

# The Dementia Experiences of People from Caribbean, Chinese and South Asian Communities in Bristol: supplementary material



The Bristol BME Dementia  
Research Group

# The Dementia Experiences of People from Caribbean, Chinese and South Asian Communities in Bristol: supplementary material

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## **Introduction and background.**

In 2016, Bristol Council commissioned the Bristol BME Dementia Research group to carry out an eight-month study to establish the dementia experiences of people from BME communities in Bristol. A researcher (Subitha Baghirathan) was employed at the University of the West of England, supervised by Professor Richard Cheston, to conduct this research.

In all, Subitha carried out 48 one-to-one interviews, and eight focus groups with participants who were recruited from three Bristol BME communities: Caribbean, Chinese and South Asian. All of the participants had varying experiences of dementia within these communities – either as carers for people with dementia, concerns that they themselves might be developing dementia, or through working for BME-led Voluntary and Community Sector Organisations (VCSOs).

The main results of this study have been published in a document entitled: *The Dementia Experiences of People from Caribbean, Chinese and South Asian Communities in Bristol*. However, it was not possible to include all of the material that related to the project in that report. Consequently, this document contains all of the supplementary information that relates to the main report. This material is of two types: first, many of the sections contain explanatory details of the way in which the study was carried out – its methodology. Thus, some sections relate to issues around ethics, whilst others give further details of the way in which participants were recruited. In addition, we have also included information about those resources which Subitha collected as part of the study – including details about the local, BME-led VCSOs which support people with dementia, as well as a list of relevant on-line and other resources that clinicians, carers and people with dementia can draw upon.

For further information about the project, please contact [richard.cheston@uwe.ac.uk](mailto:richard.cheston@uwe.ac.uk).

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## **Appendix One: Semi-structured interview and Focus Group Topic Guide.**

### **Experience of ageing**

- Are there any older people in your family that you live with or know really well? (alternatively: do you regard yourself as an older person?)

### **Perceptions of ageing**

- Do the people you know seem to have changed in any way as they get older?
- How?
- Are there particular issues or actions that you or older people you know find harder now?
- Prompt - finding your way around a familiar place; remembering the names of family members and friends.

### **Health changes associated with ageing**

- Have you found that you or your family members need to see their doctors more often as they get older?
- If yes, for what reasons?
- Have you been worried about your own or older family members' health in any way?
- Any worries apart from physical health problems? Such as worries about dementia, or memory loss, or feeling confused in a familiar place?
- Have you noticed any changes in people's behaviour or attitudes as they get older?
- Have you found that your own or other people's memory changes as they get older?
- Prompt - such as finding it hard to remember new information but having clear memories about the past?

### **Knowledge of services**

- Would you know where to go to get help if you are really worried about yourself or an older person you know?
- What are the situations in which you would consider requesting help from health services for your needs or for an older person you know?
- What kinds of support services would be helpful when you or an older person you know is experiencing health difficulties?
- Are there any worries, fears or concerns you might have about receiving support from these kinds of health services?

### **Views of services**

- Have you or anyone you know had experience of using health services, particularly for any health needs of older people?
- Prompts - the Memory Service, or visits at home by a community physiotherapist.
- If yes, what was the experience like?
- Would you request this help again if needed?
- If you would not request this help again, would you share your reasons for this?

Note: the above is based on questions used in the following research:

LaFontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyebode, J. R. (2007). "Understanding dementia amongst people in minority ethnic and cultural groups." *Journal of Advanced Nursing*, 60(6), 605-614.

## **Appendix Two: Ethical approval and considerations**

The study applied for, and received, permission from the University of the West of England (UWE), Ethics committee of the Faculty of Health and Applied Sciences (HAS.16.02.112, 11<sup>th</sup> March, 2016). Amongst the ethical issues we addressed were:

*Capacity and consent.* We intended to speak both to people affected by dementia and to their carers. However, before people affected by dementia could give consent, we needed to establish whether they had capacity to understand what taking part in a research project entails. As we did not have access to formal assessments for people with dementia who were referred to this project, we assessed capacity by consulting with people who know the person well and by SB carrying out an informal interview to establish whether the person had the capacity to understand simple information, to retain and process that information and to communicate adequately.

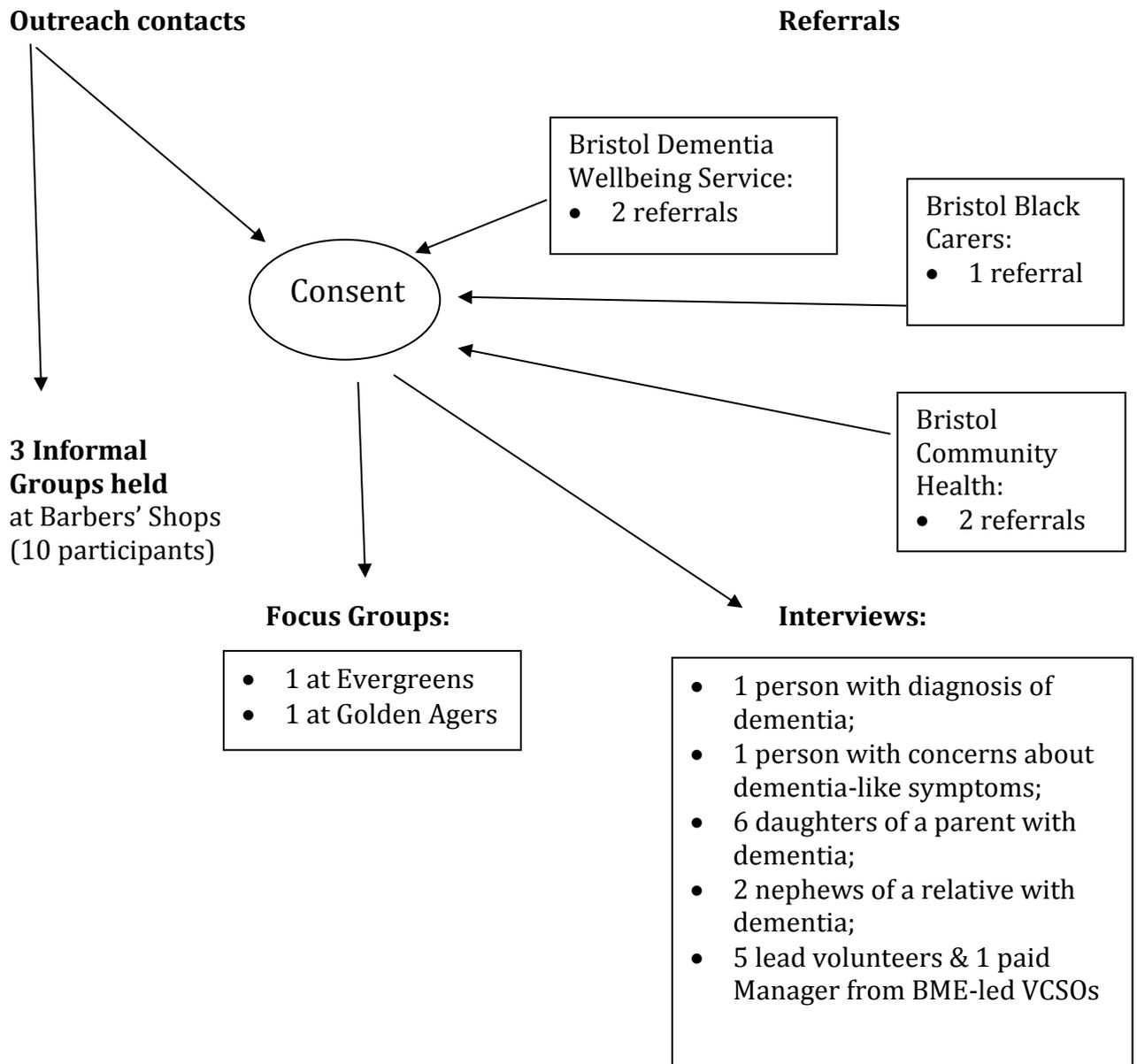
*Language.* The word '*dementia*' is often not known or used in some South Asian and Chinese communities, nor is it always easily translatable. Consequently, SB needed to become familiar with the different terms or phrases which might refer to dementia and initially avoided using the English word '*dementia*', instead describing various behaviours which could be dementia, such as asking people if they were finding it more difficult to remember their way around familiar places.

*Purposive sampling.* In order to ensure that we were collecting as many different voices as possible, we reviewed progress at a mid-point meeting. This identified that there were three particular groups that were under-represented at that stage: people of Chinese origins; people with dementia; and men, especially Caribbean men. We therefore prioritised data collection for these groups for the remaining period of evidence gathering.

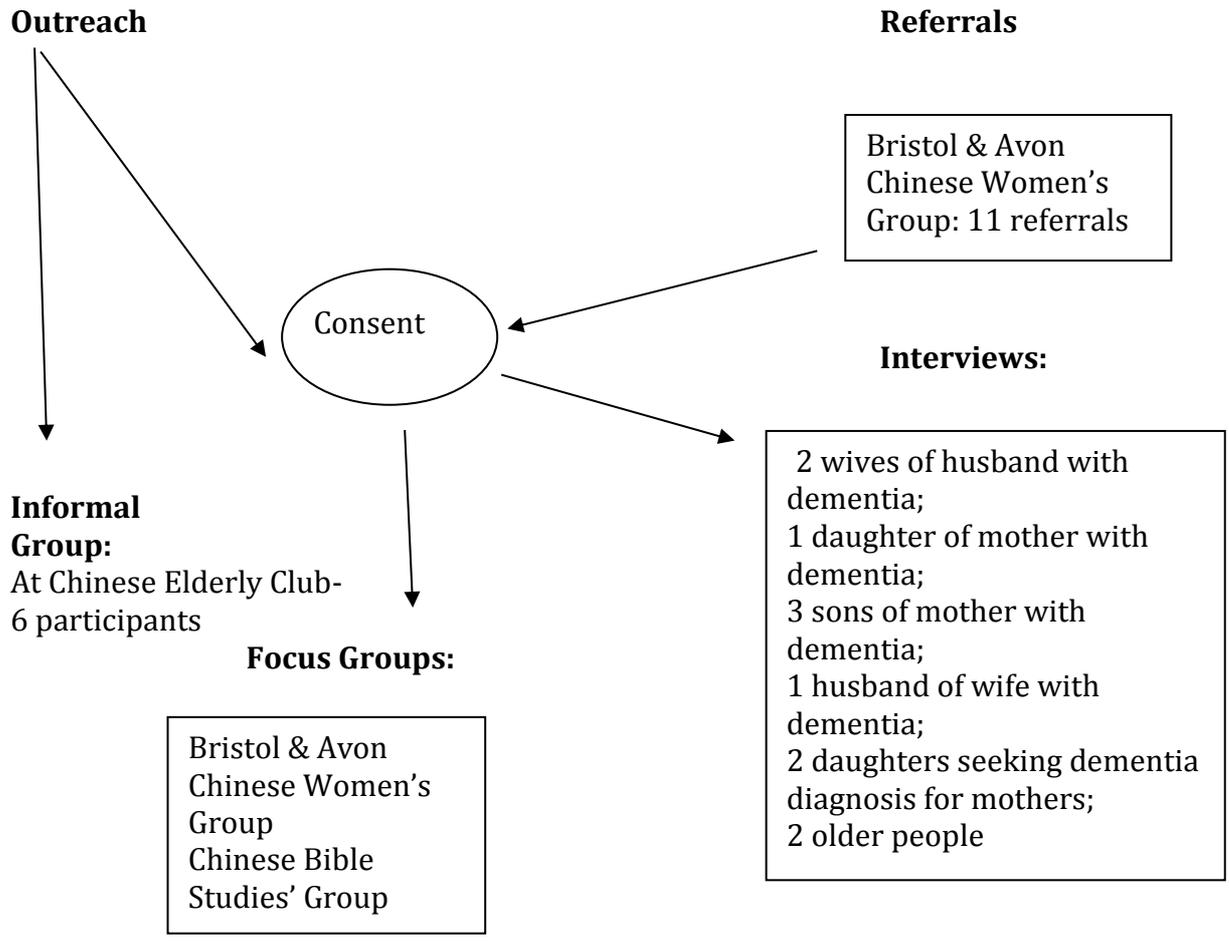
*Participant Information Sheets and Consent Forms.* These were developed for interviews and focus groups, including translated versions in traditional and simplified Chinese scripts. These documents formed part of the application for ethical approval made to UWE in February 2016. Copies can be obtained on request from Professor Richard Cheston: [richard.cheston@uwe.ac.uk](mailto:richard.cheston@uwe.ac.uk)

### Appendix Three: The recruitment process

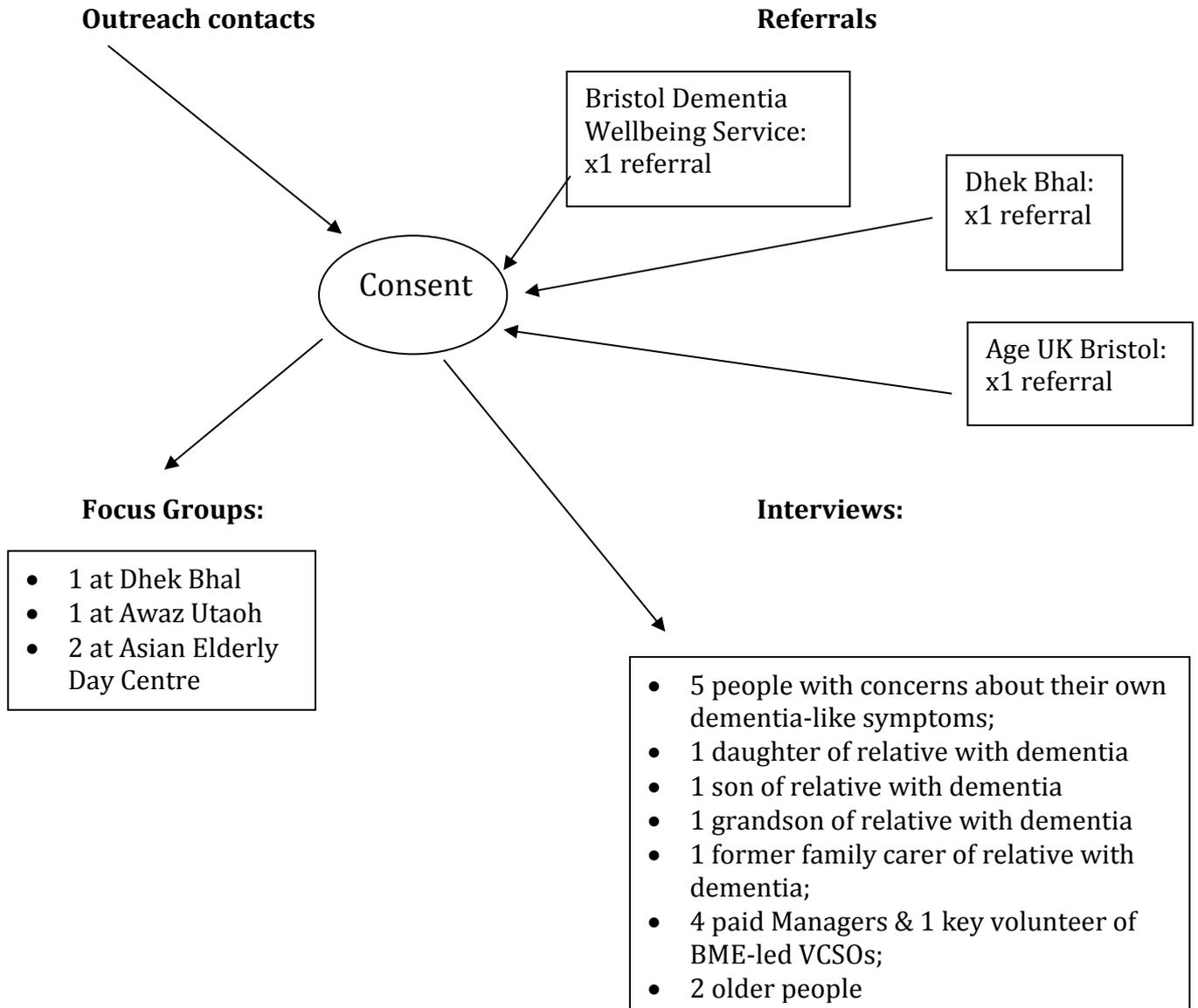
Figure One: flow chart illustrating recruitment of Caribbean participants



**Figure Two: flow chart illustrating recruitment of Chinese participants**



**Figure Three: flow chart illustrating recruitment of South Asian participants**



## Appendix Four: Participant Information Sheet



University of the  
West of England

### **Meeting the needs of older people from Black and Minority Ethnic Bristol who have memory loss**

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We would like to invite you to take part in our research study.

#### **Why are we doing this research?**

The aim of the study is to find out about the sort of health, social and voluntary services older people from Black, Asian and other minority ethnic communities receive if they have concerns with their memory. These concerns are sometimes called “*dementia*”.

Our study is organised by researchers at the University of the West of England.

We believe this is an important area to research in Bristol because elsewhere in the UK, research suggests that most services focus on the needs of white British people. We want to find out if people from Black, Asian and other minority ethnic groups are missing out on what they need.

#### **What would taking part involve?**

The study involves meeting a researcher for about an hour to talk about your experiences. The researcher’s name is Subitha Baghirathan.

Subitha will be finding out about people’s experiences in two ways.

The first method will involve Subitha visiting community groups and having a general discussion with a small group of between four and six people.

However, not everyone feels comfortable talking in a group. If you would prefer, then Subitha will arrange to visit you at home to have a chat with you about what has happened to you.

If possible, Subitha would also like to be able to talk to your family or friends about what they think. She will always ask you first if this is alright with you.

Subitha will ask you if it is alright for her to record her interview with you using a digital recorder. This helps us to make sure that we can remember exactly what you have told her.

### Do I have to take part in the study?

No. You do not have to take part if you would prefer not to.

Your participation in this study is entirely voluntary.

No part of your care, or any other aspect of the services that you receive will be affected in any way by deciding to take part or not.

If you decide not to carry on with the study or want to withdraw then you will be able to do so and this will not affect you in anyway.

### What will happen to the information we collect in this study?

The results of this study will be published in a report. The information that we collect will be used to change the way services are delivered in Bristol, so that they are more appropriate for everyone in Bristol. We will be holding events locally to let people know the results.

We also hope to publish the report so that other cities across the UK can learn from what we have found out in Bristol.

You will not be identified in any published results. All of the information in the report will be anonymised. This means that any information that could identify you, such as your name, will be changed.

The information that we collect as part of this study (for instance the recordings of the interviews) will be kept securely for a period of six years after the end of the study after which time it will be destroyed.

If you decide you would like to come to an event or be sent a copy of the report, then please let the researcher know.

### What are the possible benefits of taking part?

If you do decide to take part, then you will be helping us to understand more about the sorts of services that would support older people with memory loss better, particularly those from Black, Asian and other minority ethnic communities.

Without volunteers like you, research of this kind would not be possible. Your participation and contribution is, therefore, invaluable.

### What are the possible disadvantages of taking part?

We do not feel that there are many disadvantages to taking part.

Sometimes, however, people can feel upset at having to think about difficult subjects. If, for any reason, you feel distressed after taking part in the research then please let Subitha Baghirathan know and she will be able to help. You can also contact Professor Richard Cheston, the Chief Investigator of the project, whose details are at the bottom of this sheet.

### Who will be informed of my participation?

If you decide to take part in the study, then all of the data from the study will be kept confidentially, and nobody will be told about your participation.

### Who has funded this study?

This study has been funded by Bristol City Council (Public Health and Adult Social Care).

### Who has approved this study?

This study has been approved by the ethics committee of the University of the West of England.

### Further information

If you do decide to take part we will ask you to sign a consent form. If you decide to take part then you are still free to withdraw from the study at any time. If you decide not to take part or would like to withdraw you do not have to give a reason for doing so.

If you would like to find out more information about the study, then please do get in touch with Professor Richard Cheston (0117 3288927) at the University of the West of England.

### What do I do now?

We will get in touch with you to arrange a time for you to take part in the research.

We will make an appointment for you to meet at home when it is convenient for you.

Subitha will be happy to answer any questions you may have about the study. If you are happy to take part, she will ask you to complete a consent form. You will be able to keep a copy of the form as well as a copy of this information sheet.

## Contact information

Professor Richard Cheston Health and Social Sciences 3E01, Frenchay Campus Coldharbour Lane Bristol BS16 1QY Tel: 0117-3288927 <a href="mailto:Richard.cheston@uwe.ac.uk">Richard.cheston@uwe.ac.uk</a>	Ms Subitha Baghirathan c/o Bristol and Avon Chinese Women's Group St Agnes Church Thomas Street, St Paul's, Bristol BS2 9LL <a href="mailto:Subitha.Baghirathan@uwe.ac.uk">Subitha.Baghirathan@uwe.ac.uk</a>
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**Thank you very much for your time.**

## Appendix Five: Consent Form

**Title of project:** Meeting the needs of older people from Black and other Ethnic Minority groups in Bristol who have dementia

**Name of researchers:** Prof. Richard Cheston, Subitha Baghirathan

**Please  
initial box**

1. I confirm that I have read and understand the information sheet (version 1, dated 22/01/16) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. I also understand that no aspect of my care will be affected should I decide to withdraw.
3. I am aware that the results of the study may be presented in research reports. However, the information I provide for the study will remain confidential.
4. I agree for my data to be stored anonymously and that any published quotations or extracts from the research will maintain my confidentiality.
5. I understand that my contact details will be retained so that I can be updated about the outcome of the study.
6. I agree to take part in the above study.

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Name of participant

Date

Signature

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Name of person taking  
consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file

**Appendix Six: Records of Interviews and Focus Groups completed April to July 2016**

Key:

BDWS= Bristol Dementia Wellbeing Service

BACWG= Bristol & Avon Chinese Women’s Group

CASS= Community Access Support Service (BME mental-health support organisation)

SB= Subitha Baghirathan

**Table 1. People with a dementia diagnosis or older people self-identifying with dementia-like symptoms**

<b>BME community &amp; gender</b>	<b>Route to interview</b>
1. Caribbean man with diagnosis	Referral BDWS
2. Polish man with diagnosis & daughter	Referral BDWS
3. South Asian Muslim man (with own concerns)	SB’s outreach to Dhek Bhal
4. South Asian Muslim woman (with own concerns)	SB’s outreach to Awaz Utaoh
5. South Asian Sikh woman (with own concerns)	SB’s outreach to Awaz Utaoh
6. South Asian Muslim woman (with own concerns)	Referral from CASS
7. Caribbean woman (with own concerns)	SB’s outreach to Bristol Black Carers
9. South Asian Sikh man (with own concerns)	SB’s outreach to Siri Guru Singh Sabha Gurdwara

**Table 2. Individuals without dementia**

<b>BME community &amp; gender</b>	<b>Contact with dementia</b>	<b>Route to interview</b>
<b>Caribbean community</b>		
1. Caribbean woman	Both parents had/have dementia	SB’s general outreach
2. Caribbean woman	Stepmother has dementia	SB’s outreach to CASS event Feb. 2016
3. Caribbean woman	Mother has dementia	Referral from a Health Champion, following SB’s outreach to Inner City Health Champion Team

		(Bristol Community Health) Meeting April 2016
4. Caribbean woman	Mother & sister had dementia. Niece recently diagnosed	SB's outreach to CASS event Feb. 2016
5. Caribbean woman	Father has dementia	Referral from Bristol Black Carers
6. Caribbean woman	Mother has dementia	Referral from a Health Champion, following SB's outreach to Inner City Health Champion Team Meeting April 2016
7. Caribbean woman	Volunteer at Malcolm X Elders; former nurse with Brunelcare	SB's outreach to Malcolm X Elders
8. Caribbean man	Aunt with dementia	SB's general outreach
9. Caribbean man	Nephew of man with dementia (interviewed separately)	Referral from BDWS

**Table 3. Interviews with BME-led voluntary & community sector organisations' key workers**

<b>Named person</b>	<b>Role</b>	<b>Organisation</b>
1. Gloria Morris	Chair	Golden Agers
2. Joyce Montague	Treasurer	Evergreens
3. Evadne Hartley	Treasurer	Malcolm X Elders Group
4. Joana Allison (in Focus Group)	Coordinator	Evergreens
5. Zehra Haq (informal interview only)	Director	Dhek Bhal
6. Amerjit Singh	Director	Asian Elderly Day Centre
7. Simi Chowdhry	Director	Awaz Utaoh
8. Jade Wong (informal interview only)	Coordinator	Chinese Elderly Club
9. Anndeloris Chacon	Director	Bristol Black Carers
10. Ted Taziveyi	Coordinator	BME people with HIV+, Terrence Higgins' Trust

11. Raj Lalla	Coordinator	BME Elders' Consortium, LinkAge
12. Yan Chen (informal interview only)	Manager	Carers' Support Service, BACWG
13. Sheila Hetreed (informal interview only)	Coordinator	New Older People's Group, Nilaari (BME people's mental health/addiction recovery agency). Formerly Coordinator of BME Elders' Consortium, LinkAge

<b>Other key workers, other organisations</b>		
Sharon Harris	Key worker with Chinese tenants	Colliers Gardens, Brunelcare
Julie Walker (informal interview only)	Manager	Colliers Gardens, Brunelcare

**Table 4. Focus Groups**

<b>BME community</b>	<b>Where</b>
1. Chinese	Chinese Church Bible Studies' Group
2. Chinese	BACWG
3. Chinese	Chinese Elderly Club (informal group only)
4. Caribbean	Golden Agers
5. Caribbean	Evergreens
6. Caribbean & African	BME people with HIV+, Terrence Higgins' Trust (informal group only)
7. Caribbean	3 Barbers' shops in Easton & St Paul's (informal groups only)
8. South Asian	Dhek Bhal (Carers' support workers)
9. South Asian	Asian Elderly Day Centre (women)
10. South Asian	Asian Elderly Day Centre (men)
11. South Asian	Awaz Utaoh

## **Appendix Seven: Information about voluntary and community sector groups and organisations which provide services to and/or are led by older Black, Asian and other minority ethnic people in Bristol**

The information below is not exhaustive or fully comprehensive; and is likely to become out-of-date. It is principally developed from knowledge of voluntary and community sector groups and organisations (VCSOs) who were active partners in the BME people and dementia research project carried out by UWE from February to October 2016. These organisations and groups provide services to older Black, Asian and other minority ethnic (BME) people in Bristol and many are led by older BME people.

**Asian Elderly Day Centre (or Asian Health and Social Care Association)** is based at Easton Community Centre, and has provided day care for older members of Asian communities in Bristol and South Gloucestershire since it was established in 1994. It runs a service three times a week. Fees cover a hot lunch based on the dietary preferences of its South Asian membership. The Centre also organises accessible group exercise, massage sessions and trips away. Staff and volunteers are fully trained and competent in English and another language, e.g. Gujarati, a language predominantly used by its attendees. Its funders include Bristol City and South Gloucestershire Councils. People with dementia can and do attend Asian Elderly Day Centre; they do not need to be accompanied by a family member/friend/carer.

Amerjit Singh: Director

Tel. 0117 9540178; E. [asiandaycentre@hotmail.co.uk](mailto:asiandaycentre@hotmail.co.uk)

**Awaz Utaoh** has longevity as a VCSO in Bristol led by and for South Asian people, particularly women. Its roots are in crime prevention and raising awareness of domestic violence. It now primarily provides services to women to improve health and wellbeing, with drop-in groups twice a week: at Trinity Centre, Old Market, on Wednesdays and St Werburgh's Community Centre on Thursdays. Activities there include health cooking demonstrations; yoga; Zumba; information talks. People pay a modest fee per visit. The office is also open to provide information, signposting and advice. Paid workers and volunteers are competent in English as well as another language used by their members, such as Urdu. Its funders include Bristol Ageing Better; Quartet & St Monica's Trust. People with dementia can attend the bi-weekly drop-in groups on their own, unless they have any additional needs.

Simi Chowdhry: Director      Tel. 07968 621079; E: [awazutaoh2@gmail.com](mailto:awazutaoh2@gmail.com)

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

**Bristol and Avon Chinese Women's Group (BACWG)** exists to support the health and social care needs of Chinese women and their families in Bristol and the surrounding area, by providing assistance, advice, representation and services. BACWG are especially aware that due to language barriers, many disadvantaged groups such as older people, disabled people and families on low income often fall through the gaps in other services. By highlighting such gaps in provision, the Group builds an important networking and communication link with existing statutory agencies and VCSOs in the Bristol area and people of Chinese origins. All staff and volunteers are competent in English and another language used by its members, such as Mandarin. Services/activities provided include: monthly group offering Tai Chi, craft, information talks and chance to socialise; Sitting Service to give respite to family carers; a new, free telephone helpline run by trained and bilingual workers (Chinese Lantern Project). BACWG's offices are in St Agnes Church in St Pauls, Bristol. Its funders include Big Lottery and Bristol City Council.

Rosa Hui: Director; Ruiyan Chen: Manager of Carers' Service

Tel. 0117 935 1462; E. [office.bacwg@btconnect.com](mailto:office.bacwg@btconnect.com)

Chinese Lantern Project Telephone Helpline: 080 8802 0012

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

### **Bristol Black Carers**

Bristol Black Carers provides culturally-appropriate support and services to BME carers in Bristol. Services provided include:

Advice & Information: - one-to-one support and advocacy on issues affecting BME carers. Carers Wellbeing Service: - Provides support through peer groups, home visits, training events, complimentary health treatments and outings. Care Attendant Service/Sitting & Befriending Service. Young Carers Service: - Supports and empowers young BME carers through one-to-one casework and events, workshops and trips. The organisation's funders include Bristol City Council and The Community Fund.

Anndeloris Chacon: Manager.

Tel. 0117 379 0084

E. [manager@bristolblackcarers.org.uk](mailto:manager@bristolblackcarers.org.uk)

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

**Bristol BME Service at Rethink Bristol** works with existing Bristol Community Support Services to respond appropriately to the mental health needs of people from BME backgrounds. Rethink Bristol services support people to recover through one-to-one support in accessing community facilities. The BME service works in partnership with statutory mental health teams and the BME-led voluntary and community sector to improve access to services for BME people. Access to interpreters can be arranged. Service literature is available in Bengali,

English, Gujarati, Hindi, Punjabi, and Urdu. Their provision includes the 2-day 'Mental Health First Aid' course which can be run for VCSOs, at their premises; this course has been updated to include some introductory information about dementia. Rethink Bristol have offices in St Paul's. Their funders include The Big Lottery and Department of Health.

Narinder Chana: BME Service Community Development Officer

Tel: 0117 353 2041; E. [bristolbmeservices@rethink.org](mailto:bristolbmeservices@rethink.org)

[www.rethink.org/services-groups/services/bristol-bme-service](http://www.rethink.org/services-groups/services/bristol-bme-service)

**Chinese Elderly Club** is a community group with a large number of service-users attending its bi-weekly drop-in Mah-jong sessions. Most attendees are older people of Chinese origins. Its premises are in St Paul's. Attendees pay a sessional fee. The Coordinator also provides support such as helping to book medical appointments or reading mail. She is competent in English and another language used attendees.

Jade Wong: Coordinator      Tel. 0117 955 5225

**Chinese Church Bible Studies' Group** is affiliated with the Bristol Chinese Church which meets on Sundays at Tyndale Baptist Church, Clifton. The Bible Studies' Group runs on Mondays at Broadmead Baptist Church and is well-attended by a mixed group of men and women of various ages. Most attendees speak a language other than English although there are some group members who are also competent in English.

Reverend Irene Chan: Church leader      E. [irene\\_cocm@yahoo.co.uk](mailto:irene_cocm@yahoo.co.uk)

**Community Access Support Service (CASS)** works with community, equality and faith groups to improve awareness of mental health and provide better links to support services in Bristol. CASS was developed from the restructure and recommissioning of Bristol's mental health services in 2014, as previous services did not seem to be meeting the needs of people from BME communities. Some of its staff speak a community language in addition to English. CASS does not run services its own right but provides signposting information to relevant services; it also supports services and organisations to work well in partnership. CASS is based at Wellspring Health Living Centre, a social enterprise in Barton Hill.

Monira Ahmed Chowdhury: Director

Tel. 0117 314 1400; E. [info@cassbristol.org](mailto:info@cassbristol.org)

[www.wellspringhlc.org/cass](http://www.wellspringhlc.org/cass)

**Dhek Bhal** is a well-established VCSO, founded by volunteers in 1987, with premises at Barton Hill Settlement- another grassroots social enterprise organisation. Dhek Bhal's Aims and Objectives are to provide a range of quality services including: respite services for Carers of South Asian older people

through a Sitting Service; a bi-weekly Day Centre for frail and disabled older women; a bi-monthly group for older men; an Outreach Support Scheme for frail and disabled older people who do not often get out of their homes; and a Carers' Support Group for both male and female Carers to address their social, health, educational and training needs. Dhek Bhal runs its services on a not-for-profit basis, with services mainly either at no or at a very low cost. It has a team of paid workers and volunteers who are competent in English as well as another language spoken by their service users, e.g. Urdu and Punjabi. The Women's Day Centre provides a hot lunch based on the dietary preferences of its South Asian membership. It is supported by a range of funders including Bristol City and South Glos. Councils; Quartet; Big Lottery Fund. Its last Care Quality Commission (CQC) Inspection in Feb. 2016 rated it overall as "good". People with dementia can and do attend the Day Centre for women and the men's Support Group. They can attend on their own. People with dementia with additional needs who attend can be supported by the paid workers/volunteers.

Zehra Haq: Director; Naheed Chowdhury, Carers' Service Manager.

Tel. 0117 955 6971; E. [dhekbhal@yahoo.co.uk](mailto:dhekbhal@yahoo.co.uk)

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

**Evergreens** is a community group based at Easton Community Centre, a local social enterprise. Evergreens is a weekly afternoon social group open to people over 55 years, from diverse ethnic backgrounds. It is regularly attended by around 20 older people, predominantly from local Caribbean communities. Various activities take place, including six coach daytrips per year and an annual Harvest Thanksgiving event. There is also weekly bingo, raffle and an accessible exercise class. It is run largely by volunteers and 1 part-time paid Coordinator. Attendees pay a weekly modest fee. Evergreens is open to people with dementia who can attend on their own unless they need additional support, in which case they can attend accompanied by a family member, friend, volunteer Befriender etc.

Joana Allison: Coordinator. Tel. 0117 954 1409

**Golden Agers Club** meets twice a week in a church on Tudor Road, Easton; predominantly for BME older people to provide support, advice and information as well as an opportunity to socialise. The Golden Agers Club was established in 1991 by the Tudor Road "Church of God of Prophecy". It was once run and funded by the church, but is now open to the public for membership and is run by volunteers of the local BME community. The club is a place where BME people over 50 meet twice a week to do various activities such as dominoes games, flower arrangement, patchwork quilting and gentle exercise. Accessible exercise sessions and an IT Club also run. A hot lunch is served at a moderate price, based on the Caribbean dietary preferences of its members.

Gloria Morris: Chair

E. [contact@goldenagersclub.org](mailto:contact@goldenagersclub.org)

**Malcolm X Elders' Group** is a long-standing community group meets every Monday and is well-attended by older Caribbean people. It takes place at the Malcolm X Centre, St Paul's. Members pay a modest annual subscription which covers a hot lunch- food to suit their dietary preferences- and a music/movement session provided by 'Golden Oldies', focussed on the music preferred and remembered by members. People with dementia can and do attend. They can come alone unless they have additional needs. It is run by volunteers. There are often information talks, plus the chance to socialise, play dominoes, do craft etc.

Gloria Watson: Chair; Evadne Hartley: Treasurer

Tel. 0117 955 4497; E. [info@malcolmx.org.uk](mailto:info@malcolmx.org.uk)

**Nilaari Agency** is a community based mental health and complex needs support provider that administers accessible, high quality and culturally appropriate counselling, advocacy and support primarily to BME adults and young people in Bristol who are experiencing mental health difficulties. However, anyone in need can access their services. They are currently looking into setting up a support group for older people (potentially including people experiencing changes in memory) as this need has been identified by their current users. Nilaari has premises on Stapleton Road, in the Easton/St Paul's area of Bristol.

Jean Smith: Director; Shelagh Hetreed: Coordinator of planned Older People's Group

Tel. 0117 952 5752; E. [nilaari@nilaari.co.uk](mailto:nilaari@nilaari.co.uk)

[www.nilaari.co.uk](http://www.nilaari.co.uk)

**Siri Guru Singh Sabha Gurdwara** is Bristol's largest Gurdwara and is physically accessible. The Gurdwara is on Church Road, St George. Its members are people of Sikh faith, primarily of Indian origins. The Gurdwara is open for worship every morning and evening. On Sundays, the Gurdwara is open for the day and includes a "langar"- free, vegetarian, community lunch. On Thursdays, an Older People's Group meet. Members often walk around St George's Park before having a hot lunch together- with hot vegetarian food suiting their dietary preferences. A modest fee is charged for lunch. People with dementia can and do attend the Gurdwara, usually accompanied by a family member.

Gurdial Singh or Santokh Singh Sandhu: Company Secretaries Tel. 0117 939 7290

[gurdwarabristol.wordpress.com](http://gurdwarabristol.wordpress.com)

**Terrence Higgins Trust** provides counselling, peer support, complementary therapies, advocacy and advice for people living with & affected by HIV. Their premises are in Old Market, Bristol. Its services in Bristol include support for

older people and BME people living with HIV+. Its funders include Elton John Aids Foundation.

Ted Taziveyi: Coordinator of BME people with HIV+ Support Group

Tel. 0117 955 1000; E. [info.bristol@ttht.org.uk](mailto:info.bristol@ttht.org.uk).

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

**Wellspring Health Living Centre** is a social enterprise providing a range of health and wellbeing services in the Barton Hill area. There is also a surgery, dentist and chemist based there. Their staff team includes 3 Health Development Workers who speak English and another community language; Somali, Polish and Roumanian are languages covered by staff. Activities/services range from free to low cost. Wellspring HLC is beginning to consider dementia and related services in its locality.

Elaine Flint: Director; Rhian Loughlin: Head of Services.

Tel. 0117 304 1400; E. [reception@wellspringhlc.org](mailto:reception@wellspringhlc.org)

[www.wellspringhlc.org](http://www.wellspringhlc.org)

### **Interpreting and Translation Services in Bristol**

**Easy Translations** provide face-to-face and over the telephone interpreting, in addition to translation of written materials in a range of community languages other than English. This is a BME-led local business.

Dr Ashfaq Chowdhury: Director

Tel. 0845 200 7832; E. [info@easy-translations.co.uk](mailto:info@easy-translations.co.uk)

[www.easy-translations.co.uk](http://www.easy-translations.co.uk)

**Bristol and Avon Chinese Women's Group** provide interpreting and translation services at a fee in languages used by local people of Chinese origins, such as Cantonese. See above for contact details.

**Health Links Interpreters** are a service within Bristol Community Health, a community interest company commissioned to provide a range of health and wellbeing services. They have a bank of interpreters covering a range of languages other than English- such as Somali and Urdu- who can be booked for medical and other health appointments. E.g. there are Health Links interpreters at Baby Clinics at East Trees Health Centre on a regular basis. Their office is at Charlotte Keel Health Centre, Easton.

Russell Thomas: Manager; Harjinder Kaur: Administrator

Tel. 0117 902 7115; E. [harjinder.kaur@nhs.net](mailto:harjinder.kaur@nhs.net)

## **Appendix Eight: published resources on dementia and people of Black, Asian and other minority ethnic origins in UK**

1. Truswell, D. and Tavera, Y. *An Electronic Resources Handbook for CNWL Memory Services. Dementia information for Black, Asian and minority ethnic (BAME) communities.*  
Central and North West London NHS Foundation Trust, Feb. 2016.  
This Toolkit includes useful guidance on topics such as: how to work well with interpreters; building partnerships with voluntary and community sector organisations who work with BAME communities; and a list of relevant websites, on-line films and social media groups relating to BAME people and dementia. There are also links to Dementia Information leaflets in a wide range of languages.  
<http://www.cnwl.nhs.uk/wp-content/uploads/Memory-Services-Handbook-final.pdf>
2. Chinese National Healthy Living Centre *Defeating Dementia*  
This booklet is in Chinese and covers introductory information about dementia.  
[www.cnhlc.org.uk/booklets/Defeating\\_Dementia.pdf](http://www.cnhlc.org.uk/booklets/Defeating_Dementia.pdf)
3. Rauf, A. *Caring for dementia: exploring good practice on supporting South Asian carers through access to culturally competent service provision.*  
Meri Yaadain, Bradford, 2011.  
<http://www.better-health.org.uk/resources/toolkits/caring-dementia-exploring-good-practice-supporting-south-asian-carers>
4. *Dementia friendly Gurudwaras Toolkit*, 2014. This resource includes advice on looking at how accessible the physical environment is for people with dementia; practical ideas on ways to develop a dementia- aware and friendly gurdwara; and links to information leaflets about dementia in relevant South Asian languages.  
<http://dementiafriendlygurudwaras.files.wordpress.com/2012/06/dementia-friendly-gurudwaras-toolkit.pdf>
5. Health Education England, *Finding Patience*, 2016. These two films focus on the dementia experiences of a Caribbean older woman, Patience, and her family. Part One portrays her changing health, leading to a dementia diagnosis. Part Two depicts different types of care in the residential home Patience moves to.  
<https://hee.nhs.uk/our-work/person-centred-care/dementia/finding-patience>
6. Alzheimer's Society, *Dementia Information* booklets and *Worried about your memory?* booklets in languages including Arabic, Bengali, Chinese, French, Gujarati, Italian, Polish, Punjabi, Somali, Tamil, Turkish, Urdu and Welsh.  
[https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1138](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1138)