



THE EMPATHY PROJECT:

A BLUEPRINT FOR TRANSFORMING



DEMENTIA ASSESSMENT AND SUPPORT IN BRISTOL



The EMPATHY Project team



We would like to thank all of the people who have been affected by dementia within the three communities and who supported the EMPATHY project. This includes the many people who took part in the focus groups and interviews as well as those who trusted our community researchers with their stories. We would like to thank all of them for their support and we hope that we have done justice to their experiences here.

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Foreword

Dementia is a growing public health challenge, but its impact is not experienced equally. Too often, people from minoritised communities face delayed diagnosis, poorer access to support, and services that do not reflect their languages, cultures, or everyday realities. The EMPATHY project shows why research in this area must do more than describe inequality: it must work alongside communities to understand lived experience, build trust, and co-produce solutions that make sense locally.

This report is a powerful example of what can be achieved when community organisations, families, clinicians, and researchers work in partnership. By listening carefully to what matters to people, the team has developed an approach that is not only culturally responsive but also practical and grounded in real-world needs. The lessons from this work are clear. If we want fairer dementia care, we need to value community knowledge, invest in long-term relationships, and design pathways with communities rather than for them. That is how we create support that is meaningful, equitable, and more likely to be used.

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Introduction.

Historical summary

In 2015, the Chinese Community Wellbeing Society initiated our first research project by inviting Bristol Black Carers and Dhek Bhal to partner with the University West of England to give a voice to the people in our communities who were living with dementia or caring for their loved ones. We received funding from Bristol City Council and together with the Alzheimer's Society worked over eighteen months with Subitha Baghirathan to find out the experiences of living with and alongside dementia in our three communities.

Our report (*'The Dementia Experiences of People for Caribbean, Chinese and South Asian Communities in Bristol'*) was launched in February 2017. We highlighted major gaps in Caribbean, Chinese, and South Asian communities' knowledge about and access to dementia services. Across all communities, families told us about inadequate assessments, poor use of interpreters, culturally inappropriate diagnostic tools, and feeling unheard by professionals.

To make sure that we did not *'leave the research on the shelf'* we set up a Dementia Working Group comprising both our three communities and other dementia organisations across Bristol and developed an action plan to implement the report's recommendations.

Starting point

While several changes were made because of our initial work, we felt that more needed to be done. With support from the research department at Bristol, North Somerset and South Gloucestershire ICB we carried out a listening exercise meeting people from each of the three communities to learn from them about the challenges they faced and to identify their research priorities.

After listening to our service users, we identified that many gaps in service provision still existed for them. People within all three communities often struggled to gain access to dementia services. We therefore set out to explore how we could develop an enhanced pathway for our service users – one that led to earlier diagnosis and improve management.

Our Approach to Research

As a research group we are committed to ensuring that our work is shaped by the perspectives of those who use services — not solely by our own. Only by grounding the research in the lived experience of people (carers and cared-for) living with and alongside dementia can we hope to develop insights that genuinely reduce the stress of navigating care. The challenges they face are not only medical, physical and social but also includes a psychological impact that can so often be overlooked.


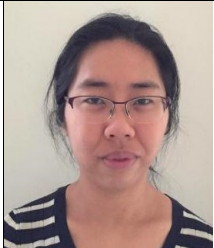

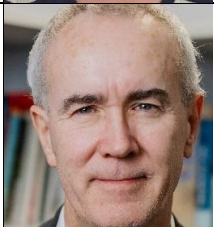
Co-production is therefore central to this study and in implementing this we have been supported by Chiara Lodi from the Black South West Network. We draw on the “three-legged race” model described in the *2024 Charter for Co-production*, which highlights the importance of shared responsibility, trust, and collaboration between academic institutions, community organisations, and individuals.





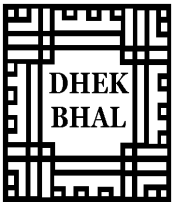




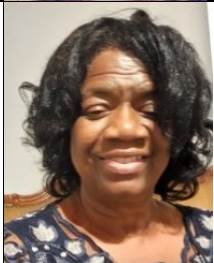
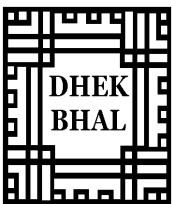

The Charter focuses on three key principles: transparency, recognition of lived experience as a valid and essential form of knowledge, and fair and equitable access to resources. It offers a practical toolkit that sets out expectations for both academic and community partners and aims to ensure that research is accountable, benefits communities, and actively challenges racism.

Securing funding for the project.

To reflect our wish to work in partnership, we designated two co-leads, Professor Richard Cheston (UWE Bristol) and Emily Choi (Chinese Community Wellbeing Society). Our project team is made up of Anndeloris Chacon (CEO, Bristol Black Carers), Zehra Haq (CEO, Dhek Bhal), Rosa Hui (Founder and Retired CEO of Chinese Community Wellbeing Society) and Chiara Lodi (Lead Researcher, Black South West Network). With support from many sources, we were able to successfully apply for funding from the NIHR – and started our project in October 2024. Key to the success of the project has been the work of three community researchers: Manazzar Sidique (Dhek Bhal) and Carmen Hutchinson (Bristol Black Carers) who joined Emily Choi in March 2025. What was initially intended to be an eighteen-month study was subsequently extended by two more months with additional funding from the NIHR to enable us to complete the study and to write this report.

The EMPATHY Research Team

		<p>Emily Choi (<i>Co-lead and community researcher</i>) has worked as a Dementia Project Coordinator at the Chinese Community Wellbeing Society since 2022, supporting Chinese speaking people living with dementia and their families.</p>
		<p>Richard Cheston (<i>Co-lead</i>) is a Professor of Dementia Research at UWE Bristol. Prior to this he worked as a Clinical psychologist in the NHS for 25 years.</p>

		<p>Dr Rosa Hui MBE DL (<i>project team</i>) is the founder and retired CEO of the Chinese Community Wellbeing Society. Although she has stepped back from day-to-day work, Rosa remains passionately and actively involved in CCWS' work on dementia.</p>
		<p>Anndeloris Chacon BEM (<i>project team</i>) is the CEO of Bristol Black Carers, and is a community leader with over forty years of nursing experience. A Dementia Advocate seeking to build trust and practical pathway to help families.</p>
		<p>Zehra Haq (<i>project team</i>) is the Chief Executive of Dhek Bhal, a community organization in Bristol, involved in various initiatives supporting South Asian communities, including dementia awareness and research inclusion.</p>
		<p>Chiara Lodi (<i>project team</i>) is a Research Manager at Black South West Network. Chiara's work analyses barriers to inclusive economic growth, generating evidence for policy to reduce inequality.</p>
		<p>Carmen Hutchinson BA (Hons) Business and Psychology (<i>Community Researcher</i>). Carmen has thirty years' experience in training and care, including dementia support, giving her deep insight into community needs.</p>
		<p>Dr Manazzar Sidique (<i>Community Researcher</i>) combines her scientific background with extensive experience of supporting people living with dementia and their carers from South Asian communities</p>

Executive Summary

Background. Dementia prevalence is rising, and while people from minority ethnic communities are at higher risk of developing dementia, they remain substantially less likely to receive a timely diagnosis, appropriate treatment, or post-diagnostic support.

Previous research identified low awareness, stigma, fragmented pathways, language barriers, and limited trust in statutory services as major obstacles. Community organisations - trusted, culturally aligned, and linguistically attuned – were seen as playing an essential role in bridging these gaps.

Research Aims and Methods. The study was funded through NIHR’s Programme Development Grant and set out to:

- understand the barriers to diagnosis within the three communities;
- co-produce a culturally sensitive intervention to support communication with GPs; test the intervention in real-world settings; and
- capture learning to inform service redesign and partnership building.

Phase one: Public Consultation. We consulted with a total of thirty-seven people affected by dementia across two rounds of focus groups and interviews. This work suggested that people’s engagement with dementia services was characterised by:

- a *mistrust of statutory services* in which many participants felt unheard, misunderstood, or judged in clinical encounters;
- *stigma* in which dementia was associated with shame, weakness, or “madness,” contributed to delays in seeking help;
- a series of *practical barriers* to assessment and diagnosis including difficulties accessing GP appointments as well as intensive family caring with limited support; and
- the *essential role of community organisations* which acted as bridges into statutory care.

Phase two: the EMPATHY letter arose from these consultations and was designed to enable people within communities to tell their story to their GP and other health and social care professionals. The letter is a personalised, structured account of an individual’s cognitive concerns written collaboratively by community researchers, the person, and their family. Three community researchers engaged with 25 people during this phase of the study. Of these 25 participants:

- Eleven people either did not meet the study criteria or could not be contacted;
- Four people completed draft letters with researchers but chose not to take them to their GP after reflecting on their difficulties and the implications of a diagnosis;
- Three participants are waiting to see their GP;
- Two people have seen their GP, shared their letters, and been referred for initial screening tests prior to referral for specialist assessment; and
- Five participants have completed screening and have been referred to specialist dementia services for full assessment.

The letter had three core benefits:

- it captured culturally specific symptoms (e.g., changes in prayer, food, or language use) that would otherwise rarely be raised in GP appointments;
- it provided therapeutic value by validating people's experiences and enabling family dialogue; and
- it improved GP consultations, reducing the communication burden on participants and increasing confidence that concerns would be taken seriously.

Conclusions. The study demonstrates that structural inequalities, stigma, cultural misunderstanding, and service design continue to impede access to timely dementia support for these communities. However, the EMPATHY Letter shows strong promise as a culturally sensitive, relational tool that bridges key gaps between communities and primary care. However, enduring concerns remain around the ability of statutory and community groups to work together to provide the personalised, joined up care that people living with dementia and their families from these three communities require.

Recommendations. Taking our findings from both phases of the study together shows that action is urgently needed to provide equity of care for people from South Asian, African-Caribbean and Chinese communities. The way to achieve this is through:

- *formal partnerships* between statutory services and community organisations;
- *a dedicated resource and research centre* where the three communities can share resources – this will initially focus on service users with dementia as a pilot, but ultimately move to other conditions;
- *embedding the EMPATHY Letter* into local dementia pathways;
- *improving Primary Care accessibility*, including appointment systems and cultural understanding;
- *strengthening assessment quality* across the dementia pathway; and
- *community-led stigma reduction strategies* delivered by community organisations in relevant languages.

Implementing these recommendations would significantly enhance equitable service delivery, improve early diagnosis and positively impact on the quality of life of people living with dementia and their families across Bristol's diverse communities.

Background.

The term 'dementia' refers to the symptoms of a disease process that results from physical changes in the brain. The chief characteristic of dementia is a severe cognitive impairment that progressively extends across almost all of a person's abilities, including their memory, language and problem-solving as well as bodily functions such as movement-related difficulties and sometimes problems in swallowing. As a result of these changes the person's ability to complete practical everyday tasks becomes progressively compromised. Many different illnesses cause dementia, but the majority of

people who live with dementia have been affected by one of three conditions: Alzheimer's disease, vascular dementia and mixed Alzheimer's and vascular dementia.

In the UK, the number of people with dementia will rise by a third between 2014 and 2025 when a million people are expected to have dementia. This rate of increase will continue so that by 2050 there will be around two million people living with dementia in the UK. Of the roughly 950,000 people who are living with dementia in the UK, a relatively small proportion (around 25,000 to 30,000 people) are from African-Caribbean, Asian or other minority ethnic communities. However, over the next thirty years, the numbers of people from non-white British communities will increase rapidly, by a factor of seven, compared to an overall doubling in numbers.

Dementia and the global majority.

While people from many ethnic communities are at greater risk of developing dementia than are their white counterparts (e.g., Mukadam et al., 2023; Sheikh et al., 2021), research consistently shows that they are less likely to access support and that when they do so this tends to be at a later stage in the illness (Department of Health, 2009; LaFontaine et al., 2007), when the patient is often more severely impaired or in crisis (Mukadam et al., 2011; Hailstone et al., 2017). For instance, a 2018 large-scale analysis of primary care data that found that despite there being a higher risk of dementia for South Asians than for white Britons, national diagnosis rates were 18% lower for South Asian women and 12% lower for South Asian men (Pham et al., 2018). Similarly, in a study of referrals to one memory service, significantly fewer South Asian patients (44%) than White British patients (62%) were likely to access dementia diagnostic services in a timely way (Ogliari et al., 2020).

Inequalities in dementia service provision persist after diagnosis. People from many ethnic minority communities are less likely to access the dementia care pathway (APPG, 2013; Hailstone et al., 2017) or to receive NICE-recommended treatments, including medication for Alzheimer's disease, than are their white British counterparts (Baghirathan et al., 2020; Parveen et al., 2017). People from ethnic minority communities who are living with dementia and their carers are more likely to evaluate NHS dementia services negatively (Mukadam et al., 2011) and to be cared for at home and have a poorer quality of life (Victor et al., 2023; James et al., 2023).

Across the research literature, a series of barriers to accessing dementia services have been identified across community, dementia services and commissioning levels (Oyebode and Parveen, 2025). Taken collectively three themes consistently emerge:

- First, dementia care pathways tend to default to a one-size-fits-all model that overlooks cultural and linguistic diversity and thus systematically disadvantages people from minority ethnic groups (Oyebode and Parveen, 2025);
- Second, the main factors that determine whether people seek to access dementia services are their trust in those services (Brown et al., 2025), whether their language

or dialect matches those provided within those services and whether dementia services provide culturally relevant care (Arblaster, 2021).

- Finally, community-led, co-produced approaches in which statutory services partner with community and faith partners provide the most credible route to earlier diagnosis and sustained engagement (Cheston et al., 2025; Chaib et al., 2025).

The Dementia Pathway in Bristol

In Bristol the statutory provider of dementia services is the Bristol Dementia Well-being Service or DWS. This is a unique partnership between Alzheimer's Society and Devon Partnership NHS Trust, fully funded by the local integrated care board, and serving the very diverse population of Bristol (Holmes and Collings, 2023). DWS was set up after extensive consultation with local people who asked for a dedicated dementia pathway providing continuity of care from diagnosis through to the end of life.

Unlike other NHS dementia services, nobody who is living with dementia and is referred to the service, is discharged from DWS. People with dementia are assigned a named dementia navigator (Alzheimer's Society role) who maintains regular contact and are supported by qualified dementia practitioners (NHS role) according to clinical need. The service recognises longstanding social and health inequalities and employs community development coordinators to build and maintain relationships with different local communities.

The dementia pathway in Bristol differs from that in most other parts of the UK as the assessment and diagnostic process sits largely within primary care. This structure frees up capacity within the dementia service to concentrate on providing specialist diagnostic services, e.g. young onset, rare dementias and ongoing post diagnostic support for people living with dementia and their families. Thus, when a patient contacts their GP about their symptoms, the GP will take a history, carry out some basic checks (e.g., blood tests and a brain scan) and carry out a brief cognitive assessment. These checks help the GP to rule out other conditions that can look like dementia.

It is expected, under their commissioning arrangements, that the GP will attempt to make a diagnosis themselves and refer the patient to the Bristol Dementia Wellbeing Service (DWS) for ongoing support. If the diagnosis is made by the GP, then a dementia navigator will then visit the person to talk through the diagnosis and explain what support is available. However, if the person's presentation is more complex (e.g., if English isn't the person's first language, or the person grew up in a culture outside the UK or is under 65), then the GP has the option of referring the person directly to DWS and to ask them to carry out the diagnostic assessment. This complex assessment will be conducted by the dementia practitioner with a multi-disciplinary discussion, including psychiatry to determine diagnosis.

National policies: the patient and carers race equality framework.

The NHS' commitment to reducing health inequalities and eliminating racial discrimination has been reflected in a series of policy documents and initiatives over recent years:

- **The National Healthcare Inequalities Improvement Programme (HiQiP)** was established in 2021 and coordinates efforts across NHS England to reduce healthcare inequalities, including those affecting ethnic minority groups.
- **Core20PLUS5** is an NHS England initiative designed to reduce health inequalities by targeting the most deprived and vulnerable populations and builds on an understanding that a “*one-size-fits-all*” approach doesn't work for equitable health outcomes. It focuses on the most deprived 20% of the population who are experiencing the greatest health inequalities and targets five key clinical priorities with evidence of significant health inequalities including adult mental health.
- The [Patient and carer race equality framework \(PCREF\)](#) was launched in the autumn of 2023 and was NHS England's first ever anti-racism framework. This mandatory framework is intended to be embedded within all NHS mental health trusts and mental health service providers across England and to support them to become actively anti-racist organisations. Importantly it emphasises that NHS trusts work with local communities to co-produce and implement concrete actions to reduce racial inequalities within their services. These action plans will then become part of Care Quality Commission (CQC) inspections. The PCREF will support improvement across three main domains:
 - *Leadership and governance* – the boards of NHS trusts are required to lead on establishing and monitoring concrete plans of action to reduce health inequalities;
 - *Data* - new data sets on improvements in reducing health inequalities will need to be published, as well as details on ethnicity in all existing core data sets; and
 - *Feedback mechanisms* - visible and effective ways for patients and carers to feedback will be established, as well as clear processes to act and report on that information.

Addressing health inequalities across Bristol.

This report is a culmination of a twelve-year collaboration between three community organisations (Bristol Black Carers, the Chinese Community Wellbeing Society and Dhek Bhal) and UWE Bristol. In 2015 we received funding from Bristol City Council to establish the experiences of people living with dementia from these three communities. This funding enabled us to employ Subitha Baghirathan as a researcher and during an eighteen-month study she talked with over seventy people affected by dementia across the city, finding out from them about their experiences both of dementia and of accessing services.

We reported in 2017 and highlighted major gaps in knowledge, access, and trust around dementia within Caribbean, Chinese, and South Asian communities. Many people, particularly in Chinese and some South Asian groups, lacked a clear term for dementia, often confusing it with normal ageing or mental illness, which reinforced stigma and delayed help seeking. Some people within African-Caribbean communities were more familiar with the condition but still faced misconceptions and significant mistrust of statutory services due to historic experiences of racism. Across all communities, families described inadequate assessments, poor use of interpreters, culturally inappropriate diagnostic tools, and feeling unheard by professionals.

The people we spoke with both needed and wanted support, but they were reluctant to accept this if it came at the cost of being diminished as a person – something that they feared would happen if they engaged with mainstream dementia services. To resolve this dilemma, informants turned to community organisations, which provided ongoing, culturally trusted support and advocated on behalf of their members. Participants emphasised the need for culturally tailored care, including appropriate food, language, religious support, and familiar environments, as mainstream services often failed to meet these needs. The report called for targeted awareness campaigns, improved ethnicity data, better training for professionals and interpreters, culturally adapted assessments, stronger support for community organisations, more diverse care staff, and expanded individualised residential and respite services.

Progress since the 2017 report - Projects in Bristol

In the eight years following the publication of the 2017 report, our group has led or contributed to a series of research and service-related projects aimed at improving the lives of people living with dementia and their families from different communities. Importantly, the report led directly to the establishment of the Chinese, Caribbean, South Asian and African (CCSAA) Dementia Working Group to co-ordinate responses to the report and seek the implementation of its recommendations. Amongst the different projects the group has worked on are the following:

- **Training for GPs.** The first round of training sessions for GPs was delivered by Subitha Baghirathan who presented the findings and recommendations of the 2017 report to GPs. A second round of training sessions built cultural understanding of the three communities and focused on how to ask the relevant questions about a person's culture respectfully and to allow them to answer with dignity.
- **Ageing Well Project: BAME Dementia Coordinator** (Emily Choi). This project delivered culturally sensitive information workshops and carers support groups to the Chinese, South Asian and African-Caribbean communities living with dementia from 2022 to 2024. Emily acted as the coordinator of the CCSAA Dementia Working Group and also delivered a series of cultural understanding training sessions to GPs and other dementia VCSOs.

- **Ageing Well Project - BAME Dementia services** enabled each community to design and deliver services that met their own needs, while sharing learning and information with one another. Additional funding was later provided to assist with coordinating the CCSAA Dementia Working Group.
- **Ageing Well Project - Dementia Support Hub for East and Southeast Asian (ESEA) Carers.** This delivered culturally sensitive information workshops and therapy/wellbeing sessions for ESEA carers as well as offering ad-hoc advice. The project additionally set up a 'dementia library' full of culturally sensitive resources including books and games.
- **Reducing Health Inequalities Project.** Beginning in 2024 this project provided 'healthy ageing' workshops, carers support groups and intervention activity sessions for older people and people living with dementia from the Chinese, South Asian and Caribbean communities. It also delivered cultural understanding training sessions to GPs.
- **NHS Charities Together.** These projects (within the Chinese and South Asian communities) aimed to improve the wellbeing of those living with dementia. In the Chinese community the project ran a series of gentle exercise sessions, while the South Asian community created and recorded a '[dementia song](#)' to raise awareness.
- **Training for communities.** This project involved training from DWS Community Development Co-ordinators ('*dementia friends*' and '*dementia awareness into action*' training) delivered to community organisation staff to increase their capacity and improve understanding of dementia.
- **Information workshops.** This involved a series of sessions where information related to dementia, including the findings of the 2017 report, was delivered to the community as well as sessions on improving understanding of dementia and highlighting risk factors for dementia.

The current position.

Roughly 230 people from Chinese, African-Caribbean and South Asian communities are living with dementia in Bristol. However, despite the initiatives we have outlined above, many people from the three communities that we work with who are either living with dementia or caring for members of their family who have dementia continue to struggle to access appropriate services. While some things have changed, much remains as it did ten years ago – and many of the recommendations from the 2015 to 2017 study were not implemented. Importantly, that report did not address a critical issue – that of improving partnership working between the statutory sector and community organisations.

Aims of this study.

The aim of this project is to transform the way in which people from Chinese, Caribbean and South Asian communities are assessed and diagnosed with dementia in Bristol. In order to do this, we set ourselves the following objectives:

- To build on gaps and recommendations identified in earlier reports, particularly the need to improve communication and trust between services and families.
- To gather lived experience perspectives and identify structural and relational barriers.
- To work with the community to deepen understanding, refine themes, and co-produce ideas with community members.
- To develop an intervention aimed at making diagnostic communication more accessible, compassionate, and culturally attuned.
- To test the intervention by piloting it in practices, followed by feedback loops with families, clinicians, and community members.
- To identify lessons we had learned from carrying out the study

The project does not set out to replace the existing diagnostic systems or to provide clinical training. Rather it focuses on improving access to those services – thus building towards a truly equitable diagnostic process built around enhanced communication, improved trust and relational, person-centred practices.

Identifying Research Priorities.

What did we do?

As a research group, our starting point in improving dementia services for members of Chinese, South Asian and African-Caribbean communities was to ask members of those communities about their experiences and to find out from them what their priorities for research were. Thanks to RCF funding from Bristol, North Somerset and South Gloucestershire ICB Research team, we were able to convene three focus groups during the summer of 2023. Each of these groups was organised by one of the community organisations – the Chinese Community Wellbeing Society (which was attended by eight people including both family carers and people living with dementia), Bristol Black Carers (six people) and Dhek Bhal (eleven people).

What did we find out?

Across all groups, dementia care is experienced as family-led, intensive, and poorly supported by statutory services. Participants shared consistent experiences of high caring burden, systemic barriers, stigma, and inadequate support, alongside a strong reliance on family and community networks.

Carers consistently described taking on responsibility long before services were involved, often providing 24/7 care with serious impacts on their physical health,

mental wellbeing, employment, and social lives. Stress, exhaustion, isolation, and carer illness were common. Support was typically accessed only at crisis point.

Diagnosis remained a major barrier for participants across all three groups. Carers reported delayed, missed, or dismissed diagnoses, narrow assessments that failed to reflect daily functioning, and little ongoing monitoring. African-Caribbean carers explicitly identified racial inequities, noting faster diagnosis and better support for white relatives. Without diagnosis, access to services and stigma reduction were severely limited.

There was widespread mistrust of health and social care, driven by experiences of not being listened to, what was perceived as culturally insensitive practice, and inflexible, fragmented services. Dementia continues to carry strong stigma, reinforced by derogatory language in community contexts, leading families to hide difficulties and delay seeking help.

Post-diagnostic and advanced-stage support was described as minimal with community organisations being repeatedly identified as trusted, effective, and essential—often compensating for systemic gaps in the statutory services.

The key research priorities identified across the groups included earlier diagnosis and sustained post-diagnostic support. Importantly, the diagnosis of dementia emerged as the most pressing need – as one participant in the Bristol Black Carers focus group told us:

“Diagnosis is a big, big problem – with diagnosis you can also fight stigma – many of the other priorities follow on from this – if you don’t have a diagnosis, then you can’t later get the support – this and others follow on from the diagnosis”

Phase One – Co-Developing the Research Intervention.

What did we do?

The feedback from these preliminary focus groups supported us in applying to the National Institute for Health Research (NIHR) Programme Development Grant Developing Innovative, Inclusive and Diverse Public Partnerships workstream. This application was successful and we received funding to establish an eighteen-month project beginning on the 1st October 2024 and ending on the 31st March 2026. A subsequent application for additional funding was also successful and extended the project until the 31st May 2026. EMPATHY has had two active phases of research.

Our first steps in the study were to understand more about the barriers to assessment and diagnosis that members of the three communities faced. To this end the two project

leads (RC and EC) actively consulted with academics, researchers and clinicians in the UK and abroad to identify as many resources related to these areas as possible. The project team also met with three local GPs as well as the Dementia Wellbeing Service and Bristol City Council to understand more about their roles and responsibilities.

During the first three months of 2025, EC and RC supported by AC, RH and ZH consulted with the public through two engagement events in each of the three communities (details of participants are provided in Appendix One). Recruitment to these events was through the three community organisations.

The first round of engagement events focussed on understanding of dementia within each community, the best way to communicate information about dementia and potential barriers to diagnosis. As these issues concerned the community at large, we did not seek to restrict attendance at these events solely to people with lived experience of dementia for these engagement events. In the first round of focus groups, we spoke with seventeen people (six South Asians, five Chinese and six African-Caribbean participants).

The second round of engagement events focussed on post diagnostic experiences and support, and here we restricted attendance to people with lived experience. This round of engagement involved both focus groups (with six South Asians and seven Chinese participants) and three interviews with seven people from the African-Caribbean community.

What did we find out?

The information that we received from participants across all three communities in Phase One can be summarised in terms of five, related, themes. A more detailed description of our findings from this public consultation is provided in Appendix 2.

1. *Mistrust of the Health and Social Care system* - A strong sense of mistrust toward statutory services was evident across all groups. Participants described feeling unheard, misunderstood, or judged. Assessments of capacity were seen as superficial and insensitive to cultural and contextual realities. For many, repeated negative interactions reinforced reluctance to seek help and deepened reliance on family care, despite escalating need.
2. *Stigma, Ambivalence, and Delays in Seeking Diagnosis* - Dementia continues to carry significant stigma, often associated with shame, “madness,” or personal failure. Derogatory terminology in community languages exacerbates fear and silence, leading families to conceal difficulties and delay help-seeking. While awareness is improving through education and community initiatives, stigma remains a powerful barrier—particularly at early stages of illness.
3. *Barriers to Diagnosis* - Across African-Caribbean, South Asian and Chinese communities, participants reported significant racial inequities in dementia diagnosis and support. In part, as we have explained above, this relates to communities’ reluctance to use services that they don’t trust, and for conditions that

are stigmatised. However, in addition, carers commonly experienced dismissal of their concerns by GPs, delayed referrals, and reliance on narrow assessments that failed to reflect everyday functioning. Across all groups, participants emphasised that cultural competence is essential to ensure dignity and safety and to meet dietary needs. They felt that statutory cultural-awareness training alone is insufficient, and that only community-based, culturally led services would be experienced as safe, respectful and meaningful.

4. *Caring on one's own* - Families across all communities provide intensive, 24/7 dementia care long before services get involved, often at great personal cost. Carers described exhaustion, declining mental and physical health, isolation, and loss of employment, with little practical support and services that often feel culturally mismatched or unresponsive. Chinese, South Asian, and African-Caribbean participants all reported major gaps in respite, night-time help, behavioural support, and timely social care. Late diagnosis also created legal and financial difficulties. Overall, carers felt overwhelmed, unsupported, and in urgent need of practical, culturally appropriate assistance. Many felt invisible to services until reaching crisis.
5. *The Essential Role of Community Organisations - essential bridges, not "nice-to-haves"* - Community organisations such as CCWS, Dhek Bhal and BBC were described across all focus groups as trusted, culturally aligned sources of safety, continuity and practical support, often bridging gaps in communication, language and navigation that statutory services failed to meet. Importantly, community organisations frequently employ people who are fluent in the language that their clients habitually use, thus building trust and acceptance by the service user. Additionally, community organisations have a nuanced understanding of their clients' cultural and personal background that maximise their ability to build rapport. Building trust involves more than just having someone from the organisation or being from the same background. Trust involves a connection with someone that is built up over many years - something that is possible within many community organisations which value continuity of staffing and have established histories within the communities that they operate. As a consequence, participants felt understood within these community settings in ways not replicated in mainstream services, relying on them for help with identifying symptoms, accessing GPs, reducing stigma, and receiving culturally meaningful post-diagnostic support. South Asian and Chinese participants emphasised the importance of linguistic and cultural understanding - particularly as the progressive cognitive decline involved in dementia can lead to people falling back on their first language. Participants commented that these organisations were often the only places offering meaningful respite or engagement. Across groups, participants called for formal, funded partnerships between statutory services and community organisations, highlighting severe gaps in post-diagnostic and advanced-stage support, where help often fell away and care was culturally inappropriate. Despite limited resources, community organisations were

consistently praised for providing the trusted, continuous, culturally competent care that families urgently needed but seldom found elsewhere.

Phase Two - Development and Testing of the Empathy Letter.

What did we do?

At the start of this phase of the study, we employed two community researchers – Manazzar Sidique (Dhek Bhal) and Carmen Hutchinson (Bristol Black Carers). Additionally, Emily Choi took on the role of Community Researcher for the Chinese community in addition to acting as co-lead for the study.

Developing the EMPATHY letter. From our Phase One consultations, we learned that many people experienced a range of barriers that delayed their assessment. These included uncertainty about whether to seek help, fears about stigma, limited knowledge of how to access support, practical difficulties in booking a GP appointment, concerns that their GP had not fully understood their situation, and confusion about what should happen next.

In response, we set out to record the stories of people in our communities who were worried about their memory but struggled to communicate these concerns to the health system. Our aim was to document their stories but to do so in a way that would be meaningful for GPs. To support this, we met with GPs to understand what information they found most useful during an initial consultation. We also consulted with clinicians and managers from the Dementia Wellbeing Service (DWS) to ensure that our intervention was consistent with the existing pathway. The intervention that emerged from these discussions had three elements.

First, the three community researchers would spend time with individuals and their families experiencing memory problems to gather their personal story.

Second, the researchers would use this information to draft a “*letter of concern*” that was structured in a way that would be useful for GPs. The researchers would then check back with participants and their families that they were happy with the letter.

Finally, where necessary the researchers would work with participants to arrange an appointment with their GP and if the participants wanted, email the letter to the GP in advance of the meeting.

We then took this back to each of the three communities in a third round of consultations where we asked participants for their views on the format of the letter and how it might be used in practice. The series of meetings was broadly supportive and made suggestions for how this model could work more effectively. Finally, we applied for

ethical approval from UWE Bristol' Health and Social Sciences College Research Ethics committee¹.

Participants and recruitment. Participants were service users of one of the three Bristol, community led partner organisations (Dhek Bhal, Bristol Black Carers and the Chinese Community Wellbeing Society). Flyers about the project were distributed across the community organisations as well as being sent to GPs, and community researchers offered informal presentations about the project in each of the organisations. Potential participants were selected through three routes: first, the service user themselves expressed concerns about their own cognitive functioning often following workshops about dementia run within the organisations; second, a member of their family contacted the team to express concerns about the person's cognitive functioning; and finally, a member of the community organisation expressed concerns about the person's cognitive functioning. We excluded people where they were already receiving treatment for conditions associated with cognitive decline, if they had serious co-morbid health needs or if they were judged to lack capacity (see Appendix two for a flow chart illustrating the process of engaging with participants across the study).

When potential participants were identified the community researcher contacted the person concerned to introduce the project. If the person was willing to meet, then the community researcher asked the person's permission to convene a family meeting. During this meeting the researcher assessed the person's capacity to provide consent by checking understanding, retention, decision-making, and ability to communicate a decision. Where potential participants were judged to have capacity, then the researcher explained further about the purpose of the study, providing the person, and members of their family with Information Sheets about the study, explaining the study's purpose, its voluntary nature, the risks and benefits of taking part, and data confidentiality. Where necessary this information was translated. Where people were willing to take part, then they were asked to sign a consent form. The study did not set a fixed sample size but anticipated recruiting between three and six eligible people from each community.

Drafting the EMPATHY letter. Following the initial meeting or meetings with the participant and their family, the Community researcher drafted the EMPATHY letter. They then took that back to participants, giving them the chance both to identify any errors or omissions, but more importantly to make a decision as to whether to take the letter to their GP. Some participants also decided to discuss this further with their family. The researcher also discussed with them whether they would like the letter to be sent to the GP surgery by email.

Where participants decided that they did want to consult with their GP, the researcher stayed in touch with them and where necessary offered to book an appointment themselves (for instance if the participant did not have internet access or lacked confidence in talking over the telephone).

¹ Ethical approval was received on the 12th August 2025 (application ID, 14541948)

Safeguarding and ethical procedures. Because the study involved potentially vulnerable participants, all work followed existing safeguarding procedures within each community organisation. Researchers monitored capacity continually and used HRA-aligned participant information sheets that had been trialled with local communities and revised based on feedback. Photos of researchers were included to support recognition.

Withdrawal and managing distress. Participants were free to withdraw at any time before data anonymisation, with reassurance that their care would not be affected. Because the study involved sensitive discussions about memory difficulties and family impact, the team implemented a protocol for responding appropriately to any distress observed during interviews or intervention activities.

How did the EMPATHY letter impact on people's lives?

The three community researchers (EC, MS and CH) engaged with twenty-five people over the course of the study (see Table One). Of these, ten people did not meet the criteria for the study due to: not wanting to engage (5 people); not having capacity (2), already having a diagnosis (2), and being physically ill (1). Additionally, one potential participant could not be contacted. Of the fourteen people who consented to be part of the study, the community researchers were able to work with them to draft an EMPATHY letter.

Table One: participants progress through the study

	Chinese	South Asian	African-Caribbean
Total number of people referred into project	11	8	6
Did not meet criteria for inclusion or not able to contact	4	3	4
Letter drafted but participant decided not to send to GP at this time	2	1	1
Letter agreed and waiting for GP appointment	0	3	0
GP referred for blood tests and scan	1	1	0
GP has referred patient on for diagnosis	4	0	1

After drafting the EMPATHY letter with community researchers, four participants decided not to continue and to take this letter to their GP. However, all four participants and their families felt that this had been helpful for them as it enabled them to talk together as a family and to come together to make a decision about care – a process that we explore below in the case studies of Charming.

Three participants are waiting for an appointment with their GP while seven have seen their GP. The feedback we have received from all participants is that being able to bring the letter to an appointment has been extremely helpful. For instance, one South Asian participant told us that she was thankful the letter had been sent by her community researcher in advance of her appointment. The GP had not read it prior to the appointment but instead read it during the consultation. Initially the GP felt the patient was too young and that it was unlikely that she had dementia. But after some insistence from the participant and her family together with the evidence in the letter, the GP had decided to make the necessary referrals. The participant and her family were thankful for this and felt that whatever the eventual outcome having their concerns taken seriously would mean that they would be given an explanation for why the participant has been experiencing the symptoms.

Two of the seven participants who have met with their GP and passed the letter over are waiting for additional tests to be carried out. These assessments (a blood test and head scan) are typically the preliminary tests that GPs are required to complete before referring patient to DWS. Finally, five participants have completed the screening process and have been referred into the specialist dementia services for an assessment.

Time between engaging with the study and GP appointment. A striking aspect of this process of engaging people in discussing their memory concerns is the time that this takes. Thus, for the five South Asian participants that MS worked with, the average time between the start of gathering information and the EMPATHY letter being agreed was 61 days. For the five Chinese participants, this average wait was 34 days, with an additional 30 days elapsing before participants were able to see their GP. The process of collecting information could be delayed due to a variety of reasons including: participants being away (e.g., making a pilgrimage, visiting Hong Kong), illness, family members not being available to check and approve letter, concerns about being placed in care home, observing Ramadhan and celebrating Eid. More generally, however, the delays seem to reflect participants' ambivalence about addressing their memory concerns exacerbated by the stigma towards dementia within communities.

Impact Across Communities.

In order to illustrate the impact of the letter we have provided case studies of the way in which the letter was used with three participants from South Asian, African-Caribbean and Chinese communities. At the time of writing, each participant had experienced a

different outcome. The first (Mr Wong) had been referred by his GP to DWS and following an assessment had received a diagnosis of dementia. However, concerns remained for his wife about how care could be delivered effectively when structural barriers prevented DWS and CCWS working together. Our second case study (Mrs Bibi) is waiting for this an appointment with her GP. The final case study (Charming) worked with CH, the community researcher, to draft the letter but ultimately decided not to make an appointment with her GP.

In order to protect the identities of all participants we have obscured their personal details and used pseudonyms.

Mr Wong – referred to dementia services

Background

Mr Wong is a man in his seventies who migrated to the UK from Hong Kong. His wife had raised concerns about his memory several years earlier, and Mr Wong visited his GP approximately two years ago, during which he completed a brief cognitive test. This did not lead to further investigations or follow-up assessment. Over the subsequent two years, his cognitive health continued to deteriorate, causing increasing concern within his family.

Despite these worries, Mr Wong was reluctant to re-engage with his GP. Language barriers made booking appointments and explaining his symptoms challenging, contributing to delays in seeking further help.

Cognitive and Behavioural Changes

At the launch of the EMPATHY project, Mr Wong, a long-standing client of the Chinese Community Wellbeing Society, was invited to participate. During an interview with EC, the community researcher, he described a pattern of increasing forgetfulness. This included difficulty remembering everyday tasks such as whether he had eaten, locked the car, or taken his medication.

Mr Wong's family had also noticed that he had become more socially withdrawn over the past two years and that there were changes in his behaviour, including mood swings and reduced attention to personal hygiene. In the months leading up to the interview, he had begun to wander, which caused significant anxiety for his family and raised concerns about his safety when left alone.

The EMPATHY Support Letter

Following the interview, the community researcher drafted an EMPATHY support letter summarising Mr Wong's experience and clearly outlining the key concerns about his cognition, behaviour, and everyday functioning. The letter was reviewed and approved by Mr Wong and his family.

EC then supported the family to book a GP appointment. This practical assistance was particularly important, as Mr Wong had previously struggled to access primary care and other health services due to language and system-navigation barriers.

Appointment with the GP

In contrast to earlier attempts to seek help, the GP appointment was structured around the EMPATHY support letter. The GP reviewed the letter with Mr Wong and his wife and used it as the basis for the consultation. A cognitive test was administered, and the GP arranged further investigations, including blood tests and a brain scan.

Engagement with dementia services

Mr Wong was then referred to the Dementia Wellbeing Service where he was assessed by a dementia practitioner and subsequently received a dementia diagnosis. Since then, Mr Wong and his family have received support provided through DWS, his GP and CCWS.

However, Mrs Wong continues to feel lost and worried about the future and has confided in CCWS staff that a number of features about her engagement with DWS continue to concern her. First, whilst DWS often translate their letters into Chinese, other dementia related materials are in English, and she continues to rely on CCWS to translate these for her. Second, DWS staff habitually suggest to clients that they visit them at home, assuming that this is more convenient for them. However, while in common with most Chinese people for reasons of privacy Mrs Wong would prefer to meet outside her home, she does not feel able to tell them this, for fear of causing offence. Finally, she does not want her daughter to continue taking time off from her job to provide language and emotional support for her parents. For all of these reasons, while Mrs Wong would like to continue to have contact with DWS, she feels it is essential to do so through the CCWS where they can interpret for her, translate materials and enable her to meet health service staff outside her home. Unfortunately, at present, there is no structure to enable DWS staff to engage with the CCWS in this way or to share patient related information with them.

Impact and Learning

Mr Wong and his wife expressed their appreciation for the support provided by the EMPATHY project, which helped them navigate an assessment process they felt unable to manage independently. Through their involvement in the project, Mr Wong and his family have been able to access much-needed treatment and support.

Mr Wong explained that the EMPATHY letter played an important role in shaping the GP consultation and making effective use of the limited appointment time. As his symptoms and concerns were clearly outlined in advance, he did not need to repeatedly describe his difficulties. He felt this enabled the GP to respond promptly and to make appropriate onward referrals.

Overall, Mr Wong and his family reported a very positive experience of the EMPATHY process. Participation in the project helped them develop a clearer understanding of dementia symptoms and to make sense of the changes they had been noticing. Having the opportunity to discuss these issues in a supportive and culturally sensitive setting increased Mr and Mrs Wong's confidence and motivation to seek medical support. This case demonstrates the value of community-based, culturally informed approaches in

reducing language barriers, improving access to care, and strengthening communication between individuals, families, and healthcare professionals. Nevertheless, moving forward, improved co-ordination and exchange of information between DWS and CCWS will be essential if Mr and Mrs Wong are to receive appropriate person-centred care that meets their needs.

Mrs Bibi – waiting to see her GP

Background

Mrs Bibi is an 82-year-old Muslim woman of Pakistani descent. She lives alone in her own home, supported by care workers from Dhek Bhal visiting three times a day, a family member staying overnight, and a strong wider family support network. She was referred to the EMPATHY project by her daughter, Nabeela, who had noticed a gradual deterioration in her mother's cognition over the past year, with a more marked decline in the last three to six months.

Mrs Bibi herself is concerned about her memory loss and reports feeling increasingly sad and lonely. The changes she is experiencing cause her significant anxiety, particularly when she feels she is not understood or believed.

MS, the community researcher, met with Mrs Bibi and Nabeela in Mrs Bibi's home. This enabled detailed discussions about her complex health history, daily living circumstances, cultural and spiritual life, and the changes in her cognitive wellbeing. Using this information, MS drafted the EMPATHY letter and then met again with Mrs Bibi and Nabeela to review, refine, and finalise it, ensuring that it accurately reflected their perspectives and priorities.

Health

Mrs Bibi has significant physical health needs. She is physically disabled and uses a wheelchair and a Zimmer frame, with extensive adaptations made to her home. Her medical history includes multiple strokes, severe arthritis, type 2 diabetes, episodes of incontinence, hearing impairment with recurrent ear infections, and sleep apnoea requiring the use of a CPAP machine at night.

Cognitive Changes

Over the past year, and particularly during the last three to six months, Mrs Bibi's cognitive difficulties have become more pronounced. She struggles to recall recent events and conversations, although her long-term and childhood memories remain relatively intact. She becomes easily distracted and distressed when she cannot follow what is being said and increasingly struggles to find the correct words.

Mrs Bibi frequently repeats herself, asks the same questions multiple times, and makes repeated phone calls to family members about issues that they perceive as minor, but which feel significant and urgent to her. According to Nabeela, she sometimes forgets whether she has eaten and may not eat between care visits. She previously managed one evening dose of medication independently, but now often forgets, leading to poorly

controlled pain. Financial matters, once carefully managed, now require written reminders, and she frequently forgets appointments or becomes convinced that they are on a different date.

One particularly striking example, highlighted during discussions with the researcher and later reflected upon by the family, was Mrs Bibi's difficulty recalling her GP. She maintained that she had only recently started seeing the doctor, despite having been under their care for many years. This concrete example helped family members better understand the extent of her memory changes.

Culturally and Spiritually Significant Changes

Mrs Bibi's faith is central to her identity. To better explore the impact of memory changes on religious practices, MS developed a faith-based screening tool, refined in collaboration with South Asian dementia researchers (see Appendix 4). This tool enabled sensitive and meaningful discussion about the effects of cognitive change on Mrs Bibi's spiritual life.

Mrs Bibi is highly motivated to follow the daily prayer timetable. However, increasing confusion about time has led her to repeatedly check the clock to determine which prayer it is, significantly increasing her anxiety. Nabeela felt that her mother had previously been reluctant to share difficulties in her prayer routine due to embarrassment and fear of being judged. The culturally informed approach adopted by MS made it easier for both mother and daughter to discuss these changes openly.

Mood and Behaviour

Mrs Bibi has withdrawn from activities she previously enjoyed and now spends much of her time isolated in her room. She keeps the television on constantly, including overnight, and has at times become confused and spoken to the TV, believing she has interacted with someone in real life.

She frequently worries about past health events such as falls or strokes, believing that these occurred more recently than they did. This contributes to ongoing anxiety, confusion, and distress, and makes it more difficult for the family to support her with current health concerns. She feels lonely, sad, and increasingly anxious about not being believed, and has become more irritable and quicker to anger, which is out of character.

Impact of the EMPATHY Letter

Before engaging with the EMPATHY process, both Mrs Bibi and Nabeela felt stuck and unsure how to raise and discuss the difficult, embarrassing, and emotionally laden changes that had taken place. Meeting with MS in the familiarity of Mrs Bibi's home created a safe and respectful environment for telling their story and identifying next steps. MS's ability to speak Punjabi and to understand the cultural and spiritual significance of these changes enabled more open and confident conversations. As a result, Mrs Bibi and Nabeela were able to agree to take the letter to their GP – and at the time of writing are waiting for an appointment.

The EMPATHY letter brought together complex medical, cognitive, emotional, cultural, and practical information into a single, structured document. This was viewed as particularly valuable for communication with the GP, given Mrs Bibi's multiple co-morbidities and the constraints of time-limited appointments. Having a comprehensive written record helps ensure that key information is not overlooked and supports consistent communication between Mrs Bibi, her family, and professionals.

Family Reflection and Wider Impact

Sharing the EMPATHY letter with other family members had a significant impact. One daughter, who had previously been uncertain about whether conclusions regarding Mrs Bibi's capacity might be premature, reported that reading the letter led to a much clearer understanding of the cognitive changes taking place. She subsequently undertook her own research and began to recognise early signs that she had not fully appreciated before.

As the letter was shared more widely within the family, including with grandchildren, it helped create a shared understanding and surfaced concerns amongst family members that had previously gone unnoticed. Nabeela reflected that while she had already had worries about her mother's cognition, participating in the interview process and reviewing the letter helped to clarify and consolidate these observations, making the changes easier to articulate and act upon.

As a result, the family began coordinating visits more effectively to ensure Mrs Bibi received consistent daily support and started considering additional care needs and future planning. Importantly, the process also enabled more open conversations with Mrs Bibi herself, who became more willing to acknowledge and discuss her memory difficulties, having previously felt embarrassed by them.

The EMPATHY letter has also been used as supporting evidence to request a social care review, demonstrating its practical value not only as a communication tool with a GP but as a catalyst for wider action and access to support.

Charming – deciding against consulting her GP

Background

Charming is an 87-year-old African-Caribbean woman who places a high value on her independence. She lives independently on her own in a two-storey home, remains socially active, regularly attends community activities, and continues to travel independently by bus. Although naturally quiet, she has been consistently engaged with Bristol Black Carers for several years and is a regular attendee at an Activity Club.

Charming herself did not express concern about her memory. However, her niece had noticed occasional lapses and concerned about her aunt's wellbeing, encouraged her to explore options for assessment and additional support. While Charming was initially

open to this discussion, she did not perceive herself as experiencing any cognitive difficulties.

Actions Taken

CH, the community researcher, followed up on the niece's concerns by approaching Charming in a clear, respectful, and sensitive manner. The voluntary nature of the assessment process was emphasised throughout their discussions. Charming responded positively, and a follow-up appointment was arranged several weeks later to allow her time to reflect.

At this subsequent meeting, Charming wanted to take part and engaged well with the process, including contributing to the drafting of a letter to her GP. She signed the consent form and agreed to a further appointment to complete the assessment.

Before this appointment took place, however, Charming chose to cancel. She explained that her brother had died with dementia and that she had seen others affected by the condition. Reflecting on the possibility of discussing memory changes with her GP led her to realise that she did not wish to pursue a diagnosis. Although she did not believe she had dementia, the idea of potentially developing the condition frightened her.

CH acknowledged and respected Charming's decision, reassuring her that she could re-engage with the process at any point in the future. It was also explained that she could complete an assessment and decide whether or not to share the outcome. Charming has continued to attend weekly activities and remains engaged with Bristol Black Carers.

Impact and Learning

Charming's ambivalence highlights the fear and stigma surrounding dementia where memory loss may be viewed as a normal part of ageing or associated with negative labelling. Her past personal experiences and wider community narratives played a central role in her decision to withdraw from the project.

This case underscores the importance of culturally sensitive, person-centred approaches, the need for continued dementia awareness work within communities, and the value of offering choice, time, and reassurance rather than pressure. Crucially, it also demonstrates the importance of maintaining trusting and supportive relationships, even when individuals choose not to proceed with assessment.

Learning from Communities.

What have we learnt?

Phase Two of the project explored the implementation and impact of the EMPATHY letter intervention across South Asian, Chinese, and African-Caribbean communities. In working with participants to write these letters so the three community researchers

engaged with participants' dilemmas about whether or not to approach their GP, and where they decided to do this, supported them in arranging an appointment. This active engagement with people has enabled us as a project team to understand more about the barriers that individuals face when seeking dementia assessment.

Our findings highlight the significant structural, cultural, linguistic, and systemic barriers that shape individuals' experiences, alongside the crucial role of community organisations in enabling access to care. Importantly, the practical impact of factors at these different levels is that even with the support of Community researchers it can nevertheless take many months for individuals to move from recognising symptoms to seeking medical assessment.

The impact of stigma on help-seeking. Across all three communities, dementia remains a deeply stigmatised condition. Consequently, many participants were highly ambivalent and uncertain about their memory problems, often questioning whether the changes represented normal ageing or a more serious condition. The stigma surrounding dementia also acted after an initial draft of the letter was produced with several participants delaying making a decision and four ultimately deciding not to make contact with their GP. Family involvement added further complexity and a reluctance to “burden” family members were also significant obstacles, particularly in the Chinese community. While families often provided important contextual information, a wish to involve families fully in making decisions frequently led to delays or even disagreements. However, these familial dynamics need to be seen within the wider context of stigma in which families may be motivated to hide concerns from wider social networks.

Mistrust of statutory services: trust in community organisations. Participants consistently reported a lack of trust in GP consultations. Many felt that they were not listened to, not taken seriously, or not understood - particularly when cultural expressions, metaphors, and non-literal phrasing could be misinterpreted by healthcare professionals, contributing to fears of being judged or labelled. These concerns often led people to withhold important information during consultations. In contrast, the trust placed in community organisations was central to the project's success. Participants described these organisations as culturally safe, accessible, and linguistically attuned environments – and enhanced participants' willingness to engage with all three Community Researchers.

Practical difficulties in booking GP appointments impact especially heavily on people from minoritised communities. Participants encountered substantial obstacles in accessing GP services. Online appointment systems (now common within primary care) were difficult or impossible for many to navigate, particularly for individuals who lacked digital literacy or where English was not their first language. The processes of booking appointments varied across GP practices, creating confusion and inconsistency. In many cases, online systems failed to provide suitable options for reporting memory concerns. Some participants who had reminded the surgery of their language needs

were nevertheless still offered telephone consultations, further undermining accessibility and clinical appropriateness. Participants were largely unaware of options such as requesting longer appointments, and many practices offered limited flexibility around appointment times. Difficulties identifying appropriate email contacts for sending the ENPATHY letters further complicated engagement. Several participants relied entirely on community researchers to navigate the appointment and triage process, and without this support they would not have attempted to contact their GP.

The impact of the EMPATHY Letter. The EMPATHY letter was designed to address these challenges by providing a culturally sensitive, person-centred method for individuals to communicate memory concerns to their GP. The three community researchers spent extended time with each individual, listening to their experiences in their preferred language and helping them to articulate symptoms that might otherwise go unreported. This process had three clear benefits.

- First the discussions often uncovered changes in areas such as prayer routines, food preferences, anxiety levels, and language use - factors that participants would not be easy to discuss in a brief appointment with their GP and which may well otherwise have gone unnoticed or unremarked.
- Secondly, by offering time, space, and support to help individuals reflect on their experiences, the letter-writing process functioned almost as a therapeutic intervention. Participants described feeling validated, heard, and reassured that their concerns were real and warranted further assessment. In many cases, the letter facilitated new conversations within families, shifting family dynamics and empowering the individual to take a more active role in decisions about their health. Many participants regarded these conversations as valuable, even when they ultimately chose not to proceed with a GP referral. For instance, in the case of a South Asian participant who ultimately decided not to consult their GP, the discussions around drafting the EMPATHY letter nevertheless enabled the family to discuss her changes more deeply together and helped her not to be embarrassed by them. The participant reported that this helped them all to acknowledge what they needed to focus on as a family and how to support her effectively.
- Finally, the EMPATHY referral letter proved to be an effective tool for facilitating discussions with GPs. Participants felt the letter provided a structured and respectful means of explaining their concerns, reducing the pressure to articulate symptoms within short consultation times. Reports from participants indicated increased feelings of being listened to and taken seriously, with three participants being referred to specialist dementia services and three others currently waiting for further assessment in primary care.

However, implementation challenges remain. GPs did not always upload the letter to the electronic system, so that this important source of information was not passed on to the DWS. Importantly, despite all participants signing a form to agree to sharing information between community and NHS services, to date community organisations have not been

approached as part of the assessment process. This risks important information including the nuanced cultural awareness that is held within community organisations being unavailable during the assessment and post-diagnostic support process.

Summary. Overall, our findings demonstrate that systemic barriers, linguistic challenges, stigma, and mistrust significantly impede access to timely dementia diagnosis within the Chinese, African-Caribbean and South Asian communities. However, the EMPATHY letter acted as an effective bridge between individuals and their families and primary care. By validating personal experiences, supporting communication, and reducing cultural and linguistic barriers, the intervention strengthens pathways to assessment and contributes to earlier, more equitable engagement with dementia services. However, the lack of engagement with specialist dementia services after the referral has been made risk compromising the assessment and limiting the care that can be offered to patients. Community organisations play an essential bridging role, offering culturally informed support that enables engagement with assessment pathways. A re-design of dementia care pathways is required, embedding cultural competence, equitable access, and sustained partnership with community organisations to ensure fair and effective diagnosis and care.

Recommendations.

The findings from this study highlight significant cultural, structural, and systemic barriers that prevent members of Chinese, South Asian and African-Caribbean communities from accessing timely dementia assessment and post-diagnostic support. Importantly, our recommendations are entirely consistent with the 2023 Patient and Carers Race Equality Framework which places an obligation on NHS trusts to work with community partners to co-produce and implement concrete actions to reduce racial inequalities within their services.

Based on these insights, we propose the following recommendations.

1. Establish Systematic Partnerships Between Statutory Services and Community Organisations. Community organisations such as the Chinese Community Wellbeing Society, Dhek Bhal and Bristol Black carers are essential - not optional - providers of culturally grounded support. Importantly, they are trusted within communities in a way that statutory services are not. However, the vital nature of the work that they do (and the work that they could do but are not funded to do) is often ignored. The consequences of this are a reduced standard of care for people living with dementia who are already marginalised and excluded from care.

We therefore recommend that:

- community organisations should become formal partners of specialist dementia providers in Bristol, in a similar way to how the DWS is a partnership between an NHS trust and the Alzheimer's Society. This partnership will benefit both

statutory services and VCSOs. For NHS dementia services it will enhance their understanding of the impact of culture, stigma and language on communities and enhance their services for these communities. For community organisations this will improve their understanding of dementia and referral pathways and routes, safeguarding, and post-diagnostic support.

- Importantly, a formal partnership will facilitate the development of routine information-sharing protocols (with appropriate consent) so that community organisations can contribute directly to assessments and post-diagnostic care planning.

Benefits for people living with dementia and their families: a formal partnership will improve care by improving the co-ordination of care and facilitating access to both culturally appropriate and evidence-based practices across the dementia pathway.

2. Create a resource and research centre specifically for people affected by dementia from minoritised communities. There is now a clear evidence base showing the need for sustained, not one-off, communication and support for people from Chinese, South Asian and African-Caribbean communities. The centre will support the NHS Well Pathway for Dementia and contribute to Integrated Care System priorities to reduce health inequalities, strengthen prevention, and improve system sustainability, whilst serving as a bridge between communities and statutory services to deepen integration across the NHS, social care, and the voluntary sector. Through improved early engagement and coordinated care, the model will prevent crisis escalation, reduce avoidable hospital admissions, and ease long-term system pressures - ultimately improving population health, enhancing quality of care, and making better use of system resources in line with the NHS Triple Aim and Core20PLUS5. Additionally, the centre would provide continuity and trust-building over time thus acting as a stable point of information, support, and culturally sensitive guidance for both families and practitioners. Incorporating a research arm will enable the working collaborations developed over the last ten years to be expanded and built upon and facilitate learning within both community and academic contexts. This will help to ensure that learning and improvements are embedded and scaled, rather than lost and has the potential to provide costs savings for instance around translation of materials and interpreters.

Benefits for people living with dementia and their families: basing specialised dementia services within a specific and dedicated community resource centre would improve post-diagnostic care by:

- Offering structured pre-diagnostic support to individuals who remain ambivalent or fearful, recognising that stigma and cultural beliefs profoundly shape participants' willingness to engage not just with assessment, but also with care after diagnosis;
- Overcoming language and communication difficulties, especially for individuals who either lack English or who whilst previously fluent in English, have now fallen back on their first language;

- Improving understanding of how symptoms of dementia may impact on religious practice, family communication, or culturally specific behaviours;
- Improving collaborative working and communication between community organisations and statutory services;
- Prioritising timely, proactive follow-up after referral to avoid delays that reinforce mistrust or discourage further help-seeking; and
- Having all services in one place helps simplify and improve the ‘dementia journey’. A ‘one-stop-shop’ not only saves resources but as they are all under one roof this also makes it easier for the client to access dementia services and avoids them having to move between different organisations to get different dementia-related services.

3. Embed the EMPATHY Letter into Local Dementia Pathways. The EMPATHY letter is an example of a co-produced intervention aimed at reducing racial inequalities that the NHS Race Equality Framework envisages. As such it should be adopted as an approved communication tool across the locality, enabling GPs to receive concise, culturally informed histories in advance of appointments. This will require a series of actions:

- *developing formal referral routes* and shared care models to recognise the essential role of community organisations in early symptom recognition, accessing primary care and advocacy after a diagnosis;
- *funding community organisations* to continue the role of Community Researchers (for instance working as dementia navigators) to work proactively to identify people where there are concerns around cognitive changes and to implement the EMPATHY process with them as a way of facilitating engagement with Primary Care services;
- *providing training to GPs and practice staff* on the purpose, value, and correct handling of EMPATHY letters;
- *introducing a standardised protocol* requiring GPs to upload letters to electronic patient records so that information is visible to the Dementia Wellbeing Service and other specialists;
- *continuing to evaluate the long-term impact of the EMPATHY letter*, including diagnostic timelines, GP engagement, and experiences of post-diagnostic care;
- *exploring adaptation of the model to other communities from the global majority*, including refugees, newer migrant groups, and individuals with no access to family support. We also suspect that this letter could be useful for those within the White British population who struggle to communicate their needs to their GP.

Benefits for people living with dementia and their families: continued funding of the EMPATHY letter will facilitate people living with dementia for each of the three communities (and potentially other communities) in Bristol to have improved access to specialised dementia services via improved assessment within Primary Care. This intervention, therefore, reduces health inequalities.

4. Improve the assessment and identification of dementia within Primary Care.

Throughout this study, participants have expressed concern about accessing appropriate help within primary care. Accordingly, we recommend:

- *improving online booking systems* by ensuring that there is a category for memory concerns on the menu of issues that patients have to select when requesting an appointment,
- *guaranteeing in-person appointments* for people with limited English or with other communication or language barriers and automatic flagging of interpreter requirements,
- *funding community organisations to provide advocates* who could support people from their communities who attend a GP appointment,
- *encouraging the uptake of double appointments* especially where multiple issues coexist. This could be achieved through clear signposting on GP practice websites and through reception staff,
- *extending cultural-competence training* using real case examples around assessment to help clinicians better understand culturally specific expressions, metaphors, behaviours, and faith-based changes associated with dementia, and
- *enhancing the current system of dementia champion contacts* within each practice by publicising their email addresses.

Benefits for people living with dementia and their families: the Bristol dementia pathway, in common with most services across the UK places a premium on Primary Care services being able to identify potential cases of dementia and referring people on appropriately. It is clear that in practice this leads to people from the communities in this project being disadvantaged. Improving identification of potential dementia cases within Primary Care will enable people to receive more timely diagnoses and improve their satisfaction with health service delivery.

5. Improving assessment and cultural competency across the dementia pathway.

People living with dementia from the three communities are diagnosed at different points in the dementia pathway – within primary care, in specialised dementia services (such as DWS, those provided by AWP and Cognitive Neurology at Southmead Hospital) and within general hospitals. Steps should be taken to ensure improved practice by:

- *providing community screening sessions.* These have previously been trialled successfully and should be continued using validated tools, first-language staff and/or interpreters trained in medical terminology,

- *establishing an online database* of validated and evidenced based assessment materials that are relevant for people from different communities. This would build on the current tools used by DWS and include information about using these appropriately similar to that found in the [ADAPT toolkit](#),
- *establishing regular case-discussion* meetings between NHS dementia teams and community groups to discuss shared patients, support plans, barriers, and learning. This requires appropriate information sharing protocols (see recommendation above),
- *increasing visibility of culturally aligned professionals*. Where possible recruit, train, or match clinicians who share patient languages or cultural backgrounds,
- *providing regular awareness and understanding raising sessions* for healthcare professionals across Bristol,
- *providing clear standards of post-diagnostic support*. As many people we spoke with were confused about what care they could expect, minimum standards of care should be established with clear timeframes,
- *developing formal training pathways* for community-based dementia support roles, recognising their unique contribution to equitable access.
- *auditing services across the dementia pathway* using, for instance, the CQC framework to assess inclusivity, strengthen data on ethnicity, and share examples of good practice.

Benefits for people living with dementia and their families: people from the communities that this study engaged are less likely to receive specialised dementia support throughout the pathway. While the reasons for this are multiple, improving the cultural competency of existing services and strengthening collaborative working between statutory and community sectors will enhance the support that people receive across the dementia pathway and improve their quality of life.

6. Address Stigma Through Community-Led Education and Family Engagement.

We consistently found that stigma, interacting with other factors, acts to impede access to dementia services across the pathway. To combat this, we recommend:

- *funding culturally tailored dementia awareness programmes* within each community, delivered in relevant languages and addressing culturally specific stigma, misconceptions, and spiritual concerns.
- *developing targeted resources* that explain how dementia symptoms may appear in culturally specific ways, such as changes in prayer routines, food preferences, and language use. These resources should be community focussed – for instance in the Chinese workshops there was a desire for clear rules distinguishing dementia from normal ageing, presented in participants’ first language. For South Asian communities there was an emphasis on family workshops and multi-channel outreach (e.g., mosques, gurdwaras, radio); and for the African-

Caribbean participants a desire for messaging to include whole-family framing such as youth voices and trusted African-Caribbean ambassadors to open conversations.

Benefits for people living with dementia and their families: Reducing dementia stigma will enhance quality of life by promoting social inclusion, challenging misconceptions, and empowering individuals to live actively and engage in daily activities without shame or discrimination.

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Appendix 1: Details of participants in Phase One Public consultation events

Details of South Asian participants in Phase One Public consultation events

First round of consultations: understanding of dementia and assessment						
ID	Age	Gender	Languages spoken	Place of birth	Time lived in UK	Religion
1.	83	Female	Punjabi and Hindi	Pakistan	68 years	Sikh
2.	72	Female	Urdu and Punjabi	Pakistan	55 years	Islam
3.	75	Female	Punjabi	Pakistan	56 years	Islam
4.	72	Female	Punjabi and Urdu	Pakistan	52 years	Islam
5.	74	Female	Gujrati and English	Kenya	28 years	Islam
6.	70	Female	English and Punjabi	India	70 years	Sikh

Second round of consultations: experiences after diagnosis		
ID	Gender	Lived experience of dementia
1.	Female	Living with dementia
2.	Female	Daughter caring for mother
3.	Female	Living with dementia

4.	Female	Caring for aunt
5.	Male	Living with dementia
6.	Female	Daughter caring for father

Details of Chinese participants in Phase One Public consultation events

First round of consultations: understanding of dementia and assessment						
ID	Age	Gender	Languages spoken	Place of birth	Time lived in UK	Religion
1.	62	Female	Cantonese	Hong Kong	40 years	Christian
2.	62	Female	Cantonese	Shenzhen	43 years	None
3.	68	Male	Cantonese/ English	Hong Kong	56 years	None
4.	74	Male	Cantonese	Hong Kong	48 years	Christian
5.	65	Female	Cantonese	Hong Kong	43 years	Christian

Second round of consultations: experiences after diagnosis		
ID	Gender	Lived experience of dementia
1.	Male	Living with dementia
2.	Female	Daughter caring for father
3.	Male	Living with dementia
4.	Female	Caring for husband
5.	Female	Living with dementia
6.	Female	Daughter caring for father
7.	Male	Son caring for mother

Details of African-Caribbean participants in Phase One Public consultation events

1st consultation meeting						
ID	Age	Gender	Languages spoken	Place of birth	Time lived in UK	Religion
1.	64	Female	English	Trinidad	20+ years	Catholic
2.	64	Female	English	Jamaica	30+ years	Seventh Day Adventist
3.	60	Female	English	England	From birth	Christian
4.	63	Female	English	England	From birth	None
5.	86	Female	English	Jamaica	40+ years	Christian
6.	49	Female	English	England	From Birth	Not stated

Second round of consultations: experiences after diagnosis		
ID	Gender	Lived experience of dementia
1.	Male	Living with dementia
2.	Female	Caring for husband
3.	Female	Living with dementia
4.	Female	Daughter caring for mother
5.	Female	Daughter caring for mother
6.	Female	Living with dementia
7.	Female	Daughter caring for mother

Appendix 2: Detailed Findings from Phase One Consultations.

Mistrust of the Health and Social Care system - A strong sense of mistrust toward statutory services was evident across all three communities. Participants described feeling unheard, misunderstood, or judged and referred to how inequalities in diagnosis and treatment and a cultural mismatch with doctors deepened their mistrust of services. Assessments of capacity were seen as superficial and insensitive to cultural and contextual realities. For many, repeated negative interactions reinforced their reluctance to seek help and deepened the reliance of participants on support from their families and from community organisations, despite escalating need.

Participants across all three communities linked trust to relationships, communication, and the ability to understand and be understood. Thus, in the two focus groups with Chinese participants, there was a strong sense that trust in care homes in particular was extremely low, influenced by negative experiences associated with discrimination, communication failures and lack of understanding of cultural norms. As one participant commented that: *“the whole Chinese community doesn’t trust the care home.”* Chinese participants emphasised the need to build trust through continuity, transparency and culturally competent practice. Similarly, mistrust of statutory services was a major issue in the African-Caribbean focus groups and contributed to participants’ reluctance to seek support. This was linked to racism, unequal treatment, negative experiences, and fear with one participant describing how *“people believe that if you ask for help, the person will be taken away”*. Another African-Caribbean participant commented that *“there is a belief that if you go into hospital as a Black person, you will die there”*.

Across all three communities, the lack of trust in statutory services impacted on service uptake in two ways. First, it was associated with a reluctance to engage with those services – for instance some participants were concerned that sensitive information shared with interpreters might leak into the wider community, particularly when interpreters were from the same cultural group.

Second, mistrust of statutory services resulted in a tendency to *“care for our own”*. Participants emphasised that this arose not out of cultural preference but from fears that mainstream services would not understand, respect, or appropriately support them. A South Asian participant told us that *“people go where they feel they’ll be understood”* with an Africa-Caribbean participant similarly adding that people *“need the same person or small group they can recognise.”*

Mistrust was a major issue in the African-Caribbean focus groups and contributed to participants’ reluctance to seek support. This was linked to racism, unequal treatment, negative experiences, and fear with one participant describing how *“people believe that if you ask for help, the person will be taken away”*.

Stigma, Ambivalence, and Delays in Seeking Diagnosis - Stigma surrounding dementia was a common theme across communities and was often associated with shame, “madness,” or personal failure. However, the nature of stigma was shaped differently across communities. Derogatory terminology in community languages exacerbates fear and silence, leading families to conceal difficulties and delay help-seeking. While awareness is improving through education and community initiatives, stigma remains a powerful barrier—particularly at early stages of illness.

In Chinese communities, stigma was intensified by use of older terminology which carried negative connotations of shame, madness, or loss of self. While new terms were described as less degrading, the legacy of stigma persisted. Chinese focus group participants described deep cultural norms around not challenging professionals and waiting to be called rather than initiating contact. One participant described help seeking as being difficult for Chinese people: *“In our culture... we just wait. We don’t challenge or ask.”*

When we talked to South Asian people there were similar concerns with people describing limited understanding, confusion with “old age,” and uncertainty around the significance of symptoms. Additionally, many participants described dementia as heavily stigmatised, often associated with being “mad,” “crazy,” or morally failing – potentially shameful characteristics that the person and their family might be reluctant to acknowledge. Because of this, one participant told us *“people don’t want to go to their GP about it.”*

Black focus group participants emphasised that the African-Caribbean community *does* have extensive experience of dementia - often because families take responsibility long before services are involved. Yet knowledge of dementia symptoms and its progression is uneven, and some families might fail to notice symptoms early because they fluctuate. A strong theme within the African-Caribbean focus groups was the expectation that families should handle care privately – concerns that seem to be driven by cultural norms, pride, and the mistrust of external services. Participants described the burden as significant and invisible. As with both the Chinese and the South Asian participants we spoke with there were strong concerns around stigma: privacy, shame, and misunderstanding. As dementia remains associated with personal weakness, madness, or embarrassment, participants told us about their reluctance to *“put dirty washing out in public”* and how this prevented them from seeking help.

Across all communities then, dementia was associated with fear, shame, and loss of control – for instance participants described fears of being taken from the home, or others *“finding out”*. These beliefs led to significant delays in acknowledging symptoms, internal family conflict about next steps, and ambivalence about approaching GPs.

Barriers to Diagnosis – Across Black, South Asian and Chinese communities, participants reported significant racial inequities in dementia diagnosis and support. In part, as we have explained above, this relates to communities’ reluctance to use services

that they don't trust, and for conditions that are stigmatised. However, in addition, carers commonly experienced dismissal of their concerns by GPs, delayed referrals, and reliance on narrow assessments that failed to reflect everyday functioning. South Asian participants reported delays, dismissive GP responses, phone-only appointments and language barriers, alongside confusing referral processes and poor-quality interpreting or translated materials. Chinese participants highlighted that the health system felt inaccessible, with many relying on community organisations to navigate services. They faced long waits, minimal post-diagnostic support and confusion about responsibilities across health and social care, and expressed a preference for community-based, bilingual screening by properly trained staff. African-Caribbean participants similarly described dismissal, inadequate assessments, and culturally inappropriate cognitive testing, with services often failing to respond to cultural or relational needs, leaving families unable to access services or plan care. Across all groups, participants emphasised that cultural competence is essential for dignity, safety and nutrition. They felt statutory cultural-awareness training alone is insufficient, and that only community-based, culturally led services are experienced as safe, respectful and meaningful.

Black carers explicitly raised concerns about racial inequities, citing stark contrasts between the speed and quality of diagnosis and support for white relatives compared to relatives of colour. Without diagnosis, families were unable to access services, plan care, or challenge stigma.

Similarly South Asian focus group participants consistently described delays, dismissive responses, phone-only GP appointments, and the challenge of managing multiple languages. A number of participants felt that they had been dismissed by GPs, who had minimised the problems they faced. Some participants also commented on slow or confusing referral processes including a "*Constant cycle of signposting*" as well as communication barriers with a low standard of interpreting and translated materials that did not make sense.

Accessing GP appointments was described as particularly challenging for older adults and individuals who did not speak English as a first language. Thus, participants in the Chinese focus group spoke about the health system as being inaccessible – for instance they did not know how to access services and relied on the Chinese Community well-being society to guide them and to complete forms. Many of the Chinese people we talked to described long delays, absence of post-diagnosis support, and confusion about responsibilities across health and social care. Rather than the current system, Chinese focus group participants favoured community-based screening delivered in familiar environments and in their own language perhaps by bilingual, community-based staff so long as these were properly trained and supervised and were delivering validated assessments.

African-Caribbean focus group participants also identified barriers to diagnosis: dismissal, poor assessments, and capacity misjudgements. These included dismissive GP

responses with people describing their concerns being minimised due to short consultations or because the cognitive tests used were inappropriate or failed to incorporate family insights. African-Caribbean participants described multiple examples of services failing to respond to cultural, linguistic or relational needs.

Participants emphasised that culturally competent care affects dignity, safety and nutrition. Overall, across all three communities, there was a strong sense that statutory cultural-awareness training alone is insufficient. Participants emphasised that only community-based, culturally led services feel safe and meaningful.

Caring on one's own - Families across all communities provide intensive, 24/7 dementia care long before services get involved, often at great personal cost. Carers described exhaustion, declining mental and physical health, isolation, and loss of employment, with little practical support and services that often feel culturally mismatched or unresponsive. Chinese, South Asian, and African-Caribbean participants all reported major gaps in respite, night-time help, behavioural support, and timely social care. Late diagnosis also created legal and financial difficulties. Overall, carers felt overwhelmed, unsupported, and in urgent need of practical, culturally appropriate assistance. Many felt invisible to services until reaching crisis.

A major shared theme was the heavy burden of care and the lack of practical support such as sitting services, night-time help, behavioural advice, or meaningful activities. Instead, carers often received only leaflets. Several participants reported stress-related illnesses, depression, or even hospitalisation.

Chinese families described taking on extreme levels of care, sometimes quitting jobs to provide round-the-clock support. They emphasised that they did not identify as “carers,” but simply as family, and requested respite and behavioural support. Some experienced legal and financial crises because late diagnosis prevented timely arrangements such as Lasting Power of Attorney.

South Asian carers reported similar strain: exhaustion, mental health decline, and worsening physical health. Their experiences with social care were often culturally mismatched, task-focused, rushed, or insensitive. Practical barriers—such as long waits for social workers and limited sitting services—were common.

African-Caribbean participants also spoke about emotional burden, stress, and isolation, with some experiencing acute mental health crises. They emphasised needs for carer training, support with setting boundaries, and especially night-time assistance.

Across all groups, carers called for practical, culturally appropriate, and timely support that recognises the intensity and emotional cost of family caregiving.

The Essential Role of Community Organisations - essential bridges, not

“nice-to-haves” - Across all focus groups, community organisations such as CCWS, Dhek Bhal and BBC were described as trusted, culturally aligned places that provided safety, navigation, continuity and emotional support—often filling gaps left by statutory services. Participants relied on these organisations for help with communication,

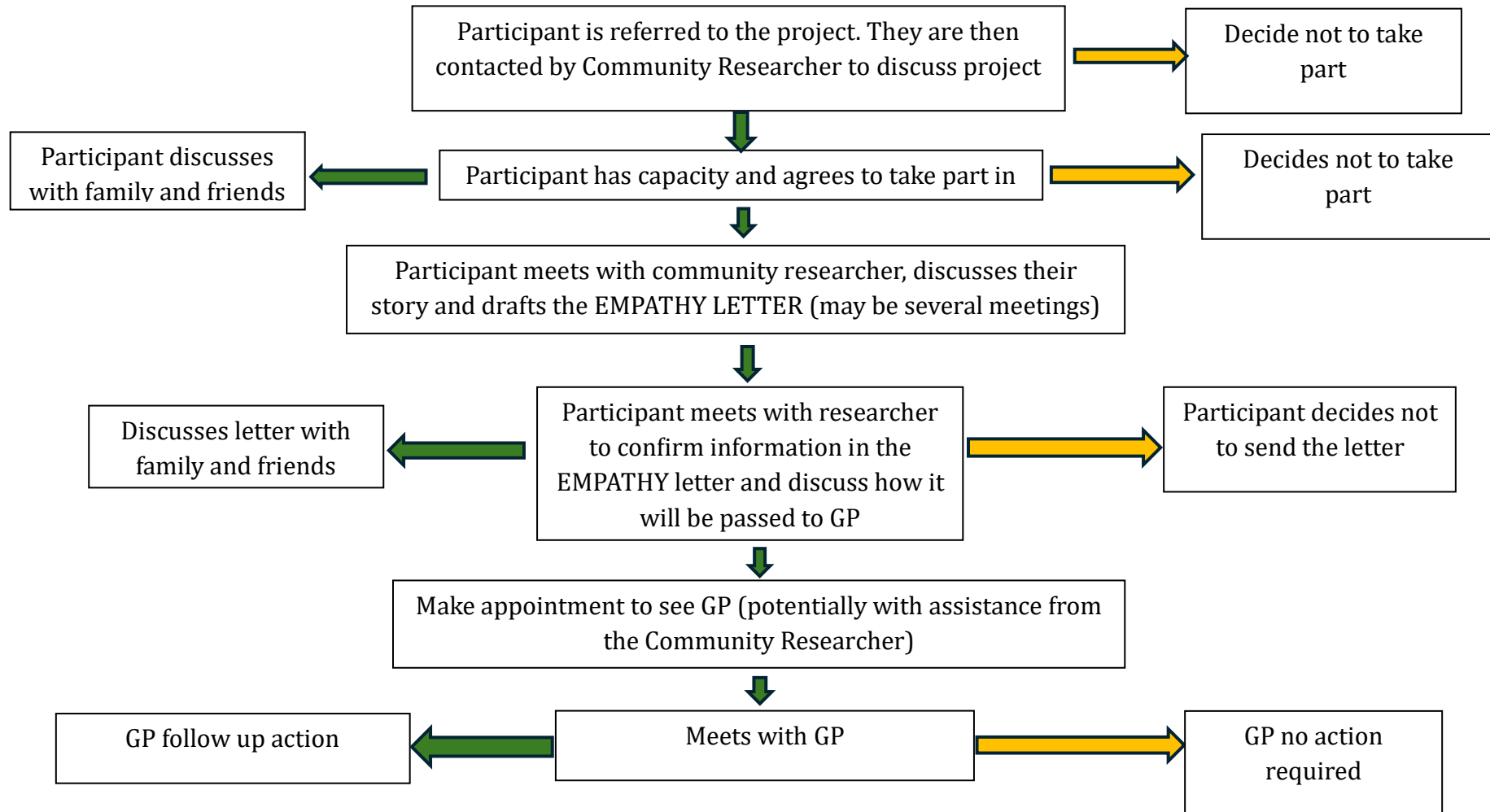
language, and navigating NHS and council systems, and felt understood in ways they did not experience in mainstream services.

South Asian and Chinese participants particularly highlighted the importance of being supported in their own language and culture, especially when the cognitive impairments of dementia meant that people fell back on using their first language. Community groups were also the only reliable source of respite, meaningful engagement, and post-diagnostic support.

Across all groups, participants called for formal, funded partnerships between statutory services and community organisations to improve cultural competence, reduce stigma, and support diagnosis and care navigation.

Participants also reported severe gaps in post-diagnostic and advanced-stage support, with help dropping away after diagnosis and services offering little more than leaflets. Access to culturally appropriate respite was described as urgently needed but largely unavailable. Community organisations, despite limited funding, were consistently praised for providing the trust, continuity and cultural understanding that statutory services lacked.

Appendix 3: Flow chart illustrating the research process





Appendix 4: Faith Based Screening Tool

EMPATHY STUDY: Faith-Based Dementia Screening Questions – using religious practice to identify possible cognitive decline.

Most faith practices, such as Islam, Hinduism, Sikhism and Christianity have structured religious routines and deeply ingrained spiritual customs. Where people have a deeply held faith and regularly practice these routines, changes in **religious memory, routine, and engagement** can provide a valuable framework for identifying **subtle cognitive changes or signs of dementia**. These screening questions are designed to be used as triggers to initiate conversation around possible changes in faith practices.

It's important to ask gentle, respectful questions in a conversational style without being confrontational or accusatory:

- Ask with compassion, not suspicion, or accusatory or made to feel like a test.
- Frame some questions around changes over time for wording sensitivity (e.g., "Have you noticed any changes in how you begin or follow your prayers/rituals?") rather than focusing on forgetting, as this could feel less stigmatising.
- Occasional forgetfulness is normal, but consistent confusion may be a sign of impairment
- Challenges with recognition could signal memory impairment e.g. people in their congregations

SUMMARY OF OBSERVATIONS:

- Confusion during rituals or prayer
- Increased repetition or disorganized prayer
- Forgetting long-held spiritual roles or community traditions
- Anxiety or distress when attempting to worship
- Withdrawal from group worship or spiritual gathering

ISLAMIC PERSPECTIVE – SALAH AND DAILY PRACTICES

Salah (five daily prayers) in particular, offers a unique perspective to identify potential cognitive changes because it is a deeply ingrained, time-bound, and structured activity.

Memory & Routine

- Have you noticed yourself forgetting whether you already prayed a certain Salah?
- Do you sometimes forget the words of Surahs or Duas you've known for years?
- Are you able to recite the Quran as you used to?
- Are you able to understand what you are reading, in salah or Quranic recitation?

Time Orientation

- Are you still able to follow the regular schedule for your prayers, or has that changed recently?
- Do you recognize when it's time for each prayer; Fajr, Dhuhr, Asr, Maghrib, or Isha

Procedural Memory (Step-by-step actions)

- Have you had difficulty remembering the steps of Wudu (ablution) or the movements in Salah? (unsure about how to begin or what comes next)
- Do you ever feel confused during prayer—like forgetting what Rakah you're in or repeating Rakah and Sujoods?

Engagement with Community/Spirituality

- Do you still enjoy going to the mosque or praying in congregation? (is there a sudden disinterest or withdrawal from spiritual practices?)
- Are you able to recognise and remember the names of people you usually see at the mosque?
- Have you noticed any changes in how you pray or how you feel during prayer?
- Has anyone close to you mentioned changes in your prayer habits or memory?

HINDU PERSPECTIVE – PUJA, MANTRAS, FESTIVALS

Daily Rituals

- Are you still able to do your daily puja or aarti?
- Do you sometimes forget what to do during puja or where items are kept?
- Are you able to remember the mantras or chants you used to recite?

Festival Awareness & Temple activities

- Are you able to remember the steps or customs for celebrating e.g. Diwali?
- Have you sometimes forgotten to observe fasts that you usually would (e.g., Ekadashi)?

Temple activities and engagement with community

- Are you still able to go to the temple or bhajan gatherings?
- Do you still enjoy going to the temple and taking part in activities? (is there a sudden disinterest or withdrawal from spiritual practices?)
- Are you still able to recognise and remember the names of people you usually see at the temple?
- Have you noticed any changes in how you pray or how you feel during prayer?
- Has anyone close to you mentioned changes in your prayer habits or memory?

SIKH PERSPECTIVE – NITNEM, SEVA, GURDWARA

Prayer & Recitation

- Are you still able to remember to do your daily Banis as you normally would (e.g., Japji Sahib, Rehras)?
- Do you sometimes forget or repeat lines while praying?
- Are you finding it harder to follow Gutka Sahib or Gurbani recitations?

Community & festivals

- Are you still able to go to the gurdwara regularly and are you still able to do Seva (e.g. Langar) as you used to?
- Can you still remember recent events in the Sikh calendar?
- Are you still able to understand and engage with Ardas or Hukamnama as before?

Temple activities and engagement with community

- Do you still enjoy going to the gurdwara and taking part in activities? (is there a sudden disinterest or withdrawal from spiritual practices?)
- Are you able to recognise and remember the names of people you usually see at the temple?
- Have you noticed any changes in how you pray or how you feel during prayer?
- Has anyone close to you mentioned changes in your prayer habits or memory?

CHRISTIAN PERSPECTIVE – PRAYER, SCRIPTURE, CHURCH LIFE

Prayer & Scripture

- Are you still able to pray your daily prayers as you normally would?
- Do you sometimes forget the Lord's Prayer or other familiar prayers?
- Are still able to recall Bible passages or hymns you've known since childhood?

Do you sometimes find yourself forgetting parts of familiar hymns or mixing up verses?

Religious Calendar Awareness

Are you able to recall recent major religious holidays (e.g., Christmas, Easter)?

Are you able to remember the traditions or customs your family follows during these celebrations?

Church activities and engagement with community

Are you still able to attend church services and do you still enjoy taking part in activities as you used to? (is there a sudden disinterest or withdrawal from spiritual practices?)

Can you remember the order of a Sunday service (e.g., prayers, hymns, sermon)?

Are you able to recognize and remember the names of your congregation members you usually see?

Do you still enjoy fellowship or Bible study groups?

Have you noticed any changes in how you pray or how you feel during prayer?

Has anyone close to you mentioned changes in your prayer habits or memory?

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