“Frailty: Everyone’s Business”

OLDER MINORITY ETHNIC PEOPLE’S EXPERIENCES OF HEALTH AND SOCIAL CARE IN IPSWICH AND EAST SUFFOLK

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Contents

1. Aim of Report.

To provide a better understanding of the minority ethnic population's experiences living with frailty in Ipswich and East Suffolk, and their health needs, to prevent escalation of need.

To understand potential gaps in the care provision and help prioritise early interventions to prevent the mild/moderate frailty that some minority ethnic people possess from becoming severe.

This report is based on previous and ongoing work done by ISCRE, desktop research and conversations with local community and faith leaders.

2. Report Limitations

The small sample sizes on this project and qualitative research method mean that the full scope of people's experiences and opinion may not be represented in this report. No older people living in care homes, sheltered accommodation or health service providers have been consulted as part of this report.

When the Census 2021 report is published, a more detailed study needs to be undertaken, which explores cultural and religious factors, socioeconomic status, physical activity levels, and diet, factors which will vary substantially among different ethnic groups. For instance, previous studies have reported the highly sedentary behaviour of South Asian and other older migrant women, leading to high prevalence of frailty.

3. Background

The NHS Constitution reiterates that comprehensive health services should be made available to all people who need them, regardless of their protected characteristics.

It is however acknowledged that minority ethnic populations experience poorer health outcomes and barriers to accessing certain services.

Numerous patient surveys reveal a consistent pattern of higher levels of dissatisfaction with NHS services amongst some minority ethnic groups, when compared with the White British population. Recent reports show that those from Pakistani, Indian and Bangladeshi backgrounds are more likely to report significantly poorer experiences (as hospital inpatients) than White British or Irish respondents, particularly on questions of prompt access, as well as their experience of involvement and choice. These negative experiences, along with

the racism and discrimination experienced by some minority ethnic groups, negatively affects their interaction with health services.

COVID-19 has intensified social and health inequalities. The pandemic has had a disproportionate impact on those from minority ethnic backgrounds; on older people; and on those with a disability or long-term condition. *Public Health England's COVID-19: review of disparities in risks and outcomes*.

Closing the health gap for people in these population groups is an important and immediate priority.

4. Who is here? *Ipswich and East Suffolk's minority ethnic population*

Suffolk, like the UK overall has become more ethnically diverse. Between 2001 and 2011 the proportion of people from increased groups increased from 6.3% to 9.2%. 10 years on, it is believed that that the demographic picture has shifted significantly, and the 2021 census will give us a better understanding of who is here and what their specific needs are. It can be assumed that the number of older minority ethnic in Ipswich and East Suffolk is increasing in line with the rest of the population, however, little research on frailty has been conducted in this group.

This growth of various ethnic communities, each with its own cultural and religious traits and health profiles, presents a complex challenge to local healthcare practitioners and policy makers in terms of achieving equitable access.

5. Groups and contacts

According to the Suffolk Office of data and Analytics Race Disparity Audit, Ipswich has the largest proportion of residents of ethnic heritage, and the main groups are from Asian, Black and Mixed backgrounds. https://www.healthysuffolk.org.uk/uploads/Race_Disparity_Audit_Suffolk_SODA_March_2019.pdf.

ISCRE's report on Black, Asian and Minority Ethnic Dementia Carers experiences highlighted that:

- Asian groups make up the largest minority ethnic group receiving services in Suffolk, followed by the African Caribbean community.

- Most BAME communities in Suffolk generally have a young profile (migrant workers in healthcare and agriculture, young professionals and their families)
- However, the most established BAME groups in Suffolk have an increasingly aging population. The risk of frailty increases with age and this is most likely to affect those in the Asian and African Caribbean groups

Ethnic background	Community Groups	Contacts
Asian *Asian British* • Bangladeshi • Pakistani • Indian • Chinese	BSC Multicultural Ipswich & Suffolk Bangladeshi Muslim Community Centre and Mosque JIMAS Shahjalal Islamic Centre and Masjid Ipswich and Suffolk Muslim Council Ipswich Hindu Samaj Sikh Guru Nanak Gurdwara Suffolk Chinese Family Welfare Association Anglo Chinese Cultural Exchange	Shayra Begum Fotik Miah JIMAS Moshud Ali Boshor Ali Dr Sushil Soni Seva Singh Olivia Boland Lydia Tse
Black African Caribbean Black British	The Caribbean and African Community Health Support Forum BME Suffolk Support Group Ipswich Seventh-day Adventist Church Ipswich and Suffolk West Indian Association Ipswich International Church Bethel United Church of Jesus Christ Apostolic Phoebe Karibu Women's Support Group Suffolk Black Community Forum	Clem Turner Funmi Akinriboya Pastor Lewis Albert Grant Harold Afflu Nathan Simmonds Molin Delve Lara Uzokwe Imani Sorhaindo

6. Frailty in minority ethnic communities

Many older people from minority ethnic communities living with frailty are not known by services. The contact with the health and social care services usually occurs at a point of crisis, for example, after a fall or infection which then results in an acute episode usually with hospital admission.

The Caribbean and African Community Health Support Forum (CACHSF), reports that, *'older Caribbean communities 50+ are experiencing a great deal of inactivity brought on by lockdown and health has deteriorated for many. The regular cultural activities and food they were eating has become limited, and this*

has led to a decline in mental well-being as well as leading to an increase in accidents or falls in the home.'

Early intervention in frail older persons can improve functional health and reduce hospital admissions, however lack of trust of NHS services and health care treatment by some minority ethnic groups leads to reluctance to seek care on a timely basis.

7. Findings

Understanding of frailty: The investigation established that the term 'frailty' is not something that most minority ethnic communities identify with. It was pointed out that some in minority ethnic communities and their families are more likely to see frailty as part of 'normal ageing'; leading to them assuming that nothing can be done to assist them. The word 'frail' is understood to refer to an irreversible state rather than something that could be improved. Some of these views are informed by their experiences of different places where people have come from where no such services exist.

Understanding of available support: Some of those engaged 'laughed off' the idea of seeking help for what they term 'normal aches and pains from ageing'. "*Doctors have more important things to do, like looking after people who are genuinely unwell"*. This also links in with the point below on resilience in communities.

"*I have been to my GP countless times with my backache and each time I am told the same thing - take Paracetamol and look after yourself, there is no point*. *Back home people get good injections which make them feel better".*

"If a member of the family is coming here from home, I usually ask them to bring me some medication."

Resilience: When people experience challenges, their first instinct tends to be to find their own solutions. Seeking medical help is not seen by many as the first port of call for receiving help with everyday challenges. There is a belief that highly respected doctors should not be 'bothered' with conditions such as elderly people 'naturally and inevitably getting slower'.

Culture - It was highlighted that there can be negative impact on self-esteem for those identified as frail and that there is stigma associated with frailty in some communities which leads to reluctance in opening up to health services. The fear

of losing independence, dignity and control over one's life as a result of frailty was highlighted.

Some cultures have a negative view of charity and those who seek help (charity) are frowned upon, leading many to not reach out to neighbours and peers.

Religion and faith – There is an inherent assumption in some communities that health services do not understand or respond well to religious needs, leading many to disengage with services. "*Try to explain to the nurse that what I am going through is all inevitable due to karma and they look at you as if you are stupid"*

Faith leaders reported being barred from accessing patients in health care settings for prayers which leads to their congregants staying away from seeking medical help.

Caring Responsibilities: Carers of people living with frailty may feel reluctant, even unwilling to ask for help, as culturally, it is their 'obligation' to look after their elderly. Some have reported that they 'get blessings' from their caring role and that by delegating that role to health services, they are giving away their blessings.

Sentiments gathered from some of the Black Caribbean communities engaged with, were that some of them were conscious of becoming a burden to their families and as such they do not open up about the challenges they are experiencing.

Language: Language barriers were also highlighted, especially in some Asian communities where the elderly do not speak English and can only access support with family support. When those family members are not available, the patients do not believe the health services can support them.

Even those who can converse in English can also believe that language is a barrier as some struggle to articulate what they are going through, leading to frustration that they are not getting the help they feel they deserve. *"I think once they hear my strong accent, they stop listening to what I am trying to tell them - they just ignore me".*

Discrimination: Some older BAME people feel directly discriminated against because of their ethnic or cultural background. Experiences of discrimination tend to relate to public spaces in healthcare settings, such as waiting rooms and hospital wards.

We heard of reluctance to visit healthcare settings due to:

- Negative attitudes of other patients in waiting rooms. "*I hate the stares and whispers every time I enter a doctor's or hospital waiting room. I think they think I am one of those NHS scroungers constantly mentioned in the media. I will only go if I have to".*

Housing: The SODA Race Disparity Report highlighted that, those from Mixed or Black ethnic backgrounds were proportionally more likely to live in single person households. This resonates with the feedback we have received of elderly people living with frailty not seeking or getting support.

Due to housing problems, many people living with frailty are more likely to live in unsuitable housing, leading to falls and other challenges.

Social connections and isolation: Some minority ethnic groups, especially recently arrived migrants, experience more isolation as they do not have many social and statutory connections. This could be down to not having peers or activities that interest them locally. This leaves them at greater risk of going without the support they need should they find themselves with health needs. This is worse for those experiencing discrimination in neighbourhoods and other social settings.

8. Physical activity: Barriers and Opportunities

Digital challenges - The Caribbean and African Community Health Support Forum report that, '*the older community value the online classes, but many do not wish to access digital activities and are waiting for face-to-face exercise to resume'.* The Ipswich and Suffolk West Indian Association report that their elderly participants have completely stopped attending their luncheon club, which was the only physical activity for most of them.

9. Recommendations

Recommendations have been drawn from findings and are categorised and presented as:

- *Prevention*
- *Identification*
- *Support and intervention*
- *Education and Training*

Prevention

- Those supporting minority ethnic people who are frail should consider engaging with them in the familiar environment of their own communities such as community groups, luncheon clubs, and places of worship. This would likely encourage forthcoming[1] and frank discussion.[2]
- There should be a focus on developing targeted appropriate information resources to encourage prevention.
- Minority ethnic people are more likely to face digital exclusion and information resources should be targeted to account for this.[3]

Identification

- 'Culturally competent' and targeted health promotion activities should be considered essential for providing support in minority ethnic groups. There is need for culturally competent strategies to understand symptom recognition, leading to better early diagnosis and earlier presentation to clinical services.
- Many elderly minority ethnic people view frailty as being just a part of them getting old. They often think that nothing can be done about it and so may not identify it as a problem that they can seek support for. This should be considered when thinking of methods to encourage identification.
- Those who are reluctant to access health services for 'normal ageing' are usually happy to seek help for other ailments. A joined-up system can help to flag these issues when a patient presents for something else.

Support and Intervention

- Health practitioners need to take into account people's sense of individual identity, and the factors that contribute to it, and consider how these may be influenced by their ethnic and cultural identity.

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[1] https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/bame-communities-advisory-group-report-and-recommendations. "Corporate Report BAME Communities Advisory Group report and recommendations", Department of Health and Social Care, 12 October 2020, Section D: BAME Communities Advisory Group recommendations.

[2] "Black, Asian and Minority Ethnic Dementia Carers Pilot Project Report 13/14", The Suffolk Minority Ethnic Community Network, the Ipswich and Suffolk Council for Racial Equality, and Ipswich and East Suffolk Clinical Commissioning Group, paras 6.1 and 6.8.

[3] https://charitysowhite.org/covid19-health-inequalities. "BAME Communities Have Poorer Digital Access and Literacy"

- Working alongside and empowering faith and community leaders and community groups with information and resources can go a long way in establishing trust with minority ethnic communities.
- Although it is important to recognise the intricacies of specific cultures, communities may differ in terms of whether they wish services to be culturally specific or mixed. This should be considered when deciding ways to support minority ethnic individuals and a range of ideas should be analysed.[4]
- Individuals seeking to support and undertake intervention should be given training on how to give culturally acceptable care and support to frail minority ethnic people. Unconscious bias training should also be explored.[5]
- Individuals seeking to support and undertake intervention with elderly frail minority ethnic people should use language that resonates with older people's desire to maintain or return to a level of independent living.
- Language barriers may also prove restrictive when offering support. This may be made worse by COVID-19 restrictions, such as the no visitor policy in hospitals, and so it is more important than ever to account for this.[6]
- Attendance at support appointments and programmes may increase if they are culturally appropriate and sensitive. For instance, it may be beneficial to consider single sex programmes and/or programmes attended by bilingual and/or multilingual staff.[7]
- It must be considered and understood that some individuals may feel that, if they find caring for a relative difficult, they are a bad person.[8] Attempts

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[4] "Black, Asian and Minority Ethnic Dementia Carers Pilot Project Report 13/14", The Suffolk Minority Ethnic Community Network, the Ipswich and Suffolk Council for Racial Equality, and Ipswich and East Suffolk Clinical Commissioning Group, para 6.4.
[5] "Older BAME people's experiences of health and social care in Greater Manchester Lessons for Practice and Policy", Dr Bethan Harris, Scarlet Harris, Natalie-Anne Hall with Natalie Cotterell, P. 34.
[6] https://charitysowhite.org/covid19-health-inequalities. "There Is No Equal Access to Healthcare and Support".
[7] https://www.bda.uk.com/resource/improving-the-quality-of-care-for-ethnic-minority-communities.html. "Improving the quality of care for ethnic minority communities. A guest blog from the National Institute for Health and Care Excellence." 10 August 2018.
[8] "Black, Asian and Minority Ethnic Dementia Carers Pilot Project Report 13/14", The Suffolk Minority Ethnic Community Network, the Ipswich and Suffolk Council for Racial Equality, and Ipswich and East Suffolk Clinical Commissioning Group, para 6.9.

should be made to ease these feelings and to encourage the allowance of support.

- The lockdown has disengaged many with their support services and some of those who are socially isolated, would have become frail due to inactivity. Work needs to be done to bring these to the attention of health services.
- Cultural activities and religious festivals in the local Chinese, Bangladeshi and Indian communities have helped to reduce isolation and linking health services to these activities enables the support provided to link to their culture to create a sense of belonging. These include:
    - The Chinese New Year
    - The One Big Multicultural Festival
    - Eid festival
    - Diwali
    - Holi Festival
- The Windrush Celebration events that are bringing together people from Caribbean backgrounds (especially the elderly) can also be useful spaces to link services into.

<u>Education and Training</u>

- It is important that work is done to foster trust within communities, which will increase engagement. It is recommended that individuals promoting and undertaking outreach of this kind have sufficient expertise to engage with these communities.[9] Such religious and cultural competency training can be co-produced with religious and community groups.
- Frontline workers within the voluntary and community sector can be upskilled on how to identify frailty and to signpost to existing services.
- It may be helpful to avoid using the term ‘frail’ or any terms not recognised by some individuals. Instead, specific examples of living with frailty in order to drive self-identification. People are more likely to talk about things like “feeling tired” or “losing strength”.

[9] “Black, Asian and Minority Ethnic Dementia Carers Pilot Project Report 13/14”, The Suffolk Minority Ethnic Community Network, the Ipswich and Suffolk Council for Racial Equality, and Ipswich and East Suffolk Clinical Commissioning Group, para 6.2.

Reference List

- “Black, Asian and Minority Ethnic Dementia Carers Pilot Project Report 13/14”, The Suffolk Minority Ethnic Community Network, the Ipswich and Suffolk Council for Racial Equality, and Ipswich and East Suffolk Clinical Commissioning Group.
- https://www.gov.uk/government/publications/social-care-sector-covid-19-support-taskforce-report-on-first-phase-of-covid-19-pandemic/bame-communities-advisory-group-report-and-recommendations. “Corporate Report BAME Communities Advisory Group report and recommendations”, Department of Health and Social Care, 12 October 2020, Section D: BAME Communities Advisory Group recommendations.
- https://www.bda.uk.com/resource/improving-the-quality-of-care-for-ethnic-minority-communities.html. “Improving the quality of care for ethnic minority communities. A guest blog from the National Institute for Health and Care Excellence.” 10 August 2018.
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- https://charitysowhite.org/covid19-health-inequalities. “There Is No Equal Access to Healthcare and Support”.

Appendix

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CARIBBEAN & AFRICAN COMMUNITY HEALTH SUPPORT FORUM

30 April 2021

Dear Phanuel

Thank you for your email and this opportunity to feed back our valuable and critical work going on in CACHSF presently. As you are aware, the African and Caribbean communities are amongst some of the communities affected disproportionately in all areas of health and well-being. We have received small pots of funding to undertake work during COVID and lockdown, however our observations through the process of collaborating with health organisations are as follows:

1) Our older Caribbean communities 50+ are experiencing a great deal of inactivity brought on by lockdown and health has deteriorated for many. The regular cultural activities and food they were eating has become limited, and this has led to a decline in mental well-being as well as leading to an increase in accidents or falls in the home.

2) The older community value the online classes, but many do not wish to access digital activities and are waiting for face to face exercise to resume. There were older people who, after consistent exercise, found that their limbs were stronger, they were more flexible and agile, and able to minimize accidents and falls in the home and outside of the home.

3) There are still a group of 50+ who, due to shielding or fear about when it is safe to venture out, are still requiring services online by culturally sensitive practitioners. Work such as reconnaissance, creating memories for the Windrush generation, have been essential in maintaining mental health, and reducing declination of memory skills.

4) It is clear that the community's health and robustness improves when culturally appropriate services are on offer, and so in addition to mainstream services, we will need to recognise this and continue to allocate funds fairly and equally.

5) Black organisations such as CACHSF are experiencing a 'racial' glass-ceiling when it comes to trying to access more substantial and longer-term funding, despite the outstanding outcomes we have achieved as a BME Charitable Organisations made up entirely of volunteers. Despite us putting in very strong funding applications to address critical health issues in our communities. As you can imagine, for volunteers to write bids is extremely time-consuming, we wait for months for the funding results, only to then be told we have not been granted funding, and it has gone to those larger, more established non-BME organisations who state they are working with our communities. We wish to have an urgent meeting around this level of inequality in Suffolk as our communities will not fare well if funds are not shared equally to serve the communities most at risk, in the way that we want the services offered.

"Let's Talk About Health"