview, including the need for service improvement. The consequences of the expressed fear led to compassion for patients and a need for primary care to improve. This is supported by claims that “we really need to pull our socks up”. The fear of lack of support did not lead to an increased negativity regarding the importance of an early diagnosis. The feared lack of support seems to be evolving and getting worse as the number of dementia patients rise and the services become more limited as a result.

### **Notes**

- Need to further investigate consequences of this fear throughout interview transcriptions
- need to compare fear between participants and understand if and why variation in fear levels occur.



Appendix E

**DEMENTIA QUIZ FOR GENERAL PUBLIC**

AGE:
GENDER:
EDUCATION (IN YEARS):
LOCATION OF TESTING:

**Part A**

**1) Do you consider dementia to be a natural part of ageing?**

YES                      NO                      DONT KNOW

**2) Can you tell me any of the symptoms of dementia?**

YES                      NO

**If yes, please list ...**

**3) Dementia and Alzheimer's disease mean the same thing?**

TRUE    FALSE    DONT KNOW

**4) What proportion of people over the age of 65 develop dementia?**

- a) 1/3
- b) 1/5
- c) 1/8
- d) 1/10

**5) Out of the 62.6 million people living in the UK today, how many have dementia?**

- a) 220,000
- b) 420,000
- c) 620,000
- d) 820,000

**6) Dementia is more common in women than men?**

TRUE                      FALSE                      DONT KNOW

**7) Dementia only affects people over 65?**

TRUE                      FALSE                      DONT KNOW

**8) Please select the populations particularly at risk of developing dementia? (More than one answer may be correct)**

- a) Down's syndrome
- b) Stroke victims
- c) Heart problems
- d) Parkinson's disease
- e) Huntington's disease
- f) Depressed
- g) None of the above

**9) Please select the symptoms that you associate with the early stages of dementia? (more than one answer may be correct)**

- a) Anxiety and depression
- b) Struggling to remember recent events
- c) Seizures
- d) A decline in the ability to talk, read or write
- e) Auditory hallucinations
- f) Forgetting the names of friends or everyday objects
- g) Headaches
- h) Sudden changes in mood and personality
- i) Struggling to remember events that happened a long time ago
- j) Vertigo

**10) What percentage of dementia patients living in the UK have received a diagnosis?**

- a) 24.1
- b) 41.1
- c) 51.1
- d) 61.1

**11) People with dementia can be treated with medication?**

TRUE                  FALSE                  DONT KNOW

**12) Dementia can be cured by the right medication, if detected in the early stages**

TRUE                  FALSE                  DONT KNOW

**13) I will now read a list of symptoms. Please state whether you believe them to be a symptom of dementia or a symptom of normal aging.**

- a) Occasional word finding difficulties
- b) Occasionally calling people by the wrong names
- c) Loss of interest in social activities.
- d) Complains of memory loss and able to detail incidents of forgetfulness
- e) Unable to operate even simple new appliances.

- f) Repeating self and losing thread of what people are saying.
- g) May have to pause in familiar territory to find their way
- h) Becomes dependent of others for daily living activities.

**14) Memory loss can be a natural part of ageing. What factors would lead you to suspect that memory loss were being caused by something more serious than typical ageing?**

**Part B**

**1) Do you consider memory loss in old age to be a serious medical condition?**

YES                      NO                      DONT KNOW

**2) Have you known/ Do you know anybody with dementia?**

YES                      NO

**3) Do you think there is a stigma attached to dementia?**

YES                      NO                      DONT KNOW

**4) What words would you use to describe a dementia patient?**

**5) Nothing can be done to help people live well with dementia?**

TRUE                      FALSE                      DONT KNOW

**6) Do you think that the early diagnosis of dementia is important?**

YES                      NO                      DONT KNOW

**Can you provide reasons for your answer?**

**7) Do you expect your memory to decline significantly in old age?**

YES                      NO                      DONT KNOW

**8) Have you heard more about dementia in the news or in other media over the last 5 years?**

YES                      NO                      DONT KNOW

**9) If you suspected that you might have dementia, would you delay voicing these concerns with your family and friends?**

YES                      NO                      DONT KNOW

If so, why?

**10) If you suspected that you had dementia, who would you first consult?**

- a) GP
- b) Family member
- c) Friend or neighbour
- d) Nurse/social worker
- e) Support group
- f) Other

If other – please list:

**11) If you suspected that a family member or friend might have dementia, what would you do?**

**12) Would you feel comfortable telling somebody that you were concerned about their memory?**

YES                      NO                      DONT KNOW

If not, why?

**13) If your doctor determined that you had dementia, would you want to be told the diagnosis?**

YES                      NO                      DONT KNOW

**14) Do you think that there is enough public awareness about the key facts of dementia?**

YES                      NO                      DONT KNOW

**15) Would you know where to find information on dementia?**

YES

NO

**If yes, where would you look?**

**16) Do you have any further comments about any of the topics we have discussed?**

## Appendix F

**Dementia fact sheet**

**Dementia is NOT a natural part of aging**

**Dementia is a set of symptoms brought on by diseases that cause changes in the brain. The most common of these is Alzheimer's disease.**

**The common symptoms of dementia include: memory loss, mood changes and problems with communication and reasoning. Warning signs may include: struggling to remember recent events, a decline in the ability to read, talk and write, frequently forgetting the names of everyday objects or friends, anxiety or depression, and mood changes.**

**1 in 3 people over 65 will develop dementia**

**2/3's of people with dementia are women**

**There are currently 820,000 people with dementia living in the UK. This is set to double over the next 40 years.**

**Currently only 41% of people with dementia have received a diagnosis**

**Although much less common, it is possible for people under 65 to develop dementia**

**Populations who may be particularly at risk from developing dementia include people who have: Down's syndrome, Parkinson's disease, Huntington's disease, Stroke and those suffering from heart problems or late life depression.**

**There are treatments and therapies available for people with dementia. Although there is currently no cure for dementia, effective treatments are available to slow down the progression of the disease.**

**An early diagnosis is vital because it may postpone long-term residential care, help financial planning, help family decisions, and facilitate treatment options.**

For further information on dementia please refer to the Alzheimer's Association website:

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

If you require any further information about this research project or have any additional questions please contact Lydia Grace via email ([l.grace@2012.hull.ac.uk](mailto:l.grace@2012.hull.ac.uk))

Information retrieved from [www.alzheimers.org.uk](http://www.alzheimers.org.uk) on 10.12.2012