



Type 2 Diabetes: Knowledge, Awareness and Support amongst Hertfordshire Residents

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About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver and regulate health and social care services to ensure the people's voice is heard, and to address gaps in services quality and/or provision.

About the Hertfordshire and West Essex Integrated Care System (ICS)

The Hertfordshire and West Essex Integrated Care System (ICS) was established as a statutory body on 1st July 2022. Integrated Care Systems are geographically based partnerships that bring together providers and commissioners of NHS services with local authorities and other local partners to plan, coordinate and commission health and care services¹. The Hertfordshire and West Essex ICS is made up of two key bodies – an Integrated Care Board (ICB) and Integrated Care Partnership (ICP).

Integrated Care Board (ICB)

The Integrated Care Board (ICB) is an NHS organisation responsible for planning and overseeing how NHS money is spent across Hertfordshire and West Essex, with the aim of joining up health and care services, improving health and wellbeing, and reducing health inequalities. The board of the ICB includes representation from NHS trusts, primary care and from Hertfordshire County Council and Essex County Council².

This report will be sent to the Hertfordshire and West Essex ICB Primary Care Board to inform how it can improve understanding and awareness of Type 2 Diabetes for those living without a diagnosis, and how it can better support people with a diagnosis to manage their condition.

Integrated Care Partnership (ICP)

The Integrated Care Partnership (ICP) is made up of representatives from different organisations involved in health and care. This includes NHS organisations, local authorities and the Voluntary, Community, Faith and Social Enterprise (VCFSE) sector. The partnership is responsible for developing an Integrated Care Strategy which will set out the priorities for Hertfordshire and West Essex for the next 10–20 years³.

¹ [Integrated care systems: how will they work under the Health and Care Act? | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/publications/integrated-care-systems-how-will-they-work-under-the-health-and-care-act-2022)

² [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk)

³ [Health and wellbeing decisions – Hertfordshire and West Essex Integrated Care System \(hertsandwestessexics.org.uk\)](https://www.hertsandwestessexics.org.uk)

Hearing Patient Views about Primary Care in Hertfordshire and West Essex

Healthwatch Hertfordshire and Healthwatch Essex have been commissioned by the Hertfordshire and West Essex Integrated Care System (ICS) Primary Care Workstream to undertake a series of engagement projects. The aims of the engagement projects include:

- Gathering lived experiences to feed directly into the Hertfordshire and West Essex ICS Primary Care Workstream
- Supporting and enabling the Hertfordshire and West Essex ICS to achieve wider participant engagement
- Engaging patients and the public on programmes covering key priorities and areas of importance at a regional and local level
- Making recommendations to the Hertfordshire and West Essex ICS Primary Care Workstream so improvements can be implemented

Using patient and public feedback, each engagement project will focus on improving the relevant service(s) within different areas of primary care by making recommendations to the Hertfordshire and West Essex ICB Primary Care Board.

From July - October 2023 the Director of Primary Care Transformation at the ICB requested Healthwatch Hertfordshire and Healthwatch Essex to explore public awareness and understanding of Type 2 Diabetes, and to understand whether those with a diagnosis feel confident and comfortable in managing their condition.

Background

Type 2 Diabetes develops when the body stops producing enough insulin or the body's cells stop reacting to insulin produced. Whilst Type 1 Diabetes cannot be prevented, the onset of Type 2 Diabetes can be delayed or prevented through support to change behaviour around lifestyle choices⁴.

According to Diabetes UK, over 4 million people in the UK are living with a diagnosis of diabetes, and more than 2.4 million people are at high risk of developing Type 2 Diabetes⁵. Approximately 90% of diagnoses are of Type 2 Diabetes, and around 8% of diagnoses are of Type 1 Diabetes, with the other forms of the condition making up the remaining 2%⁶.

Diagnoses of Type 2 Diabetes are increasing at an alarming rate and without appropriate care and support, people with Type 2 Diabetes can be at risk of developing serious

⁴ Health matters: preventing Type 2 Diabetes - GOV.UK (www.gov.uk)

⁵ https://www.diabetes.org.uk/about_us/news/number-people-living-diabetes-uk-tops-5-million-first-time#:~:text=Our%20new%20figures%20show%20that,2%20diabetes%20in%20the%20UK

⁶ https://www.diabetes.org.uk/about_us/news/number-people-living-diabetes-uk-tops-5-million-first-time#:~:text=Our%20new%20figures%20show%20that,2%20diabetes%20in%20the%20UK

complications⁷. As well as the human cost, Type 2 Diabetes costs the NHS a significant amount – with treatment for the condition accounting for 10% of annual NHS budget⁸.

However, with the right care, Type 2 Diabetes can be prevented and for those with the condition, complications can be delayed or prevented and in some cases, the condition can even be put into remission.

Risk Factors

The risk factors of Type 2 Diabetes are multiple and complex. They include⁹:

- Age
- Ethnicity
- Inactivity
- Smoking
- Sleep
- Gestational diabetes
- Family history
- Being overweight/obese
- Gender
- Alcohol
- High blood pressure
- Severe mental illness

There are significant inequalities present, with people from ethnically diverse backgrounds and those living in deprivation experiencing the greatest inequality. For example, Type 2 Diabetes is up to six times more common in people of South Asian descent and up to three times more common amongst African and African-Caribbean descent¹⁰. Prevalence of Type 2 Diabetes is also 60% more common among individuals in the most deprived quintile in England¹¹.

Complications

When blood glucose levels are raised for prolonged periods, this can lead to chronic health conditions and serious health complications, including¹²:

- Neuropathy (nerve damage)
- Nephropathy (kidney disease)
- Foot problems and amputations
- Hearing loss
- Mental health problems
- Retinopathy (eye disease)
- Cardiovascular diseases and strokes
- Gum disease
- Sexual health
- Increased risk of cancer

National Strategies and Programmes

NHS Diabetes Prevention Programme

⁷ https://www.diabetes.org.uk/about_us/news/number-people-living-diabetes-uk-tops-5-million-first-time#:~:text=Our%20new%20figures%20show%20that,2%20diabetes%20in%20the%20UK

⁸ <https://www.england.nhs.uk/diabetes/diabetes-prevention/>

⁹ <diabetes-jsna-2022.pdf> (hertshealthevidence.org)

¹⁰ [Health matters: preventing Type 2 Diabetes - GOV.UK](https://www.gov.uk/government/news/health-matters-preventing-type-2-diabetes) (www.gov.uk)

¹¹ [Health matters: preventing Type 2 Diabetes - GOV.UK](https://www.gov.uk/government/news/health-matters-preventing-type-2-diabetes) (www.gov.uk)

¹² <diabetes-jsna-2022.pdf> (hertshealthevidence.org)

In terms of prevention, the NHS Long Term Plan¹³ aims to double enrolment into the Type 2 NHS Diabetes Prevention Programme, also known as the Healthier You Programme. It is a lifestyle change programme for people at risk of developing Type 2 Diabetes and research has shown that it cuts the risk of developing Type 2 Diabetes by more than a third for people completing the programme¹⁴. A digital option will also be offered to widen patient choice and to target inequality. Given its results, it is important that those at risk of developing Type 2 Diabetes are made aware of the programme, and referred to it by healthcare professionals.

NHS Health Checks

NHS Health Checks are a check-up for adults in England aged 40–74 and can help spot early signs of stroke, kidney disease, heart disease, Type 2 Diabetes or dementia.

In Hertfordshire, 50% of patients eligible for the NHS Health Check take up the offer. This is better than the average 40% across England, but increasing this percentage would help identify those at high risk of Type 2 Diabetes and enable earlier prevention¹⁵.

Supporting People with Type 2 Diabetes

To help people with a diagnosis self-manage their condition, the NHS Long Term Plan has committed to further expanding the provision of structured education and digital self-management support tools, including increasing access to the Healthy Living Programme¹⁶.

The NHS will also continue to refer people living with obesity and a diagnosis of Type 2 Diabetes to the NHS Digital Weight Management Programme¹⁷. The NHS Long Term Plan will also introduce the Path to Remission Programme, which provides a low calorie, total diet replacement for people living with Type 2 Diabetes and obesity – although this programme is not available in 21 areas of England, it is not currently running in Hertfordshire¹⁸.

Management of Type 2 Diabetes

Alongside the provisions mentioned above, people who receive a diagnosis of Type 2 Diabetes should be offered a education programme, such as the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) Programme – which aims to support people with Type 2 Diabetes to self-manage their condition¹⁹.

According to the National Diabetes Audit (2019), 73% of people with Type 2 Diabetes living in Hertfordshire were offered a structured education session within 12 months of diagnosis.

¹³ [NHS Long Term Plan v1.2 August 2019](#)

¹⁴ [NHS England » NHS Diabetes Prevention Programme \(NHS DPP\)](#)

¹⁵ [NHS Health Check – OHID \(phe.org.uk\)](#)

¹⁶ [NHS Long Term Plan v1.2 August 2019](#)

¹⁷ [NHS England » The NHS Digital Weight Management Programme](#)

¹⁸ [NHS England » NHS Type 2 Diabetes Path to Remission Programme](#)

¹⁹ [NEWLY DIAGNOSED AND FOUNDATION – DESMOND](#)

The attendance rate was much lower at 20% – though this is higher than the national average of 13%²⁰.

An Annual Diabetes Review should also take place – NICE recommends that people with Type 2 Diabetes should receive nine recommended care processes at their Annual Diabetes Review. These include²¹:

- Measuring HbA1C (average blood glucose levels)
- Measuring blood pressure
- Measuring cholesterol
- Foot examination
- Blood test for kidney function
- Urine test for kidney function
- Measuring Body Mass Index (BM)
- Checking smoking history
- Eye screening

In 2020/21 less than a quarter of people with Type 2 Diabetes had all nine care processes (21% for East and North Hertfordshire and 18% for South and West Hertfordshire)²². Though it is important to note that this was during the COVID-19 pandemic.

Local Picture

The Hertfordshire and West Essex ICS has listed the management and prevention of Type 2 Diabetes under priorities 3 and 5 in the Hertfordshire and West Essex Joint Forward Plan 2023–28²³. Specific aims include:

- Reducing the prevalence of Type 2 Diabetes
- Improving blood glucose control
- Implementing diabetes multidisciplinary teams (MDTs) in West Essex
- Identifying pathway improvement and integration across all ages and all commissioned weight management services e.g. National Digital Weight Management and National Diabetes Prevention Programme
- Restoring proactive care processes for people living with long-term conditions and specifically for cardiovascular diseases, diabetes, neurological conditions, respiratory conditions and stroke
- Scoping and reviewing existing diabetes community services
- Implementing NHS Pathway to Remission programme
- Recovery of diabetic 8 care processes and 3 treatment targets
- Increasing the rate of diabetes structured education uptake and completion

²⁰ [diabetes-jsna-2022.pdf \(hertshealthevidence.org\)](#)

²¹ [diabetes-jsna-2022.pdf \(hertshealthevidence.org\)](#)

²² [diabetes-jsna-2022.pdf \(hertshealthevidence.org\)](#)

²³ [Hertfordshire and West Essex Joint Forward Plan 2023 – 2028 – Hertfordshire and West Essex NHS ICB](#)

A series of initiatives have already been implemented, including targeted work with people from Asian backgrounds to reduce their risk of Type 2 Diabetes.

This engagement will support ongoing work by exploring public understanding of the risk factors and symptoms of Type 2 Diabetes, as well as the experiences of those with a diagnosis in self-managing their condition.

Aims

The aims of this engagement were as follows:

- To explore public awareness and understanding of Type 2 Diabetes, and to learn how this could be improved.
- To understand how people who have been diagnosed with prediabetes are being supported by primary care services.
- To identify how people with a diagnosis of Type 2 Diabetes are being supported by primary care services to self-manage their condition.
- To propose recommendations to the Integrated Care Board Primary Care Board.

Methodology

To explore the above aims, we ran an online survey to hear from Hertfordshire residents who are over the age of 18 – whether or not they have a diagnosis of Type 2 Diabetes. Respondents had the option to request the survey in an alternative format to suit their needs and/or to contact us for support.

Using a survey to collect data was considered the most effective method in order to reach and engage the population within the timescales of this research.

The engagement period ran from August to October 2023. The survey was promoted via social media and shared with NHS and other statutory services and the Voluntary, Community, Faith and Social Enterprise sector across Hertfordshire to share and distribute via their networks, contacts and social media channels.



Key Findings

Demographics

216 Hertfordshire residents completed the online survey²⁴.



- 1%** were aged 18-24 years old
- 4%** were aged 25-34 years old
- 6%** were aged 35-44 years old
- 15%** were aged 45-54 years old
- 27%** were aged 55-64 years old
- 28%** were aged 65-74 years old
- 18%** were aged over 75+



- 71%** were female
- 28%** were male
- 1%** were non-binary



- 70%** were of a White British background
- 26%** were from an ethnically diverse background²⁵



- 13%** are a carer
- 12%** had a disability
- 36%** had a long-term condition



- 67%** stated that they had a little or a lot of disposable income
- 22%** had either just enough, or not enough money for basic necessities

²⁴ Please note that percentages do not always add up to 100% due to some respondents choosing not to answer, or preferring not to say.

²⁵ Ethnicities engaged with included: Bangladeshi, Chinese, Indian, other Asian/Asian British backgrounds, Black African, Black Caribbean, Asian and White, Black Caribbean and White, White Irish, White Italian, other White backgrounds, and ethnic backgrounds not listed in the survey.

40% of respondents had a diagnosis of Type 2 Diabetes.

- **5%** were aged 25-44, **13%** were aged 45-54, **20%** were aged 55-64, and **60%** were aged over 65.
- **45%** were male, and **55%** were female.
- **77%** were White British, and **18%** were from an ethnically diverse background.
- **10%** were a carer, **12%** had a disability, and **48%** had a long-term condition.
- **67%** stated they had a little or a lot of disposable income, while **27%** had either just enough or not enough money for basic necessities.



Respondents who had Type 2 Diabetes were more likely to be over the age of 65, male, and White British. Interestingly, only 48% with a diagnosis considered themselves to have a long-term condition.

60% of respondents had not been diagnosed with Type 2 Diabetes.

- **13%** were aged 25-44, **16%** were aged 45-54, **31%** were aged 55-64, and **38%** were aged over 65.
- **18%** were male, **80%** were female.
- **66%** were White British, **30%** were of an ethnically diverse background.
- **15%** were a carer, **12%** had a disability and **28%** had a long-term condition.
- **67%** stated they had a little or a lot of disposable income, while **20%** had either just enough or not enough money for basic necessities.



Respondents who did not have a diagnosis were more likely to be younger in age, female and from an ethnically diverse background.

30% of those without a diagnosis have been told by a medical professional that they are at risk of developing Type 2 Diabetes.

- **7%** were aged 25-44, **20%** were aged 45-54, **33%** were aged 55-64 and **40%** were aged over 65.
- **27%** were male and **73%** were female.
- **67%** were White British and **33%** were from an ethnically diverse background.
- **24%** were a carer, **10%** had a disability, and **48%** had a long-term condition.
- **62%** stated they had a little or a lot of disposable income, while **31%** had either just enough or not enough money for basic necessities.

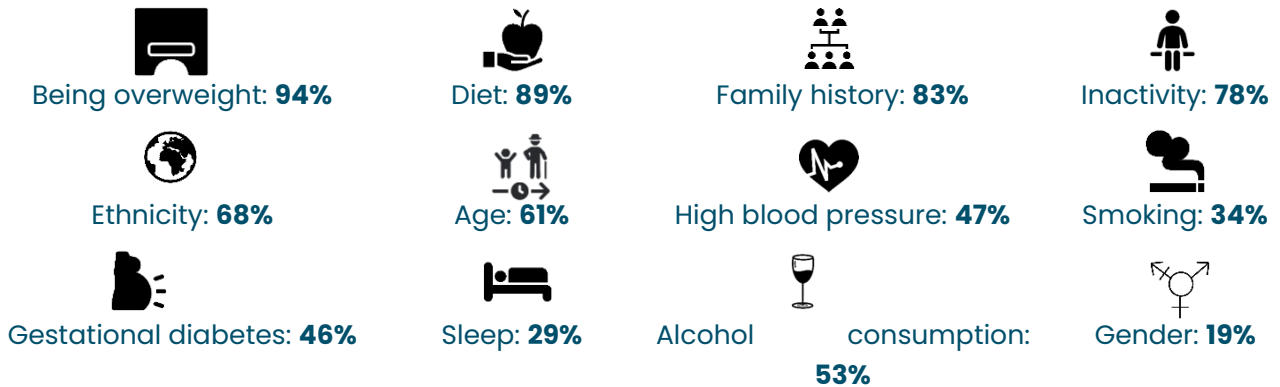


Respondents who are at risk of developing Type 2 Diabetes tended to be younger in age, but were more likely to be male and from an ethnically diverse background. They were also slightly more likely to have less disposable income.

Key Findings: People without a Diagnosis

Knowledge and Awareness

To gauge how awareness and understanding amongst people without a diagnosis, we asked them what risk factors are associated with Type 2 Diabetes:



Awareness and understanding of risk factors varied between demographic groups:

Ethnicity

White British respondents generally had an understanding of factors which was comparable to the averages listed in the table above.

Asian Respondents: Had a better understanding of factors which are less-known such as gestational diabetes (**71%**), high blood pressure (**57%**), smoking (**43%**) and sleep (**43%**). They had a poorer understanding of more common factors such as being overweight (**71%**), age (**43%**), inactivity (**57%**) and diet (**71%**).

Black Respondents: Had a better understanding of ethnicity (**83%**), high blood pressure (**83%**), age (**83%**) and sleep (**50%**) but poorer awareness of being overweight (**83%**), inactivity (**67%**) and alcohol consumption (**33%**).

White Other respondents: Generally had an understanding similar to the average, but had slightly better awareness of gestational diabetes (**56%**), smoking (**56%**), alcohol consumption (**63%**) and gender (**31%**) but a poorer understanding of being overweight (**88%**).

Gender

Men had a better awareness of high blood pressure (**63%**) and smoking (**42%**). However, they had a poor understanding in regards to ethnicity (**58%**), age (**53%**), and inactivity (**59%**).

Women had an understanding of factors comparable to the average, and only had a slightly poorer awareness of high blood pressure (**40%**) and alcohol consumption (**47%**).

Income

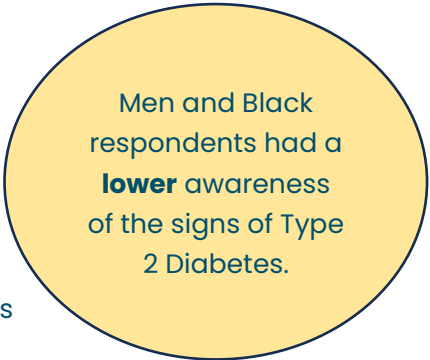
People with less disposable income were more likely to know that gender is a risk factor (**50%**) but had poorer awareness of age (**55%**), alcohol consumption (**45%**) and diet (**75%**).

People with more disposable income had a slightly better awareness of some factors, including age (**66%**), inactivity (**84%**), smoking (**40%**) and alcohol consumption (**57%**).

Respondents without a diagnosis were also asked about what they thought the signs of Type 2 Diabetes were:

- Increased thirst: **90%**
- Excessive tiredness and fatigue: **81%**
- Weeing more than usual: **77%**
- Changes to your vision: **73%**
- Tingling and pins and needles sensation in hands and feet: **66%**
- Cuts and grazes taking longer to heal than usual: **58%**
- Losing weight without trying to: **45%**
- Itching around your genitals: **28%**

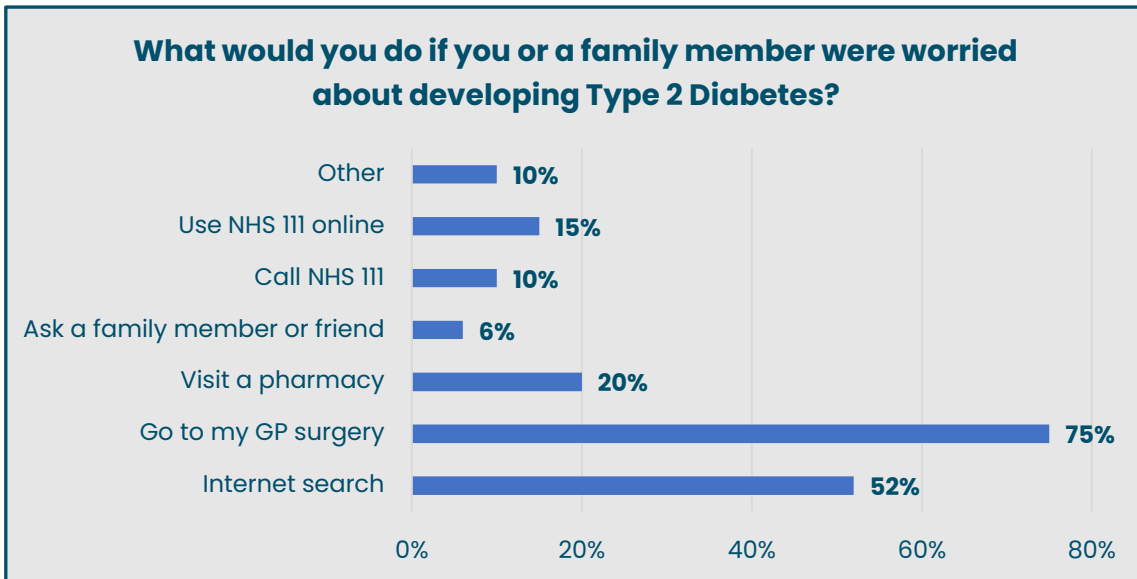
Interestingly, those aged under 55, people from other White ethnic backgrounds, and people with less disposable income were more likely to be aware of the signs of Type 2 Diabetes. Asian respondents also had better awareness, though their understanding of the most common symptoms – increased thirst, excessive tiredness and fatigue, and weeing more than usual – was lower compared to the average.



Men and Black respondents had a **lower** awareness of the signs of Type 2 Diabetes.

Accessing Support

Respondents were asked what they would do if they or a family member were worried about developing Type 2 Diabetes. Those who chose 'Other' said they would contact a diabetes charity, self-manage symptoms through exercise and diet, and see a nutritionist.



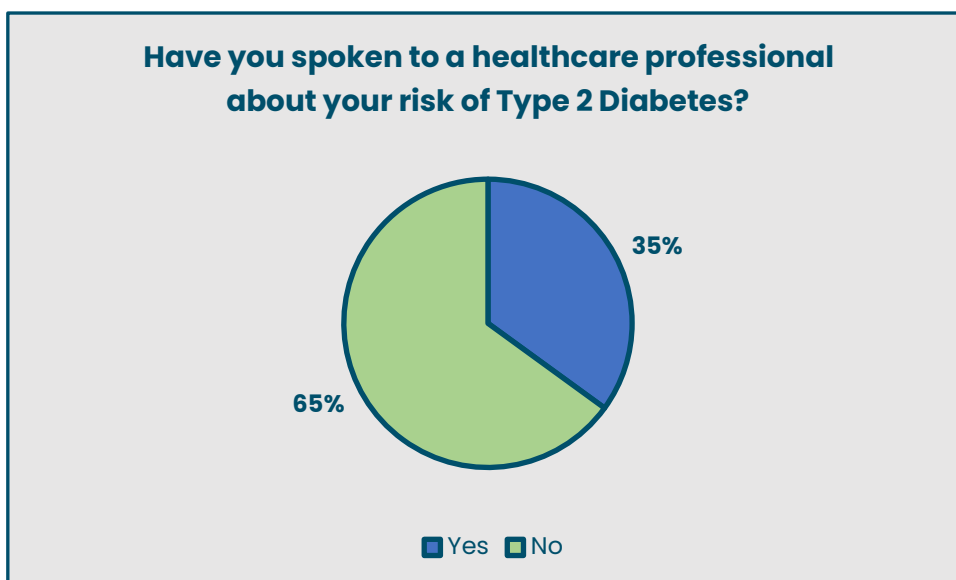
Interestingly, Black respondents and people from a White Other ethnic background were more likely to visit their GP at **83%** and **94%** respectively. Men were also far more likely at **95%**. In contrast, people with less disposable income and those aged under 55 were not as likely at **65%**.

Black respondents and people from a White Other ethnic background were also more likely to visit a pharmacy at **33%** and **25%** respectively. People from a White Other ethnic background were also more likely to contact NHS 111 (**19%**) or NHS 111 online (**13%**) compared to the average, and other demographic groups.

In comparison, no one from a White Other ethnic background said they would ask a friend or family member – while Black and Asian respondents were far more likely to do so at **17%** and **29%** respectively.

People from a White Other ethnic background were also far less likely to look on the internet for information, at **13%**. This was followed by Asian respondents at **43%**.

Respondents were then asked if they had spoken to a healthcare professional them about their risk of Type 2 Diabetes.



Of the **64%**, the majority of respondents simply said there was no reason for them to speak to a health professional about their risk of Type 2 Diabetes, as it is not something they have concerns about. A few respondents also said it was just something that they had not necessarily thought about.

"I currently have no concerns of Type 2 Diabetes."

"No one has said anything to suggest such questioning."

"I haven't considered myself to be at risk."

Some respondents said they had not spoken to a healthcare professional because they faced difficulties accessing their GP surgery, with examples including limited appointment availability and long waiting times on the phone. A couple of respondents also said they do not want to risk wasting their GP practice's time.

"Health professionals not easily available."

"No chance of getting an appointment at my surgery."

"Don't want to waste GP time."

In contrast, a few respondents said that tests such as NHS Health Checks and blood tests had shown that their blood glucose levels are normal, so they have no reason to speak to a health care professional about their potential risk of Type 2 Diabetes.

"NHS routine checks show my blood sugar level is fine."

"Blood sugar is usually normal."

Other respondents commented that they did not feel the need to talk to a healthcare professional about their risk of Type 2 Diabetes because they eat a healthy diet and/or are confident in their knowledge of the risk factors for Type 2 Diabetes.

"I know that processed foods and sugar consumption increases the risk of diabetes."

"I don't feel at risk at the moment as I try to eat low carb/sugar."

Alarming, three respondents said they have not spoken to a healthcare professional about their risk of Type 2 Diabetes, despite having a family history of the condition and/or experiencing possible symptoms. One respondent said that fear of receiving a diagnosis or being told they are at risk has prevented them from speaking to a healthcare professional about Type 2 Diabetes.

“Presumably because I’m not overweight, I’ve never been thoroughly tested despite a family history of diabetes.”

“Father had diabetes. Thinking I should [see someone as I’ve had] a couple of hypoglycaemic episodes and mild blurred vision.”

“No, fear that they will say I am at risk. Then I will need to address it.”

Positively, the majority of respondents (**93%**) said that they would not have any concerns speaking to a healthcare professional about their risk of Type 2 Diabetes.

Black respondents and people from a White Other ethnic background were more likely to have concerns about speaking to a healthcare professional at **83%** and **81%**.

NHS Health Check

The NHS Health Check is a free check-up for adults aged 40 to 74 and that can help tell you whether you’re at higher risk of getting certain health problems such as heart disease, stroke, kidney disease, Type 2 Diabetes and how to reduce your risk of these conditions²⁶.

Concerningly, **64%** of respondents over the age of 40 had not received a free NHS Health Check. This percentage was higher amongst other demographic groups – including Asian respondents (**75%**) Black respondents (**100%**) people from a White Other ethnic background (**79%**) people with less disposable income (**82%**) and men (**73%**).

The majority of respondents had not received the NHS Health Check because they have not been invited by their GP practice to have one.

“I’ve never been offered a check despite being 60.”

“Not been asked for one at the surgery.”

Similarly, many respondents simply did not know that NHS Health Checks existed, and that they should receive an invitation if they are eligible.

²⁶ <https://www.nhs.uk/conditions/nhs-health-check/what-is-an-nhs-health-check/>

“Didn’t know you could have a free health check.”

“Didn’t know there was one available.”

A few respondents said they have received an equivalent health check, and therefore did not feel the need to attend the NHS Health Check as well. In contrast, two respondents said they had been invited but it was at an inconvenient time, and one respondent simply did not want a check-up.

“I used to have a carers health check but that was when my doctor’s surgery saw patients.”

Key Findings: People At Risk

30% of respondents were told that they were at risk of developing Type 2 Diabetes. Positively, the majority (**58%**) said that the healthcare professional explained how to prevent pre-diabetes progressing into Type 2 Diabetes. This percentage was slightly lower amongst Black respondents and people from a White Other ethnic background, and higher amongst Asian respondents, men and people with less disposable income.

Information and Support

When asked what information and support they had received, respondents commented:

- Further and more regular blood tests
- Access to the Liva app (a digital weight management programme)
- Information and advice about weight, diet and lifestyle management
- Referrals to programmes such WeightWatchers and diabetic support groups
- Referral to the NHS Diabetes Prevention Programme
- Leaflets, booklets and online education

However a couple of respondents said they received no information or support.

When asked what information or support they would find useful, the majority of respondents said they would like more information and education about how to prevent Type 2 Diabetes and how to live a healthier lifestyle. Suggestions included leaflets, booklets and access to support groups.

“Leaflets, especially around food and access to exercise classes.”

“Materials provided from a doctor’s office, research tools and support group of others.”

Another common suggestion was for healthcare professionals to provide more tailored support, including the provision of meal plans, exercise plans and nutritional advice and for this to be tailored to the individual.

“More specific support i.e. diet / nutritional advice and exercise plan. What I can and can’t eat.”

“Dietary guidelines that are not only relevant to Diabetes, but also raised cholesterol levels and CKD.”

Lastly, respondents wanted more contact and support with clinicians, including regular monitoring, tests and check-ups.

“Appointment with a dietitian, appointment with a diabetes nurse, follow up blood tests.”

NHS Diabetes Prevention Programme

The NHS Diabetes Prevention Programme, otherwise known as the “Healthier You” programme, identifies people at risk of developing Type 2 Diabetes and refers them onto a 9-month lifestyle change programme. Anyone at risk of developing Type 2 Diabetes should be referred to this programme²⁷.

Concerningly **45%** of respondents at risk of developing Type 2 Diabetes had not been referred to the programme. Black respondents and people with less disposable income were even less likely to have not been referred at **50%** and **56%** respectively. In contrast, only **13%** of men had not been referred to the programme.

However, out of the **55%** of respondents who had been referred, only **45%** attended. Men and Asian respondents were more likely to have attended at **88%** and **100%** respectively. Black respondents and people from a White Other ethnic background were also more likely to have attended at **50%**.

100% of Asian respondents and people from a White Other ethnic background had been referred.

Only **22%** of people on a less disposable income attended the programme.

²⁷ <https://www.england.nhs.uk/diabetes/diabetes-prevention/>

"I didn't know anything about it and I wasn't invited to participate."

"It wasn't offered."

A few respondents felt they did not need to attend because they already understood how they can prevent Type 2 Diabetes.

"My partner is Type 1 diabetic and I felt I understood enough about the Type 2 condition as I needed to keep it at bay: diet, exercise, weight."

"Felt I know about what causes diabetes."

Two respondents had referred themselves, or had been referred by a healthcare professional to the programme, but received no response.

"Because despite referring myself twice they never got back to me."

Lastly, one respondent said they could not fit attending the programme around their working hours.

For the **45%** of respondents who did attend the programme, the majority had a positive experience and described the programme as **'helpful'**, **'informative'**, and **'useful'**. Respondents shared that they learnt new information, gained motivation, and felt the programme was helpful in providing practical advice and support.

"I already knew a lot of what was in the programme, but I did learn some new things and it motivated me to adopt a healthier lifestyle."

"Useful to know more simple and disciplinary way on diet awareness and exercises."

"I was confused, in denial at first but found the group useful."

Only a few respondents had a negative experience. Examples included having to attend the sessions online, poorly organised sessions, and lack of clear information.

“It was somewhat useful, but sessions were changed at short notice and then I was added to other clinic sessions which often repeated a session I already had. It was organised really badly. Often it was very patronising. I didn’t find the groupwork useful at all. I found the information very helpful, and I still use it. There should be one-to-one options rather than groups. Many of the groups I attended ended-up with one or two people taking over and wasting everyone’s else time.”

Key Findings: People with a Diagnosis of Type 2 Diabetes

Experience of Diagnosis

40% of respondents had a diagnosis of Type 2 Diabetes. When asked if they felt the condition was explained when they received a diagnosis, **41%** said it was and that they had a positive experience. In particular, respondents commented that the healthcare professional was **“helpful”** and **“knowledgeable”**, and that they received plenty of information, advice and support which provided them with great reassurance. Having that reassurance was important to respondents, as for some, receiving a diagnosis was quite daunting.

“This runs in my family so already had some good knowledge, but my GP practice have been brilliant and proactive.”

“The nurse did a blood sugar test amongst other checks e.g., blood pressure, and she gave me a lot of information leaflets and verbal description of what the management regime would be by way of blood tests and physical checks.”

“I had an understanding GP who was diabetic himself. Good support from our surgery over the years with regular checks etc.”

A few explained that they were referred to the DESMOND programme (a self-management programme to support people with Type 2 Diabetes to manage their condition) as soon as they were newly diagnosed, which provided them with useful information and support.

“The Desmond programme made it clear that all carbs should be limited, not just sugar, and what to look for in food labelling.”

“After diagnosis I was referred to a course which though brief, covered the issues with diabetes fairly well.”

However, **56%** felt that their condition was either not really explained to them when they received the diagnosis, or not explained to them at all. This percentage was higher amongst those aged under 55, Asian respondents and people with less disposable income at **64%**, **63%** and **75%** respectively.

For some, this was because they were not given much information about the condition itself and/or the dietary and lifestyle changes needed to manage it.

“I was told ‘you have mild diabetes, just go away and manage your diet’. Not surprisingly I failed to do that.”

“Blood test results were not fully explained. But initially I dieted and had help from dietician at the hospital. It seems it’s genetic but not given a lot of information about the illness itself. I lost weight and managed it now with careful diet and metformin.”

Likewise, some respondents were simply put on medication with little support or information about how they can manage their Type 2 Diabetes, particularly through diet, exercise and lifestyle changes.

“The doctor told me I had Type 2 Diabetes. The second doctor gave me medication. That was it.”

“It was a long time ago, so I don’t remember, other than drugs being pushed at me, rather than considering lifestyle changes.”

A few respondents felt they their diagnosis was rushed, and felt confused about the information they had received. One respondent commented that they were given conflicting information by various healthcare professionals, only adding to their confusion on how to manage their condition.

“Conflicting info/advice from GP, diabetic nurse and diet/nutrition advisor left me very confused.”

“I didn’t quite understand the long-term implications.”

Lastly, some respondents had to wait several months before being referred to either a course and/or to speak to a healthcare professional about their diagnosis.

"I was told I had type 2. No information given I was sent on a day course about 6 months later."

"I was told I was now Type 2, and to come back again for another test in six months."

Respondents were also asked if they were aware of the possible health complications associated with Type 2 Diabetes and to list them. The most common answers were as follows:

- Neuropathy: **67%**
- Heart disease: **44%**
- Stroke: **15%**
- Circulation: **7%**
- Not healing from infections: **11%**
- Retinopathy: **67%**
- Kidney disease: **39%**
- High blood pressure: **11%**
- Ulcers: **6%**
- Osteoporosis: **7%**

Concerningly, a few respondents could not list any complications, perhaps highlighting a lack of awareness and understanding, and indicating that they were not made aware of this information at diagnosis.

DESMOND Programme

People who receive a diagnosis of Type 2 Diabetes should be referred to the DESMOND programme to help them learn how to manage their condition²⁸. As mentioned, the DESMOND programme is a self-management programme for people with Type 2 Diabetes to teach them how to control and manage their condition. GPs and other healthcare professionals can refer people with Type 2 Diabetes to the programme, as well as other educational initiatives.

Of the **40%** of respondents who have a diagnosis, only **35%** had been referred to the DESMOND programme.

Positively, **77%** of those who had been referred to the DESMOND programme attended. This figure was even higher amongst Asian respondents at **100%**.

For the **22%** who did not attend reasons included wanting to do their own research and education on Type 2 Diabetes, and not being able to access the programme either due to the COVID-19 pandemic or issues with accessibility.

²⁸ <https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/education>

"Access & toileting issues due to disability."

"Covid stopped access."

"I was happy self-learning."

For those that attended the programme, the majority had a positive experience with many praising the programme and saying they would recommend it to others. Respondents found it informative, helpful and provided them with a better understanding of the condition and how it can be managed.

"Desmond bought the right knowledge to understand diabetes and manage it. I definitely recommended."

"It was very helpful in giving me a better understanding of the disease."

"It was helpful course and helped me understand Type 2 Diabetes and how to look after myself."

However, some respondents had a poor experience. A few shared that they had to wait a long time to access the course after their diagnosis, leading them to develop bad habits in the meantime. Another respondent found it hard to access the course online, despite being technically literate. A further two respondents felt that the information, particularly about carbohydrates, was incorrect.

"Not very good - I had to wait months after my diagnosis for the programme which allowed me to develop bad habits, which I've found very hard to break."

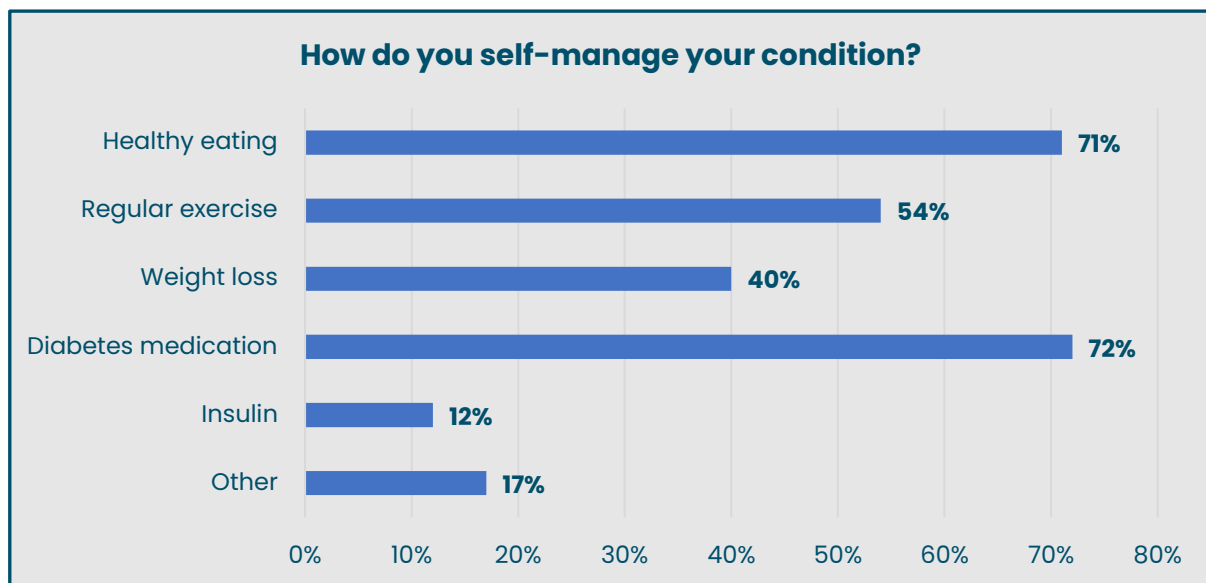
"It was complete rubbish. Diabetes is a Carbohydrate intolerant programme and therefore saying that carbs are acceptable for people who needs to manage their sugar levels is completely against the science. I have since put my T2D into remission and have done so for 3 years."

"I am technologically very literate, and yet I couldn't work out (18 months ago) what I was supposed to do."

Self-Management

Respondents were asked how they self-manage their condition.

Those who chose 'Other' mentioned having a nutritional coach, having a low carbohydrate diet, and using a glucose monitor.



Positively, the majority of respondents (**77%**) felt comfortable and confident managing their condition. However, **23%** said they did not feel confident in managing their condition. This was slightly higher amongst people with less disposable income at **38%**.

Respondents were also asked if they test their blood glucose levels, of which **49%** said they do. Of this percentage, most respondents (**47%**) only test once a day, followed by **27%** who test five or more times a day.

88% of Asian respondents and **85%** of men felt confident managing their condition.

For the **51%** of respondents who do not test their blood glucose levels, the most common reason for this was because they have never been told by a clinician, or have been told by a clinician that it is not necessary. Some respondents said it is expensive to test their blood glucose levels, while others do not like the pain of finger-pricking and/or needles.

"Mine said at this stage there is not a need for me to test at home."

"I have never been offered that option, it would definitely put my mind at rest."

"Pain perception disorder makes regular finger pricks unmanageable and cannot afford to self-fund the sensor."

Despite most respondents stating they feel confident in self-managing their condition, **59%** still said they face challenges. This was slightly lower amongst Asian respondents (**50%**)

and higher for people with less disposable income (**69%**) and those under the age of 55 (**64%**).

The most common challenge was trying to lose weight and eat healthily, with some finding it hard to distinguish what foods they should and shouldn't eat and the correct portion sizes. A few respondents shared that they can lack motivation, and find it hard to resist certain foods.

"Just the dieting and healthy eating can be a challenge."

"I am tempted by sweet food in the house."

"What to eat and portion size."

Some respondents shared that they are struggling to regulate and reduce their blood glucose levels and to get them within the correct range, and most of these respondents said they do not feel supported by clinicians to manage this.

"Blood sugar is often high report this to surgery, but nothing is done."

"HbA1c raised above normal and difficult to manage. Consultant reviews philosophical – at your age isn't not worth worrying."

Similarly, a few respondents said they found taking medication challenging, particularly those managing their insulin intake. One respondent shared that due to supply issues, their medication is changed frequently.

"Managing insulin amount on different days/times."

"Medication supply issues have meant my medication is constantly being changed without any notice/explanation from the doctor."

When asked what would help them to better manage their condition, some respondents did not have any suggestions because they are self-motivated and/or have already received enough information and support.

"Not sure there is anything. I have been giving all the knowledge and information I need. I need to take personal responsibility."

However, other respondents commented that they would like access to more monitoring of their blood glucose levels – whether this be access to self-testing, more frequent blood tests, or more support from clinicians.

“Monthly one-to-ones, quarterly blood test.”

“Continuous Glucose Monitoring on the NHS.”

Linked to this, some respondents wanted more regular contact with clinicians to discuss their condition, to have check-ups and to review their self-management.

“More regular check-ups with the diabetic nurse.”

“A review of insulin therapy to improve glucose management during the day (I’m taking long-acting insulin with no additional control).”

In contrast, some respondents would like more support to live a healthier lifestyle, including access to gym memberships or classes, health programmes and more information and advice on losing weight and eating well.

Annual Diabetes Review

People with Type 2 Diabetes should expect to be offered an Annual Diabetes Review which includes the nine care processes²⁹. Positively, **94%** of respondents said they had been offered an Annual Diabetes Review. This percentage was slightly lower amongst Asian respondents and people with less disposable income at **75%** and **81%** respectively.

“Maybe a gym membership or class to go to help lose weight with other people.”

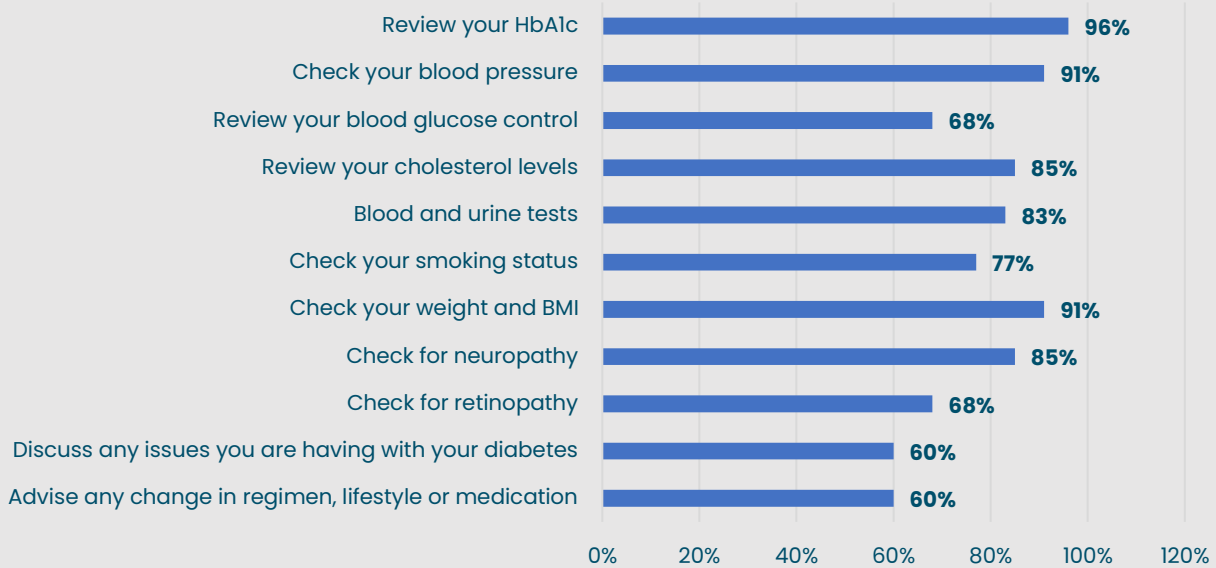
“More knowledge and support.”

Of the **94%** who were offered an Annual Diabetes Review, **77%** attended. Interestingly, this was higher for Asian respondents at **88%** but much lower for people with less disposable income at **50%**.

Promisingly, most respondents had received the checks, tests and examinations that should be expected at Annual Diabetes Review.

²⁹ <https://www.diabetes.org.uk/guide-to-diabetes/managing-your-diabetes/care-to-expect#regular>

Did the following checks take place at your Annual Diabetes Review?



When asked how their Annual Diabetes Review could be improved, most respondents said no improvements were required. Respondents praised healthcare professionals for being helpful and conducting a thorough review of their diabetes.

“The surgery is excellent on providing the annual checks.”

“I am happy – the nurse and the doctor are always helpful.”

Though some respondents felt their Annual Diabetes Review is sometimes rushed, meaning not all the required checks are carried out. Some also commented that there is not enough time to discuss any issues or concerns they may have.

“More time to discuss things. Occasionally, I have had to ask for the checks to be done, especially foot checks.”

“I feel the appointments are rushed and miss things out. I understand nurses are busy, but this might become an issue later if all checks not completed.”

Lastly, a couple of respondents would like Annual Diabetes Review to be more frequent, particularly as many do not monitor their blood glucose levels on a day-to-day basis.

“I’ve paid privately for HbA1c to understand progress I’ve had in the last six months. It’s ridiculous that I am only offered an annual test and no blood sugar monitoring in the meantime.”

Respondents were also asked whether a healthcare professional has spoken to them about their mental health in relation to their Type 2 Diabetes. This is important as people with Type 2 Diabetes are at greater risk of mental health conditions, such as depression, anxiety and eating disorder diagnoses.

Concerningly, the majority of respondents (**93%**) said a healthcare professional had not spoken to them about their mental health. However, not everyone wanted to speak with a health professional about this, with only **45%** of respondents agreeing that they would like a healthcare professional to talk to them about their mental health.

71% of Asian respondents would like a healthcare professional to speak to them about their mental health.

Education

Respondents with and without a diagnosis of Type 2 Diabetes were asked how the NHS could better educate the public about Type 2 Diabetes. One of the most common suggestions was to share and provide more information about what Type 2 Diabetes is, including the risk factors, symptoms and long-term complications.

“Make people more aware of all the risk factors, people may not realise.”

“Increase awareness of the signs and symptoms and provide information on what the effects of diabetes can be if left unchecked.”

Some respondents suggested that there needs to be more information, education and signposting about Type 2 Diabetes and the importance of living a healthy lifestyle, and for this information to be provided through a range of different means – including social media, leaflets, NHS websites, GP practices, and advertisements to name a few examples. A few respondents also suggested going out into local community groups, as well as secondary schools and colleges.

“I think face to face at community hubs for example – going to the people and being available for a chat plus leaflets/resources to take away post chat.”

“Curriculum in schools and colleagues. Introduce the topic when people are using the national health services.”

Other respondents felt there needs to be more testing for Type 2 Diabetes within both healthcare settings, but also community settings in which individuals can be more easily reached.

“Spell out the consequences and set up more testing in the community.”

“Offer a test people for diabetes whether they have symptoms or not.”

Lastly, a few respondents felt that healthcare settings should make every contact count, in which healthcare professionals use routine interactions to ask patients about their health, and in this case, information about Type 2 Diabetes.

“Use all appointments/touch points to give information and know where to signpost for one-on-one support like stop smoking service.”

Key Findings: Healthy Lifestyle

Barriers to Living a Healthy Lifestyle

Given that living a healthy lifestyle can help prevent Type 2 Diabetes for those without a diagnosis, and prevent or delay complications for people with a diagnosis, it was important for us to ask all respondents about their lifestyle, and how they could be better supported.

Firstly, when asked what prevents respondents from living a healthy lifestyle, many respondents commented that that due to work or caring responsibilities, it is difficult to find the time to do physical activity and/or to cook healthy meals.

“Also, time, as a single parent of young children I cannot go to the gym.”

“I have a job and children so fitting in the 5+ miles a day I would need to reduce my sugars is an impossibility.”

“A healthy lifestyle is one you need to plan and put effort into and sometimes I don't have the time or resources to be my healthiest.”

Another common barrier amongst respondents was lack of energy, willpower, or motivation. Some commented that due to this, they struggled to exercise regularly, lacked self-control and chose to eat unhealthy, convenient foods.

“Laziness. I don't like exercising and I find cooking a lot of effort. I do eat fruit and I have recently cut down my chocolate/pastry eating.”

“Self-discipline to exercise regularly.”

A large proportion of respondents shared that their pre-existing health conditions, lack of mobility, disability and/or pain made it much harder for them to be active, exercise, and cook healthy meals. Similarly, some respondents said they had struggled with their mental health, and/or felt “stressed” and “fatigued” which prevented them from being able to live a healthy lifestyle.

“The pain in encounter, I have had to cut down on physical activity, such as dog walks because it became increasingly painful.”

“Disability makes it impossible to exercise and to cook from scratch.”

“A lack of motivation and long term mental ill health.”

Some respondents said they did not have enough money to live a healthy lifestyle, commenting that gym memberships and classes are expensive, and that healthy food costs far more than unhealthy, processed, convenient food.

“Cost - ie cheaper to eat pre-packaged / prepared food then cook from scratch.”

“Cost of activities, gyms, classes.”

Support for Living a Healthy Lifestyle

In general terms, all respondents were asked what would support them to live healthier lifestyle. The most common answer was the need for easier access to exercise, activities and leisure facilities – ranging from physical access, greater affordability, and more availability. A few respondents wanted physical activity to be tailored, for example classes specifically for older people.

“More affordable and accessible leisure facilities.”

“Age appropriate exercise classes locally.”

The second most common response was the need for more information and education, particularly around nutrition, meal plans, exercise and portion control.

“Knowing what to eat and portion sizes.”

“Better guidance on food packaging on sugar content.”

Linked to this, some respondents felt it would be easier to eat healthily if fresh, healthy food was made more affordable, with a few respondents stating they have no choice but to purchase the cheaper, more unhealthy options.

“If fresh whole foods were less expensive, it seems cheaper to buy processed foods!”

Other respondents, particularly those with Type 2 Diabetes, said that the provision of more support groups could help them to live a healthier lifestyle, commenting that sharing issues and the support from other people is motivating and encouraging.

“Group therapy. I found it really helpful to talk with other in my situation.”

“Sharing issues with others in a similar situation.”

Lastly, a large proportion of respondents recognised that they need more willpower, less stress, and more time in their life if they want to try and live a healthier lifestyle.

“Less stress at work so not so tired on days off to cook healthily.”

Support from Healthcare Services

Respondents were also asked how the NHS specifically could help them to live a healthy lifestyle. The majority of respondents, whether they have Type 2 Diabetes or not, said they would like more regular health check-ups, and to be invited to the reviews and examinations they should be entitled to.

“Regular medical checks. I am 64 years old but don’t have any regular medical checks or MOT’s other than those I chase my GP to provide. If I don’t ring and ask for regular (annual) blood tests they would not happen.”

“Access to more regular health checks given that I am at risk of diabetes and have high cholesterol. Neither are being monitored currently.”

“Check me over now and then and reinforce my good habits whilst offering guidance with my not so good habits according to the check-up results.”

Secondly, respondents commented that they would like the NHS to provide more information and education, specifically to help them with lifestyle changes such as exercise, diet and nutrition – and for this information to be readily available in a range of formats.

“Give more facts about how to change your lifestyle where needed e.g. sleep patterns, eating habits, exercise.”

“Promote health habits through videos and internet communications.”

Linked to both points, some respondents also suggested that there should be more testing for Type 2 Diabetes and other health conditions in the community, as well as the implementation of more community prevention and health programmes.

“More easily accessible testing in the community.”

“More community based support on awareness.”

For people with Type 2 Diabetes, some respondents said they would like access to blood glucose monitoring, such as the Freestyle Libre, to help manage their blood glucose levels.

“A glucose monitor for a short time would help understand how different foods affect my blood sugar levels.”

Lastly, and perhaps unsurprisingly, a few respondents commented that they would like NHS services to be more readily available and more easily accessible, particularly GP practices.

“Make appointments easy to get to see GP.”

Conclusion

People without a diagnosis generally had good awareness of the risk factors and symptoms associated with Type 2 Diabetes – although knowledge of some of the most common risk factors and symptoms was lower across some demographic groups which needs careful consideration.

Positively, the majority of people without a diagnosis knew how to access support if they had concerns, and would feel comfortable speaking to a healthcare professional about this. However, 64% of respondents over the age of 40 had not had an NHS Health Check – this is concerning given the role NHS Health Checks play in identifying early signs of Type 2 Diabetes which could otherwise be missed.

For those who had been told that they are at high risk, encouragingly 58% felt supported in how to prevent Type 2 Diabetes. However only 55% had been referred to the NHS Prevention Programme, of which 45% attended – although referral and attendance statistics were much lower across some demographic groups. Most people who did attend had a very positive experience, highlighting the importance of ensuring anyone at risk is referred.

Findings for people with Type 2 Diabetes were also generally positive – with most respondents having had an Annual Diabetes Review in which the nine care processes were carried out, and the majority felt comfortable in self-managing their condition. Despite this confidence, most respondents still said they faced challenges and called for more information about healthy eating and more clinical support in lowering their blood glucose levels. They also felt their condition could have been better explained at diagnosis and more support given – with only 35% referred to the DESMOND programme.

Whilst these findings are promising, they also highlight key areas for continued improvements, particularly around support, information and education. For people with and without a diagnosis, there are particular demographic groups which clearly need targeted attention to ensure they are receiving the appropriate information, support and care from primary care services.

Recommendations

Based on the findings outlined in his report, it is recommended that the Hertfordshire and West Essex Primary Care Board takes forward the following recommendations.

1. Further investigate the inequalities in awareness, diagnosis and management amongst different demographic groups.
2. Consider targeted interventions and engagement with particular demographic groups, including men, ethnically diverse communities, those with less disposable income and those aged under 55.
3. Increase awareness of the risk factors, symptoms and long-term conditions associated with Type 2 Diabetes.
4. Promote NHS Health Checks and ensure eligible patients are invited.
5. Promote and refer people at high risk of developing Type 2 Diabetes to the NHS Diabetes Prevention Programme.
6. Clinicians to thoroughly explain Type 2 Diabetes and how the condition can be self-managed when giving a diagnosis.
7. Promote and refer people with Type 2 Diabetes to the DESMOND programme and/or other available courses.
8. Ensure people with Type 2 Diabetes are routinely monitored and given sufficient information and support to self-manage their condition, with a particular focus on lowering blood glucose levels and information about healthy eating.
9. Ensure all 8 care processes are carried out at Annual Diabetes Reviews and ensure enough time is given to discuss any issues and concerns with the patient.
10. Discuss mental health and wellbeing with people with Type 2 Diabetes, given that people with the condition experience disproportionately high rates of mental health problems.
11. Provide more information about healthy eating, nutrition, exercise and weight management in a range of accessible formats and in a range of settings – including

healthcare settings and community settings. Information could also take account of the added challenges to having a healthy diet in a cost of living crisis.

12. Consider the use of social prescribers when interacting with people at high risk of developing Type 2 Diabetes and those with the condition.