DiABETES UK
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TACKLING INEQUALITY COMMISSION REPORT

Executive summary

INTRODUCTION

There are now more than 5 million people living with diabetes in the UK. Diabetes is a serious condition, which can lead to serious complications and, sadly, early death. However, with the right care and support many life-altering complications can be prevented.

Diabetes doesn't affect everyone equally. People with diabetes experience systematic, unfair and avoidable differences in their diabetes, the care and treatment they receive and the opportunities they have to lead healthy lives. People from Black and South Asian communities and people living in deprivation are more likely to develop type 2 diabetes. For all types of diabetes, people from Black and South Asian communities and people living in deprivation are less likely to be able to access the care, treatments and guidance they need. They are also more likely to develop many complications related to their diabetes and have poorer outcomes.[1]

A person living with any type of diabetes in the most deprived area is around twice as likely to have a major amputation due to diabetes-related complications than a person from the least deprived area.[2]

> Access to diabetes technology can be life-changing, yet if you are from an ethnic minority group or living in deprivation you are far less likely to be able to benefit from it.[3]

Diabetes UK launched the Tackling Inequality Commission to include the voices of people directly impacted by inequality and get a better understanding of the stark data on inequality, to understand where there are barriers to improvement, and to co-produce some broad practical calls to action.

The Commission was co-chaired by Dr Faye Ruddock, Chair of the Caribbean & African Health Network and Professor Linda Bauld, Bruce and John Usher Chair in Public Health in the Usher Institute, College of Medicine at the University of Edinburgh and Chief Social Policy Adviser to the Scottish Government.

The full report discusses lived experience testimonies from a series of face-to-face and online focus groups with people living with or at risk of diabetes and those who care for them, from Black and South Asian communities or living in deprivation. The Commission also heard evidence from those working within the NHS and community organisations, as well as experts on the effects of racism, poverty, food and housing on health.

From these the co-chairs, supported by a panel of contributors, developed a set of guiding principles and calls to action.

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THE FOUR Cs

Core principles for promoting equity in diabetes outcomes

These principles can help frame your thinking and be a useful way to introduce key concepts in diabetes-related health inequality to others:

Context

Remember the wider social, environmental and economic factors that impact on health. The conditions in which we are born, grow, live, work and age, as well as ethnicity. Consider how these will impact the accessibility of events, information and services and the ability of people living with diabetes to self-manage. Think about cultural differences and the impacts of systemic racism. Are services and information set up to be properly inclusive for all ethnicities?

Curiosity

Understand your data and the communities around you. Where can you see inequality? Look beyond just health data. Who is missing from your data because you have no contact with them? What is the ethnic and socio economic make up of the population your service serves? Does your organisation reflect this? Whose views are not being heard in your consultations and participation work? Go out into different communities and ask what is wanted or needed – don't assume you know.

Collaboration

Coordinate and share insights and efforts to reach different communities across organisations and systems. Properly involve the communities you are trying to reach – as employed staff at every level of your organisation, as well as through acting as an anchor organisation.

Commitment

Create long-term and embedded funding for this work, not one-off projects. Create targets for outcomes and structures of accountability and assign named leaders to ensure this happens. Evaluate regularly, learn from and share challenges as well as success.

OUR CALLS TO ACTION

We have produced calls to action across seven areas:

1. Anti-racism – be bold
2. Address deprivation – be proactive
3. Environments – be supportive
4. Data and insights – be specific
5. Representation – be diverse
6. Co-creation – be inclusive
7. Sustainability – be persistent

These are divided into four categories of responsibility: organisation, health and social care system or regulator, national governments and individual. Please see the full report for the detailed calls to action and breakdown by category of responsibility.

1. Anti-racism – be bold

- Make a public commitment to anti-racism – support continued staff learning and review services, policies and guidelines using anti-racist practices.
- Build trust within communities through transparency, equal partnership and diversity of representation.
- Create leadership and accountability for anti-racism at all levels from individual departments within organisations, up to national governments.
- The NHS Race and Health Observatory and similar organisations in the devolved nations should examine diabetes clinical care as their next area of focus.

"For years, policymakers have discussed the need to tackle health inequities for Black African, Black Caribbean and South Asian communities. Looking forward it is time for us to address this head-on, ensuring that words translate into actions and that unnecessary discrepancies in care and outcomes are not endlessly replicated."

Dr Joan St John

2. Address deprivation – be proactive

- Recognise the wide effects of deprivation and adapt services, policies and guidelines to reflect this.
- Use anchor organisation approaches within your organisation to reduce the impact of deprivation.
- Recognise that deprivation is not caused by individual circumstances, but wider systemic problems.
- Support campaigns for more affordable healthy food, the living wage and increased investment in areas of deprivation:
  - The Food Foundation Broken Plate Report 2023.[4]
  - The An essentials guarantee report.[5]
  - Health Equity in England: The Marmot Review 10 Years On.[6]

"The doctor told me to take lots of beans, brown rice, vegetables, dairy products but these are very, very expensive. I said this to him, but I don't think they [healthcare professionals] understand what it's like to have no money."

Lived Experience Testimony

3. Environment – be supportive

- Challenge stigmatising language and behaviours.
- Support the health of employees through food options and flexible working, and the living wage amongst other approaches.
- Ensure reasonable adaptations are made for people living with and at risk of diabetes and guarantee workers the right to paid time off for medical appointments.
- Support the Obesity Health Alliance: Joint Policy Position on Obesity and Healthy Weight, to help reduce the impact of the wider environmental factors that contribute to weight gain – the obesogenic environment.[7]

"When I applied for and didn't get my first graduate job, I just assumed that it was because I said I had diabetes. Now I never tick the box on the form in case someone judges me."

Lived Experience Testimony

4. Data and insights – be specific

- Follow the recommendations of Addressing Health Inequalities in Diabetes through Research: Recommendations from Diabetes UK's 2022 Health Inequalities in Diabetes Workshop.[8]
- Develop plans to improve ethnicity and socioeconomic data collection in diabetes services and research.
- Increase trust in the data collection process within all communities.[9] Use data to drive change and determine impact.

"The system as a Black person doesn't recognise our experience. So yeah, I think everything in every clinical research is on White people."

Lived Experience Testimony

5. Representation – be diverse

- Use workforce diversity data to ensure your workforce is representative of the population you serve.
- Ensure all engagement and consultation work is informed by people of all backgrounds and ethnicities.
- Commissioners and regulators such as The Care Quality Commission (CQC) must consider Workforce Race Equality Score (WRES) and other workforce data when assessing services for people living with diabetes.[10]

"I was diagnosed young, and I went to a group and everyone else was over 65 and I felt so alone. Being able to talk to someone like me would really help."

Lived Experience Testimony

6. Co-creation – be inclusive

- Ensure all your information for people living with and at risk of diabetes is:
  - simple and accessible – both printed and digital.
  - in audio visual formats as well as written.
  - easy to share via social media and messaging apps.
  - translated and adapted as guided by input from specific communities, not based on assumption.
- Work in partnership with local community organisations and those with lived experience whenever developing services, research or information.
- Work together with other organisations to share learning and develop shared approaches to increasing trust in communities.

"We need good nutritional content of our own food, it can help to guide us, remove the dilemma of what we need to eat and see how much we need to eat."

Lived Experience Testimony

7. Sustainability – be persistent

- Create long-term and sustainable funding for different ways of working to reduce inequality, as well as for the community organisations who support their populations.
- Support capacity building for local community organisations, for example with governance and other training needs to strengthen their ability to make change.
- Recognise that the inequalities faced by people living with diabetes are due to multiple, wide-ranging factors. Change may feel slow and difficult, but it is vital to continue to work to reduce inequality.

"I just hope what we've had now with these discussions, something will be done … let's just put things in gear, let's just start walking forward instead of being stagnated."

Lived Experience Testimony

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Acknowledgements

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This report was authored by:

Aoife Slattery
Tackling Inequality Engagement Lead, Diabetes UK

Dr Faye Ruddock
Caribbean & African Health Network

Professor Linda Bauld
Bruce and John Usher Chair in Public Health in the Usher Institute, College of Medicine at the University of Edinburgh.

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Chizo Agwu
Consultant General Paediatrics, Diabetes and Endocrinology, Sandwell and West Birmingham NHS Trust, Vice Chair of National Institute for Health and Care Excellence, Diabetes update committee

Arbah Azhar
PhD student, University of Cambridge, Expert by experience

Sonia Edwards
Project Lead and Support Officer, Paul's Cancer Support, London, Expert by experience

Miebaka Tolu Fiberesima
Chairperson, African and Caribbean Community Association, Stockport, Expert by experience

Nazim Ghouri
Consultant physician in diabetes, endocrinology and general medicine, Queen Elizabeth University Hospital, Glasgow, and British Islamic Medical Association

Gerard McCartney
Professor of Wellbeing Economy, University of Glasgow

Daniel Newman
Diabetes advocate and host of the Talking type 1 podcast, Expert by experience

Nana Ocran
Health and Wellbeing Coach, Newham Health Collaborative Ltd, Expert by experience

Cordelle Ofori
Deputy Director of Public Health, Manchester City Council

Ambrose Omoma
Consultation and Involvement Officer, Southwark Council

Amobi Onumaeme
GP and lifestyle medicine doctor, The Lifestyle Wellness clinic

Surya Rajeev
Consultant and Clinical Director, Diabetes & Endocrinology, Liverpool University Hospitals – Aintree site

Jayne Robbie
Senior Lecturer in Diabetes Care at Birmingham City University and Senior Podiatrist, University Hospitals Birmingham NHS Trust

Naveed Sattar
Professor/Honorary Consultant Cardiovascular & metabolic Health, University of Glasgow

Morag Treanor
Professor of Child and Family Inequalities, University of Glasgow

Sarah Wild
Professor of Epidemiology, The University of Edinburgh

Kirsty Winkley
Reader in Diabetes and Primary Care, Kings College London

Nardos Yemane
Highly Specialist Dietician, Guys and St Thomas' NHS Trust

Waseem Zaffar
Councillor, Birmingham City Council, Expert by Experience

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Dianne Addei
Senior Public Health Advisor, National Healthcare Inequalities Improvement Programme, NHS England

David Buck
Senior Fellow, Public Health and Health Inequalities, The King's Fund

Deirdre Costigan
National Officer, Disability Equality, Unison

Hamish Courtney,
Consultant Endocrinologist, Clinical Lead Diabetes Network in Northern Ireland

Andrew Fenton
Transformation Director, Population Health & Inequalities, NHS South, Central and West CSU

Nazim Ghouri
Consultant physician in diabetes, endocrinology and general medicine, Queen Elizabeth University Hospital, Glasgow, and British Islamic Medical Association

Shona Goudie
Policy and Advocacy Manager, The Food Foundation

Melanie Gray
Diabetes Prevention Programme Lead, Cardiff and Vale UHB

Partha Kar
Consultant Endocrinologist, Portsmouth Hospitals NHS Trust, National Specialty Advisor Diabetes and Lead for the Medical Workforce Race Equality Standards with NHS England

Emma Leggott
Poverty Proofing Healthcare Team manager, Children North East

Sam Rodger
Assistant Director, Policy and Strategy, NHS Race and Health Observatory

Joan St John
GP with special interest in Diabetes, Central London Community Healthcare NHS Trust

Sarah Turner
Resident Involvement and Wellbeing Manager, Anchor Trust

Nicola Waite
Resilient Communities Programme Manager, whg

Catherine Washbrook-Davies
All Wales Nutrition and Dietetic Lead for Diabetes (Adult)

Toby Watt
Lead Economist, The Health Foundation

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NHSE Inequalities in Diabetes Clinical Working Group members:

Shivani Misra
NHSE working group lead, Consultant in Diabetes and Metabolic medicine, Imperial College University Hospitals Trust

Rebecca Haines
GP Partner, Diabetes Lead, Glenpark Medical Centre

Surya Rajeev
Consultant in Diabetes and Endocrinology, Liverpool University Hospital

Ritwika Mallik
Diabetes and Endocrinology Specialty Registrar, Barts Health NHS Trust

Helen Slee
Programme Manager, NHSE

Partha Kar
Consultant in Diabetes & Endocrinology, Portsmouth Hospitals NHS Trust

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

Diabetes UK
Wells Lawrence House
126 Back Church Lane
London E1 1FH

Call: 0345 123 2399
Email: info@diabetes.org.uk/diabetesuk

/diabetesuk
@DiabetesUK
DiabetesUK
@DiabetesUK

diabetes.org.uk