

Conversations about diabetes in African Caribbean communities



Introduction

Statistical data on diabetes

10.1% of patients over 17 years old registered with NHS G.P. Practices in **Sandwell** are recorded as having diabetes. This is higher than the **West Midlands** at **8.2%** and the **National average** at **7.3%**. Source: [Public health profiles 2021–2022 – Office for Health Improvement and Disparities \(phe.org.uk\)](https://publichealthprofiles.org.uk/)

[Diabetes UK information on ethnicity and diabetes](#) references research that states people of **African Caribbean** (and Black African and South Asian) ethnicities are at a higher risk of developing type 2 diabetes than the white ethnic population and at a younger age, 25 years old compared to 40 years old. Age related diabetes can also develop much earlier at around 50 years old compared to 70 years old for the White population.

Hearing Sandwell residents' experiences of diabetes

Healthwatch Sandwell priority project for 2023/24 is looking at:

Experiences of living with and managing diabetes and of health, care and support services to help manage the condition. The project findings, experiences, voices and views of Sandwell residents will be presented in a formal report with recommendations to help influence, inform and improve services.

Part of the project **Healthwatch Sandwell** planned **Focus Group** work is to explore in more depth the experiences for groups of people who may be more affected by diabetes and whether health, care and support services are meeting specific needs. The work from each **Focus Group** will be written up as an information resource, to help inform and influence improvements in diabetes awareness, information, prevention and management of the condition. Recommendations for improvements will be included in the formal report.

This information resource reflects the Focus Group work of:

Conversations about diabetes in African Caribbean communities

The diabetes project was embedded into the **Healthwatch Sandwell** overall programme of work which ensures engagement across Sandwell and the diverse resident populations. **12%** of project questionnaires were completed by people African Caribbean ethnic origin. **Individual conversations** were held within the community, in person and by telephone, and people were invited to join a **Focus Group conversation event**.

Sandwell African Caribbean Mental Health Foundation collaborated with **Healthwatch Sandwell** to hold a Focus Group conversation at the **Kuumba Centre** in West Bromwich with people of African Caribbean ethnicity affected by diabetes. **18** people attended.

This document is a summary of the individual and Focus Group conversation and findings to help inform improvements to Diabetes health, care and support services. It will also form part of the final project report and recommendations.

Main messages

- **Experiences of diabetes** – need for improvements in health and care services.
- **Information** – not enough on diabetes provided or culturally appropriate.
- **Food** – more education on healthy eating needed and specific to cultural diets.
- **Being active** – do more to encourage physical activity for good health.
- **Education** – consistency on diabetes courses offer needed.
- **Support** – enable and empower African Caribbean communities to raise awareness of increased risks and influence and educate local communities on diabetes.

Experiences of diabetes



The Focus Group shared some of their thoughts, feelings and experiences of diabetes:

Increased risks of developing diabetes

The Focus Group expressed thoughts on the fact that people of African Caribbean ethnicity are among those at higher risk of developing diabetes and at an earlier age.

“It’s hereditary – it’s scary!”

“My Grandmother lost a leg; another family member is on insulin.”

Stress and impacts on diabetes

The Focus Group spoke about stress, suggesting that stress levels may be higher due to ethnicity and inequalities. Stress increases cortisol and adrenaline levels which can increase insulin resistance and raise blood sugar levels, on-going stress can cause diabetes complications.

One woman shared with the group that her family had been under a lot of stress, including Covid impacts. 3 generations of women in the family had been diagnosed as diabetic.

Living with diabetes

Diabetes impacts on lifestyle and independence

Mrs A is in her 50's, she has had diabetes type 2 for over 15 years, she had not previously known there was a family history of diabetes. Mrs A visited her G.P. Practise after testing her own blood sugar levels which had high readings, inefficiencies with health services delayed original referral to the diabetes clinic services. Mrs A has ongoing struggles with stabilising blood glucose levels through diet management and insulin administration. This affects Mrs A's relationship with food, she will go without, and then binge from hunger. The diabetes has impacted Mrs A's eyesight; she is now registered blind. Her ability to work and income are also affected by her health conditions.

Healthwatch Sandwell signposted Mrs A to African Caribbean community support organisations and put in a referral to Sandwell Community Navigator services.

Diabetes impact on life expectancy

A man in the group asked:

“If there are higher risks for people of African Caribbean ethnicity developing diabetes at an earlier age than the White population does this also make a difference to life expectancy?”

There does not appear to be sufficient research to provide an answer, however:

www.gov.uk - [health information on diabetes](#) states:

It is often not type 2 diabetes itself that causes death, but complications of the disease, including cardiovascular disease (CVD).

www.gov.uk - [ethnic disparities in the major causes of mortality](#) states:

Of the 25 leading causes of mortality as measured by Years of Life Lost, Black people have better outcomes than White people for about a third, worse for about a third and with no difference for a third.



Appropriate information

None of the group had received information about diabetes and living with and managing the condition at diagnosis of diabetes or pre-diabetes.

Healthwatch Sandwell worked together with **Diabetes UK** on the project. **Diabetes UK** information booklets were provided to the Focus Group participants, including an “Enjoy Food” book with a focus on African and African Caribbean foods, plus the website and helpline details.

Healthwatch Sandwell have observed that there is a shortage of cultural relevance or relatable images in diabetes information resources, though **Diabetes UK** continue to learn from their engagement work and develop their offer. **Healthwatch Sandwell** created the images used within this report as group conversation starter resources.

Understanding diabetes

Focus Group conversations highlighted lack of awareness and understanding of diabetes:

“I have been told I am pre-diabetic, but I don’t know what this means – I am confused!”

“I don’t know how to manage diabetes – I starve, then binge eat.”

“What are the symptoms of diabetes? I get shaky, sweaty and feel faint.”

Some people in the group who had attended diabetes awareness courses were knowledgeable and able to help address some of the confusion, misconceptions and myths.

“Information books are good – but we don’t read, or share messages, enough”

Ms B told the group she was diagnosed with type 1 diabetes at 22 years old.

“I did not take it seriously and did not look after myself. Now my nerves and circulation are badly affected, I wish I had listened!”



Healthwatch Sandwell reminded the group of the higher risk of developing diabetes if of African Caribbean ethnicity, a family history, or a history of gestational diabetes. The importance of diabetes annual health checks was promoted.

National Institute for Health and Care Excellence – diabetes annual 9 key care processes:

- | | |
|--|-------------------------------|
| HbA1c blood glucose (sugar) level checks | Cholesterol levels blood test |
| Kidney function blood test | Kidney function urine test |
| Blood pressure | Feet (podiatry) |
| Eyes (Ophthalmology) | Weight check |
| Smoking status check | |

“Some African Caribbean people don’t like going to the Doctors”

“May try to help themselves with home remedies.”

“Should not wait till ready to fall over before running to the Doctors!”

“Diabetes blood tests for ethnic groups at higher risk should be done earlier.”

Healthwatch Sandwell will be making a recommendation in the main report around diabetes screening for groups at higher risk.

Impacts of poor nutrition on overall health. Michael has spinal nerve damage and type 2 diabetes, he had recently been in hospital, due to malnourishment complications. Bone density impact meant Michael has also lost some teeth, limiting his ability to chew, which can adversely affect blood sugar levels. Michael told the group he used to enjoy his Mothers cooking, but she had passed away. He has low cooking skills, and his mobility challenges make it difficult to manage as well. Michael has visiting carers, but they do not recognise or provide well for his preferred cultural diet.

Healthwatch Sandwell followed up with referrals to help improve support for Michael and by providing Diabetes UK information on nutrition and recipe ideas.



Thoughts and feelings about food

Conversations about food generated a lot of passion, emotions, beliefs and values:

There was a passion for fresh food:

“In the Caribbean you can pick foods fresh from the garden – such as thyme, scallions, pimento, marinade food overnight – it tastes beautiful and nutritious!”

“The benefits of good foods, like yams, okra and spinach should be promoted.”

“It’s good if you have an allotment or garden to grow your own food.”

“You can use good food as medicine.”

There was distrust of processed foods or additives:

The group talked about not trusting foods available for purchase, lack of freshness, including meats, additives including salt, sugar and colourings and concerns around pesticides.

“The Lord gave us a manual to live by, a clean, simple, fresh diet – but we don’t!”

“Fresh ingredients are less available or affordable in the UK.”

“The government states eat healthy – but don’t give tools to live by it and they allow promotion of foods that are unhealthy!”

“Refined sugar is an addictive substance – why is it not looked at as an addictive substance?”

Eating a balanced diet

The Focus Group talked about portion sizes, food types; carbohydrates – rice and peas, hard bread, plantain, fats in frying foods, and eating enough fruit and vegetables in a diet.

“Culturally a lot of our food is brown.”

“What are we doing with our young people to develop a taste for fruit and vegetables?”

Mrs D told the group that she had kept the traditional diet, but her diabetes was under control by adjusting to smaller portions and exercising.

“Services need understand traditional diet is what people are attached to.”

The group had conversations about teaching young people cooking skills, inspiring, perhaps through famous Black chefs, a love of cooking and eating nutritious foods.

Healthwatch Sandwell will reflect this idea in the main report within a recommendation.

Challenges with changing eating habits



“Come and sit – no-one go hungry!”

The group spoke about the cultural and sociable habits of sharing food and that this might present challenges for people with diabetes. This aspect links in with apparent low awareness and understanding of diabetes within African Caribbean communities.

“I have been diabetic for a while. I have been given advice, but I like my food and I am not changing. Sometimes the diabetes is up and down.”

This quote was from a male. **Healthwatch Sandwell** have observed during the project a few older males, of various ethnicities, seeming to be in denial of their diabetes condition or less willing to make adjustments. **Healthwatch Sandwell will highlight this in the main report with a recommendation for targeted awareness and education on diabetes and risks.**



Healthwatch Sandwell asked the group about how they kept active to help manage diabetes, there were very few examples of physical activity given.

“There is less motivation to be active living in the UK – people don’t feel like going out if the weather is bad”

“In Jamaica my Grandma climbed to get coconuts and walk to market to sell them.”

Thoughts on food and activity differences

People talked about being more naturally active when living in the Caribbean. Food growing, harvesting and collecting involved activity compared to buying from a supermarket in UK. It was thought more activity, using more calories, combined with warmer weather, meaning people sweated more, could have a positive impact on conditions such as diabetes and hypertension.

Mr & Mrs C are in their mid-eighties. Mr C has had type 1 diabetes for many decades, Mrs C has type 2. Mr & Mrs C migrated from Jamaica in the 1960’s. They chatted with **Healthwatch Sandwell** sharing thoughts on differences between living in the Caribbean and the UK related to food, activity and managing diabetes.



“In Jamaica if yuh want food, yuh pick yuh fruit fresh, yuh walk tuh di market fi meat an to di beach fi fish. In di UK people use di bus or car fi shopping, or mek them deliva it!”

Mr & Mrs C continued to be physically active when they migrated to the UK. They walked to work, and their jobs were physically demanding.

“Now it’s easy fi people fi sit down too much!”

The conversation highlighted that there may be a need to encourage and support physical activity that appeals to African Caribbean communities.

This will be highlighted with a recommendation in the main report.



“There is a lot of talk about diet and exercise, but I don’t think a lot of people are aware of the physical risks.”

The group talked about blood pressure (hypertension) and the increased risk of this in Black communities, risk to kidneys with diabetes and also possible impacts on sexual libido.

“Prevention is better than cure”

The group had lively discussions about awareness raising and education on diabetes including on increased risks to people of African Caribbean ethnicity and other ethnicities.

“Awareness and education should be starting at teenage level.”

“Education of children starts at home!”

“Older generations who hold experience and knowledge should be encouraging the younger generations.”



Mrs F has had type 2 diabetes for many decades. She told the group about how beneficial the X-PERT diabetes course had been for her.

The X-PERT course is offered to some patients through NHS commissioned services. Another course some people mentioned was Dafne for type 1 diabetes management. <https://dafne.nhs.uk/>

Healthwatch Sandwell have gathered an overview during the project of the differing diabetes support courses some patients in Sandwell have attended and will be making a recommendation regarding consistency of service offer in the main report.



Ms E suggested that counselling would be helpful when first diagnosed with diabetes.

“Taking on a diabetes diagnosis without any knowledge is scary, especially when struggling as it is!”

Ms E shared that she had sought support and said, **“I feel really well equipped to manage my diabetes since I had some support in understanding it.”**

The group felt that inequalities in health could best be addressed by empowering people in the African Caribbean communities to help educate and influence by investing in and supporting development of **Diabetes Community Champions**. The group also spoke of encouraging people with real lived experience of diabetes and health impacts to share their stories and help influence others in the African Caribbean community.

[Diabetes UK support development of Community Champions](#)

Tony Kelly, is African Caribbean, and originally trained through the Diabetes UK Community Champion programme. Tony has a role as a Diabetes Strategic Patient Partner working with the NHS Birmingham and Solihull Integrated Care System.

Healthwatch Sandwell will be making a recommendation for investment in developing Diabetes Community Champions and further support to help enable and empower local communities at “grass roots” level on awareness raising of diabetes risks and living healthily with diabetes.

Conclusion

This document has been produced to highlight key points raised by people in African Caribbean communities – to share their experiences, voices and views on:

- diabetes awareness
- living with and managing diabetes
- African Caribbean cultural aspects to consider
- Improvements to health, care and support services.

The document is intended as a useful information resource to help continue conversations to influence changes in services, to help to address health inequalities and ensure services and information meet cultural aspects.

Recommendations specific to the conversations to date and to meeting African Caribbean communities' needs for diabetes awareness raising, risk reduction, prevention and management are referenced in this document. They will be incorporated into the formal recommendations to improving health, care and support services in the main report which will be published in early 2024.

“Thank You” To everyone who took part in the conversations and



Sandwell African Caribbean Mental Health Foundation

in working together to ensure that people of African Caribbean ethnicity in Sandwell were able to share their experiences, voices and views and influence service developments.

Further information:

To feedback your comments on this report or for more information please contact:

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