Prevalence and Recognition of Dementia in Primary care:

A Comparison of Older African-Caribbean and

White British Residents of Haringey.

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Submitted for PhD examination in December 2009

I, Simon Adelman, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

ABSTRACT

Background: As the elderly population in Britain continues to grow, so will the number of people with dementia. Notably, those affected will include an increasing proportion of people from black and minority ethnic (BME) communities, as they too are reaching old age in large numbers. Preliminary studies indicate that African-Caribbean people may be at higher risk of developing dementia than the indigenous, white older population, although the findings are inconclusive. It has also been hypothesised that an excess of dementia in this group may be related to an increased risk of hypertension and its ineffective detection or treatment. Hypertension and diabetes, also common in African-Caribbean people, are established risk factors for cerebrovascular disease and dementia. However, despite these findings, it has been observed that people from BME groups, including those of African-Caribbean descent, may be less likely to have their dementia treated with an equitable level of resources.

Aims and Hypotheses: The aim of this study is to enhance our knowledge regarding dementia and its risk factors in older African-Caribbean people in Britain. It tests the primary hypothesis that the prevalence of dementia is higher in the African-Caribbean, than the white British-born older population, using General Practice lists in the London Borough of Haringey as sampling frames. The study also tests the secondary hypothesis, that dementia in African-Caribbean people is under-recognised in primary care and that the rate of referral to specialist dementia services is lower than that in the white-British population.

Methods: The study comprises a comparative cross-sectional and a medical notes survey. Five General Practices were recruited in Haringey, North London. From their practice lists, 218 African-Caribbean people and 218 white-British people aged ≥60 years were recruited and screened for cognitive impairment using culturally valid versions of the Mini Mental State Examination (MMSE). Those in either group who screened positive (scoring <26/30), were offered a standardised diagnostic interview and physical examination. Two independent assessors blind to ethnicity, used this information to diagnose dementia according to operationalised criteria and from this, the prevalence of dementia

was calculated for each group. Participants diagnosed with dementia, had their primary care medical notes scrutinised for documentation of cognitive impairment or dementia. Use of brief screening tools for cognitive impairment and referrals to secondary health care or social services were also recorded. The frequency of documented cognitive impairment, dementia and referral to specialist services were compared between the two groups.

Results: The prevalence of dementia was higher in the African-Caribbean (9.6%) than the white-British group (6.9%), and the difference was significant after controlling for age and socioeconomic status (OR=3.1; 95%CI=1.3 -7.3; p=0.012). African-Caribbean participants were on average two years younger, and those with dementia nearly eight years younger than their white-British counterparts. There was a significantly higher proportion of vascular dementia diagnosed in the African-Caribbean group, although the numbers were small and participants only met the criteria for a *possible* rather than *probable* diagnosis. There were higher rates of both treated and unrecognised hypertension in the African-Caribbean group. A history of hypertension was associated with cognitive impairment, but not dementia. The rate of documented dementia was 42% and referral to specialist dementia care 36% for all participants combined. The African-Caribbean group was at least as likely to have their dementia recognised and documented in primary care as the white-British group. However, they were less likely to be referred to specialist dementia services, although the numbers were small and this finding was not statistically significant.

Conclusions: There is now strong evidence for an increased prevalence of dementia in older African-Caribbean people in Britain and that this may occur at significantly younger ages than in the indigenous white population. There is also some evidence for an excess of hypertension and vascular dementia in this group. These findings have implications for service provision and preventative interventions. Although General Practitioners are at least as likely to recognise and document a diagnosis of dementia in African-Caribbean than white people, they might be less inclined to refer them for specialist assessment. This warrants further investigation in the form of a qualitative study.

ACKNOWLEDGEMENTS

I would like to thank my supervisors Gill Livingston and Martin Blanchard for their immense support throughout the project. I would also like to thank Gerard Leavy and Greta Rait for their expert advice.

I am grateful to the study participants, the general practice staff and staff of the residential homes for their support.

Many thanks also to those who helped me with data collection including Shilpa Bavishi, Mike Groszmann, Gemma Hardy, Shamir Patel, Azlam Pirzada, Adam Roberts and Khodayar Shahriyarmolki.

Finally I would like to thank the Medical Research Council for funding the project and DeNDRoN for their assistance.

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LIST OF ABREVIATIONS

AD	Alzheimer's Disease
AMT	Abbreviated Mental Test
APO E	Apolipoprotein E
BME	Black and Minority Ethnic
CAMDEX	Cambridge Mental Disorders of the Elderly Examination
CI	Cognitive Impairment / Confidence interval
CT	Computerised Tomography
DLB	Dementia with Lewy bodies
DSM	Diagnostic Statistical Manual
FTD	Frontotemporal Dementia
GP	General Practitioner
ICD	International Classification of Disease
MCI	Mild Cognitive Impairment
MH OR	Mantel-Haenszel Odds Ratio
MMSE	Mini Mental State Examination
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NS-SEC	National statistics – socioeconomic classification
PCT	Primary Care Trust (NHS)
QOF	Quality Outcome Framework
RCT	Randomised Controlled Trial
SPECT	Single Photon Emission Computed Tomography
VaD	Vascular Dementia
WHO	World Health Organisation

“I am thinking about my being black and growing old in Britain. Will my old age, I wonder, be a calamitous plunge deeper into the underclass, or simply part of the general heritage of the struggling old, regardless of race or class?”

Beryl Gilroy (1994)

1. INTRODUCTION

1.1. SCOPE OF THE THESIS

In my thesis, I will describe the study that I conducted during my Medical Research Council (MRC) research training fellowship in 'Health Service Research', between September 2006 and October 2009; comparing the prevalence of dementia between older African-Caribbean people and their white counterparts. I will first 'set the scene' before describing in detail, the background to the study.

Dementia is a national health and social care priority in Britain (section 1.2.4.3). Over recent years, there has been growing interest in dementia in Black and Minority Ethnic (BME) people, as they constitute an increasing proportion of the older population (section 1.3.4). This is particularly so for black people of African origin; because a relatively high prevalence of the disorder has been demonstrated in some community studies and because this may be partially related to an excess of vascular risk factors that are potentially amenable to preventative measures (section 1.5). Further research in this field will help us to understand the aetiology of dementia, identify preventative interventions, consider whether these minority groups have equitable access to health and social care and therefore allow for the planning of culturally sensitive services. These questions can be further investigated by studying older African-Caribbean people in North London, where a large number reside. Older members of this community are predominantly first generation immigrants, originally from the Caribbean, who came to the UK in the 1950s and early 1960s; invited to fill specific gaps in the labour force following World War II (section 1.4.2).

People of African-Caribbean descent contribute a significant proportion of the total London population, particularly in some Boroughs in the South East, North and North-West of the capital (section 1.4.4). For example, in the Borough of Haringey where this study is set, 11% of the population identified as being African-Caribbean or mixed race in the 2001 population census (ONS, 2003). This community is now ageing and many of its members have reached retirement, putting them in the age group where there is a significant risk of developing dementia. As this is the first generation of African-Caribbean people in this country to have reached old age, we know little about their needs pertaining to age related illnesses including dementia. Although a small number of cross-sectional studies conducted in Britain indicate a possible excess of dementia in this population, the findings have so far been inconclusive (Chapter 2). It is therefore important to identify the scale of morbidity, unmet need and to plan for the future if we are to ensure access to appropriate care, given the potential for large numbers of people with dementia in this ethnic group.

In this chapter, I will discuss the term *dementia*, its different definitions and briefly describe the main subtypes, clinical features, diagnostic criteria and risk factors. I will then consider relevant epidemiological aspects of the disorder including the prevalence, both worldwide, in the UK and at different age groups as a baseline on which to compare my findings. I will then outline relevant reports, policies and the recently published National Dementia Strategy for England. Next is a section describing health and dementia in older BME populations in Britain and then more specifically in the African-Caribbean community. To complete the picture, I will also consider aspects of dementia in other black populations of African origin including prevalence and risk factors. This is illustrated with examples from the extensive African-American literature from the USA and comparisons are made with the British, African-Caribbean population. **Chapter 2** describes the systematic review that I undertook to identify and synthesise the published literature on the rates of dementia and associated risk factors in the African-Caribbean population, living in the UK.

In **Chapter 3**, I summarise the aims and hypothesis of the study and in **Chapter 4**, the methods employed for a cross-sectional survey that forms the basis of this thesis. As well as comparing estimates for the prevalence of dementia in older African-Caribbean and white-British community participants, I examine the documentation of dementia diagnosis by general practitioners and their rates of referral to specialist dementia services in the London Borough of Haringey. In **Chapter 5,** I report the findings from the study and describe the statistical analysis and finally in **Chapter 6,** I discuss the implications and limitations of the study followed by the potential for further work, before drawing my conclusions in **Chapter 7**.

1.2. DEMENTIA

1.2.1. Definition and diagnostic criteria

The word *dementia* comes from the Latin *demens,* which translates literally as '*without mind'.* The first reference to its common usage was in Blancard's popular dictionary in 1726. There, it was defined as *'the extinction of the imagination and judgement'* (Blancard, 1726). The adjective *demented* however, appeared over 80 years earlier in the Oxford English Dictionary of 1644. A more modern dictionary definition of dementia would be of *'a chronic or persistent disorder of the mental processes due to brain disease or injury'* (Oxford English Dictionary).

There are many slightly different medical definitions of dementia. The recent National Dementia Strategy document (DoH, 2009), defined it as:

".. a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of functioning, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness" .

For clinical and research purposes, mental disorders including dementia, can be diagnosed according to sets of criteria stipulated by health or research bodies such as the World Health Organisation (W.H.O, 1992) or American Psychiatric Association (A.P.A, 1994) (described below). Such criteria are often 'operationalised', in that they define categorical entities according to a series of precise inclusion and exclusion statements. This allows for more reliable clinical diagnosis and can overcome the problem of differences between regional or national classifications (Stengel, 1959).

The most widely accepted operationalised diagnostic research criteria for dementia include those set by the two main international diagnostic classification systems; the European based International Classification of Disease, currently in its 10th edition; ICD-10: diagnostic criteria for research (W.H.O, 1993a) and the North American Diagnostic and Statistical Manual, currently in its fourth, text revised edition; DSM-IV-TR (A.P.A, 2000). Both sets of criteria have a number of common elements, but also some important differences outlined below.

To diagnose dementia according to ICD-10, conditions in four domains must be fulfilled:

- *Objective evidence of cognitive decline, affecting both memory and other cognitive abilities such as judgement or planning.*
- *Symptoms that should be present in the absence of clouding of consciousness.*
- *A decline in emotional control or social behaviour to include irritability, emotional lability, apathy or coarsening of social behaviour.*
- *Cognitive decline should have been present for at least six months.*

The ICD-10 criteria stipulate the need for a reliable informant history, which should be supplemented, if possible by neuropsychological testing. If the criteria for dementia are fulfilled, there is provision to classify this clinically as *mild, moderate or severe*.

The DSM-IV criteria could be considered broader than ICD-10, in that they don't specifically require an informant history, nor do they stipulate a minimum period for the presence of symptoms. However, like ICD-10, they do state that social functioning must be affected.

Again, four domains must be satisfied to make a diagnosis:

- *The development of multiple cognitive deficits including memory and at least one of; aphasia, apraxia, agnosia or disturbance in executive functioning.*
- *A significant decline in social or occupational functioning.*
- *That the deficits do not occur exclusively during the course of delirium.*
- *That the symptoms are not better accounted for by another psychiatric disorder such as depression or schizophrenia.*

The term *'dementia'* alone is broad and implies a clinical syndrome, rather than any particular aetiology or pathological process. There are however, specific dementia types, synonymously termed 'subtypes' and a number of diagnostic systems and criteria in use for each one. Worthy of note, is that the prevalence of each type can vary considerably depending on the set of criteria being used. This is discussed further in section 1.2.3.1.

1.2.2. Dementia subtypes: Clinical features, diagnosis and risk factors.

A clinical picture of dementia can occur at almost any age and can be caused by a number of underlying and sometimes overlapping disease processes; neurodegenerative and vascular being the most common in old age (see table 1.1). Although some causes are potentially reversible, those that are primarily neurodegenerative or due to cerebrovascular disease are not, and are usually progressive and incurable. The importance of accurate diagnosis is not only to identify and treat potentially reversible causes of dementia (e.g. hypothyroidism, B12 deficiency, syphilis), but for secondary prevention (e.g. treating vascular risk factors), symptomatic management of the condition (e.g. cholinesterase treatment for Alzheimer's disease) and to help patients and their family plan for the future.

Table 1.1 **Causes & types of dementia** **(Foster, 2008)**

AETIOLOGY	EXAMPLES
Primary Neurodegenerative	Alzheimer's disease, Dementia with Lewy Bodies, Frontotemporal dementia (including Pick's disease), Parkinson's disease, Multiple Sclerosis, Huntington's disease
Vascular	Vascular dementia; including multi-infarct dementia, post CVA, small vessel disease
Infection	HIV/AIDS, Neurosyphilis, Creutzfeldt-Jakob and other Prion diseases.
Toxins/drugs	Alcohol, recreational drugs, heavy metal poisoning,
Metabolic	Vitamin deficiencies (B12, folate, thiamine), Wilson's disease,
Endocrine	Hypothyroidism, Addison's disease
Neoplastic	Primary or secondary neoplasms, para-neoplastic syndromes (especially bronchial carcinoma)

Throughout this thesis, I will be referring to the most common types of primary dementia found in older people in Britain, namely Alzheimer's disease (AD), Vascular dementia (VaD), Dementia with Lewy Bodies (DLB) and Frontotemporal dementia (FTD). Although it is not within the scope of this work to give detailed descriptions, I will, using Alzheimer's disease as the comparator, summarise the main clinical features, diagnostic criteria and risk factors for each type in the following section.

1.2.2.1. Alzheimer's disease

World Alzheimer's Day, 21st September 2006, marked the centennial anniversary of Alois Alzheimer's identification of the destructive condition that bears his name. It was in 1906, that Alzheimer identified an *'unusual disease of the cerebral cortex'*, which had affected a woman in her early fifties, Auguste Deter, causing memory loss, disorientation, hallucinations, aphasia and ultimately her death aged only 55 (Thomas and O'Brien, 2001). His post mortem, histopathological examination was the first to identify the characteristic amyloid plaques and neurofibrillary tangles, now associated with the condition (Alzheimer, 1907). Alzheimer's disease (AD) is now recognised as the most common type of dementia, accounting for over 60% of dementia cases in Britain (Knapp, 2007). It can be characterised by so called *'cognitive'* and *'non-cognitive'* symptoms. The former include memory impairment (initially for recent events), aphasia, apraxia, agnosia and executive dysfunction. The latter may include psychotic symptoms; delusions and hallucinations (often visual), disturbance in mood; depression, anxiety, lability of mood, and other behavioural problems such as apathy, agitation, aggression and wandering. It is common for patients to undergo significant physical deterioration including weight loss (Cronin-Stubbs et al., 1997). They may also exhibit neurological signs such as primitive reflexes relatively early on (Thomas and O'Brien, 2001). Later stages are often characterised by incontinence (initially urinary), gait and balance abnormalities and eventually dysphagia, which invariably leads to aspiration pneumonia and death. Although it is not uncommon for people with AD to die *with* the disease (from other causes) rather than from it, mortality has been shown to be higher than in people without dementia, even when matched for physical illness (Paradise et al., 2009b).

As for dementia in general, operationalised criteria have been developed for the accurate diagnosis of AD. For the purpose of this thesis I will refer to the most widely used of these for research, namely the ICD-10 diagnostic research criteria (W.H.O, 1993b), DSM-IV-TR (A.P.A, 2000) and NINCDS-ADRDA (National Institute of

Neurological and Communicative Disorders and Stroke – Alzheimer's Disease and Related Disorders association) criteria (McKhann et al., 1984). In clinical practice AD is essentially a diagnosis of exclusion; defined by gradual and progressive cognitive decline with features consistent with core dementia criteria, in the absence of other possible causes. Both ICD-10 and DSM-IV are based on this premise (table 1.2) and are closely related to the more precise NINCDS-ADRDA research criteria, which has three levels of certainty for diagnosis; definite (requiring pathological evidence), probable and possible AD (Appendix 3).

Table 1.2 **ICD-10 & DSM-IV diagnostic criteria for Alzheimer's disease**

A	The general criteria for dementia must be met (section 1.2.1).
B	The course is characterised by insidious onset and progressive cognitive decline.
C	The cognitive deficits are not due to: o Other CNS conditions that cause progressive deficits in memory and cognition e.g. cerebrovascular disease, Parkinson's disease. o Systemic conditions known to cause dementia e.g. hypothyroidism, B12 deficiency, HIV. o Substance induced conditions

Identification of the predictors (risk or protective factors) for dementia is important, in that it can add to our knowledge regarding aetiology and pathology of the disorder, which can then lead to the development of new treatments. Also by identifying predictors, preventative interventions can be developed and implemented. If risk factors differ between populations or ethnic groups, such interventions or treatments can be tailored to suit the needs of each individual group. With regard to AD, a large number of risk factors have been investigated. The most widely accepted include demographic variables such as age, sex and education. I will discuss these along with vascular risks factors and will then briefly comment on the common genetic risk factors. Specific risk factors for dementia in African-Caribbean people will be considered further in section 1.5 and in the systematic review in Chapter 2.

Age: This is by far the most important risk factor for the development of AD and of dementia in general. It has been estimated that both the incidence and prevalence of the disorder doubles for every five years increase in age during adult life (Gao et al., 1998, Jorm et al., 1987, Hofman et al., 1991), although some studies have shown that the increase in rate slows down after age 90 (Ritchie and Kildea, 1995). The increase in dementia with age is pertinent to this study in that the African-Caribbean population in Britain has a younger age profile than the indigenous white population (section 1.4.4). They would on this basis, be expected to have a lower prevalence of dementia. It is therefore necessary, to adjust any estimated differences in dementia prevalence between ethnic groups for age; a probable confounder of the relationship between dementia and ethnicity.

Sex: It is thought that AD is more common in women than men, although there is no known sex difference in the prevalence of dementia overall (Gao et al., 1998, Ruitenberg et al., 2001). It has been suggested however, that women simply live longer than men and are therefore at higher risk of the disorder. Men also have a higher risk of developing vascular dementia (section 1.2.2.2) and are less likely to be diagnosed with pure AD. Meta-analyses of incidence studies indicate that women are at higher risk of AD, particularly in the very old (Gao et al., 1998). It has been suggested that the sex difference may be due to postmenopausal changes in oestrogen and one study indicated that hormone replacement therapy (HRT) can delay the onset of AD (Kawas et al., 1997). Another study only found this effect with *prior*, but not *current* use of HRT (Zandi et al., 2002). However, these findings are controversial and have not been replicated (Low and Anstey, 2006). There are likely to be confounders of the association between AD and HRT, such as socioeconomic status and education, which are known to be strongly related with HRT use (Finley et al., 2001).

Education: People of lower intelligence and educational attainment are thought to be at significantly higher risk of developing AD (Ott et al., 1999b, Stern et al., 1994). There are two commonly cited explanations for this. The first are the *brain reserve* and *cognitive reserve theories*; that people with larger brains and higher premorbid levels of intelligence (passive brain reserve) or those that make more use of their brains (active cognitive reserve) are better able to compensate for their impairment, hence delaying the onset of symptoms (Katzman, 1993, Stern, 2006, Stern, 2009). A recent systematic review found evidence that although education delays the onset of symptoms in AD, it does not lead to earlier death after diagnosis (Paradise et al., 2009a). The second explanation relates to cognitive testing, whereby screening instruments are said to be educationally biased, with less educated people more readily screening positive for cognitive impairment (Brayne and Calloway, 1990). The same principle applies to people from different cultural or ethnic groups, and screening instruments for dementia have been accused of being *'culturally biased'*, especially in people who's first language is not English (section 4.4.10.1). Whether these tests are truly culturally biased, or whether the difference in performance relates more to language and education is not always clear, although a number of culturally sensitive screening tests have been developed (section 4.4.10.1).

Vascular risk factors: There is good evidence that vascular risk factors and disease, including hypertension, diabetes, dyslipidemia and obesity are linked to a higher risk of AD and other dementias in later life (Stewart et al., 1999, Stewart, 1998). The results of a recent study indicate that these factors increase the risks differentially by sex (Hayden et al., 2006). Whether the association with AD is *causal* is not entirely clear. It may be that vascular disease has a direct impact on Alzheimer's pathology through amyloidogenesis secondary to cerebral ischaemia or that cerebrovascular disease leads to cognitive impairment that *unmasks* an unrelated AD at an earlier stage (Stewart, 1998). Interestingly, a recent study failed to demonstrate a worse prognosis from AD after 18 months in participants with vascular risk factors compared to those

without, except in those who had subsequent cerebrovascular events during follow up (Regan et al., 2006).

AD has been shown to be associated with hypertension diagnosed decades before the onset of clinical dementia (Skoog et al., 1996). Paradoxically, a Swedish cross sectional survey, demonstrated that lower blood pressure (hypotension) was associated with the later stages of AD, as well as other types of dementia (Guo et al., 1996). Raised total cholesterol (but not LDLs) has also been shown to be associated with AD decades later, with levels falling before the onset of dementia (Notkola et al., 1998). Finally, there is evidence that diabetes mellitus is a risk factor both for AD and vascular dementia, particularly in poorly controlled patients and those requiring insulin (Ott et al., 1999a). These findings have significant implications with regard to primary prevention, whereby the careful treatment of hypertension, hypercholesterolemia and diabetes earlier during adult life may reduce the risk of dementia later on (section 1.2.2.2).

Genetic risk factors: The majority of genetic risk studies for dementia have been conducted in relation to AD. Approximately 25-50% of people with AD will have an affected first degree relative, and concordance in monozygotic twins has been estimated to be 40-50% (Pericak-Vance and Haines, 1995). The rarer, early onset familial variant of AD usually has an autosomal dominant mode of inheritance. Three susceptibility genes have so far been identified; the amyloid precursor protein (APP) gene on chromosome 21, presenilin 1 (PS-1) gene on chromosome 14 and presenilin 2 (PS-2) gene on chromosome 1. These however, account for less than 2% of AD cases overall (Farrer et al., 1997). Worth noting is that people with Down's syndrome (trisomy 21), virtually all have pathological features of AD by their 4th decade although they do not all develop clinical dementia (Mann et al., 1986). This is presumably due to the extra copy of the APP gene on chromosome 21.

The more common, late onset AD does not result from a single gene mutation and is best considered to be a polygenic, multifactorial condition. The most frequent genetic risk factor currently known in this instance is the ε4 allelic form of the Apolipoprotein E (Apo E) molecule. This plasma protein has roles in lipid transport and tissue repair with its gene located on the short arm of chromosome 19. Of the three common polymorphisms, the ε2 allele is thought to be protective whilst ε4 is a risk factor for AD. The original finding (Strittmatter et al., 1993) has been replicated in all ethnic groups, although the strength of its effect has been shown to be weaker in black people of African descent (Farrer et al., 1997, Morgan et al., 1998). The precise mechanism whereby the apoE4 protein influences the onset of AD is unclear, but those possessing the risk allele seem to develop clinical symptoms earlier, and have a heavier amyloid burden. The risk of disease is dose-related and age-adjusted odds ratios for AD have been estimated at 2.6 for ε2/ε4 heterozygotes, 3.2 for ε3/ε4 heterozygotes and 14.9 for ε4/ε4 homozygotes (Farrer et al., 1997). It is important however, to put the risk associated with ApoE ε4 in context, in that nearly 50% of homozygotes for the allele will not have developed AD by age 90 and nearly 70% of people with AD, have no ε4 allele (Henderson et al., 1995).

The association of ApoE with AD is strong and the finding has been readily replicated. One main obstacle to identifying novel genetic loci, is that to detect a more modest degree of association with disease, large sample sizes are needed. One recent genome-wide association study of AD, attempted to overcome this by recruiting over 16,000 participants (Harold et al. 2009). This study replicated the association with ApoE but also observed associations at two loci not previously associated with AD; the CLU (also known as APOJ) gene on chromosome 8 and PICALM gene on chromosome 11. CLU encodes clusterin, a major brain apolipoprotein. PICALM codes for a ubiquitously expressed molecule which is predominantly found in neurones. It is involved in an essential step in the intracellular trafficking of proteins and lipids.

Other putative risk factors: A number of environmental factors have been put forward as possible contributory causes of Alzheimer's disease. Amongst the best known of these is aluminium, which has been found in the amyloid plaques and neurofibrillary tangles of AD brains at post mortem (Crapper et al., 1973, Crapper et al., 1976). One study found a higher incidence of AD in areas of the UK with higher concentrations of aluminium in the drinking water (Martyn et al., 1989). However the evidence is circumstantial and no causal relationship has yet been proved. As evidence for other causes continues to grow, the possible link with aluminium seems increasingly unlikely. The role of smoking and dementia has been similarly controversial, with some early studies showing a protective effect in AD and others suggesting that it is a probable risk factor (Ott et al., 1998). An analysis of the large Rotterdam cohort found that *current* but not *previous* smoking is associated with AD and that the effect is more pronounced in people without the APOE ε4 allele than APOE ε4 carriers (Reitz et al., 2007).

1.2.2.2. Vascular dementia

The concept of vascular dementia (VaD) as a discrete entity has become increasingly controversial over recent years (Stewart, 2002b). This is partly due to the fact that many risk factors for cerebrovascular disease are also risk factors for AD and that the two so often coexist. According to current diagnostic criteria, clear evidence of the former, excludes a diagnosis of the latter, although in clinical practice a diagnosis of *'mixed dementia'* is becoming increasingly common. Historically the classification has changed, from terms such as *'chronic cerebral hypoperfusion'* to the relatively new umbrella term *'vascular dementia'.* This simply refers to any clinical picture of dementia which is temporally related to underlying cerebrovascular pathology. This can be further divided into specific sub-types, which according to ICD-10 terminology include: *vascular dementia of acute onset* (usually following a stroke)*, multi-infarct dementia, subcortical vascular dementia, and mixed or unspecified types* (W.H.O, 1993a). The risk of dementia after clinical stroke is high, particularly when associated with lacunar infarcts, those affecting the left cerebral hemisphere or territories of the left posterior or left anterior cerebral arteries (Tatemichi et al., 1993). Other rarer syndromes contained within this category include 'Binswanger's subcortical arteriosclerotic encephalopathy' and genetic disorders such as 'cerebral autosomal dominant arteriopathy with subcortical infarcts and leucoencephalopathy' (CADASIL) and 'Familial British dementia with amyloid angiopathy'. The clinical picture of VaD varies considerably, depending on the type and area of the brain affected. However, it is likely to result in more 'patchy' cognitive deficits than that found in AD (Stewart, 2002a).

Current diagnostic criteria include those defined by ICD-10 (table 1.3), DSM-IV (table 1.4) and the National Institute of Neurological Disorders and Stroke (NINDS) / Association Internationale pour la Recherche et l'Enseignement en Neurosciences (AIREN) research criteria (Roman et al., 1993) – (Appendix 3). Diagnosis of VaD is notoriously difficult to make and clinical diagnosis tends to poorly reflect underlying pathology (Stewart, 2002b). The ICD-10 criteria for example, have been shown to be being highly selective (Wetterling et al., 1994) and the NINDS-AIREN criteria to have high specificity but low sensitivity following post-mortem examination (Holmes et al., 1999).

Table 1.3 **ICD-10 Diagnostic criteria for vascular dementia**

A	The general ICD-10 criteria for dementia must be met.
B	Deficits in higher cognitive functions are uneven (some functions affected and others relatively spared)
C	Evidence for focal brain damage with at least one of the following: o Unilateral spastic weakness of the limbs o Unilateral increased tendon reflexes o An extensor plantar response o Pseudobulbar palsy
D	Evidence from the history, examination or tests of significant cerebrovascular disease, which may be reasonably judged to be aetiologically related to the dementia

Table 1.4 **DSM-IV diagnostic criteria for vascular dementia**

A	The general DSM-IV criteria for dementia must be met.
B	Focal neurological signs and symptoms or laboratory evidence of cerebrovascular disease that are aetiologically related to the disturbance must be demonstrated.

Risk factors for the common forms of VaD include advancing age, male sex, ethnicity (section 1.5) and vascular risk factors (Gorelick, 1997, Stewart, 2002a). The vascular risks are thought to be the same as those for cerebrovascular disease in general and commonly cited factors include hypertension, diabetes, hyperlipidaemia and smoking. These have received increasing interest over recent years, in that vascular risk is potentially modifiable and there is scope for both primary and secondary preventative interventions. There may also be the added benefit of reducing the risk of other dementias including AD (section 1.2.2.1). This sentiment has been captured in the recent joint American Heart Association/Alzheimer's Association public awareness campaign (http://www.alz.org/heartbrain), entitled *'what's good for your heart, is good for your brain'.*

The most important treatable risk factor for stroke and VaD, and that which has received the most attention is hypertension. As for AD, current evidence suggests that raised blood pressure in middle age is a predictor for VaD decades later, and its careful control early on, may prevent or delay the onset of clinical dementia. One large scale controlled trial, 'The Systolic Hypertension in Europe' (Syst-Eur) trial of antihypertensive treatment found a reduction in the rates of stroke and dementia (Forette et al., 1998). Over a two year period, they demonstrated a 50% reduction in the incidence of dementia in participants who were treated. Other putative vascular risk factors for VaD include dyslipidaemia, diabetes, ischaemic heart disease and obesity (Hayden et al., 2006, Biessels et al., 2006). Worth noting, is that raised low-density-lipoprotein (LDL) is an independent risk factor for VaD but not AD (Moroney et al., 1999). The association between smoking and VaD is less clear than with AD and no association with past or current smoking was found in the Rotterdam cohort (Reitz et al., 2007).

1.2.2.3. Dementia with Lewy Bodies (DLB)

Although Frederick Lewy (1885-1950) was first to discover the abnormal protein deposits (Lewy body inclusions) in 1914, their association with a characteristic dementia syndrome was not recognised until the 1960s and it was not commonly diagnosed until the 1990s. Lewy bodies are the neuronal inclusion bodies generally associated with Parkinson's Disease, where they are found in sub-cortical structures including the substantia nigra and locus coeruleus. In DLB they are found predominantly in the cortex and are also found at relatively high rates in other dementias and in approximately 2% of older people without either dementia or Parkinson's Disease (Smith et al., 1991). Their role in the pathology of these disorders is unclear, as is the relationship between DLB, Parkinson's disease and Parkinson's dementia.

Because it is a relatively new diagnosis, DLB is not recognised in ICD-10 or DSM-IV, although it is briefly mentioned in the DSM-IV-TR under *Dementia Due to Other General Medical Conditions*. Consensus criteria for DLB were first published in 1996 (McKeith et al., 1996) and later revised in 2005 (McKeith et al., 2005) – (Appendix 3). The core clinical features include progressive cognitive impairment which fluctuates markedly over short periods of time, well formed visual hallucinations and Parkinsonism. Other features, which have been given greater prominence in the updated criteria, include REM sleep behavioural disorder, severe neuroleptic sensitivity and functional neuroimaging changes (reduced striatal dopamine transporter activity). Repeated, unexplained falls, delusions and depression are also common. DLB is often characterised by a different neuropsychological profile than that in AD, with relatively well preserved short/medium term memory but significant attention deficits and executive and visuo-spacial dysfunction (McKeith et al., 2005).

1.2.2.4. *Frontotemporal dementia (FTD)*

The term Frontotemporal dementia incorporates a spectrum of primary neurodegenerative disorders predominantly affecting the frontal and temporal lobes. Of these conditions, the most commonly described are Frontal lobe degeneration of non-Alzheimer's type (FLD), Pick's Disease and the dementia found in Motor Neurone Disease (MND). Also included with this group of conditions are progressive non-fluent aphasia and semantic dementias. The clinical presentation can sometimes overlap with frontal variants of AD and in some cases, AD pathology is found at post-mortem. Although FTD is the fourth most common type of dementia overall (Stevens et al., 2002), pure Pick's Disease is relatively rare, and is only found in 1-2 % of dementia cases at post-mortem compared to 7.5% for FLD (Gustafson, 1993).

Clinically, FTD presents with significant personality change, executive dysfunction and behavioural abnormalities. It tends to have an insidious and relatively early onset (mean age 56 +/- 7.6 years) and a relatively long duration (Gustafson, 1993). Behavioural and emotional changes are nearly always present, and usually result in either lethargy/apathy or disinhibition. The latter can be particularly problematic when socially or sexually inappropriate behaviour is exhibited. This, when combined with poor judgement and an inability to plan ahead can lead to devastating complications with regard to social relationships, finances and the law. Interestingly, overt psychotic symptoms are significantly less common than with AD (Gustafson, 1993).

A number of diagnostic criteria for FTD have been proposed over the past 15 years. The first were the Lund-Manchester criteria (Brun et al., 1994). Others include the consensus criteria (Neary et al., 1998) and more recently, the clinically orientated McKhann criteria (McKhann et al., 2001) (Appendix 3). Neither ICD-10 nor DSM-IV includes FTD as a separate entity, although they do have diagnostic codes specifically for Pick's Disease.

1.2.3. Epidemiology of dementia

1.2.3.1. Studies of dementia frequency – methodological issues

The frequency of a disease or disorder is most commonly described in terms of *point prevalence*; 'the proportion of individuals in a population who have the disease at a specific instance' or *incidence*; 'the number of new cases of a disease that develop in a population of individuals at risk during a specific time interval' (Hennekens and Buring, 1987). Prevalence is determined by both the incidence and the duration of survival with the disorder. This has practical implications for chronic conditions such as dementia, in that even a modest incidence can lead to a high prevalence over the course of a lifetime. This is borne out by the fact that the prevalence of dementia (all subtypes combined) almost doubles with every five year increase in age from 30 to 95 (Knapp, 2007).

There are a number of issues to be considered when designing or interpreting studies of dementia prevalence. Prevalence can be determined in one of two ways; case register studies and cross sectional surveys. The former is limited by the fact that it can only identify people who are, or have been known to services with a diagnosis of dementia. This would only include a minority of people with dementia, as most do not have a formal diagnosis (DoH, 2009). Cross-sectional studies or surveys on the other hand, do not just include those in contact with services, but screen a sample of participants from a defined population. Difficulties can arise when screening people with low educational attainment (Brayne and Calloway, 1990), learning disability (Strydom et al., 2009) or who are non-English speakers (McCracken et al., 1997). Another problem is that the prevalence of dementia tends to vary, depending on the diagnostic criteria used. In one study of 1879 elderly Canadians, Erkinjuntii et al. found the prevalence of dementia to vary considerably, depending on the diagnostic criteria used; from 3.1% (ICD-10 criteria) to 29.1% (DSM-III) (Erkinjuntti et al., 1997). It is therefore difficult to compare prevalence studies directly unless they have used the

same methodology. There are however a large number of dementia prevalence studies in the literature and also a number of meta-analyses which have pooled data from similar studies (see section 1.2.3.2).

1.2.3.2. Global prevalence of dementia

A number of meta-analyses have pooled dementia prevalence data from European studies (Hofman et al., 1991, Lobo et al., 2000) and from studies worldwide (Jorm et al., 1987, Ritchie and Kildea, 1995, Fratiglioni et al., 1999). Although prevalence estimates vary considerably between individual studies, pooled age-specific rates are strikingly similar between the meta-analyses, and there is a clear trend for the rate to increase with age. As a guide, dementia prevalence (all types) has been estimated at 0.7 -1.0% in 60-64 year olds, 2.8 - 4.1% in 70-74 years olds, rising to 11.1 – 13.6% in the those aged 80-84 years (Ritchie and Kildea, 1995, Jorm et al., 1987, Hofman et al., 1991, Fratiglioni et al., 1999). One meta-analysis estimated the prevalence in those aged 90-94 to be 33% or more (Ritchie and Kildea, 1995).

Estimates of dementia prevalence vary considerably worldwide, but for many regions, evidence from high quality epidemiological studies is lacking; particularly for most of Africa, South America and parts of Asia. A key publication in this respect is the *Global prevalence of dementia: Delphi consensus study,* which aimed to provide dementia estimates separately, for each world region (Ferri et al., 2005). In this study, 12 international experts were provided with a systematic review of the available data. They were asked to calculate prevalence estimates for each five-year age band in 14 regions, based on a combination of geography and patterns of mortality. For regions where data was scarce, the panel were asked to extrapolate from the existing data and give a best estimate. The group response for each region was then summarised as a 'mean prevalence estimate'. According to their findings, over 24 million people have dementia worldwide and they predicted that this is likely to double every 20 years to over 81 million in 2040. There was considerable regional variation in the prevalence of

dementia, with lower rates in less developed regions, such as Africa and South Asia. The authors suggested that this difference could be due either to methodological factors (e.g. under-detection in less developed regions), to lower survival with dementia or to lower levels of cardiovascular risk factors in poorer regions. Interestingly, despite the lower prevalence, higher absolute numbers of people with dementia live in developing countries, and this is likely to increase significantly over the coming decades (table 1.5).

Table 1.5 Worldwide estimates for dementia prevalence & incidence for 2001 with projections for 2020 and 2040*

Region	Prevalence (%) at age ≥ 60 yrs.	Annual incidence per 1000 people	Proportionate increase with dementia (%)	
			2001-2020	2001-2040
Western Europe	**5.4**	**8.8**	**43**	**102**
Eastern Europe	3.8	7.7	51	169
North America	6.4	10.5	49	172
Latin America & Caribbean	**4.6**	**9.2**	**120**	**393**
North Africa & Middle East	3.6	7.6	95	385
Western Pacific (developed)	4.3	7.0	99	189
China & developing western Pacific	4.0	8.0	96	336
Indonesia, Thailand & Sri Lanka	2.7	5.9	100	325
India & south Asia	1.9	4.3	98	314
Africa	1.6	3.5	82	235
Total	**3.9**	**7.5**	**74**	**234**

*Adapted from Ferri et. al., 2005

According to the Delphi consensus study (above), rates of dementia in Latin America and the Caribbean are similar to that in Western Europe, although the absolute numbers are likely to rise dramatically by 2040 (table 1.5). More recent publications from the region also indicate a prevalence of dementia that is equal to, or higher than that in Western Europe or the USA (Llibre Rodriguez et al., 2008b, Figueroa et al., 2008). One large cross sectional survey of 3,657 people ≥55, living on the Caribbean coast of Venezuela, estimated the overall prevalence of dementia to be 8% (Molero et al., 2007). Another estimated the prevalence of DSM-IV dementia in Cubans ≥65 years to be 6.4% (Llibre Rodriguez et al., 2008a) . This 'hidden epidemic' has the potential to explode in the coming decades, in a region with limited resources (Maestre, 2008). Worth mentioning however, is that all the available prevalence data from the Caribbean, are from studies conducted in predominantly Hispanic rather than Black-Caribbean populations (Cuba, Venezuela, Dominican Republic, Puerto Rico). I could only identify one small cross sectional survey from the English speaking Caribbean (Jamaica), which found 2.3% of over 60s to be severely cognitively impaired and 11.8 % to have questionable cognitive impairment (Eldemire, 1996).

1.2.4. Dementia in the UK: Demographics, cost, reports and policy.

1.2.4.1. *Demographics*

In a similar Delphi exercise as above, it was estimated that in the UK more than 700,000 people have dementia (570,000 in England) and with the population ageing, this number is likely to double in the next 30 years, to a projected 1.4 million in 2038 (Knapp, 2007). Approximately 15, 000 people with dementia are from BME groups (DoH, 2009) (section 1.3.4). By far the most common type in the UK is Alzheimer's disease (62%) followed by vascular and mixed dementias (27%) (Knapp, 2007).

1.2.4.2. Financial cost

People with dementia are heavy consumers, not only of health services, but more so of community and residential resources. It has been estimated that in the UK, nearly half of older people with cognitive impairment live in institutions, at a cost of £4.6 billion per year, 0.6% of the UK gross domestic product (Comas-Herrera, 2005). A more recent estimate puts this figure at nearer £6.8 billion (Knapp, 2007). Overall, the cost of dementia already exceeds that of cancer, heart disease and stroke combined at an estimated £17 billion per year (£25,472 per person with dementia), with projected costs exceeding £50 billion per year by 2038 (Knapp, 2007). In spite of this, public funding for dementia research lags far behind that for other serious medical conditions. This may be because people with dementia have relatively low status in western society and that there is little kudos given to those working in the field (Warner and Butler, 2002).

1.2.4.3. Government policy and the National Dementia Strategy

The British government now recognising the enormity of the problem, has declared dementia to be a 'National Priority' for health and social services, and announced its *National Dementia Strategy* early in 2009 (DoH, 2009). Leading up to this was the publication of a number of influential reports and guidelines, directly by the Department of Health and through various public and voluntary sector bodies such as the National Institute for Clinical Excellence (NICE), the National Audit Office (NAO), the Healthcare Commission and the Audit Commission (table 1.6).

Table 1.6 **Dementia reports & publications**

PUBLISHING BODY	YEAR	REPORT
Department of Health	2001 2005 2009	National Service Framework (NSF) for Older People. Everybody's Business – 'Integrated mental health services for older adults: a service development guide'. Securing Better Mental Health for Older Adults National Dementia Strategy.
Audit Commission	2000 2002 (revision)	Forget Me Not: *Developing Mental Health Services for Older People in England.*
National Institute for Clinical Excellence	2001 & 2007 2006	NICE guidelines for cholinesterase inhibitors. NICE guidelines for dementia.
National Audit Office	2007	'Improving services and support for people with dementia'.
KCL & LSE	2007	Dementia UK report.
King's Fund	2008	Paying the price.

One recurring theme is the need for early and accurate diagnosis of dementia and for early intervention. This was first highlighted in the Audit Commission's '*Forget Me Not'* report in 2000 (Audit-Commission, 2000), and then two years later in '*Forget me Not 2002'* (Audit-Commission, 2002). Standard Seven of the '*National Service Framework for Older People'* also advocated a similar policy (DoH, 2001a), as did the National Audit Office's 2007 report, '*Improving services and support for people with dementia' (NAO, 2007).*

Despite the recommendation that local health and social services should review their arrangements for the early detection of dementia, assessment and access to specialist services, there has been criticism that little has changed. *Everybody's Business* (DoH, 2005b), published jointly by the Department of Health and the Care Services Improvement Partnership (CSIP), did not introduce any new policies, but built on the service models outlined in existing documents such as the *NSF for Older People* (above) and *Securing Better Mental Health for Older Adults* (Philip, 2005). It provides guidance on how to develop a range of services from primary care, through to specialist mental health services, as well as residential and day care facilities. There is specific reference to memory assessment clinics to enable the early diagnosis of dementia and to integrated community mental health teams, whose role includes the management of people with dementia with complex behavioural and psychological symptoms. Interestingly, it is based on the premise that coordinating services for older people with mental health problems can be difficult, as they tend to cut across traditional social care, mental and physical health care boundaries. It states that the aim of the guide is to *"ensure that older adults with mental health problems and their carers have their needs met, wherever they are in the system without encountering discrimination or barriers to access".*

Expressing a similar sentiment, is the joint *National Institute for Clinical Excellence (NICE) / Social Care Institute for Excellence (SCIE) guideline for dementia* (NICE, 2006). It advocates integrated working across agencies and the provision of memory assessment services as a single point of referral for the early diagnosis of dementia. Also emphasised, is the need for memory clinics to avoid the labels of *'mental illness'* or *'psychiatry'* to reduce stigma and maximise the uptake of services.

Another influential review highlighting the need for a national dementia strategy, was the National Audit Office '*Improving services and support for people with dementia'* report, published in July 2007 (NAO, 2007). The investigation examined *"…what health and social care services are available for people with dementia and their unpaid carers and whether they are providing effective and good quality support; and the scope for better use of resources against a background of rising demand".* The report was compiled from data provided by the Alzheimer's Society Dementia UK report (see below) and from focus groups, internet web forums and surveys of people with dementia, carers and professionals. It concluded that overall, services are not delivering value for money to taxpayers or people with dementia and their families. Its findings are summarised as follows:

- *Health and social care services are spending significantly on dementia.*
- *Spending is late – too few people are being diagnosed or being diagnosed early enough. Early interventions that are known to be cost-effective, and which would improve quality of life, are not being made widely available. This results in spending at a later stage on necessarily more expensive services.*
- *Services in the community, care homes and at the end of life are not delivering consistently or cost- effectively against the objective of supporting people to live independently as long as possible in the place of their choosing.*

Recommendations included amongst others, more cross-agency working, case management and better day care provision for people with dementia.

The '*Dementia UK report'* (Knapp, 2007), detailing the prevalence and cost of dementia, was commissioned by the Alzheimer's Society and produced jointly by the London School of Economics and the Institute of Psychiatry, King's College London. Although not a governmental report, it provides the most comprehensive, up-to-date summary of dementia in the UK and gives projections for the future. The document concludes with seven key recommendations:

- *To make dementia a national priority.*
- *Increase funding for dementia research.*
- *Improve dementia care skills.*
- *Develop community support.*
- *Guarantee carer support packages.*
- *Hold a national debate on who pays for care.*
- *Develop comprehensive dementia care models.*

This report estimated that in total, there are nearly 11,860 people with dementia in the UK, from BME communities. This however, is based on the assumption that the prevalence in these groups is the same as for the general population and it may be an under-estimate. Although the research group was unable to calculate the projected increases in absolute numbers, they were able to predict with confidence, a significant increase in the proportion of BME older people with dementia as compared to the general population. This is because the large numbers of people who migrated to the UK from the Caribbean, Indian sub-continent and China in the 1950s, 60s and 70s are now entering old age and are therefore at increased risk of developing dementia (section 1.3.4).

A recent King's Fund Report '*Paying the Price: The cost of mental health care in England to 2026*' (McCrone et al., 2008) provided detailed information on the current and the projected need for mental health services and the associated costs. This report covered all age ranges and included data for dementia and depression, the two most prevalent mental disorders in old age. A particularly strong emphasis was given to dementia and that dementia is the most costly of all mental disorders with a projected cost of £34.8 billion by 2026.

In August 2007, Care Services Minister Ivan Lewis announced a one year programme to develop the first ever national dementia strategy and implementation plan. Drawing on evidence from a wide range of reports, working group recommendations and a series of over 50 stakeholder events involving over 4000 people, a detailed consultation document was published in June 2008 (DoH, 2008). This was a key stage in the development of the final strategy paper, that was finally published on 3rd February 2009 (DoH, 2009). The 104 page document, details a 5 year plan to radically transform the quality of care for people with dementia and their carers. The current government has pledged an additional £150 million investment over the first 2 years, to support local services in implementing the plan.

The strategy has three key themes:

- *To improve awareness of dementia, both among the public and professionals.*
- *To promote early and accurate diagnosis and intervention.*
- *To deliver high quality care and support for dementia sufferers and their carers.*

These are addressed through 17, specific objectives. Particularly pertinent to this study are the first two:

- **Objective 1**. Improving public and professional awareness and understanding of dementia:

  "Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefit of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision."

- **Ojective 2**. Good quality diagnosis and intervention for all:

  "All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area."

The strategy report acknowledges that people from all ethnic backgrounds are affected by dementia and that the proportion of sufferers from BME groups are likely to rise significantly in the coming years. There are several other references to minority groups throughout the document; for example that BME communities may need targeting in respect to public information campaigns, and may require *'a specifically tailored approach'*. Also stated is that dementia services should be inclusive; '*working for people of all ages and from all ethnic backgrounds'*.

I discuss government policy in relation to mental health in BME people further in section 1.3.5.

1.2.5. Detection and diagnosis of dementia in primary care

As discussed in the previous section, a number of reports and government policies over the past decade, have emphasised the need for early detection and diagnosis of dementia in primary care (1.2.4.3). This allows for access to treatment, planning of future care and to help individuals and their families come to terms with the prognosis; NSF for Older People (DoH, 2001a). The '*Forget me not 2002'* report points out that failing to make an early diagnosis can result in a 'crisis' situation for the person with dementia and their families (Audit-Commission, 2002). By then it can be too late to set up an effective package of supportive care, resulting in premature residential care home placement or psychiatric in-patient admission.

There are a number of potential barriers to the early detection of dementia and access to specialist services. These can be explored using Goldberg and Huxley's *'pathway to psychiatric care model'* (Goldberg and Huxley, 1992), which states that to receive secondary health care, several sequential stages must be passed and potential barriers overcome. The first stage is the appearance and recognition of an illness in the community, followed by consultation with the GP, identification and management of the illness by the GP, referral to secondary care and identification and management of the illness in secondary care. Factors relating to the patient, their family, the GP and secondary care service can all influence this pathway (Shah and Lindsay, 2005). In the following section, I will focus primarily on the patient/family/carer – GP interface.

A significant finding from the Audit Commission's survey, published in 2001 was that only 60% of GPs thought it important to look for signs of dementia or to make an early diagnosis (Renshaw et al., 2001). Little had changed in a review two years later (Audit-Commission, 2002), and again in 2007, when the National Audit Office stated that dementia is poorly recognised and managed in primary care (NAO, 2007). The reasons why GPs may fail to recognise or diagnose early dementia are multiple and complex (Woods et al., 2003, Iliffe and Wilcox, 2005). Many GPs report that they have not

received sufficient training, and '*Forget Me Not 2002'* found that those who did have sufficient training were the ones most likely to favour early diagnosis. Some other explanations given for GPs not making an early diagnosis include; that they think that there is little to be gained in the absence of adequate support services (Iliffe and Wilcox, 2005), that they find the experience of explaining the diagnosis to patients difficult (Glosser et al., 1985) and that sometimes they feel that this may do more harm than good because the family does not want to be confronted with the diagnosis (De Lepeleire et al., 1994). In one qualitative study, GPs stated that they prefer to use a 'problem solving' rather than diagnostic approach, and they argued that *"if the early changes of dementia don't cause problems, then why not wait until the situation worsens?"* (Iliffe and Wilcox, 2005). Following on from these findings have been trials of educational interventions and electronic decision support systems, which have been shown to improve detection of dementia in primary care (Downs et al., 2006). However, despite some success, training programmes along with the promotion of brief screening instruments for cognitive impairment have had limited impact over the past decade (Iliffe et al., 2009). It is likely however, that with the high profile of dementia following the announcement of the National Dementia Strategy (section 1.2.4.3), that GPs will be more aware of the disorder in the future and under increasing pressure from their patients or their families to refer them to specialist services.

The government has attempted to address the issue of early dementia diagnosis through policy, guidelines (section 1.2.4.3) and financial incentives. As part of the new general medical services (GMS) contract, implemented in April 2004, GPs have been financially rewarded for achieving a number of targets as set out in the Quality and Outcomes Framework (QOF). The 2006/2007 revision included two, new dementia 'indicators'; to have set up a register of patients diagnosed with dementia and to have carried out a review of their care in the previous 15 months (DoH, 2006). The aim of this is to improve the care of vulnerable people with dementia, although currently there is no specific incentive to detect or diagnose *new* cases.

It can be especially difficult for GPs to recognise dementia early on, in people from some BME groups (Rait and Burns, 1998). This may be for a number of reasons including language, low levels of education/literacy and problems interpreting rating scales or screening tools (Iliffe et al., 2000). A recent systematic review also found evidence that BME people with dementia tended to be more cognitively impaired at the point of referral to diagnostic dementia services in USA and Australia than the majority population (Cooper et al., 2009). This seemed to be due to later presentation to services rather than a cultural bias in screening instruments or differences in pre-morbid levels of education.

The reasons why older people with cognitive impairment and their carers/family may fail to seek a diagnosis from their GP, and/or accept help from statutory services are equally complex. Commonly, people with dementia may not recognise their symptoms, or attribute them to old age (Pollitt, 1996). Their family or carers may similarly fail to recognise the symptoms as dementia and may be reluctant to address them; due to stigma, or out of respect for their loved one (Antonelli-Incalzi et al., 1992). A recent qualitative study found that compared to a minority of white-British participants, most of the South Asian and half of the African-Caribbean participants held a *'traditional ideology'* of caring. This meant that they *'conceptualised caregiving as natural, expected and virtuous'* and were less likely to seek help from statutory services (Lawrence et al., 2008). Other factors contributing to patients and family members not seeking help include: the belief that nothing can be done; lack of awareness of available services; lack of awareness of access procedures for available services; the belief that available services are inadequate, inaccessible and culturally insensitive; previous poor experience of services (Shah and Adelman, 2009). Moreover, patients may choose to consult traditional healers or resources from their own community before consulting GPs for their mental disorder.

1.3. OLDER BLACK & MINORITY ETHNIC POPULATIONS IN BRITAIN

1.3.1. Definitions

First I will define what is meant by 'Older Black & Minority Ethnic (BME)' populations or people, but in order to do so, I need to define the terms *ethnicity*, *race* and *culture* and then consider what *older* or *elderly* means in this context.

The term *ethnicity* tends to be used interchangeably with *race* and *culture*, although their meanings are quite distinct. *Race,* describes physical appearance (Bhopal, 1997) and has been used historically to distinguish between groups of people. Although it is sometimes understood to imply distinct biological differences, such differences are far greater between individuals than between groups or populations. The term is a social rather than biological construct and not scientifically meaningful or reliable. False assumptions regarding racial attributes can lead to stereotyping and ultimately to 'racial prejudice' or 'racism' (Smedley and Smedley, 2005),

Culture, refers to *"the customs, civilisation and achievements of a particular time or people"* (Oxford English Dictionary) and describes the features that bind individuals together into a community. Keesing and Strather defined culture as *"systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in ways that human beings live"* (Keesing and Strathern, 1998).

Ethnicity is more than just race or culture and is harder to define. It does include components of both, but combined with other characteristics such as traditions, language, religion, spirituality, upbringing, nationality and ancestral place of origin (Rait and Burns, 1997). Ethnic identity *"includes a people's sense of shared history and origins, and of a common destiny"* (Pool and Geissler, 2005). Importantly it is self-defined and open to change (Smedley and Smedley, 2005).

Although within the United Kingdom, there is a shared British culture, there co-exist, a number of separate cultural and ethnic groups; the English, Welsh and Scottish indigenous groups for example. In addition to the indigenous populations there are a number of what have been known as 'minority ethnic groups', more recently termed 'Black and minority ethnic (BME) groups'. These have been defined as 'those with a cultural heritage distinct from the majority population' (Manthorpe, 1993), most commonly, but not exclusively black people of African, African-Caribbean or Asian descent. Notably, some other white groups are also considered to be ethnic minorities, including the Irish population in mainland Britain and certain other white European groups. The government document, '*Delivering Race Equality in Mental Health Care'* (DoH, 2005a) described BME groups as *'… all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage'.*

The term *older people,* in this context, relates to people of retirement age i.e. over 60 or 65 years of age. Although an arbitrary cut-off, this is of some practical value in that the prevalence and incidence of dementia is relatively low before the 6th decade and increases rapidly after that (see section 1.2.3). Worth noting is that psychiatric services in the NHS tend to use 65 years as the cut-off for old age.

1.3.2. Demographics

In the 2001 census for England and Wales, just under 8% of the total population (4.6 million people) identified themselves as coming from a non-white, ethnic minority or mixed heritage background (ONS, 2003). Indian people were the largest minority group, followed by Pakistani people, those of mixed ethnic backgrounds, African-Caribbean people, Black African people and Bangladeshi people. Irish people account for an additional 1.2% of the population. The remaining minority ethnic groups each accounted for less than 0.5 per cent each, but combined accounted for a further 1.4 per cent of the population.

Just over seven percent of all people aged 65 years of age and above came from BME groups, with an estimated total of 531, 909 (Shah, 2007). Conversely, the proportion of BME people over the age of 65 years has increased progressively over the decades, from 1% in 1981 to 3% in 1991 and 8.2% in 2001 (Shah, 2007). After the indigenous white population, those ethnic groups with the highest proportion over 65 years include the Irish and African-Caribbean communities (table 1.7).

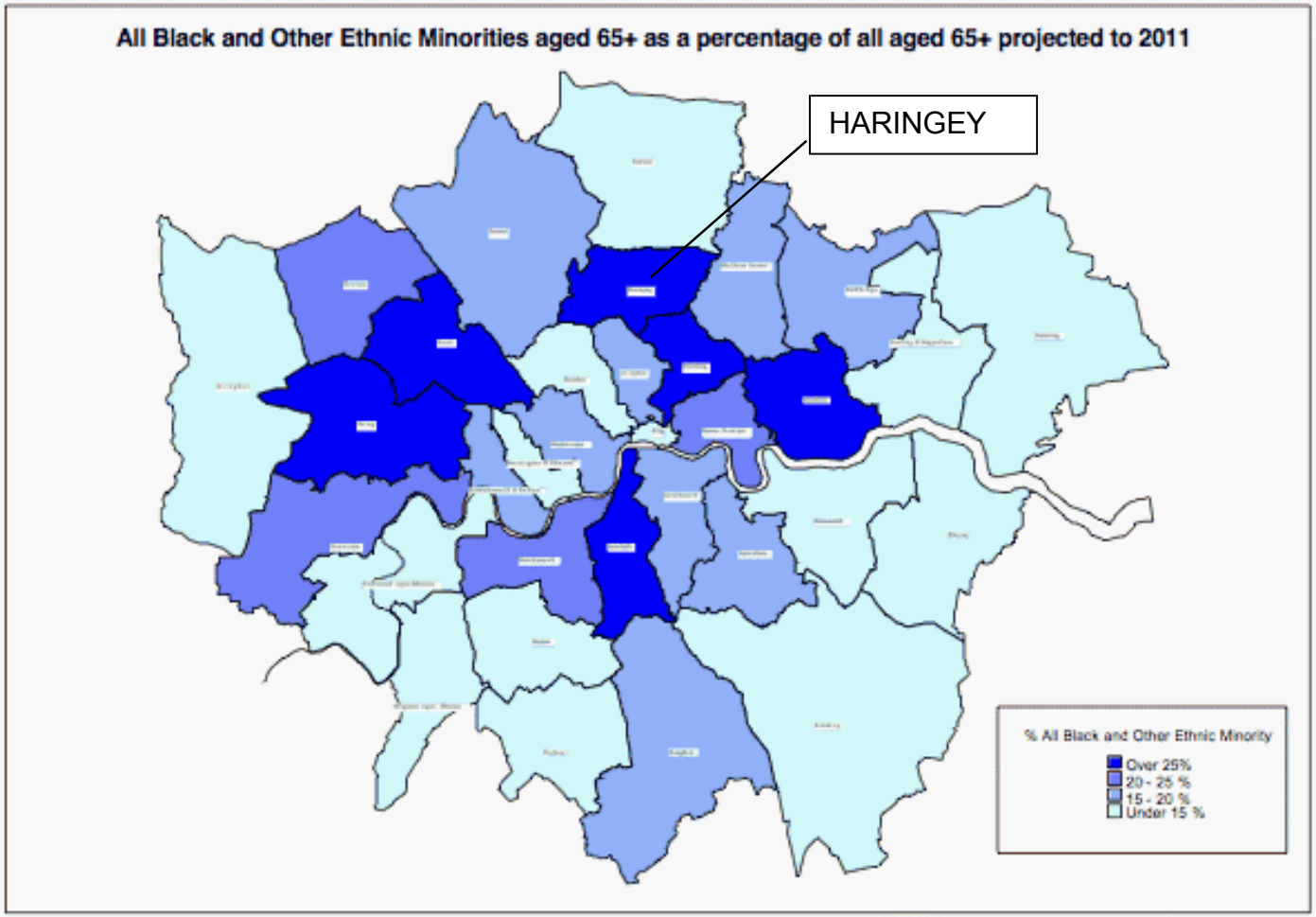
Many BME communities reside in urban areas and it is thought that London's elderly BME population will have tripled between 1991 and 2011, reaching over 25% of over 65 year olds in some boroughs (Lowdell et al., 2000) (fig. 1.1). The greatest increase will be among those of African-Caribbean origin, with large numbers currently in the 40-64 year old cohort, soon graduating to the over 65 year range (fig.1.2 and section 1.4).

Table 1.7 Demographic Summary from the 2001 Census (Shah et al., 2007)

Ethnic group	Proportion (%) aged over 65 years	* Ratio of "young old" to "old old"	Male to female sex ratio
Total Population	**15.9**	**0.74**	**0.73**
White British	**17.1**	**0.73**	**0.72**
All BME groups	**8.2**	**-**	**-**
Irish	24.9	0.82	0.72
Other white	10.4	0.75	1.08
Indian	6.6	0.85	0.99
Pakistani	4.1	0.88	1.24
Bangladeshi	3.23	0.93	1.96
Other Asian	5.18	0.86	1.11
African-Caribbean	**10.6**	**0.89**	**1.05**
Black African	2.3	0.97	1.05
Other black	3.18	0.82	0.96
Chinese	5.13	0.87	0.87
Other BME groups	2.9	0.83	0.76

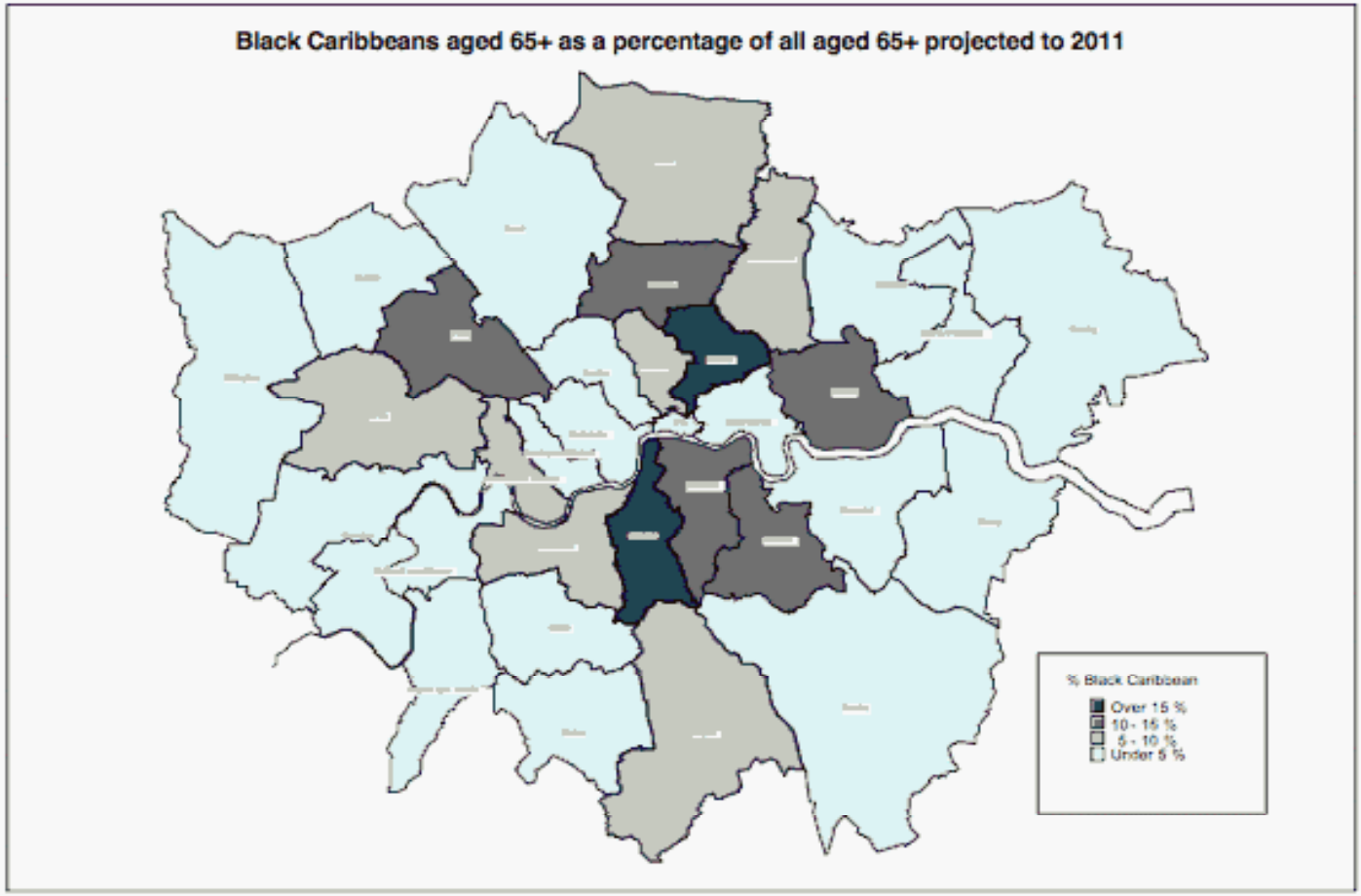
***** Defined as 65-79 years and 80 years and above respectively.

Figure.1.1



Source: London Research Centre 98 Round Ethnic Group Projections P1/M96 (London Research Centre, 1999)

Figure 1.2



Source: London Research Centre 98 Round Ethnic Group Projections P1/M96 (London Research Centre, 1999)

1.3.3. Socioeconomic and health inequalities

Ageing is associated with increased vulnerability to both medical and socioeconomic adversities and older BME people are at high risk of exposure to established risk factors for mental illness such as financial strain, poor housing, crime and physical disability as well as racism. The combination of old age and ethnic minority status was first described as *'double jeopardy'* (Dowd and Bengtson, 1978). With the addition of socioeconomic deprivation, this has been referred to as *'triple jeopardy'* or *'triple whammy'* (Norman, 1985, Rait et al., 1996). From these concepts, a model of *'multiple jeopardy'* has been developed to include multiple disadvantage due to ageism, sexism, racism, low socioeconomic status and poor access to health and social services (Boneham, 1989). It is known that in many cases older BME communities are under-represented in their use of secondary health care, although levels of contact with primary care and social services are similar to, or higher than the indigenous population (Livingston et al., 2002, Nelson et al., 2004). This inequality in access has also been shown to include old age psychiatric and dementia services (Rait and Burns, 1997, Lindesay et al., 1997, Shah and Dighe-Deo, 1998). One explanation for this is that older BME people do not make use of many statutory and voluntary services because they perceive them as being for the majority white population and being insensitive to their needs (Norman, 1985). Alternatively, it may be that General Practitioners are less likely to detect some illnesses in BME groups or refer them to secondary health services (section 1.2.5).

1.3.4. Dementia in BME populations

As the common dementias are predominantly diseases of old age, and as the elderly BME population in Britain continues to grow, so will the numbers of BME people with dementia. Forward planning for funding and development of dementia services is therefore essential, if demand is to be met. One recent study estimated the absolute number of cases of dementia in the BME population to be 11, 860 in the UK in 2004 (Knapp, 2007). Another study estimated the absolute number of cases of dementia to be between 7 270 and 10 786 and of depression between 33 559 and 52 980 among older BME people (Shah, 2008). It is important to develop mental health services that are accessible and culturally sensitive to the needs of all. This is now widely recognised and has been highlighted in a number of influential publications (section 1.3.5).

As alluded to earlier, people from BME groups are thought to be under-represented in their use of specialist dementia services. A report commissioned by London Borough of Haringey Social Services and the Alzheimer's Society found statutory services were failing to reach people with dementia and their carers from certain BME groups including the African-Caribbean, Indian Gujarati and Irish communities (Weir and Wharrad, 1998). It highlighted the lack of awareness regarding dementia and stigma attached to the diagnosis across these ethnic groups. Its recommendations included the need for better information on dementia services and how to access them and the development of multi-ethnic (rather than ethnically separate), culturally sensitive services. It also suggested providing alternative, more open methods of access to services other than through GPs.

1.3.5. Reports and policy (See publication CR156 - Appendix 2)

Over the last decade, the mental health of BME people of all ages has become a national priority in the UK, as highlighted by the government's *'Delivering Race Equality in Mental Health Care'* strategy (DoH, 2005a). When coupled to increasing awareness regarding dementia and depression in old age, issues pertaining to the mental health of older people from BME groups have become increasingly prominent. A number of reports have been published in relation to mental health in the BME population. These can broadly be divided into publications relating to BME people's mental health in general, and those relating to the mental health of older people, with specific mention of BME and cultural issues.

Primarily relating to 'working aged adults' (18-65 years), the '*NSF for Mental Health'* published in 1999 was one of the first governmental policy documents to acknowledge disparities between BME groups and the majority white population, in rates of mental illness and inequalities in mental health service provision. The report states that mental health services should be appropriate to the needs of those who use them and non-discriminatory. Although not addressing the issues in detail, it did highlight the need for a national strategy to address the mental health care needs of BME groups. This initiated the political momentum that led to the government's *'Delivering Race Equality'* policy.

The NSF for Older People was published by the Department of Health in March 2001 (DoH, 2001a). It's aim was to set standards for the health and social care of older people by targeting a number of key areas. Standard seven is concerned with promoting good mental health in older people and specifically with the treatment of dementia and depression. The standards for other functional illnesses such as schizophrenia are not specifically mentioned but are covered by the NSF for Mental Health (see above). The document states that: *"older people from BME communities need accessible and appropriate mental health services".* It covers a number of

reasons why this might not be the case, indicating that assessments may be *'culturally biased'* and that assumptions are sometimes made about the willingness of families to act as primary carers for their older relatives. Also mentioned is that information about services may not be readily available in an accessible form and tends to rely on translated leaflets and posters. Although the document emphasises that mental health services should; *"take account of the social and cultural factors affecting recovery and support",* it makes few specific suggestions as to how cultural awareness might be improved amongst mental health and social care professionals.

In 2003, The National Institute for Mental Health in England (NIMHE) published the *'Inside Outside'* report (Sashidharan, 2003). This document was one of the first to describe in detail, the ethnic mental health inequalities both *inside* and *outside* of services. Although this was previously recognised as a problem, it had not been adequately addressed by existing mental health initiatives such as NSF for mental health or NSF for older people. 'Inside Outside' highlighted the need for a national strategy to improve the mental health within BME communities and the care offered to them by mental health services. It recognised that the task would be complex and that progress and change would be *"dependent on an inclusive process, involving politicians, policy makers, service providers from both statutory and voluntary sectors, service users and carers and most importantly, black and minority ethnic communities themselves."* The report went on to outline the key components that should be part of the strategy to eliminate mental health inequalities:

- *Ensuring accountability and ownership in relation to black and minority ethnic communities.*
- *Developing a culturally capable service.*
- *Setting national standards to improve access, care experience and outcome.*
- *Enhancing the cultural relevance of research and development.*

Forget Me Not, the Audit Commission's analysis of mental health services for older people in England and Wales, was published in 2000 (Audit-Commission, 2000) and revised in 2002 (Audit-Commission, 2002). The report is consistent with the principles set out in the National Service Frameworks for Mental Health and Older People. It was largely welcomed by mental health professionals and helped to alleviate concerns that mental health in older people was being neglected by government (Benbow, 2000).

There is specific mention of the needs of BME groups at several points in the document. Early on, reference is made to studies indicating that the age profile of BME groups differ from the general population (mostly they are younger) and that this depends on the particular pattern of migration to Britain. It is also states that rates of depression and dementia may be higher in some BME groups and it challenges the commonly held assumption that minority ethnic and black families *"look after their own"* and have less need for services. Finally stated, is that when formal services are involved; *"they may be insensitive to cultural norms and may threaten carer's well-being if they do not reinforce the carer's role in an appropriate manner."*

With regard to day-care, the report states that; *"Older people from minority ethnic groups need special consideration, to ensure that appropriate services are provided for them."* Although the report did not go as far as suggesting separate services, it did recommend that this might require a change to the existing provision. Interestingly, it is quoted that BME user groups do not generally request separate day centers but ask only for mainstream services to be sensitive to their needs with regard to food, language and arrangements for religious practice.

Despite the extensive recommendations in this report, there is little addressing these issues other than suggesting that information for users and carers is distributed *"in languages and formats that can be understood easily by local people".* There is virtually no mention of BME groups in the 2002 revision.

In January 2005, the Department of Health published 'Delivering Race Equality in Mental Health Care' (DRE), a five-year action plan for achieving racial equality and tackling discrimination in mental health services in England (DoH, 2005a). The document was combined with the government's response to the recommendations made by the independent inquiry into the death of David Bennett, a 38 year-old African-Caribbean patient who died in a psychiatric unit having been restrained by staff. The DRE policy applies to all those with BME status including those of Irish, Mediterranean and East European origin and covers all age ranges from childhood to old age. It is based on three building blocks:

- *More appropriate and responsive services – specifically mentioning the improvement of clinical services for groups including older people, asylum seekers and children.*
- *Community engagement - aiming to engage communities in planning services with the recruitment of new Community Development Workers (CDWs).*
- *Better information – improved monitoring of ethnicity, better dissemination of information and good practice and a new regular census of mental health patients (see 'count me in census' below).*

The document acknowledges that older people from BME communities face the double jeopardy of old age and ethnic minority status, that they can be marginalised in society and have specific needs. Potential difficulties around communication and particularly written language are highlighted, as is the need for services to provide adequate interpretation facilities. It mentions that NHS Primary Care Trusts need to acquire *'BME age-specific expertise'* in order to develop culturally appropriate and responsive services. This is to be facilitated by NIMHE in collaboration with the voluntary sector including Age Concern, Alzheimer's Society and with the Policy Research Institute on Ageing and Ethnicity (PRIAE).

As stipulated in the 'Delivering Race Equality in Mental Health' action plan, March 2005 saw the first national mental health *'Count me in'* census (MHAC, 2008). The census is a count of all patients in mental health and learning disability beds in England and Wales on one day and is scheduled annually until 2010. It is a joint initiative between the Healthcare Commission, Mental Health Act Commission (MHAC), CSIP and NIMHE. The purpose of the census is to obtain reliable data on all mental health in-patients with regard to their admission and demographics, including ethnicity, language and religion. This information is designed to assist healthcare providers in achieving the government's DRE objectives.

Data published from the first three censuses showed similar findings. In the 2007 census, 22% of in-patients were from BME groups although in the general population this is less than 10%. Admission rates were particularly high in people from African or African-Caribbean decent (9%) and they were more likely than average to have been referred through the criminal justice system and to have been detained under the Mental Health Act 1983.

One criticism of the 2006 survey was that although one third of the 32 000 patients were over 65 years of age, no separate analysis was conducted for this age group (Shah and McKenzie, 2007). This was rectified for the 2007 census. The 2007 "Count me In " survey of all psychiatric inpatients on 31st March 2007 in England and Wales estimated that the standardised admission ratio (with the rate for England and Wales being the standard) for those aged 65 years and over were: higher in the white Irish, other white, other Asian, black Caribbean, black African and other black groups; lower in the white British and Chinese groups; and not significantly different in the Indian, Pakistani and Bangladeshi groups (Commission for Healthcare Audit and Inspection, 2007). Similar findings were observed in the 2008 census.

1.4. THE AFRICAN-CARIBBEAN POPULATION IN BRITAIN

In the following section, I will consider in more detail, some aspects relating specifically to the African-Caribbean community living in Britain. This will include sub-sections on demographics, discrimination and racism, socioeconomic inequalities and health. First, it necessary to contextualise these with a brief history of African-Caribbean migration; from their origins in West Africa, to the Caribbean where they were taken during the slave trade and more recently to their journey back across the Atlantic to Britain. The purpose of this section is to 'set the scene' before exploring aspects of dementia pertaining to populations of African origin in section 1.5 and more specifically to the British African-Caribbean population in the systematic review (Chapter 2.)

1.4.1. Terminology

The current preferred term *'African-Caribbean'* refers to black people of Caribbean descent, whose ancestors originated in Africa. It is used interchangeably with *'Afro-Caribbean'* and *'West Indian'* which is a term still often heard, particularly amongst older members of the black and white communities alike. Official government documents and statistics including national census data classify people as '*Black-Caribbean'* or *'Black-British'*. Confusingly, as immigration from Africa increased in the 1990s, *'African-Caribbean'* has also been used (incorrectly) to include people of purely African (but not Caribbean) background. The broader term *'African and Caribbean'* has been coined to refer to people of either heritage . Throughout the rest of this thesis, I will use the terms *'African-Caribbean'* or *'African and Caribbean'* where appropriate. I will also use *'West Indian'* as a historical term, to refer to inhabitants of the West Indies (Caribbean) who may be from any ethnic background (section 1.4.2).

1.4.2. A brief history

The Caribbean is a region consisting of the Caribbean sea, it's islands and the surrounding mainland coasts. The islands and reefs, of which there are more than 7000, are also known as the West Indies. They stretch in a long arc from the southern tip of Florida to the north-Eastern corner of the South American mainland (Ridvan, 2007). The original inhabitants included the Caribs and Arawaks, who were virtually extinct within a century of Christopher Columbus' arrival in 1492. The islands were subsequently colonised by European settlers, and by the 18th century, Britain had acquired much of the territory. Between 1500 and the early 1800s, the slave trade satisfied the demand for cheap labour in order to cultivate crops such as tobacco, rice and sugarcane. This practice involved the trading of goods for black slaves, mainly from the West coast of Africa (Congo, Ghana, Nigeria, Liberia) and their shipment under torturous conditions to the Caribbean. Many died from starvation, dehydration or disease during the long voyage across the Atlantic.

Although slavery was abolished in 1834, the population of the Caribbean continued to grow during the nineteenth century and settlers from India, China and the Middle East added to the ethnic and cultural mix of the region. Despite this, the Anglophone territories remained very much part of the British state, and there was no widespread drive for independence in most Caribbean islands until the late 20th century. Even by the 1950s, most 'West Indians', considered themselves to be British and saw England as the 'Mother Land'. Many were fiercely patriotic and volunteered to join the armed forces (especially the RAF) during World War II. The numbers lost in combat were high. However, for the first time young West Indians had the opportunity to visit Britain and many chose to return and settle after the war (Phillips & Phillips, 1998).

Historically, West Indians have been mobile and the workforce commonly took up offers of seasonal employment in the United States and South America, for example working on the Panama Canal. The most common destination for emigration before

Britain was in fact the USA, until strict anti-immigration legislation (The McCarran-Walter Immigration Law) was introduced in 1952 (Jones, 1985). It was only after a failed attempt to recruit European labour following World War II, that the British government encouraged people from their *colonies* to work in the UK. Several campaigns actively recruited workers from the Caribbean. The 1948 British Nationality Act gave British citizenship to residents of Commonwealth countries and the right to settle in Britain (www.opsi.co.uk). As following the war, economic conditions in the Caribbean were extremely tough, many took up the offer of what they saw as a better life in the 'mother country' and emigrated to Britain, mainly to fill low paid jobs. They included those in manufacturing, public utilities and the health service.

"Five hundred unwanted people, picked up by the trooper Empire Windrush after it had roamed the Caribbean, Mexican Gulf , and the Atlantic for 27 days are hoping for a new life. They include 430 Jamaican men. And there are 60 Polish women who wandered from Siberia, via India, Australia, New Zealand and Africa to Mexico, where they embarked in the Empire Windrush. The Jamaicans are fleeing from a land with large unemployment. Many of them recognise the futility of their life at home"
(Daily Express, 21 June 1948).

On June 22nd 1948 the famous *Empire Windrush*, a captured German troop ship, docked in Tilbury docks carrying the first immigrants to the UK from the Caribbean. At that time, Britain was just beginning to recover from the war. Housing was a huge problem and stayed that way for the next two decades (www.bbc.co.uk/history). Although there was plenty of work, African-Caribbean people first clashed with the local inhabitants over the issue of accommodation. It is estimated that during the period 1955-61, approximately 142,800 people emigrated from Jamaica, 5,000 from Barbados, 2,300 from Trinidad & Tobago, 3,500 from British Guyana, 3,500 from the Leeward Islands, 8,200 from the Windward Islands and 8,700 from the remaining colonies (Rose, 1969).

By mid-1962, over 300, 000 African-Caribbeans had settled in Britain (Jones, 1985). They initially chose to live in the main urban centres such as London and Birmingham and Manchester. New legislation (The Commonwealth Immigrants Act, 1962) essentially blocked entry to Britain other than for dependants or those with work permits (Jones, 1985). Although there was an initial surge of immigration as people came to avoid the ban, this rapidly tailed off to no more than a trickle (Peach, 1998, Peach et al., 1988).

1.4.3. Discrimination and racism

Since the arrival of the first migrants on the Windrush in 1948, the African-Caribbean community has experienced varying degrees of discrimination and racism, sometimes extreme. Initially, this was overt and new arrivals found employment and particularly housing denied to them on the basis of 'race'. The jobs that were available to them were generally semi-skilled and low paid, often not in keeping with their level of skill or education. This downward social mobility has been well documented (Smith, 1977, Heath and Ridge, 1983), Housing was in very short supply after the war, and the only options available to new migrants consisted of renting private rooms in run-down areas, often at an over-inflated price. Their concentration in poorer areas has had serious consequences for them in terms of health and for their children's education and future employment prospects. Although more subtle, discrimination still operates on a number of levels. Following the murder of teenage Stephen Lawrence in 1993, the Macpherson Report revealed what has been termed 'institutional racism' in the Metropolitan Police Service (Macpherson, 1999). Macpherson defined this term as:

"the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin, It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudices, ignorance, thoughtlessness and racist stereotyping, which disadvantages minority ethnic groups."

Other institutions including the education system have similarly been accused of racism. The Rampton Report (Rampton, 1981) and the Swann report (Swann, 1985) both disclosed that African-Caribbean children performed poorly in schools. By age ten many African-Caribbean children had fallen behind the national average and went on to achieve lower examination grades. This was particularly so for black males, and remains so today (teachernet, 2004). Teachers have been accused of having low expectations of black children and of not encouraging them. Another high profile independent enquiry was commissioned following the death of David Bennett, a 38 year-old psychiatric patient. This highlighted racism in mental health services and triggered the government's Delivering Race Equality in Mental Health Care (DRE) action plan (DoH, 2005a). Paradoxically, mental health services have been accused of both over-treating black patients in relation to psychosis, (often compulsorily under the mental health act) and under-treating them in terms of other mental illnesses, including depression and dementia (sections 1.3.3, 1.3.4 & 1.4.5.2). These allegations have been controversial and it is important to view them in relation to the prevalence of specific mental disorders in each BME population.

1.4.4. Demographics

In the 2001 population census, 565, 976 people identified themselves as 'Black Caribbean' which approximates 1% of the total population (ONS, 2003). In addition to this, 0.5% of the population (1% of the London population) were classified as mixed race (white & Black Caribbean). At the last census, 61% of African-Caribbean people lived in London, accounting for nearly 5% of the London population (ONS, 2003). The African-Caribbean population in Britain is ageing and it has a relatively high proportion of individuals over the age of 65 years (10.6% in 2001) when compared to other BME groups (table 1.7). It also has a higher proportion of people who are 'young old' compared to 'old old' in relation to the general population (table 1.7). This age distribution is in keeping with their pattern of migration i.e. those aged in their twenties, who arrived in Britain in the early 1960s are now in their seventies.

The 2001 census also gathered data on 'country of birth', with Jamaica the Caribbean nation most commonly recorded (146, 401 people) followed by Barbados (21, 601), Trinidad and Tobago (21, 283) and Guyana (20, 872). The remainder reported coming from Grenada, Saint Lucia, Montserrat, Saint Vincent, the Grenadines, Dominica, Saint Kitts, Nevis, Antigua, Barbuda and Anguilla (ONS, 2003).

There are now African-Caribbean communities throughout the UK, although the largest are found in London and Birmingham. In London, African-Caribbean people tend to be concentrated in the North (Tottenham, Hackney), North-West (Harlesden, Stonebridge) and South-East (Peckham, Brixton, Lewisham) with particularly high percentages (over 60%) in parts of Brent (Peach, 1998). Significant African-Caribbean communities are also found in most other major conurbations. Notably, although within these cities, they tend to be associated with poorer areas, levels of 'segregation' are far less than for African-Americans in the USA and are falling (Peach, 1998).

1.4.5. Socioeconomic and health inequalities

African-Caribbean people in Britain have fared less well than some other BME migrant groups economically and are less prosperous than the general population. One large survey found that compared to white people, African-Caribbeans were less likely to be in professional or managerial socioeconomic classes, more likely to be unemployed or in unskilled manual work, less likely to own their own homes outright (no mortgage) and more likely to be living in poverty (Nazroo, 1997b, Modood et al., 1997). At the 2001 census, Black Caribbean men were still three times more likely, and women twice as likely to be unemployed than their white peers (ONS, 2003).

The relationship between lower socioeconomic status and poor health in the general population has long been established. The *Black Report* concluded that this was a consequence of the material differences in the standard of living (Black et al., 1980) and a similar sentiment was echoed in the *Acheson Report* 18 years later (Acheson, 1998). Interestingly the relationship has been more difficult to demonstrate in migrant populations and Marmot et. al. found that socioeconomic status was unrelated to mortality in some ethnic groups. In his large study, for those born in the Caribbean the relationship was reversed, with wealthier African-Caribbeans having a higher mortality rate than poorer ones (Marmot et al., 1984a). The reason for this finding is not clear, although methodological problems have been suggested (Nazroo, 1999). The British, Fourth National Survey of Ethnic Minorities (FNS), a large cross-sectional survey of ethnic minorities living in England and Wales found conflicting results and demonstrated a clear correlation between socioeconomic status and health for both white and African-Caribbean people (Nazroo, 1997b, Modood et al., 1997). Given that the African-Caribbean population in Britain fall at the lower end of the socioeconomic spectrum, it could therefore be expected that this would adversely affect their health. Results of the FNS survey were consistent with this, concluding that African-Caribbean people were more likely to rate their health as poor than white people. Worth noting however, is that despite perceived poor health, they are known to have lower overall

mortality rates than the general population (Wild and McKeigue, 1997, Marmot et al., 1984b). Other plausible explanations for differences in perceived health and actual morbidity when compared to the general population would be that of cultural and genetic factors and of the direct impact of racism (section 1.4.3).

1.4.5.1. Physical health

It has been well documented that African-Caribbean people in the West, have an increased risk of hypertension and diabetes (Cooper and Rotimi, 1997, Chaturvedi et al., 1993), and that they have higher rates of mortality from related disorders, especially cerebrovascular disease (Wild and McKeigue, 1997, Marmot et al., 1984b). It has been estimated that they have twice the mortality from stroke and between four (in men) and seven (in women) times the mortality from hypertensive disease compared to the national average (Chaturvedi et al., 1993). Interestingly in spite of the excess of vascular risk factors, they have lower rates of ischaemic heart disease and also have lower mortality from respiratory disease (Marmot et al., 1984b, Wild and McKeigue, 1997). The relationship between vascular risk factors, cerebrovascular disease and dementia in African-Caribbean people will be discussed further in section 1.5 and in the systematic review in Chapter 2.

1.4.5.2. Mental Health

It has been a consistent but contentious finding that African-Caribbean people in Britain have much higher rates of psychosis including schizophrenia, than the general population (Harrison et al., 1988, Van Os et al., 1996, Fearon et al., 2006, Fernando, 1998). They are also thought to present to services with psychotic disorders later, and several studies have shown that they were more likely to be detained compulsorily, under the Mental Health Act (Morgan et al., 2005, Smaje, 1995). The reasons for this are still not entirely clear, but have included socioeconomic disadvantage, over-diagnosis by mental health services and racism (Sharpley et al., 2001, Chakraborty et al., 2009). Studies investigating psychosis and schizophrenia in older African-Caribbean people are limited and no consistent differences have been shown to date (Livingston and Sembhi, 2003).

It is likely that the rates of depression in African-Caribbean people are similar or slightly lower than in other ethnic groups (Bhugra and Ayonrinde, 2004, Lloyd, 1993). The FNS however, found an increased relative risk (RR) of 1.5 for depression amongst African-Caribbean (all ages) as compared to white people (Nazroo, 1997a). Studies of depression in *older* African-Caribbean people are also inconclusive. Given the excess of cerebro-vascular disease in this group, it is plausible, that they would be at increased risk of depression; in keeping with the "vascular hypothesis" of depression. Although the association with stroke has been clearly demonstrated, Stewart found no such association with vascular risk factors in his South London study (Stewart et al., 2001a). Neither McCracken (McCracken et al., 1997) nor Livingston (Livingston et al., 2001) found significant differences in the prevalence of depression between samples including older African-Caribbean people (over 65 years) and a white reference group. However, such findings should be interpreted in the context of the screening tool and cut-off being used. Notably, it has been shown that community screening instruments for depression, validated in white populations underestimate the rates in older African-Caribbean people (Abas et al., 1998).

1.5. DEMENTIA IN BLACK POPULATIONS OF AFRICAN ORIGIN

Most research on dementia in black populations is from the USA, where a number of studies have indicated that older African-American people may be at increased risk of developing dementia, with proportionally more vascular dementia when compared to the majority white population, (Tang et al., 2001, Demirovic et al., 2003, Krishnan et al., 2005, Heyman et al., 1991, Folstein et al., 1991, Auchus, 1997). One large study comparing community dwelling older African-American people in Indianapolis with a sample in Ibadan, Nigeria, found more than twice the incidence of dementia and Alzheimer disease in the African-American group (Hendrie et al., 2001).

In general, black people have higher rates of hypertension than their white counterparts (Lane et al., 2002, Hall, 1999), an increased rate of hypertensive end-organ disease (Dimsdale, 2000), cardio-vascular disease (Onwuanyi et al., 1998) and death due to stroke (Chaturvedi et al., 1993). As hypertension is associated with vascular dementia as well as Alzheimer's disease (Skoog and Gustafson, 2003, Stewart, 1998), it seems likely that they may suffer a relative excess of either or both dementias.

Other reasons for the excess of dementia in African-American people are less clear and a number of analytic studies have been conducted to identify possible risk factors that may account for this. For example, diabetes mellitus is common in this population (Odugbesan et al., 1989), and it has been investigated as another putative vascular risk factor for dementia. One study demonstrating an association between diabetes and dementia in an elderly African-American sample, found that one third of stroke associated dementia was attributable to diabetes (Luchsinger et al., 2001). Hypercholesterolaemia is also common and possibly reflects dietary intake. Another study found that elevated total cholesterol was associated with AD in a sample of older African-American people, but only in those who do not possess the APOE ε4 allele

(Evans et al., 2000). Interestingly this highlights the interaction between environmental and genetic risk factors for dementia. Also relating to vascular risk and diet was the Indianapolis-Ibadan study finding that not only did the Nigerian participants have significantly less AD but that they had far fewer vascular risk factors such as hypertension, diabetes and hypercholesterolaemia. They also happen to eat a low-calorie, low-fat diet consisting mainly of cereals, roots and tubers, supplemented with small amounts of fish (Hendrie, 2001). Studies of genetic risk factors including the role of APOE polymorphisms have been inconclusive, but indicate that the ε4 allele may have a relatively weak association with AD in populations of African origin when compared to Caucasians (Evans et al., 2003, Tang et al., 1998, Farrer et al., 1997).

When compared to the USA, research on dementia in British, black populations is limited, and until now, no comprehensive review of the literature was available. These populations differ from those in the USA in that generally, the older generation are first generation immigrants. The largest of these groups are people of African-Caribbean descent. As many have now reached retirement age, they may also be at high risk of developing dementia, despite evidence that they are under-represented in their use of specialist health services for their relative levels of morbidity (Nelson et al., 2004, Boneham et al., 1997) (section 1.3.3).

Although physically and culturally distinct in many respects, parallels can be drawn between the African-American and British African-Caribbean populations. These may be useful, especially when considering risk factors for dementia, some of which may be modifiable. Firstly, by definition both groups are of African descent and have some shared physical health characteristics, including an increased risk of hypertension and cerebro-vascular disease. Notably however, although rates of coronary artery disease are relatively high in the African-American population with respect to the white population, this is not so for the African-Caribbean community in Britain, who have relatively low rates (section 1.4.5.1). Secondly, both groups are considered to be ethnic minorities, and have experienced significant social adversity including socioeconomic

deprivation and racism (Modood et al., 1994). In particular, the first of these is known to be associated with hypertension (Diez-Roux et al., 2002). Sources of psychological 'stress' have been hypothesised as a risk factor for other mental illnesses (Herbert, 1997), although it is not yet clear what effect this may have on the rates of dementia. In addition, older British African-Caribbean people who are first generation immigrants will have experienced the stresses associated with making a new life in a foreign land. The African-American population in contrast, has been established for many generations, and the current older generation has not experienced migration first-hand.

1.6. SUMMARY

I conclude from this chapter, that there will be large numbers of people with dementia in Britain as the population continues to age (1.2.4) and that an increasing proportion will come from BME communities (1.3.4). One of these groups to have reached old age in large numbers are those people who migrated from the Caribbean in the 1950s and early 1960s (1.4). We know little regarding their future health and social care needs and whether these will differ from those of the general population. The literature suggests that there may be barriers to some older BME people accessing specialist health services, even if registered with a general practitioner. There are several possible explanations for this and good evidence that GPs feel poorly trained in the diagnosis of dementia, especially in older BME people (1.2.5). Whether this is so for African-Caribbean people is not yet clear and warrants further investigation.

There is now strong evidence from the United States, that some black populations of African origin such as African-Americans may be at high risk of developing dementia, and that this may be partly due to an interaction between diet, physical and genetic factors (1.5). Although some parallels can be drawn with the British African-Caribbean population, there are also many differences and inferences can only be made with caution. The primary aim of the following study is to quantify the prevalence of dementia in the British African-Caribbean community as compared to the indigenous white population. Before I describe the study, it is necessary to explore the relevant UK literature in more detail.

In the following chapter I report the findings of a systematic review of the literature, relating specifically to aspects of dementia in the older African-Caribbean community in Britain, including prevalence and putative risk factors (Chapter 2).

2. SYSTEMATIC REVIEW

A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain

(See publication in Appendix 2)

2.1. OBJECTIVES

To synthesise evidence from the literature regarding the prevalence and predictors of dementia or relative cognitive impairment in older, African-Caribbean people in Britain, as compared to the indigenous white population.

2.2. METHOD

2.2.1. Search Strategy

I performed an electronic search for all relevant publications in December 2007 using the following bibliographic databases:

- MEDLINE (1950 -)
- EMBASE (1980 -)
- PSYCHINFO (1806 -)
- CINAHL (1982 -)

Additional materials were identified from the reference lists for each paper. Two experts in the field were also contacted and asked if they knew of studies not identified electronically.

2.2.2. Inclusion Criteria

Studies reporting the frequency of (incidence or prevalence), or predictors for dementia or relative cognitive impairment, that included a sample of people of black, African-Caribbean origin, living in Britain were included.

2.2.3. Exclusion criteria

Qualitative research, single case studies, dissertation abstracts and secondary research were excluded.

2.2.4. Search terms

- African Caribbean, Afro Caribbean, Black Caribbean, West Indian, Jamaican.
- Dementia, Alzheimer's Disease, Dementia - vascular, Dementia - multi-infarct, Dementia - frontotemporal, Lewy Body Disease, Pick's disease of the brain, Cognitive impairment.

Both free text and the related thesaurus (MeSH) terms were used for each search.

2.2.5. Selection method

I performed the initial selection of studies for inclusion on the basis of titles and abstracts. Full articles were obtained and read for those appearing to fulfil the inclusion criteria. A second selection was then made through consensus, between myself and my two supervisors (MB and GL).

2.2.6. Assessment of quality

Papers meeting our inclusion criteria were randomly assigned and rated independently by two of the three assessors (myself and MB or GL). In cases of disagreement, consensus was reached through discussion. Prevalence studies were evaluated using a standardised checklist (Boyle, 1998) and given a score out of seven (table 2.1). All other studies were assigned a level of evidence (LE) grade based on the Oxford Centre for Evidence Based Medicine (CEBM) guidelines – May 2001 (http://www.cebm.net/levels_of_evidence.asp#levels). This rates research on a scale of one to five, with lower numbers indicating higher quality. Good quality systematic reviews and Randomised Controlled Trials (RCT) are level 1, good quality individual cohort and RCTs not meeting criteria for level 1 are level 2b and cohort studies not meeting these criteria are level 4 (table 2.2).

Table 2.1 **Prevalence study quality checklist**

Sampling	***Does the survey design yield a sample of respondents representative of a defined target population?*** 1. Is the target population defined clearly? 2. Was probability sampling used to identify potential respondents? 3. Do the characteristics of respondents match the target population?
Measurement	***Do the survey instruments yield reliable and valid measures of psychiatric disorder and other key concepts?*** 4. Are the data collection methods standardised? 5. Are the survey instruments reliable? 6. Are the survey instruments valid?
Analysis	***Were special features of the sampling design accounted for in the analysis?*** 7. Do the reports include confidence intervals for statistical estimates?

Table 2.2 **Oxford CEBM levels of evidence.**

1a	Systematic review (with homogeneity) of prospective cohort studies or RCTs.
1b	Prospective cohort study with good (>80%) follow up, or individual RCTs.
1c	All or none case series
2a	Systematic review (with homogeneity) of 2b and better studies.
2b	Individual cohort study or low quality RCTs.
2c	Ecological studies.
3a	Systematic review (with homogeneity) of case-control studies
3b	Individual case-control study.
4	Poor quality (not meeting above criteria) cohort and case-control studies. Case-series.
5	Expert opinion without explicit critical appraisal, or based on physiology, bench research or 'first principles'.

2.3. RESULTS

The electronic searches identified 178 references from MEDLINE, 183 FROM EMBASE, 254 from PSYCHINFO and 160 from CINAHL. The majority were excluded from the title and abstract, leaving 26 papers for the second selection. Of these, 11 primary studies were included in the review.

2.3.1. Prevalence studies

Three studies investigated the prevalence of dementia in samples of older African-Caribbean people, one of these being a mixed sample of Black African and African-Caribbean people (Livingston et al., 2001). No studies measuring the incidence of dementia were found, although a series of longitudinal studies looked at cognitive decline over a three-year period and associated risk factors (table 2.3). Two of the larger studies were designed to examine both dementia and depression in a variety of BME groups. The first of these set in Liverpool, screened 418 community dwelling people aged 65 years and over from a number of ethnic backgrounds (McCracken et al., 1997). BME participants were identified from multiple sources, including Family Health Services Authority lists, community lists, 'snowballing' (obtaining further contacts via participants) and a door-to-door survey. The computerised Geriatric Mental State Examination algorithm - GMS-AGECAT (Copeland et al., 1986) was used to make the diagnosis of dementia. Comparison was made with a reference sample from a previous study (MRC ALPHA study). A dementia prevalence of between 2% and 9% was found among the English-speaking BME groups with 8% (8/98) in the African-Caribbean participants. Although this was higher than that in the white reference sample (3%), the absolute numbers with dementia were small and the authors concluded that there was no significant difference between any of the English speaking BME groups and the indigenous white population. They did however find a higher rate of dementia in non-English speaking participants and questioned the validity of this diagnosis amongst people who do not speak the dominant language.

The Islington Study surveyed 1085 people also aged over 65, from a range of ethnic backgrounds, in an inner city borough of North London (Livingston et al., 2001). The investigators used a shortened version of the Comprehensive Assessment and Referral Evaluation; Short-CARE (Gurland et al., 1984) to elicit psychiatric symptoms and diagnoses. Participants were recruited using the gold standard method of *'door knocking*'; visiting every household within randomly selected enumeration districts. Of all the African and African-Caribbean people surveyed, 17.3% (17/98) screened positive for dementia, as compared to 10% (67/667) of the white, British respondents, despite the former being significantly younger. This study was limited by the fact that all the African and African-Caribbean participants were analysed together as one group, regardless of their country of origin. In addition, absolute numbers screening positive for dementia were small.

One small pilot study did specifically aim to compare the risk of dementia in a sample of African-Caribbean older people with that in a white control group (Richards et al., 2000). On this occasion, 45 African-Caribbean and an equal number of age and gender matched white community residents were recruited by household enumeration of an inner city, South London electoral ward. The participants were screened with the Mini Mental State Examination; MMSE (Folstein et al., 1975) and followed up with a comprehensive diagnostic interview if they screened positive. From the data gathered, an independent psychiatrist rated 22% (9/45) of the African-Caribbean participants as cognitively impaired (but not 'demented') and 34% (14/45) as 'demented' as compared to 9% (4/45) and 4% (2/45) respectively, of the white comparison group. The investigators concluded that the African-Caribbean participants were at far higher risk of dementia, even after controlling for educational and occupational factors. They could not however, exclude residual confounding by socioeconomic status or the effects of 'cultural test bias'. Other major limitations of this study were the small sample size and relatively high refusal rate in both groups.

Table 2.3 **Studies reporting the prevalence of dementia or relative cognitive impairment.**

STUDY	TARGET POPULATION	TARGET POPULATION WELL DEFINED?	PROBABILITY SAMPLING USED?	SAMPLE MATCH TARGET POP. ?	SAMPLE SIZE	DATA COLLECTION METHOD STANDARDISED	SCREENING INSTRUMENT VALID ?	INSTRUMENT RELIABLE?	PREVALENCE OF DEMENTIA (95% CI)	VALIDITY SCORE (OUT OF 7)
McCraken 1997	BME elders aged >65 living in a defined, inner-city area of Liverpool.	YES	NO	NO	418 total 100 A-C	YES	YES (but cultural validity uncertain)	YES	8% (4-15%) in A-C sample. 3% (2-4%) in reference sample. (Difference not significant.)	5
Richards 2000	A-C and white community residents aged >65 living in an inner, South London Borough.	YES	YES	Unknown	45 A-C 45 white	YES	YES (but cultural validity uncertain)	YES	34% A-C sample 4% white sample OR 8.3 (2.9-24)	5
Livingston 2001	Community dwelling residents aged >65 living in an inner city North London borough.	YES	YES	YES	1085 total 98 African/ A-C	YES	YES (but cultural validity uncertain)	YES	17.3% in African/ A-C sample 10% in white sample. RR 1.72 (1.1-2.0)	7

2.3.2. Association/risk factor studies

Eight studies were identified, investigating the association between a number of potential risk factors and dementia or cognitive impairment in African-Caribbean participants (table 2.4).

2.3.2.1. *Cardiovascular risk factors*

A small follow up to the Islington study investigated the association between dementia subtype and country of origin (Stevens et al., 2004). Of the 72 people in whom a dementia diagnosis was made, 47 were born in the UK and 10 in Africa or the Caribbean. The combined African/African-Caribbean group had nearly double the proportion of vascular dementia as compared to UK born comparisons, depending on the diagnostic system used. Interestingly, eight of the ten African/African-Caribbean people diagnosed with dementia were hypertensive at the time of interview, of which four were not diagnosed, or were presumed to have had their hypertension inadequately treated. Three conclusions were drawn from this study; that vascular dementia may be overrepresented in older people of African and/or Caribbean origin, that these populations are more likely to have hypertension that is either undiagnosed or poorly treated and that this in turn is a risk factor for dementia. Again, this study was limited by small numbers and the grouping of African and Caribbean people together.

In a series of seven publications, Stewart and his colleagues investigated the association between a number of physical risk factors and relative cognitive impairment and cognitive decline in a cohort of African-Caribbean, South London residents. The sample was identified from primary care registration lists and participants were aged between 55 and 75 years. At baseline, participants were simultaneously screened for cognitive impairment and vascular risk factors by means of eleven psychometric tests and a physical examination. Blood samples were taken where possible and used to measure further potential biological risk factors. Participants were classified as having 'relative cognitive impairment', either if they scored below the 30th percentile on six or

more tests or below the 10th percentile on four or more tests. Of the 278 participants, 79 (28%) were classified as having relative cognitive impairment. The remainder of the sample were classified as 'unimpaired'. The two groups were compared in terms of potential risk factors. Attempts to follow up the original cohort were then made after three years and data was collected on cognitive decline from baseline for further analysis.

The first of these analyses investigated the association of cognitive impairment (CI) with a number of vascular risk factors (Stewart et al., 2001b). A key finding was that the associations detected were modified by educational level. Whereas hypertension, diabetes and raised triglycerides were found to be significant risk factors for CI in those of lower educational level, low fibrinogen, high cholesterol and manual occupation were risk factors in those with normal/high levels of education. Physical exercise was negatively associated with CI.

In a three-year follow-up study of the same community sample, cognitive decline from baseline was strongly associated with ageing but not directly with other vascular risk factors. However, the age related decline was significantly stronger in those with diabetes and weaker in those reporting vigorous exercise at baseline (Stewart et al., 2003).

2.3.2.2. Genetics

The only genetics studies found in a British African-Caribbean sample were further analyses of Stewart's original cohort data. They investigated the association between Apolipoprotein E genotype and early CI (Stewart et al., 2001c) and Angiotensin I converting enzyme (ACE) genotype and cognitive decline (Stewart et al., 2004). In the first paper, APOE genotype was determined for 202 participants. Although APOE ε4 genotype has been established as an important risk factor for Alzheimer dementia in Caucasian and Japanese populations, its role in people of African origin is less clear.

In this analysis, CI was negatively associated with APOE ε2 allele and positively, but more weakly with the APOE ε4 allele. The effect of both alleles was greater after the age of 70 years and greatest in those with hypertension, diabetes and lower levels of educational attainment. In the second paper, ACE genotype was determined in 148 older African-Caribbean participants and the association with cognitive decline over three years investigated (Stewart et al., 2004). It is thought that the insertion/deletion polymorphism of the ACE gene can influence the risk of cerebrovascular disease in white populations although any association with cognitive decline or dementia remains controversial. Although no direct relationship was found between ACE genotype and cognitive decline in this sample, an interaction was demonstrated with the ACE DD genotype, strengthening the association between age and cognitive decline when compared to the ID/II genotype.

2.3.2.3. Inflammatory markers

There is growing interest in the role of inflammatory processes in the pathology of cognitive decline and subsequent dementia. In an analysis of Stewart's cohort, Jordanova et al. investigated the association between three inflammatory markers and cognitive decline in 216 older African-Caribbean participants (Jordanova et al., 2007). After adjusting for potential confounders, raised plasma interleukin-6 (IL-6) was associated with cognitive decline over three years. No associations were found for C-reactive protein (CRP) or serum amyloid A (SAA). The authors concluded that as IL-6 predicts cognitive decline in this population, cytokines may mediate cognitive decline via specific causal pathways.

2.3.2.4. Plasma Homocysteine

Moderately raised plasma homocysteine has been associated with both cardiovascular and cerebrovascular disease (Hankey and Eikelboom, 1999) and as such, this could be considered as a risk factor for cognitive decline and dementia. In this secondary analysis, Stewart et al. compared measurements of plasma homocysteine with relative CI in 248 older African-Caribbean participants (Stewart et al., 2002). They found homocysteine levels in the highest quartile to be associated with CI (OR 2.5; 95% CI 1.33-4.69) but this was only significant in those with low educational attainment.

2.3.2.5. *Leg length*

Adult leg length has been used as a marker for early life environment and is related to childhood nutritional status. It is recognised that these factors may influence health in later life and shorter leg length has been related to a number of disorders including dementia in a Korean population (Kim et al., 2003). Mak et al. carried out a secondary analysis of Stewart's data on 203 older African-Caribbean people in South London (Mak et al., 2006). Relative CI at baseline and subsequent cognitive decline over three years was compared with leg length (iliac crest to lateral malleolus). The investigators found that shorter leg length (the lowest quartile) was associated with CI but not with cognitive decline. Although statistically significant, this finding was strongly mediated by previous occupational status.

Table 2.4 Studies reporting predictors of dementia or cognitive impairment in an African-Caribbean sample of people

STUDY	RISK FACTOR(S)	OUTCOME MEASURE	STUDY SAMPLE	FACTORS ASSOCIATED WITH DEMENTIA OR C.I	LEVEL OF EVIDENCE
Stewart, R 2001	Vascular risk factors	Cognitive impairment	278 participants aged 55-75, born in the Caribbean. (28% with relative C.I)	Hypertention, diabetes & raised triglycerides in those with low education. Low fibrinogen (negative association) & raised cholesterol in those with normal/high education.	4
Stewart, R 2001	Apolipoprotein E Genotype	Cognitive impairment	202 participants aged 55-75, born in the Caribbean. (28% with relative C.I)	APOE ε4 – weakly association APOE ε2 – negative association Effects increased after age 70	4
Stewart, R 2002	Plasma Homocysteine	Cognitive impairment	248 participants aged 55-75, born in the Caribbean. (27% with relative C.I)	Raised plasma homocysteine was significantly associated with C.I (OR 2.5; 95%CI 1.33-4.69) but only in those with low education.	4
Stewart, R 2003	Age & vascular risk factors	Cognitive decline over 3 years	207 participants aged 55-75, born in the Caribbean.	Cognitive decline strongly associated with age. Association strengthened further in people with diabetes and weakened in those reporting vigorous physical exercise.	4
Stevens, T 2004	Hypertension	Dementia	98 participants from Africa or the Caribbean (from a larger sample of 1085 aged >65).	Undiagnosed or poorly treated hypertension is associated with an increased risk of dementia. Excess in vascular subtype in A-Cs.	4
Stewart, R 2004	ACE genotype	Cognitive decline over 3 years	148 participants aged 55-75, born in the Caribbean.	No direct association found but ACE DD genotype strengthened the association between increasing age and cognitive decline (effect modification).	4
Mak, Z 2006	Leg length	Cognitive impairment and cognitive decline over 3 years	203 participants aged 55-75, born in the Caribbean.	Shorter leg length (lowest quartile) was significantly associated with cognitive impairment at baseline but not cognitive decline.	4
Jordanova, V 2007	Markers of inflammation	Cognitive decline over 3 years	216 participants aged 55-75, born in the Caribbean.	Raised levels of IL-6 were associated with cognitive decline. No association was found for CRP or SAA.	4

2.4. DISCUSSION

In this, the first systematic review of the literature on dementia in the older, British African-Caribbean population, I strikingly found only three small studies that report the prevalence of dementia. Thus, although it seems likely, it cannot be shown conclusively that dementia is increased in this population. Two studies recruited participants of African-Caribbean origin and one study, a mixed sample of black African and African-Caribbean people. All have small numbers and use screening instruments of uncertain cultural validity. The study with the highest prevalence of dementia had the smallest numbers, and that with the lowest prevalence did not compare two groups recruited at the same time. The latter also used a snowballing technique that may have led to a biased estimation of the illness. Notably, all three studies found a higher rate of dementia in the 'black' population but the rate varied widely between 8% and 34%. The study with the highest validity score found a prevalence of 17% and this may therefore be the most plausible estimation. One study indicated that there may be higher rates of vascular dementia in particular, and that this may be associated with poorly controlled hypertension but this study is too small to draw any conclusion other than that further investigation is merited.

Relative CI and cognitive decline (but not dementia) in this population has been studied extensively by one group, who found that that APOE ε4 genotype and shorter leg length were associated with cognitive impairment and raised IL-6 with cognitive decline. Physical exercise was found to be protective. The links between cardiovascular risk factors and cognitive impairment were less clear and were strongly modified by education. Interestingly, the most plausible of these, hypertension and diabetes were only risk factors in the least educated participants. Vascular risk factors were not found to be directly linked to cognitive decline from baseline but to modify the strong association with ageing. None of the risk factor studies we identified, scored at the higher levels of evidence according to the Oxford CEBM criteria.

2.5. LIMITATIONS

Only two experts responded to my request for information regarding additional unpublished work, and none was identified. My systematic review therefore only included published research which is inevitably biased towards positive findings (publication bias). As research in this field is limited and the number of published studies small, I employed broad inclusion criteria. The result of this was that the studies identified were heterogeneous in design, making direct comparison difficult. All of the prevalence studies reviewed were limited by small sample sizes and used screening tools of uncertain cultural validity. The association studies all fell into category 4 of the Oxford CEBM level of evidence, indicating poor quality evidence. It was therefore difficult to draw any definitive conclusions from these.

2.6. CONCLUSIONS

I conclude from this review that further investigations are needed, to confirm an increased rate of dementia in the British African-Caribbean population, to estimate its magnitude, to further investigate predictors and ultimately to identify preventative interventions. Initially a much larger cross sectional survey would be helpful. Ideally this would achieve a high response rate, would include the use of a culturally valid screening instrument in an epidemiologically representative population and would include a white comparison group. Further, higher quality longitudinal studies would also be desirable and this is discussed further in Chapter 6.

3. AIMS & HYPOTHESES

As discussed in *Chapter One*, there is very little in the published literature regarding the prevalence of dementia in African-Caribbean people, either in the Caribbean or elsewhere in the world, but a relative wealth of data regarding the African-American community in the United States. The latter indicates that older African-American people are at increased risk of developing dementia when compared to the white majority, or to Black people living in Africa (section 1.5). Although distinct both physically and culturally, comparisons can be made with the African-Caribbean population living in Britain. I hypothesised that there may be common risk factors, potentially increasing the prevalence of dementia in both groups relative to their white counterparts. The most plausible explanation relates to vascular risk, whereby both African-American and British African-Caribbean people have a predisposition to hypertension, diabetes and subsequent cerebrovascular disease. As there is now consistent evidence that these factors are associated with both vascular dementia and Alzheimer's disease (section 1.2.2), it is a plausible that it may account for an overall excess of dementia in both groups. This warrants further investigation as there may be potential for both primary and secondary preventative interventions.

Also explored in *Chapter One* were health and socio-demographic characteristics of the ageing BME population in Britain. Notably, an increasing number are reaching the age group that puts them at risk of dementia. As the majority of first generation African-Caribbean people migrated to Britain in the 1950s and early 1960s, they are now reaching old age in large numbers. If they are at increased risk of dementia as hypothesised, their health and social care needs will be substantial, and services need to plan for this. Available evidence suggests that general practitioners may be failing to diagnose dementia early enough in this population and that they are less likely to be referred on to specialist services for assessment.

In *Chapter Two*, I concluded from my systematic review, that there may be an excess of dementia in the African-Caribbean compared to the white-British population in the UK, but the evidence was of poor quality and the findings inconclusive. Of the three studies identified, none was powered with the primary aim of measuring and comparing the prevalence of dementia between an African-Caribbean and a white reference sample of older people. None had used culturally adapted screening or diagnostic instruments, making the validity of the screening process questionable. The prevalence estimates for dementia also varied widely for the black groups from 8% to 34%. I concluded that it was necessary to determine definitively whether the prevalence of dementia is higher in British African-Caribbean as compared to the majority white population and if so by how much.

3.1. HYPOTHESES

3.1.1. Primary Hypothesis

- The point prevalence of dementia (all types) is higher in the African-Caribbean than the white-British older population.

3.1.2. Secondary hypothesis

- Dementia in older African-Caribbean people is under-recognised in primary care (according to their medical records) and the rate of referral to specialist dementia services is lower than that for the white-British population.

3.2. AIMS

The general aim of this research is to enhance our knowledge with regard to dementia; its prevalence, risk factors and access to specialist care, in older African-Caribbean people living in Britain.

3.2.1. Primary aim

- To test the primary hypothesis that the prevalence of dementia is higher in the African-Caribbean, compared to the white British-born older population, using General Practice lists in the London Borough of Haringey as a sampling frames.

3.2.2. Secondary aims

- To compare the diagnosis of dementia between African-Caribbean and white-British people, in relation to demographic and vascular risk factors.
- To investigate levels of documentation regarding dementia and rates of referral for specialist assessment in primary care and to compare them between the two ethnic groups.
- To explore the distribution of dementia subtypes between these groups.
- To further test the performance of the culturally valid, African-Caribbean version of the MMSE as compared to the standard version.

4. METHODS

4.1. STUDY DESIGN

The study design is of a two-stage cross sectional prevalence study and a medical notes survey.

4.2. ETHICS COMMITTEE & R&D APPROVAL

Ethical approval was obtained separately for the pilot and the main study. Approval for the pilot study was granted by the Moorefield & Whittington Research Ethics Committee (REC) on 19th May 2004, and for the main study by Camden & Islington Community REC on 15th November 2006 (Appendix 4).

The main ethical issues addressed by the two committees are discussed in the relevant sections as indicated below, but in summary included:

- Issues pertaining to data protection & privacy; specifically that potential participants should be invited to take part by their GP in the first instance, and that they should be able to 'opt out' of the study before being contacted by a researcher (section 4.4.8.2).
- The issue of obtaining valid informed consent from people who lack the mental capacity through cognitive impairment / dementia (section 4.4.8.3).
- Printed information and letters should be in large clear print and accessible language (section 4.4.8.2).

The final project was registered with the UCL research and development (R&D) department and with the local data protection coordinator at the Department of Mental Health Sciences (UCL), Royal Free Campus. I also obtained an honorary contract from Haringey teaching Primary Care Trust (PCT) enabling me to approach patients registered with GPs throughout the borough.

4.3. PILOT STUDY

In this section I will describe a small pilot study, which I conducted between June 2004 and July 2005. This was completed prior to my starting an MRC research training fellowship and formed part of my grant application. The aims of the pilot were primarily to test the feasibility of the selection and recruitment process in a primary care setting, and to refine the screening tool for use in African-Caribbean participants. The findings were used to inform the development of the final method for the study.

4.3.1. Pilot study method

Just one GP practice was recruited for the pilot study and a sample of 29 African-Caribbean volunteers aged 60 years and over were screened for cognitive impairment using an African-Caribbean version of the Mini Mental State Examination – MMSE (Rait et al., 2000). Validated specifically for use in older African-Caribbean people in Britain, it was designed to be less culturally and educationally biased than the standard MMSE (Folstein et al., 1975). I decided on a cut-off of <26 as screening positive for dementia as this gave an acceptable level of sensitivity and specificity (section 4.4.10.1). No white comparison group was recruited in this instance. At the time, approximately 60% of patients had been coded for ethnicity on the GP practice electronic database. With this information alone, it was possible to identify a significant proportion, but not all of the African-Caribbean patients aged 60 years and over. Potential participants were sent a letter directly from their GP, on practice headed paper, inviting them to take part in the study. I subsequently contacted them by telephone, and if they agreed, made an appointment to interview them at their own home. Each interview lasted for 30-45 minutes during which written, informed consent was obtained, and a simple demographic questionnaire was administered (Appendix 5) along with the MMSE screening tool. I had intended that those screening positive for dementia would undergo a structured diagnostic interview; The Cambridge Mental Disorders of the Elderly Examination – CAMDEX (Roth et al., 1986) (section 4.4.11.)

4.3.2. Pilot study findings

In total, 69 African-Caribbean GP patients over 60 years of age were identified from the single practice list. Of the total, 20 (29%) were not contactable by telephone and a further 15 (22%) declined. Reasons for not making contact included: no phone, unobtainable phone number, no answer, had moved house, was out of the country or died. Although 34 (69%) *of those contactable* agreed to take part, only 29 (59%) completed the screening process, the remainder having changed their mind either before or during the interview. Of those screened, just one (3.4%) screened positive for cognitive impairment. Unfortunately the participant refused further testing and no formal diagnostic interview was performed. The full diagnostic interview derived from the CAMDEX (4.4.11) was piloted for acceptability separately in a small purposive sample of patients, immediately prior to the main study. These participants were recruited from patients of the local old age psychiatry service.

In summary, the main findings from the pilot study were as follows:

- Identification and recruitment of African-Caribbean participants was feasible through existing ethnic coding of practice lists. However, it became apparent that ethnic coding alone would not identify a sufficient proportion of African-Caribbean patients, and that this might also result in a biased sample; those having attended the GP practice recently were more likely to be coded for ethnicity by receptionists than non-attenders. It was anticipated that additional methods to identify potential participants would be employed in the main study (section 4.4.8.1).

- The overall response rate (42%) was moderately low. Part of the difficulty was that the contact details for some patients were incorrect or incomplete. Also, during the pilot study it was only possible to contact people during working hours. I had expected that these difficulties would be largely overcome in the main study where more time and resources would be available to pursue all potential participants (section 4.4.8.2.)

- The screening questionnaire and interview were quick and easy to administer and acceptable to participants, who generally scored highly. The low prevalence of dementia in this pilot was accounted for by the small, biased and unrepresentative sample.

- The full, unmodified CAMDEX interview & CAMCOG cognitive assessment was found to be time consuming and some components potentially educationally or culturally biased. This led to the development of a modified diagnostic interview (section 4.4.11)

4.4. CROSS SECTIONAL SURVEY

4.4.1. Study location

The Borough of Haringey in North London was chosen as the setting for this study, primarily because it has a large and well-established African-Caribbean population (table 4.1 & figure 1.2). The area is also accessible to the research team base and links had been established with Haringey Teaching Primary Care NHS Trust (tPCT), and with Barnet, Enfield and Haringey (BEH) Mental Health NHS Trust. There is evidence that statutory services in Haringey have been failing to reach people with dementia from certain BME groups, including the African-Caribbean community (Weir and Wharrad, 1998). The local mental health and primary care NHS trusts were keen to address this problem, and have been key collaborators with this study.

Geographically, the borough of Haringey covers an area of more than 11 square miles in North London, bordering clockwise from the North: Enfield, Waltham Forest, Hackney, Islington, Camden and Barnet (www.haringey.gov.uk). Socioeconomically it is an extremely diverse borough and it ranks as the fifth most deprived in London (www.haringey.gov.uk). It spreads from the affluent suburbs of Highgate, Muswell Hill and Crouch End in the West, to the much poorer areas of Tottenham and Lower Edmonton in the East. The latter contain some of the most deprived wards in the country. According to ONS (Office for National Statistics) estimates, the total population for mid 2007 was 224,700, 3% of the total London population (www.haringey.gov.uk). It has an equal male to female ratio and an age structure similar to other London boroughs, although the east of the borough tends to have more young people and the west more older people (www.haringey.gov.uk). Its residents are ethnically diverse with approximately half coming from BME communities (table 4.1). In fact, it has the 6th highest proportion of BME people in London after Brent, Newham, Tower Hamlets, Hackney and Ealing (www.haringey.gov.uk).

Table 4.1 Ethnic composition of London Borough of Haringey (ONS 2003, 2007)

Ethnicity	2001 Census data for Haringey	2005 Estimates for Haringey	2001 Census data - National average
White British	45.3%	47.6%	87.0%
Black Caribbean	9.5%	8.3%	1.1%
Mixed white and Black Caribbean	1.5%	1.4%	0.5%
White Irish	4.3%	3.6%	1.3%
Other White	16.0%	14.1%	2.7%
Asian	6.7%	7.6%	4.6%
Black African	9.2%	9.1%	1.0%
Other Black	1.4%	1.3%	0.2%
Other Mixed	3.1%	3.3%	0.8%
Other	3.0%	3.7%	0.8%

ONS estimates for mid-2005 (http://www.london.gov.uk/gla/publications/factsandfigures/dmag-update-20-2007-ons-ethnic-group-estimates.pdf)

The first large-scale immigration into Haringey, was of the African-Caribbean community who arrived in the late 1950s and early 1960s. This was followed by the Cypriot, Turkish and Asian communities. More recently, the ethnic mix has been increased, with people migrating from Africa in the late 1980s/1990s and from Central and Eastern Europe, particularly since the expansion of the EU in the last decade. In fact, in 2001, Haringey had the third largest proportion of 'other white' residents in London (16%), with 31% of these born in Central/Eastern Europe (including Turkey) (www.haringey.gov.uk).

Although Haringey's population of African-Caribbean residents rose slightly between the 1991 and 2001 censuses, their number might now be falling. It was last estimated, that in mid-2005, approximately 18,700 (8.3%) people were of black, Caribbean origin, which represents a decrease from the 2001 census estimate of 20, 570 (9.5%) (ONS 2003, 2007). In contrast, the population of 3, 200 (1.4%) people of mixed white/black-Caribbean heritage has remained relatively stable (ONS, 2007). With specific relevance to this study, is that at least 3, 400 African-Caribbean people aged over 60 years reside in the borough (ONS, 2003). As the profile of this community begins to age, the relative number of older residents is likely to rise substantially. This is likely to have significant implications regarding the provision of culturally appropriate health care and social services.

4.4.2. Study Setting

As the aim of this study was to survey a sample of people from the general population, I chose a community setting. Participants were identified from individual General Practice lists and interviewed primarily in their own homes.

4.4.3. Study & reference populations

4.4.3.1. Study population

The *study* (target) population includes all people aged 60 years and over, who are of black, African-Caribbean origin, and who migrated to Britain from a Caribbean island or Guyana (on the North-East coast of South America). Although not technically a Caribbean island, culturally Guyana associates primarily with other English-speaking Caribbean countries such as Jamaica, or Trinidad and Tobago. I chose the age of 60 years, rather than the conventional cut-off of 65, primarily because a previous study (Livingston et al., 2001) suggested that older people of African/African-Caribbean origin might develop dementia at a significantly younger age than the indigenous white population. I felt it was important that these people were included. All such people who permanently reside in the Haringey area, whether living in their own homes or in 24-hour residential care, were included in the study.

4.4.3.2. Reference population

I chose the *reference* population to include people aged 60 years and over, who are white and consider themselves to be British. This included people born throughout the British Isles. In practice, the majority of the white participants were born in London and considered themselves to be English. As for the study population, all permanent residents of Haringey were included.

4.4.4. Sampling frame

In order to identify participants, General Practices were recruited and their patient lists used as sampling frames. These lists are relatively accessible and the patients are representative of the general population. It is known that approximately 98% of the general population are registered with a General Practitioner and that even in inner-city areas, the rates of registration for BME groups are at least as high as for the white population (Johnson et al., 1983, Richards, 1996). Practices are now expected to code their patients for self-assigned ethnicity and since April 2001, they have been using, as a National Standard, a set of 16 codes to record ethnicity (DoH, 2001b). The codes are identical to those used in the 2001 ONS census and are grouped under five headings : White; Mixed; Asian or Asian British; Black or Black British; and Chinese or other ethnic group. Although the level of completion varies between practices, this coding, in addition to other methods allowed for the identification of participants (section 4.4.8.1).

4.4.5. Sampling method

I used single stage, cluster sampling to obtain a representative sample of African-Caribbean people from across Haringey. This was achieved by simple random sampling of all GP practices from across the borough (see details below). From each participating practice, *all* eligible African-Caribbean patients that were identified, who were 60 years or over, were invited to participate in the study. This method has the advantages of producing an equally weighted, random sample of participants, and of being practical to perform. As there were many more potential white, British than African-Caribbean participants, they were randomly selected from the same GP practice lists until an equal number had been recruited. Randomisation was achieved by selecting alternate white-British names until the numbers of African-Caribbean participants had been matched.

General Practices were identified with the assistance of the primary care trust and of the North Central London Research Consortium (NoCLOR). I sent a random selection of practices a letter and information sheet asking for their involvement. This was followed up with a telephone call to the practice manager. As expected, only a small proportion of practices agreed to participate and the sampling process was repeated until the required number had been recruited (see 4.4.7). The recruitment of subsequent GP practices was ongoing, and ran in parallel with the recruitment of study participants. Experience from a feasibility study had suggested that the implementation of the project would require minimal input from each practice once recruited, both in terms of staff-time or costs. The project itself was also unlikely to generate a significant excess of clinical work for GPs and it was of potential benefit to their patients.

4.4.6. Inclusion & exclusion criteria

All patients from each practice who were selected and who fulfilled the inclusion criteria were encouraged to participate. Minimising refusals was essential, in order to reduce participation bias. This is known to be potentially problematic, especially in cross sectional studies where a minimum response rate of 70% would be considered to be acceptable, providing the demographic profiles of responders are similar to those of the non-responders (Boyle, 1998). Exclusion criteria have also been kept to a minimum in order to preserve generalisability of the findings.

4.4.6.1. Study sample.

Inclusion Criteria:

- All General Practice patients aged 60 years and over and who identified themselves as being African-Caribbean, Afro-Caribbean, Black-Caribbean, Caribbean or West Indian and who were born on a Caribbean island or in Guyana.
- All those living in any community setting including their own home, that of a relative, friend or in 24 hour residential care in the Haringey area. Potential participants, registered with one of the participating General Practices, who lived nearby, but in a neighbouring borough (usually Enfield) were also included.
- Those with, or without existing cognitive impairment or dementia, whether diagnosed or not.

Exclusion Criteria:

- People younger than 60 years or those not born on a Caribbean island or Guyana. As such, second generation people of African-Caribbean descent were excluded for clarity, and to facilitate the identification of study subjects. In any case, it was thought to be unlikely that second generation migrants over 60 would be encountered.
- Non-English speakers were excluded, as no interpreters were available for the study.
- Those with a known moderate or severe intellectual (learning) disability, as the screening tool for cognitive impairment had not been validated in this group.
- Those who were hospitalised long term, considered too physically or mentally ill, and those too frail to participate were excluded from the study.

4.4.6.2. Reference Sample

Adults aged 60 years and over, living in the Haringey area, but who identified themselves as being white-British and who were born in the British Isles were randomly selected to participate (4.4.5). Those of other European descent were excluded. Other than ethnicity, inclusion and exclusion criteria were the same as for the study sample.

4.4.7. Sample size

The systematic review (Chapter 2) indicated that in the African-Caribbean population in Britain, the prevalence of dementia in those aged 65 years and over is likely to fall somewhere between 8% and 34%, with 17% the most plausible estimate. A conservative estimate for a younger, 60 years and over group might therefore approximate **10-15%,** whilst that in the general, white population is known to be approximately **5%** (Ferri et al., 2005). Such a difference, if detected would be considered significant in terms of its impact on health and social care planning. To detect a difference between 5% and 15% with a **power of 90%** and at a **significance level of 5%** ($p \leq 0.05$), it was calculated that a sample of **207 people** (STATA statistical software package, version 9) would need to be screened in each group. Given a response rate of 70% based on previous similar surveys (60%-90%), it was expected that approximately **300** people would need to be contacted in each group (600 in total). Based on the pilot study, where 69 older African-Caribbean patients were identified from a total practice list of 6000, of which 80% were contactable, it was expected that approximately 6 similarly sized practices would need to be recruited.

4.4.8. Identification & recruitment of participants

4.4.8.1. Identification

One of the major difficulties often encountered in epidemiological research with BME communities is the challenge of identifying potential participants. This is particularly so for the African-Caribbean community, as unlike some other BME groups (e.g. South Asians), their names are often indistinguishable from those of the white population. Also, until recently, data on ethnicity or country of birth has not been routinely collected. Previous investigators have used a number of methods to identify their subjects including recall by GP practice staff, 'snowballing' (identification by existing participants), electoral and census lists and 'direct household enumeration' (Richards, 1996). Although comprehensive, household enumeration (door-knocking) is considered by many to be the 'gold standard', this method is labour intensive, lengthy and considered unacceptable by some Research Ethics Committees (RECs). In Stewart's comparison of this approach with primary care sampling, they estimated that African-Caribbean participants identified by practice staff, included 72% of the potentially eligible population whilst only 8% of those contacted were not eligible (Stewart and Richards, 2002). They also found that compared to household enumeration, the primary care sample was similar on most demographic measures. However, although highly specific and moderately sensitive, this approach is vulnerable to 'use of service' bias.

In this study, all patients 60 years and over, coded for as African-Caribbean (or equivalent), were identified primarily by searching each practice's electronic database. Most practices recruited for this study use the EMIS™ software, which encompasses a provision for generating lists of patients with pre-defined parameters (e.g. age, gender, ethnicity). In practices where ethnic coding was unavailable or incomplete, identification of potential participants was supplemented with the help of practice staff (receptionists, practice nurses & GPs), who manually identified African-Caribbean

patients from a hard copy of the patient list. Similar combinations of methods have been used successfully in other studies (Rait et al., 2000) with the aim of achieving the highest detection rate possible. The white-British comparison group was identified in the same way as the study group, but by searching for those coded as white-British (or equivalent). As there tended to be at least twice as many white-British as African-Caribbean patients on each practice list, the former were randomly selected (section 4.4.5).

4.4.8.2. *Recruitment*

All potential participants were sent a standard letter from their GP on surgery headed paper, (Appendix 6) introducing the study and asking whether they would consider participating. This initial letter was brief and written in clear, simple language. It stated that a researcher would be contacting them by telephone within two weeks, to discuss the study. They were given the choice to 'opt-out' at this stage by telephoning a dedicated number and leaving a message or by writing to me, or their surgery, in which case they were not contacted further. Between one and two weeks after the first letter was sent, potential participants were telephoned to discuss the study and to offer an appointment to meet with myself or a research assistant at a venue of their choice. This would normally be at the participant's home or that of a friend or family member. Occasionally, participants chose to be seen at a day centre or in the academic department. Participants were not seen in GP surgeries so as not to burden practice reception staff and due to space limitations. They were encouraged to invite a family member or friend to the interview. Following the telephone call, a detailed information sheet (Appendix 7) and letter, confirming the appointment date, time and venue was sent. If potential participants were not contactable on the first occasion, they were telephoned several times, including evenings and weekends to establish contact. Answer machine messages were left when it was felt appropriate. Unobtainable telephone numbers were checked online (www.thephonebook.bt.com and www.192.com). If contact was still not made, details were checked with practice staff.

4.4.8.3. Obtaining Informed consent

At the first screening appointment, participants and their relative or carer were given the opportunity to ask questions regarding the study. The investigator then carefully explained any points in the information sheet that had not been understood. Written consent was obtained directly from the participant where possible (Appendix 7). When it was apparent that the participant did not have the mental capacity to give informed consent (e.g. through cognitive impairment), approval was sought from a relative or carer and when not available, from a professional such as their GP*. If it was thought that the study would be in any way detrimental to the participant, or if the consent could not be obtained as stipulated, no further action was taken and the subject was excluded from the study. For those who were able to give verbal but not written consent, a relative or carer was asked to witness this and to provide a signature (when available). For those with sensory impairment, such as blindness or deafness, assistance was made available to facilitate their participation in the consenting procedure.

* Although the recruitment for this study was completed before October 2008 and therefore did not fall under the jurisdiction of the Mental Capacity Act 2005, the same principles were adhered to. The act clearly outlines how and when incapacitated adults can be recruited into research, specifically stipulating that:

"Carers or nominated third parties must be consulted and agree that the person would want to join an approved research project. If the person shows any signs of resistance or indicates in any way that he or she does not wish to take part, the person must be withdrawn from the project immediately. " (DoH, 2007).

4.4.9. Interviewers

Although the author conducted the majority (72%) of the screening interviews (n=314) and all of the diagnostic stage assessments (n=48), a small team of research assistants (RAs) was recruited to assist. None of the RAs was involved for the duration of the study and recruitment was staggered, with a maximum of two or three helping at any one time. The team consisted of junior psychiatrists at various stages of their training, and departmental, non-medical research assistants (RAs). All had some previous experience of interviewing patients or members of the general public. The team was composed of:

Psychiatric trainee doctors:

- SP - SHO (Senior House Officer)
- MG - SHO
- AR - SpR (Specialist Registrar)
- AP - SpR

Departmental Research Assistants:

- GH – RA with an undergraduate psychology degree
- SB – RA with an undergraduate psychology degree
- KS – RA with an undergraduate psychology degree

The psychiatric trainees volunteered their help in order to gain research experience whilst the RAs were from the local DeNDRoN (Dementias & Neurodegenerative Diseases Research Network) team. Each member was provided with an induction pack and training for the study. They initially joined me during research visits and observed a minimum of three screening interviews before conducting an interview themselves under observation. The psychiatrists who were considerably more experienced than the non-medical departmental RAs subsequently arranged their own interviews and performed them alone. The departmental RAs were given pre-arranged interview appointments as they were unable to achieve high enough recruitment rates, presumably due to their relative inexperience and non-medical status.

4.4.10. Stage 1 - Screening interview

The screening interviews were performed between March 2007 and October 2008. The interview took between 20 and 45 minutes to complete, depending on the participant. It comprised of the consent procedure as described, a brief questionnaire containing basic personal and demographic details, blood pressure reading and the cognitive screening test. Information was collected directly from the participant, or from a relative or carer for those with evidence of significant cognitive impairment (Appendix 8). The questionnaire included questions on:

Age – *Completed years*

Sex – *Male/Female*

Self-assigned ethnicity – *White-British, African-Caribbean, Other - Specified*

Country of birth – *Specified*

Years in the UK – *Completed years from migration to UK (where applicable)*

Marital status – *Single, married/partnership, divorced/separated, widowed, co-habiting*

Living with – *Spouse/partner, other family, friend/carer, alone, residential care-home*

Years of education – *Years in full-time education from primary level*

Home ownership – *Yes/No (previous home ownership if in residential care home)*

Socioeconomic classification – *based on current or last employment*

Two measures of social and economic status were included; the self coded version of the National Statistics Socioeconomic Classification – NS-SEC (Appendix 9) and home ownership (Yes or No). The NS-SEC is a measure based on a combination of current or previous employment type and supervisory/managerial status. An algorithm gives a numerical score from 1 (professionals, managers and employers) to 5 (manual workers with no supervisory responsibility). It was decided to include data on home ownership, as a single measure of socioeconomic status based on employment could introduce bias, as the African-Caribbean community were invited to migrate to the UK specifically to fill lower status jobs.

4.4.10.1. The screening questionnaire

It is well documented that screening tests tend to over estimate the levels of cognitive impairment and dementia in people from BME groups (Parker and Philp, 2004). This is thought to be due to a number of factors including language, education, literacy and cultural differences. For example, Fillenbaum et al. found that using the Mini-Mental State Examination (MMSE), 42% of black participants falsely screened positive for cognitive impairment compared to only 6% of white participants (Fillenbaum et al., 1990). Because of this phenomenon, I decided to identify and use a culturally adapted version of the Mini Mental State Examination (MMSE) in the African-Caribbean group. The original MMSE (Folstein et al., 1975) is probably the most commonly used and extensively studied of the brief dementia screening tests. It covers several areas of higher cognitive functioning including orientation, attention, registration, recall, language (reading and writing) and visual construction. The test is scored out of 30, and in clinical practice <25 is the usual cut-off for possible dementia. However, one study found the optimal MMSE cut-off to be <26, with a sensitivity of 74%, and specificity of 100% (Monsch et al., 1995). Alternatively, due to its education bias, some have proposed a cut-off of <27 in high school educated individuals and <25 in those with no high school education. Even so, it has been criticised as being strongly culturally, as well as educationally biased and it performs poorly in some BME groups, usually over-predicting dementia. This tends to be worse in non-English speaking groups, despite its translation into several Asian languages. Its widespread use is probably due to the fact that it is quick and easy to administer (10 minutes), is acceptable to most participants, and is widely recognised both in primary, and secondary care.

African-Caribbean versions of the MMSE and the shorter Abbreviated Mental Test (AMT) were developed by Rait et al. (Rait et al., 2000) – (Appendix 10). The original screening tools were culturally adapted with the assistance of a community group of African-Caribbean volunteers, alongside an academic group of health professionals. The modified screening tools were subsequently validated in a sample of 130 community residents from inner city Manchester. On direct comparison with a diagnostic computerised interview, the GMS-AGECAT (Copeland et al., 1986), the MMSE showed a high correlation ($r= -0.47$. $p<0.001$). With a cut-off of <26 the MMSE demonstrated 83% sensitivity (95%CI 76-91) and 78% specificity (95%CI 69-86), which was thought to be adequate for our study. Although a higher cut-off would have increased the sensitivity, the significantly higher numbers of participants requiring full diagnostic interview and of false positives was considered to be impractical, given the limited resources for this study. This version of the MMSE with the same cut-off was also used in the pilot study for our project, where it was found to be acceptable to participants.

In the white reference group, a standardised version of the Mini Mental State Examination *(Molloy et al., 1991)* was employed (Appendix 10). This was developed in an attempt to improve on the objectivity and intra/inter-rater reliability of the original MMSE. It is particularly useful in studies with more than one researcher, which is why I chose it in this instance. With the same components as the original test, this version comes with specific instructions on how to score each question and provides examples. It has been shown to score similarly on measures of validity and reliability to that of the African-Caribbean version when used in the general white population, and the same cut-off of <26 was used in this study.

In order to directly compare the performance of the standard and African-Caribbean versions of the MMSE in our own study sample, I decided to administer both screening tests simultaneously to all participants. As the two versions contain a high proportion of shared questions, this was best achieved by combining them into one, extended version of the MMSE, from which two scores could be obtained (Appendix 10). This was done in such a way that all the questions were included and the time for delayed recall in each test was preserved. This new, combined test was then piloted before use in the main study and inter-rater reliability calculated between researchers. African-Caribbean participants were subsequently scored on their performance on the culturally adapted version whilst white participants were scored on the standard version. An exception was made for those white participants with poor literacy, in whom the less educationally biased African-Caribbean version was used. In this test, there is no requirement to spell (as in 'spell WORLD backwards') or to write a sentence, although the instruction 'CLOSE YOUR EYES' was retained. Screening in those with visual impairment was achieved by omitting the sight dependent components and linear transformation of the scores to estimate the equivalent, full MMSE score as described by (Reischies and Geiselmann, 1997) and (Busse et al., 2002).

4.4.10.2. Blood Pressure Measurement

Blood pressure was measured after 5 minutes of sitting, both at the start and at the end of the interview with an automated BP monitor. The lowest value was used. If the first reading was high (systolic >140mm Hg or diastolic >90mm Hg) the blood pressure was repeated twice over the next 15 minutes and a mean value taken. This allowed for the objective screening for hypertension in participants according to British Hypertension Society recommendations (www.bhsoc.org). However, the limitation of a one-off blood pressure screen are recognised and discussed further in section 6.5.7.2.

4.4.11. Stage 2 - Diagnostic Interview

Those screening positive on the MMSE (<26) at the initial stage were asked for a second, structured diagnostic interview. Due to the limited time available for the screening interviews, this was generally held at a later date. A family member, friend or carer was invited to attend, and as before, the interview took place at a time and venue of the participant's choice. I conducted all the diagnostic interviews myself, although a research assistant was present if they had conducted the original screening test. The interview took between 60 and 120 minutes depending on the number of test components completed.

A number of structured diagnostic schedules have been developed, which allow for the generation of formal dementia diagnoses according to operational diagnostic criteria. However, unlike the screening tool, none was found to have been validated specifically for use in the British African-Caribbean population. I therefore decided that one of the most commonly used and acceptable interview schedules, the Cambridge Mental Disorders of the Elderly Examination (Revised) – CAMDEX-R (Roth et al., 1986) would be modified for use in this study. The full CAMDEX-R interview comprises several sections including an informant history, medical and drug history, laboratory investigations, interviewers observations, a brief physical examination and a cognitive assessment – the CAMCOG. Although all these components were retained for the study, a small number of questions were modified or removed, as they were thought to be redundant, or culturally/educationally dependent. These changes are justified, in that the data generated by the modified interview retained enough information, to allow for the diagnosis of dementia and sub-types according to the operational diagnostic criteria chosen for the study. Guided by a tick box proforma (Appendix 11), the modified diagnostic interview comprised eight sections:

A. Physical Health Questions:

- Cardio-vascular risk factors
- History of cerebro-vascular disease
- Neurological symptoms
- General health
- Drugs & alcohol history
- Family history of physical illness

B. Mental Health Questions:

- Psychiatric History
- Current mood & related symptoms
- Psychotic symptoms

C. Cognitive Functioning Questions:

- Memory problems
- General Mental Functioning
- Personality change
- Delirium/Clouding
- Everyday activities/Level of functioning

D. Current Medication

E. Relevant Physical Investigations (if known)

F. Brief Physical Examination

G. Cognitive Examination – CAMCOG

H. Interviewer Observations

4.4.11.1. *The Informant history*

Questions from the modified CAMDEX-R were asked to the participant, informant or both, where relevant. Whereas information on physical health could be obtained easily elsewhere, this was often the only opportunity to gather a clear history of cognitive decline and assess the current level of social functioning. As informants were not always available, it was sometimes not feasible to complete the assessment during the interview. In these circumstances, as much detail as possible was obtained from the participant, and the remaining information obtained from a variety of other sources.

This included speaking to relatives, friends, neighbours, paid carers and other professionals, such as wardens and residential home staff outside of the interview setting (with consent). General practice records were also scrutinised for evidence of cognitive decline, as were any records held by the local old age psychiatric service. For some participants, exhaustive investigations were required, in order to obtain enough information to make a definitive diagnosis.

4.4.11.2. Cognitive Assessment

The CAMCOG was designed to be administered in conjunction with the other CAMDEX-R components. It comprises sections that assess a number of cognitive domains including: orientation, perception, language, memory (recall, recent and remote memory), attention/concentration, calculation, praxis and executive functioning. It also incorporates questions from the MMSE and can generate an independent score for this. In its complete form, it has a maximum of 106 points, with a cut-off of 79/80 for dementia. It has an estimated sensitivity of 93% and a specificity of 96% (Roth et al., 1986). As mentioned previously, the CAMDEX-R although widely used, has not been validated or adapted for use in any specific cultural or ethnic group. When designing the diagnostic interview, I decided along with my supervisors that a small number of questions were potentially either culturally or educationally biased. I removed them for the purpose of this study. These included some questions testing executive functioning (200b – visual reasoning) and the retrieval of remote memory: (166 – 171); for example:

When did the First World War begin?

What was Mae West famous for?

Who was the famous flyer whose son was kidnapped?

What is Yoko Ono famous for?

Who was the first woman Prime Minister of India?

The questions generating the MMSE score were redundant and also omitted. As the total score no longer totalled 106, the cut-off of 79/80 was not used to guide the diagnostic procedure. Instead, performance in specific cognitive domains were used to supplement the clinical information and informant history in making the final diagnosis, in accordance with standardised criteria (4.4.12)

4.4.11.3. Medical History & Physical examination

The medical history assessed risk factors for dementia, focusing heavily on cerebro-vascular disease and its determinants, such as diabetes, hypertension and stroke. Prescribed and taken medications were recorded; in particular anti-hypertensives, diabetic treatment and psychotropic drugs. The medical history was later supplemented by information obtained directly from the participant's primary care notes, with written permission (Consent form - Appendix 7). This was accessible electronically at each of the G.P. surgeries. Recent pathology results, neuroimaging reports (when available) and other relevant physical investigations were also obtained in this way. Although desirable, it was beyond the scope of this study to request additional investigations in the form of blood tests or neuroimaging.

A brief, but structured physical examination was conducted to elicit any physical signs associated with dementia and to identify other physical disease that may account for cognitive impairment. As for the medical history the examination focussed largely on evidence of cardio-vascular and cerebro-vascular disease, and also looked for other neurological and endocrine disorders (e.g. thyroid disease) and sensory deficits. A comprehensive physical examination was rarely possible, due to the home setting and the fact that it would have been inappropriate to ask participants to undress, particularly when unaccompanied.

4.4.12. Diagnostic procedure

Data collected from both the screening and diagnostic interviews were collated and summarised in a standardised format (Appendix 12). Any identifiable participant information was removed from the original interview proforma. These were then copied, and compiled into packs, with a summary sheet for each of the diagnostic raters. Typically, batches of 5-10 interview packs were rated at meetings between myself and the two raters (my PhD supervisors; both academic old age psychiatrists). 'Blind' to the ethnicity of each participant, the raters judged whether a formal diagnosis of dementia could be made, according to ICD-10 Research Diagnostic Criteria and DSM-IV-TR criteria (section 1.2.1). They also included a clinical rating of dementia (mild, moderate or severe) based on ICD-10 criteria, and specified the dementia subtype(s) according to the following diagnostic criteria:

Alzheimer's Dementia – ICD-10, DSM-IV & NINCDS-ADRDA (McKhann et al., 1984)
Vascular Dementia – ICD-10, DSM-IV & NINDS-AIREN (Roman et al., 1993)
Lewy Body Dementia (DLB) - Revised DLB Consortium Criteria (McKeith et al., 2005)
Frontotemporal Dementia (FTD) – Consensus criteria (McKhann et al., 2001)
Other dementia – specified

Diagnoses were made independently by each rater, with the aid of a specially developed diagnostic checklist (Appendix 12) and recorded, before comparing with the other rater. In instances where raters did not agree, consensus was reached through discussion. It was possible for participants to meet the criteria for more than one subtype of dementia unless one precluded the diagnosis of another e.g. a diagnosis of vascular dementia would excluded an ICD-10 diagnosis of Alzheimer's disease.

4.5. MEDICAL NOTES SURVEY

As discussed in Chapter One, the importance of early detection of dementia in primary care is strongly emphasised in a number of governmental reports, guidelines and in the National Dementia Strategy (section 1.2.4.3). Financial incentives in the form of QOF indicators also encourage General Practices to set up a dementia register and to review the patients on it at regular intervals (section 1.2.5). The advantage of the new QOF related dementia registers to this study is that they were used as a preliminary guide to the level of detection of dementia in each general practice recruited. Participants from each practice, who screened positive for cognitive impairment, were initially checked for their inclusion on the dementia register, if in operation. Their individual medical records were then scrutinised for:

1. Mention of cognitive impairment; in terms of forgetfulness, confusion, behavioural change or functional deterioration.
2. Mention of, or formal diagnosis of 'dementia'.
3. Referral to mental health, social or voluntary services in relation to any of the above problems.
4. Pharmacological treatment received in relation to a diagnosis of dementia or cognitive impairment (e.g. cholinesterase inhibitors for AD).

For most participants, their medical records were available in electronic format and were easily accessible. Electronic records were scrutinised for the previous five years, or from first registration with the practice if sooner. For each participant, documentation of dementia in the medical records was compared with the standardised diagnosis generated through the study. The rates of dementia diagnosis and referral to dementia services were subsequently compared between the two study groups.

4.6 STATISTICAL ANALYSIS

I used SPSS version 16.0 for Mac (SPSS inc 2007) to analyse the data. Two-tailed tests were used throughout. Although multiple univariate analyses were conducted, a level of 5% ($p<0.05$) was taken as significant, only to identify those variables to include in the multivariate analysis. For univariate tests, parametric statistics were used where the data approximated a normal distribution (where Pearson's skewness statistic was less than +/- 1.0) (Miles and Shevlin, 2001). Chi squared (Chi^2) or Fisher's exact tests were performed to compare proportions (binary data), and independent t-tests or Mann-Whitney U tests to compare central values (continuous data), where appropriate. Classical stratification and binary logistic regression techniques were used for multivariate analyses. Variables chosen for the final analyses included those under investigation (i.e. dementia status and ethnic group) and potential confounders as identified from the univariate analyses.

4.6.1. Cross sectional analysis

Initially, the recruitment rate and reasons for non-participation were explored. In order to assess for selection bias, I compared the age, sex and ethnic distribution between potential participants who were contactable and those who were not. I repeated this analysis for those who agreed to participate and those who declined. I then performed univariate analyses to compare the white-British and African-Caribbean groups, in terms of their main demographic characteristics including age, sex, marital status, years of education, home ownership and self assigned socioeconomic status (NS-SEC).

4.6.1.1. Screening stage

I compared the MMSE scores (range, central value, spread) between ethnic groups on their respective, culturally appropriate versions. I then calculated and compared the crude prevalence of screening positive for cognitive impairment. To investigate the performance (cultural/educational) of the two MMSE versions, I calculated the crude prevalence of screening positive for each group on each test, separately.

Rates of measured and reported (treated) hypertension were compared between ethnic groups, separately. I also compared rates of measured hypertension with reported hypertension, in order to estimate the frequency of untreated and inadequately treated hypertension. The proportions of both were compared between ethnic groups.

I subsequently performed univariate analyses to explore the relationship between a number of demographic/health variables and screening status. These included age, sex, years of education, home ownership, socioeconomic status, reported and measured blood pressure. From the univariate analyses that reached statistical significance ($p<0.05$), the most plausible confounders or effect modifiers of the crude association between ethnicity and screening status were identified. Where appropriate (for continuous data), potential confounders were transformed into categorical data. Classical stratification techniques were then employed to control for potential confounding and to identify effect modification of the primary association. Finally, all potential confounders were entered into a logistic regression model using a stepwise approach, with screening status as the dependent variable. I entered ethnicity on step one and all other variables that reached statistical significance on univariate analysis on subsequent steps, in order to assess their effect on the model individually. I then re-examined the primary association between screening status and ethnicity when controlled for potential confounders.

4.6.1.2. Diagnostic stage

I first identified those participants who had dropped out of the study or failed to complete the diagnostic interview, and compared them by ethnic group. I then further investigated each component of the diagnostic interview for the degree of completion by participants. The crude prevalence of dementia (any criteria) was calculated and compared between ethnic groups. This analysis was performed for participants, both with and without MCI and including and excluding those in residential care homes. I then explored frequency of dementia by severity (mild, moderate or severe) and then by subtype, according to each standardised diagnostic criterion.

As for screening status (described above), univariate analyses were conducted to explore the relationship between dementia diagnosis and a number of potential covariates. From these, potential confounders of the relationship between ethnicity and dementia were identified. These were further investigated, first using classical stratification and then logistic regression techniques, with dementia status as the dependent variable. As the numbers of participants with dementia were relatively small, variables for which data was missing in more than 20% of participants (with dementia) were excluded from the final multivariate analysis, otherwise data was imputed, using SPSS software.

4.6.2. Medical notes survey

Of the participants with dementia, the proportions that had a formal diagnosis recorded in the primary care records were compared between ethnic groups, and any difference analysed. I then examined the medical note entries in more detail, in regard to mention of cognitive impairment, dementia, dementia subtype, referral and pharmacological treatment. Statistically significant differences between the groups were tested, using univariate analyses.

5. RESULTS

5.1. CROSS SECTIONAL SURVEY RESULTS

5.1.1. Recruitment rates

Of the 14 Haringey, General Practices I approached through NoCLoR, eight expressed an initial interest and five participated in the study. The remainder either declined, or did not respond. Four of the participating practices were in the suburb of Tottenham, and one in Hornsey (table 5.1).

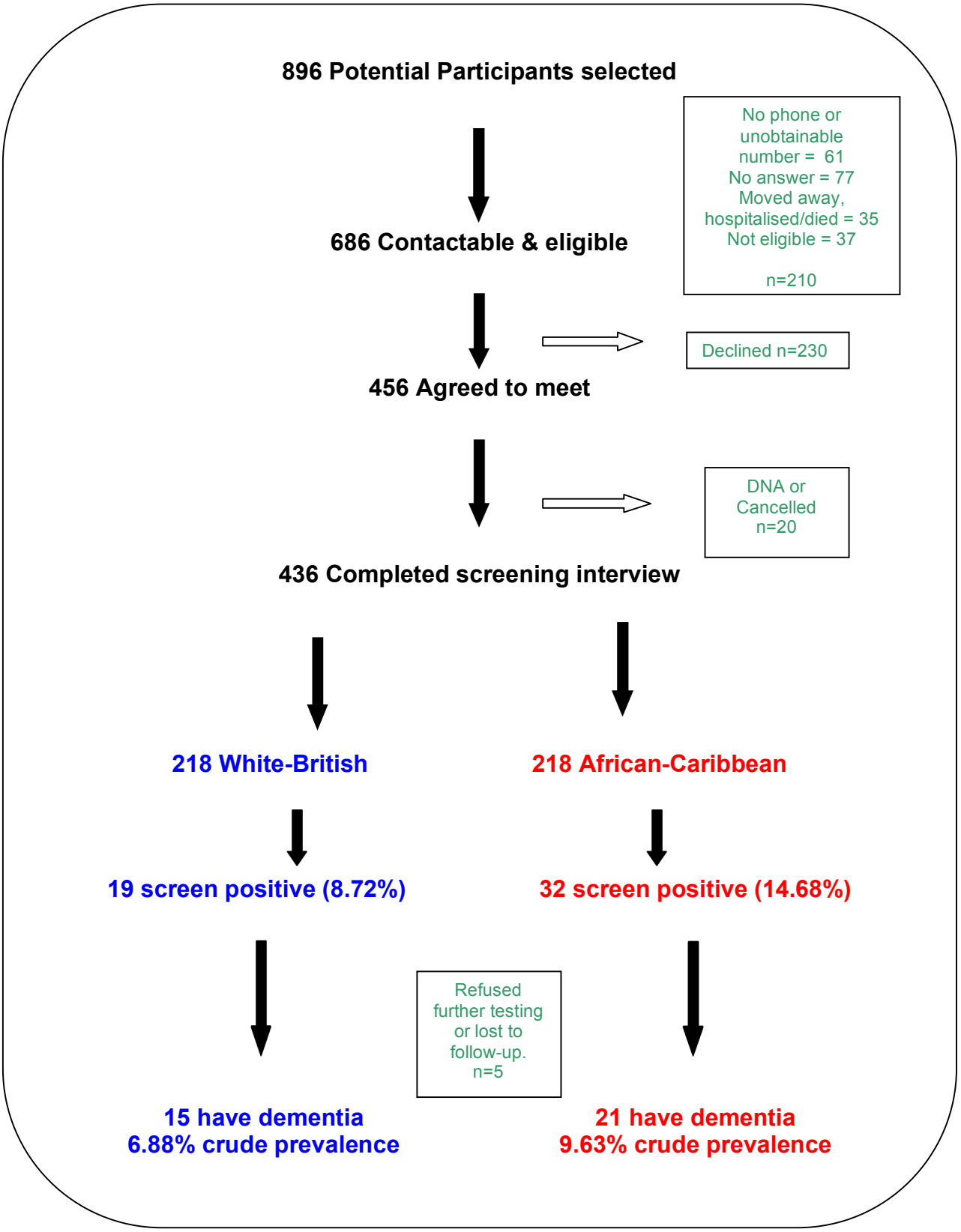
Table 5.1 **General Practices Recruited**

NAME	LOCATION	PARTICIPANTS SELECTED	PARTICIPANTS CONTACTABLE (%)	NUMBER PARTICIPATED (%)*
Westbury Avenue Surgery	Hornsey	8	8 (100)	3 (37.5%)
Charlton House Medical Centre	Tottenham	306	249 (81.4)	155 (62.2%)
Park Road Surgery	Hornsey	72	49 (68.1)	32 (65.3%)
Somerset Garden Family Healthcare Centre	Tottenham	283	210 (74.2)	130 (61.9%)
Lawrence House Medical Centre	Tottenham	227	170 (74.9)	116 (68.2%)
Total		**896**	**686 (76.6)**	**436 (63.6%)**

* % of those contactable and eligible to take part

In total, the names of 1,617 potential participants were obtained, of which 896 were selected for inclusion in the study. This included all 460 people who were coded for, or identified by general practice staff as being African-Caribbean (or equivalent) and a random sample of 436 people who were coded for, or identified as being white-British (or equivalent). The final number randomly selected for the white-British group was smaller, because a higher proportion were contactable than for the African-Caribbean group. One hundred and seventy three (19.3%) people were not contactable by phone for a number of reasons including; no/wrong/unobtainable telephone number 61 (6.8%), no answer after several attempts 77 (8.6%), moved away/ no longer with the same general practitioner/in hospital/dead 35 (3.9%). Further enquiry revealed that 18 (2%) people coded for as African-Caribbean were of other ethnicities; all came from South Asia or Africa. They were excluded from the study along with a further 19 people who did not meet the inclusion criteria for other reasons (intellectual disability, hospitalisation, acutely ill). In total, 723 potential participants were contacted by telephone and of them, 686 met the inclusion criteria. Although 456 agreed to meet with a researcher, 20 cancelled or did not keep their appointment, leaving 436 who completed the screening interview (63.6% of those contacted and eligible). As planned, half were white-British (218) and half were African-Caribbean (218). The majority of participants (96.5%) lived in their own homes or with family; the remainder living in one of two residential care homes (fig. 5.1).

Figure 5.1 **Summary of Recruitment**



5.1.2 Contactable versus not contactable

A higher proportion of white-British people were contactable (85.9%) than African-Caribbean people (80.6%), (Chi^2=4.213; p=0.040; OR 1.471, 95%CI 1.016 to 2.129) and a higher proportion of females (86.8%) were contactable than males (78.7%), (Chi^2=9.474; p=0.002; OR 0.563, 95%CI 0.389 to 0.84). Those contacted (mean age 72.9 years; SD 8.3) were on average 3.1 years older than those who were not contactable (mean age 69.8 years; SD 7.4) (t=4.104; p<0.001). In those not contactable, there was no age difference (t=0.240; p=0.810) or sex difference (Chi^2=1.596; p=0.207) between ethnic groups.

5.1.3 Participants versus those who declined

Although the participation rate was higher in the African-Caribbean group, 218/320 (68.1%) than in the white-British group 218/346 (63.0%), this was not statistically different (Chi^2=1.927; p=0.165). Participants were also similar to those who declined in terms of sex and age; 260/436 (59.6%) of participants were female compared to 128/230 (55.7%) of non-participants (Chi^2=0.981; p=0.322); the mean age of participants was 72.8 years (SD 8.0) compared to 73.1 years (SD 8.9) in non-participants, (t= -0.421; p=0.674).

5.1.4 Participant demographic data

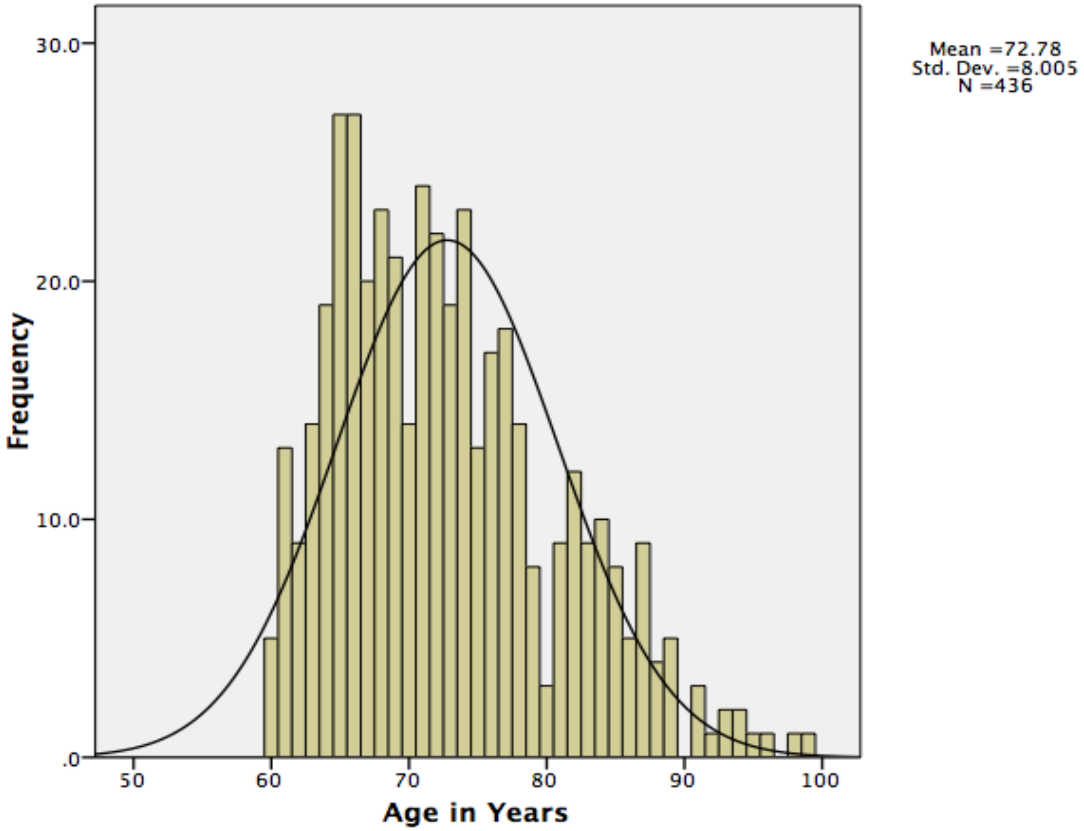
5.1.4.1 Country of Birth

As well as the United Kingdom and Ireland, participants reported coming from 11 Caribbean islands and Guyana. Of the 216 African-Caribbean participants on whom I had data, the majority were born in Jamaica 120 (55.6%) followed by Trinidad 19 (8.8%), Barbados 16 (7.4%) and Guyana 11 (5.1%). Others reported coming from Antigua, St Vincent, St Lucia, St Kitts, Nevis, Montserrat, Grenada and Dominica. Notably, none of the potential African-Caribbean participants I approached was born in the UK.

5.1.4.2 Age

The age range for participants (n=436) was 60 to 99 years (skewness statistics 0.691), with a mean age of 72.8 years (SD 8.005), (fig. 5.2).

Figure 5.2 **Age distribution of all participants.**



The mean age for white-British participants was 73.7 years compared to 71.8 years in the African-Caribbean sample. The mean difference of 1.9 years (95%CI 0.4 – 3.4) was significant (t=2.528; p=0.012). When I explored the age distribution for each ethnic group (see table 5.2), I found that 58/218 (26.6%) of white-British participants were over the age of 80 and 10/218 (4.6%) over 90 years, whereas these proportions were only 28/218 (12.8%) and 2/218 (0.9%) respectively for African-Caribbean participants. Notably, a high proportion of African-Caribbean people fell into the 65-69 & 70-74 year age bands. The difference in age structure between the two ethnic groups was highly significant (Chi^2=2.47; p=0.001).

Table 5.2 **Age distribution by ethnic group**

Ethnicity	5-year age-bands								Total
	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	
White-British (%)	32 (14.7)	59 (27.1)	35 (16.1)	34 (15.6)	25 (11.5)	23 (10.6)	6 (2.8)	4 (1.8)	218 (100)
African-Caribbean (%)	28 (12.8)	59 (27.1)	67 (30.7)	36 (16.5)	18 (8.3)	8 (3.7)	2 (0.9)	0 (0.0)	218 (100)
Total (%)	60 (13.8)	118 (27.1)	102 (23.4)	70 (16.1)	43 (9.9)	31 (7.1)	8 (1.8)	4 (0.9)	436 (100)

5.1.4.3 Sex

Of the whole sample, the majority were female (table 5.3). There was no significant difference in the proportion of females between the white-British and African-Caribbean participants (Chi2=0.152; p=0.696).

Table 5.3 **Sex distribution by ethnic group**

Ethnic group	Male (%)	Female (%)	Total (%)
White-British (%)	90 (41.3)	128 (58.7)	218 (100)
African-Caribbean (%)	86 (39.4)	132 (60.6)	218 (100)
Total (%)	176 (40.4)	260 (59.6)	436 (100)

5.1.4.4 Marital status

Information on marital status was available on 424/436 (97%) of participants. Of these, 180 (42.4%) were married or cohabiting (table 5.4). This proportion was higher in the African-Caribbean group 100/212 (47.2%) than the white-British group 80/211 (37.9%) and the difference approached statistical significance (Chi^2=3.705; p=0.054). The white-British participants were nearly twice as likely to be widowed (Chi^2=2.35; p<0.001).

Table 5.4 **Marital status by ethnic group.**

	White-British (%)	African-Caribbean (%)	Total (%)
Married	76 (35.9)	95 (44.8)	171 (40.3)
Partner/Cohabiting	4 (1.9)	5 (2.3)	9 (2.1)
Single	28 (13.2)	16 (7.5)	44 (10.4)
Divorced	28 (13.2)	44 (20.8)	72 (17.0)
Separated	3 (1.4)	12 (5.7)	15 (3.5)
Widowed	73 (34.4)	40 (18.9)	113 (26.7)
Total	212 (100)	212 (100)	424 (100)

5.1.4.5 Years of education

Data were available on 370/436 (84.9%) of participants (see figure 5.3). Time spent in full-time education ranged from five to 23 years (skewness statistic 2.00). Of all participants, the median value was 10.0 years (interquartile range 9-11 years). There was no difference in these values between ethnic groups.

5.1.4.6 Home Ownership

Data on home ownership was available on 421/436 (96.6%) of participants (table 5.5). The majority either owned, or had previously owned their own homes. The proportion of home ownership was considerably lower in the white-British group than the African-Caribbean group (Chi^2=1.56; p<0.001; OR 0.458, 95%CI 0.310 – 0.677).

Table 5.5 **Home ownership by ethnic group.**

Home ownership	White-British (%)	African-Caribbean (%)	Total (%)
YES	88 (41.7)	128 (61.0)	216 (51.3)
NO	123 (58.3)	82 (39.0)	205 (48.7)
Total	211 (100)	210 (100)	421 (100)

5.1.4.7 *Self assigned socioeconomic status*

Data on NS-SEC was available on 414/436 (95.0%) of participants (table 5.6). The majority (61.7%) fell into groups 4 and 5 indicating lower socioeconomic status according to current or previous occupation. When I compared socioeconomic status by ethnicity, I found that a higher proportion of African-Caribbean participants (74.7%) fell into NS-SEC categories four and five than white-British participants (55.3%) (table 5.6). This overall difference in NS-SEC distribution was statistically significant (Chi^2=2.07; p<0.001).

Table 5.6 **NS-SEC by ethnic group.**

		Ethnic Group (%)		Total (%)
		White-British	African-Caribbean	
Socioeconomic status 1-5	1	36 (17.3)	28 (13.6)	64 (15.5)
	2	49 (23.6)	22 (10.7)	71 (17.1)
	3	8 (3.8)	2 (1.0)	10 (2.4)
	4	36 (17.3)	53 (25.7)	89 (21.5)
	5	79 (38.0)	101 (49.0)	180 (43.5)
	Total	208 (100)	206 (100)	414 (100)

5.1.5 Stage 1 – Screening interview

A total of 436 participants (218 white-British and 218 African-Caribbean) completed the screening interview.

5.1.5.1 Performance on the MMSE

The scores ranged from zero to 30 on both the standard and African-Caribbean versions of the MMSE (skewness statistics -3.305 and -4.029 respectively). The median values for the ethnic groups combined were 28 (interquartile range 26-29) for the standard version and 29 (interquartile range 27-30) for the African-Caribbean version. Overall, the African-Caribbean participants performed less well on both tests than their white-British peers. The difference in performance between ethnic groups on both tests was statistically significant; Mann-Whitney U scores = 15060.5 ($p<0.001$) and 19065.0 ($p=0.004$) for the Standard and African-Caribbean versions respectively.

5.1.5.2 Screen positives

A total of 51/436 (11.7%) participants screened positive for cognitive impairment (<26 on their respective, culturally appropriate versions of the MMSE), (table 5.7). The difference in proportions screening positive between the two ethnic groups approached statistical significance (Chi^2=3.753; p=0.053), with an estimated MH Odds Ratio of 1.80 (95%CI 1.00 to 3.29).

Table 5.7 **Screening status by ethnic group.***

	White-British	African-Caribbean	Total
Screen Negative	199 (91.3)	186 (85.3)	385 (88.3)
Screen positive	19 (8.7)	32 (14.7)	51 (11.7)
Total	218 (100)	218 (100)	436 (100)

* With a cut-off of < 26 on the culturally appropriate version of the MMSE.

When I analysed the participants' performance on each of the MMSE versions separately, the difference was more striking. Both groups performed better on their respective, culturally appropriate versions. This effect was far more pronounced in the African-Caribbean participants of whom more than 28% would have screened positive on the standard MMSE (with the same cutoff) compared to just 8.7% of white-British participants (Chi^2=2.74; p<0.001) (table 5.8).

Table 5.8 **Participants screening positives (%) according to MMSE version.**

Participants	Standard MMSE (%)	African-Caribbean MMSE (%)
White-British	**19 (8.7)**	21 (9.6)
African-Caribbean	62 (28.4)	**32 (14.7)**
Total screen positives	81 (18.6)	53 (12.2)

***Numbers in bold indicate the respective, culturally appropriate MMSE.

5.1.5.3 Blood pressure

During the screening interviews, blood pressure measurements were taken on 361/436 (82.8%) participants (methods section 4.4.10.2). The diastolic values ranged from 48 to 114 (mean 83; SD 11.3; skewness -0.041) and the systolic values from 93 to 206 (mean 146; SD 19.3; skewness 0.367).

When adhering to British Hypertension Society guidelines, 240/361 (66.5%) of all participants were considered to be hypertensive at the time of the screening interview. When compared by ethnic group 113/180 (62.8%) of white-British participants were hypertensive compared to 127/181 (70.2%) of African-Caribbean participants. This difference was not statistically significant (Chi^2=2.211; p=0.137).

Of the 324 participants who knew their existing hypertension status, 205 (63.27%) reported taking treatment for high blood pressure. Significantly fewer white-British participants 89/163 (54.6%) reported taking treatment than African-Caribbean participants 116/161 (72.0%); (Chi^2=1.06; p=0.001; OR 0.47, 95%CI 0.29-0.74)).

I collected complete data on 317 participants with regard to *both* reported (treated) and measured hypertension (see table 5.9). Overall, 141/199 (70.9%) of those reporting treatment with an antihypertensive, were hypertensive as measured at the screening interview. There was no significant difference between the two ethnic groups in this respect (Chi^2=0.423; p=0.515). Conversely, 72/213 (33.8%) of participants with measured hypertension reported having no treatment for this and significantly fewer were white-British (50.7%) than African-Caribbean (77.8%) (Chi^2=8.591; p=0.003; OR 3.41, 95%CI 1.47-7.88).

Table 5.9 **Treated and measured hypertension by ethnic group.**

Ethnic Group	Hypertension (measured)	Hypertension (reported/treated)		TOTAL
		Yes (%)	No (%)	
White-British	**Yes**	63 (73.3) *	37 (50.7) ***	**100 (62.9)**
	No	23 (26.7) **	36 (49.3)****	**59 (37.1)**
	Sub-total	**86 (100)**	**73 (100)**	**159 (100)**
African-Caribbean	**Yes**	78 (69.0) *	35 (77.8) ***	**113 (71.5)**
	No	35 (31.0)**	10 (22.2)****	**45 (28.5)**
	Sub-total	**113 (100)**	**45 (100)**	**158 (100)**
TOTAL		**199**	**118**	**317**

* Inadequately treated hypertension ** Adequately treated hypertension

*** Undiagnosed hypertension **** No hypertension

5.1.6 Covariates relating to screening status.

All univariate analyses were performed in relation to culturally specific MMSE scores. These associations were further explored to identify potential confounders of the relationship between ethnicity and screening status.

5.1.6.1 Age

The mean age in those screening positive was significantly higher at 80.8 years (SD 9.3) compared to 71.7 years (SD 7.2) in those screening negative; mean difference 9.1 years (95%CI 6.91 to 11.28 years; t= -8.179; p< 0.001).

5.1.6.2 Sex

There was no significant difference in screening status by sex; 21/176 (11.9%) males screened positive verses 30/260 (11.5%) females (Chi^2=0.16; p=0.9).

5.1.6.3 Years of education

The median duration of full time education was significantly lower in those screening positive at 9 years (interquartile range 8-10) compared to 10 years (interquartile range 9-11) in those screening negative (Mann-Whitney U score 3895.0 ; $p<0.001$).

5.1.6.4 Home ownership

There was no significant difference in screening status when compared by home ownership; 21/216 (9.7%) of home owners screened positive, compared to 26/205 (12.7%) not owning their own home ($Chi^2=0.930$; $p=0.335$).

5.1.6.5 Self assigned socioeconomic status

Of the 414 participants on whom I had data, 229/370 (61.9%) of participants screening negative were assigned to NS-SEC groups 4 and 5 compared to 40/44 (90.9%) of those screening positive (table 5.10). The difference in distribution of screen positives and negatives between the NS-SEC groups 1 to 5 was found to be highly significant ($Chi^2=2.71$; $p<0.001$).

Table 5.10 **Screening status by NS-SEC**

		Screening Status (%)		Total (%)
		Screen negative	Screen positive	
Socioeconomic class	1	63 (17.0)	1 (2.3)	64 (15.5)
	2	70 (18.9)	1 (2.3)	71 (17.1)
	3	8 (2.2)	2 (4.5)	10 (2.4)
	4	83 (22.4)	6 (13.6)	89 (21.5)
	5	146 (39.5)	34 (77.3)	180 (43.5)
Total		370 (100)	44 (100)	414 (100)

5.1.6.6 *Blood Pressure*

Of the participants screening positive from whom I collected data, significantly more reported existing (treated) hypertension compared to those screening negative (Chi^2=5.065; p=0.024). The estimated MH odds ratio was 0.45 (95%CI 0.22 to 0.91), (table 5.11).

Table 5.11 **Screening status by reported (treated) hypertension**

	Reported hypertension	**No reported hypertension**	**Total**
Screen negative (%)	167 (60.7)	108 (39.3)	275 (100)
Screen positive (%)	38 (77.6)	11 (22.4)	49 (100)
Total (%)	205 (63.3)	119 (36.7)	324 (100)

There was no significant difference in the rates of measured hypertension in relation to screening status (Chi^2=0.007; p= 0.935), (table 5.12).

Table 5.12 **Screening status by measured hypertension**

	Hypertension	**No hypertension**	**Total**
Screen negative (%)	105 (33.4)	209 (66.6)	314 (100)
Screen positive (%)	16 (34.0)	31 (66.0)	47 (100)
Total (%)	121 (33.5)	240 (66.5)	361 (100)

5.1.7 Controlling for potential confounders

The only variables potentially confounding the association between screening positive and African-Caribbean ethnicity are age and self reported socioeconomic status (NS-SEC). Age is most likely to be a negative confounder in this instance; controlling for it strengthening the association. Conversely, socioeconomic status is likely to be a positive confounder. Controlling for this would be expected to weaken the association.

5.1.7.1 *Controlling for Age*

When stratified by ten-year age bands, the association between screening status and ethnicity was strengthened and highly significant (pooled MH OR 3.53; 95%CI 1.68 to 7.43; p=0.001), (table 5.13).

5.1.7.2 *Controlling for Socioeconomic status*

When stratified by socioeconomic status, the association between screening status and ethnicity was weakened, and not significant (pooled OR 1.45; 95%CI 0.74 to 2.84; p=0.282), (table 5.14).

Table 5.13 Screening status by ethnic group, stratified by 10-year age bands

10 YEAR AGE BANDS			ETHNIC GROUP (%)		TOTAL (%)
			WHITE – UK	AFRICAN-CARIBBEAN	
60-69	SCREEN +/-	SCREEN NEGATIVE	91 (100)	81 (93.1)	172 (96.6)
		SCREEN POSITIVE	0 (0)	6 (6.9)	6 (3.4)
	TOTAL		**91 (100)**	**87 (100)**	**178 (100)**
70-79	SCREEN +/-	SCREEN NEGATIVE	64 (92.8)	91 (88.1)	155 (90.1)
		SCREEN POSITIVE	5 (7.2)	12 (11.7)	17 (9.9)
	TOTAL		**69 (100)**	**103 (100)**	**172 (100)**
80-89	SCREEN +/-	SCREEN NEGATIVE	40 (83.3)	14 (53.8)	54 (73.0)
		SCREEN POSITIVE	8 (16.7)	12 (46.2)	20 (27.0)
	TOTAL		**48 (100)**	**26 (100)**	**74 (100)**
90-99	SCREEN +/-	SCREEN NEGATIVE	4 (40.0)	0 (0)	4 (33.3)
		SCREEN POSITIVE	6 (60.0)	2 (100)	8 (66.7)
	TOTAL		**10 (100)**	**2 (100)**	**12 (100)**

10 Year Age Bands	Pearson's Chi^2 Value	Significance (p)	Fisher's Exact Test (p) *
60-69	-	-	0.120
70-79	0.900	0.343	-
80-89	7.435	0.006	-
90-99	-	-	0.515

*Exact test score given when cells have values less than 5.

Table 5.14 Screening status by ethnic group, stratified by NS-SEC

SOCIOECONOMIC STATUS 1-5			ETHNIC GROUP		TOTAL (%)
			WHITE – UK (%)	AFRICAN-CARIBBEAN (%)	
1	SCREEN +/-	SCREEN NEGATIVE	35 (97.2)	28 (100)	63 (98.4)
		SCREEN POSITIVE	1 (2.8)	0 (0)	1 (1.6)
	TOTAL		**36 (100)**	**28 (100)**	**64 (100)**
2	SCREEN +/-	SCREEN NEGATIVE	48 (98.0)	22 (100)	70 (98.6)
		SCREEN POSITIVE	1 (2.0)	0 (0)	1 (1.4)
	TOTAL		**49 (100)**	**22 (100)**	**71 (100)**
3	SCREEN +/-	SCREEN NEGATIVE	7 (87.5)	1 (50.0)	8 (80)
		SCREEN POSITIVE	1 (12.5)	1 (50.0)	2 (20)
	TOTAL		**8 (100)**	**2 (100)**	**10 (100)**
4	SCREEN +/-	SCREEN NEGATIVE	35 (97.2)	48 (90.6)	83 (93.3)
		SCREEN POSITIVE	1 (2.8)	5 (9.4)	6 (6.7)
	TOTAL		**36 (100)**	**53 (100)**	**89 (100)**
5	SCREEN +/-	SCREEN NEGATIVE	66 (83.5)	80 (79.2)	146 (81.1)
		SCREEN POSITIVE	13 (16.5)	21 (20.8)	34 (18.9)
	TOTAL		**79 (100)**	**101 (100)**	**180 (100)**

NS-SEC	Pearson's Chi^2 Value	Significance (p)	Fisher's Exact Test (p) *
1	-	-	1.000
2	-	-	1.000
3	-	-	0.378
4	-	-	0.395
5	0.544	0.461	-

*Exact test score given when cells have values less than 5.

5.1.8 Multivariate analysis

The association between screening status and ethnicity was investigated further, by controlling for both age and socioeconomic status (NS-SEC) simultaneously. Stepwise logistic regression modelling was used (table 5.15). In step 3, data was imputed for the 22 participants on whom NS-SEC was missing.

Table 5.15 **Logistic regression model**

Variables not in the Equation			
	Score	df	Sig.
Ethnicity	**3.753**	**1**	**0.053**
Overall Statistics	3.753	1	0.053

Step 1

		B	S.E.	Wald	df	Sig.	Exp(B)	95% CI	
								Lower	Upper
Step 1	**Ethnicity**	**0.589**	**0.307**	**3.678**	**1**	**0.055**	**1.802**	**0.987**	**3.289**
	Constant	-2.938	0.517	32.292	1	0.000	0.053	-	-
Variable entered on step 1: **Ethnicity**.									

Step 2

		B	S.E.	Wald	df	Sig.	Exp(B)	95% CI	
								Lower	Upper
Step 2	**Ethnicity**	**1.373**	**0.380**	**13.074**	**1**	**0.000**	**3.948**	**1.876**	**8.312**
	Age	0.164	0.023	48.857	1	0.000	1.178	1.125	1.234
	Constant	-1.66	2.195	57.737	1	0.000	0.000	-	-
Variable entered on step 2: **Age**.									

Step 3

		B	S.E.	Wald	df	Sig.	Exp(B) **3.558**	95%CI	
								Lower	Upper
Step 3*	**Ethnicity**	**1.269**	**0.394**	**10.362**	**1**	**0.001**	**3.558**	**1.643**	**7.705**
	Age	0.166	0.025	44.245	1	0.000	1.181	1.125	1.241
	NSSEC	0.627	0.182	11.832	4	0.001	1.872	1.310	2.676
	Constant	-1.93	2.556	57.037	1	0.000	0.000	-	-
Variable entered on step 3 : **NS-SEC**.									

On step one of the regression analysis, the relationship between screening status and ethnicity was not statistically significant. When controlled for by age, the association was strengthened and highly significant (step 2). Controlling for NS-SEC added little to the model (step 3).

5.1.9 Stage 2 – Diagnostic Interview

Of the participants who screened positive for cognitive impairment, 46/51 (90.2%) completed enough of the diagnostic interview for us to make a diagnosis. Of the remaining five, three refused to participate further (all African-Caribbean) and two lacked sufficient information (one white-British, one African-Caribbean).

In total, 21/46 (45.7%) completed all components of the diagnostic interview; 33 (71.7%) completed the informant history/medical questionnaire, 22 (47.8%) the CAMCOG and 40 (87%) the physical examination. I obtained information from primary care medical notes on 45 (97.8%), and physical investigations/neuroimaging on 35 (76.1%). Although not all participants had completed all sections of the interview, we had enough information to diagnose dementia in 36 people (15 white-British and 21 African-Caribbean) and mild cognitive impairment (MCI) in a further five (two white-British and three African-Caribbean). The remaining five participants did not meet the criteria for either diagnosis (one white-British and four African-Caribbean); and were 'false positives' on the screening interview.

5.1.9.1 Crude dementia prevalence

The crude prevalence of dementia (excluding MCI), according to at least one set of diagnostic criteria was 15/218 (6.9%) in the white-British group and 21/218 (9.6%) in the African-Caribbean group. This weak association between dementia and ethnicity (OR 1.44; 95%CI 0.72 to 2.88) was not statistically significant (Chi^2=1.090, p=0.296). When participants with MCI were included, the prevalence increased to 17/218 (7.80%) in the white-British group and 24/218 (11.01%) in the African-Caribbean group (Chi^2=1.319, p=0.251). If those in residential care homes were excluded, the crude prevalence of dementia in the two groups (excluding MCI) was 10/200 (5.0%) and 16/205 (7.8%) respectively (Chi^2=1.326; p=0.250).

5.1.9.2 Dementia severity

The severity of dementia was most frequently 'mild', followed by 'moderate' and 'severe' respectively (table 5.16). The frequency of 'mild' and 'moderate' dementia was higher in the White-British group and of 'severe' dementia in the African-Caribbean group. However, there was no statistically significant difference between the two ethnic groups in the distribution of dementia severity overall (Chi^2=0.630; p=0.730).

Table 5.16 Dementia severity by ethnic group (any criteria)

Ethnic group	Dementia severity			Total
	Mild	Moderate	Severe	
White – British (%)	7 (46.7)	6 (40.0)	2 (13.3)	15 (100)
African-Caribbean (%)	9 (42.9)	7 (33.3)	5 (23.8)	21 (100)
Total (%)	16 (44.4)	13 (36.1)	7 (19.4)	36 (100)

5.1.9.3 *Dementia subtype*

Of the 36 participants that were diagnosed with dementia, 26/36 (72.2%) met the criteria for ICD-10 and 34/36 (94.4%) for DSM-IV TR diagnosis (see table 5.17). Six did not meet the criteria for any of the dementia subtypes and were classified as 'dementia unspecified'. A further six met the criteria for more than one subtype. The most common diagnosis was that of Alzheimer's dementia, followed by vascular dementia and unspecified dementia. Only two participants were diagnosed with Frontotemporal dementia and one with possible Lewy Body dementia. These three participants were also given a differential diagnosis of Alzheimer's dementia. A marginally higher proportion of White-British participants were diagnosed with Alzheimer's dementia than African-Caribbean participants, who were significantly more likely to be diagnosed with vascular (or mixed vascular/Alzheimer's) dementia (Chi^2=4.593; p=0.032).

Table 5.17 **Dementia subtype by ethnic group**

Dementia Subtype	Specific Criteria	Ethnic group (%)*		
		White-British	African-Caribbean	Combined
Any dementia	ICD-10	10 (66.7)	16 (76.2)	26 (72.2)
	DSM-IV TR	15 (100.0)	19 (90.5)	34 (94.4)
	Either criteria	15 (100)	21 (100)	36 (100)
Alzheimer's Dementia	ICD-10	6 (40.0)	8 (38.1)	14 (38.9)
	DSM-IV	10 (66.7)	10 (47.6)	20 (55.6)
	NINCDS-ADRDA:			
	Possible	4 (26.7)	7 (33.3)	11 (30.6)
	Probable	7 (46.7)	7 (33.3)	14 (38.9)
	Any criteria	11 (73.3)	14 (66.7)	25 (69.4)
Vascular Dementia	ICD-10	0 (0)	1 (4.8)	1 (2.8)
	DSM-IV	0 (0)	3 (14.3)	3 (8.3)
	NINDS-AIREN:			
	Possible	1 (6.7)	8 (38.1)	9 (25)
	Probable	0 (0)	0 (0)	(0)
	Any criteria	1 (6.7)	9 (42.9)	10 (27.8)
Lewy Body Dementia	DLB consensus:			
	Possible	0 (0)	1 (4.8)	1 (2.8)
	Probable	0 (0)	0 (0)	0 (0)
	Any criteria	0 (0)	1 (4.8)	1 (2.8)
Fronto-temporal Dementia	Consensus criteria	0 (0)	2 (9.5)	2 (5.6)
Unspecified Dementias		4 (26.7)	2 (9.5)	6 (16.7)

***** Percentage of all participants diagnosed with dementia in each ethnic group respectively.

5.1.10 Covariates relating to dementia diagnosis

5.1.10.1 Age

The mean age of those with dementia was 82.3 years (S.D. 7.3) verses 71.9 years (SD 8.9) in those without dementia; mean difference 10.4 years (95%CI 7.8 – 13.0) ; (t = 7.976; p<0.001). The mean age of African-Caribbean participants with dementia (79.1 years; SD 8.7) was significantly less than for white-British participants with dementia (86.9 years; SD 7.4); (t=2.839; p=0.008).

5.1.10.2 Sex

There was no difference in the likelihood of a dementia diagnosis according to sex; 16/176 (9.1%) male participants were diagnosed with dementia compared to 20/260 (7.7%) females (Chi^2=0.271; p=0.603). There was no difference in the sex distribution for participants with dementia between ethnic groups (Chi^2 = 2.520; p=0.112).

5.1.10.3 Years of education

Those with dementia had less full time education (9 years; interquartile range 9-10 years) than those without (10 years; interquartile range 9-11) (Mann Whitney U= 2690.0; p=0.001). There was no difference in the median duration of education for those with dementia between ethnic groups (Mann Whitney U= 74.0; p=0.852).

5.1.10.4 Home ownership

There was no difference in the likelihood of dementia diagnosis according to home ownership; 16/216 (7.4%) of home owners were diagnosed with dementia compared to 16/205 (7.8%) of those not owning their own home (Chi^2=0.024; p=0.878).

5.1.10.5 Self assigned socioeconomic status (NS-SEC)

Data for NS-SEC was available on 385/400 (96%) of participants without dementia but only 29/36 (81%) of those with dementia. Of the latter group, 27/29 (93.1%) were assigned to NS-SEC groups 4 and 5, compared to 242/385 (62.9%) of those without dementia (table 5.18). Conversely, there was just one participant (3.4%) with dementia in NS-SEC groups one and two compared to 134/385 (34.8%) of those without dementia. This difference in distribution was highly significant (Chi^2=1.44; p=0.006).

Table 5.18 **Dementia status by NS-SEC**

NS-SEC	Dementia Status		Total (%)
	Dementia (%)	No dementia (%)	
1	1 (3.4)	63 (16.4)	64 (15.5)
2	0 (0)	71 (18.4)	71 (17.1)
3	1 (3.4)	9 (2.3)	10 (2.4)
4	6 (20.7)	83 (21.6)	89 (21.5)
5	21 (72.4)	159 (41.3)	180 (43.5)
Total	29 (100)	385 (100)	414 (100)

5.1.10.6 Blood Pressure

A higher proportion of participants diagnosed with dementia reported treated hypertension than those without dementia (table 5.19), but the difference was not significant (Chi^2=1.123; p=0.289). Interestingly, proportionally more African-Caribbean participants with dementia reported treated hypertension than their White-British counterparts, but the difference between the ethnic groups was not statistically significant (p = 0.361).

Table 5.19 **Dementia status by reported (treated) hypertension**

	Reported hypertension	No reported hypertension	Total
Dementia (%)	25 (71.4)	10 (28.6)	35 (100)
No dementia (%)	180 (62.3)	109 (37.7)	289 (100)
Total (%)	205 (63.3)	119 (36.7)	324 (100)

All but three participants, who underwent the diagnostic interview, had their blood pressure measured. For those with dementia, the mean systolic value was 146 (SD 20; skewness 0.356) and the mean diastolic value was 79 (SD 14; skewness 0.038). There was no difference in the rates of measured hypertension between those with dementia and those without dementia (Chi2 = 0.001; p = 0.981), (table 5.20).

Table 5.20 **Dementia status by measured hypertension**

	Hypertension	No hypertension	Total
Dementia (%)	22 (66.7)	11 (33.3)	33 (100)
No Dementia (%)	218 (66.5)	110 (33.5)	328 (100)
Total (%)	240 (66.5)	121 (33.5)	361 (100)

5.1.11 Controlling for potential confounders

As for screening status, the only two variables plausibly confounding the association between dementia and ethnic group are age and socioeconomic status (NS-SEC).

5.1.11.1 *Controlling for Age*

When stratified by ten-year age bands, the association between dementia status and ethnic group was strengthened significantly (Pooled MH OR 2.938; 95%CI 1.254 to 6.882; p = 0.013), (table 5.21).

Table 5.21 Dementia status by ethnic group, stratified by 10-year age bands

10 YEAR AGE BANDS			ETHNIC GROUP		TOTAL (%)
			WHITE – BRITISH (%)	AFRICAN-CARIBBEAN (%)	
60-69	DEMENTIA STATUS	DEMENTIA	0 (0)	3 (3.4)	3 (1.7)
		NO DEMENTIA	91 (100)	84 (96.6)	175 (98.3)
	TOTAL		**91 (100)**	**87 (100)**	**178 (100)**
70-79	DEMENTIA STATUS	DEMENTIA	3 (4.3)	8 (7.8)	11 (6.4)
		NO DEMENTIA	66 (95.7)	95 (92.2)	161 (93.6)
	TOTAL (%)		**69 (100)**	**103 (100)**	**172 (100)**
80-89	DEMENTIA STATUS	DEMENTIA	7 (14.6)	8 (30.8)	15 (20.3)
		NO DEMENTIA	41 (85.4)	18 (69.2)	59 (79.7)
	TOTAL (%)		**48 (100)**	**26 (100)**	**74 (100)**
90-99	DEMENTIA STATUS	DEMENTIA	5 (50.5)	2 (100)	7 (58.8)
		NO DEMENTIA	5 (50.0)	0 (0)	5 (41.7)
	TOTAL		**10 (100)**	**2 (100)**	**12 (100)**

10 Year Age Bands	Pearson's Chi2 Value	Significance (p)	Fisher's Exact Test (p)*
60-69	-	-	0.115
70-79	-	-	0.529
80-89	2.734	0.098	-
90-99	-	-	0.470

*Exact test score given when cells have values less than 5.

5.1.11.2 *Controlling for Socioeconomic status (NS-SEC)*

When stratified by socioeconomic status (NS-SEC 1-5), the association between dementia status and ethnic group was weakened, and was not statistically significant (Pooled MH OR 1.00; 95% CI 0.46 to 2.20; p=0.998), (table 5.22). This analysis was however, only performed on the 414 participants on whom NS-SEC data was available (data was missing on 19% of those with dementia and 4% without dementia).

Table 5.22 **Diagnostic status by ethnic group, stratified by NS-SEC**

SOCIOECONOMIC STATUS 1-5			ETHNIC GROUP		TOTAL
			WHITE - BRITISH	AFRICAN-CARIBBEAN	
1	DEMENTIA STATUS	DEMENTIA (%)	1 (2.8)	0 (0)	1 (1.6)
		NO DEMENTIA (%)	35 (97.2)	28 (100)	63 (98.4)
	TOTAL (%)		**36 (100)**	**28 (100)**	**64 (100)**
2	DEMENTIA STATUS	DEMENTIA (%)	0 (0)	0 (0)	0 (0)
		NO DEMENTIA (%)	49 (100)	22 (100)	71 (100)
	TOTAL (%)		**49 (100)**	**22 (100)**	**71 (100)**
3	DEMENTIA STATUS	DEMENTIA (%)	1 (12.5)	0 (0)	1 (10)
		NO DEMENTIA (%)	7 (87.5)	2 (100)	9 (90)
	TOTAL (%)		**8**	**2**	**10**
4	DEMENTIA STATUS	DEMENTIA (%)	1 (2.8)	5 (9.4)	6 (6.7)
		NO DEMENTIA (%)	35 (97.2)	48 (90.6)	83 (93.3)
	TOTAL (%)		**36 (100)**	**53 (100)**	**89 (100)**
5	DEMENTIA STATUS	DEMENTIA (%)	10 (12.7)	11 (10.9)	21 (11.7)
		NO DEMENTIA (%)	69 (87.3)	90 (89.1)	159 (88.3)
	TOTAL (%)		**79 (100)**	**101 (100)**	**180 (100)**

NS-SEC	Pearson's Chi2 Value	Significance (p)	Fisher's Exact Test (p)*
1	0.790	0.374	1.000
2	-	-	-
3	0.278	0.598	1.000
4	1.511	0.219	0.395
5	0.134	0.714	0.816

*Exact test score given when cells have values less than 5.

5.1.12 Multivariate analysis

The logistic regression analysis included all 436 participants and demonstrated a strong association between dementia and African-Caribbean ethnicity, when controlled for age (table 5.23 – step 2). Data on NS-SEC was imputed for the 22 participants for whom this was missing. When adjusted for both age and NS-SEC, the association between dementia and ethnicity was weaker but remained statistically significant (table 5.23 – step 3).

Table 5.23 **Logistic regression model**

Variables not in the Equation			
	Score	df	Sig. (p)
Ethnicity	**1.090**	**1**	**0.296**

Step 1

	B	S.E.	Wald	df	Sig. (p)	Exp(B)	95.0% C.I.for EXP(B)	
							Lower	Upper
Ethnicity	**0.366**	**0.353**	**1.081**	**1**	**0.299**	**1.443**	**0.723**	**2.879**
Constant	-2.972	0.582	26.044	1	0.000	0.051		
Variables entered on step 1: Ethnicity.								

Step 2

	B	S.E.	Wald	df	Sig. (p)	Exp(B)	95.0% C.I.for EXP(B)	
							Lower	Upper
Ethnicity	**1.217**	**0.435**	**7.851**	**1**	**0.005**	**3.379**	**1.442**	**7.918**
Age	0.178	0.027	42.318	1	0.000	1.195	1.132	1.261
Constant	-1.802	2.582	48.735	1	0.000	0.000	-	-
Variables entered on step 2: Age.								

Step 3

	B	S.E.	Wald	df	Sig. (p)	Exp(B)	95.0% C.I.for EXP(B)	
							Lower	Upper
Ethnicity	**1.120**	**0.444**	**6.361**	**1**	**0.012**	**3.066**	**1.284**	**7.322**
Age	0.179	0.029	39.096	1	0.000	1.196	1.131	1.265
NS-SEC	0.491	0.195	6.372	1	0.012	1.634	1.116	2.393
Constant	-1.991	2.881	47.953	1	0.000	0.000	-	-
Variables entered on step 3: NS-SEC								

5.2 MEDICAL NOTES SURVEY

The primary care medical notes were examined for participants who screened positive for cognitive impairment. Of those that we diagnosed with dementia, 15/36 (41.7%) had a formal diagnosis of dementia and a further 5/36 (13.9%) had cognitive impairment (or similar) recorded in their notes (table 5.24). Only 13/36 (36.1%) had been referred for specialist dementia assessment; ten to local old age psychiatric services and three to a neurologist (Dementia Research Centre, Institute of Neurology, Queen's Square). There was mention of pharmacological treatment with a cholinesterase inhibitor in five participants (13.9%); one white-British, four African-Caribbean.

Although more African-Caribbean (52.4%) than white-British participants (26.7%) had a formal diagnosis of dementia documented in the notes, this was not significantly different (Fisher's Exact Test; p=0.176). Nor was there a significant difference if the less specific records of 'memory problem' or 'cognitive impairment' were included in the analysis (Chi^2=0.823; p=0.364).

For all participants with dementia (recognised and unrecognised), marginally more of the white-British group (40%) had been referred on to specialist services for assessment than the African-Caribbean group (33.3%), but the difference was not significant (Chi^2= 0.169; p=0.681). This analysis was repeated for the 20 participants for whom cognitive impairment or dementia was recorded in the notes. Although 6/7 (85.7%) of white-British participants had been referred compared to only 7/13 (53.8%) of African-Caribbean participants, the difference was not significant (Fisher's Exact Test; p=0.329).

Table 5.24 **Record of dementia diagnosis & referral, by ethnic group**

Documentation	White-British (%)	African-Caribbean (%)	Total (%)
* Screening instrument used	6 (40.0)	7 (33.3)	13 (36.1)
** Cognitive impairment	3 (20.0)	2 (9.5)	5 (13.9)
*** Dementia	4 (26.7)	11 (52.4)	15 (41.7)
Sub-total with recorded diagnosis	7 (46.7)	13 (61.9)	20 (55.6)
Referral for assessment	6 (40.0)	7(33.3)	13 (36.1)
Anti-dementia drug prescribed	1 (6.7)	4 (19.0)	5 (13.9)
Total	15 (100)	21 (100)	36 (100)

* Screening instrument score recorded e.g. MMSE, AMT
** Memory problem/Cognitive impairment recorded (not dementia).
*** Formal diagnosis of dementia recorded.

6. DISCUSSION

This is the first epidemiologically representative cross-sectional study set in the UK, powered with the primary aim of measuring and comparing the prevalence of dementia between a sample of older African-Caribbean and white-British people. It is therefore the largest study of dementia in the older, British African-Caribbean population. It is also the first prevalence study to have employed a culturally sensitive screening instrument for cognitive impairment in the African-Caribbean group. Recruitment to the study was successful in that the anticipated sample size was reached, and the response rate achieved was comparable to similar studies. The findings supported the primary hypothesis that the prevalence of dementia is higher in older African-Caribbean than white-British people. Before discussing this in detail, I have summarised the other main results as follows:

Demographics

- The mean age of African-Caribbean participants was significantly lower than that for white-British participants and the age structure of the populations differed.
- There was no difference in sex ratio between ethnic groups.
- There was no significant difference in duration of education between ethnic groups.
- Significantly more African-Caribbean participants fell into lower socioeconomic groups as defined by their previous occupation (NS-SEC), although a significantly higher proportion were home-owners.

Screening phase

- More African-Caribbean than white-British participants screened positive for cognitive impairment (14.7% vs. 8.7%) and this was significant when controlled for age and socioeconomic status.
- Both ethnic groups performed better on their respective, culturally appropriate versions of the Mini Mental State Examination (MMSE).
- African-Caribbean participants had significantly more hypertension than the white reference group (both treated and untreated).
- A history of hypertension was associated with screening positive for cognitive impairment.
- Two thirds of participants were hypertensive as measured at the screening interview, but this proportion was not significantly different between the two groups.

Diagnostic phase

- Thirty six participants met at least one set of diagnostic criteria for dementia and another five met our criteria for mild cognitive impairment (MCI).
- When adjusted for age and socioeconomic status, the prevalence of dementia was significantly higher in the African-Caribbean than the white-British group (9.6% vs. 6.9%).
- African-Caribbean participants with dementia were significantly younger than white-British participants with dementia (mean difference 7.8 years).
- A diagnosis of dementia was associated with increasing age, lower socioeconomic status and fewer years of education.
- The most frequently diagnosed dementia subtype was Alzheimer's disease, followed by Vascular dementia, unspecified dementia, Dementia with Lewy Bodies and Frontotemporal dementia, according to at least one set of diagnostic criteria.
- Marginally more white-British participants were diagnosed with Alzheimer's disease and significantly more African-Caribbean participants with vascular dementia, according to at least one set of diagnostic criteria.

Medical notes survey

- Of all the participants diagnosed with dementia, 42% had dementia and a further 14% had cognitive impairment recorded in their electronic primary care records.
- 26.7% of white-British and 52.4% of African-Caribbean participants with dementia, had this documented in their medical notes, although the difference was not significant.
- Fewer African-Caribbean (54%) than white-British participants (86%) with cognitive impairment or dementia, recognised/documented by their General Practitioner had been referred for specialist assessment, although the difference was not significant.

6.1. CROSS-SECTIONAL SURVEY FINDINGS

6.1.1. Demographics

Fifty six percent of the African-Caribbean participants came from Jamaica and the remainder from other Caribbean islands or Guyana. This figure is close to the 2001 census estimate of 61% for Haringey's Caribbean-born residents born in Jamaica, (www.haringey.gov.uk) and is one indicator that my sample may be representative of the target population (section 6.5.2). All of the African-Caribbean people I identified had migrated to Britain directly from the Caribbean rather than elsewhere, and none was born in the UK. This was expected, and suggests that there are few, if any second generation African-Caribbean people aged above 60 year living in the borough.

Compared to those born in Britain, African-Caribbean participants were on average two years younger, with relatively few people aged over 80 years. This finding is consistent with previous studies (Livingston et al., 2001, McCracken et al., 1997, Richards et al., 2000) and on their pattern of migration; based on the mean duration in Britain (study participants) being 46 years and assuming that most were in their twenties or thirties when they arrived. This age difference had a significant effect on the prevalence of dementia, and its role as a confounder is discussed later (section 6.5.6.3). The fact that more African-Caribbean participants were married or cohabiting and that nearly twice the number of white-British participants were widowed might also be partly explained by the latter group being older.

Worth noting is that there was no difference in sex distribution between the two ethnic groups. Sixty percent of all participants were female, compared to 56% of over 60 year olds in Haringey at the 2001 census (http://www.statistics.gov.uk/census). This may also indicate that my sample reasonably matches the target population.

No potential participants were excluded on the basis of language, as all spoke English fluently. Importantly, there was no difference in the number of years spent in full-time education between ethnic groups (median value 10 years) and the duration was strikingly similar to that found in the Islington study (Livingston et al., 2001). Language and education are therefore unlikely to have influenced performance on cognitive testing differentially between groups.

The significance of socioeconomic status in this instance was far less clear than for age, and I obtained conflicting results from my two measures. Whereas African-Caribbean participants were nearly 50% more likely to own their own homes than white participants, the majority fell into the lowest socioeconomic groups according to current or previous occupation. Socioeconomic status according to occupation (NS-SEC), although not a risk factor for dementia per se, might be considered to be a 'proxy' for other covariates such as educational level, general health, smoking or diet. However, this may be less meaningful for many African-Caribbean people, who migrated to Britain to fill relatively unskilled jobs for their level of education and social status (section 1.4.2). The role of NS-SEC as a potential confounder is discussed further in section 6.5.6.3.

6.1.2. Screening for cognitive impairment

African-Caribbean participants performed significantly less well on both versions of the MMSE than their white-British peers in terms of the median score. They did however score significantly better on the culturally sensitive 'African-Caribbean' version, whilst white-British participants did marginally better on the 'Standard' version. This is consistent with the notion that the African-Caribbean version is 'culturally specific' rather than just being easier, or less educationally biased. This finding supports one of the secondary aims of my study, in that it provides more evidence for use of the African-Caribbean version of the MMSE as a valid screening instrument in this population as opposed to the standard version and may be useful in routine clinical practice.

Using the same cut-off of <26 as the definition of screening positive for cognitive impairment, considerably more African-Caribbean than white participants screened positive as measured by either version of the MMSE. Strikingly, had I only screened with the standard version, over 28% of African-Caribbean participants would have failed the test (versus ~15% on the A-C version). This may have included a high proportion of false positives, although I cannot be sure with the available data. Even so, on their respective culturally appropriate versions, the difference in the proportions screening positive between the two ethnic groups, approached statistical significance. When this association was controlled for by potential confounders (age and socioeconomic class) using logistic regression modelling, the association was strengthened considerably and became statistically significant. This provides strong evidence that there is a higher prevalence of cognitive impairment in older African-Caribbean than white-British people.

For all participants combined, those that screened positive were significantly older, had fewer years of education and fell into a lower NS-SEC category than those who screened negative. They were also more likely to report a history of hypertension. These findings are in keeping with current knowledge, in that increasing age, less education and a history of hypertension are known risk factors for cognitive impairment and subsequent dementia (section 1.2.2). The significance of NS-SEC is less clear as discussed earlier (section 6.1.1), and I have interpreted its role as a potential confounder with caution. Interestingly, hypertension as measured at the screening interview was not associated with cognitive impairment. This may be due to the fact that blood pressure falls with the onset of dementia (section 1.1.2.1).

6.1.3. Screening for hypertension

According to the measurements taken at the screening interview, approximately two thirds of all participants were considered to be hypertensive using the definition recommended by the British Hypertension Society (section 4.4.10.2). No significant difference was found between the two ethnic groups in this respect, despite the literature indicating a higher frequency of hypertension in African-Caribbean people (section 1.4). This excess of measured hypertension may represent unrecognised hypertension, inadequate treatment, poor adherence to antihypertensive medication or *'white coat hypertension'* as the research interview may be anxiety provoking. Another possible explanation for this finding is observer or measurement bias (section 6.5.7.2). Significantly higher proportions of African-Caribbean than white participants reported a *known history* of hypertension. This could explain why no difference in the rate of *measured* hypertension between ethnic groups was found, in that proportionally more African-Caribbean people were receiving antihypertensive treatment than in the white-British sample.

The mismatch between *reported* and *measured* hypertension should be interpreted with caution, as data on both was only available on 317 (73%) participants. However, in those for whom we have both items of data, two thirds or more of participants reporting a history of hypertension were not receiving adequate treatment for this. This was not significantly different between ethnic groups. There was also a further one third of participants who were hypertensive at the screening interview and reported taking no treatment for this. These were potentially undiagnosed hypertensives, although it is likely that a proportion were diagnosed but had denied, forgotten or never understood their diagnosis or treatment. Notably, significantly more African-Caribbean than white-British participants fell into this category. I therefore conclude that in this study, it is probable that African-Caribbean participants had a higher rate of hypertension overall, both diagnosed (treated) and undiagnosed.

6.1.4. Diagnostic phase

Of the 51 participants who screened positive, 36 were diagnosed with dementia according to at least one set of criteria. Another five had objective evidence of cognitive impairment but no known functional impairment and were categorised as having MCI. These were excluded from the main analysis. Although the crude (unadjusted) prevalence estimates for dementia were higher in the African-Caribbean than the white group, the difference was not significant. There was no significant change to the significance 'p' value if participants with MCI were included in the analysis.

A dementia diagnosis was strongly associated with increasing age and less so with shorter duration of education. African-Caribbean participants with dementia were on average nearly eight years younger than white-British participants with dementia, although there was no information regarding the age of onset, or duration of illness. There was no sex difference in dementia diagnosis overall or between ethnic groups and these findings are what we would have expected according to current literature (section 1.1). There was also a relatively strong relationship between dementia and NS-SEC distribution and as previously discussed, socioeconomic status was probably a proxy for other risks factors such as education and other health variables. Unlike cognitive impairment however, there was no significant association between dementia and reported (or measured) hypertension, although the trend remained. This may not have reached significance due to a lack of statistical power at the diagnostic stage (section 6.5.3).

As predicted, controlling for the most plausible (negative) confounder, *age*, significantly strengthened the association between African-Caribbean ethnicity and dementia diagnosis and this reached statistical significance. Strikingly, the final logistic regression model predicted a 1.2 times increase in the prevalence of dementia for each year increase in age above 60. This is equivalent to approximately double the prevalence every five years and is in keeping with the literature (section 1.2.3.2).

Despite the unclear role as a second but weaker (positive) confounder, NS-SEC was included in the logistic regression analysis. Its inclusion had little effect on the final model and the strength of the primary association was strong, with an odds ratio approximating three (95% CI 1.3 - 7.3). I therefore concluded that there is evidence supporting my primary hypothesis.

Proportionally more participants from both groups met the less stringent DSM-IV than the ICD-10 criteria for dementia. This was because unlike DSM-IV, ICD-10 requires both a minimum period for symptoms (six months) and a reliable informant history (section 1.2.1). One of the limitations of the study was that a detailed informant history was not available for 15 (31%) of participants and it was not possible to specify a subtype in six participants, who were classified as 'dementia unspecified'. For those who were given a subtype diagnosis, the numbers were small and I have interpreted my analysis with caution. As expected the majority, approximately 69% of all participants were diagnosed with Alzheimer's Disease according to at least one set of criteria. This is close to the recent 'Dementia UK Report' estimate of 62% (Knapp, 2007), although it did vary considerably depending on the criteria used; 39% of all participants met the ICD-10 criteria, 56% DSM-IV criteria and nearly 70% the NINCDS-ADRDA criteria (possible or probable). Marginally more white-British (73%) than African-Caribbean (67%) participants met these diagnostic criteria. The overall prevalence of vascular (or mixed) dementia in the sample (28%) was also very close to the 'Dementia UK Report' estimate of 27%. Remarkably, nine of the ten participants diagnosed with vascular dementia were African-Caribbean and seven of them had a history of hypertension. This may indicate that the excess of dementia in the African-Caribbean group is vascular in origin and may be associated with a history of hypertension. However, the numbers were very small and none met the criteria for a *Probable* diagnosis according to NINDS-AIREN criteria. There was also a trend for proportionally more African-Caribbean than white participants to fall within the *severe* category, although this was not statistically significant.

6.2. MEDICAL NOTES SURVEY

The proportion of participants with dementia who had a clear diagnosis recorded in the electronic primary care records (42%) was marginally higher than that given in the National Dementia Strategy (approximately one third) (DoH, 2009). This suggests that the general practices sampled, were at least as likely to record a diagnosis of dementia as the national average. Paradoxically, when compared to the white-British group, the rate of documented dementia was higher in African-Caribbean participants (52% versus 27%), whereas the rate of referral to specialist dementia services was lower (33% versus 40%). The difference in referral rate between groups was greater, if only participants with a recorded dementia or cognitive impairment were included. In this analysis, six of the seven (86%) white-British participants compared to only seven of the thirteen (54%) African-Caribbean participants with recognised cognitive impairment/dementia had been referred for assessment. However, these findings were not statistically different, possibly due to the small numbers at this stage.

I therefore conclude from this study, that dementia recognition in primary care is equitable for the African-Caribbean older population. This is an unexpected finding and does not support my secondary hypothesis that African-Caribbean people are less likely than white-British people to have their dementia formally recognised and documented in primary care. This could be due to changing attitudes towards dementia and/or the mental health of BME people, as both have had a high media profile recently. Alternatively, it could be that African-Caribbean people present to GPs at the more severe stages of dementia and that this is more easily recognised. Another possible explanation is that the sample of general practices selected was biased, in that they had a particular interest in this subject and therefore agreed to participate. These, and other possible sources of error are discussed further in section 6.5.6.2.

The lower rates of referral for African-Caribbean participants, although not statistically significant, do provide some evidence towards my secondary hypothesis, that the rate of referral to specialist dementia services is lower for African-Caribbean than white-British people. The reasons for this are not clear from this study and warrant further investigation using qualitative methods (section 6.7).

6.3. COMPARISON OF FINDINGS WITH OTHER STUDIES

My primary findings are in line with the existing literature. For example, my estimate for dementia prevalence in white-British participants over 60 years of 6.9% is only marginally higher than the Delphi consensus study estimate for Western Europe of 5.4% (Ferri et al., 2005). Assuming that the prevalence of dementia doubles for every five year increase in age, this is also similar to the Islington study estimate of 10% in UK-born participants over 65 years, which like my study included people in residential care homes (Livingston et al., 2001).

With regard to African-Caribbean people, my estimate of 9.6% in participants over 60 years, corresponded closely to the Islington study estimate of 17.3% in those over 65. Although their sample is not strictly comparable to mine, in that it was a mixed group of black African and Caribbean people, the majority (>60%) were of African-Caribbean origin. The findings are less similar to the other cross-sectional studies identified in my systematic review (Chapter 2) in that my estimate of dementia prevalence was considerably higher than the Liverpool study (8%) (McCracken et al., 1997), and lower than the South London pilot study (34%) (Richards et al., 2000), both in participants over 65 years. The Islington study however, had the highest validity score of the studies identified and theirs was the most plausible estimate. I conclude therefore, that the evidence for an excess of dementia in older African-Caribbean people in Britain is strong, and that the prevalence is likely to be at least 50% higher than in the indigenous white population.

It is difficult to draw any firm conclusions or make comparisons with regard to dementia subtype, given the small numbers in my study. However, my findings are not dissimilar to Steven's secondary analysis of the Islington study (Stevens et al., 2002), in that we both found what appeared to be a significant excess of vascular dementia in the African-Caribbean participants and that they had very high rates of hypertension.

6.4. CLINICAL IMPLICATIONS

The evidence for a higher prevalence of dementia in the African-Caribbean population is now fairly robust and in keeping with my primary hypothesis. Although weaker, there is some evidence from this study to support part of my secondary hypothesis. The clinical implications from these findings are as follows:

i) In general terms, clinicians should readily consider dementia, but have a high threshold of suspicion when diagnosing it in older African-Caribbean patients who present with memory problems or related symptoms.

ii) Clinicians should be aware that dementia may occur at younger age groups (<65 years) more commonly in African-Caribbean than white people. As this falls below the normal cut-off for old age services, all mental health professionals should consider dementia as a differential diagnosis and when appropriate refer to a specialist team for further assessment. It also supports the move towards *'needs based'* rather than age determined health and social services.

iii) When screening for dementia or assessing cognitive performance, culturally specific tools should be used when available. My findings suggest using the African-Caribbean MMSE in this population (Rait et al., 2000). It suggests that the use or development of acceptable, valid and reliable tests for the screening and diagnosis of dementia in other BME groups would be desirable.

iv) Both primary and secondary prevention are especially relevant for African-Caribbean people in terms of vascular risk factors. Timely and effective treatment of hypertension is very important and would be expected to bring down the rates of dementia. This is in keeping with current government policy, and effective management of hypertension is one of the Quality and Outcomes Framework (QOF) indicators for

GPs. This system financially rewards GPs for good clinic care, which in this instance, includes keeping a register of patients with established hypertension, having a record of their blood pressure taken within the previous nine months and maintaining this at under 150/90 mmHg.

v) Rates of diagnosed dementia and referral to specialist dementia services are known to be low in all ethnic groups. This finding was replicated in this study, although not significantly worse in African-Caribbean than white participants. Primary care physicians may still benefit from educational interventions aimed at improving the detection of dementia and should be encouraged to refer patients to specialist dementia services for assessment, regardless of ethnicity.

6.5. METHODOLOGICAL CONSIDERATIONS & LIMITATIONS

6.5.1. Design

Cross-sectional studies have a number of limitations, such that they are often used primarily to generate hypotheses for other, more robust studies (Hennekens and Buring, 1987). They are however useful for assessing the health care needs of a population and are convenient to perform. Since exposure (risk factor) and outcome (disease) are measured at the same time, it is not usually possible to determine a temporal relationship between the two. However, this is not the case for risk factors that are fixed, such as sex or ethnicity, where r*everse causality* is not a plausible source of error (i.e. dementia cannot precede ethnicity). I therefore conclude that the cross-sectional design was appropriate for this study. There are however limitations, the main one being that I had little or no information regarding the onset of dementia and the course of the illness. As prevalence is a function of the incidence of a condition and its duration, I can not be absolutely sure whether the higher prevalence of dementia in African-Caribbean people is due to a higher incidence, or whether they live longer with the disorder. However, the latter explanation seems unlikely, given that the mean age of black people with dementia in this sample was significantly lower than in white participants. The cross-sectional design also limited the ability to investigate any temporal relationship between hypertension and dementia and it is possible, although unlikely that dementia preceded the onset of hypertension and likely that the picture was muddied by changes in blood pressure with the onset of dementia.

The two stage (screening/diagnostic) design was efficient in that only participants who screened positive went on to the full diagnostic interview. It did however result in the loss of a small number of participants who failed to complete the second phase. A more significant limitation was that a number of participants with early dementia may have been missed, falsely screening negative at the first phase (section 6.5.5.).

6.5.2. Target population and study sample

The *target population* was well defined and included all community dwelling residents of Haringey over the age of 60 years (4.4.3.1). It could be argued that people in the *sampling frame* i.e. General Practice lists, were different in some way to the target population. This is unlikely, given 98% of the population are registered with a general practice and that African-Caribbean people are equally likely to be registered as the general population (4.4.4). Importantly, both study and reference groups were sampled from the same target population, at the same time.

I would expect the *study sample* to be representative of the target population, in that all African-Caribbean patients from each practice were invited to participate in the study. However, it is likely that a proportion will have been missed due to misclassification of ethnicity on electronic general practice lists and in practices where identification was performed manually. The *reference sample* was subject to the same problems of identification as the study sample, in addition to those of randomisation. However, although the latter was achieved by a relatively unsophisticated technique (4.4.5), it was unlikely to have introduced an additional source of error. Another limitation with regard to sampling, was the necessity to exclude potential participants who had no working telephone number. This may have excluded a number of people in the poorest socioeconomic strata and possibly those with poorest health. In practise these constituted less than 5% of potential participants.

6.5.3. Sample size

The estimated sample size was recruited from the anticipated number of general practices and a statistically significant outcome detected with regard to the primary hypothesis. However, it could be argued that the study was underpowered, in that the numbers of participants reaching the diagnostic stage were very small, making it insufficiently powered to adequately examine the relationships between ethnic groups and dementia subtype or risk factors. This was not however the original intention and the numbers needed to investigate dementia subtypes would have been at least double. This approach was therefore pragmatic given the time and resources and it would not have been possible to have screened significantly more participants.

6.5.4. Response/participation rate

One of the main limitations of this study was the modest participation rate, approximating 64% of those who were contacted. If people with working phone numbers who were not contactable were included, the response was lower at 57%. This falls short of the criterion for a minimum threshold of 70% in studies which have shown responders to be similar to non-responders in terms of socio-demographic characteristics (Boyle, 1998). When compared to similar prevalence studies, the participation rate was lower than that achieved in Islington Study (85%) (Livingston et al., 2001) and the Liverpool study (83%) (McCracken et al., 1997) but higher than that in the South London study (56%) (Richards et al., 2000). All three of these studies recruited participants directly from the community through door knocking and it may be that it is generally easier to recruit people 'face to face' than on the telephone. Interestingly in their study, Steward et al. similarly identified African-Caribbean participants from primary care lists and obtained a very similar participation rate to my study (62%) (Stewart et al., 2001b). Chaturvedi et al. also used a similar method and only achieved 58% (Chaturvedi et al., 1993). I therefore conclude that my response rate although low, is comparable to other similar studies.

6.5.5. Screening and diagnostic tools

One of the main strengths of this study was that I used a culturally valid instrument for the screening phase. The advantages of such tools are well documented and it has been shown that BME people tend to be misclassified as cognitively impaired on the standard MMSE (section 4.4.10.1). Rait et. al. demonstrated that their African-Caribbean version was valid for use in this population with high sensitivity (83%) and specificity (78%) at a cut-off of <26 (Rait et al., 2000). We used the same cut-off for both versions of the MMSE, one point higher than that routinely used clinically, and found that this maximised sensitivity whilst keeping the false positive rate to an acceptable level (9.8%). Although no participants screening negative were given the full diagnostic interview (to assess for false negatives), the majority with dementia scored well below the cut-off. Only three of the 36 were borderline, scoring 25/30. I therefore conclude that very few people with dementia will have be missed at the screening stage of the study.

One limitation of the study regarding the screening instrument was that I had combined the two versions of the MMSE into one, extended tool. This was necessary, as it was not feasible to administer both versions consecutively, given that many questions were identical. Although this was designed to maintain the time interval for delayed recall, it is possible that the performance of each test was altered in some way. The combined test took longer than the usual MMSE, and I observed that participants were tiring towards the end of the test, sometimes performing less well on the final questions. Due to the order of the questions, this may have biased the scores towards a better performance on the standard version, although this was not borne out in the final results. Worth noting is that all researchers were given training and observed administering the screening test. Inter-rater reliability for scoring was also checked between each researcher and myself, and found to be 100%.

Another commonly cited disadvantage of using the MMSE is that it is particularly insensitive in those with very high levels of education (section 4.4.10.1), giving rise to a high proportion of false screen negatives. However, our sample of participants was found to be homogenous in relation to education, with relatively low levels in both ethnic groups as measured by duration in full-time study (median 10 years).

With regard to the diagnostic interview, it could again be argued that the CAMDEX-R interview was modified from the original, and had not been validated, either in white-British or African-Caribbean people. However, as justified in section 4.4.11 it was simply used to develop a structured proforma with the purpose of gathering information systematically. Similarly, the CAMCOG neuropsychological assessment has not to my knowledge, been validated in African-Caribbean people and is likely to be culturally or educationally biased (section 6.5.6.2). Therefore, rather than generating a meaningful score, specific subsections were used where necessary to assist with the diagnosis of dementia in accordance with operationalised criteria (section 1.2). Another strength of this study is that these diagnoses were made by independent assessors. They were experienced psychiatrists who did not know the ethnicity of the participants, in order to reduce observer bias (section 6.5.6.2).

6.5.6. Epidemiological sources of error.

6.5.6.1. Chance

Chance findings (random or type I error) are inherent to any epidemiological study and can be reduced but not eliminated. In keeping with convention, I set the statistical level of significance, alpha at 0.05 ($p<0.05$), indicating that the chance of falsely rejecting the null hypothesis is 5% (1 in 20). However, the probability of a chance finding increases with the number of variables being investigated. It can be argued that when multiple statistical tests are being performed, as in my univariate analyses, the likelihood of one or more chance findings are high. This is sometimes overcome by setting the level of significance, alpha at 0.01 (1 in 100). I did not do this as the hypothesis being tested was a pre-determined primary hypothesis. The rest of the univariate analyses were performed to identify which socio-demographic variables to include in the multivariate analysis, of which only two were performed. It is unlikely that the erroneous inclusion of a variable in the multivariate analysis due to a 'chance finding' would have altered the model significantly. In my final logistic regression, the primary association under investigation (ethnicity and dementia diagnosis) was statistically significant at a level of $p=0.012$. This can be interpreted as a small likelihood of it being a chance finding at 1 in 83.

6.5.6.2. Biases

Bias can be defined as *"any systematic error in an epidemiological study that results in an incorrect estimate of the association between exposure and risk of disease"* (Hennekens and Buring, 1987). It can broadly be divided into selection bias, information bias and confounding, which is discussed separately (6.5.6.3).

Selection bias can be problematic in cross-sectional surveys, especially when the response rate is low (section 6.5.4). It occurs when those who participate, differ in some way from those who do not, and that this systematically alters the prevalence of the outcome of interest. In this study for example, it could be that people who were not contactable were more likely to be working, and hence less likely to be suffering with dementia. Alternatively they may have been less likely to answer the phone or respond to letters because they had dementia. Either scenario would have biased my estimate of dementia, the former increasing the apparent prevalence and the latter reducing it. Clearly this introduces an additional source of error into an analytical study, if the bias is stronger in one group than the other.

Selection bias can be minimised by maximising response, and assessed by comparing basic socio-demographic variables between responders and non-responders, or failing that, the target population (section 6.5.4.). Non response can be viewed separately, in terms of people who were not contactable and in terms of those who were, but who declined to participate. Regarding the former, approximately 10% of potential participants with a working telephone number did not answer or reply to messages after several attempts. As those who were not contactable were on average younger and more likely to be male, it is plausible that many were still employed, especially those in the 60-65 year age group. On this basis, it is possible that I may have slightly *overestimated* the prevalence of dementia in my target population. Importantly, although marginally less African-Caribbean than white-British people were contactable, the difference in their mean age compared to contactable people was less than in whites and there was no significant difference in sex distribution. I therefore conclude that the likelihood of selection bias on this basis was low. Notably, people who participated, were very similar to those who declined in terms of age and sex and ethnicity. Therefore, this was not likely to be a source of bias.

More problematic, was with the recruitment of General Practices to the study. Rather than being a random selection, they were for pragmatic reasons *self selecting* as very few GPs agreed to participate and none could be excluded. It is therefore highly probable, that the sample of practices was biased, in that they were more likely to have had an interest in research, dementia, BME or older people. The implication, is that clinicians from the selected practices may have been more likely to recognise and diagnose dementia than from other practices in the borough. It is also plausible that their patients receive better or different treatment than the average provided in Haringey e.g. better treatment for hypertension.

Several types of *information biases* have been described, but they can be broadly divided into *differential* and *non-differential* types. In this study, non-differential information bias would simply refer to the random misclassification of participants in terms of outcome i.e. cognitive impairment or dementia. It can be due to random measurement or recall error and by definition would be distributed equally between the two study groups, diluting any observed association. Differential information bias results in the systematic misclassification of participants, depending on the group they are in (study or reference). It can either increase or reduce any observed association, depending on the circumstances. The most common types are *recall bias*, *observer* (interviewer) bias and in this case, *cultural test bias*. Recall bias is unlikely to be a source of error in this study as exposure (ethnic group) is not subject to recall and outcome (dementia) was measured using standardised instruments. Observer bias however, was a potential limitation in that it was not possible to *blind* the interviewers to ethnicity. The result of this can be the systematic misclassification of outcome between groups. In this study, it may have occurred during the screening interviews; in the way that the MMSE was administered, interpreted and scored. This was kept to a minimum, with the use of the standardised MMSE which includes guidance on how to score each answer and on the training of interviewers. The diagnostic stage was less prone to observer bias in that the diagnoses were made according to operationalised

criteria and by two raters, blind to ethnic group. Cultural test bias, refers to the propensity of a screening or diagnostic tool to perform differently in one cultural or ethnic group from another. In this case, the standard MMSE is known to overestimate the prevalence of cognitive impairment in BME groups, especially those for whom English is a second language (section 4.4.10.1). This was highlighted by the very poor performance of the African-Caribbean participants on the standard MMSE in this study. Cultural test bias was minimised by the use of the culturally specific African-Caribbean version. However, the two tests may still differ slightly in performance and an element of differential misclassification cannot be excluded.

6.5.6.3. Confounders

A confounding variable (confounder) is one that is independently associated both with the exposure and outcome of interest and can either lead to an overestimate or underestimate of the true association. By convention, *positive confounders* increase the apparent effect whilst *negative confounders* reduce or reverse it. It is possible to take likely confounders into account when designing a study and they can be adjusted (controlled) for at the analysis stage. This can be done using classical stratification techniques for individual confounders or logistic regression modelling to control for several confounders simultaneously (Results - Chapter 5). Typically, these variables include socio-demographic and health factors that are likely to be associated with the exposure and outcome of interest. In this study a number of plausible confounders were measured including age, sex, duration of education and two measures of socioeconomic status; home ownership and NS-SEC (by occupation). Notably, hypertension, either measured or reported was not considered to be a potential confounder as it likely to be on the *causal pathway* and should not therefore be controlled for during the analysis stage.

Of the potential confounders measured, age had by far the strongest effect. It was closely associated with both ethnic group and dementia diagnosis, reducing the observed difference in dementia prevalence between the younger African-Caribbean and white-British samples (results and section 6.1.4). Socioeconomic status as measured by NS-SEC was a weaker but positive confounder, although its role, especially in the African-Caribbean sample is not clear and should be interpreted with caution (section 6.1.1). Interestingly, duration of education, although associated with dementia diagnosis as expected, was not associated with ethnicity and therefore not a source of confounding in this study. It is possible that there were other, unmeasured factors that may have confounded the primary association to some degree in either direction, although it is unlikely that the overall effect would have been significant.

6.5.7. Other limitations

6.5.7.1. Physical dementia screen

It was beyond the means of this study, to request further physical investigations to assist the assessors with their diagnosis. However, such investigations are routinely performed during normal clinical practice and would as a minimum include a 'dementia blood screen' and neuroimaging in the form of a CT (computerised tomography), MRI (magnetic resonance imaging) or SPECT (Single photon emission computed tomography) brain scan. The purpose of these tests are to exclude other general medical conditions or intra-cranial pathology that may account for cognitive impairment. Neuroimaging is also helpful to distinguish between dementia subtypes, especially when a diagnosis of Vascular Dementia is suspected. Where available in the medical notes, such information was included for the diagnostic assessors, but in most cases the relevant investigations were incomplete or absent. This especially limited their ability to distinguish between Alzheimer's Disease and Vascular Dementia, making it impossible to make a diagnosis of the latter with any certainty, according to operationalised diagnostic criteria.

6.5.7.2. Measurement of hypertension

Other than for participants who screened positive, blood pressure was only measured on one day, although repeated up to three times during the screening interview. Diagnostically this is notoriously unreliable, and if hypertension were suspected clinically, measurements would be repeated several days or weeks apart. It was also not always possible to measure blood pressure under ideal conditions as recommended by the British Hypertension Society (http://www.bhsoc.org) or the Blood pressure association (www.bpassoc.org.uk). Recommendations include for example waiting at least 30 minutes after drinking tea or coffee, smoking a cigarette, physical exertion and to take the measurement on an empty bladder. None of these conditions could be guaranteed during the screening interview although a blood pressure measurement was repeated at the end, up to 30 minutes after the initial reading. Automated blood pressure monitors had been purchased new for the study, and neither the research assistants nor I, had previous experience of using one. Although the manufacturer's claimed accuracy was +/- 3mmHg, poor measurement technique may have been a source of error. Also, an additional large cuff was purchased for obese participants, but only some months into the study, and it was not available for all participants. Using the wrong cuff size is known to generate inaccurate blood pressure readings. These measurement errors are likely to have been the same for both study groups and as such, were a potential source of non-differential bias, (section 6.5.6.2) leading to an attenuation of any true difference in hypertension between them.

For many participants it was not possible to establish a clear history regarding the duration of their hypertension or treatment. I was also unable to corroborate the information, except in those that screened positive, whose medical records I checked. The frequency of reported hypertension may therefore represent an under-estimate, with participants being more likely to *under* than *over* report hypertension. It was also not possible to draw any conclusions regarding the temporal relationship between a history of hypertension and diagnosis of cognitive impairment or dementia.

6.5.7.3. Residential care homes

Another significant problem that I encountered, was in relation to participants living in residential care homes. Although they were selected in the same way as other participants, they were usually not seen until after all the other people from each general practice list. This was a pragmatic approach, as these visits were difficult to arrange and it was easier to see people from the same residential home together. An unforeseen complication was that a number had died or were in hospital by the time I asked to visit them. Another problem was that of obtaining informed consent and an informant history for people in residential care. This resulted in a relatively small number being interviewed (~3.5% of the total participants).

As a significant proportion of people at the later stages of dementia move into residential care, and the majority of people living in residential care have dementia, recruiting the correct number from each ethnic group was important in order to exclude selection bias. The possibility that people from one group may be more likely to move into residential care than the other, or that they may move into different homes, maybe out of the borough, introduced additional and unknown sources of error. However, the final numbers recruited from residential care homes were small and of these, the numbers from each group with dementia were approximately equal. Also, I found that although excluding these participants from my analysis reduced the combined prevalence of dementia, the relative difference between the two groups remained unchanged (section 5.1.9.1). I concluded that any potential selection bias in this respect would have been minimal, although I may therefore have underestimated the true prevalence of dementia overall.

6.5.7.4. Missing data

Missing data was a limitation for this study both at the screening and diagnostic stages.

Quantitative data:

Completeness for demographic data varied from 100% for age, sex and ethnicity, and ≥95% for marital status, home ownership and NS-SEC to only 85% for years of education. Blood pressure was only measured in 83% of participants whilst only 74% knew their existing hypertension status. Missing data was less problematic for analysis at the screening stage than the diagnostic stage of the study where the numbers were small (only 36 in the dementia group). In addition to this, was the complication that data was more likely to be missing for participants with dementia than those without. In the final logistic regression analysis for example, NS-SEC data was missing for 19% of participants with dementia compared to only 4% without. This was mainly due to the former being unable to recall the information. Data on age and ethnicity was not problematic as it was 100% complete. I therefore decided to *impute* data for NS-SEC using SPSS software rather than exclude participants from the analysis. As the inclusion of NS-SEC had little effect on the final model, I concluded that this did not adversely influence my final findings.

Qualitative data:

This was a significant limitation at the diagnostic stage of the study as only 46% completed all parts of the interview. It was often difficult to obtain a clear history from participants and informants were not always available. A significant proportion of participants refused to complete part, or all of the CAMCOG based cognitive assessment. Where possible, additional information was gathered from other sources, such as primary-care records, sheltered housing scheme managers and residential home staff. In practice, it was not necessary for participants to have completed all parts of the diagnostic interview for the assessors to be able to make a diagnosis according to operationalised criteria. There were a number of participants where a dementia

diagnosis was likely but the history incomplete, and it was unclear whether the cognitive deficit impacted on their level of functioning. In these situations, the assessors were conservative and categorised the participants as having MCI. It is therefore probable that I *under*, rather than *over* estimated the prevalence of dementia. It is unlikely that this varied between the two ethnic groups as the assessors were blind to ethnicity (see biases – 6.5.6.2).

6.5.7.5. Primary care records

General practices have been using electronic patient records for several years and the majority that participated in the study had EMIS™ software installed. Although I did not receive any formal training, the windows based interface is fairly intuitive and I was easily able to access data including demographics, consultation records, diagnoses, medication, investigation results and referrals. This allowed me to gather data to assist with diagnosis and to conduct the medical records survey. The main limitation of this approach was that detailed electronic records were only available for a maximum of five to ten years. This was not problematic for the majority of participants, as this usually predated the onset of cognitive impairment or dementia. However, electronic data was often missing in patients who had changed general practices, and particularly for those who had recently moved into residential care. Their previous medical records were not readily accessible, and details pertaining to their dementia diagnosis and referrals for specialist assessment were often unavailable. In some cases, a diagnosis of 'senile dementia' was recorded with no other details. It is therefore possible that I underestimated the rate of referral to specialist dementia services for participants in residential care. However, this source of error should be equal in both ethnic groups and even if all has been referred it would only have changed the rate to 73.0% in the white-British group and 52.3% in the African-Caribbean group (Chi^2=1.616; p=0.204).

6.6. Alternative study designs

Given limitations imposed by time and resources, my chosen study design was the most appropriate, and it answered my primary research question. It is also the largest study of its type with regard to the size of the African-Caribbean sample. However, although the results generated indicative data towards my secondary aims, the evidence here was weak and questions remain unanswered. The study was not sufficiently powered to adequately investigate the distribution of dementia subtypes, and the cross-sectional design precluded any further investigation of the *temporal* relationship between putative risk factors and dementia in this sample.

A larger prevalence study would address the issue of statistical power. This could be achieved simply by recruiting from additional general practices. However, given the relatively poor recruitment rate from primary care, alternative sampling methods could be used, such as door knocking or participants selected from other community lists. However, in order to further investigate risk factors for dementia, and to calculate dementia incidence, a longitudinal approach is required (section 6.5.1). Longitudinal (cohort) studies can be conducted prospectively or retrospectively. To be informative, the former would require high rates of follow up over a substantial period of time; possibly decades in the case of hypertension. Although a retrospective cohort study would be quicker and cheaper to conduct, it is subject to recall bias and missing data regarding the exposure/risk factor of interest.

6.7. FURTHER WORK

As discussed (section 6.6), further high quality longitudinal studies would be desirable, both to estimate the incidence of dementia and to further investigate putative risk factors. Such studies should consider the subtypes of dementia, as well as the association with education levels, current hypertension or a history of hypertension and adequate treatment. This may provide more evidence as to the potential of controlling hypertension to prevent Alzheimer's disease or Vascular Dementia.

Although African-Caribbean participants were at least as likely as white participants to have their dementia or cognitive impairment documented in primary care notes, the *trend* was for a lower rate of referral to specialist dementia services in this group. Another planned area of investigation is a qualitative analysis, investigating possible reasons for under-referral to, or low take-up of specialist dementia services in the African-Caribbean population. The plan is to recruit a purposively selected sample of 10-15 African-Caribbean participants with dementia from both primary and secondary care. It is anticipated that some will have a formal diagnosis and be known to local dementia services and some will not. The former group will be recruited from the local memory treatment clinic and the remainder from existing cross-sectional study participants. Participants will be interviewed with their family or carers. The extent of their access to services will be assessed by recording the help seeking pathways of each participant using in-depth, semi-structured interviews. This will include all formal and informal helping networks and agencies contacted en route to care (primary, secondary, voluntary and statutory sector services). The time between first symptoms and first contact, type of first contact, number of contacts with each agency, perception of usefulness and outcome of each contact will be recorded. Data will also be collected on i) social networks ii) other health and social service use and iii) explanatory models of dementia. These interviews will last approximately 90 minutes, will be audio-recorded and later transcribed for analysis.

7. CONCLUSIONS

My study found the prevalence of cognitive impairment and dementia (all types) to be significantly higher in African-Caribbean than white-British older people, after controlling for age and socioeconomic status. This is in keeping with my primary hypothesis and provides more conclusive evidence than that available from previous UK studies. African-Caribbean people with dementia were on average eight years younger than white participants, indicating that they are likely to develop the condition earlier, and more frequently at ages below the normal cut-off for 'old age' psychiatric teams. This has implications for dementia services as they are currently structured and supports the move towards *'needs based'* rather than *'age determined'* services. There was also evidence that African-Caribbean people have a significantly higher proportion of vascular, or mixed vascular/Alzheimer's dementia than white people. However, as numbers at the diagnostic stage were small and participants only met the diagnostic criteria for *possible* rather than *probable* vascular dementia, the data in this respect was less robust.

I found relatively high rates of inadequately treated and untreated hypertension in the study participants overall. Notably, African-Caribbean participants had significantly more hypertension than white participants (both treated and untreated) and a history of hypertension was found to be associated with cognitive impairment (but not dementia). Strikingly, seven of the nine African-Caribbean people diagnosed with possible vascular dementia reported a history of hypertension. Although not conclusive, these findings are consistent with the published literature and I hypothesise that the high rate of hypertension may contribute to an excess of cognitive impairment and dementia found in this group. This provides additional evidence supporting the benefits of effective hypertensive treatment for reducing dementia, especially in African-Caribbean people.

Another important finding from this study was that African-Caribbean participants performed significantly better on the culturally adapted 'African-Caribbean' version of the MMSE, whilst white-British participants scored more highly on the standard version. As existing screening tools have a tendency to *over-estimate* cognitive impairment in BME people, it supports the use of this tool as a valid screening instrument in this population and its use in routine clinical practice as well as research.

Findings from the medical notes survey were less conclusive and only partly supported my secondary hypotheses. Paradoxically, I found a marginally higher rate of diagnosed dementia recorded for the African-Caribbean group but a higher rate of referral to specialist dementia services recorded for the white-British group. Neither finding was significantly different, although numbers were small. This unexpected finding indicates that African-Caribbean people are at least as likely to have their dementia recognised in primary care but may be less likely to be referred to secondary care. This warrants further investigation, either through a larger quantitative survey, or using qualitative methods.

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APPENDICES

Appendix 1 – Conference Poster

- NoCLoR Annual Conference – London, March 2006

Appendix 2 – Publications

- Systematic review publication (J. Int. Ger. Psychiatry)
- Royal College of Psychiatry Report – CR156
- Meeting the mental health needs of older people from black and minority ethnic communities (Mental Health Today)

Appendix 3 – Diagnostic criteria (summarised)

- ICD-10
- DSM-IV-TR
- NIINCDS ADRDA (AD)
- NINDS AIREN (VaD)
- Consensus criteria for DLB
- Consensus criteria for FTD

Appendix 4 – Ethics committee application and approval documentation

Appendix 5 – Pilot study documentation

Appendix 6 – Participant invitation letters and information sheets

- Invitation letters
- Confirmation letters

Appendix 7 – Participant information and consent forms

Appendix 8 – Screening proforma

Appendix 9 – National Statistics Socioeconomic Classification (NS-SEC)

Appendix 10 – Screening instruments

- Standard MMSE
- African-Caribbean MMSE
- Combined MMSE

Appendix 11 – Diagnostic interview

Appendix 12 – Data summary forms and checklists