ACTIVATING CHANGE IN DIABETES

A Charter for Change – Delivering equitable care for Black African, Black Caribbean and South Asian people living with diabetes

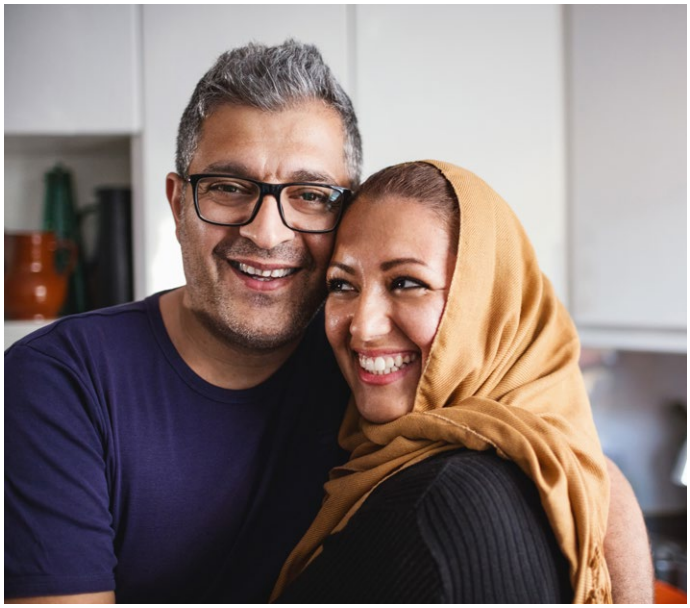
INTRODUCTION

People from Black African, Black Caribbean, and South Asian backgrounds are over-represented in the population living with diabetes, tend to develop Type 2 Diabetes at a younger age and are at greater risk of developing associated complications.[1,2]

While these groups have been historically underserved by the health system, this disparity has been recognised for a number of years, and numerous academic papers and reports have been published on this issue.[3] The NHS Long Term Plan, published in 2019, made an explicit commitment to tackling health inequalities. However, inequalities persist for these minority ethnic groups and have been further exacerbated during the COVID-19 pandemic.[3,4] As we rebuild from the pandemic and consider how to provide equitable healthcare services for the future, Lilly UK believes there is an urgent need to address these inequalities and evolve diabetes services in ways that can be better tailored to meet the needs of specific groups.

EQUITY IN HEALTH

The World Health Organisation defines equity in health as "the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequity".[5] These dimensions include sex, gender, ethnicity, disability, age, sexual orientation and religion.



Lilly UK convened a steering group of healthcare professionals, community group representatives, and people living with diabetes to share their knowledge and experience on the reasons for existing inequalities. The group consists of:

- **Patrick Vernon OBE**
  Public health campaigner (Chair)
- **Dr Joan St John**
  GP with special interest in Diabetes and Clinical Champion, Diabetes UK
- **Dr Bernadette Adeyileka-Tracz**
  Founder, Diabetes Africa
- **Michael Connellan**
  Head of External Affairs, JDRF (Juvenile Diabetes Research Foundation)
- **Dr Natalie Darko, Associate Professor**
  Stephen Lawrence Research Centre
- **Farhana Darwich**
  Senior Engaging Communities Officer, Diabetes UK
- **Tony Kelly**
  Diabetes Strategic Patient Partner, NHS Birmingham and Solihull Clinical Commissioning Group
- **Vanessa Laber**
  Engaging Communities Officer for the North of England, Diabetes UK
- **Shannon Rush**
  Diabetes Business Unit Leader, Lilly UK & Northern Europe
- **Dr Samuel Seidu**
  Head of Research, Primary Care Diabetes Europe
- **Grace Vanterpool MBE**
  Nurse Consultant, Diabetes & Service Manager, West London Mental Health Trust

With additional document review by:

- **Professor Wasim Hanif**
  Consultant Physician & Head of Service in Diabetes, University Hospital Birmingham

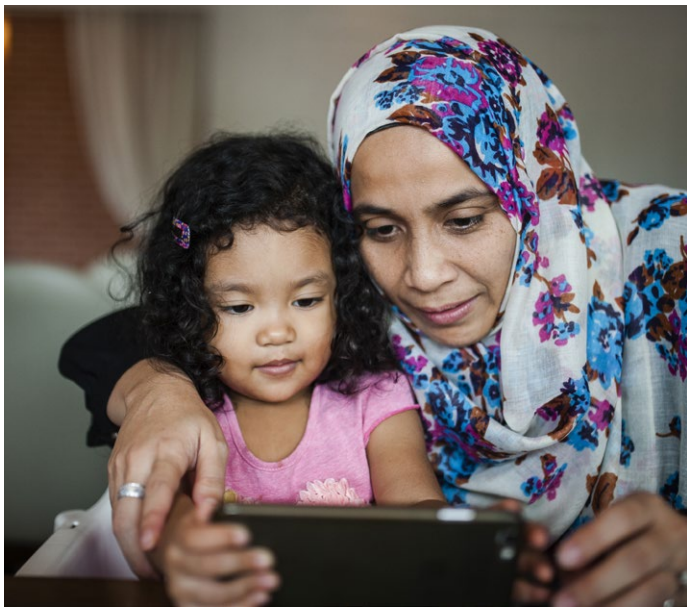
The insights from the group have been incorporated into this Charter for Change, creating the recommendations set out below to improve care and outcomes for people from Black African, Black Caribbean and South Asian groups living with diabetes.

COMMUNICATION AND CULTURAL COMPETENCE

'Cultural competence' is vital in providing healthcare that meets the needs of underserved groups. There is currently a lack of cultural competency training for healthcare professionals (HCPs), allied health professionals and NHS decision makers, which can create a significant barrier preventing Black African, Black Caribbean and South Asian people from receiving equitable diabetes care.

CULTURAL COMPETENCE

Health Education England (HEE) defines cultural competence in healthcare settings as the "ability to interact with people from different cultures and respond to their health needs", and "creating a working culture and practices that recognise, respect, value and harness difference for the benefit of the organisations and individuals".[6]



Effective communication is also closely linked to cultural competence. The language the NHS uses when communicating with those living with diabetes can be inaccessible to a wide range of people. For example, if standard appointment letters use complex medical terminology or do not convey health advice in simple terms, they can be difficult for people to comprehend and can lead to people not engaging or not realising the importance of routine appointments. In 2018, the North Central London Diabetic Eye Screening Programme trialled a variety of interventions to reduce the number of people not attending their eye screening appointments. Adjusting the wording in appointment reminder text messages to include a simple awareness-raising message notably increased appointment attendance rates.[7]

Current health advice is not always culturally appropriate and therefore often does not resonate with specific minority ethnic groups. For example, information about healthy eating, a cornerstone of diabetes care, needs to focus on a diet typical of the population in question. Furthermore, campaigns to promote physical activity often predominantly feature images not representative of the diversity of people living with diabetes or settings that are appropriate to certain cultures.

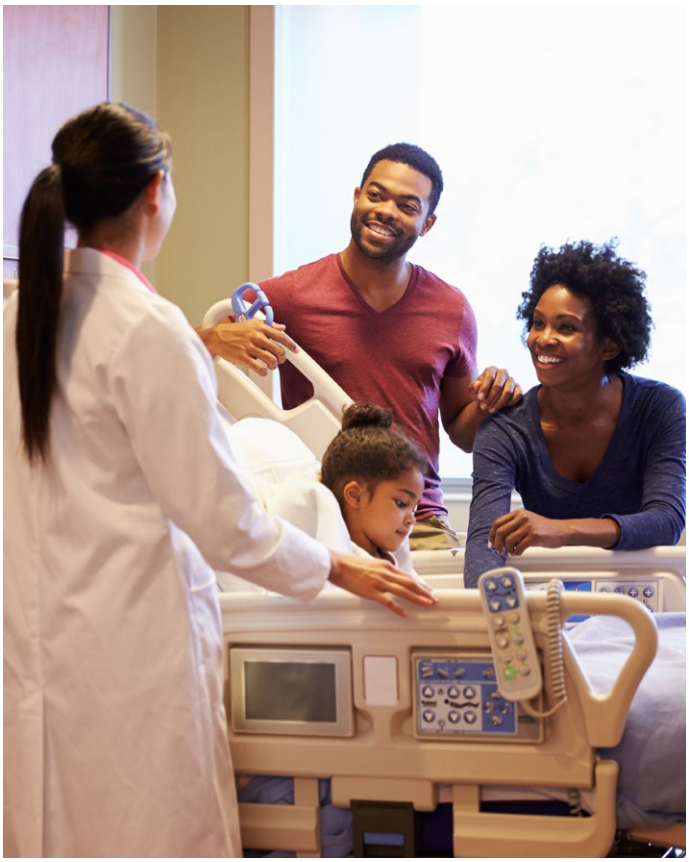
There are a number of existing NHS resources and toolkits that provide a framework for improving communication with people from minority ethnic groups living with diabetes. These include NHS England's 'Language matters' toolkit,[8] a handbook produced by NHS England and Diabetes UK,[9] a toolkit from the Centre for BME Health,[10] and a toolkit from the South Asian Health Foundation around fasting during Ramadan.[11] These resources need to be better utilised across NHS services to increase staff confidence and understanding of ethnic diversity in the UK, and to provide guidance on how to engage with audiences from a range of ethnic backgrounds.

RECOMMENDATION

- NHS England, the Royal Colleges, professional bodies and universities should work with patients and patient groups to co-produce training for HCPs and those studying for healthcare qualifications on improving cultural competency. This should include training on how to implement NHS England's 'Language matters: Language and diabetes' toolkit.
- In addition, NHS England should consider cultural competency as a mandatory training module for all HCPs.

REPRESENTATION AND TRUST

A degree of scepticism towards the NHS and healthcare professionals is present among some Black African, Black Caribbean and South Asian populations. There are multiple reasons for this, but a key cause is the perception that healthcare professionals, particularly in decision-making positions, do not reflect the communities they serve and do not understand certain cultural beliefs, practices and norms. The British Medical Association acknowledges the lack of minority ethnic representation at a decision-making level in the NHS, stating that workers from minority ethnic backgrounds are over-represented in lower pay grades, and under-represented at higher pay grades.[12] Overall, this means that diabetes services are not felt to have been planned or designed in ways that fully engage with, and meet the needs of minority ethnic groups.[13]



Greater Black African, Black Caribbean and South Asian representation within NHS decision-making structures, including giving greater weight to patient and public-voice partners, could lead to organic improvements in the experiences of people with diabetes from these minority ethnic groups across all areas, including communication, access to care, outcomes, and overall confidence in the health service.

RECOMMENDATION

- In the short term, initiatives such as community champions (individuals with lived experience who can act as conduits between the NHS and the minority ethnic groups from which they come) should be better utilised across the NHS and in campaigns to improve trust and therefore engagement between the NHS and minority ethnic populations.
- In the longer term, NHS England should set specific, measurable, achievable, realistic and timely ('SMART') targets for increasing recruitment of people from Black African, Black Caribbean and South Asian groups into decision-making roles across the health service.

DATA

To better understand the full extent of inequalities in diabetes care in Black African, Black Caribbean and South Asian populations, there is an urgent need for specific and publicly available data charting health outcomes against specific ethnic groups. However, there is currently a lack of consistency and granularity across NHS datasets in how ethnic groups are reported and defined, in terms of whether data is actually recorded, broken down by ethnic group at all, and the ethnic groups into which individuals can self-identify.[14] For example, some datasets may report outcomes for Black people, while others may distinguish between Black African and Black Caribbean people.

ETHNIC GROUP

The Office for National Statistics (ONS) defines ethnic groups as groups into which people classify themselves "according to their own perceived ethnic group and cultural background".[15]

ETHNIC MINORITY GROUP

The ONS defines ethnic minority groups as all ethnic groups except the White British group, which is the most populous ethnic group in the UK. Ethnic minority groups also include White minorities, such as Irish Travellers.[16]

Greater granularity in reporting of minority ethnic groups in healthcare data will equip NHS decision makers with the information required to improve diabetes services. In fact, when ethnicity reporting in datasets is made mandatory in US studies, it has been shown to improve outcomes and engagement with healthcare services among minority ethnic groups.[17]

RECOMMENDATION

- All NHS organisations should standardise the way minority ethnic populations are captured in datasets to understand how care is experienced by specific ethnic groups, and review outcomes to ensure service improvements can be designed accordingly.
- Official publications such as the National Diabetes Audit should break down all reported data by ethnic group.

QUALITY OF OUTCOMES AND CARE

The National Diabetes Audit records the attainment of certain healthcare metrics across the NHS diabetes patient population, including whether health checks are occurring and standardised blood pressure and blood glucose level targets are being met. Data from the Audit highlights that of all ethnic groups who present for health checks, there are discrepancies between White groups and Black African, Black Caribbean and South Asian groups in the attainment of standardised targets in blood pressure and blood glucose level targets.[18] This may suggest that Black African, Black Caribbean and South Asian groups are not experiencing equitable standards of diabetes care despite presenting for health checks in line with their White counterparts, and that alternative approaches are needed to support these groups to achieve such targets.

The NHS's lack of engagement with significant portions of Black African, Black Caribbean and South Asian populations is certainly a factor in unequal outcomes continuing to exist after health checks have taken place. Greater engagement could take place by taking some interactions outside of healthcare settings and utilising community locations or local community leaders to deliver tailored messaging around diabetes management.

RECOMMENDATION

- The NHS Race and Health Observatory should conduct a review of the diabetes care pathway specifically for people from minority ethnic groups across the NHS to identify any variation in care, experience and access to services and technology. Given the lack of consistency in reporting of ethnicity, further analysis of services should be held once more robust data reporting measures are implemented.

- Integrated Care Systems (ICSs) should consult, utilise and support community assets to develop engagement strategies to drive the improvement of outcomes, as well as to develop models of social prescribing (meaning 'prescribing' people non-clinical services/activities such as swimming, dancing, tending allotments, aerobics or yoga, funded by the NHS) that are tailored to the needs of minority ethnic groups living in the local area. This should involve the provision of training for HCPs specialising in diabetes care on how these measures can support people from minority ethnic groups to manage their diabetes.

FUNDING AND RESOURCES

If the inequities in diabetes care within Black African, Black Caribbean and South Asian groups are to be addressed, fundamental changes will be required in the way the NHS engages with them.

Existing diabetes services will require significant redesign. All of this will require additional funding and resources in order to redress the balance in offering an equitable service.

A key opportunity exists as the NHS in England evolves from Clinical Commissioning Groups (CCGs) into ICSs, with ICSs responsible for the improvement and maintenance of a local population's health. Direct enhanced service payments, both from NHS England to ICSs, and from ICSs to the Primary Care Networks that operate within them, could ensure areas with higher minority ethnic populations are equipped with the requisite funds to deliver additional and equitable health interventions and redesign services in ways that improve diabetes care and outcomes in these specific, historically underserved groups.

RECOMMENDATION

NHS England should work with ICS leaders, clinical bodies, patient groups and people with lived experience of the condition to consider how to allocate greater funding to Primary Care Networks to enhance services for people from minority ethnic groups living with diabetes.

CONCLUSION

The barriers to equitable diabetes care and outcomes in minority ethnic groups are numerous but not insurmountable. Fundamental changes are required now. Lilly UK believes that by working together across the diabetes community, these recommendations can be implemented to deliver meaningful changes for Black African, Black Caribbean and South Asian people living with diabetes. This change is long overdue, and Lilly UK is determined to play a part in bringing it about.

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