

NATIONAL DIABETES EXPERIENCE SURVEY

For each question, please choose your answer by putting a cross clearly inside one box using a black or blue pen. For some questions, you can choose more than one answer by putting a cross in more than one box.

Sometimes the box you have crossed will have an instruction to go to another question. Please follow these instructions carefully so you can skip any questions that don't apply to you.

If you make a mistake, just fill in the box and put a cross in the correct box.

If you can't answer a question, or don't want to answer it, please leave it blank and go to the next question.

If you would prefer to **fill in the survey online**, please go to www.diabetessurvey.co.uk/login



Access code:



DIAGNOSIS

You may have been diagnosed with diabetes as a child or an adult. Please answer the following questions based on your experience at that time.

1 What type of diabetes do you have?

- Type 1 diabetes
- Type 2 diabetes
- Other
- I don't know

2 How long ago were you diagnosed with diabetes?

- In the last 12 months
- 1 to 5 years ago
- 6 to 10 years ago
- More than 10 years ago
- I don't know or I can't remember

3 Which NHS service first diagnosed you with diabetes?

- GP practice
- Hospital
- Another NHS service
- None of the above
- I don't know or I can't remember

4 Which of the following describes how you were diagnosed with diabetes?

Put a X in all the boxes that apply.

- I was unwell over a period of time
- I suddenly became unwell
- I had a test to check my prediabetes
- I was seeing a healthcare professional about something else
- Other
- I don't know or I can't remember

5 Did any of the following delay your diabetes diagnosis?

Put a X in all the boxes that apply.

- I didn't recognise the symptoms of diabetes
- I needed several appointments
- I couldn't get an appointment
- I avoided making an appointment
- I was misdiagnosed
- I experienced other delays
- I didn't experience any delays
- I don't know or I can't remember

6 When you were diagnosed, did a healthcare professional share information about diabetes with you?

- Yes → Go to 7
- No → Go to 8
- I don't know or I can't remember → Go to 8

7 How useful was this information?

- Very useful
- Fairly useful
- Not very useful
- Not at all useful
- I don't know or I can't remember

8 Around the time of being diagnosed, did you have a conversation with a healthcare professional about what would happen next with your care?

- Yes
- No
- I don't know or I can't remember

NHS ANNUAL REVIEW

As part of your diabetes care you should have certain checks and tests every year. **This is called an annual review.** The review involves checking your HbA1c (your average blood sugar levels over the last three months), feet, blood pressure, cholesterol, blood and urine. You might not have all of these checks. The review may take place over several appointments. You may have a conversation with a healthcare professional to discuss the results.

9 Have you ever had an annual review for your diabetes?

- Yes → Go to 10
- No → Go to 19

10 When was your last annual review?

- Less than 12 months ago
- 1 to 2 years ago
- More than 2 years ago
- I don't know or I can't remember

11 Which NHS service was your last annual review with?

Put a X in all the boxes that apply.

- GP practice
- Hospital
- Another NHS service
- I don't know or I can't remember

12 Who did you speak to at your last annual review?

Put a X in all the boxes that apply.

- A GP or doctor
- A nurse
- Another healthcare professional
- I don't know or I can't remember

13 As part of your last annual review, which of these checks did you have?

Put a X in all the boxes that apply.

- Weight and BMI
- Blood pressure
- Foot check
- Urine test
- Blood test
- Smoking status review
- None of the above
- I don't know or I can't remember

14 Did you discuss any of the results from your annual review checks with a healthcare professional?

This could have been in person, by phone or video call.

- Yes, all of the results
- Yes, some of the results
- No
- I don't know or I can't remember

15 Thinking about your last annual review, how good was the healthcare professional at each of the following?

Involving you as much as you wanted to be in decisions about your care

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Considering your emotional and mental health needs

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Listening to you

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Sharing information that was easy to understand

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't receive any information

16 Thinking about your last annual review, did you have a conversation with a healthcare professional about what would happen next with your diabetes care?

- Yes → **Go to 17**
- No → **Go to 18**
- I don't know or I can't remember → **Go to 18**

17 How useful was this conversation in helping you manage your diabetes?

- Very useful
- Fairly useful
- Not very useful
- Not at all useful

18 Overall, how would you describe your experience of your last annual review?

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor

If you **have not** had an annual review in the last two years → **Go to 19**

If you **have** had an annual review in the last two years → **Go to 20**

19 Have any of the following meant you have not had an annual review for your diabetes?

Put a X in all the boxes that apply.

- I haven't been invited
- I don't know how to book one
- I haven't been able to get an appointment
- The appointments haven't been convenient for me
- I worry about what the healthcare professional might say
- There are too many tests and appointments involved
- I feel I manage my diabetes well so don't need a review
- Other

LAST NHS APPOINTMENT

We'd now like you to think about the **last time** you needed an appointment with a healthcare professional about your diabetes. This could have been in person, by phone or video call, and with your GP practice, hospital, or another NHS service. **Please don't include appointments for your annual review or diagnosis.**

20 When did you last have an appointment with a healthcare professional in the NHS about your diabetes?

Please don't include appointments for your annual review or diagnosis.

- Less than 12 months ago
- 1 to 2 years ago
- More than 2 years ago
- I haven't had another appointment
→ **Go to 25**
- I don't know or I can't remember

21 Which NHS service was this appointment with?

Put a X in one box only.

- GP practice
- Hospital
- Another NHS service
- I don't know or can't remember

22 Who did you speak to at your last appointment?

Put a X in all the boxes that apply.

- A GP or doctor
- A nurse
- A dietician
- A podiatrist (foot specialist)
- An optician (eye specialist)
- Another healthcare professional
- I don't know or I can't remember

23 Thinking about your last NHS appointment about your diabetes, how good was the healthcare professional at each of the following?

Please don't include appointments for your annual review or diagnosis.

Involving you as much as you wanted to be in decisions about your care

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Considering your emotional and mental health needs

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Listening to you

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't want or need this

Sharing information that was easy to understand

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor
- I didn't receive any information

24 Overall, how would you describe your experience at your last appointment?

- Very good
- Fairly good
- Neither good nor poor
- Fairly poor
- Very poor

DIABETES COURSES

25 Have you taken part in a course about diabetes?

This could be an in person or online course to help you manage your diabetes.

- Yes, in the last 12 months → Go to 26
- Yes, more than 12 months ago → Go to 27
- No → Go to 27

26 Did a healthcare professional offer you this course?

- Yes → Go to 28
- No → Go to 28
- I don't know or I can't remember → Go to 28

27 In the last 12 months, have any of the following meant that you have not taken part in a course about diabetes?

Put a X in all the boxes that apply.

- I have previously attended a course
- I didn't know a course existed
- I didn't know how to access a course
- I have not been offered a course
- It wasn't convenient for me
- I didn't see a benefit for me
- It wasn't suitable for my needs (such as dietary, cultural, or religious)
- It wasn't accessible for me
- I was on a waiting list for too long
- Other

LIVING WITH DIABETES

28 Thinking about the last 12 months, to what extent do you agree or disagree with the following statements?

My diabetes stops me being as physically active as I would like to be

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree

My diabetes stops me having the social life I want

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree

My diabetes is a constant worry

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree

I am financially worse off because of my diabetes

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree

29 Over the last 12 months, how much has diabetes affected your quality of life?

- A great deal
- A fair amount
- Not very much
- Not at all

30 To what extent do you agree or disagree with the following statement?

I have accepted that I am living with diabetes

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree

31 Over the last 12 months, how confident have you felt managing your diabetes day-to-day?

- Very confident
- Fairly confident
- Not very confident
- Not at all confident

32 Over the last 12 months, have you had support from other people living with diabetes?

- Yes → **Go to 34**
- No → **Go to 33**

33 Over the last 12 months, would you have found it useful to have support from other people living with diabetes?

- Yes
- No
- I don't know

34 Over the last 12 months, have you had support from healthcare professionals in the following areas to help you manage your diabetes?

Monitoring your blood sugar levels

- Yes
- No
- Doesn't apply to me

Taking medicine (such as tablets or insulin)

- Yes
- No
- Doesn't apply to me

Taking part in physical activity

- Yes
- No
- Doesn't apply to me

Eating well

- Yes
- No
- Doesn't apply to me

Your emotional and mental health needs

- Yes
- No
- Doesn't apply to me

35 Has a healthcare professional given you any of the following information about the medicine you take for your diabetes?

Put a X in all the boxes that apply.

- What the medicine is for
- Side effects or long-term effects of taking it
- How to take it
- Advice on adjusting it when you are not well
- I haven't been given any of this information
- I don't take medicine for my diabetes
- I don't know or I can't remember

36 Has a healthcare professional told you about the potential complications of living with diabetes?

For example, complications relating to your eyes or feet.

- Yes, in the last 12 months
- Yes, more than 12 months ago
- No
- I don't know or I can't remember

37 In the last 12 months, have any of the following made it difficult for you to manage your diabetes?

Put a X in all the boxes that apply.

- I've felt stressed or worn out from managing diabetes
- I don't know enough about diabetes
- My routine and how I manage my diabetes changes from day-to-day
- I'm managing other long-term conditions
- I'm too busy
- I don't have enough support from healthcare professionals
- Other
- I haven't found it difficult to manage my diabetes

USING DEVICES TO MANAGE DIABETES

38 Do you currently use any of these devices to help manage your diabetes?

Put a X in all the boxes that apply.

- Smart insulin pens
- Blood sugar monitor and test strips
- Insulin pumps (regularly release insulin)
- Flash glucose monitor or continuous glucose monitor (check sugar levels)
- Hybrid closed loops (check sugar levels and regularly release insulin)
- I use other devices
- I don't use any devices → Go to 40

39 How confident do you feel about using devices to manage your diabetes?

- Very confident → Go to 41
- Fairly confident → Go to 41
- Not very confident → Go to 41
- Not at all confident → Go to 41

40 Which of the following reasons explain why you do not use devices to manage your diabetes?

Put a X in all the boxes that apply.

- I don't need to use devices
- A healthcare professional hasn't offered me any devices
- The devices I need aren't available for me on the NHS
- I don't know whether I am eligible
- I don't think devices would benefit me
- I don't trust the technology
- I wouldn't feel confident using devices
- Other

ABOUT YOU

The following questions will help us see how experiences vary between different groups of people. We will keep your answers confidential.

41 How old are you?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 to 84
- 85 or over
- I would prefer not to say

42 Which of the following best describes you?

- Female
- Male
- Non-binary
- Prefer to self-describe:
- I would prefer not to say

43 Is your gender identity the same as the sex you were registered at birth?

- Yes
- No
- I would prefer not to say

44 Which of the following options best describes how you think of yourself?

- Heterosexual or straight
- Gay or lesbian
- Bisexual
- Other
- I would prefer not to say

45 Which of the following best describe what you are doing at present?

Put a X in all the boxes that apply.

- In full-time paid work (30 hours or more each week), including self-employment
- In part-time paid work (under 30 hours each week), including self-employment
- In full-time education at school, college or university
- Unemployed
- Unable to work due to long-term sickness or disability
- Fully retired from work
- Looking after the family or home
- Other

46 What is your religion?

- No religion
- Buddhist
- Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion
- I would prefer not to say

47 Apart from diabetes, do you have any physical or mental health conditions or illnesses lasting, or expected to last, 12 months or more?

- Yes
- No
- I don't know
- I would prefer not to say → **Go to 49**

48 Apart from diabetes, which of the following long-term conditions or illnesses do you have?

Put a X in all the boxes that apply.

- Blindness or partial sight
- Cancer in the last five years
- Deafness or hearing loss
- Dementia or Alzheimer's disease
- Gastrointestinal condition
- Heart or cardiovascular condition
- High blood pressure
- Joint problem, such as arthritis
- Kidney disease
- Learning disability, autism or both
- Liver disease
- Lung or breathing condition
- Mental health condition
- Neurological condition
- Stroke or TIA (Transient Ischaemic Attack)
- Another long-term condition or illness
- I do not have any other long-term conditions or illnesses

49 Thinking about diabetes and any other long-term conditions or illnesses you have, do any of these reduce your ability to carry out day-to-day activities?

- Yes, a lot
- Yes, a little
- No, not at all

50 What is your ethnic group?

A. White

- English, Welsh, Scottish, Northern Irish or British
- Irish
- Gypsy or Irish Traveller
- Roma
- Any other White background

B. Mixed or Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed or Multiple ethnic background

C. Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

D. Black, Black British, Caribbean or African

- Caribbean
- African
- Any other Black, Black British, Caribbean or African background

E. Other ethnic group

- Arab
- Any other ethnic group
- I would prefer not to say

THANK YOU VERY MUCH FOR YOUR HELP

Please return this questionnaire in the FREEPOST envelope provided. No stamp is needed.