The Dementia Experiences of People from Caribbean, Chinese and South Asian Communities in Bristol

The Bristol BME People
Dementia Research Group

Alzheimer's Society
United Against Dementia

dementia wellbeing service

Bristol City Council

Bristol & Avon Chinese Women's Group Est 1989
婦女會

Bristol Black Carers
Established 1997
Empowering & Supporting Young and Adult Carers

UWE Bristol
University of the West of England

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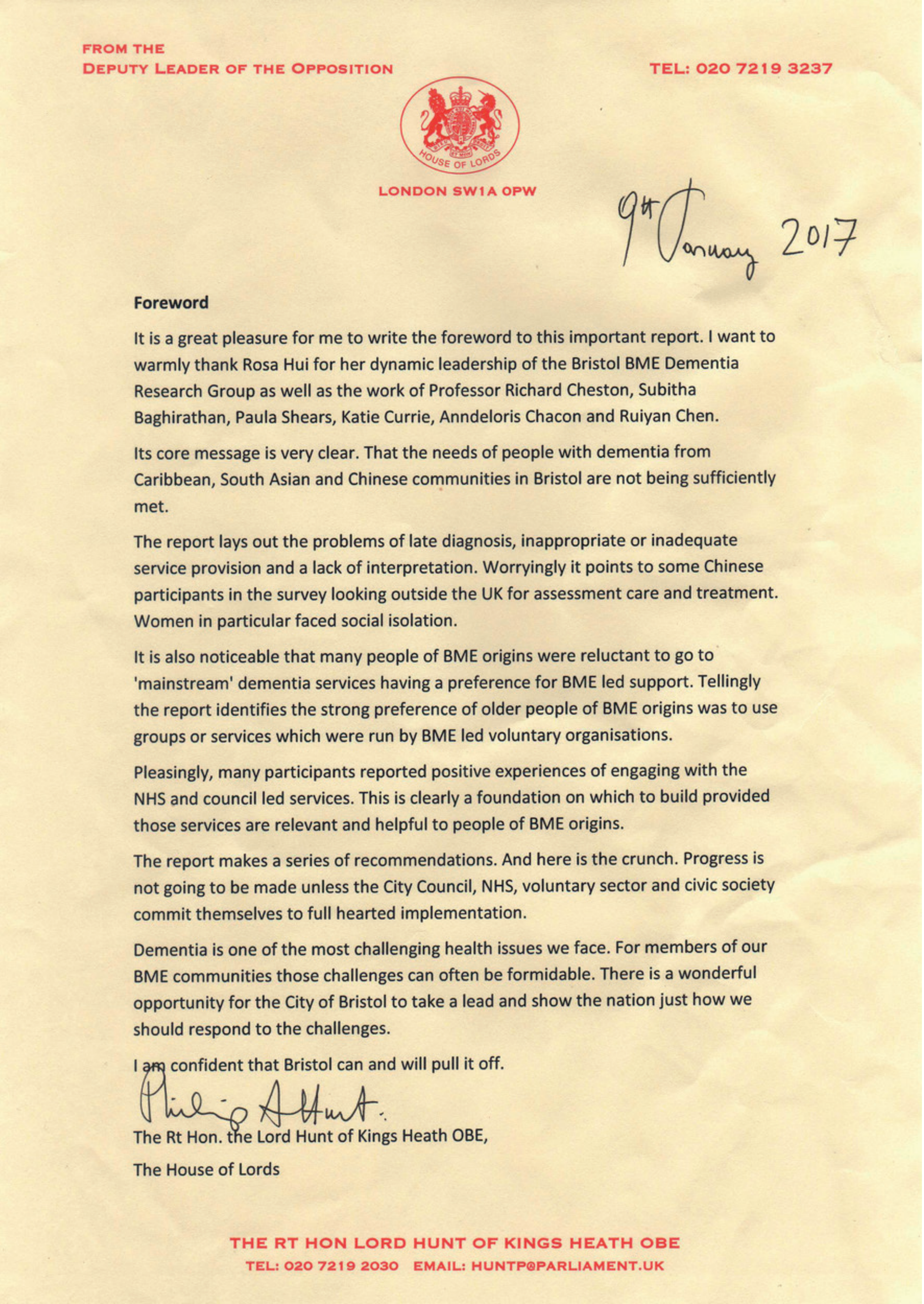

FROM THE
DEPUTY LEADER OF THE OPPOSITION

TEL: 020 7219 3237

LONDON SW1A 0PW

9th January 2017

Foreword

It is a great pleasure for me to write the foreword to this important report. I want to warmly thank Rosa Hui for her dynamic leadership of the Bristol BME Dementia Research Group as well as the work of Professor Richard Cheston, Subitha Baghirathan, Paula Shears, Katie Currie, Anndeloris Chacon and Ruiyan Chen.

Its core message is very clear. That the needs of people with dementia from Caribbean, South Asian and Chinese communities in Bristol are not being sufficiently met.

The report lays out the problems of late diagnosis, inappropriate or inadequate service provision and a lack of interpretation. Worryingly it points to some Chinese participants in the survey looking outside the UK for assessment care and treatment. Women in particular faced social isolation.

It is also noticeable that many people of BME origins were reluctant to go to 'mainstream' dementia services having a preference for BME led support. Tellingly the report identifies the strong preference of older people of BME origins was to use groups or services which were run by BME led voluntary organisations.

Pleasingly, many participants reported positive experiences of engaging with the NHS and council led services. This is clearly a foundation on which to build provided those services are relevant and helpful to people of BME origins.

The report makes a series of recommendations. And here is the crunch. Progress is not going to be made unless the City Council, NHS, voluntary sector and civic society commit themselves to full hearted implementation.

Dementia is one of the most challenging health issues we face. For members of our BME communities those challenges can often be formidable. There is a wonderful opportunity for the City of Bristol to take a lead and show the nation just how we should respond to the challenges.

I am confident that Bristol can and will pull it off.

Philip Hunt

The Rt Hon. the Lord Hunt of Kings Heath OBE,

The House of Lords

THE RT HON LORD HUNT OF KINGS HEATH OBE
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Foreword

I welcome the opportunity to introduce this research report. Since the Prime Minister launched his Dementia Challenge in 2012, dementia as a health condition has stepped out of the shadows. There has been increasing media coverage, with one family's struggle with dementia featuring as a storyline in a popular national soap opera and an Oscar nomination for an actress playing a woman with dementia. This growing awareness of dementia has been reflected in increased funding of dementia research.

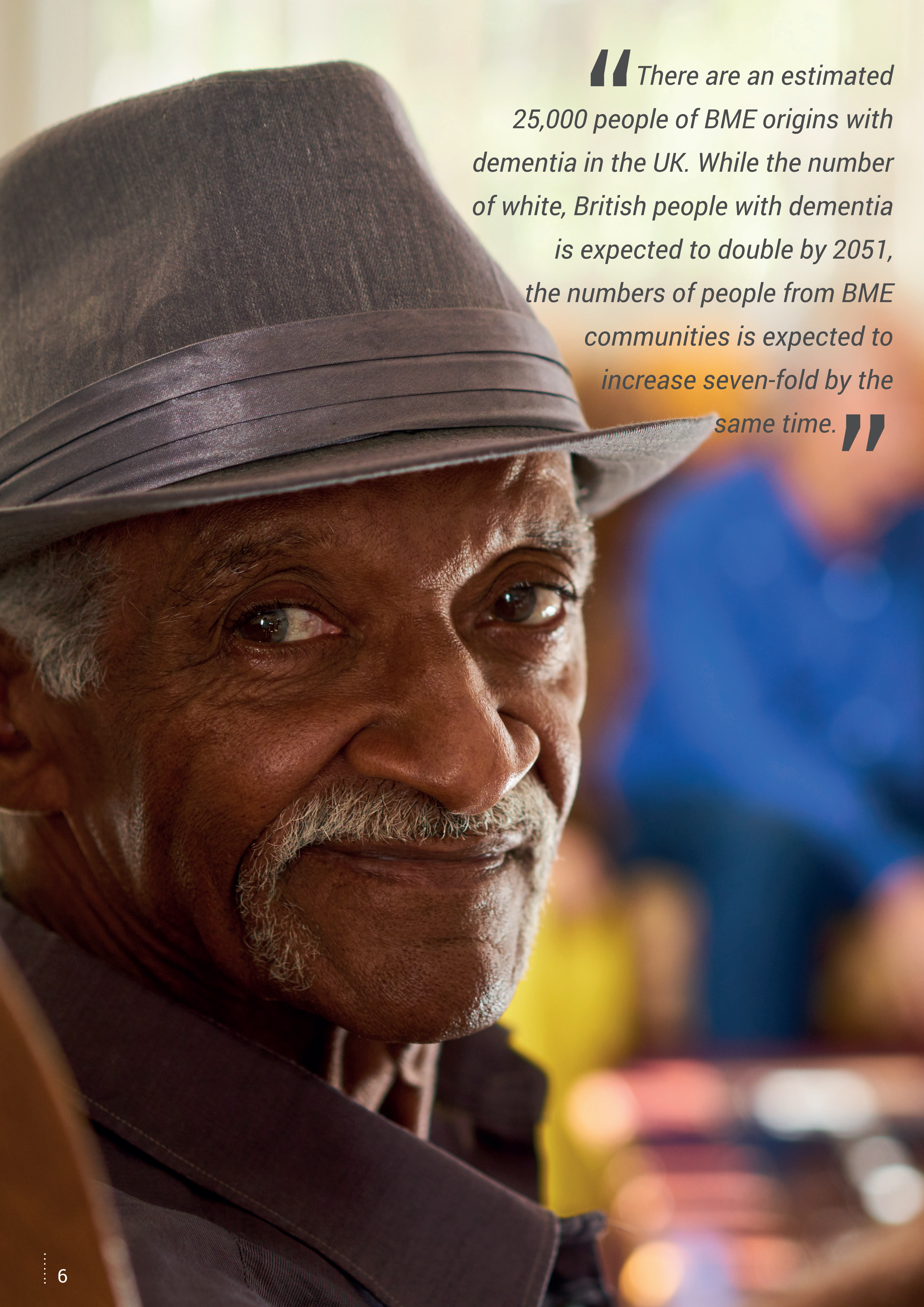
At the same time, the dementia experiences of Black, Asian and other minority ethnic people have also begun to emerge into focus. The recent All-Party Parliamentary report may have played a role in this. In order to translate this awareness into action, it is important for each city and county across the UK to ask simple questions: what is known about the needs of people from these communities? How should health and social care services try to meet these needs?

This research report is one attempt to answer these questions - it represents a significant example of how cross-sector partnerships can work at a local level to gain an authentic insight into the needs of people with dementia and their families from Caribbean, Chinese and South Asian communities. While these findings and recommendations relate specifically to Bristol, elements of this report deserve to have an impact beyond the local area, and to be considered at a strategic, national level.

Sally Greengross

The Baroness Greengross OBE
Co-Chair All-Party Parliamentary Group on Dementia and Ageing and Older People

11th January, 2017



> There are an estimated 25,000 people of BME origins with dementia in the UK. While the number of white, British people with dementia is expected to double by 2051, the numbers of people from BME communities is expected to increase seven-fold by the same time.

1.

Executive Summary

This report is the product of an eight-month research project funded by Bristol City Council which set out to establish the dementia experiences and needs of people of Black and other Minority Ethnic (BME) origins. The study was overseen by the Bristol BME People and Dementia research group, which was made up of representatives from Bristol and Avon Chinese Women's Group, Alzheimer's Society, the University of the West of England, Bristol City Council, Bristol Black Carers and Bristol Dementia Wellbeing Service (BDWS).

1.1 Background to the study

1.1.1 There are an estimated 25,000 people of BME origins with dementia in the UK. While the number of white, British people with dementia is expected to double by 2051, the numbers of people from BME communities is expected to increase seven-fold by the same time.

1.1.2 Bristol has a culturally diverse and ageing population. People from many BME communities in the UK are disproportionately affected by risk factors for dementia, including diabetes and cardio-vascular disease as well as being affected by a range of health inequalities.

1.1.3 People of BME origins experience dementia in markedly different ways from white British people. For example, diagnosis is more likely to occur at an advanced stage of the illness, there is lower take-up of mainstream dementia services and the availability of culturally appropriate forms of post-diagnostic support is variable.

1.2 Carrying out the study

1.2.1 This study focused on the experiences of people from Caribbean, South Asian and Chinese communities in Bristol. Collaborative partnerships were developed with Voluntary and Community Sector Organisations (VCSOs) led by older people of BME origins, such as Siri Guru Singh Sabha Gurdwara, Golden Agers, Dhek Bhal, Bristol and Avon Chinese Women's Group and Bristol Black Carers. Subitha Baghirathan was employed as a Research Associate on the project, working under the supervision of Professor Richard Cheston at the University of the West of England.

1.2.2 Forty-eight participants were interviewed, with eight Focus Groups being established between April to August 2016. Where necessary, interpreting provided by VCSO partners. Informal groups were also held to ensure that different perspectives were heard. Interviews and focus groups were transcribed and analysed using an adapted form of thematic analysis.

1.3 **Findings**

1.3.1 Knowledge of dementia, its symptoms and the diagnosis process varied across these different communities. This included: participants' knowledge of risk factors and preventative measures; awareness of the symptoms of dementia; the routes to seek help and advice; and knowledge of available sources of support and treatment after diagnosis. In the Chinese and some South Asian communities, understanding is limited by the lack of an equivalent term for "dementia".

1.3.2 In a number of communities, dementia was a stigmatized condition, with powerful systems of familial and cultural obligations limiting the extent to which people felt able to utilise mainstream health and social services. In the Chinese community in particular, there is an expectation that care needs will be largely provided within the family and especially by women. Consequently, many women are at risk of becoming socially isolated.

1.3.3 There were also examples of people with dementia who continued being actively engaged in social groups and activities. This was particularly the case within South Asian and Caribbean communities.

1.3.4 Older people of BME origins were more likely to use groups or services that were run by BME-led VCSOs. This was because they were familiar with these services, felt that they were more likely to meet their needs (e.g. around language) and because they did not feel that they would stand out.

1.3.5 Many participants recounted positive experiences of engaging with NHS and council-led services. However, there were also reports of many clear problems including a lack of interpreters, inappropriate or inadequate service provision and, on occasion, a lack of understanding. For some Chinese participants in particular, there were concerns that people may resort to looking outside the UK for assessment, care and treatment.

1.3.6 Many people of BME origins were reluctant to attend 'mainstream' dementia specific services, such as the Memory Cafés or Singing for the Brain groups run by Alzheimer's Society. This does not necessarily reflect a lack of cultural awareness within local services, but rather a preference for BME-led support.

1.3.7 The majority of staff and volunteers at BME-led VCSOs have received some training around dementia but there were clear gaps in their knowledge base, and staff were keen to receive further training. Organisations where the knowledge base around dementia was especially lacking, wanted help to address this as soon as possible.

1.3.8 Across all organisations, opinions were shared by staff and volunteers that their members were ageing and had increasing health needs, including dementia.

1.3.9 Many BME-led VCSOs play a vital role in educating their members about dementia, signposting them to relevant agencies and providing on-going support and care of people with dementia and their carers. However, they are carrying out these tasks in a climate of diminishing funding. A number of these organisations are managed and run by volunteers, and are consequently in a vulnerable position with limited capacity to apply for funding to support the inclusive, culturally tailored services that members of their community need.

1.4 Recommendations for consideration

1.4.1 *Raising awareness:* clearer messages need to be communicated in a range of ways about risk factors and prevention amongst BME communities.

1.4.2 *Data collection:* more accurate methods of establishing diagnosis rates for different BME communities should be established.

1.4.3 ***Targets for diagnosis rates:*** there should be separate targets for diagnosis rates amongst different BME communities in Bristol.

1.4.4 ***Engagement:*** flexible and pro-active methods of engagement with community organisations should be enhanced and developed.

1.4.5 ***Increasing awareness of GPs:*** although work to raise the awareness of GPs about the dementia needs of people from BME communities has taken place, this needs to be further developed.

1.4.6 ***Developing a toolkit of resources:*** a toolkit of validated, translated and culturally-appropriate assessment resources should be developed. This toolkit should be made available electronically, and training in its use should be provided.

1.4.7 ***Improving access to qualified, dementia-trained interpreters:*** access to interpreting services across different communities needs to be improved.

1.4.8 ***Training for VCSO staff:*** as part of partnership working that needs to be developed locally, training on dementia specific activities should be provided to BME-led VCSOs

1.4.9 ***Enhancing community engagement between specialist NHS dementia services and BME communities:*** the newly established Community Development Coordinators working for Bristol Dementia Well-being Service (BDWS), are a welcome and innovative role. It is important to develop, strengthen and support their crucial work

1.4.10 ***Increased diversity of staff:*** BDWS should continue both to ensure that recruitment reflects the needs of BME communities, and that existing staff from BME communities are fully supported.

1.4.11 ***Commissioning culturally-appropriate residential care:*** consideration should be given to ensuring that contracts with local care home providers meet the needs of different BME communities, with service providers working closely in collaboration with local BME-led voluntary groups. One possible model of care and continued support is that developed at Colliers Gardens in which Brunelcare Extra Care work with Bristol and Avon Chinese Women's Group to meet the needs of older people from Chinese communities.

1.4.12 ***Commissioning culturally-appropriate forms of domiciliary care:*** innovative approaches to meeting the needs of people from BME communities with dementia should be considered.

1.4.13 ***Investing in partnerships with BME-led community organisations:*** consideration should be given for establishing viable mechanisms of financial and partnership support for the dementia work being carried out by BME-led VCSOs.

1.4.14 ***Developing capacity:*** creative means of developing the dementia capacity of BME-led VCSOs in Bristol should be developed.

1.4.15 ***Supporting carers:*** consideration should be given to meeting the needs of people from BME communities who have previously cared for relatives, who have either now passed away, or entered residential care.

1.4.16 ***Enhancing the presence of people with dementia from BME communities in research:*** researchers and research networks should use flexible and innovative strategies to ensure that people from BME communities are present within dementia research.

1.4.17 ***Recognising the absence of people with dementia from BME communities at a strategic and commissioning level:*** policy makers (including NICE, NHS England, Public Health England and social care bodies) must take into account the specific needs of people affected by dementia from BME communities. This report can act as a toolkit to ensure that the voices of seldom heard communities, including people from BME communities, are present within services that are commissioned.

1.4.18 Identifying the dementia needs of other BME communities' research. consideration should be given to funding research to establish the wider needs of BME communities in Bristol.

2.

Introduction

This report sets out the findings from an eight-month research project that aimed to establish the dementia needs of people from Black, Asian and Minority Ethnic (BME) communities in Bristol.

The origins of this study arise from a simple question:

> *"What is being done in Bristol to meet the needs of people with dementia and their families from BME communities?"*

This question was first articulated by Rosa Hui, MBE DL, Director of Bristol and Avon Chinese Women's Group (or BACWG), and she directed it to Bristol Dementia Health Integration Team or HIT. In trying to respond to the question, it became apparent that not enough was known about what the needs and experiences of people from BME communities were - and how these might differ from white British communities.

In order to understand these needs, the Bristol BME Dementia Research group was set up in the summer of 2015. An application for funding for a research project made by this group to Bristol City Council was successful, and a part-time Research Associate (Subitha Baghirathan) was appointed in February 2016. The project was overseen by a steering group with representation by Bristol Dementia Wellbeing Service, Alzheimer's Society, Bristol City Council, Bristol and Avon Chinese Women's Group (BACWG), Bristol Black Carers and the University of the West of England (UWE).

This report brings together the results from this project and focuses on the experiences of three communities in Bristol - people whose origins lie in the Caribbean, South Asia and China. Our hope is that the report will provide a voice for people with dementia and those who support and care for them, from these communities - and that by doing so we will help commissioners, service providers and the general public to understand more about their needs. The report will hopefully act as a catalyst for change. There is no clear consensus about the most appropriate way to refer to people who are not of the majority, white UK ethnic and cultural groups.

This report will use the term "black and minority ethnic" (BME) people and communities - the term that is used in the Department of Health 2005 report on race equality and mental health[3].

Regardless of which terms and acronyms are used, it is important to acknowledge that people from minority ethnic origins are not a homogenous group with shared values and experiences. As will be clear in the later sections of this report, there is marked diversity both within and between many communities in Bristol and these differences impact on the way in which dementia is experienced. For instance, different religious structures are likely to impact upon the support that members of BME communities provide for each other, while language differences may result in different conceptions of ageing and cognitive impairment.

At the same time, research into the dementia needs of people from BME communities suggests that some tentative conclusions can be drawn.

One final note - detailed information about the research project including our appendices, a toolkit of published resources and a reference list are included in a separate document titled "Supplementary Information". This document is available on-line through the Dementia HIT, or on request from the academic lead for the project, Professor Richard Cheston (Richard.cheston@uwe.ac.uk) or other members of the steering group.

Aims of the study

The primary aim of this research study was to identify the experiences and needs of people affected by dementia within Caribbean, South Asian and Chinese communities in Bristol.

Achieving this aim involved:

- establishing the number of people with dementia from BME communities in Bristol;
- exploring the knowledge and attitudes of different communities towards dementia;
- determining the role of the voluntary and community sector (VCS) in providing support; and
- identifying any barriers that exist to accessing services including any systemic factors that may impact on the willingness of people within those communities to seek and to accept support.

3.

The wider picture for the dementia experiences of people from BME communities in the UK

In order to set our study into a wider context, we carried out two, brief additional pieces of preparatory work: first, we tried to estimate the numbers of people from BME communities living with dementia in Bristol; and secondly, we conducted a literature review to establish what is already known about how dementia affects people from BME communities in the UK - and by extension how dementia affects BME communities in Bristol.

3.1 Overview.

The population of Bristol has become increasingly diverse in the last 20 years, with 22% of the population of Bristol now viewing themselves as other than ‘White British’. The 2011 census suggests that over 90 different languages are spoken in Bristol, with Bristolians being born in at least 50 different countries and practicing more than 45 religions[26].

3.1.1 At the 2011 census there were almost 60,000 people aged over 65 living in Bristol, or one in every seven people living in Bristol. This is a lower proportion of older people than is the case in England and Wales as a whole. There are 9,100 people living in Bristol who are aged 85 and over (sometimes described as ‘old, old’)[27]. By 2039 there are projected to be 84,300 people aged 65 and over living in Bristol, an increase of an additional 25,600 older people in twenty-five years. Consequently, the number of older people as a proportion of the total population in Bristol is likely to increase from 13% to 15%[26].

3.1.2 Nationally, there are currently estimated to be 25,000 people living with dementia in England of Black, Asian and other minority ethnic (BME) origins[6]. This figure is predicted to increase to around 172,000 people by 2051. Even though the number of people with dementia in the UK as a whole is expected to double in that time[13], this seven-fold increase in the numbers of people with dementia from BME communities, represents a much higher rate of increase than for the rest of the UK population.

3.2 How many Black, Asian and other minority ethnic people in Bristol are affected by dementia?

It is not possible to give

a precise estimate of the number of people from BME, or indeed, from any other, communities, living with dementia in Bristol. In order to identify the likely number of people aged over 65 living in Bristol, we consulted the following sources: Projecting Older People's Population Information (POPPI); Local area profiles/Centre of Dynamics of Ethnicity (CoDE); and the 2011 Census[27]. As the population of all people in Bristol who are aged over 65 is estimated to have increased by 6% between 2011 and mid-2015, we have adjusted the figures by this amount to give an estimate for the population at mid-2015 point. Table One illustrates the estimated number of people in Bristol aged over 65.

3.2.1 The usual starting point for any estimate of the numbers of people living with dementia is with the widely accepted prevalence rate for dementia of 7.1% (or roughly 1 in 14) for people aged over 6528. Based on our estimate of the total number of BME people in Bristol aged over 65 as being 2,130, then if 7.1% of these people had dementia, we would around 151 people from BME communities to have dementia (see Table Two).

3.2.2 However, the data in Table Two is likely to be an under-estimate of the true number of people from BME communities who have dementia. This is because people from BME communities are more likely to experience a range of risk factors associated with dementia than their White British counterparts. This includes diabetes and cardiovascular health conditions, both of which are more prevalent in Caribbean, African and South Asian communities than in the majority white UK population16. More generally, health inequalities such as poor housing and a lack of transport, also increase the risk for developing dementia[1]. Importantly, large numbers of Asian people (including Chinese people as well as Indian, Pakistani, Bangladeshi and other Asian people) have the highest levels of health inequalities in UK[1]. Given that these additional risk factors are likely to disproportionately impact on people from BME communities living in Bristol, it seems likely that the predicted numbers of people living with dementia of BME origins in Bristol are an under-estimate of the true figure.

3.3 **How many BME people with dementia are receiving services?** Bristol Dementia Wellbeing Service (BDWS) has been providing a service to people with dementia and their family members since the spring of 2015. BDWS is an innovative partnership between Alzheimer's Society and Devon Partnership NHS Trust. Unlike the vast majority of other NHS dementia services, BDWS does not discharge patients after an assessment or brief intervention. Instead, people with dementia and their families are supported throughout their illness. This seamless service that BDWS provides is widely admired and recently won an award from the Royal College of Psychiatrists. In principle, every person diagnosed with dementia at primary

Table 1: Population figures for people of BME origins in Bristol

Black, Asian and other minority ethnic group	Overall total (people of all ages) from 2011 census	People aged over 65 (based on 2011 census)	Estimated number of people aged over 65 for mid- 2015
Pakistani	6,863	288	305
Indian	6,547	239	253
Bangladeshi	2,104	50	53
Chinese	3,886	158	167
Other Asian	4,255	106	112
Caribbean	6,727	1,170	1,240
Total BME population	30,382	2,011	2,130

Table 2: Comparison of estimated numbers of people of BME origins with dementia compared with numbers registered with Bristol Dementia Wellbeing Service (BDWS) in February 2016

Black, Asian and other minority ethnic group	Estimated number of people with dementia	Number of people registered with BDWS in February 2016	Estimated percentage of people with dementia registered with BDWS
Pakistani	21	8	38%
Indian	18	7	39%
Bangladeshi	4	3	75%
Chinese	12	4	33%
Other Asian Origins	8	2	26%
Caribbean	87	46	53%
Total	150	70	47%

care level in Bristol should be signposted to BDWS by their GP. However, we know from anecdotal reports that this process of referral is not infallible, and that there can be a number of reasons why some people can slip through the referral net.

Table Two illustrates both the numbers of people from different BME communities registered with BDWS in February 2016, and provides this figure as a proportion of the estimated overall numbers of people likely to have dementia in Bristol from the BME communities.

3.3.1 By way of contrast, it is possible to compare the percentage of people from different BME communities registered with BDWS with the overall proportion of people with dementia in Bristol who are registered with the BDWS. In total, the estimated number of people with dementia living in Bristol in February 2016 was 4,086. Of these, 1,718 people were registered with BDWS, representing 42% of the estimated number of people with dementia. As Table 2 illustrates, our estimate is that 47% of people with dementia from the three BME communities that this report focuses on (Caribbean, South Asian and Chinese communities) are registered with BDWS - a somewhat higher figure. However, as we have detailed above, there are good reasons for anticipating that as the risk factors for dementia are higher in some BME populations than in the white, British community, there are likely to be more people with dementia than we have estimated. Moreover, while these figures are encouraging, they do not tell us the stage at which people with dementia are being referred to BDWS. It may be, for instance, that people from BME who have dementia are seen at a different stage of the illness whether than is the case for the general population.

3.4 **What are the likely health needs of BME people with dementia?** There are likely to be a number of be important differences in the experiences of people with dementia from BME communities and the white, British population.

3.4.1 ***Health inequalities.*** People from BME communities are more likely to experience a wide range of health inequalities than the majority, white UK population[1]. Thus, people from BME communities are likely to have less access to, and different experiences of both mental health[4], and dementia specific, health services[5]. For example, people from BME communities are at greater risk of not being prescribed appropriate medication for dementia[6], and more likely to receive a diagnosis of dementia at a later stage in the illness[5].

3.4.2 ***Disproportionately high rates of increase in dementia.*** As the single most important risk factor for dementia is ageing[2], so, as the number of older people in the UK increases, it is inevitable that the numbers of people living with dementia will also increase. However, as we have described above, the rate of this increase is likely to be higher for people from BME communities, than for the general population.

Thus, while there will be a two-fold increase of people with dementia

Review of the literature - the national picture

Until relatively recently, there has been little UK-based literature on the dementia needs of people from BME communities[18]. Instead, the majority of the research on this area has been carried out in the US, which limits its relevance to the needs of BME people in the UK. While the situation has steadily improved over the last fifteen years, a review published in 2013[21] highlighted the fact that most research on BME people and dementia in the UK tended to consider Caribbean and South Asian communities and to be based in small, localised urban areas. Whilst these are amongst the largest, ageing BME communities in the UK, this research cannot be used as a framework to understand the dementia needs of all BME people. For instance, within South Asian communities alone, there are a range of tangible and clear differences including food preferences, religious practices and literacy levels. Of particular importance is the almost complete absence of people of Chinese origins in the research literature[21], together with an under-reporting of the perspectives of BME men - whether as carers or living with dementia themselves.

across whole UK by 2051, there will be a seven fold increase for people from BME communities[3]. This is both because of the increased risk of dementia in many BME communities and because patterns of immigration to the UK mean that many people who came to the UK as young adults in the 1960s and 1970s are now elderly.

3.5 Differences in knowledge and attitudes towards dementia.

3.5.1 ***Dementia-specific differences.*** There seem to be differences in knowledge and attitudes towards dementia between people from different communities as well as higher levels of stigma amongst some BME groups[2]. Consequently, the needs of people affected by dementia from BME communities are often significantly different from those of the general population. For instance, lack of fluency in English may affect both assessment and support after a diagnosis.

3.5.2 ***Different concepts of dementia and "normal" ageing.*** A number of studies have described how many age-associated changes in behaviour, or cognitive functioning tend to be identified as part of a natural ageing process within some BME communities, rather than as 'symptoms' of dementia. Thus, South Asian participants in one study described the experiences of people living with different symptoms of dementia as an expected part of ageing and suggested that going out more could help[8]. Similarly, a study in Wolverhampton with participants from Caribbean and South Asian communities persistently located dementia symptoms within the concept of 'natural ageing'[9].

3.5.3 ***Lack of knowledge about dementia as a distinct health condition.*** One element that adds an additional texture to the blending of concepts of dementia and normal ageing is that in many languages used within BME communities, there is no distinct, one-word translation for 'dementia'. Thus, those behaviours that are often identified as dementia symptoms may be represented instead either as a consequence of growing older, or as a facet of madness[10]. This is especially important, as we describe below, when considering the experiences of people from Chinese and South Asian communities including India and Pakistan.

More generally, alongside this difference in ways of conceptualising dementia symptoms, different communities may also identify different treatment or intervention strategies. Thus, older people of Chinese origins may prefer to consult medical practitioners who speak their language, even if this means travelling to Hong Kong. Similarly, they may be more familiar with, and have more trust in remedies from Chinese medicine practitioners rather than in conventional, mainstream health services[11].

3.5.4 ***Stigma.*** A wide range of attitudes, barriers and behaviours around dementia may all impact on the ability of people with dementia and their families to seek help[12].

While the stigma that is often associated with dementia may affect people from all communities, there is some evidence that suggests that it may be a particular problem for people from some BME communities. With specific reference to people of BME origins, stigma is sometimes associated with illnesses that are not purely physical, and may include any forms of mental ill-health as well as dementia. In this sense, stigma may influence seeking help from outside organisations and it may put a lens over how dementia symptoms are seen or experienced.

For example, one case study[13] described how, for an elderly woman who had grown up in South Asia, her dementia had caused a number of behavioural changes, including her using her garden as toilet, as she had done when growing up in a rural village in South Asia. However, to her daughter-in-law, it seemed that some members of her community were more concerned that her dementia meant that she was now unable to remember her regular practice of prayers.

Stigma can also be used as a term to describe a reluctance within some BME communities towards engaging with people who have dementia. In this way, barriers to inclusion can arise for people with dementia within groups run by and for people of BME origins. For example, in another case study, a Vietnamese husband who was caring for his wife described an unwelcoming attitude towards them at their usual Church attended predominantly by Vietnamese people: this included being asked to sit behind a pillar when they attended[13].

The changes in familial roles that accompany caring for someone with dementia may also be experienced differently by people from BME communities: for example, the adult children of elderly parents who do not speak or understand English well, may be asked to interpret personal medical details for their parents to medical practitioners.

In these circumstances, notions of unconditional respect for one's elders may create difficult dilemmas[14]. Conversely, the failure to continue with expected familial roles and duties due to exhaustion of a main carer, or increasing medical and care needs of someone with dementia, may also carry a stigma[10].

3.6 Differences in service provision

3.6.1 ***Assessment and Diagnosis.*** A central part of UK health policy over the last ten years has been to prioritise the assessment and diagnosis of dementia, so that more people are diagnosed and at an earlier point in the illness. The current Department of Health target is for 65 per cent of people with dementia to be given a diagnosis[6]. Within Bristol a number of changes have helped to facilitate the city successfully reaching this target. These include commissioning the Dementia Wellbeing Service, and creating a new pathway for dementia care in which GPs play a leading role in the assessment and diagnostic process. One of the main drivers behind these local changes has been the desire to provide a more accessible and coherent service to people including those from BME communities.

Across the UK, there is a wide variation in diagnosis rates and post-diagnostic support[15]. People from some BME communities, including South Asian communities, may be more likely to be diagnosed with dementia at a more advanced stage[5, 16]. Consequently, it is important to develop translated and culturally adapted cognitive assessment tools[16], for a wide variety of languages and people. This relates not just to people whose first language is not English, but also extends to the need for better culturally adapted dementia assessment tools for people of Caribbean and African origins, and involves adapting both assessment tools and interventions[17].

3.6.2 ***Up-take of services after diagnosis.*** Research consistently suggests that many BME people do not make use of 'mainstream' dementia-related health and social care services or the voluntary and community sector (such as Memory Cafés or post-diagnostic support groups)[6]. There seem to be a number of reasons for this, including: services being unable to provide appropriate language support; BME people being reluctant to join largely white UK groups; stigma around accepting external services; and BME people having a lack of knowledge about available services and benefits[6].

One specific example of an inequality of service provision comes from the importance of 'signposting' people with dementia and their families to relevant services, information and support post-diagnosis. This is a foundation stone of the Prime Minister's Dementia Challenge, as it aims to enable more people to 'live well with dementia'[7]. Practical means to achieve this include local key organisations such as Age UK or Alzheimer's Society being commissioned to develop Information Packs with all relevant local information. Increasingly, these Packs and resources are being translated into languages other than English.

3.6.3 ***Characteristics of services that meet the needs of BME communities.*** Almost fifteen years ago, a review of research suggested that people with dementia and their families from BME communities were often unaware of and unable to access relevant services[18]. Over 10 years later, the 2013 All Party Parliamentary Group report on dementia and BME people identified a similar picture[7].

Moreover, even where knowledge about services exists, then the research literature suggests that some aspects of the needs of people from BME communities may still not be met, for example their language needs and general cultural awareness. Indeed, the anticipation within many BME communities that their needs will not be met and that they will face discrimination and unequal treatment, may well prevent many BME people from accessing health services in the first place[19].

Much of the existing literature identifies examples of ways of working, projects, posts and activities that have increased service use and involvement from people of BME origins with dementia. The overarching themes in these improved services include: services aiming to be more flexible (e.g. being based outside 'mainstream' health service venues such as hospitals); a commitment to person-centred services, with specific skills around 'cultural competency' being of secondary importance[20]; and mainstream health and social care services developing equitable, sustainable working partnerships with voluntary and community sector organisations which are embedded within local BME communities.

One example of good practice is the Somali and Bangladeshi Mental Health Networks services which was commissioned from Voluntary Action Camden (a VCSO) after research showed there was a lack of awareness of dementia in local BME communities. Not only is this network working to tackle stigma and lack of knowledge about dementia, it also enables health service providers to meet directly with service users[6].

3.6.4 ***Post-diagnostic support.*** While research suggests that BME people are more likely to be diagnosed at advanced stage, there appears to be little research that indicates whether the post-diagnostic treatment of BME people with dementia differs from that of their white counterparts. For example, there is little evidence into how challenging behaviour (sometimes referred to as "Behavioural and Psychological Symptoms of Dementia" or BPSD) may vary between people from BME and white communities. For many people from BME communities, English is a second or third language, and increasing levels of cognitive impairment may make the individual with dementia revert to their mother-tongue. Similarly, it is unclear what impact previous experiences of racism and discrimination may have for BME people with dementia living in institutional care.

3.6.5 ***Identifying dementia competent, culturally specific services.*** While the research literature often highlights the under-representation of BME people within post-diagnostic care, examples of good quality, alternative services are less common. A rare example of such a service is a Punjabi-adapted Cognitive Stimulation Therapy group in Slough[8].

3.7 **Risk reduction.** There appears to be little research about any preventative work around dementia with BME people. Health professionals, academics and others working in the field are aware of the risk factors of cardiovascular disease and diabetes[22]. It could be relatively straightforward, for BME people who attend medical appointments to manage their diabetes or after experiencing a stroke, to be signposted at this point to accessible information about dementia. However, we could not identify any studies that have attempted to raise awareness of dementia amongst BME communities in this way.

3.8 **The impact of wider health inequalities.** There is a tendency in the research literature to focus on a number of core themes, such as how dementia is understood by BME people or the potential stigma of dementia-like behaviours/ symptoms. While this is important, nevertheless, they place the research focus on areas of deficit or difference within BME communities rather than the way in which dementia is one of a number of health conditions which occurs in the context of many other health inequalities. For example, while higher numbers of Pakistani families have a disabled child compared to white UK families[23], we do not understand how or whether these other care commitments and experiences also impact on dementia care.

Similarly, men of BME origins are more likely to fall within lower socio-economic groups than men of white UK ethnicity[1], and there is evidence that men from lower socio-economic groups are less likely to seek health advice and treatment[24]. Consequently, health service providers and commissioners will need to take a holistic view when designing services that take account of these influences.

3.9 The low level of BME participation within much dementia research.

While we have described above how research into the experiences of BME communities has grown consistently, this is still at a relatively early stage, with projects often needing to be separately funded. Often research studies, even those with a major, national remit, do not specifically look to establish the needs of people from BME communities.

4.

Methodology

> *"People from BME communities are sometimes mistakenly referred to with epithets such as "hard to reach"…"*

4.1 **People from BME communities and dementia research - ignored or hard to reach?** People from BME communities are sometimes mistakenly referred to with epithets such as "hard to reach". While such descriptions are both ethnocentric and misguided, they do reflect a reality that many people from BME communities do not live, work or socialise in the same communities as those in which researchers or clinicians often live. Consequently, researchers may not understand how to approach people with dementia from BME communities, while potential participants may be understandably reluctant to disclose personal experiences to strangers. In order to encourage recruitment, we adopted the following procedures (see Appendix 2, Supplementary Information, for more details):

4.1.1 ***Using a qualitative approach.*** We were aware that it was important to help participants to tell their own "story" about dementia, which would prioritise their experiences. Accordingly, interviews and groups were loosely structured using a topic guide (see Supplementary Material) that enabled those issues identified as being important in the literature review to be raised, but which did not otherwise constrain the flow of the interview. Participants were offered the option of being interviewed either at home, or in their chosen environment. Interviews were recorded with the consent of participants and were transcribed at the end of the study.

4.1.2 ***Recruiting through partner groups.*** SB (Subitha Baghirathan, the Research Associate for this project) made contact with staff working for the Bristol Dementia Wellbeing Service, and with key volunteers and co-ordinators working for Voluntary and Community Sector Organisations (VCSOs) embedded within BME communities in Bristol (see Appendix 4, Supplementary Material). Where volunteers or organisers of the VCSOs referred potential participants to the project, they were asked to gain permission before passing on personal information.

4.1.3 ***Direct recruitment through the community.*** SB attended as many relevant public meetings as possible to publicise the project and to invite people to contact her. She also distributed flyers about the project (for example: at a local Chinese supermarket and Sikh Gurdwara, as well as local community centres), appeared on the radio (Ujima Community Radio and BBC Radio Bristol) and put information into relevant newsletters (such as Bristol Ageing Better's e-bulletin)

4.2 **Data collection from people with dementia and their families.** Between April and August 2016, SB carried out a series of interviews and Focus Groups with people affected by dementia and their families living in Bristol from Chinese, Caribbean and South Asian communities (see Appendix 1, Supplementary Material, for more details) . Where appropriate SB identified potential translators to facilitate communication within sessions. A number of interviews were carried out with people who did not have a dementia diagnosis, but who were worried that they might have dementia.

4.3 **Interviews and focus groups with staff and volunteers.**
Staff within Bristol Dementia Wellbeing Service and local BME-led VCSOs were interviewed in order to understand their experiences of working with people from BME communities and to help to identify potential barriers to service delivery.

4.4 **Recruitment within Caribbean communities.**
Recruitment to the study drew on Black-led VCSOs for older people such as Evergreens, Golden Agers, Malcolm X Elders' Group, Bristol Black Carers and the Inner City Health Champions' Team (facilitated by Bristol Community Health).

4.4.1 ***Evergreens*** is a weekly community group based at Easton Community Centre, and is regularly attended by around 20 older people, predominantly from local Caribbean communities. It is run largely by volunteers with one, part-time, paid co-ordinator.

4.4.2 ***The Golden Agers Club*** meets twice a week in a church in Easton and is run by volunteers. This group is often attended by a small number of older men of Caribbean origins although most members are women.

4.4.3 **Malcolm X Elders** is run by volunteers and meets every Monday in a Black-led community centre in St Paul's.

4.4.4 ***Bristol Black Carers*** is a BME-led VCSO with a paid, full-time Manager. It offers advocacy, advice, signposting and a sitting service to BME carers, although the majority of their service users are of Caribbean or African origins.

4.5 **Ten people from the Caribbean community** were interviewed (one person who had a diagnosis of dementia, eight people who were supporting someone with dementia in their family, and one person who was concerned that they might have dementia). Two focus groups were also arranged at Evergreens and Golden Agers. These groups were likely to have had people with dementia, or with potential symptoms of dementia, within them but they were not individually identified as such. Figure One (see Supplementary Information) illustrates the process of recruitment of Caribbean participants.

As the research progressed, it became evident that a substantial majority of contributors were women, and that Caribbean men of any age were not participating. This recruitment bias affected both one-to-one interviews as well as the focus groups that were carried out. Thus while one social club, was attended by around eight men, none were willing to give their consent or to be involved in a focus group. The Caribbean women that SB interviewed suggested that she needed to go to where the men were - including to Barbers' shops in central and east Bristol where Caribbean men may visit regularly. Consequently, SB spent time in Barbers' shops, in order to chat and find out about the views of the men there concerning dementia and dementia services. During these meetings, SB was always clear about who she was and why she was there. The Caribbean men whom she met were adamant that while they were happy to talk in general terms, they did not want to be formally involved in the project. Information that they provided was therefore treated as background material.

4.6 Recruitment within Chinese communities.

Figure two (see supplementary information) illustrates the recruitment process for this study within the Chinese community. Eleven interviews with participants of Chinese origins were organised through Bristol and Avon Chinese Women's Group (BACWG). In order to facilitate recruitment, all the promotional material and relevant documents for this research project were translated into accessible Chinese scripts. An article about the research was included in BACWG's quarterly newsletter. An interpreter (recruited through BACWG) was employed for over half the interviews. SB also made a number of attempts to recruit participants by making outreach visits, for instance attending the Chinese Elderly Club's bi-weekly Mah-jong sessions, taking translated flyers to Chinese restaurants and a local Chinese supermarket, and distributing them to all the residents of Chinese origins at Brunelcare's Colliers' Gardens Extra Care premises. None of these actions resulted in participants coming forward. Instead, an informal group at the Chinese Elderly Club was carried out.

4.7 Recruitment within South Asian communities.

Recruitment to this study drew on those four South Asian-led organisations providing support for people

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[1] Ethics permission from UWE Faculty of Health and Applied Sciences Ethics committee on 11th March (HAS.16.02.112).

with dementia:

4.7.1 ***Awaz Utaoh*** runs a twice-weekly drop-in based at 2 different locations in Central and East Bristol. All members are women, with most aged over 55, of Pakistani and Bangladeshi origin. The focus is on health and wellbeing with regular healthy food demos, yoga and Zumba classes. The sessions are run by a small number of paid staff plus many volunteers.

4.7.2 ***Dhek Bhal*** runs a long-standing twice-weekly Women's Day Centre that includes women with dementia. They also offer a more recent Older Men's Group, which includes many male carers. Members come from all three main South Asian communities. It has a team of paid workers and volunteers and also provides a Sitting Service that provides care in people's homes.

4.7.3 ***Asian Elderly Day Centre*** (or Asian Health and Social Care Association) is based at Easton Community Centre, and runs a day centre three times a week. Most members are from Indian families, and are either of Hindu or Sikh faiths.

The service is run by paid staff.

4.7.4 ***Siri Guru Singh Sabha Gurdwara*** is a large Gurdwara that is physically accessible for many older people. It hosts a weekly Older People's Group with lunch provided, which seems to be mainly attended by older Indian men of the Sikh faith.

4.8 **Figure three (see supplementary material) sets out the recruitment process within South Asian communities.** Five managers or key volunteers at South Asian Voluntary and Community Sector Organisations (VCSOs) were interviewed based within South Asian communities. Four focus groups took place at Dhek Bhal, Awaz Utoah and (in order to engage with men) the Asian Elderly Day Centre, with an additional focus group taking place with staff at Dhek Bhal. Contact developed with a local Gurdwara also opened up opportunities for SB to hear from older Sikh men. Interpreting needs in focus groups attended by people from South Asian communities were met through informal arrangements within the partner VCSOs, with staff members or volunteers interpreting on the spot. It wasn't possible to recruit a South Asian person who had a diagnosis of dementia. Unsuccessful attempts were made to involve several key mosques in the research project. The main reason for the difficulty in engaging with mosques did not appear to be a lack of willingness to engage, but more that the function of most mosques is largely focussed on prayer, rather than social support.

4.9 **Data analysis.** SB made selective field notes during both formal and informal focus groups, interviews and general outreach work. SB listened back to recorded interviews and focus groups and selectively transcribed some of this evidence. An abbreviated form of thematic analysis was then carried out to identify key themes. Recommendations for consideration have been developed (Section Six) that are either direct suggestions from participants with lived experience or based on summaries of the findings.

5.

“Water more than flour” - the experiences of Caribbean people in Bristol who are living with dementia

“Sometimes I think the problem for the Caribbean community is that, on the surface, there seems to be a ‘closerness’ to the white English. But it is on the surface...”

5.1 **What do people from Caribbean communities tell us about their experiences of dementia?** A number of consistent themes emerged from the information we were given from interviews and focus groups

5.2 **“Keep on walking” - mental health services as oppressive.** One participant, Mr Y, stressed the importance of understanding the differences between black people from the Caribbean and those from white communities:

> *“Sometimes I think the problem for the Caribbean community is that, on the surface, there seems to be a ‘closerness’ to the white English. But it is on the surface. There are, I think, quite substantial differences: in outlook, in humour, in idiom, in food ... Things like ‘well-done’ and ‘rare’ - there’s no such things as ‘rare’ in the Caribbean. People don’t leave blood in food; you cook the food ... So it’s things like that.”*

A consistent point made throughout the study concerned the reluctance of some people from Caribbean communities, and in particular men, to engage with statutory services. Thus, a number of people at Caribbean-led older people’s VCSOs said that they associated visiting the doctor to discuss memory loss or other concerns with being “locked up”. Similarly, in an informal group at a Barber’s shop, one man referred to health services as part of “the authority” and suggested that older Rastafarian people would rarely use services such as the Carers’ Support Centre, or a reading group for people with dementia in the Central Library because of their previous experiences of racism: “it’s about protecting ourselves”, he explained.

There is a clear evidence base for these concerns. Not only are disproportionately higher numbers of Caribbean people admitted under the Mental Health Act 2007, but people of Caribbean and Caribbean/mixed ethnic origins who are admitted to hospital under this Act, spend longer periods of time on average in hospital[29]. Consequently, experiences of the mental health system such as these may serve as a barrier to help-seeking for dementia-like symptoms.

More generally, there seemed to be a doubt amongst some people that "mainstream" services were either relevant to the needs of Caribbean communities or that they would listen to or take concerns of black people seriously. One Caribbean man in an informal Barber's shop discussion suggested that if a white person wanted a haircut and looked in this shop, then because he would see a shop full of Black people, so he would "keep on walking." A woman at the Evergreens' focus group explained why people didn't use groups like Memory Cafés: "They don't want to talk about it, African Caribbean people …. they don't want to stand out." Another woman in the group added: "*You would talk more amongst people who know you more*".

5.3 "What is it [dementia]? Losing your marbles?".

In general, most Caribbean people who took part in the study were aware of the term 'dementia' and its symptoms. In part, this seemed to stem from the increasing numbers of people with dementia within extended families and local communities. In addition, the Community Development Worker from the Bristol Dementia Wellbeing Service who covers Central and East Bristol has also been very actively promoting awareness of dementia and local services. However, despite some people's awareness of the symptoms of dementia, many people still attributed dementia either to natural ageing, or as evidence of mental ill-health. Thus, one woman at the Evergreens' focus group said *"I think loneliness causes this Alzheimer's thing."*

Men, in particular, seemed to have a less clear understanding of dementia than women did, with some Barber-shop participants even being surprised that dementia affected people from African-Caribbean communities. For some people, this lack of knowledge about the causes of dementia extended to a belief that dementia did not affect black people. As a volunteer at Golden Agers explained:

> *"Most people don't know about dementia … We didn't call it 'dementia'. Most people called it 'senile', 'senility' … They put it at the back. They don't want to talk about it. You have to keep explaining to them, this is not madness. Once you can explain that to them, they can take it on board."*

None of the people from Caribbean communities who were interviewed knew that diabetes, high blood pressure and stroke (all of which are more common in Caribbean and South Asian communities) are potential risk factors for dementia. Over half of the Caribbean people involved in the study wanted more information about how to lower their risk of developing dementia.

5.4 **Assessment and diagnosis - "We go to the doctor but the doctor does not come to us."** Many people who participated in this study, described a reluctance to approach services. A Caribbean man in his 70s in a focus group described his difficulties in getting his wife to seek medical advice about her changing health and behaviour.

SB: *How was that for you both, getting her diagnosed?*

Man#1: *It was hard*

Researcher: *What was hard about it?*

Man #1: *She didn't want to go.*

Mr Y (a 40 year old man of Caribbean origins) described how his aunt received a dementia diagnosis. She had been living alone since being widowed 20 years before and had recently been getting increasingly bewildered and sometimes abusive.

"She was very resentful; she didn't think there was anything wrong with her. She wanted to maintain her independence…[…] There was some disjuncture between us noticing, 'Oh, auntie is becoming increasingly old and forgetful' and us thinking about dementia…[…] Veering from eccentricity to not being well and knowing where the boundaries of that lies… Sometimes, as a family, you need another pair of eyes…"

Similarly, when SB asked the Evergreens' focus group whether people would talk to their doctor about a memory problem, she was told:

Woman #1 (in 70s): *No, they think they are wasting the doctor's time.*

Woman #2(in 70s): *It's up to family members.*

SB: *Do you think people go to the doctor more easily for physical pain, like your knee hurting from arthritis, than if you were forgetting your children's names?*

Lots of voices: *Yes.*

Researcher: *Why?*

Woman #3 (in late 70s): *They can't give you any medicine.*

The suspicion that mainstream services won't listen or respond to concerns of black people also seems to be reinforced by experiences. A volunteer at Golden Agers described it in this way:

"It is always a family member who would detect something and take them to a doctor. They themselves would not go to the doctor. Not the older set of generation that we have … I think we could be doing lots more work (to inform next generation down). Many times, they take their elders to the doctor and … the family member does not get listened to … I'm hearing that kind of incident quite often."

A number of interview and focus group participants described concerns that the views of the person who may have dementia or already has a diagnosis is prioritised over listening to the family member or carer.

While this may reflect a person-centred approach on the part of GPs or other clinicians, for members of a community that has often experienced being ignored or discounted, elements of the assessment process may reinforce suspicions about mainstream services.
Ms E was instrumental in taking her mother for an assessment for dementia and she eventually received a diagnosis. Ms E commented:

“You have to be assertive for them, with doctors … The Doctor from the mental health team did an initial assessment with Mum, got up and was about to leave, saying what a wonderful mother I had. Then I said, “Mum, tell her about [a particular aspect of her Mother’s dementia-like symptoms]; Mum agreed, and the doctor sat back down.”

5.5 The need for culturally appropriate support.

For some people, dementia services clearly failed to provide support that met their cultural needs. Ms A helps her father to care for her mother whose symptoms of dementia have recently deteriorated. She commented:

“I spent ages looking for a day centre that was culturally appropriate. Because her daughters (who don’t live in Bristol), they were really saying, ‘If you’re going to send our mother to a day centre, we need to know it caters for black people. That she can get the meals she is used to eating’. You know - Caribbean meals. I went to a lot of different places and one place ... They had quite a lot of people who came from BME backgrounds but they did not have any spaces and it was more expensive than a lot of places.”

For Ms A, the lack of cultural sensitivity meant that her father struggled, at times, to trust the day centre they chose:

“There’s all these things that my Dad was embarrassed to say about his wife, so he wasn’t always open and honest about it. And I think it is something about cultural sensitivity. Because where they live now, you know, there’s a lot of older people but I remember when they first moved in, it was, ‘Oh! There’s another Black person.’ And they specialise in dementia so that’s quite good and the staff are good. And there are a few more people there now [i.e. a few more Black people].”

SB: *Do you think we do that, as minority ethnic people, scan to see if there are any other minority ethnic people there?*

Ms A: *Yes.*

One interviewee, Mr Y, suggested that the lack of cultural sensitivity extended to a lack of appreciation that English was not the first language of some Caribbean people. He described English as a ‘performance language’ for some older Caribbean people, particularly if they have used Creole or ‘Patois’ as their first language, rather than English.

“I think (with dementia) as we lose some of our ‘performance language’, we become more ... have elements of our young selves. So, with my auntie, with her bad language, we talked about this was how she was when she was younger. It was market-place Creole:

*'Wha' you wan'? Wha' you look 'pon? F*** off'. I don't know how dementia works but part of me thinks: 'This was you before you started going church. Or you not at church, you at home."*

For Ms B, staff at the first nursing home where her mother (who has dementia) lived, may have been confused by her mother's use of patois, as they didn't appear to recognise this as a separate language to English. She felt that this failure either to try to understand what her mother was saying, or to acknowledge that she was using a different language meant that her mother often became dehydrated. While her mother's current nursing home clearly tries hard to meet her mother's needs, there are subtle but important ways, in which the care they provided feel short of the ideal:

"I spoke to someone because I said, 'I don't think Mummy's whole needs are being met, with regards the cultural...'. She's happy, don't get me wrong. And a few months ago, they did a Jamaican Day for her, but it was a Jamaican Day that involved all white people. Don't get me wrong; they did their best; it was a great gesture. I appreciated it … but it would be great if someone within the system, the service … that I could find someone of West Indian background who could just sit with Mummy, talk with Mummy, be there with her."

5.6 **Ethnicity and gender.** As we described in section two, we deliberately prioritised the recruitment of men of Caribbean origins. The difficulties that we faced in recruiting Caribbean men seem to be reflected in the struggle of dementia specific services to ensure equity of service to men. For example, the Sporting Memories' Group in Central Bristol that was targeted at BME men has similarly struggled to recruit participants. The case study of Mr Z provides an illustration of the needs of Caribbean men who have dementia.

Just as the needs of men with dementia may be different from those of women, and less well met, so too are the needs of male carers. For instance, the only man who was part of a focus group described how his wife (who has dementia) had only left their home twice in 18 months. While this is true of white British men and women, the impact of gender in Caribbean communities may be particularly important. When a volunteer at Golden Agers was asked about the apparent invisibility of men within care services she replied:

Volunteer: *Men are not used to doing the caring … They do need the support. There's one man out there who cared for his wife in dementia until he could not do it anymore. It breaks his heart that he can't do it anymore … There are others out there like that … He came to breaking point."*

SB: *Yes, I asked him if he would speak with me but he didn't want to.*

Volunteer: *No, he won't [talk about his experiences].*

Similarly, Ms A whose father provides all the care for her step-mother was aware of how vulnerable and isolated he risked becoming:

Case Study
Mr Z

Mr Z is a Caribbean man in his 80s, who has had a diagnosis of dementia for a year. He has diabetes, and has previously suffered from cancer. One of his sisters, the one he was closest to, also had dementia and died recently. Mr Z is registered with the Bristol Dementia Wellbeing Service who referred him to the research project. Mr Z lives alone in sheltered housing and is supported by his nephew who lives nearby and visits regularly. Paid carers also visit regularly. However, even though Mr Z's nephew usually rings Mr Z to remind him to be in, he sometimes forgets and goes out. The carers then call the nephew, asking where his uncle is.

Another concern for Mr Z's nephew is that his uncle sometimes cooks large pots of food, which he does not store in the fridge. This has led to a number of stomach problems, and although Mr Z's nephew used to regularly cook fresh food to take around for his uncle, this was often not eaten. Mr Z is adamant that he wants to continue cooking his own meals. Mr Z's nephew would like his uncle to be less on his own, to go along to some of the Caribbean-led older people's groups that are nearby, but says that he rarely, if ever, does this. Instead, he prefers visiting a nearby, older male relative.

Researcher: *What about talking to other people of your own age, other older men and women from the Caribbean? Do you go to any groups?*

Mr Z: *Don't want groups, don't want groups.*

Researcher: *You go to Golden Agers sometimes you said?*

Mr Z: *The first I go is Tudor Road Church with my brother-in-law.*

Researcher: *Do you enjoy going there? To Tudor Road Church?*

Mr Z: *Yes, from that time when I was a little boy, my mother was a Christian so I know about Christianity.*

Researcher: *Aside from it being Church, is that somewhere you can go and talk about your health difficulties and you get advice. They listen to you?*

Mr Z: *They tell me if I want to come round the Church (i.e. go to the Golden Agers Club there). But I don't come, don't want to.*

Researcher: *Would you like to go to a group with other people with dementia, to find out other ways of…*

Mr Z: (interrupting) *What good would that be to me? You tell me? What would I do with people talking to me about dementia? It's something I know. What can they tell me? So I don't go."*

“I think there is something about the isolation of older Black men. Definitely. I worry about my Dad if anything should happen to his wife, he does not have much in his life apart from his family. He has the Church but no clubs. You never know, he might get a whole new lease of life ... but I think his life is so tailored around her, looking after her, and the Church. It is part of him now. It defines his life … a lot of them (Caribbean men) are hidden. I think older African-Caribbean men are almost a hidden community, in a way.”

5.7 **“We care for each other until the very end”**. A recurring theme from almost all participants was their reliance on black community groups and organisations. This was related not just to the lack of culturally appropriate support within mainstream dementia services, but also the wider identity of black people in Bristol. For some of the men in the Barber’s shop groups, the older generation of Black men were still likely to look out for each, if one of them had dementia or any other illness. Similarly a volunteer at Golden Agers commented: “It is in our culture. We care for each other until the very end. When people do go into care homes, into hospital, it is at the very last”.

Over half of the Caribbean people interviewed in this project made reference to church as a significant source of support in their lives. Indeed, in many ways, the church is integral to the wider support network - the Golden Agers Club was originally established by a church and is still based within a church, while another (the Malcolm X Elders’ group) often begins its weekly session with a prayer or a reading from a text with a Christian ethos. Ms A described how her father and step-mother were reliant on their church:

He does a lot of Church still. And she still goes with him … The Church they have been going to for a long time in St Paul’s is a very small black-led Church and everybody in the Church knows her. The congregation has been there for a long time. So he feels he isn’t going somewhere where he has to explain himself, explain her behaviour … they have seen her deterioration so they know exactly how to support him.

The impression gained in this study was that the volunteers and workers at many Caribbean-led community organisations had both a good level of dementia awareness, and also the skills and knowledge to provide a level of care to their members. However, there was a limit to their ability to provide this support and, in particular, as the needs of people with dementia progressed, so the capacity of community groups to provide this care diminished. As a volunteer at Evergreens commented:

We probably couldn’t support someone who had very advanced dementia. There would be aspects of taking them to the toilet, there’s aspects of safety. They would need individualised care, were they to be in a very advanced stage of dementia. But in a mild stage of dementia, when they can work within the group and enjoy what the group has to offer; that is probably the best time for them to attend Evergreens.

Lead volunteers often contact family members or services if people's health and social care needs become a concern. A number of volunteers from Golden Agers call members to check on them if they notice they have not attended for some time. However, the reliance on Caribbean-led VCSOs to provide culturally appropriate dementia care, means that this care is, in effect, un-funded and invisible. As Mr Y pointed out:

"We've got to be careful that we are not getting care on the cheap. Many of them (the volunteers) were nurses. They understand the cohort of the people they are dealing with. I am sure one of the positives for people with dementia is that they are around their own culture and identity."

5.8 **Meeting the needs of people with advanced dementia.** A number of participants described difficulties in accessing adequate support as their relative's dementia deteriorated. For instance, Ms B is a Caribbean woman in her 50s whose mother was diagnosed with dementia around 10 years ago. Although her mother now lives in a nursing home outside Bristol, she continued to live in her own home alone for some years after receiving the diagnosis, and during this time had some periods of hospitalisation.

Ms B: *I tried to get Mummy some support at home …. I was told so many times [that something would have to happen for measures to be put in place.] Eventually what I did was … I contacted the Fire Brigade to come and put in some smoke alarms because I was so worried. Eventually my husband and my son would come and stay at my Mum's on alternate nights. And one day, my husband came and it was obvious that the oven had been on all day because the pot that was on it was burnt to charcoal … and when my cousin came, all the cooking pans were burnt. And I would tell, there's like a Dementia Nurse you can contact at the surgery, she was there. Nothing. Nothing. There was nothing we could get."*

Ms B also felt that the care her mother received in hospital, before moving into a nursing home left much to be desired:

Hospitals are not geared for dementia. Mummy's hospital treatment was appalling. … It is the worst place for a dementia person … they need to realise it's the system that's been designed. That was the worst place for my mother. It hurts my heart to think now about how my mum was treated in hospital … Hospitals being more dementia-aware, being sensitive. Being mindful ... I don't know how to put this ... I'm aware of the fact that all dementia patients, at say the early stages, they know how to answer certain questions. But I'm also aware that some dementia patients, like my Mum, there are certain questions they don't know how to answer. What I say is, the hospital should be aware of that, sensitive of that so if that person has given you false information, don't take it on board … the families - involve them for real … This is something I had to battle with *at the hospital all the time … And a lot of family members feel intimidated by hospitals, by doctors, by staff nurse. They don't want to challenge them …"*

Although some people with dementia were living in residential care, there was a great reluctance amongst other families to initiate these moves. Some participants attributed this to having worked as front-line staff in these homes:

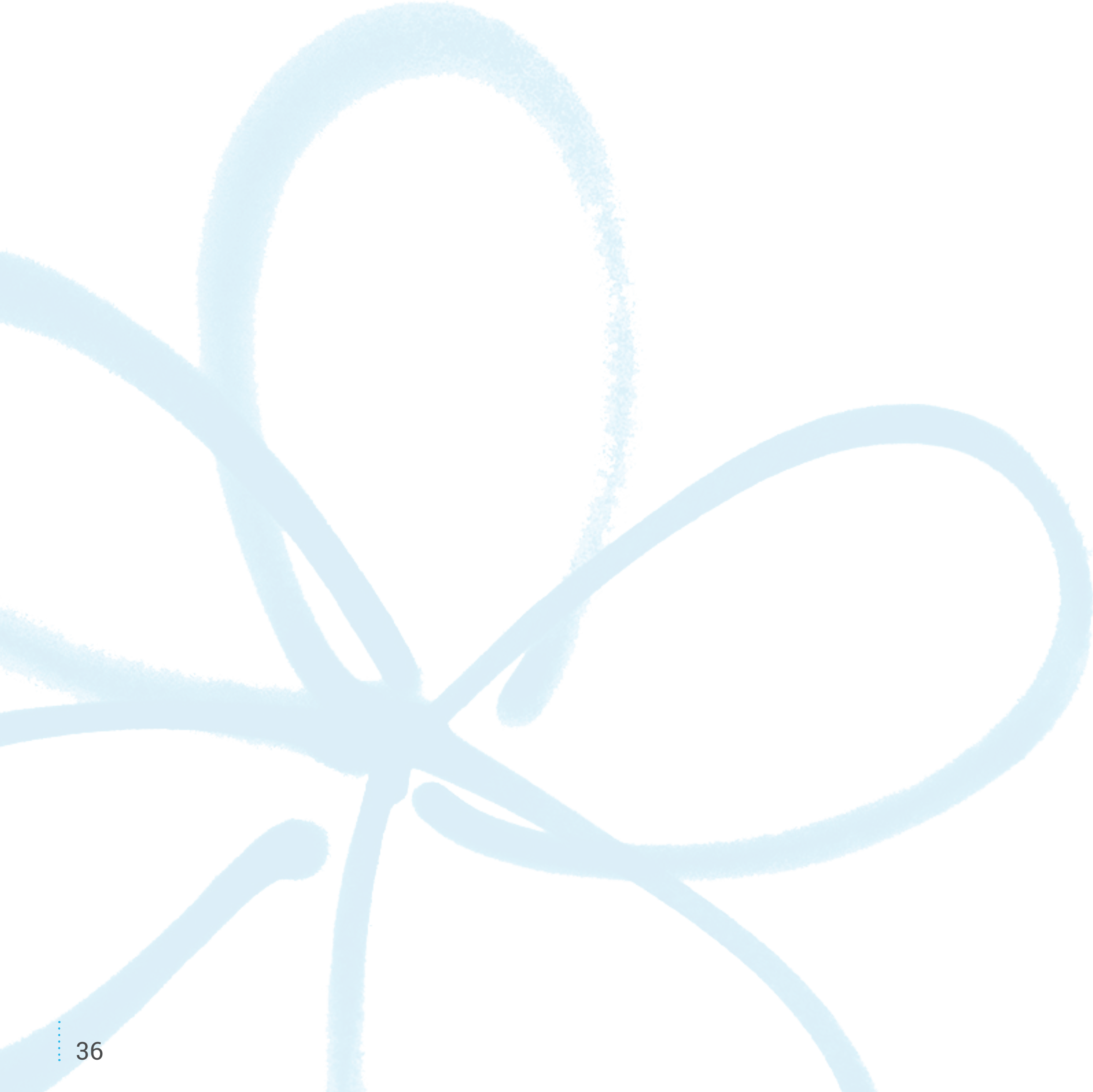
Mr Y: *I think that some Caribbean people I know who have worked in nursing homes, aren't that positive about what they've seen. I think that historically, our communities have been front-line staff in elderly care, and the more that care has been sub-contracted, they remain the front-line staff to see how that transition is managed … some people haven't liked what they have seen.*

Another commonly voiced concern was that the person might be the only Black resident there. For instance, Ms D's father (who has dementia) had stayed in a residential home, for a period of respite care, as Ms D's own health had become seriously affected by her single-handed caring responsibilities for her father. The residential home was on the outer edges of Bristol and a long way from where her father's friends and family lived so it was extremely difficult for anyone to visit. He was the only person of BME origins there during his stay. When Ms D collected him, he immediately asked for "hard food" (Caribbean vegetables such as yam), complaining that he had not been able to eat the meals offered by the residential home whilst there. This experience affected Ms D so she delayed finding a better and long-term residential home for her father to move to, despite the increasing level of risk involved in his continuing to live at home. Ms D's father now lives in a residential home in East Bristol, near family and friends who visit regularly. Ms D reported that he was happy there, had regular visitors and therefore, she was able to positively accept the situation. The support and advocacy provided by the Manager of Bristol Black Carers was pivotal in achieving this outcome.

Some families were concerned about how others in their own community would view having a relative admitted to Residential care. Mr Y described what he had observed recently:

"There have been a couple of very well-known community figures who have died but they have been living in nursing homes for a couple of years before their death and they have dementia. People of African-Caribbean background; people of community standing. People have not known apart from close family that these people are still resident in the city. I think there is a degree of… I think it is about protection. 'Do you know Mrs Such-and-such? She did this and that.' Do you really want someone to come and see her now? … And I think, looking at the families, it is not so much shame about the condition itself: it is more about managing the person's dignity or an idea of managing the person's dignity. We often do things for our parents, our family members that is more about us than them."

There is a strong body of evidence that older people of Caribbean origins in Bristol (including those with dementia and other long-term health conditions) can draw upon support, socialisation and advice from a number of Caribbean-led VCSOs. However, this should not cloud the true picture: many of these organisations/groups rely completely on volunteers and receive no long-term funding which genuinely reflects the costs of the bespoke services they provide. Being volunteer-led and stretched for funds means these organisations are currently unable to include people with more advanced dementia needs, although there was a clear commitment to being as inclusive as they possibly could to people with dementia.



6.

進退兩難 (caught in a dilemma) - the experiences of Chinese people who are living in Bristol with dementia

> *"...many people within the Chinese communities in Bristol, have very different concepts of illnesses such as dementia..."*

6.1 What does dementia mean within Chinese communities? The large majority of older Chinese people in Bristol originated from the New Territories of Hong-Kong. Consequently, they are Hakka speakers (which does not have a written equivalent), although most older people in Bristol from the New Territories can also speak Cantonese, and write using Traditional Chinese script. There are two forms of written Chinese, used by different communities: Traditional Chinese and Simplified Chinese. Due to their distinctive linguistic and cultural heritage, many people within the Chinese communities in Bristol, have very different concepts both of illnesses such as dementia, and of the changes that they witness in people affected by the illness.

6.2 Dementia as madness. Phrases relating to dementia are often negative, and at times derogatory or insulting. For instance, a commonly used Cantonese word for people with mental health issues including dementia is 'chi-seen'. It refers to the idea that two nerves in one's brain have stuck together, making one crazy. Other phrases used to describe people with dementia is the Mandarin word 'Chī-dāi' (癡呆): the character "chi" translates into English as "idiotic" or "silly", while the character "dai" means dull-witted. The equivalent Cantonese word is 'Chi-ngoi'. The Mandarin word 'fā-fēng' (發瘋) and the Cantonese word 'faat-din' (發癲) both refer to having wheels in one's head and may also be used to describe dementia-like symptoms.

6.3 Dementia as normal ageing. The second way in which dementia is understood is as a form of normal ageing: commonly used terms are 'lao-ren-chi-dai' (Mandarin) and 'lo-yan-chi-ngoi' (Cantonese), which both mean ‘senile” and can be translated as “old people’s disease”. Other phrases used by participants in this study were the Cantonese term ‘Nou-Tui-Faa-Jing’ (腦退化症) and the Mandarin word ‘Nao-Tui-Hua-Zheng’ (脑退化症) which seem to be more neutral terms relating to dementia.

One consequence of this attribution of dementia to normal ageing is that Chinese people may be more likely to fail to recognise the early signs of dementia[30]. In this study, many Chinese people were unclear about how, if at all, dementia differed from normal ageing. Thus Mr Q (a Chinese man in his 60s), had no previous knowledge of dementia before his mother was diagnosed:

> *“I have heard of dementia but I had never fully understood what it means. So, dementia is just someone who is going a little bit doolally. I didn’t realise what it meant, what the symptoms were, the range of things.”*

However, when participants had experience of caring for someone with the illness, so their understanding had, out of necessity, improved. Thus Ms L had become familiar with the word ‘dementia’ because of her father’s earlier diagnosis. While her mother’s behaviour was very different from that of her father, Ms L still recognised them both as potentially being caused by dementia and was trying to get a diagnosis for her mother. Ms K had not previously come into contact with anyone who had dementia, but had learnt about it by attending an awareness session organised by Bristol and Avon Chinese Women’s Group (BACWG). As a result, she has identified potential symptoms of dementia in her mother, and has consequently been trying to have her mother assessed.

6.4 **Dementia as a punishment.** There is a strong tendency within Confucian beliefs, and thus within Chinese cultures, for any form of mental illness including dementia, to be viewed as the result of some failing, such as a lack of harmony, within the individual and their family[31]. Dementia is sometimes thought of as representing a curse on the family as some kind of retribution or punishment, while the younger generation worry that it might be genetic. The All-Party Parliamentary report “Dementia does not discriminate” suggests that many Chinese people believe that if you do bad things then something bad will happen to you, or to your children, or even to your grandchildren[6]. Serious health problems including dementia are often assumed to be retribution for past bad deeds. Thus in this study, Mrs M (see ‘Case study’) thought her husband’s dementia may have been caused by disagreements with his extended family. Other potential causes of dementia identified by participants during this study included stress and the demands of previous life-style, such as long, unsociable working hours.

For many Chinese people, there are concerns that as it is distressing to talk about dementia it is better not to do so - as BACWG staff described “it is like death, they avoid it if they could”. Thus, the interpreter for one woman at the Bible Studies focus group explained her reaction to the word "dementia" in this way:

> **Woman #3 (via interpreter):** *As soon as she saw the name, she felt afraid. She worried that she will get it in the future.*

6.5 **Dementia, gender and duty.** A keystone of Chinese culture is that families will take care of their relatives. Under the duty-based morality of Confucianism a person's moral performance is evaluated in terms of their willingness to help others especially when this is a member of their family. In Confucianism, the Three Obediences were a prescriptive moral code that specifically related to the role that women were expected to obey. These were: obedience to their father before marriage; to their husband after marriage; and to their son in widowhood.

There are other elements of Chinese culture and history that act to disadvantage women. Before 1949, the literacy rate in China was between 15 and 25 percent[32]. In families with limited resources, it would have been common for girls to not be sent to school. For these reasons, many older Chinese women struggle to read both traditional and simplified Chinese, as well as English. Thus Mr Q described his mother's experiences:

> **Mr Q:** *My mother can read Chinese. She's quite well-educated from a Chinese point of view, for that generation … [for] many … illiteracy was a big problem.*

6.6 **Dementia, stigma and shame.** People from the Chinese community living in Bristol are potentially at risk of a double emotional burden of stigma: not only does the illness of dementia carry a stigma because of its associations with personal or familial failings, but failure to provide care is also highly stigmatised[33, 34]. The intensity of this emotional burden is felt within different generations, affecting both young and old, and extending to both traditional families and those more familiar with UK customs. The Mandarin word, diu lian (丢脸) is literally translated as loss of face – and relates to the English concept of humiliation. In traditional Confucian societies where one's behaviours are constantly evaluated by others, lian or face refers to one's dignity, self-respect, feeling of social concern, and ability to fill social obligations in front of other people. Although gain and loss of lian is impacted by one's own conduct, eventually it is determined and judged by other people. Diu lian entails the feeling of not having lived up to standards or values[34].

Xiu chi (羞耻) refers in Mandarin to an extremely strong emotion: at its strongest this is the feeling of having a hei dien (stain) on one's face, such that anyone who sees one will immediately know of one's shame and condemn one. Thus, a person experiencing xiu chi typically manages these powerful feelings in three ways: by avoid situations where the shameful aspect of oneself might be revealed; by concealing the potentially shameful element from others; and when asked about it directly, by denying its reality or its impact.

Perhaps for these reasons, many carers who contributed to this study said that they were not interested in attending support groups. Mr J, for example, wanted to be signposted to websites or online resources for information rather than to courses run by the Carers' Support Centre. Mrs N described her own experiences of how stigma had affected her life:

SB: *So, it sounds as if he has been diagnosed with some memory issues. How is it with your friends? Do they still visit? Or is there some... stigma? Is there...people keeping away a bit or they don't mind?*

Mrs N: *I'll be honest with you, our friends, we, you know, same age group. Some are returned back to Hong Kong. Whatever left, they are older now. They don't drive. So we don't have a lot of friends visit now … We don't visit other people very often now. For some reason, people very protect themselves now … some people, they very protect themselves. They don't want to, you know, let other people know where they live. It's not easy to make friends. That put me off … Even when I know them so many years, they still don't want to tell me where they live.*

By its nature, shame and other powerful emotions are difficult for a research project to explore directly, especially when the researchers are perceived as outsiders. During this study, therefore, we have relied on indirect reporting to help us to understand the experiences of participants who are living with dementia from the Chinese communities in Bristol. Thus, staff at BACWG reported that many older people would not even tell their own children when they are struggling. Similarly, a focus group participant spoke about a friend of his, whose mother had had dementia. He said that his friend felt very angry because his mother's illness had initially been misdiagnosed, resulting in her being mistreated, which had led to her death. During this time, he felt that health professionals had dismissed his family's concerns in a condescending manner. His friend was still angry about this and therefore did not want to contribute his experiences to the project. The interpreter summarised his experiences:

"He thinks it is important that you let other people know, a case like this, we should be aware of this. But he thinks, people like this [i.e. his friend with the bad experience around his Mother's dementia] probably would not come to this kind of group to share it."

6.7 **Privacy and isolation - "people protect themselves".** A repeated theme throughout the study concerned the importance that members of the Chinese community in general placed on their privacy. For instance, families frequently described their relatives who now had dementia as people who would never have wanted to attend groups, even before their diagnosis. Consequently, participants expressed little interest, even if the practical problems, such as language barriers, could be overcome, in attending services such as a Memory Café.

A volunteer at Colliers Gardens (a Brunelcare Extra Care premises with 10 reserved flats for Chinese residents) described most Chinese residents as preferring to keep to themselves.

Those residents with no direct experience of dementia preferred not to have significant contact with someone with dementia.

Given that within Chinese culture, the needs of women are often viewed as being secondary to those of men, many older Chinese women prioritise the needs of their husband and family above their own health. Consequently, the deep sense of shame and stigma associated with dementia as well as the emphasis on privacy and the obligations expected of women mean that when an older Chinese couple experiences dementia, there is a high risk that women, in particular, can become isolated.

One consequence according to BACWG staff of both the strong need for privacy experienced by Chinese people, and a lack of trust in statutory services, is that many older people feel more comfortable being assessed, and in some cases even cared for, in Hong Kong, where many continue to have relatives. We were told that many Chinese people living in Bristol returned regularly to Hong Kong for holidays, and that during this time they may well arrange hospital appointments (see the case study of Mr. and Mrs. M below).

6.8 Respect for authority. Chinese society is not only marked by a high level of shame associated with dementia, and a strong obligation to care for one's family, but also by a pronounced respect for authority. Thus staff at BACWG explained to us that many Chinese people will not complain, contradict or even argue with people in authority. This is the case even when they know deep down inside that systems and people have not worked properly for them. Instead, there is a strong tradition of respecting and concurring with the decisions that people in authority have made. Although, in this study, we did not find clear evidence to support this, it is likely that a failure to complain makes it more likely that services will not realise that they have not met the needs of the Chinese community, and thus to coin an English phrase, people within the Chinese community may consequently feel they have been "taken-for-granted".

6.9 Experiences of health services

6.9.1 ***Assessment and diagnosis.*** All six of the family members caring for someone with dementia who were interviewed in this study, described the assessment and diagnosis processes as being long, complicated and unclear.

As neither Mrs O nor her husband spoke English, it was their son, Mr R, who led the process. Mrs O had shown various signs of ill-health for a period of time. She was initially mis-diagnosed with a psychiatric health condition and prescribed medication for this. However, her symptoms and health continued to deteriorate, and Mr R became increasingly frustrated that his concerns were being ignored by her

> “We are conservative, we...like to keep things to ourselves.”

doctors. It was only after a written referral was made by BACWG, that Mrs O was diagnosed with dementia. Her symptoms continued to advance rapidly, and she and her husband then moved into residential accommodation. Both Mr R and his father were angry over the delay in a proper assessment being carried out, while Mr R felt that some aspects of his mother's deterioration could have been prevented if a more timely diagnosis had been arrived at. For Mr J, his mother's GP had also missed her signs of dementia:

SB: *Do you think a language barrier was part of the difficulty (in getting a dementia diagnosis) for your Mum?*

Mr J: *For my Mum- definitely … Even with me, I did not think about what dementia is, at that time. I think some education basically (is what is needed). I never realised … Even the GP, the surgery, I don't think they sort of asked, 'Do you think your Mum has dementia?' until very late on. You know. When she got really bad ….I don't think she has been diagnosed properly by a GP.*

6.9.2 *Language barriers.* Participants described how family members are routinely used to interpret in health appointments for older Chinese people, whether this is in GP appointments, at the hospital or in Memory Clinic. Thus Mrs N reported interpreting for her husband during his assessment six years ago at a Memory Clinic, while more recently Mr J stated that his mother's dementia was partly diagnosed by him completing a questionnaire about her.

The reliance on informal, family interpreters is problematic. Firstly, not all family members are competent or confident in both their relatives' Chinese or in English. For example, Ms K asked for an interpreter for her interview with SB, as she felt that she wasn't fluent in English. However, she has herself had to interpret for her Mother during a number of appointments with her GP. Secondly, even where relatives are fluent in both English and the appropriate Chinese language, then there can be a tension between acting as an advocate for their relative and also expressing their own concerns. Thus while Ms L was fluent in English and capable of interpreting for her Mother during health-related appointments, she nevertheless prefers to take her Mother to see a Cantonese-speaking doctor at Beechwood Surgery. She explained: *"It is more convenient, it is more direct when she sees the doctor. It is better for her and the doctor. I mean - the interpreter being a relative as well, you know, always creates that…. It is more independent, you see."*

Ms L also identified systemic failings in the way in which interpreters were used:

Ms L: *Quite often the hospitals are not able to provide interpreters. They use telephone interpreting which is hopeless. Trust me … With the GP surgery, we did ask for an interpreter once and she did turn up. She was a very nice lady. She was a big help. But it is not always possible. I made the appointment this morning for her. It is impossible to arrange an interpreter at such short notice. Unless it's like a pre-booked appointment, for a couple of weeks.*

Some participants felt that the quality of interpreting could be questionable:

Mr J: *Even with interpretation, my standard of speaking and writing (Chinese) was better than the interpreters. And sometimes, some of the interpreters were not very efficient ... Because I have been to these meetings [with Social Services] and I supplemented [i.e. the interpreting]. It's not 100% and sometimes, I get the feeling, when consent was being sought - not translated properly.*

Ms L described how the process of diagnosis was characterised by a lack of communication and clarity caused partly by problems arising from the interpreter that was used:

Ms L: *She [her mother] actually had a fall 2014 Christmas Eve and she was in hospital for over a month. They had to keep her because there was nowhere to send her to, then they sent her back home because they needed the bed-space.*

SB: *They did a cognitive assessment there, in the hospital?*

Ms L: *They did … the Memory Nurse came a few months after, I think, and did another one. And again, that was inconclusive. I was interpreting … then the Memory Nurse arranged for another one to be done. He said he'll bring his own interpreter. So, obviously, he wanted ... it was an independent interpreter, for some reason (shrugs as if unclear why this had happened, seems upset).*

For Ms L, the use of an independent interpreter presented a dilemma as she could understand both the nurse's questions and the Cantonese translation of these that were being passed to her mother. However, when she felt that this translation was not exact, and that the impression that the nurse was gaining of her mother was therefore misleading, she was reluctant to speak out, because she did not want to criticise the interpreter. As a result Ms L remained frustrated but silent.

6.9.3 ***Culturally appropriate assessments.*** A valid assessment of the language, memory and other cognitive deficits associated with dementia, involves not just finding an adequate interpreter, and identifying a translated version of an assessment tool. In addition, the assessment process and the questions asked within that process need to make sense within the daily life of patients and their families. In other words, the assessment must also be culturally appropriate. This problem was described by Mr Q, whose mother was diagnosed with dementia after she had been hospitalised following a stroke. Before this, Mr Q had taken his mother to see her GP for a number of years, and she carried out a series of cognitive assessments:

"I took her to see the GP and in front of me, she did the Dementia Test … So my job was there to interpret, to translate, but really ... .a lot of the questions are English-orientated … it didn't mean anything in the Chinese language. So, … we went through that test and,

basically, the assessment was: 'Oh, [she's] probably OK'. … So, we had 2 or 3 of those tests. And each time I mentioned it to the doctor, she said, 'I'm aware of the limitations of doing that [i.e. the test] this way. But there wasn't any other way."

Even at the end of the assessment process, a number of interviewees continued to be uncertain about what diagnosis had been arrived at. Thus, when SB asked Mrs N whether her husband had a diagnosis, she replied:

Ms N: Not really a diagnosis. But from the Memory Clinic. My GP agree, 'Take the tablets, It may help'.

6.9.4 ***Culturally-appropriate support.*** It was clear that there is relatively limited available support specifically for Chinese people with dementia and their families once a diagnosis has been provided. Mrs N, for instance, said while she had been given information about local support groups, she did not feel it would be worthwhile attending as her husband did not speak or understand English and would therefore not have been able to join in. Both she and her husband did attend sessions run by BACWG. Mrs N knows her husband enjoys getting out of the house so tries to go out daily with him, particularly using their free bus passes. She described the pressures of caring for her husband and covering all the necessary household work on her own. When she had recently gone home to Hong Kong to visit an elderly relative, her husband had moved in with their son.

Mrs N: *What kind of support can he get? He doesn't speak the language. I ask, 'Will you have someone to come and sit with you?' 'No, no'. He don't like strange people … For me, I would like someone to come once a week and talk to us and speak our language … Just come and visit. I don't mind if you come for lunch. We make a cup of tea … If you speak our language so we know what you on about.*

Many participants pointed out the crucial role played by BACWG:

Mr J: *"If someone did not have the help of family, it would be really difficult for them … I would like to bring out about the Chinese Women's Group. They do really sterling work. They interpret. They help out in many ways. I don't know whether you know about the Sitting Service? Through that they came out and visited my Mum …. the Chinese Women's Group … is a vital part of the Bristol Chinese community, I think."*

For many Chinese migrants to the UK, English is their second language. For these people, the linguistic deficits that are part of dementia often mean that they can no longer communicate in English and instead fall back on their mother-tongue. This was the case for Mrs N's husband who would only leave the house to attend BACWG events or activities:

"Yes, the language you know. It would stop me joining in. He won't understand … They do give me information (e.g. from Carers' Support Centre) - a tea party or something.

But I think no point. He won't understand..."

Many participants also spoke warmly of Colliers Gardens and hoped that their relatives would have the option of moving there, if this became necessary. This is due to the fact that there are 10 flats reserved for Chinese residents, and also because the infrastructure is inclusive of Chinese residents (e.g. the dual language signage throughout the building). Both features are due to the lobbying of Rosa Hui, the Director of BACWG.

However, when a resident's symptoms advance to a point where they can no longer be supported at Colliers' Gardens and they need to move to a nursing home, then there continue to be concerns about the capacity of these homes to meet language, cultural or dietary needs.

6.9.5 ***"That type of look".*** Some participants felt that they had been treated by health service staff in a patronising or dismissive way. Mr Q described how, when his mother who had dementia, had her stitches removed after an eye operation, he was asked to get her to keep still. Mr Q ended up having to repeat the phrase to keep still over and over again (in Cantonese) during the procedure and believed the doctor felt stressed by this.

"It was me who get the kicking end of it. My mother was being looked after. And I can understand the doctor being frustrated but he didn't have to turn around and look at me the way he did. And looked at the nurse. And you know the way some people can look at each other and then walk away? It was very down-putting. And I'm there looking after my mother, the same way the doctor was trying to. I am the carer, I am doing the best I can and...I felt really totally messed up by it ... he must be a very good doctor because he did all the work. But ... he just looked at me and thought, 'What a stupid Chink'. That type of look."

6.9.6 ***Later diagnosis of dementia.*** The impression given by many participants was that people from the Chinese community are being diagnosed at a relatively advanced stage of dementia. Sometimes diagnosis only occurred after several attempts by family members to have a formal assessment carried out through their GP. As the case study of Mr and Mrs M (see below) illustrates, for many Chinese families, the difficulties around drawing in NHS care for a variety of complaints, means that they prefer to approach a doctor in Hong Kong.

All, except one, of the participants who took part in this study were carers whose relatives were either in residential care or had passed away. This may well reflect the relatively late stage at which dementia is diagnosed, but it may also reflect concerns that people with dementia would not be able to continue being involved in every-day life. Just as the concept of dementia as a syndrome does not translate easily into Chinese language, so it may also be the case that person-centred approaches to care may also need to be adapted. Thus a participant at the BACWG Focus Group felt that someone with dementia probably wouldn't be able to continue to come to social group sessions, such as those run by BACWG every month, as they "could not follow activities". Similarly, Mr J, a Chinese man in his 60s whose mother had dementia and had lived in Colliers' Gardens before her death six months before, commented:

SB: *If time shifted and your Mum had been formally diagnosed just now- what would you want for her and your family [e.g. advice on benefits, information on support groups]?*

Mr J: *"If they're mobile [people with dementia], then it becomes a worry. If they are not looked after- let's say- 24 hours a day, they could walk out, go out the door ... they could be a danger to themselves. They need to be in a place somewhere where they get 24-hour care ... There are different types of dementia. Some get violent. They need to be somewhere else.*

6.9.7 **The need for services which respect privacy.** Given the importance of privacy for people from the Chinese community in Bristol, it is no surprise that only those forms of social support which respect both privacy and individuality are likely to be accepted. One of the few forms of support that provides this is the Sitting Service offered by BACWG, which was highly valued by many participants. This service involves people who speak the person's language visiting them in their own homes, respecting their privacy. By contrast, none of the people we spoke to wanted to be part of support services that involved meeting other people. Thus, we had a clear message that Chinese people would not attend Day Centres like the one run by Dhek Bhal for older South Asian women, or social support groups similar to those run by Evergreens

6.9.8 The need for continuity of services. According to BACWG staff, it takes many years to build up a relationship in order to be accepted within a family. It is only in the context of a long-term relationship that their staff are in a position to be able to identify that individuals may be showing the signs of dementia and that families are struggling to be able to cope. At this point, it often takes a great deal of persuasion to help families to acknowledge that they need to act - either by accepting help, or by contacting their GP.

Case Study

Mr and Mrs M - assessment and diagnosis in Hong Kong

Mrs M is in her 70s and originates from Hong Kong. Her husband, who died two years ago, had been given a diagnosis of dementia around two years before his death. The assessment in the UK took around a year, and was precipitated by a period of depression following disagreements with other members of his extended family. Mr M had also been admitted to hospital after a fall and suffering a stroke. However, it was only on their annual trip to Hong Kong that he was given a diagnosis.

Mrs M (who spoke throughout the interview with SB entirely through a Cantonese interpreter) said they had seen a doctor every time they had made their annual visit to Hong Kong over the last 10 years, and that she consequently had a great deal of confidence in him. In the past when her husband had been prescribed medication in the UK for his high blood pressure he had then developed a persistent cough. The doctor in Hong Kong had changed his blood pressure medication and the cough had cleared up. Moreover, she had been unhappy with their contact with the health services following her husband's stroke, and this affected her confidence in seeking help with doctors in the UK.

Although their doctor in Hong Kong gave Mrs M a letter to take back to the UK, their GP in the UK did not prescribe any medication for Ms M's husband, and she wasn't aware of a cognitive assessment being carried out in this country, following their return from Hong Kong. According to Mrs M, they were told that there was no cure for dementia and they were not given any information on treatment or relevant support organisations or signposted to benefits advice.

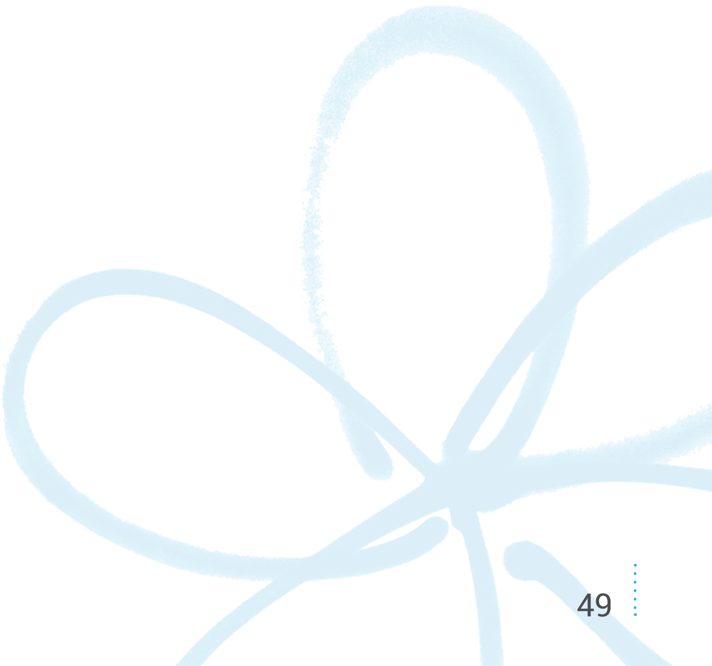
This lack of support had important implications for them as a couple, for example, Mrs M's husband seems to have often behaved violently towards her during his dementia, injuring her so that she had to have medical treatment. There appeared to have been no safeguarding measures ever put into place by any agencies for Mrs M. and she received little support or advice over his behaviour. She had provided all his care almost single-handedly, with some daytime support from their two sons but no external services at all. Finally, Mrs M's husband had to move into a nursing home when she became unable to continue to care for him.

The first nursing home that she found did not work out well for either her or her husband, and the fees were also expensive. This led directly to Mrs M's husband spending nine weeks in hospital while a more suitable nursing home was located. During this time, a friend of Mrs M suggested she contact BACWG for the first time, and they were able to support her seeking a new nursing home and helped her to secure funding for this. The second nursing home was an improvement with some care workers learning some key Cantonese phrases to enable them to respond better to her husband's needs.

SB asked Mrs M through the interpreter whether she and her sons had told friends or anyone else in their community about her husband's dementia.

She replied that she felt this was "not good" and that her sons believed that they should not talk about their situation because it was not "appropriate" and that people might "look down on them". This reluctance to tell others in their own community seems to be quite widespread amongst Chinese people in Bristol, and may reduce people's capacity to draw on support.

After his death, Mrs M had learnt some information about ways to help dementia not advance so quickly through a TV programme in Hong Kong. She was concerned that she hadn't received any similar information during her husband's illness in UK. She shared her thought that it might have been better if she had taken him to Hong Kong to be cared for.



> It was striking that none of the South Asian participants in this study had relatives with dementia who were living in nursing homes or supported accommodation.

7.

"Bhurapa Sona" ("Old is gold") - the experiences of people from South Asian communities living with dementia in Bristol.

> *"The English word 'dementia' is not widely known and is consequently used infrequently in some South Asian groups..."*

7.1 **Who are the people living with dementia from South Asian communities?** In Bristol, there are three main South Asian communities, made up of people who came or whose relatives originally came from Pakistan, India or Bangladesh, largely from the late 1940s onwards. There is also a significant group of people who identify themselves as of 'other Asian origins' which is likely to include people from Sri Lanka, Nepal and other countries in South Asia.

The origins of people from "South Asia" also determine their probable religion and the languages that they speak. It is likely that most people of Pakistani and Bangladeshi origins in Bristol are Muslims, while most people of Indian origins are likely to be either Sikhs or Hindus. The languages spoken in South Asian communities in Bristol include: Urdu, Hindi, Punjabi, Gujarati and Bengali.

There are many differences in religious beliefs and practices, language, diet and traditions between different South Asian communities. These mean that people from different communities are likely to experience life in the UK in different ways. For example, a high proportion of doctors of Indian origin work in the NHS, this may well affect the readiness of British Indians to seek medical advice for dementia-like symptoms (see comments below by some participants in the focus group with women at Asian Elderly Day Centre).

7.2 **What does "dementia" mean within South Asian communities?** The English word 'dementia' is not widely known and is consequently used infrequently in some South Asian groups. It also does not translate easily into some languages. Keeping this in mind and gaining some knowledge about terms that might be used to describe dementia and dementia-like symptoms was an important facet to encourage involvement of South Asian people in this research study.

Pagal is a word used in a range of Indian subcontinent languages, including Urdu and Hindi. It is wholly a negative word which might be used to describe someone with dementia. It is frequently used to refer to people with mental ill-health issues such as post-natal depression or schizophrenia. SB observed a visceral, negative reaction from one older South Asian woman against this word when attending a Focus Group on loneliness and isolation run by Bristol Multi Faith Forum in March 2016, when another participant suggested that a mutual acquaintance had become "pagal" as a result of not getting out of the house enough.

"Sathrya bathrya" was a Punjabi term used by some older men of Indian origins and Sikh faith at the St George Gurdwara. The suggestion is that it is not as negative as pagal but is a word they use towards each other when they notice increasing instances of forgetfulness, confusion or disorientation.

"Bolnia" is a Punjabi word for forgetful, while Pisu is a Singhalese word with a derogatory nuance to describe symptoms of memory loss and/or confusion in an older person.

7.3 **What do people from South Asian communities tell us about their experiences of dementia?** Rizwan Ahmed, the Coordinator of Bristol Muslim Cultural Society, described the way that the lack of an appropriate word for dementia might have an impact on how the symptoms associated with dementia might be construed:

> **RA:** *There isn't the word [for dementia] in Gujarati, Urdu or Hindu … Pagal … you will get conversations like that, to do with mental health. Like black magic at play. Or this person is possessed. That's the two things I've come across.*

During a number of focus groups and interviews, participants disclosed that they were not familiar with the word dementia, its likely symptoms or how to find help. For instance, Mr G, a Sikh Indian man in his 80s listened to a description of dementia and recognised some of these symptoms in himself. However, he remarked: "people have never heard that, that word, most of us." Mr L (who was in his 20s and the full-time, live-in carer for both his grandparents) said that prior to his grandmother's diagnosis, he had no knowledge of dementia. By contrast, Mr H, whose grandfather and aunt both had dementia and whose mother was diagnosed with this two years ago commented:

> *"Basically, if you are asking the question: is it well-known? Only the people that I know, most of them know … My cousins know. These are the people I most meet. So for them to know and for me to know, and we talk about it: it seems everyone knows."*

Members of the Asian Elderly Day Centre (who are predominantly Indian Hindus and Sikhs) seemed to be more familiar with the word dementia. In the focus group for women held there, some participants spoke openly of their experiences of having had their doctor carry out Memory Tests, and how they would be prepared to return for a future appointment if they noticed other changes.

More generally, mental ill-health is only recently beginning to be talked about more openly in South Asian communities. For instance, Awaz Utaoh have a history of encouraging openness about mental ill-health amongst Asian women which requires ongoing commitment. The Assertive Community Engagement service (ACE) that Avon and Wiltshire Mental Health Partnership NHS Trust (AWP) are running at Easton Community Centre is aimed at South Asian women and is well-attended[36]. For Rizwan Ahmed (the Coordinator of Bristol Muslim Cultural Society), awareness about dementia now needs to be raised as well, partly because of concerns that some people might resort to traditional faith healers:

Rizwan Ahmed: I don't think it is talked about. People are just getting their head around mental health. I don't think it has even occurred to people to think this is an issue that we have got to deal with. They are still coming to terms with the taboo around mental health. Dementia will be the next thing to tackle … From my experience, people think it is just mental health or forgetfulness or they put it down to old age. They don't realise it's dementia.

7.4 **Assessment and diagnosis.** For many participants, it had been a member of the family who had played the lead role in initiating the assessment of their relative. In each case, dementia had not been considered by anyone in the family and, prior to diagnosis, there had been no clear knowledge about it as a health condition. For two of these families, the person with dementia had not been told they had a diagnosis either because the family felt it would not help them or because it was felt that they would not understand it. For participants, the assessment and diagnostic process, once they had initiated it, seemed to go relatively smoothly, as the case study of Ms B and her mother illustrates in the case study overleaf.

In contrast to the experiences of Ms B and her mother, Mrs A (a Sikh woman in her early 60s of Indian origin) had been to see her GP as she had become concerned about her own memory. Mrs A was aware both that she struggled to speak or to understand English, and that she knew relatively little about dementia. In retrospect, she felt that this may have had an influence on her experience with the GP as she was not given a diagnosis or referred for further tests. She now felt that her symptoms had become worse, for instance she had recently got off a bus and not remembered why she had made the journey. While she was clearly distressed by episodes such as these, she was reluctant to return to the doctor because of her initial treatment.

7.5 **Carers - the vital role of families.** Without the support and help of their families,

Case Study
Ms B and her mother

Ms B is a Muslim woman, of Pakistani origin, aged in her 40s, who was living with, and the main carer for, her mother who has dementia. Ms B's mother had been diagnosed two years before with dementia and also had a number of other, long-term health conditions including diabetes. Her mother's behaviour had changed significantly before she was given a diagnosis. She frequently left her keys in the front door, had left the gas on all day and often forgot things she had been told.

SB: And with you and your sister, did you use the word 'dementia' at that point?

Ms B: Not at all.

SB: Had it been a word you had any association with?

Ms B: I knew about it a little bit from news and press and all that sort of stuff but I had not thought, 'Oh, Mum's got dementia'.

SB: OK. So what did you think?

Ms B: Senile. I just thought it was old age to be honest.

For Ms B and her sisters it was their worries of the risk caused by their mother regularly leaving the gas on all day that had led them to making a doctor's appointment.

SB: How did it go at the Doctor's?

Ms B: It went quite well. It was the Doctor who actually suggested: 'Let's get some tests done' and she didn't mention dementia then at all … She said, 'Let's get a brain scan and refer you to a clinic'... a Memory Service. That's it. Even then, I still didn't put two and two together … it was only when we went there and then they started doing the test. For some of the tests, they let me be in the room with my mum and translate and then they got an interpreter in and they separated us…

SB: How was your experience at the Memory Service?

Ms B: ... Mum was not at all stressed … They were very clear, very calm. There was no scaremongering. It wasn't like that at all. It was only when I got to thinking there could be something wrong with Mum's memory, could this be... We had to wait 2-3 weeks for the scan and then 2-3 weeks after that we got the appointment to be seen. Within 2 months of going to the doctors, the whole process was less than 2 months, I think … I was quite impressed, personally. And the staff at the clinic were brilliant. They had booked an interpreter every time, even though I was there.

many people with dementia would be unable to continue to live within the community. Many participants described a range of challenges in providing care, and in particular how a strong sense of duty meant that they continued to try to cope despite increasingly difficult circumstances. These cultural obligations to care are underlined by the perception that other people within their own communities would be critical of them if they drew on support from statutory services[21].

Mr L is a Sikh Indian man in his 20s, who is the main carer for both his grandmother who has a dementia diagnosis, and his grandfather who has a number of long-term health conditions. He felt that the service he received from the Age UK Dementia Benefits Advisor was excellent and had helped him to receive the benefits that he was entitled to as a full-time carer. Mr L was clear that both he and the other members of their extended family did not want to access any other services. He felt that many people that he knew in his local Sikh community would not accept health and social care services. His grandparents rarely leave the house now, seemingly from their own choice, although the family try to take them to the Gurdwara or shopping. There was an intricate and strong network of care within this family, with Mr L's mother cooking all their meals and coming in the mornings to bathe her mother-in-law. Despite this, the isolation and exhaustion of Mr L was clear, as he shared experiences of being woken frequently at night to respond to his grandparents' care needs.

All of the people providing care to a member of their family with a dementia diagnosis who took part in this study described the stress that caring created for them. Mr H is a Sikh Indian man in his 50s who lives in an extended family of three generations, including his mother who was diagnosed with dementia two years ago. A Dementia Practitioner from Bristol Dementia Wellbeing Service, had been instrumental in getting Mr H's mother diagnosed. Following this diagnosis, the family had arranged extra support through regular paid carers coming to meet Mr H's mother's various needs. The first care agency had not been satisfactory, and a female relative was now coming to the family home to provide care for Mr H's mother, being paid for out of Direct Payments. All the family were happy with this arrangement; they had received information about Direct Payments from the local authority after his mother was diagnosed. Mr H was also pleased with the "signposting" information on support groups such as Dhek Bhal that had been provided by the Dementia Practitioner. However, his Mother was not keen to begin going there, and she had also stopped going as regularly to the local Gurdwara.

During the interview with Mr H, he described the enormous stress that juggling the health needs of his parents around his paid work and in addition co-ordinating input from his immediate and extended family created for him. It seemed to be this difficulty in drawing on reliable, appropriate support that created the greatest strain for him, rather than any stigma or lack of understanding around the condition itself.

Mr H: *“[The Dementia Practitioner] actually spoke about support. On occasions, it gets difficult because I work [night shifts]. I don’t get home until 11.30, 12 o’clock. And my wife goes to work early. And you’ve got appointments for my Dad, appointments for Mum … We try to book appointments in the morning so I can take them. If there are appointments in the afternoon, my sister takes them. Saying that, it gets quite congested … Again, I don’t know whether you have studied the extended family, mmm, there is plenty of conflicts.”*

Ms B, another family carer living with a mother with dementia suggested the importance of having more flexible, ‘culturally competent’ short-term residential care:

Ms B: *The other thing I think would be really, really good, would be a respite place where needs could be met. And again, it could be any ethnic minority. I know my friend’s grandmother, they struggled to find any kind of support, and she was Chinese. And it would cater for her needs: the occasional Chinese meal. Because they live off that all their lives and all of the sudden they are not given it, they are just give English food all the time. They can’t cope with it.*

During 2015, Ms B had hoped to be able to go away for her birthday. She had worked out a package which included regular involvement from other family members, but in addition she needed extra care covered from Social Services for a short period:

Ms B: *Last year was my 40th and I really struggled … I needed respite, someone to look after Mum … And Social Services turned around and said, ‘It’s too expensive to combine the care you are asking for at home’ … They said, ‘Put her in a home’. I said, ‘How can I put her in a home where she doesn’t speak the language, there’s her food, the TV channels she is familiar with (i.e. Islamic ones etc.)?’ It would just push her back … She would just lay there and cry.*

Consequently, Ms B cut short her holiday and her extended family worked with her to cover the extra needs amongst themselves. This included extra pressure on her sister and brother-in-law who have other caring responsibilities.

Mr J is a Muslim man in his 50s who, together with his brothers has been supporting their mother for over 10 years due to a variety of health needs. Recently, he has become concerned that his mother may have dementia as she has been showing new symptoms. The first assessment carried out by the GP was inconclusive. However, although Mr J feels his mother needs further assessments, he feels that the health services saw his mother as an "oppressed Asian woman whose sons were trying to push her into a diagnosis." Mr J's mother was becoming increasingly paranoid as a consequence of her forgetting things she has done and has refused to go out to Dhek Bhal or Awaz Utaoh. For example, his mother regularly forgot she had taken her tablets and became convinced someone had come in the house and stolen them. Mr J fits caring for his mother around part-time work, and had recently missed work deadlines due to his role as a carer. Although he had been offered a Carers' Assessment this had not yet happened.

> *"It's a very toxic environment. I've noticed I've become very snappy and irritable with my brothers. Because I am so over-burdened … Between the three of us, we have to rotate, so Mum is never left alone."*

It was striking that none of the South Asian participants in this study had relatives with dementia who were living in nursing homes or supported accommodation. During a focus group with South Asian women, the researcher described Colliers Gardens, a Brunelcare Extra Care residence which includes 10 flats reserved for Chinese people and a range of culturally sensitive facilities and services (described in detail in Section Five). The focus group participants (mainly women of Indian origins and of Hindu/Sikh faiths) asked why there was nowhere like this for people of their backgrounds in Bristol.

Although many South Asian people with dementia in Bristol are living with members of their family, often within the same home, there also appear to be growing numbers of South Asian older people who live alone. For instance, Bristol Multi Faith Forum ran a focus group on loneliness and isolation, held during a regular session of Dhek Bhal's Older Women's Day Centre in March 2016. Of the women attendees on that day, half reported they lived alone.

7.6 **Culturally appropriate support.** Just as there is no single South Asian community, so the level and type of community support available for people with dementia and their families also varies. Thus during the interview with Mr F (a 50 year old Muslim man of Pakistani origins), he described how his local mosque did not include the kind of social support groups or events that, for instance, are provided by the Gurdwara which supported this research. The mosque, in contrast, largely focuses on being a place of worship. Mr F expressed regret about this but also hoped that wider-ranging community support might become possible at the mosque in the future, including information sessions about dementia.

Study participants described Dhek Bhal and the Gurdwara as "lifelines", because they were places of socialisation, support and information. It was clear from the Focus Group with paid staff from Dhek Bhal's Sitting Service that this VCSO has invested in training in dementia awareness and competency. Health and social care commissioners, therefore, have a solid foundation on which to further develop their working partnerships with Dhek Bhal. However, other VCSOs have not yet been able to provide such training. The Manager and Chair at Asian Elderly Day Centre, for instance, were both open about the training needs of their own staff around dementia. Simi Chowdhry, Manager of Awaz Utaoh, was positive about a first step in partnership working with Bristol Dementia Wellbeing Service in May 2016, when two staff members came to a drop-in session, gave a presentation and handed out leaflets. However, Simi Chowdhry felt that more thought needed to be put into further work.

Everyone was too shy so they said they understood … I said, 'How did you get on?' The Wellbeing Service said, 'Very well. They have all decided to come to us to seek support.' But after they left, they [Awaz Utaoh members] said, 'No, Simi, I didn't understand what they will do to us'. … You see, what new people think is, 'Oh, everyone can speak English' because they can say a few words … The group you are targetting, the elderly, 99% don't understand … .but by just getting a number to someone - how do they expect they will have that courage to dial that number? … By handing out telephone numbers, you are assuming all of them are empowered enough to pick up that 'phone and speak. So, there should be someone intermediate who will support …. There is a name they can associate, so there is familiarity.

The evidence gathered from interviews and focus groups suggests that there continue to be a range of barriers to people of South Asian origins seeking support and advice. This can range from services or appointments being offered on a Friday (the focal day for religious worship for all of the main South Asian religions) to a lack of awareness of the different ways in which dementia is referred to in the range of languages spoken in South Asian communities. More generally, there is a lack of respite care and supported accommodation that entirely meets the dietary, social, language and other needs of people from South Asian. This places greater pressure on family members who are providing substantial care for people with dementia.

It was clear that South Asian religious centres and community groups are becoming increasingly aware of dementia. Leaders of these groups and centres were clear in their requests for training, partnership working and information on dementia, as well as showing a commitment to keeping their settings inclusive of members with dementia. However, if dementia-specific activities such as Reminiscence Therapy are to be offered within South Asian VCSOs, then there is a clear need for more training and support. For instance, the Chair of the Asian Elderly Day Centre commented that there had been "absolutely nothing about dementia at our centre". Both she and the Manager of the Asian Day Centre were keen to have dementia awareness training for staff and members, and to develop the dementia competency of their staff.

8.

Recommendations for consideration

Data collection for this study was carried out over a four-month period in the summer of 2016. Although we made a number of attempts to hear as wide a variety of views as possible we were, inevitably, limited in the voices that we were able to hear. One obvious limitation is that was not possible to hear from many people from BME communities who had, themselves, been diagnosed with dementia.

A second, major, limitation of this report is that due to pressure of time, we focussed on those three Black, Asian and other minority ethnic (BME) communities which our initial scoping suggested had the highest numbers of people with dementia. Consequently, we did not explore the dementia needs of a number of other communities including Somali, Polish or Irish communities.

Thirdly, the majority of participants that we recruited to this study were referred to us through local BME-led Voluntary and Community Sector Organisations (VCSOs). It is likely that this resulted in a bias towards those experiences of people who took up services from these community-based providers. Finally, resource constraints meant that we were unable to gather reliable data about a range of other issues, including the ethnicity of local health and social care staff and the numbers of people of BME origins who have participated in dementia research.

In structuring these recommendations, we have adapted the "***Dementia Well Pathway***" set out by the NHS England Transformation Framework[36].

Recommendations are based on analysis of the evidence gathered from interviews, focus groups and informal groups.

8.1 Preventing well - the risk of people developing dementia is minimised

8.1.1 *Reducing the risk of dementia in BME communities.*

Older people from a number of BME communities are at an increased risk of developing dementia. However, many people who contributed to this study from each of the three communities that we worked with, knew little about dementia including actions that they could take to reduce their risk. In at least one case, a participant believed that dementia was not a condition that affected his community.

Moreover, across all three communities, participants wanted more information about prevention and risk factors (5.3; 7.3).

Recommendation:

Raising awareness: there is a need for clearer messages to be communicated in a range of ways about risk factors and prevention, including through public health campaigns. For instance, as many people from BME communities attend health services for treatment for other health conditions such as diabetes or asthma, these could be opportunities to pass on messages about reducing the risks of dementia. Consideration should be given to developing a co-ordinated public health campaign to help reduce the stigma of dementia within BME communities.

8.2 Diagnosing well - timely, accurate diagnosis, care plans and reviews within first year

8.2.1 *Establishing dementia diagnostic rates of BME communities.*

Currently, the overall diagnosis rate of people with dementia in Bristol is around 67%, which exceeds the government-set target of 65%. However, we were unable to establish a definitive diagnosis rate for people with dementia from BME communities, as data about diagnosis rates is not analysed in terms of ethnicity. While the estimated number of people from BME communities registered with the Bristol Dementia Wellbeing Service (BDWS) is proportionate to that of the white, British community, two factors limit our ability to draw conclusions from this. First, higher levels of risk factors means that people from BME communities are likely to be at greater risk of developing dementia. Secondly, data about the point at which people are diagnosed is not collected, meaning that we cannot be sure if people with dementia from BME communities are being diagnosed at a late stage. Anecdotal evidence that we collected suggests that this is the case for at least some people from Caribbean (6.9.1) and Chinese (7.4) communities.

Recommendations:

Data collection: more accurate methods of establishing when diagnoses are made for different BME communities should be established. This could help plan or commission relevant services for people at different stages of dementia.

Targets for diagnosis rates: in addition to having an overall target for dementia diagnosis in Bristol, the national target of 65% should also be set as a distinct target for different ethnic communities in Bristol.

8.2.2 *Improving diagnostic rates through partnership working.*

In order to improve access to diagnostic assessments, more flexible partnership working should be considered with each of the different BME groups who participated in this stage of the research (7.6). For instance, in order to improve awareness and diagnoses rates amongst people of Pakistani origins (currently 40% of estimated figures are registered with BDWS), work may need to be developed through local mosques and other, South Asian-led VCSOs. The model of engagement carried out by the University of York to raise awareness of second-hand smoke through local mosques might serve as a model[37].

Recommendation:

Engagement: flexible and pro-active methods of engagement with community organisations should be enhanced and developed. For instance, just as there is a clinical co-ordinator for sickle-cell anaemia whose responsibilities include helping patients and carers to engage with services, consideration should be given to developing a post with specific responsibilities for co-ordinating care for people with dementia from BME communities.

8.2.3 *Improving awareness amongst GPs.*

A consistent theme across participants from all three BME groups who contributed to this research concerned difficulties in being heard by GPs. In some cases, this may contribute to patients going elsewhere for diagnosis or medical advice. For instance, staff at Bristol and Avon Chinese Women's Group (BACWG) described Chinese people who went to Hong Kong for medical consultations. The Coordinators of Awaz Utaoh and Bristol Muslim Cultural Society expressed concerns that in the absence of an understanding of dementia as a medical condition, the role of faith-based healers might become more prominent (6.9.6; 7.3).

Recommendation:

Awareness: although work to raise the awareness of GPs about the dementia needs of people from BME communities has taken place[38], this needs to be further developed. These sessions should include the perspectives of carers of BME origins so that GPs can more fully understand what carers experience when they try to get advice and support for the person with dementia.

8.2.4 *Validated, translated and culturally-appropriate assessments.*

The accurate diagnosis of dementia relies on a number of elements including screening out reversible causes of memory loss, for instance through blood tests, taking a reliable history, and, where appropriate, through brain scans. A key element of this process is a cognitive assessment that involves identifying key features of the person's overall cognitive functioning. Such an assessment needs to be validated (by comparing scores to a normative population), in a language that the person habitually uses and using concepts which are familiar to that person. There are increasing numbers of recognised tests which meet these criteria, and which should be used in an assessment. However, it was apparent in this study that knowledge about these tests was not as widespread as it might be (6.9.3; 7.4).

Recommendation:

Developing a toolkit of resources: *a* toolkit of validated, translated and culturally-appropriate assessment resources should be developed. This toolkit should be made available electronically, and training in its use should be provided.

8.2.5 *Improving access to interpreters.*

Throughout this study, the importance of accessible, expert interpreters was emphasised. Although this study did not have the resources to specifically consider how interpreting needs could be met, it appears that Health Links (the service within Bristol Community Health which is commissioned to provide most of the face-to-face interpreters for health services in Bristol) has enough interpreters for a number of South Asian languages. However, interpreters for people of Chinese origins may be more of a scant resource (6.9.2). Although people of Caribbean origins are not considered to have distinct language needs, the use of patois appears not to be well understood.

Recommendations:

Improving access to qualified, dementia-trained interpreters: *a*longside the current national Race Equality Foundation consultation on quality standards for interpreting services within mainstream health provision (commissioned by NHS England), consideration should be given locally, towards ensuring equal access to interpreting services across different communities. The need for improving access to interpreters for people from Chinese communities is especially acute, and the experiences of staff from BACWG should be drawn on. There should also be consideration of advocacy support for people with dementia from these communities, as well as their carers.

8.3 Supporting well - providing access to high quality health and social care for people with dementia and their carers

8.3.1 *Improving access to evidence-based dementia interventions.*

One consequences of the reliance of people with dementia and their families from BME communities on local VCSOs, rather than dementia specific organisations, is that people with dementia and their families do not have access to evidence-based interventions such as reminiscence therapy or Cognitive Stimulation Therapy. This is also complicated by the fact that many of these activities have not been translated (5.2; 7.6).

Recommendations:

Toolkit of resources: there is a need to bring together those resources which have been translated and are available for use, for instance by developing a toolkit which staff and volunteers can draw on similar to that developed by David Truswell and Yolanda Tavera for Central and North-West London NHS Trust[39]. Training linked with these resources could develop confidence in service providers in using them.

Training for VCSO staff: part of the partnership working that needs to be developed locally should involve training from local Occupational Therapists and Clinical Psychologists in dementia specific activities (5.2; 7.6).

8.3.2 *Enhancing community engagement.*

The Bristol Dementia Wellbeing Service (BDWS) formally took over the delivery of NHS Dementia services in Bristol in April 2015. BDWS is a collaboration between Devon Partnership NHS Trust (DPT) and the Alzheimer's Society. Amongst many innovative and ground-breaking ways of working, BDWS employs Community Development Coordinators, as part of their clear desire to be more pro-active in reaching out to a wide-range of people with dementia and their carers. This is a welcome development and coordinators clearly have an important role to play in developing responsive services.

Recommendation:

Community Development Coordinators: As co-ordinators are a new role, it is especially important to develop, strengthen and support their crucial work. This might appropriately form part of the remit of the newly established Equality, Diversity and Inclusion (EDI) subgroup, which is led by DPT's equality, diversity and human rights co-ordinator.

8.3.3 *More diverse staffing.*

Improvements in people of BME origins coming forward for diagnosis and for support are likely to be enhanced if there is more diversity in staffing of key posts (e.g. front-line staff and senior management roles). BDWS are aware of the importance of this, and have used innovative methods of ensuring that recruitment practices reflect the diverse needs of Bristol. BDWS has also established three EDI champions, who promote EDI engagement across the service, including regular contributions to staff newsletters, highlighting resources and EDI advocacy within clinical discussion. Staff in the service are further supported through staff networks led by Devon Partnership NHS Trust. Supporting staff from BME communities is thus an important way to ensure that the voices of BME communities as a whole are not marginalised.

Recommendation:

Increased diversity of staff: BDWS should continue both to ensure that recruitment reflects the needs of BME communities, and to ensure that existing staff from BME communities are fully supported.

8.3.4 *Culturally-sensitive residential care.*

Participants from all three communities in this study stressed the importance of flexible and culturally sensitive residential and respite care. Brunelcare's Extra Care residential home, Colliers' Gardens, could serve as a model of good practice for promoting culturally diverse and inclusive care [5.5; 6.9.4; 7.5]. As we have described, Colliers' Gardens has ten flats that are reserved for tenants of Chinese origins. A worker from BACWG also regularly liaises with care staff whose experiences of working with people from Chinese communities also appears to make staff sensitive to the cultural needs of residents from different communities. One example of this was that when an older tenant of Caribbean origins who lived alone was no longer able to continue safely cooking the Caribbean dishes for himself he preferred, staff had cookery lessons from a local Black-led Church so that they could support the tenant to continue to make his own meals.

Recommendations:

Commissioning culturally-appropriate residential care: consideration should be given to ensuring that contracts with local care home providers meet the needs of different BME communities, with service providers working closely in collaboration with local BME-led voluntary groups. One possible model of care and continued support is that developed at Colliers Gardens in which Brunelcare Extra Care work with Bristol and Avon Chinese Women's Group to meet the needs of older people from Chinese communities.

Commissioning culturally-appropriate forms of domiciliary care: innovative approaches to meeting the needs of people from BME communities with dementia should be considered. One example of this is the new, paid for service run by a Caribbean woman, who provides Caribbean food at the weekend to the homes of older people who live alone, in the Easton and St Paul's areas of Bristol.

Training for staff: health and social care organisations providing domiciliary and residential care must ensure staff are regularly trained, drawing on the local and personal experiences of people of BME origins with dementia and their carers. For example: in 2016, Alzheimer's Society commissioned Dhek Bhal to run a training session with all staff, to gain more awareness of the dementia needs and experiences of people of South Asian origins.

8.4 Living well - people with dementia can live normally in safe and accepting communities

8.4.1 *The importance of BME-led community groups.*

It was clear that the majority of participants in this study preferred to turn for support, not to dementia specific services such as those run by the Alzheimer's Society or by BDWS, but to organisations and community groups that they were familiar with, where there were shared languages and dietary preferences. At the same time, as the majority of participants in this study were recruited from these settings, it may be that this sampling procedure has created a bias within the findings. While it is always important to increase the cultural competency of mainstream, dementia services, the primary role in caring for people with dementia from BME communities will, for the foreseeable future, be carried by VCSOs in their community (5.5; 6.9.7; 7.6).

Many community organisations already provide a range of services to people with dementia. Some of these are funded, although the majority are not. These services provide a vital function, often being described by participants as "a lifeline". However, there is a danger that because many of these services are invisible to commissioners, they will also be unfunded.

Recommendation:

Investing in partnerships with BME-led community organisations: Consideration should be given for establishing viable mechanisms of financial support for the dementia work being carried out by BME-led VCSOs.

8.4.2 *Improving the capacity of BME-led VCSOs.*

While this study has highlighted the important role of BME-led VCSOs, it is also apparent that the capacity of these organisations is variable. For example, most of the Caribbean-led organisations in the study are volunteer-led, and are heavily reliant on older, female Caribbean volunteers. Their financial resources are stretched, making careful use of the small membership charges topped up by small, often short-term or one-off grants. The Chinese Elderly Club runs weekly, open sessions that are well-received, but these are based on the time, knowledge and skills of a single, part-time worker.

A key figure in developing the capacity of BME-led VCSOs has been a dedicated worker within LinkAge who supported BME-led VCSOs with funding applications and more joined-up, strategic working. This position became redundant at the end of August 2016. Although Voscur (Bristol's Council for Voluntary Service) may be able to take on some of this work, it is highly likely that there will be a reduction in the focussed support to these organisations.

Recommendation:

Developing capacity: creative means of developing the dementia capacity of BME-led VCSOs in Bristol should be developed.

8.4.3 *Supporting BME carers.*

Caring for someone with dementia is often exhausting, challenging and isolating, regardless of ethnicity, age, gender etc. of the people involved. There is evidence that for carers of BME origins, particularly those who do not either speak English confidently or who do not speak it at all, this isolation carer can be compounded by language barriers. When the person with dementia passes away, the former carer's isolation often continues as their health is likely to have deteriorated over the course of their years as a carer. This is experienced more acutely for an older person caring for a spouse but can also be felt by adult children who become carers.

Recommendation:

Supporting carers: consideration should be given to meeting the needs of people who have previously cared for relatives, who have either now passed away, or entered residential care. The needs of these "survivors", especially those from BME communities, should be addressed by both VCSOs and by statutory services.

8.5 Researching well with dementia

8.5.1 *Increasing the numbers of people from BME communities with dementia in research.*

People from BME communities are consistently unrepresented in dementia research at both a national and regional level. For instance, some large, publically-funded, studies exclude people with dementia from participation if they do not speak fluent English. At a local level, we understand that the Brain Bank in Bristol has recently had only its first ever donation from a deceased person with dementia of BME origins. More generally, we may assume, the lack of recruitment of people from BME communities is likely to come about, in part, because dementia research networks do not have a significant presence within BME communities. The absence of people with dementia of BME origins from research has a significant impact on the continuing lack of knowledge of how dementia is actually experienced by these communities. This lack of a voice in dementia research impacts on the abilities of service planner and commissioners to provide appropriate services. In turn, this impacts on both the cost-effectiveness and the efficacy of services. A commitment for dementia research to make planned and documented efforts to include people of BME origins would mean that more concrete knowledge is gained about how dementia affects different communities across the UK. This will enable services to be more cost-effective and better targeted.

Recommendations:

Enhancing the presence of people with dementia from BME communities in research: people from BME communities need to be present within dementia research. Research networks such as the Join Dementia Research (JDR), the Research Design Service (RDS), and the CLARHC should all actively consider recruiting people with experience of dementia from BME communities. This is likely to require flexible and innovative strategies, similar to those that have been described in this report. Where research evidence is being critically appraised, for instance by NICE, then the needs of people with dementia from BME communities should be actively considered.

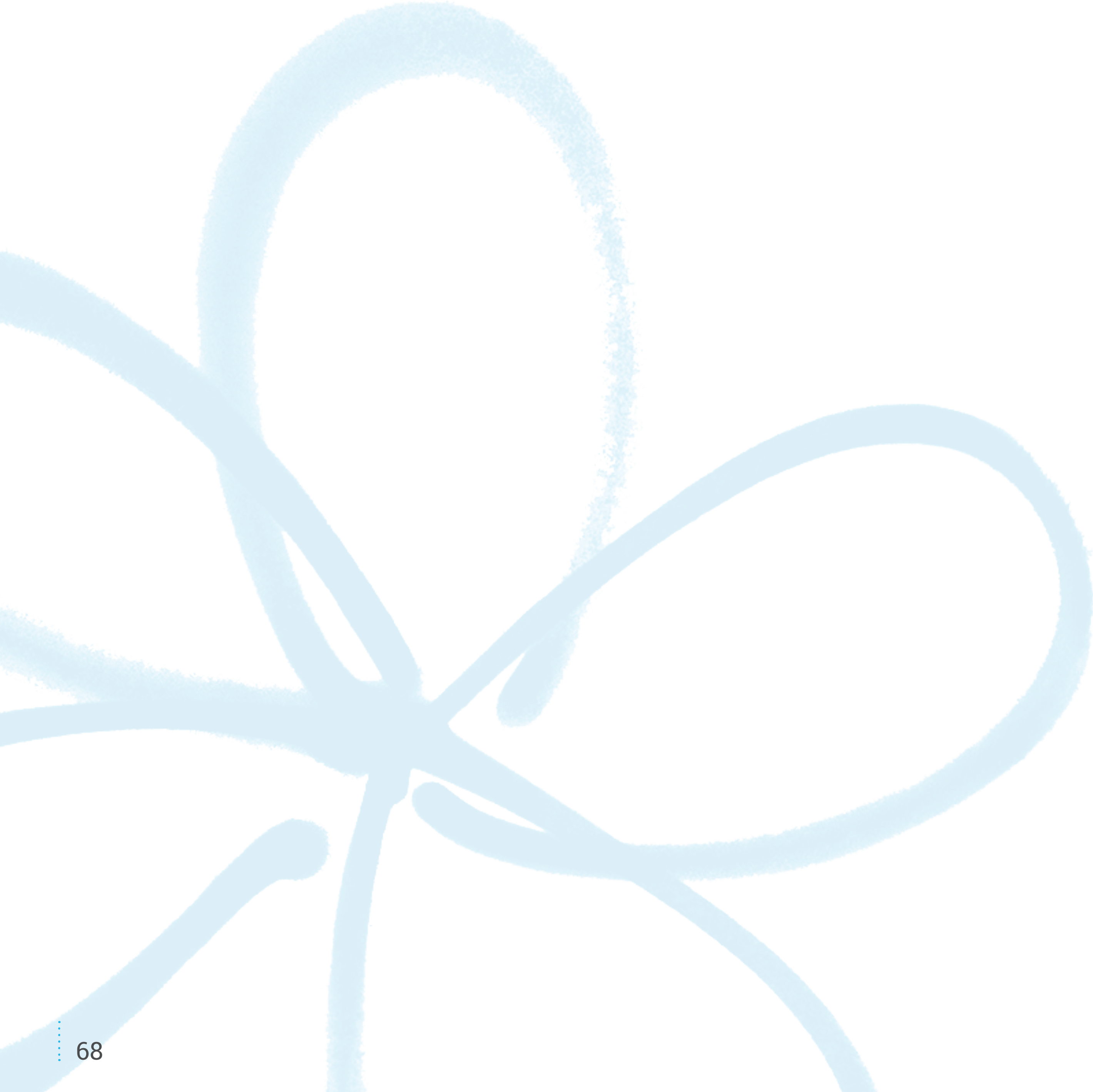
Recognising the absence of people with dementia from BME communities at a strategic and commissioning level: it is important that policy makers (including NHS England, Public Health England and social care bodies) take into account the specific needs of people affected by dementia from BME communities. Existing research, including this report, that uses innovative means of ensuring that the voices of seldom heard communities, including people from BME communities, can act as a toolkit for service development. This includes commissioning: appropriate training for NHS and social care staff; developing partnerships with BME-led VCSOs to provide them with the resources to become dementia competent; and to provide additional services, such as appropriate interpreters.

8.5.2 *Identifying the needs of people with dementia from other BME communities in Bristol.*

This study focussed on the needs of people with dementia and their families from Caribbean, South Asian and Chinese communities. However, there are a number of other communities that we did not approach - including the Irish and Somali communities.

Recommendation:

Identifying the dementia needs of other BME communities': consideration should be given to funding research to establish the wider needs of BME communities in Bristol such as the Somali and Irish communities.



Acknowledgements

We would like to thank all members of the public who took part in this study including those people who have a diagnosis of dementia, their families, friends and carers. The study would not have been possible without the personal experiences, concerns and ideas that people gave to us through interviews and by participating in Focus and Informal Groups.

We would also like to thank the contributions made by:

Kevin Chong and Ruiyan Chen
Bristol and Avon Chinese Women's Group

Funding for the project launch event from the Quartet Community Foundation

Zehra Haq- *Dhek Bhal*

Gloria Morris
Golden Agers' Club

Joana Allison
Evergreens

Gloria Watson and Evadnee Hartley
Malcolm X Elders

Amerjit Singh and Sharda Panchal
Asian Elderly Day Centre

Simi Chowdhry
Awaz Utaoh

Rizwan Ahmed
Bristol Muslim Cultural Society

Allyson Ng
Chinese Bible Studies' Group

Jade Wong
Chinese Elderly Club

Various members of Siri Guru Singh Sabha Gurdwara

Angela Etienne, Trish Caverly, Rebecca Pracownik, Kiran Rajput, Charlie Jones and others
Bristol Dementia Wellbeing Service

Ted Taziveyi
Terrence Higgins Trust

Sheila Hetreed
Nilaari Agency

Narinder Chana
Rethink

Monira Ahmed Chowdhury
CASS

Ruth Pitter
Voscur

Paulette North, Judeline Ross and Cheryl Morgan
Ujima Radio

Mohammed El-Sharif and Kaye Grant
Bristol Community Health

Julie Walker
Colliers Gardens, Brunelcare

Workers at Urban Concept, Super Tonic and Clippers Barbers' shops

Tony Hall
Bristol Dementia Action Alliance

Dr Jude Hancock
Bristol Dementia HIT

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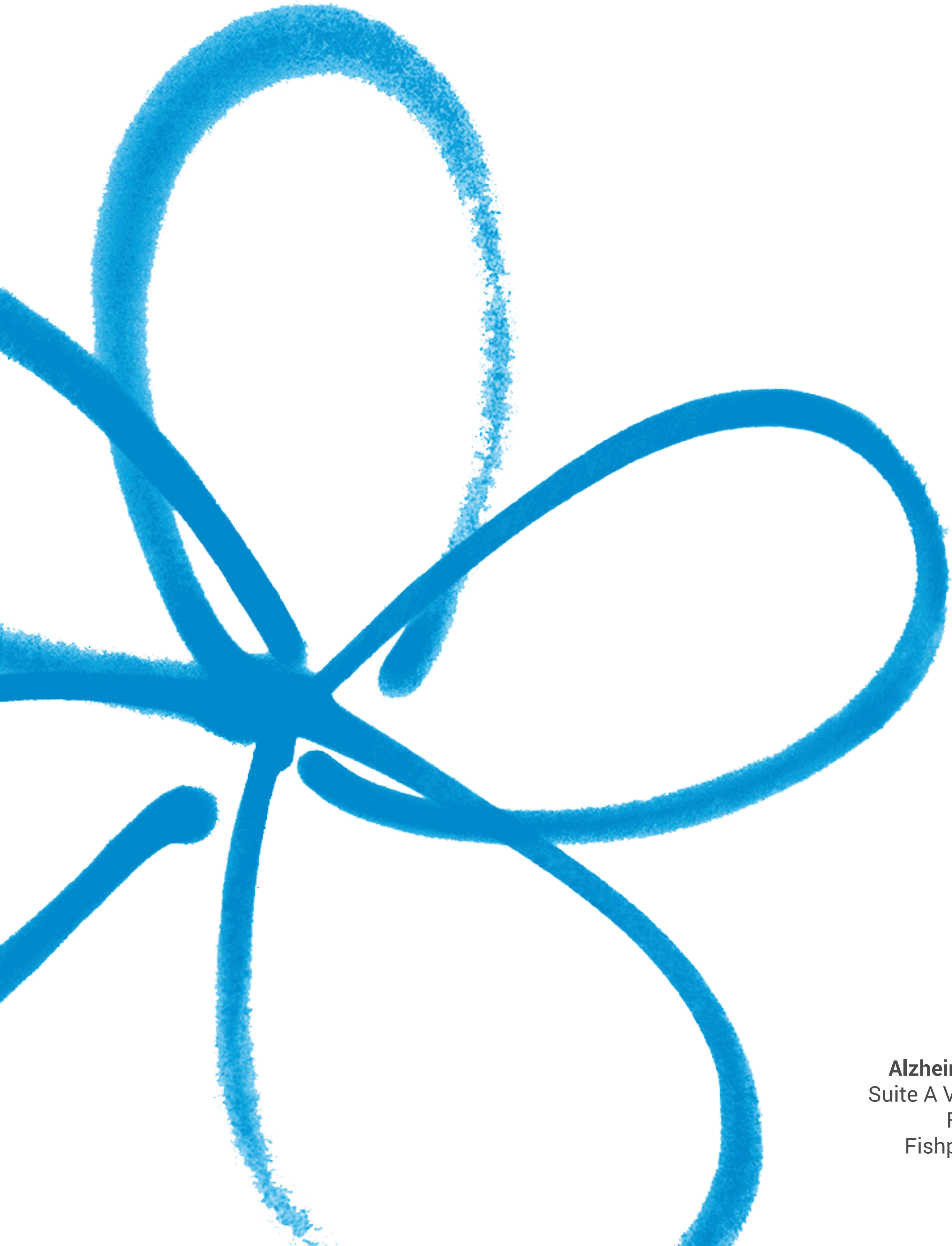

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