

# Health Inequalities: Full Stop



SOUTH ASIAN HEALTH  
FOUNDATION

Sarah Ali, Kiran Patel, Kamlesh Khunti, Wasim Hanif, Amitava Banerjee, Amal Lad,  
Ranjit Dhillon, Harpreet Sood, Vinod Patel

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## FOREWORD BY DR KAMRAN ABASSI

(on behalf of our Patrons)

Inequalities in health access and outcome have existed for not decades, but centuries. The last century has generated the knowledge upon which actions to ameliorate inequalities have been defined. Sadly, despite knowing what those actions are, we struggle to implement them and make the world a fairer place. After 25 years of tireless campaigning and educating by the South Asian Health Foundation, it is a genuine pleasure to see this report and acknowledge it is now time to drive to stop the inequalities which blight the lives of people and communities in our civil society.



# INTRODUCTION

Health inequalities are defined as “unfair and avoidable differences in health status between different groups of people or communities”. Inequalities refer not only to health status (e.g., long-term illness and life expectancy) but also access to health care, quality of care (including the experience of care by an individual) and wider determinants of health.

Differences in health status are impacted by factors such as socioeconomic deprivation, geographic location, specific protected characteristics (such as ethnicity and gender), disability and homelessness. People often experience different combinations of these factors.

It has been recognised for some time that health inequalities are widely reported in certain disease areas, such as diabetes and cardiovascular disease, where those from Black and South Asian communities and those who are socioeconomically deprived suffer disproportionately.

The South Asian Health Foundation (SAHF) UK is a registered charity which was founded in 1999 to reduce health inequalities experienced by the UK's South Asian communities and to promote their good health.

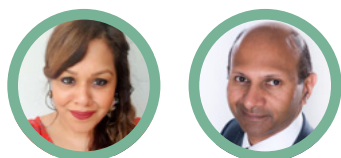
In 2008, the Secretary of State for Health, Alan Johnson, asked Professor Sir Michael Marmot, Professor of Epidemiology at UCL and the UCL Institute of Health Equity, to chair an independent review of inequalities in access to health care in England. His report ‘Fair Society, Healthy Lives: the Marmot Review’ published in 2010 made evidence-based recommendations to address these health inequalities impacted by inequalities in society. This report added compelling impetus to a collection of reports over the previous century, stating what needed to be done to reduce the health inequalities blotting our landscape. Despite these reports, here we are in 2024, noting from Sir Michael Marmot that health inequalities have actually worsened. For the first time in more than a century, life expectancy has failed to increase across England and for the poorest 10% of women, life expectancy has in fact decreased.

Despite advances in medical science, medicines, availability of medical knowledge, digital health and technologies, health inequalities have in fact disappointingly widened. The COVID-19 pandemic, coupled with a cost-of-living crisis and economic instability has taken the health of the nation back decades.

Like other organisations, SAHF has strived to achieve its mission in reducing health inequalities; by promoting evidence-based guidelines, by promoting the need for high quality research in ethnic minority groups, by driving advocacy for those most vulnerable to inequality and by empowering and educating communities.

Yet, here we are, still discussing, conversing, deliberating, conferring, and talking about health inequalities... so why is it still not fixed? We don't have all the answers, but we know that now is as good a time as ever bring health inequalities to a full stop. Let us not only stop inequalities widening further, but start to narrow the gap.

This report collates a series of short articles from many fields in medicine, highlighting issues driving inequality or disparity and more importantly, we discuss potential solutions. The list of conditions here, are admittedly only a sample of the breadth of inequalities which exist in society today. Our online version will be fully referenced and will grow as we add more and more articles this 25th anniversary year. Recurrent themes are a lack of cultural competence, a failure to hear voices from the communities we serve, and a failure to engage communities in research, pathways and policies. Let us now stop failing.



**Sarah Ali and Kiran Patel,**  
**on behalf of the South Asian Health Foundation**

# ALCOHOLIC LIVER DISEASE



## Tackling alcohol-related liver disease in South Asian communities.

Dr Neeraj Bhala

### Alcoholic liver disease (ALD) background and strategies

Alcohol use is the third leading risk factor for death and disability in the United Kingdom, estimated to affect 600,000 people in England alone, and costs the National Health Service (NHS) £3.5 billion a year. Twenty-seven people in the UK are estimated to die every day as a consequence of alcohol misuse currently. The Office for National Statistics published figures show that in 2022 there were 10,048 deaths from alcohol-related causes, the highest number on record and 32.8% higher than in 2019 before the Covid-19 pandemic.

ALD poses a significant burden on the UK's healthcare system and its population. ALD is one of the leading causes of liver disease in the UK, accounting for a substantial proportion of liver-related hospital admissions and deaths. In fact, approximately 60% of liver disease deaths in the UK are attributed to alcohol consumption. The burden of ALD is more pronounced among middle-aged individuals, particularly men although there are marked inequalities in some groups. Concerningly, rising trends in alcohol consumption among women have led to increasing rates of ALD in this group as well.

ALD contributes significantly to healthcare costs in the UK, including costs related to hospital admissions, outpatient care, liver transplants, and long-term treatment for chronic liver disease. ALD is a major cause of premature mortality and also contributes to significant morbidity, including complications like cirrhosis, liver failure, and hepatocellular carcinoma. ALD leads to frequent emergency hospital admissions, often due to acute complications such as gastrointestinal bleeding, ascites, and hepatic encephalopathy.

Beyond direct healthcare (costs), ALD has broader economic implications, such as loss of productivity due to illness, absenteeism, and premature mortality. The economic burden extends to families and communities emotionally and physically affected by ALD. There is a notable geographic variation in the prevalence of ALD, with higher rates in urban areas of socioeconomic deprivation. Regions in the North of England and Scotland tend to have higher incidence rates compared to the South. Individuals in lower socioeconomic groups are at greater risk of developing ALD due to higher levels of alcohol consumption, stress, and limited access to healthcare, driving a cycle of health inequalities.

The UK government has implemented various policies to reduce alcohol-related harm, including minimum unit pricing in Scotland, restrictions on advertising, and public awareness campaigns. However, the effectiveness of these measures varies, and continued efforts are needed to prioritise and address the root causes of alcohol misuse. Early identification and intervention for individuals at risk of ALD can significantly reduce the burden, including routine screening for alcohol misuse in primary care settings and access to community support services. Access to effective treatment for alcohol dependence and liver disease is crucial. This includes medical treatments, liver transplant services, and psychosocial support.

Continuous monitoring of alcohol consumption patterns and ALD prevalence is essential for informing public health strategies. Improved data collection can help identify trends and at-risk populations. Ongoing research into the causes, prevention, and treatment of ALD is vital. This includes understanding the genetic, environmental, and social factors that contribute to ALD. The burden of ALD in the UK is substantial, affecting individuals, families, and the healthcare system. Addressing this burden requires a comprehensive approach that includes effective public health policies, early intervention, accessible treatment, and ongoing research. By tackling the underlying causes of alcohol misuse and providing targeted support, the UK can reduce the impact of ALD.

Ethnic inequalities in alcoholic liver disease (ALD) in the UK are a significant public health concern, reflecting broader patterns of health disparities influenced by socioeconomic, cultural, and environmental factors. ALD is predominantly linked to excessive alcohol consumption. Patterns of alcohol use can vary significantly among different ethnic groups, influenced by cultural norms, socioeconomic status, and accessibility to alcohol. For example, in South Asian communities, some Sikh and Hindu men are more prone to higher alcohol consumption and resultant liver harms: the initial papers based on Punjabi names suggested 4-fold ALD mortality increased risks in the West Midlands. However, larger studies based on linked data using country of birth in England & Wales and then self-reported census ethnicity

in Scotland suggested these were closer to 50% increased risks for ALD. Conversely, studies have shown that White populations in the UK tend to have higher levels of alcohol consumption compared to some minority ethnic groups. Some South Asian groups such as women and Islamic populations do not drink alcohol, with resultant lower relative risks of ALD harms.

Socioeconomic factors such as deprivation are a major risk factor for ALD. Ethnic minorities in the UK are disproportionately represented in lower socioeconomic groups, which can contribute to higher levels of alcohol-related harm due to factors such as stress, poor living conditions, and lack of access to healthcare. Employment status, income levels, and educational attainment are crucial determinants of alcohol misuse too. Ethnic minorities facing economic hardship may be at a higher risk for developing ALD due to these compounded stresses. This appeared to occur during the COVID-19 pandemic.

Disparities in healthcare access and utilization also play a critical role. Ethnic minorities experience barriers to accessing healthcare services due to language differences, discrimination, or lack of culturally sensitive care. This can lead to delayed diagnoses, poorer management of alcohol consumption, and less effective treatment for ALD among these populations. Cultural attitudes towards alcohol consumption and seeking help for alcohol-related problems vary among different ethnic groups. In some cultures and family groups, alcohol use may be more stigmatized, leading individuals to hide their drinking habits and avoid seeking help. Stigma and lack of culturally appropriate services exacerbate health outcomes for ethnic minorities suffering from ALD.

## Recommendations

Effective public health strategies must be tailored to address these inequalities, focusing on culturally sensitive education, community engagement, and targeted interventions to reduce alcohol consumption. Policies aimed at reducing alcohol related harm should consider the specific needs and circumstances of different ethnic groups to ensure equitable health outcomes. Unfortunately, public health investment and resource in tackling alcohol-related harms and ALD in particular in the UK has reduced over time, and availability has increased, resulting in worse population health outcomes especially for stigmatized groups within South Asian communities.

Further research is needed to understand better the specific patterns and determinants of ALD among different UK ethnic groups. Improved data collection and analysis can help identify at-risk populations and inform better policy decisions. UK longitudinal studies and detailed demographic data can shed light on the intersectionality of ethnicity, socioeconomic status, and health outcomes related to ALD, especially in large-scale UK prospective studies. Addressing ethnic inequalities in ALD requires a multifaceted approach that considers the complex interplay of cultural, socioeconomic, and healthcare factors. By acknowledging and addressing these disparities, public health efforts can better support all individuals in achieving healthier lives free from alcohol-related diseases for South Asian populations in the UK and beyond.





## Is alopecia treatment becoming a story of the haves and have-nots?

### Alopecia UK

#### What is alopecia?

Alopecia is a medical condition which leads to hair loss. Different types of alopecia exist, from scarring, patchy hair loss, to total baldness. Alopecia areata (including totalis and universalis) is the most prevalent form amongst the individuals who are in touch with Alopecia UK, and the focus of most research funding. It can affect anyone, but incidence is higher in women, in non-white ethnicities, and in socially deprived and urban environments.

Alopecia areata is not simply a cosmetic issue but affects every aspect of life. Uncomfortable physical complications arise from the absence of body hair, and living with a visible difference has profound psychological consequences. Nearly 70% of people with alopecia experience depression and 65% experience anxiety. It has a devastating psychosocial impact, where shame at looking so different can affect every social interaction, resulting in high levels of absenteeism from work, education and avoidance of socialising. For some people with alopecia, this can lead to isolation, reinforce mental health challenges, diminish life outcomes, and even lead to suicidal ideation.

It is conceivable that the mental health impacts are proportionally larger for those in the South Asian communities, who may not feel they should or can access formal support. A review of 15 studies in 2022 argued that alongside institutional racism, cultural dissonance marginalises some South Asian people from access to quality and effective mental healthcare in the UK.

#### Who is affected by alopecia areata?

The National Institute for Health and Care Excellence (NICE) estimate that, in the UK, 1 person in every 1,000 has alopecia areata. A 2022 population-based cohort study in UK primary care including over 4 million people suggests there are approximately 17,000 new cases each year. The lifetime risk is 1 in 50. Incidence of alopecia areata is higher in women than men. It can develop at any age from childhood to old age, but onset is most common between the ages of 25-29, a significant time of life in terms of work, relationships, and social life. Alopecia is more common amongst non-white ethnicities; in people of Asian descent incidence of alopecia is three times as common as in the white population. Alopecia is more common among people living in urban environments, and more frequently occurs amongst those from socially deprived areas.

#### What are the current issues with healthcare pathways?

The NHS response to alopecia has historically been, and remains, inconsistent, inadequate, and ill-equipped. There is a generalised lack of education about alopecia, with an underlying misconception from some that alopecia is cosmetic. The received wisdom is that hair will regrow in most cases, leading to a 'watch and wait' prognosis, with only 1 in 4 patients receiving a secondary referral to a dermatologist. The 2022 study demonstrated that despite higher rates of AA, specialist referral rates are lower in people from more socially deprived areas. Whilst there is little research on referral rates by ethnicity, it is reasonable to suspect that people with low health literacy or language barriers will also have lower referral rates.

Those who receive a dermatology referral will usually wait over one year. Some patients might see a dermatologist within a few months, while others can wait up to five years. Once in front of a dermatologist, patients will learn that alopecia can be life-long and incurable. NHS treatments are limited. Patients are regularly told there is nothing to be done and discharged.

We are in a critical moment of alopecia care. For the first time, innovative JAK inhibitors have been licensed to treat alopecia areata - an unprecedented development which could have life-changing consequences for some of the 17,000 people diagnosed each year. In Spring 2024, one such medicine, Litfulo was approved by NICE for routine commission on the NHS in England and Wales for people over 12 years of age and was accepted by the SMC for routine use within the NHS in Scotland. We await news from Northern Ireland. Just as with other health conditions, we expect different approaches to prescribing across the NHS Trusts.



## The haves and the have-nots

This health inequality is nothing new; historic treatment pathways for alopecia on the NHS have been inconsistent and uneven. The main support offered is a wig, yet provision depends on which trust a patient falls under, with access frequently determined by a postcode lottery. What is more, many trusts are slashing budgets for wigs as alopecia is de-prioritised amongst healthcare practitioners. While wigs are offered on prescription to all cancer patients as a prosthetic treatment, this provision does not exist for all people with alopecia, whose hair loss is lifelong.

It is well documented that significant income equality exists between ethnic groups in the UK. With many alopecia patients turning to private dermatology appointments, paying for their treatments and wigs, we are facing the reality of those trying to manage their alopecia falling into groups of 'the haves and the have nots'. An Alopecia UK-led study on the socioeconomic impact of Alopecia Acreata noted that the financial burden of AA found that women, people of Asian ethnicity, those who report worse symptoms of AA, and those who had less disposable income spent a higher percentage of their disposable income on products and services to manage AA. There is no reason to suspect this differs for other types of alopecia, and currently no research to prove this. This is inequitable and there is a concern that some people in the South Asian community will be amongst the groups who are most disadvantaged.

## Recommendations

The truth is there is a lot we don't know about how alopecia affects South Asian communities in the UK, so our primary recommendations are research, research, more research! Research into the referral pathways and care for people from South Asian communities, research into the methods of support that people want access to and research into the availability of culturally appropriate support services. We also feel there is more research to be done to understand the relationships between hair, culture, and patient outcomes.

At a more practical level there is space for hair loss to be discussed more openly. We'd invite community groups to help us understand the reality of care and support in the UK today so that we can advocate more impactfully with the governing bodies in the UK. But also, so that we can develop culturally appropriate resources to help people advocate for themselves better with their health care providers across the country.





## Bowel cancer and Inflammatory Bowel disease in South Asian populations

Dr Ajay M Verma

### Bowel cancer

Bowel cancer is the fourth most common cancer in the UK. An average of 43 000 people per year were diagnosed with bowel cancer in 2016-18. It is the third most common cancer after prostate and lung cancer, and the third most common cancer in women after breast and lung cancer. Bowel cancer kills an average of 17 000 people per year (2017-19), accounting for 10% of all cancer deaths in the UK, the 2nd most common cause after lung cancer. Thankfully bowel cancer mortality is falling; one reason for this is due to bowel cancer screening.

The national bowel cancer screening programme (BCSP) was launched in 2006 for individuals aged 60-69, and it has expanded over time. By 2025, it will be offered to individuals aged 50-74, every 2 years by way of a stool sampling kit sent in the post. Those with positive tests (2%) are offered colonoscopy, to assess and remove pre-malignant polyps (found in 40-50% of patients undergoing screening colonoscopy), and to hopefully diagnose individuals unfortunately found to have bowel cancer at an earlier stage (bowel cancer is found in up to 10% of screening colonoscopies). Bowel cancer and polyps are less common in South Asian populations, nevertheless bowel cancer is a common cause of illness and death in middle-aged and elderly people from a South Asian background.

Alarming studies have shown uptake to the bowel cancer screening programme is lower in South Asian populations. A large study looking at 155 000 from West London residents (2012-17) showed an uptake of 52.6% for White British individuals, 41.0% of Indian individuals, 33.2% of Pakistani individuals and 29.4% of Bangladeshi individuals. It is not fully understood what exactly the barriers are that hinder participation rates in South Asians and research continues into this.

It is of crucial importance that individuals from South Asian populations are made aware of the bowel cancer screening programme and its benefits at detecting disease early, thereby reducing bowel cancer deaths. Avenues to enhance screening programme uptake, includes community education including in faith and community centres, as well as the use of social media, multi-language literature, infographics and videos.

### Inflammatory bowel disease

Inflammatory bowel disease (IBD) – namely ulcerative colitis (UC) and Crohn's disease (CD) are chronic autoimmune conditions resulting in significant ill health for affected patients who can suffer from debilitating gastrointestinal symptoms including rectal bleeding, diarrhoea, abdominal pain, fatigue and weight loss for many years. This can have a profound effect on sufferers, affecting relationships, causing absenteeism from school and work, generalised poor physical and mental wellbeing, and the need to take potent immunosuppressant medication (and perhaps the need for major surgery) to control the disease. The impact of IBD is often under-recognised by medical professionals.

The incidence of IBD globally is higher in Western populations, however South Asian immigrant populations are known to suffer from IBD at comparable rates, especially if they were born in the UK. Analysis of areas with a high South Asian population has shown that the incidence of IBD, especially UC is higher in Indian individuals than British white individuals.

A systematic review has shown that South Asians had limited understanding of IBD, hindered by language and literacy barriers, particularly for older generations, suggesting that culturally relevant information is needed. Family support was limited, and Muslim South Asians referred to religion to understand and self-manage IBD. South Asians experienced poor dietary intake for IBD, and cultural conflict in self-managing diet for IBD which increased anxiety.

Given that South Asian individuals often experience difficulties with IBD diagnosis/misdiagnosis, there is a clear need for better quality of, and access to, healthcare services to ensure high quality treatment and management for South Asian patients with IBD.



# BREAST CANCER



## Brown women get breast cancer too

Dr Sarah Ali

That's all I keep thinking since I was diagnosed with stage 3 breast cancer 12 years ago at the age of 36 years. It seems obvious, yes? But then why did I feel isolated from the moment I was diagnosed? The moment my great breast surgeon uttered the words 'you have breast cancer', I was transported back 12 years to the second row of the John Radcliffe Hospital lecture theatre. The lecturer was telling us the typical woman with breast cancer was a white woman in her 50s. Yet here I was, South Asian in origin, mid-30s and wondering how to move on from breast cancer. As I sat visit-after-visit in the oncology waiting room and the chemo suite, I willed harder and harder, for someone who looked like me to walk in. And as the weeks went on, I felt more isolated and questioned where was my tribe?

My fierce mother, hugely instrumental in supporting my young family during my breast cancer treatment, told me not to tell any of our South Asian community or my extended family. To this day, none of my very many first cousins or their families know what I've been through. Why, you ask? It was the usual South Asian concern; people will pity you, think you are defective, think you're receiving illness to clear your sins. My mother didn't believe this herself but she's right, I've heard these things since some people have found out. To be honest, it didn't bother me that my community didn't know. I had to focus on treatment and get better for my 6- and 2-year-olds and my husband, rather than focus on numerous visits from Indian Auntie-Ji's.

Not only is ill health often a taboo discussion subject in South Asian communities, but so are women's bodies and women's health. As far as I am aware, there is no word used openly in South Asian languages for "breast". In Urdu, it is usually referred to as simply the "chest". How then are we to begin to have discussions around cancer of a body part that has no clear name?

Ethnicity data recording for breast cancer is variable and needs to improve. A descriptive study in 2014, looking at English breast and gynaecological cancer registries over a 6-year period showed 20.4% of cancers had no recorded ethnicity data.

Some ethnicity data is emerging. One UK study more recently from Gathani et al and Breast Cancer UK show ethnic minority groups have lower breast cancer awareness and knowledge of symptoms and risk factors, are less likely to attend breast screening compared to white women in the UK and present late for diagnosis resulting in poorer survival outcomes. South Asian women who present with breast cancer are more likely to be younger at diagnosis and have a more aggressive phenotype.

Estee Lauder launched a breast cancer campaign in 2021, involving a survey of 2000 UK women aged 18 - 80 years. 78% of women were not self-checking regularly, with Black women being least likely (76% of those asked), followed by South Asian women (63% of those asked). In these ethnic minority groups, 12% did not check due to stigma and 21% of South Asian women were worried their community or family would judge them if they were found to be checking their own breasts regularly. It is unclear what is meant by being judged - was this due to sexual connotations or that 'our women don't get cancer'.

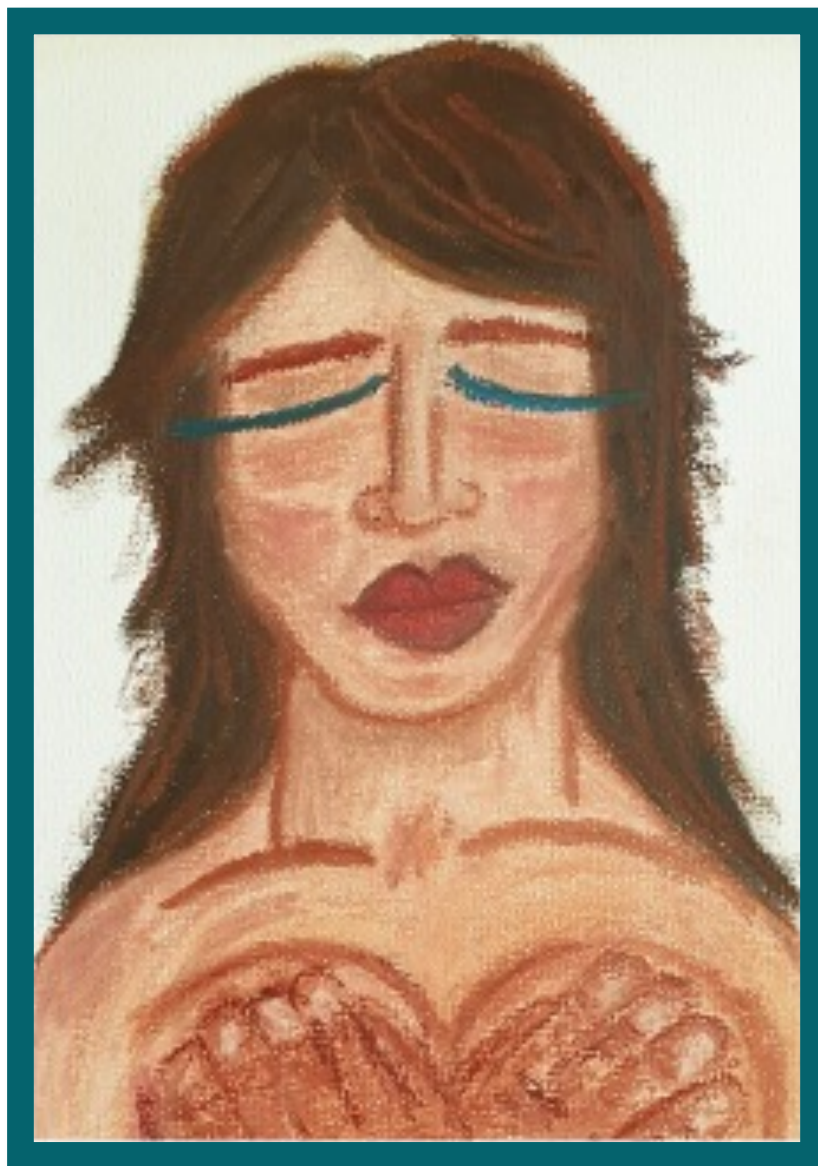
Conversations in the South Asian communities are beginning to happen. The charities Breast Cancer Now and SAHF are committed to making change. Breast Cancer Now has recently issued a statement to prioritise reduction in health inequalities for minority groups including South Asians – I myself am representing SAHF in round table discussions including with NHS England. Breast Cancer Now is also holding a panel discussion in 2024 for South Asian women in Ethnic Minority Cancer Awareness Month (EMCAM) to share narratives and discussions on how to break the taboos and barriers and move forward in improving outcomes and reducing health inequalities for South Asian women. I will be part of the panel, representing both my lived experience of breast cancer but also as a SAHF trustee.

In addition to these community narratives, we need to improve the cultural competence of healthcare workers. How clinicians and other healthcare professionals discuss with South Asian women sensitively and understand the challenges and differences for these ethnic minority groups. One example of this I experienced, was 12 years ago when I met an NHS genetic counsellor to discuss whether I was eligible for the BRCA gene testing. Whilst an extensive family history was taken and I had a maternal aunt who had breast cancer 40 years ago in Pakistan, it was deemed

that I did not fit the criteria for genetic testing. What was not taken into account, in order for my family history to be significant was: my family members being diagnosed with cancer 40-80 years ago in India or Pakistan (how good was cancer pick up in the Indian subcontinent then?), but also at a time when in fact South Asians were more likely to die of infection or cardiovascular disease in the Indian subcontinent before a diagnosis of cancer was made, postmortems are also unlikely in Indian subcontinent Muslims (and therefore tumours not diagnosed) and ill-health is not discussed openly in the community, reflective of my mother's own wishes. My genetic testing has since shown in fact that I have a pathogenic BRCA 2 gene mutation with a high risk of both new breast and ovarian cancer. A new issue arises of how to discuss the "defective" genetic result with my unknowing relatives.

What is clear for South Asians and breast cancer, is that health inequalities exist at every level of care. SAHF is currently drafting evidence-based guidelines targeted at every step of the breast cancer journey (screening and diagnosis to living beyond cancer). We need to ensure we improve ethnicity-related data collection and records, improve communication & awareness within the community and for the community, as well as targeted research to understand the problem and the needs of the community.... Because brown women get breast cancer too.

### **"Brown women get breast cancer too"**



**By Sarah Racanière (aka Dr Sarah Ali) 2022**

**Self Portrait, Oil Pastels on Paper**



## Differences in heart health between in South Asian and White populations

Dr M Justin S Zaman

In the 1950s, studies around the world started reporting differences in coronary heart disease rates between ethnic groups, and in particular higher rates in the South Asian group (predominantly people from India, Bangladesh, Pakistan and Sri Lanka), with UK studies of mortality first reporting differences in cause of death between different immigrant groups in the 1970s and 1980s. By the time the 21st century had come along, the prevalence of heart conditions such as angina was reported to be higher in some South Asian peoples compared to the majority White population, such as in the Health Survey for England in 2004. Then, to add to the controversy, reports emerged that in patients with angina, those of South Asian origin were reported to be less likely to undergo treatments such as coronary revascularisation than those of White origin.

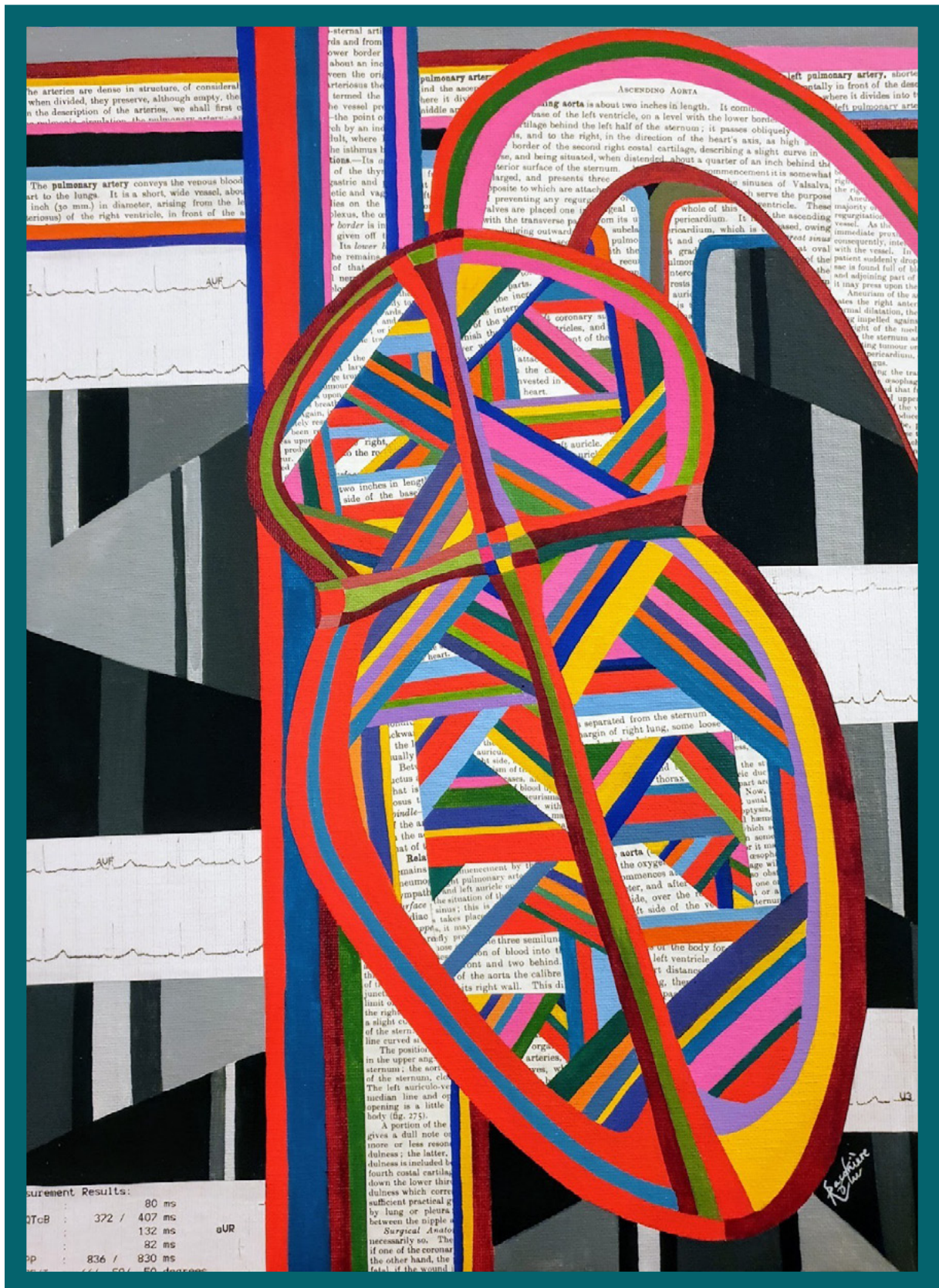
An inequality merely means a difference. Differences in height, eye colour and athletic ability are not considered unfair. An inequity is an unfair inequality. Thus, with any inequality, one should ask firstly whether it is unfair, or fair. Then to examine why inequalities exist, one needs to seek causes. An inherited susceptibility to type 2 diabetes may be more prevalent in South Asian populations, though the biological basis of differences between South Asian and White European origin populations in cardiovascular diseases has not been clarified despite decades of intense study of a multiplicity of explanations. Researchers in the field have long encouraged South Asian populations to undertake the same measures towards healthier lifestyles as advocated to other ethnic groups, just stricter, such as aiming for a lower body mass index.

The comparative heart health of South Asian and White patients is also affected by factors that are not only biological but social too. Previous research has shown a higher socioeconomic status is associated with a lower coronary mortality, and that the social deprivation of areas influences the aetiology and prognosis of coronary disease. South Asian populations are more likely to live in areas with relative social and economic deprivation. Is this an unfair inequality? Initial findings reported that South Asian patients received worse clinical management associated with the deprived areas they lived in were soon reversed - access to coronary revascularisation services was found to be, paradoxically, increased in deprived areas in the UK, probably as a result of their proximity to specialist cardiac centres such as teaching hospitals, and in due course it was found that in fact South Asian patients (in the UK National Heart Attack registry MINAP) were found to have a better survival than White patients.

Cardiovascular risk within South Asian peoples themselves is heterogeneous, pointing pertinently more towards social causes over biological ones, with those of the lowest socio-economic status having the highest rates of coronary disease.

This field still remains an academic and public health issue more than half a century on. The issues remain largely the same – more diabetes, worse diet, and blaming biology and genes. There are even new causes postulated such as ethnic differences in vascular repair mechanisms. Ethnic inequalities in heart health are an epidemiological example where - given plausible scientific hypotheses, good quality plentiful supportive data, diligent research, and translation into ensuing policy change – inequities can be reversed. The first 20 – 30 years of research in the area suggested hope. Risk prediction, primary prevention and early detection remain the top targets to aim for. As we enter the second quarter of the 21st century, we still have much to do in order to prevent coronary heart disease by managing risk factors and for those unfortunate enough to be afflicted, promote early access to treatment and optimal, culturally sensitive rehabilitation.

# “Hope. The Beats of My Heart”



By Sarah Racanière (aka Dr Sarah Ali) 2021

Gouache, Gray's Anatomy and ECG tracings on canvas



### The hidden crisis affecting children and families in temporary accommodation in the UK

Professor Monica Lakhanpaul, Dr Nadia Sviryzdenka, Marta Koch

#### What is the problem?

Professionals across sectors (housing, education, health, and social care) are increasingly aware that there are thousands of children living in overcrowded and unsuitable conditions in temporary accommodation in the UK due to the impact of the COVID-19 pandemic, and now housing and cost-of-living crisis. Research shows that unsuitable accommodation has a real impact on children experiencing homelessness that include mobility issues, delayed speech and breathing difficulties, respiratory infections, malnutrition, sleep and behavioural difficulties directly related to their home environments. Prolonged lockdowns, social isolation, poor environments, and lack of support during the pandemic exacerbated and introduced new, physical and mental health, developmental and behavioural issues affecting children and families. There were 109,000 homeless households in temporary accommodation as of 2023, up 10% in single year, including 142,490 children living in temporary accommodation in England alone as of March, 2024. Notably, the term 'temporary' is a misnomer, with as many as 14,000 households living in temporary accommodation for more than 5 years, with numbers of households and length of stay on a continuous increase due to the COVID-19 pandemic and following economic crisis. Support professionals across sectors are under extreme pressure, with decline in UK Health Visitor numbers, housing crises announced across the UK, and NHS and educational support at their limits. In essence, the key issues driving inequalities affecting children and young people living in temporary accommodation are their lack of access to adequate housing, healthcare, and education, that are in turn having short and long-term detrimental effects on their wellbeing, socialisation, physical and mental health and their ability to keep up academically.

#### Why are the current solutions not enough?

Policy efforts to address the unique needs of children who are experiencing homelessness in the UK have involved a combination of social support programs, mental health services, policies that facilitate integration and inclusion and advocacy work, but this is not enough. The UCL and De Montfort University-led CHAMPIONS (Children in Homeless Accommodations Managing Poverty Invisibility Or Non-inclusive Strategies) project has found that families have reported experiencing stigmatisation from the individuals who are supposed to support and aid them. Essential resources for healthy child nutrition, hygiene, and development such as kitchen appliances, sanitation and laundry provisions, and safe spaces to play and learn are not part of standards for temporary accommodation to be considered safe for a family with young children to occupy. There is also no mandatory data collection from families, control of environmental health risks, monitoring of the maximum length of time children are allowed to stay in unsuitable accommodation, or regulations to minimise the amount of moves families experience. Lack of standards and little oversight results in detrimental short- and long-term effects on child health, development, and wellbeing. In addition, many families are also unaware of the benefits they are entitled to, and of the assistance that is available to them, such as food and baby banks, moving services and legal advice. Finally, the study found that families in temporary accommodation are frequently moved to new neighbourhoods or areas of the country with little support to aid continuation of services and support systems such as food banks, nurseries, children's centres, legal support, housing officers, this causing them additional ongoing trauma and stress from having to re-identify those services, register, and retell their experiences.

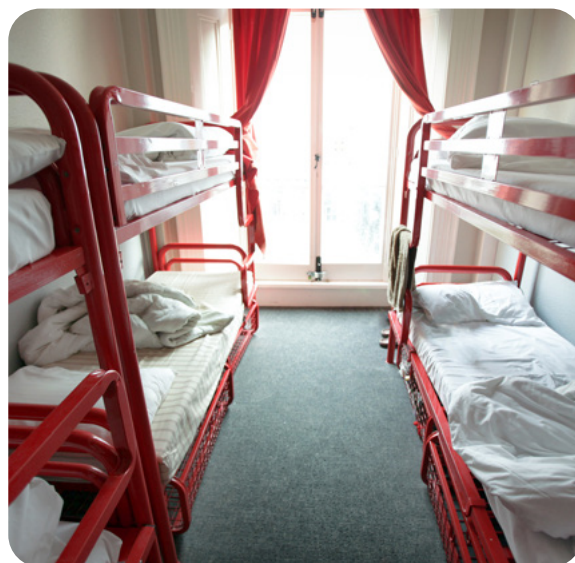
#### How can we solve this?

Firstly, more participatory research to give families and children living in temporary accommodation a voice and treat them as research partners with valuable lived experiences is critically needed. Public Health England and the Royal Society for Public Health UK recommend taking advantage of closer partnerships with community facilitators and champions with local knowledge and community know-how in order to improve the accuracy and relevance of research being undertaken with child and family participants directly. The CHAMPIONS 'HEAR US' research project at UCL and De Montfort University in partnership with YouthZones, for example, used the creative arts as a novel methodology to both create a safe space to have conversations with young people about sensitive topics and gather meaningful evidence about their experiences to inform possible solutions and pathways to resilience. The project focuses on



evidence-gathering, advocacy, and awareness-raising among professionals, policy-makers and the public through arts-based roundtable discussions and workshops using ceramics and drawing to facilitate safe conversations around sensitive topics such as mental health and bereavement with children and young people in 2022. Targeted and tailored support groups run at YouthZones (e.g. HIMpact tailored to issues and needs of young males aged 8-19 years, and EmpowHER focused group for young females aged 8-19) have shown to be successful in improving confidence, health and wellbeing, social skills and relationships, emotional skills and aspiration and achievement among the child participants – they were all shown to increase in comparison with the average. Overall scores after group participation for girls increased by 61% and boys by 83%. Therefore, effectiveness of interventions, designed with and for the target population are likely to have higher impact and positive change. Taking time to create safe and trusted environment to have sensitive conversations with communities that have been systemically and systematically overlooked, marginalised, and underserved is essential for accurate and meaningful data.

Secondly, further support for evidence-based policy change is needed now. Public improvement policy-making to help children experiencing homelessness should take the form of what is called health systems strengthening (HSS) focused on challenging the health inequalities these vulnerable children are facing daily in all aspects of their lives. World Health Organization (WHO) recommends this approach: ‘changes in policy and practice in a country’s health system, so that the country can respond better to its health and health system challenges improvements in access, coverage, quality or efficiency.’ In light of this, the CHAMPIONS project’s Policy Brief, launched in 2023 in collaboration with UCL Public Policy, key UK charity partners working on child homelessness and The Childhood Trust highlighted key policy recommendations for improving public service support for children in the health, social care, housing, and education sectors: (i) implementing a mandatory child-centred minimum standards framework for temporary accommodation which is clear and usable, with accountability and monitoring in place; (ii) introducing community service navigation advisors to aid and direct families to helpful information and support; (iii) developing digital and physical materials to support families with navigating local services; (iv) collaborating and sharing relevant information across sectors using secure data-sharing methods in order to alert relevant sectors when a new family is rehoused (allowing for quick access to health, education and social services); (v) encouraging a change in the narrative and stigma around families experiencing homelessness among public sector support professionals; and, (vi) supporting local areas in ensuring the adequate provision of doctors, health visitors and midwives for the timely assessment and support of children.



Experiencing homelessness has significant and long-lasting effects, and although varying in appearance, impacts children of all ages, ethnicities, and genders. For truly effective policy and social change, government representatives, civil society organisations, and NGOs including charities, human rights organisations, faith groups, think-tanks, local authorities, academia and parents and carers with children currently living, or with experience of living, in temporary accommodation, need to address the two objectives set above in order to overcome the widespread negative effects of homelessness on children in the long-term. Action is needed at local and national levels not only to build more houses – which of course is important and needed – but also to ensure that the accommodation children are placed can support children’s rights to safety, health, and education and those professionals who come into contact with children in temporary accommodation from the housing, education, health, and social care sectors are able to provide the best support in order to give these children a better future.

***‘Every child has the right to a standard of living adequate for the child’s physical, mental, spiritual, moral and social development.’ Article 27, UN Convention on the Rights of the Child***



## Dementia inequalities: across prevention, diagnosis, and care

Dr Naaheed Mukadam

### What is dementia?

Dementia is defined as an acquired impairment of cognitive function that results in loss of function, meaning a change in brain processes that leads to people being unable to do things they previously managed to do. There are different types of dementia, depending on the underlying brain pathology and what symptoms are more prominent. The most common type is Alzheimer's dementia but vascular dementia (caused by strokes) and mixed dementia are also common.

### Who is affected by dementia?

Dementia affects the person living with it, as well as their family members and it also has an impact on society due to the costs and impact of dementia on health and social care. Dementia currently costs the UK economy £34.7 billion annually with costs expected to rise to £94.1 billion in 2040. Dementia is most common in those over the age of 65, with incidence roughly doubling for every 5-year age band after this age. People under the age of 65 can also be affected but often experience longer delays in getting a diagnosis.

### Dementia prevention

Many long-term studies of populations have shown that dementia rates have fallen over time in many countries, including the UK. This has led to a growing body of research into risk factors for dementia and how this could reduce dementia rates over time. The Lancet Commission on Dementia Prevention, Intervention and Care estimated that up to 40% of dementia cases may be prevented by tackling 12 risk factors (less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution).

Research in this field often excludes people from minority ethnic groups but there have been some more recent studies that have explored differences in dementia risk and risk factors across ethnic groups. People from South Asian backgrounds have been found to have higher rates of dementia and a younger age of onset. They are also more likely to have some risk factors for dementia such as obesity, hypertension, and diabetes, and moreover, some of these risk factors have a greater impact on South Asian people with regards to dementia risk than in the White population. Overall, there may therefore be greater potential for dementia prevention in the South Asian population but one which is not yet being implemented.

### Dementia diagnosis

Timely diagnosis in dementia means getting a diagnosis when the person with dementia or their family wants it. This has potential benefits such as enabling people with dementia to plan for the future while they retain the mental capacity to do so, and allowing them to access help and support in a timely manner so they can live as well as possible for as long as possible. Unfortunately, there are inequalities here as well: South Asian people receive a diagnosis of dementia later than their White counterparts and their dementia is more severe when diagnosed. Survival after dementia diagnosis is also shorter for South Asian people compared to White people with dementia. Some of these delays in diagnosis may be due to reluctance of people of South Asian backgrounds to seek help for dementia because of lack of understanding about what dementia is, and concerns about stigma but some may also be due to healthcare related delays or bias. Accurate diagnosis can be challenging due to language barriers and the fact that many cognitive tests are not suitable for assessing cognition in people from different cultural or educational backgrounds.

## Post-diagnostic support

National dementia guidelines are often written with the majority population in mind and rarely include guidance about helping more diverse groups. Support and care after diagnosis is important to ensure all needs are met but there can be assumptions about what South Asian families want, and those with least resources often receive less support. It's important to provide good quality information and signposting for all people living with dementia – this may require translated materials for some South Asian people with dementia. In addition, NICE guidance recommends Cognitive Stimulation Therapy which is a group therapy that can help improve cognition but there are often limits as to which languages these can be provided in, so may limit access in the South Asian population who are less comfortable speaking English.

## Recommendations

We firstly need better quality data on ethnic groups in primary and secondary care so that we can have a data driven approach to studying and addressing inequalities. Awareness around dementia, including risk reduction and stigma reduction campaigns can help reduce dementia rates and start to improve attitudes to help-seeking for memory problems in South Asian people. Greater education about culturally appropriate cognitive tools and more widespread use of these in primary and secondary care can help to improve diagnostic accuracy and timely diagnosis. Finally, taking a person-centred approach and not making assumptions about what services people will want can help to improve equity in post-diagnostic support and could address differences in outcomes.



# DIGITAL HEALTH INTERVENTIONS



## Digital Interventions for South Asian with Cardiometabolic Disease

**Professor Amitava Banerjee, Dr Mel Ramasawmy, Dr Nushrat Khan, and Dr David Sunkersing for the DISC Study consortium**

Digital health interventions (DHIs) are apps, websites, and other digital tools that help people manage their health. The NHS uses such DHIs for various reasons, including disease prevention or monitoring of certain conditions, and this has been accelerated during the COVID-19 pandemic. We know that these technologies can be helpful, but we risk some groups of people being disadvantaged, especially those who already experience health inequalities. In the Digital Interventions for South Asians in Cardiometabolic Disease (DISC) Study, we looked at whether and how people of a South Asian background with heart disease and diabetes use DHIs, as this group is at a higher risk of these conditions, and may face more barriers to using digital health. This can help us understand and improve the way digital health care is delivered.

As part of the study, we reviewed published research and policy documents to search for existing information on whether there are differences in uptake and use of DHIs. Through a survey, interviews and focus groups, we heard from patients, healthcare professionals, policy makers and technology developers about factors that contribute to differences in uptake, use and effect of DHIs used in heart disease and diabetes.

South Asian patients described common barriers to using DHIs, such as the cost of mobile devices and data, lack of confidence, and limited language options or relevant information (e.g., on diet). They felt that they may not have been offered DHIs due to assumptions from their health care team that they would not be able to use them. During the COVID-19 pandemic, many people increased their digital skills, such as for staying in contact with friends and family. People we spoke to were interested in DHIs if they could help them manage their health, and wanted support to find out about relevant DHIs, as well as learn how to use them.

Health and care staff told us that they needed more information and support around recommending digital tools to patients – for example, a national approach to commissioning. In busy services, particularly primary care, they did not have the time to introduce and provide ongoing support for digital tools and suggested a role for other health and care staff or community services. Differences in how IT systems work made it more difficult to use patient data from these DHIs effectively.

Amongst technology developers there was good awareness of how DHIs can be designed to be useful to more of the population (e.g., through language, audio, and including more personalisation and diverse information). Improving how DHIs are evaluated and regulated can help make them more inclusive in who can use and benefit from them. In addition, increasing opportunities for learning from successful implementation of DHIs can help us to understand how things can be improved.

People working in national policy highlighted that ensuring equitable access to digital health is complex and is exacerbated by sociodemographic inequalities, a lack of integration within the NHS, and a lack of shared understanding of actions needed to tackle these inequalities. Ideas for improvement at the system level include developing expertise within communities, structured evaluation process of DHIs and identification of responsible partners, among others.

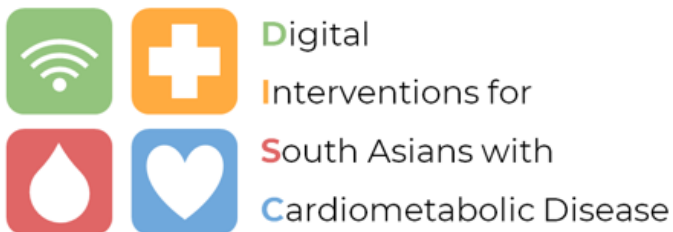
## Recommendations to address digital health inequality

A workshop was held in May 2023, including patients, doctors, technology developers, health charities, and policy makers. Recommendations were developed across four areas identified from study findings:

- Improve access and benefits for patients: engage communities in the process from design, implementation and support, such as digital skills training.
- Inclusive DHI design: engaging target users in design and testing, producing guidance on accessibility, sharing learning between projects
- Evaluation and regulation to embed inclusivity: evidence-based standards, evaluation frameworks that consider all groups, and recognition of community input
- Improve data for equality: better communication to the public, training and support for staff to collect sensitive data, and appropriate data categories.

You can find out more about the DISC Study on our website: <https://www.doctorasdatascientist.org/the-disc-study>

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## Dyslipidaemia in the South Asian population

**Dr Aneesha Chauhan, Dr Lavandan Jegatheeswaran, Dr Shaan Sahota, Dr Haneesh Kaur Johal, Professor Vinoda Sharma, Professor Amitava Banerjee, Dr Pankaj Gupta, Dr Rubin Minhas, Professor Kiran Patel**

Cardiovascular disease (CVD) causes a quarter of all deaths in the UK and is the largest cause of mortality worldwide. In order to tackle this issue, it is important to acknowledge that cardiovascular (CV) risk is not equally distributed. It has been estimated that there is a two-fold higher risk in South Asians of incident atherosclerotic CVD when compared with individuals of European ancestry.

Dyslipidaemia, amongst other risk factors, is a well-established contributor to this risk. Worldwide, South Asian ancestry accounts for 1.8 billion individuals – 23% of the global population – demonstrating the impact of this issue. Population differences (unique aspects of a population) must be understood, and disparities (secondary to health inequity) eliminated. We outline our recommendations for healthcare professionals, researchers, and policymakers below.

### Recommendations for healthcare professionals:

- Healthcare professionals should take opportunities to screen for dyslipidaemia earlier in South Asians, and consider testing lipoprotein (a) at index presentation
- Those with borderline risk scores, where risk may have been underestimated, should be considered for lipid lowering therapy, particularly if lipoprotein (a) or Apolipoprotein B are raised
- Consider using lifetime risk scores to assess and demonstrate long-term risk
- As with the general population, those with suspected familial hypercholesterolaemia should have management commenced promptly and be referred early. A high index of suspicion is needed to ensure patients are appropriately screened and referred
- Lifestyle modification should include culturally appropriate advice, education, and intervention
- Where medical management is indicated for the primary prevention of cardiovascular disease, statin therapy should be considered at the index presentation. Care should be taken to ensure appropriate statin dosages are prescribed; Simvastatin 80mg and Rosuvastatin 40mg are not recommended in South Asians
- Where possible, reports of statin intolerance without biochemical evidence of toxicity should be explored, and patients supported to try a lower dose rechallenge
- For those on secondary prevention who do not meet their LDL-C targets, PCSK9 inhibitors should be considered according to NICE guidance
- An understanding of patient beliefs and culturally appropriate patient education is essential in improving medical therapy uptake and adherence
- Treatment of dyslipidaemia to reduce cardiovascular risk must include parallel management of other known cardiovascular risk factors in South Asians, such as diabetes, hypertension, and BMI > 23 kg/m<sup>2</sup>

### Recommendations for Researchers:

- Large, representative, prospectively followed databases of South Asians providing information on various CVD risk factors, their proatherogenic lipid markers, and their contribution to incident CVD should be developed in order to validate more personalised risk scores that focus on lifetime risk
- Further research into the pathogenic variants of Familial Hypercholesterolaemia is required, in order to allow increased identification and family screening
- Efforts should be made to include more South Asians in medical therapy trials and develop clinical trials in those of South Asian descent where possible

### Recommendations for Policy makers:

- Early detection and screening programmes should be explored, with consideration for targeted screening of high-risk populations
- Campaigns to increase awareness of cardiovascular risk by ethnicity for both clinicians and patients should be funded
- Low-cost interventions such as polypills, and culturally specific patient education and interventions to improve uptake and compliance should be considered for funding on both a local and national level



## South Asian Health Behaviour

**Dr Farhin Ahmed**

The prevalence of chronic diseases among South Asians highlights the importance of understanding the psycho-social-cultural dimensions of health behaviour for developing effective health interventions and improving health outcomes within and across South Asian communities.

Research has shown that psychosocial and cultural factors, such as social norms and networks, significantly influence adherence to medical advice and lifestyle modifications among South Asian populations in the UK. Studies focusing on disease management, particularly for conditions like type 2 diabetes (T2D), underscore the pivotal role of these cultural constructs. These studies provide insights into the underlying cultural constructs shaping health behaviour among South Asians.

While altering health behaviour is a multifaceted process, behaviour change interventions rooted in social and behavioural sciences have demonstrated efficacy compared to those lacking theoretical foundations. South Asians' distinct genetic makeup, combined with environmental factors and cultural practices, heightens their susceptibility to specific health conditions. Dietary habits and lifestyle choices prevalent in these communities, characterised by unhealthy diets and sedentary lifestyles, contribute significantly to the risk of chronic conditions like T2D.

Moreover, social and economic factors, including limited healthcare access, language barriers, and discrimination within healthcare systems, exacerbate health inequalities. Addressing these systemic challenges requires holistic interventions encompassing biological, socio-cultural, and economic determinants to improve health outcomes for South Asians.

### Recommendations

To effectively reduce the disparities in health outcomes among South Asians living in the UK, it is crucial to implement interventions that are specifically tailored to their unique needs. Policymakers and healthcare professionals must gain a deep understanding of the complex interplay between genetic, environmental, and lifestyle factors that affect the health of this population. The proposed measures to address this issue include policy changes, community engagement initiatives, cultural competency training, educational programs, and increased research efforts.

### Community initiatives

Community engagement has been recognised as a crucial approach to involve South Asian communities in co-creating and implementing health programs that are tailored to their specific needs. To improve communication and foster trust, healthcare professionals need to receive cultural competency training. Educational initiatives to enhance health literacy within the community are also pivotal in promoting preventive care. Bridging the knowledge gap through culturally sensitive educational initiatives is essential for promoting a proactive approach to healthcare, empowering South Asian individuals to make informed health decisions and reducing the burden of preventable diseases.

### Research

A commitment to increased research and data collection is critical to informing evidence-based interventions to address the root causes of health disparities and to understand the effective behaviour change techniques that facilitate positive and healthy lifestyle changes. Providing research funding, collaborating with grassroots organisations that serve as gatekeepers in South Asian communities, and exploring targeted approaches to health information dissemination will support the need for increased health education and research within the South Asian community.

### Conclusion

Collective action is needed to address the health inequalities faced by South Asians in the UK. This can be achieved by advocating for policy changes, promoting community engagement, enhancing cultural competency, investing in education, and fostering research. By working together, stakeholders can bring about positive and sustainable changes in the health outcomes of this diverse and dynamic community.

# HEART FAILURE



## Heart failure – the 25in25 Initiative

Ms Janine Hogan, Professor Amitava Banerjee, Ms Lynn Mackay-Thomas

### Background:

Heart failure (HF) presents a significant public and population health challenge. With prevalence predicted to double by 2040, we need to act now. The British Society for Heart Failure-led 25in25 initiative aims to address this by reducing mortality from HF by 25% in the next 25 years, translating to over 10,000 lives saved annually. Uniquely, the BSH convened a Summit in March 2023 with 48 (now ~60) healthcare organisations intersecting with HF care, who signed the 25in25 declaration committing to collaborate, including the South Asian Health Foundation and devised a road map for implementation. Using a community-based, quality improvement approach, data is to be collected from 5 domains; prevalence, risk, diagnosis, treatment, and quality of life, to change the trajectory of HF at grassroots level. An AI-enabled dashboard to extract data from General Practice records is being developed and tested in 7 pilot implementation sites across the UK and Jersey through 2024 with national rollout in 2025. QI measures, such as risk assessments and targeted interventions, aim to identify undetected cases of HF and provide timely treatment. The 25in25 initiative will ultimately improve outcomes, reduce hospitalisations, avoidable deaths and inequalities, for those with HF.

### 25in25 Initiative:

HF is the final common pathway and endpoint for most cardiovascular disease (CVD) and a significant cause of mortality across the wider cardiorenal-metabolic spectrum. Over one million people in the UK have HF, with 200,000 new diagnoses every year. Estimates suggest there are a further ~400,000 people that are currently undetected and undiagnosed, missing out on life-preserving treatments. Numbers are set to increase by 92% by 2040 due to several factors, including anticipated growth in the elderly population, in the next 25 years. HF care currently accounts for up to 2% of the entire National Health Service (NHS) budget costing ~£2 billion annually. A significant proportion of this is due to delayed diagnosis with 80% of HF first diagnosed as an emergency admission in hospital where 40% should have triggered an earlier assessment in primary care. 1 in 10 do not survive the emergency admission and 1 in 3 do not survive up to one year after discharge. The human and economic costs are huge.

Data indicates that lack of awareness and understanding of HF contributes significantly to late diagnosis which can then result in avoidable hospitalisations and deaths. 98% of people with HF are living with at least one other long-term condition, such as diabetes, kidney disease, high blood pressure and depression. From epidemiology to pathophysiology, there are overlaps with many organ systems and clinical specialties.

### 25in25 Collaboration:

Traditional siloed working in the NHS brings the clinician's focus onto the disease in which they specialise rather than looking at the whole patient in a more personalised way. The 25in25 initiative recognises that this silo model does not serve the earlier detection of HF or the detection of currently undetected disease and that a strategy is needed to change this paradigm. HF is a journey that starts from many different locations (often beginning in risk factors such as raised blood pressure and cholesterol) to end up at the same place. Those start points offer opportunity for earlier intervention by a broader spectrum of healthcare professionals across wider healthcare settings, to change the trajectory away from HF. The strategy addresses current and future under resource against the growing prevalence of HF by reaching out to intersectional organisations and gaining their cooperation to help manage the oncoming caseload by detecting HF earlier.

Raising awareness, providing information, improving education of the public; policymakers; supporting and training the wider spectrum of health care professionals in their communities, will detect undetected HF and improve outcomes. Addressing HF at a community level is essential as we recognise 'one size does not fit all'. It disproportionately affects underserved populations and those living at the intersection with socioeconomic deprivation. Highlighting the need for targeted interventions to reduce disparities in health outcomes and improve population health is crucial.



## Freedom from Failure:

Poor recognition of symptoms leads to late diagnosis and acute admissions which worsen outcomes. The BSH awareness campaign: 'Freedom from Failure – the F word' encourages people to look for common symptoms of HF (F words: 'fighting for breath, fatigue, fluid retention) in themselves and others and seeking medical advice. Detecting undetected HF ('Find me'), particularly in underserved communities, is key. Hence the strategy to reduce mortality from HF in the first year after diagnosis by 25% in the next 25 years. This would mean 5 fewer deaths for every 100 patients newly diagnosed with HF every year, translating to over 10,000 lives saved per year.

## Community Power:

The 25in25 initiative marks a departure from traditional top down, single condition approaches to CVD management. It is the first-time stakeholders across the health landscape have united to address the condition proactively in a wider context and agree a clear consensus to act together to reduce avoidable deaths.

The innovation in 25in25 lies in its comprehensive approach to early detection and intervention, leveraging community-based screening and multifunctional care models. This is a unique community-led, grass-roots approach to detection (involving extensive education and awareness), driving quality improvement to find people at risk of or with HF.



## 25in25 Implementation:

For the implementation phase of the 25in25 initiative, the BSH has embarked on a comprehensive discovery phase to enhance our understanding and knowledge of HF management. It focuses on driving progress through quality improvement, by linking data on HF and CVD in the community in real time, as opposed to auditing 'snapshots' during illness in hospitals. The goal is to develop a fully functioning dashboard, launching and testing it across pilot sites within 12-months (2024), showcasing the potential for early detection and intervention to save lives. The insights will inform future strategies, emphasising the importance of community engagement and holistic care approaches. Continuous evaluation and adaptation will be integral to sustaining progress and achieving long-term success. For fine-tuning the product specification for data collection for the quality improvement programme, 4 domains will be measured: risk, diagnosis, treatment, and patient empowerment, in preparation for the platform-build.

The 25in25 initiative has global reach and support and whilst it is currently in the pilot implementation phase in England, Scotland, Wales and Jersey, concomitantly, we will be assessing the replicability and scalability of the initiative outside of the UK, referencing the international quality standards for HF and the World Heart Observatory global burden of disease. The programme has been fully endorsed by the Heart Failure Association of the European Society of Cardiology (HFA-ESC).

The 25in25 initiative is poised to bring about significant progress on accessing datasets and integration of community-based information into the fabric of the NHS and promoting health and disease prevention inclusively. By monitoring and acting on near-real time data, there is real scope to reduce inequalities in heart failure diagnosis and management.



## Unveiling Ethnic Divides: Tackling Disparities in Liver Health and Metabolic dysfunction-associated steatotic liver disease (MASLD)

Dr Saima Ajaz

### Current Landscape of Liver Diseases and Health Disparities:

Liver health disparities have been a major concern in healthcare, impacting numerous individuals from diverse demographic backgrounds. According to British Liver trust, every day over 40 people die from liver disease in the UK, making it the third leading cause of premature death. Alarming, 90% of liver diseases are preventable. However, about three-quarters of these cases are diagnosed at an advanced stage, when it is often too late for lifestyle changes or interventions to have an effect. The impact of liver disease also varies significantly based on socioeconomic factors and geographical location. Among liver conditions, Metabolic dysfunction-associated steatotic liver disease (MASLD) stands out due to its complex interplay with metabolic health, lifestyle choices, and socioeconomic factors. Despite its high occurrence, there remains a significant lack of awareness and understanding of MASLD among those most at risk.

### Community Initiative: Addressing Key Issues in MASLD Management

From October 2021 to April 2023, a team from Kings College Hospital conducted a service development project in the Lambeth Diabetes Intermediate Care centre. The main objective of this study was to assess the awareness and prevalence of MASLD among underserved community in South London focusing particularly on how multi-ethnic backgrounds and associated lifestyle preferences influence these health outcomes. Transient elastography accompanied by questionnaires and detailed health assessments were used to assess liver conditions. The results based on 223 patients highlighted the following points:

#### Educational Gaps:

Awareness of MASLD was low (30.9%) and the majority of patients with liver fibrosis (69%) had never heard of this condition. Understanding varied between ethnic groups and the highest levels were demonstrated in the Caucasian/white population (of whom 41.5% within ethnicity were aware of MASLD). This was followed by black African/Caribbean (32.5%), Latin/Hispanic (23%), Mediterranean (20%), Asian (18%) and Middle Eastern (16.7%).

Surprisingly, the average BMI was 32kg/m<sup>2</sup> but only 48% of patients considered themselves to be 'overweight'. There is a critical need for education on the risks and prevention of MASLD, as awareness is often lacking even among at-risk populations. Cultural perceptions and stigma associated with liver disease can hinder awareness and timely medical intervention

#### Lifestyle preferences:

According to our structured questionnaires, most patients preferred diets that were rich in carbohydrates (66%), including ultra-processed foods/sweets (41%). Most subjects preferred high carbohydrate diet with subjects from Middle East leading with (83.3%), followed by Asians (81.8%), Mediterranean (72%), Latin /Hispanic (69.2%), Black African (62.9%) and White/Caucasians (62.5%).

Only 43% subjects performed moderate exercise daily, despite the majority (96%) receiving specific lifestyle advice from healthcare professionals. Subjects of Black African/ Caribbean ethnicity performed the most exercise (50%) followed by Caucasians (46%) and those from the Middle East (33%). 99% of participants were strongly supportive of a multidisciplinary approach and lifestyle guidance in clinics.

#### Socioeconomic Status:

Individuals from lower socioeconomic backgrounds often experience higher rates of MASLD. Limited access to healthy foods, safe environments for physical activity, and preventive healthcare exacerbates risks and outcomes.

## Co-morbidities:

In the study group diagnosed with type 2 diabetes mellitus (T2D), only 15.7% had a normal weight, while 28.6% were overweight, and the majority, 55.7%, were classified as obese. Additionally, a significant proportion of these patients also suffered from hypertension (62%) and dyslipidaemia (59.5%).

## Potential Solutions and Recommendations

**Community-Based Interventions:** Implementing community health programs that focus on diet, exercise, and lifestyle education can effectively reach at-risk populations. Tailored programs to meet community-specific needs can bridge knowledge gaps and foster healthier choices.

**Enhanced Access to Care:** Mobile health clinics and telemedicine can extend the reach of liver health services, especially in geographically isolated regions. Such initiatives ensure that more individuals have access to early screening and ongoing management for MASLD.

**Policy Initiatives:** Policymakers should consider subsidies for healthy foods, funding for local sports and recreation facilities, and incentives for medical professionals to work in underserved areas. Additionally, integrating liver health education into school curriculums could promote early preventive practices.

**Collaborative Research and Advocacy:** Strengthening collaborations between research institutions, healthcare providers, and community organizations can enhance the focus on MASLD. Advocacy for increased funding and research into liver health disparities can propel these issues into public and political discourse.



## Summing up

It has been shown that there is a strong relationship between MASLD and deprivation. The prevalence of MASLD is higher in socially deprived communities due to the commonality of obesity and diabetes. Only recently there has been changes in guidelines which now recommend screening for high-risk population such as patients with T2D. Addressing the disparities in liver health, particularly MASLD, requires a multi-faceted approach that combines community engagement, improved healthcare access, educational initiatives, and robust policy support. By targeting the root causes of these inequalities and implementing effective solutions, we can pave the way for a healthier future for all individuals, irrespective of their background or location.



## Maternal Health Inequalities in the UK

Dr Quratulain Sadiq, Miss Vinita Singh

### Introduction

Maternal health outcomes in the UK exhibit significant disparities linked to socioeconomic and ethnic factors. This report synthesizes data from the MBRRACE-UK Maternal Surveillance Report 2023 and other studies to highlight these inequalities and propose avenues for improvement.

### Maternal Mortality

Between 2019 and 2021, 241 women died during or shortly after pregnancy out of 2,066,997 births, resulting in a maternal mortality rate of 11.7 per 100,000 maternities. Excluding deaths due to COVID-19, the rate was 10.1 per 100,000. Leading causes included cardiac disease, blood clots, mental health conditions, and sepsis. COVID-19 notably impacted maternal mortality rates, especially in 2020 and 2021.

### Socioeconomic and Ethnic Disparities

The MBRRACE-UK report reveals stark ethnic and socioeconomic disparities in maternal mortality. Black women experienced a mortality rate nearly four times higher than White women (37.2 vs. 9.7 per 100,000 maternities), while Asian women faced a mortality rate almost double that of White women (17.6 vs. 9.7 per 100,000). Additionally, women in the most deprived areas had a maternal mortality rate twice as high as those in the least deprived areas (17.7 vs. 8.7 per 100,000).

### Inequalities in Pregnancy

Outcomes Data from the National Maternity and Perinatal Audit, including a Population Attributable Fractions (PAF) analysis on births in England from April 1, 2015, to March 31, 2017, indicate that socioeconomic inequality significantly contributes to adverse pregnancy outcomes. Approximately 23.6% of stillbirths, 18.5% of preterm births, and 31.1% of births with foetal growth restriction (FGR) were attributed to socioeconomic disparities.

### Ethnic Impact

Studies highlight ethnic disparities in pregnancy outcomes. The risk of stillbirth ranges from 0.3% in White women to 0.7% in Black women, while the risk of preterm birth is 6.0% in White women, 6.5% in South Asian women, and 6.6% in Black women. Moreover, 11.7% of stillbirths, 1.2% of preterm births, and 16.9% of FGR could be attributed to ethnic inequality.

### Group-specific Attributable Fractions

Studies found exceptionally high group-specific attributable fractions, particularly among the most socioeconomically deprived South Asian and Black women. For instance, 53.5% of stillbirths in South Asian women and 63.7% in Black women, as well as 71.7% of FGR in South Asian women and 55.0% in Black women, were attributed to ethnic inequalities.

### Government and Health Sector Responses

The NHS aims to halve the rates of stillbirths, neonatal deaths, maternal deaths, and brain injuries during birth by 2025 from a 2010 baseline. This goal requires concerted efforts across healthcare professionals, policymakers, and public health experts to address these disparities effectively, focusing on socioeconomic and ethnic inequalities.

## Recommendations for Addressing Inequalities

Public health initiatives should address the specific needs of minority ethnic groups at high risk of adverse pregnancy outcomes. Enhanced data collection on how inequalities intersect with women's societal circumstances and health conditions is essential. Addressing wider determinants of health, such as poverty and access to healthcare, is crucial in mitigating these disparities.

## Conclusion

Persistent disparities in pregnancy outcomes, particularly among Asian women, underscore the urgent need for targeted interventions and policy changes. Despite efforts to improve maternal health, Asian women continue to face disproportionately high risks of adverse outcomes, including stillbirths, preterm births, and foetal growth restriction.

Addressing the specific needs and challenges faced by Asian women—such as cultural and language barriers, access to healthcare, and socioeconomic inequalities—can significantly improve equitable maternity care. It is imperative that public health initiatives prioritize the unique circumstances of Asian women and ensure their voices are heard in decision-making processes.

Through concerted efforts to address these disparities and implement culturally sensitive and inclusive healthcare practices, the UK can improve maternal health outcomes and create a brighter future for all mothers and their babies.





## Menopause symptoms, health risks and management challenges in Asian women

Professor Annice Mukherjee

### Background

It is thought that most women worldwide experience menopause symptoms. However, most data are derived from white, socially privileged women. Research shows that South Asian women often have different menopause experiences from their white peers, and these are not currently considered in conversations about menopause.

After menopause, increased abdominal fat, adverse changes in metabolic health and bone loss add to chronic disease risk in women. It is known that a woman's risk of heart attack and stroke, weight gain and osteoporosis (brittle bones) can increase after menopause.

### Multi-morbidity; key background evidence in South Asian women

South Asian women store more excess fat in their abdomen (abdominal obesity) compared with White populations and develop obesity-related diseases at a lower body mass index (BMI). The prevalence of abdominal obesity is estimated to be around 58% in men and 78% in women in South Asian populations. Underestimation of obesity-related health risks, based on BMI, in postmenopausal South Asian women is in itself a concerning and undefendable inequality.

Obesity is a risk factor for developing a range of conditions, including heart disease, type 2 diabetes, dementia, muscular disorders, and a host of other health issues. British South Asians have higher rates of obesity compared to the broader population. The cause for this is unclear, but diet and physical activity issues appear as a theme, with lower rates of physical activity among these women compared with their white counterparts.

South Asian women have up to 50% higher heart disease risk, independent of all measured factors, compared with the white population in the UK.

The prevalence of type 2 diabetes, which also increases several health risks, is up to 6 times higher in South Asian populations than in other ethnic groups.

So, South Asian women are at greater risk of heart disease, and those with type 2 diabetes and obesity have significantly higher overall health risks than other groups. In the presence of multiple predisposing factors, postmenopausal status amplifies health risks in Asian women substantially more than their white Caucasian counterparts.

And when it comes to bone health, South Asian women are also at greater risk. Multiple factors, such as lactose intolerance, vitamin D deficiency and lower rates of strength training and exercise, may be contributory.

### Menopause treatment in South Asian women in the UK

There is sparse evidence for the efficacy and safety of any treatments for menopause in women of South Asian backgrounds, especially those with diabetes, heart disease, obesity or experiencing socioeconomic adversity. South Asian women often face challenges when navigating healthcare systems, which can be a barrier to accessing support during the menopausal transition.

### Can we extrapolate research evidence from healthy white women to South Asian women?

Oestrogen-based hormonal therapies (HRT) are the most studied treatments for menopause symptoms. They are considered generally safe for healthy women below age 60 and within ten years of onset of menopause. However, the research evidence for the efficacy and safety of HRT is almost exclusively limited to white, socially privileged women who have no significant medical conditions or risks. This is often described as “healthy user bias”. It confounds the results of both observational and randomised menopause trials.

There is often a reference to women from South Asian backgrounds and socioeconomic diversity not having “access” to HRT. However, as described above, by the time they reach menopause, such women are more likely to have multiple health issues, which may make HRT less effective and possibly riskier. For example, obesity and diabetes both increase the risk of womb thickening, heavy menstrual bleeding, and womb cancer; high doses of oestrogen in HRT can also increase these risks. There are no quality data to demonstrate heart disease outcomes in high-risk groups of women, only in healthy white women without heart disease. Offering HRT in minority ethnic groups is based on poor-quality evidence and is effectively “pseudo-inclusive”. It may result in improved well-being based on pseudo-empowerment but could potentially result in significant longer-term harms.

### **Unmet needs for menopause care in South Asian Women**

Research into treatments, including HRT, that improve the menopause experience and postmenopausal health outcomes in South Asian women is grossly lacking. Assumption and extrapolation of evidence from treatments in predominantly healthy, white, socially privileged women are effectively blindsiding the genuine needs of South Asian women, who have wildly different social backgrounds, demographics, health signatures and risks.

Lifestyle strategies are well evidenced to improve menopause symptoms and long-term disease reduction. They could be initiated quickly and proactively within primary care, with support from stakeholders and utilising relatable facilitators. Such strategies carry zero risk and are a simple example of better care at lower cost. Similar risk reducing programmes are already available within the NHS and could easily be adapted; for example, the Diabetes Prevention Programme.

There is an unmet need for increased awareness, dissemination of trustworthy information resources, real-world data collection and clinical research to help South Asian women manage menopause symptoms and reduce future health risks. It is also crucial that health professionals, politicians, and the wider public start to recognise the diversity of menopause experience and specific health risks in non-white and non-privileged groups of women.





## A Call to Action: Prioritising Mental Health in South Asian Communities in the UK

Dr Syka Iqbal, Dr Santosh Bhanot

### Defining mental health, mental health conditions/disorders and wellbeing

“Mental health is a state of mental well-being that enables people to cope with the stresses of life, realise their abilities, learn and work well, and contribute to their community”.

In this report, we refer to mental health conditions as a broad term including disorders and problems. The WHO’s International Classification of Diseases (ICD -11) is the framework currently used in UK healthcare to diagnose mental health disorders. This includes depressive disorders, bipolar disorders, and anxiety disorders.

### Overview

Mental health challenges place immense burdens on individuals, their families and society, particularly those experiencing inequality and belonging to ethnic minority groups. South Asians face disproportionate rates of psychiatric disorders and struggle to access adequate care. Rates of service use provide little indication of illness in South Asians. Racism, discrimination, and stigma play a major role in creating double and triple burdens on South Asians who choose not to seek help.

Moreover, various factors such as anthropological factors, early adverse life experiences, social deprivation, and complex relationships with services further exacerbate this problem. These are further evidenced by the observed effects of COVID-19 on ethnic minorities. Mental health services in the UK are underpinned by values, norms, and practices of Western culture. This is problematic in the psychiatric diagnoses of ethnic minorities given that significant socio-cultural processes such as systemic racism, complex trauma and socioeconomic inequality are often oversimplified. This highlights the need for a comprehensive strategy addressing the underlying social determinants of health. It also emphasises the importance of culturally sensitive approaches in mental health care delivery.

### Key Evidence

There are disproportionately high rates of mental health disorders among South Asian communities in the UK. South Asians in the UK exhibit higher susceptibility to mental health disorders such as anxiety and depression than their white counterparts. Recent epidemiological evidence also highlights higher rates of psychosis in South Asians in the UK, and they are likely to present later to intervention services.

Cultural differences, stigma surrounding mental health, and past negative experiences with healthcare services deter South Asians from seeking help promptly, leading to untreated conditions. A 2021 report in the UK found over a third of South Asians experience stigma and discrimination, this can be worsened by the lengthy NHS waiting lists. The stigma around mental health is a barrier to getting the right help at the right time. Moreover, a double burden means that the impact of the mental health challenge itself and the fear of being labelled reduces the likelihood of South Asians seeking support. It is, therefore, crucial to ensure approaches to improving South Asian mental health include a renewed will and support for reducing stigma. Anti-stigma campaigns should highlight illness and wellness and incorporate the wider life context and how these impact people across all social, cultural, and religious groups.

### Policy Recommendations:

Establishment of a system-wide approach: Implementing an ambitious and comprehensive capacity development programme is crucial to fostering a diverse ecosystem of research-active systems, services, and communities. This will facilitate system-wide collaboration and trust-building among key stakeholders.

Establishment of South Asian Mental Health Working Group: The working group should comprise academics, practitioners, community and voluntary sectors and South Asians with lived experience of mental health challenges, representing diverse socio-economic and ethnic backgrounds across the UK South Asian diaspora.



**Enhanced Cultural Competence:** Mental health service providers and practitioners must undergo training and be supported to understand the cultural nuances of South Asian communities and ensure services are delivered in a culturally sensitive manner. We recommend an approach that will be inclusive, embedding a culture of Equity, Diversity, and Inclusion (EDI) practices and development of professionals across all career stages.

**Importance of Culturally Adapted Interventions:** Traditional mental health services often fail to meet the unique needs of South Asian communities. Culturally tailored interventions, including language-specific resources and community partnerships, are crucial in bridging this gap. Allocating resources to develop culturally competent mental health services is key.

### **Our Strategy:**

**Co-development of South Asian Mental Health Strategy:** Working closely with the working group to co-develop a strategy that addresses identified challenges in South Asian people's mental health, focusing on issues relevant to South Asian members.

**Mapping and Repository Development:** Map organisations and established South Asian groups and invite them to join an online repository. Identify and engage with new groups, including NHS, faith-based organisations, and community groups, thereby improving representativeness and reach. The register should be reviewed and developed by the working group, facilitating access for other groups. The creation of a data repository can provide cross-governmental oversight and facilitate evidence-based policies to address mental health disparities among ethnic minority groups, including South Asians.



**Community Engagement and Co-design:** Involve South Asian communities in decision-making processes and co-design mental health services to ensure they are accessible, comprehensive, and responsive to community needs. An example of this is the Peepul Mental Health Café based in Leicester, which opened in 2022 and runs in partnership with the NHS and is a free, confidential drop-in support service for communities suffering from Mental Health

**Evaluation and Building Best Practice:** The strategy should be evaluated within the working group, allowing the identification of best practices, and addressing any emerging challenges effectively.

### **Conclusion**

Addressing mental health disparities among South Asians in the UK requires a collaborative effort involving policymakers, healthcare providers, community leaders, and advocacy groups. By prioritising culturally sensitive interventions, enhancing access to care, and promoting community engagement, we can strive towards equitable mental health outcomes for all members of society.

# MENTAL HEALTH ACT: USE AND ABUSE



## Preventing and Reducing the Mental Health Act Use in Black and Ethnic Minority Populations

Dr Nagina Khan

### The Mental Health Act (1983)

The Mental Health Act (1983, MHA) is utilised in England to regulate the involuntary hospitalisation of patients on psychiatric grounds. The MHA is the main piece of legislation that covers the assessment, treatment and rights of people with a mental health disorder in England and Wales.

### The rising rates of the use of the Mental Health Act (1983)

Concerns about its use stem from the increasing number of involuntary hospitalisations, rising from 43,356 in 2007–08 (83.7 per 100 000 individuals) to 63,049 in 2015–16 (114.1 per 100 000 individuals); indicating a rise of 36.3%.

Furthermore, ethnic minorities and migrants experience more adverse pathways to mental health care, including higher rates of compulsory admission and treatment (CAT), more contact with the police and criminal justice agencies, as well as poorer long-term outcomes compared with White British people. These data reflect the pattern also found in North America and Europe.

Involuntary admission occurs as a result of the professionals' judgements about risk to oneself and/or to others, and the need for treatment.

### Ethnic inequalities in mental healthcare and social justice

There are several explanations for ethnic inequalities in CAT; including the cultural competence and quality of services. This means that people of ethnic minority background do not find mental healthcare and social justice services supportive and easy to navigate. There appear to be reports of not trusting public services generally. Additionally, austerity measures undermine efforts to prevent detention or promote wrap around services that are personalised.

Little preventive work is possible in the current time of reductions in service capacity and staff shortages, and therefore, those least engaged or avoidant may well be more likely to enter into a crisis. Cultural and ethnicity related variations in help-seeking behaviours and clinical assessment, decision-making, and judgements of greater risk at the time of crisis may contribute on the pathways to CAT.

Importantly, judgements of suicide risk even among those completing suicide, indicate that professionals considered ethnic minorities to be less at risk than White British people, and so underestimating risk when preventive work might be useful.

The Independent Review of the Mental Health Act (MHA) confirmed the escalating levels of CAT among Black, South Asian, and migrant communities. The review gathered evidence from all sources, and concluded there were several possible explanations:

- More social difficulties that are specific to ethnic minority populations.
- Living in inner-city environments, that often lack, adequate resources or services, with high unemployment rates.
- Chronic experiences of exclusion, racism and discrimination.
- Multiple mutually reinforcing structural influences operating across interpersonal and societal levels.

## Conclusions

The Mental Health Act has not been developed with equality and equity as a fundamental base. Service user led research has been challenging traditional professional perceptions regarding the path and outcomes of mental illness. Whilst, individuals may not recover completely from mental health illness, they can learn how to deal with their disorder with appropriate treatment plans and supportive measures. Evidence suggests that mental health recovery, and its processes happen over time and sometimes outside of prescribed medicinal settings.

To conclude, accessing help in crises from formal mental health services, creates a Mental health treatment interface, which is marred by restrictive processes via the MHA that increase the individual's vulnerability, and enforces policy to work in ways that reinforce negative past experiences of individuals from Black and ethnic minority backgrounds.



## Recommendations

When ethnicity is part of the equation, MHA powers are enacted in the most restrictive pattern by Psychiatrists. Hence, mental health is understood to be a restrictive environment for all population groups accessing help, and service user context needs to be taken into consideration in routine pathways as a necessity; including post detention reviews.

Police, CPN, allied health professionals who have a long-term involvement with patients, need to nourish and develop the relationship. Therefore, this involvement should include other professionals to create a trusted support system that can offer continuity. For example, social workers need to support the system of provision and prevention that could sustain recovery process and reduce the chance of coercive pathways and impacts of restrictive practices.

Consultations and Balint groups need to be implemented to support professionals who use the MHA in the care of Black and ethnic minority groups. Education and training need to be targeted specifically at increasing the experience of individuals working with a wide range of Black and ethnic minority population in cultural appropriate mental healthcare.

There need to be mechanisms to challenge poor care for people from Black and ethnic minority communities to allow safety in speaking out; i.e. whistleblowing about inappropriate care and linking it to quality improvement work to increase positivity of speaking out.



## Understanding Missingness in Healthcare

Dr David Baruffati and Professor Andrea E Williamson on behalf of the Missingness in healthcare team

### What is Missingness?

Missed appointments have long been a focus of political, media and research attention. However, they are typically framed as a problem caused by patients and a problem for NHS services. This framing is unhelpful, in that it obscures both the substantial barriers to accessing and engaging in healthcare services which many people face, and the stark consequences for patients' health which can stem from these. Studies exploring missed appointments have typically conflated single, situational missed appointments with more enduring patterns of missed appointments, which limited our understanding of the causes and consequences of multiple missed appointments and how these may be addressed.

A large-scale epidemiological study started to address this and investigated patterns of missed appointments in over half a million GP patient records in Scotland between 2013 and 2016. This study found that nearly 1 in 5 (19%) patients missed an average of more than two appointments per-year across the three-year study period, and this pattern continued into hospital care.

We define this as 'missingness'; "the repeated tendency not to take up offers of care, such that it has a negative impact on the person and their life chances". Focusing on these enduring patterns of multiple missed appointments, our research explores who is at risk of missingness, its causes and consequences, and how this important issue may best be addressed.

### Who is at risk of missingness?

The epidemiological study found that these challenges for patients are not equally distributed; patients experiencing high rates of missed appointments were more likely to have multiple health conditions, and to experience significant socioeconomic disadvantage.

The relationship between ethnicity and missingness remains poorly understood, with ethnicity too poorly recorded by GP practices to be able to count who is affected by ethnic group. Our review of the existing literature and sixty interviews conducted with professionals working in health and social care and experts by experience of missingness tell us that there are a range of drivers more likely to affect people from minoritized communities. Intersectionality is important; with some South Asian populations in the UK disproportionately affected by socioeconomic deprivation and multimorbidity, these groups are likely to face compound barriers to engagement.

### What are the consequences of missingness?

Missingness represents a significant indicator that a patient is at risk of harm. The epidemiological research demonstrated that people experiencing missingness face a far higher mortality risk than those who miss no appointments, with this risk increasing with the number of missed appointments. This was apparent for all-cause mortality across all patient groups, but most stark for patients with long-term mental health conditions only. Among this patient group, those experiencing missingness had a mortality rate eight times higher than patients with similar diagnoses who missed no appointments, often dying younger and from non-natural external causes.

### What causes missingness?

Missingness is caused by an interaction between service- and patient-side drivers, shaped within a wider structural context. While the precise causes differ between individual patients and population groups, we found enduring, interlinking, and often reinforcing barriers at every stage of patients' journeys through healthcare.

Past experiences of care can lead patients to perceive services as not ‘for them’. They may feel that their health is normal or manageable, that improvements are not achievable, or that appointments are not likely to be appropriate or useful for their needs. The incompatibility between rigid appointment systems and the often-unpredictable demands which arise in people’s lives – particularly for those in precarious circumstances – can make appointments less of a priority. Journeys to appointments can be prohibitively expensive, complex, or risky. Communication barriers and unequal power dynamics can also provide a barrier; services might not communicate in ways which are understandable, particularly to those with language barriers, and people may not be given the time, space or support they need to communicate their needs. With relational aspects of care playing an important role, cultural insensitivity, stigma, discrimination, or hostility from anyone present at services are likely to damage trust and reduce the likelihood of patients returning.

### **What can be done about missingness?**

Our findings suggest a range of principles for policy and practice which can help to address missingness and reduce the risk of it developing among at-risk populations. The evidence suggests a need to identify and actively reach out to patients experiencing missingness to identify barriers, and to deliver targeted interventions to address these. These interventions should move beyond generic, ‘one-size-fits all’ approaches in health and social care towards interventions addressing the needs of individual patients while informing the development of a localised understanding of barriers affecting at-risk population groups. In doing so, there is a need to recognise the wider social determinants of health as both driving missingness and as a target for interventions through collaboration with relevant services. Embedding such interventions across mainstream healthcare settings requires sustainable resourcing and is an important step towards achieving health equity for all in the UK.

The demonstration of a substantial increase in mortality risk for those experiencing missingness creates an imperative for policymakers, practitioners, and all of those responsible for the care of our population to work to reduce the barriers which people face in engagement with healthcare.



# NUTRITION-RELATED CHRONIC DISEASE (NRCDS)



## Nutrition-Related Chronic Diseases

Ms Sheena Bhageerutty

### What are the issues and/ or inequalities?

South Asians have a higher prevalence of Nutrition-Related Chronic Diseases (NRCDS), such as Type 2 Diabetes (T2D) and cardiovascular disease (CVD), leading to increased morbidity and mortality.

According to the National Child Measurement Programme (NCMP), a higher percentage of British South Asian children are overweight compared to White British groups. Specifically, the NCMP report highlighted that Year 6 children from ethnic minority backgrounds were more likely to be overweight; when looking at South Asian children, those of Bangladeshi background had the highest rate of overweight body mass index (45.1%), followed by children of Pakistani heritage (41.8%) and children of Indian background (35.6%).

South Asians face a complex health risk profile that arises due to a combination of genetic, environmental and lifestyle factors. South Asian children are at a higher risk of obesity and associated health problems because of their genetics. Their genetic makeup tends to cause fat storage around their abdominal area, resulting in insulin resistance, which increases the likelihood of developing T2D. To address this issue, the World Health Organization recommended a lower BMI cut-off for South Asian populations of adults. However, no ethnic-specific growth charts are available for children, meaning that South Asian children may get overlooked and need increased support and input from healthcare professionals from an early age.

Cultural dietary practices, immigration, and socio-economic factors all contribute to the higher prevalence of NRCDS. South Asian cuisine is known for its rich flavours and spices but is often high in saturated fat, sugar, salt, and refined carbohydrates. Fried snacks such as pakoras, samosas, jalebi, and mithai (Indian sweets) are commonly served during festivals, celebrations, and gatherings. Consuming large quantities of these foods can increase the risk of NRCDS.

Immigration can increase the risk of NRCDS in the South Asian population. The traditional South Asian diet is deeply connected to cultural practices, social interactions and identity. However, when individuals immigrate to a new host country with a different environment, their diet may be affected by a process called dietary acculturation. This often results in a shift towards consuming more processed, convenient food products that are high in fat, sugar, and/or salt. Urbanisation and a nutrition transition have further exacerbated the issue, leading to an increase in NRCDS.

In addition, social and economic factors significantly impact health disparities. Food access and affordability, limited access to healthcare services, and language barriers can worsen health inequalities.

### Recommendations

Cultural competency involves understanding beliefs, dietary practices, and values from different cultural backgrounds, which can influence preferences and health behaviours. Cultural humility is an ongoing process that goes one step further than cultural competency. The process enables health professionals to self-reflect on their perspectives and behaviours with a willingness to learn from the public.

Healthcare professionals must understand South Asian cultural nuances and dietary practices to increase cultural sensitivity and address health inequalities in service provision and access. This will aid in facilitating effective communication and encourage understanding and respectful care of individuals' experiences.

Tailoring public health initiatives to be culturally appropriate is integral to reducing health inequalities and ensuring adherence to the programmes. This includes Tier 2 weight management sessions and preparing balanced and nutritious meals that are cost-effective and culturally appropriate. An example is the Nurture Early for Optimal Nutrition (NEON) project in Tower Hamlets and Newham, where a three-phase study aims to optimise infant feeding amongst British Bangladeshi infants. WhatsApp, a popular and preferred messaging platform, was used to increase engagement and attendance across participants.

A whole systems approach is required to tackle ethnic health inequalities to improve the outcomes of this diverse community. Various factors influence individual dietary choices, and therefore, interventions should address the broader context. Policymakers and healthcare professionals should better understand the complex interplay of genetic, environmental, and lifestyle factors that contribute to health inequalities. Such understanding can lead to tailored interventions that meet the unique needs of this population.

Community engagement is a vital strategy in addressing health inequalities. Patients and the public are at the centre of healthcare. By involving the South Asian community in co-designing, developing, and implementing health initiatives, it is possible to identify and take action on their unmet needs. This involves building a rapport with communities, religious institutions, community organisations, and gatekeepers to empower individuals to take an active role in their health. Community engagement can be achieved by utilising Photovoice, Participatory Action Research, Chai & Chat. It also tackles structural and cultural barriers to health initiatives, such as language barriers and the time and date of sessions during religious occasions such as Ramadan. Additionally, food education and cooking classes are crucial to adopting a healthier lifestyle and empowering individuals to make an informed choice for healthier alternatives and reduce health inequalities across the South Asian community.





### **The experiences of working as a GP in a predominantly South Asian, underprivileged area**

**Dr Samara Afzal**

I am a GP working with a high prevalence of South Asian patients in an area of socioeconomic deprivation. On a daily basis, I see first-hand, the challenges that face my patients. Here are the reflections of my experience:

#### **Communication barriers**

Many of the South Asian patients I see, do not speak English and they struggle to explain to reception staff what their problem or medical issue is. Most of the time if a child is unwell, the mother is the one seeking an appointment. A vast number of female patients born in South Asia are illiterate. Therefore, they struggle with both online and telephone booking systems, where they are faced with people who can't speak their language or are navigating an online system in a language they cannot read. Many practices do not allow patients to walk in first thing in the morning to make appointments and will turn them away to either call back or use the online system. Furthermore, many elderly South Asian patients can't use online services and neither may they be able to phone through due to language or hearing difficulties. I am seeing more and more elderly South Asians living alone with no family to help them. These are some of the most vulnerable people with multiple co-morbidities. The NHS does not serve these patients well.

#### **Lack of Knowledge/ awareness**

Social media and television have been instrumental in making people aware of many debilitating conditions and their management. Each month we see a new topic being discussed, for example when Davina McCall spoke up about menopause, I saw a massive rise in Caucasian women coming to see me for menopause treatment. Recently there has been huge media interest in weight loss medications, and many patients have requested referrals to specialists for initiation. Teenagers have seen videos on Tik Tok about PCOS and consulted me, as they have noticed they have the symptoms mentioned and want to be treated. In practice, I have yet to see a South Asian tell me that they have seen something on social media or TV which has prompted them to consult me.

The Covid pandemic highlighted a huge problem about lack of awareness of vaccines. The lack of initial uptake sadly contributed to many more avoidable deaths in the South Asian community. Campaigns across the media in Hindi, Urdu, Bengali etc. helped dispel the myths surrounding them. A similar scenario was seen recently with the MMR vaccine controversy and the rise of measles. In practice, I have seen that most patients will comply with vaccine uptake once they have gone through their concerns with their trusted healthcare practitioner.

Around 40% of GP appointments are for mental health. Many patients in the South Asian community do not present with typical symptoms and it is only after excluding all other causes of their vague symptoms, do they let you delve in to their mental health. Many do not want to take medications due to side effects and having to work or look after young children. The standard counselling services are English, so of no use to those who can't speak the language. Due to untreated mental health these patients then lose motivation and struggle to comply with treatments for their other co-morbidities such as Diabetes and Hypertension leading to a vicious cycle where one exacerbates the other.



## The shift in the GP model

The Additional Roles Reimbursement scheme is an initiative to improve access to primary care. Many practices now employ more ARRS staff such as Physicians Associates, Paramedics and Pharmacists instead of Doctors, as they are provided free by Primary Care network funding. As a result, many practices are employing fewer Doctors. This is making it harder for some patients for example those with gynaecological problems, which cannot be dealt with by ARRS staff. Additionally, if they only want to see a female Doctor and one who speaks their language, this will make it even more challenging to access healthcare. These patients can wait for weeks for an appointment.

The concept of the traditional 'Family GP's' who would provide continuity of care is also fading out. I have seen many female South Asians who have built a rapport with me and have then revealed traumatic events like domestic violence and sexual abuse after many years of hiding it and suffering alone. I worry that these women, without continuity of care, would not feel comfortable disclosing their problems.

## Prevention is better than cure!

South Asians tend to have a high carbohydrate, low protein diet which predisposes to type 2 diabetes and coronary heart disease. They also tend to do less exercise, either due to cultural barriers or due to having more sedentary jobs with unsociable hours. There is an increase of young South Asians presenting with early-onset type 2 diabetes, hypertension and obesity. There is a huge rise in childhood obesity, services are limited and I constantly get referrals to weight loss programmes bouncing back as there is no longer funding for them.

Tackling obesity early will not only help alleviate the burden on the NHS but will improve the quality of life for many and give better health outcomes. Education programmes need to start early and across all organisations such as schools, places of religious worship, public gatherings such as cricket matches etc. For all these resources, funding is needed and that's where part of the problem lies. Without better funding to prevent these illnesses the cycle will continue, leading to poor outcomes for patients and a massive financial burden on the NHS. Drastic changes are needed for what sadly appears to be a sinking ship. I fear the provision of high-quality primary care to those most in need is becoming more and more challenging.





# “Angularenal”

By Sarah Racanière (aka Dr Sarah Ali) 2020



Gouache and Gray's Anatomy on canvas



“With Every Breath”

“پہر سانس کے ساتھ” in Urdu

By Sarah Racanière (aka Dr Sarah Ali) 2021



Gouache on Chest X-ray

# RHEUMATOID ARTHRITIS



## Rheumatoid Arthritis and the South Asian community

Dr Leher Gumber

### What is rheumatoid arthritis?

Rheumatoid arthritis (RA) is a medical condition that causes pain, swelling and stiffness in the joints. It is caused by the immune system mistakenly attacking the healthy tissues in the body. RA can affect any joints in the body, but the most common joints that are involved are the small joints in the hands and feet as well as knees and shoulders. Both sides of the body are usually affected. It is a relapsing and remitting condition, characterised by periods of high (flare) and low (remission) disease activity. If left untreated, it can lead to permanent damage to the joint, cartilage and nearby bones.

### Who is affected by rheumatoid arthritis?

The National Institute for Health and Care Excellence (NICE) estimate that in the UK, 1 person in every 100 has RA. It is estimated that approximately 34,000 people are diagnosed with RA every year in the UK. RA can affect anyone, but the incidence is two to four times higher among females compared to males. The most common age of diagnosis is 30-50 years. Being overweight and smoking is associated with an increased risk of developing RA. RA can also run in families.

### What is the impact of rheumatoid arthritis?

RA doesn't just impact the joints but affects the whole body leading to tiredness, reduced appetite and inflammation in other organs of the body. This can have a big impact on the individual from day-to-day activities, work and on their psychological health. It is estimated that approximately one third of people stop working because of RA within the first two years after diagnosis. RA is also associated with an increased risk of premature cardiovascular disease and stroke.

### What are the current issues?

Health inequalities in RA are nothing new. Studies have documented ethnic disparities at every stage from time to diagnosis, access to specialist care and medications, and ultimately long-term outcomes. Individuals from Asian and Black descent are more likely to have higher levels of disease activity and are less likely to remain in remission compared to white patients. They also have poorer outcomes in terms of pain, function, disability, and psychological health.

It is conceivable that the impact of RA is proportionally larger for those from a South Asian community. This is due to issues around health literacy, reduced help-seeking behaviours, misconceptions about the condition and its treatments, and not having information presented in a culturally appropriate way. There is a lack of awareness about RA, and generalised aches and pain are often put down to older age or osteoarthritis. This can lead to delays in diagnosis and initiation of treatment. Diagnosis requires a high level of suspicion and timely referral to rheumatology services. Rheumatology services, like many other specialist services across the NHS are experiencing a high burden of referrals which ultimately leads to long waiting times for patients. NICE recommends that patients with persistent joint swelling should be assessed by a specialist within 3 weeks. The National Early Inflammatory Arthritis audit shows that just under 50% of patients are currently seen within this time period.

To tackle some of these issues, the National Rheumatoid Arthritis Society launched Apni Jung (Our Fight) initiative in 2016. They provide educational resources in different languages to enable better understanding of RA and help individuals from the South Asian community to self-manage their condition. However, there are still many areas of care that are yet to be explored.

## Recommendations

Although positive steps have been taken in the right direction, we are still far from addressing health inequalities in the care of South Asian patients with RA. Our primary recommendation is research. There is an urgent need for research into access to care, culturally appropriate tools to support better self-management and adherence to treatment. We know from recent studies that RA increases risk of cardiovascular disease, but many of our patients don't. We need to better understand the perception of this risk and ways to mitigate it.

We also feel that more outreach work needs to be done to engage members of the South Asian community on various levels. This includes educating patients, families and the wider community on the symptoms and signs of RA, treatments, complications and tackling misconceptions at every stage. Representation of diverse populations in health research has been a struggle for many years. Greater efforts need to be made to ensure recruitment and representation of minority groups in future RA research.



## Sexual health and HIV – an under-recognised issue for South Asians in the UK?

Dr Indira Mallik, Dr Rageshri Dhairyawan



### What is sexual health?

Sexual health, which is defined by the World Health Organisation (WHO) as “a state of physical, emotional, mental and social well-being in relation to sexuality” is an important part of a person’s physical and mental health. Good sexual health includes prevention, testing and treatment of sexually transmitted infections (STIs), promoting reproductive health whilst, as the WHO affirms, maintaining “a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.” In the UK, sexual health services are free to everyone, regardless of immigration status.

### Sexual health and South Asians – an under-prioritised issue

Compared to other ethnic groups in England, South Asians have historically used sexual health services less and had lower rates of STIs. However, there are signs that this could be changing. Between 2018 and 2019, the largest proportional increase in STI diagnoses was in people of Asian ethnicity (15%, from 17,783 to 20,495 total diagnoses). This was mainly gonorrhoea (36%) and chlamydia (27%) in Asian gay and bisexual men who have sex with men (GBMSM). The reasons for this increase are unclear, but may include increased testing leading to more STI detection or change in sexual behaviours resulting in more STIs.

Rather than attending routine screening, South Asians are more likely to attend sexual health services having been referred by other sources such as their GP when unwell, suggesting they may be less aware of the existence of these services or less able to access them. Research has shown that some South Asians have a lack of knowledge about sexual health, which may stem from difficulties discussing sex and sexuality at home, contending with community attitudes to pre-marital sex and lack of culturally-specific sex and relationship education at school. Stigma, both internalised, and fear of being judged by their community can play a large role. Studies show that some South Asians feel nervous attending sexual health clinics in person due to concerns about confidentiality, being judged by staff or embarrassment. On the other hand, in multigenerational households where young people live with parents and grandparents, home testing kits or phone or internet-based appointments may be difficult to use due to concerns around privacy. Language may be an issue, and some migrants may not be aware that sexual health services are free, or may be wary of being reported to immigration authorities. Many barriers to accessing services transcend cultural differences: services have been described as inaccessible due to their location, opening times and long waiting times. Studies have shown that South Asians deprioritise their sexual health, and housing and financial precarity in a climate of a nationwide cost of living crisis may exacerbate this.

### HIV and South Asians – continuing and emerging inequalities in testing and prevention

HIV is now a long-term condition, where with treatment, people can have a normal life expectancy, work, and have families. When on effective antiretroviral treatment suppressing their HIV viral load levels to undetectable, people cannot pass on HIV through sex to their partners (Undetectable = Untransmittable). There are now many ways to prevent getting HIV, including condoms and medications called pre-exposure prophylaxis, (PreP) and post-exposure prophylaxis (PEP). HIV testing, medication and prevention is free to anyone in the UK regardless of immigration status.

Approximately 3.5 million people are living with HIV in South and South-East Asia, 2.1 million in India alone. This represents the largest proportion of people living with HIV beyond sub-Saharan Africa. However, in England, HIV is less common in South Asian communities than amongst other ethnic groups. In 2022, 4324 South Asian people were seen for care at HIV clinic (3191 men and 1121 women). This is just 4.6% of all people seen in HIV care that year in England, however this proportion has been rising from 4.0% in 2018.

HIV amongst South Asians in the UK remains a pressing issue due to a number of key health inequality markers. Due to advances in HIV prevention and care, new diagnoses overall in England are reducing. However, between 2021 and 2022, new HIV diagnoses increased among South Asian GBMSM (17% from 75 to 88) and by 21% (52 to 63) in

South Asian heterosexual men and women. South Asians are also more likely to be diagnosed late with advanced HIV disease, compared to people from other ethnic groups. This has been shown particularly among heterosexual men and women who are more likely to get a test when they are unwell from HIV, as opposed to GBMSM who are more likely to routinely test for HIV. Late diagnosis has a huge impact on people's health and chances of dying from HIV, particularly in the first year after diagnosis. Once diagnosed, South Asian people living with HIV do as well as other ethnic groups with regards to taking treatment and maintaining an undetectable viral load.

However, health is more than medication and blood results. South Asians living with HIV face significant stigma from their communities, which can negatively affect mental health. Research has found that South Asians had lower levels of HIV knowledge on average than the general public and thought HIV was associated with taboo sexual behaviours and not an issue for South Asian communities. This needs to change.

## Recommendations

- More research that is co-produced with South Asian communities
- Normalise and encourage HIV testing in general practice and secondary care as part of wider health checks
- Making sure public health campaign for STI testing and prevention include South Asian representation
- Relationship and sex education – how can we make sure it reaches every child in a culturally competent way?
- Sexual health clinicians should work with local communities to make in-person and online services more acceptable and welcoming





## Stroke in neurology

Professor Pankaj Sharma

### What is stroke?

Stroke is the commonest vascular neurological disease in the world, and the third largest cause of mortality after ischaemic heart disease and cancer. Most commonly it is caused by a blockage of an artery in the brain which results in deprivation of oxygen to the neurons supplied by that artery. The consequence of this lack of oxygen can range from a fleeting focal neurological symptom, or loss of use of one side of the body, to a catastrophic event. As around 2 million brain cells die every minute in the absence of oxygen, the faster treatment is started the better the clinical outcome; 'time is brain'.

### Stroke globally

Globally, there are ~12 million new stroke cases each year: with ~53% of these being in women, and ~47% in men. Stroke incidence has been transitioning between high-income to low and middle-income countries. Between 1970 to 2008 there has been a ~42% decrease in stroke incidence in high-income countries and over a 100% increase in stroke incidence in low to middle-income countries. Little is known about its epidemiology in lower- and middle-income countries.

### Stroke in the UK

In the United Kingdom (UK), stroke occurs more than 100,000 times a year and is responsible for over 35,000 deaths annually. Similar to most high-income Western countries, the incidence of stroke among the general UK population has reduced but data on the trends in stroke over the years has not been well documented among UK ethnic minorities. It is well established that wealth and health inequalities exist between ethnic groups due to socioeconomic disparities and several environmental stresses. Mortality data reported by the Office of National Statistics demonstrates that each ethnic group suffers from stroke differently, with the highest rate of stroke mortality being considerably higher in South Asians compared to all other ethnic groups in the UK.

### Stroke in South Asians

Compared to other ethnic minority groups, South Asians are inadequately represented in health research and thus the current understanding of stroke could also be misguided when applied to South Asians. Many of the traditional stroke risk factors such as hypertension, diabetes mellitus etc, were identified in a primarily Caucasian population from the Framingham Heart Study in Massachusetts USA. There is considerable evidence to suggest that risk factors themselves are not uniform across ethnic populations, with South Asians displaying an adverse risk profile. These health inequalities not only affect South Asians but also black and other ethnic minority groups in the UK.

The total societal cost of stroke, including both the NHS and social care expenses, amounts to ~£26 billion annually, with NHS and social care costs accounting for £8.6 billion of the total. Current management guidelines for stroke do not appropriately account for ethnicity and could add to these costs. The national clinical guidelines for UK stroke aim to establish a standardised level of care for all stroke patients. However, the latest guidelines do not account for the variability of risk factors, including cultural and physiological factors, among individuals from different ethnic backgrounds. It has been reported that preventative measures for stroke including cholesterol monitoring and thus treatment is less likely to occur in UK South Asians compared to white British individuals. This oversight raises concerns about whether the guidelines are truly optimal for all stroke patients and highlights the need for further research and consideration of how to tailor stroke care to address the unique needs of diverse patient populations.

Data from BRAINS, one of the few stroke studies that have specifically recruited South Asians show that British South Asians suffer from stroke ~9 years earlier than their white British counterparts. The prevalence of traditional risk factors such as hypertension and diabetes mellitus were significantly increased in British South Asians.



## Recommendations

A current shortfall of epidemiological data regarding ischaemic stroke is due to the relatively low proportion of studies being conducted in ethnic minority groups in comparison to white populations in the West. This has largely resulted in our understanding of ischaemic stroke and its risk factors being largely based on Western populations and Western environmental factors. Preventative measures and post-event treatments thus rely on information that potentially does not apply to every ethnic group in any country. Clinical investigators and policy makers should focus on recruiting stroke patients from different ethnic groups which will then allow guidelines to better reflect the needs of their national populations.



# TRANSPLANTATION



## Transplantation among ethnic groups

Mr Majid Mukadam

### Introduction

Transplantation offers a much-needed lifeline to patients suffering from end-stage organ failure but its success depends on the generosity of organ or stem cell donors. One organ donor can potentially help at least nine patients by donating kidneys, liver, heart, lungs, pancreas, and small bowels.

### Challenges

Patients from ethnic minority and mixed heritage face a “dual challenge of inequity”. They have a higher burden of cardiovascular, diabetes and renal diseases, as well as sickle cell disease, and sadly are less likely to find appropriately matched organ or the right blood or stem cell donor. Selecting compatible organ or stem cell is vital to ensure optimal success. Compatibility is determined by blood group, HLA matching and antibody screening; most of these factors are genetically determined and are more likely to be found among donors from a similar ethnic background. Weight and height of the donor and recipient also plays a role in matching of organs.

Access to transplantation is dependent on two main factors: limited organ availability and inefficient referral networks. Together, these barriers can lead to avoidable excess mortality among individuals with end-stage organ disease. Limited information and health literacy especially among ethnic minorities can have a negative effect on transplant rates. We know that there is a delay in referring ethnic minority patients to tertiary services and this can lead to late presentation and can potentially exclude these patients from access to transplantation.

NHSBT's UK Transplant Activity report (2023) suggests that 49% (N=2083) of white and 33% (N=429) of ethnic minority groups were transplanted one year after being listed for a transplant (all organs). Five years after listing, 77% (N=3318) of white and 72% (N=921) of ethnic minority groups were transplanted, while 7% (n=310) of white and 6% (N=77) of ethnic minority groups died on the list. Also, median waiting times to transplant are longer for patients from ethnic minority compared to their white patients. More strikingly, one year after being listed for a kidney transplant, 81% of minority ethnic and mixed-heritage patients will still be waiting for a new kidney, compared with 65% of white patients. Similarly, the chances of finding a well-matched stem cell donor are 72% for white patients and just 37% for BAME people.

We know that organ donation rates are lower amongst the ethnic minority groups. Current statistics report just 7.1% of blood donors, 16.7% of stem cell donors and 10.2% of organ donors are of minority ethnic or mixed background. This group seems to do better marginally with living kidney donation. Studies have identified the main barriers for lower rates of organ donation as ignorance, distrust of health services, religious beliefs, socio-cultural and apathy. Ethnic minority groups, historically marginalized and underserved, may harbour distrust towards medical institutions due to past injustices, discrimination, or unequal treatment. The absence of representation of their communities in healthcare leadership roles further exacerbates this mistrust. Inequality of access to health services were further highlighted during COVID pandemic when the mortality was higher amongst the minority ethnic communities.

### Potential solutions to reduce inequity.

1. **Improving access to services:** educate health professionals to diagnose and refer patients early to transplant services.
2. **Representation and Outreach:** Increasing representation of ethnic minority healthcare professionals within transplant programs can foster trust and facilitate communication. Outreach efforts should involve community-based organizations, religious institutions, and grassroots initiatives to engage with underserved populations directly.
3. **Culturally Competent Healthcare Services:** Healthcare providers must receive training in cultural competence to deliver respectful and sensitive care to diverse patient populations. Culturally competent services encompass language interpretation, understanding cultural norms, and incorporating patients' beliefs and preferences into treatment plans. This is important when a Specialist Nurse for Organ donation (SNOD) makes the initial approach to the family to request organ donation. Employing SNODs from ethnic minority can help to achieve this.

4. **Policy Reform and Systematic Changes:** This is the Top-down approach and includes initiatives like implementation opt-out organ donation systems, enhancing data collection on ethnicity within transplantation registries, and allocating resources towards initiatives targeting marginalized communities.
5. **Transplant Tourism Regulation:** To mitigate the practice of transplant tourism, where individuals travel abroad for organ transplants due to lengthy waiting times domestically, regulatory measures must be strengthened. This involves collaborating with international stakeholders to enforce ethical standards and discourage exploitation of vulnerable donors.

Indeed, efforts made by individuals, community groups, NHSBT & the Department of Health (DoH) has helped to improve the awareness of organ donation and dispel some of the myths surrounding this important issue to some extent. The Community Investment Schemes funded by the DoH enabled to empower many religious and social organisations with resources, information and know how to address some of the concerns and helped to improve the acceptance of organ donation amongst the minority ethnic groups. It is worth citing examples of good initiatives supported by NHSBT that helped to improve awareness in the minority ethnic communities: (i) activities of Jain & Hindu organisation for organ donation (JHOD) has helped to raise awareness amongst the Hindu community & (ii) the release of Fatwa on organ donation by one of the Islamic scholars in UK helped to provide guidance to Muslim community. This is just the beginning and lot more needs to be done.

Formation of local organ utilisation groups at all transplant centres has helped to improve utilisation of donated organs and benefit more patients. The revised kidney offering scheme that was introduced in 2019 was designed to reduce the disparity in waiting times across ethnic minority groups. The scheme prioritises patients who have been waiting the longest, regardless of their ethnicity. This initiative is likely to help bring down waiting times for long-waiters that include a large proportion of ethnic minority patients.

Achieving equity in organ donation and transplantation among ethnic minority groups in the UK demands a multifaceted approach encompassing education, community engagement, policy reform, and cultural competence. By addressing the unique challenges faced by these communities and implementing inclusive strategies, it is possible to strive towards a healthcare system where every individual, regardless of ethnicity, has equitable access to life-saving transplants. Transplantation should not be a privilege reserved for a select few but a fundamental right accessible to all.



# TYPE 1 DIABETES



## Addressing Health inequalities in Technology and Type 1 Diabetes

**Professor Muhammad Ali Karamat, Professor Kamlesh Khunti, Professor Wasim Hanif**

Around 400,000 people are currently living with Type 1 Diabetes (T1D) in the UK with the rate rising by 4% every year. People with T1D cannot survive without insulin delivery either via injections or insulin pump. Checking and acting on blood glucose levels forms an important part of management of T1D and access to continuous glucose meters (CGM) can make it easier.

### Health inequalities in type 1 diabetes

It is well established for several years that inequalities in access to care and outcomes for people with diabetes have existed. These inequalities affect a number of factors including acute and chronic diabetes complications, morbidity and mortality as well as access to care pathways, glycaemic control, and access to technology. The reasons for inequalities include factors such as ethnicity, social deprivation, mental, physical, and learning disabilities.

### Role of Technology in management of T1D and access to CGM and pumps

Technologies such as CGMs and insulin pumps have been shown to improve the average blood test for diabetes i.e. HbA1c which in turn reduces the risk of long-term complications. Access to CGMs for people living with T1D in the UK had been quite limited until 2017 when they first went on to the NHS tariff. Initially the roll out was slow and until 2020 only a third of people living with T1D had access to CGMs. By 2022 the figure had improved to over 50% with trend continuing to show improvement. Despite this we can still see variation in access. According to figures from the national diabetes audit (NDA), people of white ethnicity and less deprived groups were more likely to be using diabetes technology. 8.5% of people living in the most deprived group were pump users and 44.7% had been prescribed CGM, compared to 13.9% and 55.8% respectively in the least deprived group. Similarly, only 4.3% of people with black ethnicity were insulin pump users and 33.4% had been prescribed wearable glucose monitors, compared to 12.1% and 52.0% respectively of people with white ethnicity. There were variations in diabetes technology use at ICB level that were not fully related to the age, ethnicity and deprivation. Insulin pump use between ICBs spanned 6.4% to 18.4% and wearable glucose monitoring 33.7% to 64.0%. During pregnancy, CGM should be offered to all women with T1D with a clear improvement in universal access across England and Wales over the last year.

Findings from the national paediatric diabetes audit (NPDA) in 2019/20, as well as 2021/22, showed children and young people (CYP) with type 1 diabetes from ethnic minority backgrounds are more likely to have higher average blood glucose levels (HbA1c) compared to white children. Black children and young people were found to have the highest average HbA1c levels, followed by children with Mixed ethnic background and Asian children, and then White children, respectively. Additionally, children in the most deprived areas were more likely to have higher average HbA1c levels than those in less deprived areas.

While the NPDA reported an upward trend in the use of diabetes technologies overall, technology use is lowest in children and young people from socially deprived areas and from ethnic minority backgrounds; the percentage of Black children with type 1 diabetes using CGMs is 11.7% and for insulin pumps 26.7%, whereas for White children these percentages are close to double at 20.2% and 39.8% respectively. In children and young people, insulin pump use was 31.7% in the most deprived quintile and 44.3% in the least deprived, with figures for CGM 14.0% versus 25.2%. There is little improvement with latest figures from the NPDA suggesting variation in access persists with 22.2% and 25.4% access to CGM for Black and South Asian CYP versus 30.8% for White CYP. Similarly access to pump use remains variable with 29% and 33% access for Black and South Asian CYP versus 42.2% for White CYP. Social deprivation remains a factor with figures of 23.9% versus 37.7% for CGM and 34% versus 42.2% for insulin pump.

### Access To Hybrid Closed Loop in T1D

In 2021 a national pilot was rolled out looking at the use of hybrid closed loops (HCL) in people living with T1D. HCL insulin delivery systems combine insulin pump with CGM sensors to automate insulin delivery to maintain glucose near a prespecified target level using algorithmic software contained within the insulin pump or a separate device (e.g., smartphone). The results of the pilot from 520 adults with T1D were excellent showing a significant reduction in

HbA1c and improvement in hypoglycaemia and Quality of Life. However, only 7% of the individuals were from a non-Caucasian ethnicity and 10% from lowest deprivation centile limiting the generalizability of these findings.

The results of the NHS England Closed Loop Study in CYP showed improvements in glycaemic control, time in range, frequency of hypoglycaemia, fear of hypoglycaemia and quality of sleep when using HCL for 6 months. However, of the 251 CYP in the pilot 89 % were of White ethnicity, 3% Asian, 4% Black and 3% Mixed ethnicity, again raising concerns about the generalizability of these findings.

Since then, there has been a NICE Technology Appraisal (TA) published looking at universal roll out for all people with T1D. It is important that equity of care is established and people from minority ethnic backgrounds and lower socioeconomic strata are not left behind in this roll out.

### **Cultural Competence and Access to Technology**

The cultural background in people living with diabetes may constitute a barrier for healthcare professionals when providing optimal diabetes care. Cultural competence is an important skill and related education could support the healthcare professionals to develop interaction skills.

A relevant example of the use of technology in diabetes could be during the Muslim holy month of Ramadan fasting. People with T1D are considered high risk due to the perceived increase in hypoglycaemia or hyperglycaemia during fasting. The use of new technologies such as HCL in T1D has been shown to reduce the risk and improve the confidence allowing Muslim people with Diabetes to fast safely during Ramadan.

### **Summary**

At SAHF we have been at the forefront of some of the work with NICE, looking at equity for rollout of new treatments and technologies in diabetes. However, despite some improvement as the data shows there is plenty of scope for improvement. At SAHF our mission is to see a health care system where the access to technology for people living with T1D is universal for all ethnicities and socioeconomic strata. To achieve this several barriers as identified above need to be addressed.



# TYPE 2 DIABETES



## Addressing Health inequalities in Type 2 Diabetes

**Dr Sarah Ali, Professor Muhammad Ali Karamat, Professor Kamlesh Khunti, Professor Wasim Hanif**

Currently, 4.8 million people (estimated to rise to 5.5 million by 2030) live with diabetes in the UK, with up to 90% having type 2 diabetes (T2D); a further 600,000 people live with undiagnosed T2D. People of Black and South Asian ethnicity are twice as likely to develop T2D compared to white Europeans. Even within ethnic categories, there is significant heterogeneity impacting health risk; a meta-analysis within the European South Asian community highlighted differences in the risk of T2D, with Bangladeshis having highest risk, followed by Pakistanis, then Indians.

More alarming is the increasing number of early onset T2D (< 40yrs), those still in education or early in their careers. It is striking in England, that the number of young adults with T2D (< 40yrs) now surpasses young adults with type 1 diabetes (T1D). The proportion of young people with T2D is increasing most rapidly compared to older age groups (18% vs 11% over the last 5 years in the UK) and disproportionately affects those already at risk of health inequalities i.e. socioeconomically deprived and ethnic minority groups. T2D onset is earlier in ethnic minority groups (some 10-12 years earlier), with a greater risk of early onset in South Asians compared to white Europeans.

Ethnic minority groups, including South Asians with T2D are at greater risk of developing diabetic complications compared to white Europeans for a number of reasons; genetic, epi-genetic predisposition, maternal malnutrition, earlier onset, delayed diagnosis, difficulty in access, treatment inertia, and not being prescribed most appropriate therapy (usually newer agents with good evidence and higher costs).

However, it is becoming apparent that early onset T2D appears to represent a more aggressive form of metabolic dysfunction; young individuals present with or develop early on diabetic complications, including premature heart, liver, kidney, nerve damage, and earlier mortality (approx. 14yrs life lost when T2D diagnosed age 30yrs). Additionally, young women from ethnic minority backgrounds with T2D have worse pregnancy outcomes relative to T1D.

Whilst data is lacking for the socioeconomic cost of early onset T2D, given its aggressive nature, early diabetic complications, and impact on the working population, it is likely that early onset T2D will have higher financial burden on the NHS and the economy compared to later onset T2D.

### Health inequalities in diabetes

Knowledge about diabetes care and outcome inequalities is not new and has been recognised for decades. The COVID-19 pandemic brought the vulnerability of people with diabetes back into the limelight when it was noted that people with diabetes had increased risk of in-hospital death. Additionally, the increased risk in those within the South Asian community was identified early in the pandemic, first by the South Asian Health Foundation, (SAHF).

It is not rocket science to state that socioeconomic deprivation increases the risk of developing both T2D and obesity, but it also influences outcomes for people with T2D; those with T2D living in the most deprived areas were less likely to receive the eight diabetes care processes (52.3% most deprived vs 57.3% least deprived), less likely to achieve all three targets (HbA1c, BP, cholesterol targets; 39.8% vs 43.1%) and less likely to complete the NHS England National Diabetes Prevention Programme. The cost-of-living crisis has worsened the situation with decisions between putting food on the table or managing T2D, where food choices and lifestyle play an important role.

### What are the solutions?

**Cultural and socioeconomic competence:** Without acknowledging the cultural and socioeconomic backgrounds of people with T2D will create barriers for healthcare professionals providing optimal diabetes care; for example, dietary advice to those needing food bank support or cultural considerations, identifying barriers for National Diabetes Remission Programme.

Cultural competence is an important skill for healthcare professionals and has been the forefront work lead by SAHF with development of culturally competent guidelines for T2D management, diabetes and Ramadan, SAHF medical conferences and work with NICE. There is a need for further cultural competence-related education and this needs to

start early – in medical school, student nursing and other allied health professional undergraduate courses, as well for healthcare professionals in areas of highly diverse populations.

**Access to Technology in T2D:** NICE has allowed for certain people with T2D in England or Wales to be offered continuous glucose monitoring (CGM) e.g. recurrent or severe hypoglycaemia, impaired hypoglycaemia awareness, pregnant women with T2D, people with learning disabilities. Another culturally relevant use of technology in diabetes could be during the Muslim month of fasting, Ramadan. The use of CGM in people with T2D on multiple insulin injections has been shown to reduce the risk of fasting (hypoglycaemia and hyperglycaemia) allowing people with T2D to fast safely during Ramadan. In the absence of associated NICE Technology appraisal guidance, it has been left to individual English and Welsh Integrated Care Boards (ICBs) to roll out technology, leading to variation in care and inequity in access. We are particularly concerned at SAHF that some ICBs from the most deprived and multi-ethnic parts of England and Wales have the highest prevalence of diabetes, thus leading to difficult financial decisions, creating a postcode lottery and potentially exacerbating health inequalities.

**Tackling early onset T2D head on:** We need focussed research and therapeutic evidence-based guidelines for our growing young T2D population. Consideration of newer diabetes therapies early in this group, as well as stamping out therapeutic inertia needs to be prioritised.

The NHS has been the global leader for early onset T2D by targeting diabetes care for under 40s with the T2DaY programme (Type 2 Diabetes in the Young). This ambitious endeavour will allow patients to benefit from extra one-to-one reviews, access to newer agents and enhanced care to women of child-bearing age.

## Summary

SAHF has been at the forefront of national culturally competent work, including with NICE. There is still much work to be done, rolling out culture competence to all healthcare systems, equitable access to technology, tackling the disproportionate impact of early onset T2D in ethnic minorities and maternal diabetes. SAHF will continue its mission, together with the NHS and other organisations, such as NICE and Diabetes UK, to ensure a healthcare system where the access to optimal diabetes care is universal regardless of ethnicity and socioeconomic status.





## How South Asian women are being failed when it comes to Women's Health

Dr Nighat Arif

### Background

You might want to take a seat when I tell you that the UK has the widest gender health gap of the G20 countries. Is it controversial to say that this is a result of men designing a healthcare system for men? I believe not. Men have historically been treated as the default patient in clinical practice and medical research, resulting in women's needs being consistently ignored and neglected. This isn't a recent phenomenon. In ancient Greece, Hippocrates and Plato first used the term 'female hysteria', when it was believed that women's wombs wandered through their bodies, causing madness (hysteria = womb; hysterikos = of the womb); a practice that continued into the 18th and 19th centuries with female hysteria being the most diagnosed 'disorders'.

This gender health disparity in the UK was recognised by the UK government in the summer of 2022, with the launch of the Women's Health Strategy. This health strategy promises to tackle the deep health inequalities in our NHS to improve the health and wellbeing of our women. Unsurprisingly, the gender health gap is more pronounced for women from ethnically diverse groups. The COVID-19 pandemic brought these long-standing health disparities for ethnic minority women back into the limelight.

Black or ethnic minority women and their babies experience worse outcomes during pregnancy and the postnatal period as shown in the MBRRACE-UK report. In the UK, the South Asian population constitutes the largest ethnic minority category; yet UK South Asian women have lower uptake of breast screening services, higher proportion have never attended cervical screening, higher breast and cervical cancer mortality than their white counterparts, are more likely to present with advanced cancerous disease and have worse cancer-related health outcomes, with the exception of some Indian groups.

In response to the Women's Health Strategy for England, Wellbeing of Women formed The Health Collective – a collaboration of grassroots Black, Asian and other marginalised groups that supports women's health in their communities. The Health Collective has been integral in exploring the inequalities, barriers and seeking solutions. I have been leading on this in collaboration with Professor Dame Lesley Regan, Ambassador for the Women's Health Strategy in England.

### Barriers

Poor access to health care is most commonly a result of a number of barriers in the delivery of health services. Some of these barriers are listed below.

**Language challenges:** Some South Asian women cannot speak or read the English language, though it is more than just the lack of comprehension of English. Having a comprehension of English is separate to having a proficiency of English and being health literate. The complexity of our healthcare systems requires individuals to access health information, understand and appraise, make decisions, and communicate their concerns effectively about health in order to have 'health literacy'. Nearly half of adults in Europe have low or marginal health literacy, especially in marginalised groups.

**Lack of adequate health information:** Leading on from health literacy and language barriers, health information materials are rarely available in other languages or using simpler to understand English text, or are often not culturally relevant or translated poorly (often relying on husbands or relatives which can be misrepresented due to bias or not fully translated). Additionally, mainstream information rarely represents diversity in both imaging or text. Little literature or discussions cover taboos or stigmatisation.

Possible explanations for why cancer screening rates are lower in South Asian populations appear to reflect this lack of adequate health information dissemination – individuals and communities had poorer individual knowledge and awareness of breast and cervical cancer, display of poorer communication between health professionals and patients.



**Cultural competence:** The NHS has a patient community with a diverse cultural background. The Health Collective report showed that women noted that healthcare providers regularly displayed unconscious bias when delivering care with these diverse cultural and religious health beliefs; with a failure to understand and tailor care accordingly.

South Asian communities are lumped into the monolith of being BAME, however, we see from health risks in different conditions (take Type 2 diabetes) that even within the 'South Asian' category it is itself heterogeneous, with different quantified risks, as well as different cultural nuances and varying needs within the Asian community. Intersectionality is lost when we are placed with other ethnic groups, who have different needs and barriers.

Understanding, for example, the cultural connotations that go with menstruation. Something that is clearly physiological, but for some in the South Asian community is associated with the perception that 'periods are unclean' and opt to impose restrictive measures on women during the menstruation and can lead to challenges in health discussions about normal and abnormal symptoms such as dysmenorrhoea and menorrhagia.

Too often assumptions of attitudes are made. Examples that I have encountered are the South Asian LGBTQ communities feel ignored, unheard; and that it is assumed that South Asian women do not want to discuss taboo subjects such as sex and sexual dysfunction. My clinical work has shown that South Asian women do want to discuss these subjects and need the healthcare professional to have the cultural nuances understood to elevate their shame in discussions.

Additionally, faith and religious belief impacts on health and health coping strategies. Unfortunately, there can be a fatalistic view of how to manage their care that can be ajar with common NHS practice.

## Recommendations

- Cultural competence of healthcare professionals working in women's health is essential to allow for women to trust and have open discussions about their health and receive adequate management of their conditions.
- We need community campaigners or champions who have lived experiences, sharing their experience and breaking down the taboos and shame, allowing for the building of trust.
- Both my and Professor Dame Lesley Regan's work with The Health Collective and Wellbeing on Women will continue to map South Asian grassroots, who have the trust with their communities to deliver women's health effectively
- To continuously have inclusion and places in spaces where decisions are made about the care delivered for South Asian women
- We need greater integration between the South Asian communities to understand and create learning from different cultures when it comes to all of women's health
- Ensuring inclusion of ethnic minority women in research, media and policy conversations

## TAKE HOME MESSAGE

**Kiran Patel and Sarah Ali**

Let's not fall asleep at the wheel of health inequality. Whilst this report feeds us with intellectual curiosity, scientific evidence and provides tangible action, it is for all of us to collectively put the brakes on. The incredible momentum driving health inequality will accelerate unless people like you help to question why we cannot put a full stop to widening health inequality.

### **Our thanks**

We wish to extend our thanks once again to our experts who have contributed to the articles in this report. Full authors' affiliations will be provided in the online version of this report.

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-  [www.sahf.org.uk](http://www.sahf.org.uk)
-  [@SouthAsianHF](https://twitter.com/SouthAsianHF)
-  [info@sahf.org.uk](mailto:info@sahf.org.uk)

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