

DiABETES UK
KNOW DIABETES. FIGHT DIABETES.

TACKLING INEQUALITY COMMISSION REPORT

November 2023



FOREWORD FROM CO-CHAIRS



Dr Faye Ruddock

Chair of the Caribbean & African Health Network (CAHN), and Director of the Health Equity and Social Justice Institute, University of Bolton.

The covid-19 pandemic vividly highlighted stark ethnic health inequalities, as the disproportionate effect on Black and South Asian populations was shown clearly in nightly news reports.

Unfortunately, poorer health outcomes in communities that experience racial inequality are not new, nor are they confined to covid-19. So I was very glad to be asked to co-chair this commission to help Diabetes UK build on their own work as well as have the opportunity to co-create a set of recommendations for other organisations.

I was delighted that we were able to hear from so many different people during the process of the Commission, who shared their personal experiences of inequality to help focus our discussions. As well as hearing about the number of organisations working either directly in communities or pushing for the population level changes needed to bring about lasting change.

The causes of ethnic health inequality are complex and there is variation between the outcomes for different ethnic groups as well as the overlying effects of deprivation, which is more likely to affect these communities. It is vital that we recognise the impact of structural racism and listen to the experiences of underserved communities to ensure inclusive systems and equitable outcomes for all.

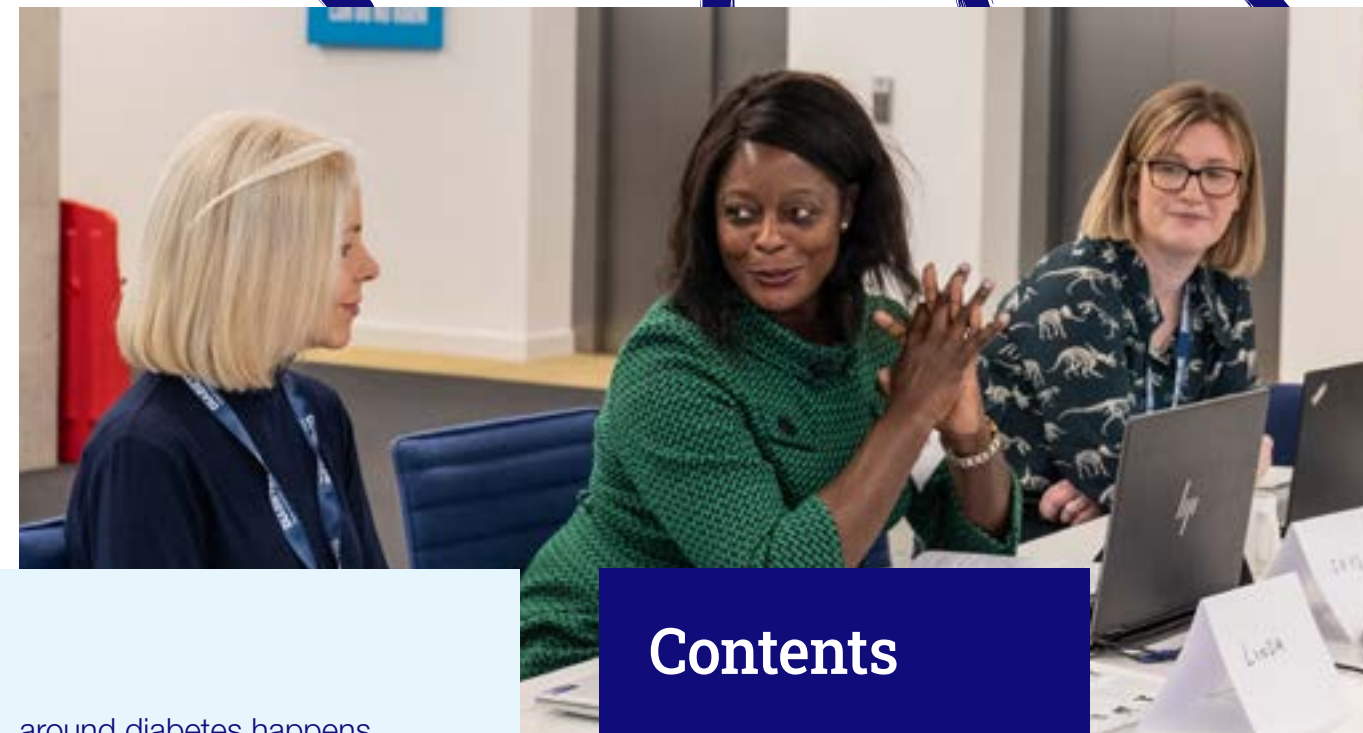


Professor Linda Bauld

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.

Our health is influenced by the conditions we are born, grow, live, work and age in – the wider determinants of health. These factors have a particularly strong influence on the risk of developing type 2 and gestational diabetes.

They also influence our ability to access care and rates of complications of all types of diabetes. If we wish to reduce the inequality seen within diabetes it is vital that we address these at a population level as well as seeking to mitigate their effects at an individual level. To do this we need to ensure the discussion



around diabetes happens beyond clinical networks and settings, including social scientists, those working in local government and wider community organisations and people living with diabetes and facing the day-to-day challenges that this brings.

The recommendations in this report are broad and reflect the many different levels at which change is needed, from each individual working within diabetes services all the way to national governments. I am delighted we are able to bring these together and share them widely, to ensure diabetes is a focus in all health inequality conversations.

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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.

NHS England defines health inequalities as unfair and avoidable differences in health across the population and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care available to them.

Diabetes does not affect everyone equally, and the interactions between different kinds of inequality and the factors that drive them are often complex and interrelated.

People from Black and South Asian communities and people living in deprivation are more likely to develop type 2 diabetes but are less likely to be able to access the care, treatments and guidance they need for all types of diabetes.

Diabetes UK launched the Tackling Inequality Commission to invite people living with and at risk of diabetes who are most affected by health inequalities and those working closest to health inequality to share their experiences. The Commission aimed to add the voices of lived experience

to the stark data on inequality, to understand where there are barriers to improvement, and to produce some broad practical calls to action.

The Commission was 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 Commission was fortunate to have input from a wide range of people through surveys, focus groups, one-to-one interviews, and online workshops. We are extremely grateful to all of those who contributed, who included:

- people living with and at risk of diabetes
- frontline healthcare professionals
- community organisations
- local government
- social policy and poverty experts
- health economics experts and researchers

- public health experts and researchers
- representatives from food, housing and employment organisations.

The lived experience testimonies are from a series of focus groups and one-to-one interviews which took place both online and in person across the UK between February and April 2023. In all, there were 131 participants across all four nations of the UK.

The respondents ranged from 18 to 80 and included those at risk of type 2 diabetes, those living with type 1, type 2 or gestational diabetes, and carers of adults or children with all types of diabetes.

In forming the recommendations of this report, we recognised that the 2022 position statement, **Addressing health inequalities in diabetes through research: Recommendations from Diabetes UK's 2022 health inequalities in diabetes workshop**¹, already provided detailed recommendations for researchers and research funders on where research

activity should be focused for maximum impact.

We were grateful for the recommendations of **A Charter for Change – delivering equitable care for Black African, Black Caribbean and South Asian people living with diabetes**² to take forward and build upon during our workshops.

In forming the calls to action, we considered several structures and were grateful to David Buck of the King's Fund for leading a workshop discussion on different frameworks, which helped us structure our calls for action.^{3,4} We were thankful to the NHSE Inequalities in Diabetes Clinical

Working Group and those who filled in their survey asking for examples of projects aiming to reduce health inequalities in diabetes care. Some of these have been used as examples in this report and all of those submitted are being considered for inclusion in best practice guidance to be published by NHSE in the future.

We were also grateful to the clinicians who attended the workshops to discuss the current challenges and examples of work from their nations and regions. As well as the representatives of community and NHS based organisations, working to reduce inequality.

We were thankful to Professor Partha Kar for presenting the findings of the NHS Workforce Race Equality Standard in his role as Speciality Advisor, Medical Workforce Inclusion for NHS England.

We were also grateful to the NHS Race and Health Observatory, The Health Foundation, The Food Foundation and Unison for attending workshops to present evidence and discuss their work.





THE FOUR **C**s

When deciding on an approach the Commission considered four key principles – context, curiosity, collaboration and commitment. These are referred to as the four Cs. 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 your local population or 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

Key words

Anchor institutions

Anchor institutions are large organisations that are unlikely to relocate and have a significant stake in their local area.⁵

Community organisations

Throughout this report, you will see this term used to refer to small and medium-sized organisations that are embedded in local communities. These are run by members of the local community and are often charities or rely heavily on volunteers and goodwill.

We also use this term to cover religious groups such as church or mosque groups and non-corporate small sports clubs such as non-league football or cricket clubs. It also refers to small, place-based charities focusing on particular groups or communities, such as ex-offender groups or those supporting people to get into work. It may also include locally run food banks or discount food clubs.

Deprivation

In deciding the original focus of this report we looked at the National Diabetes Audit for England and Wales and the Scottish Diabetes survey to identify inequalities of risk and care. It was apparent that deprivation was a major factor. When referring to deprivation in this report we are referencing the index of multiple deprivation tool,

which provides a relative scale of deprivation for each of the four nations. These are different for each nation but include measures of deprivation beyond just income, such as access to services, education, health, housing and community safety.

Ethnicity

The other major area in which the data shows inequality for diabetes risk and outcomes is ethnicity. The ethnic groups most affected by this in the UK are South Asian, Black African and Black Caribbean communities. Within these groupings there are of course, many individual ethnic groups, facing different, specific inequalities.

Where the data allows, we have referenced these specifics and throughout the report we have emphasised the need to work in partnership with individual communities to recognise the fact there is no one size fits all solution to inequality.

Our seven calls to action are divided into four categories of responsibility:

Organisations

Organisations directly supporting people living with or at risk of diabetes as well as

those who work with people in any capacity. From NHS services, like GP practices, hospital and community trusts etc, to local councils, community groups and charities, employers and small businesses. It also includes universities and organisations involved in research and charities involved in supporting anyone impacted by diabetes.

Health and social care system or regulator

Health and social care systems in all four nations. Large national and statutory organisations, including regional and national NHS bodies, the Care Quality Commission (CQC) and major research and policy organisations.

National Governments

Governments in all four nations of the UK.

Individuals

This category allows anyone who is supporting people living with or at risk of diabetes in any capacity – as a service user or patient or as a loved one, a colleague, or an employee – to take an active part in reducing inequality.

1. ANTI-RACISM

BE BOLD

Health and social care system or regulator

When assessing services for people living with diabetes as a regulator or commissioner:

- review services, access and outcomes, broken down by ethnicity and socioeconomic groups
- review Workforce Race Equality Scores (WRES) and other workforce data
- require targeted plans for improvement within specified timescales.

Follow the recommendations of **Addressing health inequalities in diabetes through research: Recommendations from Diabetes UK's 2022 health inequalities in diabetes workshop, including calls for:**

- better representation of ethnic minority groups, both in trials and the research community
- use of implementation science to ensure equality of access to new research benefits
- collation of examples and principles of best practice.

Support small community organisations to ensure they

are sustainable and stable so all communities in your local area can be represented in partnership working and engagement opportunities.

Fund NHS projects to reduce inequality for a minimum of three years to allow enough time for proper community involvement and evaluation.

The NHS Race and Health Observatory and similar organisations in the devolved nations should examine diabetes clinical care as their next area of focus. This work should include a review of how structural racism impacts on diabetes pathways, guidance and access to care.

Organisation

Make a public commitment to become an anti-racist organisation and sign up to or develop a framework to do so.

Provide staff training and continued opportunities to reflect on and learn about:

- anti-racist practices
- cultural awareness and competency.

Cultural competence and inclusive anti-racist practices demand an ongoing commitment and a comprehensive, multi-faceted approach. Establish an infrastructure that supports culturally competent practices.

Expose organisational policies or practices that act as barriers to specific communities and adjust them to ensure they meet the needs of people from all communities.

Opportunities to build cultural insights and anti-racist reflective discussions should

be built into usual staff meetings such as handovers or case reviews, to ensure there is continual shared learning and a space to raise concerns.

Incorporate education on the impact of racism and the principles of social justice into training for healthcare professionals from an undergraduate level. Create named leadership roles, including at board level, responsible for overall reduction in inequality.

Require all senior leaders to take responsibility for reducing inequality and leading anti-racist practices within their teams. This should include psychological safety education and training to reduce workplace harm for those communities experiencing racial inequality.

Build increased trust in your organisation with ethnic minority communities through:

- transparency around data collection and demonstration of targeted efforts to improve inequality

- equal partnership on co-production of services
- diversity of staff at every level to reflect the diversity of the communities you serve.

Work in partnership with community organisations to review your policies and practices to understand where you need to improve and adapt services to make them accessible to all ethnicities.

Use community outreach programmes so that services and staff who work in them are visible in trusted community spaces.

Governments

Acknowledge the impact of systemic racism on health and promote anti-racism.

Create a named individual with national responsibility to narrow health inequality for communities that experience racial inequality.

Develop an overarching national policy for anti-racism within health services for each devolved nation.

Individual

Reflect on how you interact with others and proactively look for opportunities to learn about different experiences from your own.

Attend training sessions and take opportunities to learn more on:

- anti-racist practices
- cultural awareness and competency.

Challenge racist behaviours and talk to others about anti-racism.

2. ADDRESS DEPRIVATION

BE PROACTIVE



Organisation

Provide staff training and continued opportunities to reflect on and learn about poverty.

Use the principles from staff training, along with engagement with community organisations and people with lived experience to review services and information to be more accessible for those living in deprivation. Provide signposting to general and local information on financial support, which includes people without access to mainstream benefits.

Become an anchor institution for your local area. Consider how you can support the wellbeing of your community through:

- sharing your buildings and estates
- employment practices such as mentoring or paid internships for people from different backgrounds, cultures, and diverse ethnicities in your local area to widen recruitment
- procurement practices that invest in your local economy.

Fund small, local community-based organisations to provide input, services and training, where possible and appropriate.

Become a living wage employer.

Governments

Implement the calls of the **An essentials guarantee report**⁶ to ensure the minimum wage and benefits provide enough income to cover life's essentials, including a balanced diet.

Implement the calls of **The Food Foundation Broken Plate Report 2023**⁷ to ensure that price isn't a barrier to accessing more sustainable and healthy options, especially for people on low incomes.

Ensure Free School Meals provision is consistent across the UK and increase and expand Healthy Start and equivalent schemes in the devolved nations.

Guarantee workers a right to paid time off for medical appointments.

Address digital exclusion through a national strategy for each devolved nation.

Take action to reduce health inequality as set out in the recommendations of **Health Equity in England: The Marmot Review 10 Years On**⁸, across the six key areas identified:

1. Develop a national strategy for action on the social determinants of health with the aim of reducing inequalities in health.

2. Ensure proportionate universal allocation of resources and implementation of policies.
3. Early intervention to prevent health inequalities.
4. Develop the social determinants of health workforce.
5. Engage the public.
6. Develop whole systems monitoring and strengthen accountability for health inequalities.

Health and social care system or regulator

Develop and strengthen local support services and social prescribing, and ensure they are well linked with local health services.

Individual

Attend training sessions on and take opportunities to learn more about poverty awareness. Normalise talking about finances and the hidden costs of diabetes. Think about whether your advice is possible and practical and how can you adapt it. Talk about the available support and reduce the stigma of poverty.

3. ENVIRONMENTS

BE SUPPORTIVE



Individual

Support others around you to access healthy options and avoid stigmatising or stereotyping people living with and at risk of diabetes or obesity.

Challenge stigmatising language and behaviours towards those living with and at risk of diabetes or obesity.

Organisations

Support employees by:

- improving access to healthy options and where food is provided ensure healthy, affordable options are available
- providing flexible working options
- making timely workplace adaptations for people living with diabetes

- avoiding stigmatising or stereotyping people living with and at risk of diabetes or obesity and overweight and guiding staff on how to do this
- allowing paid time off for medical appointments
- becoming a living wage employer.

Health and social care system or regulator

Assess the need for access to healthy, affordable food outlets and space to exercise in all planning decisions.

Aim to create social value and equality with all the assets available in your system, for example, through developing anchor institution approaches.

Governments

Introduce policies which address the wider environmental factors that contribute to weight gain – the obesogenic environment – as recommended in the **Obesity Health Alliance: Joint Policy Position on Obesity and Healthy Weight.**⁹

Tackle industry influence on policy making, and the commercial determinants of health.

4. DATA AND INSIGHT

BE SPECIFIC

Individual

Talk to people about why collecting data is important and reassure them about the role data plays in highlighting and reducing inequality.

Organisations

Plan to improve data collection on ethnicity across diabetes services within the next three years to be greater than 95%.

Publish diabetes data broken down by socioeconomic status and ethnicity and include your plans to reduce any apparent inequalities.

Use community outreach programmes within services to gain better insights on how services are used by, and can be adapted for, different communities.

Health and social care system or regulator

Work with local community organisations to ensure local data is as accurate as possible.

Make it a requirement that all trials and observational studies capture sex, ethnicity, and socioeconomic data in a standardised manner to facilitate aggregation and meta-analysis.

Publish diabetes data broken down by socioeconomic status and ethnicity and plans to reduce any apparent inequalities.

Use an unmet needs assessment or similar to understand local need and use the results to inform and develop plans for underserved communities in your area.

Governments

Use health inequality impact assessments for all policies.

Coordinate and help to link together large-scale, disaggregated data sets across health and social care to allow a better understanding of inequality.

Use these data sets to identify and act on inequalities through both policy change and by holding health and social care systems and organisations to account on their outcomes.

Plan to improve data collection on ethnicity to greater than

95%

across diabetes services within the next three years.

5. REPRESENTATION

BE DIVERSE

Health and social care system or regulator

Ensure all user feedback or engagement initiatives include those from different backgrounds, cultures, and diverse 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.

Organisations

Publish staff diversity and pay gap data for people of different backgrounds, cultures, and diverse ethnicities.

Develop information and support programmes such as mentoring or paid internships for people from different backgrounds, cultures, and diverse ethnicities in your local area to ensure your staff is more representative of the communities you serve.

Fund and work in partnership with local community-based organisations to increase the diversity of views and experience influencing your organisation.

Individual

Support people of different backgrounds, cultures, and diverse ethnicities to speak up in your workplace and in applying for leadership positions.

Governments

Hold organisations to account on the diversity of their leadership.



6. CO-CREATION

BE INCLUSIVE

Organisations

Develop relationships with small community organisations and listen to them as well as to those with lived experience, before developing or reviewing research, services or materials.

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 and produced with input from people with lived experience of different backgrounds, cultures, and diverse ethnicities at all stages of the process.

Governments

Only provide funding for work that is designed or delivered in partnership with the community sector.

Health and social care system or regulator

Fund, on a sustainable basis, a network of community organisations who can offer advice and represent underserved communities as advocates during the planning and review of all diabetes services.

Individual

Involve people with lived experience whenever designing or reviewing research, information or services. Actively seek out others doing similar work to share learning and insights about engaging with people of different backgrounds, cultures, and diverse ethnicities and think about how your work contributes to wider, long-term goals.



7. SUSTAINABILITY

BE PERSISTENT

Health and social care system or regulator

Create stable funding cycles for small community organisations of three to five years to allow them to work sustainably and strategically and make long-term change.

Fund NHS projects to reduce inequality for a minimum of three years to allow more time to integrate new ways of working into usual practice.

Coordinate and help link together community-based projects and NHS systems to allow sharing of learning and holistic, sustainable impact.

Support capacity building for local community organisations, for example with governance and other training needs to strengthen their ability to make change.

Organisations

Build inequality practice into existing work, where possible, rather than creating standalone inequality projects.

Support local community organisations with funding for partnership work or offers of shared training opportunities or jointly employed roles.

Governments

Create long-term and sustainable funding and capacity building for community groups and sector.

Ensure the NHS has the funding and workforce available to support people with and at risk of diabetes.

Individual

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.

Actively seek out others doing similar work to share learning and insights about engaging with people of different backgrounds, cultures, and diverse ethnicities and think about how your work contributes to wider, long-term goals.

DIABETES-RELATED HEALTH INEQUALITY

A GROWING PROBLEM

Inequalities of risk

Your chances of developing type 2 diabetes are higher if you are Black, South Asian, or living in deprivation.

People of South Asian ethnicity are 2 to 4 times more likely to develop type 2 diabetes than someone of White European ethnicity. And people of Black ethnicity are 1.5 to 3 times more likely to develop diabetes than someone of White European ethnicity.¹⁰ People of Black and South Asian ethnicity are also more likely to develop type 2 diabetes at a younger age and for people of South Asian ethnicity, at a lower BMI.¹¹

People from ethnic minority backgrounds are also more likely to be living in deprivation than those of White ethnicity, creating layers of different risk factors which interact with and can amplify each other.^{12,13}

Of people living with type 2 diabetes, 24% live in the most deprived areas of England and Wales versus 14% in the least deprived. For the under 40s, including children, the difference is even more marked, with 35% of those living with type 2 living in the most deprived areas versus 8% in the least deprived.¹⁴

Inequalities of care

Yet you are less likely to be able to access the care you need, for all types of diabetes.

The Diabetes UK Diabetes is Serious Report¹⁵ in 2023 found that while many people had difficulties contacting their healthcare team in 2022, those in the most deprived areas were more likely to experience this. And 1 in 10 in the most deprived areas reported having no contact at all in over a year.

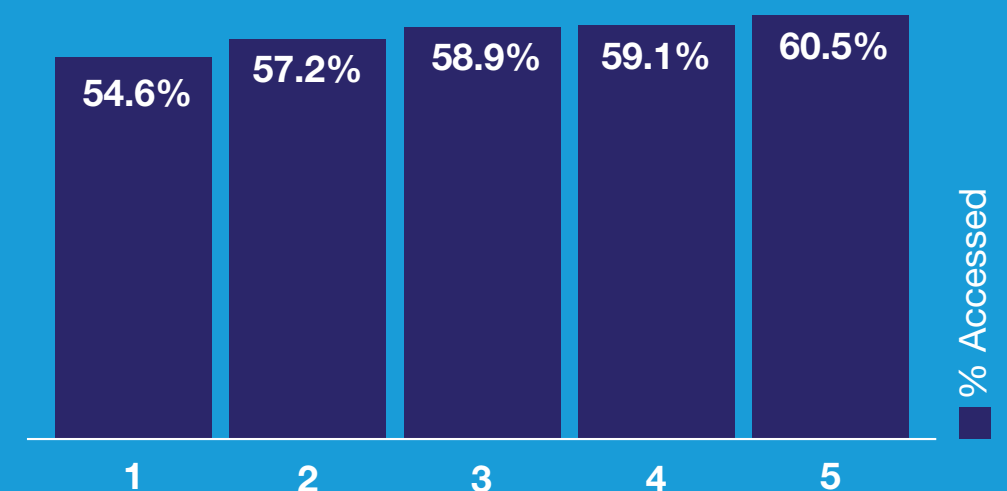
Receiving vital healthcare checks, known as the eight

care processes from a healthcare professional has been shown to reduce the chances of developing many complications of diabetes.¹⁶

The National Diabetes Audit data in England and Wales shows that those from the most deprived areas are less likely to have received all eight care processes than those from the least deprived for both type 1 and type 2 diabetes.

Accessed eight care processes in England – type 2

1 – most deprived, 5 – least deprived



Taken from National diabetes audit data 2022-23 E4



People of Black and South Asian ethnicity are less likely to be offered more up to date treatments than those of White ethnicity.¹⁷ People from ethnic minority backgrounds or living in deprivation are also less likely to use technology such as wearable glucose monitors or insulin pumps to manage their diabetes. The graphs illustrate this starkly.

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

Early-onset type 2 diabetes, which is far more common in areas of deprivation and in ethnic minority groups, carries a much higher risk of complications and even early death.¹⁸

As the number of younger people living with type 2 diabetes has risen, so has the number of people becoming pregnant with type 2 diabetes. 36.5% of people living with type 2 diabetes in pregnancy are from the most deprived areas versus 6.5% in the least deprived.¹⁹

Pre-pregnancy care, including a review of the suitability of medications for use in pregnancy and a chance to plan any extra care that may be needed is important to improve outcomes. But it is least likely to happen for women from ethnic minority backgrounds or those living in deprivation in all types of diabetes.

Inequalities of outcome

With good quality care the risk of complications can be reduced, however people living in deprivation and from ethnic minority backgrounds have higher rates of many complications, across all types of diabetes.

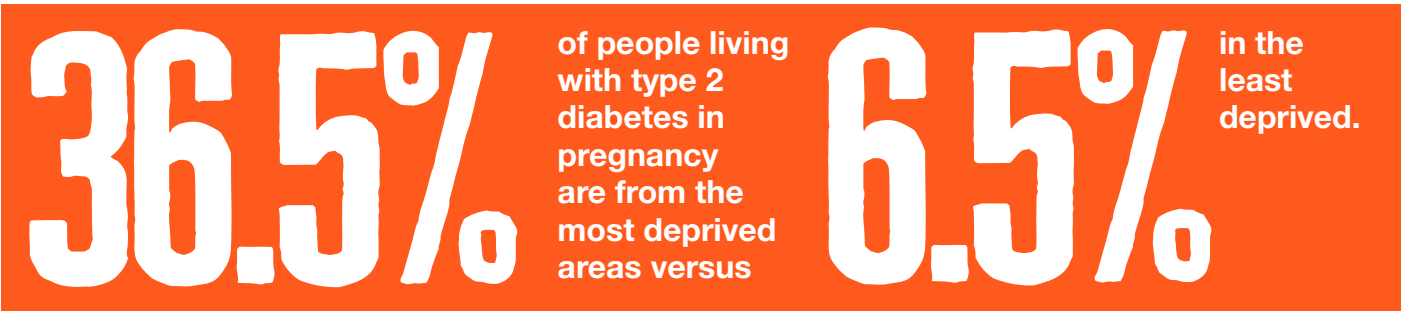
People living in the most deprived areas are more likely to develop heart diseases such as heart failure or angina and kidney-related complications, leading to higher rates of dialysis or kidney transplants.

A person living with type 1 diabetes from the most deprived area is **more than twice as likely to develop angina** than a person from the least deprived area.

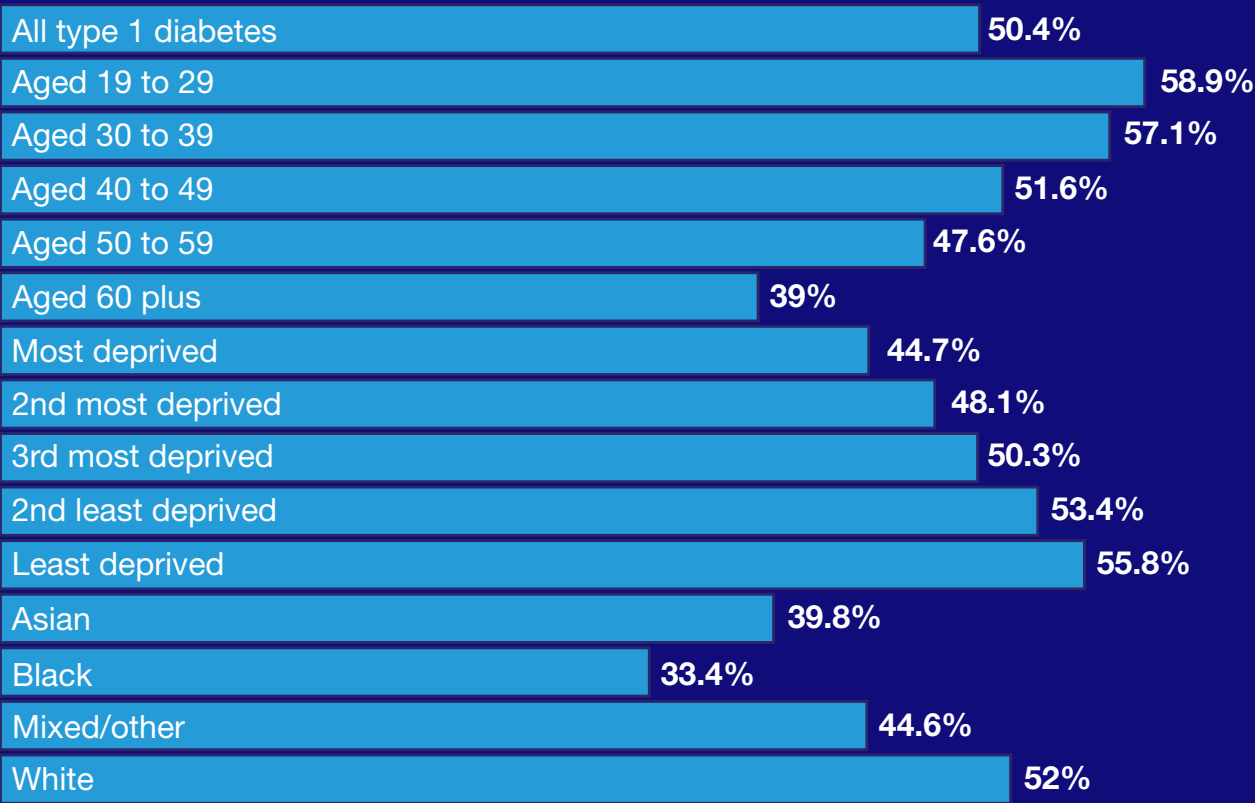
A person living with any type of diabetes in the most deprived area is around **twice as likely to have a major amputation due to diabetes-related complications** than a person from the least deprived area.

A Black or South Asian person living with type 1 diabetes is around **twice as likely to develop kidney-related complications which require dialysis or transplant because of diabetes-related complications** than a White person living with diabetes.

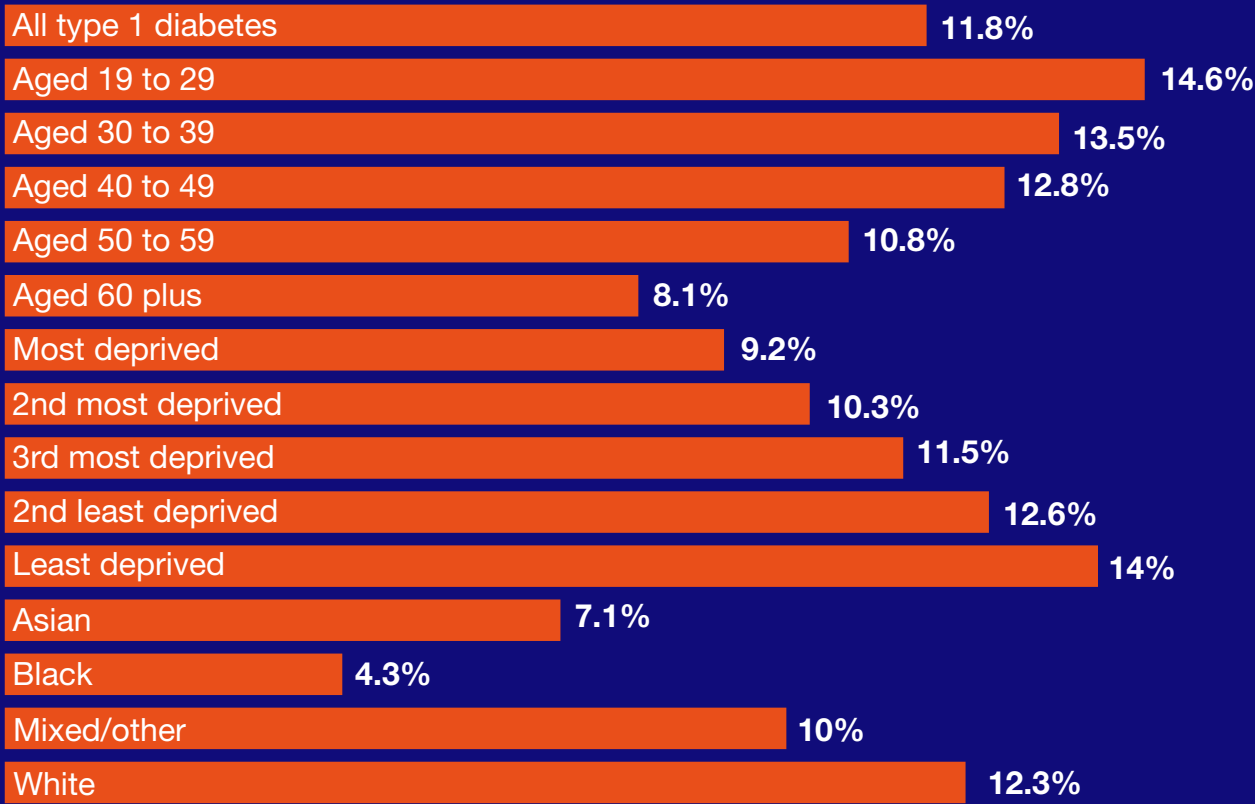
People from a South Asian background living with type 1 diabetes are **more likely to develop heart failure or angina, or to have a heart attack** than those of White ethnicity. While people from a Black background are more likely to develop kidney-related complications.²⁰



Percentage of adults with type 1 diabetes prescribed wearable glucose monitors, by demographics, England, 2021-22



Percentage of adults with type 1 diabetes using insulin pumps, by demographics, England and Wales, 2021-22



Data from National Diabetes Audit 2021-22, Type 1 diabetes

But there have been some improvements

Since the first publication of data on the number of children living with type 1 diabetes who were using diabetes technology like wearable glucose monitors or insulin pumps, healthcare professionals have proactively worked to narrow the gap. This has led to a reduction in the difference in levels of use, although a gap still remains.

There is ongoing research to better understand the barriers which have created the gap in technology use. But insights gathered from frontline clinicians found that reviewing their own practice and considering bias and assumptions has made a difference.

Some diabetes units are also developing ways of supporting wider digital inclusion, such as a lack of access to or ability to use laptops and smartphones, as a way of improving the accessibility of diabetes-specific technology.²¹ And Diabetes UK is supporting further research to understand how we can continue to close the gap.²²

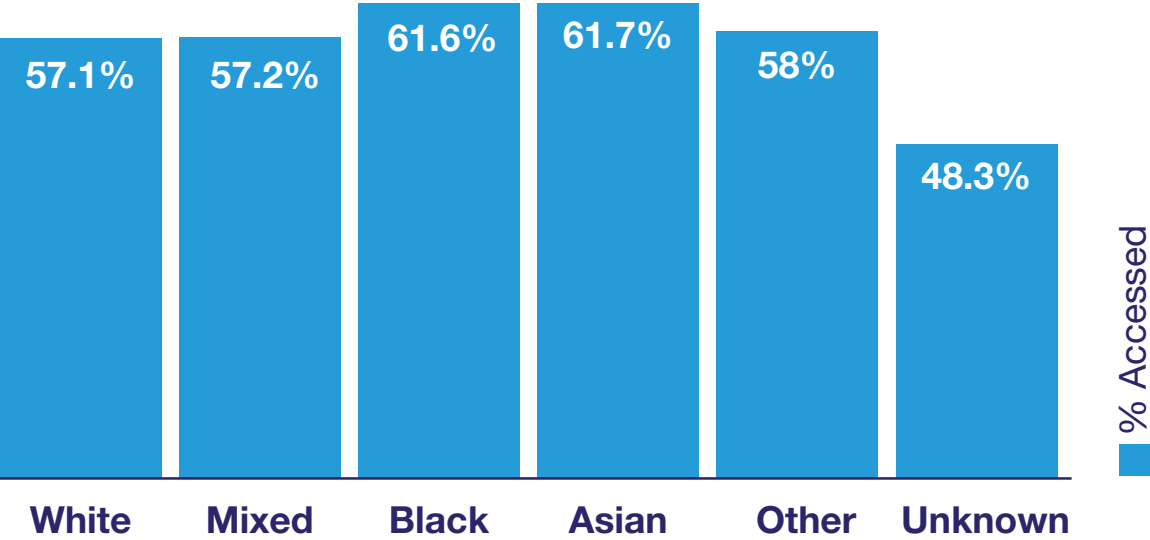
The NHS Diabetes Prevention Programme in England has seen an increase in the number of people of Black and South Asian ethnicity referred to the programme. This has been achieved through targeted advertising on community radio and in South Asian print media, proactive invitations sent through their GP practice and community engagement events. People from ethnic minority backgrounds have had a higher dropout rate than people of White ethnicity, and

so attempts to improve this are now following the increased referrals.²³

There has also been a marked improvement in the completion of the eight care processes for those from minority ethnic backgrounds. This follows an effort to prioritise this community by many across the NHS, particularly as part of the recovery process after the pandemic, where poorer outcomes for those from ethnic minority backgrounds were in the spotlight.

Providers used proactive methods to contact those in need of checks and in many areas offered these as part of outreach clinics. Further prioritisation and outreach are now needed to ensure those in deprivation can also catch up.

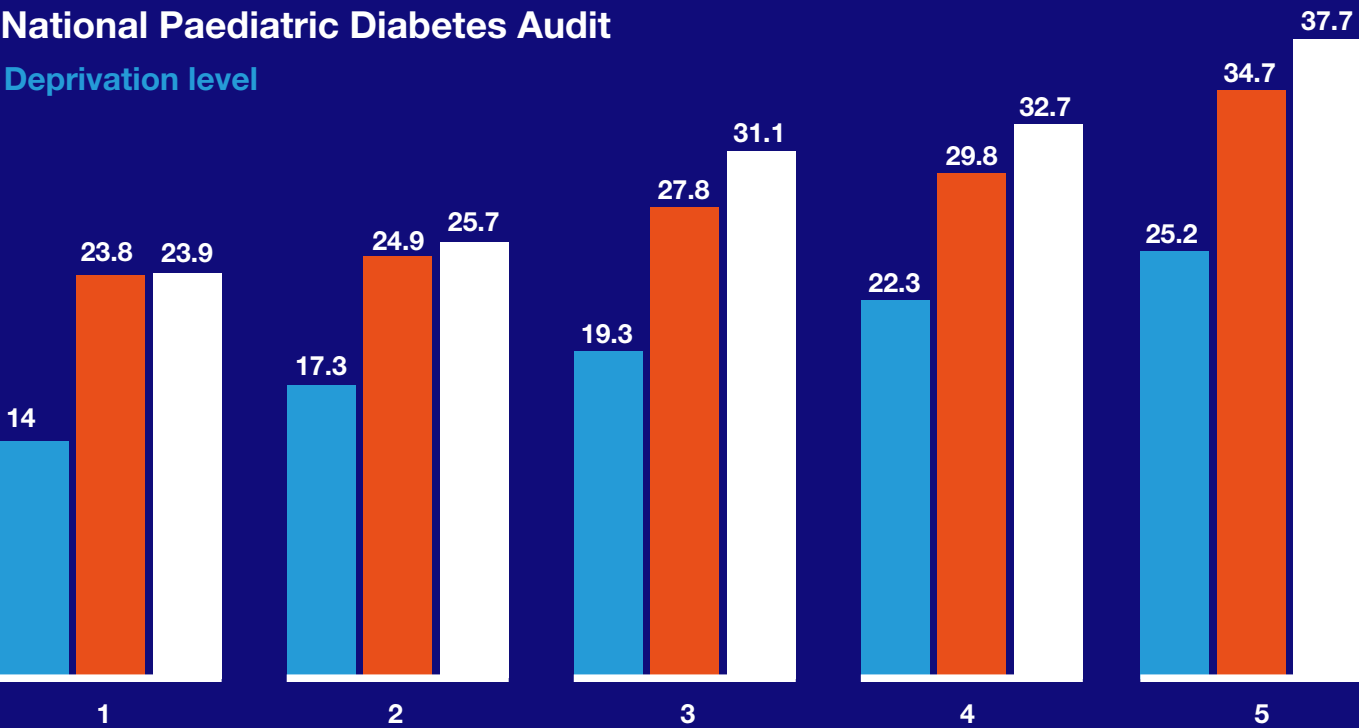
Accessed eight care processes in England – type 2



Taken from National diabetes audit data 2022-23 E4

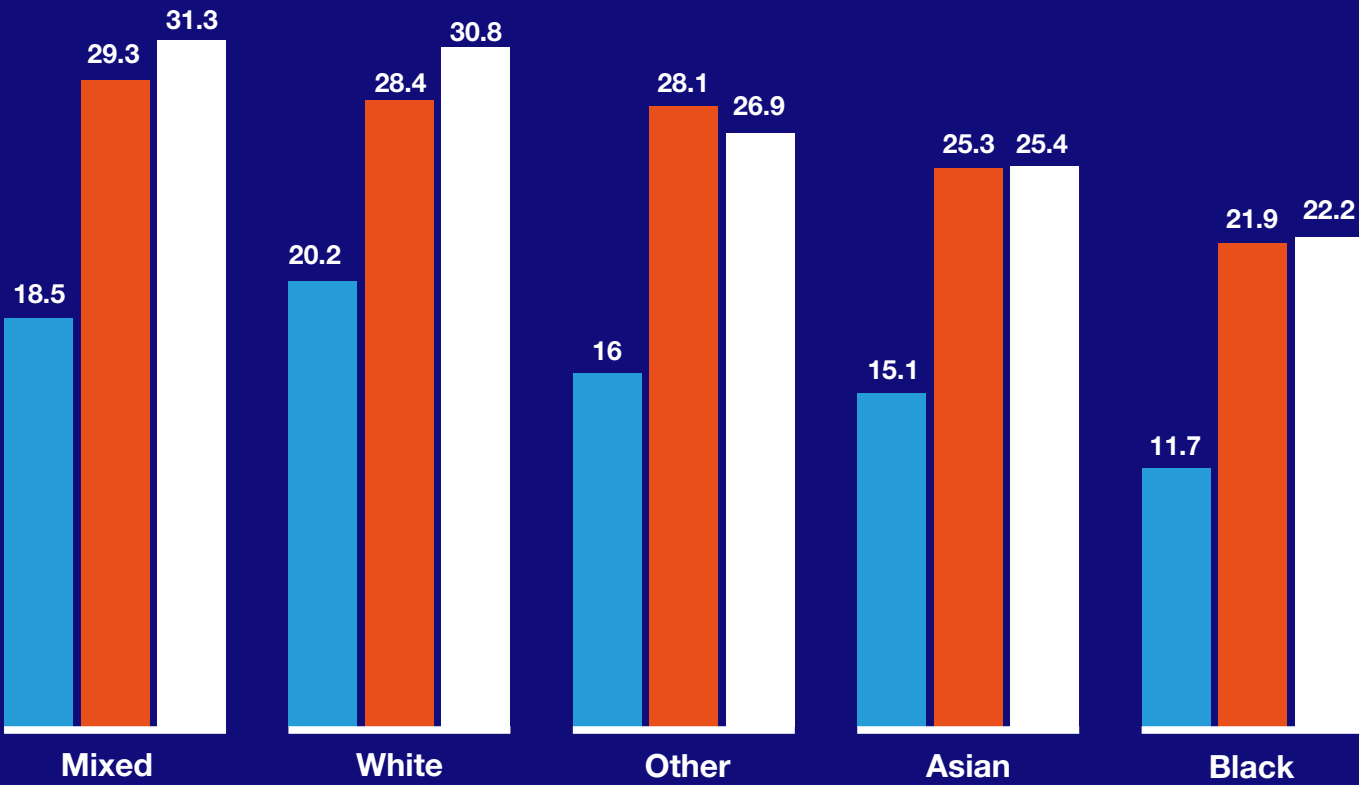
National Paediatric Diabetes Audit

Deprivation level



1 – most deprived, 5 – least deprived
% of children and young people with type 1 diabetes using rtCGM by deprivation level
■ 2019/20 ■ 2020/21 ■ 2021/22

Ethnicity



% of children and young people with type 1 diabetes using using rtCGM by ethnicity
■ 2019/20 ■ 2020/21 ■ 2021/22

CONTEXT

Recognising the role of multiple and wide-ranging factors is vital to understanding health inequality. Diabetes touches every part of a person's life and is affected by everything around them.

Our health is not just determined by the care we can access. Social, economic and environmental factors can all play a part in influencing someone's physical and mental health. The conditions in which we are born, grow, live, work and age, as well as our ethnicity affect our health and, in some cases, even shorten lives. In fact, it's generally agreed that as little as 10% of a population's health and wellbeing is linked to access to healthcare.²⁴

So, to fully examine inequalities experienced by people living with and at risk of diabetes, we must consider other factors surrounding them as in the Health Foundation's **What makes us healthy** infographic.²⁵

“Why treat people and send them back to the conditions that made them sick?”²⁶

Sir Michael Marmot,
Professor of Epidemiology
at University College
London, Director of the UCL
Institute of Health Equity

Over the course of the Commission, we heard about the impact of racism, poverty, living and working conditions, and the availability of food.



Every day of my life is being affected by this – like it's overwhelming. So watch what you eat, where you go, when you go – just literally everything. Everything in my everyday life is being affected.

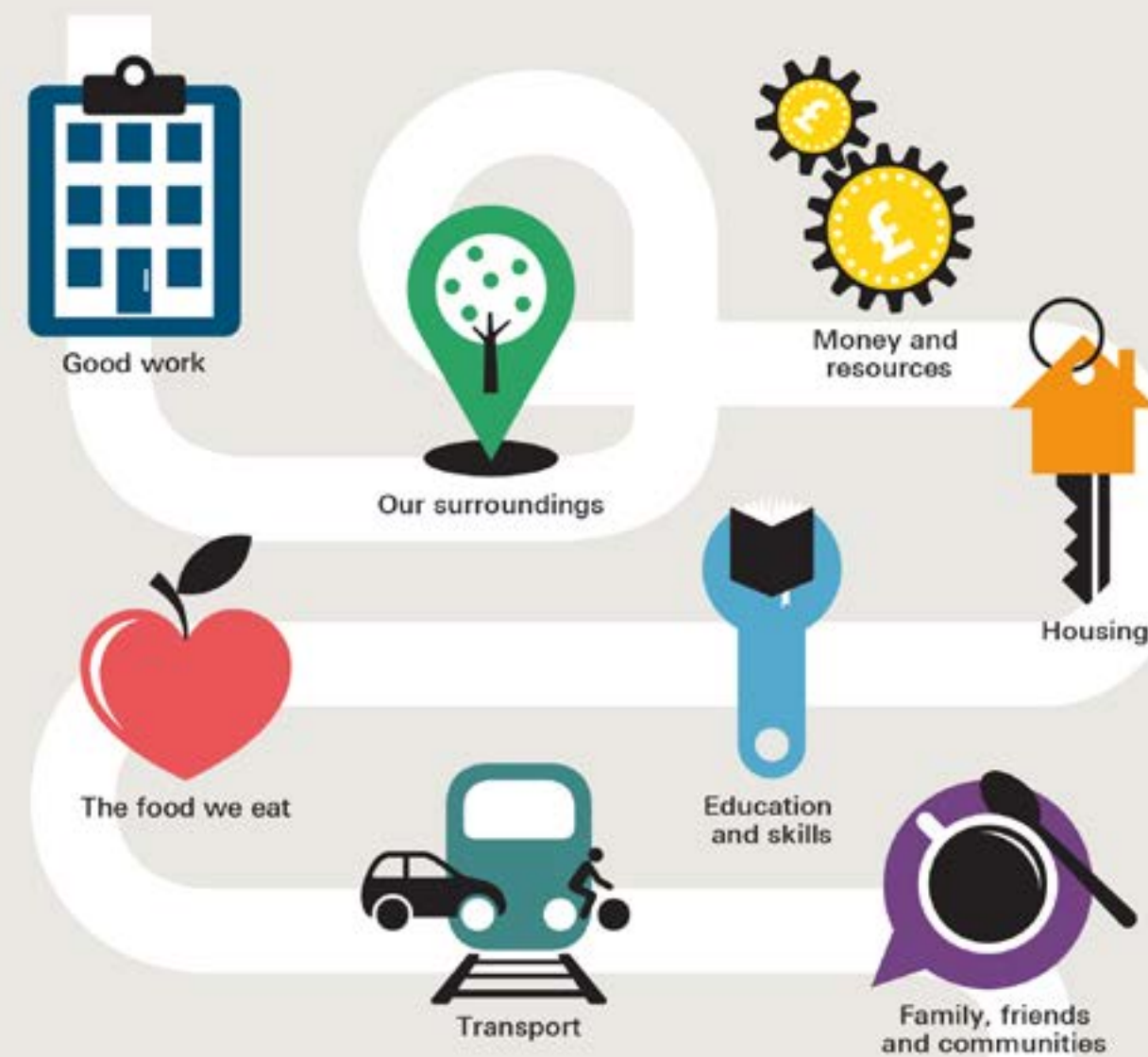
Lived Experience
Testimony



What makes us healthy?

Good health matters, to individuals and to society. But we don't all have the same opportunities to live healthy lives.

To understand why, we need to look at the bigger picture:



The healthy life expectancy gap between the most and least deprived areas in England is over **18** YEARS

Find out more: health.org.uk/what-makes-us-healthy



ANTI-RACISM

There is a long history of anti-racism activism within the UK. Recent events, such as the killing of George Floyd by a White police officer in the USA in 2020, prompted anti-racism protests across the UK.

“I don't feel like they put in a lot of time like they're so used to dealing with people with diabetes, put on top of that we're from a Black and ethnic minority, they just, I don't know, categorise us. Maybe they'll stereotype that kind of thing, like it's inevitable to have diabetes, but it's not inevitable.”

Lived Experience Testimony

The Black Lives Matter movement resonated with the experiences of many people and led to many more joining the anti-racism conversation. The covid-19 pandemic statistics highlighted ethnic inequality further as the disproportionate effect on Black and South Asian populations became a focus of media attention.

In June 2020, **Beyond the data: Understanding the impact of COVID-19 on BAME groups**, was published by Public Health England²⁷. The report confirmed that covid-19 did not affect all ethnic groups equally, and that people of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to people of White British ethnicity.

In February 2021, the Association of Directors of Public Health London published a position statement: **Supporting Black, Asian and minority ethnic communities during and beyond the COVID-19 pandemic**²⁸. The statement referenced

the disproportionate effects of covid-19 on these communities, highlighting that even after controlling for many other variables, such as sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death than people of White British ethnicity.

“The pandemic has shone a light on structural racism and health inequality, and its roots associated with the immediate and structural factors that have impacted ethnic minorities. Racism is a public health issue.”

Association of Directors of Public Health London

Speaking at the time of the report, Professor Kevin Fenton, Regional Director London, Office for Health Improvement & Disparities said, “Developing a deeper understanding of possible links between racism and health and addressing it is central to eliminating racialised health disparities.”

On behalf of the Equality and Human Rights Commission (EHRC), The Runnymede Trust gathered evidence from a range of organisations and presented it to an independent civil society review on the progress on race and racism in England over the previous four years.

The report contained evidence from over 100 civil society organisations across the country and was endorsed by 78 non-government organisations and race equality organisations. Its conclusions

discussed the wide-ranging systemic racism still evident in England.

“Our report shows that racism is systemic in England and impacts BME [Black and minority ethnic] groups' enjoyment of rights. Legislation, institutional practices and society's customs continue to combine to harm BME groups. As a result, in England, BME groups are consistently more likely to live in poverty, to be in low-paid precarious work and to die of covid-19. Disparities facing BME groups in England are sustained across the areas of health, housing, the criminal justice system, education, employment, immigration and political participation.”

England Civil Society Submission to the United Nations Committee on the Elimination of Racial Discrimination – Drafted by the Runnymede Trust²⁹

The panel heard a presentation and discussion of **A Charter for Change – delivering equitable care for Black African, Black Caribbean and South Asian people living with diabetes** from the initiator and convenor of the original steering group, Dr Joan St John.

Dr St John is a GP with special interest in Diabetes in North West London and co-author of **Carbs and Cals World Foods**, the first book to provide a comprehensive and uniquely visual way to illustrate the carbohydrate content of traditional foods of African, Arabic, Asian, and Caribbean communities. She described the levels of scepticism, disbelief and lack of trust within the Black

and South Asian communities, during the pandemic, particularly in the uptake of the covid-19 vaccine. The Windrush Scandal and historic unethical practices in medical research on ethnic minority groups mean institutional mistrust is widespread.

The vaccine campaign consequently had to adapt and consult community leaders and develop the cultural competency of staff working on the programme.

The Commission found the charter a very useful foundation for several of our recommendations and in particular calls for:

- mandatory cultural competency training
- improved representation

- improvements in ethnicity data collection – particularly with regards to quality and outcomes and care
- NHS Race and Health Observatory to review diabetes care.

The NHS Race and Health Observatory was established in 2021 to identify and tackle the specific inequalities faced by people from Black and minority ethnic backgrounds in England. Over the past two years, they have explored the issues of structural, institutional and interpersonal racism, particularly through their work in mental health and maternity. They have highlighted a lack of action and a lack of representation at a senior level in the NHS which has led to mistrust of the system.



“

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 John³⁰

”

“

Is the system or the NHS itself racist? Yes, it is, if you look at any dataset. Top jobs still go largely to people who are white: even in 2020, it's an occasion to rejoice when someone from an ethnic minority background actually makes it.

Professor Partha Kar³²

”



Their work emphasises the need for communities not just to be consulted but to be empowered to drive improvements in health.³¹

In a presentation to the Commission, Sam Rodger, Assistant Director, Policy and Strategy at the Observatory highlighted some key learning points that the Commission took forward into their recommendations:

- the need for better understanding of racism
- improvements in ethnicity data
- community participation, not just consultation
- accountability.

Professor Partha Kar, Consultant Endocrinologist and national specialty advisor for diabetes and lead for

Medical Workforce Race Equality Standards with NHS England highlighted the importance of anti-racism and the need to acknowledge the systemic racism in the NHS when he joined a workshop for the Commission. He urged the Commission to consider the following:

- be bold on racism and call for more anti-racism in the NHS
- the Care Quality Commission should consider Workforce Race Equality Scores when rating services.

The Commission heard lived experience on the impact of ethnicity, poverty, and English as an additional language. There was a feeling, in South Asian and Black communities, that they had lived with diabetes even before they were

diagnosed, as it is so common among their family and friends.

“Diabetes in our family is very prevalent. So, the odds of me getting it were highly likely. Anybody with the same surname as myself has a high susceptibility of diabetes on this planet, which is a real shame.”

Lived Experience Testimony

Many in Black and South Asian communities saw diabetes as a particular issue for their community, and some talked about how this had made them passionate to advocate for the needs of their community.

Some described feeling that because diabetes is so common in their communities, it is inevitable and so not taken as seriously. Some Black and South Asian people also told us they see this feeling of inevitability reflected by healthcare professionals, which means they are not offered the same prevention support as White communities.

“It’s basically an ethnic minority situation. So we need to be heard. And we want to be seen, and we want to know that something is being done for the ethnic community.”

Lived Experience Testimony

Language barriers, the use of translators and difficulties around translated materials, because not everyone reads in other languages, were also raised. When professional healthcare translators are used, they don’t always explain medical terminology in simple terms. And sometimes written translation is the only alternative, which is not helpful for people who are unable to read or write.

Black and South Asian people within the focus groups described how important food is within their communities and

that this made it particularly difficult for them to change their diet in a way that would help them manage their diabetes. A lack of culturally appropriate food information was raised throughout the lived experience feedback.

“We don’t know these foods. We don’t eat these foods, have never eaten these foods. What about yam or plantain?”

Lived Experience Testimony.

The impact of diabetes and food relating to family and friends was a common theme amongst focus group participants. Many described a lack of understanding or support from family members about changes in their diet.

Some disliked eating in front of other people, particularly outside of the home, as they felt they would face questions and judgement about what they were eating. For some participants, there was a feeling of being a burden or forcing their diet on their families, and this was particularly resonant for those with type 1 diabetes.

“I feel because of me, my whole family has to live like they have diabetes.”

Lived Experience Testimony.

Beyond just food, South Asian and Black people in the focus groups also felt that many health resources lacked culturally appropriate examples and illustrations. Some people described feeling like healthcare professionals

see them as a problem or just a number rather than an individual. This feeling of being caught in a system that doesn’t allow for individual needs and experiences was particularly present for people from Black African and Black Caribbean communities and those who were receiving benefits.

The lack of clinical research with specific ethnic groups was also described as a problem with participants stating that this has led to some healthcare professionals not understanding symptoms, care or treatment needs for different communities.

Particular conditions which are more prevalent in ethnic minority communities such as sickle cell disease and HIV were raised in the workshop discussions as areas that the communities felt were less understood.



ADDRESS DEPRIVATION

The pandemic also highlighted the socioeconomic and geographical health inequalities in the UK. Toby Watt, of the Health Foundation, attended a workshop to present data on the health inequality seen in areas of deprivation, and the predicted future funding needs for the NHS to continue to care for an aging population.³³

“People living in the poorest areas are ‘10 years sicker’ than those in the least deprived. A 60-year-old woman in the most deprived decile has the same rate of diagnosed long-term conditions as a 76-year-old in the least deprived.”

Toby Watt, Health Foundation

While those living in deprivation are more likely to develop a long-term condition, they are also more likely to have been caught up in the NHS pressures, such as longer waiting lists.

The inverse care law, first defined by GP Julian Tudor Hart 50 years ago, describes how people who need care most are least likely to receive it. A recent report from The Health Foundation highlighted how this affects primary care, resulting in less time with a GP per patient for a population with greater health needs. In the most deprived areas, people consult their GP more often on average, and tend to have more conditions and complexity than in less deprived areas.

This is paired with a lower number of GPs per patient, shorter appointments and higher staff turnover in the most deprived areas.³⁴

“Many staff currently feel that they are not providing the care they wish to with the pandemic recovery pressures. The burden to the individual and NHS of not getting this right is huge.”

Diabetes clinical lead

In November 2022, Diabetes UK conducted a survey of people living with or who have been told they are at risk of diabetes, across the UK, to understand how they were being affected by the cost-of-living crisis.³⁵

77% said the rising cost of living was negatively impacting how they manage their diabetes or risk of diabetes.

66% had cut back on essentials like food or energy or have gone without entirely. This included eating cheaper but less healthy food, cooking less to save energy, using a food bank, or switching off the fridge – impacting food and medication storage.

It is important to recognise that deprivation and poverty are about more than just income, although the cost-of-living crisis has highlighted the impacts of money.

The Joseph Rowntree Foundation highlights the difference in perceptions of poverty. They use the wider social context description and see the systemic causes and outcomes as most important, whereas the public tends to focus on the individual and

their lack of means.

There is also a crossover between race and poverty, with more people of Black and South Asian ethnicity living in poverty. Ethnic minority households are more likely to have higher rates of in-work poverty and child poverty.

Within ethnic groups there are also disparities in levels of poverty. **The Joseph Rowntree Foundation UK Poverty 2023: The essential guide to understanding poverty in the UK** report shows that 51% of people from the Bangladeshi ethnic group were living in poverty between 2018/19 and 2020/21, versus 44% of the Pakistani ethnic group and 42% of the Black Ethnic group. This contrasted with 19% of people from the White ethnic group and 22% of people from the Indian ethnic group.³⁷

The foundation’s cost of living tracker, as of May 2023, shows 5.5 million

low-income households have had to cut down on or skip meals in the last 30 days because they can’t afford food, and 2.7 million have reported having a poor diet because of the cost-of-living crisis over the last two years.³⁸

We heard from those with lived experience that physical activity was seen as increasingly unaffordable due to the cost-of-living crisis, with some participants stating that they had cancelled gym memberships or stopped attending sessions in the past six months. The rising costs of food, particularly healthy food, was a common theme across all the focus groups.

Most participants expressed concerns about balancing the cost of food with eating foods they thought they needed to help manage their diabetes. As one participant simply put it, ‘carbs are cheap, and protein and vegetables are expensive.’



Poverty means not being able to heat your home, pay your rent, or buy the essentials for your children. It means waking up every day facing insecurity, uncertainty, and [having to make] impossible decisions about money. It means facing marginalisation – and even discrimination – because of financial circumstances.

Joseph Rowntree Foundation (JRF)³⁶





ENVIRONMENTS



The poorest fifth of UK households would need to spend 50% of their disposable income on food to meet the cost of the government-recommended healthy diet. This compares to just 11% for the richest fifth.

The Food Foundation Broken Plate 2023



The food environment

Shona Goudie, Policy and Advocacy Manager at The Food Foundation, gave a presentation to the Commission on the impact of food poverty and how our environments and the availability, marketing and pricing of food influences what we eat.

From people with lived experience, we heard about the difficulty of accessing appropriate food because they live in places where without a car or good public transport, the options for buying food are really limited. Some people in the focus groups only had access to small convenience stores or fast-food shops.

Food shortages due to Brexit or other supply issues were also discussed by some and whilst expressing gratitude for food banks trying to help, there was frustration that they are not able to offer suitable foods for people, whether at risk of or living with diabetes. One participant said it felt like his family was a dumping ground for food that nobody else wanted.

“Currently our food environments, for the most part, are set up in a way in which healthy foods are less affordable, less available, and less appealing than unhealthy foods.”

Shona Goudie,
The Food Foundation

The Food Foundation statistics show that in January 2023, 9.3 million adults, which is 17.7% of households, reported experiencing food insecurity. The price of a basic basket of food has increased by approximately 25% since April 2022. And more healthy foods are over twice as expensive per calorie as less healthy foods.³⁹

Low levels of social security provision and in-work poverty, where people are paid low wages, pose real challenges in terms of the food people can afford. In addition, the cheapest options are very rarely healthy foods and are more likely to be processed foods with low nutritional value.

Time pressures and energy price rises, alongside poor-quality housing and lack of kitchen appliances also make food preparation more of a challenge for people on a low income.⁴⁰

“We experience food poverty really because we haven't got the shops around us. And when you want the good stuff, it's too expensive. And I mean, even when you go to the food bank, the food bank doesn't give you stuff like that.”

Lived Experience Testimony

Some participants described a constant lack of time to shop for and prepare food due to work and other pressures. And mental and physical health problems also impact people's ability to cook the food they feel would be right for their

diabetes. There was also a lot of confusion about what to eat and not to eat. Many say they receive contradictory advice or are just told what not to eat rather than what they can eat.

“I'm struggling because Universal Credit actually hasn't changed – like risen you know. For example, the rent increased in the last year, the electricity is going up... We're not buying that food because it's too expensive now.”

Lived Experience Testimony

The impact of diabetes and food relating to family and friends was a common theme from lived experience testimonies. Many described a lack of understanding or support from family members about changes in their diet.

Some disliked eating in front of other people, particularly outside of the home, as they felt they would face questions and judgement about what they were eating. For some, there was a feeling of being a burden or forcing their diet on their families, and this was particularly resonant for those with type 1 diabetes.

Participants with type 2 diabetes with young children were also really worried about making sure their children ate well to try to prevent them from developing type 2 diabetes. But this was seen as a real struggle, both in terms of cost and because their children didn't like the food or understand why they couldn't eat certain things.

The work environment

The Commission heard about the difficulties of managing diabetes in the workplace from those with lived experience.

A lack of understanding from employers, who made assumptions about the limits diabetes has on someone’s ability to do a job or to understand the reasonable adjustments needed, prevented many from discussing their health at work.

Some people felt diabetes prevented them from accessing higher paid jobs. A report on stigma commissioned by Diabetes UK of 450 people living with and at risk of diabetes found that 1 in 5 reported experiencing stigma in the workplace at least every few weeks.⁴¹

“When I applied for and didn’t get my first graduate job, I just assumed that it was because I said I had diabetes. That really stuck with me and now I never tick the box on the form in case someone judges me.”

Lived Experience Testimony

Managing diabetes alongside other responsibilities can feel overwhelming, even for those who have put their type 2 diabetes into remission. One participant said that having diabetes and working was like having two full time jobs and not being able to do either of them well. Some felt their diabetes impacted their ability

to do their job properly but also that their work impacted their ability to manage their diabetes properly. Travel and working patterns, particularly for those in lower paid employment, working shifts and at night, were raised as issues. Accessing care that was only available during work hours was a particular issue.

“I’m absolutely knackered because I’m working 12-hour shifts. And sometimes I’ll be working back-to-back – like five in a row now. I’m so tired it’s hard like finding the time to meal prep and everything. And like, if I do need things from a shop, sometimes I’ll like get to the shop after work and they’re closing.”

Lived Experience Testimony

Many participants described a lack of understanding of diabetes from current or previous employers, which led to a lack of support. This ranged from not being allowed breaks to use the toilet to being penalised for taking time off sick. Focus group participants also suffered judgments or stigma from employers or other colleagues.

People said they had experienced being called lazy or not as productive as their team members, which led to feelings of being a burden. Some participants, particularly those who had developed complications related to diabetes, explained that they’d had to work reduced hours, change jobs, or stopped working completely.

Many people living with diabetes can be considered to live with a disability and be covered by protections under the Equality Act’s right to reasonable adjustments.⁴² Unfortunately, this is not always well recognised. Many people with diabetes struggle to get the time off they need for healthcare appointments or even just the flexibility to plan breaks for food and medication.

Beyond these direct measures for people living with diabetes, workplaces also have a role to play in supporting healthy environments. Ensuring that staff have access to affordable, healthy foods, where food is provided and that everyone has appropriate breaks to reduce the impact of sedentary work.

Employers can also help to fight stigma in the workplace, ensuring that those who live with diabetes feel comfortable talking about their condition. And that those around them understand the importance and impact of diabetes on a person’s life.

More information on how businesses can support people living with diabetes can be found in the NHS **10 ways businesses can help to reduce health inequalities infographic.**⁴³



Other environments

Many people lacked access to appropriate or safe spaces to exercise and even local exercise on prescription schemes had barriers due to shift work or lack of transport to access. Even for those who were able to access exercise classes or the gym there were other barriers.

Many people were concerned about the lack of knowledge of diabetes within the fitness industry which made it harder for them to exercise safely. Some participants said they had been advised to avoid

strenuous exercise since their diagnosis, whilst others had faced fluctuating blood glucose levels during exercise that they just didn't know how to treat effectively. Some participants had encountered really poor experiences of low blood sugar, whilst at the gym and how staff members had been unable to help them which had scared them off exercise.

A lack of services in some local areas and difficulties with transport in rural areas also contributed to feelings of loneliness and social isolation for some people. For some, there had been a noticeable difference in support available before and after the pandemic.

“

There used to be other services round here like for looking after your feet or things to help with feeling lonely, but they’ve all gone now.

”

Lived Experience Testimony



CURIOSITY

The Commission heard from those with lived experience and the community organisations who support them. There was strong agreement that services and policymakers need to listen to those affected by inequality and to avoid making assumptions about the issues and solutions. The panel heard from clinicians on the frontline across the four nations. Although there were many similar challenges, there was also significant local variation which required flexibility and locally led approaches.

DATA AND INSIGHTS

The Commission heard about the importance of gathering accurate data to understand where inequality lies and better show where there has been improvement.

“

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

Lived Experience Testimony

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When Toby Watt from The Health Foundation attended a workshop, he explained that to fully highlight the difference between the most and least deprived people in health data, it is important to show deprivation by decile rather than quintile. If it is not broken down finely enough, then it is harder to see the significant difference in health outcomes between the 10% most deprived and 10% least deprived.

The Commission has already fed this back to the National Diabetes Audit (NDA), who will review their data dashboards to ensure the difference made by deprivation is highlighted. The data on the difference in terms of ethnicity has previously been less complete

as a large proportion of participants have their data listed as “not known” or “not stated”.

Improvements in data collection in England through the NDA mean that now only 6.3% of people living with diabetes are listed as ethnicity “not known” in England. However, the rates for Wales (48.2%) and Scotland (19.3%) are still considerably higher.⁴⁴

Understanding Patient Data (UPD), published research last year, describing the nervousness some people in ethnic minority groups felt about sharing their data with the NHS.⁴⁵ With many concerned about their data being shared with other third parties.

Many of the people surveyed also described not seeing evidence of data on race, ethnicity, culture or religion being considered by local services.

The research showed the process of collecting data was often confusing for participants and only one in five could recall having the process explained verbally. One of the major changes called for in the report was for better training and support for healthcare professionals to have these conversations and reassure people about why data is needed. The UPD website has resources to facilitate these conversations, including guidance for clinicians and easy read materials.⁴⁶

Research data

Last year Diabetes UK published **Addressing health inequalities in diabetes through research: Recommendations from Diabetes UK's 2022 health inequalities in diabetes workshop**.

Among other recommendations on representation and involvement, as well as the need to collate examples of best practice, the position paper noted that key data informing health inequalities, such as sex, ethnicity and deprivation, are not routinely collected, linked, and shared in all care and research settings. They suggested the following

recommendations on data:

- Understand the reasons why and define the barriers preventing relevant routine data collection and data sharing across all care and research settings and make recommendations to improve this.
- Define the level of understanding of the benefits of relevant data collection and data sharing across all care and research settings.
- Identify ways to increase public trust in the collection, sharing and use of data, including the use of Trusted Research Environments (TREs).
- Funders to require that all trials and observational

studies capture sex, ethnicity, and socioeconomic data in a standardised manner to facilitate aggregation and meta-analysis.

- Widely promote government guidance around how to record ethnicity and socioeconomic data.
- Improve the quality of recording of ethnicity and socioeconomic data captured in the NHS and elsewhere by understanding the barriers to data capture.



The importance of non-health data

The Commission also discussed the use of non-health data to better understand the populations within areas accessing services for diabetes.

The need to use multiple data sets and particularly to look beyond just health data was a common theme in the discussions. Collecting more socioeconomic data would allow greater research into the relative influence of different determinants of health such as income and education. Localised integration of health

and social care systems will allow better data sharing and the creation of community health profiles will help to identify priority areas as well as routes into these communities.

During the covid-19 vaccine campaign, the use of census data allowed vaccine programme leads to better understand who lived in their local area and how to approach them – for example through religious leaders.

Unmet need

The Commission discussed the need to remember to consider those who don't access services, where services aren't available, or people are unable

to reach the services they need. A health needs assessment⁴⁷ is a good way of doing this for populations.

The Commission also discussed the concept of equity, rather than equality, considering that due to the wider systemic issues faced by some groups, there needed to be greater allocation of resources for underserved communities where the data shows inequality. The Office for Health Improvement and Disparities (OHID) provides a useful explanation of these terms:

Equality

We want everyone to have equally good health. However, the term 'equality' is sometimes used to describe equal treatment or access for everyone regardless of need or outcome.

Equity

We want fair outcomes for everyone. What is important is addressing avoidable or remediable differences in health between groups of people. Ideally, the barriers to good health would be removed for everyone, so adjustments wouldn't be required – however, this is not always possible.

Access

Ensuring everyone can access services equitably according to need is a key priority for the NHS.⁴⁸

Andrea Williamson, Professor of General Practice and Inclusion Health at the University of Glasgow, and team, have described patterns of missed appointments and associations with morbidity and mortality outcomes.⁴⁹

Their work describes missingness as the 'repeated tendency not to take up offers of care that has a negative impact on the person and their life chances'.

"Missingness in health care is a strong risk marker for a poor outcome so needs urgent attention from the healthcare community."

Andrea Williamson, Professor of General Practice and Inclusion Health at the University of Glasgow⁵⁰

Professor Williamson is a member of GPs at the Deep End Scotland, a network of GP surgeries in Scotland which cover the 100 most socio-economically deprived patient populations.

One of the most impactful developments from the network has been the introduction of the Community Links Worker Programme. Deep End GPs worked with the Alliance for Health and Social Care to develop a model to create better links between practices and local community organisations to support people with complex health and social care problems.

The programme also helps patients overcome issues such as lack of confidence and social isolation and helps to rebuild trust in services. Originally piloted in seven Deep End practices, the Community Links Worker Programme is now being rolled out across Scotland.

The Commission heard about the importance of going out to meet people in places that they trusted and felt comfortable to find those who were not engaging with healthcare. Working through trusted organisations such

as sports clubs or religious organisations helped build trust for projects such as British Sikh Nurses, which aims to bridge the gap between the NHS and the hard-to-reach South Asian communities in promoting healthy lifestyles and wellbeing.⁵¹

Working with religious leaders is particularly important for engagement with Black and South Asian communities. During the lived experience focus groups we heard about how religious beliefs can influence acceptance of diagnosis. Some people felt it was 'not in God's plan for them', or in contrast, that it was prescribed to them at birth. As well as affecting their ability to accept their diagnosis, this also impacted their beliefs about prevention or remission of type 2 diabetes.



I've had severe complications from diabetes from ignoring the fact that I was diagnosed because I thought it was not my portion. God has not given me diabetes.

Lived Experience Testimony



COLLABORATION

Involving community organisations allows clinicians to have more direct conversations and better understand how people access their services.

This approach also helped reach people with lived experience to take part in the focus groups which fed into this report. Approaching people through trusted organisations in community spaces such as community supermarkets and support cafes was a far

more successful way to recruit rather than social media or local radio.

The Commission reflected on the fact that some groups are less heard than others. Following on from the discussions on how ethnic

minority communities felt 'othered' during the covid-19 vaccine campaigns, and the impacts of systemic racism within the NHS, the panel considered how people living with diabetes felt about their interactions with professionals.

During the focus groups, nearly all participants with all types of diabetes, raised issues with feeling judged by healthcare professionals. They also mentioned a sense of unfairness given the issues with access and lack of culturally relevant or appropriate support available.

Digital exclusion and confusion and a feeling of getting lost in the system were also raised as issues. Wider digital exclusion also affected people's ability to access diabetes related technology. According to the 2021 Technology Tracker⁵², 7% of UK adults are affected by device poverty, meaning they have limited access to the internet because they do not own a PC, laptop, tablet or smartphone.

"I found myself that the medical professionals themselves, the so-called diabetic specialists, or, you know, your diabetic team can often be some of the most judgmental people you'll meet. There are times where it feels like when you were a kid and you sat outside the principal's office."

Lived Experience Testimony

"Everything's online and it's impossible to access it. I don't have good internet access or really know how to use it."

Lived Experience Testimony

Projects such as one in the Wirral, are providing devices to families of children living with type 1 to mitigate this. Audit data has shown some improvement in confidence and engagement as well as baseline HbA1c⁵³.

People did not feel seen as individuals or involved in decision-making about their care, which led to disengagement.

"Sometimes it's confusing to know what would really help you as an individual? See us as humans – people who live with diabetes are human beings. But the issue is, it's the systems that are overriding the human part of it."

Lived Experience Testimony

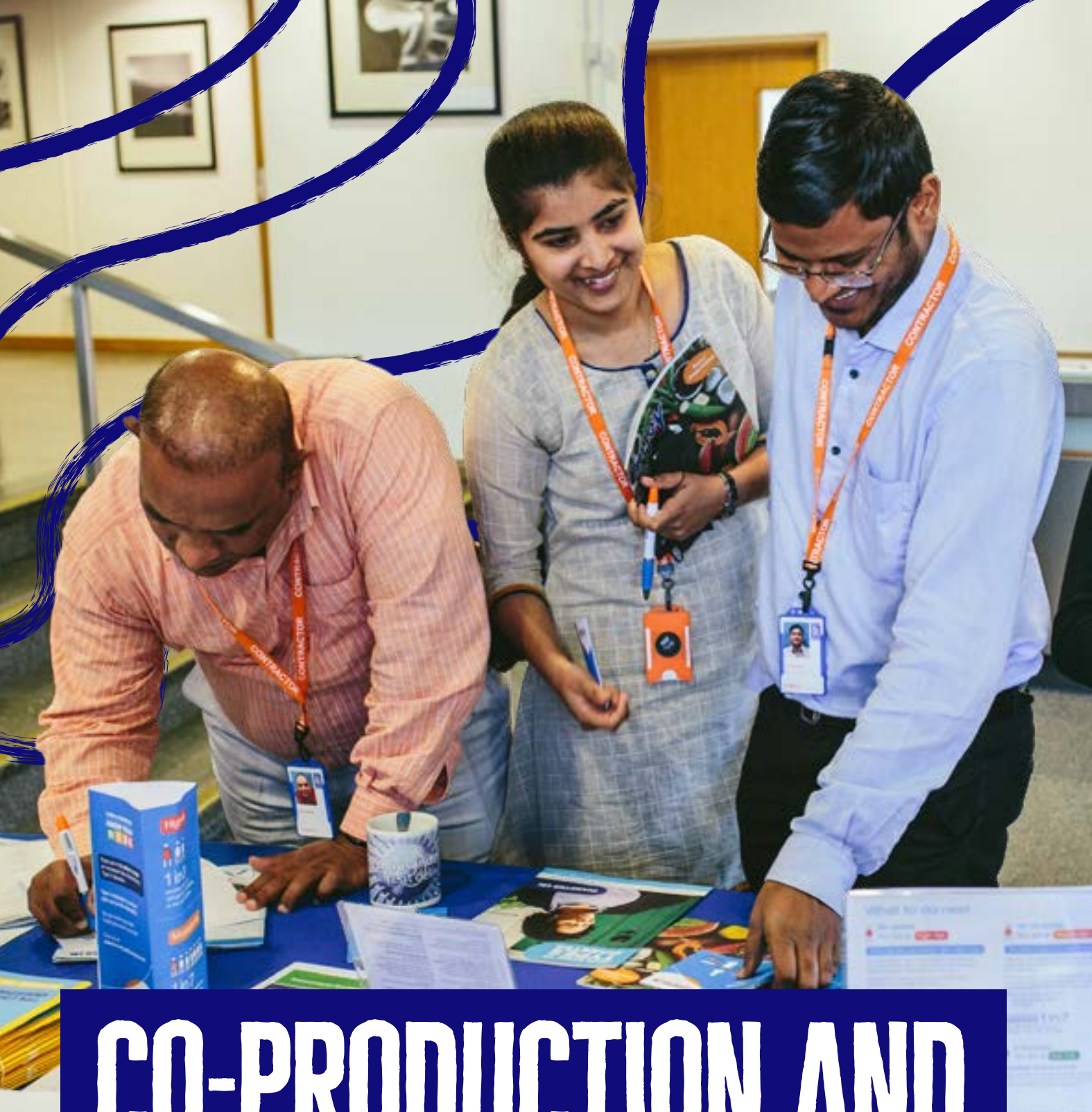
“

There are loads of communities out there that we don't know exist, it's just a case of how you find them and connect with them. We were shocked to find these communities.

Diabetes UK Tackling Inequality Lab Participant

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CO-PRODUCTION AND REPRESENTATION

The Commission heard about the feeling of being caught in a system that doesn't allow for individual preferences and a lack of understanding of different communities from healthcare professionals.

“My problem is that the GPs give us only 10 minutes and when you tell them they reply with their information and there's a lot sometimes. It's confusing on what would really help you as an individual?”

Lived Experience Testimony

Information was an area where focus groups participants felt action was needed. Many felt overloaded at the point of diagnosis, when they felt unable to take in anything at all and then left to get on with it alone.

Some described being handed bags and bags of resources and not knowing where to start. Participants felt healthcare professionals should do more to check their understanding and to show them where to access further information and support when it was needed.

“You're given so much information when you get diagnosed, it's like overload and you're shell-shocked and can't take much in. But then you're left to it like – oh you know everything you need to know now, but you don't.”

Lived Experience Testimony

Participants preferred information that was tailored to their own circumstances and wanted to know what they could do to help themselves.

People felt services were hard to access, confusing and hit and miss. In particular with

prevention and remission services. People felt knowing what care to expect would help them navigate the system a bit more easily.

The Commission recognised the importance of co-production and heard examples of culturally competent and co-produced work. Like the Healthy Eating & Active Lifestyles for Diabetes ('HEAL-D') – a group-based type 2 diabetes training and support programme which was co-designed with adults of African and Caribbean heritage.⁵⁴

As well as the Digibete South Asian Foods resource, which provides carb-counted meals for South Asian diets.⁵⁵ These resources provide an alternative to traditional NHS advice but are not always offered unless the healthcare professional has specific knowledge on culturally appropriate advice.

The All Wales Diabetes Prevention Programme has recognised the importance of culturally appropriate resources and incorporated them into their new rollout. It involves a 30-minute intervention, delivered face-to-face, in a familiar setting in a local GP surgery.

The programme has developed desktop resources which are pictorial, culturally appropriate and easy to understand. The programme used input from the All Wales Patient Reference Group as well as insight collected via survey of ethnic minority groups. A short wait

between referral and appointment along with local location has also meant the service has a very low rate of patients not attending appointments.

“

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

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Understanding deprivation

Focus group participants discussed feeling that healthcare professionals did not understand deprivation and the impact it has on your ability to manage diabetes.

The **Reclaim Report on Class Diversity – Missing Experts** – said respondents felt if there were more working-class people at all levels of their organisation, it would use different language about people on low incomes (70% agreed), would have different influencing priorities (54% agreed) and would feel less stuffy (50% agreed).⁵⁶

There are multiple local organisations working across all areas of the UK who have developed trusting relationships with their communities over many years.

The benefits of including those with lived experience and community organisations earlier include the development of more effective information resources, which are better understood and trusted by communities.

As well as allowing trusted communicators to be more effective when they have received more training and can be more knowledgeable about services themselves.

“We are building on the 3Ts – Trusted Leaders, Trusted Places, Trusted Voices through partnership working with Enfield Council, Primary Care, local Faith leaders and the local Caribbean association.”

Riyadul Karim – Assistant Director of Primary Care NHS North Central London ICB, co-chair London Bangladeshi Health Partnership

The NHSE Core20PLUS5 community connectors scheme aims to recruit members of the community who can help support others to engage with health services. It builds on the learning from other connector roles including the vaccine champions and social prescribing link workers.

Social prescribing services have provided a valuable link between the NHS and wider community and third sector organisations, like in the work of GPs at the Deep End, and are able to support people living with diabetes to reduce the impact of wider issues such as deprivation.⁵⁷

Everton in the community diabetes prevention project sugar free toffees offered an alternative for those who had declined referral to the usual diabetes prevention programme education.⁵⁸ The project was described as ‘harnessing the powerful bond between premiership football teams and their supporters to reach people who have little contact with the NHS.’



“

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

”

Train and develop people from within communities

Addressing health inequalities in diabetes through research: Recommendations from Diabetes UK's 2022 health inequalities in diabetes workshop, recognised the need to ensure the research community is representative of the general population.

Additionally, the report notes people in the UK from the lowest socioeconomic backgrounds are three times less likely to go to university and seven times less likely to go to a selective institution than those from the highest socioeconomic backgrounds.

The report calls for increased diversity to help promote participation of people from ethnic minority groups and more deprived communities. Among other ways to reduce racial inequality, the report calls for mentorship and sponsorship programmes

for students and researchers in underrepresented groups.

Peer support is highly valued by people living with diabetes and allows people to find groups who share their common interests and develop mutually supportive relationships.

"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

In the Black Country, an NHS funded partnership between the community diabetes service, the Black Country Integrated Care System (ICS) and housing association WHG aims to support 400 people over the next two years through a peer support model.

A team of local residents, who all have lived experience of diabetes, have been recruited as community health champions working in areas of deprivation and high levels of diabetes.

The champions encourage and increase access to support services, including diabetes education sessions and supporting people to positively manage their condition. The champions speak 15 community languages between them and so can engage with customers who have language barriers to understand their health needs.⁵⁹

Developing services starting with what the community would like to do, rather than what health services feel should be done, helps deliver longevity and increases the reach of services.

Community organisations often feel frustration when they are consulted when plans are already in motion, as the opportunity to properly shape services has passed. They can ensure that the views of communities who have been considered 'hard to reach' are heard but need to be included from the start to have the most impact.

"Housing associations such as WHG and other Council for Voluntary Services (CVS) organisations have deep knowledge and trust within their communities. This knowledge needs to be integrated early on into the design of services and materials to ensure that services will be fit for purpose for those furthest away from service access. In Walsall we are integrating health and housing services to benefit the health outcomes of those with the worst health and the least access to services."

Fay Shanahan Corporate Director of Operations and IT WHG

Training and involving small community organisations provides support that allows them to attract more funding and staff and become more sustainable. Community organisations felt it was vital that those designing health and social care services involved them directly.

Instead of sending out third parties to gather insights for reports and continuing to allow there to be barriers and distance between their communities and institutions.

"How we engage with marginalised communities should deeply trouble us. In the charity sector there is this notion that they don't know anything, we have to go there and solve it. We will pay someone a high salary to go into those

communities and manage projects when there is local expertise that is being paid substantially less. We need to break away from this and let go of our need for control and dominance."

Khadijah Diskin, head of education and resident scholar at JMB Consulting in an interview with Civil Society⁶⁰

In Northern Ireland, The Interethnic Forum, based in Ballymena, provides a link between minority ethnic groups and statutory and voluntary bodies, as well as community groups.

They support members of ethnic minority communities through assistance with activities such as filling in housing and benefit forms, accessing healthcare and education, and managing employment issues.

They are seen as a trusted source of information, helping deliver health messages to their community and ensuring people's views are heard by those designing services. Most recently they were able to gather members to feed into the Equality Commission for Northern Ireland at an engagement session.⁶¹

3%

of the UK population is made up of Black British citizens, but only

0.8%

of UK professors identify as Black, according to 2022 Higher Education Statistics Agency figures.





Develop cultural competency and poverty awareness within staff groups

Health Education England describes cultural competency for individuals as the 'ability to interact with people from different cultures and respond

to their health needs.' For organisations it entails 'creating a working culture and practices that recognise, respect, value and harness difference for the benefit of the organisation and individuals.'⁶²

The lived experience testimony heard during the Commission showed that there was still a need to support staff learning on cultural competency and poverty awareness.

NHS England launched a practical programme on cultural competence via a free e-learning module in 2021.⁶³

Undergraduate medical training institutes have also recognised the importance of cultural competency for all healthcare staff during their training. Kings College London launched their Cultural Competency Unit in 2021 and have incorporated learning on cultural competency from the beginning of their undergraduate medical course.⁶⁴

Their ethnographic investigation of medical students' cultural competence development in clinical placements paper discusses the varied ways in

which learning in cultural competence can be supported, beyond just simple direct teaching. Allowing students to be immersed in diverse environments, to observe others behaviour and have time to reflect all allowed a better understanding of cultural competence.⁶⁵

Children North East have developed a service and delivered training to NHS staff to reduce and remove barriers to healthcare faced by people experiencing poverty. They worked with the Paediatric Diabetes Networks in the

North East, North Cumbria, Yorkshire and Humber regions to 'poverty proof' three settings in Hull, Gateshead and Grimsby.

Their report highlighted among many other things, the need for healthcare professionals to normalise talking about the expense of diabetes which helps remove stigma and allows people to more easily access financial support when needed.⁶⁶

The Commission also recognised the importance of guarding against these

becoming a tick box exercise, but rather a core value and a culture change across all services for people living with and at risk of diabetes. So that people from all backgrounds were properly represented and included at all levels of the organisation. And while training and awareness courses can be a good place to start, these need to be part of an ongoing Equality, Diversity and Inclusion strategy.

COMMITMENT

Sustainability

The Commission heard an early summary of responses to a survey asking for examples of best practice which was run jointly by Diabetes UK and NHS England. Responses included a number of short-term projects, which had already ended.

Many were funded by short-term, non-recurrent funding found from underspends and had very short time frames, with little time for any evaluation or shared learning. Healthcare professionals also found it difficult to measure their success when many outcomes were either very long term, or qualitative in nature.

Throughout the workshops, the Commission heard about the need for proper, long-term investment to bring about long-term change. There is an urgent need for national governments to address racism and poverty, and their systemic nature, through policy levers.⁶⁷

The Commission also heard about the need to invest in those areas most affected by inequality to improve the accessibility of and range of services.

“Since the 2010 Marmot Review, the most deprived communities and places have lost more funding than less deprived communities. Poorer areas, where council tax receipts and business rates are already low, require a greater proportion of their funding from central government grants to local authorities, yet it is in these areas, with the greatest need, where grants have been cut the most.”

Health Equity in England: The Marmot Review 10 Years On.

There also needs to be a commitment to funding and creating capacity for changes to services within the NHS. A Royal College of Physicians Survey in March 2023 found that 67% of respondents had not received any training or teaching in health inequalities during their degree or training programme⁶⁸.

At a time of unprecedented pressure for the NHS, many healthcare professionals cited a lack of time and headspace to transform and develop services to make them more culturally appropriate and accessible as issues when trying to reduce inequality.

“It’s a challenge to get the engagement and traction with the staff who are barely able to do their core roles let alone anything else.”

Diabetes UK Tackling Inequality Lab Participant

Healthcare professionals understood the need to develop trust and relationships within communities over time. But found that current work pressure and short-term funding hampered this.

“Meaningful public involvement requires significant time and resource, [we need to] ensure time and funding for involvement of the public is embedded within the project plan.”

Health Care Professional working on inequality project

Community organisations also struggle with a lack of longer-term funding options. Healthcare professionals found it difficult to know which organisations operated in their area, as they often changed name or stopped operating when their funding ended. The organisations themselves found it difficult to recruit staff and develop longer term plans as they were unable to predict

“We have to prove everything we’re doing, so we’re hoping now that we’ve got so much data, we can take it to our consultant body and say, come on, you need to do something.”

Diabetes UK Tackling Inequality Lab Participant

how much funding they would have.

Healthcare professionals appreciated having colleagues working on similar projects to support them. The Commission also saw the benefits of collaboration where it allowed those working on similar projects to share their learning and use shared resources to publicise best practice. The North West Coast Clinical Networks

used underspend to support local health inequality projects and were able to help those involved share their learning through a celebration event and develop posters to publicise their work.⁶⁹

During the collection of the lived experience testimony in this work, much of which took place within community spaces, it was notable how many other organisations were seeking engagement

and insights from the same community. The Commission heard that participants were being asked very similar questions by multiple different groups. This demonstrated the importance of sharing insights and best practice across organisations and systems, rather than all asking the same questions of communities, especially if these do not lead to any positive change.





CONCLUSION

Over six months, the Commission heard from over a hundred people aged 18 to 80 about the daily struggles people living with all types of diabetes face in all four nations of the UK.

It heard about the pressures facing healthcare professionals in the UK who talked about the many different projects they were involved in to adapt and develop services for those affected by health inequality. The Commission also heard from organisations and services working within communities who face health inequalities, about the many wider issues that affect their lives, beyond just access to basic healthcare.

The inequalities faced by those living with diabetes are complex, interwoven and different for every individual. This is reflected in the many different projects, schemes and organisations across the country, working to reduce the gaps not just in healthcare outcomes, for all those whose face inequality.

This report identifies four principles to help frame conversations and provide an easy-to-remember approach to reducing inequality – the 4Cs principles – and more targeted, direct asks in our calls to action.

Diabetes-related health inequality cannot be viewed in isolation and is not within the gift of any one organisation or profession to solve. This report aims to provide a case for change, evidence to provoke conversation and practical steps for everyone who is ready to join Diabetes UK's mission to create a world where diabetes can do no harm.

“

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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