

National Diabetes Experience Survey 2024

Technical annex



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1 Introduction

This technical annex provides details of the 2024 National Diabetes Experience Survey conducted by Ipsos on behalf of NHS England.

1.1 Background and overview of the survey

The National Diabetes Experience Survey is a new survey of people living with type 1 or type 2 diabetes in England. The survey has been created to address a gap in knowledge around variations in experience of diabetes care and treatment, as evidenced by the National Diabetes Audit (NDA).

The survey is designed to provide:

- an opportunity for people living with diabetes to feedback on their experience of diabetes care and self-management, supporting the development of a more person-centred approach to delivering services for people living with diabetes
- actionable data about experiences at a national, Integrated Care System (ICS) and sub-ICB level
- evidence of any variation or inequalities experienced by different demographic groups or type of diabetes

1.2 Survey methodology

The survey used a sequential push-to-web methodology. This means that respondents were encouraged to respond online, but the option to complete the survey via paper was also made available. This is based on tried and tested approaches used on other national patient experience surveys, to help optimise the overall response rate and deliver high-quality and representative data. It takes into consideration inclusivity and cost effectiveness.

Three invitation letters were sent via post. Each letter was followed by an SMS reminder if a mobile number was available for the individual. All mailings included information about how to access the online survey; a paper questionnaire was included in the final mailing.

Copies of the questionnaire and materials are available in the appendices.

1.3 Survey governance

Since February 2023, the governance of the survey has involved input from an Advisory Group and the existing governance structures of the NHS England Diabetes Programme. The Advisory Group membership included:

- Lived Experience Partners (people living with type 1 or type 2 diabetes, or carers of people living with diabetes)
- NHS clinicians from primary and secondary care
- NHS Integrated Care System representatives

- NHS England Insight and Voice Team representatives
- NHS England Diabetes Programme representatives

These groups provided invaluable input on the development of the questionnaire, to ensure it was gathering the correct information to understand the experiences of people living with type 1 or type 2 diabetes, the design of high-quality survey materials and the content and design of the survey outputs.

More information on their input throughout the project can be found in the Questionnaire and Survey Development Report (https://www.diabetessurvey.co.uk/latest-survey-materials).

2 Questionnaire and material development

2.1 Overview of development work

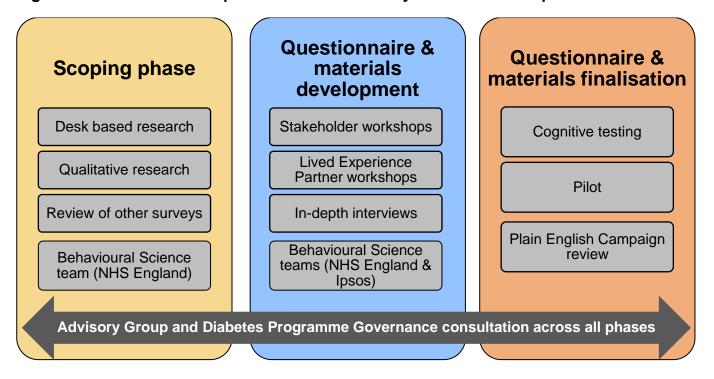
The approach to developing the questionnaire and materials for the National Diabetes Experience Survey centred on engaging key stakeholders and people living with diabetes. This ensured that the survey reflected what is important to people living with diabetes and framed questions in a sensitive manner. In addition, including clinical and non-clinical stakeholders ensured that the survey data could be used to improve and design services that best support people living with diabetes.

This section of the report provides an overview of the activities involved in the development of the questionnaire and survey materials. A separate report with further detail is available on the website (https://www.diabetessurvey.co.uk/latest-survey-materials).

A framework for development

Ipsos and NHS England carried out three separate phases of engagement to inform the development of the questionnaire and survey materials. Overall, 12 distinct engagement activities took place between March 2022 and October 2023, as detailed in Figure 2.1 below.

Figure 2.1: Framework for questionnaire and survey materials development



The scoping phase

The scoping phase, which took place between March and December 2022, focused on developing an understanding of the existing evidence base and experiences of people living with diabetes.

Desk-based research

NHS England commissioned desk-based research which was conducted by Innovas between March and April 2022. This involved a review of existing research on the experiences of people living with type 1 or type 2 diabetes in the UK and a demographic analysis of National Diabetes Audit (NDA) data by NHS England.

The desk-based research identified existing gaps in knowledge and priority areas for further research. This informed the focus of the qualitative phase of the programme and was also used to help develop the survey outline.

Qualitative research

NHS England commissioned a qualitative phase of research conducted by Solutions Research between September and December 2022. A mix of focus groups, online and in-person, and indepth interviews were conducted with 147 people across England.

The qualitative research highlighted key areas that the questionnaire should focus on and was key in developing the initial questionnaire outline.

Reviewing other surveys and validated toolkits

Several patient experience surveys and validated diabetes toolkits were reviewed, in conjunction with the findings from the desk-based research and qualitative research. The aim of this review was to gather information on the types of surveys and toolkits that already exist, understand what data is currently collected from people living with diabetes, and identify validated wording for questions.

Behavioural Science Team

The Behavioural Science Team at NHS England provided input from an early stage in the scoping phase to maintain the focus on understanding behaviours and attitudes of people living with diabetes. For example, they provided input into the design of the materials used in the qualitative research discussions. In addition, their input throughout the questionnaire development phase was important in identifying questions that could facilitate analysis to develop segments based on the behaviours and attitudes of people living with diabetes.

Questionnaire and materials development

Questionnaire development

The requirement to design a questionnaire that meets the needs of stakeholders and people living with diabetes was a key objective for the survey. To meet this intended outcome, a number of engagement activities were undertaken.

Table 2.1 summarises the key elements of the questionnaire development process along with their key purposes.

Table 2.1: Summary of questionnaire design engagement activities

Engagement phase	Purpose	Activities
Questionnaire structure	 To confirm the high-level topics and structure of the questionnaire To identify key information needed to inform policy and local commissioning decisions and prioritise high-level topics To explore how people would feel about being asked questions on their experience of living with diabetes To understand whether any topics might prove too sensitive or difficult to answer in a survey 	 Two workshops with stakeholders and Lived Experience Partners (people living with type 1 or type 2 diabetes, or carers of people living with diabetes) Three in-depth interviews with people living with diabetes
Drafting questions	 To draft questions with a focus on ensuring that the survey provides relevant and actionable information To test the relevance of questions for people living with type 1 or type 2 diabetes. To check that response code lists are comprehensive To test the level of comfort with answering specific questions 	 Two workshops with stakeholders and Lived Experience Partners Three in-depth interviews with people living with diabetes
Prioritisation of questions	 To ensure that the questionnaire focused on providing actionable data To achieve a questionnaire length that does not burden participants To ensure that the questionnaire content remained relevant 	Two workshops with stakeholders and Lived Experience Partners

The Advisory Group and NHS England, including the Behavioural Science Team, were involved at all stages of the questionnaire development phase, providing responses to ad hoc queries, attending workshops and scheduled meetings and helping to develop the survey questions.

Survey materials development

To develop the initial drafts of the survey invitation letter, two reminder letters, and three text message reminders, Ipsos reviewed several other patient experience survey invitation letters and text message reminders.

The key principles and content of the draft invitation letter and reminder letters were then reviewed by members of the Advisory Group to make sure they were satisfied with the language used, the format, and the signatory included on the letters. The group also fed back on the SMS reminder messages, including content and sender name, and suggestions were made to amend the language to ensure they were seen as genuine and trustworthy.

Questionnaire and materials finalisation

Cognitive testing

Cognitive testing is a method used to critically evaluate questions. It employs specialist techniques to help understand how participants process and respond to materials, in this case, the questionnaire and survey materials.

Ipsos conducted 40 cognitive interviews in September 2023 with participants who reflected the diversity of people living with diabetes (e.g. by age, diabetes type, ethnicity, education level, geographical region, language spoken and presence of a long-term health condition in addition to diabetes).

The interviewing was conducted iteratively across three rounds, with analysis sessions conducted between each round. In these sessions, the Ipsos team who undertook the interviews discussed the emerging themes, including problems identified with questions and recommendations for improvements to both the questionnaire and survey materials. Participant feedback was used to ensure that the response options and terminology used in the questionnaire were well understood.

Survey pilot

A pilot was carried out with seven people living with diabetes. This tested experiences of completing the questionnaire independently, with no guidance from the research team, and gathered feedback on the questionnaire's usability. The findings were used to identify improvements which fed into the final round of cognitive testing.

Following this feedback, a further five telephone interviews were conducted with pilot participants. These interviews were used to test any queries which had not been resolved after the third round of cognitive testing.

The Plain English Campaign review

The survey questionnaire and materials were reviewed by the Plain English Campaign before the first round of cognitive testing and after the third round. Where possible, changes were made to content to meet criteria laid out by the Plain English Campaign. Following their final review of the questionnaire, the Plain English Campaign awarded the survey data collection materials a Crystal Mark, in recognition of the clarity of the documents. More information can be found at www.plainenglish.co.uk.

2.2 The final questionnaire

Below is a list of the topics covered in the 2024 questionnaire. The full questionnaire is available on the website and in the <u>appendices</u>.

- Diagnosis
- NHS Annual Review
- Last NHS Appointment
- Diabetes Courses
- Living with Diabetes
- Using Devices to Manage Diabetes
- About you (demographics)

2.3 Survey materials

The full set of letters and SMS wording used are available in the appendices.

3 Sampling

3.1 Sample overview

The National Diabetes Experience Survey was sent to just under 109,000 people living with type 1 or type 2 diabetes in England. The sample was designed with the aim of collecting 1,000 responses per ICS, to provide confidence in the overall results and allow subgroup analysis where appropriate.

The sampling procedure involved two distinct stages. Firstly, NHS England provided a list of people living with type 1 or type 2 diabetes from the National Diabetes Audit (NDA), excluding contact details at this stage, for sample size determination and individual patient selection. The selected records were returned to NHS England, and a second file containing the contact details of the selected patients was provided.

3.2 Dissent process

Ahead of sample selection, people living with diabetes were given the opportunity to "opt-out" of being invited to take part in the survey. A series of posters (physical and online) were distributed to notify people of the survey, containing details of how to opt-out of the survey sample. Any individual that opted out during this period was removed before sampling took place. During fieldwork, people that were sent invites to the survey, were able to opt-out of future mailings.

3.3 Sample selection, including eligibility criteria

To be eligible for selection to take part in the survey, the sample had to meet a number of eligibility criteria, which is outlined in the table below:

Table 3.1: Summary of eligibility criteria

Item	Criteria
Age	Only those aged 18 and over at the time of sampling were eligible to take part
Gap between entry to adult	Only those that were diagnosed at least 12 months ago (at the
services	time of sampling) were eligible to take part
Diahataa tuna	Only people recorded as living with Diabetes in the NDA were
Diabetes type	eligible to take part. Those coded as "unknown" diabetes type were also included in the sample.

It was agreed that the sample would be selected to over-sample ICSs with a predicted low response rate. The aim was to achieve 1,000 responses per ICS, with each ICS aiming for a 70 (type 2): 30 (type 1) split by diabetes type. This modelling is based on the GP Patient Survey (GPPS) 2023 and NDA data.

3.4 NHS England population extraction procedure

NHS England provided a file of a patient data for all eligible patients who were living with Diabetes, resided in England and were registered with a practice in England at the time of sampling. The file contained an individual's NHS numbers, practice code, sex/gender, age

band, type of diabetes (including information from the National Diabetes Audit) and postcode, but did not include contact details.

3.5 Sample size calculation and sample selection

The expected response rate for each ICS, by diabetes type, was calculated by weighting GPPS response rates for each ICS to the age, IMD, and ethnicity demographics of those living with type 1 or type 2 diabetes within that ICS.

This was then used to calculate the number to be selected for those living with each type of diabetes within each ICS to achieve 300 responses from people living with type 1 diabetes and 700 responses from people living with type 2 diabetes. The number of expected responses per sub-ICB were then modelled and any sub-ICB with fewer than 100 expected responses was boosted to aim for 100 responses.

The sample was selected by diabetes type within each ICS, using a one in n approach, to ensure a random probability sample. The sample was also stratified by all variables provided within the population.

3.6 Personal data extraction

On receipt of the selected records from Ipsos, the PDS team at NHS England extracted the contact details for each person to be included in the sample. The extracted file contained, for each person, their GP practice code, NHS number, name, address, month and year of birth, sex/gender, and mobile number (if available). Where a selected individual had become ineligible since the provision of the data, an "exclusion" record was sent instead, containing the unique survey serial number and no other details.

3.7 Sample cleaning and exclusions

In addition to profile checks to ensure the accuracy of the data provided by the PDS team, checks were made by Ipsos on the supplied names, mobile numbers and addresses to remove or amend inappropriate records. These checks included:

- duplicates (identified by an individual's NHS number)
- removal of invalid mobile numbers (i.e. those not starting with 07 and/or not 11 digits long).
- non-address details or other inappropriate information contained in the address. This could include:
 - key safe numbers, telephone numbers and any other numeric not related to the address
 - unexpected words or phrases in the name or address (including "unknown", "homeless", "deceased", "test", etc.)
 - incomplete addresses

It was also checked against the Ipsos "Do Not Contact" database, to ensure that those who have previously expressed a wish not to be contacted by Ipsos, were not included.

For the SMS reminders, duplicate mobile numbers (where more than one person had the same mobile number listed) were removed, as it would not be possible for the recipient to determine which link corresponded with which survey.

All those included in the final sample were randomly sorted before being allocated a 12-character alphanumeric ID.

3.8 Final mailed sample after cleaning and exclusions

The final number of people living with diabetes to whom invites were sent after all sample cleaning had been conducted was 108,895.

4 Communications

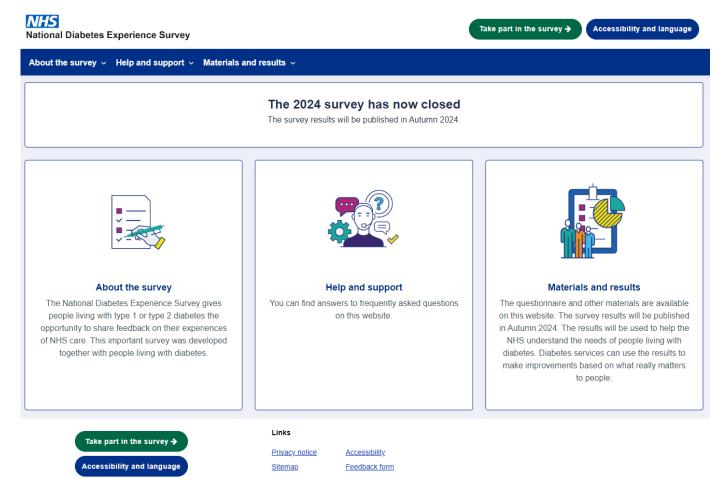
To raise the profile of the National Diabetes Experience Survey and provide people with support and information about the survey, a series of communication activities were undertaken.

These activities are described in more detail below.

4.1 Survey website

A dedicated survey website is maintained and hosted by Ipsos. The advertised web address is www.diabetessurvey.co.uk. The site is designed to reflect the branding of the questionnaire and all other related materials (see www.diabetessurvey.co.uk).

Figure 4.1: The <u>www.diabetesurvey.co.uk</u> homepage



Developing the National Diabetes Experience Survey website

A new website was required to support the National Diabetes Experience Survey programme. At an overall level, the website needed to meet the following objectives:

 Act as the public face of the survey, providing a resource for potential participants, including background information about the survey, a set of frequently asked questions, contact information for the Ipsos helpline, accessibility information, as well as access to the online survey during fieldwork.

Increase the impact and value of the data generated for users which, in addition to
participants or potential participants, includes policymakers, clinicians, diabetes
organisations and patient representatives as well as other people living with or
supporting those living with diabetes. Its aim was to provide access to information about
the survey methodology and materials, reporting outputs and support for data users.

To achieve this, Ipsos worked closely with NHS England, the programme's Advisory Group and a small group of potential users, from a range of stakeholder groups, to iteratively develop a website that meets these objectives in a user-friendly way.

Launching the National Diabetes Experience Survey website

The website was initially launched in November 2023, ahead of the start of fieldwork, to provide support for potential participants, including the dissent process.

The full website was launched in February 2024 to support the survey fieldwork. It consists of the below sections:

- 'Take part in the survey' is a link to the online questionnaire where participants can complete the survey.
- 'Survey background' outlines the purpose and importance of the survey. Additionally, this section explains the invitation process for participants.
- 'Meet the survey team' introduces users to various members of the Advisory Group and highlights their contributions to the survey at each stage of its development process.
- 'Promote the survey' offers downloadable resources which can be used by the NHS or suitable charities to raise awareness of the survey. It contains downloadable web banners, icons and a communications toolkit, which includes details on key messaging, a newsletter and blog copy, social media posts and promotional materials.
- 'Communications Assets Poster' provides posters in English and 11 other languages, which can be printed out or displayed on a website or on social media.
- 'FAQs' provides information about the survey, guiding users on how to participate, opt-out, and addresses queries related to confidentiality and data protection.
- 'Accessibility and languages' ensures accessibility by providing information about the survey, the invitation letter and FAQs in 11 languages other than English: Arabic, Bengali, French, Gujarati, Italian, Polish, Portuguese, Punjabi, Romanian, Spanish and Urdu.
- 'Latest survey materials' takes users to the survey questionnaire, invitation letter and survey development report.

- 'Latest survey results' takes users to the survey datasets and reports at national and ICS level.
- 'Contact us' provides an email address for the project team at Ipsos.
- 'Sitemap' provides a list of all the pages on the website.
- 'Accessibility' provides information on how to adapt the website for users with different accessibility needs. This includes guidance on adjusting text size, background colours, using keyboard navigation, and screen readers.
- 'Privacy notice' outlines the information the website collects, such as cookies and device type, and describes how this information is used and held securely.
- 'Feedback form' allows users to give feedback on the website.

4.2 Posters and promotional materials

A poster was made available for GP practices to display in English and 11 additional languages. Copies of the posters were available on the website for download and printing or displaying on electronic notice boards at https://www.diabetessurvey.co.uk/promote-the-survey.

A communications toolkit is also available on the website, designed to help NHS services and relevant charities promote the survey, to raise awareness and encourage invited individuals to participate. It includes details on key messaging, a newsletter and blog copy, social media posts, videos of the Advisory Group, posters, website banners and icons and FAQs. The toolkit can be found at https://diabetessurvey.co.uk/promote-the-survey.

4.3 Support for participants

Telephone helpline

Ipsos offered a Freephone helpline for participants who had any questions about the survey, with separate numbers for English and 11 additional languages. In total, 2,211 calls were handled by the helpline team over the course of fieldwork.

English language telephone helpline

Respondents who contacted the telephone helpline initially reached a pre-recorded message which explained the purpose of the survey and asked the caller to leave a message and telephone number if they wished to be called back.

Call handlers were available to respond to voicemails between 10am to 4pm Monday to Saturday from 18 March to 8 July 2024. Voicemails left outside of these hours were responded to as soon as call handlers became available.

Call handlers were provided with a manual containing a complete list of over 40 FAQs to answer participants' queries. Where the call handlers could not answer a query, the details were passed on to the Ipsos project team who responded directly.

As well as being a source of information for participants, the helpline also enabled participants to complete the survey over the telephone.

In addition, participants could opt out of the survey by providing their access code or contact details to the helpline. The sample was refreshed ahead of each mailing to ensure that those that did not wish to be contacted again, were removed.

In total 2,211 calls were made to the telephone helpline.

4.3.1 Additional language telephone helpline

To make the survey as accessible as possible, separate helplines for each of the 11 additional languages that the survey is offered in were available. Each language had its own Freephone number which was connected to a voicemail message in the corresponding language. As with the English language voicemail, a message briefly explained the purpose of the survey and asked the caller to leave a message and telephone number if they wish to be called back. Ipsos arranged for Language Line to return the calls within two working days. Respondents calling the additional language telephone helpline were able to complete the survey over the phone or opt out of taking part.

4.3.2 Email helpline

As well as using the telephone helpline, participants were also able to email the project team at lpsos with any queries. In total, 155 email queries were received and responded to during fieldwork.

4.3.3 Written correspondence

The survey generates mail returned to the Freepost address, including letters and notes addressed to the Ipsos project team or to NHS England. This is separated from the returned questionnaires and delivered to the helpline team on a weekly basis for review. There were 15 letters received over the course of the fieldwork period.

4.3.4 Safeguarding

Most calls and other correspondence received about the survey were relatively straightforward, and the helpline team were well briefed and experienced in engaging with respondents ethically and sensitively. A formal protocol, agreed with NHS England, outlined the procedures staff should follow when a safeguarding concern occurs, though this was not required.

4.3.5 Data protection protocols

Several formal protocols were in place to respond to data protection queries, such as subject access requests, requests to update personal information or to delete data. These protocols (agreed with NHS England) outlined the steps that would be followed by Ipsos and NHS England in response to these requests. The protocols also include secure storage information and retention periods for these communications.

Note that during fieldwork, following the initial mailing a potential data breach was reported by a survey participant concerned the name of the survey being printed on the outer survey envelope

as the address for undeliverable post. This was escalated immediately to the NHS England team, as data controller, for a decision on next steps. Subsequently, two other participants got in touch about the same issue. It was agreed that the envelopes for all subsequent mailings should be reprinted without reference to the survey name.

All three survey participants who contacted lpsos about the envelopes were either contacted by NHS England or lpsos, outlining the steps taken in response.

4.3.6 Easy read information sheet

An easy read information sheet, which could be found on the website during fieldwork provided information about the survey in an easy read format. The information sheet included details about the how the survey could be completed, as well as directing participants to the helpline to answer any other questions.

5 Data collection

5.1 Overview of survey methodology

The survey methodology was designed with three key principles in mind:

- To provide actionable insights into experiences of care.
- To deliver robust data which is representative of people living with diabetes at national and ICS level.
- To codesign the survey with people living with diabetes and stakeholders, ensuring the questionnaire reflects the experiences of people living with diabetes.

The survey used a sequential push-to-web methodology. The approach was used to invite people to take part in the survey with three invitation letters sent via post. Each letter was followed by an SMS reminder if a mobile number was available for the individual. All mailings included information about how to access the online survey. A paper questionnaire was included in the final mailing only.

5.2 Contact strategy and fieldwork dates

An initial invitation letter was sent to all survey participants on the first day of the survey, 18th March 2024, as outlined in the table below (Table 5.1). This was followed one week later by an SMS reminder to all those in the sample with a valid mobile phone number.

The first letter reminder was sent out on 10th April followed by a SMS reminder. The second letter reminder mailing, which included a copy of the paper questionnaire, was sent out from 7th May, with a final SMS reminder a week later.

An additional paper mailing reminder, with the questionnaire enclosed was sent out in June to a small proportion of survey participants who had, in error, not received the reminder letter in May. This additional mailing was sent out as soon as possible to take advantage of the previous contact points, with a view to maintain a high response rate. The online survey and helpline remained open during the fieldwork extension.

Copies of all letters and SMS reminders can be found in the <u>appendices</u>.

Table 5.1: Survey mailout and SMS reminder dates

	Dates
Initial paper mailing	18 March 2024
First SMS reminder	25 March – 26 March 2024
First postal reminder mailing	10 April 2024
Second SMS reminder	17 – 18 April 2024

	Dates
Second postal reminder mailing inc. questionnaire	7 May – 9 May 2024
Third SMS reminder mailing	15 May – 16 May 2024
Additional reminder mailing inc. questionnaire*	19 June 2024

^{*}Only sent to those who did not receive the second reminder mailing.

5.3 Mailing process

The final survey sample was delivered to the printing house via secure file transfer protocol (SFTP), using high level encryption. A downstream access provider was used for processing the mailing packs, and items were then handed over to Royal Mail for 'final mile' delivery.

All letters and questionnaires were digitally printed as required, ahead of each postal mailing. C5 Business Return envelopes, and C5 outer envelopes were also printed in advance. The letters were personalised with name, address, and the individual's unique access code, which also appears on the questionnaire. They were then packed, ready for collection by the downstream access provider.

5.4 Text messages

The final mobile number sample was delivered to the text message provider via secure file transfer protocol (SFTP), using high level encryption. All SMS messages were personalised with a short URL that was unique to each participant, allowing them direct access to the online survey.

To manage the volume of text messages that was issued into the mobile network at any time, an automated system scheduled a set number of messages in batches, every 5 minutes from 9am to 8:55pm over a two-day period.

5.5 Handling reminders

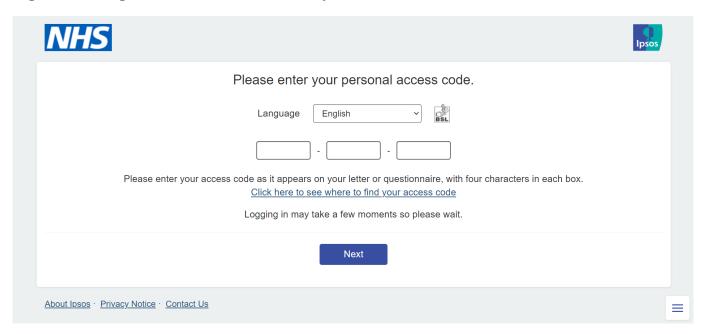
Participants who were **not** sent a reminder, included those who met the following criteria at the point of the relevant deadline:

- Had taken part in the survey online (or returned a paper questionnaire ahead of SMS3).
- Had taken part in the survey via the helpline.
- Had telephoned or emailed the helpline and opted out of the survey.
- Had opted out via NHS England.
- Were identified via letters returned as undeliverable.
- Individuals recorded as deceased or no longer eligible on the NHS England database.

5.6 Online completion

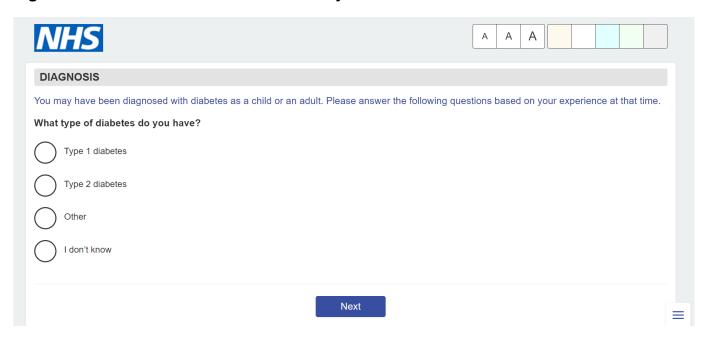
Each participant in the sample was assigned a unique access code (printed on the letter and on the front page of the paper questionnaire) that allowed them to access the online survey either via the survey website (www.diabetessurvey.co.uk/take-part-in-the-survey) or by using a shortened URL available in the letter (www.diabetessurvey.co.uk/login). To complete the survey online, participants were required either to enter their unique access code on a login screen (see Figure 5.1), or to click on the unique URL in the SMS reminder.

Figure 5.1: Login screen for online survey



The questions in the online survey were identical to those on the paper questionnaire in terms of wording and design. To ensure comparability between the online survey and paper questionnaire, participants were able to skip questions in the online survey. However, a soft prompt asked them if they were sure they wanted to skip each question, to encourage completion. The online survey included large answer option buttons, keyboard navigation, and labelled 'Next' and 'Back' buttons to improve accessibility. The online survey was also compatible with screen reader software on both desktop and mobile devices.

Figure 5.2: Question from the online survey



Only one online response per participant was accepted. If participants tried to complete the survey more than once online, a message appeared letting them know they had already completed it. If they did not complete the survey in one sitting, their unique access code returned them to where they had left off.

5.6.1 Total number of online returns

Overall, 33,440 people living with diabetes completed the survey online during fieldwork in 2024, which made up 78.7% of all completes.

5.6.2 Alternative online formats

Participants were offered several alternative methods of completion to ensure the survey was as accessible as possible. This included the option to complete the online survey in one of 11 languages offered (in addition to English), or in British Sign Language (BSL). These versions of the survey were accessible from the specific language pages on the website or via a language drop down on the online survey login page (see Figure 5.3). Using one of these routes, participants could choose the language in which they wished to complete the survey (English, Arabic, Bengali, French, Gujarati, Italian, Polish, Portuguese, Punjabi, Romanian, Spanish or Urdu).

For those entering the online survey via the shortened URL in the letter (www.diabetessurvey.co.uk/login) or the short link in the SMS, there was a language selection option on the login page (see Figure 5.3).

Figure 5.3: Introduction page for SMS route to online survey with language selection option



Likewise, participants were able to access the BSL version on the page dedicated to supporting BSL users. This involved showing video clips of a BSL user signing the instructions, questions, and options available (see Figure 5.4).

Figure 5.4: Viewing the questionnaire in BSL

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.

What type of diabetes do you have?

\bigcirc	1 - Type 1 diabetes
\bigcirc	2 - Type 2 diabetes
\bigcirc	3 - Other
\bigcirc	4 - I don't know

Table 5.2: details of additional language and BSL survey completions

Completes

Arabic	46
Bengali	18
French	4
Gujarati	8
Italian	12
Polish	95
Portuguese	30
Punjabi	18
Romanian	43
Spanish	18
Urdu	16
Total	308
BSL	23

5.7 Telephone completion

Participants were also able to complete the survey questionnaire on the telephone (including in the 11 additional languages) by calling the Freephone helplines. Participants were asked for their unique access code before they could complete the survey and there was an automatic check on the access code to ensure that it was valid for the live survey. Helpline staff entered callers' answers directly into the online version of the survey. In total, the helpline team assisted 33 participants in completing the survey during 2024 fieldwork, mostly because they preferred to complete the survey over the phone, they had a visual impairment or lacked internet access.

5.8 Braille and large print versions

Braille users were offered the opportunity to receive the questionnaire and letter in Braille and could then take part in the survey online. They were sent a braille copy of the questionnaire which, once returned, could be entered online by the team. During fieldwork, there was one request for a Braille version, which was returned.

Large print was also made available for those who request a copy of the letter and questionnaire in this format. Returned large print questionnaires were entered manually into the online survey by the helpline team, using the participant's unique access code. There were 19 requests for a large print survey, of which six were returned.

6 Data analysis

6.1 Questionnaire processing

Questionnaire data collected online is logically prevented from containing data contrary to the questionnaire instructions (such as multiple responses to a question requiring a single answer).

Paper questionnaires are returned in supplied freepost Business Reply Envelopes (2nd class) to the scanning house. Envelopes are machine opened and questionnaires collated, guillotined and prepared for scanning. Any other items of correspondence are set aside for review and response by Ipsos or NHS England, as appropriate.

Paper questionnaires are processed using access codes, allocated to each case in the sample. All marks on the forms are recognised at this stage, regardless of whether they are in accordance with the questionnaire instructions.

The deadline for the survey closing was 8th July 2024. However, to allow for any postal delays, paper questionnaires were accepted and included if they were received by 16th July 2024. This was extended from 27th May 2024 to allow the small proportion of survey participants who incorrectly did not receive a paper questionnaire in the third mailing to return it if they wished.

Therefore, the fieldwork period is defined as 18th March to 16th July 2024.

6.2 Inclusions and exclusions

The rules and protocols used for delivering the data for the 2024 survey are as follows:

- All completed online responses where the respondent has clicked on the final "submit" button, along with all paper questionnaires received with identifiable access codes, are eligible for inclusion.
- Returned questionnaire figures are based only on those qualifying for inclusion in the dataset as described in this document.
- The published response rates are based on all completed, valid questionnaires returned and all questionnaires sent. They have not been adjusted to exclude questionnaires which did not reach the sampled individual, e.g. where envelopes have been returned undelivered etc. However, weighted and adjusted response rates have also been included in Chapter 7: Response rates, which take into account the selection likelihood and undelivered questionnaires.
- The following are excluded from the data:
 - All questionnaires marked as completed by under-18s.
 - All questionnaires where there is only data for a limited number of questions (e.g. only the first page was completed, or only the demographic questions were completed).
 - All blank questionnaires.

Questionnaire data are combined from online and scanned data sources. Where duplicates between mode of completion exist, the data used are selected according to the case that is the most complete (i.e. with the fewest unanswered questions). If there is no difference in completeness, the data used are then selected according to a priority order with online data having precedence.

6.3 Quality assurance

A number of checks were undertaken at key stages of the survey, including during the sample preparation and data cleaning stages. These help to identify obvious errors in the sample and response data, such as the inclusion of ineligible patients or incorrect coding.

6.4 Editing the data

For the completed paper questionnaires, there is a degree of completion error that occurs (e.g. ticking more than one box when only one response is required, answering a question that is not relevant, or missing questions out altogether). Therefore, it is necessary to undertake a certain amount of editing to ensure the data is logical. For example:

- If a respondent ticks more than one box where only one answer is required, then their reply for that question is excluded.
- Where respondents are allowed to select more than one box for a particular question, the reply for that question is excluded if they select two conflicting answers for example, at Q4 ('Which of the following describes how you were diagnosed with diabetes?'), if a respondent ticks any of the first five options as well as 'I don't know or I can't remember, then their response for that question is excluded. The following list shows the questions this applies to, as well as the response options that are treated as single code only:
 - Q4 'Which of the following describes how you were diagnosed with diabetes?' 'I don't know or I can't remember'
 - Q5 'Did any of the following delay your diabetes diagnosis?' 'I didn't experience any delays' and/or I don't know or I can't remember'
 - Q11 'Which NHS service was your last annual review with?' 'I don't know or I can't remember'
 - Q12 'Who did you speak to at your last annual review?' 'I don't know or I can't remember'
 - Q13 'As part of your last annual review, which of these checks did you have?' 'None of the above' and/or 'I don't know or I can't remember'
 - Q22 'Who did you speak to at your last appointment?' 'I don't know or I can't remember'

- Q35 'Has a healthcare professional given you any of the following information about the medicine you take for your diabetes?' – 'I haven't been given any of this information' and/or 'I don't take medicine for my diabetes' and/or 'I don't know or I can't remember'
- Q37 'In the last 12 months, have any of the following made it difficult for you to manage your diabetes?' – 'I haven't found it difficult to manage my diabetes'
- Q38 'Do you currently use any of these devices to help manage your diabetes?' 'I don't use any devices'
- Q40 'Which of the following reasons explain why you do not use devices to manage your diabetes?' – 'I don't need to use devices'
- Q48 'Apart from diabetes, which of the following long-term conditions or illnesses do you have?' – 'I do not have any other long-term conditions or illnesses'
- If all boxes are left blank the reply for that question is excluded.
- If a respondent fails to tick the relevant answer for a filter question, any responses are excluded from the subsequent questions relating to that filter question. For example, if a patient responds to Q7 ('How useful was this information?') without having first responded 'Yes' at Q6 ('When you were diagnosed, did a healthcare professional share information about diabetes with you?'), their reply to Q7 is excluded.
- For the question on whether they have any physical or mental health conditions or illnesses lasting 12 months or more (Q47), respondents who initially answer other than 'Yes' have their answer recoded to 'Yes' if they went on to select any long-term conditions or illnesses at Q48.

6.5 Reporting of diabetes type

Reporting and data outputs for the National Diabetes Experience Survey typically present the results by type 1 and type 2 diabetes separately. The only exception being a set of summary results included in the data tables.

Diabetes type is derived from data held for each respondent in the National Diabetes Audit (NDA), rather than being taken from self-reported diabetes type as provided at the first survey question (Q1 What type of diabetes do you have?).

NHSE and Ipsos agreed to use NDA information, rather than self-reported diabetes type, as 5% of responses to Q1 in the survey did not clarify whether the respondent had type 1 or type 2 diabetes. Utilising sample data ensures that 100% of records will be shown where the results are provided separately for type 1 and type 2, it mirrors the approach taken for the NDA analysis and the approach for weighting (which is based on sample data).

Information collected via the survey questionnaire for self-reported diabetes type is shared in reporting outputs to help survey stakeholders understand the proportion of people who appear to be unsure of their diabetes type.

6.6 Weighting strategy

Weights were generated to correct for the sampling design and to reduce the impact of non-response bias. The weights were calculated using the following three stages:

- Step 1: creation of design weights to account for the unequal probability of selection.
- Step 2: generation of non-response weights to account for differences in the characteristics of responders and non-responders.
- Step 3: generation of calibration weights to ensure that the distribution of the weighted responding sample across practices resembles that of the population of eligible patients, and that the age and gender distribution within each Integrated Care System (ICS) matches the population of eligible patients within the ICS.

Weights for patients living with type 1 diabetes and type 2 diabetes were calculated separately, based on sample data. These produced two weights, one for use for analysing the experiences of patients living with type 1 diabetes and one for patients living with type 2 diabetes. A third weight was produced to look at experiences of patients living with diabetes overall. This was calculated by adjusting the individual weights to account for the unequal probability of selection by type of diabetes.

Design weights were computed to correct for the disproportionate sampling of patients by ICS, sub-ICB boosts, and experiment sample selection, as the inverse of the probability of selection, e.g. by dividing the total number of eligible patients in the ICS at the time of sampling by the number sampled.

Non-response weights were constructed using a model-based approach to estimate the probability of taking part in the survey. This model, created using the current year's data, estimated the probability of responding based on the sample data of the patient and the socio-economic characteristics of the neighbourhood in which the patient lived. These weights aim to reduce the demographic and socio-economic differences between respondents and non-respondents.

Data from the sampling frame (patient's age, sex/gender, region, and data from the National Diabetes Audit) was linked to external data using the home postcode of the patient. This consisted of measures from the 2021 Census: output area aggregated measures of ethnicity, marital status, overcrowding, household tenure and employment status, as well as the indicator of multiple deprivation score (IMD) and ACORN group.

The probability of response was estimated using a logistic regression model with response (or not) as the outcome measure and the measures described above included as covariates. Standardised design weights were applied when running the model to obtain unbiased estimates for the coefficients.

The model allows us to identify patterns in non-response behaviour: female patients were more likely to respond than male patients, younger patients were less likely to respond than older patients, and those using insulin were more likely to respond than those using other treatment approaches. There were also some differences by region, with response lowest in London and

highest in the South West. Response was also lower in ACORN groups N ('Urban Diversity'), S ('Cash-strapped Families'), T ('Constrained Pensioners'), and U ('Challenging Circumstances').

Response also decreased for patients living in Census Output Areas (OAs) with the following characteristics:

- higher levels of deprivation based on IMD scores
- a higher proportion of people from ethnic minority backgrounds
- a higher proportion of single, separated, or divorced people
- a higher proportion of households with three or more people
- a higher proportion of privately rented households; and/or
- a lower proportion of employees

The non-response weights were calculated as the reciprocal of the predicted probability of response estimated from the model. To avoid very large weights, the non-response weights were capped for the 0.25% largest values. The non-response weights were multiplied by the design weight to obtain the starting weights for the calibration.

The starting weights were then calibrated to practice population counts, and to population counts by age and sex/gender within each ICS. The population totals used for the calibration were estimated from the sampling frame.

To avoid very large weights, the ratio of the calibration weights to their starting weights was trimmed at a value of 2.5. Finally, the weights were standardised to sum to the sample size.

The sex/gender data supplied as part of the sample was used for weighting, as this allowed for non-response weights to account for those who have not participated. However, all analysis is based on the data provided during the survey, to ensure there is transparency on the questions asked and options provided when the data were collected.

6.7 Statistical significance

The ICS data tables and slide packs include significance testing to help demonstrate where a difference between two results is genuine, rather than down to chance. Significance is tested using a two-sample t-test.

In the ICS data tables, this is shown by the word "higher" or "lower" to compare the ICS result to the national result. In the PowerPoint reports, this is shown by an up or down arrow. When the change is not statistically significant, the column is left blank. For both outputs, the significance testing has only been applied to the ICS result and the national result.

7 Response rates

7.1 Overall response rates, including by diabetes type

The overall response rate for England was 39.0%, based on 108,895 questionnaires sent out and 42,502 valid returned.

The type 1 diabetes response rate was 41.9%, based on 43,067 questionnaires sent out and 18,051 valid returned.

The type 2 diabetes response rate was 37.1%, based on 65,828 questionnaires sent out and 24,451 valid returned.

Table 7.1: Surveys sent, returned and unadjusted response rates

	Number sent	Number returned	Response rate	
Total 108,895		42,502	39.0%	

Table 7.2: Response rates for type 1 and type 2

	Number sent	Number returned	Response rate
Type 1	43,067	18,051	41.9%
Type 2	65,828	24,451	37.1%

8 Reporting

8.1 Presentation of results

Many of the National Diabetes Experience Survey outputs lead with a summary result; a single statistic that provides a quick way of viewing the result for a question. This is usually an aggregation of two individual responses (e.g. '% Useful' is a combination of '% Very useful and '% Fairly useful') or a single response option (e.g. '% Yes').

For some questions it is not appropriate to present a summary result; for instance, where it is more useful to look at the responses individually and there is not a particular answer that suggests a more (or less) positive experience. An example of this is Q4 'Which of the following describes how you were diagnosed with diabetes?'.

For details of the summary results for each relevant question, please see the appendix.

8.2 Bases

The base is used to show how many people answered each question. Not all questions are asked of, or answered by, everyone. For example, some questions only apply to respondents depending on their answers to a previous question. This document provides both the weighted and unweighted bases.

Where base sizes in some ICS areas are relatively small, results should be treated with caution. In the ICS-level Excel data tables small base sizes are indicated in the weighted base row, where a single asterisk (*) denotes a small effective base (<100) and a double asterisk (**) denotes a very small effective base (<30).

The effective base, rather than the weighted base, is used as it is designed to reduce the likelihood of statistical tests producing significant results because of the adjustments made by weighting. The effective base can also be a check to see if the weighting is inflating the answers from a particular group by a large factor. The effective base is calculated by dividing the squared sum of weights for all of the respondents in the weighting matrix table by the sum of the squared weights.

8.3 Calculation of results and percentages

Typically, all response options are included in the calculation of a question result. However, for some questions certain response options are excluded from the result calculation where appropriate (e.g. 'I haven't tried', 'I can't remember', 'I don't know'), to provide a more accurate reflection of how those using a service evaluate it. These responses in general do not provide information about a patient's experience of diabetes services. Using Q7 as an example, removing those who said 'I don't know or I can't remember' if the information they received from a healthcare professional when they were diagnosed was useful, provides a better reflection of the views of people who do remember. This is shown in the table below using dummy data. Numbers and percentages are presented for the four response options 'Very useful', 'Fairly useful', 'Not very useful', and 'Not at all useful'. For details of the summary results for each relevant question, please see the appendix.

Q7 How useful was this information?					
Resul	ts		Summary r	esults	
	n	%		N	%
Very useful	30	30%	Useful	60	60%
Fairly useful	30	30%			
Not very useful	20	20%	Not useful 40	40	400/
Not at all useful	20	20%		40	40%
I don't know or I can't remember	/	/	/	/	/
Base	100	100%		100	100%

If you have any questions about the presentation of the results, please email the Ipsos research team.

8.4 Suppression

Suppression has been used to ensure results based on very small numbers of respondents are not released.

Two levels of suppression have been applied to the data in the National Diabetes Experience Survey:

- In cases, where the total number of responses to a question is fewer than 10, the results for that question have been suppressed, and results will not appear within the Excel data tables or reports.
- 2) In addition, where fewer than 10 individuals in total have selected a specific response option for a question, this response has been suppressed for all sub-groups; and in the case of questions about the individual (Q41-Q50) the total response at ICS level has also been suppressed.

For surveys providing analysis below national level e.g. by organisation or region, a check is made to ensure that the eligible population exceeds 1,000 or more individuals. In circumstances where the eligible population is less than 1,000 individuals individual response option counts below 5 (but excluding 0) and corresponding percentages are suppressed. This check was carried out for the National Diabetes Experience Survey, as data is provided in separate reports and excel data tables at ICS level by type. However, all ICSs have a population that exceeds 1,000 individuals for both type 1 and type 2 diabetes, so this suppression rule was not applied.

8.5 Outputs

Reporting specifications were created by Ipsos in collaboration with NHS England, which detail the content and layout of each of the outputs.

All data and reports were encrypted and supplied to NHS England via a secure FTP (File Transfer Protocol) site.

Tables 8.1 to 8.2 describe the reports and datasets which were produced, including the presentation of statistics in each.

Table 8.1: Reports published on https://diabetessurvey.co.uk/latest-results

	Detail / purpose
National report	National results presented in a PowerPoint report Headline findings are shown for selected questions to highlight key results
National results	National results for all questions, presented in table format (Excel) with crossbreaks to provide a breakdown of results by key subgroups
National infographic	Selected national headline results in a visual format
ICS slide packs	42 PowerPoint reports containing results for a selection of key questions for individual ICSs
	Headline findings are shown for selected questions to highlight differences at an ICS level. These questions have been selected as the results are actionable for each ICS
ICS results (Excel)	An Excel report containing the ICS-level results and the national results (and variation by sub-ICB within ICS, where relevant) presented in a table format with crossbreaks to provide a breakdown of results by key subgroups
National report	National results presented in a PowerPoint report Headline findings are shown for selected questions to highlight key results

Table 8.2: Technical documents (published via the website)

	Detail / purpose
Technical annex	Report to communicate operational details of survey
Presentation of results	Excel report to explain how results are calculated and presented across the various survey outputs

8.6 The National Diabetes Experience Survey 'Materials and Results' page

The <u>Materials and Results page</u> (<u>https://diabetessurvey.co.uk/latest-results</u>) on the National Diabetes Experience Survey website allows users to access and download the published surveys and reports including ICS slide packs, excel/csv reports, and National Infographic. Users select the output type and are presented with the materials relevant.

9 Appendix

9 Appendix

Glossary of terms

Term	Definition
Index of Multiple Deprivation (IMD)	This is the official measure of relative deprivation in England, and broadly defines deprivation based on an individual's living conditions. IMD segments range from IMD1 (most deprived) to IMD5 (least deprived).
Unadjusted response rate	This response rate is based on the total number of unique responses received.
Adjusted response rate	This response rate is based on the total number of unique responses received, removing ineligible sample.
Weighting	Weighting ensures results are more representation of the population of people living with diabetes in England. For more details on the weighting strategy used for this survey, see section 6
National Diabetes Audit (NDA)	The National Diabetes Audit (NDA) is a clinical audit that measures the effectiveness of diabetes care in England and Wales.
Personal Demographics Service (PDS)	The Personal Demographics Service (PDS) is a national master database of all NHS patients in England, Wales and the Isle of Man. It holds basic patient details such as name, address, date of birth, registered GP and NHS number.

Questionnaire

Please note that questions 42 and 43 are under review by NHS England.

+



NATIONAL DIABETES EXPERIENCE SURVEY

For each question, please choose your answer by using a black or blue pen. For some questions, you a cross in more than one box.	putting a cross 🖾 clearly inside one box a can choose more than one answer by putting
Sometimes the box you have crossed will have an ollow these instructions carefully so you can skip a	instruction to go to another question. Please any questions that don't apply to you.
f you make a mistake, just fill in the box 📰 and put	t a cross 🗵 in the correct box.
you can't answer a question, or don't want to he next question.	answer it, please leave it blank and go to
you would prefer to fill in the survey online, ple	ase go to www.diabetessurvey.co.uk/login
Access code:	
	, (2)
DIAGNOSIS ou may have been diagnosed with diabetes as child or an adult. Please answer the following lestions based on your experience at that time.	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
What type of diabetes do you have?	I suddenly became unwell
	☐ I had a test to check my prediabetes
☐ Type 1 diabetes ☐ Type 2 diabetes	I was seeing a healthcare professional about something else
☐ Other	Other
☐ I don't know	☐ I don't know or I can't remember
How long ago were you diagnosed with diabetes?	Did any of the following delay your diabetes diagnosis?
☐ In the last 12 months	Put a X in all the boxes that apply.
☐ 1 to 5 years ago ☐ 6 to 10 years ago	 I didn't recognise the symptoms of diabetes
☐ More than 10 years ago	☐ I needed several appointments
☐ I don't know or I can't remember	☐ I couldn't get an appointment
	☐ I avoided making an appointment
Which NHS service first diagnosed you with diabetes?	☐ I was misdiagnosed
with diabetes? GP practice	☐ I experienced other delays
☐ Hospital	☐ I didn't experience any delays
Another NHS service	☐ I don't know or I can't remember
☐ None of the above	

+	
When you were diagnosed, did a healthcare professional share information about diabetes with you?	11 Which NHS service was your last annual review with?
_	Put a X in all the boxes that apply.
☐ Yes → Go to 7	GP practice
□ No → Go to 8	☐ Hospital
☐ I don't know or I can't remember → Go to 8	Another NHS service
	☐ I don't know or I can't remember
7 How useful was this information? □ Very useful	12 Who did you speak to at your last annual review?
☐ Fairly useful	Put a X in all the boxes that apply.
☐ Not very useful	☐ A GP or doctor
☐ Not at all useful	☐ A nurse
☐ I don't know or I can't remember	 Another healthcare professional
8 Around the time of being diagnosed, did	☐ I don't know or I can't remember
you have a conversation with a	13 As part of your last annual review, which
healthcare professional about what would happen next with your care?	of these checks did you have?
	Put a X in all the boxes that apply.
∐ Yes	☐ Weight and BMI
∐ No	Blood pressure
☐ I don't know or I can't remember	☐ Foot check ☐ Urine test
NHS ANNUAL REVIEW	Blood test
As part of your diabetes care you should have	
certain checks and tests every year. This is	Smoking status review None of the above
called an annual review. The review involves checking your HbA1c (your average blood sugar	☐ I don't know or I can't remember
levels over the last three months), feet, blood	☐ I don't know or I can't remember
pressure, cholesterol, blood and urine. You might not have all of these checks. The review	14 Did you discuss any of the results from
may take place over several appointments. You	your annual review checks with a healthcare professional?
may have a conversation with a healthcare professional to discuss the results.	This could have been in person, by
9 Have you ever had an annual review for	phone or video call.
your diabetes?	Yes, all of the results
☐ Yes → Go to 10	Yes, some of the results
□ No → Go to 19	□ No
	☐ I don't know or I can't remember
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	

nnual review, on with a bout what our diabetes
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meant you view for your at apply. ok one et an
meant you view for your at apply. ok one et an n't been nealthcare
meant you view for your at apply. bk one et an n't been nealthcare

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.

for your annual review or diagnosis. 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 Which NHS service was this appointment with? Put a X in one box only. GP practice Hospital Another NHS service

	.6
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
6	A podiatrist (foot specialist)
	 An optician (eye specialist)
	☐ Another healthcare professional
	☐ I don't know or I can't remember

I don't know or 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
1	☐ I didn't want or need this
	Listening to you
	☐ Very good
	☐ Fairly good

☐ Very poor ☐ I didn't want or need this Sharing information that was easy to

I didn't receive any information

Neither good nor poor

Fairly poor

understand

Very good

Fairly good

Neither good nor poor

Fairly poor

Very poor

+	
24 Overall, how would you describe your	LIVING WITH DIABETES
experience at your last appointment?	
☐ Very good	28 Thinking about the last 12 months, to
☐ Fairly good	what extent do you agree or disagree with the following statements?
☐ Neither good nor poor	My diabetes stops me being as
☐ Fairly poor	physically active as I would like to be Strongly agree
☐ Very poor	☐ Tend to agree
	☐ Neither agree nor disagree
DIABETES COURSES	☐ Tend to disagree
25 Have you taken part in a course about	☐ Strongly disagree
diabetes?	My diabetes stops me having the social
This could be an in person or online	life I want
course to help you manage your diabetes.	☐ Strongly agree
☐ Yes, in the last 12 months → Go to 26	☐ Tend to agree
Yes, more than 12 months ago	Neither agree nor disagree
→ Go to 27	 ☐ Tend to disagree ☐ Strongly disagree
No → Go to 27	My diabetes is a constant worry
	Strongly agree
Did a healthcare professional offer you this course?	☐ Tend to agree
☐ Yes → Go to 28	Neither agree nor disagree
□ No → Go to 28	☐ Tend to disagree
I don't know or I can't remember	☐ Strongly disagree
→ Go to 28	I am financially worse off because of my
100	diabetes
27 In the last 12 months, have any of the	Strongly agree
following meant that you have not taken	Tend to agree
part in a course about diabetes?	☐ Neither agree nor disagree
Put a X in all the boxes that apply.	☐ Tend to disagree
☐ I have previously attended a course	☐ Strongly disagree
I didn't know a course existed	Over the last 12 months, how much has diabetes affected your quality of life?
I didn't know how to access a course	☐ A great deal
I have not been offered a course	☐ A fair amount
☐ It wasn't convenient for me	☐ Not very much
I didn't see a benefit for me	☐ Not at all
 It wasn't suitable for my needs (such as dietary, cultural, or religious) 	To what extent do you agree or disagree with the following statement?
☐ It wasn't accessible for me	I have accepted that I am living with
☐ I was on a waiting list for too long	diabetes
☐ Other	☐ Strongly agree
	 ☐ Tend to agree ☐ Neither agree nor disagree
	☐ Tend to disagree
	☐ Strongly disagree

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 Over the last 12 months, have you had support from other people living with diabetes? □ Yes → Go to 34 □ No → Go to 33	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
Over the last 12 months, would you have found it useful to have support from other people living with diabetes? Yes I don't know	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
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	No I don't know or I can't remember 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.
Taking medicine (such as tablets or insulin) Yes No Doesn't apply to me Taking part in physical activity Yes	☐ 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
□ No □ Doesn't apply to me Eating well □ Yes □ No □ Doesn't apply to me Your emotional and mental health	☐ I don't have enough support from healthcare professionals ☐ Other ☐ I haven't found it difficult to manage my diabetes
needs Yes No	

ABOUT YOU

+

USING DEVICES TO MANAGE DIABETES

	DIABETES	The following questions will help us see how
38	Do you currently use any of these devices to help manage your diabetes?	experiences vary between different groups of people. We will keep your answers confidential.
	Put a X in all the boxes that apply.	41 How old are you?
	☐ Smart insulin pens	□ 18 to 24 □ 65 to 74
	☐ Blood sugar monitor and test strips	□ 25 to 34 □ 75 to 84
	☐ Insulin pumps (regularly release	☐ 35 to 44 ☐ 85 or over
	insulin)	
	Flash glucose monitor or continuous glucose monitor (check sugar levels)	☐ 45 to 54 ☐ I would prefer not ☐ 55 to 64 to say
	 Hybrid closed loops (check sugar levels and regularly release insulin) 	Which of the following best describes you?
	☐ I use other devices	Female
	☐ I don't use any devices → Go to 40	Male S
		☐ Non-binary
39	How confident do you feel about using devices to manage your diabetes?	Prefer to self-describe:
	☐ Very confident → Go to 41	☐ I would prefer not to say
	☐ Fairly confident → Go to 41	43 Is your gender identity the same as the
	Not very confident → Go to 41	sex you were registered at birth?
	Not at all confident → Go to 41	Yes
		∐ No
40	Which of the following reasons explain	☐ I would prefer not to say
	why you do not use devices to manage your diabetes?	44 Which of the following options best
	Put a X in all the boxes that apply.	describes how you think of yourself? Heterosexual or straight
	☐ I don't need to use devices	Gay or lesbian
		☐ Bisexual
	 A healthcare professional hasn't offered me any devices 	☐ Other
	☐ The devices I need aren't available for	☐ I would prefer not to say
	me on the NHS	140 1 1 541 5 11 1 1 1 1 1 1 1 1
	☐ I don't know whether I am eligible	what you are doing at present?
	I don't think devices would benefit me	Put a X in all the boxes that apply.
6		☐ In full-time paid work (30 hours or more
,	☐ I don't trust the technology	each week), including self-employment
	☐ I wouldn't feel confident using devices	☐ In part-time paid work (under 30 hours
	☐ Other	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

Jewish Muslim Sikh Any other religion I would prefer not to say Irish 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 Caribbean White and Black African White and Black African White and Black African 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 African Any other Asian background D. Black, Black British, Caribbean or African Arican Any other Black, Black British, Caribbean or African Any other Black, Black British, Caribbean or African background D. Black, Black British, Caribbean or African background Arab Any other ethnic group I would prefer not to say I would p	 □ No religion □ Buddhist □ Christian (including Church of England, Catholic, Protestant, and other Christian denominations) □ Hindu 	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
Sikh		
Any other religion I would prefer not to say		
I would prefer not to say		
Apart from diabetes, do you have any physical or mental health conditions or illnesses lasting, or expected to last, 12 months or more?		
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 cardievascular 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	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	Gypsy or Irish Traveller Roma Any other White background B. Mixed or Multiple ethnic groups White and Black Caribbean White and Black African
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 Luang or breathing condition Mental health condition Mental health condition Stroke or TIA (Transient Ischaemic Attack) Another long-term condition or illness I do not have any other long-term	Assert from all abotes with the addition	
conditions or illnesses	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	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 Any other Black, Black British, Caribbean or African background E. Other ethnic group Arab Any other ethnic group
	CONDITIONS OF INITESSES	

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

+ *Questions 42 and 43 are currently under review by NHS England.

8

Initial letter



[TITLE] [FIRST NAME] [SURNAME] [ADDRESS1] [ADDRESS 2] [ADDRESS 3] [POSTCODE]

Access code: [ACCESS CODE]

March 2024

Dear [TITLE] [SURNAME]

Help the NHS improve diabetes care

We are writing to ask you to take part in the National Diabetes Experience Survey. Ipsos are carrying out this survey on behalf of NHS England.

Share your experience of living with diabetes

The survey asks about your experience of living with diabetes and the care you have received from NHS services. This important national survey has been developed with the help of people who are living with diabetes. The NHS will use your answers to improve care and support for people like you.

Take part online in two easy steps





- 1. Go to www.diabetessurvey.co.uk/login
- 2. Enter code [ACCESS CODE] to take part

Or you can scan the QR code above using the camera on your smartphone of another device.

It should only take 15 minutes to take part in the survey.

You can help to save the NHS money by taking part as soon as possible. That way we won't need to send you any reminders.

Your information will be kept confidential

No one involved in your care will know whether you have taken part in the survey. There is more information about the survey and confidentiality on the next page and on our website at **www.diabetessurvey.co.uk**. If you have any questions, or need help taking part in the survey, phone lpsos on **Freephone 0800 470 2983** (10am to 4pm Monday to Saturday).

Thank you very much for giving your time to help the NHS improve diabetes care.

Yours sincerely

Dr Sophie Harris
Clinical Lead and NHS Consultant in Diabetes
National Diabetes Experience Survey Team





Why are you carrying out this survey?

The results of the National Diabetes Experience Survey will help the NHS provide better care and support for people living with diabetes. The NHS will publish the findings at www.diabetessurvey.co.uk in the autumn of 2024. The survey has been developed with help from people living with diabetes. You can read more about our team at www.diabetessurvey.co.uk/meet-the-survey-team.



Do I have to take part?

Taking part is voluntary. If you do not want to take part, it will not affect your care and you do not need to give a reason. If you do not want to receive any reminders about this survey, contact lpsos on Freephone 0800 470 2983 or diabetessurvey@ipsos.com.



How are my details used?

The NHS holds a list of people who are living with diabetes, called the National Diabetes Audit. Your name was chosen at random from this list. NHS England matched this information with your contact details from the list of patients registered with a GP. An independent group, which includes members of the public, gave their support for confidential patient information to be used to identify people living with diabetes and invite them to take part in this survey. Your personal information is held in line with the UK General Data Protection Regulation (UK GDPR) and Data Protection Act 2018.

NHS England is the data controller for this survey which means they are responsible for how your personal information is used. To read NHS England's privacy notice, which explains how your information is used and your rights, visit

www.england.nhs.uk/contact-us/privacy-notice. Ipsos is the data processor for this survey. They are processing your personal information to carry out this survey, on behalf of NHS England. Ipsos, and any suppliers they work with, will keep your personal information confidential and destroy it once the survey is over. For more information, visit www.diabetessurvey.co.uk/confidentiality-and-data-protection.



What happens to my answers?

By taking part in the survey, you give permission for your personal information to be used in the following ways. Ipsos will put your answers together with the answers from other people and publish the results of the survey. Your answers will be kept confidential. Nobody will be able to identify you in any published results.

Ipsos will send all the survey responses to NHS England. NHS England will remove any personal details which could be used to identify you from the data. They will link the survey responses with information in the National Diabetes Audit and other healthcare databases. The NHS will use this information to plan diabetes services. You can ask for your survey responses to not be given to NHS England. However, once NHS England has received the survey data, your responses cannot be deleted.

NHS England may share your survey answers with approved researchers, but only in a way that doesn't identify you. NHS England will only share your answers in line with strict rules about data processing. For more information, visit

www.diabetessurvey.co.uk/confidentiality-and-data-protection.



What if I can't take part online?

If you cannot take part in the survey online, we will send you a paper version of the questionnaire, and a free return envelope, in early May. You do not need to request this.



How can I get help with my diabetes care?

If you are worried about your diabetes or would like to learn more about living with diabetes, you can contact your diabetes team, GP or another healthcare professional. You can also find information online at www.nhs.uk/conditions/diabetes.

First reminder letter



[TITLE] [FIRST NAME] [SURNAME] [ADDRESS1] [ADDRESS 2] [ADDRESS 3] [POSTCODE]

Access code: [ACCESS CODE]

April 2024

Dear [TITLE] [SURNAME]

Have your say in how the NHS supports you with diabetes

We sent you a letter in March asking you to take part in the National Diabetes Experience Survey to help the NHS improve diabetes care. If you have already taken part, thank you for your time – you do not need to do anything else.

Your experience matters – there is still time to help people living with diabetes

If you have not already taken part, please go online to give us your views on NHS diabetes care.

Hearing from as many people as possible means our results will reflect the views of different people living with diabetes.

Take part online in two easy steps





- Go to www.diabetessurvey.co.uk/login
- 2. Enter code [ACCESS CODE] to take part

Or you can scan the QR code above using the camera on your smartphone or another device.

It should only take 15 minutes to take part in the survey.

Your information will be kept confidential

No one involved in your care will know whether you have taken part in the survey. There is more information about the survey and confidentiality on the next page and on our website at **www.diabetessurvey.co.uk**. If you have any questions, or need help taking part in the survey, phone Ipsos on **Freephone 0800 470 2983** (10am to 4pm Monday to Saturday).

Thank you very much for giving your time to help the NHS improve diabetes care.

Yours sincerely	
De:	
Dr Sophie Harris	
Clinical Lead and NHS Consultant in Diabetes	
National Diabetes Experience Survey Team	



Why are you carrying out this survey?

The results of the National Diabetes Experience Survey will help the NHS provide better care and support for people living with diabetes. The NHS will publish the findings at www.diabetessurvey.co.uk in the autumn of 2024. The survey has been developed with help from people living with diabetes. You can read more about our team at www.diabetessurvey.co.uk/meet-the-survey-team.



Do I have to take part?

Taking part is voluntary. If you do not want to take part, it will not affect your care and you do not need to give a reason. If you do not want to receive any reminders about this survey, contact lpsos on Freephone 0800 470 2983 or diabetessurvey@ipsos.com.



How are my details used?

The NHS holds a list of people who are living with diabetes, called the National Diabetes Audit. Your name was chosen at random from this list. NHS England matched this information with your contact details from the list of patients registered with a GP. An independent group, which includes members of the public, gave their support for confidential patient information to be used to identify people living with diabetes and invite them to take part in this survey. Your personal information is held in line with the UK General Data Protection Regulation (UK GDPR) and Data Protection Act 2018.

NHS England is the data controller for this survey which means they are responsible for how your personal information is used. To read NHS England's privacy notice, which explains how your information is used and your rights, visit

www.england.nhs.uk/contact-us/privacy-notice. Ipsos is the data processor for this survey. They are processing your personal information to carry out this survey, on behalf of NHS England. Ipsos, and any suppliers they work with, will keep your personal information confidential and destroy it once the survey is over. For more information, visit www.diabetessurvey.co.uk/confidentiality-and-data-protection.



What happens to my answers?

By taking part in the survey, you give permission for your personal information to be used in the following ways. Ipsos will put your answers together with the answers from other people and publish the results of the survey. Your answers will be kept confidential. Nobody will be able to identify you in any published results.

Ipsos will send all the survey responses to NHS England. NHS England will remove any personal details which could be used to identify you from the data. They will link the survey responses with information in the National Diabetes Audit and other healthcare databases. The NHS will use this information to plan diabetes services. You can ask for your survey responses to not be given to NHS England. However, once NHS England has received the survey data, your responses cannot be deleted.

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What if I can't take part online?

If you cannot take part in the survey online, we will send you a paper version of the questionnaire, and a free return envelope, in early May. You do not need to request this.



How can I get help with my diabetes care?

If you are worried about your diabetes or would like to learn more about living with diabetes, you can contact your diabetes team, GP or another healthcare professional. You can also find information online at www.nhs.uk/conditions/diabetes.

Second reminder letter



[TITLE] [FIRST NAME] [SURNAME] [ADDRESS1] [ADDRESS 2] [ADDRESS 3] [POSTCODE]

Access code: [ACCESS CODE]

May 2024

Dear [TITLE] [SURNAME]

In March and April, we asked you to share your views on living with diabetes to help the NHS improve diabetes care. If you have already taken part in the National Diabetes Experience Survey, thank you for your time – you do not need to do anything else.

Your last chance to take part in this survey about living with diabetes

Please share your views if you have not already taken part. This will help to make sure the NHS supports people living with diabetes and provides the care that you need.

Please take part in the survey by 27th May





- Go to www.diabetessurvey.co.uk/login
- 2. Enter code [ACCESS CODE] to take part

Or you can scan the QR code above using the camera on your smartphone or another device.

Taking part online is cheaper for the NHS. If you cannot take part online, please fill in the questionnaire sent with this letter and send it back to us in the Freepost envelope. It's free – you don't need a stamp.

It should only take 15 minutes to take part in the survey.

Your information will be kept confidential

No one involved in your care will know whether you have taken part in the survey. There is more information about the survey and confidentiality on the next page. If you have any questions, or need help taking part in the survey, visit **www.diabetessurvey.co.uk** or phone lpsos on **Freephone 0800 470 2983** (10am to 4pm Monday to Saturday).

Thank you very much for giving your time to help the NHS improve diabetes care.

Yours sincerely	
Di.	
Dr Sophie Harris	
Clinical Lead and NHS Consultant in Diabetes	
National Diabetes Experience Survey Team	i L





Why are you carrying out this survey?

The results of the National Diabetes Experience Survey will help the NHS provide better care and support for people living with diabetes. The NHS will publish the findings at www.diabetessurvey.co.uk in the autumn of 2024. The survey has been developed with help from people living with diabetes. You can read more about our team at www.diabetessurvey.co.uk/meet-the-survey-team.



Do I have to take part?

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www.england.nhs.uk/contact-us/privacy-notice. Ipsos is the data processor for this survey. They are processing your personal information to carry out this survey, on behalf of NHS England. Ipsos, and any suppliers they work with, will keep your personal information confidential and destroy it once the survey is over. For more information, visit www.diabetessurvey.co.uk/confidentiality-and-data-protection.



What happens to my answers?

By taking part in the survey, you give permission for your personal information to be used in the following ways. Ipsos will put your answers together with the answers from other people and publish the results of the survey. Your answers will be kept confidential. Nobody will be able to identify you in any published results.

Ipsos will send all the survey responses to NHS England. NHS England will remove any personal details which could be used to identify you from the data. They will link the survey responses with information in the National Diabetes Audit and other healthcare databases. The NHS will use this information to plan diabetes services. You can ask for your survey responses to not be given to NHS England. However, once NHS England has received the survey data, your responses cannot be deleted.

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www.diabetessurvey.co.uk/confidentiality-and-data-protection.



What if I can't take part online?

If you cannot take part in the survey online, we will send you a paper version of the questionnaire, and a free return envelope, in early May. You do not need to request this.



How can I get help with my diabetes care?

If you are worried about your diabetes or would like to learn more about living with diabetes, you can contact your diabetes team, GP or another healthcare professional. You can also find information online at www.nhs.uk/conditions/diabetes.

SMS reminders

First SMS reminder

We recently sent you a letter inviting you to take part in an NHS survey to help improve diabetes care. Please click the following link to take part in the survey - https://tx.vc/r/4soFV/2ercDY/7SWFtHM You don't need to log in. Any questions? Phone Freephone 0800/470/2983. Thank you.

Second SMS reminder

The NHS needs your help to support people living with diabetes and improve care.

There's still time to have your say. Please click the following link to take part in the survey - https://tx.vc/r/4soFV/2fDu9v

//SWFtHM Any questions? Phone Freephone 0800 470 2983. Thank you.

Third SMS reminder

It's your last chance to take part in this NHS survey about living with diabetes. Please click the following link to take part before the survey closes on 27 May - https://tx.vc/r/4soFV/2h06CC/7SWFtHM Your answers are confidential. Any questions? Phone Freephone 0800 470 2983. Thank you.

Presentation of results

Question number	Question wording	Full results answer codes	Summary results answer codes	Excluded answer code/s
Q1	What type of diabetes do you have?	Type 1 diabetes Type 2 diabetes Other I don't know	N/A	
Q2	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	N/A	I don't know or I can't remember
Q3	Which NHS service first diagnosed you with diabetes?	GP practice Hospital Another NHS service None of the above	N/A	I don't know or I can't remember
Q4	Which of the following describes how you were diagnosed with diabetes?	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	N/A	I don't know or I can't remember
Q5	Did any of the following delay your diabetes diagnosis?	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	N/A	I don't know or I can't remember
Q5	Did any of the following delay your diabetes diagnosis? Data shows responses for those who experienced a delay in their diabetes diagnosis.	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	N/A	I don't know or I can't remember, I didn't experience any delays
Q6	When you were diagnosed, did a healthcare professional share information about diabetes with you?	Yes No	N/A	I don't know or I can't remember
Q7	How useful was this information?	Very useful Fairly useful Not very useful Not at all useful	% Useful % Not useful	I don't know or I can't remember

Q8	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	N/A	I don't know or I can't remember
Q9	Have you ever had an annual review for your diabetes?	Yes No	N/A	N/A
Q10	When was your last annual review?	Less than 12 months ago 1 to 2 years ago More than 2 years ago	N/A	I don't know or I can't remember
Q11	Which NHS service was your last annual review with?	GP practice Hospital Another NHS service	N/A	I don't know or I can't remember
Q12	Who did you speak to at your last annual review?	A GP or doctor A nurse Another healthcare professional	N/A	I don't know or I can't remember
Q13	As part of your last annual review, which of these checks did you have?	Weight and BMI Blood pressure Foot check Urine test Blood test Smoking status review None of the above	N/A	I don't know or I can't remember
Q14	Did you discuss any of the results from your annual review checks with a healthcare professional?	Yes, all of the results Yes, some of the results No	% Yes	I don't know or I can't remember
Q15a	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	% Good % Poor	I didn't want or need this
Q15b	Thinking about your last annual review, how good was the healthcare professional at each of the following? Considering your emotional and mental health needs	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	I didn't want or need this
Q15c	Thinking about your last annual review, how good was the healthcare professional at each of the	Very good Fairly good Neither good nor poor	% Good % Poor	I didn't want or need this

	following? Listening to you	Fairly poor Very poor		
Q15d	Thinking about your last annual review, how good was the healthcare professional at each of the following? Sharing information that was easy to understand	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	I didn't receive any information
Q16	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 No	N/A	I don't know or I can't remember
Q17	How useful was this conversation in helping you manage your diabetes?	Very useful Fairly useful Not very useful Not at all useful	% Useful % Not useful	N/A
Q18	Overall, how would you describe your experience of your last annual review?	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	N/A
Q19	Have any of the following meant you have not had an annual review for your diabetes?	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	N/A	N/A
Q20	When did you last have an appointment with a healthcare professional in the NHS about your diabetes?	Less than 12 months ago 1 to 2 years ago More than 2 years ago I haven't had another appointment	N/A	I don't know or I can't remember
Q21	Which NHS service was this appointment with?	GP practice Hospital Another NHS service	N/A	I don't know or I can't remember
Q22	Who did you speak to at your last appointment?	A GP or doctor A nurse A dietician A podiatrist (foot specialist)	N/A	I don't know or I can't remember

		An optician (eye specialist) Another healthcare professional		
Q23a	Thinking about your last NHS appointment about your diabetes, 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	% Good % Poor	I didn't want or need this
Q23b	Thinking about your last NHS appointment about your diabetes, how good was the healthcare professional at each of the following? Considering your emotional and mental health needs	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	I didn't want or need this
Q23c	Thinking about your last NHS appointment about your diabetes, how good was the healthcare professional at each of the following? Listening to you	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	I didn't want or need this
Q23d	Thinking about your last NHS appointment about your diabetes, how good was the healthcare professional at each of the following? Sharing information that was easy to understand	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	I didn't receive any information
Q24	Overall, how would you describe your experience at your last appointment?	Very good Fairly good Neither good nor poor Fairly poor Very poor	% Good % Poor	N/A
Q25	Have you taken part in a course about diabetes?	Yes, in the last 12 months Yes, more than 12 months ago No	% Yes	N/A
Q26	Did a healthcare professional offer you this course?	Yes No I don't know or I can't remember	N/A	I don't know or I can't remember

Q27	In the last 12 months, have	1 I have previously attended a	N/A	N/A
	any of the following meant	course		
	that you have not taken	2 I didn't know a course existed		
	part in a course about	3 I didn't know how to access a		
	diabetes?	course 4 I have not been offered a		
		course		
		5 It wasn't convenient for me		
		6 I didn't see a benefit for me		
		7 It wasn't suitable for my needs		
		(such as dietary, cultural, or		
		religious)		
		8 It wasn't accessible for me		
		9 I was on a waiting list for too		
		long		
000-	This lie such a set the least 40	10 Other	0/ 4 =====	NI/A
Q28a	Thinking about the last 12 months, to what extent do	Strongly agree Tend to agree	% Agree %	N/A
	you agree or disagree with	Neither agree nor disagree	% Disagree	
	the following statements?	Tend to disagree	Disagree	
	My diabetes stops me	Strongly disagree		
	being as physically			
	active as I would like to			
	be			
Q28b	Thinking about the last 12	Strongly agree	% Agree	N/A
	months, to what extent do	Tend to agree	%	
	you agree or disagree with	Neither agree nor disagree	Disagree	
	the following statements? My diabetes stops me	Tend to disagree Strongly disagree		
	having the social life I	Strongly disagree		
	want			
Q28c	Thinking about the last 12	Strongly agree	% Agree	N/A
	months, to what extent do	Tend to agree	%	
	you agree or disagree with	Neither agree nor disagree	Disagree	
	the following statements?	Tend to disagree		
	My diabetes is a constant worry	Strongly disagree		
Q28d	Thinking about the last 12	Strongly agree	% Agree	N/A
	months, to what extent do	Tend to agree	%	
	you agree or disagree with	Neither agree nor disagree	Disagree	
	the following statements?	Tend to disagree		
	I am financially worse off	Strongly disagree		
020	because of my diabetes	A great dool	0/ A Croot	NI/A
Q29	Over the last 12 months, how much has diabetes	A great deal A fair amount	% A Great deal/A fair	N/A
	affected your quality of	Not very much	amount	
	life?	Not at all	% Not	
			very	
			much/Not	
			at all	
Q30	To what extent do you	Strongly agree	% Agree	N/A
	agree or disagree with the	Tend to agree	%	
	following statement?	Neither agree nor disagree	Disagree	
	I have accepted that I am	Tend to disagree		
	living with diabetes	Strongly disagree		

Q31	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	% Confident % Not confident	N/A
Q32	Over the last 12 months, have you had support from other people living with diabetes?	Yes No	N/A	N/A
Q33	Over the last 12 months, would you have found it useful to have support from other people living with diabetes?	Yes No	N/A	I don't know
Q34a	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	N/A	Doesn't apply to me
Q34b	Over the last 12 months, have you had support from healthcare professionals in the following areas to help you manage your diabetes? Taking medicine (such as tablets or insulin)	Yes No	N/A	Doesn't apply to me
Q34c	Over the last 12 months, have you had support from healthcare professionals in the following areas to help you manage your diabetes? Taking part in physical activity	Yes No	N/A	Doesn't apply to me
Q34d	Over the last 12 months, have you had support from healthcare professionals in the following areas to help you manage your diabetes? Eating well	Yes No	N/A	Doesn't apply to me
Q34e	Over the last 12 months, have you had support from healthcare professionals in the following areas to help you manage your diabetes? Your emotional and mental health needs	Yes No	N/A	Doesn't apply to me

Q35	Has a healthcare professional given you any of the following information about the medicine you take for your diabetes?	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	N/A	I don't know or I can't remember and I don't take medicine for my diabetes
Q36	Has a healthcare professional told you about the potential complications of living with diabetes?	Yes, in the last 12 months Yes, more than 12 months ago No	% Yes	I don't know or I can't remember
Q37	In the last 12 months, have any of the following made it difficult for you to manage your diabetes?	l'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 dayto-day I'm managing other long-term conditions I'm too busy I don't have enough support from healthcare professionals Other	N/A	I haven't found it difficult to manage my diabetes
Q38	Do you currently use any of these devices to help manage your diabetes?	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	N/A	N/A
Q38	Do you currently use any of these devices to help manage your diabetes? Data shows responses for those who use devices to help manage their diabetes.	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	N/A	I don't use any devices

Q39	How confident do you feel about using devices to manage your diabetes?	1 Very confident 2 Fairly confident 3 Not very confident 4 Not at all confident	% Confident % Not confident	N/A
Q40	Which of the following reasons explain why you do not use devices to manage your diabetes?	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	N/A	N/A
Q41	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	N/A	N/A
Q42	Which of the following best describes you?	Female Male Non-binary Prefer to self-describe [TEXT BOX] I would prefer not to say	N/A	N/A
Q43	Is your gender identity the same as the sex you were registered at birth?	Yes No I would prefer not to say	N/A	N/A
Q44	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	N/A	N/A

Q45	Which of the following best describe what you are doing at present?	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	N/A	N/A
Q46	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	N/A	N/A
Q47	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	N/A	N/A
Q48	Apart from diabetes, which of the following long-term conditions or illnesses do you have?	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 Ischemic Attack) Another long-term condition or illness I don't have any long-term conditions or illnesses	N/A	N/A

Q49	Thinking about diabetes, and any other long-term conditions or illnesses you have, do any of these reduce your ability to carry out your day-to-day activities?	Yes, a lot Yes, a little No, not at all	% Yes % No	N/A
Q50	What is your ethnic group?	English, Welsh, Scottish, Northern Irish or British Irish Gypsy or Irish Traveller Roma Any other White background White and Black Caribbean White and Asian Any other Mixed or Multiple ethnic background Indian Pakistani Bangladeshi Chinese Any other Asian background Caribbean African Any other Black, Black British, Caribbean or African background Arab Any other ethnic group I would prefer not to say	% White % Mixed or Multiple ethnic groups % Asian or British Asian % Black, Black British, Caribbean or African % Other ethnic group	N/A
Q50	What is your ethnic group?	White Mixed or Multiple ethnic groups Asian or Asian British Black, Black British, Caribbean or African Other ethnic group I would prefer not to say	See above	N/A

Our standards and accreditations

Ipsos's standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Moreover, our focus on quality and continuous improvement means we have embedded a 'right first time' approach throughout our organisation.





ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos UK was the first company in the world to gain this accreditation.



Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos UK endorse and support the core MRS brand values of professionalism, research excellence and business effectiveness, and commit to comply with the MRS Code of Conduct throughout the organisation & we were the first company to sign our organisation up to the requirements and self-regulation of the MRS Code; more than 350 companies have followed our lead.





ISO 9001

International general company standard with a focus on continual improvement through quality management systems. In 1994 we became one of the early adopters of the ISO 9001 business standard





ISO 27001

International standard for information security designed to ensure the selection of adequate and proportionate security controls. Ipsos UK was the first research company in the UK to be awarded this in August 2008.



The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos UK is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.



HMG Cyber Essentials

This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.



Fair Data

Ipsos UK is signed up as a "Fair Data" company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

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About Ipsos Public Affairs

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