



National Diabetes Experience Survey 2024

**Questionnaire and Materials
Development Report**

March 2024



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1. Background

The National Diabetes Experience Survey is a new survey of people living with type 1 or type 2 diabetes in England. The survey is commissioned by NHS England and has been developed in collaboration with Ipsos. This report summarises the development process of the questionnaire and survey materials, namely invitation letters and text message reminders.

1.1 Survey background

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 NDA provides a clinical view of diabetes care in England and Wales. This includes collecting data on the nine key processes of diabetes care, the achievement of treatment targets for glucose control, blood pressure and blood cholesterol, structured education, and acute and long-term complications.¹ However, there is currently no measure or programme on a national scale that provides data on the experiences of people living with diabetes.

1.2 Survey aims

The National Diabetes Experience Survey provides:

- 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 and Integrated Care System (ICS) level, but not for individual services
- evidence of any variation or inequalities experienced by different demographic groups or type of diabetes

The data will be used to develop a segmentation of people living with diabetes who respond to the survey. Segmentation involves analysis of respondents' answers to the questionnaire and grouping them with others that have similar attitudes or behaviours. The segmentation aims to understand what is required to deliver a positive experience of care for different segments of the population.

The survey findings will be published in Autumn 2024 at www.diabetessurvey.co.uk.

¹ <https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-diabetes-audit>

1.3 Survey methodology

The survey methodology has been 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 uses a sequential push-to-web methodology. This means that respondents will be encouraged to respond online, but the option to complete the survey via paper will also be available. This is based on tried and tested approaches used on other national patient experience surveys, which have delivered high-quality and representative data, while also being cost effective.

The approach used to invite people to take part in the survey is three invitation letters sent via post. Each letter is followed by an SMS reminder if a mobile number is available for the individual. All mailings will include information about how to access the online survey, and a paper questionnaire is included in the final mailing only. This approach has been agreed based on learning from other national surveys to help optimise the overall response rate and encourage participants to take part online where possible. It takes into consideration inclusivity and cost effectiveness, and has been tailored to the diabetes population.

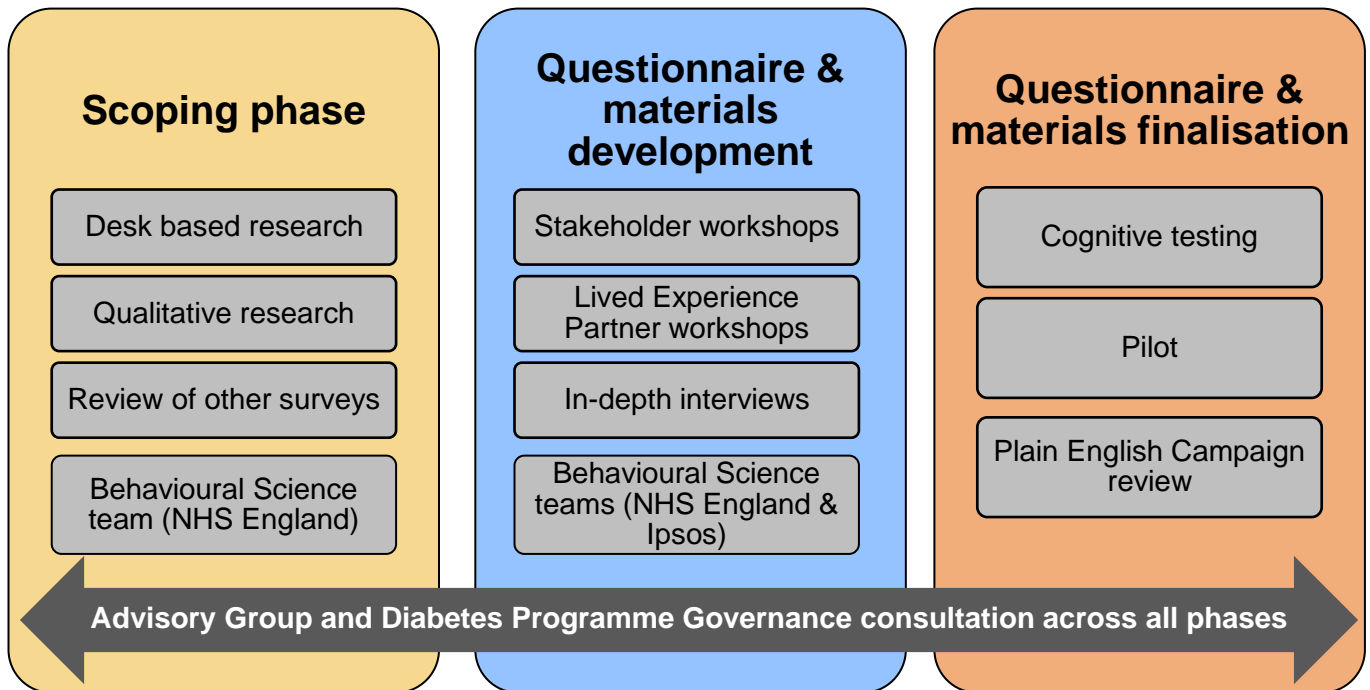
1.4 Summary of development activities

The approach to developing the questionnaire and materials centred around 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 design services that best support people living with diabetes.

The project team has carried out 12 distinct engagement activities to inform the development of the questionnaire and materials. Figure 1.1 summarises the three separate phases of engagement along with the timescale they were carried out within.

This report provides details of each of these activities in the following chapters, including the methodology for each activity and how this informed the design of the final questionnaire and survey materials.

Figure 1.1: Survey Development Activities and Timings



Activity	2022												2023								
	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	
Scoping phase	Desk based research																				
	Qualitative research																				
	Review of other surveys																				
	Behaviour Science teams (NHS England & Ipsos)																				
Questionnaire & materials development and design	Stakeholder workshops																				
	Lived Experience Partner workshops																				
	In-depth interviews with people living with diabetes																				
	Behaviour Science teams (NHS England & Ipsos)																				
Finalising questionnaire	Cognitive testing																				
	Pilot																				
	Plain English Campaign review																				
All phases	Diabetes Programme Governance consultation																				
	Advisory Group consultation																				

2. Governance

It was important to establish a clear governance process to provide direction and leadership for the development of the questionnaire and survey materials. An Advisory Group was established and the existing governance structures of the NHSE Diabetes Programme were consulted throughout the process. These two groups provided invaluable input on the design 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, and to design high quality survey materials.

2.1 Advisory Group

An Advisory Group was established specifically to provide input and oversee the development of the National Diabetes Experience Survey. The 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

The group have provided recommendations throughout the development process on a variety of areas that have helped to support decision-making. In relation to the development of the questionnaire and survey materials, this included:

- the questionnaire structure
- several iterations of the questionnaire content and wording
- the design and wording of the invitation letters and reminder letters
- the text message reminders

Their input has been invaluable, resulting in the development of materials that were sensitively written, considered the appropriateness and suitability of the content for people living with diabetes, and ensured the information included was relevant to understanding experiences of care.

2.2 NHS England Diabetes Programme Governance

The existing governance of the NHS England Diabetes Programme were consulted at several key stages of the development process. The Diabetes Programme provided clinical and policy expertise that were fundamental in shaping the content of the questionnaire. This input helped to ensure that the survey was accurate and captured information to align with policy priorities.

3. Scoping Phase Methodology

The four activities of the scoping phase, which took place between March and December 2022, are detailed below. These activities focused on developing an understanding of the existing evidence base and experiences of people living with diabetes, ahead of more focused engagement to develop the questionnaire content.

3.1 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. After screening, 172 published research papers and a wide range of grey literature were reviewed and synthesised.

In addition, a demographic analysis of NDA data for people living with type 1 and type 2 diabetes was conducted by NHS England. This looked at trends in care process completion and treatment target achievement by deprivation, sex, ethnicity, age, diabetes duration and BMI.

The overall aim of the desk-based research was to identify whether a knowledge gap existed in relation to people's experiences of diabetes care and self-management in England. The research objectives were:

- to gain insights into how people experience diabetes services, self-management and living with diabetes
- to identify any areas that impact on experience, such as demographics or type of diabetes
- to identify which service user populations are under-represented in the existing literature
- to recommend target population groups and key areas of focus to inform the next phases of research

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 (see section 3.2) and was also used to develop the survey outline.

3.2 Qualitative research

Following the desk-based research, NHS England commissioned a qualitative phase of research. This was conducted by Solutions Research between September and December 2022.

The overall aim was for any findings to inform the design and delivery of the national survey. The research objectives were:

- to understand experiences of people living with diabetes day to day
- to gain insight into the 'journey' of people living with diabetes, from initial diagnosis to current times

- to gain insight into self-management routines, including what supports self-management and to identify any gaps in support
- to understand awareness levels and access to care processes, including which services are most valued, and identifying the barriers and enablers to service use
- to gain insight into the most effective design and delivery of future diabetes services, and to understand what would help individuals to self-manage their diabetes

A mix of focus groups, online and in-person, and in-depth interviews were conducted with 147 people in total. The research was carried out across England with four main groups of people living with diabetes:

- people living with type 1 diabetes
- people living with type 2 diabetes
- South Asian and Black ethnic groups with type 2 diabetes
- specialist audiences including people with diabetes-related complications, people with additional long-term health conditions, people with mental health conditions, carers for those with a learning disability, and traveller communities

This qualitative research highlighted key areas that the questionnaire should focus on and helped to develop the initial questionnaire outline. In addition, once the survey results have been published, NHS England are aiming to triangulate the qualitative research, survey data, and other data sources such as the NDA.

3.3 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, to help create the questionnaire structure.

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 utilise validated wording for questions where appropriate. In addition to diabetes specific documents, other patient experience surveys were also reviewed, as set out below.

Diabetes specific surveys or toolkits:

- Natividad Diabetes Self-Management Questionnaire (<https://www.natividad.com/community/diabetes-education/>)
- Problem Areas in Diabetes (PAID) Toolkit (<https://professional.diabetes.org/professional-development/behavioral-mental-health/behavioral-health-toolkit>)
- Health Measures, Diabetes Specific Guide (<https://www.healthmeasures.net/explore-measurement-systems/promis>)
- Swedish National Diabetes Register Questionnaire (<https://nдр.registercentrum.se/in-english/the-swedish-national-diabetes-register/p/BJyILnupi>)

- The UK Diabetes and Diet Questionnaire (UKDDQ) (<https://sps.onlinesurveys.ac.uk/the-uk-diabetes-and-diet-questionnaire-ukddq>)

Other patient experience surveys:

- NHS England GP Patient Survey (<https://www.gp-patient.co.uk/>)
- The Care Quality Commission's Inpatient Survey (<https://nhssurveys.org/surveys/survey/02-adults-inpatients/>)
- NHS England Cancer Patient Experience Survey (<https://www.ncpes.co.uk/>)

This review helped to inform both the questionnaire structure and the wording used in specific questions.

3.4 Behavioural Science Team

The Behavioural Science Team at NHS England provided input from an early stage to maintain the focus on understanding behaviours and attitudes of people living with diabetes, meaning a segmentation analysis of the survey results would be possible. 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.

4. Questionnaire Development Methodology

The requirement to design a survey that meets the needs of stakeholders and people living with diabetes was a key objective for the survey. To meet this intended outcome, engagement activities were undertaken to consider and provide advice on the development of data collection materials, including the questionnaire, invitation and reminder letters, and text message reminders.

Table 4.1 summarises the key elements of the questionnaire development process along with their objectives.

Table 4.1: Summary of engagement activities

Engagement phase	Purpose	Activities
Questionnaire structure	<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> Workshops with stakeholders and Lived Experience Partners. In-depth interviews with people living with diabetes.
Drafting questions	<ul style="list-style-type: none"> To begin drafting 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. 	<ul style="list-style-type: none"> Workshops with stakeholders and Lived Experience Partners. In-depth interviews with people living with diabetes.
Prioritisation of questions	<ul style="list-style-type: none"> To ensure that the questionnaire is focused on providing actionable data. To achieve a questionnaire length that is good practice. To ensure that the questionnaire content remained relevant. 	<ul style="list-style-type: none"> Workshops with stakeholders and Lived Experience Partners.

Activities carried out during the questionnaire development phase are outlined below. Detailed evidence on the content of the questionnaire and survey materials development is included in the following chapters.

The Advisory Group and NHS England, including the Behavioural Science Team, were consulted at all stages of the engagement phase, providing responses to ad hoc queries, and attending workshops and scheduled meetings.

4.1 Agreement of questionnaire structure

The findings from the scoping phase were used to create a draft questionnaire structure. To gain input on this questionnaire structure, Ipsos and NHS England conducted two workshops in February 2023. One was held with a mixture of stakeholders including clinical and management leaders working at national, regional and Integrated Care Board (ICB) level. The other was with Lived Experience Partners. Three in-depth interviews with people living with diabetes were also carried out in February 2023. Details of these engagement exercises are set out below.

4.1.1 Workshops with stakeholders and Lived Experience Partners

During the two workshops conducted in February 2023, attendees were given background information about the survey aims and approach (methodology, sampling, and contact strategy). Following this, attendees were split into groups to discuss the proposed questionnaire structure and to provide feedback on:

- the most and least important of the suggested topics
- key information needed to inform policy and local commissioning decisions
- priorities for the behavioural and attitudinal segmentation
- new topics which might not have been identified in the scoping phases and consider their inclusion
- topics which might be considered too sensitive or difficult to answer in a survey questionnaire

4.1.2 In-depth interviews with people living with diabetes

Three interviews were conducted at this stage with people living with diabetes. These interviews helped to understand the appropriateness of covering certain topics in a survey questionnaire and to explore potential recall problems.

Participants were asked to consider the following questions for each of the proposed sections:

- how they would feel about being asked questions on these areas
- if there were any topics they might find difficult to answer
- if there were any topics they did not understand
- which of these topics were the most and least important

- if there was anything missing

4.2 Development of survey questions

Once the questionnaire structure was agreed, Ipsos and NHS England started to develop survey questions and answer codes. Details of the engagement activities undertaken during this phase are outlined below.

4.2.1 Workshops with stakeholder and Lived Experience Partners

During these workshops, attendees were updated on the survey development progress and shown an overview of the questionnaire.

Each workshop included a focused discussion on the different options for how to frame questions on access to and experience of services. Stakeholders were presented with the potential benefits and drawbacks of different options for this section of the questionnaire.

In addition, during group discussions in each workshop, stakeholders reviewed sections of the questionnaire and assessed survey questions against six key considerations:

- how they would use the question
- would the question provide them with the information they need
- appropriateness for people living with type 1 or type 2 diabetes
- what the potential response code lists would include
- priorities for the questionnaire
- language and comprehension

4.2.2 In-depth interviews with people living with diabetes

A further three in-depth interviews were conducted with people living with diabetes to gain input from the target audience of this survey. Participants were asked to consider the following for key questions in the questionnaire:

- how they would respond to the question, confirming if their desired response was included as an answer on the pre-code list
- level of comfort with being asked the question
- the relevance of the question to their experience
- appropriateness of language

Interviews with people living with diabetes were valuable in highlighting how easy or difficult it would be to answer some of the proposed questions based on their experience, specifically questions on the impact of living with diabetes or levels of confidence of self-management.

4.2.3 Behavioural Science Team and NHS England governance groups

The Behavioural Science Team at NHS England attended workshops and fed into reviews of the questionnaire to ensure questions that captured the behaviours and attitudes of people living with diabetes could feed into behavioural and attitudinal segmentation analysis.

NHS England Diabetes Programme Governance was also given sight of the questions developed. Their input was considered between iterations of the questionnaire.

4.3 Prioritisation of survey questions

Following the development of the survey questions, a second round of consultation with stakeholders and Lived Experience Partners took place to help prioritise which questions should be included in the final questionnaire.

4.3.1 Workshops with stakeholders and Lived Experience Partners

In June 2023, Ipsos and NHS England consulted with stakeholders and Lived Experience Partners in a further two workshops. The aim of these sessions was to:

- confirm if the questions would be relevant for people living with type 1 and type 2 diabetes
- ensure the questions provide actionable data
- prioritise which questions are included in each section of the questionnaire to ensure it is a manageable length for a respondent (around 50 questions)

Workshop attendees were asked to review options for questions within each section and prioritise what is included. Attendees were then asked to review the wording and answer options available to ensure that the above aims were met.

5. Questionnaire finalisation

To finalise the questionnaire, Ipsos conducted 40 interviews, as part of cognitive testing, as well as a small-scale pilot with seven people living with diabetes.

5.1 Cognitive testing

Cognitive testing is a method used to critically evaluate materials. It employs specialist techniques to help understand how participants process and respond to materials, in this case, the questionnaire and survey materials. The aim is to understand the processes used by a range of people to answer survey questions: do they understand the questions in the way that they were intended to be understood, and do the questions produce accurate answers? Through this process it is possible to reduce the impact of measurement error, maximise comprehension and increase the validity and reliability of the data collected.

Cognitive testing the National Diabetes Experience Survey took place in September 2023. During these interviews, participants reviewed the questionnaire. They were encouraged to 'think aloud', to allow for further understanding of their thought processes. This enabled the interviewer to discuss specific aspects with them, including issues that arose spontaneously, the suitability of response options, the terminology used and probing for comprehension. Each interview was conducted by a member of the Ipsos team and lasted around 60 minutes. Participants were offered an incentive to thank them for their time.

Participants were recruited to reflect the diversity of people living with diabetes. Fixed quotas were set on age, diabetes type, ethnicity, education level, geographical region, language spoken and presence of a long-term health condition in addition to diabetes. Further factors that might impact on living with or managing diabetes, such as sex, time since diagnosis, religion, and attendance at an annual review, were monitored to ensure a breadth of experience was captured.

During these interviews, respondents were asked to focus on the following when reviewing the questionnaire:

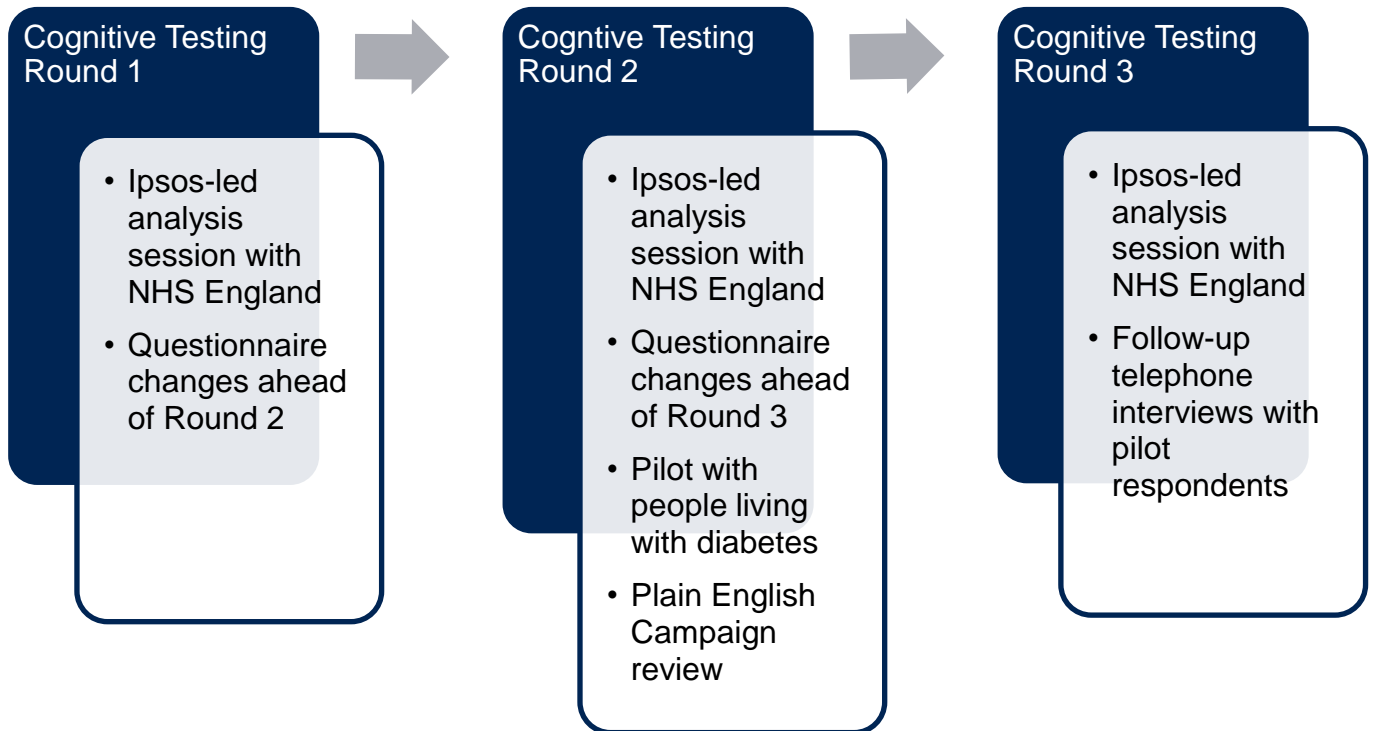
- what they were thinking about when they chose their answer
- what was their understanding of the questions
- if there were any words or phrases that were unclear or made them feel uncomfortable
- if the response options made sense and were comprehensive

The interviewing was conducted iteratively across three rounds, with analysis sessions conducted between each round. The analysis sessions involved a meeting of the Ipsos team who undertook the interviews to discuss the emerging themes, including problems identified with questions and recommendations for improvements. The output from the session was shared with the NHS England team in the form of a detailed feedback note and discussed in analysis sessions between each round of interviewing. This is a crucial element of any

qualitative methodology, which ensures changes and improvements can be made before the next round of testing.

Figure 5.1 provides an overview of the iterative cognitive testing and piloting process.

Figure 5.1: Cognitive testing and pilot process



5.2 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.

Once pilot participants had independently completed the questionnaire, they were asked to complete a short feedback form about their experience of completing the survey. This included:

- how long it took them to complete
- how easy or difficult they found it
- how they used the instruction text
- if the questions were well understood
- how they felt about answering these questions
- how they found the flow of the questionnaire

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.

5.3 The Plain English Campaign Review

The Plain English Campaign is an organisation specialising in applying the principles of plain English to public facing documents. It helps to ensure information is presented in a clear and concise format so that it can be understood by all. In the context of the National Diabetes Experience Survey, applying the principles set out by the Plain English Campaign could effectively reduce barriers to participation, including for people with language barriers, literacy issues and learning disabilities.

The National Diabetes Experience Survey questionnaire and survey 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.

6. Questionnaire Content

This chapter outlines the content of the questionnaire, and how each of the questionnaire sections were developed based on evidence from the scoping and engagement activities. The questionnaire is structured into seven sections as shown in Figure 6.1 below.

Figure 6.1: National Diabetes Experience Survey questionnaire sections



6.1 Overall principles

Across all strands of engagement, several themes emerged as being important for both people living with diabetes and stakeholders planning to use the data to inform policy and practice. These included the following points which were reflected on as core principles in the design of each section of the questionnaire:

- **Relevance:** It was important to include questions that were relevant to most people living with type 1 or type 2 diabetes. This would improve engagement with the questionnaire and provide higher quality data.
- **Actionability:** Topics which were felt to be actionable were prioritised for inclusion. This meant focusing on questions which could be used by stakeholders to design support based on what matters to people living with diabetes.
- **Flow:** The flow of the questionnaire was considered. It was important to not overwhelm respondents at the start of the questionnaire with sensitive or difficult questions.
- **Language:** Clear, accurate and non-judgemental language was used within the question text and answer options.

For reference, the final questionnaire can be found in the appendix.

6.2 Diagnosis

6.2.1 Summary of rationale for inclusion

The desk-based research identified experience of diagnosis as an area of focus for future research. Patient-practitioner interactions at diagnosis, in particular the impact of communication by healthcare professionals and the importance of their ability to respond to people's emotional needs, was highlighted. Findings from the qualitative research also highlighted that many people felt that the emotional impact of diagnosis went unrecognised, with adequate support and information often not provided.

This was further reiterated by the initial in-depth interviews and workshops with stakeholders and Lived Experience Partners. There was appetite from both stakeholders and people living with diabetes to gather information on experiences of diagnosis. The following areas were identified as important to cover:

- experience leading up to the diagnosis
- expectedness of diagnosis
- usefulness of conversations and information provided at diagnosis

Once this was agreed as a section to include, the cognitive testing provided an opportunity to further develop and test these questions with a wider group of people. From this, it was clear that the section worked well and could be answered by everyone, even those who were diagnosed at a young age or many years ago.

6.2.2 Topics included in the diagnosis section

Topic	Rationale for inclusion
Diabetes type	<p>This question will enable subgroup analysis and reporting of type 1 and type 2 diabetes experience separately.</p> <p>The self-reported data on diabetes type will be used to validate the data that is available in the NDA.</p> <p>In the in-depth interviews with people living with diabetes, including this question provided reassurance that the questionnaire would be relevant for both types of diabetes.</p> <p>It was also suggested by stakeholders that some people may not know their diabetes type and it would be useful to understand the proportion and experiences of those who answer 'don't know' to this question.</p>
Which NHS service diagnosed the individual	<p>Stakeholder feedback indicated that this information is important to allow for contextual analysis of the diagnosis experience, for example in primary or secondary care, and to identify whether an individual was diagnosed within the NHS.</p>

Time since diagnosis	<p>Stakeholder workshop groups identified time since diagnosis or age at diagnosis as a key variable to frame experience against other survey responses and to understand whether experience of recent diagnosis differed in terms of service delivery. Workshops with Lived Experience Partners raised potential recall issues and childhood diagnosis as key considerations for developing survey content on this topic. When this section was cognitively tested it showed no problem with recall but indicated that the timeframes should be amended to match how respondents wanted to provide their answers.</p>
Diagnosis circumstance	<p>The workshops with stakeholders and Lived Experience Partners and in-depth interviews highlighted that the circumstance of a diagnosis could impact experience. Due to sensitivities of asking about expectedness of diagnosis, raised by people living with diabetes, it was agreed that a question focused on understanding the events prior to diagnosis would be asked.</p> <p>Stakeholders fed back that this question would provide actionable data on the different pathways into diabetes care. For example, if someone was engaging with a healthcare service ahead of diagnosis due to prediabetes, or if their diagnosis came about suddenly. This information could potentially feed into service planning, in combination with other responses.</p>
Diagnosis delays	<p>Feedback from the workshops with stakeholders and Lived Experience Partners mirrored the desk-based research findings. Poor experiences at the point of diagnosis, such as delays to being diagnosed, were highlighted as potentially causing disengagement with services.</p> <p>Stakeholders fed back that it would be useful to understand whether barriers to being diagnosed are being experienced. It was also agreed that this question could be used to understand awareness of symptoms before diagnosis, which in turn could be used to inform future communication campaigns.</p> <p>A question on diagnosis delays was tested in the cognitive testing. There were some concerns as to whether this question could appear judgemental, for example if the reasons for the delay were focused on the individual not recognising or accepting that they might have diabetes. However, overall, this question tested well; it was broadly understood and there were no issues with recall.</p>
Information received at diagnosis	<p>Qualitative research in the scoping phase highlighted that patient-practitioner interactions at diagnosis were fundamental in defining experience. In particular, the impact of communication and information provision by healthcare professionals, and their ability to respond to people's emotional needs at the time of diagnosis. It was suggested that including a question on</p>

this would help to understand how information provision at diagnosis could impact later behaviours and attitudes for people living with diabetes.

Feedback from the **workshops** was that this would be an actionable area to collect information on. **Stakeholders and Lived Experience Partners** prioritised questions to focus on within this topic, such as how useful the individual found information provided at diagnosis, and if next steps were discussed with the healthcare professional. These questions would be used to identify information gaps that exist and can therefore be addressed.

The usefulness of the information received at diagnosis was felt to be particularly important from the **qualitative research** and discussions with **Lived Experience Partners**. In both activities it was clear that some people felt they were not being given information that was relevant to their situation. The intention is that this question will provide an indication of the quality of the information provided so that it can be explored further.

Several respondents in the **cognitive testing** mentioned how important it was to include this topic in the survey and welcomed the ability to provide feedback.

6.2.3 Topics out of scope

While the scoping phase and engagement activities identified additional topics for inclusion in the questionnaire, it was agreed they were less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
Expectedness of diagnosis	<p>This question was considered during the stakeholder workshops and in-depth interviews with people living with diabetes. The rationale was that it could highlight differences in experiences between people who expected to be diagnosed with diabetes (for example, due to family history or related health problems) and those who had no such expectation.</p> <p>However, workshops with stakeholders and Lived Experience Partners highlighted the sensitivities and challenges with capturing expectedness. Following the development phase of engagement, it was also not felt to be a key driver of experiences, particularly for individuals that were diagnosed a long time ago.</p> <p>Therefore, it was deprioritised and a specific question was not included in the questionnaire. However, the question on diagnosis circumstance includes answer codes which address this topic. This was felt to be more actionable as it provides specific information on the circumstance, whereas a question on expectedness would not provide information about what drives expectedness.</p>
Acceptance of diagnosis	<p>A question on an individual's acceptance of their diagnosis was considered. It was identified in the qualitative research as an area that informed behaviour relating to the management of diabetes.</p> <p>It was decided in the questionnaire finalisation round of the engagement with stakeholders and Lived Experience Partners, that this question would be better placed in the Living with Diabetes section, given that for some the diagnosis may have been a long time ago and it would be more accurate to reflect on how they were currently feeling.</p> <p>Additionally, it was acknowledged that current levels of acceptance may be more actionable for stakeholders, rather than acceptance of diagnosis. A question on current levels of acceptance has been included in the Living with Diabetes section – see section 6.6 for further details.</p>

6.3 NHS Annual Review

6.3.1 Summary of rationale for inclusion

To capture information on experience of care, questions were designed to focus on the annual review, which is a contact point with healthcare services that everyone with type 1 and type 2 diabetes should have each year. This aligned with an initial request from clinicians who were keen to capture information about experiences of the annual review. In addition, the need to gather information on the uptake of an annual review was identified as a key requirement in exploring the management of diabetes.

The following areas were highlighted as important to cover:

- checks carried out at annual review

- experience of annual review
- follow up conversation and next steps
- barriers to attending an annual review

The qualitative research and desk-based research reiterated that interactions with NHS diabetes services often vary for individuals, and the relationships with healthcare professionals are integral in shaping a person's experience. This was further highlighted during stakeholder engagement during the development phase; stakeholders fed back that a key focus for this questionnaire was to understand experiences of NHS diabetes care.

Lived Experience Partners and in-depth interviews with people living with diabetes offered support for this topic but highlighted that the term 'annual review' was not a commonly used phrase. Engagement with people living with type 1 and type 2 diabetes, along with clinicians' support, enabled the development of a definition of an annual review and structuring of this questionnaire topic. This was cognitively tested and understood well by people living with diabetes.

6.3.2 Topics included in the annual review section

Topic	Rationale for inclusion
People's attendance at their annual review – ever and most recently	To help contextualise the experience at the annual review, stakeholders agreed that it was important to understand how recently an annual review had been attended (if ever). Although the option of combining these two questions was presented, it was recommended to have separate questions for ease of understanding and flow.
Details of the service and health professional the review was with	Stakeholder feedback indicated that it was also important to allow for contextual analysis of the annual review experience, to identify which NHS service someone had their last annual review with, and the healthcare professional spoken to. It was also recognised that this would help to frame the section for those that are answering the survey.
Details of the checks carried out as part of annual review and discussion of results	Stakeholder workshops highlighted that the inclusion of this question would provide an understanding of what people with type 1 or type 2 diabetes associate as the tests in their annual review. The question would also help respondents to pinpoint which appointment they are being asked to think about. During these discussions clinicians were consulted to help identify the list of checks conducted as part of the annual review. Stakeholder discussions also highlighted the need to capture conversations about results and if/how people were able to get them. This was further reiterated during conversations with Lived Experience Partners , who highlighted that they sometimes have tests and don't receive results.

	<p>However, given the variations in the way annual reviews are undertaken, feedback from the cognitive testing suggested that a separate set of questions on who delivers the results and how that happens would prove confusing for some respondents. It was therefore agreed that this would be asked as one question rather than asking about the results for each test.</p>
<p>Experience of annual review and next steps with diabetes care</p>	<p>Understanding the experience of care for people living with type 1 and type 2 diabetes was one of the key aims of this survey. Therefore, the metrics used to understand this were carefully considered. The aim was to try and capture aspects of the ‘ideal consultation’ and the statements were developed through drawing on findings from the desk-based research and qualitative research with people living with diabetes.</p> <p>Over multiple rounds of stakeholder and Lived Experience Partner workshops, several measures were shared that could be used to help understand the experience of care. These covered a range of concepts: mental health, information provision, involvement in care decisions and tone/approach taken. These statements were developed based on other patient experience surveys and diabetes toolkits.</p> <p>Stakeholders and Lived Experience Partners were asked to prioritise which measures should be included in the questionnaire. It was agreed to include an overall experience question and four statements about involvement in care, emotional and mental health needs, being listened to, and receiving information that was easy to understand.</p> <p>Stakeholders and Lived Experience Partners also highlighted the importance of discussing what the next steps in a person’s care would be. It was highlighted that it is good practice to discuss both results as well as next steps in care based on their results. Clinicians noted that these conversations often happened as part of the annual review.</p>
<p>Barriers to attending an annual review</p>	<p>Evidence from the NDA shows that not all people living with diabetes attend an annual review, which was further corroborated in the workshops with stakeholders and Lived Experience Partners.</p> <p>Clinicians and other stakeholders highlighted the need to collect data around potential barriers to attending an annual review, as this could reveal attitudinal and behavioural drivers or help to improve uptake.</p> <p>Given that barriers to attending an annual review can be wide ranging, a multitude of sources were consulted to inform the answer options provided at this question including clinicians, qualitative research, Lived Experience Partners, people living with diabetes during the cognitive testing and other desk-based research. It was important that all answer options provided actionable data to support with addressing these barriers in the future.</p>

6.3.3 Topics out of scope

While the scoping phase and engagement activities identified additional topics for inclusion in the questionnaire, it was agreed they were less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
Enablers to attending an annual review	<p>In addition to the question around barriers to attending an annual review, stakeholder workshops suggested that understanding the reasons for attending an annual review would also be useful. However, this question was deprioritised as it was felt there was too much overlap with the barriers question.</p> <p>It was agreed that including a question on barriers was more actionable, as it provides data for people who haven't attended recently, rather than asking a hypothetical enablers question.</p>
Eye screening	<p>When deciding the list of checks that would be included in the annual review section, the inclusion of eye screening was discussed at length. Lived Experience Partners and people living with diabetes who took part in the cognitive testing highlighted that this check could be conducted at the same time.</p> <p>However, clinicians and the NHS England Diabetes Programme highlighted that it would not be accurate to measure experience of eye screening in this section. Although this is an annual care process, eye screening is a separate service which does not always happen at the same time as the annual review. As such its inclusion could make it difficult to answer the follow-up questions.</p> <p>It should be noted that NHS England are collecting data on eye screening uptake and follow-up tests separately. There is also the opportunity for people to feedback about experiences of seeing an optician (eye specialist) in the "Last NHS appointment" section of the questionnaire.</p>

6.4 NHS Last Appointment

6.4.1 Summary of rationale for inclusion

To capture the experience of diabetes care from all respondents for a range of primary or secondary services, a section was added to ask about the last NHS appointment respondents had attended. This meant it would be possible to collect data on experiences of NHS services for people who had not attended a diabetes annual review.

The section was framed to work for all respondents and would mirror the path for the annual review questions, to understand how experiences compare for annual review versus other ad-hoc appointments.

Topic	Rationale for inclusion
People's last attendance at a healthcare appointment – timeframe	The section starts with a question on when the last appointment took place to provide context for analysis. It will also be used to frame the section and help participants pinpoint a specific appointment to think about for the rest of the section.
Details of the appointment	Stakeholder feedback indicated that it was important to allow for contextual analysis of the diabetes care experience, specifically to identify which NHS service the appointment was with, and the medical professional spoken to.
Experience of the appointment	<p>The experience statements developed for this section were agreed at stakeholder and Lived Experience Partner workshops.</p> <p>These covered a range of concepts such as mental health, information provision, involvement in care decisions and tone/approach taken. These statements were developed based on other patient experience surveys and other diabetes surveys. The aim was for these statements to reflect the “ideal consultation”.</p> <p>Stakeholders and Lived Experience Partners were asked to prioritise which should be included in the questionnaire. Following this exercise, it was agreed that the same set of statements could be used for both the annual review and the last appointment sections.</p>

6.4.2 Topics out of scope

While the scoping phase identified an additional topic for inclusion in the questionnaire, it was agreed this was less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
Experiences in primary and secondary care	<p>During the scoping phase of engagement, a variety of options were presented for this section. This included asking this set of questions by service, for example GP practice, inpatient in hospital, outpatient in hospital, A&E, and pharmacy. However, this approach was not used for two key reasons:</p> <ul style="list-style-type: none"> • Burden: It would be burdensome for respondents to complete questions about each service separately. Some sections may not be relevant to participants, as there is variation in which services people living with diabetes access, and this could impact response rate. • Data quality: If people had not accessed services recently, recall could be problematic and impact data quality. The approach used for this section, asking about last NHS appointment, overcomes this challenge.

6.5 Diabetes courses

6.5.1 Summary of rationale for inclusion

Qualitative research undertaken during the scoping phase identified the important role that structured education courses play, noting that they are widely appreciated by those who have attended. Alongside this, the desk-based research report noted that people who attended structured education courses felt it improved their ability and confidence to manage their condition. However, as indicated in NDA data, not all people have been offered a diabetes structured education course within 12 months of diagnosis, and of those that have take-up is low.

Topic	Rationale for inclusion
Being offered and attending a diabetes course	<p>Collecting data on whether people living with diabetes had been offered a course was flagged as a priority early in the development of the questionnaire.</p> <p>Stakeholders were keen to explore whether people living with type 1 or type 2 diabetes had attended a course in the last year, and whether this had been offered by a healthcare professional. This was outlined as another aspect of the annual review process, as part of which most people should be offered a course.</p> <p>Reservations over whether this would duplicate data collected in the NDA were raised by stakeholders. However, by including the questions in the survey, it is possible to ask follow-up questions on why courses had not been attended.</p>
Barriers to attending an education or training course	<p>Stakeholders were also keen to understand what might prevent people from attending courses and whether the reasons were practical ones, or personal to them, alongside differences by diabetes type. This reflected the findings of the desk-based research which highlighted that the high levels of non-attendance at structured education programmes are currently not well understood.</p> <p>Knowledge gathered from the scoping stage was brought together to develop the list of barriers for the questionnaire. For example, the qualitative research highlighted limitations around access to in-person courses at convenient times, long waiting times, alongside cultural or religious barriers. The scoping phase also identified a lack of awareness of courses.</p>

6.5.2 Topics out of scope

While the engagement phase identified an additional topic for inclusion in the questionnaire, it was agreed this was less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
Enablers – what makes people attend an education or training course	<p>Stakeholders felt that a question on what might encourage people to attend courses would be beneficial to help understand how courses might need to be adapted in the future. However, it was acknowledged that the list would have to be long to capture all the potential responses, and people might find it hard to prioritise the factors which would encourage them to attend a course, and instead select them all.</p> <p>Additionally, as with the annual review section, it was agreed it was more useful to capture barriers from people who have not attended as it would provide us with more actionable data.</p>

6.6 Living with Diabetes

6.6.1 Summary of rationale for inclusion

The scoping phase qualitative research, in-depth interviews, and workshops with Lived Experience Partners identified the need for a range of questions to be included in the survey that would provide a measure of quality of life for people living with diabetes. Proposed topic areas included physical, emotional, and mental health, social life, and finances. In the development phase, stakeholders agreed that with careful design these questions would help to inform the segmentation analysis.

It was clear from discussions that self-management is a huge part of daily life for people living with diabetes. Stakeholders were keen to understand how services can better support self-management and ensure that people have an overall sense of empowerment. The development work suggested questions on the support people receive from their peers and healthcare professionals would be valuable. Data from questions in this section will be used to understand any differences in support by diabetes type.

6.6.2 Topics included in the 'Living with Diabetes' section

Topic	Rationale for inclusion
The impact of diabetes	<p>The importance of recognising the impact of diabetes on an individuals' life was a key finding from the qualitative research. The Lived Experience Partners and cognitive testing participants echoed the importance of including this topic to enable people living with diabetes to have a voice in this area.</p> <p>Stakeholders fed back that exploring whether diabetes had a positive or negative impact on individuals' lives could be used to understand gaps in support or whether support measures currently in place were having an impact. This included understanding experiences between demographic sub-groups and type of diabetes.</p> <p>Questions were therefore included to understand impact on quality of life, and on physical, emotional, social, and financial impact.</p> <p>A key consideration from the stakeholder workshops was that the framing of the questions should not be overly negative, as it may put people off completing the survey or cause upset. However, Lived Experience Partners were keen to ensure that the statements used in this section of the questionnaire reflected the reality of living with diabetes. The questions on impact of living with diabetes was designed with both considerations in mind.</p> <p>It was agreed that these questions would be useful to inform the segmentation analysis. The hypothesis being that the responses to the attitudinal statements may tell us something about self-management approaches.</p>
Acceptance of diabetes diagnosis	<p>Feedback from in-depth interviews and the qualitative research suggested that that it was hard for some people to accept their diagnosis but felt it was an important part of their journey. In the qualitative research, a refusal to accept a diabetes diagnosis could be associated with disengagement in managing the condition and accessing help and support.</p> <p>While some stakeholders questioned the actionability of a question on acceptance, others highlighted the importance of this question in terms of data analysis, for example to assist with understanding drivers of behaviours through the segmentation analysis.</p>
Confidence managing diabetes day-to-day	<p>Lived Experience Partners and stakeholders wanted to explore how confident people feel in managing their diabetes day-to-day. The qualitative research highlighted the variability in self-management routines and motivation over time. It also outlined that confidence influenced how people manage or interact with services. It is likely that this will be a key factor in the segmentation analysis.</p>

Support from peers and healthcare professionals	<p>Engagement phase workshops highlighted the need to gather information on all types of support that people living with diabetes access. However, providing a comprehensive list was challenging. Instead, the focus turned to the availability of peer support which was identified in the in-depth interviews as key for some. It was also highlighted by stakeholders that the offer of peer support was set to become more widespread and so capturing thoughts on this from people living with diabetes could inform how this is rolled out.</p> <p>Healthcare professional support was also seen to be an important aspect to capture by both stakeholders and people living with diabetes. This question has been designed to highlight any gaps in self-management support from healthcare professionals as well as inform the segmentation analysis.</p>
Information about medicines	<p>The stakeholder workshops and NHS England Diabetes Programme Governance highlighted that the inclusion of this question would be useful to help identify knowledge gaps in information provision for diabetes medicine. This was further reiterated by Lived Experience Partners and the in-depth interviews with people living with diabetes, who were able to recall occasions where little or no information was provided when they were prescribed medicine.</p>
Knowledge of diabetes related complications	<p>The qualitative research demonstrated that a fear of complications was a potential driver of self-management. Therefore, it was hypothesised that this will be useful to feed into the segmentation analysis. Stakeholders were also keen to capture information on people's understanding of the complications associated with diabetes and whether people are receiving the information needed about this from healthcare professionals.</p> <p>Lived Experience Partners highlighted how this question would have to be phrased carefully, given that people's understanding of the complications associated with diabetes could be limited, and recommended that a list of possible complications was not included.</p>
Barriers to managing diabetes	<p>Feedback from the qualitative research and Lived Experience Partners highlighted that there are several barriers that can make it hard to manage diabetes. It was agreed by stakeholders and people living with diabetes that understanding these barriers to managing diabetes may allow for additional support to be put in place to help those that are struggling.</p>

6.6.3 Topics out of scope

While the scoping phase and engagement activities identified additional topics for inclusion in the questionnaire, it was agreed they were less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
The ability to take diabetes medicine when in hospital	<p>Stakeholders were keen to capture experiences of managing diabetes while in a secondary care setting. It was felt important to understand if people managing diabetes found this changed while they were receiving inpatient care or receiving treatment for diabetes or another condition.</p> <p>However, as space in the questionnaire is limited, it was felt that asking just one question on this subject would not provide sufficient understanding. It was also noted that it would not be possible to target sampling to those who have had a recent inpatient stay, therefore there would be limited analysis possibilities. Furthermore, it was recognised that this information is captured in other patient experience surveys, such as the Care Quality Commission Inpatient survey which provides service level data.</p>
Changing the way diabetes is managed	<p>The scoping phase highlighted a desire to capture information on whether a respondent had recently made any changes to how they managed their diabetes. Similarly, the qualitative phase identified "treatment transitions" as moments of opportunity for behaviour change and moments where NHS support was essential. It was suggested that these questions would provide data on experiences for those who have recently changed their treatment.</p> <p>However, it was recognised that multiple questions would be required to understand the circumstances of the change in diabetes management. Additionally, it was recognised that a qualitative study would be more suitable for this topic given the level of nuance. The qualitative research conducted as part of this study was able to provide an evidence base for this.</p>
Access to prescribed medicine and taking the medicine as prescribed	<p>This was considered a difficult subject to broach in a questionnaire due to the inability to follow up with individuals for further understanding. Lived Experience Partners outlined the sensitivities around asking whether individuals are taking medicine as prescribed.</p>
Care taken in managing diabetes as required	<p>Stakeholders outlined that understanding how vigilant someone thought they were in terms of managing their diabetes could provide a useful understanding of their self-management behaviour.</p> <p>However, Lived Experience Partners felt this was a very subjective question and would be too difficult to quantify.</p>
Enablers to self-management	<p>During workshops with stakeholders and Lived Experience Partners a list of possible enablers to improve self-management was drafted. However, it was difficult to devise a standard set of responses that was appropriate for both people living with type 1 and type 2 diabetes. After the last round of</p>

	workshops, this question was deprioritised as it was felt that understanding barriers would provide more actionable information.
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6.7 Using devices to self-manage

6.7.1 Summary of rationale for inclusion

The qualitative research and desk-based research identified the importance of considering people's experiences of using devices to manage their diabetes, such as glucose monitoring devices. It was clear from the qualitative research that the use of devices is often life-changing, particularly for people living with type 1 diabetes. It was therefore agreed that this topic would be covered in the questionnaire. The priorities highlighted included identifying which devices are used, levels of confidence with devices and the barriers to using them. This was then reiterated in the stakeholder workshops.

6.7.2 Topics included in the using devices to self-manage section

Topic	Rationale for inclusion
Current devices used for managing diabetes	Collecting information on the types of devices used in self-management was identified by stakeholders as an important metric to help people when answering the survey. It will frame the section for respondents and provide context when conducting analysis on the data.
Confidence in using devices	The qualitative research outlined the importance of ensuring an individual has confidence in their ability to manage their diabetes. It was clear that a lack of confidence in using devices to manage diabetes may result in disengagement with self-management and cause additional stress. Stakeholders confirmed that a question on devices should be followed with a question on confidence aimed specifically at current device users. It was felt this could be used to inform the segmentation as well as further analysis on self-management habits and behaviours.
Barriers to using devices for self-management	Stakeholders identified the need to capture data on reasons why people do not use devices to manage their diabetes. This could help to understand how services can better support use of technology, or alternative self-management support for those who don't wish to use technology.

6.7.3 Topics out of scope

While the engagement phase identified an additional topic for inclusion in the questionnaire, it was agreed this was less of a priority. The rationale for this is summarised below.

Topic	Rationale for exclusion
Testing blood sugar levels	Stakeholders highlighted how the recommended number of daily tests differs by individual. As such captured data would need to be set in the context of how many times individuals are required to test their levels. Consequently, it was agreed that specific questions around testing were not appropriate and that it would be more valuable to explore how confident people are in using devices to monitor their blood sugar.

6.8 About you

During the development of the questionnaire structure, it became clear that allowing users of the data to analyse the results by key sub-groups will be important. The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. There is a duty under the Act to consider ways in which health inequalities that exist can be reduced. To conduct this analysis, questions about protected characteristics (such as ethnicity, religion, sex, gender reassignment, sexual orientation, disability status and age) are included to help identify where this was a potential factor in the quality of their experience of diabetes care. It was therefore agreed that a final section would be included in the questionnaire to capture additional demographic data.

The questions that are included are tried and tested on other surveys. They are based on the Government Statistical Service (GSS) question standards and were used in the 2021 census. Where possible they are aligned with the GP Patient Survey.

7. Materials Design

This chapter outlines how the survey invitation letter, two reminder letters, and three text messages were developed and tested for the survey.

Table 7.1 outlines how people will be contacted to take part in the survey. This includes a mixture of letters and text message reminders that will be sent out to participants over an 11-week period to encourage them to take part. This method is tried and tested on patient experience surveys of a similar nature.

Table 7.1: Contact with participants

Contact number	Contact mode	Week
1	Initial letter with URL and log-in details for online survey only (accessibility information sheet also included)	1
1.1	Text message with unique link to online survey	2-3
2	Reminder letter with URL and log-in details for online survey (accessibility information sheet also included)	4
2.1	Text message with unique link to online survey	5
3	Reminder letter with URL and log-in details for online survey and paper questionnaire (accessibility information sheet also included)	7
3.1	Text message with unique link to online survey	8

7.1 Methodology

7.1.1 Review of other survey materials

To develop the initial drafts of these letters and text message reminders, Ipsos reviewed several other patient experience survey invitation letters and text message reminders. This included the Care Quality Commission Patient Surveys, the GP Patient Survey and the Office for Health Improvement and Disparities (OHID) Infant Feeding Survey. From this review it was clear that there are several key principles that could be applied to the letters that were drafted.

Ipsos also drew on the following principles to draft the letters and text message reminders:

- **Variation:** in each letter and text message the messaging is slightly different, with the aim of targeting different motivations to take part and different groups within the survey population.
- **Prominence:** that key messages are prominent on the letters, for example using headings and sufficient spacing on the page.

- **Relevance:** key information about the survey is included and signpost to information sources for those that wish to find out more.
- **Clarity:** details on how to complete the survey should be easy to understand in the centre of the page. This could include the use of a QR code as well as the online link and the unique access code for participants.

These letters were then drafted and reviewed through several activities outlined below.

7.1.2 Advisory Group

Over a few meetings, the members of the Advisory Group reviewed the key principles and content of the letters to make sure they were satisfied with the language used, the format, and the signatory included on the letters. The key points highlighted were:

- Including a QR code on the letters was considered helpful and evidence from other patient experience surveys highlighted the effectiveness of this. It was felt that the instructions on the letter about how to take part in the survey should be as simple as possible. Therefore a 2-step set of instructions about taking part online was included on the letters.
- The importance of highlighting to readers that the survey has been developed with people living with diabetes. It was suggested that the signatory could include a member of the Lived Experience Partners as well as healthcare professional. This could be tailored based on the type of diabetes the person receiving the letter had.
- The headings on the front of the letters were highlighted as an important aspect, as respondents did not often read all the detail and would scan these headings. The group suggested some amends to this language to ensure it was suitable for the survey audience.
- The icons on the reverse of the letter were reviewed and it was agreed that they were important to help break up the volume of text.

The group also fed back on the text messages. Both the content and sender name were reviewed and suggestions were made to amend the language to ensure they were seen as genuine and trustworthy.

7.1.3 Cognitive testing

Following the feedback from the Advisory Group, the letters and text messages were tweaked to incorporate their amends and reviewed by the NHS England Diabetes Programme. The materials were then tested in six cognitive interviews across two rounds.

Participants were asked to review the letters in turn and consider the following:

- their immediate reaction to the letter
- aspects they like and dislike

- if it was clear and easy to understand
- if there was anything that was surprising in the letter
- if they would take part in the survey based on the letter

Following this, participants were asked to review the proposed text message reminders and sender name. For the text message reminders, they were asked to consider the following:

- their immediate reaction to the text message reminders
- legitimacy of the letters and text messages
- aspects they like and dislike
- if the content was clear and easy to understand
- if there was anything that was missing or could be improved

From these interviews the following conclusions were made:

- The letters were largely well-received and many were interested in taking part in the survey.
- The letters had to be direct and to the point, participants largely agreed they were, and felt that the key points were conveyed on the first page of the letters.
- The signatory from a Lived Experience Partner was found to be confusing. Only the first name of the Lived Experience Partner had been included for anonymity reasons, however participants felt this did not look legitimate. Most participants were happy with a singular signatory from a healthcare professional related to diabetes.
- The text messages overall were well received and participants thought this was an effective way of encouraging people to respond given the ease of accessing the online survey. There were a few suggestions to alter the content to ensure they reflected what was captured in the letter and would encourage people to respond.

Following this cognitive testing, the letters and text messages were amended to reflect the feedback received and changes were agreed with the Advisory Group. The final letters and text messages can be found in the appendices in this report.

8. Appendices

The National Diabetes Experience Survey questionnaire and materials are copyright of NHS England and cannot be used without permission from NHS England. If you have any questions about the materials, you can get in touch at england.digitaldiabetes@nhs.net.

8.1 Initial survey letter



[TITLE] [FIRST NAME] [SURNAME]
[ADDRESS 1]
[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

		<ul style="list-style-type: none"> • Go to www.diabetessurvey.co.uk/login • Enter code [ACCESS CODE] to take part
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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.

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 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

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

Please turn over  M1



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 Ipsos 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.

8.2 Reminder letter (1)



[TITLE] [FIRST NAME] [SURNAME]
[ADDRESS 1]
[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

 	<ul style="list-style-type: none">• Go to www.diabetessurvey.co.uk/login• Enter code [ACCESS CODE] to take part
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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

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

Please turn over ➔



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 Ipsos 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.

8.3 Reminder letter (2)



[TITLE] [FIRST NAME] [SURNAME]
[ADDRESS 1]
[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

 	<ul style="list-style-type: none">• Go to www.diabetessurvey.co.uk/login• 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 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

Dr Sophie Harris
Clinical Lead and NHS Consultant in Diabetes

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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 Ipsos 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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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.

8.4 Text message text

Text message 1:

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://EXAMPLE>. You don't need to log in. Any questions? Phone Freephone 0800 470 2983. Thank you.

Text message 2:

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://EXAMPLE>. Any questions? Phone Freephone 0800 470 2983. Thank you.

Text message 3:

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://EXAMPLE>. Your answers are confidential. Any questions? Phone Freephone 0800 470 2983. Thank you.

NATIONAL DIABETES EXPERIENCE SURVEY

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

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

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

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

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



Access code:



DIAGNOSIS

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

1 What type of diabetes do you have?

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

2 How long ago were you diagnosed with diabetes?

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

3 Which NHS service first diagnosed you with diabetes?

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

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

Put a X in all the boxes that apply.

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

5 Did any of the following delay your diabetes diagnosis?

Put a X in all the boxes that apply.

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

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

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

7 How useful was this information?

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

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

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

NHS ANNUAL REVIEW

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

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

- Yes → **Go to 10**
- No → **Go to 19**

10 When was your last annual review?

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

11 Which NHS service was your last annual review with?

Put a X in all the boxes that apply.

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

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

Put a X in all the boxes that apply.

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

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

Put a X in all the boxes that apply.

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

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

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

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

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

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

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

Considering your emotional and mental health needs

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

Listening to you

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

Sharing information that was easy to understand

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

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

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

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

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

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

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

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

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

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

Put a X in all the boxes that apply.

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

LAST NHS APPOINTMENT

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

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

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

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

21 Which NHS service was this appointment with?

Put a X in one box only.

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

22 Who did you speak to at your last appointment?

Put a X in all the boxes that apply.

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

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

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

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

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

Considering your emotional and mental health needs

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

Listening to you

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

Sharing information that was easy to understand

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

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

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

DIABETES COURSES

25 Have you taken part in a course about diabetes?

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

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

26 Did a healthcare professional offer you this course?

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

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

Put a **X** in all the boxes that apply.

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

LIVING WITH DIABETES

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

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

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

My diabetes stops me having the social life I want

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

My diabetes is a constant worry

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

I am financially worse off because of my diabetes

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

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

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

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

I have accepted that I am living with diabetes

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

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

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

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

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

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

- Yes
- No
- I don't know

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

Monitoring your blood sugar levels

- Yes
- No
- Doesn't apply to me

Taking medicine (such as tablets or insulin)

- Yes
- No
- Doesn't apply to me

Taking part in physical activity

- Yes
- No
- Doesn't apply to me

Eating well

- Yes
- No
- Doesn't apply to me

Your emotional and mental health needs

- Yes
- No
- Doesn't apply to me

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

Put a X in all the boxes that apply.

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

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

For example, complications relating to your eyes or feet.

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

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

Put a X in all the boxes that apply.

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

USING DEVICES TO MANAGE DIABETES

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

Put a X in all the boxes that apply.

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

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

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

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

Put a X in all the boxes that apply.

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

ABOUT YOU

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

41 How old are you?

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

42 Which of the following best describes you?

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

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

- Yes
- No
- I would prefer not to say

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

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

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

Put a X in all the boxes that apply.

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

46 What is your religion?

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

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

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

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

Put a X in all the boxes that apply.

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

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

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

50 What is your ethnic group?

A. White

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

B. Mixed or Multiple ethnic groups

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

C. Asian or Asian British

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

D. Black, Black British, Caribbean or African

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

E. Other ethnic group

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

THANK YOU VERY MUCH FOR YOUR HELP

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

For more information

3 Thomas More Square
London
E1W 1YW

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NHS England email address: england.digitaldiabetes@nhs.net
www.diabetessurvey.co.uk/

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